



Psychosocial issues experienced by young women with breast cancer: the minority group with the majority of need

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Purpose of review

The ways in which biological, social, and psychological factors characteristically unfold and interact for young women with breast cancer yields complex and acute challenges that are not clearly understood by all healthcare professionals. Better knowledge of the unique needs of young women with breast cancer would assist in matching younger women with the right services at the right time.

Recent findings

Younger women (<50 years) represent a minority of breast cancer cases, yet they tend to be overrepresented with respect to demonstrating the poorest psychosocial adjustment during and following treatment. Concerns most frequently reported in this age group pertained to body image, sexual functioning, fertility, relationships, fear of cancer recurrence, and caring for children; failure of healthcare providers to initiate conversations to educate women about treatment side effects early on and/or safely discuss sensitive issues; lack of widespread availability of professional psychosocial programs that are tailored to the unique needs of this age group.

Summary

Young women with breast cancer are at greater risk for psychosocial adjustment problems, yet their needs are often overlooked. Proactive discussions by healthcare providers early on in treatment, and referrals to relevant services as part of standard care are needed to mitigate younger women's concerns and reduce the likelihood of problems becoming longstanding.

Keywords

breast cancer, psychosocial needs, quality of life, young women

INTRODUCTION

A breast cancer diagnosis is a potentially devastating event for any woman. However, for younger women (<50 years), who make up just 18% [1] of breast cancer cases, a breast cancer diagnosis and treatment are associated with greater distress and poorer quality of life in several domains (e.g., health, social, and psychological) relative to older women [2–6,7]. What is more concerning is that the situation does not seem to get better over time; studies demonstrate that relative to older women, younger women's distress is more likely to persist after breast cancer treatment and progressively worsen as long as 10 years later [8–10]. The picture is more troubling for young women because of disruptions to developmental goals and tasks imposed by the physical impact of a breast cancer diagnosis and treatment. Younger women are at a greater risk for more aggressive tumors, higher local recurrence

rate, and poorer overall prognosis [11,12]. Certain adjunct treatments, such as chemotherapy or hormone-based therapies, are more likely to be prescribed and confer risk of temporary or permanent biological losses or changes such as infertility, loss of libido, weight gain, hair loss, and fatigue. Most women in this younger age group are at a stage in their life when they are still in the process of establishing their careers, finding life partners, and

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KEY POINTS

- Younger women (<50 years or premenopausal) with breast cancer (YWBC) experience significantly poorer quality of life and more psychological distress relative to older age women.
- Younger women with breast cancer have more unaddressed needs following breast cancer that include how to deal with relationship concerns, sexual dysfunction, children, fertility and body image concerns.
- Younger women's unaddressed needs have the potential to result in longer term disruptions to their developmental stages including finding a partner, establishing their careers, and starting or growing their family, and to marital satisfaction and emotional well-being.
- Recommendations based on feedback from YWBC include: open dialogue and education about such issues initiated early on by healthcare professionals, referrals to counselors and programs that are targeted to this age group, and peer support.
- Barriers preventing YWBC from pursuing and/or accessing existing support services include time spent away from dependent children, logistical and financial burdens of traveling to treatment centers, and the out-of-pocket expenses often incurred by these services, which are especially onerous for YWBC at early stages of their careers.

having children; the social implications of such treatment side effects are therefore much more devastating.

Given the disproportionately greater negative impact of breast cancer on younger women, it is not surprising that they report a greater need for age-specific information and services on how to manage issues such as fertility, sex, body image, and family [13–15]. Proactively informing YWBC about the social and emotional consequences of breast cancer is important given that the level of preparation they feel they had prior to treatment is positively related to their consequent quality of life [3]. Yet despite psychosocial issues being ranked high in importance by younger women, they frequently report dissatisfaction with the quality of information they receive in this area [16]. Moreover, in cases where professional psychosocial support is warranted, YWBC have indicated a desire to receive these services at critical time points – particularly at diagnosis and at the transition from treatment to survivorship [17]. They also prefer their cancer specialists to initiate these referrals because it normalizes the experience of cancer-related psychosocial distress,

and underscores the importance of providing a comprehensive approach to their care [18]. The purpose of this article is to closely examine the impact of breast cancer on younger women by summarizing research to date and to highlight areas for improving psychosocial care and supportive interventions for this breast cancer minority.

INTRUSIVE WORRY ABOUT CANCER REOCCURRENCE

With respect to psychological well-being, YWBC demonstrate elevated levels of depression and anxiety relative to older age breast cancer survivors and age-matched healthy peers [7]. A psychological condition that resembles anxiety but, based on research with YWBC, is likely distinct from worry as a trait or anxiety disorder [19,20] is the fear of cancer reoccurrence (FCR). FCR entails persistent and intrusive worry that the cancer will return. YWBC have consistently been found to be at a greater risk for struggling with FCR and FCR has been found to negatively impact a young woman's mood and ability to set goals and plan for the future [19,20,21,22]. Such intrusive and uncontrollable worry has important implications for YWBC healthcare decisions and costs; unmanaged worry predicts likelihood of opting for more aggressive surgical options even if not recommended [23], greater number of unscheduled visits to the family physician, greater amount of money spent on additional alternative health care (e.g., naturopathic treatment), and more frequent breast self-examination associated with anxious preoccupation [21].

Studies have found as many as 70% of YWBC survivors experience clinically significant levels of FCR and FCR is independent of factors that would be expected to mediate such fears such as time since diagnosis, prior cancer diagnosis, objective risk of recurrence, receipt of chemotherapy [19,21], and cancer stage [20]. What *does* appear to mediate fear of recurrence is the level of intrusiveness of cancer on a woman's valued life activities in social, physical, and economic domains [20], and maladaptive beliefs about the benefit of worrying that perpetuate the tendency to worry [24]. An important target for psychosocial interventions would therefore be helping YWBC to better manage their fears so that they can reengage in important life activities.

FINANCIAL AND EMOTIONAL 'COSTS' TO FAMILY AND WORK

YWBC incur much greater direct and indirect costs because of breast cancer treatment. Younger women

are more likely to take sick leave because of breast cancer [25,26], and feel burdened by out-of-pocket expenses for medical treatment when they are in the process of establishing their careers and are still short of reaching their full earning potential [27]; in fact, younger women are more likely to express dissatisfaction with their careers and a desire to change their careers after a breast cancer diagnosis [25,26,28]. A population-level study in Australia found that younger women (<50 years) incurred anywhere from 67% (node negative breast cancer) to 80% (node positive breast cancer) more costs relative to older women due to greater healthcare use, greater loss of income, and of time away from valued activities (e.g., quality time with children, volunteer work) [29].

Young women report finding it difficult to care for themselves when they have dependent children, and on a logistical level, plan their own medical treatment around the needs of their children and other family responsibilities [28]. Difficulty securing adequate childcare, for example, may hinder women's abilities to receive treatments that require prolonged or frequent hospital visits such as radiation [23]. Women with dependent children (typically age 10 or younger) tend to experience even poorer well-being and greater levels of intrusive worry about the cancer and dying of cancer [30,31,32], and express greater need for timely counseling around coping with concerns for younger children [30,32]. They report struggling with how to care for and address the needs of dependent children, including how to communicate with their children about the illness in a way that is appropriate to the child's developmental stage [33,34]; manage children's feelings in relation to their physical changes such as hair loss; cope with their own guilt about not keeping up with regular activities with children, or fears of potentially dying and leaving their children motherless; and finally, how to address concerns in relation to possibly passing on a breast cancer gene mutation to their children [17].

SOCIAL SUPPORT

Relative to older age women, level of social support is an important predictor of longer-term adjustment [8,35] as well as survival for young women with advanced breast cancer [36]. Therefore, the reduction in social contact with the healthcare team as well as friends and family following the active treatment phase can be acutely isolating for young women [17]. Even when family supports are available, they may do more harm than good, depending upon family members' ways of coping with the stressor and the nature of her relationship with

her family. Following completion of active treatment, family may assume the worst is over and interact with the young woman in ways that inadvertently convey a hastening, denying [37] or trivializing of the cancer experience leaving YWBC feeling very isolated. In the case of family such as parents or siblings, YWBC struggle with feeling on the one hand, supported by and grateful for such support, but also guilt for causing them worry or for being a financial burden, or frustration over feeling like they have to manage their family members' worries in addition to their own [17,38]. For example, many YWBC report that their mothers were an important source of practical support such as assisting with household responsibilities and caring for dependent children as well as emotional support such listening to their cancer related fears and concerns [38]. However, not all YWBC feel they can share the diagnosis with their mothers because of guilt about emotionally burdening them, especially if their mother lives far away, or is ill or very elderly. When mothers were perceived as being able to remain strong upon news of the diagnosis (e.g. maintaining a comforting and supporting demeanor despite their own feelings of anxiety and despair) YWBC were less prone to experience such guilt [38].

For YWBC in committed romantic relationships, having a supportive partner is predictive of better adjustment to cancer, however having an unsupportive partner contributes to higher levels of anxiety when compared to both nonpartnered women or women in more supportive relationships [39]. Breast cancer profoundly affects not only the woman herself but also her intimate partner and the relationship they share and these effects are that much greater for younger couples. By virtue of having fewer years together and thus fewer opportunities to develop dyadic coping skills in relation to adversity, younger couples may be less likely to demonstrate resilience in the face of a major illness such as breast cancer [40–42]. Younger couples are susceptible to relationship strife particularly when partners' coping styles at different stages of treatment are misaligned, such as at the end of treatment when, for example, the well partner's focus on putting breast cancer behind is at odds with the woman's need to take time for recovery [37]. On the positive side, studies have found that having breast cancer presents an opportunity for couples to strengthen their relationship [43] because of the potential for greater emotional intimacy and personal disclosure between partners, the well spouse's demonstrated care and nurturance, and the experience of cancer as a shared stressor that they overcome together [17,37].

FERTILITY AND REPRODUCTIVE HEALTH

Adjunct breast cancer treatments such as chemotherapy have the unfortunate effect of temporarily or permanently leading to premature menopause and infertility. Regardless of whether or not they wanted to have children or already have children, young women experience infertility as a significant loss by virtue of the fact that they no longer have the choice to conceive and bear a child [17[•],44[•],45]. This is particularly difficult for women who are single and childless and who perceive themselves as potentially undesirable to a future partner [45–47].

Several studies have found young women to be poorly, if at all, informed about fertility issues and available fertility preservation options, such as egg harvesting and freezing of embryos, early enough for them to take advantage of such options. These studies further report that women are not provided with sufficient time or support to think through fertility-related decisions, and very often felt rushed by their healthcare providers who are prioritizing life-saving treatment [17[•],46–48]. At the most extreme, women report feeling their practitioners ‘shut them down’ or discouraged them from pursuing such options, particularly women who are single or already have children [46,48,49]. Being ill informed, and thus ill prepared, for infertility robs these women of a critical choice – the ramifications of which cannot be undone [48].

Fear of infertility is seldom a reason for not pursuing chemotherapy or other life-saving treatment [48,50], and most younger women pursue the recommended treatment [44[•]]. However, the discussion in and of itself is important in order for women to feel empowered and to reduce the likelihood of experiencing regret later. Suggested timing of discussing fertility options is as early as possible [46,47], within the first week of presentation of a diagnosis [48]. The desire for accurate, written material to complement verbal information with which to reflect upon is a frequent theme in feedback provided by YWBC, along with requests for referral for fertility-specific counseling (not simply to get information but to assist with decision making) [46–48]. Materials and procedures to standardize fertility discussion and to fast-track the process of referral to a fertility clinic, if appropriate, are clearly necessary.

SEXUAL FUNCTIONING AND BODY IMAGE

Adjuvant therapies not only affect fertility but also sexual functioning and body image, and their co-occurrence is even more traumatic for young women’s adjustment [3,51^{••}]. YWBC report problems with sex and need for more supports in this area

in far greater numbers than do older women with breast cancer [14]. Chemotherapy-induced menopause leads to reduction in sexual desire and arousal [52[•]], and associated vaginal dryness and atrophy can make intercourse painful. Moreover, chemotherapy-induced menopause among younger women is related to greater sexual difficulties than natural, age-related menopause [7]. Treatment-related bodily changes such as loss of breast, hair loss, and weight gain negatively impact upon a young woman’s body esteem [53^{••}] and such concerns are closely tied to sexual functioning [51^{••},54]. Treatment-related fatigue, memory issues, and depression resulting from cancer and its treatment can also affect a woman’s sexual interest [51^{••},54]. For single women, successful navigation of the dating world after breast cancer requires a difficult process of self and bodily acceptance that can take several years to achieve [55^{••}], and poor self-esteem and concerns about rejection based on their ability to have children and physical disfigurement may preempt some single YWBC from dating [17[•],49].

Studies have found that as many as half or more of YWBC report sexual dysfunction [54,56[•]]. Relative to age-matched healthy peers, YWBC are at least twice as likely to demonstrate diminished sexual desire, satisfaction, and lubrication [51^{••},56[•]], engage in sex less frequently [57] and experience more sexual distress (e.g., feelings of guilt, difficulty enjoying sex, and/or not feeling adequate or desirable) [58[•]]. Although these issues can remit following active treatment, as many as 46% of YWBC continue to experience sexual distress after completion of active treatment [58[•]] and have been found to continue to be less sexually active than age-matched healthy peers at least 10 years into survivorship [8].

The significant role of relationship quality in recovery of sexual functioning cannot be overlooked, particularly for younger couples for whom relationship satisfaction and adjustment are closely related to sexual adjustment [51^{••},58[•]] to a greater degree than older couples [59]. Of particular importance are the findings that sexual adjustment is positively associated with the degree to which a woman can openly discuss her feelings, wishes, and desires related to sex and the illness, and the extent to which the partner can accept and understand her feelings [51^{••},54,58[•]].

Young women report feeling their healthcare team did not adequately prepare them for the range of side effects impacting sexual function, sexuality, and body image [17[•],54]. Although YWBC who undergo breast-conserving surgery demonstrate better body image posttreatment than those that undergo radical mastectomy [53^{••},54], Pinto’s

review [51¹¹] suggests that healthcare providers' enlisting of a young woman's involvement in the decision-making process around type of surgery, further contributes to better body image. YWBC prefer the healthcare provider to initiate discussion around their sexual function, yet such conversations are not a standard part of practice, contributing to a current norm of silence in relation to sexual health [51¹¹]. When the topic does surface, women report that there is insufficient time for discussion or that the issue is treated as something that is 'a given' and uncontrollable [51¹¹]. Both physicians and patients wait for the other to broach the topic of sexuality. Single women are particularly disadvantaged in relation to this 'code of silence' because of healthcare providers' decreased likelihood of raising the topic with them in particular [49]. Sexual functioning assessment and timely referral for sexual health intervention where indicated have been strongly recommended for YWBC [51¹¹,52¹²].

NEED FOR AGE-SPECIFIC PSYCHOSOCIAL INTERVENTIONS

YWBC report profound feelings of isolation given their minority status not only within their peer group, but also among the breast cancer population [15]. Within the breast cancer population, younger women report feeling different and more alone by virtue of their age and life stage [37]. Given that YWBC account for less than 20% of all women with breast cancer, it is not surprising that they feel out of place in breast cancer support groups, which are generally composed of women more than 50 years of age [15]. YWBC who are single and childless are a particularly vulnerable subgroup in this regard [49]. Very little work has been done to develop comprehensive psychosocial interventions that target younger women, with few noted exceptions [60,61]. A national survey of YWBC in Canada that found relative to their older counterparts, young women (≤ 45 years) experience more difficulty in navigating the healthcare system and finding information and resources targeted to their age-specific needs, especially women 20 to 29 years of age, because of their relatively limited experience in dealing with the medical system [62].

Despite the expressed need for, and reported benefits of, professional psychosocial support, young women underutilize services targeted for them when offered [61] owing to difficulty with finding time and resources to take part in such services on top of all other responsibilities [18,63] and guilt in relation to taking care of themselves when they have dependent children. These barriers notwithstanding, YWBC demonstrate preferences for using online

forms of psychosocial support [64] and this is particularly advantageous for YWBC residing in under-resourced, rural areas [18]. Another lacuna in current care is supports catering to both women and their partners. It would be expected that partners of YWBC experience elevated levels of distress, even beyond what is commonly reported by caregivers [65,66] based on their younger age and earlier life stage, and the additional responsibilities characteristic of this stage such as caring for dependent children. In an effort to help younger couples adjust to the range of challenges posed by breast cancer in as convenient and accessible a way as possible, a new professionally facilitated online support program called 'Couple-links' has been custom designed for YWBC and their male partners and is currently being evaluated in a Phase III trial [67¹³,68¹⁴].

YOUNG WOMEN WITH GENETIC RISK FOR BREAST CANCER

YWBC who also are known to carry a Breast Cancer (BRCA) gene 1 or 2 mutation are estimated to represent 10 to 15% of YWBC (defined here as diagnosed < 40 years of age) [69; E. Warner, personal communication], although these rates are higher in subgroups such as Ashkenazi Jews. For YWBC, genetic testing will often have been triggered by the diagnosis itself – the results of which may be used to inform treatment planning. Interviews with women recently diagnosed with breast cancer who were considered to be at high risk for a BRCA mutation because of young age, family history, or Ashkenazi Jewish ancestry found that women viewed genetic testing favorably because it greatly informed their decision-making process [70]. These women further emphasized that, despite the risk of having to cope with an added health concern should they test positive, they did not feel the risk of psychological burden outweighed the potential benefits [70,71].

Findings from a large current cohort study of 560 women diagnosed with unilateral, primary breast cancer at or before the age of 40 showed that testing positive for a BRCA mutation was a major predictor of a decision to pursue contralateral prophylactic mastectomy (CPM) [69]. For YWBC who do not undertake CPM, it is recommended that they undergo regular MRI in addition to mammographic surveillance because of the much higher sensitivity of these screening methods when combined. By the same token, however, MRIs yield more false-positive results adding to the stress of survivorship for this subgroup of YWBC [72].

Other than no longer living in fearful anticipation of a breast cancer diagnosis [73], YWBC

who harbor a mutation share similar concerns to unaffected women with BRCA1/2 mutations. Common issues include perceiving themselves as 'damaged' due to having undergone a mastectomy or prophylactic oophorectomy, associated loss of fertility, and concerns in relation to dating and establishing new relationships [74–76]. Moreover, if there have been one or more cancer-related deaths in the family, female mutation carriers may be even more reluctant to disclose their cancer risk to loved ones for fear of burdening them further [76]. YWBC carriers' position of being both a carrier and patient affected by cancer adds another layer of complexity where disclosure to family members is concerned because the news of their own carrier status further intensifies the perceived inevitability of a diagnosis for other known carriers (in the natal or extended family [74,75]).

Unlike unaffected women, however, YWBC mutation carriers have fewer options available to them in order to counteract the deleterious side effects of prophylactic surgeries. For example, with respect to sudden onset menopause after risk-reducing salpingo-oophorectomy, YWBC are dissuaded from pursuing hormone replacement therapy, particularly if they had estrogen receptor positive cancers. Moreover, because many of these women will also require radiotherapy, their breast reconstruction options become more complicated than those of women undergoing elective risk-reducing bilateral mastectomy [77]. Although YWBC often have too little abdominal wall fat for optimal autologous reconstruction, they are at risk for a suboptimal cosmetic result from an immediate implant reconstruction that requires postoperative radiotherapy, and a latissimus dorsi flap is often necessary to increase the blood supply to a delayed ipsilateral implant reconstruction. Thus, overall, being both affected by breast cancer and possessing a hereditary predisposition for the disease is doubly challenging and this subgroup should be considered at higher risk for psychosocial distress and/or in need of even more specialized forms of psychosocial support.

CONCLUSION

Although young age predisposes women to poorer adjustment, the specific social and emotional sequelae of breast cancer can only be truly understood – and addressed – by understanding their personal goals, wishes, and desires. Young women express a need to talk about aspects of their care with their healthcare provider and be able to contribute to their treatment decisions through a dialogical form of engagement. Initiating conversations about the potential/actual impact of breast cancer and

treatment on areas such as fertility, body image, sex, and relationships is of utmost importance. Such conversations not only educate women and help assess their needs, but are in themselves empowering and instill a sense of agency in patients' treatment. Moreover, the observed declines in quality of life of YWBC after treatment completion is concerning as these may not be anticipated by the healthcare team and may only become apparent to the women themselves when they have far fewer opportunities to interact with their healthcare team. Consideration of effective ways of mitigating psychosocial distress that can be incorporated into usual care practices should be a priority focus for YWBC, both during active treatment and at the juncture from treatment to survivorship. These may range from simply sharing written materials at opportune times, to providing innovative, comprehensive forms of intervention that target young women's specialized needs [60,61,68**] and those of their family members [38].

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