The epistemology of epidemiology

One of the perks of the job of editor is the view from the sidelines of scrimmages out on the field. We witnessed one of these, a big one, about 6 months ago when we published a report by Nancy Baxter and the Canadian Task Force on Preventive Health Care.[1,2] The report showed that the routine teaching of breast self-examination (BSE) to women couldn't be credited with an increase in breast cancer survival or even with the detection of tumours at an earlier stage. The message that BSE may be wishful and even wasteful triggered a spirited exchange among epidemiologists, commentators, breast cancer survivors, journalists and advocacy groups (see Letters, page 163). Now that the dust has settled, let's venture onto the field for another look at this issue.

At one end is a team of epidemiologists fixed on cancer mortality and tumour detection rates as their end points. At the other end are individual patients and their advocates, padded with anecdotal evidence, determined to keep the locus of control within their own hands and bodies. Seen in this light, these 2 groups, while desirous of the same outcomes, are scarcely playing in the same match. Where and how do the locus of control and anecdotal evidence factor into cancer mortality rates? Should they?

Perhaps, at root, these are questions of epistemology — of what constitutes knowledge, and of the means of our knowing. Is the problem simply that patients and epidemiologists know, and want to know, different things? In the diagnosis of endometriosis there has been a recent rapprochement between these means of knowing. The conventional definition based on histologic findings, which led to inflated prevalence rates, has been supplanted by one that includes the patient's experience of the disease (e.g., dysmenorrhea, pain and infertility).[3]

But what faces us in the BSE scrimmage is also a failure to communicate how our ideas about disease are changing. Barron Lerner[4] (page 199) dates BSE to the early 1900s when Halsted popularized the theory that breast cancer begins as a local disease and then metastasizes. Early detection and removal made sense. Ever since the 1950s the Canadian and American cancer societies, encouraged by proselytizing researchers and physicians, have vigorously promoted BSE. Nuance and doubt largely disappeared. It is understandable that most women faced with the possibility of an invisible cancer invading their bodies welcome the hope offered by BSE.

But this model of breast cancer is now in question. The finding that 29% of women with stage 1A breast cancer already have micrometastases in their bone marrow[5] suggests either that the metastases occur very early or, perhaps, that in some women the disease begins simultaneously in many parts of the body. (Another unexpected finding is that nephrectomy appears to benefit at least some patients with metastatic renal cancer.[6])

The skirmish we are witnessing is an effect of many things, including a failure to frame research questions that are meaningful to patients and a failure to communicate what we do, and do not, know. — *CMAJ*

References

1. Baxter N, with the Canadian Task Force on Preventive Health Care. Preventive health care, 2001 update: Should women be routinely taught breast self-examination to screen for breast cancer? *CMAJ* 2001;164(13):1837-46.
2. Nekhlyudov L, Fletcher SW. Is it time to stop teaching breast self-examination? [editorial]. *CMAJ* 2001;164(13):1851-2.
3. Holt V, Weiss N. Recommendations for the design of epidemiologic studies of endometriosis. *Epidemiology* 2000;11:654-9.
4. Lerner BH. When statistics provide unsatisfactory answers: revisiting the breast self-examination controversy [editorial]. *CMAJ* 2002;166(2):199-201.
5. Braun S, Pantel K, Müller P, Janni W, Hepp F, Kentenich CRM, et al. Cytokeratin-positive cells in the bone marrow and survival of patients with stage I, II, or III breast cancer. *N Engl J Med* 2001;342(8):525-33.
6. Tannock IF. Removing the primary tumor after the cancer has spread [editorial]. *N Engl J Med* 2001;345(23):1699-700.