Symptoms, survivorship concerns, and alleviation methods among young adults newly diagnosed with early-stage breast cancer

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

[1]Department of Medical Oncology, Dana-Farber Cancer Institute, Boston, MA; [2]Department of Medicine, Harvard Medical School, Boston, MA; [3]Department of Population Health Sciences, Weill Cornell Medicine, New York, NY; *Presenting author

BACKGROUND

- Many adolescents and young adults (AYAs; diagnosed ages 18-39 years) with early-stage breast cancer experience acute and chronic symptoms and survivorship concerns.
- Approaches used by AYAs to alleviate unmanaged symptoms and concerns and their perceived effectiveness remain poorly understood.
- **Purpose:** This study qualitatively explored patient-reported symptoms, survivorship concerns, and alleviation methods reported by female AYAs newly diagnosed with early-stage breast cancer enrolled in a supportive care intervention study.

METHODS

- Women (18-39 years) newly diagnosed (<3 months) with early-stage (0-III) breast cancer at Dana-Farber Cancer Institute and who were enrolled in Young, Empowered, and Strong (YES Newly Diagnosed & Metastatic Study; NCT04379414), a web and app-based supportive care intervention study, were invited to participate in a virtual semi-structured interview.
- The interview guide was developed to explore burdensome treatment symptoms, side effects, concerns, and experiences managing them (**Table 1**).
- Transcripts were thematically analyzed.
- Clinical information was abstracted via medical records.

Table 1: Sample semi-structured interview questions

What are the most burdensome or hard to manage symptoms or side effects you have experienced since your breast cancer diagnosis?
Is there anything you have found that manages your symptoms or side effects well? What about anything that you have tried that does not lessen symptoms or side effects?
Have you experienced any concerns around survivorship issues since completing breast cancer treatment? If so, what types of concerns?
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?

PARTICIPANTS

Table 2: Participant characteristics (N=20)

	N (%)
Age at diagnosis (Median)	35.0
Range	33-39
Race	
White	15 (75.0)
Asian or Asian American	<5
Black or African American	<5
Hispanic/Latina ethnicity	
No	19 (95.0)
Yes	<5
Highest level of education	
Less than a college degree	<5
College degree or above	19 (95.0)
Marital status	
Partnered	16 (80.0)
Unpartnered	<5
Currently insured	20 (100.0)
Stage at diagnosis	
0	<5
I	8 (40.0)
II	8 (40.0)
III	<5

RESULTS

Treatment symptoms or side effects: Physical symptoms or side effects of treatment were the most frequently reported (e.g., menopausal symptoms, fatigue, nausea, pain, gastrointestinal issues, concentration/memory, neuropathy) by AYAs.

Pain

"Oh, the side effects of the radiation, the burning sensation of the radiation in my breasts. Radiation itself wasn't as bad as the lumpectomy, but the radiation side effects were horrible. My god, that was tough." - **1.1 years post-diagnosis**

"I would say that the mastectomy, the dissection, combined with the radiation side effects. I still experience a lot of pain in that area." - **1.59 years post-diagnosis**

Concentration and memory

"I had a lot of trouble with concentration after completing radiation and chemo." - **0.65 years post-diagnosis**

"I'd say my number one side effect is the fatigue and brain fog, exhaustion, kind of all grouped together." - **1.04 years post-diagnosis**

Menopause and libido

"Now I'm in early menopause and just being comfortable with the physical look of my own body and my own sexual interest is very low, like libido and everything. So, I feel like that puts a strain on my relationship with my husband…I'm 37 years old and I'm in menopause, and my outward appearance is young, but I feel like an old woman in that I already have varicose veins now, then hot flashes." - **1.10 years post-diagnosis**

Methods to alleviate treatment symptoms or side effects: Various methods were effective at alleviating (e.g., oncologist support, mindfulness/yoga, time) or somewhat alleviating (e.g., cold/heat therapy, medical marijuana, acupuncture/massage) treatment symptoms or side effects. Several methods, including diet, exercise, medication, and physical therapy, were effective for some but not effective for others.

Exercise to alleviate symptoms

Effective: "I just have to walk around and, awful to say, but you just definitely feel like you know what an older person feels like getting out of bed in the morning." - **1.77 years post-diagnosis**

Not effective: "For the exhaustion and fatigue, I haven't found anything. I try everything they recommend, better nutrition and water, enough rest and yoga, all the things, but that's been my biggest issue. I tried riding a bike to exercise. I don't know, that made my cording worse." - **1.04 years post-diagnosis**

Physical therapy to alleviate symptoms

Effective: "For the lymphedema, I started physical therapy, and in addition to kind of like general touching and manual lymph drainage." - **1.26 years post-diagnosis**

Ineffective: "Physical therapy, I wouldn't say I've found anything to help." - **0.85 years post-diagnosis**

Medication to alleviate symptoms

Effective: "They prescribed me Compazine for the Neulasta when I was on that, which at first, I didn't think was going to help, and then I realized I take it prior to treatment, which helped." - **0.71 years post-diagnosis**

Not effective: "All of the oncology-supportive meds were not very helpful because they just constipate me." - **0.65 years post-diagnosis**

Survivorship concerns: Concerns spanned psychosocial (e.g., stress, anxiety, depression, isolation, fear of long-term treatment or recurrence, financial toxicity, fertility, sexual health, body image), and clinical (e.g., transition from treatment to survivorship) domains.

Financial toxicity

"Financially, it does affect you because now, I was on leave for like 5.5 almost 6 months last year until October. I went back to work in October. Now, I'm going to have to take another leave 3 or 4 months from now, and then who's taking care of the bills? I was just on my way paying some of the debt that I have, like credit cards that I use and all this. Now, I'm back on leave again." - **1.13 years post-diagnosis**

Fertility

"The biggest issue that was a concern was that I couldn't have any more children. I have one now. I'm blessed with one, and at first when they told me that, it's hard to take because you don't want somebody to tell you, you can't have another child, even if you don't have one, but to have somebody tell you that you can't, it's hard, it's a whole process." - **0.71 years post-diagnosis**

Fear of recurrence

"I'm terrified all the time of recurrence, all the time. I have my next mammogram set for early July, and it's already, I wake up, I think about it every single day, multiple times a day. My life will now revolve around these six-month scans. I think it is really hard for me to get my head around it and know how to deal with it." - **0.89 years post-diagnosis**

Methods to alleviate survivorship concerns: Various methods were effective at alleviating (e.g., religion/spirituality, medical marijuana) or somewhat alleviating (e.g., journaling, online research) concerns. Several methods, including therapy, medication, positivity/advocacy, staying busy, and social support, were effective for some but not effective for others.

Social support to alleviate concerns

Effective: "I met a young woman who's a survivor yesterday for coffee and I found that to be very helpful, just to have somebody else who's living it as well, who can really relate." - **1.10 years post-diagnosis**

Ineffective: "I joined the SoulMates program thinking that it would be helpful to talk to other people and I haven't gone because I feel like I would actually feel worse if I were to hear other stories right now." - **0.65 years post-diagnosis**

Staying busy to alleviate concerns

Effective: "Otherwise, I just try not to let it occupy my mind too much because you can drive yourself crazy." - **0.65 years post-diagnosis**

Ineffective: "Distractions, doing activities, things like social activities, church with my friends [do not help]." - **1.14 years post-diagnosis**

Medication to alleviate concerns

Effective: "Using the lower doses of Ritalin helps with being able to work. I have a 2-year-old, so that helps me have the energy to get through, not only the workday, but also picking my son up and doing bath and bed and the whole shebang, just live life." - **0.65 years post-diagnosis**

Ineffective: "I have experimented with antidepressants; I did not find that they were helpful." - **1.07 years post-diagnosis**

CONCLUSION

- Female AYAs newly diagnosed with early-stage breast cancer who are receiving a supportive care intervention continue to report symptoms, side effects, and survivorship concerns.
- Survivorship concerns spanned both psychosocial and clinical domains, highlighting the breadth of challenges encountered during early survivorship.
- AYAs use multiple methods to manage symptoms and concerns that vary in effectiveness, highlighting the need for diverse methods tailored to evolving patient needs alongside personalized survivorship care delivery to improve patient quality of life.
- The variety in coping strategies employed by AYAs, including medical, social, behavioral, and spiritual approaches, illustrate the value of multidisciplinary supportive care teams.

Corresponding Author: Julia Stal, PhD, julia_stal@dfci.harvard.edu, @JuliaStal1 | **Funding:** Funding for this study was provided by the Breast Cancer Research Foundation (Partridge), Susan G Komen (Partridge), and Dr. Partridge is an American Cancer Society Research Professor. Julia Stal was funded by the NCI F99/K00 Predoctoral to Postdoctoral Transition Award (4K00CA284291-02); Kate Dibble was funded by the Helen Gurley Brown Presidential Initiative at Dana-Farber Cancer Institute.