A Focused Evaluation of Young Adults Living with Metastatic Breast Cancer: Patient-Reported Strategies to Alleviate Symptoms, Treatment-Related Side Effects, and Survivorship Concerns

Kate E Dibble, PhD[1,2]; Julia Stal, PhD[1]; Shoshana M Rosenberg, ScD, MPH[3], Craig Snow, MHA[1] & Ann H Partridge, MD, MPH[1,2]

[1]Dept of Medical Oncology, Dana-Farber Cancer Institute; [2]Dept of Medicine, Harvard Medical School; [3]Dept of Population Health Sciences, Weill Cornell Medicine

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BACKGROUND

- Female adolescents and young adults (AYAs) with metastatic breast cancer (MBC) experience many physical and psychosocial symptoms heightened by a disrupted life trajectory and the burden of ongoing treatment, though MBC-specific data are lacking.
- We qualitatively explored how female AYAs with MBC alleviate their symptoms, treatment-related side effects and survivorship concerns.

METHODS

- AYAs with MBC aged 18-39 at diagnosis participated in an ongoing prospective intervention, Young, Empowered and Strong (YES) at Dana-Farber Cancer Institute. AYAs respond to electronic patient-reported outcomes and receive tailored information to support managing symptoms and concerns.
- AYAs enrolled in YES were invited to participate in a semi-structured virtual interview regarding their survivorship experiences.
- Clinical information was abstracted from their medical record.
- Transcripts were thematically analyzed.

Table 1. Sample interview questions

- What are the most burdensome or hard to manage symptoms or side effects you have experienced since your diagnosis with MBC?
- What resources have you used to try to manage your symptoms or side effects?
- Is there anything you have found that manages your survivorship concerns well? What about anything that you have tried that does not lessen your concerns?

SAMPLE

- The sample comprised 20 women with a **median age of 42 years at study enrollment** (*SD*=3.81, range: 32-48) and **36.9 years at MBC diagnosis** (*SD*=3.39, range: 28-41).
- Most were **non-Hispanic (85%)**, **white (80%)**; half had a graduate degree (50%).

RESULTS

Figure 1A. Symptoms and side effects reported by participants (N=20)

THEMES	SUBTHEMES
Surgery side effects n=4/20 (20%)	• Asymmetric breasts (n=1/4, 25%) • Muscle cramps (n=1/4, 25%) • Limited arm rotation (n=1/4, 25%) • Low libido (n=1/4, 25%)

Treatment-related side effects and symptoms n=20/20 (100%)	• Fatigue (n=10/20, 50%)
	• Gastrointestinal issues (n=7/20, 35%)
	• Menopausal symptoms (n=5/20, 25%)
	  - Vaginal dryness (n=5/5, 100%)
	  - Hot flashes/night sweats (n=4/5, 80%)
	  - Low libido (n=1/5, 20%)
	• Nausea (n=5/20, 25%)
	• Hair loss (n=4/20, 20%)
	• Joint pain (n=4/20, 20%)
	• Pain (n=3/20, 15%)
	• Hand-and-foot syndrome (n=3/20, 15%)
	• Neuropathy (n=3/20, 15%)
	• Concentration/memory (n=3/20, 15%)
	• Headaches (n=2/20, 10%)
	• Weight gain (n=2/20, 10%)
	• Skin itchiness (n=2/20, 10%)
	• Mouth sores (n=2/20, 10%)
	• Insomnia (n=1/20, 5%)
	• Swelling (n=1/20, 5%)
	• Headaches (n=1/20, 5%)
	• Palsy (n=1/20, 5%)
	• Photosensitivity (n=1/20, 5%)

"Because now I live with **chronic pain**, we experimented with both opioids to manage the pain, and Ritalin to help combat some of the fatigue that came from the opioids. **That just didn't work – nothing works**." – 44 years of age, 6 years post-diagnosis

"Side effect-wise, **each treatment presents different side effects**. I've had everything from GI upsets and diarrhea, to constipation, to hair loss and thinning, to the inability to have a sexual relationship with my husband, because I'm in menopause clinically. **It affects every part of my life**." – 40 years of age, 4 years post-diagnosis

Figure 1B. Alleviation methods for symptoms/side effects (N=19)

SUCCESS OF ALLEVIATION METHODS	ALLEVIATION METHODS
Successfully alleviates N = 15/19 (78.9%)	• Prescription medication (n=7/15, 46.7%) • Exercise (n=5/15, 33.3%) • Diet/hydration (n=4/15, 26.7%) • Over-the-counter medication (n=4/15, 26.7%) • Warm baths (n=2/15, 13.3%) • Medical marijuana (n=2/15, 13.3%) • Physical therapy/chiropractor (n=2/15, 13.3%) • Acupuncture/massage (n=2/15, 13.3%) • Sleep (n=2/15, 13.3%) • Oncologist support (n=2/15, 13.3%) • Mouth rinses (n=1/15, 6.67%) • Cold/heat therapy (n=1/15, 6.67%) • Speech therapy/brain training (n=1/15, 6.67%) • Podiatrist (n=1/15, 6.67%)
Somewhat alleviates N = 11/19 (57.9%)	• Over-the-counter medication (n=3/11, 27.3%) • Prescription medication (n=3/11, 27.3%) • Exercise (n=3/11, 27.3%) • Acupuncture/massage (n=1/11, 9.1%) • BedJet (n=1/11, 9.1%) • Cold/heat therapy (n=1/11, 9.1%) • Medical marijuana (n=1/11, 9.1%) • Meditation (n=1/11, 9.1%) • Physical therapy/chiropractor (n=1/11, 9.1%) • Sleep (n=1/11, 9.1%)
Does not alleviate N = 9/19 (47.4%)	• Prescription medication (n=5/9, 55.6%) • Over-the-counter medication (n=3/9, 33.3%) • Nothing works (n=2/9, 22.2%) • Exercise (n=1/9, 11.1%) • Diet/hydration (n=1/9, 11.1%)

"If I did not have MBC, **I would not be reaching for prescription medications like I do**. That has been mentally difficult for me. I'm a natural, homeopathic person, but I'm at the point now where I'm like give me all the meds to make me function." – 37 years of age, 3 years post-diagnosis

Figure 2A. Survivorship concerns reported by participants (N=19)

THEMES	SUBTHEMES
Fear of disease progression N=13 (68.4%)	• Realization of longevity (n=8/13, 61.5%) • Need for ongoing treatment (n=3/13, 23.1%) • Symptoms of progression (n=3/13, 23.1%) • Afraid to connect with others with MBC (n=1/13, 7.7%) • Need for ongoing tests/scans (n=1/13, 7.7%)
Mental health N=10 (52.6%)	• Stress/anxiety (n=9/10, 90%) • Depression/isolation (n=3/10, 30%)
Financial toxicity N=7 (36.8%)	• No endpoint to medical bills (n=5/7, 71.4%) • Insurance coverage (n=2/7, 28.6%) • Juggling job and treatment (n=2/7, 28.6%) • Maintaining health insurance (n=1/7, 14.3%) • Getting to treatment (n=1/7, 14.3%) • Limited supplemental funding (n=1/7, 14.3%) • Supportive care costs (n=1/7, 14.3%) • Time off work/disability (n=1/7, 14.3%)
Future of family/children N=7 (36.8%)	• Length of time with family/children (n=6/7, 85.7%) • Burden on husband/partner (n=3/7, 42.9%) • Burden on parents/community (n=3/7, 42.9%)
Feeling trapped N=3 (15.8%)	• Trapped near treatment center (n=2/3, 66.7%) • Threatened by disease management (n=2/3, 66.7%)
Fertility/childbearing N=3 (15.8%)	• Stolen fertility (n=2/3, 66.7%) • Not worried about fertility/childbearing (n=1/3, 33.3%)
Sexual health N=3 (15.8%)	• Decreased sexual interest/libido (n=3/3, 100%)

Figure 2B. Alleviation methods for survivorship concerns (N=1

SUCCESS OF ALLEVIATION METHODS	ALLEVIATION METHODS
Successfully alleviates N = 15/17 (88.2%)	• Social support systems (n=8/15, 53.3%) • Talk therapy (n=7/15, 46.7%) • Staying busy (n=5/15, 33.3%) • Exercise (n=4/15, 26.7%) • Journaling/blogging (n=4/15, 26.7%) • Mindfulness/yoga (n=4/15, 26.7%) • Acupuncture/massage (n=2/15, 13.3%) • Care team support (n=2/15, 13.3%) • Researching MBC (n=2/15, 13.3%) • Diet/hydration (n=1/15, 6.7%) • Prescription medication (n=1/15, 6.7%) • Religion/spirituality (n=1/15, 6.7%) • Self-care (n=1/15, 6.7%) • Speech therapy/brain training (n=1/15, 6.7%)
Somewhat alleviates N = 11/17 (64.7%)	• Staying busy (n=3/11, 27.2%) • Exercise (n=1/11, 9.1%) • Journaling/blogging (n=1/11, 9.1%) • Self-care (n=1/11, 9.1%) • Social support systems (n=1/11, 9.1%) Formal support groups (n=1/11, 100%) • Talk therapy (n=1/11, 9.1%)
Does not alleviate N = 1/17(5.8%)	• Talk therapy (n=1/1, 100%)

"**Positive thinking** – that's always my thing. I always say if I sat in a corner and cried all of the time, what would that accomplish?" – 41 years of age, 6 months post-diagnosis

"The hardest thing is **feeling trapped**. I have come to terms with for the foreseeable future, I cannot leave Boston, at least for any extended period. I have to be at the hospital physically every 3 weeks – it severely limits where I can go and what I can do." – 42 years of age, 1 year post-diagnosis

"I have a really strong meditation practice. I do yoga which helps physically and I also do reiki regularly. I would have drowned, honestly, if I didn't have them." – 37 years of age, 3 years post-diagnosis

Alleviation of Symptoms & Side Effects

- Of the 19 participants who reported efforts to alleviate symptoms and side effects of MBC and its treatment(s), **18 (94.7%) had tried more than one method**.
- Of the 18 participants that had tried more than one method to alleviate symptoms and side effects, **all had tried more than two methods** and **7 (38.8%) had tried more than four.**

Alleviation of Survivorship Concerns

- Of the 17 participants who reported efforts to alleviate survivorship concerns regarding MBC, **15 (88.2%) had tried more than one method.**
- Of the 15 that had tried more than one method to alleviate their survivorship concerns, **all had tried more than two methods** and **10 (66.7%) more than four.**

CONCLUSIONS

- Young women with MBC have a high burden or symptoms, side effects and concerns and utilize numerous strategies to alleviate them.
- Multiple approaches were often employed, both because symptoms, side effects and concerns changed with new treatment and because methods were ineffective.
- Supporting women to streamline these efforts may address symptoms, side effects and concerns and may help to manage disease expectations and optimize overall well-being during survivorship.

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