

Misattributed paternity discovery: A critique of medical organizations' recommendations

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Summary

The five authors recently discovered their misattributed paternity (MP), two ascertaining that, decades ago, their pediatricians abetted the paternity deception. From their unique perspective, the authors critique medical organizations' current MP discovery guidance, identifying shortcomings, contradictions, and clinical and legal hazards. They also discuss opportunities to improve MP discovery management.

It is a wise child that knows its own father.—Homer
That which can be destroyed by the truth, should be.—Seeker's Mask

Introduction

Whether to disclose the discovery of misattributed paternity (MP) to a genetic or non-genetic parent(s) or the child persists as a perplexing dilemma for medical professionals.^{1–11} Historically, most professionals have opted for non-disclosure, an action that poses legal perils, as captured in these medical literature quotes:

... [it is] difficult to construct a [genetic test] report that pleases those who do not wish to disclose [MP] yet accurately states ... results for legal purposes.¹²

... I think we're lucky in that legal didn't ask us to submit to them ... how [MP non-disclosure] played out. I was worried ... because we didn't end up doing what legal wanted us to do.²

Clinical perils exist, too: testing a non-genetic parent with a proband could yield the misinterpretation of a genomic variant's pathogenicity.^{13–15}

In modern society, the viability of genetic secrets (such as MP) continually dwindles; an estimated 20% of US adults have submitted their direct-to-consumer (DTC) DNA tests.^{3,16} Among a quantitative study's approximately 23,000 adult DTC testers, 5% discovered they were genetically unrelated to their parent(s), 8% discovered their parent(s) had a child that was not previously revealed, 12% learned of an unexpected family health history issue, and 29% discovered an unexpected race or ethnicity.¹⁷ Extrapolated to the US population, millions of people are currently mistaken about—and in the coming years will likely learn—the identity and other information about

their genetic parent(s)/relatives (<https://www.census.gov/popclock/>). Importantly, the testing of children can be easily performed and, unfortunately, DTC companies' pediatric test safeguards remain lax.^{18,19}

In recognition of DTC tests' emergent impact, a genetic counselor's recent MP commentary states that "... lying, fudging, and avoiding the truth should no longer be [clinicians'] default position."³

Misattributed parentage experience

In recent years, we—this article's authors—disturbingly discovered that the men that we have always known to be our fathers are not our genetic fathers.^{20–24} Evidence substantiates that one author's pediatrician actively propagated a false paternity narrative for decades, including during face-to-face conversations. A different author's pediatrician appears to have knowingly concealed the paternity and misrepresented the author's race. For both authors, evidence (including from one author's mother [the other mother is deceased]) indicates that their conceptions were non-consensual. Worse, one of these genetic fathers assaulted additional young women in subsequent years: among the most serious hazards of MP non-disclosure is enabling criminals to evade prosecution while simultaneously failing to provide support to victims.

Besides MP, adoption and donor conception (DC) are common reasons that a child's genetic parent(s) differs from whom the child, relatives, or friends believe. Uncommon reasons also exist, such as a newborn child mistakenly discharged by a hospital to the wrong parent(s). The medical and layman literature lack taxonomy consensus for describing these circumstances, resulting in numerous, potentially confusing acronyms and terms (<https://righttoknow.us/terms/>). For example, misattributed parentage experience (MPE) regards a child whose parent(s)

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is genetically unrelated due to adoption, DC, MP, or another reason. In contrast, MP specifically regards a non-genetic father believed to be the genetic father. Thus, MPE and MP are non-interchangeable acronyms. Another example is “NPE,” ordinarily defined by genealogists as a non-paternal event to signify an issue with the genetic father but also defined (mainly in lay literature) as not parent expected to signify an issue with one or more genetic or non-genetic parents. Terms used to describe a parent also vary: “genetic,” “birth,” or “biological” versus “raising,” “social,” “birth certificate,” or “non-genetic,” among others.

A parent(s) would be aware that a DC or adoption process occurred; various laws, public funding, and other assistance facilitate DC and adoption, and a parent(s) must proactively engage social service providers, medical professionals, or attorneys or meet other requirements as part of the become-a-parent process. Moreover, adoption and DC are generally viewed by society in altruistic terms.

MP involves no comparable become-a-parent process. Instead, MP is spontaneous conception from sexual activity and the subsequent portrayal of a non-genetic father as being the resulting child's genetic father.^{1,6,7} We believe that these pregnancies are overwhelmingly unintended and that, in the aftermath, a parent(s) intentionally distorts the genetic truth; these issues merit further research. Few health care professionals receive MP management training, and sparse public discourse exists about how to assist individuals coping with MP circumstances.^{25,26}

Hereafter, we critique several medical organizations' recommendations regarding how clinicians should navigate MP situations.

MPE discovery

Recent qualitative and quantitative research offers empirical data regarding the consequences of MPE discovery, including new data specific to MP discovery. A qualitative interview study recruited 25 adult MPEs from online support groups; via a DTC test, 24 had discovered their MP and one his adoption.²⁷ An analysis of all participants' responses yielded six themes.

- (1) Reactions to the DTC test results: these were complex and predominantly negative.
- (2) Reconciling past experiences and relationships: half of participants expressed long-standing intuitions that a parent was not their genetic parent, and many described “not fitting in” with their family in terms of appearance or personality.
- (3) Relationship changes after MPE discovery and revelation: the MP participants' most common feeling was anger toward their mother for concealing an affair's pregnancy, which contributed to a strained relationship, although participants recognized that the decades-long secret had negatively impacted their mothers' overall well-being and familial household relationships.

- (4) Connection to newly discovered family members: most participants communicated with and met with their newfound genetic relatives, gaining a sense of satisfaction from seeing people physically resembling themselves.
- (5) Impact on sense of identity: the major psychological effect was adapting to the reality of a new identity,
- (6) Grief and loss: these included self-identity losses and the loss of a presumed genetic connection to their raising father.

A quantitative study surveyed 731 adult MPEs (adoption was excluded) in a private online support community who discovered their unexpected paternity via a DTC test, of which 2% were DC, while the remaining 98% were MP, and their conceptions were as follows:²⁸

- (1) 49% were from their genetic parents' short or prolonged affair.
- (2) 11% were from their genetic mother's romantic relationship immediately prior to the relationship with their raising (non-genetic) father.
- (3) 10% were from a romantic relationship of an unknown nature.
- (4) 2% were from a single consensual sexual encounter.
- (5) 3% were from sexual assault or prostitution.
- (6) 23% did not know the nature of their genetic parents' relationship at the time of conception.

Compared to historical control groups, this surveys' respondents showed statistically significant higher mean Patient Health Questionnaire (PHQ-9) depression scores, including a higher proportion of moderate-severe or severe depression. Several factors influenced mental health consequences in a positive fashion, including family members' supportive reactions to the discovery, the ability to openly discuss the discovery within one's social circle (rather than maintaining secrecy), and an MPE individual's acceptance of the discovery. Mental health outcomes for those conceived by rape or prostitution fared worse than other MPE individuals.

A survey of 605 adult MPE respondents from an online support group showed that 67% learned of their genetic secret via DTC tests and 40% experienced post-discovery strained dynamics with existing or newly discovered close family members, including estrangement from raising mothers and raising fathers.²⁹ Of respondents, 63% were MP from consensual encounters, and 3% were MP from rape or assault. Specific to the consensual group, 61% felt shock, 55% grief, and 51% an “identity” crisis. A close relative asked 40% to maintain the genetic secret—consciously deny the facts of their existence—most commonly (25%) by their genetic mother. 84% told their raising mother about the DNA discovery, 59% told their raising father, and the majority of these MPE individuals reported a positive impact on these relationships. “Medical history

changed" was reported by 64%, of whom 15% said this was "for the better," 29% "for the worse," and 35% "not better or worse." 60% discovered a different ethnicity than what they believed. A mental health professional's help was sought by 33%, although only a minority reported that the professional provided effective support. Podcasts and Facebook groups dedicated to unexpected genetic discoveries were the principal sources of support and information. Only 5% sought a genetic counselor's assistance, and none reported seeking a physician's help.

A qualitative study of 27 adults discovering their MP via the use of a DTC test showed several themes: a traumatic emotional response to the life-altering MP discovery, engaging in identity exploration, identity reconstruction, and coming to terms with their new genetic reality and corresponding social implications.³⁰ None described an indifferent or positive reaction to the genetic secret's revelation, and most expressed fears of losing connections to the man they regarded as their father.

Another qualitative study of 18 MP and 15 DC adult MPE individuals who discovered their unexpected paternity via DTC tests showed three emergent themes in both groups: sadness, grief, and loss; seeking connection and belonging; and betrayal and anger.³¹ Importantly, 75% of these MPE individuals would have preferred to know their genetic truth earlier in their life, enabling this information's integration into their self-identities as well as affording opportunities to develop relationships with genetic relatives. In contrast, only 9% reported not wanting to know sooner, while 9% were conflicted about knowing sooner.

Childhood distress

Evidence refutes non-disclosing parents' and clinicians' presumptions that a child is oblivious to and unaffected by a false genetic narrative. During childhood, MPE individuals experience various types of distress, in particular, genealogic bewilderment; 39% report always feeling different from or not belonging to their raising family, while 28% report always searching for their self-identity.^{30,32,33} As we can attest, MP children can be keenly aware of appearing dissimilar to their raising family, especially when of a different race or ethnicity. MP can foster a "mistrust of self" phenomenon for the child, who is repeatedly told by the important individuals in their lives, including medical professionals, to disregard what the child rightly perceives: a lack of family members exhibiting physical, personality, and other traits resembling the child's own, a phenomenon known as genetic mirroring.^{29,31}

Organizations' guidance

The following organizations offer MP policy (or similar) statements.

- (1) American Society of Human Genetics (ASHG)³⁴
- (2) American Academy of Pediatrics (AAP)³⁵
- (3) American College of Medical Genetics and Genomics (ACMG)³⁶

- (4) National Society of Genetic Counselors (NSGC)³⁷

Table 1 contains these organizations' statements, all of which either endorse or permit MP non-disclosure. No organization provides empirical evidence of non-disclosure's benefits. None specifically define when, or even if, MP should be ultimately disclosed; ASHG's, AAP's, ACMG's, and NSGC's approval of children forever living with a false paternal genetic narrative can be reasonably inferred.

The ASHG statement uses "clear," "harms," and "benefits" without definitions of or suggestions as to who should define these terms: a parent(s) knowingly withholding factual genetic information would undoubtedly define these terms differently than an unaware parent(s) or child, and disputes with a clinician's definition are possible.³⁸ Also, ASHG's statement proposes an oxymoronic act: the dichotomy of "be truthful" and "avoid disclosure" cannot transpire simultaneously.

All four organizations' MP guidance violates the American Medical Association's (AMA) code of ethics, which states the following: "except in emergency ... withholding information without the patient's knowledge or consent is ethically unacceptable,"³⁹ "withholding ... creates a conflict between the physician's obligations to promote ... welfare and to respect patient autonomy,"³⁹ "... offer full disclosure when the patient is able to decide ... according to a definite plan, so that disclosure is not permanently delayed,"³⁹ and "... be honest in all professional interactions, and strive to report physicians ... engaging in fraud or deception ... to appropriate entities."⁴⁰

MP involves deception; thus, physicians—and, we would argue, any licensed health care professional—not disclosing should be reported, in accordance with the AMA's recommendation. The AMA does not define "appropriate entities," but we believe these could include the clinician's state licensure board, state medical error reporting system, or institutional ethics, quality, or patient safety committees.

Specific to children, the AMA says that "... parents/guardians are expected to safeguard their [child's health] and to nurture their children's developing personhood and autonomy"⁴¹ and should "develop a ... plan ... that will best serve [the child and that] will not foreclose important future choices by the adolescent and adult the patient will become."⁴¹

Non-disclosure of MP can foreclose various choices for the child: open communication (versus isolation) within their family, developing relationships with unacknowledged genetic relatives, fully informed health care decisions (including into adulthood) based on a factual family medical history (FMH), and opportunities and choices to develop genetically authentic identities.

Therapeutic privilege

The AMA describes "therapeutic privilege" (TP) as the temporary withholding of important medical information

Table 1. Organizations' misattributed paternity statements

Organizations	Publication year and type	Applicable language	Comment
American Society of Human Genetics	2015, position statement	"while honoring their broad responsibility to be truthful with patients and their families, we recommend that health-care providers avoid disclosure of misattributed parentage unless there is a clear medical benefit that outweighs the potential harms" ³⁴	no explanation provided regarding who defines "clear," "benefit," or "harms"
American Academy of Pediatrics	2013, policy statement	"misattributed paternity ... may be uncovered 'incidentally' whenever genetic testing is performed ... This risk should be discussed, and a plan about disclosure or nondisclosure should be in place before testing" ³⁵	non-disclosure is permissible if decided proactively
American College of Medical Genetics & Genomics	2021, policy statement for secondary findings	"[disclosure] should be offered ... regardless of the [patient's] age" ³⁶	"should be offered" is not absolute language; thus, MP non-disclosure is an option
National Society of Genetic Counselors	2023, position statement for secondary findings	"the pre-test counseling process should establish clear expectations for what categories of results will and will not be returned" ³⁷	"will not be returned" can be applied to MP discovery

from a patient that ordinarily would be shared based on a clinician's belief that the information's revelation threatens the patient's well-being.^{42,43} Notwithstanding their TP acknowledgment, the AMA states that "[TP] has been widely criticized as no longer ethically appropriate in modern medicine"⁴⁴ and "in contemporary ... practice, paternalism has given way to patient autonomy ... bodily dignity and self-determination."⁴⁵

Other medical literature similarly denounces TP, including the lack of justification to withhold medical information merely to safeguard a clinician, a patient, or a patient's family from the discomfort of confronting a difficult reality.^{46–52} The AMA cites four TP hazards, all relevant to MP.⁴⁴

(1) What if a child hears it from another source?

At any moment, the MP could be intentionally or unintentionally revealed via a DTC test, someone (parent, relative, friend) disclosing the secret, or other methods; we know of an instance where a child's innocuous grade school science project regarding blood type inheritance patterns yielded MP discovery.

(2) The child may already know.

Children can perceive how their appearance and other traits are dissimilar to family members and speculate about or ascertain a reason(s) for the dissimilarity.

(3) Not knowing could be worse.

Non-disclosure creates a mutual pretense environment; people knowingly and unknowingly pretend that a false genetic narrative is true. As we can attest, in the void of factual information, a child's imagination can fabricate dis-

treasing explanations, including that they are somehow to blame for their puzzling life circumstances.

(4) Evasive answers do not resolve the issue.

This self-explanatory hazard accentuates the major defect of MP non-disclosure. Despite this defect and the other TP denouncements, the ASHG's, AAP's, ACMG's, and NSGC's MP non-disclosure recommendations represent the endorsement of not only TP but everlasting TP. We ask: toward what end?

In lieu of TP, the AMA says the following: "physicians should offer education and support to minimize the psychosocial impact ... including putting the patient and parents/guardians in contact with [people having faced] similar decision ... Negotiate ... a shared understanding of the [child's needs],"⁴¹ "monitor the patient carefully and offer full disclosure when [able],"³⁹ "... promote the developing autonomy of a minor [to make decisions] commensurate with the child's abilities,"⁵³ and "encourage parents to share genetic information ... appropriate to the child's ... development."⁵⁴

Information sharing

Speaking generally about medical information sharing, the AAP advocates "... the process model, in which medical decision-making is a longitudinal process [that] ... fosters better communication and understanding between clinicians and patients/surrogates."⁵⁵

Yet the AAP and other three organizations depict their MP non-disclosure recommendations as a discrete event rather than a circumstance that could be effectively managed longitudinally.

Several ASHG statements acknowledge genetic information's perpetual nature: "... genetic tests provide

Table 2. Organizations' statements endorsing sharing of genetic information

ASHG	"... the development of mechanisms for sharing family history and genetic results with family members" ³⁴ "... genetic testing in children should include a long-term communication plan for all results and the staging of [genetic] information sharing on the basis of age, maturity, and capacity to understand" ³⁴
AAP	"at the time of genetic testing, parents or guardians should be encouraged to inform their child of the test results at an appropriate age" ³⁵ "health care providers should encourage patients and families to share this information ... explain the results to the extended family or refer them for genetic counseling" ³⁵ "share medical information with children and families in ways that are useful and affirming ... complete, honest, and unbiased" ³⁸
ACMG	"pre-test and post-test genetic counseling should be provided to any person receiving [secondary findings] ... to discuss the types of possible results, limitations of testing, and medical implications" ³⁶
NSGC	"the healthcare provider should discuss strategies with the parents/guardian for sharing the results as [the child] develops capacity, or by the age of majority" ⁵⁷
AMA	"encourage parents to share genetic information with the child in a manner appropriate to the child's stage of development" ⁵⁴

information of a permanent nature about an individual and potentially their family"³⁴ and "... recommends ... permanent storage of genetic data in electronic health records."³⁴

Unfortunately, ASHG as well as AAP, ACMG, and NSGC fail to acknowledge that MP non-disclosure correspondingly thwarts factual genetic data's presumed permanent nature.

Parents justifiably have wide discretions regarding sharing information with their child, albeit not absolute; medical professionals can impose clinical and legally enabled limitations. An AAP policy statement supports overriding a parent's wishes: "physicians have both a moral obligation and a legal responsibility to question [or] contest ... medical decisions if they put the patient at significant risk of serious harm."⁵⁵

Similarly, ASHG says that "... when there is strong evidence that a secondary finding has urgent and serious implications for a child's health or welfare, and effective action can be taken ... communicate those findings to parents or guardians regardless of [their stated] preferences,"³⁴ while ACMG states that "... the ability to identify a significant medical risk for the child that could avoid future morbidity takes precedence [to disclose]."⁵⁶

As discussed below, we believe that MP non-disclosure's false FMH constitutes a significant medical risk.

Table 2 lists organizations' policy recommendations advocating the sharing of genetic information with children.^{34–36,54,57,58} Yet these recommendations conflict with MP non-disclosure recommendations. For example, this AAP patient- and family centered care policy statement says "... share ... information with children and families in ways that are useful and affirming. This information should be complete, honest, and unbiased."⁵⁸

Obviously, MP non-disclosure is not affirming, complete, honest, or unbiased and is useful only toward deceit rather than medical decisions based on facts. The ASHG and ACMG have similar conflicts.

Several organizations use terms such as "best interest of the child," "maturity," or "appropriate ... development" but fail to describe who should and how to define these terms. Moreover, we challenge these organizations'

sincerity toward protecting a child's best interest given their failure to explicitly suggest that clinicians do the following:

- (1) Assess whether and how the MP impacts the child's/family's well-being. An MP parent(s) could incur stress from keeping the genetic secret, similar to a secret-keeping DC parent's stress, which could cause the parent(s) to consciously or unconsciously mistreat the child.⁵⁹
- (2) Offer therapeutic assistance to the child or family.
- (3) Support the child through their genetic discovery, including into adulthood.

We also challenge these organizations' sincerity toward advantageously utilizing a child's maturity since none specifically recommend assessing the child's current maturity or to disclose MP upon reaching a suitable maturity.

Family medical history

Individuals misinformed about their genetic heritage are correspondingly misinformed about their FMH. Unfortunately, despite FMH long being imbedded in numerous health evaluation processes, guidelines explaining how to compensate for a missing or erroneous FMH remain absent.^{25,60} Adopted and DC individuals with a missing or distorted FMH report challenges navigating health care encounters, including feelings of loss, frustrations, fears of the unknown, a desire for greater self-empowerment, and efforts to claim information that is "rightfully" theirs, as well as hazards such as the following.^{61–70}

- (1) Missed or delayed opportunities to identify, assess, and mitigate disease risks.
- (2) Medical insurance denying disease test coverage for asymptomatic patients when such tests are reimbursed for FMH-positive asymptomatic patients.
- (3) Non-genetic but believed-to-be-genetic relatives' medical histories prompting unwarranted tests, care, or concerns.

Table 3. Organizations' family medical history statements

Organization	Applicable language
ASHG	"collecting a patient's [FMH] remains the single most important and informative genetic test for most individuals ... [FMH] can help identify a genetic predisposition for disease, guide subsequent testing, and inform prevention strategies" ⁷⁷ "... for some heritable conditions, genetic testing can provide powerfully predictive information." ³⁴ "clarifying the pattern of inheritance of pathogenic variants is a key goal of genetic testing" ³⁴
AAP	"Family Health History Plays a major role in ... identifying familial and hereditary disorders ... determining inheritance patterns and ... risks for ... genetic disorders" ⁷⁸
ACMG	"... DNA-based risk identification in the absence of relevant [family medical history does not have] sufficient consensus on clinical classification and management ... Individuals with ... family history should be assessed for the potential need for DNA-based diagnostic testing ... The issues raised by ... family history should be handled as part of appropriate clinical care by medical professionals" ⁷⁹
NSGC	"that patients and their healthcare practioners jointly collect [a FMH] to facilitate comprehensive risk assessment for routine and specialty care" ⁸⁰

- (4) Lack of knowing genetic risks that can impact future reproductive choices.
- (5) Conveying missing or incorrect FMH onto offspring, thereby perpetuating the hazards.

Literature describes adopted children's FMH void as a "health disparity."⁶⁶⁻⁶⁸ MP children face a similar, if not worse, disparity: half of their factual FMH is not merely missing but rather fabricated.

In recent years, DC has shifted away from anonymity toward sharing information, including FMH, ideally via a gradual process before the child reaches 10 years of age.^{69,71-76} Moreover, DC literature notes that a distorted FMH is, in and of itself, problematic: "... not all DC individuals who remain uniformed [about their conception's method] are necessarily harmed; however, they are all treated wrongly when they are deprived of the ability to access information about their genetic origins. Succinctly, they can be wronged without being harmed."⁷⁴

Unfortunately, MP-specific research about a false FMH's consequences remains lacking.

Table 3 lists the ASHG, AAP, ACMG, and NSGC statements endorsing an FMH's value, including ACMG's recognition that in an FMH's absence, genetic testing for most illnesses lacks clinical utility.^{34,77-80}

Despite ASHG's FMH endorsement, they paradoxically devalue FMH for paternity determination: "... genetic information is increasingly being used for ... non-clinical purposes, such as ... determining paternity"⁸¹ and "... disclose secondary findings ... only when the information has clear clinical utility for the child and/or his or her family member."³⁴

The ASHG must clarify how paternity lacks clinical utility.

Regarding children of adoption, the AAP says "a complete medical history, including ... genetic history obtained from both parents, is ideal..."⁸²

We were unable to locate a similar AAP suggestion for MP children.

A false FMH's risk is perhaps best illustrated via the recommendation from AAP's task force on prevention of sudden death in the young's: "[sudden cardiac arrest and

death (SCAD)] screening should be performed for all children ... many of the cardiovascular diseases [creating SCAD risks] have a familial inheritance pattern."⁸³

Similarly, the NSGC is a committee member for an SCAD expert consensus statement that recommends⁸⁴ that "... identification of inherited cardiac conditions that predispose [SCAD] should be made a public health priority, as diagnosis may prevent future ... events in affected family members ..." and to "provide information tailored specifically to the family about their inheritance risks."

How can all children be effectively SCAD screened when some children's familial inheritance patterns are distorted by MP non-disclosure?

The AMA's adult family history form asks for the "biological father of index patient" and the "biological mother of index patient"; obviously, MP can result in false paternal information on this form.⁸⁵

Race and ethnicity

Although they are social constructs, a person's race or ethnicity can impact genetic disease risk determinations.⁸⁶ For example, there are higher occurrences of Tay-Sachs disease in Ashkenazi Jewish populations and sickle cell disease in people of African descent.⁸⁷ Additionally, incorrect ethnicity can yield false genetic carrier screening test results.⁸⁸

The AMA recognizes ethnicity's importance: "a [FMH] helps physicians and other ... professionals provide better care ... The [FMH] should be detailed, including ... Ethnicity (some genetic diseases are more common in certain ethnic groups)."⁸⁵

An AAP core principle is "honoring racial, ethnic, cultural ... background and patient and family experiences."⁵⁸

Other AAP publications either advocate to define race, ethnicity, and ancestry "rigorously" when used in clinical protocols, describe patient safety inequities arising from race and ethnicity differences, show disparities for marginalized populations' access to specialty care, or conclude that erroneously classifying newborns' race and ethnicity skews morbidity and mortality data to underestimate these

burdens in minorities and overestimate them in White populations.^{89–92}

Clinicians' MP disclosure practices stratified by race and ethnicity remain unknown, but we can provide a first-person example to illustrate this issue. One author grew up in an overwhelmingly White, rural area and incurred decades of internalized emotional distress due to her physical appearance's stark contrast to everyone in her family and the surrounding community despite her parents', relatives', friends', and pediatrician's tacit and explicit statements that she was only White (<https://righttoknow.us/2020/05/01/jodi-beavers-girard/>). In truth, the author is biracial with a physical appearance of being Black.

A physician's fundamental responsibility includes investigating clinical presentation incongruences, yet over the span of many years, this author's pediatrician failed to inquire about or refute the White-only narrative imposed on her. In adulthood, this author checked "White" or "Caucasian" on countless medical forms, yet no clinician ever probed these responses. Ultimately, her false FMH resulted in adverse consequences: one of her children was unexpectedly hospitalized and diagnosed with diabetic ketoacidosis, a potentially fatal event. Had her genetic paternal family's pervasive diabetes history been known, screening and proactive care could have occurred, and this child's hospitalization may have been avoided.

We believe that asking whether a patient has concerns about their genetic heritage's validity should become standard practice during clinicians' history-taking processes.

Protected health information

The ASHG's MP statement says that "... there is an asymmetry of risk. Only the fidelity of the mother is at stake [from disclosure]. For this reason, it is common practice to disclose only to the mother pre-test counseling could include confidentially informing the mother of the potential detection of non-paternity."³⁴

The ASHG makes no mention of the child's asymmetric risks. Worse, ASHG presumes—wrongly—that MP results only from infidelity. Yet medical literature describes chimerism as causing incorrect paternity identification.^{93–96} Another cause is the switching of newborns upon hospital discharge, which impacts two families. This may occur more commonly than clinicians realize; in 2019, The Joint Commission issued a "distinct newborn identification" requirement for this nation's hospitals, aimed at improving misidentifications causing a host of medical mistakes.⁹⁷ In the aftermath of a discharge error, when future discovery of genetic unrelatedness occurs, MP could be blamed, at least preliminarily and perhaps indefinitely. Incorrect paternity has also resulted from *in vitro* fertilization mistakes.⁹⁸ Medical professionals' MP non-disclosure facilitates non-reporting of these medical errors, contravening mandates requiring error reporting.^{99–101} Furthermore, non-disclosure permits the root causes of the mistake to persist and be perpetuated.

Other causes of genetic unrelatedness that might be incorrectly categorized as MP include child abductions, illegal adoptions, and abandoned babies; these situations carry legal and possibly criminal implications.⁴

The ASHG's suggestion to inform only the mother does not withstand scrutiny. Genetic tests proving or disproving MP only involve a father's (genetic or non-genetic) DNA sample compared to the child's; the mother's DNA need not be tested. The idea that the laboratory analysis of two individuals' biological samples somehow creates confidentiality for a third, non-tested person remains difficult to rationalize. Furthermore, the Health Insurance Portability and Accountability Act (HIPAA) grants every adult access to their protected health information (PHI) and a legal parent/guardian access to their child's PHI, so denying the father's access is a violation of HIPAA.^{102,103} The opposite of ASHG's "only inform the mother" is, in fact, true: per HIPAA, the father could request that his PHI (genetic test results) not be disclosed to the mother.¹⁰⁴

Family unit

Several organizations seek to justify MP non-disclosure based on not disrupting the family unit, such as the ASHG: "non-disclosure could be exercising prudence in avoiding interference in the family relationships."³⁴

No organization offers evidence that the consequences of disclosure would be negative or that non-disclosure will only yield positive consequences. None acknowledge that the existing family unit was created and is sustained by duplicity or explain why clinicians are to prioritize a fictionalized genetic family narrative over the ethically and legally expected conveyance of factual medical information. Indeed, the circular logic of the mere existence of a genetic lie self-serving as clinicians' justification to continue the lie remains difficult to vindicate.

We note that per pediatric oncology literature, mediated disclosure of distressful medical information has a higher probability of yielding long-term family stability versus non-disclosure, while other literature illustrates that children's capabilities to understand and cope with difficult circumstances are underestimated by parents and clinicians.^{105–107} Whether similar phenomena occur with MP merits further investigation.

Utilizing the family unit as justification for withholding MP information hinders a family's ability to authentically thrive and adjust to factual information.^{105,106} Additionally, a child or family member(s) may sense the pretense, the risk of family dysfunction could escalate over time due to avoidance of the genuine issues, and the revelation of the genetic truth could be weaponized in emotionally strained situations, such as divorce, death, financial disputes, or other arguments.

Regarding the impact of DTC test results on a family unit, the ACMG says that "the consumer [could receive] unexpected results that ... [have] implications ... for family members."¹⁰⁸

This comment again highlights the futility of genetic secrets given the increasing availability of DTC tests.

Another ACMG statement says that “family dynamics may be negatively affected ... it may be difficult to discuss these findings and there is the possibility of revealing previously unknown nonpaternity or adoption status.”¹⁰⁹

A myriad of positive, negative, or neutral family dynamics can occur from MP disclosure, yet for reasons unknown, ACMG only acknowledges the negative.

Regarding minors' genetic data in electronic records, ACMG says to “... avoid unintentional ... disclosure, yet results should be readily accessible at the appropriate time ... [test results could contain] biological relationships [different than] the perceived family structure. Inadvertent disclosure is a potential risk.”¹¹⁰

The ACMG does not explain why the current time is inappropriate for disclosure, how to determine an appropriate time, or who is responsible for the accessibility of results. Also unanswered is why factual genetic data disclosure (even if inadvertent) constitutes a potential risk while the disclosure of false genetic data apparently lacks risk. Moreover, this statement contradicts this ACMG practice guideline: “... the ability to identify a significant medical risk for the child that could avoid future morbidity takes [disclosure] precedence.”⁵⁶

As previously discussed, a false FMH constitutes a significant medical risk.

The ACMG suggests that “additional privacy protection mechanisms for ... genomic information such as ... misattributed parentage could include the designation of these test results under a separate ... ‘sensitive’ or ‘confidential’ notes.”¹¹⁰

Recent literature recommends a similar electronic record design for MP.¹¹¹ Yet additional access barriers do little to resolve the fundamental question of how to effectively disclose MP. Plus, is such a “protection” lawful? Patients are legally entitled to access their information, and undue barriers could be deemed illegal.¹¹² Although conceptually plausible, these types of barriers are often technologically impractical in real-world settings.¹¹³ Finally, in our opinion, they are pointless: in time, the child will be an adult and legally entitled to access their records.

National Society of Genetic Counselors

We were unable to locate specific guidance from the NSGC regarding how clinicians should disclose MP, a conspicuous absence given their mission.¹¹⁴ Relatedly, what should genetic counselors document in instances where genetic test results show MP? Should genetic counselors knowingly falsify medical records, as some counselors recently admitted to doing?² If so, what accountability should counselors incur when their false records impact future patient(s) or clinician(s) decisions?

For adoptees, the NSGC states the following: “[collect] available health information (including medical, genetic, and family history) for children entering the adoption process.”¹¹⁵

We were unable to locate a similar NSGC suggestion for MP children.

Their at-home genetic testing policy states to “... offer genetic counseling ... to help consumers understand ... results with potential healthcare implications in the context of family and medical history.”¹¹⁶

A just-published NSGC hypertrophic cardiomyopathy practice resource states that “both clinical diagnosis and family history should [be assessed] for an underlying genetic etiology.”¹¹⁷

These two statements highlight FMH's importance; the NSGC should explain how to navigate a false FMH, such as with MP, for instances of cardiomyopathy as well as genetically linked diseases in general.

Another NSGC policy states the following: “ensure that practitioners correctly interpret and deliver results Create transparency and improve public awareness ...”¹¹⁸

Obviously, MP non-disclosure fails to meet these goals.

Per their confronting racism, oppression, and inequity position statement, they “... [promote] ethical and accurate use of genetic information.”¹¹⁹

MP non-disclosure involves inaccurate genetic information, which is not only unethical (per the AMA) but can yield inaccurate race- or ethnicity-based genetic health risk assessments. Thus, NSGC's MP non-disclosure guidance conflicts with their aspirations of confronting racism.

Finally, their genetic testing of minors for adult-onset conditions policy says that “if a minor undergoes genetic testing and results are not disclosed ... the healthcare provider should discuss strategies with the parents/guardian for sharing the results as [the child] develops capacity, or by the age of majority.”⁵⁷

While MP may or may not constitute an adult-onset condition, knowledge about—and lack of knowledge about—a child's MP can impact medical management. Thus, the NSGC should specify if they intend for this policy's results-sharing recommendation to be applied to MP and, if not, why.

Discussion

Genetic relatedness between a child and any person (1) can be proven or disproven via many methods, including inexpensive DTC DNA tests, (2) is unalterable, and (3) when misrepresented, can become known at any moment.

Unfortunately, guidance from the ASHG, AAP, ACMG, and NSGC seeks to deny these realities. Their guidance arguably has an ulterior motive: allow a clinician to ignore the dilemma, escape immersion into likely difficult family dynamics, and dispatch the problem onto a future clinician(s) or other individual(s) to resolve.

These organizations' tacit, if not explicit, approval of clinicians' willful misrepresentation of a child's race, ethnicity, and other identities strikes us as particularly offensive. An individual's self-view of “who they are” shapes how a person interfaces with society as well as

how society interfaces with that person.^{30,86} A child's visible discordance with their stated race or ethnicity, as well as their discordance to family members, can be obvious to and not accepted by society at large; as we can attest, the resulting tensions can negatively impact a child. We can also attest that discovering your authentic genetic heritage in mid-life yields difficult-to-answer existential questions as well as feelings of betrayal against supposedly trustworthy people, including parents and health care professionals.

The majority of MP conceptions result from genetic parents consensually engaging in sexual activity and then a parent(s) perpetually misrepresenting the resulting child's paternity, thereby passing the onus of their sexual activity's consequences onto the child.²⁸ Why a parent(s) chooses this course of action has been sparsely investigated, but the reason(s) is undoubtedly complex and requires further understanding to ultimately craft improved resolutions.

Speaking of our own raising parents, we acknowledge, appreciate, and respect the lifetime of innumerable efforts they expended on our behalf, yet we remain troubled by their decades-long deceptions and today struggle to repair relationships. We hold similar sentiments toward the organizations endorsing MP non-disclosure as well as those clinicians adhering to that guidance.

Recommendations

Genetic secrets are incurring a righteously deserved demise.¹²⁰ Today's MP debate should focus on how to create intentional, effective disclosure methods; the long-standing disclosure versus non-disclosure debate will soon succumb—and arguably already has succumbed—to the general public's ease of attaining factual genetic information.¹²¹ Medical organizations should promote restorative, equitable, data-driven recommendations not reliant on the present day's haphazard, case-by-case tactics. Recent research, input from MPE individuals and parents, and recognition of the impact of DTC tests should guide the development of new recommendations.

Organizations should call for and tangibly support research; perhaps reflecting MP's enduring taboos, sparse MP medical literature exists regarding the prevalence, precipitating factors, impacts, or outcomes, among other topics. Such research could be modeled after tools developed for DC's disclosure to children.¹²²

No professional can be forced to knowingly propagate false data. Medical organizations should endorse that every MP discovery merits clinicians' prompt efforts toward transparency; non-disclosure should be a last resort. Even with non-disclosure, upon the MPE individual reaching 18 years old (or a similar milestone), previously withheld information must be released; professionals would need to make long-term provisions to disclose.

As a practical matter, virtually every MP disclosure discussion should begin with the genetic mother. We concede

that a parent(s) cannot be forced to articulate factual genetic information and that a parent(s) electing not to speak truthfully presents complex challenges for health care professionals; a parent(s) may protest the disclosure of information, cite real or imagined harm, or focus on self-interests. Numerous recognized reasons^{123,124} can cause a parent(s) to evade medical care for their child, including financial, religious, and cultural concerns; whether fear of MP discovery could similarly cause a parent(s) to avoid pediatric medical care merits further research. Notwithstanding these challenges, someone needs to advocate on behalf of the child; we believe that clinicians must fulfill this crucial role.

No medical organization recommends that clinicians assess MP's origin or reason(s) for persistence; purposely falsifying a child's genetic heritage is not "normal" or "natural" parental behavior, so a precipitating cause(s) lurks and must be addressed. Currently, most of society apparently believes that health care professionals will actively participate in genetic deceptions; thus, professionals must unequivocally state the following:

- (1) No matter the parent's wish, the clinician will not portray a false genetic narrative, use bogus FMH for clinical decisions, or forge medical records.
- (2) Clinicians can facilitate interdisciplinary collaboration to engage psychological services and social workers, help with legal issues (e.g., updated birth certificates), and other needed assistance.
- (3) If specific circumstances suggest that physical harm is a *bona fide* disclosure risk, then law enforcement or other appropriate resources will be involved.
- (4) A difference exists between privacy and secrecy³¹: a parent can expect privacy, which involves sharing information (like FMH) exclusively with individuals having a genuine need for and use of this information. In contrast, secrecy seeks to deny information to everyone, including those entitled to the information.

We note that mistrust—believing that engaging a health care professional could yield harm, not help—typifies contemporary medicine's failure to cope effectively with MP discovery. Changing this mistrust will require dedicated educational campaigns to teach parents and clinicians that they no longer function as genetic information gatekeepers. Thus, time and resources should be proactively focused toward a methodical, resource-supported disclosure, an act with the best possibility to minimize negative consequences as well as being in everyone's long-term best interests. If not, the omnipresent chance of an unexpected, chaotic, and likely damaging genetic revelation will continue.

Although routine paternity testing of all newborns has been suggested, various concerns exist: costs, storage of genetic data, access to data, the legalities of information sharing with a non-genetic parent, and how to support a

family with an unexpected paternity result.^{35,125–128} Whether such a practice could become a viable, long-term solution to avoid MP should be further examined.

Clinicians' legal risks

Upon MP discovery, the key questions a clinician(s) confronts regard what legal obligations dictate the disclosure of this information and to whom; in other words, what does the duty of care (DOC) require?^{129–131} An in-depth discussion about a DOC's legal implications for MP is beyond this article's scope. Nevertheless, we believe that when a clinician owes a DOC to a parent(s) and their child (such as a genetic counselor discussing test results based on comparisons of the father's, mother's, and child's genetic information or when a pediatrician provides care for a child, among other clinical scenarios), medical professionals electing to withhold the MP information or selectively disclosing (such as only to the mother) have violated their DOC obligations. We also believe that, as a result, the clinician could be subject to sanctions imposed by state licensing boards or medical negligence lawsuits, as well as other consequences. For example, could a liability insurance company deny a non-disclosing clinician's insurance coverage claim in MP litigation circumstances? A possibility exists that the company asserts that the clinician knowingly and intentionally falsified medical records and/or verbally conveyed false information to a patient(s), acts typically exempt from liability coverage. Similarly, could health insurance companies seek to deny or recoup payments for the child's medical care upon discovery that the payment would be or was based (wholly or partially) on falsified medical information? These issues merit further discussions.

We look forward to the day when MP non-disclosing clinicians face accountability. We are aware of current advocacy efforts toward bringing litigation against MP non-disclosing clinicians, which could provide clarity about whether non-disclosure constitutes medical negligence, among other unresolved issues. Such lawsuits typically hinge on whether a clinician's actions did or did not meet a DOC.^{130,132,133} We speculate that such a lawsuit's outcome would depend on convincing a judge or jury that the applicable DOC is the AMA's current code of ethics (or similar) favoring the disclosure of medical information rather than an organization's MP non-disclosure recommendations. Since several organizations' MP non-disclosure recommendations conflict with their other recommendations favoring medical information sharing, explaining these discrepancies to a judge or jury could be problematic. We note that a clinician's MP non-disclosure may go undetected for years or even decades; a DOC from exactly what point in time should be used to assess a clinician's MP non-disclosure decision?

Legislative changes are also occurring. Largely because of MPE individuals' advocacy efforts, approximately 20 states have enacted or proposed various legislation requiring ge-

netic truth; nine states now criminalize physician fertility fraud (a doctor using his own sperm to inseminate a patient without their knowledge or consent), and to date, at least six physicians have faced civil lawsuits or criminal prosecution.^{134,135} Other MPE advocacy efforts yielded the Protecting Families from Fertility Fraud Act of 2023 introduced in the US Congress.¹³⁶ In 2022, Colorado became the first state to ban anonymous sperm and egg donations; other states may follow.¹³⁷ Nine states permit adoptees' full access to their adoption records, while 19 states permit limited access, and other states are considering similar actions.¹³⁸

Pertinent to MP, legislation against paternity fraud—a father financially supporting a child based on a falsified genetic relationship—is being sought.^{139,140} Indeed, what defines a “father” as being responsible (financially and otherwise), and does the discovery of a lack of genetic relatedness exonerate a father from financial obligations to a child?^{141–146}

We note that individuals mistakenly discharged to the wrong family as newborns have successfully litigated against hospitals; one woman's legal battle resulted in a Wyoming Supreme Court precedent-setting ruling that allows for financial compensation for emotional damages.¹⁴⁷ This precedent could offer a blueprint for future litigation against clinicians whose willful MP non-disclosure contributes to emotional damage.

Finally, unlike yesteryear's paper records (where MP information could be easily hidden), today's electronic records are indefinitely stored, readily retrievable, easily examined, and commonly admitted to pre-trial discovery or other court proceedings.^{111,148}

Conclusion

Driven by DTC DNA tests, false genetic narratives such as MP are being continually exposed, as recently happened to this article's authors. Contemporary research illustrates the pre- and post-truth genetic discovery harm that MPE individuals incur. The ASHG, AAP, ACMG, and NSGC endorse or permit MP discovery non-disclosure, an action conflicting with the AMA's code of ethics. Several organizations' non-disclosure guidance also conflicts with their other policies favoring genetic information sharing. No organization recommends assessing how MP impacts the child or family, suggests therapeutic support, or cautions that non-disclosure can distort a child's race and ethnicity identities. These organizations unequivocally endorse the value of a factual FMH, yet none describe how to address the risks of false FMH resulting from MP non-disclosure.

Failure to resolve the MP dilemma remains the major defect of non-disclosure, and urgency exists to update organizations' antiquated MP guidance.

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