CASE 3-MR. AND MRS. E: CYSTIC FIBROSIS MISATTRIBUTED PATERNITY/GENETIC TESTING/DISCLOSURE

Danielle Nadeau, Quynh Ngo, Chukwudi Okeke, Laura Recupero, Joncie Slate
Old Dominion University
INTRODUCTION

Nature and scope of the problem

- Parents of a child with cystic fibrosis receive genetic testing
- After genetic testing, the mother informs the genetic counselor that the husband is not the biological father and he is not aware
- Patient confidentiality is a responsibility that healthcare workers are required to maintain unless consent has been released by the patient
This paper will discuss:

- The scope of practice
- Legal implications of informing the husband and/or the biological father
- The pro perspective, con perspective, and nursing responsibilities of maintaining or breaking patient confidentiality
PRO PROSPECTIVE

- Genetic testing differs in that if “the rationale is based on preventing harm, as opposed to maintaining a personal right to confidentiality, then disclosure of genetic information can be justified when it can prevent foreseeable and significant harm” (Suarez, 2012, p. 496-497).

- The standard duty to warn is different from violating the release of medical information.

- Duty to warn is based on the fact that the “disclosure of genetic information to relatives can sometimes prevent or decrease harm if the information is actionable” (Suarez, 2012, p.496).
In the case of Mrs. E.:

- She does not reveal the father’s name to anyone but tells the genetic counselor that Mr. E is not the biological father.
- The counselor has the duty to tell the father solely for the fact that he should be tested to know whether or not he is the carrier for the gene responsible for cystic fibrosis.
- This becomes extremely important for the father so that he can make an informed decision on whether or not he desires to father any more children that may suffer from cystic fibrosis.
Although it may be beneficial for the father of Mrs. E’s 10-month-old son to find out about being a carrier of the CFTR allele and the possibility of having future offspring with Cystic Fibrosis, it is \textbf{NOT} the counselor’s responsibility to inform him of such. The counselor’s duty is to reveal to the \textbf{client} (and only the client for confidentiality purpose) information from genetic testing that may be used to prevent harm when reproduction comes in question.

The father of Mrs. E’s infant son is \textbf{NOT} the client.
The counselor should consider that it might be *unethical* to contact him directly even if Mrs. E refuses to disclose this information.

“In general, it is inappropriate to bother people with information that they do not appreciate. Obviously, this general rule of conduct also applies to family members at risk. They have a right not to know, which should be respected.” (Gordijn, 2007).

Contacting the father of Mrs. E to warn him of his genetic predisposition for CF with or without Mrs. E’s consent still violates *his own right* to not know such information.
NURSE'S RESPONSIBILITIES

According to International Society of Nurses in Genetics (2010),

- Nurses must uphold and maintain their clients confidentiality
- Be aware of the provisions and protections afforded to individuals by any law pertaining to genetic information
- Adopt the guidelines of ethical practices
- Be knowledgeable of state or national legislation affecting the nurse/client relationship
- Obtain a consent before releasing a client's information
- Understand that family cultures and beliefs affect the sharing of genetic information
- Recognize that each individual in the family is autonomous with regards to any genetic information that may be compromised by the decisions of other family members
In this case study:
- the nurse/genetic counselor has fulfilled the responsibility of giving the right genetic information to the patients

For the misattributed pregnancy,
- The nurse is mandated to obtain a consent from Mrs. E before divulging the information to her husband
  - If she refuses,
    - The nurse will determine if the case fits into the provisions of duty to warn
    - Duty to warn exists in situations where maintaining a client’s confidentiality is poses a threat to another person
CONCLUSION

Genetic counselors and nurses need to have a comprehensive knowledge base & understanding of patient confidentiality. This includes knowledge of:

- Ethical and legal obligations
- Rules governing patient confidentiality
- The implications and consequences of disclosure and non-disclosure of patient’s confidential information
- Continued controversy between Patient Confidentiality and Genetic Testing should be anticipated by Nurses and Genetic Counselors as the use of Genetic Testing becomes more prevalent in medicine.
Mr. E. is unaware that he is not the child’s biological father.

Mrs. E. has not yet disclosed the biological father’s name or contact information.

Contacting the biological father without Mrs. E’s consent violates patient confidentiality is nearly impossible.
REFERENCES


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