FIGO Human Rights and Women's Health Case 6 Discussion

The illness of withholding information

This case highlights the right to information, which includes seeking, receiving, and imparting information on sexual and reproductive health, both information of a general nature and as well as that specific to the patient. This right is closely tied to the right to private life. A comprehensive understanding of safe and effective sexual and reproductive health services is essential for women to protect their health and to make informed decisions about sexuality and reproduction.

The obligation to obtain informed consent from a woman before any medical examination or treatment is performed derives from respect for her fundamental human rights. Informed consent is a consent for medical assessment or treatment obtained freely, without threats or improper inducements, after appropriate disclosure to the patient of adequate and understandable information in a form and language the patient understands. Such information covers the diagnostic assessment; the purpose, method, likely duration, and expected benefit of the proposed treatment; alternative modes of treatment, including options that may be less intrusive; and the possible pain or discomfort, risks, and side effects of the proposed treatment. Consent can be withdrawn at any time (FIGO 2012, UNFPA,CRR 2011).

Learning objectives

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

- Communicate the risks, benefits, and alternatives of accepting and declining therapies to patients.
- Offer full disclosure of test results and provide full information unless the patient specifically requests otherwise.
- Use language that is culturally sensitive and understandable to the patient.
- Provide up-to-date, clear, evidence-based information to help patients make informed decisions.

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

Case study

At the time of consultation for a pelvic mass, the family of S.Y. asks the gynecological surgeon to withhold the diagnosis from S.Y. if she proves to have cancer. S.Y. is a 46-year-old woman from a very traditional family, as is her surgeon. Their families share a long-held belief that if a patient is diagnosed with a terminal

illness, the doctor should inform the family members but not the patient herself, as a kindness to the patient. The surgeon listens to S.Y.'s family's request and responds, "Let's wait and see how the surgery goes first."

Surgery reveals that S.Y. has stage II epithelial ovarian cancer. The surgeon informs her family of the diagnosis and of the need for further treatment. The family repeats their request to withhold the information from S.Y. Thus, the doctor informs S.Y. that the surgery has gone well but that further treatment will be required to prevent recurrence of the mass. S.Y. asks no further questions. Her doctor prescribes oral chemotherapy, which he refers to as "medication" and which her family calls "health supplements."

Soon, severe medication-related nausea and vomiting limits S.Y.'s ability to conduct her daily duties for several days following each administration. S.Y. refuses to continue taking the drugs. In response to incessant pressure from family members to "take her health supplements," she moves to another small town, where she dies of cancer within 8 months.

Questions for discussion

1. What are the medical issues in this case? Specifically:

a. What is the appropriate treatment for stage II ovarian cancer?

Patients with stage II ovarian cancer should undergo staging laparotomy with total abdominal hysterectomy combined with bilateral salpingo-oophorectomy and tumor debulking to remove as much tumor as possible. When the diagnosis and stage are confirmed, the surgery should be followed by postoperative adjuvant combination chemotherapy. For stage II ovarian cancer, 5-year survival rates can be as high as 90% with the recommended drug regimen of three courses of intravenous paclitaxel and carboplatin. Without treatment, 5-year survival rates are estimated at 65%. Because of cost, many low-resource settings still use oral cyclophosphamide or etoposide.

b. What are the health consequences of the interruption of postoperative chemotherapy for stage II ovarian cancer?

Consequences include poor prognosis for a cancer that otherwise would have a good survival rate. The patient may eventually develop symptoms of recurrence such as pelvic pain, bowel symptoms, and wasting.

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

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Numerous human rights are implicated when a patient is denied information that she needs in order to make an informed decision about her health. These rights include the right to information, the right to life, the right to health, the right to respect for private life, the right to autonomy, and the right to enjoy the benefits of scientific progress and its applications.

The right to information includes information for making informed choices about one's sexual and reproductive health. International standards explicitly endorse the principle of informed consent as fundamental to the exercise of an individual's human rights. Informed consent, which includes the right to information, is particularly critical in provision of reproductive health care.

International human rights and medical standards require that medical providers give each patient objective and comprehensive information about his or her proposed treatment, including its purpose, nature, consequences, and risks, in order to enable the patient to make an informed decision. Information on risks should include those inherent in the type of intervention as well as risks related to the specific characteristics of the patient.

It is within these rights that the patient may withdraw her consent once she has been fully informed of the consequences. The exception occurs intraoperatively, at which time the doctor may be obliged to continue with a surgical procedure so as to avoid seriously endangering the health of the patient (Council of Europe 1997).

3. What are the health consequences of failing to fully inform the patient of her condition and treatment?

Without full information regarding her diagnosis, recommended therapies, and the expected results of those therapies compared with the results of refusing therapy, the patient is unable to make an informed decision about her health. In this case, the lack of information may have led to her failure to comply with the medical treatment and contributed to her death.

4. What hospital policies and laws in your state/province/country protect patients' rights to health information?

Laws governing informed consent vary, but all should be written to ensure provision of information sufficient to allow the patient to make an informed choice. Hospitals and clinics will have references; most (but not all) countries have policies published through the department of health. In some countries, laws regulating informed consent exist but regulations have not been passed to ensure their effective implementation in practice.

Students should not only be skilled in outlining and obtaining informed consent from patients but should also know how patients are to be informed about their rights to receive information.

FIGO Human Rights and Women's Health Case 6 Discussion

The illness of withholding information

5. How would you respond to the strong cultural pressures to comply with the family's wishes and meet the ethical obligation to support the patient's right to information about her diagnosis, prognosis, and treatment?

This is a difficult decision for a provider who also comes from a traditional family and a difficult conversation for any provider. However, when one recognizes that the right to information is essential to the right to health − and in the case of this diagnosis, to life − everyone should recognize how important it is to have as complete a conversation with the patient as possible regarding the risks and benefits of treatment choices. The policies of the health care center and the laws of the state will support the physician's actions of providing the necessary information to the patient and either obtaining her fully informed consent to treat or respecting her choice not to pursue recommended therapies.

6. What measures need to be put in place to avoid similar situations occurring in the future?

Irrespective of the social-cultural setting, health care professionals need to recognize the patient's agency and authority. It is important to train health care professionals on the provision of health information and on informed decision-making. Guidelines for health care professionals and for patients regarding the right to informed decision-making improve care. These can include checklists explaining appropriate informed consent procedures that are embedded into patient information for treatment.

FIGO Human Rights and Women's Health Case 6 Discussion

The illness of withholding information

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FIGO Human Rights and Women's Health Case 6 Discussion

The illness of withholding information

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