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Acute PTSD and Depression Symptoms in African American Women Newly Diagnosed With
Breast Cancer

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Abstract

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The purpose of the current study was to measure PTSD and depression symptoms in $N=4$ women at three time points: baseline (pre-biopsy), six weeks post-diagnosis (before adjuvant treatment), and six months post-diagnosis (after adjuvant treatment). An additional ethnographic interview was conducted with three of the four women approximately two years post-diagnosis to further assess symptoms and to get a deeper understanding of their emotional circumstances throughout the process past what can be learned through diagnostic surveys. The PCL-5 and BDI were used to evaluate PTSD and depression symptoms at all three time points respectively. Blood, spit, and skin conductance samples were also taken. Prior to their cancer diagnosis, 75% and 50% of participants fell above the threshold for a PTSD and major depressive diagnosis respectively, reflecting symptoms related to their prior life stressors and potentially cancer-related anxieties. At the six week time point, 25% and 100% of participants fell above the threshold respectively. Finally, at the six month time point, 0% and 50% fell above the threshold respectively. The results of the ethnographic interviews indicated that over two years post-diagnosis, two out of three women were still experiencing symptoms of PTSD, and one out of three women was still experiencing symptoms of depression. Overall, it was found that over three time points, symptoms of PTSD decreased, while depression symptoms peaked at the six week time point, and decreased by the six month time point. However, some women who had experienced extensive PTSD and depressive symptoms in the time following their diagnosis still had complaints of psychiatric disturbances over two years later. These results indicate that mental health intervention and treatment at the time of diagnosis and before adjuvant treatment is critical in the prevention of long term psychological distress.

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1. Personal Statement

In the beginning of my second month of college, I got a phone call that would change my life, and inform my ongoing view of oncological study. I feared for my parents' well-being when I traveled south from Boston to study at Emory, but I never expected that only a few weeks into my first semester my mom would call me and express the words that no child ever wants to hear. "I have cancer."

At first, my mind went blank; all I could do was try to process that my family's life would be forever altered. The next few weeks consisted of trying to deal with what was to come. For my mom, this meant surgery, which I would fly home for. Luckily, the surgeon was able to discern, in the course of performing a full hysterectomy, that the cancer had not gone past the walls of the uterus into any nodes. Her surgeon told my mom that the surgery was the cure, and although my mom did not undergo any adjuvant therapy, the cancer diagnosis itself shook both her and my entire family.

My mom still often mentions how traumatic her experience of being diagnosed was; she recalls that prior to diagnosis, she had gone through a series of procedures, each one showing something was abnormal. Doctors assured her she was fine - that there was likely nothing major wrong with her. At the follow-up visit from a biopsy, the surgeon said that there was good news and bad news. My mom told me that tears began streaming down her cheeks, and she asked the surgeon in a choked voice, "Is it cancer?" The surgeon confirmed that it was, and held my mom's hand as she cried. She told my mom that they had likely caught it early, and that my mom would be fine after the surgery. My mom felt dizzy, and panic-stricken. She had watched her father die of lung cancer in 1985, and her mother come close to dying of lymphoma in 1989. Her mother

had ongoing medical issues for the rest of her life, including chronic pain. My mom was terrified that, even if she didn't die, she would never fully be herself again.

One of the things my mom told me was that she felt she had no control over what was going to happen. Fortunately, the surgery went well, but still my mom worried constantly. Depression overtook her, and she disappeared into herself. Even when the full report came out, saying that the cancer had been contained in the uterus, and hadn't gone through its wall or into any lymph nodes, she didn't believe or trust it. She became convinced she was going to die. My mom still cries about having had cancer; her depression has never fully left her, nor has my family ever fully recovered from the devastation. While my mom was never evaluated for cancer-related PTSD, I believe it is something she suffers from, and I believe it originated from the diagnosis itself.

When I joined the Grady Trauma Project, it became my mission to learn as much as I could about the effects of cancer diagnoses on mental health. While doing my literature review, it became evident that most of the current research on cancer-related PTSD and depression only covered mental health issues that arose during the grueling process of adjuvant therapy. What most research did not cover was any PTSD or depressive symptoms initiated by the cancer diagnosis itself. Thus, while the Avon study took survey data on PTSD and depression and quantitatively analyzed symptoms, I wanted to take a more qualitative approach with my portion of the study, so I sat down with participants to talk with them about their experience of being diagnosed and how they believed it affected their mental health in both the short-term and long-term. The conversational approach was much more personal in my opinion, and allowed me to gather data that I would not have gotten from the quantitative data gathered. These interactions have humbled me as a person, and I believe they will help me become a better physician.

2. Introduction

a. Rationale & Relevance

Major advances in medicine and technology have led to increased rates of cancer survivorship; however, many cancer survivors, including women who have been diagnosed with breast cancer, often report experiencing symptoms of traumatic stress and depression. Those who go untreated for cancer-related traumas may suffer from higher rates of psychiatric and medical morbidity (French-Rosas et al., 2011). For people who experience or witness traumatic events in their lifetime (including cancer-related traumas), the collection of detriments to mental health that results can manifest as post-traumatic stress disorder (PTSD). While associations with PTSD by the general public strongly relate to military or rape traumas, PTSD can occur in those who have experienced a wide variety of traumas, including cancer-related traumas. The incident risk of PTSD is approximately 10-20% among individuals who experience a traumatic event (Hinrichs et al., 2019), women being twice as likely as men to receive a PTSD diagnosis (Glover et al., 2012), and African American (AA) women being more likely than Caucasian women to receive a PTSD diagnosis (Vin-Raviv et al., 2013). In those with a breast cancer diagnosis, PTSD develops in approximately 4% of patients undergoing active chemotherapy and other adjuvant therapies (Andrykowski et al., 1998). A longitudinal study also revealed that cancer-related PTSD correlates with poor functioning and lower quality of life (Shelby et al., 2008).

It is not yet clear when the optimal timing is for the delivery of mental health interventions or other resources, as much of the research that has been conducted only takes into account PTSD and depression symptoms that have accumulated due to treatments such as chemotherapy and radiation. What is still ambiguous is whether patients will show acute symptoms of PTSD before the onset of adjuvant therapy. The current study conducted a series of

longitudinal interviews at the time of diagnosis, six weeks, and six months after receiving a breast cancer diagnosis, as well as an ethnographic, conversation-based interview taken approximately two years post-diagnosis. We then compared the six-month visit to the six-week and baseline visits to assess changes in PTSD and depression symptoms, for the purposes of early intervention and appropriate treatment.

b. Background & Literature Review

Approximately 60% of individuals have experienced one or more traumatic events in their lifetime (Hinrichs et al., 2019); however, only a small fraction of this population will develop and be diagnosed with PTSD. Approximately one in every eleven people will be diagnosed with PTSD in their lifetime (American Psychiatric Association). PTSD may be caused by either experiencing or witnessing a traumatic event, and symptoms can manifest as early as one month after the event. According to the American Psychiatric Association, the DSM-5 measures four major categories of PTSD symptoms which can vary in severity: intrusion, avoidance, alterations in cognition and mood, and alterations in arousal and reactivity. Intrusion may include intrusive thoughts, nightmares, flashbacks, or unwanted and involuntary memories. Avoidance refers to avoiding thoughts of the traumatic events itself, or avoiding people, places, activities, objects, and situations that they may associate with the traumatic event, or that may trigger unwanted memories. Alterations in cognition and mood include lack of memory surrounding the traumatic event, distorted or negative feelings about the self or others, blaming oneself for the cause of the event, ongoing fear, horror, guilt, or shame, and finally a significantly decreased interest in activities that one previously enjoyed. Alterations in arousal and reactivity specifies irritability, angry outbursts, recklessness, self-destruction, being easily startled or overly watchful, and difficulty concentrating or sleeping. To be classified as PTSD, symptoms must last

for more than one month and must negatively affect one's daily functioning by causing regular distress, as well as other issues.

Similarly to PTSD, acute stress disorder (ASD) can occur through witnessing or experiencing a traumatic event. Symptoms can also manifest similarly; however, they occur between three days and one month after the trauma. Approximately 50% of people diagnosed with ASD go on to be diagnosed with PTSD (American Psychiatric Association). A study conducted a series of clinical interviews to identify cancer-related ASD, PTSD, anxiety, and depression in women diagnosed with breast cancer (Mehnert et al., 2006). The general consensus among the women in the study was that the cancer diagnosis itself and subsequent feelings of uncertainty were the most traumatic of their experiences. Of the $N=127$ participants in the study, researchers found a 2.4% prevalence for both cancer-related ASD and PTSD, a lifetime PTSD prevalence of 8.7%, and a 4.7% prevalence of major depressive disorder. Mehnert noted that it had yet to be evaluated whether feelings of uncertainty throughout the treatment process could be considered traumatic stressors in the DSM-IV diagnostic course. Predicting PTSD symptoms can be challenging in cancer-related PTSD assessment, as factors including age, prognosis, cancer stage and severity, and differing treatment plans can serve as extraneous variables in the experimental trajectory. Another study used Andersen's model of psychologic morbidity following cancer treatment to predict symptoms of PTSD in women who had undergone treatment for breast cancer, and to assess the underlying variance in symptom reports. Physical comorbidity, education level, disease stage, cancer treatment course, depression history, and social support accounted for 39% of the variance, while time since treatment completion, pre-cancer traumatic stressors, age at diagnosis, and tamoxifen usage accounted for an additional 16% of variance. They also found a significant correlation between higher levels of PTSD

symptoms and less social support, greater pre-cancer trauma history (pre-existing PTSD diagnoses), a more recent treatment completion, and more advanced disease (Andrykowski et al., 1998).

Although there are many factors that can influence whether or not someone will be diagnosed with PTSD, individual differences in resilience can also have a major impact on resistance to and/or recovery from psychiatric disorders. Alim et al., 2008 conducted structured diagnostic interviews in $N=259$ AA adults exposed to a variety of severe traumas in order to examine the psychosocial factors associated with resilience to psychiatric disorders. 47 participants were found to be resilient (no lifetime psychiatric disorders), 85 participants were recovered (no current disorder, but previously had fallen above the threshold for at least one DSM-IV disorder), and 127 participants were currently ill (fell above the threshold for at least one DSM-IV disorder). They found that a lower lifetime trauma load, and having a strong sense of purpose in life, were associated with the resilient and recovered groups, while being female was associated with the currently ill group. Additionally, resilience in the face of trauma could manifest in many unexpected ways; as, for example, the use of self-enhancing biases potentially being detrimental in social circumstances, but could lead to resilience under extremely adverse circumstances (Bonanno 2005).

Furthermore, cancer-related depression can often have a negative impact on disease outcome, and must be taken very seriously. According to the American Psychiatric Association, depression (major depressive disorder) can have a significant impact on cognition and behavior. Symptoms can include the following: feelings of sadness, loss of interest or pleasure in activities once enjoyed, changes in appetite, insomnia or hypersomnia, fatigue, feeling worthless or guilty, difficulty concentrating and making decisions, and even suicidal ideations. Any or all of these

symptoms may range from mild to severe, and may manifest in different ways. In order to receive a diagnosis of major depressive disorder, symptoms must last for two weeks or more, and must produce a significant change in previous levels of functioning. Major depressive disorder is represented in approximately 6% of the population, and is more prevalent in women than in men. As many as one-fifth of cancer patients can develop chronic depressive illness (Aapro & Cull 1999). Aapro and Cull conducted a study with $N=546$ cancer patients, and diagnosed 9% with major depression, while 47% were diagnosed as depressed. Vahdaninia et al., 2009, conducted a study with $N=99$ women diagnosed with breast cancer, using questionnaires to assess anxiety and depression at three time points: baseline (pre-diagnosis), three months after initial treatment, and one year after treatment completion (18 months post-diagnosis). They found that both anxiety and depression decreased over the three time points; however, at the 18 month follow-up, 22.2% of participants presented with severe depression, suggesting that psychological distress should be assessed regularly in women with breast cancer diagnoses. Together, the literature suggests that breast cancer-related stressors have major impacts on mental health for a large percentage of patients, particularly AA women. However, key questions remain open.

Breast cancer is the most frequently diagnosed invasive cancer in the United States in women of all racial/ethnic groups (Coughlin et al., 2014), with 2.3 million documented diagnoses and 685,000 deaths worldwide in 2020 (Breast Cancer Research Foundation). At an early stage, breast cancer symptoms can include lumps in the breast(s), inverted nipples, nipple discharge, and changes in breast shape. As the cancer advances, it spreads first to the lymph nodes, creates a blood supply, and invades (most commonly) the liver, bones, and lungs, sometimes eventually metastasizing to the brain. Depending on the type, stage, and severity of breast cancer, many women will undergo individualized treatment plans, lasting upwards of

decades. In early stage disease, local treatments including lumpectomy, mastectomy, or double mastectomy may leave the patient cancer-free, however once metastasis occurs, treatment plans can also include systemic treatments, most commonly chemotherapy and radiation. According to the American Cancer Society, chemotherapy in breast cancer is most commonly administered using a combination of two to three of the following drugs: anthracyclines, taxanes, 5-fluorouracil, Cytosan, and Paraplatin. Neoadjuvant chemotherapy may be given to shrink the tumor before surgery is performed, while adjuvant chemotherapy is used to kill any additional cancer cells left behind after surgery, or to target metastasized cells that do not appear on imaging tests. Chemotherapy can be injected intravenously and/or orally, traveling through the bloodstream and targeting most parts of the body. Although the treatment kills cancer cells, it also eradicates healthy cells, leading to myriad negative side effects, including nausea, vomiting, weakness, mouth sores, neuropathy, chills, and other reactions. Radiation therapy, delivered by a linear accelerator, uses high doses of radiation to target and kill malignant cells or tumors on specific body sites (American Cancer Society). It does this by damaging the DNA of malignant tissue, thus causing cell death and controlling cell growth.

The combination of surgery and adjuvant therapy in cancer treatment can, both individually and in combination, be considered as traumatic event(s) that can lead to the development of cancer-related ASD and/or PTSD. Recent literature has assessed PTSD symptoms in breast cancer survivors in order to study its prevalence. One study (Shelby et al., 2008) aimed to obtain a better understanding of PTSD symptomology through the completion of a series of diagnostic interviews at the time of diagnosis/surgery, and then again 18 months later. The sample consisted of $N=74$ breast cancer patients, broken into three categories based upon diagnostic interview results: PTSD, subsyndromal PTSD, and no symptom groups were

identified. The results indicated a distribution of $n=12$ for the PTSD group, $n=5$ for the subsyndromal PTSD group, and $n=47$ for the no symptom group. There was also evidence that PTSD symptoms fluctuated over the course of one's diagnosis and treatment plan (Andrykowski et al., 2000; Chan et al., 2018). Regardless, PTSD symptoms declined considerably in the majority of breast cancer patients within the first three months post-diagnosis, and again after the completion of treatment. Andrykowski et al., 2000 conducted a longitudinal study with PTSD assessments administered at 14 months post-treatment completion and again 12 months later. The study found that 13% of individuals maintained moderate levels of avoidance symptoms, while a similar number of individuals experienced a significant decline in avoidance and arousal symptoms after the completion of the treatment course. A longitudinal study (Chan et al., 2018) observed PTSD symptoms in cancer patients in South-East Asian populations over four years, finding a 21.7% incidence of PTSD at the 6-month follow-up assessment, and a 6.1% incidence at the four-year follow-up assessment. While overall rates of PTSD decreased over time in the cohort, 34.1% of the patients who were initially diagnosed experienced worsening symptoms at the four-year mark, suggesting the need for early identification and intervention in patients diagnosed with cancer-related PTSD.

The concept of cancer as a trauma has been challenged by many professionals, in part because it is associated with a long course of stressful experiences, making it difficult to identify a single traumatic event, as is done in the case of most other traumas. According to Leano et al., 2019, patients with a cancer diagnosis did not receive a psycho-oncology services referral due to the misconception that high levels of sadness and anxiety were normal reactions to cancer diagnosis and treatment. "Thinking positively" and "fighting" are often the only advice patients are given, which can lead to feelings of inadequacy if they do experience any symptoms of

PTSD and/or depression. Recently, there has been a growing awareness of the psychological impacts of cancer diagnosis and treatment in the medical community. Life-threatening illness, including cancer, has been identified as a trauma that can lead to a PTSD diagnosis, due in part to the fact that when untreated, cancer related PTSD symptoms can increase psychiatric and medical morbidity (French-Rosas et al., 2011).

Associated with higher levels of PTSD are fewer years of education, less social support, a greater pre-existing trauma history, and being Black (Vin-Raviv et al., 2013). There are a number of racial disparities between Caucasian and AA women diagnosed with breast cancer. Keeping in mind that AA women have a higher mortality rate from breast cancer than do Caucasian women, Coughlin et al., 2014 looked into how socioeconomic factors, biological factors, and access to medical care such as mammography and treatment, can affect mortality rates, given that AA women tend to have less access to healthcare and maintain a lower socioeconomic status on average. Coughlin noted that even taking into account the stage of disease and tumor characteristics, Black-white survival disparities are still extremely prevalent, meaning that social factors are partially to blame for increased AA mortality rates. Additionally, although white women are more likely to be diagnosed with breast cancer, its mortality rate is higher in Black women (Bach et al., 2002). This does not mean that Black women are less likely to have breast cancer, but rather that they are less likely to be diagnosed before meeting their fate with the disease. Additionally, more often than white women, Black women are more likely to be diagnosed at a more advanced stage of the disease (Anders et al., 2008). Biological underpinnings of disease structure in Black women also suggest that they have significantly more high-grade breast cancers (Smith-Bindman et al., 2006), and are more likely to develop triple negative (hormone receptor and HER2-negative) breast cancer (Carey et al., 2006). All of

these factors must be taken into account keeping in mind that the participants in our study were overwhelmingly Black, low socioeconomic status, low education, women with pre-existing trauma history. Women who fall within these categories can experience a plethora of additional detriments to mental health, not only because of additional social factors, but because the common lack of access to preventative measures such as routine screening and mammograms makes breast cancer a greater threat to life.

c. Study Design & Hypotheses

This study as a whole, operating under the umbrella of Grady Trauma Project PTSD research and investigation, worked exclusively with inner-city AA women being biopsied, diagnosed, and treated for breast cancer, with the hopes of identifying the prevalence of PTSD, its biological predictors, and its neurobiological risk factors in this high-risk population. $N=25$ English-speaking (primarily low socioeconomic status AA women) between and including the ages of 18 and 65 were approached prior to their biopsy visit at the Avon Breast Cancer Center at Grady Memorial Hospital. During a series of two initial visits, and three follow-up visits at six weeks, six months, and one year post-diagnosis, participants underwent an in-depth trauma history and assessment of psychiatric symptoms. Blood and spit samples and a skin conductance test were also taken. Approximately two years post-diagnosis, an additional one hour conversational interview was conducted, assessing the participant's own thoughts about diagnosis, mental health, family relations, and outlook on prognosis. The hypotheses were four-fold. (1) We expected that compared to the pre-biopsy baseline visit, women at six weeks post-diagnosis would be experiencing more symptoms of ASD and some symptoms of PTSD from the traumatic events of diagnosis and surgery. (2) Similarly, we expected women at six weeks post-diagnosis to be experiencing more depressive symptoms than at baseline. (3) We

expected that PTSD symptoms would be less severe at the six-week visit than those found at the six-month visit. (4) Similarly, we expected that depressive symptoms would be more severe at the six-month time point than at either of the other two time points. We anticipated this symptom increase at the six-month time point due to the increase of stressful experiences during the course of treatment.

3. Methods

a. Participants

$N=25$ women ages 18 to 65 were recruited from the Avon Breast Center at Grady Memorial Hospital. Women were approached and recruited by study team members in the waiting room prior to a biopsy visit. All study team members who interacted with participants were blinded to participants' medical/cancer-related information. Individuals of all races and ethnic backgrounds were eligible for the study. However, the patient population was primarily composed of low-SES (87% with monthly household income < \$1000), minority individuals (>90% AA and 5% Hispanic). Individuals who were interested in participating in the study completed an initial assessment interview, beginning with the appraisal of inclusion and exclusion criteria. In order to be included in the study, participants were required to be between the ages of 18 and 65 years old, English speaking, and must have attended a biopsy visit for a potential first onset of breast cancer. We did not exclude based on stage or subtype of breast cancer. Factors that excluded potential participants were any of the following, including self-reported diagnosis of major psychiatric conditions including PTSD, depressive disorder, schizophrenia, or bipolar disorder, or history of neurological disease or cognitive disability. Since a portion of the study was dedicated to an MRI visit, potential participants were excluded for any

contraindication to MRI, including pregnancy, breastfeeding, or physical contraindications such as implants containing ferrous metal.

Of the initial $N=25$ participants recruited, four women were subsequently diagnosed with breast cancer, whereas the remaining $N=21$ had benign findings. The mean age of the four women was 58 years, which was unsurprising, considering that advancing age is the number one carcinogen, with the risk of cancer diagnosis rising exponentially by the age of approximately 60 years (DePinho 2000). All of the participants identified as AA women. None of the women had a history of treatment for any of the following: PTSD, schizophrenia, or substance abuse. One participant had previously attempted suicide, and was treated for subsequent anxiety through group therapy without medication. One participant was diagnosed with depression prior to her diagnosis and was treated with 20mg Celexa. Two of the four women reported a monthly household income of \$1,000-\$1,999, and two reported a monthly household income of above \$2,000.

b. Quantitative Measures

We collected basic information related to age, sex, ethnicity, race, relationship status, education level, employment, income, previous treatment for a variety of mental health disorders, religion, sleep, body mass index (BMI), and support from friends.

The Traumatic Events Interview (TEI) is a self-report questionnaire that is used to assess the existence, intensity, and duration of traumas occurring over the lifetime (Sprang, 1997). Specifically, an inventory of exposure to Criterion A traumatic events is assessed. A Criterion A trauma event includes at least one exposure to a stressful event such as death, threatened death, actual or threatened serious injury, or actual or threatened sexual violence (DSM-5 Criteria for PTSD). This exposure can occur in any of the following ways: direct exposure, witnessing the

trauma, or being confronted with a trauma. The TEI has two parts; in the first section, there are a total of 16 questions, asking if participants have experienced, witnessed, or been confronted with any of the following in their lifetime, including their age at the time of exposure, and how many times that exposure occurred: a serious accident or injury, a sudden life threatening illness, an attack with a gun, knife, or other weapon (and who specifically attacked them), and violence between parents or caregivers. Part B of the TEI contains 11 questions, inquiring whether participants experienced any of the following during their childhood, including being beaten or physically punished, talked to in mean ways, unwanted sexual contact or sexual abuse from an older teenager or adult between the ages of 0-13, 14-17, and/or older than 17. Finally, the TEI incorporates more open-ended questions, asking whether the participant feels that the home they grew up in was stable or unstable, what they believe to be their worst trauma, and how old they were when they were experiencing, witnessing, or being confronted by it. It is imperative for the purposes of this study to take a clear trauma history in order to take into account previous trauma to better understand any new cancer-related trauma, especially since most of the women being interviewed were predicted to have previously diagnosed or undiagnosed PTSD symptoms. For the purposes of the current study, a cumulative "prior trauma load" index was calculated as the sum of different types of traumatic experiences endorsed across the 17 items of the TEI.

The Index of Race-Related Stress (IRRS) is intended to sample some of the experiences that Black people have in this country because of their "blackness." There are many experiences that a Black person can have in this country because of his/her race. Some events happen just once, some more often, while others may happen frequently. These events may cause stress if they have happened to that person, or if someone close to them has experienced those events. This 22-question survey assesses five levels of experience with race-related stress, on a 0-4

scale; 0 = this event never happened to me, 1 = this event happened, but did not bother me, 2 = this event happened and I was slightly upset, 3 = this event happened and I was upset, and 4 = this event happened and I was extremely upset. The questions involve topics such as Black versus white crime, lack of white courtesy and respect, police violence against AA people, Black versus white portrayals in the media, false assumptions about level of education, intelligence, and income, racist jokes and comments, and Black people's desire to be white. Data from the IRRS was used in this study to assess the potential affects of racial discrimination on AA participants, and to assess how this may affect a PTSD or depression diagnosis. A sum total across the 22 items was used to index cumulative race-related stress.

The Childhood Trauma Questionnaire (CTQ) (Bernstein et al., 1994) is a 28-item self-report questionnaire that aims to provide a reliable measure of a broad range of traumatic experiences that may have occurred throughout childhood. The questionnaire measures five categories of abuse and neglect, including physical abuse, emotional abuse, sexual abuse, physical neglect, and emotional neglect. For each question, participants are asked to rate statements as never true, rarely true, sometimes true, often true, or always true. The assessment concludes with a total score for childhood trauma, in addition to scores for each of the five categories of abuse and neglect.

The PTSD Checklist for DSM-5 (PCL-5) is a 20-item self-report checklist that assesses the DSM-5 symptoms of PTSD, with the purposes of measuring and screening for PTSD, monitoring the change in symptoms during and after treatment, and making a provisional PTSD diagnosis (National Center for PTSD). The PCL-5 asks the participant to rate how bothered they were by a list of experiences within the past month, on a scale of 0-4; 0 = not at all, 1 = a little bit, 2 = moderately, 3 = quite a bit, and 4 = extremely. Participants who receive a score of 31 or

higher can be considered to have a probable PTSD diagnosis (National Center for PTSD). Skin conductance response (SCR) is also acquired during the PCL-5 measure. SCR data is acquired by two 5 mm Ag/AgCl electrodes filled with isotonic paste attached to middle phalanges of the second and third finger of the non-dominant hand during administration of the PCL-5. When the eSense recording begins, a trained study team member asks the participant to briefly describe what happened to them that led up to their biopsy visit at the breast cancer center, and follows up by asking them to rate how stressful that experience was.

The Beck Depression Inventory (BDI) is a questionnaire consisting of 21 group statements, in which one word is provided by a study team member, and the participant is given a choice among a group of six statements, and asked to choose the statement that best applies to them at the time. The list of words given are sadness, pessimism, past failure, loss of pleasure, guilty feelings, punishment feelings, self-dislike, self-criticalness, suicidal thoughts or wishes, crying, agitation, loss of interest, indecisiveness, worthlessness, loss of energy, changes in sleeping patterns, irritability, changes in appetite, concentration difficulty, tiredness or fatigue, and loss of interest in sex. The BDI is used to evaluate current depressive symptoms and their severity. Thus, scores are totalled at the end of the questionnaire, and symptom severity is considered minimal if the score lies between 0 and 9, mild between 10 and 18, moderate between 19 and 29, and severe between 30 and 63. Participants who receive a score of 16 or higher can be considered to have a probable major depression diagnosis (Smarr & Keefer 2011).

c. Qualitative Measures

Approximately two years after their initial diagnosis, three of the four participants were re-contacted for a followup ethnographic, conversation-based interview. The purpose of this interview was to fill in the gaps that the quantitative measures may not otherwise cover, such as a

more in-depth patient history, the impact of diagnosis on relationships with family members and other loved ones, and any other raw emotions that may have been brought up given more freedom to speak freely. The questions are included in the appendix. While the quantitative measures aimed to evaluate *what* symptoms were experienced at certain points in time, the qualitative measures aimed to provide insight into *why* those symptoms were occurring. These questions aided in getting a more complete perspective of the trauma relating specifically to the cancer diagnosis itself, and any symptoms or other forms of distress the participant may have experienced after their diagnosis. Since this study aimed to better understand PTSD and depression symptoms experienced before the onset of adjuvant therapy, this conversation related primarily to that portion of time, but also gave insight into current psychological wellbeing.

d. Procedures

During the course of the study, there were a total of four visits, including the biopsy visit, and three follow-up visits at six weeks, six months, and 12 months post-diagnosis. Demographic information, as well as extensive assessments of trauma history and in-depth psychiatric symptoms, were administered at the biopsy visit, prior to participants' diagnosis visit with the surgeon, and then at each of the proceeding follow-up visits. Trained interviewers from the Grady Trauma Project (GTP) study team collected all relevant information from participants through RedCap - a secure clinical software used to manage survey information. The following assessments were administered for this particular study during the biopsy visit: Demographics form, TEI, IRRS, CTQ, PCL-5, and the BDI. The follow-up interviews (six week, six month, and 12 month) included psychological assessments (CTQ, PCL-5, and BDI). Six-week data was then compared with data from the six-month and 12-month follow-up visits, to understand how symptoms changed over the course of cancer treatment. In addition, at approximately two years

post-diagnosis, the 16-question ethnographic survey was given in conversational context, in order to learn more about the participant's experience with cancer diagnosis, and to assess for potential PTSD symptoms after receiving only a diagnosis and surgery, as well as to evaluate for any current symptoms.

e. Quantitative Statistical Analysis

Scores from the PCL-5 and BDI were taken from each individual participant across each time point; scores for both procedures were subsequently averaged at each time point across four women at the baseline and six-week time point, and across two women at the six-month time point. These averages were taken so it could be determined whether women were above the threshold for a PTSD or depression diagnosis at each time point. Once this was determined, we analyzed trends in the scores across time and across women.

f. Qualitative Analysis

Using MAX-QDA, a statistical coding software used for qualitative analysis, words associated with PTSD intrusion, avoidance, alterations in cognitions and mood, and alterations in arousal and reactivity symptoms were extracted from each of the three ethnographic interviews, and coded into appropriate categories. The number of words used in each category, along with an explanation of symptoms that participants may have explained during the interview that did not include any of the words from that category, were recorded and analyzed. The number of words used under each category were recorded individually and compared to the individual PCL-5 scores from the quantitative analysis. Similarly, words and conversations were coded for depression symptoms individually and compared to data obtained from BDI scores during quantitative analysis. This data was used to better understand the emotions and experiences that

each individual went through when they were experiencing the trauma, and how they were coping with the symptoms over two years later.

4. Results

a. Participants

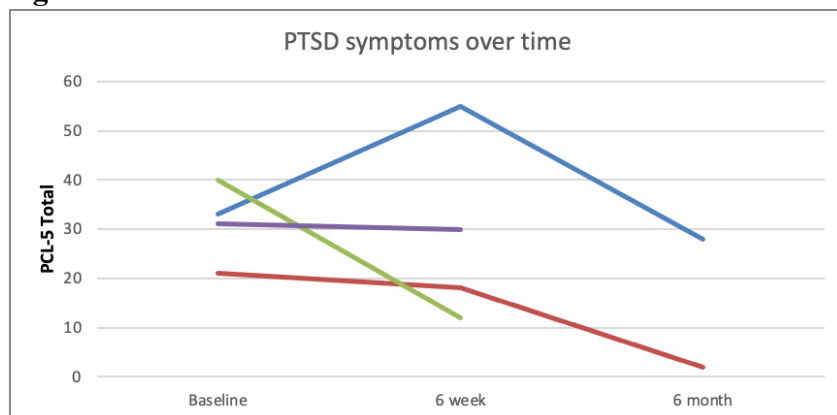
Four participants who were diagnosed with breast cancer took part in a baseline and six-week post-diagnosis interview, in which a series of survey questions quantitatively assessed for PTSD and depression symptoms at each timepoint; two of the four participants also participated in a six-month interview with similar followup assessments. Three of the four participants were recruited for a followup case study consisting of an ethnographic interview lasting approximately one hour after which the patterns in the wording of their responses were qualitatively examined to assess for PTSD and depression symptoms following diagnosis.

b. Quantitative Data Analysis

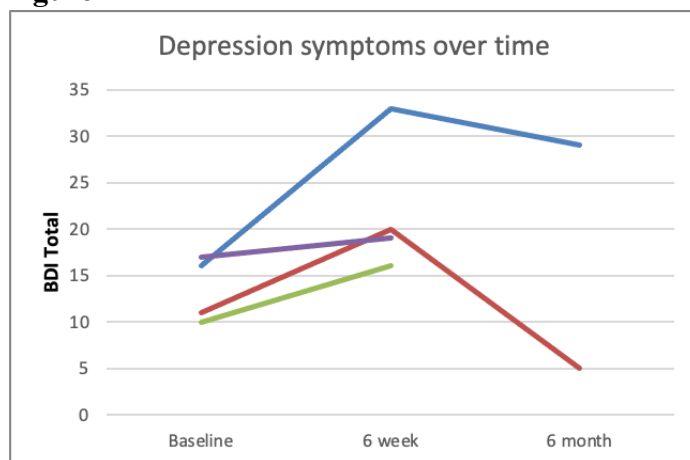
Table 1

	Depressive symptoms baseline (BDI)	Depressive symptoms 6 weeks (BDI)	Depressive symptoms 6 months (BDI)	PTSD symptoms baseline (PCL-5)	PTSD symptoms 6 weeks (PCL-5)	PTSD symptoms 6 months (PCL-5)
Participant One	11	20	5	21	18	2
Participant Two	16	33	29	33	55	28
Participant Three	17	19		31	30	
Participant Four	10	16		40	12	
Average	13.5	22	17	31.25	28.75	15

This table indicates the participant scores for both the Beck Depression Inventory, which assesses depression symptoms (blue) and the PCL-5, which assesses PTSD symptoms (purple). These scores are exhibited for each of the four participants at the baseline visit, and six-week visit, and for two of the participants at the six-month visit.

Figure 1

This figure describes the PCL-5 total scores for each of the four participants at the baseline, six-week, and six-month follow-up visits. The PCL-5 assesses PTSD symptoms, and thus this figure conveys severity of PTSD symptoms in each participant at each time point. Participant one is represented by the red line, participant two is represented by the blue line, participant three is represented by the purple line, and participant four is represented by the green line.

Figure 2

This figure describes the BDI total scores for each of the four participants at the baseline, six-week, and six-month follow-up visits. The BDI assesses depression symptoms, and thus this figure conveys rates of depression symptoms in each participant at each time point. Participant one is represented by the red line, participant two is represented by the blue line, participant three is represented by the purple line, and participant four is represented by the green line.

Participant one was diagnosed with Stage II (pT1a pN0 cM0 G2 ER- PR- HER2-) invasive ductal carcinoma of the right breast, and was treated with a simple lumpectomy followed by six rounds of 42.56 Gy with 10 Gy boost radiation therapy. The TEI and TEI part B

revealed a prior history of trauma, with the murder of her son recorded as her worst trauma. Represented by the red line in Figure 1, PCL-5 scores indicate that the participant experienced a peak of PTSD symptoms at the baseline visit, with symptoms slightly less severe at six weeks post diagnosis, and very low at the six-month visit. Represented by the red line in figure 2, BDI scores revealed a peak of depression symptoms at the six-week visit, with the score being approximately halved at the baseline visit, and dropping down significantly by six months. Her symptoms of PTSD were sub-threshold or did not meet the criteria for a PTSD diagnosis across all timepoints. Her elevated depression symptoms at six weeks would meet criteria for a probable major depression diagnosis, and she was below the cutoff at the first and third time points.

Participant two was diagnosed with Stage IA (pT1c pN0(sn) cM0 G1 ER+ PR+ HER2- Oncotype DX score: 21) Infiltrating ductal carcinoma in the left breast, and was treated with a simple lumpectomy followed by two months of docetaxel cyclophosphamide (chemotherapy) and one month of 42.56 Gy with 10 Gy boost radiation therapy. Additionally, she was prescribed Anastrozole 1mg/day (aromatase inhibitor), which interferes with the amount of estrogen in the body post-menopause, reducing estrogen exposure to the tumor and thus reducing its growth. Participant two had also experienced trauma before her breast cancer diagnosis, including an unstable home life. Her worst reported trauma was finding out that her daughter had been sexually assaulted. Represented by the blue line in Figure 1, PCL-5 scores indicated that the participant experienced a peak of PTSD symptoms at the six-week follow up visit, with a significant decrease in symptoms at the baseline and six-month follow-up visits. Represented by the blue line in Figure 2, BDI scores revealed a peak of depression symptoms at the six-week follow-up, with a slight decrease at the six-month follow-up, and significantly fewer symptoms at baseline. PCL-5 scores across the first two time points indicated that the

participant was within the threshold to be diagnosed with PTSD (above a score of 31). Based on BDI scores, participant two was above the cutoff to be diagnosed with clinical depression at all three time points.

Participant three was diagnosed with grade 3 (ER- PR-) comedo type Ductal carcinoma in situ, stage 0, with microcalcifications. She was treated with a partial mastectomy followed by four weeks (120 rounds) of 42.56 Gy with 10 Gy boost radiation therapy. Additionally, she was prescribed atorvastatin (20mg/day), losartan (100mg/day), chlorthalidone (25mg/day), levothyroxine (88mcg/day), omeprazole (20mg/day), and prednisone (20mg) for a few days prior to radiation. The worst reported trauma prior to diagnosis was being confronted with her brother's death, which was deemed suicide by police, but which she believed was murder. Represented by the purple line in Figure 1, PCL-5 scores indicated a slight decrease in PTSD symptoms from the baseline to the six-week follow-up visit. These scores fell within the middle range of symptoms for all participants at both time points. It is unknown what level of symptoms the participant was experiencing at the six-month time point. Represented by the purple line in Figure 2, BDI scores revealed a slight increase in depression symptoms from baseline to the six-week follow-up visit. Once again, the symptoms fell in the middle range of all of the participants. Her symptoms were unknown after the six week time point. PCL-5 scores at the first two timepoints indicated that the participant had either subthreshold symptoms of PTSD or did not meet the criteria for a PTSD diagnosis (National Center for PTSD). Based on BDI scores, participant three was above the cutoff for clinical depression at both time points.

Participant four was diagnosed with Stage II (ER+ PR+ HER2-) Infiltrating ductal carcinoma; two tumors with the same pathology were found in the right breast, and a metastasis to lymph nodes was found at the time of surgery. She was treated with a full mastectomy and a

sentinel node biopsy. She then moved out of the state without further treatment given at Grady Hospital. It is unknown whether she received any adjuvant therapy after the six-week follow-up visit. The participant had a history of trauma, with a worst reported trauma of experiencing a sexual assault. Represented by the green line in Figure 1, PCL-5 scores indicated that the participant had a peak of PTSD symptoms at the baseline visit, followed by a significant decrease in symptoms at the six-week follow-up visit. It is unknown whether her symptoms were worsened or relieved by the six-month follow-up. Represented by the green line in Figure 2, BDI scores revealed a significant increase in depression symptoms from the baseline visit to the six-week follow-up visit. The PCL-5 score at the baseline visit was within the threshold for the participant to be diagnosed with PTSD; however, the second time point score did not meet the threshold. Based on BDI scores, participant four was below the cutoff for clinical depression at the first time point, and above the cutoff at the second time point.

Taken together, it is notable that all of the participants had a significant life history of impactful trauma prior to their cancer diagnoses. Mean PCL-5 scores (Table 1) across all participants decreased from baseline to six weeks, and again from six weeks to six months. At the baseline time point, the mean score was above the threshold for a PTSD diagnosis, indicating a high stress response at the time of diagnosis. At the second two timepoints, the average score was under that threshold, indicating a lower stress response at those time points. Mean BDI scores exhibited in Table 1 across all participants increased from baseline to the six-week time point, where they peaked, and then decreased at the six-month time point. The cutoff score for clinical depression is 16 and above; the mean scores were above that cutoff for the second two time points, indicating higher levels of depression symptoms at the six-week time point, and lower levels at the other two time points.

c. Qualitative Data Analysis

Table 2

Participant One	PTSD Symptom-Related Words	# of Times The Word Was Used
Intrusion-Related Words	Dreams/nightmares	0
	Flashbacks	0
	Memories	0
	Rumination	0
Avoidance-Related Words	Denial	0
	Disbelief	0
Alterations In Cognition & Mood Related Words	Angry	0
	Cried	0
	Retreated/private	3
	Alone	0
	Guilt	0
	Numb	0
Alterations In Arousal & Reactivity Related Words	Fear	0
	Scared	0
	Anxiety/anxious/nervous/worry	2
	Freaked out	0

Table 3

Participant One Depression Symptom-Related Words	# of Times The Word Was Used
Sad	0
Hopeless	0
Tired	0
Cried	0

Participant one (represented by the red line in Figures 1 and 2) used no intrusion-related words, no avoidance-related words, one word associated with alterations in cognition and mood, and one word associated with alterations in arousal and reactivity during the course of her one hour ethnographic interview. She kept a positive outlook on life, stating that “other people in the world have other issues that are more complicated than [hers]. When [she] was diagnosed [she] refused to delve into self pity. Do what you gotta do and deal with whatever comes at you.” She repeated multiple times that she felt lucky the diagnosis was not worse, although she still suffered from chronic breast pain due to the lumpectomy she received over two years ago; physical pain was the main complaint that she had. She also mentioned that she was a private person in general, and did not want to burden others with her illness at the time of her diagnosis. She mentioned that she “didn’t tell many people what [she] was going through until after surgery.” Participant one used no other words associated with PTSD symptoms. Further, she used no words to indicate that she was experiencing any depressive symptoms at the time of her diagnosis, or over two years post-diagnosis, although she did mention that the pain after surgery was considerable, possibly leading to a temporary depressive state around the time of the six-week interview, which would have been consistent with the elevated depressive symptoms in

Table 1 compared to baseline and six months. Overall, participant one used the least number of PTSD and depressive-related words in her interview. It was clear from our conversation that she did not have cancer-related PTSD symptoms, regardless of her prior traumas.

Table 4

Participant Two	PTSD Symptom-Related Words	# of Times The Word Was Used
Intrusion-Related Words	Dreams/nightmares	0
	Flashbacks	0
	Memories	0
	Rumination	0
Avoidance-Related Words	Denial	0
	Disbelief	0
Alterations In Cognition & Mood Related Words	Angry	1
	Cried	0
	Retreated/private	2
	Alone	0
	Guilt	0
	Numb	0
Alterations In Arousal & Reactivity Related Words	Fear	0
	Scared	0
	Anxiety/anxious/nervous/worry	7
	Freaked out	1

Table 5

Participant Two Depression Symptom-Related Words	# of Times The Word Was Used
Sad	0
Hopeless	0
Tired	0
Cried	0

Participant two (represented by the blue line in Figures 1 and 2) used no intrusion- or avoidance-related words, but did use three words associated with alteration in cognition and mood, and eight words associated with alterations in reactivity. Participant two had by far the highest levels of PTSD and depression symptoms based on PCL-5 and BDI scores across the second two time points. She mentioned multiple times that she was a control freak, and that when she was diagnosed she “felt a complete loss of control.” She mentioned this loss of control multiple times throughout the interview. Based on our conversation, the participant seemed to be experiencing intrusion symptoms, although she did not use the associated words. Distressing memories and intense psychological distress when reminders or cues of the traumatic event are brought up are two examples of intrusion symptoms (DSM-5 Diagnostic Criteria for PTSD); these are symptoms that the participant described during the interview. When asked about her treatment regimen, she repeatedly expressed that she would never take part in any sort of treatment again if she were to relapse. Her voice became shaky as she stated “I am more anxious now two years after my diagnosis than I ever have been. I think about those months constantly. I did not agree with the treatment they put me on, and felt like I was dying to live...so many studies on breast cancer do not support the medical care that women of color need. If the cancer

comes back, I will not be taking part in any more treatment.” This is also a clear exhibition of avoidance symptoms with regard to external reminders of the trauma.

The participant noted that relationships with friends and family changed markedly after her diagnosis. She avoided people and kept to herself, as she did not want them to see her in that vulnerable position. She went so far as to drive herself to her chemotherapy appointments because she refused to ask for help, guarding her privacy. Feelings of detachment from others and a persistent negative emotional state (two symptoms of alterations in cognition and mood) were also evident from speaking with the participant. She reported feeling detached from her friends, and constantly felt angry and guilty about her diagnosis. Lastly, she explained that she had been having angry outbursts, the most significant of which was on the day that she was diagnosed. She reported being calm and collected all day, but after receiving a boot on her car at a restaurant later that night, she broke down and could not control her anger. In addition, she reported having difficulty concentrating. These symptoms fell under the category of alterations in arousal and reactivity. Although her wording did not match up exactly with the data analysis used, it was clear from the conversation that the participant experienced one or more intrusion symptom, one or more avoidance symptoms, two or more negative alterations in cognition and mood, and two or more alterations in arousal and reactivity. Thus, at more than two years post-diagnosis, the participant was still experiencing high levels of distress, self-inflicted social isolation, and aversion to future treatments owing to her prior experience with breast cancer.

The participant did not use any of the depression-related words (Table 5), and did not mention any sort of depressive symptoms during the time between diagnosis and adjuvant therapy. Although this is contradictory to data found in the quantitative analysis portion of the study, this could be due to the amount of time that had passed between her diagnosis and the

current interview, which was over two years. It is possible that she may have blocked out memories of depression, or that she remembered her outlook differently with the passage of time.

Table 6

Participant Three	PTSD Symptom-Related Words	# of Times The Word Was Used
Intrusion-Related Words	Dreams/nightmares	0
	Flashbacks	0
	Memories	0
	Rumination	0
Avoidance-Related Words	Denial	1
	Disbelief	3
Alterations In Cognition & Mood Related Words	Angry	2
	Cried	2
	Retreated/private	0
	Alone	2
	Guilt	0
	Numb	0
Alterations In Arousal & Reactivity Related Words	Fear	2
	Scared	4
	Anxiety/anxious/nervous/worry	5
	Freaked out	0

Table 7

Participant Three Depression Symptom-Related Words	# of Times The Word Was Used
Sad	2
Hopeless	1
Tired	2
Cried	2

Participant three (represented by the purple line in Figures 1 and 2) used no intrusion-related words, four avoidance-related words, six words associated with alterations in cognition and mood, and eleven words associated with alterations in arousal and reactivity. Throughout our conversation it was clear that she had been exhibiting PTSD symptoms during the time after her diagnosis and before surgery. Of the three women I interviewed, participant three was by far the most emotional about her experience with cancer. She was originally unsure if she wanted to participate, as she was worried it would bring up too many negative emotions and memories for her (a sign of avoidance), but called me back and told me she wanted to help in any way she could with early mental health intervention research. The participant had clear reactions to the external cues given by the ethnographic questions that symbolized aspects of the trauma of being diagnosed with cancer in particular. She mentioned that she received her cancer diagnosis via an online patient portal through Grady Hospital, rather than through a face-to-face interaction with a medical professional. As soon as she got her diagnosis she “went to the internet to look up the specifics. [She] started crying and didn’t know what to do because [she] didn’t know how bad it was. [She] didn’t have the words to describe the fear and hopelessness, and immediately broke down.” Speaking about the trauma over two years later, she began to cry,

and had to take multiple breaks to compose herself throughout the interview. It was clear that any cue or reminder of the event was a trigger for her. Exhibition of avoidance symptoms included significant efforts to avoid memories and other feelings that were closely related to the trauma of her diagnosis. She mentioned multiple times that she secluded herself after her diagnosis, and felt that although she had a considerable support system, she was fighting the battle completely alone, avoiding those around her who were reminders of the life she used to have. The major negative alterations to her cognition and mood were a persistent negative emotional state, and an inability to experience positive emotions. She was “very very sad all the time, and so anxious. [She] had always been an anxious person, but the anxiety went up to a whole other level after the diagnosis. [She] was scared constantly and couldn’t enjoy anything else.” Negative alterations in arousal and reactivity included hypervigilance at certain times, as she explained that she was always on guard and anxious for the uncontrollable; she also reported being easily startled. The participant reported one or more intrusion symptoms, one or more avoidance symptoms, two or more negative alterations in cognition and mood symptoms, and two or more negative alterations in arousal and reactivity during the time after diagnosis and before surgery. It should be noted that she stated that the diagnosis itself felt like a much larger trauma in her life than any of the additional treatment that she received.

In addition to directly reporting that she was depressed in the time following her diagnosis, the participant used all of the words associated with depression symptoms in Table 7 during her interview. This information was consistent with high BDI scores at both the baseline and six-week time points. Thus, it can be concluded that the participant continued to experience high levels of distress continuing for several years after the diagnosis.

5. Discussion

a. Interpretation of Results

The current study examined the effects of a breast cancer diagnosis on PTSD and depression symptoms in AA women at three timepoints: pre-biopsy baseline, six weeks post-diagnosis, and six months post-diagnosis. Three of the four Avon study hypotheses ran contrary to the quantitative data analysis. The first hypothesis expected more ASD and acute PTSD symptoms to be found at the six-week time point than at the pre-biopsy baseline visit; however, data from Table 1 exhibited an average PCL-5 score of 31.25 at baseline versus an average score of 28.75 at the six-week visit across all four participants, which was a 2.5 point decrease; for these women, acute PTSD symptoms appeared to decrease from the time of diagnosis to the time immediately following surgery. Since the cutoff for a preliminary PTSD diagnosis is a score of 31 or higher, this PCL-5 score decrease also suggested that, on average, women started above the cutoff at baseline, and fell below the cutoff at six weeks. Another hypothesis expected acute PTSD symptoms to be less severe at the six-week visit than at the six-month visit; however, Table 1 exhibited a further PCL-5 score decrease from 28.75 to 15; a 13.75 point decrease. Lastly, we expected depressive symptoms to be more severe at the six-month time point than at either of the other two time points; however, Table 1 exhibited an average BDI score of 17 at the six month time point, compared to an average score of 22 at the six-week time point and an average score of 13.5 at baseline. Thus, depressive symptoms were more prevalent at the six-month time point than they were at baseline; however, symptoms decreased on average from six weeks to six months. The results were consistent with the expectation that women would experience more depressive symptoms on average at six weeks post-diagnosis than they did at baseline. It can be concluded that for the four participants in this study, PTSD symptoms

decreased on average over the six months that they were monitored, whereas depression symptoms increased from baseline to six weeks, and decreased at six months, while still staying higher than symptoms at baseline.

Our work with both quantitative and qualitative analysis concludes that acute PTSD symptoms were most elevated in AA women at the time of diagnosis. Through qualitative analysis, it can also be concluded that cancer-related distress can linger for over two years post-diagnosis. While these conclusions are based on trends in both data and ethnographic conversation, there was some variance at the individual level. Given these findings, more studies should continue to analyze PTSD and depressive symptoms at given time points through qualitative analysis with a larger volume of participants.

With respect to PTSD symptoms steadily decreasing on average through time, these findings were consistent with research from Chan et al., 2018, who found that PTSD symptoms declined considerably in the majority of breast cancer patients within the first three months post diagnosis and again after the completion of treatment; however, 34.1% of the patients who were initially diagnosed in this study experienced worsening symptoms at the four-year mark. This was also consistent with the qualitative findings in our study, in which two of the participants who had initially qualified for a PTSD diagnosis were still experiencing symptoms over two years later, indicating a possible correlation between strength of initial reaction to the diagnosis and chronic PTSD symptoms. This being said, the current study demonstrates that cancer-related PTSD in women diagnosed with breast cancer may decline over time due to the fact that the cancer diagnosis itself, in addition to consequential feelings of uncertainty, seem to be the most traumatic experiences in the process, as consensus information provided by Mehnert et al., 2006 also acknowledges. That being said, Mehnert et al. accept that it is difficult to account for factors

such as age, prognosis, cancer stage and severity, race, differing treatment plans, prior trauma and mental health histories, etc and how they may affect an ultimate PTSD diagnosis. All of the participants in the current study were AA with low grade cancers; however, there was variation in treatment plans, prior trauma, mental health histories, and age, which could have accounted for individual variation in PTSD symptomology. Thus, further longitudinal research should be conducted on correlations between early signs of cancer-related PTSD and later chronic symptoms, taking into account extraneous factors, particularly race.

Surprisingly, Andersen's model of psychologic morbidity, which can be used to predict both symptoms of PTSD and underlying variance in self report systems, was not accurately matched in many regards in this study. Andrykowski et al., 1998 found a significant correlation between higher levels of PTSD symptoms and less social support, greater pre-cancer trauma history (pre-existing PTSD diagnoses), a more recent treatment completion, and more advanced disease. Andrykowski's study and the current study differ in major ways, which could explain some of the different findings between them. Only 4% of participants in Andrykowski's study were AA, whereas 100% of the participants in the current study were AA. Additionally, the participants in the current study all had previous histories of trauma, whereas Andrykowski's study did not evaluate previous trauma; this could create major differences in experimental outcomes, as participants with trauma histories might view a cancer diagnosis (especially of low severity) as a minor event, compared to previously experienced traumas. Of the three participants in the current study who were interviewed for qualitative analysis, the participant with the least social support and the greatest pre-cancer trauma history scored far below the average of the other participants on the BDI and PCL-5 at every time point, and expressed during the ethnographic interview that she did not feel like her diagnosis was a significant trauma, as she

had been through “much worse.” Additionally, the participant with the least advanced disease (stage 0) seemed the most likely candidate for a chronic PTSD diagnosis of the three women, and scored above the average of the other participants on the BDI and PCL-5 at almost every time point. While this case study may not have had a large enough sample size to see the patterns that Anderson’s model predicts, these findings could also point towards temperament as a critical factor that the model does not mention. Temperament can affect the way we react to everything, from a small inconvenience to a life-altering event starting in infancy. While environmental influence may also play a huge role, temperament could be a driving force for predicting PTSD symptoms after cancer diagnosis and treatment. Future studies should look into correlations between temperament and both short-term and long-term PTSD symptoms.

Finally, the average depression symptoms of the four participants were most elevated about a month after their breast cancer diagnosis, and declined at the six month mark. This finding runs somewhat contrary to previous literature, namely Vahdaninia et al., 2009, whose findings suggested that similarly to PTSD symptoms, depression symptoms also declined over three time points from the time of diagnosis. Among the four participants in the current study, all BDI scores increased at the six-week time point, meaning either that the sample size was insufficient, or that more exploration needs to be completed in relation to longitudinal studies of depression symptoms in breast cancer patients. Vahdaninia’s study also found that 22.2% of patients presented with severe depression at the 18-month followup; the current study yielded similar results through ethnographic exploration. One out of the three participants exhibited multiple symptoms of cancer-related depression over two years after her diagnosis, using every word associated with depression in her interview, and explicitly mentioning how much she still struggled with the symptoms. If depression symptoms peak at six weeks, but still remain in

20-30% of cases, it is imperative that early mental health intervention takes place in order to alleviate symptoms as they occur. This intervention may serve as somewhat of an adjuvant therapy, as anxiety and depression can have an extremely negative impact on disease outcome, as Aapro among others mentioned in previous literature.

From the ethnographic interviews, we were able to obtain an understanding of what the participants were experiencing throughout their journey with cancer, which we could not have inferred from PCL-5 or BDI scores. One understanding that became clear was that all three women coped with their diagnosis by self-isolating, which in turn led to social reclusion, changes in the dynamics of and relationships with loved ones, and symptoms of depression. Participant two mentioned multiple times that she didn't want her husband to see her as weak. "We had only been married for a year when I was diagnosed. He married a strong, independent, go-getter woman, and I didn't want him to worry. The process of losing my hair, nose bleeding, not being able to walk, and so much else really affected our relationship. We aren't physical anymore," she stated in a dejected tone. She also mentioned that she lost touch with most of her friends between the diagnosis and the pandemic, and refused help most of the time, often driving herself to the hospital and back to receive chemotherapy. While participant two isolated herself for fear of vulnerability, participant one did not reveal her diagnosis to family or friends, stating that "[she] was a private person. [She] didn't want anyone to worry so [she] didn't tell them and kept it to [her]self." Having external social support often plays a significant role in decreasing the number of PTSD symptoms experienced, according to research by Andrykowski. Notably, all three participants in the current study lacked this social support. We concluded through ethnographic study that social isolation and withdrawal had a negative impact on the mental and emotional well-being of these women during the time after their diagnosis; mental health intervention and

treatment at the time of diagnosis could have played a role in preventing some of these negative impacts from becoming long term problems.

Another critical theme brought up in the ethnographic section of the current study was the idea of gaps in the healthcare system relating to medical treatment. Participants were shocked at the lack of communication between medical professionals and patients. For instance, participant three received her diagnosis via a patient portal, rather than through face-to-face interaction. Participant two had been diagnosed in person; however, she was told with absolute certainty that she would only need surgery. When it became clear she would also need both chemotherapy and radiation, she was not properly warned about any of the side effects. Because of this, the participant felt cheated by the healthcare system, and lost all of her trust in the doctors who did not reveal the difficulties of treatment, instead focusing solely on survival over palliative care. The concept of “dying to live,” as participant two put it, reflects a huge gap in the way healthcare is provided. Medical professionals are taught to cure, and don’t often learn how to treat keeping the patient’s full well-being in mind. Treating to cure without adequate empathic communication, can lead to a cancer-free, but PTSD and/or depression-ridden patient, who may never be willing to go through further treatment for any future diagnoses. This was the case for participant two. It is therefore critical for medical professionals to take into consideration the entire story of the person they are treating, keeping in mind what that patient wants and needs during their cancer journey. This could establish trust and cooperation between doctor and patient, and possibly lead to a decrease in symptoms of PTSD and depression due to a higher overall satisfaction with treatment.

b. Strengths

The current study has many strengths. Previous studies on breast cancer and mental health often used white women for the majority of their population samples, thus only representing a small portion of the total population of women with the diagnosis, and ignoring how the health disparities between Caucasian and AA women might have affected how they experienced the trauma of diagnosis and treatment. This study looked only at a population of AA women, which allowed us to account for the factor of race as a major influence on PTSD and depression symptoms during the course of diagnosis and treatment. The Grady Trauma Project works largely with low income individuals with previous histories of trauma. This study worked with low income women who had previously experienced traumatic events, while many studies do not take into account previous trauma or income levels, but rather look at severity of disease as the driving force for psychological distress. Additionally, the second part of this study looked past the survey and bloodwork data that previous studies assessed, and augmented them through an ethnographic approach. To sit down and have a conversation with someone about their experience of a traumatic event is very different than probing them with a long list of yes or no questions. Through the ethnographic interview process, I was able to connect with the women and obtain information about their lives after trauma that one could realistically not obtain from a survey. The ethnographic information could then be compared to the survey data to successfully obtain a much fuller picture of the traumatic process, and could thus be analyzed given that supplementary data.

c. Limitations

There are several limitations to consider that impacted the development and trajectory of the study. First and foremost, the study was stalled unexpectedly for two years during the

pandemic; what had once been a highly interactive and in-person recruitment system became a virtual effort. Study team members had to restart the project under completely different circumstances, and found much less success in virtual recruitment. It was much more of a challenge to find women who were willing to participate in the lengthy study. We have not been able to recruit any new participants since 2020, thus requiring a complete change from the proposed procedure. Originally, the ethnographic interview was to take place at the six-week time point, in order to more fully assess PTSD and depression symptoms before the onset of adjuvant therapy. Because no new participants were recruited, we decided to use the quantitative data from the four previously recruited participants, and to reach back out to them for the ethnographic portion of the study. One of the previous participants was unreachable, leaving only three accounts of trauma over two years post-diagnosis. This being said, the study was able to acquire a different perspective, and look at trauma recovery with more longevity taken into account. Despite the small sample size, we were still able to obtain sufficient data for a case study. An additional limitation has been that due to the pandemic, Grady Hospital has had to make room for incoming COVID patients, and has unfortunately had to turn away many cancer patients with lower severity disease. This means that women with low grade cancers like the participants recruited before the pandemic were refused treatment at Grady and sent to other hospitals; if they were never patients at Grady, then the study team would not have access to their contact information to attempt to recruit them. Thus, there was a far smaller group of people that were even eligible to be recruited for the study, and those who were eligible were most likely far more ill than those who were previously interviewed, which introduced its own set of obstacles. Finally, due to the small sample size and the lack of new recruitment, there was little diversity in cancer severity, which can be a huge factor for variation in PTSD and depression symptoms. The

women in the current study were all diagnosed with low grade cancers which reached complete remission within months of diagnosis. In the future, when more participants are recruited, I would like to incorporate groups with high grade cancers who may need much more intensive treatment regimens and may even be looking into more palliative care than curative care. I believe that this will further diversify the sample and allow for comparative analysis between groups of participants. Future investigation should also compare groups of women based on race, income, age, and level of support, to account for any further disparities in mental health resources between these groups, and how this affects PTSD and depression symptoms.

d. Conclusion

Overall, this study supports the conclusion that a breast cancer diagnosis can be considered a traumatic event, and that psychological distress, including PTSD and depression, can arise immediately at the time of diagnosis, even becoming chronic in a minority of cases. When treating cancer, it is therefore imperative to enter the process with systems in place to support and tackle mental health issues that may arise. Unfortunately, many medical professionals and oncologists do not take into account the person behind the disease they are suffering from. As one of the participants angrily mentioned, she felt like she was “dying to live,” and that “the doctors weren’t concerned with anything but keeping [her] alive.” Another participant cried as she recalled being diagnosed for the first time through a patient portal; she was astounded by how impersonal medical care had become, and felt like no one was looking out for her. Patient care could be drastically improved with a simple change in mindset by providers. From the findings of this study and other previous literature, it is clear that a cancer diagnosis can cause immense distress, and can lead to long term mental health consequences. If resources such as therapy, medication, support groups, and face-to-face medical consultations

were instituted from the time of diagnosis, and were consistently and readily available throughout the entire course of treatment, the cancer-related mental health battles would likely not result in lifetime trauma disorders. Unfortunately, it is important to mention that while there is some support provided in wealthier communities, there is little to no support provided in low income, often largely AA communities. Since cancer-related stress can be extremely detrimental to disease outcome, many AA cancer patients do not get access to equal medical and psychological care. This is only one of many health disparities experienced by AA women diagnosed with breast cancer. With more access to support systems, along with more understanding and individualized medical care, it is likely that we would see a dramatic decrease in both long term PTSD and depression symptoms in many of these patients.

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7. Appendix

The following appendix exhibits the list of ethnographic questions asked during the one hour conversational interview for qualitative analysis. It must be noted that this list of questions went through IRB approval prior to their use.

1. Just to get some logistics, what was the exact diagnosis you received, and what did the treatment plan entail?
2. Bring me through the time leading up to your diagnosis. When did your symptoms first begin if you had any, and what were they?
3. During the time leading up to your diagnosis, how were you feeling emotionally?
4. When did you know that you could possibly be diagnosed with cancer? What were you feeling during this time?
5. Bring me through the moments when you were officially diagnosed with breast cancer. When you heard the words “you have cancer” for the first time, what was going through your mind?
6. What did you do the rest of the day after your diagnosis? Can you describe a little bit about what was going through your mind during this time? What were your biggest concerns?
7. How would you describe your mood in general after you were diagnosed but before you started treatment?
8. How did your anxiety levels change after you were diagnosed but before you started treatment?
9. Did you have surgery to remove any or all of the cancer? Did you undergo a lumpectomy or a full mastectomy? Was this in one or both breasts? Have you undergone or are you thinking of undergoing reconstructive surgery?
10. How were you feeling before surgery? Were you concerned about anything in particular?
11. How were you feeling after surgery? This could include feelings of relief, anger, being invaded, etc.

12. Are you currently in a serious relationship or marriage? If so, how do you feel this relationship was impacted by your diagnosis itself?
13. Do you have children? If so, how do you feel this relationship was impacted by your diagnosis itself?
14. How do you think being diagnosed with cancer impacted your relationship with friends and extended family immediately following the diagnosis?
15. If you received additional treatment such as chemotherapy or radiation, how were you feeling about this right before its commencement? Were you feeling a lot of anticipation? Trying not to think about it?
16. Is there anything else that you feel is important to add that you haven't previously mentioned?