Some medical decisions are fairly straightforward. If you break a leg, the recommended treatment is a cast, elevation, and crutches. But if your breast biopsy leads to a diagnosis of ductal carcinoma in situ (DCIS), the treatment path is much less clear.

A diagnosis of DCIS brings uncertainty. With the introduction of population-wide screening mammography, radiologists have increasingly recommended evaluation of subtle breast abnormalities. Concurrently, the incidence of DCIS has dramatically
increased. Because DCIS of the breast represents a broad biological spectrum of disease, we cannot tell with certainty whether any given lesion will remain stable for 40 years or ultimately develop into invasive breast cancer.

Once a diagnosis of DCIS is made, women move onto a conveyer belt of medical care. In the United States, women diagnosed with DCIS almost invariably receive initial surgical treatment. Some choose breast-conserving surgery (BCS)—that is, wide tumor excision—followed by radiation therapy to eradicate residual disease. Others choose mastectomy. Studies that compare mastectomy with BCS followed by radiation have demonstrated equivalent long-term survival. However, local recurrence rates are higher with BCS.

According to new data by Nekhlyudov et al. (1) in this issue of the Journal, women who choose to preserve their breasts with BCS may be embarking on a more extended journey than anticipated—a journey replete with diagnostic testing that can span many years. Nekhlyudov et al. (1) describe a high rate of subsequent diagnostic imaging and invasive breast procedures among nearly 3000 women who were initially treated with BCS after a diagnosis of DCIS. Unfortunately, not all women may be aware of this potential outcome when they consider their treatment options.

The study highlights two distinct phases of clinical care following BCS. First, in the initial 6 months, a substantial number of women undergo additional tests and invasive procedures. Nekhlyudov et al. (1) report that about half (51.5%) underwent additional ipsilateral invasive procedures in the first 6 months following surgery. Although most of these early procedures were likely re-excisions, a troubling degree of variability in re-excision rates after BCS has now been reported in the literature. For example, a recent article by McCahill et al. (2) noted that almost half of re-excisions were performed in women with negative margins, and re-excision rates varied considerably by surgeon (0%–70%), as well as by institution (1.7%–20.9%). Given this extensive variability, the appropriateness of many early re-excisions following BCS has been questioned (3).

The second phase of clinical care following BCS ensues after the first 6 months have passed, when women who choose BCS remain at high risk of diagnostic and invasive procedures. Nekhlyudov et al. (1) show that almost one out of every three women who chose BCS underwent additional invasive procedures in the decade following that 6-month mark. This rate is more than three times higher than in the general population of healthy women undergoing routine annual screening mammography (4).

Although these findings are compelling, the estimates are possibly conservative because they excluded data on 96 women who underwent mastectomy within 6 months of diagnosis. In addition, most study patients were diagnosed before 2000, and surveillance and treatment patterns have since changed.

How will these new findings influence women’s decisions regarding DCIS treatment? Unfortunately, we live in an era characterized by fear of cancer and a preference for invasive cancer treatment (5). Whereas several studies have noted an association between women’s surgical choices and their views about body image and cosmetic results (6–9), a desire to avoid local recurrence has also been associated with the choice of mastectomy (8–11). Notably, studies have shown that more women choose mastectomy over BCS after they review detailed educational material (12) and become more engaged in their own treatment decisions (13). Thus, concerns about the substantial risk of subsequent invasive procedures documented by Nekhlyudov et al. (1) may possibly sway more women to choose initial mastectomy over BCS. It is also conceivable that such concerns may contribute to the increasing rate of contralateral prophylactic mastectomy that has been noted in recent years. Among women with DCIS in one breast, the rate of double mastectomy rose from 6.4% in 1998 to 18.4% in 2005 (14).

Understandably, women and their doctors try to do what is right. But doing the right thing means making sure women understand the implications of their screening and treatment options. Not only do women need to know the data on benefits and risks, but they also need to factor in their preferences, values, and tolerance for risk.

Informed decision-making about DCIS is currently hampered by incomplete information on prognosis and treatment. When is a diagnosis of DCIS helpful, and when does it represent overdiagnosis? Can a subset of women be identified as candidates for watchful waiting, as is increasingly common in low-grade early-stage prostate carcinoma? How can clinicians support women in the decision-making process while honestly communicating the many uncertainties surrounding DCIS?

To reduce the uncertainties surrounding DCIS, we need to learn how to avoid overdiagnosis by calling back fewer women for additional testing after screening mammography; we also need better prognostic biomarkers to minimize overtreatment of lesions that are unlikely to progress to invasive cancer. In the meantime, we urgently need to assist women in making the best treatment decisions for themselves. Carefully constructed decision aids have been shown to assist patients in understanding medical evidence as well as areas of uncertainty (15), and the data reported by Nekhlyudov et al. (1) should be incorporated into extant decision aids. The perspectives of patients and providers on key facts and goals of treatment options can differ; thus, decision aids reflecting all viewpoints are important to help women make decisions that are right for them (16).

As the science of DCIS progresses, informed decision making should remain a motivating priority for clinicians. Informed patients feel better about the decision process, and their decisions are more likely to reflect their preferences, values, and concerns. Informed patients are more likely to adhere to treatment and report better self-rated health than less-informed patients. Signposts are needed along the path so that a woman’s treatment decision for DCIS feels less like a gamble and more like the right choice for her—a reasoned choice, grounded in personal insight and an understanding of existing scientific knowledge.

References

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