

Incidental Findings of Nonparentage Should Be Disclosed

In “Incidental Findings of Nonparentage: A Case for Universal Nondisclosure,” the authors argue for universal nondisclosure in cases of incidentally discovered nonparentage during a genetic workup for a pediatric patient. I could not disagree more. In making their case, they portray the potential damage done by disclosure but dismiss well-established ethical principles for the argument to disclose.

Ironically, the authors label current case-by-case decision-making as paternalistic but fail to realize that applying it wholesale rather than ad hoc does not absolve them from this guilt. It is not easy to anticipate correctly how any particular family will handle such information, nor can it be an assurance that a family will not have to confront this information at a later date. Therefore, denying the information to any family is inappropriate.

No ethical consideration is absolute, but truth-telling is as close to being paramount as possible without denying others primacy. The consequences of withholding truth, even with the protection of a nondisclose policy, are substantial. Savvy parents in the scenario portrayed would likely have asked about the odd results, putting the physician in an awkward position: either reveal despite the policy or remain adamant behind lawyer-like language that they will have to seek that information elsewhere. For those who do not ask, the physician’s knowledge of nonparentage will introduce a subtle barrier to frankness.

Lastly, in discussing the “undue burden” on physicians who have to confront this dilemma, alleviating physician discomfort should not come at the expense of an otherwise ethically appropriate action.

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Findings of Nonparentage: A Case for Autonomy

We read with interest Palmor and Fiester’s recent article arguing for a blanket ban on reporting incidental findings of nonparentage (IFNP) when conducting pediatric genetic testing.¹ The decision whether to disclose IFNP creates disruptions in clinical care, they argue, because it “undermines consistency, transparency, and uniformity across the institution or practice” (p. 184) and places the “moral burden” of these decisions on health care providers, where they do not belong (p. 187).

This argument is reminiscent of the 2013 recommendations by the American College of Medical Genetics (ACMG), which recommended uniformly returning 57 actionable genetic findings from whole genome and whole exome sequencing (WGS/WES). The recommendations (since revised) noted that parents had the option to refuse WGS/WES if they were not interested in receiving information about these 57 conditions.² Like Palmor and Fiester, the ACMG argued for institutional consistency in the selection of its predetermined panel because it was too burdensome for physicians to decide which results to return.

One common thread for these arguments is that allowing for autonomous decision-making places too much of a burden on physicians, institutions, and parents. The ACMG argued that “to respect preferences in the same manner as with targeted testing . . . the patient . . . would have to undergo an extensive, and possibly overwhelming, amount of genetic counseling.”³ Palmor and Fiester, in contrast, argue that parents should not be expected to make decisions about IFNP when seeking a diagnosis, saying, “The clinician’s and parents’ focus in that instance should remain on the clinical condition, not on the separate,

life-altering finding of nonpaternity or nonmaternity.”¹ This approach does not constitute paternalism, they say, because the clinician has not asked for the parents’ view on returning results and therefore is not consciously overriding them.

We find these arguments troubling. To deny someone the opportunity to express a preference then deny that it is paternalistic to ignore that preference, is moral sophistry. Furthermore, to presume to tell parents where their time and energy should be focused while shepherding their child’s genetic testing is simply condescending. It is true that patient autonomy is hard. It is hard for patients, who often feel overwhelmed. It is hard for providers, who may feel a commendable desire to ease patients’ emotional burden. It is hard for health care systems, which must devote additional resources to the consequences of patient choices. However, none of these difficulties make it ethically acceptable to prioritize assumed beneficence over autonomy.

We share Palmor and Fiester’s conviction that many parents, perhaps most, do not want this information. However, most parents are not all parents, and clinicians have a responsibility to give individuals the opportunity to choose whether they would like to know about IFNP or any other category of finding. How, and to what extent, any additional costs are passed along to payors is a worthwhile subject for debate, but these concerns do not justify abandoning patient autonomy in the name of efficiency and false beneficence.

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Conflict of Interest:

None declared

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Author's Response Re: Findings of Nonparentage: A Case for Autonomy

We thank both Dr Chandler and Drs Michie and Allyse for their thoughtful and challenging responses to our article, "Incidental Findings of Nonparentage." The subtle arguments that the authors provide is precisely the kind of debate we hoped to spark in writing this article.

We have several responses. The first is directed to Dr Chandler, who makes a principle-based argument regarding truth-telling. Dr Chandler is concerned that our recommendation might undermine the clinician's obligation of truth-telling, which he holds to be an absolute ethical duty. However, an explicit policy of universal nondisclosure removes both the clinician's ethical obligation of truth-telling and the parental expectation that information of nonparentage be shared. Consider an analogous case of nondisclosure: if I take my minor child to a physician for

a suspected sexually transmitted disease, the physician will tell me that she or he will not disclose to me the truth of what is found because children are treated as emancipated minors in the context of sexual health. Against the backdrop of an explicit nondisclosure policy, I can have no expectation of receiving information about my child's diagnosis, and the clinician has no grounds for any ethical qualms about withholding the information from me. Policies of nondisclosure remove the obligation of truth-telling.

Our second response is directed to the concerns raised by Drs Michie and Allyse that our policy of universal nondisclosure undermines parental autonomy. There are 2 comments to make in response to this worry. First, our proposal includes the recommendation that parents be told that paternity or maternity testing is available to them if they intentionally seek it out. In that case, there would be a separate informed consent process that would ensure that they had considered the risks and benefits of such a test and the consequences of the results. Our proposal merely stipulates that an incidental finding of nonparentage (IFNP) will not be disclosed. Such a policy does not erode autonomy but enables parents to have the most robust form of autonomy possible because they have the ability both to obtain any information they desire and also the ability to avoid being saddled with information that they do not want.

Our second comment anticipates an obvious rejoinder that Drs Michie and

Allyse might make: why shouldn't parents be allowed to choose whether to receive information of IFNP discovered in the current test? The answer is that such a choice only looks like autonomy; it is actually coercion. Consider the following example: imagine that Mr and Mrs Smith are being consented for a genetic test for their child, and the clinician asks them if they want to know about any IFNP. Mr Smith immediately says that he wants to know (either because he suspects that he might not be the biological father of his child or because he has no concerns at all that the baby is someone else's child). Mr Smith has made an autonomous choice. However, Mrs. Smith knows that there is a chance that her husband is not the baby's father. If she says she doesn't want the information, or even hesitates in answering the question, she has already revealed to her husband that there is cause for concern. So Mrs. Smith will be forced to agree to receive the information. She will not be able to make a noncoerced choice; therefore, her choice does not qualify as autonomous. Allowing the possibility of disclosure of IFNP prioritizes the protection of autonomy of some parents over the harm of coercion of others.

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Findings of Nonparentage: A Case for Autonomy

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