We may get this horse to water, but will it drink?

Neill A. Iscoe, MD, MSc

Medicine . . . is mobile and many of us get breathless not so much by trying to keep up with medical progress as by trying to avoid being run over by it.

Roger Lee

Modern medicine is practised under increasingly challenging conditions. The accelerating pace at which new information becomes available can be overwhelming. The physician is asked to function as a dual agent: to serve the patient’s interests and, at the same time, to be responsible to society (through government) for the appropriate management of limited resources. As if this weren’t enough, the structures we associate with modern medical practice are undergoing a revolution. Care is moving into the community with great speed, a change often accompanied by concerns that the foundations to support that care have not been adequately established.

Against this backdrop of constant change we have the guidelines movement and its products. At first glance, guidelines appear to be the answer to everyone’s problems. They have been identified as a means to improve the quality of care and address issues of practice variation, to decrease health care costs and address issues of rationing, to deal with competition and improve access, and to promote physician autonomy and enhance patient empowerment. Quite clearly, guidelines have the potential to do a great deal — but what is the reality, and what can we expect from the new guidelines on the management of breast cancer developed by Dr. Maurice McGregor and colleagues and published as a supplement to this issue of CMAJ?

The report of the National Forum on Breast Cancer noted that practice variation can make patients anxious about the care they are receiving. Practice guidelines were seen as a way to make care more consistent and, presumably, better. The new guidelines should be assessed against these objectives and against the formidable barriers, such as the need to ensure “buy-in” by professionals and to make the process “broad, participatory and continuing, with . . . regular review and evaluation.”

McGregor and colleagues have done important work in compiling a comprehensive set of guidelines for the care of women with breast cancer in a manner that reflects the merit of the information on which they are based. The authors have used the levels-of-evidence approach throughout the document; in doing so, they make it clear that there are areas in which the most basic of notions have not been rigorously investigated. An example is the statement that “Smooth, well-demarcated lumps are usually benign (level IV evidence).

It is useful to examine the process by which these guidelines were developed. Was it “broad, participatory and continuing”? Who was involved, and how was each guideline developed? In contrast to provincial initiatives in guideline development, this work, as mandated by the Forum, had a broad Canadian perspective. However, the participation of survivors does not appear to have been uniform from guideline to guideline. To what extent this is an issue may depend as much on the particular guideline as it does on one’s perspective on the contribution survivors make to this process and, through their “buy-in,” to the desired outcomes.
In Ontario there was a rapid and substantial change in surgical practice after the publication of results from the National Surgical Adjuvant Breast Project trial comparing outcomes in women who had undergone modified radical mastectomy and breast-conserving surgery. This change was not brought about by any guideline. Given public awareness of the trial results and the undercurrent of change that was already present, women with breast cancer may have played a significant role in accelerating the changes that followed their release. If so, the participation of consumers in both the development and the implementation of guidelines may be critical.

The new breast cancer guidelines, as well as guidelines on similar topics from other groups, are now appearing slightly more than 4 years after the Forum. This is not meant to criticize McGregor and colleagues; the problem of timeliness plagues all clinical practice guidelines. Delays are not surprising when one considers that guideline development represents an add-on to the tasks borne by most physicians and may not be at the top of their priority list. Parallel to the challenge of simply doing the work is the proliferation of groups involved in guidelines and differences in working method: some processes are very detailed, whereas others are less structured.

Are all of the new guidelines for breast cancer management necessary, or could some have been adopted from the work of other groups? As they are presented, it is unclear when their development commenced. Perhaps the dates on which work on a given guideline began and ended would be valuable information, particularly as at least one of the current guidelines (related to the management of node-positive premenopausal patients) may be viewed by some as already out of date.

The speed with which clinical recommendations are disseminated is an issue of great importance in view of the possible impact of the Internet, where new ideas appear without delay and, in some cases, out of context and without scrutiny. All oncologists have been faced with a small cadre of patients who come to them armed with information from the Internet, which some of them regard as being authoritative as any guideline. If lay versions of clinical practice guidelines are to have an impact, they need to appear promptly and to be promoted in a way that shows they have undergone thoughtful development. The participation of consumers in this process will only add to their credibility and, one hopes, speed up the process of guideline adoption.

However, a more fundamental issue shadows the guidelines movement. How good is the evidence that guidelines bring about desired change is patchy. On balance, it appears that the most successful programs to effect change are multifaceted. Although the lay version of the guidelines is a wonderful addition, it is not readily apparent that a strategy has been developed to make lay guidelines both available and meaningful to women with breast cancer and those providing care for them. Should every patient who is diagnosed with breast cancer be made aware of existing guidelines? If so, how can this be done? Even if a single point of access could be identified, there is no reason to believe that patients routinely acquire information at the same time in the course of their illness or in the same manner. The same comments likely also apply to physicians. If guidelines are the “water,” is there a way to induce either physicians or patients to step up and drink? The challenge is not only to develop guidelines but also to make them relevant, so that they are acted on. Without a strategy for evaluation, it will be difficult to know whether the hard work done by McGregor and colleagues has met the objectives set by the Forum.

References


