



Suffering in Silence:

**A Mixed Methods Analysis Exploring the Relationship
between Clinically Significant Distress and Mental Health Service Use
in Breast Cancer Survivors**

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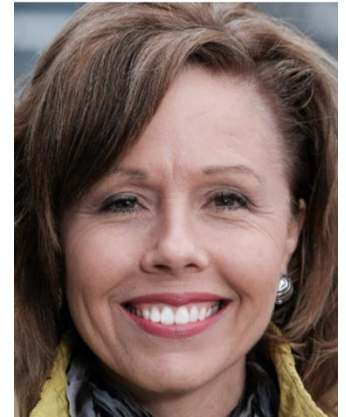
BACKGROUND



- ❑ **With over 4.1 million** in the United States,¹ breast cancer survivors (BCS) have an **increased risk for psychological distress**, including anxiety, depression, and post-traumatic stress.²
- ❑ **Fear of cancer recurrence (FCR)** is one of the most **common forms of distress** and **unmet needs** in cancer survivors.³
- ❑ Approximately **50%** of **BCS** report **clinically significant FCR**.⁴



- ❑ Designed to increase **psychological flexibility** through behavioral alternatives to avoidant coping,⁵ **acceptance and commitment therapy** (ACT) has shown promise in reducing anxiety, depression, and FCR in a recent meta-analysis.⁶
- ❑ The efficacy of ACT for FCR in BCS is currently being further researched in a **randomized control trial (RCT)** with PI Dr. Shelley Johns.
- ❑ The primary objective of this study was to explore relationships between **psychological distress** and **mental health service (MHS) use** in BCS with clinically significant FCR.
- ❑ **Limited MHS use** in distressed BCS prompted further **qualitative research** aimed at identifying barriers unique to this population.



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PARTICIPANT DEMOGRAPHICS



Table 1	N=384
Age, mean (SD)	56.07 (11.31)
Race & Ethnicity, N (%)	
White	309 (81.75%)
Black or African American	53 (14.02%)
Other	16 (4.23%)
Hispanic or Latina	6 (1.63%)
Partner Status, N (%)	
Partnered	262 (68.41%)
Not Partnered	121 (31.59%)
College Degree, N (%)	274 (71.35%)
Employed Full Time, N (%)	185 (48.18%)
Income Situation, N (%)	
Comfortable	254 (66.67%)
Just enough to make ends meet	100 (26.25%)
Not enough to make ends meet	27 (7.09%)
Months Since Cancer Diagnosed, mean (SD)	35.98 (66.35)
Breast Cancer Treatment(s) Received, N (%)	
Surgery	358 (93.23%)
Radiation therapy	292 (76.04%)
Chemotherapy	206 (53.65%)
Hormone/endocrine therapy	268 (69.79%)
Targeted therapy	33 (8.59%)
Other	12 (3.13%)



METHODS



- ❑ A **mixed methods sequential explanatory design** was used
- ❑ **Secondary quantitative analysis** of data from self-report questionnaires at baseline in 384 BCS enrolled in a 3-arm RCT aimed at establishing the efficacy of ACT for FCR
 - **Eligible participants met the following criteria:**
 - ✓ Age \geq 18 years
 - ✓ Stage I-III A breast cancer diagnosis
 - ✓ Completed breast cancer treatment \leq 5 years ago
 - ✓ Clinically significant FCR (FCR-7 score \geq 17 at screening)
- ❑ **Qualitative interviews** were then conducted to explore perceptions of and barriers to MHS use in BCS



MEASURES



- ❑ **FCR: Fear of Cancer Recurrence-7 (FCR-7)**
 - Measures FCR with scores from 6-40.⁷
- ❑ **Anxiety: Generalized Anxiety Disorder Scale-7 (GAD-7)**
 - Measures anxiety symptoms using a 4-point scale with total scores from 0-21 and clinical significance at ≥ 10 .⁸
- ❑ **Depression: Patient Health Questionnaire-8 (PHQ-8)**
 - Measures depressive symptoms using a 4-point scale with total scores from 0-24 and clinical significance at ≥ 10 .⁹
- ❑ **Post-traumatic stress: Impact of Event Scale-Revised (IES-R)**
 - Measures intrusion, avoidance, and hyperarousal using a 5-point scale with total scores from 0-88 and clinical significance at ≥ 33 .¹⁰
- ❑ **Mental Health Service Use: Treatment Inventory of Costs in Patients with psychiatric disorders (TiC-P)**
 - Participants reported how many times they used outpatient MHS, private practice services, hospital services, and support groups in the past 3 months.¹¹
- ❑ **Psychological Flexibility: Cancer Acceptance and Action Questionnaire (CAAQ)**
 - Scores from 1-7 with a lower score indicating greater psychological flexibility/less cancer-related avoidant coping.¹²



STATISTICAL ANALYSES



- ❑ Associations between clinical significance of psychological distress scores and use of mental health services were tested with the Chi-Square and Fisher's Exact tests.
- ❑ Poisson regression was used to assess association between psychological distress scores and how many times mental health services were utilized.
- ❑ Spearman's correlation coefficients, ρ , indicated the strength and direction of correlation between FCR and psychological flexibility.
- ❑ P -values below 0.05 were considered statistically significant.



QUANTITATIVE RESULTS

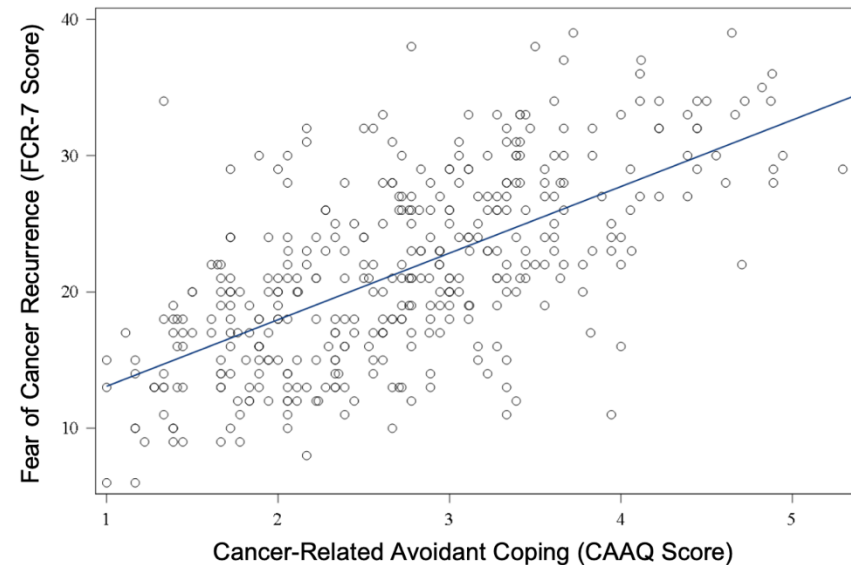


- ❑ At baseline, **285 participants (74.22%)** reported **clinically significant FCR**, though all had clinically significant FCR at eligibility screening.
- ❑ **Clinically significant levels of at least one form of psychological distress other than FCR** were reported in **226 (58.85%)** participants; 85 (22.14%) with anxiety symptoms, 91 (23.70%) with depressive symptoms, and 100 (26.04%) with post-traumatic stress symptoms.
- ❑ Of BCS with at least one significant psychological distress score, **only 61 participants (20.47%)** reported using **any mental health services** within the 3 months prior to baseline.
- ❑ **Clinically significant anxiety** ($p = 0.0027$), **depression** ($p = 0.0015$), and **post-traumatic stress symptoms** ($p = 0.0227$) were significantly associated with use of any of the 4 mental health services assessed.



- A **one-point increase in FCR-7** score was associated with a **2% decrease** in the number of visits with private practice services ($\exp(\beta) = 0.98$, $p = 0.0476$) and a **4% decrease** in the number of support group visits ($\exp(\beta) = 0.96$, $p < .0001$).
- **FCR was strongly correlated with decreased psychological flexibility and increased cancer-related avoidant coping** ($\rho = .631$, $p < .001$) as shown in **Figure 1**.

Figure 1. Relationship Between Fear of Cancer Recurrence and Avoidant Coping

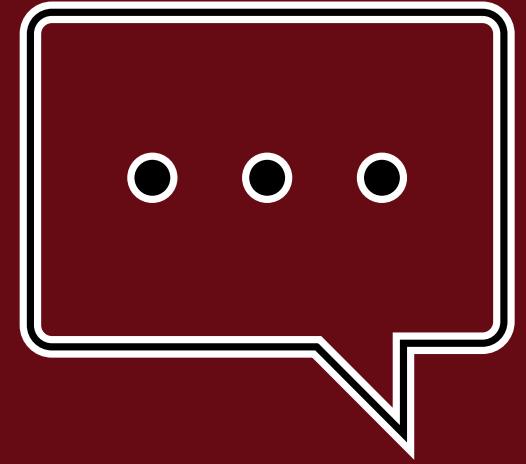


QUALITATIVE FOLLOW-UP



- ❑ Participants with **≥ 2 clinically significant distress measures** throughout the RCT and **no MHS use** were eligible to participate in a focus group interview.
- ❑ Eligible, consenting BCS (n=24) completed a **90-minute focus group interview** via Zoom Health. **Five broad questions** were posed to assess **perceptions of MHS, barriers impacting their motivation and/or desire to access MHS, and any suggestions for improved holistic support for BCS**. Thematic results related to the barriers are being reported at this time, with additional emphasis on tangible suggestions for improvement.
- ❑ The **8 qualitative interviews** were transcribed verbatim. **Episode profiles** for each interview were completed by **≥ 2** members of the qualitative analytic team to capture participants' responses in an organized format. Team members then collaborated to construct a **consensus episode profile** for each interview. Ultimately, **broad themes** emerging from this qualitative data were agreed upon through consensus.





QUALITATIVE THEMES



INTERNAL HESITANCY



- ❑ “To go to someone to talk about cancer, **breast cancer especially**, I just don’t think I could go in and talk to somebody about that...**when you talk about it, you feel it more...it makes it hurt more...It’s like opening the floodgates.**” – SID 255
- ❑ “I found myself in my experience really trying to be like not scared for the **benefit of family...I kind of had to just push it down.** And then you know, just **raising kids too, and prioritizing their emotional wellbeing...I was not really thinking about myself as much.**” – SID 335
- ❑ “...I have this thing where **I don’t want to complain.** I feel like it would be complaining because **people have been in worse situations than I have been in...I’ve gotten past [cancer treatment]. I just need to get past the fear of [cancer] coming back,** but it’s going on my 4th year and **I’m still having it just the same way...the same initial feeling of getting that diagnosis.**” – SID 374



LOGISTICAL BARRIERS



- ❑ “It was almost **impossible to find a therapist that had availability for me**. [My PCP] gave me a list, but it was that I had to go through a site and look at each of them and how to reach them and share what I need...**it’s hard to go and talk to different people about the same thing...So I gave up.**” – SID 211
- ❑ “The psychologist that I like so well is really busy, so **I couldn’t get in on a regular basis with her**. Sometimes, I would get virtual appointments...and **my technology wouldn’t work.**” – SID 093
- ❑ “**Insurance for me is like the #1 [barrier]**. *Do they accept your insurance? Do they not accept your insurance? What is it going to cost me to come and see you? Do I have to make more than one appointment?...***I hate that insurance dictates our care.**” – SID 343
- ❑ “[Mental health services] got business hours...**I work business hours**. They’re not open on Saturdays. I don’t have any PTO time. **So how am I gonna fit this in?**” – SID 257



SOCIODEMOGRAPHIC FACTORS



- ❑ “Sometimes I feel like I cannot put into words exactly what I’m thinking. **It’s hard to share your feelings in a different language...I couldn’t find someone that speaks my language through my insurance** here in the U.S. ...I am more open when I’m talking my own language. – SID 211
- ❑ “I was diagnosed during COVID, so availability, getting in...was hard. **I wanted to find a woman who was Black who dealt with breast cancer patients** or cancer patients. **I don’t know if she exists.**” – SID 122
- ❑ “There’s **only certain doctors and therapists that will accept [Medicare and Medicaid], and it’s hard to find a provider**...You just have to call, and they’ll say, ‘Oh no, we don’t accept’ or ‘We only have a certain amount of patients and **we’ve reached that max** and can’t take anymore.’” – SID 133



SO...
HOW CAN WE DO BETTER?



- ❑ **Normalize** the unique mental health needs of breast cancer survivors

“[We need] more intentional conversation about like fear of recurrence is really normal. And here are some pathways to sort of navigate that.” – SID 326

- ❑ **Continue** an open dialogue and offer resources at **follow-up visits** and **post-treatment**

*“When you are going through the treatment...if you come to me and give me, “you can reach for that, and you can reach for that.” We are not prepared for this at this moment. But once you finish [treatment]...I think that’s the right point to talk to somebody and help you to address what is important for you after the treatment. **Because we get a lot of [information] during the treatment, but our brain doesn’t process all these things. It’s too much to deal with. We are like in a survival mode.**” - SID 211*

- ❑ Advocate for **integration and prioritization of physical and mental health care services**

*“I think that would be so helpful just to automatically have [mental health services] set up like with your navigation. **Part of your package.** That probably would have helped me a lot...I didn’t think that I needed those services. **But had they been offered and scheduled, I’m a person that will go to my appointment.**” – SID 210*

- ❑ Stay up-to-date on the **resources available within your community** and **empower your patients** as they navigate

*“I don’t know if IU could **like give a list of providers or therapists they partner with...**if that’s not possible, then a way to at least **streamline your own research so it’s not just one more daunting task when you don’t really know how to look for somebody...**someone who specializes in breast cancer. **If that’s done for you, then I’m more likely to pick up the ball at that point rather than start the whole process all by myself.**” – SID 218*



CONCLUSIONS



- ❑ Anxiety, depression, and post-traumatic stress symptoms may be better predictors of seeking MHS than FCR given the tendency for patients with **fear** to practice **avoidant coping**.
- ❑ A limitation of the current study is the largely White, affluent, college-educated sample, which may limit generalizability.
- ❑ **Accessible, affordable, and convenient** MHS options should be readily available and promoted **throughout** one's breast cancer treatment and **survivorship** journey.
- ❑ Future studies could explore the **feasibility of integrating opt-out mental health services** throughout breast cancer treatment and continuity of care thereafter, as well as other suggestions for improved support expressed in interviews with distressed BCS.



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Thank you so much for your time!

I am happy to take any questions!

Please feel free to email me at anadann@iu.edu if you'd like to connect!