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Ethics and informed consent: What breast cancer patients want to know

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When I was diagnosed in 2011, like most people, I knew almost nothing about breast cancer. I imagined that my doctors would work with me as a team to help me figure out the treatment choices that were best for me. However, I quickly found out that this is not how oncology works in the U.S. Oncologists follow a standard of care consisting of some combination of surgery, chemotherapy, radiation, and hormones. The for-profit system of medicine in the U.S. rewards doctors for seeing a lot of patients in a short time, so unless I was a relative or a VIP, I was not going to get more than the standard of care. The problem was that I didn't feel safe with the standard of care. I needed to find out for myself all the treatment options, the statistical outcomes for each option, and all the side effects before I felt comfortable making treatment decisions. When I asked my questions, I got incomplete and often conflicting answers from different doctors, and I didn't feel that I had enough information to make good decisions. I scrambled for whatever information I could find from other patients and in the literature, and I found a great deal that cancer patients are frequently not aware of. Each patient must weigh the expected benefits of treatments against the possible harms and come up with her own decisions, but she will not be able to do this without solid information. In cases where the data are controversial, I believe that doctors should present the controversies and allow patients to make their own decisions, rather than making decisions on their patients' behalf. Some patients will prefer to follow their doctors' advice rather than making their own decisions, but I believe the information should at least be offered. My presentation will focus on essential information that I uncovered in my own research which breast cancer patients are rarely, if ever, told. I will discuss key points related to Surgery, Chemotherapy, Radiation, and Remission Maintenance.

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