

*Autonomy and Equality:
The Misattributed Paternity Conflict in Genetic Counseling*

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Introduction

Informed consent in genetic testing is complicated by the uncertain and emotional nature of the burdens genetic information can place on tested individuals. For this reason, tests for some untreatable and particularly debilitating genetic disorders, such as Huntington's disease, require an especially intense informed consent process (Elias and Annas; Andrews). But even more routine genetic testing can inflict heavy emotional burdens when it reveals unanticipated information such as misattributed paternity. Currently, discovering misattributed paternity presents the genetic counselor with a conflict concerning whether or not to disclose the information, and to whom, *after* a test is performed. When testing reveals nonpaternity, the counselor's duty to treat both partners equally and her role as facilitator in decision making come into direct conflict. She has a piece of information required for the couple to make a medical decision, but by its very nature that information creates an inequality between the two partners. The counselor must decide what to do with the information, and she must do so without the couple's input—that is, without knowing how the information will affect the couple, or how they would prefer to handle the situation. Thus, by forcing the counselor to make a decision for the couple, misattributed paternity puts the counselor in a role she is not supposed to play. Therefore, to preempt the problem and put the decision in the hands of the clients rather than the counselors, it has been suggested that clients be informed before testing is performed that nonpaternity may come to light. It turns out, however, that although informing clients prior to testing does give them the opportunity to guide the counselor in what to do with the information, the warning cannot prevent the counselor's principle of

treating clients equally from clashing with her fundamental goal, which is to facilitate informed decision making for her clients. Over the course of this paper I will show why this is so.

I begin by framing in more detail the problem presented by the discovery of misattributed paternity, summarizing the arguments put forward by those who advocate telling both clients and those who call for telling only the woman. I then consider the purported benefits of raising the issue prior to testing, which lead directly into the criticisms of the proposal to include misattributed paternity in the informed consent process for genetic testing. This discussion will show that the problem of misattributed paternity is an instance of a wider problem manifesting itself in the context of bioethics.

1. The conflict: equality and autonomy

Literature on misattributed paternity and the problem it presents for genetic counselors deals mostly with the situation in which testing has already been performed and nonpaternity is a surprise (Ross, Mahowald, Pencarinha et al.). In such cases, the main debate concerning what a counselor should disclose to which clients takes place between the values of preserving clients' autonomy and protecting the woman's or family's interests. On the highest level, the problem is that on the one hand the woman has (probably) been unfaithful to her husband, and revealing nonpaternity may put her and her child in danger of abandonment or abuse; on the other hand, the man, who gave genetic material for the test and whose future reproductive decisions will be influenced by its results, ought to be told out of respect for his autonomy. In addition, counselors

often cite the mother's confidentiality as a reason not to disclose misattributed paternity (Pencarinha et al.; Ross).

In general, the situation looks like this: a couple approaches a genetic counselor because they have reason to believe they have passed or could pass a genetic disease to their child. After a meeting with the counselor, which usually (according to Jacobson et al.) includes information about the disease in question, how it is passed on, and what procedures the couple needs to consider when results come back, the couple chooses to have or not to have the test done. In some of the cases in which testing is performed, the test reveals not only the desired information concerning the genetic disorder but also the fact that the husband is not the father of his wife's child. In light of the information the couple already has about the disorder, the counselor must decide whether to tell the couple (particularly the man, since it is likely that the woman already knows or suspects) this extra piece of information.

Because the information may affect different parties in unpredictable ways, there is significant debate about what to do when such unanticipated information is uncovered. In surveys conducted in the 1980s Wertz and Fletcher discovered that an overwhelming majority of genetic counselors confronted with a situation like that described above would inform the mother alone, invoking the woman's confidentiality and protection of the family (Ross 120, citing Wertz and Fletcher). A 1994 recommendation by the Institute of Medicine's Committee on Assessing Genetic Risks endorses this course of action; but the 1983 report of the President's Commission for the Study of Ethical Problems in Biomedical and Behavioral Research recommends disclosure to both partners (Ross 120).

Those who contend that nonpaternity should be disclosed to both partners base their arguments on two main points: 1) the purpose for the genetic counseling session is to inform clients in order to determine courses of action best for them and their child (or future children); 2) a narrow construal of the counselor's duty to treat both clients equally. I will call this position the "narrow-context view."¹

A particularly well-constructed defense of this position is put forward by Lainie Friedman Ross. Her argument works from the assumptions that genetic counseling is supposed to be a process which enables clients to make choices based on good information, and that genetic counseling is not, nor should it be, marriage or family counseling. "What is best for the couple must be determined by the couple," she asserts (123). One of Ross's key premises is her interpretation of the principle of treating clients equally: when both partners approach a genetic counselor, they are equal clients and therefore the counselor "has a moral obligation to disclose the test results to both" (127). To offer the information only to the woman would therefore be against the counselor's obligations to *each* of the clients, Ross claims. This is a narrow construal of client equality in that the context considered is only the genetic counseling situation, paying little attention to the couple's social position and economic situation outside the medical context. The narrow interpretation allows Ross to dismiss the argument from the woman's confidentiality, as well as lending weight to her observation that in most cases it is impossible to tell how misattributed paternity will affect the family. Disclosure could just as easily turn out to be a good thing as a bad thing. "[Disclosure's] impact will

¹ This label may be slightly misleading, because the view stresses context less than it stresses autonomy considerations. I chose it, however, because it brings out the contrast between this view and the view employed by those who argue against full disclosure.

depend on the specific details of the particular family” (123), and family preservation is not the domain of the genetic counselor. In addition, failure to disclose the finding to the husband will usually require not just omission but active deception, which is a blatant violation of his autonomy. The man’s genetic information is his, and since it has relevance for reproductive decisions, it is important to him that he know that the child is not his.

Opponents of full disclosure, who advocate reporting nonpaternity findings to the woman only, agree that the purpose of genetic counseling is to promote client autonomy; however, they interpret the clients’ equality in broader terms which take general social structures into consideration. As Lori D’Agincourt-Canning puts it, this view requires us to “rethink traditional discussions regarding disclosure in which [disclosure] is seen as if it is simply a moral duty devoid of context. The abstract allocation of responsibility denies the complexity of disclosure...” (236). I will call this position the “broad-context view.” An example of an argument based on this view is that given by Mary Briody Mahowald, who claims essentially that although respect for autonomy requires revealing any information pertinent to the decisions the couple is in the process of making, whether requested or not, there may be structural social inequalities between the man and the woman which complicate the matter (Mahowald 170-171).

One way to make this claim clearer is to formulate risk as the product of probability and magnitude of harm. Both clients may stand to lose the same thing—a marriage—so each has equal *probability* of harm when the information is revealed. But the *magnitude* of loss may be much greater for the woman, because of the salary differential between genders, the way society treats single mothers, and other factors.

Thus even though each member of the couple is equally a client of the counselor, the woman is usually at greater risk than the man is. To even this inequality, those who take the broader understanding of equality usually contend that the counselor should keep the information from the man. In other words, defenders of the broad-context view urge the counselor to consider carefully the family dynamics in order to determine whether the risk for both the husband and the wife are equal. If the details are too murky, as the details often will be, “we invoke valid generalizations as the only means available by which to approximate the real situation. Here is where the gender generalizations... are necessary even though inadequate” (Mahowald 173). Thus, on this view, unless it is clear that the risks to both partners are equal, the information should be imparted only to the woman.

In this section I have discussed the origin of the problem misattributed paternity presents, i.e. whether and to what extent to disclose the unanticipated information, and canvassed arguments for full disclosure, put forward by those who stress autonomy and construe the genetic counseling context narrowly, and arguments against full disclosure, advanced by advocates of a broader interpretation of the context, who stress equality issues. Having thus framed the debate, I will turn to examining the suggested solution to the conflict, which is to provide clients, through the informed consent process, with the opportunity to decide how they would like to proceed should nonpaternity be discovered. Before I can assess this suggestion, however, some background concerning informed consent and genetic counseling is necessary.

2. *Promoting patient autonomy through informed consent*

There is wide agreement that the goals of genetic counseling are chiefly to educate clients and enable them to make decisions based on this information in concert with their own values. According to the web site of the National Society of Genetic Counselors, counselors strive to:

1. Equally serve all who seek services.
2. Respect their clients' beliefs, cultural traditions, inclinations, circumstances, and feelings.
3. Enable their clients to make informed independent decisions, free of coercion, by providing or illuminating the necessary facts and clarifying the alternatives and anticipated consequences.
4. Refer clients to other competent professionals when they are unable to support the clients.
5. Maintain as confidential any information received from clients, unless released by the client. (NSGC)

Specifically concerning informed consent, the NSGC states:

[We support] an individual's right to full disclosure of all appropriate medical options regarding reproductive testing and management of genetic diseases and birth defects. It is the care provider's responsibility to provide effective communication of all available options and to obtain informed consent for procedures involving risk to the individual or fetus.

Burgess et al. further note that the purpose of genetic counseling is to help individuals navigate through complicated information on procedures, probabilities, options and the lifestyle changes these may involve, including follow-up (1312).

The informed consent process is designed with these goals in mind. *Ideally*, the counselor sits down with the patients to explain to them the procedure that will be used and to give them a mini-education in genetics, consisting of general and specific

background information on the condition they are there to be tested for. She takes a family history.² At this time she also reveals the risks and benefits of the test and its results, along with the options the couple may have to face in light of the findings. The possibility that unsought information may come to light should be included among the risks, along with insurance issues, psychological risks, and the possibility of social stigmatization. (In practice, not all of this is always done, according to Lori Andrews and Burgess et al.) The counselor should add that the genetic information (both sought and unsought) provided by the test may have relevance for future medical decisions that they cannot now foresee. This way the clients are to have the opportunity to take this possibility, which they may not think of themselves, into account. Benefits of testing should be stressed as well, in order to provide a balanced body of information. After the information has been presented, the clients have the opportunity to ask all the questions they want. At the end of the session, the counselor should ask the couple to take time to consider whether they want to go through with testing, and if so, exactly what they are seeking to learn from their test: Do they want only the answer to their specific question (e.g. whether any future children will develop CF, or whether they have a genetic predisposition to certain kinds of cancer)? If other information is detected, do they wish to learn that as well? The couple should try to make their goals as explicit as possible both for their own benefit and so that the counselor can support them in the most appropriate way.

The session described above is idealized. Unfortunately, in practice there is little uniformity to the content of the sessions. According to Burgess et al., “[c]ounseling [*sic*] should...clearly establish that there is a possibility that paternity might become an issue,

² For more information, see Jacobson et al.

but this is not typically included in the information disclosed” (1312). A study of informed consent sessions conducted by Jacobson et al. reveals that only 60% of the counselors surveyed would include nonpaternity on an informed consent document (though this does not rule out verbal discussion of the issue). In the discussion, Jacobson et al. suggest that part of the purpose of an informed consent session should be to set the boundaries for the counselor-client interaction as well as provide information on procedures and options—i.e. informed consent should be about the *counseling* as well as the medical procedures (7). Kolker and Burke observe that disagreements between husbands and wives, such as those potentially set off by disclosure of nonpaternity, are among the most challenging aspects of counseling: “Imparting genetic risk information is impersonal; mediating between a husband and wife and attempting to be even-handed... rank among the most stressful professional challenges a counselor may confront” (60). If a policy of informed consent about the counseling itself were implemented uniformly, counselors could conceivably choose a policy concerning how to deal with couple disagreements. They might explain (for instance) that misattributed paternity can be uncovered in testing, and that they do not consider it part of their job to act as family or marriage counselors but, if appropriate, they can refer the couple to such a counselor.

The main reason to include misattributed paternity in any informed consent process for genetic counseling is to promote the autonomy of all clients. This is one of the fundamental premises of genetic counseling, as I noted above. If counselors do not bring up the possibility that misattributed paternity could come to light before a couple undergoes testing, they are forced to decide without the couple’s guidance what to do with the information. They run the risk of making a decision that is not the best one for

the couple, because they cannot have perfect information about the couple's values, stability, and so on. Couples run the risk of making a mistake themselves, of course, but it has been argued that there is some value simply in making one's own decisions even if they turn out to be bad ones—that is, self-determination is itself a value, so that a bad decision made by the couple is better than a bad decision made for them by the counselor.

3. *Advantages of including nonpaternity in informed consent: client control and narrow equality*

Implementing a policy of including nonpaternity among the psychosocial issues which may arise with counseling has a number of attractions. First, it allows the counselor to treat all clients openly and evenhandedly. The information made available in pre-testing information sessions is given to both partners, and both have the opportunity to ask questions of the counselor. Each partner knows what the other knows, and they both have a share in the decisions that must be made. Recall that equality between partners is a key issue when misattributed paternity comes to light *after* testing. Even people arguing from the broad-context position would prefer to treat partners equally, in the narrow sense, whenever possible. Thus, if including nonpaternity in informed consent procedures will allow a counselor to treat all clients equally, it is important to do so. I will return later to the question of whether discussing what to do about nonpaternity during the informed consent process actually can allow this.

A second advantage of bringing up nonpaternity ahead of testing is that it promotes client autonomy by allowing the couple to choose their own tradeoffs. By broaching the subject up front, the counselor can assure the couple of support by

including the possibility of referring them to a marriage counselor if they desire. That is, she not only gives them an opportunity to decline testing, but also gives them a chance to go through with it knowing they can get help if they need it. Ross asserts that “[g]enetic counselors need to help clients decide what information they want to obtain and what information they would rather not have” (126). For most clients, there will be no question of misattributed paternity. But since there will be some for whom it is an issue, informing them ahead of testing allows them to direct the counselor about what to tell or not tell them. If the couple has recognized and worked through their problems, for instance, they may prefer not to be told in order to preserve the reconciliation, or they may be committed enough that it will not matter to them whether the child is theirs. In other cases, the woman might welcome the opportunity to air the difficulties, and will opt for full disclosure if the man asks for it, trading privacy and possibly a difficult marriage for peace of mind. Perhaps the man will be in complete ignorance, his wife having every intention of keeping it that way, and he will prefer not to know anyway; in such a case he trades his full autonomy for stability. Or maybe the woman is unsure whether the child is her husband’s, and she may be willing to undertake the risk of exposure in order to plan for the future, dealing with complications as they arise. In all of these cases, the couple has been given the opportunity to exercise their autonomy and the counselor can easily abide by the decision they make.

The difficulty arises when the woman does not want the information revealed but her husband does; Kolker and Burke mention that disagreement between partners on a range of issues is not at all uncommon (59). There may be no way for her to maneuver,

in these circumstances, unless she can confront the counselor privately. When I return to this issue in the next section, I will investigate whether this difficulty is surmountable.

In theory, including the possibility of uncovering misattributed paternity in the pre-test informed consent session would be intended to free the counselor from a difficult decision about what to do with the awkward information by ensuring that it is not, after all, unanticipated. The clients will have been given the opportunity to make an informed decision about exactly what they are seeking to learn from the genetic tests, which is to say that the patients' autonomy is respected fully. If they choose not to learn of nonpaternity, it will have been their decision and not the counselor's. Knowing ahead of time what they may learn, they have determined what information they need for the decisions at hand, and they will be content to work with only that information. They have, theoretically, freed the caregivers from the need to tell the truth by saying that they don't want it, or they have explicitly given permission to hear the truth and by implication are willing face whatever familial consequences may result from it. If the woman has a concern about her confidentiality, she has the opportunity to protect it, give it up, or prepare for the consequences before complications arise. As I mentioned earlier, Mahowald cites a study by Wertz and Fletcher in which three-quarters of the patients thought that both clients should receive the information on misattributed paternity, but that the counselor should give the woman advance notice (174). This way, the clients have had the opportunity to back out of the test altogether, and by going ahead with it they consent to the conditions they set before undergoing it, and the counselor is freed from responsibility.

4. *Critique of the policy: the conflict remains*

I have outlined the reasons for including misattributed paternity in the informed consent process prior to undergoing testing. In the process, I noted several difficulties with such a policy. In this section I discuss these and others, with the aim of determining what can and cannot be accomplished by the policy.

One important problem with the policy is that it may be impossible for the counselor not to reveal the information in question. For example, consider a case³ in which a couple has a child with cystic fibrosis, and they have come to the counselor to assess the risk to children they may choose to have. Suppose the child is not the husband's but he, at least, is not aware of this fact. If the counselor has given the couple an adequate education about the disease and how it is inherited, they should be able to deduce that the husband is not the father of the child when the counselor informs them that it is safe for them to have more children. The 25% risk of having a second child with CF is suddenly reduced to “negligibly small”—which means the husband cannot carry a CF gene, since the disease only occurs if the child inherits two CF genes. To keep this information from them, the counselor could blame the child's disease on a rare mutation, as this is not an impossibility. This course of action would, however, constitute a deception on the counselor's part, which is against the counselor's code of ethics. The couple may have asked not to receive the information, but they did not ask to be lied to. Did they, however, implicitly consent to being deceived when they put the counselor in the position of either lying to them or disrespecting their expressed wishes? Although lying generally violates the autonomy of the person lied to, the purpose of the session is

³ This is a case with which both Ross and Mahowald anchor their arguments.

to allow the clients to choose what they need to know in order to plan for the future. If they have opted not to learn about misattributed paternity and the counselor can respect that wish while still giving them the information they need to make their decision, perhaps this small lie is not unjustified. But if the counselor has no option which allows them to make their decision unless she disregards their previous wishes, she must decide between disrespecting an autonomous choice on the one hand and withholding information instrumental to autonomous decision making on the other. In other words, the difficulty here is that the counselor has a piece of information she knows is relevant to the couple's decision making as they have presented it to her, and they have a false belief (namely that they are both carriers of CF because they think the child is related to both of them) of the sort a counselor is usually supposed to correct, but she cannot do so without disrespecting their wishes in some way. This is hardly a better position to be in than the one the original dilemma represents.⁴

Recall that above I presented an argument that bringing up misattributed paternity prior to testing helps promote client autonomy in that it allows the clients to decide for themselves what information they want and need for the decisions they are trying to make. This looks good, except when the couple disagrees on what information they want—particularly when the man wants to know about misattributed paternity and the woman doesn't. In this case, she cannot exercise autonomy by choosing what she shall learn from the test without admitting her infidelity to her husband, unless she can talk to

⁴ One could try to argue that the counselor could mention up front that she may have no choice but to reveal the information or lie to the clients. Such an argument is extremely problematic, however, because it either strips the clients of the autonomy we are trying to protect, or asks the clients to give permission to be lied to. The second option is unacceptable in that it undermines any results the clients are given; they will never know whether they have been told the truth.

the counselor privately. After all, only the woman's infidelity can be revealed by the test, and in protecting herself from having that infidelity exposed, she would be forced to show her hand. "How," Ross asks, "can the woman...ask to know the risk of their future children, but not be told about misattributed paternity? Such a request would be an admission of previous infidelity" (127).

One possible way to avoid this problem is for the counselor to call the woman or meet with her separately, to discuss the issue in an "uncoerced non-threatening environment" (Ross 127) so that she can decide whether there is a risk and whether she wants to confront it. This is clearly not treating the clients equally in the narrow sense, however, which is one of the key bases for Ross's argument that both clients should be told, as well as one of the principles of genetic counseling. For broad-context arguments such as Mahowald's, though, this is no difficulty at all given that women are confronting greater risk than men and therefore deserve some extra consideration. But there is still a problem here even if one is willing to treat the clients unequally in the narrow sense. Suppose the counselor does hold the private conversation with the woman, who admits the possibility that the child is not biologically her husband's, and she does not want him to find out. How is the counselor to proceed?

If the woman wants to go through with the test *and* protect her secret, the counselor may simply omit the misattributed paternity section of the informed consent process. Then the woman is protected, but at the expense of the man's autonomy, for he will not be adequately informed about the procedure's possible outcomes. For proponents of the broad-context view, this may be tolerable; but it goes against the principles of genetic counseling by infringing on the man's self-determination. Thus the

counselor is in a bind: shall she protect the wife and treat the husband deceitfully, or adhere to the principles of respect for autonomy and (narrow) equality, which together indicate that the husband should be told, and override the wife's wishes? This is the same dilemma which arose when the clients were not warned ahead of time about the possibility of discovering nonpaternity.

Can the counselor avoid omitting nonpaternity in informed consent but still protect the woman? Apparently not, unless the woman is willing to give up testing altogether. In this case, perhaps the counselor has the option of mentioning the possibility of misattributed paternity but assisting the woman to steer the informed consent session in such a way that the other medical, psychological and social risks appear to outweigh the benefits of undergoing testing. Thus they would manipulate the man into agreeing with the woman that the procedure is not worth undertaking after all. This seems to be a viable option for cases such as cancer screening, because the insurance risk is probably not negligible and no particular decisions are currently under consideration. The woman might argue that it would be too burdening to live with the knowledge that she or her children are at increased risk for cancer, or that having the insurance company find out would be a worse problem than worrying about cancer. But when there is an immediate decision on the line, this tactic is much less appealing because of the test's relevance for decision making. In the CF case above, for example, the woman and her husband must already be aware that they carry a gene for CF, given that her child has the disorder, so she couldn't argue plausibly that the psychological burden of knowing that she is a carrier would be too much for her. In fact, since the couple already has a child with CF and are therefore living with the consequences of it,

the psychological and social risks that go with the presence of the disorder probably cannot outweigh the relevance of the test for future reproductive decisions. Thus, for practical reasons, this option seems to be closed or at least extremely risky if the woman does not want to reveal her infidelity. Even if it seemed plausible practically, however, the tactic would again involve acting disingenuously toward the man and would therefore be ethically questionable. The counselor's principle of nondirectiveness is directly violated, as well as her commitment to helping clients make independent decisions by clarifying anticipated consequences of the various alternatives.

5. *Conclusion: Include nonpaternity, or omit it?*

In all of these scenarios, the problem is that the counselor's own principles come into conflict because of the diverging interests of the two clients, to both of whom she has duties. It therefore seems that there is no general way of avoiding the conflict involved in deciding how to deal with misattributed paternity. What I have shown here is that informing clients of the risk that misattributed paternity may be discovered in the course of genetic testing for other concerns does not avoid a conflict between autonomy in decision making and equality of treatment between partners. The resolution of this conflict turns on a difference in the interpretation of the setting in which counseling takes place: Is the counselor operating in the narrow setting of the clinic alone, or must she also take broader social issues into consideration? Perhaps one way to decide this question is to consider whether or to what extent the counselor-client relationship is a contractual one which would, possibly, obligate the counselor to reveal the information because it automatically narrows the context of counseling. Whether or not this approach is a

fruitful one is the topic of another paper; in any case, it is clear that the question of what a counselor should do with misattributed paternity information touches debates which go beyond the clinical setting, and this paper shows that any clinical solution will be only half-baked.

The critique presented here, however, does not constitute an argument that the possibility of uncovering misattributed paternity should not be a regular part of the informed consent process. Until we can resolve the broad question of whether counselors should take the narrow- or broad-context view, the best we can do is use informed consent as a warning. (Ross makes a related suggestion that the public-at-large be better informed about what genetic testing can and cannot reveal, so that potential clients for whom nonpaternity may become a problem can avoid testing in the first place.) Clients should know that nonpaternity may be discovered through the test they are considering, and that the counselor may be unable to avoid disclosing this information when reporting the test results. I have already pointed out the difficulties with this approach. But we cannot know in advance the specific risks and options for the woman, and we *can* predict that omitting to inform the couple of the possibility of discovering nonpaternity will not only undermine the man's autonomy-based claim to information about himself, but also restrict the woman's opportunities to protect herself from the consequences of the disclosure. In light of this, together with the fact that the inclusion leaves us no worse off in relation to the dilemma than the omission does, it seems clear that misattributed paternity ought to be included among the issues addressed by informed consent.

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