From Preparedness to Social Support: How Individuals Navigate Misattributed Parentage Experiences

Betty Cohn

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Reading Committee:

Stephanie M. Fullerton, Chair

Annie T. Chen

Katherine E. MacDuffie

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Betty Cohn

University of Washington

Abstract

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Betty Cohn

Chair of the Supervisory Committee:

Stephanie M. Fullerton

Department of Bioethics and Humanities

Advances in genetic testing have made it easier than ever for individuals to learn about their ancestry, health risks, and biological relatives, but results are not always as expected. Both direct-to-consumer (DTC) genetic testing and clinical genomic sequencing can reveal misattributed parentage experiences (MPEs), in which a presumed parent is discovered not to be a biological parent. MPEs can profoundly disrupt one's identity, cause psychological distress, and erode trust in one's parents. Despite the growing number of people who have a MPE, little research has examined how individuals are prepared for the possibility of having a MPE prior to testing or how they are supported afterward. This dissertation addresses these gaps across three studies. First, a content analysis of 43 consent forms from DTC genetic testing companies and academic/commercial laboratories offering whole-exome, whole-genome sequencing or genotyping was conducted. Findings revealed substantial variability in whether and how MPEs

were mentioned, and disclosure practices lacked clarity. Reading level required of most consent forms exceeded recommended standards. These results suggest that many individuals undergo DTC genetic testing or clinical genomic sequencing without adequate preparation for a MPE. Next, social support exchanged in an online setting was examined through a content analysis of the 100 most commented posts and their 3,797 associated comments identified from the public Reddit community, r/donorconceived. Informational support, particularly situation appraisal and sharing one's own experiences, predominated, though emotional, esteem, and network support were also present. Informational support frequently functioned as emotional support when perceived as personally relevant, blurring traditional distinctions between support categories. Lastly, the experiences of individuals who learned of their MPE from DTC genetic testing were explored through in-depth qualitative interviews, comparing those who joined MPE-specific online communities with those who did not. Findings revealed that people with MPEs are a heterogeneous community with diverse emotional responses and support needs. While online communities provided valuable social support, others found them to be overwhelming, and some desired in-person support in addition to online social support. Together, these studies demonstrate that current informed consent practices inadequately prepare individuals for the possibility of a MPE, and that online communities, while valuable, may not meet all support needs.

Table of Contents

List of Figures

List of Tables

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Chapter 1: Introduction

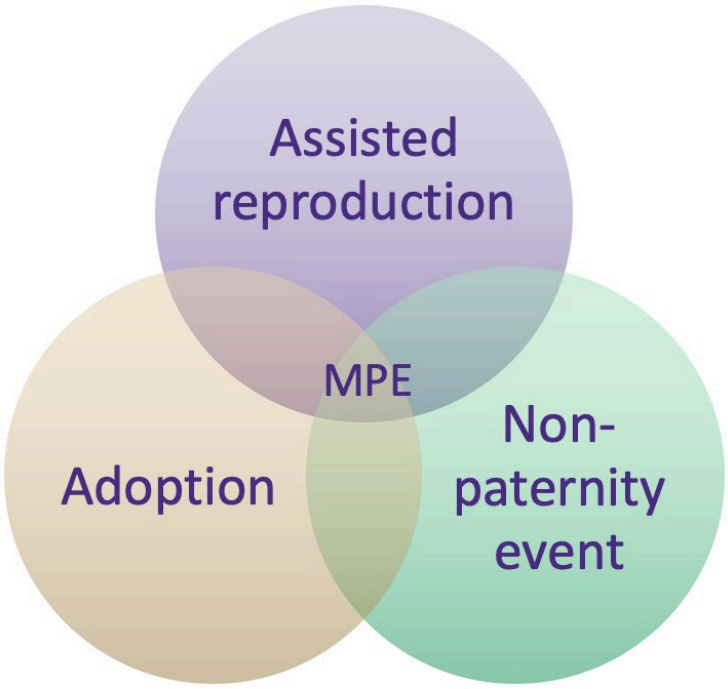
Advances in genetic testing have made it easier than ever for individuals to learn about their ancestry, health risks, and biological relatives, but results are not always expected. Both direct-to-consumer (DTC) genetic testing and clinical genomic sequencing can reveal misattributed parentage experiences (MPEs), in which a presumed parent is discovered not to be a biological parent.[1] The frequency of MPEs is estimated to range from 1.9% to 30%.[2–4]

DTC genetic tests have remained popular since the first genetic test was made commercially available in 2007. Now, almost two decades later, the DTC genetic testing market has only continued to increase, particularly with sales for such tests being offered during high-traffic purchase times such as Black Friday and Christmas.[5,6] With an estimated 40 million Americans having participated in DTC genetic testing,[7] the number of MPE cases could be higher than previously reported. A recent Pew Research study described that 27% of individuals who had undergone DTC genetic testing reported learning of previously unknown relatives,[8] while another study suggests that among almost 24,000 DTC genetic testing consumers, 61% learned new information about their biological origins (e.g., learning the identity of their biological father).[9] These findings illustrate how DTC genetic testing can reveal unexpected familial relationships, often without guidance from a healthcare professional.

MPEs can result from adoption, gamete donation, an extramarital affair, or sexual violence.[8,10] (Figure 1). Historically, parents who used donor gametes to have a child were often told by their doctors and society to keep this choice a secret due to stigma surrounding assisted

reproduction.[10,11] To maintain this secret, fertility clinics offered, and parents often chose, to use an anonymous donor. However, due to widespread uptake of DTC genetic testing, anonymity can no longer be guaranteed to parents or donors. Indeed, DTC genetic testing has profoundly reshaped this landscape, making it common for individuals to discover their donor-conceived status without parental or donor disclosure.[12–14]

Figure 1.1: Three communities involved in misattributed parentage experiences. Non-paternity is defined as "an individual conceived from an extramarital affair, tryst, rape, assault, or other sexual encounter that results in hidden, undisclosed, or unknown paternity". (Adapted from the Right to Know Us (https://righttoknow.us/terms/))



Having a MPE can be profoundly disruptive to one's personal identity,[15–18] lead to psychological distress,[19,20] and engender distrust of one's parents.[21] With the ripple effect of these unexpected findings, adjusting to a MPE will become a more common life experience. Despite the increasing number of people who have had a MPE, little research has been conducted to learn how to better

prepare people for the possibility of a MPE and better support people who have a MPE. Individuals are often not adequately prepared for the possibility of discovering a MPE prior to testing, and once one has a MPE, individuals may lack access to appropriate forms of support to help them navigate the emotional, relational, and informational consequences of that discovery. The overall goal of this dissertation is to address these gaps by examining how individuals are prepared for MPEs via the consent process and how they are supported afterward through social support exchanged in online communities.

Genetic testing and genomic sequencing

DTC genetic testing refers to genetic tests marketed directly to consumers that provide information about an individual's genetic makeup without involvement of a healthcare provider.[22,23] Consumers typically purchase a test kit online, collect a saliva sample at home, and mail the sample to a laboratory for analysis, with results delivered through an online account or application. Depending on the company, results can include information about one's traits, wellness and health, ancestry, and genetic relatives. Genetic relative finder services allow consenting users to be matched with other consenting users in a company database.[24] DTC genetic testing companies, such as 23andMe can identify relatives (with decreasing accuracy) up to about the sixth degree.[25,26]

Genomic technologies are also increasingly being used in clinical care. Clinical genomic sequencing is typically ordered by healthcare providers to investigate suspected genetic conditions, guide diagnosis, or inform medical management, with results generally communicated to patients by healthcare professionals, such as genetic counselors. As the use of

clinical genomic sequencing expands, results may reveal unexpected findings unrelated to the original reason for testing, including discoveries associated with biological relationships.

Informed consent plays a key role in preparing individuals for potential outcomes of genetic testing, including unexpected familial findings. However, the structure of the consent process differs substantially across testing environments. In clinical settings, informed consent is typically a process that involves discussion with a healthcare provider. This interaction allows individuals to ask questions and receive clarification regarding the purpose of testing, potential results, and possible risks. Healthcare providers, including genetic counselors, may also emphasize particularly important aspects of testing, such as the possibility of incidental findings. In contrast, DTC genetic testing generally relies on electronic consent. Consumers agree to lengthy consent documents online without direct interaction with a healthcare professional (or any other type of company representative) in order to complete the purchase of a test.[27] The electronic consent form may represent the only opportunity for consumers to learn about potential outcomes such as a MPE, and as is common in other online transactions, it is unlikely to be carefully reviewed.

Online communities as social support

Online communities have become central spaces where people with MPEs seek and exchange information.[20,28,29] Use of online peer support groups is a common choice for anyone who may be reluctant or unable to discuss experiences with family or professionals including genetic counselors, and mental health care providers. Online communities can offer validation, informational support, and a sense of belonging, particularly when individuals lack support

offline.[30] Studies focused specifically on MPE communities similarly indicate that individuals value the opportunity to engage with others who understand the unique emotional and relational challenges associated with MPEs.[20,31] Yin et al. (2022) suggested that future research focus on the scope of people's use of online communities as a resource for managing surprising discoveries made from DTC genetic testing.[28] Directly analyzing the contents of one or more such online communities presents an opportunity to explore the support needs of people with a MPE.

While support from family, friends, therapists, and genetic counselors, remains important, these sources may be ill-equipped to address the unique challenges experienced by those with MPEs. Family members may themselves be affected by the MPE creating relational strain that limits their capacity to provide neutral support.[29] Additionally, many healthcare providers, including genetic counselors, report difficulty navigating MPE disclosures in clinical settings, suggesting a gap in professional preparedness to support this population.[32] Online communities, by contrast, offer a space where individuals can connect with others who share directly analogous experiences, and may serve as a form of peer support that may be especially valuable for those managing stigmatized or taboo MPEs.[33] Given that professional and personal support networks are often underprepared to support those with MPEs, online communities — where individuals with MPEs have self-organized to meet their own needs — represent a uniquely valuable source of knowledge about what effective support looks like in practice. Findings of research concerning the function of these communities can ultimately inform how family members, friends, therapists, and genetic counselors provide care to this population.

While prior work has focused on the benefits of online support communities for those with MPEs,[20,29,31] less attention has been paid to potential limitations of these groups. Understanding the benefits and drawbacks of participation in such communities and why individuals choose to join, stay, or leave can provide insight into the evolving support needs of individuals following a MPE.

Study overview

This dissertation is structured to examine both preparedness and support in the context of MPEs.

Chapter 2 evaluates consent forms used for DTC genetic testing and clinical genomic sequencing, to assess how the possibility of MPEs is communicated to consumers and patients.

Chapter 3 examines types of social support exchanged within an online community of those who are donor-conceived.

Chapter 4 explores participants' experiences (or lack thereof) of joining an online community for people who have had a MPE.

By comparing practices of DTC genetic testing and clinical genomic sequencing, the results from Chapter 2 offer new insights into how different sectors approach the potential for a MPE. Previous research has only analyzed consent forms related to each context separately, using only a small subset of consent forms.[34–36] The knowledge gained through this chapter has the potential

to improve informed consent practices in the context of MPEs which can help to minimize psychological distress and promote patient autonomy.

The remaining two chapters focus on online social support sought after having a MPE. Prior research has identified online communities that discuss the aftermath of DTC genetic testing, identifying the companies that consumers purchased their tests from and the type of information they learned (e.g. health, kinship, ancestry, etc.).[28,37–46] However, none of these studies have assessed how these online communities function as a form of social support. Assessing the contents of these groups and the motivations for joining, staying, or leaving these communities provides a unique opportunity to explore the needs of people with MPEs. Disseminating the results of chapters 3 and 4 will elevate the voices of people who have had MPEs and illustrate various paths for support after a MPE.

Chapter 2: Beyond consent: A content analysis of misattributed parentage experience mentions in genetic testing consent forms

Abstract

Purpose: Given the increasing likelihood of potential misattributed parentage experiences (MPEs) through direct-to-consumer (DTC) genetic testing and clinical genomic sequencing, it is important to understand how individuals are prepared for the possibility of a MPE prior to testing during informed consent. This study examined how informed consent documents describe MPEs, disclosure practices, and related supports across testing contexts.

Methods: A content analysis was conducted of 43 consent forms obtained from DTC genetic testing companies and academic/commercial (AC) laboratories offering whole-exome sequencing, whole-genome sequencing, or genotyping. Consent forms were systematically identified through public document searches and direct outreach. An *a priori* codebook guided independent coding by two researchers, with consensus meetings to resolve discrepancies. Coding focused on the presence, framing, and location of MPE-related content, disclosure practices, support resources, and policy references. Readability was evaluated using Flesch-Kincaid Grade Level and Flesch Reading Ease scores.

Results: Among 22 DTC consent forms, 27% (6/22) mentioned MPE explicitly, 50% (11/22) mentioned MPE indirectly, and 23% (5/22) forms did not reference MPE at all. Among 21 AC consent forms 48% (10/21) mentioned MPE explicitly, 48% (10/21) mentioned MPE indirectly, and one form had no MPE mention. The majority (64%) of DTC consent forms provided MPE information throughout the form, whereas AC consent forms most often (14/21, 67%) provided MPE information in the "Risks" section. Disclosure practices varied: 52% (11/21) of AC forms

indicated results may be disclosed to clinicians, but few specified that clinicians would communicate results to patients (5/21, 24% AC). Mental health support was rarely recommended (2/22, 9% DTC; 0/21, 0% AC), though most forms referenced genetic counseling (13/22, 59% DTC; 16/21, 76% AC). Fewer than half discussed familial (9/22, 41% DTC; 11/21, 52% AC) or personal impacts (10/22, 45% DTC; 7/21, 33% AC). Policy references differed, with ACMG guidelines more commonly cited in AC forms (14/21, 67% AC vs. 2/22, 9% DTC) and GINA more frequently mentioned in DTC forms (10/22, 45% DTC vs. 7/21, 33% AC). Readability estimates exceeded recommended levels, with mean grade levels of 15.6 (DTC) and 14.7 (AC) and Flesch Reading Ease scores indicating high difficulty (means: 24.5 DTC; 27 AC).

Conclusions: Consent forms across DTC genetic testing and clinical genomic sequencing inadequately and inconsistently prepared individuals for the possibility of a MPE. These results suggest the need for important changes to the informed consent process, including: (1) state the possibility of identifying misattributed paternity; (2) ensure understanding during the consent process; and (3) standardize disclosure practices.

Introduction

Advances in genetic testing have made it easier than ever for individuals to learn about their ancestry, health risks, and biological relatives, but results are not always expected. Both direct-to-consumer (DTC) genetic testing and clinical genomic sequencing can reveal misattributed parentage experiences (MPEs), in which a presumed parent is discovered not to be a biological parent.[1] The frequency of learning that one's assumed biological parent is not their biological parent is estimated to range from 1.9% to 30%.[2–4]

With an estimated 40 million Americans having participated in DTC genetic testing alone,[7] a recent Pew Research study suggests the number of MPE cases could be higher than previously reported. The study noted 27% of individuals who reported they had undergone DTC genetic testing learned of new relatives they had not known previously known existed.[8]

Both DTC genetic testing and clinical genomic sequencing have the potential to cause MPEs. MPEs can result from adoption, gamete donation, an extramarital affair, or sexual violence.[8,10] Learning of such a result can be profoundly disruptive to one's personal identity and lead to adverse psychological impacts for individuals and their families.[15,17–20,29] With the ripple effect of surprise DNA discoveries impacting multiple family members, adjusting to such discoveries will become a more common life experience. Yet little is known about how individuals are prepared for this possibility prior to testing. This study addresses that gap by examining how consent materials across DTC genetic testing and clinical genomic sequencing contexts address MPEs.

Settings for Genetic Testing and Genomic Sequencing

DTC genetic testing refers to genetic tests marketed directly to consumers that provide information about an individual's genetic makeup without the involvement of a healthcare provider.[22,23] Consumers typically purchase a test kit online, collect a saliva sample at home, and mail the sample to a laboratory for analysis, with results delivered through an online account or application. Depending on the company, results can include information about one's traits, wellness and health, ancestry, and genetic relatives. Genetic relative finder services allow consenting users to be matched with other consenting users in a company database.[24] DTC genetic testing companies, such as 23andMe, can identify relatives (with decreasing accuracy) up to about the sixth degree.[25,26]

Consumers choose to pursue testing for a variety of reasons. The most recent published data suggests that among almost 24,000 DTC genetic testing consumers, one of the most common motivations for pursuing testing was to build a family tree (76%), meaning that most consumers in that study were trying to identify familial connections and potentially unknown relatives.[9] 10% of participants in that study learned the identity of their biological father or biological mother.[9] These findings illustrate how DTC genetic testing can reveal unexpected familial relationships.

In addition to DTC genetic testing, genomic technologies are increasingly being used in clinical care through whole-exome sequencing (WES) and whole-genome sequencing (WGS). WES analyzes the protein-coding regions of the genome, known as exons, which represent approximately 1–2% of the genome but contain a large proportion of known disease-causing

variants. In contrast, WGS analyzes the entire genome, including both coding and noncoding regions. Clinical genomic sequencing is typically ordered by healthcare providers to investigate suspected genetic conditions, guide diagnosis, or inform medical management, with results generally communicated to patients by healthcare professionals, such as genetic counselors. As the use of WES and WGS expands, results may reveal unexpected findings unrelated to the original reason for testing, including discoveries related to biological relationships.

Variation in Disclosure and Consent Across Contexts

The way in which individuals come to a MPE differs between testing contexts. In the DTC setting, discoveries typically occur through relative-matching services when consumers identify unexpected genetic relationships within company databases. These discoveries occur without the guidance of a healthcare professional, and individuals often interpret results independently. In contrast, when MPEs arise during clinical genomic sequencing, results are typically communicated by healthcare providers, such as genetic counselors, who are trained to explain complex genomic information and discuss its potential implications for patients and their families. However, professional guidelines regarding whether and how to disclose MPEs are inconsistent. While the American College of Medical Genetics and Genomics (ACMG) has issued recommendations regarding the reporting of medically actionable incidental findings identified through genomic sequencing,[47,48] these guidelines do not specifically address incidental discovery of unexpected familial relationships. The American Society for Human Genetics (ASHG) recommends that clinicians should not report a misattributed paternity unless the medical benefit exceeds potential harms of disclosure.[49] As a result, clinical laboratories vary in their approaches to disclosure.[35]

Informed consent plays a critical role in preparing individuals for potential outcomes of genetic testing, including unexpected familial findings. However, the structure of the consent process differs substantially across testing environments. In clinical settings, informed consent is typically a process that involves discussion with a healthcare provider. This interaction allows individuals to ask questions and receive clarification regarding the purpose of testing, potential results, and possible risks. Healthcare providers, including genetic counselors, may also emphasize particularly important aspects of testing, such as the possibility of incidental findings. In contrast, DTC genetic testing generally relies on electronic consent. In this format, consumers agree to lengthy consent documents online without direct interaction with a healthcare professional (or any other type of company representative) in order to complete the purchase of a test.[27] The electronic consent form may represent the only opportunity for consumers to learn about potential outcomes such as a MPE, and as is common in other online transactions, it is unlikely to be carefully reviewed.

Another important consideration is the readability of consent materials. Previous studies evaluating genomic sequencing consent forms have used readability measures such as the Flesch–Kincaid grade level and the Flesch Reading Ease score.[36,50–52] The Flesch-Kincaid scale [53] measures reading level (by grade) needed to understand a text by assessing the number of syllables of words in a certain number of sentences. The Flesch Reading Ease scale measures overall difficulty of a piece of writing and assigns a score between 1 and 100, with 100 indicated the highest reading difficulty.[54] This scale is based on sentence length and word length. The Office of Human Subjects Research Protections (OHRP) under the U.S. Department of Health

and Human Services recommends that consent forms be written at a 6th-8th grade reading level[55] to ensure accessibility. However, many consent forms for WGS/WES are written well above the recommended 8th grade reading level.[36,50–52]

Study rationale and objectives

Given the increasing likelihood of having MPEs through DTC genetic testing and clinical genomic sequencing, it is important to understand how individuals are prepared for the possibility of a MPE prior to testing. Previous research has only analyzed consent forms related to each context separately, using only a small subset of consent forms.[34–36] By comparing practices of DTC genetic testing and clinical genomic sequencing, this study offers new insights into how different sectors approach the possibility of a MPE. Content analysis of consent documents with sector-specific comparison sets the groundwork for future guidelines for informed consent that prioritize transparency, ethical responsibility, and psychological preparedness with respect to MPEs. Ultimately, the goal of this research is to ensure that consumers and patients are better supported through their MPE.

Methods

Data collection

DTC genetic testing companies and academic and commercial (AC) laboratories that offer clinical WES, WGS, genotyping, or combinations of these services were identified using online databases (**Figure 2.1**). Tracxn, a market intelligence platform with one of the largest databases of companies, was used to identify DTC companies. On July 28th, 2025, the top 20 DTC

companies by revenue that offered WES, WGS, genotyping, or related services were identified. On the same date, the National Genetic Testing Registry (GTR; www.ncbi.nlm.nih.gov/gtr/) was searched to identify AC laboratories that were CLIA-certified, based in the United States, and offered WES, WGS, or both. These searches yielded 36 academic or commercial laboratories and 20 DTC genetic testing companies, for a total of 56 organizations.

Between August 8, 2025, and September 3, 2025, two members of the study team (BC and HF) conducted a systematic search of publicly available online information to identify consent forms from all 56 organizations. Using the Google search engine, the team searched for consent forms associated with each identified company or laboratory using the following search terms: "[Company/Lab Name] AND 'whole exome sequencing' AND 'consent form;'" "[Company/Lab Name] AND 'whole genome sequencing' AND 'consent form;'" and "[Company/Lab Name] AND 'genetic' AND 'consent form.'" This search identified consent forms from 12/20 (60%) DTC genetic testing companies and 16/36 (44%) AC laboratories and from.

For companies and laboratories without publicly available consent forms (n=28), two members of the study team (BC and HF) contacted employees of the organizations directly to request copies of their consent forms. Contact information for these requests was identified using a structured approach tailored to entity type. For AC laboratories, the team first searched the GTR website to identify the laboratory director and their email address. When listings did not include director contact information, the team contacted the next most senior administrator or genetic counselor listed. If no individual contact information was available, the main contact email listed on the laboratory's website was used instead.

For DTC companies, the team reviewed company websites (typically the "About" or leadership sections) to identify appropriate contacts. When available, the team contacted lab managers; otherwise, they identified individuals in senior, technical, scientific, or medical leadership roles (e.g., Chief Technical Officer, Chief Scientific Officer, or Chief Medical Officer). The team then conducted a systematic search of publicly available online information using each individual's name and company affiliation to identify email addresses. When they could not identify an individual email address, they used the general contact email listed on the company website.

The team sent out three email requests to each company or laboratory: (1) an initial request on September 29, 2025, (2) a second request on October 6, 2025, and (3) a final request on October 10, 2025. Follow-up emails were only sent when there was no response to a prior message.

Through direct outreach, the team obtained five additional consent forms. Because some companies and laboratories used different consent forms for each service offered, the final sample included 43 consent forms from 34/56 identified companies and laboratories. Specifically, 22 forms were identified from DTC genetic testing companies, and 21 forms from AC laboratories.

Figure 2.1: A flow diagram of the data collection process.

Data analysis

We conducted a content analysis by using an *a priori* codebook (see Appendix A) created and used by two members of the research team (BC and HF).[56] The *a priori* codebook was developed based on similar criteria used to categorize consent forms in previous studies.[34–36] Consent forms

were then independently coded by the same study team members. It is important to note that "direct MPE mention" does not refer to use of the acronym 'MPE' itself, but rather to language that explicitly names and describes the concept using related terminology such as non-paternity. Forms coded as having an indirect mention used vaguer language that alluded to unexpected familial findings without using words like "paternity." Coders met weekly to review coding decisions and resolve any discrepancies through discussion. Discrepancies were rare and typically arose from ambiguity in subcode boundaries such as distinguishing between direct and indirect mentions of MPE.

The readability of the consent documents was assessed by using two scores: the Flesch-Kincaid scale and the Flesch Reading Ease scale. The Flesch-Kincaid scale [53] measures the reading level (by grade) needed to understand a piece of writing by assessing the number of syllables of words in a certain number of sentences. The Flesch Reading Ease scale measures how hard or easy a piece of writing is to read and assigns a score between 1 and 100, with 100 indicating the lowest difficulty.[54] This scale is based on sentence length and word length. Both scales were calculated in Microsoft Word software. Readability was assessed only for the coded portions of each consent form by examining the sections pertaining to MPE-related content, rather than the document in its entirety. This allowed us to evaluate how comprehensible the MPE-specific material was to a prospective patient/consumer, including whether the form clearly communicated the presence and nature of a potential MPE result, where that information was located within the document, disclosure procedures and who would be responsible for delivering results, recommended resources for support, the personal and familial impact of such results, and any relevant policy protections.

Results

Presence of MPE Discussion

Among DTC consent forms (n=22), 6/22 (27%) mentioned the possibility of a MPE explicitly, 11/22 (50%) mentioned MPE indirectly and 5/22 (23%) forms did not mention MPE at all (**Table 2.1**). Among AC consent forms (n=21), 10/21 (48%) mentioned the possibility of a MPE explicitly, 10/21 (48%) mentioned MPE indirectly, and only one (5%) form had no MPE mention. Consent forms coded as having a direct MPE mention named and described the concept accurately (i.e., realizing that a presumed parent is not one's biological parent), using terminology such as non-paternity. For example, in one consent form from an academic/commercial lab, it states that "this test may find unexpected changes in a family tree. Testing multiple family members may reveal that familial/biological relationships are not what they were assumed to be. The test may show, for example, that a child has a different biological father (non-paternity), that a donor egg or sperm was used for a pregnancy, or that a child has been adopted" (AC 14). In contrast, indirect mentions of MPE were typically more vague, and at times did not include the word "paternity" or "parental" at all, with one consent form explaining that "looking at your genetic data might uncover information that some people find surprising. This information can be relatively benign. At other times, the information you learn can have profound implications for both you and your family," (DTC 2).

Table 2.1: Frequency of codes across DTC and AC consent forms

Code	Subcode	DTC consent forms (n=22, %)	AC consent forms (n=21, %)

Presence of MPE Discussion			
	Direct MPE mention	6, 27%	10, 48%
	Indirect MPE mention	11, 50%	10, 48%
	No MPE mention	5, 23%	1, 5%
Location of MPE Discussion			
	Risk section	8, 36%	14, 67%
	Not specifically labeled	14, 64%	7, 33%
Disclosure/Return of results			
	Disclosure to clinician	-	11, 52%
	Not disclosed	2, 9%	2, 10%
	Explicit mention of the person who delivers results	-	5, 24%
Recommended resources			
	Mental health	2, 9%	0, 0%
	Genetic counseling	13, 59%	16, 76%
Impact of results			
	Familial impact	9, 41%	11, 52%
	Personal impact	10, 45%	7, 33%
Policy mentions			
	ACMG guidelines	2, 9%	14, 67%
	GINA	10, 45%	7, 33%

Location of MPE Discussion

The majority (14/22, 64%) of DTC consent forms provided MPE information at any point in the form, whereas AC consent forms often (14/21, 67%) specifically provided MPE information in the "Risks" section of their forms.

Disclosure/Return of Results

Given that DTC genetic testing companies do not have an ordering clinician we did not assess whether the DTC consent forms mentioned disclosure by a clinician. Approximately half (11/21, 52%) of AC consent forms mentioned MPE result disclosure by a clinician. The language around whether or how potential misattributed paternity would be disclosed to the ordering physician varied. Some forms stated that an indication of non-paternity will only be disclosed to a physician "if it potentially impacts medical care, and [the patient has] consented to receive this type of result," (AC 19). In contrast, other forms suggested that misattributed paternity would be disclosed to the physician, but not to the patient (e.g. "If testing reveals the family relationships are not as expected (for example, non-paternity), this information will be relayed to the healthcare provider(s) for discussion, but will not be included in the patient's report," (AC 17). One form claimed that a non-paternity result would only be "verbally reported to the ordering healthcare provider but will not be written in the final report" (AC 21). Only a few forms (2 forms from each consent form type) stated that misattributed paternity will not be disclosed "unless [such results] have direct clinical significance" (AC 12). However, a clear definition of what constitutes clinical significance was not provided. Only 1 (5%) DTC consent form, and 5 (24%) AC consent forms explicitly specified that the ordering healthcare provider will be responsible for reporting the results to patients, placing the onus on healthcare providers to return a non-paternity result.

Recommended resources

While learning an unexpected parentage result through either DTC or AC lab results may be upsetting, only 2 (9%) of DTC consent forms recommend seeking mental health support, whereas no AC labs recommend seeking mental health support. However, the majority of both

DTC (13/22, 59%) and AC (16/21, 76%) labs either mentioned the importance of speaking with a genetic counselor or directly offered genetic counseling support. Two DTC consent forms "[recommend] that [the patient] consult with a genetic counselor or [their] healthcare provider before consenting to this testing, and that [they] speak to a genetic counselor or [their] healthcare provider about [their] results (DTC 13, DTC 15). Similarly, two AC labs' consent forms had a specific section titled "Access to Genetic Counseling" and stated the following: "Genetic counseling is recommended as it can help you understand genetic testing and your results. Access to a genetic counselor may be provided by the research project or company/institution facilitating this testing or through your doctor. Furthermore, you can find a genetic counselor local to you or a genetic counselor that offers telehealth services through the National Society of Genetic Counselors (https://findageneticcounselor.nsgc.org/)" (AC 5, AC 6). Only one other form from a DTC company provided a link to find a genetic counselor.

Impact of Results

Consent forms were analyzed for discussion of the potential impact of results on one's family, and for oneself. Less than half of the DTC (9/22, 41%) and half of the AC (11/21, 52%) consent forms describe how results may impact the patient's family members. This description was either in reference to a potential MPE finding or heritability of mutations found. Two forms provide a description of this which might be as simple as "Your relatives may be upset to learn that they may be at risk for a disease" (AC 15; AC 11), or as complex as "Your test results may reveal information about the genetic makeup of your relatives. In some cases, it may reveal unexpected relationships, such as non-paternity. If this is a risk for the test you are taking, you should consider whether you want to tell family members you are being tested," (DTC 7). In terms of

addressing the personal impact of results, more DTC (10/22, 45%) mentioned this concern as compared to AC consent forms (7/21, 33%). These discussions focused on the psychological ramifications of learning of one's results. For example, one DTC consent form stated that "You may learn unexpected or potentially distressing information about your health or ancestry" (DTC 21), while an AC consent form stated that "Genetic testing may cause emotional stress. Some people may feel anxious or depressed after learning genetic information about themselves and/or their children." (AC 21).

Policy mentions

Consent forms were specifically searched for mentions of both the ACMG and the Genetic Information Nondiscrimination Act (GINA), given that the knowledge of specific policies may influence people's decisions to participate in DTC genetic testing or clinical genomic sequencing. The ACMG has published guidelines on reporting results of medically actionable, secondary or incidental findings, as well as variants of uncertain significance. Few (2/22, 9%) DTC consent forms mentioned these guidelines, whereas 14/21 (67%) of the AC consent forms mentioned ACMG guidelines. Most often, when the AC consent forms refer to the guidelines, this was in reference to an explanation of which variants will be reported. For example: "The American College of Medical Genetics (ACMG) has published a series of guidelines for the reporting of these types of medically actionable or secondary findings (including PMID: 34012068). These guidelines include a list of genes, which are updated occasionally, that are considered medically actionable and indicate laboratories should report pathogenic (disease-causing) and likely pathogenic findings in these genes. In accordance with an update to this policy statement (PMID: 25356965), you and your provider may choose to opt-in to have these

findings reported — please indicate this selection in the Patient Reporting Options and Release of Updated Results section below," (AC 6).

In contrast, more DTC consent forms (10/22, 45%) included GINA mentions, as compared to AC consent forms (7/21, 33%). Some forms provided more detailed descriptions of GINA protections, as seen in the following statement:

"The Genetic Information Non-Discrimination Act ("GINA") is a federal law that prohibits discrimination in health coverage and employment based on genetic information of individuals. GINA…prohibits most health insurers or health plan administrators from requesting or requiring genetic information of an individual or an individual's family members, or using such information for decisions regarding coverage, rates, or pre-existing conditions. GINA also prohibits most employers from using genetic information for hiring, firing, or promotion decisions, and for any decisions regarding terms of employment…." (DTC 16). Other consent forms were less detailed e.g., "Within the United States, the Genetic Information Nondiscrimination Act (GINA), a federal law, provides some protections against genetic discrimination" (DTC 13).

Readability

A readability analysis was conducted for each consent form's coded statements that were relevant to this study. Both the Flesch Kincaid Grade Level and Flesch Reading Ease scores were calculated. The Flesch Kincaid Grade level was calculated to compare the collected consent forms' grade levels to OHRP's benchmark. As noted above, the OHRP recommends that consent

forms are written at a 6th-8th grade reading level [55]. In contrast, calculating the Flesch Reading Ease score provides a score that can be attributed to any education system with lower scores between 0-30 indicating a very difficult item to read equivalent to post-graduate abilities. Across all AC consent forms that were analyzed the Flesh Kincaid Grade Level ranged from 10.9-17.7 (mean=14.7). Across all DTC consent forms, the Flesch Kincaid Grade Level ranged from 12.1-20.6 (mean=15.6). Therefore, the difficulty level of both types of forms was well above the OHRP's recommendation. Similarly, across all AC consent forms the Flesch Reading Ease score ranged from 12.1-50.9 (mean=27), and across all DTC consent forms the Flesch Reading Ease score ranged from 10.1-42.9 (mean=24.5; Figure 2. These scores indicate that both types of forms are very difficult to read or at graduate level difficulty.

Figure 2.2: Readability of Informed Consent Documents

Discussion

This study analyzed 43 consent forms (22 from DTC companies and 21 from AC laboratories) in order to determine how genetic testing organizations prepare people for the possibility of a MPE discovered from the results of genetic testing. Findings revealed substantial variability across forms from both types of organizations. While nearly half of AC forms (48%) included a direct mention of MPE compared to just over a quarter of DTC forms (27%), a notable proportion of forms in both categories either addressed the topic only indirectly or omitted it entirely. When MPE was discussed, it was frequently located outside of a dedicated risk section, particularly among DTC forms. It is possible that this is due to the lack of standardization among the DTC forms resulting in more variability in structure. Disclosure practices were inconsistently defined, with variation in whether results would be shared with a clinician, whether the patient would be informed, and who would bear responsibility for delivering MPE findings. Mental health

resources were rarely recommended, and a readability analysis revealed that both DTC and AC forms exceeded the reading level recommended by the OHRP, with mean Flesch Kincaid Grade Levels of 15.6 (DTC) and 14.7 (AC). These findings point to a gap between what individuals may need to make a truly informed decision about genetic testing and what current consent practices provide. The potential discovery of a MPE carries significant psychological and familial consequences, yet the consent process, as it currently exists, does not consistently equip individuals to anticipate or navigate such an outcome. Standardization and intentionality in how MPEs are addressed at the point of consent are therefore warranted. Based on these findings, the following changes to the informed consent process are recommended: (1) state the possibility of identifying mis-attributed paternity; (2) ensure understanding during the consent process; and (3) standardize disclosure practices. Results related to each of these recommendations are discussed here, in turn.

Recommendation 1: State the possibility of identifying mis-attributed paternity

AC laboratories more frequently explicitly referenced MPE than DTC companies, and when referenced it was more often embedded within the risk or limitations sections of the consent form. Even when referenced, vague phrasing could result in readers not understanding that the consent form was alluding to the possibility of a MPE. These findings are consistent with prior analyses demonstrating variability and ambiguity in DTC company and AC laboratory consent language regarding the possibility of a MPE.[34–36] Instead, it would be better if all patients and consumers who choose to obtain genetic testing or WGS/WES are prepared for the possibility of a MPE. This would require that the possibility be clearly addressed in the consent form *and* discussed during pre-test counseling.

Recommendation 2: Ensure understanding during the consent process

Over half of both types of consent forms mentioned meeting with a genetic counselor for either pre-test or post-test counseling. However, it was difficult to determine from the consent forms alone whether pre-test counseling was standard for either the DTC companies or the AC laboratories, although it is more commonly offered when ordering genomic sequencing from AC laboratories. Some researchers,[57] and professional organizations such as ASHG, recommend noting the possibility of a MPE in the consent form or more preferably discussing it during pre-test genetic counseling.[49] The emphasis on pre-test counseling by the genetics community, in tandem with informed consent, underscores the broader point—often emphasized in the bioethics literature—that informed consent should not be conceptualized solely as a document but as an ongoing communicative process.[58] Pre-test counseling offers an opportunity to extend the informed consent conversation, and discuss the possibility of an MPE result in a way that is tailored to patients' informational needs.[32] Empirical research demonstrates that interactive informed consent discussions, particularly those incorporating teach-back methods in which genetic counselors ask patients to explain in their own words the information that was discussed with them, improve comprehension and support informed consent during the genetic testing process. [59,60]

As another challenge to consent form understanding, the readability of the consent forms was found to substantially exceed the recommended 6th-8th grade reading levels.[55] None of the consent forms we analyzed fell below a 10th grade reading level and had average Flesch Reading Ease scores hovering between college- and graduate-level difficulty. Similarly, prior studies

demonstrate that genetic testing and genomic sequencing consent forms are often written at 7th-17th grade reading levels and have Flesch Reading Ease Scores ranging from 24-49.[36,50,51,61] Elevated literacy demands are especially problematic in DTC settings, where it is unclear whether pre-test counseling is provided or accessible. At least in the clinic, genetic counselors and other health care providers can discuss the possibility of a MPE, explore patients' readiness to receive such information, and clarify preferences regarding disclosure.

To better support comprehension, consent forms from DTC companies and AC laboratories should be made more accessible and digestible to the average patient and consumer. Some suggestions for changing consent forms to be more accessible and digestible include writing the consent form for a fifth grade reading level, adding images (e.g. cartoon illustrations), adding a "teach back" protocol as an assessment of understanding, and engaging with patient advisory committees to get feedback on consent documents while they are being developed.[62] Given that implementing pre-test genetic counseling in the DTC genetic testing environment may be challenging, one alternative is to implement video education instead with opportunities for consumers to ask follow-up questions to a genetic counselor if necessary.[63]

Recommendation 3: Standardize disclosure practices

Among AC laboratories, many forms indicated that MPE findings would be communicated directly to the ordering clinician. However, disclosure policies varied considerably. Some laboratories limited MPE disclosure to findings deemed medically relevant, others specified that clinicians, but not patients, would be informed, and a minority restricted communication about such results to a verbal discussion only. Notably, terms such as "clinical significance" were not

clearly defined, introducing ambiguity regarding thresholds for disclosure. This finding aligns with prior work documenting variability in return of results practices and laboratory policies for disclosing mis-attributed paternity results to parents or families in genomic sequencing.[35,64]

While a majority of the consent forms reviewed suggested reaching out to a genetic counselor to discuss one's results, the field of genetic counseling has not come to consensus on whether genetic counselors should disclose results suggesting non-paternity. This has resulted in disclosure occurring on a case-by-case basis.[32] Professional guidelines further illustrate this lack of consensus. While the ACMG has issued recommendations regarding the return of incidental or secondary findings in WES/WGS sequencing,[47,65] those recommendations suggest that non-paternity does not have the same clinical importance, and thus should not be disclosed as a formal result.[66] Other organizations such as ASHG also recommend avoiding disclosure of non-paternity,[49] whereas the National Society of Genetic Counselors (NSGC) in their statement on secondary and incidental findings do not provide any recommendations for non-paternity disclosure.[67] This lack of uniform guidance across professional organizations likely contributes to the heterogeneity observed in the consent forms regarding disclosure practices. Moreover, if the ordering healthcare provider or a genetic counselor chooses to disclose likely non-paternity to their patient, there are no guidelines for how to do so responsibly, and in ways that might reduce potential harms.[32,68] It is imperative that relevant professional societies align on their guidelines for disclosure to avoid continued confusion and provide guidance for clinicians tasked with delivering this kind of sensitive information to patients.

Policy references differed by sector. AC laboratories more frequently cited ACMG recommendations, whereas DTC companies more commonly referenced GINA. Although inclusion of policy references may signal regulatory awareness, reference alone does not resolve ambiguity regarding mis-attributed paternity disclosure practices, especially considering that the ACMG does not recommend disclosure. Referencing this policy does not ensure that the patient is prepared for the possibility of a MPE if non-paternity is disclosed.

Across both sectors' consent forms, there was a lack of focus on the familial and personal impact of results. Therefore, it was unsurprising that very few consent forms recommended seeking mental health support or provided resources for mental health support to help cope with potentially upsetting results. However, this is in direct contrast to research indicating the negative psychosocial impacts of a MPE and recommending immediate mental health support following non-paternity disclosure.[1,16,17,19,20,31,69] Failure to include information about mental health implications or support suggests DTC companies and AC laboratories may not feel responsible for providing assistance for potentially upsetting results. However, arguably, the companies and laboratories should provide assistance after disclosing potentially upsetting results. Therefore, where non-paternity is indicated, the genetic counselor or ordering healthcare provider should, at minimum, provide a list of mental health resources or referrals to the patient, and in cases where there isn't a genetic counselor or ordering healthcare provider like in the context of DTC genetic testing, mental health resources or should be offered as part of the return of results process.

Limitations

Despite systematic searches and direct outreach, consent forms were not obtained from all eligible organizations, and the sample described here may not fully represent universal consent practices. Additionally, our analysis was limited to written documentation and did not assess the broader consent process, which in clinical and research settings may include verbal pre-test counseling or other verbal consent conversations that help mitigate difficult readability or gaps in written or electronic consent forms. Readability analyses were confined to coded MPE-related sections and may not reflect the overall readability of each document.

Conclusion

As DTC genetic testing and clinical genomic sequencing continue to expand, MPEs will likely become more common. Our analysis shows that consent forms across both DTC genetic testing and clinical genomic sequencing in academic and commercial laboratories vary widely in how they communicate the possibility of a MPE, often exceed recommended readability levels, and present inconsistent disclosure practices. Notably, very few forms recommended or provided mental health resources to help cope with the psychological implications of a MPE. These findings suggest that many individuals may enter testing without adequate preparation for the potential discovery of mis-attributed paternity. Organizations offering genetic testing should therefore strengthen the informed consent process by clearly stating the possibility of a MPE, helping individuals understand the potential implications of such findings, establishing more consistent disclosure practices, and ensuring that mental health resources or referrals are made available as part of the return of results process. Addressing these issues will better support informed decision-making and may help reduce potential psychosocial harms associated with unexpected MPE discoveries.

Chapter 3: Characterizing Social Support for Donor-Conceived People on Reddit: A Content Analysis

Abstract

Purpose: The widespread use of direct-to-consumer (DTC) genetic testing has transformed donor conception by eliminating donor anonymity and enabling people to discover their donor-conceived status without prior disclosure. In response, donor-conceived people (DCP) have turned to online communities for support. This study examines how social support is requested and provided within one online community for DCP.

Methods: A content analysis was conducted of the 100 most commented posts and their 3,797 associated comments from the public Reddit community, r/donorconceived. Using the Social Support Behavior Code – informational, esteem, emotional, and network support – as an *a priori* codebook, posts and comments were categorized in terms of the type of social support represented.

Results: Informational support predominated, appearing in 86% of messages, with situation appraisal and sharing one's own experience emerging most frequently. Discussions focused on disclosure timing, family relationships, donor contact, ethical concerns about the fertility industry, and access to donor medical history. Esteem support (20%), emotional support (14%), and network support (5%) appeared less frequently but played meaningful roles in validating emotions, showing appreciation, and alleviating isolation. Informational support often functioned as emotional support when perceived as personally relevant, blurring traditional distinctions between support categories. These findings highlight the central role of peer informational

exchange in helping DCP make sense of their experiences and underscore the importance of timely disclosure, access to medical history, and transparent fertility practices.

Conclusions: Online communities represent a critical source of support for DCP navigating identity, family relationships, and ethical concerns in the DTC genetic testing era.

Introduction

Background

Parents who used donor eggs, sperm, or embryos, to have a child were historically told by their doctors and society to keep it confidential due to the stigma surrounding needing assistance to conceive.[10,11] To maintain this secret, fertility clinics offered, and parents often chose, to use an anonymous donor. However, due to the widespread uptake of direct-to-consumer (DTC) genetic testing genetic testing, anonymity can no longer be guaranteed to parents or donors. Indeed, DTC genetic testing has profoundly reshaped this landscape, making it common for individuals to discover their donor-conceived status without parental or donor disclosure.[12–14] These shifts have intensified debates about donor anonymity, identity-release policies, and what information clinics and gamete banks should maintain and share with offspring throughout donor-conceived people's (DCP) lives.[70]

Prior research documents a variety of preferences among DCP regarding contact with donors and donor siblings, with motivations such as curiosity, identity, and access to health history driving preferences.[71,72] For some, discovering one's donor-conceived status via DTC genetic testing is intertwined with identity disruption and complex renegotiations of family relationships, underscoring the value of supportive communication and developmentally appropriate, ongoing storytelling about origins within families.[16,17,19,73–76] Family context matters: supportive environments, regardless of donor type, are associated with more favorable psychological adjustment.[74,77] As DCP seek clarity about genetic heritage and attendant disease risks, calls have grown for systematic maintenance and sharing of updated donor medical histories to meet DCP's health information needs.[70,78]

Online communities have become central spaces where DCP seek and exchange information.[20,28,29] Thousands seek online peer support groups for a range of experiences which people may be reluctant to discuss with family or other professionals including genetic counselors, social workers, family therapists, and psychologists. Utilizing online communities for social support also transcends geographic boundaries—an important characteristic given that a person may not know anyone else who is donor-conceived within their local community or social network. Prior research has identified DTC genetic testing communities on social media, such as Reddit, Twitter, 4chan, YouTube, and TikTok, focusing on which DTC companies consumers used and the type of information they learned (e.g., health, kinship, ancestry, etc.).[28,37–46]

Despite preliminary evidence from qualitative interviews that individuals turn to these online groups for general support,[20,29] prior studies have not analyzed how such subgroups serve as a place to exchange informational support. Yin et al. (2022) suggested that future research study the scope of people's use of online communities as a resource for managing surprising discoveries made from DTC genetic testing.[28] Directly analyzing the contents of one or more such online communities presents an opportunity to explore the informational support needs of DCP.

Objectives

This study aims to identify the types of social support given and received via an online community for those who are donor-conceived. This study had two research questions: (1) What

types of social support are *users requesting* in an online community focused on donor conception?; and (2) What types of social support are *users providing* in an online community focused on donor conception?

Methods

Data source

Reddit is one of the most popular social media platforms in the world, with approximately 765 million monthly active users.[79] Reddit also houses more than 138,000 active subreddits addressing different topics, which often accompany a variety of community-made rules (e.g., be respectful, no exposing group member's identities) to help govern the group.[80,81] Subreddit titles have the following format "r/" and the created topic name. Reddit is mainly a public platform where, with few exceptions, any person, whether they have a Reddit account or not, can access the content.[80] Reddit also affords users the ability to create pseudonymous usernames so that they can remain unidentified while interacting on the platform, which may reinforce user's comfort in sharing private information and participating in conversations regarding potentially taboo, sensitive or controversial topics.[82] While prior work suggests that users who remain anonymous on platforms such as Wikipedia may be mistrusted,[83] Reddit-specific research indicates that user anonymity on the platform results in more helpful and emotion-centered feedback, especially in the context of asking for and receiving social support.[33]

Data collection and sampling

To identify relevant donor-conceived public subreddits three selection criteria were used: (1) community rules restrictions, (2) at least 100 relevant posts with comments, and (3) an indication

that the subreddit was used for social support. A subreddit was regarded as unusable if its community rules discussed stipulations or prohibitions against participating in research activities. Relevant posts and comments were assessed according to whether they included keywords such as “23andMe”, “Ancestry”, “AncestryDNA”, “DNA”, or “genetic.”

Three donor-conceived subreddits were identified: *r/donorconception, r/askadcp, and r/donorconceived*. *r/donorconception* had no posts with the aforementioned keywords and was excluded. *r/askadcp* has community rules that indicate that this group is for those who are not donor-conceived to ask questions to those who are. As this does not serve as a support group for donor-conceived people, this group was excluded. Finally, *r/donorconceived* had no community rules restrictions, contained over 100 relevant posts, and had several posts and comments stating that this group serves to provide support. Thus, only this subreddit was used for the current study.

Using Reddit API Wrapper (PRAW), the top 1,000 posts and all (n=12,289) corresponding comments were downloaded from the *r/donorconceived* subreddit spanning February 2015-March 2025. Given the size of *r/donorconceived*, the top 1,000 posts and corresponding comments includes all content from the above date range. Next, any posts or comments that were marked deleted by the user were manually removed from the dataset. Finally, to focus on posts regarded as most successful within the *r/donorconceived* community, the top 100 most commented posts were sampled, with comment values taken as proxies for levels of community engagement.[82,84] The top 100 posts and their 3,797 associated comments were organized chronologically into separate documents, with one document per post (n=100), each document

containing all corresponding comments in the order they are displayed to users on the web (e.g., in a hierarchical thread showing replied and ordered by the number of "upvotes" and time according to Reddit's internal algorithm).

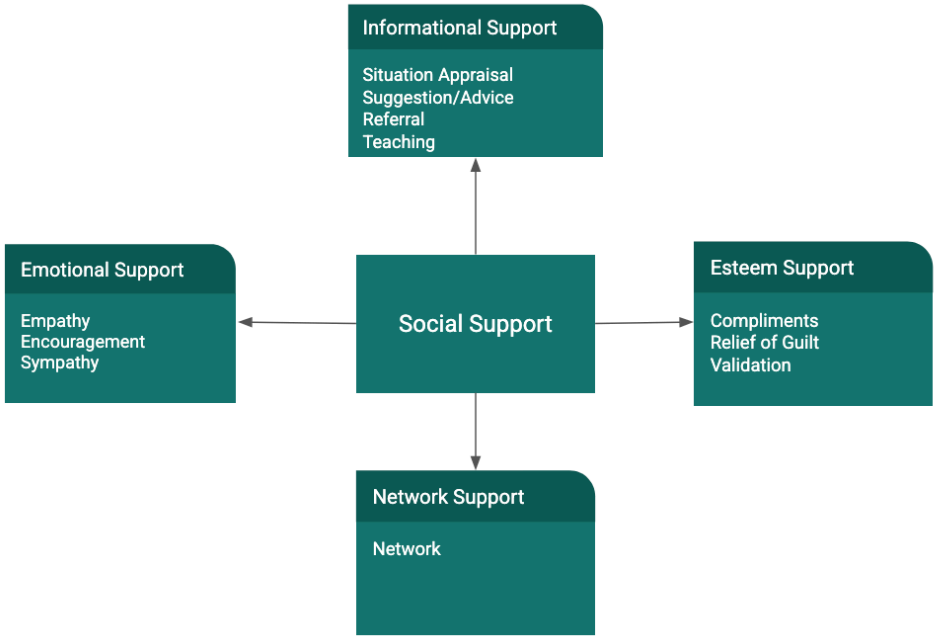
Data Analysis

A directed content analysis, or "research technique for making replicable and valid inferences from texts to the contexts of their use", was used to analyze the final dataset.[56] All extracted posts and their associated comments were analyzed by categorizing or "coding" texts and writing research memos throughout the coding process. *Atlas.ti*, a qualitative analysis software, was used to conduct the analysis. Each post and its associated comments served as the unit of analysis and were coded in their entirety as one entity.

Deductive Coding

A deductive codebook was developed for analysis, based on Cutrona and Suhr's (1992) Social Support Behavior Code (SSBC),[85,86] one of the most frequently used frameworks for the analysis of social support. The SSBC outlines five categories of social support: informational, emotional, esteem, network, and tangible. Because tangible support is less relevant in many online communities, where physical or material aid is rarely exchanged, that category was excluded from the codebook.[87,88] Each of the remaining four categories can be broken down into more specific subtypes of social support (see Figure 1 for more details).[85,87,89]

Figure 3.1: Social Support types and subtypes adapted from the Social Support Behavior Code[84]



Inductive Coding

Two additional, inductive subcodes were included that frequently emerged in the data but were not included in the original SSBC framework: appreciation and sharing one's own experience. Though neither of these subcodes were originally included in the SSBC, the latter has been identified by previous researchers as an important, subtype of social support.[90]

To characterize the nature of exchange of support in the online discussion, each coded post or comment was categorized as "support seeking" or "support providing". In some cases, a comment was categorized as both, when the user both provided support and requested support. Support seekers were defined as someone who writes a post either asking a question or expressing emotional upset, whereas a support giver was defined as someone who comments on a post offering an answer to a question, a similar life experience, or emotional validation.

Additionally, a post or a comment could be coded as both support seeking and support providing or multiple types of support (e.g., situation appraisal and empathy). See Appendix B for final codebook.

Two coders (BC and MP) independently coded all posts and corresponding comments. During the coding process each coder wrote detailed memos describing any questions that came up while coding. Intercoder reliability was calculated over all judgements and deemed sufficiently reliable (Krippendorf's alpha =.85).[56] The two coders met on a weekly basis after coding each week for reconciliation.

Ethical considerations

I am committed to protecting participant privacy to the extent that I am able. Given that the data that I analyzed includes sensitive topics from a potentially vulnerable population such as those who are donor-conceived,[80] I have not included exact quotes or usernames. Instead, I have included fabricated or synthetic quotes, developed using a method known as ethical fabrication, which involves borrowing information from multiple quotes and paraphrasing to preserve the privacy and autonomy of the users in this subreddit – consistent with guidelines for social media research.[80,91] As part of the analysis phase, I conducted a Google search of each fabricated quote to ensure that the quote used cannot be traced back to the original Reddit user. I received approval from the University of Washington IRB to conduct this study. The IRB waived the need for consent. While this waiver allowed me to proceed without obtaining user consent, I recognize that some users might still have preferred the opportunity to provide it.

Reflexivity statement

Newton (2022), a donor-conceived person and scholar, argues that qualitative research on donor conception requires researchers to reflect on their positionality given that their experiences and perceptions may influence their research findings.[92] The analysis was informed by the complementary expertise of two coders: one with extensive experience in qualitative research, bioethics, and public health genetics (BC), and another with qualitative research training in related health contexts (MP). While no team members had personal experience with donor conception, we sought to approach the data with sensitivity to the topic and a commitment to accurately representing the community's perspectives. Regular reconciliation meetings allowed us to compare coding, address ambiguities, and consider alternative interpretations, strengthening the reliability of our analysis. We documented each stage of data preparation, coding decisions, and the creation of ethically fabricated quotations to ensure transparency and auditability.

Results

Of the total 3,797 posts or comments in our dataset, 351 of them were coded as "nothing" because they did not request or provide any type of support. Percentages for each social support subtype were calculated across both support providers and support seekers, with all messages serving as the denominator (n = 3,797; Table 1). Overall, users who participated in this subreddit were mostly individuals who found out that they were donor-conceived, but there were also some individuals who identified as current or soon-to-be recipient parents (i.e., parents who received a donor egg, donor sperm, or donor embryo), donors (of egg, sperm, or embryos),

researchers interested in donor conception, or medical or legal professionals who work in the fertility industry. Non-DCP usually identified themselves before writing a post or comment. Because it was often unclear who was posting or commenting all posts and comments were included in the analysis regardless of poster type, and we are unable to estimate the relative proportions of different poster types (e.g., donor-conceived people, recipient parents, donors). Unless explicitly noted otherwise, the focus of our qualitative findings, themes, and quotes has been on DCP posters. Informational, esteem, emotional and network support and their subcategories are discussed below.

Table 3.1: Frequency distribution of social support (N=3,797)*

Support Category	**Provisions n (%)**	**Requests n (%)**	**Overall n (%)**
Informational	**2,925 (77)**	**472 (12)**	**3,281 (86)**
Referral	195 (5)	16 (<1)	195 (5)
Sharing Own Experience	850 (22)	146 (4)	956 (25)
Situation Appraisal	1364 (36)	168 (4)	1480 (39)
Suggestion/Advice	329 (9)	77 (2)	406 (11)
Teaching	187 (5)	65 (2)	244 (6)
Esteem	**722 (19)**	**23 (1)**	**743 (20)**
Appreciation	249 (7)	0 (0)	249 (7)
Compliments	127 (3)	0 (0)	127 (3)
Relief of Guilt	59 (2)	5 (<1)	64 (2)
Validation	287 (8)	18 (<1)	303 (8)
Emotional	**514 (14)**	**23 (1)**	**537 (14)**
Empathy	205 (5)	20 (1)	225 (6)
Encouragement	154 (4)	3 (<1)	157 (4)
Sympathy	155 (4)	0 (0)	155 (4)
Network	**161 (4)**	**44 (1)**	**197 (5)**

Network	161 (4)	44 (1)	197(5)

*The n represents the number of posts exhibiting each support type. As each post could exhibit more than one support type, the overall does not represent the sum of provisions and requests, and the number of posts exhibiting a support category (e.g., informational) may not be the sum of its component support types. Percentages were calculated by taking the number of excerpts and dividing by the total number of posts (N=3,797).

Informational Support

Informational support was the most common type of social support offered or received (3281/3,797, or 86% of total posts and comments). The following subtypes of informational support were identified among the posts: situation appraisal, sharing one's own experience, suggestion/advice, teaching, and referral.

Situation appraisal is defined as asking for or helping someone to provide perspective or analyze a situation. Situation appraisal was the most common (1480/3,797, 39%) type of informational support across support seekers and support providers. Quotations coded as this subtype covered several topics including reflections on discovering one's donor conception status. Support providers tended to share their emotional reactions related to the timing of learning their donor-conceived status. For example, users (who were donor-conceived) noted that their perspective on their donor-conceived status was positive when they (1) knew that they were donor-conceived from birth (or a young age) and/or (2) had both a good relationship with their family, the donor, the donor's family, or half-siblings. Users' perceptions tended to skew negative (noting that their donor conception experience was "traumatizing") when they found out later in life and/or had difficult relationships with their recipient parents, the donor, the donor's family, or half-siblings. In general, users echoed the need for recipient parents and donors to listen to DCP's perspectives to better understand how donor conception affects them. Users also expressed opinions that DCP

should have access to their donor's medical history, regardless of the contact preferences of the donor or donor-conceived offspring. Additionally, users requested and provided thoughts on the ethical implications of donor conception including critiques on the fertility industry more broadly. Many users felt that the fertility industry was unethical, and various reforms would be required for the industry to become "ethical." For instance, one user stated that "the only ethical way for donation is using a known donor", while another stated that "to do donor conception ethically, there should be a rule about how many pregnancies can result from one donor."

Sharing one's own experience was defined as asking for or providing one's personal life experience. Sharing one's own experience was the second most common (956/3,797, 25%) subtype of informational support across support seekers and support providers. Both support seekers and support providers detailed anecdotes of learning that they were donor-conceived, expressing emotions such as shock, confusion, curiosity, betrayal, anger, overwhelm, identity disruption, and reevaluation of family dynamics. A common experience was that a support seeker would divulge a detailed narrative of their experience and follow this with a request for others to do the same. Support providers responded by providing equally, if not more, detailed responses with their experiences. Nearly 20% of support provider responses also included their perspective (situation appraisal) on their experience as well. Experiences often contained descriptions of the number of half siblings that were identified from DTC genetic testing, the age at which users learned that they were donor-conceived (ranging from birth to 63 years old) and attempts to contact newly identified family members. As part of sharing their experiences, both support seekers and support providers often ended up re-evaluating family dynamics. For

example, users often remarked that the parents who raised them were their parents, whereas donors were thought of as only being valuable for contributing biological material.

Notably, some users who received responses that were categorized as situation appraisal or sharing one's own experience described these interactions as emotionally supportive. Although these responses were primarily informational in content, users frequently expressed appreciation, indicating that the information provided helped them make sense of their situation and reduced feelings of isolation. For example, users thanked others for "sharing [their] story", for "expressing [their] opinion" which made the user feel "less crazy" or explicitly stating that the response was helpful. These reactions suggest that informational support may take on an emotional function when users perceive the information as personally relevant and validating. In these cases, the act of contextualizing one's experience or normalizing uncertainty appeared to foster reassurance and affirmation, blurring the distinction between informational and emotional support. Figure 2 presents a sample pathway through which informational support might function as emotional support, contingent upon the perception of its relevance.

Figure 3.2: An example pathway from informational support to emotional support.

Suggestion/advice was the third most frequent (406/3,797, 11%) subtype of informational support. Many of the questions in this category were posed by current or future recipient parents. Advice centered around the following types of recommendations: (1) for those questioning their relatedness to their parents and siblings, users recommended DTC genetic testing using a search angel (i.e., a volunteer who helps people identify their biological parents and families), and how to have conversations with a donor, half-siblings, and parents; (2) for those questioning when to tell their donor-conceived children about their conception, users recommended telling children from birth (and if it is past that time, as soon as possible), (3) for those intended parents

questioning what type of donor arrangement they should enter into, users recommended an open/known donor, and (4) lastly, users recommended attending therapy and joining support groups to cope with the news of donor conception.

Teaching was defined as asking for or giving instructions or an explanation about biological or legal information. Teaching came up in 244/3,797 (6%) of all messages. Users requested clarification about scientific/biological implications and possibilities (e.g., demand on the body to extract eggs, oldest age to have a safe pregnancy, health risks for children born from IVF, fertility industry practices including information about sperm banks and their databases, while others asked about country- (and in the U.S., state-) specific legal policies regarding assisted reproduction. In response, users typically provided answers to the questions. In terms of country-specific regulation, support providers pointed out that some of their home countries forbade donors to make money from their donation, while in other countries, like the U.S., financial compensation for both sperm and egg donation often paid for donors' educational expenses (e.g., medical school). Additionally, several users discussed both country-specific and U.S. state-specific legal landscape regarding rights of donor children, donors, and recipient parents. Referral was the least frequent (195/3,797, 5%) subtype of informational support. Users gave referrals for various types of resources including for books (e.g., *Inheritance* by Dani Shapiro, *Three Makes a Baby* by Jana M. Rupnow), other online communities (e.g. a large known community on Facebook, various TikTok videos), podcasts, specific DTC genetic testing companies or third-party services (e.g. 23andMe, GEDMatch), news articles, laws, organizations (e.g., Right to Know, Donor-conceived Community), and academic research papers.

Esteem Support

Esteem support, the second most common type of social support, was requested or provided by users 20% (743/3,797) of the time. Esteem support was captured using four subtypes: validation, appreciation, compliments, and relief of guilt.

Validation was the most common (303/3,797, 8%) type of esteem support. Users requested validation by asking community members whether their feelings "make sense", or if anyone else felt the same way they did. At times, users explicitly confirmed that they felt validated by others' responses. Examples of users' validating responses include saying things like "I agree," "that makes sense," "you are 100% right," and "your feelings are valid."

Users offered appreciation in 7% (249/3,797) of messages. Messages of appreciation were evident in the form of statements of thanks for asking questions, supportive messages, thoughtful perspectives and advice, and sharing experiences of learning that they are donor-conceived.

Compliments were offered even less frequently than notes of appreciation (127/3,797, 3%). Compliments spanned several categories including complimenting other users' behaviors, choices, and experiences regarding how users interacted with known and newly identified family members, telling their child from birth that they were donor-conceived, and using a non-anonymous donor.

Relief of guilt was defined as reassurances or explanations that help reduce feelings of blame, shame, or guilt. Relief of guilt was the least common (64/3,797, 2%) support subtheme among

all esteem-associated messages. The three requestors that shared feelings of guilt did so in the context of (1) feeling ashamed about continuing to express emotions about their newfound donor conception status, (2) feeling immoral for thinking that donor conception is ethically problematic, (3) feeling, as a donor-conceived person, like they were "… made wrong. Like [they] [were] never meant to belong. It's suffocating feeling unwanted. [They] just wish [they] could feel close to [their] family again." Conversely, support providers sought to relieve requestors' guilt with statements like "it's not your fault", "you did nothing wrong", and letting users know that they should not feel shame or blame for being donor-conceived or about their behaviors since learning of their donor-conceived status.

Emotional Support

Emotional support included three subtypes: empathy, encouragement, and sympathy. Overall, emotional support was identified in 14% of all messages.

Among both support requestors and support providers, empathy was present in 6% (225/3797) of posts and comments centered around emotional support. When requesting empathy, some users directly asked if anyone else feels the same way or described that they are just "venting" in their post, while other users didn't request empathy in the form of a question or explicitly. For example, users may have described not knowing "how to feel" and needing help from someone who understands them. In contrast, users provided empathy by making statements like "I totally understand how you feel", or "the same thing happened to me," indicating that they understand and often share the feelings that the requestor has because they went through the same or similar experience.

Encouragement was rarely mentioned (157/3,797, 4%) across all messages. When requestors asked for encouragement, they did so by asking for reassurance or encouragement. When support providers offered encouragement, it tended to be at the end of their message with wording along the lines of "wishing you good luck", "wishing you the best", "it's going to be okay" and hope for finding or connecting with previously unknown relatives.

Like encouragement, sympathy was also rarely requested or provided (155/3,797, 4%) across all messages. Sympathy was given using statements like "I am so sorry" in response to requestors voicing their upset towards their experiences of finding out they were donor-conceived including: their parents telling them sooner (or more often, not telling them at all), difficulty in contacting their donor, and finding out about numerous half siblings (including several cases where a fertility doctor used his sperm instead of that from a chosen donor or the father).

Network Support

Network support was the least identified (197/3,797, 5%) type of social support across all messages. Users tended to request network support by asking things like "I need someone to talk to about this," or "I felt the need to come here because I didn't know anyone else like me." In response, those who chose to provide network support made statements like "you are not alone" or offered fellow community members to send them a direct message if they needed someone to talk to. Additionally, a few group members explicitly stated that this subreddit serves as a "support group" for those who have learned about their donor conception at any point in their lives.

Discussion

This study's sample of posts and comments mainly centered around the exchange of informational support with situation appraisal and sharing of one's own experiences predominating. Members frequently sought and provided perspectives on donor conception experiences, discussed complex family dynamics, analyzed the ethical implications of donor conception, and shared insights into the practices of the fertility industry. Personal storytelling was central to these exchanges, with many users recounting their own experiences of learning they were donor-conceived, discovering half siblings through DTC genetic testing, and navigating contact with donors. Although exchanged less often, suggestions and/or advice-giving was another common feature of the subreddit's discussions. Community members offered recommendations related to DTC genetic testing, disclosure timing, donor type selection, and accessing professional mental health support. Teaching exchanges were focused on describing factual explanations of biological processes, legal regulations, and international differences in donor conception practices. Referrals to books, advocacy groups, online communities, and other external resources further underscored the online community's role as a place for information sharing.

Interestingly, emotional support and esteem support were exchanged less frequently than informational support. It is possible that this is because some recipient parents were a part of this subreddit instead of DCP only and were mainly seeking information rather than seeking emotional and esteem support, which could result in this frequency distribution. Nevertheless, emotional support and esteem support still seemed to play a meaningful role in community

interactions. Members validated each other's feelings, expressed appreciation for shared perspectives, offered compliments, and sought to alleviate feelings of guilt or shame. Empathy, encouragement, and sympathy were present in responses to stories of difficult family relationships, delayed disclosure, or unexpected donor sibling discoveries. Network support, while rare, reflected the community's function as a social connection point for those who felt isolated in their offline lives.

One key finding from this study is that the boundaries between support categories may be less distinct than traditionally conceptualized in studies of health-related online communities. Though this literature has frequently operationalized informational support and emotional support as separate constructs,[87,93] Chen (2021) has argued that the process for searching and obtaining information can result in emotional reactions.[94] In our study, though informational support emerged as the most frequently exchanged type of support, as reflected in social media authors' appreciation for situational appraisal and shared experiences provided by others, the receipt of information also served as emotional support. While emotional support was expected to dominate interactions in a community such as this one discussing potentially traumatic experiences, in many cases the provision of information appeared to provide comfort. Receiving relevant information seemed to generate emotional relief, effectively acting as emotional support. This study provides novel evidence that within this donor-conceived community, contingent upon it being perceived as relevant, informational support may serve as a pathway to emotional support. For example, users often asked if others were sharing the same experience as them, and when other users answered that they did, users felt understood and validated.

Situation appraisal posts and comments frequently addressed how and when recipient parents disclose donor conception, with DCP highlighting the importance of telling a child at birth, a finding consistent with prior literature demonstrating that early disclosure and supportive family environments are associated with more positive adjustment among DCP.[73,74,77,95] The subreddit's emphasis on the timing of initial disclosure suggests that members primarily offered guidance on *when* to disclose rather than *how* to sustain these conversations over time, indicating that within this community informational support often centered on concrete decision-making rather than ongoing relational processes, highlighting both the practical orientation of online social support and potential gaps where continued guidance could be beneficial.

Discussions around contacting one's reproductive donor were mentioned across informational and emotional support categories. Like the users studied here, Jadva et al. (2023) found that there was variability in whether donor-conceived persons wanted to meet their donor, and if they were already in contact, and the nature of their connection (close vs. followed each other on social media, etc.),[71] demonstrating that there is not a uniform desire to contact, or experience of contacting one's donor. Additionally, a longitudinal study found that motivations for contact included curiosity around the personality of one's sperm donor and understanding one's family medical history.[72] Donors from this longitudinal study also supported giving out their health information without necessarily making themselves identifiable in order to provide an updated medical history information.[96]

Among those who shared their own experiences, identity disruption was often mentioned, indicating a need for esteem and emotional support. Carone et al. (2025), in a study evaluating the psychological impact of being donor-conceived, also observed identity disruption, and advised donor-conceived persons, especially adolescents, to seek out support to help navigate identity issues.[74] Similarly, past researchers have also identified the psychological impact of identity disruption, recognizing the need for support to address this issue.[16,17,19,75] Additionally, users in our study shared their experiences of identifying new donor siblings and integrating them into their families. Research on donor-conceived young adults demonstrates that a majority were able to create meaningful relationships with their donor siblings, however, it was difficult for new donor siblings to integrate into pre-existing networks, with original siblings tending to have the closest relationships.[76]

Practice implications

The study findings have implications and considerations for both the fertility industry and how DCP, recipient parents, donors, and their families can be supported. Understanding what informational needs DCP express and seek to meet in peer spaces offers useful context for thinking about how the fertility industry might better prepare and support individuals before and after consequential genetic discoveries. As informational support was the most discussed category among this online community, implications for informational support subcategories, including situation appraisal, sharing own experience, suggestion/advice, teaching, and referral, are considered here (Table 2).

Table 3.2: Practice implications for the fertility industry and improvements to support DCP, recipient parents, donors, and their families.

Support Category	Observation	Implication/Consideration
Situation appraisal	• Donor-conceived people's s (DCP) perceptions were positive when they learned of their donor conception early in life and had good relationships with their family, the donor, the donor's family, or half-siblings. • Perceptions were negative when discovery occurred later in life and had difficult relationships with their recipient parents, the donor, the donor's family, or half-siblings. • DCP discussed the need for recipient parents and donors to listen to their perspectives to understand the impact of donor conception. • DCP believed that they should have access to their medical history. • The community viewed the fertility industry as unethical, advocating for reforms (e.g., only using known donors, a quota for the number of pregnancies that can result from one donor.	• Fertility clinics may wish to consider offering guidance and resources to help encourage recipient parents to disclose donor conception from birth. • Donor medical history should be accessible to DCP in perpetuity. • Fertility clinics should require all donors to provide and regularly update their medical history. • Regulations should consider limiting the number of children conceived from a single donor.
Sharing one's own experience	• DCP reported emotions such as shock, confusion, curiosity, betrayal, anger, feeling overwhelmed, identity disruption, and reevaluation of family dynamics. • DCP generally agreed that recipient parents were their	• It may be helpful for clinics and relevant organizations to provide mental health resources such as support groups and professionals trained to help donor-conceived people.

	true parents while donors contributed biological material.	
Suggestion/advice	• For users questioning their genetic relatedness recommendations included direct-to-consumer genetic testing, using a search angel, and guidance on contacting newly identified relatives • Users recommended telling donor-conceived children from birth (and if it is passed that time, as soon as possible) • When selecting a donor, users recommended an open and known donor • Users recommended attending therapy and support groups to help cope with donor conception.	• Fertility clinics should offer resources on disclosure guidance. • Fertility clinics should offer a list of mental health providers who specialize in assisting DCP. • Fertility clinics should only allow open or known donors.
Teaching	• Users sought clarification on biological and legal aspects of donor conception including egg extraction risks, pregnancy age limits, IVF health risks, and fertility industry practices such as sperm bank databases. • Providers noted donor compensation varies by country (some prohibit payment, while others like the U.S., provide financial compensation for both sperm and egg donation). • Users discussed country specific and U.S. state specific legal landscape regarding rights of donor children, donors, and recipient parents.	• Fertility clinics should make information about their practices accessible. • There is a need for additional research to be conducted to examine implications which can later be conveyed to DCP.

Referral	• Users gave referrals for books, online communities, podcasts, DTC genetic testing companies or third-party services, news articles, laws, organizations, and academic research papers.	• Resources related to donor conception should be organized, available, and accessible to those impacted by donor conception.

In the context of users providing their perspectives (situation appraisal), many donor-conceived users wrote online that their perception of their donor conception was more positive when they were told beginning at birth or from a young age, and more negative when they found out later in life. Harrigan et al. (2015) argue that this is due to the identity disruption that ensues when learning of one's donor-conceived status.[97] As such, fertility clinics might consider offering guidance for recipient parents to tell their children from birth or a young age and provide resources to help facilitate these conversations. The Donor-conceived Network offers books about various family configurations for heterosexual couples, same-sex couples, and single parents using an embryo donor, a sperm donor, an egg donor, or surrogate.[98] Participants of *r/donorconceived* also recommended related resources for donor-conceived people. Alternatively, a research group at the University of Michigan developed and tested the Empower Parental Telling and Talking (TELL) Tool to assist recipient parents in disclosing their child's genetic origins.[99,100] It could be helpful to have resources like these made available to recipient parents by fertility clinics.

A commonly expressed informational need was the need for medical history, regardless of whether the donor wants to have any contact with the DCP or if the DCP wants contact with the donor. Accordingly, fertility clinics should require their donors to update medical history so that

DCP can always have current information of their medical history without having to contact the donor. The Ethics Committee of the American Society for Reproductive Medicine echoes this recommendation by arguing that health providers and fertility clinics should request and maintain health records of donors to ensure that the DCP receives their full medical history.[70]

In the context of posts and comments coded as situation appraisal, there was concern about the lack of a quota for the number of pregnancies that were permitted from one donor. While some countries may have legislation that governs the fertility industry, other countries have only professional guidelines, most of which have no legal authority. Additionally, there is limited evidence as to what the "right" number of children from one donor should be, with some sources offering 10 children being born per donor as the acceptable value, while others noting that up to 200 children is acceptable as long as this is not in an isolated population.[101,102] However, without an international registry it is impossible to know how many gamete banks donors may have donated to and how many resulting children a donor may have because some donors travel internationally to donate.[78] This becomes even more complex for donors who do not donate through formal channels such as sperm banks, but instead find recipient parents through Facebook groups, a common and cheaper alternative to identifying a sperm donor.[103] While the importance of establishing a quota to avoid consanguinity is self-evident, in practice it may be difficult to implement.

Users described several adverse emotions (e.g., shock, confusion, curiosity, betrayal, anger, feeling overwhelmed, identity disruption and reevaluation of family dynamics) and reactions to finding out that they were donor-conceived. To support people through learning of their donor-

conceived status, in addition to online communities like *r/donorconceived*, it would be helpful to have resources such as mental health providers who have specific training in helping DCP or who have the lived experience of being donor-conceived themselves. Some nonprofit organizations provide lists of therapists who have such specialized training.[104,105]

DCP present in *r/donorconceived* recommended that fertility clinics should only permit known or open-identity donors, with many users framing such arrangements as the only ethical option. Identity-release, also referred to as open-identity, describes when a donor-conceived person requests their donor's information once they turn 18 years old, and their donor's information is given to them by the bank. The majority of the sperm donors in Graham's (2022) study agreed, stating that it was a positive development that UK donors were no longer permitted to donate anonymously.[106] Moreover, research from sperm banks indicates that donors also prefer to donate as an identity-release donor.[96,107] This recommendation is based on a person's "right to know" their genetic origins. This recommendation is especially salient now as fertility clinics can no longer guarantee anonymity due to the ability to identify the donor using DTC genetic testing services. Even donors who did not submit their DNA to these companies can still be identified via matches with relatives who did. In practice, this would decrease the need to use DTC genetic testing services to identify donors, and limit the repercussions of identification without donor consent, given that donors will only be able to donate if they agree to be identifiable either as soon as possible, or when the child turns 18 years old. Several countries have created legislation either removing the option of donor anonymity or increasing accessibility to donor information.[74]

Users requested information about scientific/biological implications of using assisted reproduction technologies as well as the legal landscape of the fertility industry. Increasing transparency about clinic practices could help meet some of these informational needs. However, these changes alone may not fully address them. Future research, particularly studies that draw on larger or more diverse samples or that directly assess information gaps among individuals who are donor-conceived, could help clarify how best to support users' informational needs and evaluate whether increased transparency from clinics would meaningfully improve individual understanding.

Lastly, users also requested and provided referrals for various resources. It would be helpful for these resources to be organized and available for all parties impacted by donor conception.

Limitations

This study is limited in that its analysis reflects content from a single subreddit, meaning that the results may not be generalizable to other online donor-conceived communities. Furthermore, the results are only indicative of the most commented posts on *r/donorconceived*. It is possible that a different ratio of subtypes of social support from the SSBC may have been identified among posts/comments from other subreddits or if the subreddit had been sampled differently. Moreover, this subreddit may not be representative of all DCP because not all DCP may choose to join an online community, and the group of people who did join this online community may be systematically different than those who do not join any online communities. For example, this subreddit may over-represent those who seek peer interactions and underrepresent those who avoid disclosure of their donor conception status, do not feel like they need social support, or do

not want to seek information from online communities. Additionally, we included posts and comments from recipient parents, not just DCPs which may have influenced the results of this study.

Chen points out that using predefined measures such as the SSBC, while validated in other studies, may cause the researcher to miss overarching alternative themes in the data because coders are only looking at these preconceived categories.[108] The SSBC may not identify all the benefits of online social support groups, as it was created before these groups were popularly used. Additionally, at times we had trouble differentiating between subcategories of support types, as users would outline multiple ideas and forms of support in a single sentence or a longer comment. Ultimately, such comments were often double coded when it was hard to tease the differences apart.

Conclusions

This study evaluated the discussions on *r/donorconceived* by categorizing the top posts and corresponding comments by type of social support. Discussions on *r/donorconceived* mainly centered around informational support needs, especially conversations focused on situation appraisal and sharing lived experiences. Esteem, emotional, and network support topics were also identified, but appeared less frequently. The results of this study have practical implications for fertility clinics, sperm banks, direct-to-consumer genetic testing companies, international fertility regulations, and future research.

Chapter 4: Adjusting to life after a misattributed parentage experience: diverse needs and experience of online social support

Abstract

Purpose: The popularity of DTC genetic testing has led many individuals to report a Misattributed Parentage Experience or MPE, in which a presumed parent is revealed not to be

one's biological parent. MPEs can profoundly disrupt one's personal identity, cause psychological distress, and erode trust of one's parents. To cope, many consumers turn to MPE-specific social media groups for online peer support. While prior work has focused on the benefits of these communities, less attention has been paid to the limitations of such groups. Understanding why individuals join, stay, or leave such communities can provide important insight into the evolving support needs of individuals following a MPE.

Methods: A qualitative study was conducted using semi-structured interviews with 27 adults who experienced a MPE through DTC genetic testing. Participants were recruited from a larger study of FamilyTreeDNA users across two groups: those who joined MPE-focused social media support groups (n=18) and those who did not (n=9). Interviews were conducted via Zoom, transcribed, and analyzed using thematic analysis with iterative codebook development and consensus coding.

Results: Findings from this study emphasized that individuals who have a MPE are a heterogenous group with a variety of emotional responses and support needs. While some individuals who have a MPE view it as deeply distressing and actively seek support from online social support groups and mental health professionals, others integrate the information with relatively little disruption to their sense of self. The results suggest that online communities can play a vital role for some people, while for others may result in negative experiences. Participants from this study noted that opportunities for hybrid or additional in-person support are valuable.

Conclusions: This study is the first of its kind to focus primarily on both the benefits and limitations of MPE-specific online support communities. The findings emphasize that individuals who have MPEs are a heterogenous group with a variety of emotional responses and

support needs. Recognizing this diversity of experiences is essential for families, friends, mental health care providers, genetics providers/genetic counselors, and support organizations working with individuals experiencing MPEs to provide the most appropriate support.

Introduction

Direct-to-consumer (DTC) genetic tests have remained popular since the first genetic test was made commercially available in 2007. Now, almost two decades later, the DTC genetic testing market has only continued to increase, particularly with sales for such tests being offered during high-traffic purchase times such as Black Friday and Christmas.[5,6] As of 2024, over 40 million people in the United States have purchased a DTC genetic test.[7] DTC genetic tests are advertised

and sold directly to the consumer usually without the need for healthcare provider intervention,[109] and depending on the company, can provide information about the genetic basis of one's traits, wellness and health, and ancestry, as well as permit identification of genetic relatives. Identification of relatives most often occurs through genetic relative finder services where the user consents to their data being added to a company database with other consenting users' data so that the company can identify similar genetic profiles consistent with close biological relationship.[110] DTC genetic testing companies, such as 23andMe can provide information (with decreasing accuracy) to up to sixth degree relatives.[26,110]

While many people purchase such tests purely for leisure, others have identified more specific motivations for purchasing their test and using the genetic relative finder feature. For example, a 2022 study of approximately 24,000 FamilyTreeDNA users reported that those users chose to purchase a test and use the genetic-relative finder service for many reasons including to build a family tree or help a relative build one, search for a relative including a (biological) parent or child, and investigate something about a relative.[9] Significantly, 10% of participants in that study learned the identity of their biological father or biological mother.[9] That study is currently the most up-to-date and comprehensive research on why consumers have pursued DTC genetic testing to identify genetic relatives.

The popularity of DTC genetic testing has led a significant number of individuals to report a Misattributed Parentage Experience or MPE. A MPE suggests that one's presumed parent is not one's biological parent; in some cases, genetics-informed familial matching may identify the true biological parent instead.[1] MPEs can result from adoption, gamete donation, an extramarital

affair, or sexual violence. The prevalence of MPEs is estimated to range from 1.9% to 30%.[2–4] Furthermore, a recent Pew Research study suggests that the number of MPE cases could be even higher, at least amongst those who have participated in DTC genetic testing. The latter study found that 27% of individuals who self-identified as DTC genetic testing participants stated that they learned of new, previously unsuspected, relatives as a consequence of testing.[8] With the ripple effect of surprise DNA discoveries, the adjustment to an unexpected DNA discovery will become a more common life experience even for those not making a discovery involving their own genetic parentage.[8,10]

Having a MPE can be profoundly disruptive to one's personal identity,[15–18] lead to psychological distress,[19,20] and engender distrust of one's parents.[21] To cope with the potentially life-changing MPE resulting from a DTC genetic test, consumers have turned to social media for online peer support; a common choice seen in thousands of online peer support groups for a range of experiences of which people may be reluctant to discuss with family, friends, or professionals. Prior research on online communities suggests that these spaces can offer emotional validation, informational support, and a sense of belonging, particularly when individuals lack support offline.[30] Studies focused specifically on MPE communities similarly indicate that individuals value the opportunity to engage with others who understand the unique emotional and relational challenges associated with MPEs.[20,31]

While prior work has focused on the benefits of online support communities for those with MPEs[20,29,31], less attention has been paid to the potential limitations of these groups. Understanding both the benefits and drawbacks of participation in such communities and why

individuals choose to join, stay, or leave can provide important insight into the evolving support needs of individuals following a MPE. As a result, this study seeks to advance understanding of how individuals navigate MPEs that arise from DTC genetic testing. Here, the experiences of individuals who joined MPE-focused social media groups are compared with those who did not. By examining differences in emotional responses, family dynamics, and engagement with both professional and peer support, this study aims to capture a more comprehensive view of the range of adjustment processes following a MPE.

Methods

Sample and Recruitment

Two categories of participants were recruited: (1) people who experienced a MPE, and who subsequently joined a group on social media for support and (2) people who experienced a MPE but chose not to join a social media support group. Going forward these two groups will be referred to as the "social media group", and "no social media group" respectively. Potential participants were recruited from a larger study conducted at Baylor College of Medicine involving users of FamilyTreeDNA, a DTC genetic testing company.[9] In that parent study, Baylor College of Medicine staff emailed approximately one million FamilyTreeDNA customers. A total of 23,196 users responded, including 646 individuals who reported learning through FamilyTreeDNA results that at least one presumed parent was not biologically related to them. These individuals were invited to complete a follow-up survey, and 206 respondents indicated willingness to be recontacted for an interview study. From this pool, 60 individuals (30 in wave 1 of recruitment, and 30 in wave two of recruitment) who (1) consented to being recontacted, and (2) reported learning through FamilyTreeDNA results that at least one

presumed parent was not biologically related to them, were invited via an emailed recruitment flyer to participate in this qualitative interview study. A reminder email was sent out one month after each wave of recruitment. Snowball sampling was also used to supplement recruitment. During interviews, participants were asked whether they knew others who might be interested in participating and were requested to share the recruitment flyer with those potential participants.

Participants were eligible for the study if the met the following criteria: (1) they were 18 years of age or older; (2) were fluent English speakers and (3) had received a MPE as a result of DTC genetic testing. A MPE indicated that a presumed parent was not a biological parent; this could result from adoption, gamete donation, extramarital relationships, or sexual violence.

Potential participants were screened for eligibility by requesting they fill out a screening questionnaire on Qualtrics based on the above eligibility criteria. If they met the eligibility criteria, they were then asked to provide electronic informed consent. After consent was obtained, participants were then contacted via email to schedule an interview. Recruitment continued until thematic saturation had been reached, which is the point at which no new themes were emerging from interviews.[111] In practice, this was determined by reviewing notes after each interview to determine whether additional interviews were needed or if interviews were yielding redundant themes. After 27 interviews, we ended recruitment.

Data collection

All semi-structured interviews (n=27) were conducted over Zoom between June -September 2025. The semi-structured interview guide included questions about participants' initial

misattributed parentage experiences, use and accessibility of professional support, baseline social media use, motivations for joining an online social support community, motivations for leaving an online social support community, type of social support received, type and frequency of engagement within the online social support community, and demographic questions (see **Appendix C**). The interview guide was pilot tested with a member of the MPE community to ensure the questions were sensitive to the MPE community's terminology and needs. Feedback was incorporated into the final interview guide. Interviews lasted about 45 minutes on average. At the start of each interview, the interviewer reiterated the study purpose, procedures, potential risks and benefits, and participants' rights, including the option to decline to answer questions or withdraw at any time. Participants were given the opportunity to ask questions before proceeding. With participant consent, interviews were recorded and transcribed using Otter.ai. Transcripts were reviewed and de-identified by removing or replacing names and locations. De-identified transcripts were uploaded to Dedoose (Version 10.0.59), a qualitative software program for analysis.[112]

Data analysis

Interview transcripts were analyzed using qualitative thematic analysis.[113] The study interviewer (BC) and a secondary coder (LL) independently coded all transcripts in Dedoose. The coders developed an *a priori* codebook based on the interview guide. As coding progressed, the coders iteratively refined the codebook resulting in a final codebook (see **Appendix D**). During the coding process, both coders wrote memos documenting emerging patterns and questions. The

coding team met weekly to compare coding, discuss discrepancies and reach consensus. Once consensus was achieved, the finalized codebook was applied consistently across all transcripts.

Results

Participant characteristics

18 participants who joined at least one MPE-specific online group were interviewed, as well as 9 participants who did not join any MPE-specific online groups (Table 1). Participants who used social media (SM) (n=18) were younger on average than those who did not join a social media group (NSM) (mean= 61.5 years old vs. mean= 71.7 years old). Most participants across both groups identified as White and reported having obtained a bachelor's degree or higher level of education. Household income varied across both groups, with most participants reporting annual incomes between $100,000 to $200,000. The majority of participants also reported living in suburban areas.

Table 4.1: Participant characteristics

Demographic Information	**Used social media (n=18)**	**Did Not Use social media (n=9)**
Age		
Mean	61.5	71.7
Range	41-77	53-95
Race		
White	18	7
Asian	0	0
Black/African American	0	0
Native Hawaiian/other Pacific Islander	0	0
American Indian	0	1

Education		
High school	2	3
Associate's	1	0
Bachelor's	7	3
Master's	6	1
Doctoral	2	2
Income		
Less than $50,000	3	0
$50,000-$100,000	6	1
$100-$200,000	7	6
Greater than $200,000	2	2
Geographic area		
Urban	3	3
Suburban	11	4
Rural	4	2
Reasons for purchasing direct-to-consumer genetic test		
Genealogy interest	12	5
Advertisement	4	1
Christmas gift	1	1
Health reasons	3	1
Fun	0	1
Finding family	2	2
Active use of social media platforms		
Facebook	18	9
Instagram	7	3
TikTok	2	1
Reddit	2	1
Snapchat	1	0
Threads	1	0
Bluesky	1	0
X (Twitter)	0	1
Professional support		
Therapist	9	0
Psychic	2	0
None	7	9

*Participants can provide multiple answers which is why totals may equal more than the number of participants.

During the interview, participants were asked why they chose to purchase the DTC genetic test that led to their MPE. Genealogy interest was the most frequent motivation across both groups (n=12 SM; n=5 NSM). Seeing advertisements for DTC genetic tests was cited as a reason for testing primarily among the social media group (n=4), while health-related motivations were reported by a smaller number of participants in both groups (n=3 SM; n=1 NSM). Interest in finding specific biological family members was reported by two participants in each group, and one participant from each group described purchasing the test as a Christmas gift. When asked about general social media use (for any purpose), the majority of participants across both groups reported using Facebook and Instagram. Use of professional psychological support specifically in relation to participants' MPE differed across groups. The majority of the SM group participants also sought help from either a therapist or a psychic for their MPE, whereas none of the NSM participants reported accessing any professional psychological support.

Social Media Group Participants

Initial MPE

Almost all social media group participants reported feeling negatively when they first discovered their MPE status. Negative feelings included feelings of betrayal, anger, mourning/grief, shock, trauma, and sadness. Some of these negative feelings were due to the betrayal felt because at least one parent knew and never told them. As noted by one participant:

> "I felt like somebody pulled the rug out from under of me, it was so destabilizing, and I was angry because I had talked to my mother about this. I took care of my mother when she was dying… and she had every opportunity to come clean, and she never did." (Participant 04 social media).

However, others reported feeling sadness and sympathy for their parent(s). For example, one participant said:

> "I felt very sorry for my mother, who had long passed… because, number one, I thought she didn't feel that she could talk to me. And secondly, I felt bad for her, because I assumed that she just never knew [who my father was]" (Participant 10 social media).

Other negative feelings centered around grieving relationships with parents or family members who were still alive because of discovering they were no longer biologically related to them. Only a few participants from the social media group did not report the same feelings of intensity stating, "it wasn't an upsetting thing" (Participant 18 social media).

Within the sample, it was more common for participants to report that their biological mother knew who the participant's biological father was and kept it a secret than either the birth certificate father or the biological father knowing about their relationship to the participant. Some mothers appeared to have known (or strongly suspected) the truth about the participant's parentage but intentionally kept this information secret for decades. Alternatively, several

participants suggested that mothers did not definitively know who the participant's biological father was, often due to overlapping relationships, casual dating, or unclear timelines. For instance, one participant described:

> "My mother genuinely was like, 'Holy shit, like, I forgot about this guy.' Like, literally, she had a one-night stand… and then about a week or so after that event, my birth certificate father tracked her down… And then probably four weeks or five weeks later… she found out she was pregnant, and never once crossed her mind that it was anybody other than my birth certificate father. And her immediate thing was like, 'I'm so sorry. I feel like I've done something wrong. I should have known all this'" (Participant 15 social media).

Some participants described situations in which the birth certificate father knew that they were not the biological father but continued their paternal role. When participants questioned their birth certificate fathers, they acknowledged their lack of paternity (e.g., "My mom and dad didn't meet until I was two…it was known to everybody in the family, but me" (Participant 25 social media). Other participants suggested that their birth certificate fathers had suspicions or doubts that they were the true biological father saying things like "'I've been asking [your mom] if you were mine since you were born'" (Participant 11 social media). Some participants also reported that neither their birth certificate father nor their biological father could say who fathered them.

Some social media participants described their discovery positively, by noting that they were glad they found out the truth and had enjoyed meeting new relatives and learning more about their ancestry. For example, as Participant 27 (social media) described their experience:

> "By June, I met my brother, who was living only five minutes from me, and then a few weeks later, I connected with my cousin and my sister. We went to lunch, and here I'm by myself meeting these people that I haven't known. First time in 54 years, and they're older than me, and feeling I've known them all my life, talking in ways and styles and idioms and all that were just so comfortable, and seeing my face look back at me, never realizing it was like and you hear this repeatedly through others. It was a jigsaw puzzle that I found that I didn't know was missing, and so it was an 'aha' moment. It was a Wow. It kind of it all makes sense."

Professional support

Many of the participants who stated that they received professional mental health support described their provider as being "helpful" in processing their MPE. Two participants specifically mentioned that trauma therapists were the most helpful because of their specified training in supporting them through what they felt was a traumatic experience. In contrast, some participants felt that their mental health care providers did not have the right expertise explaining "I'm on my fourth therapist, because it's not something that most therapists, unless you're doing adoption related trauma most therapists don't really know what to do with this," (Participant 11 social media), or at worst "firing" their therapist because they said that "your dad's still your dad" (Participant 17 social media).

Engagement and content of social media group

Participants who joined an MPE-specific online group (n=18), interacted with their chosen group in various ways (Table 2). All participants noted that their chosen MPE-specific online group was a group on Facebook. Many participants (n=12) actively engaged within the group by writing their own posts and describing their stories. The majority of these participants (n=10) also commented on others' posts, offering guidance. In addition to online interactions, many (n=9) reported participating in activities beyond the online group such as in-person activities (e.g. retreats), or synchronous activities like Zoom meetings (n=6). Some participants mentioned seeking out other types of social media in addition to their online group for support such as listening to or speaking on podcasts (n=4).

Table 4.2: Type of engagement reported in MPE-specific Facebook groups for support

	Number of participants (n=18)
Type of Engagement	
Posts	12
Comments	10
Reads	5
Modality	
In-person	9
Zoom	6
Podcast	4

Joining the group

To find a social media group for MPEs many participants searched on Facebook for groups with words such as MPE, NPE or "my dad's not my dad." Alternatively, six participants learned that there were Facebook groups for MPEs from watching one of the first, known founders of a

popular MPE Facebook group on Good Morning America or the Today Show in 2018. One participant described this experience:

> "Pretty quickly I saw Catherine St Claire on the Today Show, and she had discovered the same type of thing. And this is when it was really new to the world. And she developed a Facebook support group, which I sought out, and I joined" (Participant 04 social media).

Participants described several reasons for joining a group on social media including: (1) interest/curiosity, (2) learning about similar experiences of others, (3) and help searching for the identity of their biological parent(s). Once participants found their specific group, they reported that they had to answer specific questions to be allowed into the group. Participants noted that these entry requirements were created to preserve participants' privacy so that people who had not had a MPE could not see what they were sharing. As one put it: "trying to keep the group closed to 'Looky Loos' and just have people that are personally experiencing the same stuff together…. [If outsiders joined] it would kind of break the whole trust that everyone has with each other." (Participant 77 social media).

Positive Aspects of the Social Media Group

Almost all participants who joined an MPE social media group described the group as helpful or supportive because they were able to seek and obtain emotional support from fellow group members who were going through the same thing:

> "… the great thing about the Facebook group, because everybody was going through the same thing is you could ask any question, and somebody had already done it, somebody had gone through it, somebody was feeling the absolute horror of being, my age, and finding out that everything you thought was true is no longer true," (Participant 25 social media).

Participants reported that this still held true even when people had different experiences, as they often still experienced similar emotions:

> "And everybody's story is unique, but the feelings that go along with it are all very similar, so I have found it to be very helpful, absolutely." (Participant 12 social media)

Participants remarked that finding a community of people with stories like theirs felt comforting especially when they did not know anyone else personally who had learned about a MPE. For example, one participant noted:

> "So, the bottom line is just you see that other people are confronting similar situations. You're not alone. This is widespread… that this is probably affecting millions of people. And so, there's knowledge and comfort in that." (Participant 24 social media).

Helping others in the group was also suggested as being a part of what helped participants feel better after learning about their MPE. As participant 29 (social media) noted: “It’s better to give than to receive… It's about being a good person. And I think that does help you to process your own stuff sometimes.”

Negative Aspects of the Social Media Group

Despite numerous reports of participants receiving support, some of those interviewed also reported negative aspects of social media group participation. Due to these negative aspects participants either chose to decrease their participation or leave the group entirely. Some participants described clashing personalities and group in-fighting:

> “… there's kind of like the general rule you don't talk about politics and religion, there are still obviously very different personalities, and sometimes navigating that is challenging, if there's somebody that just rubs you the wrong way. So, there's been a couple of times where… somebody might be talking, and I'm just like, I can't be here. This person is driving me crazy, so I'll just log off...” (Participant 77 social media).

Other participants described difficulties staying with negative discussions:

> “And I think it became, to some degree, all-consuming for quite a while… because you're reliving the same feelings in the same moments over and over

again, and it's just reliving that trauma constantly… But seeing that rawness sometimes you do have to step away...” (Participant 98 social media).

Others were surprised of the degree of pain people were describing. For example, one participant stated:

> “I found out that some people were just freaking out over it, and I just plain don't understand that… I was surprised at the degree of negativity from some of the people, and I guess maybe it's just that they were a lot younger. You know, I think the people in their 20s who find out… might be more dramatic.” (Participant 18 social media).

Similarly, a range of reactions based on the ages of the group members, was noted:

> “There's a huge spectrum of experiences… we're of ages where a lot of our siblings are gone. Bio families are gone. So, I think our experiences are much different than like, say, people maybe [in their 20’s or 30’s] …. A lot of us will never know who they are, or our mothers are gone, and we'll never have those answers. So, there's a lot of discussion about, what do I do with these feelings, what do I do when there's nobody left to answer my questions?” (Participant 11 social media).

Some participants also recognized that their chosen social media group could be both negative and positive simultaneously. For example, one described group interactions this way:

> "People do celebrate their good news. They also will look for sympathy. Sometimes, when they don't have such good news… So less than 50% of these stories that have happy endings, the parent who's living doesn't want anything to do with the child... and people will relay their disappointment and their frustration. So that that kind of tenor comes out on there, as well as the people looking for help, and people saying, you know, we won here. This was a huge thing for me. So, it's a mixture of things". (Participant 73 social media)

Although some participants stated that they decreased their participation in their social media group or left entirely because of the negative aspects of the group, others explained that they decreased their use or left because of their personal healing over time. Participants no longer felt like they were in crisis mode and needed immediate and intense support. For example, Participant 98 (social media) described their participation in the group as "In the beginning constantly. All day, every day. … Over time, I have gravitated away from [the MPE group] … I would say around year three is when I probably stopped integrating as much with these groups and interacting." Another participant explained their decreased use as "I'm not craving the counseling and the answers and the I'm not craving the healing [anymore]" (Participant 15 social media).

Suggested Changes

In light of participants' experiences and feelings towards their MPE social media groups, we asked whether and how the groups could be improved. Some participants emphasized that their current groups functioned well and complimented the administrators for maintaining the groups. For instance, one participant explained:

> "They have several admins that police the group... So, they do a really good job with policing it. I don't know if that's the best word, but you know what I mean, making sure that it stays functional and helpful. So, I'm really pleased with that group on a lot of different levels" (Participant 73 social media).

In contrast, other participants thought offering more opportunities to meet outside of the traditional online setting would be helpful.

> "The only thing I think I would change is encourage more face-to-face meetings, even if it's a small group, like in a restaurant or something. I think it's different when you're screen to screen versus face to face. And to get that feeling, and a sense of closeness to somebody else who's been through it, I think you really need to be in person. So, I would encourage probably more meetups and stuff." (Participant 98 social media).

No Social Media Group

Initial MPE

The majority of those interviewed who did not join a social media group for their MPE reported that at least one parent had passed away before participants their MPE. This often contributed to participants' negative feelings as it created obstacles to finding out how their biological parents knew each other and other lingering questions about their conception. As one participant noted:

> "My mother passed in the year of 2015… and suffered with Alzheimer's for approximately 10 years before she did pass. And my regret is that there's no opportunity to actually gently speak with her and try to figure out what really happened," (Participant 94 no social media).

In contrast, almost all participants who didn't join a social media group for their MPE discovery described their emotions neutrally, explaining that they felt secure about themselves. Participants from this group mainly described feeling surprised:

> "I was surprised, a little distraught and a little angry… It was a surprise to find out that my father was Italian, because the person who was attributed to be my father was not Italian, and I was 48.5% Italian, you know, half Italian" (Participant 69 no social media).

Similarly, another described:

> “At that point my life, no matter what and I'm not upset with my dad that raised me. I am not upset with my mom that raised me. So, no. … It was a surprise, but not a shock, and I quickly got over the surprise.” (Participant 28 no social media).

Instead, those who chose not to join a social media group generally expressed less concern about the discovery:

> “You are already there. You’re a house. Your house is already built… If you need something else, when you find this new information, okay, you're adding a facelift. You're renovating, you're making it into the new thing. It was the old. Now it's the same old, but it's just got these new parts. And that's how I viewed it. I do not come from the history that I thought I did. I'm not connected to that at all. That's, a death. So, there's a loss, but as far as support for that loss, I just deal with things,” (Participant 45 no social media).

Other participants did not see the point in feeling angry because their family members are no longer alive saying “I don't see any use in anger at ancestors, because ancestors did whatever they did. There's nothing I can do to change that,” (Participant 94 no social media). Similarly, another said:

> “I just got to keep living in the present, because I can't change anything that's happened back then. I can't worry about what's going to happen in the future… So just that's where I'm at and it helped me to deal with that issue, instead of just

having that lingering doubt about, who's who and what's what, because a lot of those people were dead now, you know, and nothing can change, and even if they're contained, it is what it is," (Participant 36 no social media).

Professional support

All participants who chose not to join an MPE social media group also did not seek out professional support. When asked why they chose not to join an MPE social media group, participants tended to reply with similar reasoning for why they also did not need professional support: they don't need any type of support. For example, Participant 53 (no social media) stated "I didn't feel I needed any social support, really. I shared a lot of this with my family, and they were interested, but that's really been my support group." Other participants also noted that they are private people and don't wish to share their story online. While some participants noted that they knew that such social media groups exist and intentionally chose not to join them, other participants did not know about or did not think to join such groups.

Discussion

This study explored how individuals who experience a MPE after receiving a result from a DTC genetic test navigate their emotions, familial relationships, professional support and online social support. By comparing individuals who joined MPE-specific social media groups with those who did not, our findings highlight the heterogeneity of processing and seeking support following a MPE.

Many participants in this study described their initial MPE as emotionally distressing. Participants who joined social media groups frequently reported feelings of shock, anger, betrayal, grief, and confusion. Several prior qualitative studies also document strong negative reactions following a MPE.[16,20,69] However, our findings also demonstrate that these experiences are not universal. Several participants who did not seek online support described their reactions as relatively neutral or manageable. These individuals often framed their discovery as surprising but not destabilizing and emphasized their ability to incorporate their newly learned parentage information into their already established sense of self. This lack of distress in some was also identified in a qualitative study by Cerfontyne et al. (2024).[1]

One explanation for the observed heterogeneity may be due to the self-selection into online support communities. Individuals who experience stronger emotional distress may be more likely to seek online social or professional support. In contrast, individuals who feel less affected by the discovery may not perceive a need for such resources. As a result, studies that recruit participants from online support groups [16,17,20,29,31,69,114] may disproportionately sample individuals experiencing greater distress. Our findings support this possibility: participants who did not join social media groups often reported that they simply did not feel that they needed additional support.

A person's age may also influence their response to a MPE. Participants in this study who joined social media groups were younger on average than those who did not. Generational differences in comfort with or familiarity with social media may play a role in this difference as well. Some participants suggested that younger individuals may experience more intense emotional

reactions, whereas older adults may feel more capable of integrating new information about their parentage. This is in direct contrast to findings from Cerfontyne et al. (2025), who suggest that identity disruption may be particularly complex later in life, when individuals have already constructed a long-standing sense of self.[114] Additionally, older adults are often unable to speak to their biological parents given that they have already passed away. For some, this lack of closure may contribute to their distress, while others may feel content not diving further into their genealogy. As a result, it would be valuable to conduct future research to understand how a person's age at MPE discovery affects individuals' emotional responses, identity reconstruction, and support needs.

Participants who joined social media groups frequently reported also seeking professional mental health support. Participants who had positive experiences with their mental health care provider emphasized the value of those providers recognizing their discovery as a traumatic event. Participants who had therapists with specialized trauma training felt those providers were well qualified to help them process their MPE. However, others described difficulties finding mental health care providers who understood the unique psychological implications of a MPE. Several participants reported frustration with therapists who minimized their experience with statements like "your dad is still your dad." Participants in the study described by Careau et al. (2025) also reported therapists using the same phrasing.[20] These experiences reflect broader concerns regarding the preparedness of mental health professionals to support individuals with MPEs.[31] These findings suggest a need for greater awareness and training among mental health professionals regarding the psychosocial impact of MPEs.

Online peer support communities may be particularly valuable for individuals experiencing rare life events.[30] Participants in this study emphasized the value of connecting with others who had gone through similar experiences. Many described feeling comforted by realizing that they were not alone and learning that others had navigated similar concerns. Prior studies similarly highlight the importance of shared lived experience in peer support communities. Careau et al. (2025) found that participants valued online support groups because they allowed them to discuss their experiences with others who truly understood the emotional complexities involved in their MPE discovery.[20]

While online communities are typically thought of in the context of Facebook groups, subreddits, or related discussion fora, podcasts are beginning to emerge as another form of social media that serves as online support. Participants from this study as well as participants from Lawton et al.'s (2024) study reported that listening to MPE-related podcasts was another helpful way to process their MPE, by actively listening to a conversation about someone else's story, making the experience feel asynchronous.[31] Recent research has indicated that positive outcomes from podcast listening are associated with feelings of belonging and development of parasocial relationships (i.e., a one-sided psychological bond between an audience member and a person in the media).[115,116]

Participants reported that reciprocating the support that they received online provided personal benefit. These findings align with broader theories of online community participation, including social exchange theory and generalized reciprocity.[117] Rather than expecting direct reciprocation from a specific individual, members often contribute with the expectation that support will cycle

through the community over time. In many online support communities, individuals initially join to seek support but later remain active by providing support to others.[117] Preece and Shneiderman (2009) explain that users tend to begin by reading the content posted by other community members, next they may start to complete smaller tasks such as agreeing with a comment on a post, before contributing in more substantive ways like providing support, collaborating with others, and finally becoming a leader in the group.[118] Users may be motivated to move through this "reader to leader" progression because of a desire to reciprocate the help they have received.

Despite the many reported benefits, participants also identified several drawbacks to participating in online support groups. Some participants described interpersonal conflict, clashing personalities, or disagreements within groups. Others found the emotional intensity of group discussions overwhelming, particularly when members repeatedly shared painful or traumatic experiences. These findings are consistent with previous research on online support communities, which has identified potential downsides such as exposure to distressing content, emotional over-identification with others' experiences, and interpersonal conflict among members.[119]

Participants also noted that spending extended periods reading about others' negative experiences could be emotionally draining and potentially prolong feelings of distress. As a result, some participants reduced their engagement with the group over time or eventually left their online community altogether. Decisions to disengage sometimes reflected negative experiences within the group, but in other cases participants explained that they simply no longer

needed the same level of support as they had earlier. These dynamics suggest that online support communities may function as temporary resources that individuals draw upon during periods of heightened emotional need. Future research should be conducted to ascertain the way that support needs of people who have an MPE discovery change over time.

Decisions to leave the group can be understood by theories of participation in collective settings. Hirschman (1970) writes that if a member of a group is unhappy about how the group is functioning, there are several options: one can leave, express one's voice, or do neither and remain loyal to the group.[120] The higher the cost of exit, the more likely one is to exercise their voice. Similarly, when one weighs the costs against the benefits of remaining in the group, the net benefit of staying in the group will depend on the quality and accessibility of alternatives.[121] In the context of MPE support communities, however, exit may be less about finding the better alternative and more about no longer needing the support, an acute need that once met, may result in members leaving or reducing participation. If these negative experiences outweigh the perceived benefits of remaining in the online community, then this may cause a member to leave. While widespread departure could threaten the community's ability to serve as a resource for social support,[122] the MPE context appears self-sustaining: given the continuous influx of people newly learning of their MPE through genetic testing, departing members are likely to be replaced by newcomers seeking support.

Although online communities provided valuable support, some participants expressed a desire for more opportunities for synchronous, verbal exchange (whether in person or virtually through platforms such as Zoom). Participants suggested that real-time exchange could foster deeper

relationships and provide forms of emotional support that are difficult to replicate in asynchronous, text-based online communication. Even among individuals who benefited from online communities, the desire for synchronous interaction highlights the continuing importance of real-time, conversational connection alongside asynchronous online engagement. This finding suggests that hybrid models of support, combining asynchronous online communities with opportunities for synchronous gatherings (both in-person and virtually) may be particularly beneficial for individuals navigating MPEs. Indeed, some Facebook groups have become larger organizations such as Hiraeth Hope and Healing.[123] They have begun to create a hybrid community offering Facebook groups, Zoom calls, and in-person retreats to assist with support.[123]

Limitations

The primary limitation of this study is that the sample may not be generalizable to the entire population of those with an MPE due to participants being English speakers only, mostly White, mostly Facebook users, and comfortable discussing their MPE. Those who do not reflect the characteristics from our study may have differing experiences of their MPE. Second, although this study compares individuals who engaged with online support communities to those who did not, engagement was often dynamic over time, and the categories identified here may oversimplify patterns of support-seeking behavior.

Conclusions

This study is the first of its kind to focus primarily on both the benefits and limitations of MPE-specific online support communities. The findings from this study emphasize that individuals

who experience MPE discoveries are a heterogenous group with a variety of emotional responses and support needs. While some individuals who have a MPE view it as deeply distressing and actively seek support from online peer groups and other mental health professionals, others integrate the information with relatively little disruption to their sense of self. Notably, participants who did not engage with MPE specific online communities also did not seek professional support, suggesting that the major differentiator among individuals with MPEs may be whether they need support at all, rather than whether they prefer peer online versus professional support. Our results suggest that online communities can play a vital role for people seeking support. Simultaneously, it is important to acknowledge that joining these communities may result in negative experiences for some, and the need for such support may change over time. Individuals may find online communities most valuable immediately after their MPE, with that need diminishing over time as they process and integrate the experience into their sense of self. The need for hybrid or additional in-person support may also shift over time. Recognizing this diversity of experiences, including that some may not need support at all, is essential for families, friends, mental health care providers, and support organizations working with individuals experiencing MPEs to provide the most appropriate and timely support.

Chapter 5: Conclusion

Summary

The three studies described in this dissertation examined how people can be prepared for the possibility of a Misattributed Parentage Experience (MPE) and supported after such a discovery following direct-to-consumer (DTC) genetic testing or clinical genomic sequencing.

In Chapter 2, consent forms from DTC genetic testing companies and academic/commercial laboratories were analyzed to assess how the possibility of a MPE is communicated prior to testing or sequencing. Findings revealed variability in whether and how MPEs were mentioned, with many consent forms using vague language rather than describing the possibility explicitly. Readability levels consistently exceeded recommended standards, limiting comprehension. Additionally, disclosure practices described in the consent documents were inconsistent and often poorly defined, reflecting broader disagreement across professional guidelines. Overall, the study demonstrated that many individuals may undergo DTC genetic testing or clinical genomic sequencing without being adequately prepared for the possibility or implications of an MPE.

In Chapter 3, types of social support (e.g., informational, emotional, esteem, and network support) exchanged within an online community of those who are donor-conceived were examined. Findings from this chapter showed that informational support, particularly situation appraisal and sharing one's own experiences, was the predominant type of support experienced. Users exchanged perspectives on day-to-day experiences of being donor-conceived, discussed complex family dynamics, analyzed the ethical implications of donor conception, and discussed

ethical issues related to fertility industry practices. Personal storytelling was central to these exchanges, with many users recounting their own experiences of learning they were donor-conceived, discovering half siblings through DTC genetic testing, and navigating contact with donors. Emotional and esteem support were less frequently exchanged, although they were often embedded within informational support exchanges. It became clear that the boundaries between support categories may be less distinct than traditionally conceptualized. Accordingly, it was argued that informational support can function as a pathway to emotional support, and that the provision of information can provide emotional relief.

Building on Chapter 3, in Chapter 4, the experiences of individuals who had a MPE after receiving a result from a DTC genetic test were explored using semi-structured interviews. People who joined MPE-specific social media groups were compared to those who did not, focusing on both the benefits and limitations of MPE-specific online communities. Findings from this study emphasized that individuals who have a MPE are a heterogenous group with a variety of emotional responses and support needs. While some individuals who have a MPE view it as deeply distressing and actively seek support from online social support groups and mental health professionals, others integrate the information with relatively little disruption to their sense of self. The results suggest that online communities can play a vital role for individuals seeking support, although some participants reported negative aspects along with the perceived benefits of the community. Additionally, people's support needs may change over time, resulting in perceiving the online group as helpful soon after a MPE, but months or years after this discovery perceiving it as less important or helpful. Participants from this study also suggested that opportunities for hybrid or additional in-person support are valuable. Recognizing

this diversity of experiences is essential for families, friends, mental health care providers, and support organizations working with people with MPEs to provide the most appropriate support.

Overall, this dissertation highlights that individuals with MPEs utilize mental health professionals and peer communities for support. The characteristics of these communities vary, resulting in different types of people engaging with them, each with different priorities and support needs. For example, in chapter 3, a Reddit community was studied. Users on Reddit tend to skew younger, whereas in chapter 4 participants were older on average, and notably very few had used Reddit as a source of support and instead relied on Facebook groups. This difference suggests that social media platform choice is not random but may reflect generational differences in social media use. Additionally, Reddit allows users to engage in the platform anonymously, which provides an opportunity for users to share and seek information on topics they are reluctant to discuss publicly. In contrast, users who participate in Facebook groups, although they can be marked as private -- so that no one outside the group can see that they are in them or what they post -- are still connected to their real identities which may shape what people are comfortable sharing or searching for. This difference may result in people who are more private joining Reddit, and people who are more comfortable sharing their story publicly or having their story being connected to them joining Facebook groups. Future work should examine how platform anonymity shapes what individuals feel able to disclose and what types of support they seek and receive, as this has implications for both the design of support spaces and the interpretation of data collected within them.

Despite differences between social media platforms and those that choose to engage with them, a consistent pattern emerged across all three studies: individuals with MPEs have diverse support needs that can be met through participation in anonymous and non-anonymous, asynchronous and synchronous, online and in-person, professional and peer support communities. These communities are valuable to their members, particularly in the form of informational support and the normalization of what can be a profoundly isolating experience, but they are not without limitations; people's support needs may change over time.

Limitations and opportunities for future research

The main challenge of the study described in Chapter 2 was the reliance on consent forms as the primary unit of analysis. Given that informed consent should (ideally) be approached as a process, a form alone may not capture the full scope of the informed consent for consumers and patients. This is especially true in clinical contexts where pre-test counseling may supplement written consent forms. As a result, future studies should strive to evaluate the entire informed consent process. For example, future work can observe pre-test counseling sessions to better understand whether there is a discussion around the possibility of a MPE. Additionally, interviews can be conducted with patients/consumers and genetic counselors to assess their understanding of the possibility of a MPE before completing genetic testing or genomic sequencing. After such descriptive studies are conducted, there would be an opportunity for experimental studies to be conducted which test different consent and pre-test counseling approaches and their impact on comprehension and preparedness for MPEs.

In Chapter 3, applying a predefined coding framework (the Social Support Behavior Code) presented both strengths and challenges. While it provided the opportunity for systematic categorization of support types; it also introduced challenges in capturing the emotional complexity of online interactions. The frequent need to double-code content reflected the difficulty of disentangling informational and emotional support which led to the key insight that these categories may not be as distinct as traditionally conceptualized. In addition, the decision to analyze only the top posts and corresponding comments from the subreddit limited generalizability but was necessary given the size of the dataset. This tradeoff highlights an ongoing challenge in qualitative research using large-scale social media data: balancing depth with representativeness. As a result, future research should leverage computational methods to analyze larger online community datasets in a more comprehensive fashion. For example, supervised machine learning models trained on the coded dataset from this study could enable classification of social support types across entire corpora of posts and comments. Expanding analyses to other communities (e.g., adoptee forums or broader MPE-related spaces) would also help determine whether the patterns observed here are consistent across groups or are context-specific. Furthermore, given that many AI chatbots gather data from Reddit, another research endeavor can include examining perceived helpfulness and supportiveness of engaging with AI chatbots for those with MPEs.

In Chapter 4, participant recruitment and sampling posed concerns associated with generalizability. Participants were mainly White, English-speaking, active on social media, and willing to discuss their MPEs, which may exclude people with MPEs who are not active on social media or who are not comfortable speaking about their MPE. Hence, those perspectives

may be systematically different from those of the people that I interviewed. Additionally, participants were interviewed at different times relative to learning about their MPE, revealing the temporal complexity of categorizing support-seeking behavior, as engagement and support needs changed over time. Likewise, this study was limited in that it did not seek to sample based on age, time of MPE, or length of time since joining a social media group. Future longitudinal research (e.g. surveys) will be needed to better understand variation in responses across these variables to determine if they impact emotional responses and support needs and how those needs evolve over time.

Additionally, each study used a different qualitative analysis software, rather than using the same software across all three studies. This was because in chapter 2, the second coder did not have access to any paid qualitative software, as a result, we needed to use one of the only free, cloud-based qualitative analysis software, called Taguette. In chapter 3, we used Atlas.ti because the second coder had access to this software through remote desktop access via the University of Washington. Lastly, in chapter 4, we used Dedoose, because the university purchased a free license for students in the School of Public Health at the University of Washington.

This dissertation further highlighted that there is a need to develop and evaluate interventions to support individuals with MPEs. This includes training programs for mental health professionals, development of guidelines for disclosure, and the integration of in-person support in conjunction with online support organizations or communities. Ideally, post-MPE support from DTC genetic testing and AC laboratories could look like providing information regarding what types of resources may be helpful such as links to online communities both on traditional social media

platforms such as Facebook and Reddit, but also to podcasts (that provide both asynchronous online and synchronous online and in-person support). Information should also remind people that their support needs may not look the same as someone else's needs who also has an MPE, and that these needs may change over time. Evaluating the effectiveness of these interventions will be essential for translating research findings into practice.

Finally, future work should continue to explore the clinical, ethical, and social implications of increasing access to genetic testing technologies. As DTC genetic testing and clinical genomic sequencing continue to be offered, the likelihood of discovering a MPE will continue to increase. Addressing the gaps identified in this dissertation, particularly in preparedness and support, will be essential to ensure that individuals are not only informed about the possibility of a MPE when doing genetic testing or genomic sequencing, but also supported after their MPE.

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Appendix

Appendix A: Chapter 2 Codebook

Code	Subcode	Description
Presence of MPE Discussion		
	Direct MPE mention	The consent form explicitly names "misattributed parentage experience" or a related term (e.g., non-paternity) or provides a definition or concrete example of what a MPE result may reveal.
	Indirect MPE mention	The consent form alludes to the possibility of unexpected familial findings without using specific MPE terminology.
	No MPE mention	The consent form contains no reference to the possibility of discovering a misattributed parentage experience through genetic testing.
Location of MPE Discussion		

	Risk section	MPE-related content appears in a clearly labeled "Risks" (or equivalent) section of the consent form.
	Not specifically labeled	MPE-related content is present but distributed throughout the consent form without placement in a dedicated or labeled risk section.
Disclosure/ Return of Results		
	Disclosure to clinician	The consent form indicates that MPE results may be reported to the ordering clinician or healthcare provider.
	Not disclosed	The consent form states that MPE results will not be disclosed to the patient/consumer.
	Explicit mention of the person who delivers results	The consent form specifically identifies who is responsible for communicating MPE results to the patient/consumer.
Recommended Resources		
	Mental health	The consent form recommends that individuals seek mental health support (e.g., therapy or counseling) to help process the emotional impact of unexpected genetic results, including a potential MPE discovery.
	Genetic counseling	The consent form references genetic counseling as a resource, either encouraging individuals to consult a genetic counselor before or after testing or directly providing access to or a link for finding a genetic counselor.
Impact of Results		
	Familial impact	The consent form addresses how genetic results, including MPEs, may affect family members.
	Personal impact	The consent form acknowledges the potential psychological or emotional consequences of genetic results for the patient/consumer undergoing the testing.
Policy Mentions		
	ACMG guidelines	The consent form references any American College of Medical Genetics and Genomics (ACMG) guidelines.
	GINA	The consent form mentions the Genetic Information Nondiscrimination Act (GINA).

Appendix B: Chapter 3 Codebook

Category	Subtype	Definition
Informational Support		
	Referral	Asking for or recommending someone to a resource, service, or person who may be able to provide help or information.
	Sharing Own Experience	Requesting or providing a personal experience of learning they were donor-conceived, discovering half-siblings through DTC genetic testing, or navigating contact with donors or newly identified relatives.
	Situation Appraisal	Helping/asking someone to interpret or make sense of a situation by providing perspective or analysis.
	Suggestion/Advice	Offering a potential course of action or personal recommendation to address a problem or decision.
	Teaching	Asking for or providing factual explanations of information to help a

		community member build their understanding.
Esteem Support		
	Appreciation	Expressing thanks to a community member for sharing their story, offering a thoughtful perspective, providing advice, or contributing to the community.
	Compliments	Positive affirmations or praise intended to reinforce someone's choices or behaviors.
	Relief of Guilt	Reassurances or explanations that help reduce feelings of blame, shame, or guilt.
	Validation	Acknowledging and affirming someone's feelings, thoughts, or experiences as understandable or legitimate.
Emotional Support		
	Empathy	Demonstrating shared emotional understanding by relating to a community member's specific experience.
	Encouragement	Offering motivation or positive reinforcement to help someone feel hopeful.
	Sympathy	Expressing compassion in response to a community member's distress.
Network Support		
	Network	A community member affirming shared identity or extending an invitation for direct connection
Support Providers		Users giving any type or subtype of support.
Support Requestors		Users asking for any type or subtype of support.

Appendix C: Chapter 4 Interview Guide

INTRODUCTION

Thank you for agreeing to talk with me today. My name is Betty Cohn, and I am a PhD candidate at the University of Washington. Before we get started, I just wanted to review a few housekeeping details:

Our interview will last about an hour. Your participation in this discussion is completely voluntary. You can decline to answer any question, and you are free to leave/stop at any time. With your permission, we will record our conversation so that we can transcribe it into a written version to review. Our discussion is confidential, and no personally identifying information about your will be associated with the notes, recordings or transcripts. If you are ready to start, I will start recording now.

Purpose of the interview: Today, we'll be discussing your experiences with having a misattributed paternity experience, or MPE and your involvement in online peer support communities related to that experience. I'll be asking questions about what motivated you to join, your participation over time, and any other support you may have sought out. Do you have any questions for me before we begin?

SECTION 1: WARM-UP

1. Thinking back to when you first decided to pursue direct-to-consumer genetic testing, can you please tell me a little bit about what made you decide to do that?

Probe: If you didn't buy the test yourself, can you tell me how you came to be tested by FamilyTreeDNA?

2. Did you learn something interesting about your ancestry or health?

SECTION 2: INITIAL MPE AND SEEKING SUPPORT

3. At what point after receiving your results did you realize that they might indicate misattributed paternity? Can you walk me through what that experience was like for you?

4. Did you seek out professional support or help after receiving your results?

5. How soon after your realization did you decide to seek out support or help? What sort of support did you look for?

Probe: Maybe someone like a therapist, or a genetic counselor, small support groups?

6. How would you describe the support that you received from that [professional/group/person]?

7. Did you have difficulty accessing/finding the support that you felt like you needed?

8. Are you still receiving support from that [professional/group/person]? Why or why not?

SECTION 3: SOCIAL MEDIA GROUP PARTICIPATION

9. Can you please tell me a little bit about your social media use in general? Do you use it at all? What do you mainly use it for?

10. Can you describe the types of social media groups you have participated in that relate to your MPE? For example, were they public or private? What platform were they on?

Probe: If you are comfortable, can you tell me the name of the group[s] that you joined?

11. About how many such groups have you joined since having your MPE?

Motivations for joining the group

12. What made you decide to join an online support group also?

Probe: Were you looking for guidance on a specific question(s)?

Probe: Did someone recommend the group to you? Who? (no need to name names, just their role in your life, e.g. friend, spouse, therapist)

13. Now, I'd like to invite you to think about the social media group that you participate in the most [or: Have participated in for the longest amount of time]. How long have you been a member of [insert name of group]?

14. Were there any entry requirements, like answering questions or agreeing to group rules, before you could join?

15. What was it like to participate in the group? Did anything surprise you?

Type of Engagement

16. In what ways have you tended to participate in this group? For example, do you just read others' posts, respond to the group, respond to individuals?

17. How often do you interact with this group (several times a day, daily, frequently, rarely)?

18. Have you ever posted your own message to the group?

Probe: If so, what types of things have you posted about?

Probe: If not, why not?

19. When you posted, did you post anonymously, or did you share detailed information about yourself? Why did you choose to post in that way?
20. [If HAVE responded] What sort of posts or topics have you been most likely to respond to?

21. Tell me about the process and length of time it took you from joining the group, to posting questions, to commenting on other group members' posts?

22. How have your feelings about the group changed since you started to post/comment?

Motivations for leaving the group [if they left]

23. Are you still in the group? If yes, what keeps you participating? If not, why have you left?

Probe: If you are still in the group, can you see a reason why someone might want to leave?

24. If you haven't left the group, have you considered leaving? Or have you stopped being as active (stopped reading posts, posting, or commenting?)

SECTION 3: SOCIAL MEDIA SUPPORT

25. In what ways would you say that participation in this group has supported you?

Probe: Has it helped emotionally, provided information, or simply been a place to share?

26. What would you say, for you, is the main benefit of being part of this group?

27. How would you describe the overall tone of the group—positive, negative, or a mix of both?

Probe: Have you noticed certain types of posts (e.g., celebratory vs. seeking advice) that tend to get more engagement?

28. Has there been any downside, again for you personally, of being part of this group?

29. If you could make any changes to the group, what would they be? What do you think is missing or could be done differently?

SECTION 4: CLOSING

30. Has our conversation brought up any new thoughts or insights about your experience that you hadn't previously considered?

SECTION 5: DEMOGRAPHIC CHARACTERISTICS

1. What is your age?

2. How do you describe your gender identity?

3. How do you describe your ethnicity?

4. How do you describe your race?

5. What is the highest level of education that you have completed (High School, Associate's degree, Bachelor's degree, Master's degree, Doctoral degree)?

6. What is your household income level (less than $50,0000, $50,000-$100,000, $100,000-$200,000, or greater than $200,000)?

7. What type of geographic area do you live in (urban, suburban, rural)?

That is all the questions I have planned. Do you have any questions for me?

Appendix D: Chapter 4 Codebook

Code	Subcode	Description
Purchasing a DTC GT		Questions about motivations for purchasing a direct-to-consumer genetic test.
	Advertisements	Saw an ad on TV, social media, etc. that influenced decision to buy a genetic test.
	Genealogy Interest	Interest in family tree motivated purchase of the test.
	Christmas/New Years/Father's Day	Sale or specific time mentioned.
	Other	Other reasons for purchasing the test.
Initial MPE		What participants found out when they discovered their misattributed parentage experience (MPE).
	Negative Emotions	Experienced trauma, distress, sadness, anger, betrayal, surprise, or other negative emotions upon finding out their MPE.

	Neutral Emotions	Experienced neutral emotions to finding out their MPE.
	Positive Emotions	Experienced positive emotions to finding out their MPE.
	Parent reactions: positive	Parent reacted positively to MPE.
	Parent reactions: negative	Parent reacted negatively to MPE (e.g. denial, anger)
	Telling family	Experience of telling family results or deciding not to tell them.
	Mother knows	Whether or not mother knew of MPE.
	Father knows	Whether or not father knew of MPE.
	Family knows	Whether or not family knew of MPE.
	Identity	Any discussion around impact on identity.
	Deceased parent	When participant found out about their MPE, their parent(s) were deceased so they couldn't discuss it with them.
Professional support		Seeking or not seeking professional support after results.
	Type of Professional Support	Described professional mental health support such as a therapist, small support group.
	Timing of Professional Support	How soon after realization participants sought help.
	No Professional Support	Did not seek out/need professional support.
	Good Quality of Support	Therapist was helpful, understood MPEs.
	Bad Quality of Support	Therapist did not understand MPEs or said the wrong thing.
	Continuity of Support	Whether participant is still seeing the therapist and why or why not.
Social Media Group Participation Experience		Participation in online groups related to MPE.
	General Social Media Use	Platforms used and for what purposes.
	Length of Time in Group	How long the participant has been in the MPE social media group.

	Entry Requirements	Requirements before joining (rules, questions, etc.).
	Type of Engagement	Forms of participation (reading, posting, commenting).
	Interaction Frequency	How often participants engage with the group.
	Content of Posts/Comments	When they posted or commented what did they say.
	Reason for posting/commenting	Participants posted or commented because they were looking for support or trying to support others.
	Changing feelings	How attitudes toward the group changed over time.
	Motivations for Leaving	Reasons for leaving a group (if applicable).
	Decreased use	Participant describing interacting with the group less often over time.
	Podcast listener	Any mention of listening to a podcast that served as support.
Motivations/reasons for joining and staying		Reasons for joining an online support group.
	Specific Questions	Looking for guidance on a particular issue.
	Finding the group	How the participant found the social media group related to their MPE.
	Feeling less alone	Reason for joining the group, staying, or commenting.
	Helping others	Reason for joining the group, staying, or commenting.
Social Media Support		Perceived benefits, tone, and challenges of online groups.
	Supportive/helpful	Description of how the group has been supportive.
	Negative Group Tone	Description of the tone of the group being negative.
	Positive Group Tone	Description of the tone being positive.
	Both (negative and positive) group tone	Description of having both tones.
	Downsides	Negative aspects of group participation.

	Suggested Changes	What participants would/wouldn't change about the group.
No Social Media Use		
	Reason for not joining	Why the participant decided not to use social media for social support.
	Knowing not joining	Knew about social media groups but decided not to join.
	Not knowing/not thinking not joining	Did not know/think about social media groups.