

## **FIGO Human Rights and Women's Health Case 4 Discussion**

### **Protecting confidentiality**

This case highlights the right to confidentiality in relation to information on health care and health status. Confidentiality refers to the duty of providers and others who handle private medical or health information on patients to keep secret or private the information to which they have access. Confidentiality is intertwined with the right to privacy (see Case #3 for more information on the right to privacy). Both are critical to ensuring patient trust and usage of the health care system.

In the context of health care, including HIV-related care, this right places an obligation on those who have access to personal information to ensure that that information is not shared with third parties, including patients' partners, family, or friends, without the patient's full and informed consent. Women are particularly vulnerable to personal harm or discrimination from breaches in medical confidentiality, particularly when domestic violence, sexually transmitted diseases, or predisposition testing is involved. Because the risks women face from breaches in confidentiality are greater than the risks men face, health care professionals have a greater obligation to ensure strict confidentiality in women's health care. (CEDAW, General Recommendation #15, 1990)

### **Learning objectives**

For physicians to competently apply this principle to daily practice they must be able to:

- Maintain patient confidentiality and avoid unnecessary disclosure of information.
- Communicate to patients how confidentiality of all written and digital personal information is maintained.
- Discuss the potential harm and benefit of release of confidential information to third parties.
- Discuss how interpretation of the laws on confidentiality affect the provision of health care for women.
- Discuss how decisions to protect or disclose confidential information are made.

Note that although the case highlights the right to confidentiality, it also addresses a variety of other ethical, human rights, and policy issues. Similarly, although the medical issues of the case focus on pregnancy and HIV status, the standards of practice are applicable to the requirements of confidentiality regarding medical records in general.

### **Case study**

J.M., a 35-year-old professional woman, attends her first pregnancy visit at 8 weeks' gestation. As per the clinic's routine, she is offered an HIV antibody test. She



## FIGO Human Rights and Women's Health Case 4 Discussion

### Protecting confidentiality

accepts after stating that she does not want her partner to find out that she has taken the test, whatever the result may be.

When her doctor telephones to inform her that her HIV test is negative, she reminds him of her request that her partner is not to be informed about the test. The doctor reassures her that it is standard practice to record test information only in her medical record, which is confidential.

At her next visit, J.M.'s partner accompanies her for the ultrasound scan to date the pregnancy. After a particularly long wait, J.M. goes to the bathroom. Before she returns, the nurse calls her to see the doctor; in J.M.'s absence, the nurse hands her antenatal record to her partner, saying, "Please go in to see the doctor as soon as she comes back." Glancing through her antenatal notes, J.M.'s partner discovers that she has undergone an HIV test.

He is happy that J.M. is HIV negative but concerned that she needed to take the test and that she did so secretly. Earlier in their relationship, they had undergone HIV testing together, and they had both been found negative.

### Questions for discussion

1. What are the risks and benefits of HIV screening in pregnant women?

Risks of HIV screening in pregnant women vary according to results. False-positive results may lead to anxiety and false-negative results to a false sense of security. Positive results may have repercussions such as violence, discrimination, abandonment, and divorce.

The benefits of HIV screening in pregnant women are substantial. When a pregnant woman is found to be HIV positive, measures may be taken to prevent transmitting infections to others, including the fetus/newborn. Early treatment of the mother's infection leads to better outcomes for the mother and, in turn, her family.

2. Using the Integrating Human Rights and Health Checklist, identify the human rights that were infringed in this case.

Clearly the patient's right to privacy was breached when the record was handed to her partner. This small action breached confidentiality and ultimately the patient's right to health (see Competency on Privacy and discussion of Case #2 for more details about general obligations around confidentiality).

International human rights bodies have noted that states should ensure that HIV testing and treatment are voluntary and confidential, emphasizing the rights and needs of women. In order to fulfill this standard, HIV services must be "acceptable", which means that they must be respectful of medical ethics and culturally appropriate to all individuals and communities, inclusive of culture, gender, and life-cycle requirements. International human rights standards recognize that health care



## FIGO Human Rights and Women's Health Case 4 Discussion

### Protecting confidentiality

should be culturally sensitive but that culture cannot be used as an excuse to violate human rights. For instance, in places where women are perceived as subordinate to men, doctors may not use this as an excuse to disclose a woman's test results to her husband or partner without her permission.

However, although confidentiality and patient privacy are important, individual patients still have an ethical responsibility to prevent harm to others. Informed consent must be obtained prior to testing for HIV infection and before communication of test results. Through counseling, patients should be advised of their responsibility to others, including the importance of allowing the sharing of such information to protect their sexual partners as well as health care workers with whom they come in contact.

#### 3. What are the potential consequences to the patient of this loss of confidentiality?

A positive test may lead to discrimination against the woman and strain the relationship with her husband, sometimes leading to violence against the woman. Human rights bodies have recognized high rates of violence against women due to HIV status.

In this case, even a negative result may result in discrimination and may stress the patient's relationship with her husband, particularly because of the manner in which her husband discovered the testing.

The longer-term result may be that the patient loses her trust in the health care institution and its providers and either does not divulge further confidential information or does not return for needed care. If this is the only clinic available to her or if she fails to register for health care at another clinic, she will not receive the care she needs to maintain her health and to have a healthy baby.

#### 4. How could the clinic staff have better protected the patient's record?

Health care records are to be shared only among involved health care providers and the patient. The simple act of waiting for the patient to return and to hand the records to her directly, in private, without the presence of her partner, would have averted this breach. In addition, records should be stored securely in folders in such a way that documents cannot be viewed inadvertently because folders fall open or unsecured papers fall out. Students may think of other ways that record systems and modes of record delivery may ensure confidentiality.

#### 5. What are the laws/policies/regulations regarding medical confidentiality in your country/region?

States should have laws and written policies governing access to medical records. Students should know the laws and policies in the locale where they practice. They can be found in clinic policies and medical council guidelines.



## FIGO Human Rights and Women's Health Case 4 Discussion

### Protecting confidentiality

6. How would you have counseled the woman about the sharing of results before she undertook the HIV test?

Appropriate informed consent requires offering the patient information about the results of testing, including the implications of false-positive and false-negative results. She should know that her information will be kept confidential in her record, but that if she is HIV positive, she will be advised to share the results with her partner(s). If she lives in a country where results are notifiable, she should be informed that the clinic is required by law to report positive results to the department of health. Such information is kept in confidential files by the health authorities and is used for following up with her and her contacts.

If the patient has acknowledged that she understands the testing and the consequences of the results, she should be informed, objectively and without judgment, that she has the right to refuse to give consent for sharing her test results. Only then, with her consent, should her blood be drawn for testing.

7. What actions would the doctor need to take if the woman's HIV test result had been positive?

The first action would be to notify the patient directly of her test results, making sure that she receives the news at a time and place where she can have a private conversation, and providing information about the recommendations for treatment. She should be encouraged to report the results to her partner and to encourage her partner to take the test, if his HIV status is not already known. If she is worried about her safety, measures should be taken to minimize her risk by involving the relevant disciplines such as the medical social worker. She should then begin treatment as soon as possible.

In some states, positive results must be reported to the health authorities. She should be reminded of this and strongly encouraged to share her results with her partner, affording him the ability to seek early treatment if he should prove HIV positive also.

In states in which positive results are not reportable, the provider must judge the degree of potential harm to the patient, her partner, and others before breaking confidentiality with the patient.



## FIGO Human Rights and Women's Health Case 4 Discussion

### Protecting confidentiality

#### References

##### *HIV testing in pregnancy*

American College of Obstetrics and Gynecology (ACOG). New Perinatal HIV Guidelines. Washington, DC: ACOG; 2010.

[http://www.womenandhiv.org/sites/default/files/pdf/Perinatal%20HIV%20Purple.Folder\\_2012.pdf](http://www.womenandhiv.org/sites/default/files/pdf/Perinatal%20HIV%20Purple.Folder_2012.pdf)

Anderson JR, Cohan D, Cu-Uvin S. HIV and reproduction: fertility, contraception, and preconception issues and interventions. *Infect Dis Obstet Gynecol* 2012;2012:736864.

Chou R, Cantor A, Bougatsos C, Zakher B. Screening for HIV in Pregnant Women: Systematic Review to Update US Preventive Services Task Force Recommendations 2012. Rockville, MD: Agency for Healthcare Research and Quality; 2012. <http://www.ncbi.nlm.nih.gov/books/NBK114880/>

Watts HD. Human Immunodeficiency Virus in Obstetrics. *The Global Library of Women's Medicine*. London, UK: Foundation for the Global Library of Women's Medicine. 2008. doi: 10.3843/GLOWM.10184. [http://www.glowm.com/section\\_view/heading/Human%20Immunodeficiency%20Virus%20in%20Obstetrics/item/184](http://www.glowm.com/section_view/heading/Human%20Immunodeficiency%20Virus%20in%20Obstetrics/item/184)

##### *Addressing human rights*

Cook RJ, Dickens BM, Fathalla MF. *Reproductive Health and Human Rights: Integrating Medicine, Ethics, and Law*. New York, NY: Oxford University Press; 2003:121–8.

International Federation of Gynecology and Obstetrics (FIGO). Committee for the Study of Ethical Aspects of Human Reproduction and Women's Health. Confidentiality, Privacy and Security of Patients' Health Care Information. 2005. In: *Ethical Issues in Obstetrics and Gynecology*. London, UK: FIGO; 2009. <http://www.figog.org/files/figo-corp/Ethical%20Issues%20-%20English.pdf>



## FIGO Human Rights and Women's Health Case 4 Discussion

### Protecting confidentiality

International Federation of Gynecology and Obstetrics (FIGO). Committee for the Study of Ethical Aspects of Human Reproduction and Women's Health. Ethical Aspects of HIV Infection and Reproduction. 1996. In: Ethical Issues in Obstetrics and Gynecology. London, UK: FIGO; 2009. <http://www.figo.org/files/figo-corp/Ethical%20Issues%20-%20English.pdf>

Global Commission on HIV and the Law. HIV and the Law: Risks, Rights and Health. New York, NY: United Nations Development Programme; 2012. <http://www.hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>

Grover A. Report of the Special Rapporteur on the Rights of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health: The Right to Health and Informed Consent. A/64/272. 2009. <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/N09/450/87/PDF/N0945087.pdf?OpenElement>

Office of the High Commissioner for Human Rights and Joint United Nations Program on HIV/AIDS (UNAIDS). International Guidelines on HIV/AIDS and Human Rights. 2006 Consolidated Version. New York, NY: United Nations; 2006. [http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines\\_en.pdf](http://data.unaids.org/Publications/IRC-pub07/jc1252-internguidelines_en.pdf)

United Nations. Committee on Economic, Social and Cultural Rights. General Comment No. 14, Article 12, Right to the Highest Attainable Standard of Health. E/C.12/2000/4. New York, NY: United Nations; 2000, paras. 12(b), 16, 18, 28.

United Nations. Committee on the Elimination of Discrimination against Women (CEDAW). General Recommendation No. 24: Women and Health. Twentieth session. A/54/38/Rev. 1. New York, NY: United Nations; 1999, paras. 18 and 318(b).

United Nations. Committee on the Elimination of Discrimination Against Women (CEDAW). General Recommendation No. 15: Avoidance of Discrimination against Women in National Strategies for the Prevention and Control of Acquired Immunodeficiency Syndrome (AIDS), 1990, A/45/38, <http://www.refworld.org/docid/453882a311.html>

United Nations. Committee on Economic, Social and Cultural Rights. General Comment 20, Non-discrimination on Economic, Social and Cultural Rights. E/C.12/GC/20.2009. New York, NY: United Nations; 2009, para 33.

United Nations. UN Trust Fund to End Violence Against Women. Effective Approaches to Addressing the Intersection of Violence Against Women and HIV/AIDS. New York, NY: United Nations; 2012. [http://www.unwomen.org/wp-content/uploads/2012/04/UNTF\\_2012\\_VAW-and-HIV.pdf](http://www.unwomen.org/wp-content/uploads/2012/04/UNTF_2012_VAW-and-HIV.pdf)



## FIGO Human Rights and Women's Health Case 4 Discussion

### Protecting confidentiality

World Health Organization (WHO). Gender, Women and Health: Violence Against Women and HIV/AIDS. Geneva, Switzerland: WHO; 2014.

<http://www.who.int/gender/violence/vawandhiv/en/>

United Nations. General Assembly. We Can End Poverty. Millennium Development Goal 6. Combat HIV/AIDS, Malaria and Other Diseases. New York, NY: United Nations; 2000. <http://www.un.org/millenniumgoals/>

United Nations Population Fund (UNFPA) and Center for Reproductive Rights (CRR). ICPD and Human Rights: 20 Years of Advancing Reproductive Rights Through UN Treaty Bodies and Law Reform. New York, NY: UNFPA and CRR; 2013.

[http://www.unfpa.org/webdav/site/global/shared/documents/publications/2013/icpd\\_and\\_human\\_rights\\_20\\_years.pdf](http://www.unfpa.org/webdav/site/global/shared/documents/publications/2013/icpd_and_human_rights_20_years.pdf)

