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Contextualizing the Young Adult Female Breast Cancer Experience: Developmental, Psychosocial, and Interpersonal Influences

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Abstract

Breast cancer is the most common cancer among American women (American Cancer Society [ACS], 2016b). Adolescents and young adults (AYAs) as a group have a worse prognosis when compared to older adults (e.g., Tichy, Lim, & Anders, 2013). Due to limited understanding of the biology of cancers for AYAs, inadequate representation of AYAs in clinical trials, and AYAs' unique psychosocial healthcare needs, the prognosis for this group, as compared to older women, is comparatively poor. One step in addressing the survival gap for AYAs is to explore the developmental and psychosocial factors that shape their illness experiences. This qualitative study explored the illness experiences of women diagnosed with breast cancer between the ages of 18 and 39 years old. Using a phenomenological approach, 23 breast cancer survivors were interviewed using a semi-structured interview. Findings indicated the centrality of developmental, sociocultural, and psychosocial systems in shaping women's health care experiences. Future studies should explore the ways in which medical providers attend to these systems across the breast cancer trajectory.

Keywords

Breast Cancer, Psychosocial Healthcare, Qualitative Research

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Breast cancer is the most common cancer among American women (American Cancer Society [ACS], 2016b). Adolescents and young adults (AYAs) as a group have a worse prognosis when compared to older adults (e.g., Tichy, Lim, & Anders, 2013). Due to limited understanding of the biology of cancers for AYAs, inadequate representation of AYAs in clinical trials, and AYAs' unique psychosocial healthcare needs, the prognosis for this group, as compared to older women, is comparatively poor. One step in addressing the survival gap for AYAs is to explore the developmental and psychosocial factors that shape their illness experiences. This qualitative study explored the illness experiences of women diagnosed with breast cancer between the ages of 18 and 39 years old. Using a phenomenological approach, 23 breast cancer survivors were interviewed using a semi-structured interview. Findings indicated the centrality of developmental, sociocultural, and psychosocial systems in shaping women's health care experiences. Future studies should explore the ways in which medical providers attend to these systems across the breast cancer trajectory. Keywords: Breast Cancer, Psychosocial Healthcare, Qualitative Research

Breast cancer is the most frequently diagnosed cancer among women, with 249,260 new cases diagnosed in 2016 (American Cancer Society [ACS], 2016b). Breast cancer statistics for adolescent and young adult (AYA) populations are complicated by widely disparate definitions of young adulthood (Barr, 2011; Zebrack, Matthews-Bradshaw, Siegel, & Young, 2010). The AYA Progress Group, a National Cancer Institute (NCI) and Lance Armstrong coalition, define AYAs as individuals diagnosed with cancer between 15 and 39 years old (Bleyer et al., 2008; NCI, 2006a). Using this definition, breast cancer and melanoma are the most common cancers among women aged 25 to 39 years old (NCI, 2015).

According to Bleyer and colleagues (2008), when woman younger than 45 years old are diagnosed with breast cancer, the younger she is the worse the projected outcome. Breast cancer in AYAs has a worse prognosis, greater frequency of high-grade and larger-sized tumors, lower estrogen/progresterone receptor-negative (Gnerlich et al., 2008). In some cases, tumors demonstrate a heightened expression of human epidermal growth factor receptor 2 (HER2) when compared to those found in older women. Overproduction of HER2 genes and proteins triggers uncontrolled breast cell growth and division, which can cause breast cancer to grow and recur at a higher rate when compared with HER2 negative cancers (Anders et al., 2006).

Factors considered to contribute to these poor outcomes include a limited understanding of the biology of cancers most common in AYA populations, the inadequate representation of AYAs in clinical trials, and AYAs' unique psychosocial healthcare needs (e.g., Tichy, Lim, & Anders, 2013). A diagnosis of cancer during adolescence and young adulthood generates unique medical and psychosocial issues due, in part, to the developmental tasks associated with this age group, such as family planning and career development (Barnett et al., 2016). Key stakeholders, such as the Institute of Medicine (IOM) and the NCI, identified an increased need

for healthcare providers to address the developmental and psychosocial factors that influence individuals' cancer experience (Adler & Page, 2007; NCI, 2006b).

Developmental Stage and Breast Cancer

The medical and social science literatures contain varied ways of operationalizing young adulthood (Barr, 2011; Zebrack et al., 2010). Discordance regarding the young adult age range exists at international and national levels. For example, the upper age limit for AYAs varies considerable among Eurocare (24 years old; Gatta et al., 2013), the Surveillance Epidemiology and End Results Program (29 years old; Bleyer, O'Leary, Barr, & Ries, 2006), and the NCI and Lance Armstrong Foundation (39 years old; Bleyer et al., 2008; NCI, 2006a). The oncology literature in the United States follows the AYA Progress Group's recommendations to define AYAs as individuals diagnosed with cancer from age 15 to 39 years old (Bleyer et al., 2008; NCI, 2006b).

AYAs share salient biologic, physiologic, medical, and psychosocial characteristics when compared with pediatric, middle, and older adults (NCI, 2006b). For example, a slim minority of AYAs develop chronic medical conditions such as type II diabetes, alcoholism, and hypertension, which causes organ dysfunction. AYAs' experiences with disease are typically limited to brief stints of infectious disease, sports-related injury, or other mild illnesses. Additionally, biologic and physiologic maturity remains relatively stable during one's 20s and 30s. Young adults have passed puberty but have not yet experienced hormonal or immune response decline. AYAs also share similarities in terms of adherence to recommended treatment and follow-up care, and, ultimately, disease outcomes (NCI, 2006b). AYAs vary in terms of their survivorship needs as they relate to long term consequences of treatment (Barr, 2011). A cancer diagnosis and subsequent treatment interrupts key developmental milestones, which in turn creates unique psychosocial and medical needs for individuals and their families (Barnett et al., 2016).

Young adulthood is marked by inherent instability and transitions, including separation from family of origin (Tanner, 2006). Instability and transition for AYAs may be exacerbated with a diagnosis of breast cancer due to factors such as invasive treatment and long-term recovery, which are unique to their illness experience. For example, young adult women diagnosed with cancer renegotiate their relationships with their family of origin, romantic partnerships, and peer relationships in light of the cancer diagnosis and treatment. These renegotiations vary within the AYA population and for their significant others. Tanner (2006) describes a recentering process for young adults:

> Recentering constitutes a shift in power, agency, responsibility, and dependence between emerging adults and their social contexts—primarily experienced by emerging adults as a period during which parent regulation is replaced with self-regulation. (p. 27)

In addition to renegotiating relationships with family of origin, individuals diagnosed with breast cancer also must renegotiate the relationships they have built with medical and social systems and establish new relationships with medical and social service personnel during the breast cancer experience (Klimmek & Wenzel, 2012). A recent systematic literature review by Siembida and Bellizzi (2015) highlight the importance of medical providers attending to adolescent cancer patients' and their families preferred communication preferences, with particular focus on adjusting methods of communication to meet the needs of the parents, the adolescent, and the family unit.

Sociocultural and Psychosocial Influences

Since Betty Ford publicly shared her experiences with breast cancer in the 1970s, the psychosocial impact of cancer has received increased attention, funding, and research (Travado et al., 2012). For example, the ACS started the Psychosocial Collaborative Oncology Group and the IOM wrote a report called, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs* (Adler & Page, 2007). Research on, and clinical attendance to, the role of development across the cancer trajectory and its relationship to psychosocial concerns gained attention with the Adolescent and Young Adult Oncology Progress Review Group's report (NCI, 2006b).

In 2005-2006, the NCI partnered with the Lance Armstrong Foundation to conduct an Adolescent and Young Adult Oncology Progress Review Group to address the special research and cancer needs of the AYA age group. The progress review group convened a multidisciplinary group of more than 100 experts related to AYA cancer research and recommended next steps toward a national agenda to improve cancer prevention, early detection, diagnosis, treatment, survivorship, and outcomes in AYAs.

The team determined that health care provider training programs and health care professionals in general are not effectively recognizing AYA-specific issues, which result in AYAs receiving substandard medical and psychosocial care (NCI, 2006b). Among several recommendations, the team suggested that more research is needed to understand patient and survivor life stage and developmental characteristics across six domains: intellectual, interpersonal, emotional, practical, existential/spiritual, and cultural. The final recommendation was to ensure excellence in service delivery across the cancer care continuum (NCI, 2006b).

In 2013, the National Cancer Policy Forum of the IOM conducted a workshop on quality of life concerns and survivorship experiences of AYAs diagnosed with cancer. Shortly thereafter, the NCI held a complementary conference to identify research gaps in oncology, with a focus on basic biology, epidemiology, and clinical trial enrollment. Summaries from these workshops echo previous research findings regarding the deleterious impact of cancer on psychosocial and developmental adjustment for AYAs (Bellizzi et al., 2012; Clark & Fasciano, 2015; IOM, 2013). For example, cancer diagnosis and treatment disrupts completion of developmental milestones, at times permanently altering individuals' abilities to fulfill personal and professional life goals. Areas of life that are prone to disruptions for AYAs include: financial, career/education, trust in health, emotions, body image, self-esteem, health behaviors, peer relations, fertility, future plans, and family dynamics (Bellizzi et al., 2012; Clark & Fasciano, 2015; Institute of Medicine [IOM], 2013). According to workshop findings, there are several potential late psychosocial effects of cancer, which include: affective disorders (e.g., anxiety, depression), post-traumatic stress, sexual dysfunction, relationship problems, employment and educational problems, insurance discrimination, and adaptation and problem solving (Nass et al., 2015). Barnett and colleagues (2016) conduced the most recent systematic review of the psychosocial needs and outcomes of AYAs diagnosed with cancer. They uncovered the nuanced experience of AYA cancer survivors, describing the interaction effect between medical and psychosocial challenges that impact outcomes following treatment.

Philosophical Orientation

The primary aim of this study was to elicit the illness narratives of women diagnosed with breast cancer during young adulthood. Specifically, this study addresses women's perceptions of environmental systems that influence their illness experience. Environmental systems are defined as cultural, societal, community, and family (Rigazio-DiGilio, 2000;

Rigazio-DiGilio, Ivey, Kunkler-Peck, & Grady, 2005). This study was informed by the philosophical orientation of phenomenology and the ecosystemic perspective.

The philosophical underpinning of phenomenology is the belief that an essential, perceived reality exists for individuals who experience a shared phenomenon (Starks & Trinidad, 2007). With that being said, phenomenology acknowledges that idiosyncratic experiences exist for individuals, even if they experienced the same phenomenon. Phenomenology invites a deep and nuanced understanding of the process by which individuals make meaning of their lives (Stewart & Mickunas, 1974).

The ecosystemic perspective is the broad frame by which to understand the ways in which individuals and environmental systems develop over time and in relationship to other individuals and systems (Rigazio-DiGilio, 2000; Rigazio-DiGilio et al., 2005). Development and adaptation are explained through transactions among individuals, families, and wider systems, called the interactive triad. The connection among these domains has been validated in the literature as critical influences in worldview development, or, the ways in which individuals make sense of the world around them (Harland, 1987; Ivey, 1986, 2000; Luria, 1928; Vygotsky, 1986). Although this framework was originally created to reconstruct psychological illness from a relational standpoint, the concepts were readily translatable to physical illness (Rigazio-DiGilio & Cramer-Benjamin, 2000). A phenomenological and ecosystemic framework was utilized to offer awareness of women's experience with breast cancer and the influence wider environmental systems in shaping said experience.

Addressing Researcher Bias

Phenomenology requires that researchers engage in a self-reflection process called "bracketing," or, the identification and recognition of *a priori* assumptions and biases. The goal of this process is to ensure that the research design is created and analysis is conducted with an open mind, meaning that the research team must be fully aware of their preconceived biases regarding the phenomenon being studied (Sokolowski, 2000). Bracketing practices include triangulation with colleagues and supervisors and writing memos to track the evolution of ideas across the research trajectory (Charmaz, 2006; Speziale & Carpenter, 2007). I, Cameron Froude (principal investigator), Danielle Green (secondary coder), and Jaylen Williams (secondary coder) engaged in a variety of bracketing practices during project conceptualization, data collection, and data analysis.

We constructed memos regarding our assumptions and biases regarding the phenomenon under investigation and discussed these findings across the research process. Based on our limited personal experience with AYAs diagnosed with breast cancer, we believed that young adults would experience substantial hardship during the breast cancer experience and rely primarily on the medical community to shape their healthcare experience. Danielle and my professional experiences as marriage and family therapists informed our belief in the centrality of family and community as key factors in shaping AYAs' psychosocial experience. We believed in participants' demonstration of resilience in the face of breast cancer, demonstrated by their pursuit of life goals with the support of friends and family.

Danielle and I discussed the role of power and privilege in the data gathering phase, sharing the belief that when an individual holds the role of researcher and/or healthcare provider, the relational dynamic shifts. Furthermore, we discussed the ways in which we account for power and privilege in our clinical practice as marriage and family therapists, exploring ways that these practices may be translated to data collection and analysis. Jaylen, secondary coder, joined conversations about the role of power and privilege as an undergraduate student, drawing connections to her experience as a student in relation to

academic professors as well as her role as a resident advisor to students in the dormitory in which she lives.

All team members indicated a shared belief that providing healthcare in ways that align with patients' cultural background and values is imperative to the practice of good medicine. We shared the belief that young adults were at a particular disadvantage due to their lack of representation in the literature. Additionally, all team members were part of the young adult cohort. Reflecting on our present experiences, we believed that young adulthood was a developmental phase marked by periods of instability and ambiguity, a collective worldview also present among the study sample.

All team members acknowledged significant overlap in terms of our worldviews despite distinct difference in our personal histories. This realization alerted the team to pay careful attention to instances when agreement came easily and quickly, ensuring that our collective worldview did not eclipse other ways of analyzing the data. We engaged in the analytic process with full knowledge that objective research is impossible. Rather, we strived to make our biases and assumptions transparent in order to account for them as completely and thoroughly as possible.

The co-authors on this manuscript were members of my dissertation committee, who assisted with editing the document and approving the methodological approach. They were not closely involved in data collection or analysis. They did not complete memos regarding their assumptions/biases. Rather, they self-monitored bias while they read and discussed their predominant orientations and assumptions with me during monthly research meetings. Sandra Rigazio-DiGilio, Laura Donorfio, and Keith Bellizzi conduct research on developmental, cultural and psychosocial aspects of illness across the lifespan. Each of them has studied chronic illness using a range of quantitative and qualitative methodologies, which laid the foundation for rich discussions with me regarding study conceptualization and research design.

Methods

I optimally utilized tenets of phenomenology and grounded theory to inform the identification of research questions, approach to data collection, and analysis. Phenomenology allowed for flexibility regarding study design and identification of organic themes in data analysis. Grounded theory provided a necessary structure that informed the process by which we analyzed the data. Said another way, I utilized phenomenology to elicit women's narratives with breast cancer and grounded theory to interpret women's narratives.

Health research often focuses on aspects of life that are considered sensitive topics because they have the potential to prompt emotional or psychological distress for both participants and researchers (Sieber & Stanley, 1988). Qualitative methods, including in-depth interviewing, are an ideal methodology to investigate such sensitive topics (Elam & Fenton, 2003). This is especially true when researchers create opportunities to build rapport with participants by demonstrating care and empathy, conditions considered crucial for eliciting information on sensitive topics (Dickson-Swift, James, Kippen, & Liamputtong, 2007).

Setting

Data was collected over the phone with 23 participants, in-person with five participants, and on a face-to-face Skype call with one participant. The constant among all interviews was that participants chose their preferred communication modality. During the interviews, I took detailed notes of the discussions and also wrote key points that arose during the discussions. Individual interviews were audiotaped and transcribed. Each interview lasted between 40 and 150 minutes, with the average interview lasting 75 minutes.

Population

The population of interest included the following: (a) women who were diagnosed with breast cancer between the ages of 18 to 39 with stage zero, one, two, and three breast cancer and (b) women who were last diagnosed with breast cancer more than four and less than ten years ago. For example, one participant was 56 years old at the time of the interview. Her last breast cancer diagnosis was 7 years ago at 49 years old and her first breast cancer diagnosis 19 years ago at the age of 37 years old.

Individuals diagnosed with stage four cancer were excluded because of the unique illness trajectory and psychosocial needs associated with end-of-life (Siegel, Naishadham, & Jemal, 2012). The five-year survival rate for stage four breast cancer is 22% (ACS, 2016a) and the median survival is 18 to 24 months (NCI, 2000). This is remarkably low when compared with five-year survival rates for stages zero to three, which range from 100% to 72%.

The Surveillance, Epidemiology, and End Results Program (SEER) database reports the five-year survival rate for women with stage zero, one, and two breast cancer is between 93% and 100% (ACS, 2016a). The five-year survival rate for stage three is 72% and the median survival rate is 4.9 years. Given these statistics, women diagnosed with stage zero, one, two, and three breast cancer were included if they were diagnosed four to ten years ago. Conversely, women diagnosed with stage zero, one, two, and three breast cancer were excluded if they were diagnosed less than four or more than ten years ago. Additionally, women diagnosed with breast cancer before age 18 or after age 39 were excluded.

Sample

The sample included a random selection of 23 participants from the 111 women who met inclusion criteria and expressed interest in participating. On average, participants were 39 years old at the time of the interview, ranging from 30 to 56 years old. At the time of the interview, participants lived in the following U.S. geographic regions: seven resided in the Northeast (NY, PA, NJ, MA), four resided in the Midwest (IN, IL, OH, SD), five resided in the South (TX, DC, MD, NC), and seven resided in the West (HI, CA, MO, AZ, CO). Concerning salient cultural identity markers, all participants identified as young adult breast cancer survivors. Eighteen participants identified as White American, two participants identified as African American, one participant identified as Russian, one participant identified as Russian-American, and one participant identified as Native American.

Eighteen participants reported a lifetime history of one breast cancer diagnosis, four reported two diagnoses of breast cancer, and one reported three diagnoses of breast cancer. Age at first diagnosis spanned from 23 years old to 39 years old, with the average age being 31 years old when first diagnosed. Age at last diagnosis spanned from 23 years old to 49 years old with the average age being 33 when last diagnosed. At the time of the interview, participants were, on average, seven years out from their first diagnosis and six years out from their last diagnosis, with the range being zero to 19 years out from a cancer diagnosis. To illustrate the lower limit, there was one participant in treatment for breast cancer recurrence at the time of the interview, approximately seven years after her first diagnosis. On the other end of the range, one participant received a second diagnosis of breast cancer seven years ago, approximately twelve years after her first diagnosis. Breast cancer type, stage, and treatment shifted considerably across the cancer continuum.

Participant Recruitment

Following approval from the University of Connecticut's Institutional Review Board, participants were recruited through a flyer posted on the Young Survivors Coalition Facebook page and word-of-mouth. After the participant initiated contact, I reviewed the consent form with the participant over the phone and secured her verbal consent. Upon obtaining verbal informed consent, I began the interview. After the completion of data analysis, participants received a brief summary of study findings and provided additional information either through e-mail or verbally on the telephone. Participants were compensated $25 at the completion of the interview.

Data Collection Procedures

The semi-structured interview included a qualitative demographic section followed by questions related to the phenomenon of interest. The opening section of the interview elicited sociodemographic information. This section began with the question, "how would you describe your identity?" Participants included information about their age, development, religious beliefs, relationship status, financial situation, friend group, health conditions, and other salient aspects of their identity. I probed further for more information with questions such as "what relationships have you been in from the time you suspected you had a health problem through today?" and "what was your financial situation from the time you suspected you had a health problem through today?"

Thereafter, the interview was informed by the Barts Explanatory Model Inventory (Rüdell, Bhui, & Priebe, 2009) and the McGill Illness Narrative Interview (Groleau, Young, & Kirmayer, 2006). Interview questions guided participants in using their own language to describe the health problem, discuss its consequences, and explain their experiences. The interview elicited participants' perceptions of their illness, preferred treatment approaches, and personal evaluation of relationships with medical and social support networks.

For example, in eliciting the history of the health problem, I asked questions such as, "Can you tell me about the first time anyone knew you experienced the health problem and describe what happened in your life from that time until today?" Inquiry about participants' healing community and social support included questions such as, "could you tell me about interactions you've had with medical doctors and/or healers from the time you suspected you had a health problem until today?" Follow-up probes included questions such as, "did your doctor and/or healer give you any treatment, medicine, or follow-up from the time you suspected you had a health problem to today?" and "how have you dealt with each of these recommendations?"

Questions regarding self-identity and social support included inquiry into participants' perception of self and self-in-relation to others. For example, I asked questions such as, "how do you think your health problem changed the way you feel or think about yourself?", "how do you think your health problem changed the way you think and feel about others?", and "how do you think your health problem changed the way that others feel or think about you?". I used principles of microskills, well-known and validated approaches to systematic information gathering, to facilitate interviews (Ivey & Ivey, 2007). Microskills are the communication building blocks that provide the foundation for meaningful interaction, for example: attending (e.g., vocal qualities, useful silence, encouraging elaboration), tracking (e.g., open ended questions, closed ended questions, encouragers), and active listening (e.g., paraphrasing, synthesizing, summarizing). My utilization of microskills during the interview allowed me to anticipate how the participant would respond to various modes of interacting and tailor interview strategies to the unique needs of the participant (Ivey & Ivey, 2007).

Data Analysis

The research team analyzed transcripts using an iterative, inductive process whereby data was decontextualized to identify codes of meaning and then recontextualized to identify patterns and themes. We then confirmed themes across all transcripts (Ayres, Kavanaugh, & Knafl, 2003; Morse & Field, 1995). The following four phases comprised the analytic process.

Phase One: Identifying Initial Categories, Core Ideas, and Expanded Categories

Phase one included open and structural coding to identify initial categories. The transcribed text of all interviews was coded according to the research question. A chunk of data ranged from one line to entire paragraphs (Dey, 1993; Glaser & Strauss, 1967; Strauss & Corbin, 1990). I coded data associated with the initial categories to identify core ideas and expanded categories. I identified core ideas. Next, core ideas were re-evaluated to determine their relationship to each other.

Phase Two: Verifying Categories, Core Ideas, and Expanded Categories across Interviews

Phase two included comparing core ideas and expanded categories across interviews to determine the reliability findings. Two questions guided this process: "To what extent I observe evidence of these themes in the data?" and "What additional themes emerge from memos?" (DeCuir-Gunby, Marshall, & McCulloch, 2011).

Core ideas and expanded categories were organized into a codebook, which is a structured way in which to guide data analysis (Crabtree & Miller, 1999; Fereday & Muir-Cochrane, 2006; MacQueen, McLellan, & Kay, 1998). Following Boyatzis' (1998) structure for describing a useful, meaningful code, I included the following in descriptions of core ideas and expanded categories: name; definition; a description of how to know when core idea/expanded category occurs; a description of any qualifications or exclusions to the identification of the core idea/expanded category; and examples, both positive and negative, to eliminate confusion when looking for a core idea and/or expanded category. The process resulted in a codebook to identify environmental systems, the purpose of which is to identify the system influencing a participant's experience.

Phase Three: Operationalizing Categories, Core Ideas, and Expanded Categories into Codes

After creating the codebook, I refined the utility and reliability of the codebook with Danielle and Jaylen, secondary coders and revised any and all sections of the codebook according to their feedback. Coding collaboratively allowed us to maintain consistency in our interpretations of the text and application of codes. For example, women discussed their perceptions of others engaging in selfless ways with them across the cancer trajectory. In turn, these women engaged selflessly with others, particularly other individuals diagnosed with cancer. Danielle and I checked whether these experiences of selflessness fit within previously established codes. They did not. I then searched throughout all interviews and saw that women shared examples that reflected the concept, "altruism." This code was then integrated into codebook as an example of a sociocultural value present in the cultural group, young adult cancer individuals from the point of diagnosis through recurrence and/or survivorship.

I engaged in selective coding, which helped to determine how codes related to one another and contributed to the broader conceptual themes identified in the early stages of

coding. A core aspect of selective coding is the identification and analysis of negative cases, or, data that diverge from and/or contradict codes and themes. Identification and exploration of negative cases was an integral part of proposing future research directions. Negative cases often signaled an experience particular to one participant or two participants who shared similar life and illness experiences and/or aspects of cultural identity, such as age at diagnosis and genetic predisposition to breast cancer. Examining parts of the data that tell a different story allows for the development of, a rich, nuanced narrative (Strauss & Corbin, 1990). Discussions concluded when there was 100% agreement on the correct usage of the code.

Phase Four: Coding for Themes across Transcripts

Throughout the coding process, beginning with open and structural coding until the completion of coding, I utilized memoing and relied on memos from Danielle and Jaylen to inform future coding. These memos documented thoughts and questions about codes created from the text, which we discussed during research meetings. During meetings with Danielle and Jaylen, we discussed the possibility of coding line by line. We decided to code large chunks of data, sometimes multiple paragraphs, because the codes were quite broad as they correlated directly to the three research questions. This was appropriate because the purpose of structural coding was to divide the data based on the research questions.

Following structural coding, we attempted to code line by line. However, line by line coding decontextualized the data and results were less meaningful. When we coded by question or paragraph the results were far too broad and lacked necessary nuance. Therefore, we decided to forgo strict rules regarding the length of a code. Instead, we coded based on the meaning of a given piece of data. A code could be as short as a sentence or as long as a paragraph so long as every piece of data shared a common theme (MacQueen et al., 1998).

Strategies to Ensure Rigor and Trustworthiness

Guba and Lincoln (1981) provide a framework for assessing and ensuring rigor and trustworthiness in qualitative research, which included: credibility (i.e., evaluation of whether or not the research findings represent a credible conceptual interpretation results), transferability (i.e., degree to which the findings can be applied or transferred beyond the boundaries of the project), dependability (i.e., consistency of findings), and confirmability (i.e., objectivity of data and interpretations).

First, I utilized MacQueen et al.'s (1998) approach to collaborative coding. I engaged in peer review and debriefing of audiotapes and transcripts every fifth interview with Danielle. I engaged with Danielle in open discussions to overtly examine aspects of my personal and professional worldviews that are accessed, become salient, and significantly influence my approach to each interview and my responses to particular types of exchanges that occur or information that is shared during the immediacy of the interview. Peer review acts for qualitative research as inter-rater reliability acts for quantitative research. Utilizing secondary coders to analyze data requires that the research team establish inter-rater reliability, or, consistency of coding among coders (Morse, Barrett, Mayan, Olson, & Spiers, 2002; Saldaña, 2009).

Danielle, Jaylen and I identified aspects of my personal and professional worldviews (e.g., values, assumptions, preconceived hypotheses, beliefs, biases) that, through review and discussion, were seen as influencing my approach to interviews and the ways in which I tended to respond to certain types of interactions or responses as these occurred in the immediacy of the interview. Danielle and Jaylen asked difficult questions about my coding process, meaning making, and interpretations. Danielle, Jaylen and I kept written accounts of these peer

debriefing sessions (Lincoln & Guba, 1985). Written accounts described what we learned or became aware of and informed future interviews.

Throughout the analysis process, I met with Jaylen and Danielle to review every fifth transcript for inter-rater reliability. We coded every fifth interview individually according to the codebook. During our meetings, we engaged in a detailed review of the transcript, discussing our decision-making process for coding. We noted, discussed, and resolved all discrepancies between our coding. Staying true to MacQueen et al.'s (1998) collaborative coding approach, Danielle, Jaylen, and I engaged in discussions about when and why we applied specific codes. When Danielle, Jaylen, and I utilized the codebook with no discrepancies between our codes, I documented 100% agreement. When we determined that some codes were consistently miscoded, we engaged in consensus discussions to arrive at conclusions about the meaning of the data. When there were new definitions of codes identified, we continued to utilize MacQueen et al.'s (1998) collaborative coding approach using the new definitions of the codes until there was 100% agreement after discussion.

Results

As a result of the data analysis process, three themes emerged: environmental systems of influence, quality of systems, and power in relation to systems. For the purposes of this paper, I describe the first theme, environmental systems of influence, which included the following: (a) developmental, (b) temporal, (c) sociocultural and political, (d) medical, (e) social, (f) work-school, (g) religious and spiritual, and (h) exercise. Descriptions of each system are detailed in further detail below, including representative quotations from participants that describe common experiences.

Developmental

Participants described their experiences with breast cancer as a period of time within the context of their lifespan. Therefore, the outermost category was identified as *developmental milestones*. The *developmental milestones* category reflected shared experiences, including illness, which marked individuals' developmental trajectory. Participants identified developmental milestones as part of their cancer experience.

The sub-category, *moratorium*, described the dramatic impact that illness had on participants' developmental course and the ways in which illness challenged their ability to achieve developmental milestones. For example, participants discussed their desires to launch from their family of origin, build a family, establish a career, among others, and uncertainty regarding the degree to which cancer would prevent them from achieving these milestones. One participant discussed the impact of illness on her ability to find a partner and conceive a child:

> So I was still actively trying to find a partner that I could – that I could possibly marry and have a kid with. Once I got diagnosed, of course all of that went on hold…I decided that I wasn't going to have kids. But it felt like more of a decision that was taken away from me because of my diagnosis and because of my body now being so different because I had the reconstruction. I had the radiation. I'm on the Tamoxifen. 'Cause if I was gonna have a child, I couldn't be on the Tamoxifen, too. So it felt like the decision was taken away from me.

Participants who were employed at the time of diagnosis noted the negative impact that breast cancer had on their ability to achieve career traction and longevity. Frequent medical

appointments combined with arduous treatment and long recovery times prevented participants from fully engaging in work tasks. Even in cases when employers accommodated participants' needs and expressed empathy toward them, women believed that breast cancer deleteriously impacted their career trajectory. For example, in spite of having "plenty of skills and trades"," one participant shared that she was unable to work due to chronic illness symptoms preventing her from consistent attendance. She explained, "If I go to work tomorrow and I don't call off, I'm probably going to mess up really bad with something really important. I'm going to get fired, and that's providing I make it there tomorrow."

Temporal

The definition of the temporal system transformed during consultations with the secondary coder. Originally, the temporal system reflected the ways in which women measured their lifespan and, by extension, the breast cancer experience. For example, when speaking about her life as a whole, participants described the breast cancer experience as a phase in life that delineated a literal and figurative mark in time. One participant shared that she "completely missed" a critical life phase, young adulthood, due to breast cancer. This participant stated, "I was basically in treatment or recovering from my treatment my entire 30s. I woke up, and I was 41." The breast cancer experience also marked a symbolic phase of time when individuals' life philosophies shifted. Take, for example, a participant who reported "feeling happier and more grateful for…small things that we might take for granted otherwise" after she recovered from breast cancer.

When asked to share their experiences specifically related to breast cancer, participants explained their story in a linear fashion. Participants began at the time when they suspected they had a health problem and described the sequence of events through survivorship and/or recurrence. Participants followed the temporal sequence outlined in the cancer continuum, beginning their story with early detection and continuing through diagnosis, treatment, recurrence, remission, and survivorship. In this case, narratives often included cancer prevention efforts at the end of the narrative as participants expressed concern regarding a recurrence.

After meetings with the secondary coder, we broadened the definition of the temporal system to include participants' changing perceptions of self and/or systems over time. For example, one participant described the slow process it took for her to perceive herself as feminine after losing feeling in her breast. The participant explained, "Having to find your new normal...I guess I just feel that I'm more used to it and accepted...it is what it is." In this case, the participant shared the importance of the passage of time in facilitating her sense of a "new normal" and accepting her body post-surgery.

Sociocultural and Political

These sociocultural and political systems emerged from categories within women's breast cancer narratives, including: illness attitudes, socioeconomic status, and young adult woman. The category, *illness attitudes*, reflected women's perception of society's cultural attitudes regarding illness. Participants' described a range of illness attitudes that individuals in medical and social support networks adopted around illness, oftentimes projected unwillingly onto participants. For example, the attitude that traditional medical doctors have expert knowledge that should be followed and individuals must fight illness and eradicate it from the body.

The category, *socioeconomic status*, reflected women's descriptions of the influence of socioeconomic status on their quality of life and decision-making processes. Socioeconomic

status included participants' financial stability (e.g., employment history, housing) and accessibility to resources (e.g., transportation, medical information). Participants' socioeconomic status varied as a sample and across the breast cancer trajectory. At the time of the interview, participants' socioeconomic status ranged from lower to upper income. All participants identified as belonging to the cultural group, young adult women, categorized as *young adult woman*. This category reflected the cultural groups to which women identified and the ways in which gender and phase of development framed the illness experience.

Medical

The following sub-categories were identified for the broader category, *medical support networks*: *traditional medicine* (e.g., oncologist), *complementary medicine* (e.g., acupuncturist), and *medical research* (e.g., randomized clinical trial). Every participant described the role of traditional medicine in their breast cancer experience, namely the presence of primary care doctors, oncologists, breast surgeons, nurses, and mental health providers. Participants discussed medical professionals' styles, focusing on approaches that were concordant and discordant with their personal values. One participant described the relationship she built with an oncologist, a doctor who the participant credits for facilitating her physical and socioemotional healing:

> My doctor, yeah, my oncologist out in Boston, she's my age; she's a redhead, she's on the leading edge. She's the Chair of the women's breast center…She had the credibility and the gumption to push me [emotionally]…

By contrast, the same participant described a relationship with a doctor to whom she was referred by a breast surgeon:

> So I had experience with other doctors who didn't fit my style…He was paternalistic. He was a dad. You know, he was a grandpa. He was like, "Don't worry, dear, I've got it all under control. I understand...." He was just patronizing. That didn't comfort me. He wasn't hearing me…So I went on the hunt for interviewing different doctors.

Participants discussed *medical research* in terms of their awareness of and/or interest in: (a) participating in clinical trials, (b) accounting for research findings when engaging in medical decision-making, and (c) describing medical professionals' summary of research findings to explain their medical choices. Medical research, in all of the above forms, influenced women's perceptions of risk, and, by extension, their medical decision-making. One participant, who reported that her diagnosis vacillated between stages three and four due to the tumor's close vicinity to the brain and spine, explained the role of medical research in her decision to undergo a prophylactic hysterectomy:

> I then also read up on Tamoxifen, and a very low percentage of – there is a very low rate, but a rate is there, of Tamoxifen can cause endometrial or uterine cancer, and those words were followed by the word "fatal". So knowing I would be on [Tamoxifen] at least five years, and since then the course of treatment has changed to ten, I sought out and got a hysterectomy.

Social Systems

Participants identified *social support* networks as part of their breast cancer experience. The following sub-categories were identified for the broader category, social support networks: *family of origin* (e.g., father, mother, brother), *chosen family* (e.g., husband, step-children), *friends* (e.g., college roommate), and *cancer survivor network* (e.g., support group). Social support systems played distinct yet complementary roles for women across the breast cancer continuum.

Participants relied on social systems in a variety of ways depending on the particular system's knowledge base. For example, a participant would not solicit advice from her husband regarding alternative approaches to pain reduction from lymphedema. Rather, she would likely consult with a fellow breast cancer survivor. On the other hand, participants with children leaned on their male partners for assistance with childcare rather than soliciting that type of support from a member of a support group.

Participants spoke both about the centrality of *family of origin*, *chosen family,* and *cancer survivor networks* across the breast cancer continuum. Both family of origin and chosen family members provided affective and instrumental support to participants. After discussing her desire to be "in the driver's seat" of her life after breast cancer treatment, one participant described the role of her family of origin and chosen family in assisting her during treatment: "I really, really relied on…my mother and I relied on my boyfriend and my father a lot because I just – I mentioned that I sort of shut down during it."

Another participant, who self-identified as an "army wife," discussed the importance of friends during the cancer experience, particularly during times when her significant other was deployed abroad. This participant discussed the ways in which friendships blossomed into activism through women publishing stories in local media and newspaper outlets about the challenges of women maintaining their health in the context of a military lifestyle. Specifically, she and others "raised awareness of young Army wives who[se]…lives get so absorbed in our husbands' careers and trying to take care of kids that sometimes we forget to take care of our own health because our lives are so crazy all the time." Most participants described friendships evolving from shared experiences with cancer. These friendships often became an informal cancer survivor network as illustrated above.

Participants discussed formal *cancer survivor networks*, such as a hospital-created support group targeted toward women with breast cancer. Some participants found solace in connecting in person for a structured gathering with other breast cancer survivors. However, others noted that they were the youngest members of breast cancer support groups, which prevented them from engaging in a meaningful way with other members. For example, one participant accepted an invitation from another young breast cancer survivor to attend a breast cancer support group at a local hospital. The participant reflected:

> Everybody else there was like in their fifties and sixties and late forties…I was younger and was enjoying life and living life a lot differently than a lot of these older women were, and it just – the group just didn't fit me anymore. The younger women was where I needed to be…

This participant ultimately found an online support group for young women with breast cancer.

Work-School

Work system and school system were combined because participants' experiences as graduate students, often including a paid assistantship, reflected women's experiences at their

places of employment and vice versa. A theme included participants' negotiation process with authority figures regarding participants' need for modified work duties at various points along the cancer continuum.

Authority figures both accommodated and failed to accommodate participants' changing needs in the workplace. For example, one participant explained that a professor with whom she worked relinquished her teaching assistantship after she experienced prolonged medical complications that impacted her ability to perform as she did prior to these complications. The participant hypothesized as to the reasons for the professor's behavior: "I think in some ways [the medical complications] just became more than – because it was going on longer than maybe what [the professor] thought was normal." Alternatively, a participant working in a training department described the supportive nature of her team, explaining that instead of having her perform "big, complex tasks" they "went ahead and reassigned [her] to some smaller, not so complex tasks."

Religious and Spiritual

Religious networks and *spiritual networks* were combined due to their intertwined nature. The religious network category reflected religious communities to which women belonged, such as a church and/or prayer group. The spiritual network category reflects participants' metaphysical beliefs that may or may not be connected to a religious network. Religious networks always included elements of spirituality. However, spiritual networks did not always include elements of a religious network. One participant illustrated this distinction in her description of herself as a "spiritual empath": "I'm definitely tied to the energies of the earth. I don't have any particular doctrine that I follow or rituals."

Another participant described the interconnected nature of spirituality and religiosity in her description of the ways in which Alcoholics Anonymous (AA) provided a foundation for prayer on which she relied during her 17 years of sobriety from alcohol and subsequent breast cancer diagnosis. After describing the influence of her "higher power" during recovery from alcohol and breast cancer, this participant shared the role of prayer in securing strength from God. She explained:

> So me praying to God, helping God give me strength, was important to me. So I'm not religious, but praying to God every day gives me strength. I actually learned that in AA, even though I did grow up as a Lutheran.

When asked to describe her identity, one participant share that she was "born and raised Southern Baptist" who did not recently attend church. However, this participant shared her "personal relationship with God" as she "look[ed] to Him for guidance." When asked how prayer influenced her relationship to health, the participant responded that she had "the belief that everything happens for a reason, and there's some reason behind me having to go through this struggle." Spirituality offered many participants with philosophical explanations for their illness. Religious rituals, such as prayer, offered participants a structure with which to reflect on their experiences and choices.

Exercise

The term *exercise network* for this category may include a group of people engaging in exercise (e.g., walking group members) and/or it may include an establishment intended for exercise (e.g., yoga studio, gym). Participants who reported a routine exercise regimen considered exercise as a central part of their identity.

Participants utilized exercise as a way to relieve stress and cope with the psychological and emotional challenges associated with illness. Some participants exercised alone, whereas others used exercise as a vehicle to connect with others. One explained that part of taking care of herself included going to the gym in the morning and evening. After exhausting the traditional medical community's approaches to chronic pain, this participant created her own approach to pain management. She explained the role of daily exercise in alleviating pain and increasing mobility:

> Everything gets really tight up into the whole cancer-treated area, 'cause I also had upper lymph nodes involved, into my armpit and neck. I have a nice little scar on my right – in my armpit and on the neck besides also radiation contacting the area. I've come to notice that if I don't exercise for a few days – I do wear lymphedema compression sleeves, and even with wearing those, though, if I'm not making it to the gym to do some serious movement, with scar tissue and just with the lymphedema, everything just settles into this vise grip if I don't work out enough.

Discussion

Participants' narratives provided us with information on the systems that influenced their psychosocial and medical experiences during the young adult breast cancer experience. According to Klimmek and Wenzel (2012), the process by which individuals constitute and reconstitute their lives and relationships is highly dependent on individuals' particular illness and social context as it encompasses the full scope and diversity of patients' lives and health related processes. Participants' experiences were nested within the wider systems in which they were situated. Women navigated breast cancer in the context of the social systems within which they live and maintain relationships.

Not surprisingly, all participants described the centrality of their stage of development, young adulthood, in framing their breast cancer experience. Research demonstrates that women navigate chronic illness, such as breast cancer, and its psychosocial consequences within the context of their stage of development (Barr, 2011; NCI, 2006a). This research showed that participants were living in a time of their lives marked by instability and uncertainty. Within that wider context, participants strived to maintain and build stable relationships on which they could rely. Participants reported heightened motivation to build new relationships that could support them during breast cancer. Women described the process by which they attempted to maintain systemic stability with social support networks they relied on historically. Participants also engaged in processes to create systemic stability with newer social supports, such as breast cancer networks.

Additionally, participants must maintain relationships, negotiate occupational work, manage finances, address complex emotional and psychological responses to illness, and maintenance of overall health Klimmek and Wenzel (2012), Women also must manage the planning efforts necessary to engage in these simultaneous processes. Persons with cancer do not engage in these processes alone. Rather, transactional exchanges among people, namely those in medical and social support systems, create a context for individuals with cancer to engage in these concurrent processes (Klimmek & Wenzel, 2012).

This study reflected those findings, demonstrating that participants' relationships with social support networks were in constant flux across the cancer care continuum. True to findings in the developmental literature, participants in this study varied in their developmental stage, which impacted their relationship to others and role within systems (Barr, 2011; NCI, 2006a). For example, one participant, diagnosed at age 23, described her eagerness to move

back into her own apartment after living with her parents during cancer treatment. The participant explained that the transition moving home "was hard because [her] parents are very strict." She added, "So I had only lived on my own for two years and then moved back home, but I knew that, like, I wanted back out."

Barnett and colleagues (2016) conducted a systematic literature review, which demonstrated that AYAs present psychosocial and quality of life concerns, namely physical, psychological, and social, are significantly impacted by developmental challenges. For example, the authors describe the stark contradiction between AYAs' medical and psychosocial needs and the hallmark features of young adult development, which include autonomy and independence. During a phase in development when individuals develop their own beliefs, values, and worldview as distinct from their family of origin, cancer challenges AYAs' abilities to assert their independence and autonomy from parents (Siembida & Bellizzi, 2015).

Participants spoke about the ways in which they re-negotiated relationships with individuals in their social and medical support networks to fulfill their immediate needs (e.g., asking parent to provide transportation to radiation) while striving to maintain their autonomy (e.g., living in a private apartment instead of moving in with parents). Participants' description of this negotiation reflects the recentering process described by Tanner (2006) as a shift in power, agency, responsibility, and dependence between individuals and their social contexts. Rather abruptly, young adult women diagnosed with breast cancer must adjust to additional social and medical contexts with which most are unfamiliar. Women then must renegotiate these relationships in the context of their life and also their illness. Research shows that individuals diagnosed with breast cancer also must establish and renegotiate the relationships they have built with medical and social systems across the illness trajectory (Klimmek & Wenzel, 2012).

Another important finding was women's report of the developmental moratorium they experienced because of breast cancer. Reflecting Barnett and colleagues (2016) systematic review findings, participants discussed a variety of developmental milestones that they hoped to achieve or actually achieved during young adulthood. These included, but were not limited to: launching from family of origin, marrying a romantic partner, conceiving children, and building a career. Consistent with other research (Bellizzi et al., 2012), participants spoke about the negative impact of breast cancer on achieving professional and personal milestones, such as moving into a work position with more power and having children. Areas of life that are prone to disruptions for AYAs include: financial, career/education, trust in health, emotions, body image, self-esteem, health behaviors, peer relations, fertility, future plans, and family dynamics (Bellizzi et al., 2012; Clark & Fasciano, 2015; IOM, 2013). Participants in this study affirmed the several late psychosocial effects of cancer identified by Nass and colleagues (2015), including relationship problems, employment and educational problems, insurance discrimination, and challenges with adaptation and problem solving.

Additionally, participants spoke at length about the ways in which developmental milestones, such as romantic relationships and employment/education, impacted their psychosocial and medical decision-making processes from diagnosis through survivorship. Klimmek and Wenzel (2012) found that salient examples of health-related processes particularly for persons with cancer include: maintenance of medical treatments, symptom management, diagnostic and ongoing surveillance, crisis prevention, recurrence, and maintaining continuity of care. In light of chronic biological, physical, and psychosocial effects of cancer treatment, participants adjusted their future planning to account for these changes. Participants tied their identities to their future plans, particularly when plans were connected to family planning. Plans for the future, such as having a child, moving out on their own, and educational and career advancement reflected participants' core value. Therefore,

when cancer treatment challenged the viability of those plans, participants experienced a threat to their identity.

Limitations

The present study has limitations that must be documented. First, the essence of the method is its inductive nature. This inductiveness requires the researcher to approach the data from a perspective of relative neutrality, the main goal being to describe and understand, rather than to evaluate patterns within and across cultures. Health research, for the most part, has taken the direction of evaluation, its purpose being to develop state-of-the-art practice. Thus, health research usually approaches its data with a great deal of knowledge about literature on the topic being studied, as well as a set of beliefs about healthcare. Furthermore, because most topics in health research have some controversial aspect, the researcher is challenged to pay close attention to her personal biases, whether based on treatment choice, ethnicity, race, socio-economic status, or any other aspect of an individual's identity and experience.

Third, data for the study consists of participants' verbal responses to interview questions. As is the case with most qualitative investigations, the present study relied on self-report, retrospective information provided by participants. The broad inclusion criteria placed minimal restrictions on time since diagnosis, including women at least four and no more than 10 years post diagnosis. Given this, participants could be at any phase of the survivorship/recurrence stage. Therefore, participants could range from being five to 10 years post-treatment. Depending on participants' experiences across the illness trajectory and other factors, their recall of events would vary, causing retrospective recall error (Patton, 1990). Needless to say, recall error would influence research findings.

In addition, participants' descriptions of their experiences with family members and wider systems reflect only the perspective of the participant herself. Perspectives of family members and individuals in wider systems cannot be directly inferred from participants' experiences. Therefore, the subjectivity of the interviews must be acknowledged. Regarding this limitation, it should be noted that the purpose of the research is not to garner an objective account of events during breast cancer. Rather, the purpose is to explore participants' subjective experiences across the illness trajectory as a way to understand the ways in which individuals' make sense of their experiences in the context of their medical and social support systems.

Significance

Breast cancer is optimally managed via multidisciplinary care, involving a team of specialists from a variety of diverse disciplines. Given the current challenges in cancer care, it is important to gain an understanding of the systems that women perceive as particularly facilitative and constraining as they and their families navigate the breast cancer trajectory, as well as the potential avenues for reconciling patient care and needs. Findings derived from this process would yield results that are relevant to specific health-related disciplines as well as broader research efforts integrating disciplines.

From an interdisciplinary perspective, studies of this nature could be replicated with other populations of women with breast cancer (i.e., Black women, older adult women) and other cancer trajectories. Research could also study the experiences of medical professionals working with diverse populations of individuals diagnosed with cancer, exploring their experiences with patients across the illness trajectory. These studies could address similar questions and objectives as the present study. Such studies could: (a) further extend and expand the understanding of the nature and degree of difficulty administering patient-centered care,

(b) examine efforts within or across disciplines that have led to patient-centered care programs as well as factors that have hindered such progress, and (c) determine the degree to which addressing women's systemic needs at particular junctures of the illness trajectory invites consideration of multidisciplinary, patient-centered care. Such research could inform the development of transdisciplinary cancer research and care, investigating the usage, benefits, and limitations of such endeavors.

Conclusion

As evidenced in this analysis, individuals exist at the center of a layered nest of systems; the patient, herself, is only one small part of the larger illness experience. A host of sociological and institutional factors complicate the medical experience, leaving women mired in challenging interpersonal and intrapersonal dynamics. A truly integrated approach to healthcare should include continued analysis of how women are influenced by and influence the systems that govern daily life and healthcare in America.

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