Prenatal diagnosis requests for Huntington's disease when the father is at risk and does not want to know his genetic status: clinical, legal, and ethical viewpoints

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Clinical genetics units of hospitals occasionally receive requests from women for prenatal diagnosis for Huntington's disease when their male partners are at risk and do not want to know their genetic status for the disease. These cases raise significant legal and ethical concerns for the clinical team because such prenatal tests can reveal that the woman's partner has the genetic mutation for Huntington's disease when he does not want this information and may be unprepared for it. In this paper we present clinical, legal, and ethical appraisals of this situation. We conclude that there is no easy answer to such requests and that clinical teams need to deal with them on the basis of the individual circumstances

Huntington's disease is an autosomal dominant, incurable neurodegenerative disorder caused in virtually all cases by a trinucleotide repeat expansion in the IT15 gene.[1 2] Predictive and prenatal testing are available through clinical genetics units, but most people at risk choose not to have predictive testing.[3]

Predictive testing is undertaken according to international guidelines, which make recommendations on providing information and counselling support throughout the testing process.[4] The principle of respect for autonomy is protected by allowing people to refuse to have genetic testing after they have been counselled.

Summary points

- When the father is at 50% risk of having Huntington's disease, there is a 1 in 4 chance that prenatal testing will show that he has the mutation and will develop the disease
- Testing for Huntington's disease normally follows international guidelines that protect an individual's right to know or not know their genetic status
- It is unclear whether prenatal testing should be done without the consent of the man at risk
- Either performing the prenatal test or refusing it if the man at risk does not consent are legally acceptable

Hypothetical case

Clinical genetics units sometimes face situations such as the one outlined in the following hypothetical case.[5] A woman who is eight weeks pregnant discovers that her partner is at 50% risk of developing Huntington's disease. He is not interested in pursuing predictive testing. The woman is adamant that she does not want a child who will develop Huntington's disease in later life, and she requests a prenatal test.

There is a 1 in 4 chance that the prenatal test will show that the fetus has the mutation for Huntington's disease, and therefore the test also presymptomatically diagnoses the father. Such prenatal requests highlight the uncertainty of the legal position taken by the international guidelines. Cases like this pose considerable ethical and legal dilemmas for clinicians. Does the right of the pregnant mother to know the status of her fetus outweigh the right of the father at risk to not know his genetic status?

In a clinical ethics consultation the lawyer and ethicist presented the clinical team with their ideas on the subject and had the team reconsider its procedures in the light of the different viewpoints.

Clinical team's viewpoint

Does the clinical genetics team have a duty of care to the male partner at risk? If the fetus, and therefore the male partner, are found to have the mutation, this information may or may not become known to the man at risk. Because the woman has been counselled by the clinical team, her decisions are likely to be informed, autonomous, and confidential. Her emotional and psychological needs are addressed. But the needs of her partner are not similarly met.

The clinical team's preferred course of action is to test the male partner first, and, if he is found to have the mutation, to offer prenatal diagnosis. Alternatively, exclusion testing (testing to exclude the risk of the condition in the fetus) preserves the man's preference to not know his status for being at risk.[6] Both these options involve the man in the decision making

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processes, thereby meeting his needs for information and emotional support.

Why might the woman choose not to involve her partner at risk? She might want to protect her partner from the distress of possibly learning he has the mutation for the disease; at times, people who are at risk state that they would commit suicide if they knew they had the mutation. Although the woman's motive may be altruistic, testing in secret may leave her with a great emotional burden. She may be faced with the option of terminating the pregnancy, as well as grief for her and her partner's future. She is likely to take into consideration her partner's genetic status when making a range of long term decisions relating to finance, career, and family planning, for example.

If a pregnant woman and her partner are having relationship difficulties, the knowledge that her partner has the mutation could be a potential and powerful weapon. If the man learns of his status in the setting of domestic conflict, the consequences could be disastrous. Literature on the process of predictive testing continues to emphasise the need for clients to be supported throughout the process. The role of self selection continues to be essential.[7]

Does the right of the pregnant mother outweigh the right of the father at risk?

Should clinicians breach confidentiality, the practice of which is legally sanctioned in some medical settings (for example, HIV testing), to directly determine the views of the man who is 50% at risk? Under Australian law, decisions about prenatal testing can be made solely by the mother; the father's consent (or even knowledge) is not required because the law states that these are tests on her body.

This prenatal test is unlike most others because a third party can be greatly affected by the outcome. Therefore, such a test should not go ahead without the man at risk giving informed consent and having appropriate psychological support. Exclusion testing can be offered or he can have predictive testing; if he is found to have the mutation, the parents can choose prenatal testing. A fundamental shift is needed in the legal framework to better deal with such circumstances.

Legal considerations

Although there is little legal authority on whether a pregnant woman's request for prenatal testing for Huntington's disease should be granted when her male partner at risk does not want to know his genetic status, the law in Australia and the United Kingdom would probably focus on the woman's request and consent. Clinicians are unlikely to be liable regardless of whether they perform the prenatal test for Huntington's disease without involving the man at risk or refuse to do the test unless they have his consent.

Under the law of battery, it is lawful to do the test with the consent of only the woman, after she has been well informed about it, because her body only is touched.[8 9] Under the law of negligence, counsellors must take reasonable care to provide the woman with information,[9] advice, and treatment; the same care does not have to be given to the man unless he is also a patient. Counsellors would have a duty to involve him only as part of their reasonable care of the woman—for example, in advising her of the potential consequences if the man is not involved and encouraging her to involve him.

The law of negligence in Australia and the United Kingdom imposes a legal duty on all health professionals to take reasonable care in dealing with patients. If professional guidelines recommend involving men who are at risk, a court might say that "reasonable care" requires that the man should be counselled and asked to give his consent before the test can be carried out. Even so, the man could not prevent the woman from having the test if she wanted it. Nor could he sue if he was not involved; the duty to take reasonable care is owed to the patient (the woman, or possibly the unborn child) and not to other parties. Cases in which the law has acknowledged a duty to someone else are rare and were based on a statutory duty to the third party.[10 11]

The final decision of whether or not the test should be done is up to the judgment of clinicians; a court will not override their decision, regardless of the woman's wishes. If the clinical team refuses to perform the test and the child has the mutation, the woman or child would probably not be entitled to sue for failure to test. Disabled children have recently recovered compensation because a properly performed genetic test would have detected their condition.[12] A child born with a condition of late onset like Huntington's disease is likely to have years of healthy life. Even if negligence were established in not advising or not properly undertaking a genetic test, what damages could be awarded?

It is unlikely that clinicians will face legal repercussions if they test for Huntington's disease without involving the man or if they refuse to do the test without his consent. Ultimately, it is a matter for their discretion, acting with reasonable care in what they perceive to be the woman's best interests.

Ethical considerations

The law allows testing to be provided or withheld. Health professionals have an ethical obligation to offer testing in these circumstances.

Health professionals have a duty of care to act in their patient's best interests. If a couple present together, then a professional may face a dilemma: acting in the best interests of one may be against the interests of the other.

One way to resolve this dilemma is by maximisation—that is, promoting the interest that is likely to have the greatest impact. This is the utilitarian approach. What if the male partner at risk had previously threatened suicide if he were to find that he has the mutation? The psychological and possible physical harm to the man as a result of testing might be greater than the harm to the pregnant woman as a result of not testing. In this case, maximising the man's interests favours not testing. If, however, we include the interests of any future children, there is more reason to test. This is because a person without Huntington's disease is expected to have, overall, a happier, longer, and better life than a person with the disease. According to utilitarianism, the interests of future generations provide grounds for testing and for terminating an affected pregnancy if the woman would go on to have an

unaffected child. These considerations must be weighed against the harm to the man as a result of testing.

But there are other reasons to support testing. For example, withholding information seriously frustrates a person's autonomy. Autonomy involves choosing which possible course of action is best for one's own life. But to evaluate the consequences of a course of action, we require relevant information.[13] For a pregnant woman to choose to continue to carry a pregnancy autonomously, she requires relevant information about that pregnancy. This is one of the reasons why prenatal testing is offered.

The possibility that a person might commit suicide may cause concern. However, if a person is competent to make decisions about whether to continue to live or not, then that person is responsible for the consequences of their behaviour. A clinician who provides information that contributes to a person's suicide is not necessarily morally responsible for that suicide.

As discussed in the clinical team's viewpoint, the woman might be harmed by knowing the genetic status of the fetus and her partner. She must be informed of this risk, but it would be outrageous paternalism to withhold testing to protect her from being burdened with information that she might find difficult to handle.

Moreover, the adverse effects of genetic information on other family members is not a good reason to withhold information about the patient when the patient may benefit from it. As a general principle, a patient should be offered a test or procedure—if they are entitled to it—regardless of what others will think about it, or do. Harm to others should be minimised through support and counselling of the patient. But information that might be relevant to other people should only rarely (if ever) be withheld from the patient to protect those people. For example, if two people have been jointly exposed to a communicable disease, and one wants testing and the other does not, we should test even if the information harms the person who does not want the test.

Conclusion

The types of cases discussed here have generated diverse views about the appropriate clinical response to a request for prenatal diagnosis where the result may reveal the genetic status of a third party who does not wish to have this information. The law in Australia and the United Kingdom may need to be reconsidered in the light of such a scenario and perhaps clarified by legislation. At present, clinicians cannot be sure what their legal obligations are because legal opinions may differ. In Australia, in a situation similar to the hypothetical case, the legal opinion was that the prenatal test should be performed.[14] Only when such cases are tested in the courts can the legal obligations of clinicians be known with greater certainty.

Ethical views about a particular situation will often differ. In this instance, the clinical team has different views from those of the ethicist about the status of the at risk father's rights.

In this discussion, general views only have been offered. Each clinical presentation needs to be dealt with individually, and the final decision about which way to proceed may differ accordingly. Even after considerable legal and ethical discussion, the clinical team faced with the same situation would still place considerable weight on the at risk man's rights in making a decision about offering prenatal testing. The clinical team would take all possible steps to ensure that the informed consent of the male partner was obtained and, if this were not possible, it would not proceed with the prenatal test.

In the end, the clinical team's view of what was right was not shifted by considerable discussion with a lawyer and ethicist; nevertheless, the team believed its view had become more considered and circumspect. We consider this a success of clinical ethics consultation in that the clinical team can disagree with legal and ethical experts, even after informed discussion.

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Correction

Institutional corruption in medicine

Some confusion over titles of places and people arose in this Education and Debate article by Peter Wilmshurst (23 November, pp 1232-5). Professor Peters was an employee of the academic institution King's College—not King's College Hospital Trust (as implied in this article), with which he held only an honorary contract. This confusion over the name of the institution occurred throughout the article—for example, an inquiry, once Dr Banerjee came under suspicion, was started in 1990 at King's College [not at the NHS trust]. Additionally, in the first paragraph in the section entitled "Academic institutions involved" (p 1233) Professor Roger Williams was described as professor of gastroenterology at King's; in fact, his chair was in hepatology, but the chair was not conferred until 1994—after the British Society of Gastroenterology meeting referred to in that paragraph. Finally, the reference in the "summary points" box (p 1232) to King's College Hospital Medical School should have been to King's College School of Medicine and Dentistry of King's College London.