



Psychosocial and supportive care concerns of young women living with advanced breast cancer: baseline findings from a prospective virtual support intervention study

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Abstract

Purpose Adolescent and young adults (AYAs) with metastatic breast cancer (MBC) experience high physical and psychosocial burdens compounded by a disrupted life trajectory. We sought to determine the psychosocial and supportive care concerns of this population to better understand and address unmet needs.

Methods AYAs diagnosed with MBC (18–39 years) participating in a prospective interventional study (Young, Empowered, and Strong) at Dana-Farber Cancer Institute completed an electronic survey following enrollment. Measures evaluated sociodemographics, health behaviors, quality of life, and symptoms, among others. We used two-sided Fisher's exact tests to determine associations between concerns (e.g., cancer progression, side effects, lifestyle, finances, fertility) and demographic variables.

Results Among 77 participants enrolled from 9/2020–12/2022, average age at MBC diagnosis and survey was 35.9 (range: 22–39) and 38.3 years (range: 27–46), respectively. Most were non-Hispanic white (83.8%) and 40.3% reported their diagnosis caused some financial problems. Many were concerned about fertility (27.0%), long-term treatment side effects (67.6%), exercise (61.6%), and diet (54.1%). Select concerns varied significantly by age, race/ethnicity, and education. Younger women at survey reported greater concern about familial cancer risk ($p=0.028$). Women from minority racial/ethnic groups more frequently reported issues talking about their cancer to family/friends ($p=0.040$) while those with more education were more frequently concerned with long-term effects of cancer on their health ($p=0.021$).

Conclusion Young women living with MBC frequently report psychosocial, health, and cancer management concerns. Tailoring supportive care and communications to address prevalent concerns including disease progression and treatment side effects may optimize wellbeing.

Keywords Metastatic breast cancer · MBC · Cancer survivorship · Quality of life · AYAs

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Background

Breast cancer remains the leading cause of cancer-related death among adolescent and young adult (AYA) women in the United States, and AYAs with advanced breast cancer may live for many years with the disease. [1–4]. The definition of AYAs may differ by country or region, but in the United States, AYAs usually include individuals aged 15 to 39 years. AYA women with metastatic breast cancer (MBC) experience unique treatment and survivorship challenges. Despite advances in targeted treatment and care, women with MBC face ongoing, intensive chemotherapy in conjunction with other treatments, and in the case of AYAs with hormone receptor-positive disease, they face endocrine therapy with ovarian function suppression that has associated burdensome side effects [5, 6] (e.g., effects on sexual functioning, fertility and family planning, mental health, relationships, employment) [5, 7–11] coupled with changes in life trajectory. [12, 13]

MBC care has largely focused on optimizing survival combined with the palliation of disease symptoms and treatment-related side effects. However, ongoing improvements in MBC treatment have also led to an increased focus on quality of life and survivorship concerns for this population. [6, 14]. Over time, psychosocial and mental health distress (e.g., depression, anxiety, body image) have the potential to worsen quality of life. [15, 16]. The age-specific needs and concerns of AYAs in particular remain underrecognized and overlooked within the context of the MBC disease trajectory. As part of a prospective intervention study for AYAs with breast cancer (Young, Empowered, and Strong [YES], NCT04379414) [7], we sought to address this gap and characterize the baseline psychosocial and supportive care concerns of those who enrolled with MBC.

Methods

Study population & recruitment

Eligible participants were systematically identified through the following databases at the Dana-Farber Cancer Institute (DFCI), a large comprehensive cancer center in Boston, Massachusetts (United States): DFCI's Program for Young Adults with Breast Cancer (Young and Strong) and DFCI's Ending Metastatic Breast Cancer for Everyone (EMBRACE) clinical program databases, as well as the DFCI ONCology Data Retrieval System (OncDRS). Study coordinators also screened clinic lists and received referrals by DFCI oncologists to identify potentially eligible

patients. This research opportunity, including eligibility criteria, was also shared with patients via program communications (i.e., monthly newsletters, informational emails). Patients could contact study staff directly if interested and were determined eligible by a DFCI study coordinator.

Patients were eligible if they met the following criteria: female, initially diagnosed with breast cancer between 18 and 39 years of age (i.e., being diagnosed with breast cancer while an AYA), diagnosis of MBC (de novo stage IV or metastatic/unresectable recurrence of early stage breast cancer), fluency and ability to read English, and access to the internet on a regular basis to support the YES web-based portal. AYA status was dependent on age at breast cancer diagnosis, not age at survey completion, and therefore, some participants were over age 39 at time of survey completion. There was no upper age limit pertaining to study enrollment. DFCI research coordinators approached potential participants in clinic or contacted them by phone and/or email to verify study eligibility and obtain informed consent. Once consented, participants completed a baseline survey via REDCap. After baseline survey completion, participants received access to the YES web-based portal. Follow-up surveys are completed via REDCap at baseline and every six months for three years then annually after, collecting information including sociodemographic information, financial burden, lifestyle behaviors such as alcohol use and smoking, quality of life, the presence of breast cancer symptoms, AYA concerns (including a write-in option), anxiety and depression, as well as fertility. Portal assessments were weekly for the first 12 weeks then monthly for one year. Through the YES portal, participants responded to electronic patient-reported outcomes (ePROs) and automatically received information in the portal on ways to manage the symptoms and concerns they endorsed (i.e., side effects of treatment including sexual dysfunction) in addition to other informational and supportive care resources. [7]. The YES portal ePRO data were not evaluated in the current study. The prospective study began in September 17, 2020 with planned enrollment of 400 women. Here, we present baseline survey data from participants enrolled as of December 1, 2022 to evaluate the presence of concerns among AYAs with MBC. The study was reviewed and approved by the DFCI Institutional Review Board (#20–124).

Measures

Sociodemographic characteristics were collected via self-report. Race (white, Black or African American, American Indian or Alaska Native, Asian or Asian American, Native Hawaiian/other Pacific Islander, other specified, don't know, prefer not to answer) and ethnicity (not Hispanic/Latina, Hispanic/Latina, don't know, prefer not to answer) were combined and dichotomized as non-Hispanic white

(NHW) v. “other” due to small subgroup sizes. Partner status was dichotomized as partnered (including married, domestic partnership) v. unpartnered (including widowed, divorced, separated, never married), as was education (college degree or above v. less than a college degree) and current employment status (not currently working v. currently working). Age at survey completion (≥ 39 years v. < 39 years), time since initial breast cancer diagnosis to survey completion (≥ 2 years v. < 2 years), time from MBC diagnosis to survey (≥ 1 years v. < 1 years), age at MBC diagnosis (dichotomized, ≥ 37 years v. < 37 years), and type of MBC (metastatic recurrence of early stage v. de novo stage IV) were determined using information from participant enrollment and patient medical records.

Metastatic survivorship concerns were assessed with items adapted from the AYA Health Outcomes and Patient Experience (HOPE) Survey. [17]. Items prompted participants to rate their degree of concern (4-point Likert scale ranging from not at all to very) for the following: possible long-term side effects of treatment, possibility of the same type of cancer worsening, how to check signs that cancer has worsened, possibility of getting another type of cancer, having financial support for medical care, concerns about finances, physical fitness or getting enough exercise, nutrition or having a healthy diet, a family member’s risk of getting cancer, having children in the future (fertility/reproduction issues), having enough information about treatment, potential long-term effects of cancer on health, how to talk about cancer experience with family or friends, meeting other adolescent or young adult cancer patients or survivors, body image and beauty after a breast cancer diagnosis, quitting smoking, and alcohol consumption and cancer. Additionally, participants were provided the option to report and rate any other concerns they have experienced via an open-ended free text option. Free text responses allowed for any concerns not included in the adapted HOPE measure to be identified and rated. Responses were dichotomized (not at all/a little v. somewhat/very concerned) to account for small subgroup sizes. To provide greater insight into survivorship concerns relating to smoking and alcohol consumption, current smoking status (every day, some days, not at all), length of time since last cigarette, current alcohol consumption status (yes, but only in the past; yes, currently; no, never) as well as current and pre-diagnosis alcohol consumption were analyzed.

Financial burden was assessed with two items adapted from the National Health Interview Survey. [18]. One item assessed financial burden from diagnosis (“To what degree has your diagnosis caused financial problems for you and your family?”) and was dichotomized (a lot/some v. a little/none). A second item asked about the presence (yes v. no) of delay of medical care due to financial burden.

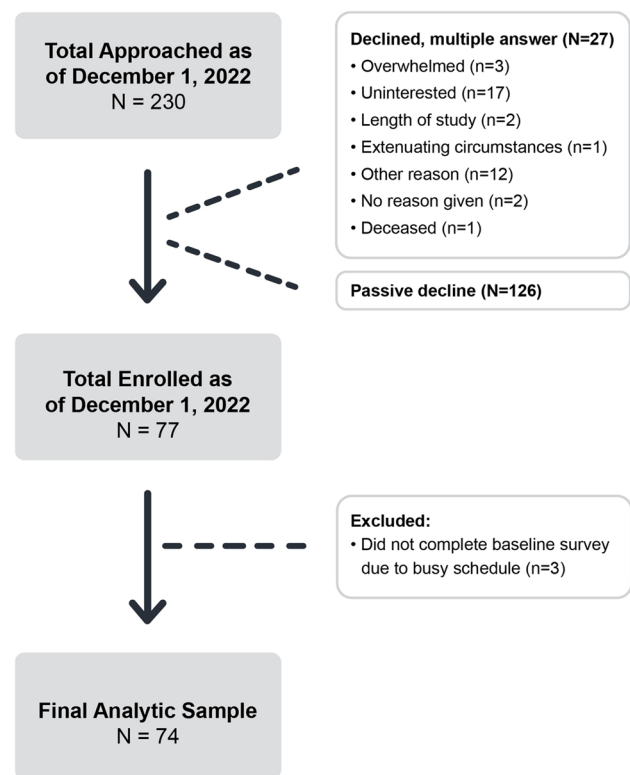


Fig. 1 The Young, Empowered, and Strong (YES) metastatic study enrollment flow chart

Data analysis

We used descriptive statistics to present the sample of participants with MBC. Frequencies and proportions, means and standard deviations (*SD*), medians and ranges were summarized for sociodemographic, clinical cancer, and lifestyle behavior characteristics, as well as metastatic survivorship concern and financial burden items in the analytic sample. We also examined differences in survivorship concerns by age at survey completion, race/ethnicity, education, time since initial breast cancer diagnosis, time from MBC diagnosis to survey completion, age at MBC diagnosis, employment status, partner status, and type of metastatic cancer, respectively. Fisher’s exact tests were used to compare the differences by subgroup. Participants with missing variables of interest (outcomes, stratification variables) were excluded from overall and stratified analyses. All statistical analyses were performed using Stata version 17. [19]

Results

Participant characteristics

A total of 230 MBC survivors were approached as of December 1, 2022, with 77 enrolled in the study (Fig. 1). Enrollment for this study remains ongoing. Three enrolled patients did not complete the baseline survey and were excluded from the current analytic cohort. Of the 74 participants who completed the baseline survey (response rate: $n = 74/77$, 96.1%), most were partnered ($n = 56$, 75.7%), had a college degree ($n = 60$, 81.1%), and identified as NHW ($n = 62$, 83.8%). Few identified as Black or African American ($n = 5$, 6.8%) or Asian or Asian American ($n = 5$, 6.8%). The average age at initial breast cancer diagnosis was 33.7 years ($SD = 4.08$, range = 22.0–39.0), age at MBC diagnosis was 35.9 years ($SD = 3.80$, range = 26.0–45.0), age at survey completion was 38.3 years ($SD = 4.33$, range = 27.0–46.0), and time from MBC diagnosis to survey completion was 1.33 years ($SD = 1.73$, range = 0.02–8.03). Forty-nine women had a metastatic recurrence of early-stage breast cancer (66.2%) and 25 were diagnosed with de novo disease (33.8%). The vast majority did not currently smoke (93.5%) and have not smoked at least 100 cigarettes in their lifetime (71.4%). Alcohol consumption was split, with 44.2% of participants reporting current and 42.9% of participants reporting past usage. Additional participant characteristics are presented in Table 1.

Overall concerns

Endorsed concerns and their severity are presented in Fig. 2. Most participants reported being somewhat or very concerned about the possibility of their cancer worsening ($n = 69/74$, 93.2%), the possibility of experiencing long-term side effects from treatment ($n = 50/74$, 67.6%), and about the potential of long-term effects of cancer on their health ($n = 49/74$, 66.2%). Similarly, 61.6% of women ($n = 45/73$) were somewhat or very concerned about how to check for signs that their cancer has worsened. Regarding health behaviors, concerns about maintaining physical fitness or getting enough exercise ($n = 45/73$, 61.6%) as well as nutrition or having a healthy diet ($n = 40/74$, 54.1%) were prevalent in contrast to concerns about alcohol consumption ($n = 6/73$, 8.2%) and quitting smoking ($n = 2/74$, 2.7%) which were infrequently endorsed. Approximately one quarter of women ($n = 20/74$, 27.0%) were somewhat or very concerned about their fertility and having children in the future. Regarding financial burden, more than half ($n = 29/72$, 40.3%) reported at least some

degree of financial problems due to their diagnosis, however most ($n = 67/74$, 90.5%) did not report any delays in medical care due to cost.

Relationship between concerns & patient characteristics

Degree of concerns varied by several sociodemographic characteristics. Interestingly, compared to participants who were ≥ 39 years at survey completion (Table 2), participants aged < 39 years at survey completion reported greater concern regarding familial cancer risk (23.0% v. 13.5%, $p = 0.028$), future childbearing (18.9% v. 8.1%, $p = 0.009$), and financial problems post-diagnosis (25.0% v. 15.3%, $p = 0.031$). Severity of selected concerns also differed significantly by race/ethnicity (data not shown), with concerns relating to physical activity (91.7% v. 55.7%, $p = 0.020$) and how to talk about their cancer experience with family or friends (58.3% v. 25.8%, $p = 0.040$) more frequent among participants from minority racial or ethnic groups compared to NHW participants, a novel finding. Participants with at least a college degree more often reported being somewhat or very concerned with the potential of long-term effects of cancer on health compared to those who did not have a college degree (73.3% v. 38.5%, $p = 0.021$) while those without a college degree reported more severe concerns relating to financial problems compared to those with at least a college degree (83.3% v. 31.7%, $p = 0.002$, data not shown). There were no significant differences in severity of any concern by time since initial breast cancer diagnosis, time from MBC diagnosis to survey completion, age at MBC diagnosis, employment status, partner status, or type of metastatic cancer (data not shown).

Participant free-text responses

Participant-reported free-text responses included concerns related to one's family and children throughout disease progression and the patient's own mortality (i.e., "How well my children will handle my death", "Trying to make life seem as 'normal' as possible for my children", "How to prepare for the future for my family if I'm gone", "Best way to tell friends, family, and children") most often (Table 3). Other concerns, such as intimacy/sex (i.e., "Marriage with bad sex and no kids", "Intimacy with spouse"), mental health (i.e., "My mental health", "Emotional detachment"), and fear (i.e., "Living with the constant fear of the cancer returning or returning worse", "Death") were also listed as concerns that were not present in the overall concerns measure.

Table 1 Sociodemographic and clinical cancer characteristics among metastatic breast cancer patients from the Young, Empowered, and Strong (YES) study (N = 74)

	N (%)
<i>Age at survey completion</i>	
≥ 39 years	41 (55.4)
< 39 years	33 (44.6)
<i>Marital status</i>	
Partnered	56 (75.7)
Unpartnered	18 (24.3)
<i>Biological children born before breast cancer diagnosis</i>	
Have biological children	16 (21.6)
Do not have biological children	9 (12.2)
Missing*	49 (66.2)
<i>Annual household income</i>	
< \$20,000	5 (6.8)
\$20,000—\$49,999	7 (9.5)
\$50,000—\$89,999	7 (9.5)
\$90,000—\$119,999	17 (23.0)
≥ \$120,000	32 (43.2)
Don't know	5 (6.8)
Prefer not to answer	1 (1.4)
<i>Education</i>	
College degree or above	60 (81.1)
Less than a college degree	13 (17.6)
Missing	1 (1.4)
<i>Current employment status</i>	
Not employed	36 (48.6)
Employed	38 (51.4)
<i>Race</i>	
White	63 (85.1)
Black or African American	5 (6.8)
American Indian or Alaska Native	0 (0.0)
Asian or Asian American	5 (6.8)
Native Hawaiian or Other Pacific Islander	0 (0.0)
Other	2 (2.7)
<i>Hispanic/Latina ethnicity</i>	
No	68 (91.9)
Yes	5 (6.8)
Prefer not to answer	1 (1.4)
<i>Combined race/ethnicity</i>	
Non-Hispanic white	62 (83.8)
Other (Black/African American, Asian, Latina, etc.)	12 (16.2)
<i>Sexual preference</i>	
Asexual	1 (1.4)
Bisexual	1 (1.4)
Gay	0 (0.0)
Heterosexual or straight	20 (27.0)
Lesbian	0 (0.0)
Pansexual	1 (1.4)
Other	0 (0.0)
Don't know	0 (0.0)
Prefer not to answer	3 (4.1)
Missing*	48 (64.9)

Table 1 (continued)

	N (%)
<i>Currently have active health insurance</i>	
No	0 (0.0)
Yes	72 (97.3)
Prefer not to answer	1 (1.4)
Missing	1 (1.4)
<i>Current smoking status</i>	
Every day	2 (2.6)
Some days	0 (0.0)
Not at all	72 (93.5)
<i>Length of time since last cigarette</i>	
1 day or less	2 (2.6)
1–7 days	0 (0.0)
8–30 days	0 (0.0)
31–90 days	0 (0.0)
91 days–1 year	1 (1.3)
Between 1–5 years	3 (3.9)
Greater than 5 years	11 (14.3)
Have not smoked at least 100 cigarettes in my life	55 (71.4)
Missing	2 (2.6)
<i>Current alcohol consumption status</i>	
Yes, but only in the past	33 (42.9)
Yes, currently	34 (44.2)
No, never	7 (9.1)
<i>Current alcohol consumption (N = 34)</i>	
None	0 (0.0)
Less than 1 drink per week	18 (23.4)
1–4 drinks per week	14 (18.2)
5–9 drinks per week	2 (2.6)
10–19 drinks per week	0 (0.0)
More than 19 drinks per week	0 (0.0)
<i>Pre-diagnosis alcohol consumption</i>	
None	0 (0.0)
Less than 1 drink per week	24 (31.2)
1–4 drinks per week	23 (29.9)
5–9 drinks per week	18 (23.4)
10–19 drinks per week	2 (2.6)
More than 19 drinks per week	0 (0.0)
Missing	7 (12.9)
<i>Age at initial breast cancer diagnosis</i>	
≥ 35 years	33 (44.6)
< 35 years	41 (55.4)
<i>Age at metastatic breast cancer diagnosis</i>	
≥ 37 years	37 (50.0)
< 37 years	37 (50.0)
<i>Type of metastatic breast cancer</i>	
De novo	25 (33.8)
Recurrence of early stage	49 (66.2)
<i>Time from initial breast cancer diagnosis to survey completion</i>	
≥ 2 years	48 (64.9)
< 2 years	26 (35.1)

Table 1 (continued)

	N (%)
<i>Time from metastatic breast cancer diagnosis to survey completion</i>	
≥ 1 years	29 (39.2)
< 1 years	45 (60.8)
<i>To what degree has your diagnosis caused financial problems for you and your family?</i>	
A lot or some	43 (58.1)
A little or none	29 (39.2)
Don't know or prefer not to answer	2 (2.7)
<i>Has medical care been delayed for you because of worry about the cost?</i>	
No	67 (90.5)
Yes	7 (9.5)
	N (SD), Range
<i>Age at survey completion</i>	38.1 (4.33), 27 – 46
<i>Age at initial breast cancer diagnosis</i>	33.7 (4.08), 22 – 39
<i>Age at metastatic breast cancer diagnosis</i>	35.9 (3.80), 26 – 45

*n=48, survey completed prior to 04/13/2022, where item was not asked

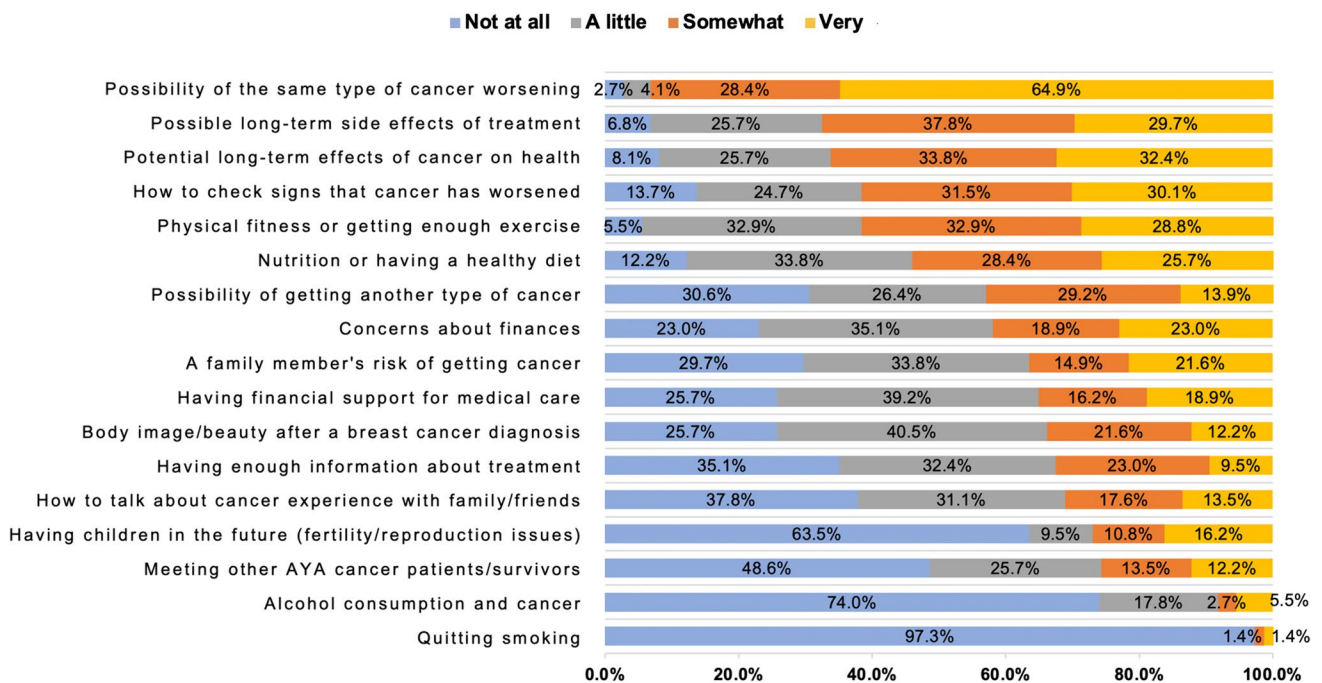


Fig. 2 Frequency and severity of survivorship concerns (N=74)

Discussion

In this study, we found that AYAs living with advanced breast cancer have a number of psychosocial concerns and informational needs. Prior studies of both early-stage and advanced breast cancer have detailed unmet concerns relating to menopausal symptoms, fertility, and sexual functioning issues due to treatment, [8–10], which often have a negative effect on mental and social health. [8, 15].

Among younger women with MBC in particular, the presence of chronic treatment-related side effects and incurable disease state may worsen psychosocial distress related to planned life trajectories and changes in life situation. [14, 16, 20]. Our findings indicate that many AYAs living with MBC are concerned about disease progression, treatment-related side effects, and health behaviors (e.g., exercising, eating healthily), which is consistent with and expands on findings from other studies inclusive of MBC patients but not focused on those diagnosed young. [21–25]. The

Table 2 Survivorship concerns among metastatic breast cancer patients from the Young, Empowered, and Strong (YES) study stratified by age at survey completion

	≥ 39 Years at Survey N = 41		< 39 Years at Survey N = 33		<i>p</i>
	Not at all/A little con- cerned N (%)	Somewhat/ very con- cerned N (%)	Not at all/A little con- cerned N (%)	Somewhat/ very con- cerned N (%)	
Possible long-term side effects of treatment (N = 74)	12 (16.2)	29 (39.2)	12 (16.2)	21 (28.4)	0.62
Possibility of the same type of cancer worsening (N = 74)	2 (2.7)	39 (52.7)	3 (4.1)	30 (40.5)	0.65
How to check signs that cancer has worsened (N = 73)	18 (24.7)	22 (30.1)	10 (13.7)	23 (31.5)	0.23
Possibility of getting another type of cancer (N = 72)	25 (34.7)	14 (19.4)	16 (22.2)	17 (23.6)	0.23
Having financial support for medical care (N = 74)	26 (35.1)	15 (20.3)	22 (29.7)	11 (14.9)	0.81
Concerns about finances (N = 74)	23 (31.1)	18 (24.3)	20 (27.0)	13 (17.6)	0.81
Physical fitness or getting enough exercise (N = 73)	16 (21.9)	24 (32.9)	12 (16.4)	21 (28.8)	0.81
Nutrition or having a healthy diet (N = 74)	22 (29.7)	19 (25.7)	12 (16.2)	21 (28.4)	0.16
A family member's risk of getting cancer (N = 74)	31 (41.9)	10 (13.5)	16 (21.6)	17 (23.0)	0.028
Having children in the future (fertility/reproduction issues) (N = 74)	35 (47.3)	6 (8.1)	19 (25.7)	14 (18.9)	0.009
Having enough information about treatment (N = 74)	28 (37.8)	13 (17.6)	22 (29.7)	11 (14.9)	1.00
Potential long-term side effects of cancer on health (N = 74)	14 (18.9)	27 (36.5)	11 (14.9)	22 (29.7)	1.00
How to talk about cancer experience with family/friends (N = 74)	28 (37.8)	13 (17.6)	23 (31.1)	10 (13.5)	1.00
Meeting other adolescent/young adult cancer patients/survivors (N = 74)	34 (45.9)	7 (9.5)	21 (28.4)	12 (16.2)	0.07
Body image and beauty after a breast cancer diagnosis (N = 74)	29 (39.2)	12 (16.2)	20 (27.0)	13 (17.6)	0.46
Quitting smoking (N = 74)	40 (54.1)	1 (1.4)	32 (43.2)	1 (1.4)	1.00
Alcohol consumption and cancer (N = 73)	37 (50.7)	3 (4.1)	30 (41.1)	3 (4.1)	1.00
	A little/None N (%)	A lot/Some N (%)	A little/None N (%)	A lot/Some N (%)	<i>p</i>
To what degree has your diagnosis caused financial problems for you and your family? (N = 72)	28 (38.9)	11 (15.3)	15 (20.8)	18 (25.0)	0.031
	No N (%)	Yes N (%)	No N (%)	Yes N (%)	<i>p</i>
Has medical care been delayed because of worry about the cost? (N = 74)	38 (51.4)	3 (4.1)	29 (39.2)	4 (5.4)	0.69

Bold font indicates significant two-sided Fisher's exact test analysis, $p < 0.05$

finding that the majority of young women in our study reported concerns about the long-term effects of cancer and its treatment on their health represents both an optimism about the current reality for some AYAs with MBC living longer, and an area that can potentially be addressed with ongoing supportive care and information. [1–4]

Fertility and future reproductive plans were salient concerns reported by one-quarter of AYAs with MBC, and have been observed in prior research as well. [7, 26]. Fertility is especially pertinent given the age of participants combined with the unintended side effects of MBC treatment such as treatment-induced ovarian failure and infertility. [27]. Small qualitative studies [28, 29] have suggested that young MBC survivors' fertility-related concerns reflect their experience with the increasingly chronic nature of MBC. [30]. It is evident that fertility concerns including expectation management and/or potential fertility preservation options for women living with MBC need to be addressed for those

interested at diagnosis and through their care trajectory. [11]. Fostering open discussions with patients may be helpful to maintain a realistic view concerning prognosis and the concerns that are more likely to impact patients. [31]. Resources are available online for patients to help start this discussion with their providers, including a comprehensive guide for discussing fertility expectations and preservation in the setting of a MBC diagnosis, [32], if warranted.

Concerns relating to financial stability, familial cancer risk, family, fatigue, exercise, diet, stress, and social support have been documented, [5, 7, 21, 23, 33], but addressing these concerns among AYA women with MBC remains a challenge. In our study, more than half of women reported experiencing some degree of financial worry as a consequence of their diagnosis; further, there were differences by age at survey and education, where those younger at survey completion (< 39 years) and/or who reported having less than a college degree were more concerned about financial

Table 3 Open-ended survivorship concerns among metastatic breast cancer patients from the Young, Empowered, and Strong (YES) study

Open-ended response	Concern Level	
“How well my children will handle my death.”	Very concerned	
“Being a parent of young children.”		
“Making sure my daughter is taken care of.”		
“Trying to make life seem as ‘normal’ as possible for my children.”		
“How to prepare for the future for my family if I’m gone.”		
“Best way to tell friends, family, and children.”		
“Marriage with bad sex and no kids.”		
“Knowing my realistic life expectancy timeline, so I can prepare accordingly.”		
“Losing more weight.”		Somewhat concerned
“Living with the constant fear of the cancer returning or returning worse.”		
“Intimacy with spouse.”		
“Access to clinical trials, knowing about cutting edge research that could help my health outcomes.”		
“My mental health.”		
“I am worried about whether an oncologist will take special interest in helping me to be a long-term responder and/or find a cure one day.”		
“Death.”	A little concerned	
“Emotional detachment.”		

problems relating to their diagnosis. It is known that AYAs with MBC often experience the highest total costs related to their diagnosis compared to other patients/survivors at different ages and stages. [34]. Previous literature has suggested that other costs relating to ongoing treatment can negatively impact overall financial stability including credit score decreases, time off work, debt collection, lacking money for basic necessities, and spending more than 10% of income on medical expenses. [26, 35]. Due to their young age, younger MBC patients may be more concerned about longitudinal financial planning for themselves and their families and may not have accumulated the financial reserves available to some older women. Additionally, distinct family concerns not currently assessed by the adaptation of the HOPE measure were prevalent within free text responses. Future research should include supplementary prompts related to familial concerns, such as those noted in Table 3.

Although only some AYAs endorsed being concerned about smoking and/or alcohol consumption, it should be noted that most participants reported not currently smoking; while alcohol consumption has decreased since being diagnosed, as expected.

Our findings also identified subgroups of women diagnosed with breast cancer as AYAs now with MBC that may benefit from further support including women under the age of 40, those identifying as a racial/ethnic minority, and those with lower educational attainment. Disparities in care delivery and support exist across the breast cancer care continuum [36–38] including among AYAs with MBC. Previous literature has suggested that younger women with MBC often experience a more difficult disease trajectory due to

the chronic nature of the disease and impact it has on many facets of life. [30]. Future interventions may focus on integrating peer or familial support for patients with MBC, as suggested by these results. Thus, compounding racial, ethnic, and socioeconomic factors may influence survivorship care access and quality even among MBC patients, a group already at high risk for disparate outcomes. [33]

Clinical implications

Patient-centered resources, education, and strategies that foster patient-provider communication may help support AYAs with the MBC issues that they may experience throughout survivorship. Thus, MBC care coordination should focus on symptom and side effect monitoring and management, coupled with psychosocial-, health behavior-, and palliative/advance care planning-related supports. [30]. Interdisciplinary supportive care has been useful in promoting open discussion about salient concerns and other worries, especially when care is tailored according to age, disease progression, cancer site, and symptomology. [30]. Prior to and throughout treatment, healthy lifestyle behaviors, fertility preservation, contraception, and symptom/side effect tracking should be discussed to optimize care as well as symptom management. [7, 39], especially among those of reproductive age. To manage mental health concerns, there are promising psychosocial interventions that leverage educational coping strategies to alleviate symptoms that may be useful to young MBC patients. One such example is Cognitive and Behavioral Cancer Stress Management (CBCSM), a comprehensive group-based program that helps survivors identify

symptoms of physiological, emotional, cognitive, and behavioral symptoms of stress and learn self-management strategies to reduce symptoms. [40]. This intervention has been shown to reduce anxiety, depression, fatigue, and sleep disturbance, coupled with improvements in quality of life, social functioning and support, as well as relaxation. [40] Other cancer-oriented psychosocial interventions include mindfulness training, virtual reality, role playing, yoga, and couple's therapy, which have been shown to improve coping, quality of life, communication, as well as mental and sexual health. [40–43]. Although the goal of these interventions is to assist in the management of psychosocial distress and provide coping strategies, AYAs with MBC continually report issues in managing uncertainty about their future. It may be beneficial for such interventions to be used in tandem to support informational and coping strategies for this population. One such interventional trial, Pathways to Wellness, utilized mindfulness-based meditation and survivorship education to reduce breast cancer-related physiological and psychosocial symptoms in young breast cancer survivors with elevated depressive symptoms, although this intervention has not yet been tested in women living with MBC. [44, 45]. Future interventions should consider a multifaceted approach in alleviating the concerns reported by AYAs with MBC, as the current study has shown that they experience a variety of concerns that span across biological, psychological, and social facets of life.

Within the YES portal, it may be beneficial to assess and provide education and/or support for the most commonly-endorsed concerns (i.e., signs cancer is worsening, long-term treatment side effects, long-term effects of MBC on health, exercise, diet, fertility, body image/beauty, sexual dysfunction, etc.). Utilizing the open-ended concern item responses reported in the current study, we plan on continually updating the YES portal with new concerns, such as the wellbeing of children, to increase patient impact. Patient-provider conversations regarding these concerns should be prioritized to foster ongoing discussion of concerns and how they may shift over time. Additionally, accounting for characteristics shown to be pertinent in the current analysis, such as age, race/ethnicity, and education, when assessing patient-reported concerns can help tailor the delivery of resources to those most likely to benefit from intervention. Future research is working to refine the YES portal for implementation in more diverse populations such as racial/ethnic minority groups, those living in rural areas, and sexual/gender minority groups, among others.

For providers, programs such as VitalTalk, [46], an online and mobile application that offers ongoing education for clinicians discussing difficult news concerning serious illnesses with patients, may be beneficial not only among clinicians, but also if implemented more widely among non-clinicians (e.g., caregivers) working with individuals with serious

illnesses, such as AYAs with MBC. Web-based MBC resources for both patients and providers are widely available and include the Young Survival Coalition, [47], Living Beyond Breast Cancer, [32], Susan G. Komen, [48], the Metastatic Breast Cancer Alliance, [49], and the Metastatic Breast Cancer Network, [50], among others. Importantly, the current study raises unanswered questions regarding metastatic concerns reported by patients, which is challenging for oncologists and other providers to navigate. How should oncologists discuss long-term challenges (i.e., late effects, fertility) in young women with advanced disease and poor prognosis? If providers address these concerns more routinely, are we suggesting that prognosis is better than the reality, or are we helping patients to manage their worries? There is currently no consensus on how to address these concerns sensitively, recognizing that hope for longer survival may be lessened by prognosis transparency.

Study limitations

Our findings should be considered in light of some limitations. Eligibility criteria was based on AYA status (aged 15–39 years) at initial breast cancer diagnosis, not AYA status at metastatic diagnosis. Further, AYAs with MBC are considered an at-risk health group and can be more difficult to recruit due to the progression and treatment of the disease. [51, 52]. Thus, study participants may be healthier and experience fewer side effects from their cancer and treatment, and findings may not reflect the experiences of all individuals living with MBC with poorer prognoses who may have been less likely to enroll to the YES study. We also did not analyze ePRO data from the YES portal, and doing so will allow us to make conclusions based on symptoms, treatment side effects, and other variables, including sexual dysfunction. Additionally, this is a single-center study with a predominantly NHW, partnered, and educated patient population, which may limit generalizability to more diverse populations. While stratified analyses were unadjusted, exploring specific subgroups can help inform more targeted care coordination and future intervention. The current study did not include information about treatment at time of survey completion or breast cancer subtype (i.e., luminal, Her2, triple negative). Sexual dysfunction, intimacy, and specific family-related concerns (e.g., concern about young children) are well-known among this population [7, 53, 54] but were not included in the overall concerns measure. It may be beneficial for future research to include these variables to fully understand how they may relate to the unmet concerns AYAs with MBC are experiencing. Previous research has found that cancer patients from racial, ethnic, educational, and socioeconomic minority groups are less likely to engage in online portals. [55, 56] Therefore, future research should promote inclusivity of these diverse groups.

Conclusion

AYAs living with MBC express a high level of concern about their care across various psychosocial and supportive care domains. Ensuring care planning across many life domains and optimizing patient-provider communication remains critical. Ongoing and future research will provide valuable information regarding the efficacy of the YES portal in improving quality of life and symptom burden as well as addressing unmet needs and concerns in young adults living with advanced breast cancer.

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Data availability The datasets generated during and/or analyzed are available at the Principal Investigator's (PI) discretion upon reasonable request.

Code availability Syntax and statistical coding is available upon reasonable request from the corresponding author.

Declarations

Competing interests Dr. Kate Dibble has no conflicts of interest to disclose. Dr. Shoshana Rosenberg reports grant funding from Pfizer/Conquer Cancer. Yue Zheng has no conflicts of interest to disclose. Dr. Tal Sella reports honorarium from Roche, Novartis, and Eli Lilly; advisor for Eli Lilly; and travel support from Gilead and AstraZenica. Dr. Poorvu has no conflicts of interest to disclose. Craig Snow has no conflicts of interest to disclose. Sonja Darai has no conflicts of interest to disclose. Christamar Rene has no conflicts of interest to disclose. Dr. Jennifer Mack has no conflicts of interest to disclose. Dr. Partridge reports receiving royalties from Wolters Kluwer for authorship of UpToDate and has received research funding from Novartis.

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Consent to participate Study coordinators reviewed the consent form, verifying interest, and confirming eligibility with each potential participant. This study was granted a waiver of documentation of consent. Passive consent was granted by marking a check box on REDCap stating they were willing to participate in the study.

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