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Informed Consent: Principle vs. Practice

BY THE BOSTON WOMEN'S HEALTH BOOK COLLECTIVE

The doctrine of informed consent is based on the premise that every person legally deemed an adult has the right to decide what happens to her body. Before a patient allows any treatment, the medical practitioner has to explain the following: What is being planned. The risks and benefits. The alternatives, including the option of doing nothing. If the treatment is experimental that too must be stated. And if it is, the patient must be told whether or not the study involves being given no treatment or inadequate treatment as a means of comparing results. If drugs are used, the client should be told if they've been approved by the government for this purpose. All information must be given in language that is understandable. And the use of explicit or implicit coercion to steer a patient toward a specific course of action is forbidden.

Handled correctly, informed consent ensures that the patient becomes an expert able to determine whether the benefits of her medical treatment outweigh its risks. But, although these principles have the force of common law, they are not codified, and no monitoring agency ensures medical compliance. To be effective, informed consent requires the full cooperation of physicians and other medical professionals, and therein lies the rub.

Despite the fact that the use of language that the patient doesn't understand is a violation of medical ethics, doctors often distance themselves from their clients by talking in medical speak. And often the instructional materials (including some informed consent statements) fail to clearly and simply provide the necessary information. As a result, people often become overwhelmed or intimidated and confused by the terminology; they don't ask questions, often because they aren't sure what to ask, and they end up acquiescing to whatever is requested.

Language barriers and cultural differences also serve to deprive patients of their rights. Clients who speak English as a second language may find that doctors talk to them loudly (as if volume is the problem) instead of using simpler terms or arranging for a translator. And some physicians assume that women from different cultures are incapable of understanding what is being done to them. This is a mind-set that can lead to blatant abuse of the doctrine of informed consent.The book *Ethical Dilemmas in Contemporary Nursing Practice* details one such case that involved patients in a pregnancy clinic who spoke and read little English. Doctors signed the women up for an experimental project involving multiple amniocentesis procedures by handing them a three-page consent form written in college-level English. Although they understood the mechanics of the procedure, the women didn't know that they were part of an experiment.

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Sometimes medical professionals consciously withhold information in a Frankenstein-like quest for human subjects. Such was the case in the infamous Tuskegee experiments that were designed to follow the natural

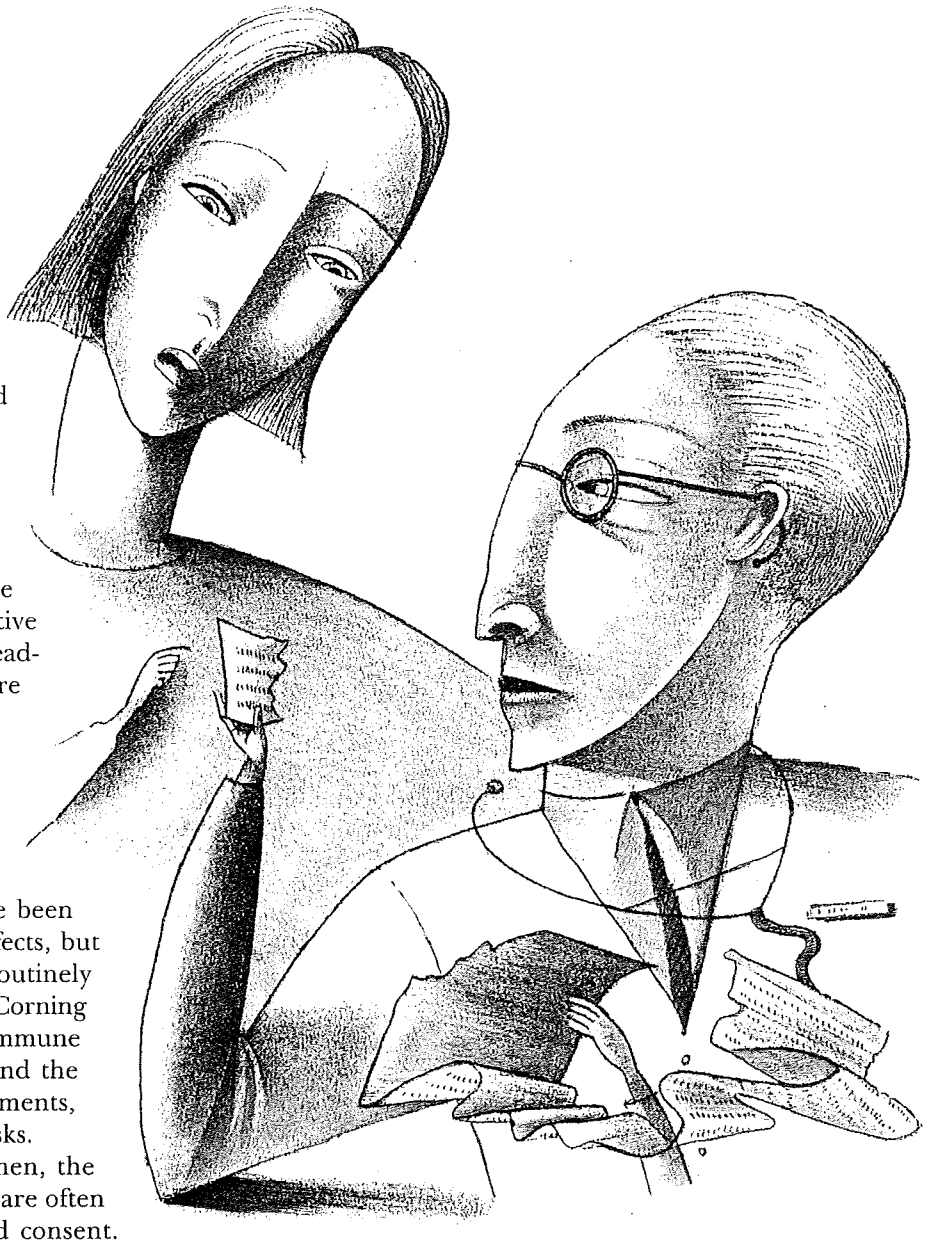
HEALTH NOTES

We're all smokers. A study by the Centers for Disease Control and Prevention found a nicotine by-product in the blood of all 800 people tested (including nonsmokers), ages 4 to 91.

A premature baby is born every two minutes in the United States.

New AIDS cases among women and men 65 and older have increased by 65 percent nationwide in the last two years, according to the Gay Men's Health Crisis. In New York City, this is the fastest growing age group with AIDS.

ILLUSTRATION BY WHITNEY SHERMAN



course of syphilis. For 40 years poor, illiterate African American men were misinformed of their diagnoses, involuntarily enrolled in an experiment, and denied medical treatment.

Racism was undoubtedly a factor in the Tuskegee case, just as sexism and greed were undoubtedly key to why women were so woefully misinformed about the possible risks involved with silicone implants by the American Society of Plastic and Reconstructive Surgeons and by Dow Corning, one of the leading breast implant manufacturers. Before 1991, breast enlargement was the second most common cosmetic procedure, after liposuction, so plastic surgeons as well as corporations had a strong financial interest in minimizing or denying implant complications. In the 30 years these implants have been manufactured, few studies have been conducted on their long- or short-term effects, but plastic surgeons and manufacturers have routinely assured women that they are safe. And Dow Corning hid the few studies linking implants to autoimmune problems. But despite the horror stories and the damaging information found in Dow documents, some physicians are still downplaying the risks.

It should come as no surprise that women, the main recipients of medical care in the U.S., are often the primary victims of abuses of informed consent. One of the most common occurrences is when a woman is pregnant and arguably at her most vulnerable. For example, if a doctor asks a woman who's been in labor for 18 hours if she'd like a drug to numb the pain she'll probably scream: "Yes, make it stop!" In a situation like this, when she is preoccupied with pain, it is impossible to weigh the risks and benefits of a medication. She should have been alerted to the possibility at a time when she could think clearly about it.

Many people aren't aware of the fact that any drug that is government approved for one purpose can be prescribed by a doctor for something totally different. This is called "off-label" use. Many drugs used routinely during labor fall into this category. For example, Terbutaline, a drug approved for asthma treatment, is so fre-

ILLUSTRATION BY WHITNEY SHERMAN

Progress! The sale of nonprescription diet products declined by 39 percent in 1992.

One out of four U.S. women does not receive prenatal care during the critical first trimester of pregnancy. One reason increasing numbers of poor women do not receive prenatal care is that Medicaid pays obstetricians less than half their customary fees.

Breast-feeding for the first four months of life may protect infants from ear infections.

quently used to stop preterm labor that it is the fourth most common prescription given to pregnant women.

In other cases relevant information is not available because of research priorities. The regular use of superovulatory drugs that stimulate the ovaries to produce many eggs at once during in vitro fertilization (IVF) is a case in point. Not until ten years after the first "test-tube baby" was born in 1978 did anyone start to formally investigate the effects of these drugs on the women. Previously, researchers had focused solely on fetal safety.

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There is now concern that the use of some of those drugs can lead to ovarian cancer. Have the women who underwent this procedure been informed? Are women currently being fully informed before opting for IVF?

So what can we do? Our ultimate goal must be to end society's unquestioning love affair with medicine. True informed consent can only happen when the fundamental place of medicine as an instrument of social control changes. A careful critique is necessary to decipher exactly whose values shape assumptions/conclusions that some medical procedures are appropriate while others are not, and which clients are targeted to receive medical care and under what circumstances. Only then will women start the process of being fully informed.

You can contact and support organizations that monitor and testify about issues relating to informed consent and women's health. For example, the National Center for Patients' Rights is an advocacy and support group concentrating on malpractice and patients' rights (666 Broadway, Suite 410, New York, N.Y. 10012; 212-979-6670). Two organizations that offer information and can help you find a consumer group focused on an issue of interest are the National Women's Health Network (1325 G Street N.W., Washington, D.C. 20005; 202-347-1140) and the Boston Women's Health Book Collective (P.O. Box 192, West Somerville, Mass. 02144).

There are also some steps you can take to become a more independent consumer of medical care:

- Write down your questions and concerns before you go to the medical practitioner.
- Ask a friend to come with you to your medical appointment. She can help you ask questions, take notes, and go over any information you might have missed. If you have trouble with spoken English, try to bring someone who can help you interpret, or check to see if someone on staff can interpret. While private physicians may not have a staff interpreter, some clinics and hospitals do provide this service.
- If the practitioner has trouble explaining some condition or procedure in terms that you understand, ask if you can talk with someone else. Nurses often are good educators because of their training.
- Ask the medical practitioner to justify any recommendation for treatment or lack thereof. If your practitioner becomes defensive, look elsewhere if you can.
- If you are asked to undergo a test or procedure that is not an emergency, and you can afford to return, wait until your next visit before you consent so that you can find out more information.
- If your medical practitioner recommends a procedure that is invasive, either for diagnosis or treatment, get a second opinion. If possible, seek a doctor not associated with the original practitioner or her/his institution. Your medical practitioner should be willing to share the results of any tests or slides with the second doctor.
- Do your homework. Contact independent sources such as the National Women's Health Network for more information. Ms.

The Boston Women's Health Book Collective is the author of "The New Our Bodies, Ourselves" (Simon & Schuster).

HEALTH NOTES

According to the American Heart Association, more than 485,000 U.S. women will die from cardiovascular disease this year; 39 percent of women who have had a heart attack will die within a year—compared to 31 percent of men.

"I've had catfish in my freezer for almost a year. Is it safe to eat?" The FDA's Seafood Hotline will answer this question and more. Call (800) FDA-4010. Washington, D.C.-area callers dial (202) 205-4314.

One out of eight births in the United States is to an adolescent.