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# UNDERSTANDING THE IMPACT OF HOBBY PARTICIPATION ON QUALITY OF LIFE DURING CANCER TREATMENT

BY

#### **BETHANY KEUTER**

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Chair, Advisory Committee

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# UNDERSTANDING THE IMPACT OF HOBBY PARTICIPATION ON QUALITY OF LIFE DURING CANCER TREATMENT

BY

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May 2011

Submitted to the Faculty of the Graduate School of
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in partial fulfillment of the requirements for the degree of
MASTER OF SCIENCE IN OCCUPATIONAL THERAPY
2019

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#### **DEDICATION**

I would like to dedicate this thesis to my maternal grandmother, Sharon; the woman who continues to inspire me to live every day with intentionality and to strive in making our world a better place. Your personal experience with breast cancer and the use of gardening to bring light and meaning into your darkest days through your cancer journey inspired this project. I've been blessed to have such a strong, resilient, female role model in my life. Your strength shines through with the multiple generations of strong women who follow you. Thank you for everything you have done and continue to do for me. Words will never be able to describe my love and appreciation I have for you.

#### **ACKNOWLEDGEMENTS**

First and foremost, I would like to thank the three amazing women who volunteered their time and their stories to make this idea become reality. You have overcome such adversity in your lives through your breast cancer journeys and continue to shine a light of positivity into this world. Listening and learning from your personal stories has been such an incredible learning experience and has inspired me to continue to learn more about breast cancer in order to become a stronger advocate for cancer survivors. I'm so thankful out lives have crossed paths.

Additionally, I would like to thank my advisor, Dr. Julie Duckart, and committee members Drs. Dana Howell and Anne Fleischer. You are incredible women who I have been so lucky to learn from. I thank you for the time you've invested in me throughout my academic career at Eastern Kentucky University. You've challenged me to strive for my best and have provided the tools necessary to do so. I've greatly appreciated your continued mentorship as I have grown both personally and professionally these past three years.

Finally, to my parents, family, and friends who have encouraged me to follow my dreams and never let anyone tell me I can't. There was a time when I doubted myself and my abilities to reach my dream. It has not always come easy, but your love and support has made this road a bit smoother. Thank you for always believing in me.

#### **ABSTRACT**

**Objective:** Over the past two decades there has been significant research on the benefits of leisure participation in increasing quality of life (QoL). Additionally, there is a substantial foundation of research exploring the role of leisure engagement in life-threatening illness and cancer. The aim of this study is to explore the role of regular hobby participation on QoL with regards to finding purpose and meaning making, increased coping skills, and social support through hobby participation during breast cancer treatment.

**Method:** Qualitative descriptive study using snowball sampling for participant recruitment. Data collected through semi-structured interviews. Data analysis completed through process of in vivo coding, categorization, and theming.

**Findings:** Major themes found were (1) hobby participation was unimportant during early stages of cancer diagnosis, (2) level of participation impacted overall emotional state, (3) hobby participation strengthened relationships, and (4) cancer experience led to post-traumatic growth.

Conclusion: Hobby participation during cancer treatment is believed to increase quality of life during the course of breast cancer treatment based on data collected from participants after completion of cancer treatment. With increased understanding of the role of occupational engagement during cancer treatment, there is room for occupational therapy to increase preventative services for individuals experiencing cancer.

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#### **Chapter 1: Literature Review**

#### Introduction

As of 2018, the current leading form of new cancer cases for women in the United States at present is breast cancer (Siegel, Miller, & Jemal, 2018). New cases of breast cancer are estimated to occur twice as often the rate of cancers of the lung and bronchus, the second leading cause of cancer for women (Siegel et al., 2018). It is estimated that approximately 30% of new cancer cases for women diagnosed in 2018 were breast cancer (Siegel et al., 2018). This means breast cancer continues to be a growing concern to women's overall health and wellbeing.

Fortunately, with today's advanced medical techniques, the likelihood of surviving breast cancer is becoming commonplace. It is estimated that the survival rate for all stages of breast cancer is 90 percent (Siegel et al., 2018). Breast cancer deaths declined by 38 percent between the years of 1989 and 2014; this has been attributed to improvements in early detection and cancer treatments (Susan G. Komen, 2018a). However, with growing numbers of breast cancer cases and increased survivorship, it is important to examine how survivors' find purpose and meaning, develop coping skills, and receive social support through hobby participation after breast cancer treatment.

At present, common breast cancer treatments include surgery, chemotherapy, radiation, and hormone therapies (Susan G. Komen, 2018b). Common side effects to the cancer diagnosis and associated treatments include increased anxiety and depression, cancer-related fatigue, cognitive dysfunction, sleep disturbance, nausea, and pain (Aboalela et al., 2015; Ahles, Root, & Ryan, 2012; Hubert-Williams, Neal, Morrison, Hood, & Wilkinson, 2011; Scott, Lasch, Barssevick, & Plault-Louis, 2011). These

negative side effects to treatment have been noted to decrease occupational engagement resulting in decreased QoL (Miedema, Hamilton, & Easley, 2007; Hack et al., 2015; Newman, 2013; Scott et al., 2011; Tachi et al., 2015).

#### Occupational Engagement and Quality of Life

The impact of cancer treatment on QoL has been a rising concern as the effects of treatment are often chronic in nature and lead to challenges and disruptions throughout life (Scrignaro, Barns, & Magrin, 2011) beginning with initial diagnosis and may continue beyond the completion of cancer treatments. Recent research has investigated the impact of outpatient chemotherapy treatments on QoL (Hamidou et al., 2017; Tachi et al., 2015). Tachi et al. (2015) found patients undergoing outpatient chemotherapy treatments for breast cancer noted similar declines in QoL when compared to declines noted after surgical procedures used for cancer treatment. This study found the greatest impacts to participants' QoL were psychological and physical impairments attributed to chemotherapy treatments (Tachi et al., 2015).

Research has demonstrated increases in occupational engagement, be it through exercise (Baruth, Wilcox, Der Ananian, & Heiney, 2015; Husebe, Dyrstad, Mjaaland, Soreide, & Bru, 2014; Leach, Danyluk, & Culos-Reed, 2014; Waked, Attala, & Delghidi, 2016), maintaining routines, providing service to others (Sleight, 2017), and participating in religious practices (Bussing, Matthiessen, & Ostermann, 2005) to increase QoL during and after cancer treatment. Participation in leisure occupations have been documented to provide a multitude of benefits attributed to increased QoL and will be discussed in depth below. Increased occupational engagement allows

individuals with cancer hope, especially after noted decreases in engagement caused by cancer (Lyons, 2006).

A breast cancer diagnosis has great potential to lead to major life changes including changes in employment, familial roles, ability to complete self-care regimens (Shannon & Shaw, 2005) and has the potential to decrease overall occupational engagement in all areas of occupations. The Occupational Therapy Practice Framework (OTPF) states occupations are "central to a client's identity and sense of competence..." and further defines occupation into categories of activities of daily living (ADLs), instrumental activities of daily living (IADLs), rest and sleep, education, work, play, leisure, and social participation (AOTA, 2014, p. S4). During initial periods of illness, individuals may consider occupations such as play and leisure as less important than those viewed to be necessities to daily function such as ADLs, IADLs, and work (Shannon & Bourque, 2005). However, leisure participation has shown to have a positive role in coping with stress during life-threatening illness or times of crisis (Hutchinson, Loy, Kleiber, & Datillo, 2003; Iwasaki & Mannell, 2000; Kleiber, Hutchinson, & Williams, 2002; Shannon & Bourque, 2005).

Engagement in occupations during times of illness is important as the occupations individuals engage in contribute to provide a sense of identity for the individual (Hasselkus, 2011; Lyons, 2006). In other words, when an individual loses their ability to engage in desired occupations due to illness, it is likely to result in loss of personal identity. For example, a working mother may lose the ability to continue to work due to illness which impacts her role of being able to provide for her family.

Lyons (2006) states "one reason cancer is sometimes interpreted as a threat to identity is

because the person with cancer may struggle to independently and effectively complete the occupations that define who he or she is" (p. 9). When typical occupations are disrupted by illness, it is important to fill this void through modification of the occupation or environment, for the individual experiencing cancer (Lyons, 2006).

#### The Role of Occupational Therapy in Occupational Engagement

Many individuals experiencing cancer would benefit from occupational therapy services to address changes in occupational engagement. At present occupational therapy services are underutilized in the area of cancer rehabilitation (Baxter, Newman, Longpre, & Polo, 2017). According to Cheville, Troxel, Basford, and Kornblith (2008), a study found that less than a third of women living with metastatic breast cancer needing rehabilitation services received them. Additionally, it was found in the same study of women with metastatic cancer that those who were low socioeconomic, minority status or elderly were most limited in access to occupational therapy services despite limitations in functional ability in daily tasks (Chevile et al., 2008). Women living with metastatic breast cancer represent a small group of breast cancer survivors. The focus of this study however, is on the larger group of breast cancer survivors living in remission who would benefit from occupational therapy services to increase and enhance occupational engagement.

The role of the occupational therapy is to identify barriers and supports to occupational engagement while considering the individual's physical, social, temporal, and cultural contexts (AOTA, 2014). Occupational therapists have the knowledge base and necessary tools to offer services that address and educate the client on how to overcome the functional limitations and side effects experienced during and after cancer

treatment. Occupational therapy's role involves remediation of impairments, modification of occupations or adapting the environment (AOTA, 2012). Occupational therapists may work with individuals with breast cancer at any point across the continuum of care from diagnosis to recovery (AOTA, 2012) with the main goal of treatment being to increase engagement in meaningful occupations (AOTA, 2014).

The occupational therapy role falls under supportive care, which is "defined as any treatment or service designed to help people cope with cancer and its psychological, physical, and emotional consequences" (Sleight & Duker, 2016, p. 1.). Occupational therapy brings a unique role among all other supportive care team members through the use of holistic methods to provide care and intervention to our clients (Sleight & Duker, 2016), which is currently underutilized. Impairment driven approach persists where occupational therapy treatment is provided as a reactive measure to clients' impairments from treatment; such as lymphedema. There continues to be a need, to educate physicians and other medical professionals on the unique opportunities occupational therapists are able to provide breast cancer patients such as in-depth activity analysis, leisure education, and education on transition into cancer survivorship (Baxter et al., 2017).

## The Role of Hobby and Leisure Participation in Cancer

There is evidence to suggest that increased participation in leisure provides positive benefits to increase quality of life during stressful times (Lyons, Orozovic, Davis, & Newman, 2002) and assists in providing a buffer against such stressful events, especially for women (Ponde & Santana, 2000). Leisure is defined by Parham and Fazio as a "nonobligatory activity that is intrinsically motivated and engaged in during

discretionary time, that is, time not committed to obligatory occupations such as work, self-care, or sleep" (as cited in AOTA, 2014, p. S21). Leisure participation during times of life-threatening illness, such as cancer, has also been found to enrich lives through adding meaning and purpose (Unruh & Hutchinson, 2011; Tedeschi & Calhoun, 2004), developing coping strategies (Crosnoe & Elder, 2002; Kleiber et al., 2002; Shannon & Bourque, 2005) and increasing social support (Guerin & Datililo, 2001; Shannon,m 2015).

Meaning and purpose. Previous research regarding leisure engagement during cancer has sought to gain a greater understanding of how individuals utilize leisure during times of stress. An early study by Shannon and Shaw (2002) was aimed to determine the role of leisure participation in women diagnosed with breast cancer due to the unique nature that women hold as caretakers of the home and family. These women shared that leisure became a more important aspect of their lives and leisure pursuits were spent doing purposeful activities that became avenues to achieve specific goals (Shannon & Shaw, 2002). Participants noted conflict between their attitudes regarding leisure and behavioral changes, meaning they realized the importance in leisure but felt guilt when home management tasks were left undone (Shannon & Shaw, 2002). However, behavioral change was noted by most participants (Shannon & Shaw, 2002), suggesting increased satisfaction with chosen leisure pursuits and meaning making.

Women described their views of leisure transitioning from activities that take time to activities that provide importance to the time spent engaging in them (Shannon & Shaw, 2002). This agrees with other findings that leisure pursuits have been shown to add meaning to life (Unruh & Hutchinson, 2011), personal fulfillment (Hack et al.,

2015), and sense of personal satisfaction (Lloyd, Lampe, & McDougall, 2001). Additionally, participants in Shannon and Shaw's study (2002) noted a motivation to increase and maintain a healthy lifestyle through leisure due to a fear of reoccurrence of breast cancer, suggesting leisure may be used as a form of health maintenance (Keays et al., 2008).

Leisure adaptations and coping. Shipp, McKimstry, and Pearson (2014) completed another study examining the patterns of leisure in men experiencing colorectal cancer through their treatment journey. They found that during initial stages of cancer treatment, patients decreased their participation in active and community leisure-pursuits to complete more passive leisure activity (Shipp et al, 2014). Bakitas noted a similar trend of patients limiting their activity in social and community-based leisure (2007). Participants changed their leisure pursuits during treatment to homebased activities until they were able to gradually return to more physically demanding leisure pursuits (Shipp et al., 2014).

The transition of types of leisure pursuits these men made over the course of treatment suggests that continued engagement in leisure was important enough to make changes to continue to spend time participating in such pursuits. This change in leisure pursuits is an example of problem-focused coping efforts described by Kleiber, Hutchinson, and Williams (2002). Problem-focused coping efforts is a way of coping that involves the individual to define the problem, determine alternative solutions, and determine which solutions work best for the individual (Kleiber et al., 2002). The men in the Shipp et al. (2014) study found new ways to participate in leisure to cope with the

side effects of cancer treatment which provided a sense of gratification (Kleber et al., 2002).

Social support. Leisure participation has been found to have great impacts on social support and familial relationships (Guerin & Datillo, 2001; Shannon, 2015; Shannon & Bourque, 2005). Shannon (2015) completed a study examining the impact of breast cancer diagnosis on male spouses. This study found that male spouses tended to reorganize their previous leisure pursuits in order to spend more meaningful time with their wife with breast cancer (Shannon, 2015). It was noted that this increased time spent engaging in couple's leisure activities continued even after life returned to "normal" following cancer treatment (Shannon, 2015). Guerin and Datillilo (2001) noted the importance of family leisure in families with a chronically ill member to enhance family communication and stability.

Components of quality of life. As demonstrated, leisure participation assists with meaning making and increases in social support. This is of value to note as finding purpose in life and increased social support have been found important in increased quality of life (Chambers et al., 2011; Chun, Heo, Lee, & Kim, 2016). It was found in a study by Chun et al. when examining leisure predictors in reference to finding purpose in life of elderly adults with cancer, that individuals had a stronger purpose in life when they were satisfied with their leisure pursuits (2016). Additionally, Chun et al. found that greatest satisfaction was when engaging in indoor activities and hobbies during cancer treatment (2016). This finding shows a link between the men in the Shipp et al. study (2014) and their changes in the type of leisure activity they engaged in,

suggesting that a change to more passive pursuits still allowed these men to find a purpose in their leisure activities.

Based on the research presented, there is a clear connection between leisure participation and its ability to create purpose and meaning in life, leading to increased quality of life. To recap, leisure has demonstrated a number of benefits for the individuals with cancer including increased social support (Guerin & Datillo, 2001; Hamidou et al., 2017; Shannon & Shaw, 2005), personal fulfillment and satisfaction (Hack et al., 2015; Lloyd et al., 2001), and health maintenance (Keays et al., 2008; Shannon & Shaw, 2002) to name a few. All of these benefits of leisure participation are positive forces in overcoming or enduring the many negative side effects associated with cancer treatment.

#### Barriers to hobby and leisure participation for cancer patients

Changes in leisure participation has been noted in previous studies discussed, in regards to the multiple negative side effects cancer treatment may cause. To review, negative reactions to cancer treatment includes increased anxiety and depression, cancer-related fatigue, cognitive dysfunction, sleep disturbance, nausea, and pain. Men participating in the Shipp et al. (2014) study noted decreases in leisure that was active and community-based in nature until they were feeling better physically. Cancer-related fatigue is well documented in decreasing the ability to complete daily activities (Bakitas, 2007; Scott et al., 2011). Additionally, the men in Shannon's (2015) study noted changes in leisure pursuits to home-based leisure pursuits to spend time with their loved one with breast cancer due to limited activity tolerance.

Research has been completed on the impacts of arm morbidity and lymphedema on leisure participation (Hack et al., 2015; Miedema et al., 2008; Radina, 2009).

Lymphedema is a negative reaction to successful breast cancer treatments (Radina, 2009) characterized by a buildup of protein-rich interstitial fluid causing swelling leading to pain, discomfort, or functional limitations (Kambhampti & Rockson, 2015).

Additionally, other arm morbidities have been noted due to breast cancer treatments including increased pain and limited range of motion or strength (Hack et al., 2015).

Research suggests that women affected by arm morbidities may choose to disengage or decrease participation in previously enjoyed leisure pursuits due to concern for their arm and causing further damage (Hack et al., 2015; Radina, 2009). Additionally, Miedema et al. (2008) found that women who have difficulties with arm morbidity are likely to experience problems engaging in all types of leisure or recreational activities.

#### Conclusion

Individuals with breast cancer may find that increased leisure participation is important due to the multitude of intrinsic and tangible benefits outlined above. Leisure participation is believed to play an influential role in increased quality of life during times of crisis based on the increases of finding meaning and purpose, developing coping strategies, and increasing social support associated with it by increasing occupational engagement. Thus, increasing leisure participation is a means of reducing the impact of negative side effects to cancer treatment that may lead to decreases in quality of life

At present there is research demonstrating that leisure participation has a positive impact on quality of life during cancer. Additionally, there is documentation on

how cancer-related adverse side effects may impact leisure participation well beyond the treatment stage and into survivorship. However, the field of occupational therapy would benefit from additional research on the benefits of specific types of hobby participation and how it impacts quality of life in specific cancer populations.

Continued refined research in the benefits of hobby and leisure participation during cancer treatment will add to occupational therapy's role within cancer rehabilitation

#### **Chapter 2: Journal Article Manuscript**

#### **Literature Review**

Introduction. As of 2018, the current leading form of new cancer cases for women in the United States at present is breast cancer (Siegel, Miller, & Jemal, 2018). New cases of breast cancer are estimated to occur twice as often the rate of cancers of the lung and bronchus, the second leading cause of cancer for women (Siegel et al., 2018). It is estimated that approximately 30% of new cancer cases for women diagnosed in 2018 were breast cancer (Siegel et al., 2018). This means the potential for breast cancer continues to be a growing concern to women's overall health and wellbeing.

Fortunately, with today's advanced medical techniques, the likelihood of surviving breast cancer is becoming commonplace. It is estimated that the survival rate for all stages of breast cancer is 90 percent (Siegel et al., 2018). Breast cancer deaths declined by 38 percent between the years of 1989 and 2014; this has been attributed to improvements in early detection and cancer treatments (Susan G. Komen, 2018a). However, with growing numbers of breast cancer cases and increased survivorship, it is important to examine the effects today's cancer treatments have on the body and the overall impact on quality of life (QoL) in regards to finding purpose and meaning making, increased coping skills, and social support through hobby participation during breast cancer treatment.

At present, common breast cancer treatments include surgery, chemotherapy, radiation, and hormone therapies (Susan G. Komen, 2018b). Common side effects to the cancer diagnosis and associated treatments include increased anxiety and depression,

cancer-related fatigue, cognitive dysfunction, sleep disturbance, nausea, and pain (Aboalela et al., 2015; Ahles, Root, & Ryan, 2012; Hubert-Williams, Neal, Morrison, Hood, & Wilkinson, 2011; Scott, Lasch, Barssevick, & Plault-Louis, 2011). These negative side effects to treatment have been noted to decrease occupational engagement resulting in decreased QoL (Miedema, Hamilton, & Easley, 2007; Hack et al., 2015; Newman, 2013; Scott et al., 2011; Tachi et al., 2015).

Occupational engagement and quality of life. The impact of cancer treatment on QoL has been a rising concern as the effects of treatment are often chronic in nature and lead to challenges and disruptions throughout life (Scrignaro, Barns, & Magrin, 2011) beginning with initial diagnosis and may continue beyond the completion of cancer treatments. Recent research has investigated the impact of outpatient chemotherapy treatments on QoL (Hamidou et al., 2017; Tachi et al., 2015). Tachi et al. (2015) found patients undergoing outpatient chemotherapy treatments for breast cancer noted similar declines in QoL when compared to declines noted after surgical procedures used for cancer treatment. This study found the greatest impacts to participants' QoL were psychological and physical impairments attributed to chemotherapy treatments (Tachi et al., 2015).

Research has demonstrated increases in occupational engagement, be it through exercise (Baruth, Wilcox, Der Ananian, & Heiney, 2015; Husebe, Dyrstad, Mjaaland, Soreide, & Bru, 2014; Leach, Danyluk, & Culos-Reed, 2014; Waked, Attala, & Delghidi, 2016), maintaining routines, providing service to others (Sleight, 2017), and participating in religious practices (Bussing, Matthiessen, & Ostermann, 2005) to increase QoL during and after cancer treatment. Participation in leisure occupations

have been documented to provide a multitude of benefits attributed to increased QoL and will be discussed in depth below. Increased occupational engagement allows individuals with cancer hope, especially after noted decreases in engagement caused by cancer (Lyons, 2006).

A breast cancer diagnosis has great potential to lead to major life changes including changes in employment, familial roles, ability to complete self-care regimens (Shannon & Shaw, 2005) and has the potential to decrease overall occupational engagement in all areas of occupations. The Occupational Therapy Practice Framework (OTPF) states occupations are "central to a client's identity and sense of competence..." and further defines occupation into categories of activities of daily living (ADLs), instrumental activities of daily living (IADLs), rest and sleep, education, work, play, leisure, and social participation (AOTA, 2014, p. S4). During initial periods of illness, individuals may consider occupations such as play and leisure as less important than those viewed to be necessities to daily function such as ADLs, IADLs, and work (Shannon & Bourque, 2005). However, leisure participation has shown to have a positive role in coping with stress during life-threatening illness or times of crisis (Hutchinson, Loy, Kleiber, & Datillo, 2003; Iwasaki & Mannell, 2000; Kleiber, Hutchinson, & Williams, 2002; Shannon & Bourque, 2005).

Engagement in occupations during times of illness is important as the occupations individuals engage in contribute to provide a sense of identity for the individual (Hasselkus, 2011; Lyons, 2006). In other words, when an individual loses their ability to engage in desired occupations due to illness, it is likely to result in loss of personal identity. For example, a working mother may lose the ability to continue to

work due to illness which impacts her role of being able to provide for her family.

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The transition of types of leisure pursuits these men made over the course of treatment suggests that continued engagement in leisure was important enough to make changes to continue to spend time participating in such pursuits. This change in leisure pursuits is an example of problem-focused coping efforts described by Kleiber, Hutchinson, and Williams (2002). Problem-focused coping efforts is a way of coping that involves the individual to define the problem, determine alternative solutions, and determine which solutions work best for the individual (Kleiber et al., 2002). The men in the Shipp et al. (2014) study found new ways to participate in leisure to cope with the side effects of cancer treatment which provided a sense of gratification (Kleber et al., 2002).

Social support. Leisure participation has been found to have great impacts on social support and familial relationships (Guerin & Datillo, 2001; Shannon, 2015; Shannon & Bourque, 2005). Shannon (2015) completed a study examining the impact of breast cancer diagnosis on male spouses. This study found that male spouses tended to reorganize their previous leisure pursuits in order to spend more meaningful time with their wife with breast cancer (Shannon, 2015). It was noted that this increased time spent engaging in couple's leisure activities continued even after life returned to "normal" following cancer treatment (Shannon, 2015). Guerin and Datillilo (2001) noted the importance of family leisure in families with a chronically ill member to enhance family communication and stability.

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quality of life (Chambers et al., 2011; Chun, Heo, Lee, & Kim, 2016). It was found in a study by Chun et al. when examining leisure predictors in reference to finding purpose in life of elderly adults with cancer, that individuals had a stronger purpose in life when they were satisfied with their leisure pursuits (2016). Additionally, Chun et al. found that greatest satisfaction was when engaging in indoor activities and hobbies during cancer treatment (2016). This finding shows a link between the men in the Shipp et al. study (2014) and their changes in the type of leisure activity they engaged in, suggesting that a change to more passive pursuits still allowed these men to find a purpose in their leisure activities.

Based on the research presented, there is a clear connection between leisure participation and its ability to create purpose and meaning in life, leading to improvements in one's quality of life. To recap, leisure has demonstrated a number of benefits for the individuals with cancer including increased social support (Guerin & Datillo, 2001; Hamidou et al., 2017; Shannon & Shaw, 2005), personal fulfillment and satisfaction (Hack et al., 2015; Lloyd et al., 2001), and health maintenance (Keays et al., 2008; Shannon & Shaw, 2002) to name a few. All of these benefits of leisure participation are positive forces in overcoming or enduring the many negative side effects associated with cancer treatment.

Barriers to hobby and leisure participation for cancer patients. Changes in leisure participation has been noted in previous studies discussed, in regard to the multiple negative side effects cancer treatment may cause. To review, negative reactions to cancer treatment includes increased anxiety and depression, cancer-related fatigue, cognitive dysfunction, sleep disturbance, nausea, and pain. Men participating in

the Shipp et al. (2014) study noted decreases in leisure that was active and community-based in nature until they were feeling better physically. Cancer-related fatigue is well documented in decreasing the ability to complete daily activities (Bakitas, 2007; Scott et al., 2011). Additionally, the men in Shannon's (2015) study noted changes in leisure pursuits to home-based leisure pursuits to spend time with their loved one with breast cancer due to limited activity tolerance.

Research has been completed on the impacts of arm morbidity and lymphedema on leisure participation (Hack et al., 2015; Miedema et al., 2008; Radina, 2009).

Lymphedema is a negative reaction to successful breast cancer treatments (Radina, 2009) characterized by a buildup of protein-rich interstitial fluid in the arms causing swelling in the arm or arms leading to pain, discomfort, or functional limitations (Kambhampti & Rockson, 2015). Additionally, other arm morbidities have been noted due to breast cancer treatments including increased pain and limited range of motion or strength (Hack et al., 2015). Research suggests that women affected by arm morbidities may choose to disengage or decrease participation in previously enjoyed leisure pursuits due to concern for their arm and causing further damage (Hack et al., 2015; Radina, 2009). Additionally, Miedema et al. (2008) found that women who have difficulties with arm morbidity are likely to experience problems engaging in all types of leisure or recreational activities.

#### **Purpose**

Based on the research presented, there appears to be a connection between leisure participation and its ability to create purpose and meaning in life. To recap, leisure has demonstrated a number of benefits for the individuals with cancer including

increased social support (Guerin & Datillo, 2001; Hamidou et al., 2017; Shannon & Shaw, 2002), personal fulfillment and satisfaction (Hack et al., 2015; Lloyd et al., 2001;) and health maintenance (Keays et al., 2008; Shannon & Shaw, 2002).

At present there is a limited knowledge regarding how specific hobby participation impacts quality of life in targeted cancer populations. The purpose of this study was to describe the perceptions of the use of hobby participation during cancer treatment among women with a history of breast cancer.

#### Methods

**Design:** This study used a qualitative descriptive design (Sandelowski, 2000) to answer the grand question of "how does regular participation in desired hobby occupations impact an individual's perceptions of the use of hobby participation during cancer treatment among women with a history of breast cancer? The aim of this study was to present each participant's experiences and share themes that appeared across all participant experiences.

Participants: Protection of participants was ensured by gaining approval for the study from the Eastern Kentucky University Institutional Review Board. Participant recruitment was completed through a combination of purposive and snowball sampling (Taylor, 2017). Initial participants were invited through personal connections of the principle investigator of the study who fit the criteria. Additional participants were then recruited through enrolled participant invitation, or snowball sampling (Taylor, 2017). Interested parties were asked to send interest to a protected email account and then asked to complete an online informed consent form and short survey to ensure inclusion criteria were met. Inclusion criteria for the study included the participant to be over the

age of 21, English speaking, and completed with their cancer treatment. Participants meeting all inclusion criteria were sent a formal invitation to participate in the study. Individuals agreeing to participate completed a full-length informed consent form. Five individuals showed interest in the study and three completed all aspects of the study. Participants were each assigned a pseudonym for purposes of privacy in order to describe their experiences.

Data Collection: Data were collected through semi-structured interviews focused on gathering information regarding participants' cancer diagnosis and treatment experience, perceptions on hobby participation prior to diagnosis, impact of diagnosis and treatment on hobby participation, and how participation in hobbies impacted routines involving daily occupations after treatment. See Appendix C for interview script. Interviews were held at the participant's home or in a desired location of their choice. The two participants who lived out of state completed the interview using video conferencing technology. This technology allowed both audio and video recording formats to be saved for further analysis. The participant who lived in-state completed a face-to-face interview which was audio recorded. Field observation notes were taken to record participant observations. All interviews were transcribed verbatim using HyperTranscribe software.

**Data Analysis.** Data were analyzed through a process of coding, categorization, and theming. Interview transcripts were read line-by-line thoroughly and repeatedly by the investigator and then coded using in vivo coding methods. In vivo coding is the use of the participants exact words for each code (Creswell & Poth, 2018). Further refining of codes was completed in the process of collapsing the codes into categories regarding

the participants use of their desired hobbies over the course of cancer treatment. A total of 103 codes were collapsed into 17 categories. Finally, categories were further synthesized into themes regarding the impact of hobby participation on the participant over the course of cancer treatment.

Trustworthiness. A coding index was created and organized with themes as headings and the categories and codes listed underneath (Taylor, 2017). The index was then checked and agreed upon by the project faculty advisor. Additionally, a reflexive journal was kept by the investigator throughout the entirety of the project. Frank (as cited in Ahern, 1999), states "reflexivity involves the realization that researchers are part of the social world that they study." Reflexive journals are used to reduce opportunity for research bias on part of the researcher by creating an audit trail documenting feelings and emotions over the course of the research project. Here, first author and primary researcher Keuter reflects on her position of the subject matter:

My interest in discovering more about how the use of leisure and hobby occupations impact individuals over the course of their cancer treatments has been influenced by my grandmother. The stories my she has shared with me regarding the power of the use of gardening as a personal healing tool during her own battle with breast cancer inspired me to further investigate this phenomenon. Tending to her garden provided motivation to work through fatigue and provide her family something in case she lost her cancer battle..

Cancer has taken the lives of many loved ones. I was witness to the awful side effects of cancer drugs and have made it my passion to find ways to positively influence individuals who are going through cancer treatment using occupation.

I recognize that not everyone will experience hobby participation in the same capacity as my grandmother and will keep this in mind through the course of this project.

# **Findings**

Summary of participant sample: The sample consisted of three women, all of whom were breast cancer survivors. Each individual was diagnosed with differing forms of stage II breast cancer and underwent a combination of surgery, chemotherapy, and radiation to treat their cancer. All participants resided within the southeastern region of the United States. Inclusion criteria did not include a breast cancer diagnosis; however, the first two participants enrolled had a breast cancer diagnosis and purposeful sampling was used to find a third participant meeting inclusion criteria with breast cancer. This effort was made to create a homogenous sample of participants (Table 1).

**Table 1. Participant Information** 

	Margaret	Julia	Renee
Age at Diagnosis	24	35	53
Current Age	25	36	73
Marital Status	Married	Married	Married
Education Level	Bachelor's	Bachelor's	Some college
Employment Status	Employed, not	Employed, working	Employed, worked
During Treatment	working	fulltime	part-time second half
Dependents in Home	No	Yes	Yes
Chosen Hobby	Wreathe-making	Exploring nature	Scrapbooking

*Margaret.* Margaret was diagnosed with lobular carcinoma at age 24. At the time of diagnosis, Margaret was new to her career of nursing, working at a large hospital in her hometown and recently engaged to her significant other in a long-distance relationship. During this time, Margaret lived with family in her childhood home, where she received care and support primarily from her parents and

intermittently from her fiancé who was limited due to geographical location. Margaret's cancer treatment began with a successful surgery followed by hormone therapy. After a recurrence, Margaret was then treated with outpatient chemotherapy drugs and then an aggressive and abbreviated course of radiation in order for her to make it to school in time to begin her doctoral program. Over the course of treatment, Margaret maintained employment, but was unable to work due nausea, fatigue, and weakness she experienced during her chemotherapy and radiation treatments. Her chosen leisure activity was making wreathes, as her ability to travel and engage in her previous leisure pursuits was restricted due the extreme fatigue and nausea, as well as immune system concerns from spending time in public.

Julia: Julia was 35 years-old when she was diagnosed with triple negative invasive ductal carcinoma. At the time of her diagnosis, Julia was working as a nurse on the medical/surgical floor of a major hospital in a neighboring town. She was married and had a 17-month-old daughter at home. Julia underwent a major career change at the time of diagnosis, switching roles from a floor nurse to a nurse educator. Julia maintained fulltime employment through her treatment, which consisted of surgery, chemotherapy, and radiation. Julia noted she has a very supportive employer that was understanding and flexible with her needs during treatment. Julia experienced many setbacks over the course of her breast cancer treatment including infection resulting in a second surgery, neutropenia, and stomatitis on top of cancer-related fatigue and nausea. Julia self-identified a limited interest and engagement in hobbies or leisure prior to her cancer diagnosis. Her chosen hobby was exploring nature with her family.

Renee: Renee was 53 at the time of diagnosis of estrogen positive breast cancer and working as an aide in a special education classroom. She was married and had two college-aged daughters who lived at home during breaks from school. Renee had a family history of breast cancer and had experience providing care for her mother and husband during their own cancer experiences. Renee's cancer treatment included surgery, chemotherapy, radiation, and anti-hormone therapy. Renee maintained employment through the course of treatment but took time away during initial stages of treatment. She returned to work in a new classroom part time once she began radiation. At the time of the interview, Renee was nearly 20 years past her diagnosis, but noted she recalled experiencing continued fatigue and nausea during treatment. Renee lives with lymphedema that began several years after the conclusion of her treatment. Her chosen hobby was scrapbooking, in which she has continued to engage.

**Themes**: In summary, early stages of diagnosis were characterized with understanding the breast cancer diagnosis, hobby participation continued to increase over the course of treatment as adverse treatment reactions were managed. These four themes found through data analysis will be discussed in depth below.

Hobby participation was unimportant during early stages of cancer treatment.

The early stages of cancer treatment were described as an overwhelming period for the study participants. The period from diagnosis to surgery, and then beginning chemotherapy passed quickly not allowing time for hobby participation. Participants utilized their time and energy to learn about and begin to understand their diagnosis and respect the needs of their bodies. Early chemotherapy treatments of Adriamycin and Cytoxan (AC) described by two of the three participants led to extreme fatigue and

nausea, which restricted involvement in hobby occupations. Margaret reflected on the initial chemotherapy treatments stating:

Once I started chemo and stuff, you're too tired to do anything. I mean, there's a 3-day period after you're treatment you're doin' good to get up and go to the bathroom.

Participants described the importance of understanding how the chemotherapy drugs impacted their abilities to participate in ADLs and IADLs. Margaret also reflected early treatments and working to understand the cycle of symptoms that would occur after each round of chemotherapy to plan her days accordingly.

Additionally, all three participants described limited importance in hobby participation prior to their diagnosis. Two of the participants were early in establishing their careers in the medical field as nurses and did not designate time to hobby participation during this time. Another participant stated that "work was my hobby." Prior to receiving a cancer diagnosis, all participants regarded their working occupations and providing for their families as high importance with limited attention placed on hobby participation.

The level of hobby participation impacted overall emotional state. As participants adjusted to their diagnosis and course of treatment, feelings of cabin fever and depression began to set in due to lack of participation in meaningful occupations. Chemotherapy protocols limited the participants on where they could go and what activities they were able to participate in due to their immunocompromised state. A participant spoke about the oncology office and her home as being the only two places she had been in several weeks, leading to boredom and frustration. She further stated:

You get really frustrated and you're like "I just want to do something. I want to go somewhere. I'm sick of looking at these same four walls!"

The extreme nausea and fatigue associated with the AC chemotherapy drugs decreased as treatments progressed to Taxol chemotherapy noted by two participants. Participants continued to experience side effects from the cancer treatment through the later chemotherapy treatments as well as radiation but described these side effects as more manageable in nature and not requiring the amount of rest as in earlier stages of treatment. As symptoms lessened, motivation to participate in meaningful occupations increased. Hobby discovery and participation became more important to study participants. Margaret described a realization at a turning point in the recovery process as she began investing her time in hobby participation:

You start to feel a little normal, you're like OK, like I'm makin' this, I'm getting back to normal, everything's gonna be okay.

Furthermore, participants described benefits from their hobby participation ranging from an increased positive emotional state to tangible benefits of better rest and increased time spent with loved ones. Renee described how her desired hobby made her feel by stating "[scrapbooking] makes me feel good, and that's what's for me." Julia reflected how her increased time spent exploring nature with her family by visiting local parks changed her emotional state:

I wasn't really in the house feelin' all depressed. I was outside doin' stuff... just enjoying God's beauty and I loved every minute of it!"

Hobby participation strengthened relationships. All three participants described their hobbies being performed with important people in their lives. All chosen

hobby occupations—scrapbooking, wreathe-making, or exploring nature; are occupations able to be completed alone. Participants described fond memories of completing these hobbies with members of their families and how these activities aided in strengthening these bonds. The motivation behind completing these occupations with others may have been driven by the need for additional interaction with others after a period of cabin fever, limited occupational engagement, and wanting to spend time with those who were most important to them. Renee described her scrapbooking endeavors as an opportunity to spend time with her husband:

He [husband] would help me pick out what he thought were the best ones [pictures]. I would take most of the pictures, but he had an eye for placement on the page.

Additionally, hobby participation was used by the participants to create a legacy for their loved ones in the chance of not surviving their battles with cancer. Julie described her intentions of spending time in nature with her family for her toddler-aged daughter:

I was spending time with my baby and makin' sure she had that time together in case something did happen. I wanted to watch her have fun, and enjoy her childhood even though I was goin through somethin'.

Cancer experience led to post-traumatic growth. Participants described their cancer experience as being life changing and attributing to how they now view the world. Prior to being diagnosed with cancer, all participants had described hobby participation with minimal to no importance. Since experiencing cancer, participants highlighted how their routines and focus on enjoying their hobbies has impacted their

daily lives. Renee describes how the weather no longer impacts her desire to participate in her chosen hobby:

Before I would be like "oh, it's so hot outside." It would inconvenience me because I would sweat a little [laughs]. Lookin' back, I was like "wow, I was a really spoiled person". But now I'm just like "oh I don't have any hair, it's ok whatever, like I'll just wipe my head off and we'll be fine." I look at it like, "this day is never gonna come again, you may not have another day, let's just do it!

#### **Discussion**

The findings in this study support the previous research by exploring the specific hobbies the participants used over the course of breast cancer treatment. Each of the three women in this study engaged in different hobbies during their cancer treatment, though they followed a similar course in participation over the course of treatment. All three women noted that either their work was what they considered to be their form of leisure or they did not participate in a leisure occupation prior to cancer diagnosis.

Despite previous notions regarding leisure being of minimal importance, all three women eventually increased their leisure participation into chosen meaningful activities and making engagement a greater priority. This change in mindset is similar to that discussed in Shannon and Shaw (2002). Tedeschi and Calhoun (2004) also discussed how individuals facing cancer may re-evaluate their lives and re-consider their priorities

We found that participants engaged in activities that were more passive, similar to the participants in the Shipp et al. study (2014). Scrapbooking and wreath-making can both be done at home, at a leisurely pace. Julie described spending time in nature

with her family, but also stated they would do so with the use recreational vehicle due to her low tolerance for activity..

Participants indicated negative feelings during periods of low hobby participation and increased positive feelings at points where they were able to increase their leisure engagement. This suggests that leisure participation increases the ability to engage in meaningful occupations and contributes to increased quality of life (Lyons et al., 2002). Lyons et al. (2002) examined leisure participation among individuals in a hospice setting, where it was found that individuals who were able to watch others engage in leisure occupations, the survivor experienced pleasure even though they were frustrated that they could not complete the occupation themselves. Julie stated that even on her worst of days, she tried to get outside with her family and watch. Being able to watch her daughter engage in nature allowed her to be a passive recipient of hobby participation until she was stronger and more able to actively participate. Margaret indicated a sense of normalcy felt as she was able to increase her participation in making wreathes with her mother. Kleiber et al. (2002) suggested that participating in leisure during traumatic life events is a way for individuals to regain normalcy in life. Additionally, Lyons (2006) stated that feelings of normalcy from occupational engagement increase hope for the future. Normalcy and hope are likely to attribute to an increased quality of life.

Each participant completed their chosen leisure occupation with other people, whom they each claimed to have a stronger relationship with post-treatment. Leisure participation has been found to increase social relationships and coping skills (Shannon, 2015; Shannon & Bourque, 2005). Participants chosen occupations could have been

completed on their own; however, each participant described the roles of others involved. For example, Renee engaged in scrapbooking, an activity often completed in solitary. However, it was the job of her husband to assist in picking out the pictures and she also noted he had an eye for arrangement. Renee's experience demonstrates connections with the findings in Shannon (2015), where her husband made time with her a priority and reorient his own leisure to fit with hers.

Lastly, post-traumatic growth was suggested through each of the participant's experiences. Post-traumatic growth has been described as positive psychological change resulting after a traumatic or difficult life event, such as the experience of cancer (Calhoun & Tedaschi, 1999). The trauma associated with cancer is not the resultant of post-traumatic growth, instead this growth is contributed to the psychological change that occurs after the event (Tedaschi & Calhoun, 2004). Life goals and priorities are redefined, and the individual experiences a greater appreciation for the life such as spirituality, interpersonal relationships, and personal resources (Tedaschi & Calhoun, 1995). Each participant described a shift in priorities in their lives from life before cancer to life after cancer in reference to their increased leisure participation and overall life views on what is important. Each participant indicated importance in spending time with their loved ones engaging in their hobbies provided a great sense of fulfillment.

Application to occupational therapy practice: Many individuals experiencing cancer would benefit from occupational therapy services to address changes in occupational engagement. The role of the occupational therapist is to work with clients in order to identify barriers and supports to occupational engagement of meaningful

occupations while considering the individual's physical, social, temporal, and cultural contexts (AOTA, 2014).

#### Conclusion

Based on our knowledge regarding aspects contributing to increased quality of life including engagement in leisure participation (Lyons et al., 2002), having strong social support (Chambers et al., 2011), and feeling a sense of purpose in or meaning making (Chun et al., 2016). It can be implied that the participation in hobbies over the course of cancer treatment improved the quality of life of these three women.

Additionally, each participant noted that the cancer experience provided them a new outlook on life in which they are more careful in how they spend their time by spending time in creating meaning through their chosen hobbies. This is similar to findings in Shannan and Shaw (2005) where the women described finding importance in spending their time creating meaning in the activities they engaged in, which was found in leisure rather than completing ADLs and IADLs..

#### Limitations

This study contained limitations regarding the sample size, overall sample of participants, and variations in interview processes. The sample size was small; thus, saturation was not met during the data collection process (Taylor, 2017). Based on the nature of the project, there was not sufficient time to recruit and complete participant interviews to reach saturation. Additionally, the participants recruited varied in the length of time since treatment completion. Two of the three participants completed cancer treatment less than three months from beginning of the study. The final participant completed her cancer treatment nearly 20 years ago. This provided a varied

data set for analysis; however, created an increased chance for outlying data from the remainder of the sample due to the broad difference in time since completing cancer treatment. This increased time since diagnosis and treatment, allowed the participant to share and reflect on how hobby participation was influenced by her cancer experience, but was limited in depth on specifics of how scrapbooking was used throughout the treatment in comparison to participants who recently completed treatment.

Finally, the overall interview process was varied based on geographic location of the interviewers compared to the principle investigator. Interviews completed via video conferencing did not elicit the same level of rich content to that of the face-to-face interview. This is important to keep in mind as future research is designed and considered in data collection methods. Face-to-face eliminates the opportunity for technological difficulties and also helps to create a greater rapport with the interviewee through the use of shared space.

#### **Further Research**

Opportunities for further research include continuing the study to saturation with a more specific cancer survivor population. Gaining partnerships with local cancer treatment centers would increase opportunity to grow the sample and create a more selective sample. Additionally, it would be beneficial to explore occupational engagement through leisure and hobby participation in a quantitatively to understand the amount of or percentage of time participating in hobby occupations and measuring changes in QoL over the course of treatment and recovery, measurement.

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**APPENDICES** 

# Appendix A:

Notice of IRB Approval



#### EASTERN KENTUCKY UNIVERSITY

# **NOTICE OF IRB APPROVAL**

**Protocol Number: 1861** 

Institutional Review Board IRB00002836, DHHS FWA00003332

Review Type: □Full ⊠Expedited

Approval Type: ☐New ☐Extension of Time ☐Revision ☐Continuing Review

Principal Investigator: Bethany Keuter Faculty Advisor: Dr. Julie Baltisberger

Project Title: Understanding the Impact of Hobby Participation on Quality of Life During

**Cancer Treatment** 

Approval Date: 9/24/18 Expiration Date: 5/31/19

Approved by: Dr. Pat Litzelfelner, IRB Member

This document confirms that the Institutional Review Board (IRB) has approved the above referenced research project as outlined in the application submitted for IRB review with an immediate effective date.

**Principal Investigator Responsibilities**: It is the responsibility of the principal investigator to ensure that all investigators and staff associated with this study meet the training requirements for conducting research involving human subjects, follow the approved protocol, use only the approved forms, keep appropriate research records, and comply with applicable University policies and state and federal regulations.

**Consent Forms**: All subjects must receive a copy of the consent form as approved with the EKU IRB approval stamp. You may access your stamped consent forms by logging into your <a href="InfoReady">InfoReady</a> Review account and selecting your approved application. Copies of the signed consent forms must be kept on file unless a waiver has been granted by the IRB.

**Adverse Events**: Any adverse or unexpected events that occur in conjunction with this study must be reported to the IRB within ten calendar days of the occurrence.

**Research Records**: Accurate and detailed research records must be maintained for a minimum of three years following the completion of the research and are subject to audit.

**Changes to Approved Research Protocol**: If changes to the approved research protocol become necessary, a description of those changes must be submitted for IRB review and approval prior to implementation. Some changes may be approved by expedited review while others may require full IRB review. Changes include, but are not limited to, those involving study personnel, consent forms, subjects, and procedures.

**Annual IRB Continuing Review**: This approval is valid through the expiration date noted above and is subject to continuing IRB review on an annual basis for as long as the study is active. It is the responsibility of the principal investigator to submit the annual continuing review request and receive approval prior to the anniversary date of the approval. Continuing reviews may be used to continue a project for up to three years from the original approval date, after which time a new application must be filed for IRB review and approval.

**Final Report**: Within 30 days from the expiration of the project, a final report must be filed with the IRB. A copy of the research results or an abstract from a resulting publication or presentation must be attached. If copies of significant new findings are provided to the research subjects, a copy must be also be provided to the IRB with the final report. Please log in to your <u>InfoReady Review</u> account, access your approved application, and click the option to submit a final report.

# Other Provisions of Approval, if applicable: None

Please contact Sponsored Programs at 859-622-3636 or send email to <u>lisa.royalty@eku.edu</u> with questions about this approval or reporting requirements.

# **Appendix B:**

Informed Consent Form

# **Consent to Participate in a Research Study**

# Understanding the Impact of Hobby Participation on Quality of Life During Cancer Treatment

# Why am I being asked to participate in this research?

You are being invited to take part in a research study about the impact of hobby participation on an individual's quality of life over the course of cancer treatment. You are being invited to participate in this study because you have self-identified that you have completed cancer treatment after being diagnosed with cancer. If you take part in this study, you will be one of about 10 people to do so.

# Who is doing the study?

The person in charge of this study is Bethany Keuter, a Master's in Occupational Therapy student at Eastern Kentucky University. She is being guided in this research by faculty advisor, Dr. Julie Baltisberger, PhD, OTR/L. There may be other people on the research team assisting at different times during the study.

# What is the purpose of the study?

By doing this study, we hope to learn about how an individual's participation in desired hobbies over the course of cancer treatment may impact their quality of life. For the purpose of this study, hobbies are defined as an activity an individual participates in for a minimum of one hour per week that provides a sense of relaxation or accomplishment. Through this study we want to learn about each participant's own story to better understand what their experiences were regarding participation in required and desired daily activities.

#### Where is the study going to take place and how long will it last?

The research procedures will be conducted at the individual's home or desired location of their choice that provides privacy for an interview with the researcher. If participant is outside a 2 hour radius from Lexington, KY, the interview may be completed via video conferencing. This study will involve a single interview which will take 1-2 hours in total. Interviews will be completed by October 15, 2018.

#### What will I be asked to do?

Participants will be asked to share their story regarding their experience leading up to cancer diagnosis, the course of treatment, and reflect on their participation in hobbies during treatment. Information will be collected from participants through an audio-recorded interview with the researcher.

Prior to scheduling the interview, to ensure all inclusion criteria is met, participants will be asked to participate in a short survey through mail or in an online format. Once criteria has been established, the researcher will contact the participant to schedule an interview at the participant's home or an alternative location that allows for privacy and is comfortable for the participant.

# Are there reasons why I should not take part in this study?

Anyone under the age of 21, currently undergoing cancer treatment, and is unable to speak English will not be considered to participate in the study.

# What are the possible risks and discomforts?

To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life.

Although we have made every effort to minimize this, you may find some questions we ask you to be upsetting or stressful. If so, we can tell you about some people who may be able to help you with these feelings.

You may, however, experience a previously unknown risk or side effect.

# Will I benefit from taking part in this study?

There is no guarantee that you will get any benefit from taking part in this study. However, some people have participated in interviews requiring them to reflect on their life experiences have found it rewarding to contribute to furthering knowledge. We cannot and do not guarantee that you will receive any benefits from this study.

# Do I have to take part in this study?

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering.

#### If I don't take part in this study, are there other choices?

If you do not want to be in the study, there are no other choices except to not take part in the study.

### What will it cost me to participate?

The only cost associated with participation in this study is transportation and parking costs to an interview site if you prefer to interview outside of your home. Participants using video conferencing to complete the interview will need to have access to a computer with internet access.

# Will I receive any payment or rewards for taking part in the study?

You will receive a \$10 gift card as a thank you for your time and participation in my research. Gift cards will be mailed to the participant after the interview is completed.

## Who will see the information I give?

Your information will be combined with information from other people taking part in the study. When we write up the study to share it with other researchers, we will write about this combined information. You will not be identified in these written materials.

We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what that information is. For example, your name will be kept separate from the information you give, and these two things will be stored in different places under lock and key.

However, there are some circumstances in which we may have to show your information to other people. For example, the law may require us to show your information to a court or to tell authorities if we believe you have abused a child or are a danger to yourself or someone else. Also, we may be required to show information that identifies you to people who need to be sure we have done the research correctly; these would be people from such organizations as Eastern Kentucky University.

## Can my taking part in the study end early?

If you decide to take part in the study, you still have the right to decide at any time that you no longer want to participate. You will not be treated differently if you decide to stop taking part in the study.

The individuals conducting the study may need to end your participation in the study. They may do this if you are not able to follow the directions they give you, if they find that your being in the study is more risk than benefit to you, or if the agency funding the study decides to stop the study early for a variety of scientific reasons.

# What happens if I get hurt or sick during the study?

If you believe you are hurt or if you get sick because of something that is done during the study, you should call Bethany Keuter at 608.732.8312 immediately. It is important for you to understand that Eastern Kentucky University will not pay for the cost of any care or treatment that might be necessary because you get hurt or sick while taking part in this study. That cost will be your responsibility. Also, Eastern Kentucky University will not pay for any wages you may lose if you are harmed by this study.

Usually, medical costs that result from research-related harm cannot be included as regular medical costs. Therefore, the costs related to your child's care and treatment because of something that is done during the study will be your responsibility. You should ask your insurer if you have any questions about your insurer's willingness to pay under these circumstances.

#### What if I have questions?

Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions about the study, you can contact the investigator, Bethany Keuter at 608.732.8312. If you have any questions about your rights as a research volunteer, contact the staff in the Division of Sponsored Programs at Eastern Kentucky University at 859-622-3636. We will give you a copy of this consent form to take with you.

You will be told if any new information is learned which may affect your condition or influence your willingness to continue taking part in this study.

opportunity to have my questions answered, and agree to participate in this research study.	
Signature of person agreeing to take part in the study	Date
Printed name of person taking part in the study	
Name of person providing information to subject	

# Appendix C:

Interview Script

- 1. Tell me about your experience with cancer (treatment, etc.).
- Describe your feelings regarding the importance of using your time to participate in hobbies.
- 3. What types of hobbies did you spend time doing (if any) in your free time prior to cancer diagnosis?
- 4. How did the cancer diagnosis impact your ability to participate in these hobbies?
- 5. Describe any side effects you experienced from your treatment.
- 6. How did these side effects impact your ability to participate in the preferred hobbies you previously enjoyed?
- 7. Describe how your hobby participation changed after your treatment began.
- 8. Descrive any other people involved in your desired hobby participation through the course of treatment.
- 9. How did it feel if you were not able to participate in a desired hobby due to the adverse effects of cancer treatment?
- 10. Describe how you felt when you were able to devote time to hobby participation during treatment.
- 11. What types of tangible benefits (if any) did you get from engaging in your hobby.
- 12. How did your daily routines change once you began devoting time to your hobbies?