

“Sir, You’re Hurting Me!»: The Perspectives of Survivors of Interpersonal Violence and Breast Cancer

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Abstract

Background: Studies suggest that experiences of interpersonal violence victimization (i.e., partner violence, childhood sexual or physical abuse, and sexual assault) might play a role in breast cancer diagnosis and treatment. To address gaps in knowledge, our study aimed to understand how prior interpersonal trauma affects breast cancer. We conducted 20 semi-structured in-person interviews and asked patients how their interpersonal trauma affected their breast cancer experience and if they had suggestions to improve breast cancer care.

Methods: Patients were recruited through flyers or from providers to whom they had previously disclosed a history of interpersonal violence. One-on-one interviews lasted approximately one hour each. Results were thematically coded in an iterative fashion and analyzed for main themes.

Results: Three themes addressed the relatedness of interpersonal violence and cancer care: 1) perceptions that violence caused the cancer or led to worse outcomes, 2) how breast cancer diagnosis and treatment can trigger interpersonal violence memory (triggers), and 3) difficulty trusting. In addition, three suggestions emerged that related to improving care: the importance of female providers, improved provider communication, and the potential benefits of a buddy system to pair newly diagnosed breast cancer patients with a history of interpersonal violence with breast cancer survivors with a similar background.

Conclusion: Interpersonal violence can influence how women feel about their breast cancer diagnoses, interactions with health care providers, and receiving care for cancer. Improving trauma-informed health care practice would be beneficial for women with breast cancer.

Keywords: Breast Cancer; Domestic Violence; Intimate Partner Violence; Interpersonal Violence; Trauma.

Abbreviations: BC: Breast Cancer; PTSD: Post Traumatic Stress Disorder

Background

Given the widespread prevalence of breast cancer (BC) and interpersonal violence, understanding the breast cancer experience in this population is essential. An estimated 1 in 8 women in the United States will be diagnosed with breast cancer and there are over 3.5 million breast cancer survivors [1]. Recent studies suggest that prior experiences of interpersonal violence (i.e. lifetime experiences of partner violence, childhood sexual or physical abuse, and sexual assault) might play a particularly important role in influencing

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the receipt of quality care from diagnosis through treatment of breast cancer care. A history of violence exposure has been correlated with high rates of depression, anxiety, advanced stages of breast cancer, and increased risk for post-traumatic stress disorder (PTSD) [2]. Psychological distress affects patient compliance and these factors may influence the receipt of breast cancer care [2-4]. Studies report that fear of cancer itself may delay symptom presentation and diagnosis. And, there is evidence that a cancer diagnosis is a disrupting event and can be triggering for patients with a history of childhood abuse [5-7]. Although research suggests that interpersonal violence is associated with suboptimal cancer response, the mechanisms underlying this association have not been completely explored. Extensive research has found that interpersonal violence can impact the nervous, endocrine, and immune systems, and has identified several potential biological mechanisms [4,8-10]. In addition, cumulative exposure to stress may deplete survivors' capacity to cope or ability to recover from cancer [3]. These outcomes, along with the increased healthcare costs for abuse survivors [11], highlight the lifelong consequences and potentially more complicated health profiles of patients with a history of interpersonal violence. To date there has been limited investigation into the affect of having breast cancer and a history of interpersonal violence. Prior work has focused more generally on understanding the impact of trauma in general healthcare and cancer settings. It is estimated between 20% and 50% of cancer patients have experienced some interpersonal trauma [12]. Already, being diagnosed with a life threatening condition can precipitate a form of PTSD, with cancer-PTSD being included in the DSM-IV [13]. Gallo-Silver and Winer found that cancer diagnosis brought up previously unrecognized memories and trauma symptoms for survivors of sexual abuse. During this time, the provider relationship is critical to support patients through treatment [14]. This study used in-depth one on one interviews to understand how prior interpersonal violence may affect breast cancer patient experiences. In addition, we asked about how to support these types of patients and improve experiences for this understudied population.

Methods

We used a qualitative methodology with semi-structured interviews in order to capture detail about the lived experiences of patients. This study was approved by the Boston University Institutional Review Board.

Participant Recruitment

Eligibility included being 18 years of age or older, English speaking, and having had breast cancer within the last 10 years. Participants independently opted in from flyers placed in oncology waiting rooms. After receiving phone calls, patient eligibility was verified, consent was obtained for the interviews to be recorded, and a time to meet was

scheduled. In addition, patients who had previously self-disclosed a history of interpersonal violence to their provider were invited to participate by their trusted provider.

Data Collection

Interviews were completed in person and in private. Interviews were conducted between 2015 and 2018, recorded, and lasted approximately 60 minutes. Patients received a \$25 gift card as compensation for their time and were offered optional mental health and trauma related support material upon interview completion. Twenty interviews were conducted and completed. Participants were asked to speak to 1) how a history of trauma might affect the breast cancer experience and 2) how to better support these patients. Our interview guide (See Appendix) permitted participants to talk about the influence of interpersonal violence on cancer-related care but did not require that they disclose their own experiences of abuse. This method allowed participants to speak freely about the impact of interpersonal violence without having to reveal personal and difficult incidents about their own experiences.

Data Transcription and Analysis

Audio recordings were transcribed and verified by two research assistants. Written transcripts was analyzed using the NVivo software program (version 12.5.0). Two independent coders holistically read all interviews, developed a preliminary codebook and then coded the interviews line by line while iteratively finalizing the codebook. The data was analyzed based on the perspectives participants shared in the interviews. All coding was conducted independently, then reviewers met to discuss coding disagreements and applied consensus codes to any discrepancies. After completion of coding, the research team met and consolidated codes to identify main themes. (Table 1).

Table 1: Themes specific to a breast cancer experience for women with a history of interpersonal violence.

Theme	Quote
Causality of IPV	I felt like it was a punishment for whatever I did in life, you know. It was like a 'Why me?'
Trust	You may have trusted a parent and been abused or hurt...and here you are putting your life in a doctor, a nurse, radiologist's hand. You've been abused by people you put your life in their hands. And, you have to do it again, and it takes everything you have.
Triggers	Sharp movements make me jump back. People don't know why. Loud voices, things that no one would ever understand or know if you weren't asked...I need a specific type of nurturing that doesn't scare me.
Suggestions	
Female Providers	Some women would rather see a man. It depends on their experiences. I personally cannot. I feel like-like you're being violated all over again.
Buddy System	Like a buddy system...someone that could maybe replace like maybe a family that's weak...who would maybe even call you or check on you.

Results

We identified three main themes regarding the relationship between interpersonal violence and BC: 1) thinking that the violence caused the cancer or led to worse cancer outcomes, 2) triggers, and 3) difficulty trusting. Additionally, there were three main themes related to improving health care and supporting these patients: 1) the importance of female providers, 2) the need for improved provider communication, and 3) the potential benefits of a buddy system to pair newly diagnosed breast cancer patients with a history of interpersonal violence with breast cancer survivors of a similar background.

Relationship Between Interpersonal Violence and Breast Cancer

a. Causality of Interpersonal Violence

Women commonly felt that there was a causal link between the violence experienced and their breast cancer. Some worried that their maltreatment caused their cancer, while others thought their cancer was a form of punishment.

Participant 4: “The tumor I had the first time was not hormone receptive, it was negative. I don’t know whether it came as a result of the punching.”

Participant 13: “...thinking that by being sexually abused that that’s what brought on her cancer.”

Participant 20: “Fear of the cancer itself...like they were being punished for what happened to them as a child.”

Some women found it incomprehensible that they were diagnosed with cancer and in response blamed themselves for somehow causing it. They reported that they deserved cancer because of something inside of them which brought on both the abuse and breast cancer. Alternatively, some said that their negative moods that resulted from interpersonal violence victimization, such as anxiety and depression, led to the cancer.

Participant 15: “Why me? Why did I get the cancer? What could I have done differently? Where did I have the most stress? What caused my body to go through these changes to get to this point?”

Participant 12: “I felt like it was a punishment or whatever I did in life, you know. It was like a ‘Why me?’”

Participant 5: “I think that she would feel like how I feel now. It’s like a punishment... like I deserved it.”

Similarly, patients stated that being overwhelmed contributed to poorer outcomes. And, they cited their negativity, hopelessness, or overall mental occupation as hindering better responses to cancer care.

Participant 19: “I’m not as positive as I should be. It’s

not the doctors, the biggest part is me. I understand that. And maybe my cancer was less and it got worse because of me.”

Participant 4: “When your mind and you are depressed, sometimes it ends up prolonging the healing process.”

Participants often drew parallels between their cancer care and interpersonal violence history.

Participant 5: “It’s the same process as trying to leave... You just don’t leave, just like with the cancer. You have steps to take. A lot of blood drawn appointments, MRIs. So it’s like steps, just like it would be steps to leave that person.”

b. How breast cancer diagnosis and treatment can trigger interpersonal violence memory – Triggers

Several women discussed the need for medical providers to be sensitive to and discuss triggers explicitly with their patients.

Participant 2: “Sharp movements make me jump back. People don’t know why. Loud voices, things that no one would ever understand or know if you weren’t asked... I need a specific type of nurturing that doesn’t scare me.”

The physical exam was identified as something dreaded, uncomfortable or unpleasant.

Participant 5: “You’re like damn, they touch me so much, I don’t even have breasts. And then you like, you thinking, it’s, it’s your fault because at the first. Maybe you should have said something so it didn’t have to go that far.”

The waiting period before an appointment was also referenced as fraught with anxiety and uncertainty.

Participant 5: “You’re in that room by yourself...I remember my situation with my domestics. When he used to come in I used to hate it because I knew how he’d make me feel. And then when you hear that knock, it like, you just. It’s a lot. I get anxiety for waiting too long in a doctor’s office.”

c. Difficulty Trusting

Every participant discussed being less trusting when it came to their cancer experience. Consistently, women expressed vulnerability and fear resurfacing from their history of interpersonal violence in the context of working with their medical providers and cancer care team.

Participant 2: “So, you may have trusted a parent and been abused or hurt...and here you are putting your life in a doctor, a nurse, radiologist’s hand. You’ve been abused by people you put your life in their hands. And, you have to do it again, and it takes everything you have.”

Some women also discussed not being able to trust family and friends and being unable to share their experiences with breast cancer or maltreatment.

Participant 2: “The people in your life, maybe you

couldn't tell them that you were being physically hurt because they wouldn't have got it. So, how are they gonna get that you have cancer now and get it?...Because those people probably aren't strong enough to handle the fact that you were being beaten 'cause sometimes - or whatever you were being abused verbally or whatever, those people couldn't support you in that."

Participant 3: "She would be very careful as to who she would tell what the diagnosis would be because of...the physical aspects of the danger to her. A lot of this is going to come back to him. She's going to be afraid to even let anybody know that she was diagnosed with cancer."

Suggestions to Improve Cancer Care

a. Female Providers

Many participants spoke about their sensitivity to male providers and the importance of being empathetic and respectful of requests for a female provider.

Participant 8: "I was going into my first biopsy, it was a male. I told him that he was hurting me. I felt it go in and clench down and twist and be pulled out. And I was crying. I was trying to withstand all this pain. And then I finally said to him — I said, 'You're hurting me. Can I have some more local anesthesia?' And he just kept on. I go, 'Sir, you're hurting me!' And he turned to his nurse, snarled at her, and said, 'Get her some more!'"

Though positive encounters were recounted, the majority of patients reported having had negative experiences with, and experiencing negative attitudes from, male providers. This was especially true during physical exams, in part because they were not comfortable being touched by a man. Patients said that they wished providers would be more understanding rather than dismissive or labelling patients as difficult. Most women said that having a male provider for any aspect of their cancer care, from the mammogram technician to their medical oncologist, might lead to avoidant behavior and nonadherence such as missing appointments.

Participant 14: "Sometimes...you go for a mammogram, and you have a male technician. Not being asked or anything you're like, 'Can I have a woman?' 'Well, this is who you have, and you have to have that technician.' And I'm like, 'Then, cancel the appointment and I'll be seen another time.'"

Participant 3: "She may not show for her cancer appointment because she thinks that maybe her doctor who will touch her inappropriately."

Some women also addressed the need for staff to be trained on how to recognize signs of interpersonal violence.

Participant 3: "I think the visiting nurse could have been trained a little bit more. There was one particular time that

the domestic abuser, he went to take a shower and he comes back in the room and goes, 'Oh, I don't want to look at that.' Speaking about one of my wounds. And that should have been a red flag to [the nurse] right there. Those little things right there that you know, that could be a danger sign because I couldn't come on my own and tell her that yeah, I'm afraid that he's going to hit me in my wounds. I couldn't tell her that because he was behind me."

Participant 2: "The providers and people could be more attentive to those little signs. Like, this person's missing appointments and stuff."

b. Improved Communication

In discussing their provider encounters, participants highlighted the need for caregivers to explain what they are doing during medical exams and procedures.

Participant 11: "I think it's very helpful if the provider explains everything that's going to happen and describes what's going to happen."

Suggestions for improved care included a provider verbally laying out the details of what will happen during individual appointments and over the course of treatment. In addition, careful explanation of the reasoning or necessity behind procedures was recommended. The physical exam was identified as a crucial flashpoint given participants' anxiety and discomfort at being touched, especially at sensitive sites such as their breasts which may have previously been sites of abuse.

Participant 3: "For somebody...that's been touched inappropriately before in the past, I have to explain to her that there's going to be a lot of touching. And they could, they're going to want to probe. And that it doesn't mean that it's a bad thing. It means that they have to do it to find out if there's any lumps there. Because if there's any lumps there, they're going to have to do further testing. And, and that doesn't necessarily mean it's going to be a bad test. But it's going to be testing. It's going to have to be done...They would have to really better know that this is needed. It's needed. It's not anything that they're doing just to touch her. It's more than that. That she needs to have it done. It's for her health."

Respondents also said that they liked when their providers made sensitive recommendations for their breast cancer care following the disclosure of their maltreatment. Participants explained this meant doctors' used their expertise to recommend a particular treatment plan or to connect patients with resources and counselling after discussing the abusive situation. In both situations, women felt relieved of the burden of needing to lead the conversation about their interpersonal violence victimization or to lead the discussion about their treatment plan decisions.

Participant 9: “Just get them to start talking and get it out about how they really feel about the cancer. You get it out. If you hold it in it gets worse. The feelings get worse and everything and before you know it you’re in turmoil and everything.”

Participant 3: “It’s hard for them to tell. Yeah. But once they tell, hopefully the provider can kind of take the lead in helping them a little bit when it comes to that.”

Patients brought up suggested questions that would be effective for providers to engage in conversations around a history of interpersonal violence.

Participant 11: “But, nobody ever said anything about ‘Oh, did anything happen when you were five years old? When you were 12 years old?’ So that particular history-I don’t even think that particular history is in my file. So, I think they should do a more thorough history, so the provider will be aware of whatever the history is... Well, it’s gotta be discussed. You have to ask and then the details, has your husband ever touched you in a way you didn’t like? What’s going on in your sex life and how things are happening?”

c. Buddy System

The value of peer-support, especially that of fellow survivors, was repeatedly referenced. Women who had robust support networks and those lacking in social support discussed the potential benefits of being paired with survivors of similar experiences.

Participant 16: “I did have actually somebody that was a stage 4 survivor. And her and her grandson came with me every day, and I believe today that if I didn’t have her with me, I probably wouldn’t have completed my treatment.”

Guidance and companionship during appointments, as well as coaching and encouragement through the most difficult aspects of treatment were listed among the possible benefits.

Participant 14: “During my treatment, it would’ve been nice to have someone there going through, not going through the same things, but just like a guidance type thing, you know someone to support.”

Participant 16: “Now if there’s compliance or noncompliance, we have a little buddy that comes out and will walk you through it daily. They need it daily...[They] have already been through it, number one, experience is the best teacher. And is not ashamed or embarrassed to share their experience with somebody newly going into it.”

During their interviews, many women volunteered to attend appointments with a hypothetical patient, showing a willingness to be a ‘buddy’ if such a support program existed.

Participant 20: “If I had a chance I’d probably go with

her and help her. Give her encouragement and make her feel comfortable if I could.”

Though some participants had attended cancer group therapy sessions offered by the hospital, the buddy system suggestion repeatedly emerged as distinct in its one-on-one pairing. Specifically, the aspect of someone available to talk any time and to accompany patients at appointments seemed most important.

Participant 2: “Like a buddy system...someone that could maybe replace like maybe a family that’s weak...who would maybe even call you or check on you.”

Participant 4: “If you paired up with like a buddy or something, someone who can help you out. That would be a good way to help you get through. Keep you positive. It also helps even the one who is encouraging, you also get encouraged yourself.”

Not knowing people with similar experiences was related to a larger theme that most felt no one understood what they were experiencing either in regards to their abuse or having cancer.

Participant 16: “I think people who haven’t had breast cancer, you don’t feel what I feel. You don’t have this scar on your body, you don’t, you’re not laying on the table for an hour. But if you’ve experienced it, that might shorten the burden that the new person that’s going for treatment is receiving.”

Participant 1: “They don’t understand that a certain kind of pain might be related to your past or with trauma. But certain kind of pain, whether it’s physical, emotional or otherwise may not be something that they can diagnose easily cuz it may not be something that’s part of the 80 percent norm.”

Discussion

This qualitative study explored the impact of interpersonal violence on patients’ breast cancer experiences and sought to identify suggestions for improvement of care. Opportunities to hear and learn from women who have had trauma histories and breast cancer are rare. To our knowledge, this qualitative study is novel in helping to understand the relationship, impact and solutions for improvement in care. In our study, a main theme that emerged was the link made between a cancer diagnosis and interpersonal violence history. We found that women also identified triggers that bridge this association. Echoing the results of previous studies, triggers during physical exams and at bodily sites of abuse such as breasts were identified [17]. In the context of breast cancer, this has important implications during screening and treatment given that breast examinations are a routine and required part of care. To date, numerous studies have found

that being asked for consent helped patients feel in control before performing or continuing procedures. This small effort can mitigate patient distress and can increase patient autonomy, two aspects in accordance with the six tenants of trauma informed care: safety, choice, collaboration, trustworthiness, and empowerment [16,18,19]. Another theme from our study was the difficulty of patients with a history of interpersonal violence to be trusting. Research has found that the largest barriers to disclosing history of abuse was a fear of not being believed or providers not being sensitive to the large impact of interpersonal violence history to a patient's health care experience [20]. There is preliminary evidence for gender-specific responses to cancer, particularly that women experience the medical setting as more stressful [21]. It is important to recognize that women who have experienced abuse are more vulnerable to depression and other psychological disorders and additional stressors may have a detrimental effect or quickly compound with other burdens [2-4]. With regard to suggestions for improvement in breast cancer care delivery, we identified the importance of female providers. The importance of having a female physician was highlighted as one area in which patients' request were often seen as a nuisance rather than a legitimate request. Prior research has found that patients with a history of interpersonal violence may have difficulty advocating for themselves and may hesitate to ask clinical staff for support [2]. Developing a sensitivity and opportunity to report patient preferences could be considered. Research on trauma informed care has prioritized accurate assessments of trauma prevalence, identifying affected persons, and community level interventions to foster resilience [19]. One suggestion that emerged was to create a buddy system. This recommendation is consistent with literature which identified openness to discuss both interpersonal violence and health issues, emotional availability, ease of contact, and willingness to take extra time during appointments as valued in providers. Being paired with an patient of a similar background can similarly facilitate meaningful and trusting relationships [15]. Someone available to talk represents opportunities to disclose anger or fear which can promote better adjustment [3].

Study Limitations

The results of our study are explorative. For example, we did not control for the type of interpersonal violence experienced nor the timing of abuse relative to breast cancer care. Potential limitations to generalizability include the small sample size, and an inability to assess sample heterogeneity. Sensitivity to specific demographic features, such as age, may be important given differential responses to a cancer diagnosis [3,10,13,23-25]. The limited information that participants volunteered about themselves and their history of abuse suggest a somewhat diverse sample. Finally, our data is vulnerable to self-selection bias as patients with

different experiences of interpersonal violence may opt to not participate in an interview study. Overall, our study reveals several themes linking a history of interpersonal violence and a breast cancer diagnosis. We report themes including causality, trust and triggers. Suggestions for improvement of care include female providers, detailed communication and a buddy system. Future studies to improve our understanding and approach to this population is warranted.

Ethics approval and consent to participate

This study was reviewed and approved by the IRB at Boston University School of Medicine, Boston Medical Center IRB# H-33713. Informed consent was obtained from all individual participants included in the study.

Consent for Publication

The authors affirm that human research participants provided informed consent for publication of their statements in this manuscript.

Availability of data and material

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Competing Interests

The authors have no relevant financial or non-financial interests to disclose.

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Author Contributions

Study conception and design: EPR, MBM, NYK

Material preparation: EMR, MBM, NYK

Data collection and analysis: KH, TF, AS, NYK

Manuscript preparation and editing: CLSP, MBM, EPR, NYK

All authors read and approved the final version of the manuscript.

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