

Case 3.3: Confidential Care for Minors and Protecting Genetic Information

Case Presentation

Ms Johnson brought her daughter, Mandy, to see Dr. Jones for her first gynecological visit when Mandy was 14 years old. Dr. Jones performed a regular physical, but not a vaginal exam, and talked to Mandy about the changes that were leading her to sexual maturity.

Dr. Jones did not see Mandy again until she was 16 when she made an appointment and showed up on her own worried that she was pregnant. She had used a home pregnancy test, which supported her suspicion. Still, she wanted Dr. Jones to confirm her pregnancy. After getting a history of her sexual activity, Dr. Jones diagnosed the pregnancy using a hormonal assay. Upon completing the test, he informed Mandy that she was in fact pregnant. Based on her history, he estimated that she was around 10 weeks pregnant. Upon general examination, she was in good health.

Mandy and Dr. Jones were now in a difficult situation. Dr. Jones, who treats her immediate family and some extended family members, was well aware that Mandy's paternal grandmother had been diagnosed with Huntington's. Her father (in his early 40s) did not exhibit any symptoms at this point, but he had chosen not to be tested. Mandy appeared to be well informed about her family's medical history and informed Dr. Jones that she wanted to be tested for Huntington's.

"If I have Huntington's, my baby might have Huntington's, and I couldn't put my baby through that."

What should Dr. Jones do? (select an option)

- A. [Contact Mandy's parents to inform them of her intention to get tested for Huntington's.](#)
- B. [Begin the process of testing Mandy for Huntington's disease.](#)
- C. [Refer Mandy to a genetic counselor and/or adolescent psychologist.](#)

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Option Assessment

- A. Contacting Mandy's parents to inform them of her intention to get tested for Huntington's should be **avoided**; it likely violates the *Code* in Opinion 5.055, "Confidential Care for Minors": "Where the law does not require otherwise, physicians should permit a competent minor to consent to medical care and should not notify parents without the patient's consent...For minors who are mature enough to be unaccompanied by their parents for their examination, confidentiality of information disclosed...should be maintained."
- B. Beginning the process of testing Mandy for Huntington's disease is premature and should be **avoided**; it is not supported by the *Code* and may violate Opinion 2.12, "Genetic Counseling": "Counseling should include reasons for and against testing as well as discussion of inappropriate uses of genetic testing." Simply beginning the process of Mandy's genetic testing, without any counseling on the implications and significance of a test, does not provide Mandy with the necessary basis for informed decision making about the implications for her or her pregnancy.
- C. Referring Mandy to a genetic counselor and/or adolescent psychologist is **preferable** and supported by the *Code*. Opinion 5.055, "Confidential Care for Minors" states: "Physicians should permit a competent minor to consent to medical care and should not notify parents without the patient's consent. Depending on the seriousness of the decision, competence may be evaluated by physicians for most minors. When necessary, experts in adolescent medicine or child psychological development should be consulted."

[Compare these options](#)

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Option Comparison

Mandy's readiness to be tested conceals how she feels about learning her genetic status. Hence, referring her to a genetic counselor or adolescent psychologist (option C) is preferable, and beginning the process of genetic testing (option B) should be delayed. An opportunity to discuss her thoughts and feelings about her genetic status is important because it's unknown whether she has explored the topic with her parents, or anyone else.

Although discussion with an adolescent psychologist may indicate the need to inform Mandy's parents of her desire for a genetic test, there is no clear evidence that this is necessary. Accordingly, option A (informing Mandy's parents) should also be avoided.

Preferable: Option C

Avoid: Options A and B

[Additional discussion and information](#)

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Additional Information

Adolescent patients create a particularly troublesome set of concerns about confidentiality. Minors are not legally empowered to make health care decisions independent of a parent or legal guardian. And yet, minor patients are regularly encouraged to make, or at least help make, their health care decisions, and minors are tried as adults in a court of law with increasing regularity.

Opinion 5.055, "Confidential Care for Minors"

When minors request confidential services, physicians should encourage them to involve their parents...Physicians should permit a competent minor to consent to medical care and should not notify parents without the patient's consent...Use of the courts for competence determinations should be made only as a last resort.

When an immature minor requests contraceptive services, pregnancy-related care..., or treatment for sexually transmitted disease, drug and alcohol abuse, or mental illness, physicians must recognize that requiring parental involvement may be counterproductive to the health of the patient...When the physician does breach confidentiality to the parents, he or she must discuss the reasons for the breach with the minor prior to the disclosure.

...Confidentiality may be justifiably breached in situations for which confidentiality for adults may be breached, according to Opinion 5.05, "Confidentiality."

Parents generally are responsible for making health care decisions for their children, but, as children mature and approach adolescence, this patient-physician-parent relationship changes. While it is true that young minors lack the capacity to make autonomous health care decisions, many older minors are mature enough to do so. In general, adolescents 14 and above should be evaluated carefully to determine whether they are mature enough to make decisions about their medical care.

Minors who are determined to be capable due to their maturity are entitled to the same degree of autonomy and confidentiality as an adult patient. Parental involvement should always be encouraged, but parental consent should not be required for the treatment of mature minors, and information disclosed in the patient-physician interaction must not be disclosed to the parents or third parties without patient consent.

Because Mandy is in a position where she may request an abortion if she has the Huntington's allele, it is also important to consider whether or not her parents should be informed if she requests an abortion.

Opinion 2.015, "Mandatory Parental Consent to Abortion"

Physicians should ascertain the law in their state on parental involvement to ensure that their procedures are consistent with their legal obligations.

Physicians should strongly encourage minors to discuss their pregnancy with their parents...

Physicians should not feel or be compelled to require minors to involve their parents before deciding whether to undergo an abortion....Physicians should explain under what circumstances (eg, life-threatening emergency) the minor's confidentiality will need to be abrogated.

Physicians should try to ensure that minor patients have made an informed decision after giving careful consideration to the issues involved...Minors should be urged to seek the advice and counsel of those adults in whom they have confidence, including professional counselors, relatives, friends, teachers, or the clergy.

Where law does not require it, parental consent need not be obtained before providing contraceptive services, treatment of sexually transmitted diseases, pregnancy-related care (including pregnancy testing, prenatal/postnatal care, delivery services, and abortion), drug and alcohol abuse treatment and mental illness treatment to minors who request these services. The absence of confidentiality may keep adolescents from seeking health care that is necessary to prevent serious harm.

An important consideration to be weighed when deciding whether to breach a minor's confidentiality is the possibility that disclosing sensitive information such as sexual behavior, pregnancy, or drug use to the parents might place the minor in danger.

[Related topic: Genetic information](#)

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Related topic: Genetic information

Many people believe that, because of its sensitive nature, some medical information warrants higher standards of confidentiality than other medical information. For instance, psychiatric records and HIV status often are protected more rigorously because of social stigmas and the potential for discrimination based on such information. The following Opinions address physician responsibilities regarding genetic information:

Opinion 2.131, "Disclosure of Familial Risk in Genetic Testing"

1) Physicians have a professional duty to protect the confidentiality of their patients' information, including genetic information. (2) Pre- and post-test counseling must include implications of genetic information for patients' biological relatives... [P]hysicians should make themselves available to assist patients in communicating with relatives to discuss opportunities for counseling and testing, as appropriate. (3) Physicians who order genetic tests should have adequate knowledge to interpret information for patients.

Opinion 2.138, "Genetic Testing of Children"

...Before testing of children can be performed, there must be some potential benefit from the testing that can reasonably be viewed as outweighing the disadvantages of testing, particularly the harm from abrogating the children's future choice in knowing their genetic status...

When a child's genetic status is determined incidentally...[t]his information should not be disclosed to third parties. Genetic information should be maintained in a separate portion of the medical record to prevent mistaken disclosure. When a child is being considered for adoption, the guidelines for genetic testing should be the same as for other children.

Opinion 2.137, "Ethical Issues in Carrier Screening of Genetic Disorders"

All carrier testing must be voluntary, and informed consent from screened individuals

is required. Confidentiality of results is to be maintained. Results of testing should not be disclosed to third parties without the explicit informed consent of the screened individual.

There are other situations where genetic information may be sought by third parties. Specifically, insurance companies may attempt to procure a patient's genetic information. Opinion 2.135, "Insurance Companies and Genetic Information" states that "Physicians should not participate in genetic testing by health insurance companies to predict a persons' predisposition for disease. As a corollary, it may be necessary for physicians to maintain separate files for genetic testing results." Physicians should also make it clear to insurance companies that they will not provide genetic information for any of their patients.

[Module 3 Feedback Questionnaire](#)

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Module 3: Privacy and Confidentialty

Feedback Questionnaire

In Module 3 on privacy and confidentiality, how would you rate the relevance of the cases?

- Excellent
- Very good
- Good
- Fair
- Poor

How would you rate the explanation of courses of action?

- Excellent
- Very good
- Good
- Fair
- Poor

How would you rate the overall coverage of the topic?

- Excellent
- Very good
- Good
- Fair
- Poor

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