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"It Takes a Village to Get Through Cancer," A Photo-Elicitation Study Exploring Lived Experiences
of Community Cancer Survivors

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Under the direction of the research advisor:

Dr. Katie Polo, Associate Professor

A Research Project Entitled

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Abstract

Introduction: Cancer survivors continue to experience complications that last months to years following diagnosis and treatment which can impact daily life. The purpose of this study was to explore the lived experiences of adult community cancer survivors related to daily activities and occupational performance.

Methods: Phenomenology study design and photo elicitation, types of qualitative visual methodology were utilized to blend photos and words from survivors. Thirteen adult cancer survivors were recruited for this study at a community-based cancer support organization in central Indiana. Open coding, axial coding and constant comparative analysis approach was utilized to achieve trustworthiness and conceptual saturation.

Result: Investigators identified that participants experienced a shift in cultural context, wherein they took on a new context defined by their cancer survivorship. This shift of cultural context is dynamic, inter-related, and ultimately paralleled by the experiences of the researcher identified themes, of distress, changes in perspective, client factors, and in occupational performance. The themes of distress, changes in perspectives and client factors dynamically influenced occupational performance and engagement.

Conclusion: In order for occupational therapists to provide client-centered, holistic, and evidence-based practice into cancer survivorship care, occupational therapists need to understand the unique changes in roles, routines, and occupations and consider how this cultural context shift, along with distress, changes in survivors perspective, and client factors, lead to changes in occupational performance.

"It Takes a Village to Get Through Cancer," A Photo-Elicitation Study Exploring Lived Experiences of Community Cancer Survivors

Life expectancy and remission rates have increased, and as a result, two out of every three people diagnosed with cancer are expected to live for at least five years after initial diagnosis (Bluethmann, Mariotto, & Rowland, 2017; National Cancer Institute, 2019).

According to the National Cancer Institute (2019), 16.9 million cancer survivors are living in the United States today. Due to these changes in life expectancy, the definition of a cancer survivor has evolved to a person living with cancer from initial diagnosis to the end of life (CDC, 2017; National Coalition of Cancer Survivorship, 2014).

Cancer survivorship is an emerging area of practice within occupational therapy, as survivors are often left with lingering complications that may pose challenges when engaging in meaningful activities in everyday life (Baxter, Newman, Longpré, & Polo, 2017). The side effects of cancer can last months or years after treatment ends; therefore, cancer is now being considered a chronic condition (Baxter et al., 2017; Peoples, Brandt, Wæhrens & la Cour, 2017; Hwang, 2015; Lyons, Lambert, Balan, Hegel, & Bartels, 2013). A systematic review found that 36.7%-54.6% of cancer survivors reported having disabilities related to performance in basic and instrumental activities of daily living (ADLs) after cancer treatments (Neo Fettes, Gao, Higginson, & Maddocks, 2017).

Occupational therapy practitioners provide intervention strategies and individualized care for cancer survivors to help combat the impact of late side effects, improve occupational performance, and enhance quality of life (Braveman, Hunter, Nicholson, Arbesman, & Lieberman, 2017; Polo & Smith, 2017). In order to meet the needs of this growing population, it is necessary to first understand survivors' feelings, thoughts, and perceptions regarding their

journey. The purpose of this study was to understand the lived experiences of adult cancer survivors living in the community and how their occupational performance was impacted by cancer.

Literature Review

Fatigue

Cancer-related fatigue (CRF) is a distressing, persistent, subjective sense of tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning (National Comprehensive Cancer Network, 2014, p.FT-1).

Cancer-related fatigue differs from other forms of fatigue, as it is brought on by or experienced as a result of cancer. The fatigue is constant and not alleviated by sleep or rest and can influence one's ability to perform daily activities (American Cancer Society, 2016a; Iwase et al., 2015; Hall, Mishel & Germino, 2014). Survivors have been found to reduce or change participation in occupations within multiple studies in which CRF was the primary cause for lifestyle alterations (Dorland et al., 2016; Lyons et al., 2013; Morrison & Thomas, 2014).

A cancer survivor's reduction in occupational participation has negative impacts on various areas of the person's life. Sexual activity is one area of occupational performance that is at risk for reduced participation of the cancer survivor due to the negative impacts of CRF (Bober et al., 2013; Hopkins et al., 2015). Cancer-related fatigue also creates issues related to participation in leisure activities. Shipp, McKinsty, and Pearson (2013) and Sleight (2017) identified disruption to normal leisure patterns of cancer survivors—survivors felt the need to alter or cease engagement in their usual leisure occupations and engage in more passive activities because of low energy levels. A cancer survivor's lack of participation in these areas can have significant impacts on quality of life (Holm et al., 2012; Peoples et al., 2017).

In addition to reduced participation in sexual activity and other leisure activities, individuals who experience CRF reported increased difficulty participating in social occupations (Curt et al., 2000). There is strong evidence that the social lives of survivors are negatively affected due to poor endurance and cognitive changes (Hall et al., 2010; Hopkins et al., 2015; Peoples et al., 2017). Social interactions were a cause of stress for individuals experiencing CRF as a result of the unpredictable impacts of the fatigue—survivors have voiced concerns about not knowing when it would occur or how it would affect their mood, ultimately inhibiting their motivation to engage in interactions with others (Fleming, Gillespie & Epsie, 2010; Myers, 2012; Peoples et al., 2017). Furthermore, effects of CRF on mood and motivation create a misunderstanding by friends and family members when attempting to understand why survivors seemed different from their “pre-cancer selves” (Von Ah, Habermann, Carpenter & Schneider, 2013; Fleming et al., 2010; Peoples et al., 2017).

The effects of CRF are not localized to only physical energy and drive—it affects a variety of other contexts and occupations, as well (Curt et al., 2000; Morrison & Thomas, 2014). Fatigue can significantly impact employment, as employers require both physical and mental endurance (Dorland et al., 2016; Mackenzie, 2014; Morrison & Thomas, 2014). Cancer-related fatigue is one of the main reasons that cancer survivors decide to take a leave of absence or delay their return to work post-treatment (Groeneveld, de Boer & Frings-Dresen, 2013; Morrison & Thomas, 2014). Some survivors reported benefits from returning to work due to the sense of normalcy and routine it provided them; however, other survivors expressed the need to reduce their work hours to cope with their diagnosis (Dorland et al., 2016). Cancer-related fatigue can reduce a survivor's energy to work physically, and it slows down cognitive processes that are necessary for the workplace (Todd, Feuerstein & Feuerstein., 2011). Returning to work is

multifactorial and is influenced by more than just a diagnosis (Dorland et al., 2016; Mackenzie, 2014; Morrison & Thomas, 2014).

Cognitive Deficits

Cognitive deficits are among the most frequently documented symptoms experienced during cancer survivorship (Boykoff, Moieni & Subramanian, 2009; Morrison & Thomas, 2014; Von Ah et al., 2013). Cancer survivors have identified some of the cognitive impairments experienced as deficits in memory, attention, and ability to think clearly (Duijts et al., 2014; Myers, 2012; Von Ah et al., 2013). These issues occur during treatment and remain present after treatment for up to three to 10 years (Harrington et al., 2010; Von Ah et al., 2013). Researchers have classified this side effect as "invisible" and one of which the general population is not aware (Dorland et al., 2016). Cancer survivors have reported feelings of frustration and emotional distress due to the unexpected occurrence of this symptom (Boykoff, Moieni & Subramanian, 2009).

Cognitive impairments significantly impact occupational performance, creating obstacles for survivors when attempting to engage in ADLs and their routines as they did before diagnosis (Calvio et al., 2010; Todd, Feuerstein, & Feuerstein, 2011; Von Ah et al., 2013). Impaired cognitive performance influences the ability to manage responsibilities, such as driving, making payments on bills, cooking, doing chores, and remembering to shut off ovens or lights throughout the house (Groves, Fossa & Dahl, 2010; Myers, 2012; Peoples et al., 2017).

Cognitive impairments also impact social participation and employment. Survivors have difficulty engaging in social interaction with others due to the cognitive demands of conversation, including word finding and memory (Myers, 2012; Boykoff et al., 2009; Von Ah et al., 2013). Such deficits led to disengagement in social participation, as survivors reported

feeling embarrassed or frustrated when cognitive issues disrupted their interactions (Boykoff et al., 2009; Von Ah et al., 2013). Other cognitive deficits, mainly flaws in memory and attention, are a prevalent experience of cancer survivors in the workplace due to the impact of these deficits on work performance (Groeneveld et al., 2012). For example, compromised attention impacts one's ability to perform his or her job as efficiently as was done before diagnosis (Duijts et al., 2014; Von Ah et al., 2013). Survivors described instances where they were unable to cope with the demands of previous work tasks due to cognitive issues, which led them to either quit or seek early retirement (Calvio et al., 2010; Duijts et al., 2014; Fleming, Gillespie, & Espie, 2010).

Survivors identified a combination of cognitive issues and CRF cause deficits in occupational performance (Curt et al., 2000; Myers, 2012; Steirner et al., 2008). Cancer-related fatigue has an adverse impact directly and indirectly on the mental functioning of cancer survivors, which results in decreased occupational participation in areas including education, employment, and social interactions (Curt et al., 2000; Groeneveld de Boer & Frings-Dresen, 2013).

Psychosocial Changes

According to the American Cancer Society (2015), one in four people who are diagnosed with cancer experience clinical depression during and after treatment. Depression is brought on by the fear of body changes, as well as worrying about passing cancer along to future children (Robinson, Miedema & Easley, 2014; Sadovsky et al., 2010).

Psychosocial factors, along with other late effects of cancer, can lead to difficulty of cancer survivors engaging in meaningful occupations, including sexual activity and social interactions (Baxter et al., 2017; Frumovitz et al., 2005). Klaeson, Sandell, and Berterö, (2013) along with Robinson et al., (2014) and Sadovsky et al., (2010) have found that cancer survivors

who experience changes in body image or changes in masculinity or femininity struggled with low self-esteem and lacked the motivation to engage in sexual activity. These bodily changes include hair loss, weight gain, scars, and changes in body shape (Robinson et al., 2014).

Social participation is negatively affected by the lack of drive and low self-esteem in cancer survivors (Frumovitz et al., 2005; Klaeson et al., 2013; Robinson et al., 2014). Men purposely avoided social interactions when they experienced changes in their masculinity, while women avoided these situations when they were experiencing low self-esteem (Boykoff et al., 2009; Klaeson et al., 2013; Robinson et al., 2014). The lack of motivation to socialize was also due to other people not understanding what the cancer survivors were going through (Boykoff et al., 2009; Fleming et al., 2010; Von Ah et al., 2013). This lack of empathy affected the way survivors interacted with others and engaged in social occupations.

Work participation is negatively impacted by psychosocial factors, as survivors struggle to find support from family members, co-workers, and management that is necessary in order to be successful after returning to work (Duijts et al., 2014). Changes upon returning to work often include being assigned fewer or more simplified responsibilities, as well as changed attitudes of peers toward the survivor's performance in the workplace (Duijts et al., 2014; Stein, Syrjala, & Andrykowski, 2008). These changes can negatively impact a survivor's self-esteem and increase stress related to returning to work (Asher, 2011; Duijts et al., 2012; Steiner et al., 2008).

Survivorship Needs

Cancer survivors feel uneducated by healthcare professionals regarding potential side effects of cancer treatment that can have significant influences on occupational performance (Klaeson et al., 2013; Morrison & Thomas, 2014; Von Ah et al., 2013). Healthcare professionals tend to minimize client concerns when they attribute symptoms to age and other factors, leaving

patients uninformed about what to expect (Boykoff et al., 2009; Von Ah et al., 2013). Even when healthcare professionals addressed concerns, survivors stated that they felt uneducated regarding potential side effects, as well as when to apply adaptive treatment and coping methods (Klaeson et al., 2013; Morrison & Thomas, 2014; Peoples et al., 2017). This lack of guidance leads to survivors attempting to create self-coping strategies to overcome limitations that prevent them from functional occupational performance (Koch et al., 2013; Morrison & Thomas, 2014; Peoples et al., 2017). These reported inconsistencies regarding the information provided to survivors explain the poor transition between ongoing treatment and post-treatment experiences of cancer survivors (Baxter et al., 2017; Koch et al., 2013; Peoples et al., 2017).

Available literature about cancer survivorship and occupational performance has justified the concerns that survivors have regarding their symptoms. Reportedly, side effects, such as fatigue, sexual dysfunction, depression, anxiety, and cognitive deficits are present and can last up to three to ten years post-treatment (Harrington et al., 2010; Klaeson et al., 2013; Von Ah et al., 2013). Healthcare professionals should acknowledge the side effects that cancer survivors experience and look further into these issues in order to alleviate or accommodate for problems (Groves et al., 2010; Harrington et al., 2010; Koch et al., 2013). No studies have collectively explored the lived experiences of cancer survivors with varying cancer diagnoses. The purpose of the study was to explore the lived experiences of adult cancer survivors living in the community related to their daily activities and occupational performance.

Significance

Being able to engage in meaningful occupations is essential to one's identity. (Morrison & Thomas, 2014). As demonstrated in the literature, the onset of late side effects from cancer limits one's occupational performance and can be detrimental to their quality of life (Hwang et al.,

2015; Iwase et al., 2015; Koch et al., 2013). The challenge related to finding satisfaction in leisure and social activities due to CRF may prevent an individual from reaching maximum potential (Sleight, 2017). When a person is not able to engage in leisure and social activities to the extent to which they were once able, feelings of depression and anxiety may occur (Fong, Scarapicchia, McDonough, Wrosch, & Sabiston, 2017; Yonemoto et al., 2016). The anxiety and depression experienced may then prevent further engagement or cause hesitation in participating in meaningful occupations (Duijts et al., 2014).

Detecting occupational deficits and addressing these concerns by an occupational therapist can help improve the quality of life of cancer survivors. Occupational therapists can assist in identifying difficulties caused by the late side effects of cancer and provide client-centered care and interventions to overcome these roadblocks (AOTA, 2014; Polo & Smith, 2017). Occupational therapy is an underused resource when it comes to cancer survivorship, where only 32% of survivors used occupational therapy services (Pergolotti, Cutchin, Weinberger, & Meyer, 2014). Occupational therapy services can improve the quality of life, not only by providing intervention and treatment, but also by providing knowledge on how the late side effects impact the survivor and their occupational performance (AOTA, 2014; Polo & Smith, 2017). By raising awareness about what to potentially expect during cancer survivorship, cancer survivors can take preventative measures to avoid the inability to participate in meaningful and necessary occupations throughout their life.

Methodology

Study Design

In order to gain the perspective of cancer survivors living in the community, we used a phenomenology study design and photo elicitation, a type of qualitative visual methodology.

Photo-elicitation is a method that uses photographs to elicit verbal discussion in focus groups and elicits feelings, memories, and information from individuals (Glaw, Kable, Hazelton & Inder, 2017). By using this method, researchers can identify different layers of meaning and allow for triangulation between different information sources (Glaw, Kable, Hazelton & Inder, 2017).

Photo-elicitation is becoming more widely used in various disciplines and is an effective and acceptable method for qualitative research (Pain, 2012).

Procedures to address trustworthiness and credibility

Krefting (1991) suggests rigor of qualitative data can be established by implementing more than one of the four qualitative criteria for trustworthiness which include: credibility, transferability, dependability and confirmability into the study design. Creswell and Poth (2017) recommend qualitative researchers engage in at least two of these validation strategies in any given study. The researchers of this study used several strategies to support the trustworthiness within each of the criteria by implementing triangulation, reflexivity, and the use of an audit trail throughout the process.

Triangulation of data methods. Various sources of data were used during the study including demographic surveys, participant captured photographs, audio recordings, transcriptions, and field notes from focus group discussions. The researchers cross-referenced the various data sources throughout the research process, allowing the identification of patterns and recurring themes that reinforced the findings and limited bias to ensure the perspectives of the participants were accurately captured (Fusch, Fusch, & Ness, 2018; Morse, 1990).

Reflexivity. Researchers engaged in reflexive thinking during the research process by considering how their biases and past experiences may impact their understanding of the data (Creswell & Poth, 2018). Researchers had discussions and debriefings following focus groups to

ensure participants' comments were interpreted as intended. A total of four focus groups took place over three weeks, allowing for the opportunity for researchers to collaborate and reflect over data collected and interview tactics used. Further ensuring reflexivity, at least two researchers were present for each focus group.

Member checking. Researchers completed member checking throughout the interview process to increase the credibility of findings and interpretations of this study (Creswell, 2013). Member checking is a technique that involves establishing the truth of the findings by sharing either a portion of the research findings, or the entire findings with the research participants (Krefting, 1991). This took place by researchers restating and summarizing information and then questioning the participants to determine accuracy during all focus groups. Researchers applied this in individual groups and across all focus groups to increase the credibility and transferability of the study results.

Audit trail. An audit trail began upon development of the study in order to increase dependability and confirmability from the start (Krefting, 1991). Authors kept all raw data throughout the development of the findings as suggested by the six Halpern audit trail categories (Halpern, 1983). Raw data included initial coding, theme development, process notes, preliminary forms, and surveys. Overall, intentional implementation of various strategies that warrant trustworthiness and credibility of the study adds to the merit of our findings.

Memoing. Memoing procedures were used for reflective notes in formulating the process researchers used to develop the final themes and logic diagram depiction (See Appendix C) with organizing the data (Creswell & Poth, 2017, p. 84). This process of researcher driven memoing adds to the trustworthiness and credibility of this research as it provides a record of the meanings derived from the data and logic diagram depiction.

Participants

Once receiving approval from the University of Indianapolis Human Research Protection Program (HRPP), researchers of this study used purposive sampling methods for participant recruitment through flyers, face-to-face conversations, and electronic email recruitment at the Central Indiana Chapter of Cancer Support Community. Creswell (2013) recommends when using phenomenology methods, a sample size of 3 to 10 should be recruited. When using photovoice, a visual methodology similar to photo elicitation researchers recommend a sample size of 10 (Palibroda, Krieg, Murdock, & Havelock, 2009; Wang, 1999); therefore, the investigators aimed to recruit 10 participants for the study to engage in both image capturing and focus group discussions. Individuals interested in participating in the study contacted one of the authors and were screened for the following inclusion criteria: (a) At least 18 years of age, (b) has present or past diagnosis of cancer, (c) has access to Central Indiana Chapter of Cancer Support Community, (d) able to consent to participation, (e) able and willing to take photos, (f) able and willing to participate in demographic survey and education training session, (g) able and willing to participate in one focus group session, and (h) able to speak and understand English. Researchers did not include participants who were under 18 years of age or those with legal guardianship. Eligible participants included in the study participated in a first-come, first-basis where recruitment ended once researchers successfully secured 13 participants for the study.

Data Collection

An introductory meeting between investigators and participants took place at a predetermined time at the Cancer Support Community of Central Indiana. The authors read the informed consent document to the participants and requested their written consent to participate. Once receiving approval, participants completed a demographic survey and took part in an

educational session about the use of the assigned digital camera and the role of occupational therapy in survivorship care. Once all initial procedures were completed, and cameras were assigned and distributed, participants spent the next three to seven days taking photos that reflected their experience as a cancer survivor. The investigators collected cameras, and the captured photos through blurring out faces, blacking out names, and personal information were de-identified as necessary. The photos were then printed and numbered in preparation for the focus group discussion. Researchers conducted four focus groups consisting of three to four participants in each. Investigators implemented the SHOWeD method recommended for photovoice in order to frame descriptions and promote reflection on photos during the focus groups gaining a deeper understanding of the participants' cancer survivorship experience (Wang, 1999). Appendix A includes the SHOWeD questions researchers used to elicit reflection and description of participants photos and lived experiences. Participants discussed their survivorship journey and shared photographs as a means of expressing and reflecting upon their experiences. All focus group sessions were audio-recorded and transcribed verbatim by investigators.

Data Analysis

All data collected throughout the study was placed on an encrypted Google Drive, which included photos taken by participants, demographic surveys, and audio recordings of focus group sessions. Researchers implemented thick rich description by developing textual descriptions of the participants' experiences and supported the descriptions through the use of quotes, fieldnotes, and photos provided by the participants (Creswell & Poth, 2017).

Six researchers individually read transcriptions twice before using individual open coding. Once all researchers completed initial open coding, they met as a group multiple times to

discuss similarities and differences between each member's version and to determine final collaborative codes. During the coding process, researchers took notes, used memoing procedures, and sketched reflective thinking to identify emergent ideas. Axial coding was then used to identify additional categories and relationships among the open codes. While researchers were actively identifying patterns in the data with axial coding, they implemented constant comparative analysis to ensure all emerging themes were true to participant experiences. When a new pattern emerged, researchers referred back to all transcriptions and field notes to capture significant statements, sentences or quotes creating a foundation of support for the emerging theme (Creswell & Poth, 2017). Participant photos were analyzed using a cross-photo comparison, this process paralleled the focus group analysis until researchers achieved conceptual saturation. Selective coding was then used to intersect the categories into the emerging theory that researchers present as a logic diagram (See Appendix C).

Results

Participants

Thirteen adult cancer survivors living in the community were recruited for this study at Cancer Support Community of Central Indiana. All thirteen recruited survivors completed the study including filling out a demographic survey (See Appendix B), participation in the introductory educational session, photo collection process, and focus group discussion session. Of the participants, three were male and ten were female. Participants' ages ranged from 23-74 years old with an average age of 48.5 years. Less than a quarter (23%; n=3) of the participants reported that they were actively undergoing treatment. Close to half (46.2%; n=6) of participants were five years or less from their initial cancer diagnosis and over half (53.8; n=7) were five to

ten plus years since their diagnosis. Less than a quarter (23%; n=3) of the participants reported receiving occupational therapy services in their survivorship journey.

Findings

Researchers found four emergent themes and underlying sub-themes after data analysis. These themes consisted of: (a) Distress due to lack of education from their healthcare providers, issues of juggling and engaging in many pre-existing roles, and financial strain associated with the burden of a chronic condition, (b) Changes in perspective about mortality and appreciation for life, (c) Changes in client factors and, (d) Changes in occupational performance.

Distress

Participants described overall distress within their survivorship due to the identified subthemes of lack of education from their healthcare providers, issues of juggling and engaging in many pre-existing roles, and financial strain associated with the burden of a chronic condition. One participant described the feeling as shown in Figure 1: "I felt like an unmade bed...things just weren't the way they were supposed to be. I guess I was thinking this wasn't supposed to happen to me...what did I do to deserve this?"



Figure 1. Participant's unmade bed captured to describe general distress of cancer

Lack of education. As survivors of the study began to describe distress, they described feeling overwhelmed and upset due to the lack of preparation offered by their healthcare providers. Data collected during the focus group interviews suggested that most participants' experiences with healthcare professionals were negative. As stated by one participant:

I just never felt like they gave me much information. And what really irritates me now that I think back on it, I would probably go at it a different way. No, they didn't tell me anything. In fact, the second chemo round...I thought, well I'm just going to look that up online. Boy, was I sorry I did that. Because they said the worst side effects was like losing your fingernails, your skin will flake, losing your toenails. I'd already lost all body hair. And then I heard that, and I thought boy I hope I don't have all that. Well darned if I didn't. The whole nine yards. And I thought, I wish now... I don't know if I'd go online and look. But I couldn't get them to...[educate me]. I kept having so much nausea, and they, they kept giving me these stupid pills. They didn't relate to me too well. And the nurses didn't either.

Participants shared feelings of distress as a result of a lack of education from unanswered questions, unexplained methods of self-management, and having feelings that some needs were being minimized by their healthcare providers.

Well, how could I ask questions when I don't know what is what?... I don't know what to ask...First, tell me something. Give me some literature or something. Yeah, that just kinda bothered me 'cause, to me, it's insensitive.

Self-advocacy and reliance on personal resources for researching unanswered questions were actions expressed by participants as an effort to fill knowledge gaps left by providers. As described by one participant and displayed in Figure 2:

They didn't tell me, when I was diagnosed I went and got the stitches out, [they] sent me home. I went online to find out what I had, let alone the medicine. [when] I left that day, the doctor told me that I would be getting some medicine in the mail but she didn't tell me what. So it came in that hazard bag, I opened it up and I read the side effects, so I didn't know, I thought who knows? You say, I'm sending you cream, and like you said, do you have any questions? Well how could I ask questions when I don't know what is what. I don't know what to ask.



Figure 2. Participant's collection of pills used to describe the confusion associated with a lack of education and need for self-resourcing

Role strain. Some participants experienced role strain as they attempted to continue fulfilling roles even with their diagnosis, including but not limited to the roles of being a spouse, parent, and caregiver. Participants of this study reported difficulty in marital relationships as their spouses attempted to empathize with their experiences of survivorship. Additionally, intimacy following the acquisition of a caregiver role was challenging:

So my wife was a caregiver. And that plays in our marriage; we're still married. We just went to counselors this afternoon. We still love each other, but nothing much else is the same. I just don't know how to be intimate with my caregiver [wife]. Because of that role that she [wife] assumed or that I assigned to her.

Participants shared distress of juggling and engaging in many pre-existing roles and the desire to perform these "normally", as evident in one survivor's experience engaging with friends as a young adult:

I got my first full time job so I'm just gonna pick up this picture (See Figure 3). I drew a picture of a birthday cake that said 21 on it. I think there's a lot to it, but in the middle of my treatment was my 21st birthday...I worked a part time job well I tried [to] cause I needed money. And so I think when my friends were my age and doing standard things that you do when you're 21/22 and then I was going through treatment it was real cliché like it was a lot different. I always tried to like feel or be as normal as [I] possibly could or try to feel my age and then I knew that I had to go and get my shot on Wednesday.



Figure 3. Drawing made by a participant of a 21st birthday cake taken to show how she differed from other young adults due to her diagnosis

Financial burden. Cancer survivors discussed the financial burden brought about by their cancer diagnosis and treatment. One participant stated in a matter of fact way: "It was financial toxicity." Financial stress was a relatable topic for the participants because healthcare costs accumulated throughout their cancer survivorship journey even if they had health insurance as one participant shared (Figure 4): "Financially, it was devastating. I ended up having to file bankruptcy; I wasn't going to pay all them bills. I mean 20, 30 thousand dollars."



Figure 4. Picture of a dollar bill used to describe the financial burden associated with a cancer diagnosis

Participants also described the overwhelming feelings associated with receiving bills and navigating healthcare costs which contributed to distress. One participant shared Figure 5, and reflected:

Then the bills start coming in and they are just frightful bills you know a quarter of a million dollars you know and of course the insurance people negotiate with the hospital and so on but you know we have a deal now where we pay a certain amount every month and probably will until they settle my estate you know.

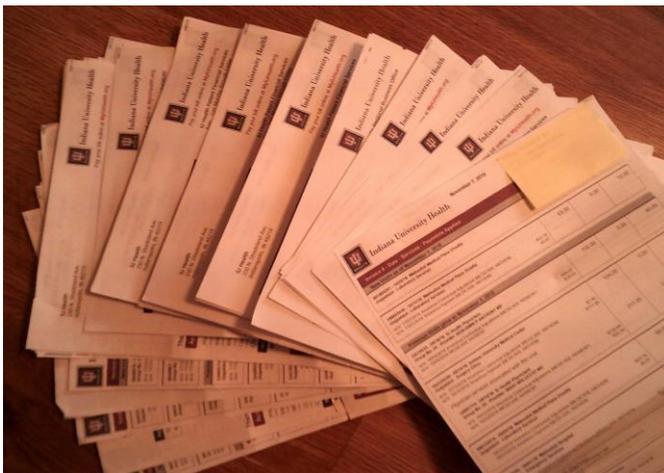


Figure 5. Picture of a stack of medical bills used to show the fear brought on by receiving surmounting debt

When discussing financial strain related to cancer survivorship, the participants mentioned struggling to complete various financial management tasks. Examples of factors participants shared that contributed to their struggle included decreased attention and concentration, dependency on their parents for financial support, and premature return to work in order to generate a source of income.

Change in perspective

The experience of cancer survivorship has an impact on an individual's perspective about mortality and appreciation for life. These changes in perspective can lead to changes in occupations, most often causing participants to take up new occupations or find more meaning in existing occupations.

Awareness of mortality. The shift from cancer being a death sentence or, as one participant described, an "order your flowers now kinda thing," to a survivable diagnosis allowed some participants to "start over." Being diagnosed with cancer was a reminder to participants that life is finite. This awareness of mortality often allowed participants to find deeper meaning in things life has to offer. One participant supported this theme and shared Figure 6 with a reflection:

And it's just a reminder to me that we have so many pages in our book, you know so many days in our life. And you can do with it what you want. I mean, you can waste them or you can...do all kinds of things. It's a reminder that we are all gonna end up some place like this someday whatever we do.



Figure 6: Picture of a cemetery where a participant

reflected on his own mortality

Appreciation for life. Having a new appreciation for life and savoring the moment more often was discussed by many of the survivors in this study. One survivor discussed how she decided she was not going to “work herself to death,” while others mentioned that they have slowed down and become more patient and tolerant of things since dealing with cancer. One participant shared Figure 7 and described its meaning:

I just have a different perspective now that I’ve gone through, you know, cancer and stuff. I try and savor the moment and be in the moment and enjoy like ‘oh, god, those leaves are so pretty’ and ‘oh, look at those flowers,’ and I try to enjoy stuff as it happens and just enjoy the peace and quiet.



Figure 7: Participant's area to enjoy the peace and quiet and savor the moment

Client factors

Many participants voiced changes due to their cancer diagnosis and treatment in the form of cognitive issues, energy levels, sensation, and psychosocial factors that researchers identified at client factors. One participant summed this up by stating:

It messes with your thinking. It messes with your brain. It messes with your diet. It messes with the way you look. You know it makes you tired all the time, practically all the time. You have short term memory. Brain bursts, you know, stuff like that. And neuropathy. I hated [it].

Cancer-related cognitive impairments. Cancer-related cognitive impairments (CRCI) caused difficulties in day-to-day living as participants struggled to attend to, concentrate on, and recall during daily activities. As one participant explained the meaning of Figure 8:

It's just a person walking around in a fog. And that's kind of how I felt for a long time after well during chemo and then after it ended. I felt, I was just in a fog for a long time. I think there's a name for it, chemobrain.



Figure 8: Image showing a man walking in a fog

used to describe the feelings of cognitive changes.

Cancer-related fatigue. Cancer-related fatigue (CRF) was the most frequently discussed client factor impacting occupational performance that participants identified. Participants described how low energy levels and poor endurance reduced their engagement in occupations, as they were unable to complete activities that they were able to do before their cancer diagnosis. Cancer-related fatigue also influenced motivation as participants began to prioritize certain activities as a means of saving energy:

Yeah I laid on the couch. I turned the TV on a lot of times but I'd sleep like I said. I remember saying to my husband one time, Oh if I didn't have to go to the bathroom I wouldn't get up. And all he could say was please do. (laughs) But I just.. I just couldn't move.

Neuropathy & other sensory changes. Survivors also experienced the onset of neuropathy and other sensation changes affecting the hands, feet, breasts and digestive system. Neuropathy and other sensation changes impacted clients' abilities to engage in meaningful and necessary occupations due to loss or change in appetite, decreased sensation impacting intimacy,

and trouble manipulating objects during daily activities. One participant expressed his issues with how neuropathy created difficulties in the kitchen:

It's like I lost all sensitivity in my hands. I pick something up, and the next thing I know, it's not there... I get something out of the refrigerator and all of a sudden I drop it...out of the shelf of the pantry. That's a big change.

Psychosocial changes. Participants also discussed psychosocial changes that affected how they viewed themselves. At times, physical changes to one's body or physical abilities impacted participants' psychosocial wellbeing. Psychosocial factors resulting from the physical and cognitive changes they experienced included altered beliefs, self-identity, and emotions. Where some participants felt they had lost their identity, others felt they had taken on a new one. One participant proudly shared her new identity of being a cancer survivor as shown in Figure 9 stating: "You always have the scars, but I call them battles scars, they show I'm a survivor".

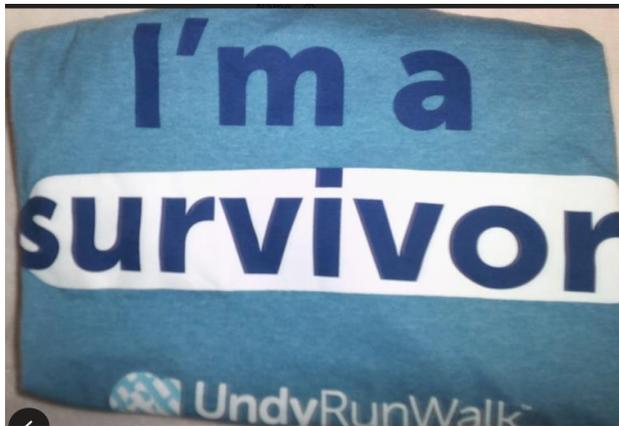


Figure 9: Survivor's shirt from a cancer walk

which she used to describe herself as a survivor

Change in Occupational Performance

Participants expressed either a loss, gain, or modification in occupational engagement. Much of the loss in occupational engagement occurred due to client factors impacting motivation and one's ability to perform the occupation. One participant reflected: "There's a bunch of stuff

that we're not able to do that we were able to do." This inability to perform in ways in which they were previously able left many of the participants with feelings of frustration. Regardless of how enjoyable or meaningful some occupations were, participants discussed having to cease participation or admitted to avoiding participation due to challenges they experienced.

Upon encountering challenges, participants shared that they felt alone and were unaware of ways to modify certain activities in order to continue participating, which resulted in disengaging altogether. "Nothing that I used to love to do I can do anymore. You know that kind of thing, so you have to reinvent yourself with not too much success."

Occupational participation was modified in some cases when participants believed that occupations were too physically or mentally demanding. Often, this modification involved assistance from family members or significant others who aided in self-care, medication management, and home management tasks. At times, this increased need for assistance and support changed the relationship dynamic, as one participant stated, "That was the roughest year I think we've had the whole time we've been married."

There was a reduction in occupational participation because participants were unable to balance these activities on top of attending treatments and doctor visits. As one participant described: "I was trying to work and keep my head above water." In terms of employment, participants discussed choosing to work part-time hours or even quitting their job because they were unable to work at the level to which their bosses and co-workers expected of them:

They wanted you to work at the capacity that you worked when you were better, and you can't do it. And after it's all said and done, they'll tell you, 'well, you didn't really do a good job.' And that, you know, you're already feeling like crap anyway, and then they turn around and talk to you that way.

At times, participants shared finding ways to replace lost occupations by engaging in a new one. Motivation to adopt new, meaningful occupations were often brought on by a participant's change in perspective. For instance, one participant discussed how she left her existing work position and returned to college in order to pursue her dream job: "I'm not going to over-work myself for a company or an organization who is not going to help me stay healthy. And stress is ridiculous, and it does horrible things to you."

Although participants mentioned avoiding social interaction, they discussed engaging in cancer support groups in order to interact with people who could better empathize with them and understand their experiences. The social aspect of the support groups led to the introduction of new leisure activities, such as crafts, gardening, and games. Participants mentioned building meaningful friendships with other members of the support groups by traveling on day trips together. Participants admitted that participating in these new activities and social interactions added value to their cancer survivorship experience and their lives.

External Supports

Participants relied on external support to help navigate obstacles associated with the themes distress, changes in perspective, client factors, and occupational performance. These external supports consisted of community and family, religion and spirituality, and engagement in occupations. While the experiences of each participant were found to be unique, a positive component of their cancer survivorship journey included their external supports. One participant described this support in the following way: "We've always seen that quote that says it takes a village, and I think it takes a village to get through cancer."

External supports varied and were unique to everyone's experience. For example, two participants who were husband and wife, both being cancer survivors, kept a tally board (See

Logic Diagram & Description

Researchers created several renditions of a diagram to capture relationships between themes which developed into a final visual diagram (See Appendix C). The American Occupational Therapy Association (AOTA) (2014) describes cultural context as one's "customs, beliefs, activity patterns, behavioral standards, and expectations accepted by the society of which a client is a member" (p. S28). Investigators identified that participants experienced a shift in cultural context, wherein they took on a new context defined by their cancer survivorship journey. It is suggested that "the cultural context influences the client's identity and activity choices" (AOTA, 2014, p. S28). This shift of cultural context is dynamic, inter-related, and ultimately paralleled by the experiences of the researcher identified themes of distress, changes in perspective, client factors, and in occupational performance.

Shift in Cultural Context

The shift in cultural context included a sense of belonging to a new community stemming from newly found empathy for other cancer survivors. There was also a realization among participants that they felt different after receiving their diagnosis; thus, this culture context shaped their identity and how they viewed themselves: "It's just a different, it's a completely different mindset." However, participants shared that they found solace and a sense of belonging within the cancer survivorship community and its cultural context. As one participant stated: "I felt like I was joining the group; this is the breast cancer stamp...I knew I had a lot of sisters."

Being a part of the new cultural context impacted interactions with non-survivors. More specifically, participants felt that non-survivors viewed and treated them differently, which, at times, resulted in a dissonance among relationships and decreased social participation or social avoidance:

I think the people who haven't had the opportunity to have cancer or certain types of treatments don't really understand. Especially the change. Because I have tried to explain to my loving wife that I'm not the same person I was a year ago.

Ultimately, survivors of this study found their shift to this new context as a barrier between them and non-survivors in their lives. This belief is because the non-survivor group did not empathize with the participants new identity and survivorship experiences. The survivors felt that people who have not had cancer lack understanding of their cancer-related experiences and even referred to them as "outsiders." As one participant explained, "You know you don't understand unless you've been through it because you're not the same. You change."

Discussion

This study adds to the literature about the lived experiences of cancer survivors by identifying a shift in cultural context that happens concurrently with distress, changes in perspectives, client factors, and occupational performance. The themes of distress, changes in perspectives and client factors dynamically influenced occupational performance and engagement. Previous studies have focused on recruiting participants who have certain cultural backgrounds but did not identify this new survivorship cultural context that has been added to their lives (Sleight, 2017). Newman et al. (2019) identified that the construct of participation involves a deeper understanding of various factors, including cultural expectations.

With photo-elicitation methodology, researchers identified another important theme: change in perspective. Participants in this study expressed changes in perspectives that were framed positively about having a new appreciation for life, setting these findings apart from previous studies (Klaeson, Sandell, & Berter, 2013; Robinson, Miedema, & Easley, 2014). The positive lens through which changes in perspectives transpired is perhaps a result of how the

photo-elicitation methodology accurately captures the point of view and meaning of issues relevant to the participants (Glaw, Kable, Hazelton & Inder, 2017). In other qualitative studies, authors Klaeson, Sandell, and Berter (2013) as well as Robinson, Miedema, and Easley, (2014) used a researcher-driven methodology and found negative psychosocial implications of survivorship that included: anxiety, depression, poor body image, and lower self-esteem. Our study found participants shared that psychosocial changes impacted engagement in intimacy, social participation and their self-identity. The opportunity to reflect upon experiences and discuss feelings related to one's journey provided the participants insight into ways that cancer has impacted their outlook on life. The results of our study support the results other researchers results in that survivors experience a loss of occupations and the need for modifying engagement in occupation due to the various client factors associated with survivorship (Dorland et al., 2016; Hopkins et al., 2015; Shipp, McKinstry, & Pearson, 2013). However, investigators in this study uncovered a new finding, which was that some survivors described a gain in occupation. A "gain" in an occupation means the individual adopted a new occupation, often replacing a lost occupation or as a result of a change in perspective. Participants expressed that new meaningful occupations formed as a result of a change in perspective.

The results of this study mirror those of previous researchers—the financial strains of having a chronic condition and a lack of education provided to the survivors cause distress (Duijts et al., 2014; Holm et al., 2012; Lyons et al., 2013). Additionally, the researchers of the current study found that role strain was a significant area of distress among the participants, as they had difficulty managing their previous roles due to changes experienced.

Participants in this study expressed a loss of occupation due to the dynamic and interrelated issues of survivorship such as distress, changes in perspectives, client factors and

occupational performance. More than half of the participants in this study were five years or more into their survivorship journey and only 23% ever received occupational therapy services. While our sampling was small given the research approach, these findings are similar to a larger quantitative study. Pergolotti et al. (2015) found that among an estimated 87% of older cancer survivors who were considered to be in need of occupational therapy, only 32% were treated by occupational therapy within the first two years of the cancer diagnosis.

Study Limitations

Although researchers used member checking during and throughout the data collection process, member checking of results is forthcoming. Furthermore, ongoing peer examination was not implemented into the design of this study throughout the research process; however, it did take place during the final editing phase. Having a peer review throughout the study's process would have improved the dependability of findings. Lastly, the chosen methodology poses a limitation to the study—Wang and Burris (1997) suggest that participants may struggle to capture pictures that symbolically define their journey due to the abstract nature of the design. Researchers tried to control for this by holding picture training sessions and handing out resources on the purpose of the study prior to participants taking photographs.

Implications for Clinical Practice

The authors of this study suggest that survivors experience a shift in cultural context and unique changes in roles, leaving them feeling unprepared to navigate and adequately compensate for the obstacles inherent in survivorship. Based on these findings, the authors support the need for occupational therapy among cancer survivors due to participants expressing issues in occupational performance and engagement. The participants of this study arrived at solving many of their own occupational performance issues by replacing or giving up some of their

meaningful activities. Therefore, it is imperative that screening and referral to occupational therapy services happens for survivors in order to assure that their occupational performance and engagement issues are being addressed. Occupational therapists can show survivors how to modify or improve their engagement in activities in order to avoid a loss of meaningful occupations.

Intentionally looking into the perspectives and personal experiences of cancer survivors related to their survivorship journey adds value to the body of occupational therapy literature. Occupational therapists who regularly interact and treat this population can use these findings to inform their understanding of the experiences of cancer survivors in order to best meet their unique needs and assist with activity modifications to prevent loss of occupational performance and engagement.

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Appendix A

SHOWeD Methodology

SHOWeD**Opening Statement/Question:**

Does someone want to share the story behind their photo or what your photo means to you?

Adapted SHOWeD (Wang & Burris, 1997).

S: What do you see here?

- Why did you take this photo?
- What was going through your mind when you took this?
- What do others see in this photo?

H: What's really happening here?

- How does this make you feel?
- Does anyone else view this differently?
- What did you think when you took this photo?

O: How does this relate to our lives?

- How does this reflect your experience with cancer?
- Can anyone else relate to this?

W: Why does this problem or strength exist?

- How have you overcome this problem? How long did it take you to overcome this problem?
- How did you feel about this problem when it was occurring?
- Did you seek help? What help did you seek? Did they help you?
- Where did you find this strength? Did you already have it?
- *D: What can we do about this?*
- What would you recommend to those who are cancer survivors?
- What do you think could have been done to help you cope with your cancer survivorship?
- Based on what you have shared today in terms of your survivorship, in what ways do you think occupational therapy could have helped you?

Prompts

- Did other participants have similar experiences?
- For those of you who haven't shared all their photos, is there photos that you would like to share that is meaningful to you?

Appendix B

Demographic Table

Table 1: Participant Demographics by Number of Participants

| | Variable | n (%) |
|--|-------------------------------|-----------|
| Age (years) | 20-29 | 1 (7) |
| | 30-39 | 1 (7) |
| | 60-69 | 6 (46.2) |
| | 70-79 | 3 (23.1) |
| | n/a | 2 (15.4) |
| Ethnicity | African American | 1 (7) |
| | Black- American | 1 (7) |
| | Caucasian | 11 (84.6) |
| Gender | Male | 3 (23.1) |
| | Female | 10 (76.9) |
| Type of Cancer | Breast | 4 (30.8) |
| | Colon | 3 (23.1) |
| | Fallopian Tube | 1 (7) |
| | Lung | 1 (7) |
| | Melanoma | 1 (7) |
| | NET (carcinoid) | 1 (7) |
| | NSCLC adenocarcinoma | 1 (7) |
| | Pancreatic | 1 (7) |
| | T-Cell Non-Hodgkin's Lymphoma | 1 (7) |
| Stage of Cancer | I | 5 (38.5) |
| | II | 4 (30.8) |
| | III | 2 (15.4) |
| | IIIb | 1 (7) |
| | IV | 1 (7) |
| | Unknown | 1 (7) |
| Treatment Type | Surgery | 2 (15.4) |
| | Radiation | 3 (23.1) |
| | Chemotherapy | 9 (69.2) |
| | Chemotherapy and Radiation | 3 (23.1) |
| | Other | 1 (7) |
| Cancer Survivorship (years) | 1-5 | 6 (46.2) |
| | 5-10 | 2 (15.4) |
| | +10 | 5 (38.5) |
| Received Occupational Therapy Services for Survivorship Care | Yes | 3 (23.1) |
| | No | 10 (76.9) |

Appendix C

Logic Diagram Depiction

