

Putting clinical practice guidelines into the hands of cancer patients



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Delivering and receiving a diagnosis of cancer is still one of the most difficult circumstances that arise in physician-patient relationships. Many patients feel powerless and immobilized when they are told they have cancer. However, we are no longer in an era in which most people are willing to defer completely to their physician's judgement as to the best course of action.

Today, Canadian cancer patients want information about their disease. Some want to know a little. Others have a great hunger for any information they can find on cancer and its treatment. How can the medical profession help to meet this need? One way may be to promote patients' access to evidence-based guidelines on the treatment of their cancer.

The new Canadian clinical practice guidelines on the care and treatment of breast cancer, published as a supplement to this issue of *CMAJ*, are accompanied by an important innovation: a lay version of the guidelines for patients and their families. Now Canadian women will have an opportunity to learn a great deal about cancer care and, even more important, to participate in a more informed way in treatment decisions. The dissemination of the guidelines is extremely important for all Canadians living with breast cancer, and the lay versions represent a clear invitation to patients and their families to become actively involved in treatment planning if they desire.

Several large surveys sponsored by the Canadian Cancer Society revealed that a source of credible and easily understood information was high on the list of unmet patient needs.¹ In response, the Society developed the Canadian Cancer Encyclopedia, a database of up-to-date information on cancer prevention, early detection, active treatment and palliation (see box). Many cancer patients are also interested in learning about the unproven therapies that they hear of through the media or friends. In order to make unbiased information available, the Canadian Breast Cancer Initiative has developed annotated bibliographies as well as summaries of the literature on the more popular of these therapies (see box).

Just as some cancer patients are inclined to seek out information, some patients want to be actively involved in the choice of cancer treatments. On the whole, Canadian women with breast cancer appear to be more interested in participating in treatment decisions² than many British women with breast cancer,³ Canadian men with prostate cancer⁴ and Canadians with other forms of cancer.⁵ Although younger, well-educated patients are especially likely to want to become involved, it can be hard to predict which patients will want to take an active role in treatment planning and which will prefer that the physician make the decisions.

Breast cancer survivors tell us that Canadian physicians do a poor job of judging the degree of involvement that each patient wants. In a survey of 1012 consecutive women receiving breast cancer care in Manitoba, 34% wanted to delegate treatment decisions to their physician, 22% wanted to select treatment by themselves, and 44% wanted to select treatment options in collaboration with their physician.² There appeared to be a large discrepancy between the preferred and actual level of participation achieved by patients; this suggests that physicians should make a conscious effort to determine what level of involvement in decision-making each patient desires.

Physicians may be reassured to learn that patients are not harmed psychologi-

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‡ See related article page 345 and the supplement to this issue



cally by being offered a choice of surgical methods for their breast cancer, even if they don't want to decide themselves.⁶ Further, we have been told that breast cancer patients are more likely to be satisfied with the treatment choices they make when information is provided to them in a supportive manner.⁷ To prepare themselves to deal with treatment choices, many patients educate themselves before meeting with their oncologist, and there is evidence that this strategy can help patients to gain a meaningful understanding of their options.⁸ The development of lay summaries for the new clinical practice guidelines should help women to be better prepared to discuss treatment options with their physicians and — if they so wish — to participate in treatment decisions.

It is important to bear in mind that the discussion of treatment options will be less urgent to women with breast cancer than learning the answer to 2 important questions: What is the chance of cure? and How much has the cancer spread?² The availability of clinical practice guidelines will be more meaningful to patients if physicians first address these issues and then explore and respect patient preferences about obtaining information and becoming involved in treatment decisions.

The trend toward greater patient participation at the level of the individual mirrors a growing collective involvement of lay women and breast cancer survivors in breast cancer advocacy. The Canadian Breast Cancer Research Initiative (CBCRI) was established in 1993 in response to concerns raised by women that breast cancer is a health risk of such magnitude that it requires dedicated resources for research on a broad range of topics. The CBCRI has taken steps to address the priorities brought forward by women, such as encouraging the scientific evaluation of unproven therapies. The participation of lay women and breast cancer survivors on the management committee is a vital feature of the CBCRI that helps to ensure that the priorities and concerns of patients and their families are kept at the forefront while the integrity of rigorous scientific investigation is maintained.

The Canadian Cancer Society applauds the efforts of Dr. Maurice McGregor and his many colleagues who participated in the extensive process of developing new Canadian guidelines for the treatment of breast cancer. These guidelines offer many things: an opportunity to reduce variability in cancer care, an evidence-based means for cancer treatment facilities to advocate for appropriate resources, and all the other potential advantages and pitfalls associated with the implementation of new guidelines. And, not least, these new guidelines offer a chance for physicians to help empower breast cancer patients to become better informed about their disease and to have input into its treatment.

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Patient information sources

Patients can access the Canadian Cancer Encyclopedia database from anywhere in Canada by calling the toll-free Cancer Information Service of the Canadian Cancer Society. Calls are taken by specially trained staff, many of whom are oncology nurses. The number for the service is 1 888 939-3333.

Physicians and patients can obtain the Canadian Breast Cancer Research Initiative's annotated bibliographies on unproven therapies free of charge by calling 416 961-7223. Systematic reviews of the literature will be published in upcoming issues of *CMAJ*. Briefer summaries suitable for patients are currently available free of charge through the Cancer Information Service and local offices of the Canadian Cancer Society.