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Managing psychosocial issues faced by young women with breast cancer at the time of diagnosis and during active treatment

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Abstract

Purpose of review—This review examines recent literature on the psychosocial needs of and interventions for young women. We focus on the active treatment period given the toxicity of treatment, the incidence of anxiety, and depressive symptoms in these women during treatment. This review summarizes research relevant to addressing their social and emotional concerns.

Recent findings—Young women undergoing treatment for breast cancer remain understudied despite unique needs. Psychoeducational interventions help to relieve symptoms and emotional distress during treatment, but effects do not appear to persist over the longer term. In the clinical context, the performance of prognostic-risk prediction models in this population is poor. Surgical decision-making is often driven by fear of recurrence and body image rather than prognosis, and decision aids may help young women to synthesize information to preserve their role in the treatment process.

Summary—First, shared decision-making, second, balancing body image, fear of recurrence, and recommended treatment, and third, palliative care for metastasis are essential research priorities for the clinical setting. In the larger social context, unique family/partner dynamics as well as financial and insurance concerns warrant particular attention in this population.

Keywords

breast cancer treatment; psychosocial; shared decision making; young women

INTRODUCTION

‘At 25 you are thinking about getting a job and getting married and having kids and buying a house. But when you are 25 and have cancer, you are not thinking about any of that. You are

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Conflicts of interest

There are no conflicts of interest.

thinking, ‘I’m going to die, and this is going to suck, and how am I going to pay for this, and what am I going to tell my parents?’”

This candid and poignant quotation from a cancer survivor at the Institute of Medicine workshop on addressing the needs of adolescents and young adults with cancer illustrates the unique social context in which young women may experience a breast cancer diagnosis and enter treatment [1[■]]. Breast cancer, disruptive regardless of age, can be especially isolating and frustrating when social support resources and clinical care are designed for women who are a generation older. Young women experience unique decision-making challenges when battling breast cancer, including fertility preservation, surgical options with variable effects on physical appearance, and financial burden [1[■],2[■]]. These decisions occur in the context of potentially filling the simultaneous roles of parent, partner, and child. Furthermore, young women will likely experience a much longer period of survivor-ship, making posttreatment quality of life, fear of recurrence, body image, and employment salient concerns at the time of active treatment.

This article examines recent advances in the management of the psychosocial challenges facing young women at the time of a breast cancer diagnosis and during treatment. The article in this issue by Karen Fergus and her coworkers examines psychosocial support issues in depth, and we, therefore, summarize these issues only to provide context for our discussion of managing psychosocial issues during active treatment. In the clinical context, we examine the need for shared decision-making and the use of decision aids in fostering the patient-provider relationship; and risk perception, fear of recurrence, and body image in surgical management. Considering the broader social context, we discuss the use of technology and online social networks, supporting family – including parents and children, and the financial burden of cancer.

MEETING PSYCHOSOCIAL NEEDS IN THE CLINICAL SETTING: PATIENT-PROVIDER COMMUNICATION AND SHARED DECISION-MAKING

Shared decision-making, a collaborative process that allows patients and their providers to make health-care decisions together, taking into account the best scientific evidence available, as well as the patient’s values and preferences, is a hallmark of patient-centered breast cancer care [3]. Women who participate in their treatment decisions at their comfort level demonstrate lower decisional conflict and greater treatment satisfaction [4]. This has led to a deluge of breast cancer care decision aids, which are tools for patients and providers to share information and create a conversation about the options and their relative merits and downsides [4,5[■],6]. Anxiety and depressive symptoms are highest around the time of diagnosis and treatment, and young women experience particularly severe psychological symptoms [7]. For example, women who take on primary decision-making status (as opposed to shared decision-making with their clinician) more often choose to have a contralateral prophylactic mastectomy [8]. They, therefore, stand to benefit from a decision-making approach that ameliorates the emotional burden of breast cancer when deciding among primary surgical options, including reconstruction preferences, and weighing the benefits of adjuvant hormonal therapies against adverse effects.

Communicating risks and prognosis

In the era of personalized medicine, genetic predisposition to breast cancer and tumor histology inform treatment. Understanding one's risk is associated with reductions in distress and improvements in wellbeing and knowledge [9]. Individuals, thus, increasingly demand information about their risk profiles and associated prognosis. However, women under 40 with breast cancer are more likely to have tumors with aggressive biology, which may engender greater anxiety in the absence of actionable information [2¹¹,10]. Gene expression profiles also show an increased rate of less favorable cancer subtypes that are characterized by higher proliferation rates, worse prognosis, and lack of receptor expression [2¹¹,10]. In comparison with older women, younger women present with more advanced disease – larger size, higher degree of nodal involvement, and meta-static disease [2¹¹]. Communicating how these complex factors influence survival, recurrence, and treatment options is essential to preserving women's role in decision-making and minimizing uncertainty in the treatment process.

Risk prediction models help tailor prognosis to the individual woman, leading to demonstrable improvements in patient knowledge, engagement in care, and accurate risk perceptions. However, a recent review demonstrates that existing risk prediction models for breast cancer prognosis based on genetic information do not incorporate clinical factors, and women under 40 are one of two subgroups for which model performance is suboptimal [10]. Creating validated, accurate prognostic models for young women with breast cancer is an essential area of research to inform treatment needs and decision aids [2¹¹,10].

Concurrently treating any psychological morbidity in this population is especially important for preserving decision-making roles while facilitating coping with aggressive disease. In addition, participating in treatment decisions is associated with better adherence to adjuvant hormonal therapies, which can improve odds of cancer-free survival [11]. Current guidelines recommend ongoing screening for anxiety and depression during treatment and within the clinical setting. Brief, validated instruments such as the Patient Health Questionnaire, are recommended for clinical use, particularly during periods of transition (e.g., hospital discharge, receiving diagnosis, transition to survivorship, etc.) [12]. The recent screening guideline from the American Society of Clinical Oncology contains a comprehensive list of validated screening tools [12]. In addition, standardized clinical protocols for psychological referral are essential to receiving timely and appropriate treatment for symptoms of distress [13].

Psychosocial considerations for surgery, treatment, and reconstruction

The increasing popularity of bilateral and prophylactic mastectomy in the absence of genetic predisposition illustrates how fear of recurrence and confrontation with mortality pervade care. Although no survival benefit is demonstrated for prophylactic mastectomy, women still choose this option in an effort to improve their survival odds and to mitigate the anxiety associated with ongoing surveillance and the potential for false positives [14–15]. In addition, greater side-effects and morbidity are associated with mastectomy. Patients should be fully informed of the increased risk of complications, including reoperation and readmission, when considering risk-reduction surgery [16,17¹¹]. Accordingly, women who

use decision aids for primary surgery are often more likely to choose recommended breast-conserving surgery (BCS) with radiation [18]. Information regarding the potential for complications and long-term morbidity is particularly important for young women, who may be confronting their own mortality for the first time, but will likely live for a long period with any adverse effects associated with surgical prophylaxis [19[■]]. As such, support of young women's preferences for surgical therapy should incorporate body image concerns and minimize the role of fear of recurrence and anxiety [19[■]]. In addition, psycho-educational efforts to minimize barriers to shared decision-making – such as low health literacy, patient stress, and care fragmentation – can facilitate the treatment process [20]. For example, the Hitch-cock Breast Center at Dartmouth University refers all newly diagnosed patients to a center for shared decision-making to assess their preferences and improve knowledge prior to starting treatment [20].

Young age is an independent-risk factor for recurrence after both BCS and mastectomy, making radiation in this population more important [21,22]. Although a booster dose of radiation significantly reduces 10-year local recurrence rates, any use of radiation results in breast fibrosis, compromising esthetic outcomes [23,24[■]]. Weighing body image concerns and long-term side-effects of radiation, such as organ damage, against the benefits is important to ensuring that women receive appropriate treatment. Notably, young women often fail to receive recommended radiotherapy, likely owing to a lack of childcare needed to undergo intensive treatment [25].

When mastectomy is the surgical therapy of choice, nipple-sparing techniques may provide better cosmesis, tumor location permitting, without compromising oncologic control. Sparing the nipple may be particularly important to meeting the expectations of young women, who seek normal physical breasts and reconstruction more frequently than their older counterparts [20,24[■]]. Notably, immediate reconstruction is associated with improved self-esteem and lower anxiety when radiation is not needed. Young women should, thus, be aware of the esthetic and psychosocial compromises when delayed reconstruction is necessary, particularly for tissue expansion and radiotherapy [26,27]. They also have to live with their reconstruction for a longer period, making the long-term failure of implant reconstruction, including rupture, migration, and capsular contracture, important concerns [28]. Young women in particular must, therefore, be educated about the long-term failure rates (and associated costs of reoperation) of different types of reconstruction when making decisions about their appearance.

Treatment considerations for young women with metastatic cancer

Palliative care, which is care focused on ameliorating symptoms and suffering associated with the disease and treatment, is underutilized for young women with metastatic cancer. Often confused with hospice and end-of-life care, patients and providers alike avoid discussions about palliative care, which has the potential to relieve the pain burden on young women and their families, facilitate better physical and role functioning, and improve quality of life [1[■]]. Women who have advanced cancer stand to benefit from earlier referral for palliative care, and all women with a high symptom burden stand to benefit from multidisciplinary palliative care. Moreover, palliative care that addresses psychological

coping, rehabilitation, and pain management with attention to promoting normal activity can improve quality of life for patients' families as well as patients. Recent policy directives, thus advocate for the use of palliative care specialist teams 'consisting of a nurse, a social worker, a psychologist, a palliative care physician, and an oncologist' that crosscut care settings and promote spiritual well-being as well as physical functioning [1[■]].

BEYOND THE CLINIC: PSYCHOSOCIAL SUPPORT NEEDS FOR YOUNG WOMEN WITH BREAST CANCER

Given that anxiety, depression, and compromised quality of life are highest around breast cancer treatment, and even more so in the cohort of young women who commonly have unmet psychosocial needs, psychosocial interventions for this population are essential to promoting wellbeing and psychological adjustment to the disease [19[■]]. Moreover, newly diagnosed young women with preexisting mental health concerns may be especially in need of support and referral to address these issues. Interventions must also be culturally sensitive [29]. Aforementioned recent guidelines support the implementation of routine and frequent screening for psychological morbidity. Moreover, existing research supports the use of psychoeducational support interventions to improve symptoms and emotional wellbeing for, approximately, 6–12 months, but not over the longer term [30–32]. In addition, psychosocial interventions may be effective in reducing pain, with educational interventions showing greater preliminary promise than relaxation-based or supportive group therapies [30–32]. Several systematic reviews assess psychosocial interventions for breast cancer patients with preliminary evidence supporting quality of life benefits for cognitive behavioral therapy, exercise and yoga, and mindfulness-based interventions [31–36]. However, the heterogeneity of the interventions and evaluation methods precludes definitive conclusions regarding their effectiveness. Well designed, randomized studies are needed to assess these interventions, as well as, to determine how they produce change – for example, by reducing allostatic load or relieving psychological symptoms associated with physical morbidity (e.g., upper limb dysfunction). Although group therapies may confer a peer-support advantage, patients and survivors can also experience an emotional tailspin resulting from the rapid deterioration or loss of a group member.

Young women with newly diagnosed breast cancer are often considered part of a 'wired generation' with the use of technology, the Internet, and smartphones integrated into their daily life for communication, education, and organization [1[■]]. This phenomenon provides a unique modality for meeting informational and emotional support needs during treatment, particularly given the ease of access. Ten years ago, 400 000 cancer-related support groups already existed on the Internet [37[■]]. The Internet serves as a primary hub of education, social support, and provider communication for all cancer patients and can be an effective tool for intervention implementation and dissemination. Notably, the largest effect sizes for physical activity interventions are found for telehealth modalities, likely owed to lower attrition rates [33]. Additionally, a number of smartphone apps are available for pill management, chemotherapy information, and social networking with other patients and survivors. Moreover, younger cancer patients expect to be able to communicate with their

healthcare team using the Internet, making telehealth and the associated security an essential part of cancer care for young patients [1[■]].

Family relationships present a particularly diverse and salient set of concerns for young women with breast cancer [19[■]]. Young women may be in the position of communicating their diagnosis to their small children, caring for those children through the exhaustion and trials of treatment, and explaining the physical changes that result from treatment. They may also need to support their parents through coping with their daughter's diagnosis [19[■]]. Others may be single and interested in dating or finding a future partner. Although many women find support and improvement in family relationships following breast cancer treatment, intimate partner relationships are often more strained for younger women. Resources are available to support partners, such as those listed at Susan G. Komen for the Cure's website, and interventions have been developed, such as Fergus' Couplelinks, an online support intervention for young couples coping with breast cancer [38,39]. Many women express an immediate need for support in helping their children through the diagnosis [40], and books with pictures are a main source of information for young children. More than 200 books for young children on mothers' cancer are published, and the majority offers coping strategies and plain language to inform children about the disease and its effects. However, few books address financial concerns, impact on school, or guidance about reader age, which are major limitations of children's cancer literature [41].

In addition to relationship stress, financial concerns resulting from disruptions in employment or paying for treatment can be destabilizing for both women and families, who may have variable insurance status. Young cancer patients are often frustrated by the lack of resources in clinical setting that offer information about covering periods of lower income owed to treatment or paying for treatment, and debt and bankruptcy are more significant concerns for younger cancer patients [1[■]]. In addition, many young adults need help understanding their payment options, whether insurance covers their chosen provider, and how/whether to maintain employment while undergoing treatment [1[■]]. The American Cancer Society offers resource guides and workshops on financial management for cancer, and Komen offers a list of organizations that offer information and financial assistance for childcare and treatment [39,42]. However, younger patients, who have fewer resources and more anxiety about employment than older patients, find their need for financial support and information unmet in the clinical care setting.

CONCLUSION

As young women with breast cancer transition to being young survivors, transitional care and surveillance plans must be tailored based on tumor histology and genetic predisposition. Secondary cancers and recurrence are more common among young women, and adherence to adjuvant hormonal therapies, management of their side-effects, and recommended surveillance are essential to long-term health. However, these care plans are often multidisciplinary and fall to the primary care physician, who is often less involved in treatment than patients desire [1[■]]. As a result, these women can often be lost in transition, experiencing the shortcomings of a fragmented health system at a critical juncture in their care. Research gaps unique to young women with breast cancer require further study,

including addressing psychosocial needs of women and families, fertility preservation, access to care, and financial assistance [43].

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KEY POINTS

- Psychoeducational interventions in particular can ease symptoms and emotional distress during treatment, but effects do not appear to persist over the longer term.
- Surgical decision-making is often driven by fear of recurrence and body image rather than prognosis, and decision aids may help young women to synthesize information.
- Multidisciplinary palliative care that includes psychological counseling is an essential priority for patients with metastatic cancer.
- In the larger social context, family/partner relationships, financial stress, and heterogeneous insurance coverage are unique needs.