January 2017

No One Fights Alone: Exploring Social Participation of Young Adults with Cancer

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Recommended Citation

Hodgson, Susan Blake, "No One Fights Alone: Exploring Social Participation of Young Adults with Cancer" (2017). *Online Theses and Dissertations*. 533.
https://encompass.eku.edu/etd/533

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EXPLORING SOCIAL PARTICIPATION OF YOUNG ADULTS WITH CANCER

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Submitted to the Faculty of the Graduate School of
Eastern Kentucky University
in partial fulfillment of the requirements
for the degree of
MASTER OF SCIENCE IN OCCUPATIONAL THERAPY
August, 2017

DEDICATION

This thesis is dedicated to my best friend
and guardian angel Torsie Haugli,
whose unmatched strength, friendship, and love will never be forgotten.

ACKNOWLEDGMENTS

I would like to thank my advisor, Dr. Julie Baltisberger, for her unwavering support and guidance. I would also like to thank the other committee members, Dr. Dana Howell and Dr. Anne Fleischer, for their support, passion, and strength. I would like to express my sincerest thanks to Dana Haugli for being our rock and my biggest advocate. I would like to thank my friends, family, and my love, Josh Gordon for their unconditional love and support that means so much to me.

ABSTRACT

Background: Young adults are relatively understudied and often misrepresented in oncology research and practice, as they are often over looked or clumped in with pediatric or older adult patients. There is a gap in literature for young adults with cancer and this study was done in an effort to help bridge that gap while exploring social participation along with peer support. Social participation is the interweaving of occupations to support desired engagement in community and family activities as well as those involving peers and friends (American Occupational Therapy Association, 2014). This will not only elicit a better understanding of the impact that cancer has on social participation, but also provide evidence for age-appropriate services to facilitate social participation for young adults with cancer.

Method: Four young adults were interviewed about their experience with cancer and social participation. Interviews were recorded and transcribed verbatim. Data were analyzed using a qualitative descriptive approach, which included coding and collapsing codes into themes.

Results: Study findings suggest a significant need for social participation opportunities for young adults with cancer.

Discussion: Occupational therapists can provide unique ways to overcome barriers to social participation within the community, and with family, and friends for young adults with cancer.

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CHAPTER 1

Introduction

One in every 168 Americans between the ages of 15 to 30 years develops an invasive form of cancer (Bleyer, 2007). During this age interval, cancer creates unique disruptions in health, independence, relationships, finances, education, and social well-being. The spectrum of cancer concerns for the young adult population is unique and different from the pediatric and older population. Because of these concerns, young adult patients should be managed by a multidisciplinary team of healthcare professionals, including occupational therapy, who are well versed in the specific developmental issues relevant to this patient population (Coccia, et al., 2012).

Along with differences in their response to treatment from other age groups, young adults' developmental and life stage, psychosocial effects, and fertility are also unique, requiring treatment approaches specific to young adults with cancer, including fostering social participation (Hayes-Lattin, Mathews-Bradshaw, & Siegel, 2010).

When considering the complete health of the patient, social well-being plays a pivotal role. A component of social well-being is social participation, According to the American Occupational Therapy Association (2014), social participation is the interweaving of occupations to support desired engagement in community and family activities as well as those involving peers and friends. Without the presence of social participation opportunities, a young adult with cancer's health is at risk.

Literature Review

In order to build a foundational understanding of young adults with cancer, it was important to review and explore literature about the incidence rates of young adults with cancer, the psychosocial development of young adults, as well as any unmet needs young adults face with cancer diagnosis and treatment. This assists in developing a psychosocial foundation and lens to move forward into the study. Research for the literature review was found through databases such as CINAHL Complete, JSTOR, OT Search, OTseeker, Psychology and Behavioral Sciences Collection, Psyc ARTICLES, PubMed, and more.

Incidence and Prevalence of Young Adults with Cancer

The incidence of cancer in young adults who are between 15 to 30 years, has steadily increased over the past 25 years (Monteiro, Torres, Morgadinho, & Pereira, 2013). According to Surveillance, Epidemiology, and End Results (SEER), the average annual percent increase in invasive cancer in young adults age 20-24 is about 1% each year. The average annual percent increase in invasive cancer in young adults age 25-29 is about 1.9% each year (Bleyer, et al., 2006). About 70,000 young people (ages 15-39) are diagnosed with cancer each year in the United States – accounting for about 5 percent of cancer diagnoses in the United States. This is about six times the number of cancers diagnosed in children ages 0-14 (National Cancer Institute, 2015).

Lack of Focus on Young Adults in Oncology

Despite advances in oncology early detection, treatment, survival rates, and quality of life outcome measures, adolescents and young adults diagnosed with cancer have not improved to the same extent over the past several decades as younger children and older adults (Monterio, et al., 2013). A relative lack of progress has resulted in the majority of cancers in the age group having a worse overall survival rate than in younger patients, and several of these having a worse prognosis than in older patients (Bleyer, 2007). Patients in this age group have the lowest rate of health insurance coverage, frequent delays in diagnosis, and the lowest accrual to clinical trials (Bleyer, 2007). This is likely a consequence of young adults being relatively understudied and often misrepresented in oncology research and practice, as they are often grouped in with the more represented populations of pediatrics and older adults (Monterio, et al., 2013).

There is a relative lack of focus on the “age group in between,” which is apparent in the national clinical research agenda. This agenda offers a host of treatment and nontreatment trials for children and older adults with cancer, and few, if any, national clinical trials for older adolescents and young adults with cancer (Bleyer, Budd, & Montello, 2006). These young adult patients in this age group are now behind patients in other age groups (Bleyer, Budd, & Montello, 2006). For example, less than 2% of young adult cancer patients are entered onto treatment trials that could improve their chances of a better outcome, in comparison with approximately 60% of patients younger than 15 years of age and 3%–5% of older adult cancer patients (Bleyer, Budd, & Montello, 2006).

Psychosocial Development of Young Adults

In line with the theory of emergent adulthood (Arnett, 2000), young adults are in a challenging period of psychosocial development as they navigate through the many tasks associated with this phase of life, such as education and career attainment, dating, family relationships, and developing a healthy body image (Monteiro, et al., 2013). A diagnosis of cancer as a young adult can significantly disrupt or delay achieving typical developmental milestones leading to reduced independence at a time of when independence is normally developing. Developmental milestones include: a) development of peer and intimate relationships, b) achievement of academic degrees, and c) independent living (Monteiro, et al., 2013). When adding to the period of confusion and self-discovery, other negative psychological factors may occur.

Lack of Psychosocial Research in Young Adults with Cancer

Young adults face distressing cancer-related issues such as premature confrontation with mortality, physical appearance changes, increased dependence on parents, social life and school/employment disruptions, loss of reproductive capacity, and health-related concerns (Zebrack, 2011). Isolation and alienation are commonly reported among young adult cancer patients and survivors because they often miss out on experiences that their peers are enjoying at this stage in life, leading to psychosocial distress. (Zebrack & Isaacson, 2012). Research studies inclusive of adults of all ages with cancer suggest that rates of psychological distress are significantly greater among young adults compared with older adults (Zebrack & Isaacson, 2012).

However, research in psychosocial issues among young adults with cancer is nearly nonexistent (Belizzi, et al., 2012). In 2005, the National Cancer Institute (NCI) partnered with the Livestrong foundation, and conducted a progress review group that addressed the research and cancer care needs for adolescents and young adults, which indicated a need to research psychosocial impact of cancer diagnosis (National Cancer Institute, 2006). Despite the findings from this research, most studies continue to focus on the biologic health outcomes, or strategies to increase enrollment within cancer clinical trials for this age group (Burke, Albritton, & Marina, 2007; Bleyer, Budd, & Montello, 2006; Tricoli, Seibel, Blair, Albritton, & Hayes-Lattin, 2011), and not on the psychosocial impact of being diagnosed with cancer (Bellizzi et al., 2012). Social functioning has been known to be one of the areas most affected by cancer diagnosis and treatment for young adults (Evan & Zeltzer, 2006; D'Agostino, Penny, & Zebrack, 2011; Zebrack, 2011).

Identity development is a key aspect for healthy growth and development of adolescents and young adults, and it occurs within the context of social interaction (Arnett, 2000). However, young adults with cancer have disrupted social interactions and social opportunities, often resulting in social isolation and alienation. In order to minimize the impact of feelings of social isolation, the health care environment must recognize the important role of peers and socialization and facilitate the maintenance of face-to-face interaction and social participation (e.g., providing spaces where the hospitalized young adults may interact with their friends), online opportunities and/or access to new technologies (Monteiro, et al., 2013).

Few empirical studies of cancer patients and survivors have distinguished the unique psychosocial outcomes and service needs of young adults (Zebrack, 2011). Too often, young adults are placed in categories of pediatrics or older adults, and their needs are not met by either group, leading to inadequate understanding of the psychosocial impact of cancer for young people diagnosed in their late teens or young adult years (Zebrack, 2011). Included in the lack of understanding of the psychosocial implications is the experience of social participation among young adults with cancer. Because peer support and social involvement are valued so much during this time in life, there is a need to be explore how social participation has been impacted by cancer and if there are any service needs that could assist young adults with cancer through social participation. Age appropriate programs and services have the potential to minimize negative impacts of cancer diagnosis and treatment and promote positive psychosocial adjustment; however, the availability of these services are still minimal, resulting in unmet needs for a large proportion of the young adult population (Zebrack, 2011).

Occupational Therapy in Oncology for Young Adults

The role of occupational therapy in oncology is to facilitate and enable an individual patient to achieve maximum functional performance, both physically and psychologically, in everyday living skills regardless of his or her life expectancy (Penfold, 1996). Common side effects of cancer or its treatment include fatigue, pain, weakness, cognitive difficulties, anxiety or depression, and changes in self-esteem or self-image. Occupational therapy practitioners can address these effects through intervention aimed at restoring function such as developing home exercise programs to improve strength and mobility; modifying activities such as teaching individuals ways to conserve energy during important everyday activities; or modifying environments such as the workplace, home, or community (Longpré & Newman, 2011).

A multidisciplinary oncology care team is needed to support and care for patients with cancer. For example, although oncologists treat the disease itself, occupational therapists along with physical therapists can address the physical impairments resulting from cancer and its treatment (Sleight & Duker, 2016). Typically, psychosocial issues are most often addressed by psychologists or social workers, although occupational therapy practitioners and nurses can be involved in these treatments as well (Sleight & Duker, 2016). Cognitive impairments are treated primarily by social workers and psychologists, but rehabilitation professionals such as occupational and physical therapists can be utilized as members of the team to address this impairment (Sleight & Duker, 2016).

Despite all efforts occupational therapy has put into oncology care, there has been a lack of focus on the young adult population within oncology. Young adult cancer survivors report substantial unmet service needs related to everyday function (Burg et al., 2015). The unmet needs of young adult survivors most often include mental health care and occupational therapy for rehabilitation services (Sleight & Duker, 2016). Within the young adult oncology population, unmet needs in the areas of social support, mental health, and occupational and physical therapy have been strongly associated with decreased emotional functioning, lower health-related quality of life, and reduced functioning at school or work (Smith et al., 2013). An increase in occupational therapy services for young adults with cancer could have the potential to reduce some of these unmet needs.

Conclusion

Approximately 70,000 adolescents and young adults are diagnosed with cancer in the United States each year. Yet, there is a relative lack of focus on this age group. This is a population with unique developmental and psychosocial needs. However, young adults with cancer are reporting unmet needs within their oncology care, primarily psychosocial implications. The purpose of this study is to explore the social participation of young adults with cancer. This description will not only provide a better understanding of the impact that cancer diagnosis and treatment have on social participation, but also provide support for age-appropriate services to encourage social participation for young adults with cancer. The next chapter is a journal article to support the research in young adults in oncology.

CHAPTER 2

Journal Article Manuscript

Introduction

One in every 168 Americans develops invasive cancer between the ages of 15 to 30 years (Bleyer, 2007). During this age interval, cancer creates unique disruptions in health, independence, relationships, finances, education, and social well-being. The spectrum of cancer concerns for the young adult population is unique and different from the pediatric and older population. Because of these concerns, young adult patients should be managed by a multidisciplinary team of healthcare professionals, including occupational therapy, who are well versed in the specific developmental issues relevant to this patient population (Coccia, et al., 2012).

Along with differences in their response to treatment from other age groups, young adults' developmental and life stage, psychosocial effects, and fertility are also unique, requiring treatment approaches specific to young adults with cancer, including fostering social participation (Hayes-Lattin, Mathews-Bradshaw, & Siegel, 2010).

When considering the complete health of the patient, social well-being plays a pivotal role. A component of social well-being is social participation. According to the American Occupational Therapy Association (2014), social participation is the interweaving of occupations to support desired engagement in community and family activities as well as those involving peers and friends. Without the presence of social participation opportunities, a young adult with cancer's health is at risk.

Background

Approximately 70,000 young people (ages 15-39) are diagnosed with cancer each year in the United States – accounting for about 5 percent of cancer diagnoses in the United States. This is about six times the number of cancers diagnosed in children ages 0-14 (National Cancer Institute, 2015). Despite advances in oncology, early detection, treatment, survival rates, and quality of life outcome measures, adolescents and young adults diagnosed with cancer have not improved to the same extent over the past several decades as younger children and older adults (Monterio, et al., 2013). A relative lack of progress has resulted in the majority of cancers in the age group having a worse overall survival rate than in younger patients, and several of these having a worse prognosis than in older patients (Bleyer, 2007). This is likely a consequence of young adults being relatively understudied and often misrepresented in oncology research and practice, as they are often grouped in with the more represented populations of pediatrics and older adults (Monterio, et al., 2013).

Significance and Need

There is a relative lack of focus on the age group in between pediatrics and older adults, which is apparent in the national clinical research agenda. This agenda offers a host of treatment and nontreatment trials for children and older adults with cancer, and few, if any, national clinical trials for older adolescents and young adults with cancer (Bleyer, Budd, & Montello, 2006). These young adult patients in this age group are now behind patients in other age groups (Bleyer, Budd, & Montello, 2006). For example, less than 2% of young adult cancer patients are entered onto treatment trials that could improve their chances of a better outcome, in comparison with approximately 60% of patients younger than 15 years of age and 3%–5% of older adult cancer patients (Bleyer, Budd, & Montello, 2006).

In line with the theory of emergent adulthood (Arnett, 2000), young adults are in a challenging period of psychosocial development as they navigate through the many tasks associated with this phase of life, such as education and career attainment, dating, family relationships, and developing a healthy body image (Monteiro, et al., 2013). A diagnosis of cancer as a young adult can significantly disrupt or delay achieving typical developmental milestones leading to reduced independence at a time of when independence is normally developing. Developmental milestones include: a) development of peer and intimate relationships, b) achievement of academic degrees, and c) independent living (Monteiro, et al., 2013). When adding to the period of confusion and self-discovery, other negative psychological factors may occur.

Young adults face distressing cancer-related issues such as premature confrontation with mortality, physical appearance changes, increased dependence on parents, social life and school/employment disruptions, loss of reproductive capacity, and health-related concerns (Zebrack, 2011). Isolation and alienation are commonly reported among young adult cancer patients and survivors because they often miss out on experiences that their peers are enjoying at this stage in life, leading to psychosocial distress. (Zebrack & Isaacson, 2012).

Problem

In spite of the impact of cancer on young adults, research about psychosocial issues among young adults with cancer is nearly nonexistent (Belizzi, et al., 2012). In 2005, the National Cancer Institute (NCI) partnered with the Livestrong foundation, and conducted a progress review group that addressed the research and cancer care needs for adolescents and young adults, which indicated a need to research psychosocial impact of cancer diagnosis (National Cancer Institute, 2006). Few empirical studies of cancer patients and survivors have distinguished the unique psychosocial outcomes and service needs of young adults (Zebrack, 2011). Too often, young adults are placed in categories of pediatrics or older adults, and their needs are not met by either group, leading to inadequate understanding of the psychosocial impact of cancer for young people diagnosed in their late teens or young adult years (Zebrack, 2011). Included in the lack of understanding of the psychosocial implications is the experience of social participation among young adults with cancer.

Identity development is a key aspect for healthy growth and development of adolescents and young adults, and it occurs within the context of social interaction (Arnett, 2000). However, young adults with cancer have disrupted social interactions and social opportunities, often resulting in social isolation and alienation. In order to minimize the impact of feelings of social isolation, the health care environment must recognize the important role of peers and socialization and facilitate the maintenance of face-to-face interaction and social participation (e.g., providing spaces where the hospitalized young adults may interact with their friends), online opportunities and/or access to new technologies (Monteiro, et al., 2013).

Because peer support and social involvement are valued so much during this time in life, there is a need to be explore how social participation has been impacted by cancer and if there are any service needs that could assist young adults with cancer through social participation. Age appropriate programs and services have the potential to minimize negative impacts of cancer diagnosis and treatment and promote positive psychosocial adjustment; however, the availability of these services are still minimal, resulting in unmet needs for a large proportion of the young adult population (Zebrack, 2011).

The role of occupational therapy in oncology is to facilitate and enable an individual patient to achieve maximum functional performance, both physically and psychologically, in everyday living skills regardless of his or her life expectancy (Penfold, 1996). Despite all efforts occupational therapy has put into oncology care, there has been a lack of focus on the young adult population within oncology. Young adult cancer survivors report substantial unmet service needs related to everyday function (Burg et al., 2015). The unmet needs of adolescent and young adult cancer survivors most often include mental health care and occupational therapy for rehabilitation services (Sleight & Duker, 2016). Within the young adult oncology population, unmet needs in the areas of social support, mental health, and occupational and physical therapy have been strongly associated with decreased emotional functioning, lower health-related quality of life, and reduced functioning at school or work (Smith et al., 2013). An increase in occupational therapy services for young adults with cancer could have the potential to reduce some of these unmet needs.

Purpose

Approximately 70,000 adolescents and young adults are diagnosed with cancer in the United States each year. Yet, there is a relative lack of focus on this age group. This is a population with unique developmental and psychosocial needs. However, young adults with cancer are reporting unmet needs within their oncology care, primarily psychosocial implications. The purpose of this study is to explore the social participation of young adults with cancer. This description will not only provide a better understanding of the impact that cancer diagnosis and treatment have on social participation, but also provide support for age-appropriate services to encourage social participation for young adults with cancer.

Methods

This study was approved through the Institutional Review Board at Eastern Kentucky University.

Recruitment

For the purpose of this study, a snowball sampling method was utilized to recruit participants. Information about the research and its purpose was dispersed via word of mouth amongst student peers and professors. Research flyers were dispersed and posted on social media including information regarding the research purpose, inclusion criteria, and primary researcher’s contact information. Inclusion criteria were that potential participants must have had a) a cancer diagnosis between the ages of 18 and 29 years old, b) completed treatment within the last 10 years, and c) received either chemotherapy or radiation. Potential participants were instructed to contact the primary investigator. Using the snowball method for recruitment, potential participants were asked to identify anyone who would be interested in participating in the study and met the inclusion criteria. If the potential participant was willing, he/she distributed information about this study to others who then contacted the primary investigator, if interested in participating in this study.

Procedure

Seven potential participants contacted the researcher. After explaining the research purpose, inclusion criteria, and the requirements and demands of the study, four participants agreed to participate in the study. Informed consent was obtained then semi-structured interviews guided by an interview guide were conducted for 45 to 90 minutes within a location convenient to the participant. The interviews were digitally recorded by the researcher and the researcher took field notes during the interviews, noting emotions, tone of voice, environmental observations, etc.

Data Analysis

Data was analyzed following a qualitative descriptive method. Qualitative descriptive studies aim to present a comprehensive summary of events in the everyday terms of those events. Qualitative descriptive designs typically are an eclectic but reasonable combination of sampling, and data collection, analysis, and representation techniques (Sandelowski, 2000). A qualitative descriptive method was chosen for this study to present straight descriptions of the phenomenon. Participant interviews were transcribed verbatim using Hyper Transcribe (ResearchWare) technology. Each transcribed interview was coded, placed into categories, and finally collapsed into themes. Coding was completed through highlighting significant statements, sentences, and quotes. The highlighted statements were then developed into clusters of meaning and consequentially themes. Ten categories were developed and collapsed into four themes to describe the phenomenon.

Trustworthiness

To ensure trustworthiness and rigor, bracketing was applied in order to set aside bias and take a fresh perspective on the experiences being studied (Creswell, 2013). The bracketing technique was implemented throughout the entire research process through reflexive journaling about personal preconceptions or biases by the primary researcher. Finally, member checking was also implemented to safeguard the accuracy and trustworthiness of this research.

Results

Participants

Four young adults participated in this research study. Pseudonyms were used in place of the real names of each participant. The first participant is Ellie, who is 27 years old, and was 20 years old when first diagnosed with ovarian cancer. Ellie received chemotherapy treatment, and had surgery to remove a 20 pound tumor from her ovary. Later, Ellie not only discovered that she had another tumor on her other ovary, but the cancer had also spread. Ellie's recurrent cancer included ovarian and uterine. Ellie had another surgery to remove the tumor, additional chemotherapy and radiation treatments. During this time, Ellie had to defer her college enrollment, was unable to work, and had to move back in with her mother.

The second participant is Harper. Harper is 30 years old, who was 25 when she was diagnosed with Stage 2A Hodgkin's Lymphoma. Harper underwent surgery and received chemotherapy treatment. Prior to her diagnosis, Harper had accepted a position at a physical therapy clinic. She delayed working at her new job and also had to move back in with her parents during her treatment.

The third participant in this research study is Phelps. Phelps is now 25 years old. He was the youngest participant in this research study and was diagnosed with cancer at the age of 18. Phelps was a senior in high school when he was diagnosed with Mucoepidermoid Carcinoma of the Submandibular Gland. Phelps had surgery to remove his tumor, and received chemotherapy and radiation treatments. Phelps was able to graduate high school on time, but had to make adjustments to his schedule and school work.

The fourth and final participant is Penelope. Penelope is now 29 years old. She was 25 years old when she was diagnosed with Stage 4B Classical Hodgkin's Lymphoma Subtype Nodular Sclerosis. Penelope was living and working in Spain at the time when diagnosed. Because of treatments, finances, and social support, Penelope moved back to the United States and moved in with her mother. She received chemotherapy treatment. Table 1 indicates each participants' demographics.

Table 1

Participant Demographics- this table displays each participant, their current age, their age when they were diagnosed, and the type of cancer each participant was diagnosed with.

Name	**Current Age**	**Age at Diagnosis**	**Type of Cancer**
Ellie	27	20	Ovarian and Uterine
Harper	30	25	Stage 2A Hodgkin's Lymphoma
Phelps	25	18	Mucoepidermoid Carcinoma of the Submandibular Gland
Penelope	29	25	Stage 4B Classical Hodgkin's Lymphoma Subtype Nodular Sclerosis

Themes

After transcribing and coding, codes were collapsed into themes. Four themes emerged: 1) Reduced independence at a time when independence is typically emerging; 2) Social participation is limited because of depression, anxiety, fear, and fatigue; 3) Cancer is the loneliest experience in the world; 4) There is a need to relate and understand.

Reduced Independence at a Time When Independence is Typically Emerging

Young adulthood is a time of graduating high school and college. It is a time of moving out of parents' houses, getting a first job, attending graduate school, moving somewhere new, dating, and getting married. It is really a time when young adults are establishing independence. But for young adults who are living with cancer, this independence is taken away. Participants expressed that they had to move into their parent's home when they were diagnosed with cancer. Additionally, they also lost employment because none of the participants could work while they were receiving treatment. Ellie, Harper, and Penelope were all working and living on their own. When they described having to move back in with their parents and give up their independence, it was extremely hard for them. Penelope stated in a reflection:

> *My mom tries to understand, but I don't think she ever really understood how hard it was for me to go from being so independent to then having to rely on her for pretty much everything- for a roof over my head, food on the table, rides to places, and not being able to be independent again. And that was really hard.*

Participants also expressed a feeling of reduced independence when describing the way that doctors, parents, friends, and other health care professionals would tell them what they could and could not do. These young adults stated that going from being so independent to living with their parents was extremely difficult. They felt as if they were reverted to their childhood again where people told them what to do. Developmentally, young adults are making their own decisions, choices, and mistakes. But when young adults are being told everything they can and cannot do, they experience reduced independence at a time when independence is supposed to be emerging.

Not only did they lose independence, but also a loss of autonomy. Cancer diagnosis and treatment determined their schedules, and the ability to do whatever they wanted when they wanted to do it. Phelps said, that because of travel and treatment time, cancer treatment really affected the way he scheduled things like school, meals, and even his social activities. Being a senior in high school, he was no longer able to "rip and run" like a senior in high school should. His schedule was determined by a) his treatments, b) doctors' appointments, and c) day- to-day treatment side effects. For a young adult, losing this sense of independence and autonomy can evoke certain feelings such as depression, anxiety, and loneliness, which in turn, negatively affects social participation.

Social Participation is Limited Because Of Depression, Anxiety, Fear, and Fatigue

Each participant discussed feelings of depression during their illness. Much of the depression manifested from seeing friends and peers moving on with life. Harper reflected on this time in her illness and expressed:

> *I was depressed because I'm seeing all these people my age getting out and being able to do things or being able to move on and do stuff with their lives, like going to school and getting jobs and all that. And then I was just sitting there waiting. Waiting while everyone else was doing their own thing. So I was depressed a lot during that time.*

Additionally, Ellie communicated the same feelings of being left behind when stating:

> *My friends were my biggest support group, but they were also my biggest hindrance too. Because I got to see them continue going to school and I got to see them build their lives and here I was, hairless, sick, and I was depressed. I was severely depressed and my anxiety was higher than it had ever been.*

Not only was social participation limited because of feelings of depression, but also significant anxiety and fear. Cancer diagnosis and treatment, medical bills and finances, fears of treatments and dying, and feeling of being left behind by friends and peers provoked anxiety. In addition to all of these emotions, cancer treatments induced extreme fatigue. Because of this level of exhaustion, participants' social participation was restricted. Penelope describes this as:

> *There were a lot of times when I just didn't feel like going out. I didn't have the energy for it. I was exhausted. And other people can't really understand this level of exhaustion unless they have been through it.*

Cancer is the Loneliest Experience in the World

When factors such as depression, anxiety, fear, and fatigue limit social participation, loneliness arises and social isolation is present. Participants described their cancer experience as a lonely one. Although family and friends were supportive, an overwhelming feeling of loneliness was present amongst the participants. One participant went so far as to say that cancer is the loneliest experience in the world. Social isolation surfaces when there are no other young adults with cancer present. Harper describes her feelings of isolation in the analogy of "living on an island by herself":

> *I think young adult supports definitely would have helped with a lot of the depression, a lot of the feelings of just feeling alone, and feeling like I was the only person to have cancer my age. When you don't know anybody else your age going through this and when you don't see anybody else just out and about that*

> *is your age with cancer, you start to feel like I am here on this island and I live here by myself.*

Other participants also expressed these feelings of loneliness because of the age difference amongst the people that were receiving treatments and seeing in the doctors' offices. Penelope explains further stating:

> *I was definitely the youngest person with cancer by like 40 years everywhere I went. I didn't see a single young person. And that really increased the feeling of isolation. If I were to see other young people around I would know that I truly wasn't alone. Or otherwise it does make you feel like you are an outlier and this isn't happening to anyone else—and that it is only happening to you. And that is really hard.*

Additionally, when young adults with cancer are hospitalized for any period of time, feelings of social isolation and loneliness surface. Participants stated that they were hospitalized at least once during their illness. Although they had visitors and family were with them, an overwhelming sense of loneliness was experienced. Again, they did not come across any other young adults in the hospital. The majority of patients were older adults, further perpetuating their feelings of social isolation. Phelps described his hospitalization in a reflection:

> *When I was hospitalized I had a roommate in the hospital who was much older than me. And that is where it all kind of sunk in. Like this is really happening to me. And that is where I got into more of a sad state because I felt alone. I felt even more alone.*

Feelings of depression and anxiety contributed to the experience of social isolation and the lonely experience that these young adults experienced. Because of this, they felt a desire to relate to other young adults who were experiencing the cancer diagnosis and treatment, so they could be truly understood.

There is a Need to Relate and Understand

There is an innate and inherent need as humans to relate to one another. Intrinsically, humans desire to be understood by one another. For instance, if a recovering alcoholic falls into a relapse, he is not going to call his brother who has never tasted a drop of alcohol. From the brother, he will only receive sympathy. Instead, he is going to go to an Alcoholic Anonymous meeting and talk to people who can relate to what he is going through. From these supports, he will receive empathy. These young adults with cancer were looking for--empathy versus sympathy. Phelps reflects on having another young adult support and understanding for what he was going through:

> *Having another young adult, they would be able to provide empathy instead of sympathy. I really truly wish I would have had an empathy experience.*

Phelps and the other participants desired an empathic experience partly because they felt pitied all the time. Participants explained that they were pitied by family, friends, and even through a stranger's expression on the streets. The general attitudes of others around them changed, whether intentional or not. Phelps further explains:

> *I felt pitied all the time. At school in the halls, it shifted from 'Hey Phelps, what's up?' to 'Hey Phelps, how are you?' And that was a really hard thing.*

Another part of the desire to relate and be understood, by another young adult who is experiencing cancer, is to share similar frustrations. Because each participant had to move back in with parent(s), a lot of frustration stemmed from this change in living environment. Participants said that they would get so frustrated with their moms, when she tried to help who didn't always know how to help. Penelope said that she could not even count the number of times that she would get frustrated with her mom. She reflects:

> *I just felt like I couldn't relate on a social level to the people that I was receiving treatment with—just to even be able to share frustrations with, because there were a lot of frustrations.*

These young adults could not share their frustrations with the 70-year-old patient receiving treatment next to them. They needed to relate with another young adult with cancer, such as frustrations that they were having with their parents.

In order to fulfill the desire to relate with and be understood by someone else, young adults undergoing cancer treatment need other young adults for support by providing opportunities to socially participate and interact with other young adults with cancer. Penelope describes why she may not have had any of those opportunities:

> *I get that it is hard, that maybe there aren't enough young adult specific support groups because there aren't enough of us. But even having* ***one other person is enough.*** *And I think that is what people just don't understand.*

Participant Solutions

Overall, participants expressed a desire to have another young adult who is also experiencing cancer diagnosis and treatment to truly understand their loss of independence, feelings of depression and anxiety, loneliness, and desire for someone to understand them. Participants expressed how they tried to engage in social participation, but were unsuccessful because there were not any services or methods for connecting with other young adults who were undergoing cancer treatment. As a result, none of the participants were able to communicate with another young adult cancer patient. Harper explained:

> *No, I never had the chance to meet or interact with any other young adults with cancer. Not in person, just through social media. And that was on my own. I initiated that. The hospital, the oncology department, nobody ever mentioned anything about meeting other young adults. They never mentioned any sort of social support groups. Nothing was ever offered. The only thing that was ever offered to me was chemo.*

Similarly, Penelope tried to initiate and inquire about social participation opportunities, but was left unsatisfied saying:

> *I asked my doctor. I said, 'I know this affects other young people. I know there are other young people like me, but where are they? Why am I always in a room with people who are 40 years older than me? That aren't necessarily alone. That aren't dealing with the same consequences that I am—having to move back in*

with my mother, of no longer having a job, of not being able to get a job?' And the doctors never gave me anything.

During the interviews, participants were asked for potential suggestions of interventions and ideas that they would have liked to have had during their treatment. In terms of social participation, what was it that they would have liked to have had along their journey and what do they hope to see implemented in the future for other young adults with cancer? Table 2 indicates the participant's potential solutions:

Table 2

Participant Solutions- this is a table representing the potential solutions participants offered during their interviews to address social participation within young adult oncology treatments.

Participant	**Solution**	**Supporting Quotes**
Phelps	Support Groups	"There are so many different options for support groups in community centers for every kind of disorder—brain injury, people living with Down syndrome, Alzheimer's—I don't see why there can't be one for young adults with cancer. Or even cancer in general and then having a young adult's night."
Ellie	Face-to-Face Interactions	"Sometimes the best thing anyone could say to me was nothing. And there is no way to communicate that better than somebody holding your hand or somebody giving you a hug—and you just can't do that through text or a computer screen."

Table 2 (continued)

Participant	Solution	Supporting Quotes
Penelope	1. Support Groups—they do not have to be cancer specific	1. "As a young adult, there is so much going through our minds like finances, dating, trying to find a job, having to move back in with your parents, etc. But we can all relate regardless of cancer diagnosis. I wish there were groups like this."
	2. One Other Person is Enough	2. "Maybe when other people think support groups that is has to be a ton of people. But when you are going through cancer at a young age, when you haven't really fully established your life yet, you don't have kids to support you when you are going through this, or maybe you are not married or even if you are married you are still dealing with trying to get a stable life together and this is thrown in. Just having one other person who can truly understand can really help."
Harper	1.Buddy System	1. "I think it would have been helpful to have a list to be able to exchange phone numbers and to be able to have buddies. To be like, ok here is your buddy, she is a young adult who has just been diagnosed with cancer too."
	2. Mentor Program	2. "It would have also been helpful to get somebody who had cancer and then they become a mentor to somebody who is going through cancer. Just to be able to talk to them and get advice."

Discussion

This study sought to explore the social participation of young adults with cancer. From the research and the participants within the current study, it is evident that there is a clear connection between social support and the four themes that have emerged in this research: loss of independence, depression and anxiety limiting social participation, loneliness, and a need to be understood. The findings from this study echo the findings from a study conducted by Zebrack, et al., that peer involvement is important to young adults with cancer.

In a study by Zebrack, et al., (2006) young adults with cancer along with health professionals were sought out to identify important health and supportive care needs for adolescent and young adult patients and survivors. Compared with health professionals, young adults ranked the importance of opportunities to meet other young adult survivors at a relatively higher level, and they also ranked those opportunities higher than the importance of support from family and friends (Zebrack, et al., 2006). In fact, 50% of young adults ranked support from family and friends as one of the top 5 needs at diagnosis and during treatment, whereas 100% of young adults ranked opportunities to meet other young adults with cancer as one of their top 5 needs (Zebrack, et al., 2006). However, these opportunities were reported as an unmet need.

In the current study, social opportunities with other young adults with cancer were also reported as an unmet need. As a result, the four themes of the study developed. The first theme is that young adult participants experienced a loss of independence when independence is typically developing. These findings replicate the findings of Monteiro, et al., (2013). This study found that a diagnosis of cancer as a young adult can significantly disrupt or delay achieving typical developmental milestones, leading to reduced independence. Additionally, the current study suggests that this loss of independence stems from factors such as moving in with parents, not working, and reduced autonomy. This is significant because not only does it echo the findings of Monteiro, et al., (2013), but it also provides reasoning as to why there is a reduction in independence amongst these young adults with cancer.

The second theme of the current study, that factors such as depression, anxiety, fear, and fatigue all limit social participation for young adults with cancer, replicate findings from Bellizzi, et al., (2012), which state that poor relationships in this population have been related to distress and poor quality of life and likely have implications for social functioning in general. Furthermore, social functioning has been known to be one of the areas most affected by cancer diagnosis and treatment for young adults (Bellizzi, et al., 2013). In the current study, findings not only suggest that social functioning is affected, by why it is affected. These findings are meaningful because participants state why that social participation is limited, because of depression, anxiety, fear, and fatigue. These negative psychosocial implications stemmed from being left behind by peers, worrying about treatments, medicines, finances, and more. Knowing the root of the limited social participation helps to better understand what these young adults are experiencing and create potential ways to help.

Another important finding in this study was the third theme, that cancer for these young adults is a lonely experience. The participants stated that their experience was lonely because of being the only young adult in the doctor's offices and hospitals, and not having another young adult to talk to about their experience. In the same regard, the participants also reported that they desired to relate with and be understood by someone else, the fourth theme. These findings support research from Monteiro, et al., (2013), stating that young adults are relatively understudied and often misrepresented in oncology research and practice, as they are often grouped in with the more represented populations of pediatrics and older adults. Because the young adult population is often clumped in with pediatrics or older adults, this can lead to the feeling of loneliness. The participants in this study reported that they did not see any other young adults with cancer in the doctor's offices or hospitals, and because of this, they did not have anyone their age to relate with or anyone who could understand what they were experiencing.

Additionally, research from Zebrack (2011), suggest that too often, young adults are placed in categories of pediatrics or older adults, and their needs are not met by either group, leading to inadequate understanding of the psychosocial impact of cancer for young people diagnosed in their late teens or young adult years. The findings of the current study echo Zebrack's research (2011). The participants were surrounded by older adults in the healthcare environment. In addition, the current research finds that because of this, young adults have a lonely cancer experience and desire a peer to relate to and be understood by. These findings are meaningful because they reveal a glimpse of an understanding of the psychosocial impact of cancer for young people when they are grouped together with younger and/or older populations.

Occupational Therapy Implications

Findings from the current study, in addition to other research, make it clear that there is a strong connection between social support and the four themes that have emerged in this research: loss of independence, depression and anxiety limiting social participation, loneliness, and a need to be understood. There are several ways that occupational therapists could address social support either directly and/or indirectly within their treatment plan.

For example, when treating a patient for typical cancer side effects and impairments such as edema, range of motion, and fatigue, occupational therapists could use this time not only to address impairments, but also social support. The occupational therapist could collaborate with the oncology social worker or nurse navigator to find support groups or other cancer young adult cancer patients. Occupational therapists can become knowledgeable about what is available for young adult cancer patients within their community. If there are not any opportunities within the community, the occupational therapist, in collaboration with other health care oncology providers, could create a “meetup” to enable individuals to find other young adult cancer survivors locally who share an interest of sharing their cancer experience (Sander, 2005).

There are many opportunities for occupational therapists to address social participation within the four themes that have emerged from this study. First, to address loss of independence that young adults are experiencing, occupational therapists can create adaptations to increase independence, such as modifications to work from home, assistive technology to depend on rather than all the help coming from parents, etc. They can also educate young adult patients on energy conservation techniques that can increase their independence and autonomy. In addition, occupational therapists could educate young adult patients and their parents on assertiveness training. Teach the patient about communication strategies, open dialogue with parents, and how to be honest and have effective communication when their parents are not meeting their needs or being overbearing. It is also within the scope of occupational therapy practice to teach the young adult patients how to be an advocate for themselves; an advocate when dealing with insurance companies, an advocate that gives them a role, and an advocate for young adults with cancer.

To address depression, anxiety, fear, and fatigue limiting social participation, occupational therapists could educate young adult patients on depression and anxiety management before, during and after treatments, when going to doctor's visits, when handling finances, and when seeing friends move on into typical life roles . Occupational therapists could also teach fatigue management and energy conservation techniques. Another way for occupational therapists to address these factors that are limiting social participation is to help the patient to keep looking forward. The occupational therapist could help the young adult build a resume. This would be an activity that would not require a lot of physical energy, and that would help the patient in moving forward, past the cancer. Participants also expressed fears and anxieties about finances. The occupational therapist could assist with budgeting and organizing medical bills and finances.

Within the third theme, loneliness when they do not see any other young adults with cancer, the occupational therapists could also address social participation and peer support. Finding a “meetup” for young adults with cancer in the local area would be a great resource for the patient. If there is not one, collaborating with other health care professionals and with the patients to create a “meetup” would be a viable option. Working with young adult cancer patients to start a peer support service where they can find meaning and belonging could be very beneficial for the patients. This may require educating the patient, again, on how to be an advocate. In treatment sessions, incorporating the patient’s friends into therapy could also be an effective way to bring in peer support. Depending on the young adult’s health, the occupational therapist could take him/her out in the community and teach the patient ways to overcome barriers and make adaptations and modifications so the patient can come together with friends in different community settings.

Finally, to address social support within the last theme, needing to relate and be understood by other young adults with cancer, the occupational therapist could schedule clients in clusters within the clinic to meet one another. Group occupational therapy sessions would be a practical and reasonable way for young adults with cancer to meet one another. The occupational therapist could also collaborate with the oncology social worker or oncology nurse to find other young adults with cancer in the area and facilitate communication. Occupational therapists could also provide young adult patients with opportunities to build new interests. They could help patients find meaningful activities that will meet their energy levels and connect them with others who are also interested in that activity.

Limitations and Future Research

One limitation that should be noted when interpreting the results of this study is the limited sample size. Due to restricted time and resources, four participants were interviewed and saturation may not have been reached. Another limitation of this study includes the primary researcher's bias as a friend of a young adult with cancer. To limit bias stemming from this, the researcher participated in reflexivity. Additionally, there were a variety of cancers and treatment regimens among the participants that may have influenced answers to interview questions. Although the participants were diverse in their cancer diagnoses, they were all from the same area geographically which could have influenced answers based on treatments and availability of young adult supports in this particular area. Furthermore, one of the participants is an occupational therapist, which may have influenced their perspective.

Further research is needed to explore the social participation of young adults with cancer. In the future, it is important for research to explore social participation within a larger population of young adults with cancer to understand their unique. Another research area in need of attention are larger sample sizes exploring psychosocial implications and needs of young adults with cancer. Finally, future research is needed to evaluate the effectiveness of implementing the recommendations provided by the young adult survivors in this study or other programs supporting social participation.

Conclusion

The healthcare system is currently not providing young adults with cancer age-appropriate opportunities for social participation. Occupational therapy practitioners and other healthcare providers have the opportunity to develop programs to encourage social participation, which would promote a health.   According to the World Health Organization, the definition of health is “A complete state of physical, mental, and social well-being and not just the absence of disease or infirmity” (American Occupational Therapy Association, 2014, p. S4) and social participation is a component needed for promoting health during and after cancer treatment.

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APPENDIX A:

Notice of IRB Approval

Graduate Education and Research
Division of Sponsored Programs
Institutional Review Board

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NOTICE OF IRB APPROVAL

Protocol Number: 000157

Institutional Review Board IRB00002836, DHHS FWA00003332

Review Type: ☐ Full ☒ Expedited

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

Principal Investigator: **Susan Hodgson** Faculty Advisor: **Dr. Julie Baltisberger**

Project Title: **No One Fights Alone: Exploring Social Participation of Young Adults with Cancer**

Approval Date: **8/1/16** Expiration Date: **5/1/17**

Approved by: **Dr. Jim Gleason, 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 InfoReady 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 InfoReady Review 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 lisa.royalty@eku.edu with questions about this approval or reporting requirements.

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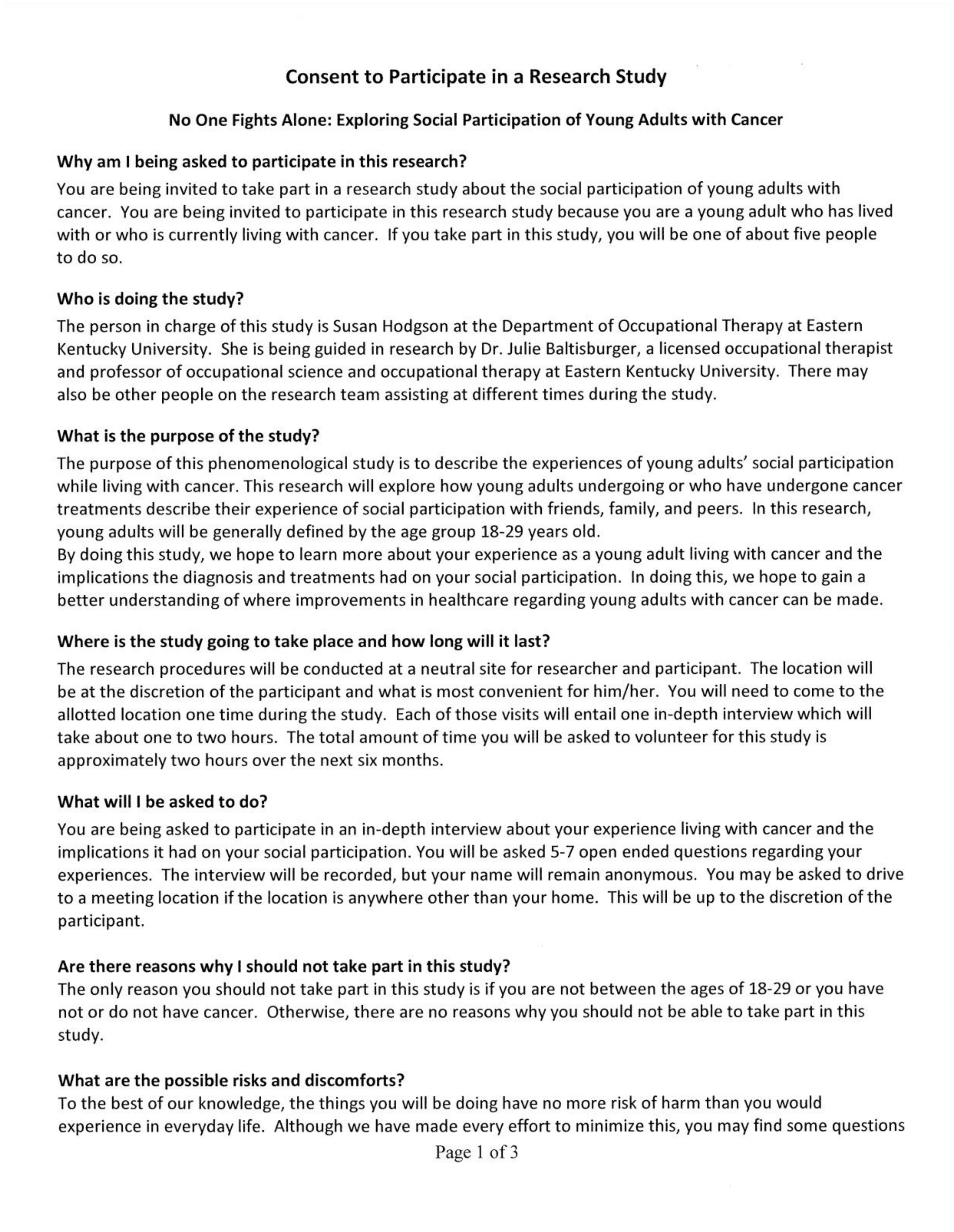
APPENDIX B:

Informed Consent Documents



Consent to Participate in a Research Study

No One Fights Alone: Exploring Social Participation of Young Adults with Cancer

Why am I being asked to participate in this research?

You are being invited to take part in a research study about the social participation of young adults with cancer. You are being invited to participate in this research study because you are a young adult who has lived with or who is currently living with cancer. If you take part in this study, you will be one of about five people to do so.

Who is doing the study?

The person in charge of this study is Susan Hodgson at the Department of Occupational Therapy at Eastern Kentucky University. She is being guided in research by Dr. Julie Baltisburger, a licensed occupational therapist and professor of occupational science and occupational therapy at Eastern Kentucky University. There may also be other people on the research team assisting at different times during the study.

What is the purpose of the study?

The purpose of this phenomenological study is to describe the experiences of young adults' social participation while living with cancer. This research will explore how young adults undergoing or who have undergone cancer treatments describe their experience of social participation with friends, family, and peers. In this research, young adults will be generally defined by the age group 18-29 years old.

By doing this study, we hope to learn more about your experience as a young adult living with cancer and the implications the diagnosis and treatments had on your social participation. In doing this, we hope to gain a better understanding of where improvements in healthcare regarding young adults with cancer can be made.

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

The research procedures will be conducted at a neutral site for researcher and participant. The location will be at the discretion of the participant and what is most convenient for him/her. You will need to come to the allotted location one time during the study. Each of those visits will entail one in-depth interview which will take about one to two hours. The total amount of time you will be asked to volunteer for this study is approximately two hours over the next six months.

What will I be asked to do?

You are being asked to participate in an in-depth interview about your experience living with cancer and the implications it had on your social participation. You will be asked 5-7 open ended questions regarding your experiences. The interview will be recorded, but your name will remain anonymous. You may be asked to drive to a meeting location if the location is anywhere other than your home. This will be up to the discretion of the participant.

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

The only reason you should not take part in this study is if you are not between the ages of 18-29 or you have not or do not have cancer. Otherwise, there are no reasons why you should not be able to take part in this 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 evoke memories of a difficult time in your life. If so, we can tell you about some people who may be able to help you with these feelings.

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 found it to be therapeutic and rewarding when they talk about their experience and become an advocate for other young adults with cancer. Nonetheless, 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?
There are no costs associated with taking part in this study. However, you may have to pay for the cost of getting to the study site.

Will I receive any payment or rewards for taking part in the study?
You will not receive any payment or reward for taking part in this study.

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, 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 Susan Hodgson at 859-274-6197 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 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, Susan Hodgson at 859-274-6197. 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.

What else do I need to know?

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.

I have thoroughly read this document, understand its contents, have been given an opportunity to have my questions answered, and agree to participate in this research project.

____ ____________________________

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

IRB Approval
17-000157
THIS FORM VALID
8/1/16 - 5/1/17

Appendix C

Research Recruitment Flyer

No One Fights Alone: Exploring Social Participation of Young Adults with Cancer

Health care providers would like to understand the young adult cancer survivor's experience of social participation throughout cancer diagnosis and treatments.

To gain an understanding of this experience, this study is looking for young adults cancer survivors who:

- Have had a cancer diagnosis between the ages of 18-29
- Are 10 years of less post final cancer treatment
- Have had radiation and/or chemotherapy

In order to minimize the impact of feelings of social isolation, the health care environment must recognize the important role of peers and socialization and facilitate the maintenance of social participation.

If interested, please contact Susan Hodgson at 859-274-6197 to see if you qualify.

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