Breast cancer treatments today are likely to cause less physical deformity from surgery than a half-century ago, but are more complex and extend over a longer period of time. Women today are often well informed about the details of their cancer diagnosis and prognosis, and are increasingly involved in shared decision-making regarding treatment.

ABSTRACT: Breast cancer treatments today are likely to cause less physical deformity from surgery than a half-century ago, but are more complex and extend over a longer period of time. Women today are often well informed about the details of their cancer diagnosis and prognosis, and are increasingly involved in shared decision-making regarding treatment. Although serious depression is not seen in the majority of breast cancer patients and survivors, many will experience treatment-related distress, fear of recurrence, changes in body image and sexuality, as well as physical toxicities that result from adjuvant therapy. This paper discusses the importance of identifying the psychological and social concerns of breast cancer patients in the medical setting, and assisting them in obtaining appropriate psychosocial services.

In delivering care for breast cancer patients today, it is expected that the health-care team will carefully evaluate the tumor pathology, biomarkers, extent of disease, and other medical aspects of the woman’s condition, to facilitate specific recommendations for oncologic management. This has been increasingly true in the past decade, as the understanding of the molecular pathology of breast cancer has increased and treatments have become more tailored.

In the past 50 years, breast cancer has been transformed from a disease in which all women were treated with a radical and disfiguring surgical procedure that amputated the breast, removed pectoral muscles, and included an extensive axillary dissection. Now, for the majority of women, it is usually managed with only minimal removal of breast tissue and sampling of a few axillary nodes. During this same period of time, women with breast cancer have become increasingly involved in treatment decision-making, and have made it clear that they have need for attention to the psychological and social aspects of their care, in addition to the targeted treatment of their tumors.

Sample Publications Authored or Coauthored by Martin Abeloff on the Psychosocial Aspects of Cancer

This was not always the case, and we must be grateful to the pioneering work of Dr. Martin Abeloff and his colleagues, who more than 3 decades ago recognized the intimate relationship between the psychological and social impact of cancer and its treatments on patients’ lives (see Table 1). In his passing, many tributes noted Marty’s important contributions to oncology, as a pioneer in the treatment of breast cancer and as the leader of a major cancer center. The one that caught my attention noted remarks he made at a Johns Hopkins event in the year before his death, where he is reported to have said, “Therapies have been lengthy, toxic, and disfiguring, adding to the amount of suffering that a patient and family endures. You simply can’t treat cancer without paying attention to the psychological and social aspects of the disease.”

To this end, I review what we have learned about the psychological and social aspects of breast cancer in the past 50 years.

TABLE 1

Sample Publications Authored or Coauthored by Martin Abeloff on the Psychosocial Aspects of Cancer
cancer during Dr. Abeloff’s distinguished career, and how leaders such as he have promoted the integration of psychosocial services into the standard care of oncology patients through their words and their actions.

**Psychological and Social Impact of Breast Cancer: Historical Reflections**

For almost a century, the Halsted radical mastectomy was the standard surgical treatment for breast cancer. Women receiving this treatment suffered terrible cosmetic deformity, with loss of arm function through resection of the pectoral muscles, high risk for lymphedema as the result of extensive axillary nodal dissection, and significant pain and tightness across the chest wall. Attempts to restore body image with external prostheses were variably effective, and reconstructive surgery with implants did not become widely available until the last 2 decades of the 20th century. Reconstruction was often delayed for several years after initial treatment, requiring a second surgical procedure. Immediate reconstruction and autologous tissue flaps, widely used today, did not become widespread until the turn of the 21st century.

Not until the 1990 National Institutes of Health (NIH) Consensus Conference on early-stage breast cancer was a concerted effort made to encourage breast conserving surgery, based on the mounting evidence of its efficacy in randomized trials conducted in the 1980s. Further refinements in surgical staging, including the sentinel lymph node biopsy, have now begun to limit the extent of axillary surgery for women with small tumors and low metastatic potential. The trauma of breast cancer surgery has diminished substantially in the past 2 decades, but women are still left with many physical and psychological problems as a result of complex multimodal treatments, including chemotherapy and adjuvant endocrine therapies.

The earliest research on the psychological impact of breast cancer focused on its attack on femininity, with amputation of the breast, and subsequent threat to sexual attractiveness. In addition to these concerns, the life-threatening nature of cancer itself contributed to psychological distress. The involvement of mental health experts in the problems of persons with health conditions began to accelerate during the 1960s and 1970s, just as the national focus on cancer treatment and the war on cancer was taking shape. In her classic 1980 paper on the psychosocial correlates of breast cancer and its treatments, Meyerowitz pointed out that during this time, most patients were not told their diagnosis, for fear of the emotional response it would evoke. Much of the literature of the time also postulated that personality traits could be causal in the development of cancer, and that postoperative behavior might reflect pre-illness characteristics, rather than be the result of treatment.

The stress of breast cancer was described as arousing depression, anxiety, and anger. In some of the first systematic and comparative studies, mastectomy patients were found to be more distressed than women with benign lumps, and often this distress persisted for more than a year following surgery, but over time seemed to resolve. These findings in the late 1970s were gradually disseminated to physicians and patients, and resulted in the beginnings of psychosocial support groups in the early 1980s.

Meyerowitz also noted the identification of changes in life patterns that resulted from the diagnosis and surgical treatment of breast cancer, including insomnia, recurrent nightmares, loss of appetite, difficulty returning to usual household activities and work, and inability to concentrate. Although these may have been manifestations of depression, they were only considered abnormal if they persisted beyond the period of physical recovery from surgery (i.e., several months). The physical disruption of the radical mastectomy was substantial, making it difficult to sleep, have sexual intimacy, and adapt to clothing and body image problems. Return to usual physical and social activities was also reportedly diminished in many women.

Finally, Meyerowitz described common fears and concerns that women reported, and these include fear of recurrence—tumors were much larger and 50% of women could expect to have a recurrence in spite of radical surgery—as well as the mutilation and loss of femininity as a result of mastectomy. For many women, every ache and pain would trigger fear and anxiety about potential recurrence. Given the limited amount of information exchanged between doctors and patients at this time regarding the natural history of breast cancer and its prognosis, as well as the lack of adjuvant therapies to prevent a recurrence, it is not surprising that these fears were commonplace. Today, with extensive patient education, in the doctor’s office as well as from many patient-focused resources (Internet websites, breast cancer organizations, professional organizations), patients may still have legitimate fears, but they are much better armed with facts. Another important aspect of this historical time in breast cancer treatment was the stigma...
associated with a cancer diagnosis, and the lack of support for patients beyond their families as they went through cancer diagnosis and treatment. In today’s environment, a woman who has an image-guided breast biopsy and receives a cancer diagnosis is immediately approached by other women—from her work, church, or other social network—who are breast cancer patients/survivors, and who are immediately ready to help her get through the early diagnosis and staging of the cancer, and provide support and encouragement.

Management of Breast Cancer in the Abeloff Era: Psychological and Social Aspects

The first large trials of adjuvant chemotherapy were reported in high-profile medical journals in the 1970s and 1980s,[7-10] leading to the rapid expansion of clinical trials of this treatment across all stages of breast cancer throughout the world, with testing of new drugs and their combinations, including the addition of endocrine therapies to the treatment strategy. Gradually, treatments became more intensive[11,12] and there was increasing interest in the measurement of quality-of-life outcomes in these clinical trials.[13-16] This culminated in the widespread use of high-dose chemotherapy with autologous bone marrow or stem cell transplantation, which was ultimately found to be ineffective as well as highly toxic.[17] Since the 2000 NIH consensus conference on adjuvant therapy of breast cancer,[18] adjuvant therapy has been recommended for all women with invasive breast tumors greater than 1 cm, including chemotherapy in all and endocrine therapy if hormone receptor-positive. High-dose therapy has been largely abandoned, and treatments have been further modified through better understanding of the molecular risk profiles for primary breast cancer, including HER2 overexpression.

Thus, today there is even more information to discuss with newly diagnosed breast cancer patients than before. The shared decision-making process may be stressful, and use of decision aids, as discussed in the 2000 consensus conference,[19,20] has become more common. How this complex information is communicated, and how the physician assesses the woman’s psychological status and desire for detailed information vs more general concepts, often sets the stage how the woman will adapt to her diagnosis and need for treatment.

The major psychological and social stressors under these circumstances are related to the woman’s understanding of her disease, its prognosis, the complexity of treatment, and all too often, her access to care and/or choice of providers. Even the most psychologically strong individual will be overwhelmed by the number of medical visits, procedures, and waiting times during the initial diagnostic process. This is then followed by the need to organize care with multiple providers (surgeon, radiation oncologist, medical oncologist, plastic surgeon) and often second opinions to assist in decision-making.

The complexity of primary treatment, information overload (from health-care providers, well-meaning acquaintances, books, and the Internet), the move toward shared decision-making, and the vulnerability that a cancer diagnosis engenders, all threaten the emotional well-being of the woman. Facing many months of treatment leads to disruption in social activities (childcare, work, caregiving) and decreases the ability to plan and multitask. This is exacerbated by the physical toll that primary treatment often extracts.[5]

Who Is at Risk for Psychosocial Distress?

Psychosocial distress refers to a broad range of affective and cognitive concerns that go beyond psychiatric diagnoses of major depressive illness or anxiety disorder. These range from cancer-specific concerns, such as fear of cancer recurrence, to more generalized symptoms such as worry, trouble sleeping, fatigue, being anxious about going to the doctor. In addition, the relevant literature on psychosocial distress also includes more global and broad concepts such as the domain of emotional well-being, within a quality-of-life framework.[21,22]

The literature on the psychosocial aspects of breast cancer suggests that the vast majority of women adjust well to the diagnosis of breast cancer and manage to endure the complex and sometimes toxic treatments associated with primary treatment and later recurrence.[3,23-27] In studies that have examined quality of life and depression after breast cancer, most patients and survivors demonstrate high levels of functioning in the early and later years after primary treatment, for those who remain disease-free.[3,23,27,28] Even for women with a recurrence of breast cancer,
psychological well-being is often maintained.[26,27,29] Fortunately, most women manage their psychosocial distress relatively well, using personally available support systems (spouse, family, friends, clergy) as well as some professional resources that are accessible within many clinical settings (nurses, social workers, community resources, and support groups). However, women uniformly report that they appreciate the attention and support from their health-care team, and referral to appropriate resources as necessary. Most women will not anticipate the common side effects and complications of breast cancer treatment, so that professional guidance and more intensive support as appropriate will be appreciated. Support groups often provide this type of assistance and should be offered.

**Risk Factors**

### TABLE 2

**Factors That Put Women at Higher Risk for Psychosocial Distress**

A number of risk factors have been identified that are associated with psychosocial distress (see Table 2).[24,25,30-34] The specific type of breast cancer surgery, and whether a woman is receiving chemotherapy or radiation therapy does not seem to influence the level of distress.[3,4,31,35,36] In fact, women with noninvasive breast cancer have similar concerns about recurrence as women with invasive disease.[37,38]

What makes each of these patient characteristics a risk factor for psychosocial distress after breast cancer?

- **Younger Age**—Most breast cancer occurs in women older than 50 years (about 75% of cases). Thus, for women in their 30s and 40s who are diagnosed with breast cancer, this is a relatively uncommon event, and certainly one that is not expected. In addition, breast cancer in younger women is often temporally related to a recent pregnancy or may occur during pregnancy, and thus, these women often have small children to care for at the same time that they must deal with a life-threatening disease. For younger women who have not already had their children, the diagnosis and treatment of breast cancer leads to the specter of death, the likelihood of infertility as a result of treatments, and the symptomatic burden of premature menopause, in addition to the acute toxicities of chemotherapy treatments.

  All of these medical factors contribute to the risk of greater psychological distress in these younger women. Moreover, for women who do not have a spouse or intimate partner, there may be heightened concerns about future potential for such a relationship after a breast cancer diagnosis. Finally, for younger women this is often the first encounter with the health-care system (other than childbirth or minor health conditions), and this adds considerable distress. In contrast, older women may have had other medical conditions or operations, or may have cared for loved ones with cancer, thus blunting some of the initial distress with having to face a new illness.

- **Preexisting Mental Illness or Psychological Distress**—Although it appears that cancer, in general, does not heighten the risk for serious depression in women with breast cancer,[39] a prior history of depression and the presence of pain and physical limitations are associated with a greater likelihood of depression after diagnosis. In a prospective study of newly diagnosed breast cancer patients, Maunsell et al.[25] found that a past history of depression and serious life events in the 5 years preceding the cancer diagnosis were both predictive of higher levels of distress after breast cancer. It is not surprising that a woman who is already having ongoing depression or psychological distress prior to the cancer diagnosis would have it exacerbated as a result of the stress associated with a new cancer diagnosis and its treatment. With the prevalence of clinically significant mental disorders among adults estimated at 15%.[40] it is not uncommon for women with breast cancer to be predisposed to cancer-related psychosocial distress.
• **Comorbid Conditions**—Several studies have indicated that women with comorbid conditions or impaired performance status report higher levels of psychological distress after a breast cancer diagnosis.[39,41] This appears to be independent of age,[42] although the likelihood of greater comorbidity at diagnosis is increased with age.[43] Physical recovery after breast cancer surgery may be impaired in women with greater comorbidity,[44] and this may contribute to greater psychological distress as well.

• **Social Support**—Social support for the woman with breast cancer includes instrumental support, such as transportation to appointments, preparation of meals, and help with activities of daily living, as well as emotional support, meaning the availability of someone to share ones fears, feelings, and concerns. Inadequate levels of either of these two forms of social support can increase the likelihood of psychosocial distress. This may be particularly important in patients with advanced breast cancer.[45-47]

### What Are the Common Psychosocial Concerns of Women With Breast Cancer?

#### TABLE 3

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<tr>
<th>Common Psychosocial Issues in Women With Breast Cancer</th>
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<tbody>
<tr>
<td>- Fear of recurrence</td>
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<td>- Body image disruption</td>
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<td>- Sexual dysfunction</td>
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<tr>
<td>- Treatment-related anxieties</td>
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<td>- Intrusive thoughts about illness/persistent anxiety</td>
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<tr>
<td>- Marital/partner communication</td>
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<tr>
<td>- Feelings of vulnerability</td>
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<td>- Existential concerns regarding mortality</td>
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Common Psychosocial Issues in Women With Breast Cancer

Table 3 lists some of the most common psychosocial concerns reported by women with breast cancer. To some degree, all of these concerns are expected and are experienced by all women at some point after their diagnosis and treatment for breast cancer. What varies, however, is the extent to which a woman accepts these concerns, copes with them, and adapts to living with a degree of uncertainty about the future, as opposed to living in a state of persistent rumination about the illness and the inability to control what will happen to her.

Effective strategies for enhancing coping are actively being studied by many research groups. For most women with breast cancer, active coping strategies that focus on realistic expectations and approach-oriented coping can facilitate adaptation to the illness over time. In a recently completed randomized controlled trial,[48] Stanton and colleagues found that a 23-minute video, designed to facilitate emotional and physical recovery after breast cancer treatment, significantly enhanced the return of vitality. The “Moving Beyond Breast Cancer” video is available at no cost through the National Cancer Institute Cancer Information Service (1-800-4-CANCER or [http://cis.nci.nih.gov/](http://cis.nci.nih.gov/)). For women with some of the increased risk factors for psychological distress described earlier, adaptation and coping may be more challenging, and professional counseling may be indicated. Such resources are widely available in the community. Needs assessment and referral should be integrated into routine oncology care, as recently suggested by an Institute of Medicine report.[49]

### Conclusions

Long before psychosocial services for women with breast cancer were widely available, Martin Abeloff and his colleagues took on the challenge of describing the experience of patients with cancer, and noted the importance of addressing these concerns as part of the care of the whole patient. Over time, recognition of the importance of assessing patient needs, distress, and concerns, as well as the social context in which care is delivered, has become more evident.[49] Our challenge today is to translate what we know is the right thing to do into the routine delivery of cancer care. Accessing psychosocial services is easier today than ever before, through electronic
and other media, as well as through in-person support services. However, it is the responsibility of the health-care team to orient women to the likelihood of needing these services at some point along their journey with breast cancer. Whether breast cancer patients are newly diagnosed, survivors, or at the end of life, attending to their psychological and social concerns will enhance the effectiveness of our treatments and palliation of symptoms.

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References:
