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Examination of Participation and Occupation After Cancer

Darla Coss

A doctoral project submitted in partial fulfillment of the requirements for the degree of

Doctor of Occupational Therapy,

St. Catherine University, St. Paul, Minnesota

May 20, 2016

Doctoral Advisor: Dr. Julie Bass, PhD, OTR/L, FAOTA

Doctoral Committee Members: Dr. Julie Bass, PhD, OTR/L, FAOTA

Dr. Kathleen Lyons, ScD, OTR/L

Dr. Kate Barrett, OTD, OTR/L

St. Catherine University
Doctor of Occupational Therapy

Certification of Successful Doctoral Project

We, the undersigned, certify that

Darla Coss
Student Name

has successfully completed the clinical doctoral project titled

Examination of Participation and Occupation After Cancer

Dr. Julie Bass, PhD, OTR/L, FAOTA	5/20/2016
Doctoral Advisor	Date
Dr. Kathleen Lyons, ScD, OTR/L	5/20/2016
Doctoral Committee Member	Date
Dr. Kate Barrett, OTD, OTR/L	5/20/2016
Doctoral Committee Member	Date

Certification for Approval for Final Copy of Doctoral Project

I, the undersigned, approve the final copy of the doctoral project by

Darla Coss
Student Name

Dr. Julie Bass, PhD, OTR/L, FAOTA	5/20/2016
Doctoral Advisor	Date

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Abstract

Cancer and treatments for cancer can have negative consequences on one's ability to participate in life. Side effects of treatment, including pain, cognitive changes, and fatigue can last months to years after treatment. Community based support and services are emerging to fill a gap in care, specifically related to the psychosocial needs of the survivor. The purpose of this project was to provide information to Gilda's Club Twin Cities (GCTC), a community based cancer support center, on the participation levels and quality of life (QOL) of their new members, with the secondary goal of collecting data on fatigue and cognitive issues. The study employed a cross sectional descriptive approach with self-report tools to examine the cancer population receiving services at a community based center. Standard, quantitative measures were used to describe participation in life activities, QOL, fatigue and cognition. Overall activity levels decreased 27% following a cancer diagnosis, with the subscale of high physical demand affected most. Participation in new activities was reported by 56%, with most of those activities falling into the instrumental category (doctor visits, resting). Social activities were identified as most important. QOL and fatigue mean scores were lower than the normative data for the general population and the cancer population in the United States. Opportunity and need exist in community based centers to provide effective programming related to participation levels, including fatigue management, role resumption, and the necessary performance skills to achieve personal participation goals. Occupational therapists should take the lead in supporting survivors in community based settings to achieve improved health, well being, and participation.

Keywords: participation, cancer, occupation, fatigue, cognition

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Introduction

Treatments for cancer have become increasingly successful, with survival rates of five or more years for 60% of cancer patients (Howlader et al., 2016), but the effects of cancer treatments can have consequences on the survivor's quality of life. Cognitive changes, pain, fatigue, and sexual dysfunction are just a few of the side effects of cancer (American Cancer Society, 2014). Although these issues resolve over time for some, many survivors are left with long-term problems after cancer treatment. Lack of awareness of the late effects of cancer and its treatments is associated with difficulty in providing quality interventions and care for survivors in the post treatment phase (Hewitt, Greenfield, & Stovall, 2006). Additionally, the economic burden related to cancer and its aftereffects, with loss of productivity, morbidity, and healthcare costs are real concerns for the future (Yabroff, Lund, Kepka, & Mariotto, 2011).

Community based support and services, beyond the medical model, are emerging to fill a gap in care for cancer survivors. Gilda's Club Twin Cities (GCTC) is a community based, non-profit cancer support center that provides free social and emotional support for those living with cancer and their families (GCTC, 2016). Membership at GCTC, located in Minnetonka, Minnesota, has grown steadily, as has program development. The Mission of Gilda's Club is "to create welcoming communities of free support for everyone living with cancer- men, women, teens and children, along with their families and friends" (GCTC, 2016).

Attendance at a new member orientation meeting is recommended for all new Gilda's Club members. At these meetings, members are made aware of all the offerings at the club, fill out intake information, and report on their perceived needs as a survivor. This study utilized the new member orientation in recruitment of community members for participation. Study questionnaires, focusing on participation in daily activities and occupations, and the specific

symptoms of fatigue and cognition, were available for those new members that qualified and wished to participate. These participants were asked to remain after the orientation, with the researcher present, to fill out the questionnaires and consent. Alternatively, they were allowed to take them home and return them to a folder at the front desk the next time they visited the club.

This study explored life with cancer for survivors new to Gilda's Club, specifically participation in activities and quality of life. Information on fatigue and cognitive issues was collected for secondary analysis. Participation in valued activities and occupations encompasses much more than a return to work or disability statistic. Specifically, this project intended to explore areas that are often overlooked: activities of daily living, instrumental activities of daily living, rest and sleep, social participation, leisure, and education. Additionally, physical and cognitive impairments have been reported across multiple cancer types, with breast cancer as the predominant diagnosis (Cramp & Byron-Daniel, 2012; Scott et al., 2013). Although there is literature describing impairments, less is known about activity engagement and participation for those living with cancer.

Fatigue and cognitive changes in those living with cancer are common complaints. Survivors rate cancer related fatigue (CRF) above pain, nausea and depression in affecting daily activities and quality of life (Hofman, Ryan, Figueroa-Mosley et al., 2012). Cognitive deficits during and after cancer treatment are reported by as many as 75% of the population, and can last months to years after treatment ends (Janelsins et al., 2011). Cognitive impairment can have an impact on overall quality of life, impacting areas like work and social well-being (Von Ah, 2015).

The primary goal of this study was to provide information to Gilda's Club on the participation levels and quality of life of their new members, with the secondary goal of collecting data on fatigue and cognitive issues. Understanding the limitations faced by those dealing with cancer may help in the development of new intervention approaches for community based settings. Insight into participation and occupation, along with understanding two common complaints survivors have, fatigue and cognitive changes, could help those dealing with cancer live more productive and meaningful lives.

Select Review of Literature

Cancer is now considered a chronic illness (Centers for Disease Control and Prevention [CDC], 2015a), and was the second leading cause of new disability claims in 2013, accounting for 15.1% of new claims and 9.1% of ongoing claims (Council for Disability Awareness [CDA], 2014). Survivorship, defined from the time of diagnosis through end of life (NCI, 2014) has become a long-term norm rather than an exception. This has prompted the call for increased awareness of the needs of the survivor, including research, education, and advocacy (Hewitt, Greenfield, Stovall, 2006).

Cancer treatments contribute to secondary health problems for many people. Two such effects are cancer related fatigue (CRF) and mild cognitive impairment (MCI). CRF is one of the most common side effects of cancer treatment (American Cancer Society, 2016a), and is rated above pain, nausea and depression in affecting daily activities and quality of life (Hofman, Ryan, Figueroa-Mosley, Jean-Pierre, & Morrow, 2007). Although most cancer survivors will live with fatigue during the course of treatment, up to 30% will have lasting, significant fatigue for years post treatment (Bower et al., 2014). The incidence of cognitive dysfunction after cancer is less clear, with up to 75% of the population reporting issues months to years after treatment ends (Janelsins et al., 2011), and potentially longer lasting issues in the breast cancer population (Wefel, Saleeba, Buzdar, & Meyers, 2010). Although cognitive issues are often connected to chemotherapy, there is evidence to support other causes, such as endocrine therapy and radiation (Denlinger et. al, 2014; Merriman, Von Ah, Miaskowski, & Aouizerat, 2013). Additionally, relationships between cancer and cognition beyond treatment itself may exist. Attentional fatigue, sleep disturbances, age, and anxiety have all been related to issues with cognition in survivors (Merriman et al., 2013). Regardless of the cause, cognitive impairment can have an

impact on overall quality of life, impacting areas like work and social well-being (Von Ah, 2015).

Participation as a concept, particularly participation in valued activities, has been identified as a contributor to quality of life and general well being and is a measure of overall health for cancer and many other chronic conditions. According to the World Health Organization (WHO) International Classification of Functioning (ICF), participation is defined as "involvement in a life situation" (WHO, 2002, p. 10). Disability can occur due to participation restrictions, activity limitations, and/or impairments (WHO, 2002). It is known that those living with cancer experience participation restrictions to a greater extent than those without cancer, (Ness, Wall, Oakes, Robison, & Gurney, 2006) and that long term, negative consequences from cancer treatments affect everyday activities (Hwang, Lokietz, Lozano, & Park, 2015; Silver, Baima, Newman, Galantino, & Shockney, 2013). It has also been established that participation in occupation is helpful in coping, restoring power, and gaining a sense of self, particularly when dealing with illness or chronic disease (Lyons, 2006; Newman, 2013; Palmadottir, 2009; Palmadottir, 2010; Vrkljan & Miller-Pogla, 2001).

Cancer and treatments related to cancer have been identified as having a negative effect on participation in many realms of daily life, and with a variety of types of cancer. Studies related to breast cancer survivorship are more typical than those related to other cancers, with specific attention to participation in exercise after breast cancer (Chan, Lui, & So, 2010; Cormie et al., 2013; Dieli-Conwright & Orozco, 2015; McNeely et al., 2006). Participation in activities as a whole has been the subject of only a few studies. Lyons, Lambert, Balan, Hegel, & Bartels (2013) found, on average, a 12% decrease in activity participation levels in older adults with cancer. Lyons et al. (2011) reported a 25% reduction in overall activity participation amongst

stem cell transplant (SCT) survivors 6 months post SCT. In a study of upper limb disability after breast cancer, participation and activity limitations were found for up to two years post surgery (Yang, Kang, Kim, & Lim, 2015). In an analysis of over 700 cancer survivors, more than half of survivors reported physical performance limitations, and roughly one third reported participation restrictions (Ness et al., 2006). The authors also found deficits in long-term survivors, years after diagnosis, and in those that were not elderly. More recent contributions to specific survivorship issues have identified employment (Brearley et al., 2011; Crist, 2013; Desiron, Donceel, Rijk, & Van Hoof, 2013; Mbengi et al., 2016; Mehnart, 2011), leisure (Shipp, Mckinstry, & Pearson, 2015), and social activities (Hwang et al., 2015) as areas of participation negatively affected by cancer.

Community based support services, beyond the medical model, are emerging to fill a gap in care for cancer survivors. The Institute of Medicine (IOM, 2012) has identified cancer as one of nine chronic illnesses in which care must be promoted in a community based setting, not as a substitute for quality medical management, but to provide interventions aimed at controlling, understanding, and living well with chronic disease. Limits in activities of daily living, fatigue, cognitive impairment, and pain are considered cancer-induced physical stressors, and discussed in the spectrum of psychosocial needs of cancer patients (Adler & Page, 2008). Psychosocial health services are a recommended standard of care and defined as "psychological and social services and interventions that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological/behavioral and social aspects of illness and its consequences so as to promote better health" (Adler & Page, 2008, p. 9). Services often encompass education on healthy lifestyle habits, disease or treatment education, stress and anxiety management, and social activities. These types of services, though

recommended as necessary components to improving the overall health and quality of life of survivors, are not readily supported through health insurance (Adler & Page, 2008; Levit, Balogh, Nass, & Ganz, 2013).

Chronic illnesses, like cancer, have been recognized as a major public health problem. They affect productivity in economic and self care realms, and represent 75% of the 2 trillion spent annually on health care in the US (IOM, 2012). The cost of caring for cancer alone was 157 billion in 2010, with an anticipated 30% more cancer cases projected by 2020 (National Cancer Institute, 2011). As these trends continue, services related to maximizing participation and activity and minimizing impairment may be necessary provisions in a community setting.

The primary purpose of this study was to explore the activity participation levels and quality of life of cancer survivors seeking community based support. The secondary purpose was to collect data on this population related to fatigue and cognitive issues. Understanding the limitations faced by those living with cancer may help in the development of new intervention approaches for community-based settings.

Methods

Research Design

This study used a cross sectional descriptive approach with self-report tools for examining the cancer population receiving services at a community based center, Gilda's Club Twin Cities (GCTC). The primary long-term objective was to inform a community based cancer center of self-reported activity participation and quality of life (QOL) of its new members. The secondary purpose was to provide descriptive information on two specific cancer related issues, fatigue and cognition, within this sample. Standard, quantitative measures were used to describe participation in life activities, QOL, fatigue, and cognition in the community based cancer

population. The study protocol was approved by the Institutional Review Board at St. Catherine University.

Participants

Participants were recruited through Gilda's Club Twin Cities, a community based cancer support center, for a three month period. A sample was recruited through new member orientation at GCTC. Members of GCTC were community dwelling cancer survivors of any age, at any stage of treatment/survivorship, with any type of cancer. Eligible GCTC members also included individuals involved in supporting a friend, family member, coworker, or significant other who is living with cancer, but this cohort was not the target population for this study. Members were eligible if they had a cancer diagnosis, were 18 years of age or older, new to GCTC, community dwelling, and able to read English and participate in self-report and consent. Those unable to complete a self-report due to cognitive or literacy issues were excluded. Members meeting eligibility criteria were introduced to the study during new member orientation, and asked to remain after orientation to complete the self-report measures.

Instruments

Demographic and Employment Information. Demographics collected included: Age, sex, ethnicity, type of cancer, type of treatment (surgery, radiation, chemo, other), stage in treatment (undergoing current treatments or completed current treatment), employment status and type of work, education, marital status. Additional questions included: Did you participate in paid work prior to your cancer diagnosis? Are you currently employed in the same job you had prior to cancer? Have you reduced your hours due to cancer? To what degree has your cancer diagnosis interfered with your ability to participate in employment? (Likert scale). These

additional questions served to further describe the activity levels of Gilda's Club members related to paid employment.

Activity level. The Activity Card Sort 2nd edition (ACS) (Baum & Edwards, 2008) was developed to measure activity engagement in older adults in four domains: instrumental activities, low-demand physical leisure, high-demand physical leisure, and social activities. The ACS was developed as a manual card sort, and requires clients to sort 89 cards with pictures of people participating in a variety of activities into mutually exclusive categories. The community living version additionally encourages the client to disclose the five activities that are his or her favorites, regardless of whether these have been given up. This study utilized a modified version of ACS, referred to as ACSm, developed by Lyons, Li, Tosteson, Meehan, & Ahles (2010) in measuring activity after stem cell transplant. ACSm involves using the tool as a self-report checklist and utilizes modified mutually exclusive categories (Never done prior to cancer diagnosis, Do now as often as before diagnosis, Do less or differently than before diagnosis, Not done since diagnosis, New activity since diagnosis) (Lyons et al., 2010). Scoring the ACSm follows the original scoring procedure by dividing the sum of all current activities by the sum of activities done previously for a total score and subsection scores using the modified categories. A total score of 100 indicates the participant has retained all of the activities participated in prior to cancer, or had added new activities to make up for the loss of old. A lower score indicates loss of participation, and/or the lack of new activity. The ACS has been validated as a self-report checklist (Everard, Lach, Fischer, & Baum, 2000; Lyons et al., 2010) and is a well-accepted measure of activity. Additionally, it has been used with the cancer population in several studies (Berg, Neufeld, Harvey, Downes, & Hayashi, 2009; Lyons et al., 2013; Lyons et al., 2010).

Self-report measures leave interpretation of instruction up to the individual. Although participants were instructed to circle only one answer or mark only one box, several individuals circled or marked multiple answers, or wrote in a number or answer. The ACSm does not provide specific direction in managing multiple responses, write-in answers, or areas left blank. Occasional blanks were coded as "never done", representative of what the investigator deemed the participant meant to convey. This occurred with five participants ACSm surveys, on multiple questions. It was concluded that these individuals simply did not mark "never done" and instead, left these areas blank. One individual left an entire page blank, and this was coded as missing data. Two individuals wrote in answers on several questions, instead of marking the box. In one case, the answer was written across multiple boxes, requiring the investigator to interpret which category to code. In another case, multiple items were answered by the participant writing in only one box, allowing the investigator to code according to the box the answer was written in.

Quality of Life. The Functional Assessment of Cancer Therapy-General (FACT-G) measures quality of life (QOL) in four domains: physical-well being (PWB), social well-being (SWB), emotional well-being (EWB), and functional well-being (FWB) (Cella et al., 1993). The FACIT (Functional Assessment of Chronic Illness Therapy) measurement system is based on FACT-G, the 27 item core questionnaire, and is targeted for populations with chronic illness, including cancer and other conditions (Cella et al., 1993). FACIT instruments are well validated, commonly used self-report measures and have been used in quality of life cancer studies worldwide (Brucker, Yost, Cashy, Webster, & Cella, 2005). Scoring the FACT-G involves adding all subscales, taking into account negatively stated items (which are reversed by subtracting the response from 4) for the total score. Higher scores indicate higher QOL. The

FACT-G has a test-retest reliability of .92, and measures of internal consistency range from a =0.69 to a=0.82 (Cella et al., 1993).

The FACIT organization provides direction as to how to handle multiple responses. Those processes were followed, specifically for two individuals who circled more than one answer. Any unanswered questions on the FACIT tools were coded as missing data. As suggested, a coin toss was utilized to randomly select the answer used in data analysis.

Cognition and Fatigue. Symptom specific measures for fatigue and cognition from the FACIT measurement system were used. Inclusion of the Functional Assessment of Chronic Illness Therapy-Fatigue Scale Version 4 (FACIT-Fatigue) (Appendix D.2) and Functional Assessment of Cancer Therapy-Cognitive Function Version 3 (FACT-Cog) (Appendix D.3) (Cella et al., 1993) allowed for additional descriptive information on the specific issues of fatigue and cognition, two areas of interest in the cancer population. The FACIT-Fatigue subscale (13 items) has a test/retest reliability of 0.90 and internal consistency of a =0.93 to a =0-.95 (Yellen, Cella, Webster Blendowski & Kaplan, 1997). Although limited psychometric data is available for FACT-Cog (36 items), internal consistency is reported at a =0.96 (Wagner, Sweet, Butt, Lai, & Cella, 2009). Scoring FACIT-Fatigue involves adding all individual scores, taking into account negatively stated items (which are reversed by subtracting the response from 4) for the total score. The FACT-Cog is scored differently than the other FACIT tools. Although there are four subscales (perceived cognitive impairments, comments from others, perceived cognitive abilities, and impact on quality of life), this symptom specific measure is best reported as a score only for the subscale “perceived cognitive impairments”, as this part of the tool has undergone more development than the other subscales (J. Bredle, personal communication, January 26,

2016). Higher scores indicate higher QOL in all FACIT tools, with the exception of the FACT-Cog. A lower score indicates less perceived cognitive impairments on this scale.

Procedures

This study was approved by the St. Catherine University Institutional Review Board. Recruitment coincided with new member meetings at GCTC between Jan 2016 and March 2016. Meetings were held on a variety of days and times, in order to best accommodate most individual's schedules. New members had reserved spots for a meeting by calling in or emailing GCTC. The new members received a packet of Gilda's Club orientation materials upon arrival, along with a written lay description of the study in the new member packet. During introductions, a brief verbal description of the study was provided and the meeting facilitator allowed the investigator to introduce the study. Following the new member business (typically an hour long informal presentation of services and a club tour), the staff facilitator allowed the doctoral project to be further described by the investigator. Members were then briefed on the purpose and procedure for the study including a description of informed consent, and asked to sign consent and remain in the room after the orientation, if they wished to participate. Study packets and writing materials were handed out as consent forms were turned in. The investigator remained in the room to answer any questions while participants filled out materials. Participants were allowed to take study packets with them for return at a later date, and a drop box was created at the front desk at Gilda's Club. Staff members were informed of the procedure for returning completed study packets. No identifying information was asked, and participants were assigned a number to ensure confidentiality. All completed surveys were kept in a locked file cabinet and electronic access to data was password protected. Additional information is summarized in Appendix B.

Data Analysis

Results were analyzed using SPSS software (Version 23). All data entry was checked initially by primary investigator, and then checked again by randomly selecting seven participant's packets (20%) and utilizing a second individual to check data entry. Data were screened and cleaned for errors by running several frequencies until all errors were addressed. Descriptive statistics for demographics, FACIT data, and ACSm were obtained. The ACSm data were utilized to identify the frequency of participants reporting a new activity. Additionally, ACSm data, written in by participants when asked to identify their five most important activities, were categorized into the four subscales utilized for ACSm. Frequencies for each category, based on the top three responses for each individual, were computed to determine which categories of activities were most important to this sample. Pearson's correlations were calculated for ACSm, FACT-G, and FACIT-Fatigue. Independent samples t-tests with separate variances were obtained for group comparisons for variables of age, stage of diagnosis, income, and married/partnered status. Group comparisons of those currently receiving chemo and/or radiation vs. those not currently in treatment were obtained post hoc to further understand the results. Additional questions related to employment were analyzed for frequencies (yes/no questions) and Likert scale scores were analyzed for degree to which a cancer diagnosis has interfered with ability to participate in employment.

Results

Participants

Attendance at new member meetings yielded 87 new members, of which 49 met eligibility requirements. A total of 27 eligible new members chose to participate in the study (response rate of 57%). Two surveys were not used; one member turned in an incomplete packet

(less than 75% complete), and one member turned in an incomplete packet with inconsistent responses to the completed portions. Members who chose not to participate cited several reasons including: not enough time, did not feel they were appropriate due to undisclosed circumstances, too tired to participate, and other plans requiring they leave immediately following orientation. This left 25 surveys for analysis. Of note, one of the 25 included surveys did not have any portion of the FACIT-Fatigue filled out, although the rest of the packet was completed.

Participant characteristics are described in Table 1. Most participants in the study were female (*n* = 22, 88%) and identified as white (*n* = 22, 88%). Those with a bachelor degree or higher constituted 56%. The average age in the study was 57 years old, with a range of 26-82 years old. Married respondents made up 56% (*n* = 14) of the total, while 12% (*n* = 3) were widowed or divorced, and 32% (*n* = 8) were never married. Retired participants made up slightly less than half of all respondents (*n* = 12, 48%), with remaining participants described as those employed full time (*n* = 3, 12%), those not employed and not looking for work (*n* =4, 16%), those looking for work (*n* = 3, 12%) and those on disability (*n* = 3, 12%). Income levels were reported as: less than $24,230 (*n* = 6, 24%), between $24,231-$53,657 (*n* = 8, 32%), more than 53,658 (*n* = 10, 40%) and not reporting (*n* = 1, 4%).

Table 1

Sample Characteristics (N=25)

Characteristic	N (%)
Age, years	
25-34	4 (16)
35-44	1 (4)
45-54	5 (20)
55-64	5(20)
65-74	8 (32)

75-84	2 (8)
Gender	
Male	3 (12)
Female	22 (88)
Marital status	
Married/partnered	14 (56)
Widowed	1 (4)
Divorced	2 (8)
Never married	8 (32)
Education	
Less than high school	1 (4)
High school graduate or equivalent	2 (8)
Some college but no degree	6 (24)
Associate degree	2 (8)
Bachelor degree	10 (40)
Graduate degree	4 (16)
Employment	
Full or part time	3 (12)
Retired	12 (48)
Not working	7 (28)
Disabled	3 (12)
Type of Cancer	
Breast	8 (32)
Hematologic	5 (20)
Genitourinary	5 (20)
Lung	3 (12)
Head and neck	1 (4)
Bone	1 (4)
Brain	1 (4)
Type of treatment	
Chemotherapy	20 (80)
Radiation	9 (36)
Surgery	15 (60)
Other[a]	5 (20)
None	1 (4)

Note. Type of treatment: Total percentages exceed 100% because some participants had more than one treatment.
[a]Other includes bone marrow transplant, stem cell transplant, hormone therapy, oral chemotherapy.

All cancer diagnoses occurred between 2003 and 2016 with over half (52%) reporting a diagnosis in 2015. Types of cancers reported were: breast 32% (*n* = 8), hematologic 20% (*n* = 5), genitourinary 20% (*n* = 5), lung 12% (*n* = 3), head and neck 4% (*n* = 1), brain 4% (*n* = 1), bone 4% (*n* = 1), gastrointestinal 4% (*n* = 1). Treatment interventions reported were: surgery (*n* = 15, 60%), chemotherapy (*n* = 20, 80%), radiation (*n* = 9, 36%), no treatment (*n* = 1, 4%) with

20% reporting additional treatments (bone marrow transplant (*n* = 1, 4%), hormone therapy (*n* = 2, 8%), oral chemo (*n* = 1, 4%), and stem cell transplant (*n* = 1, 4%). Of note, totals for treatment interventions are greater than number of participants due to many individuals reporting more than one treatment. Participants who were currently undergoing chemotherapy or radiation accounted for 44% (*n* = 11).

Activity Levels

Table 2 displays the mean percentage of activities retained after a cancer diagnosis overall, and in each category of the ACSm. Overall activity levels decreased 27% among the 25 participants. The subscale of leisure- high physical demand was affected most, with a decrease of 45%, followed by a 27% decrease in social activities, a 26% decrease in instrumental activities, and a 23% decrease in leisure- low physical demand activities.

Table 2

Descriptive Statistics for ACSm (N=25)

	M % retained	*SD*	Min	Max
Instrumental	.74	.22	.41	1.04
Leisure-LPD	.77	.21	.38	1.06
Leisure-HPD	.55	.27	.13	1.00
Social	.73	.31	.25	1.61
Total	.73	.22	.38	1.09

Note. Scores displayed in percentages. Max scores may be over 100% as some participants added new activities beyond loss of previous activities. LPD= low physical demand. HPD= high physical demand.

Participation in new activities was reported by 56% (*n* = 14) of participants, with 21 different activities across all subscales listed as new. The highest frequency of new activities fell in the subscale of instrumental activities, with "going to doctor or therapy" chosen by 36% (*n* = 9) of respondents, and "resting" by 20% (*n* = 5). Volunteer work was a new activity listed by

12% (*n* = 3) participants. The remaining new activities were across all subscales with low frequencies (only one or two participants identifying them as new).

Participants were asked to identify the five most important activities to them (including things they may no longer do) by writing in answers on a list numbered one to five. Those who listed two or more responses were analyzed, for a response rate of 88% (*n* = 22). Activities within the social realm were identified most, as social activities accounted for the majority of the top three most important activities, with half of the respondents (50%, *n* = 11) listing a social activity as number one. Specifically, social activities involving spending time with friends/family, travel, and going to a place of worship were identified. Beyond social, other important activities were spread across the remaining three categories. Leisure- low physical demand examples included watching television, reading and crocheting. Important instrumental activities were specifically listed as sleeping, working, cooking and cleaning. Walking, fishing, hunting, four wheeling, agate hunting, and being active were examples that fit into the leisure-high physical demand domain.

Participation in Employment

Participants responded to several questions related specifically to employment. A total of 56% (*n* = 14) participated in paid work prior to diagnosis, with 16% (*n* = 4) reporting they were in the same job they had prior to diagnosis. Of those participating in paid work prior to diagnosis, 57% (*n* = 8) reported a reduction in work hours due to cancer. All participants responded to the following statement: "Cancer has interfered with my ability to participate in paid employment". Almost half (48%, *n* = 12) strongly agreed (*n* = 6) or agreed (*n* = 6), 20% (*n* = 5) did not know, 8% (*n* = 2) disagreed, 12% (*n* = 3) strongly disagreed, and 12% (*n* = 3) did not report.

Quality of Life

Table 3 represents the mean, standard deviation, minimum and maximum scores of perceived QOL as measured with the FACIT tools. The lowest mean subscale score of 14.44 was emotional well being, followed by functional well being at 15.89, physical well being at 16.40 with the highest mean subscale score in social well being at 19.74. The overall range of scores was wide, with a low of 19.83 overall, and a high of 101.00. The FACIT-Fatigue, a symptom specific measure, was completed by 24 participants (one participant left it blank). The mean score was 25.91 with a minimum score of 5.00 and a maximum score of 52.00. The FACT-Cog mean score was 28.64. This tool is less developed than the other FACIT tools and only the subscale of perceived cognitive impairments was used for the mean score.

Table 3

Quality of Life Psychometric Properties (N=25)

Facit Tools	*M*	*SD*	Min	Max
PWB	16.40	6.02	7.00	27.00
SWB	19.74	7.18	3.00	28.00
EWB	14.44	5.52	3.00	22.00
FWB	15.89	6.40	3.00	28.00
FACT-G Total	66.47	20.02	19.83	101.00
FACIT-Fatigue[a]	25.92	12.69	5.00	52.00
FACT-Cog	28.64	21.14	0.00	64.00

Note. PWB = Physical Well-being, SWB = Social Well-being, EWB = Emotional Well-being, FWB = Functional Well-being, Total = Total FACT-G score. Higher scores equal better QOL in all scales except FACT-Cog. Lower scores in FACT-Cog indicate less cognitive issue. FACT-Cog mean based on only perceived cognitive impairments subscale.

[a]FACIT-Fatigue $N = 24$

Correlations

Pearson correlations were obtained for all ACSm subscales and total mean score, FACT-G subscales and total mean score, and FACIT-Fatigue mean score. All correlations were positive, moderate to strong, and statistically significant ($p < .05$). Strong correlations were

noted between the total mean ACSm score and the ACSm subscales (r = .78-.91), the FACT-G total mean score and FACT-G subscales (r = .72-.87) and the FACIT-fatigue total mean score and PWB, FWB, and the FACT-G total mean score (r = .79-.81).

Group Comparisons

Comparisons were made between several groups utilizing the ACSm, FACT-G, and FACIT-Fatigue mean scores. Independent samples t tests with separate variances were used to compare age (younger vs. older), income level (higher vs. lower), partnered vs. non-partnered status, early vs. late stage of diagnosis (early- stage 1 or 2; late stage 3 or 4), and treatment status (currently in chemo or radiation vs. not currently receiving chemo and/or radiation). There was a significant difference in the means of the FACT-G subscale SWB (p = .02) for higher income (M = 23.58, SD = 4.18) and lower income (M = 17.26, SD = 8.01) groups. In addition, differences in the means of the FACT-G total and FACIT-Fatigue approached significance (p = .12, p = .11) in the high (FACT-G total M = 74.08, SD = 13.78; FACIT-Fatigue M = 31.22, SD = 11.41) and low (FACT-G total M = 61.83, SD = 23.04; FACIT-Fatigue M = 22.57, SD = 11.41) income groups. Differences in the means of the FACT-G subscale SWB approached significance (p = .09) for the partnered (M = 22.06, SD = 4.70) vs. non-partnered (M = 16.79, SD = 8.83) groups.

Discussion

For many cancer survivors, life saving treatments can result in residual and chronic issues, limiting their ability to participate fully in life during and after cancer. Gaps in care, particularly in the psychosocial realm, lead survivors to seek support in community based settings. The primary goal of this study was to provide information to a community based cancer support center on the participation levels and quality of life of their new members, with the

secondary goal of collecting data on fatigue and cognitive issues. Understanding these issues is important in improving care in cancer survivorship.

Participants

This study was based at a relatively new cancer support center, Gilda's Club Twin Cities, located in a suburb of Minneapolis, in Minnetonka MN. The participants were recruited through a convenience sample of willing new members. The majority of participants were white female cancer survivors. Comorbidities were not accounted for, although two new members declined to participate as they considered their advanced age more of a factor on activity participation than cancer. Several participants that were included in the study disclosed comorbidities (advanced age, recently gave birth, recent hip replacement) and were encouraged to participate regardless. People living with cancer are at increased risk for comorbidities. Developing a secondary cancer or having additional chronic illnesses, cardiovascular disease or osteoporosis (Hewitt et al., 2006) is more common in survivors than in the general population. It is not clear whether the reduction in participation in this study is attributed to cancer, or if this can be explained by additional comorbidities or other factors.

The participants in this study represented a wide range of ages, along with a number of different cancers and stages of treatment. Cancer risk increases with age, with 86% of cancer survivors 50 years of age and older (American Cancer Society, 2016b). The mean age in this study was 57, with a range of 26-82. This blend of ages, treatments, and types of cancers, although representative of the overall population at GCTC, could contribute to the differences between this study and similar studies of activity levels. Of note, this study had relatively equal numbers of survivors who were married/partnered, compared to those who were not partnered. A recent meta analysis showed that longevity of survivors is directly related to partnered status and

size of social support network (Pinquart & Duberstein, 2010). This is further support of the importance of providing community based cancer care, with increased efforts to involve those survivors that may not have large support networks.

Activity levels

Some survivors in this study had little to no change in activity levels or QOL, while others were greatly impacted. On average, survivors reported a 27% decrease in their activity level after a cancer diagnosis, with the greatest loss of activities in the leisure- high physical demand and social categories. These findings indicate a greater loss of activity participation in comparison to similar studies in which the ACSm was utilized. Older adult cancer survivors were found to have a 12% average reduction in activity levels three months post treatment (Lyons et al., 2013) while stem cell transplant recipients had a 23% decline in activity level six months post transplant (Lyons et. al, 2011). This discrepancy may be related to a difference in settings; participants at GCTC were driven to seek support in a community based setting for self-perceived psychosocial needs, whereas participants in the two other studies were recruited through more traditional health care settings. Although overall activity loss was greater in the GCTC sample than in similar studies, there is consistency amongst subscales. Leisure-high physical demand was most affected, succeeded by social, instrumental and leisure-low physical demand, which mirrored similar studies. A population-based analysis found physical performance limitations and participation restrictions impacted to a greater degree than reported in any of the aforementioned studies, with physical performance limitations in over half of cancer survivors, and participation restrictions in one third of survivors (Ness et al., 2006).

Participants in this study valued social activity above the categories of instrumental, leisure-high physical demand, and leisure-low physical demand, with 50% identifying a social

activity as most important to them. Specifically, spending time with family and friends, followed by travel, were identified with most frequency. The most common new activities were "going to the doctor/therapy", and "resting", with a combined number of 14 participants choosing one or both of these as new activities. Although certainly a new activity, this may not be something one necessarily wants to participate in, as no participant chose either of these as a top priority when asked to list important activities. It would be interesting to compare time spent in activities before and after cancer along the same scope of activities listed in ACS. This might provide further insight into participation restrictions and barriers to participation in a community based population.

Quality of life

The overall quality of life total mean score in this study, as measured with the FACT-G, was lower than normative data for the US general population (80.1) and normative data for the US cancer population (80.4) (Brucker, Yost, Cashy, Webster, & Cella, 2005). The FACT-G mean in this study was 66.47, 18.1 points below the general population, and 15.9 points below the cancer population norms in the US. The largest difference noted was in the PWB subscale, with GCTC sample mean well below the norm for the US cancer population. All subscale mean scores on the FACT-G were below the norms for the cancer population in the US. Notably, the subscale of SWB within this study was slightly higher than the general US population, but not as high as the cancer population norm for SWB in the US. It is not surprising to note that over half the participants in this study indicated activities in the social realm as most important to them. Social well-being seems to be a priority for the GCTC group, and perhaps a priority for most cancer survivors, based on the norms for the population.

The mean score on the subscale measuring fatigue, the FACIT-Fatigue, was 25.92 in this study. This is above the mean score found in the norms for the anemic cancer population (23.9), and below the norm for nonanemic cancer populations (40.0) as well as below the norm for the general US population (40.1) (Cella, Lai, Chang, Peterman, & Slavin, 2002). This difference could be partially or fully explained by the methodology of the GCTC study; participants were asked to stay after an hour-long meeting to fill out surveys, which took between 20-45 minutes to complete. The FACIT-F was positioned after the ACSm and FACT-G in the study packet, likely contributing to overall fatigue. Another consideration for FACIT-Fatigue data is the number of participants currently in treatment (chemotherapy or radiation). There were 11 participants (44%) in current treatment. Cancer treatments tend to have increased negative effects based on the treatment cycle. For example, a participant who underwent a chemotherapy treatment the day before this research study would likely have a different level of fatigue than the same participant several days after a chemotherapy treatment.

The differences in QOL mean scores between the cancer population in the US as a whole, and the sample from GCTC indicate a great need for survivorship support. One explanation for this difference could be that the GCTC population has been motivated to seek support. These individuals have identified a need, and were driven to take steps to improve their QOL. It could be postulated that a self-identified need in this particular population is simply due to lower QOL, therefore QOL scores would be expected to be lower than the general US cancer population. The convenience sample in this study also included a high percentage of unpartnered individuals, which may also affect QOL scores. Differences in the means of the FACT-G subscale, social well-being (SWB) approached significance for the partnered and non-partnered groups.

Employment

Ability to participate in work remains an issue for many cancer survivors. Organizations like Cancer + Careers (http://www.cancerandcareers.org) and initiatives through the American Cancer Society are working to dedicate funds and efforts to address this problem. Although almost half of the participants in this study were retired at the time of the survey, 56% reported they were working prior to their cancer diagnosis. Of those who worked prior to diagnosis, over half reported a decrease in work hours due to cancer. Almost half of all participants strongly agreed or agreed with the statement "Cancer has interfered with my ability to participate in paid employment". Although minimal research exists regarding the causes of employment issues after cancer, a small, preliminary descriptive study found chronic conditions of fatigue, sleep disturbance, depression, neuropathy, and cognitive deficits and chronic pain as contributors to difficulty with employment (Christ, 2013). This area of work participation was not a considerable focus of this study, but the brief findings amongst the GCTC sample population indicate the need for more research and support in this area.

Challenges with the GCTC population

The results of this study indicate a great need for improved QOL, activity participation, and fatigue management in the population seeking services at GCTC. One of the challenges lies in providing appropriate support, education, and services to groups of individuals with varying needs. The results of this study indicate a great need to address participation and fatigue issues, but with attention to groups of survivors at very different need levels. For instance, some survivors had very mild fatigue, while others had fatigue at a level that could potentially interfere with participation in many realms of life. Programming could be tailored to specific groups of

survivors, based on utilization of tools like the FACIT system or ACSm, to allow for some individualization in a group based, community centered atmosphere.

There is a subgroup of the GCTC population seeking support related to end of life care. Two individuals who participated in the study were seeking support related to end of life issues, which was not the focus of this study. Although these individuals were included in the sample, there were no significant differences in mean scores for any measures in the group comparison for early vs. late stage of diagnosis. This is an example of another subgroup with likely very different needs than the newly diagnosed cancer survivor or the survivor seeking support after successful treatment.

Although treatments for cancer have become very successful for long-term survival, a cancer diagnosis is one of the few chronic illnesses which brings with it anxiety related to fear of recurrence or disease progression. A systematic review of quantitative studies found most long term cancer survivors have a modest intensity of fear of recurrence, impacting QOL and psychosocial well-being (Koch, Jansen, Brenner, & Arndt, 2013). Long term survivors are yet another example of a potential subgroup that could benefit from services specific to improving psychosocial well-being in a community based environment.

Limitations

These results need to be considered with the limitations of this study in mind. This was an exploratory study, therefore no controls for experiment wise error were applied. It is inappropriate to generalize results to the survivor population as a whole, as this was a small, ethnically homogenous sample of individuals who were self-seeking support in the community and volunteered to participate. This sample also included a wide range of ages, cancer diagnoses, and treatments, representative of those seeking services in this setting. No

consideration was taken for co morbidities, although three individuals disclosed issues to the investigator and were encouraged to complete the survey despite comorbidities.

This study used self-report measures to obtain information on participation and activities, QOL, fatigue, and cognition. Self-report is an accepted format, and is used extensively in healthcare and social science (Center for Disease Control, 2015b), despite identified issues with this type of data. Social desirability bias is common in self-reported measures, particularly when the trait is something deemed desirable or non-desirable. For example, asking participants to self-report on cognitive issues could result in social desirability bias. One participant in this study reported no cognitive issues at all, and another reported two minor issues. There are no norms available for the FACT-Cog, but in reviewing the question set, it is likely that most individuals would self-report issues with at least one or two items. The FACT-cog provides a statement and asks the participant to circle the category that fits best. Statements on the FACT-Cog include: "I have walked into a room and forgotten what I meant to get or do there", and "I have forgotten the names of people soon after being introduced". The participant is then asked to circle or mark a response based on the categories of "Never", "About once a week", "Two to three times a week", "Nearly everyday", "Several times a day". Another issue with self-report is the reliance on participants' memories. Participants were asked to report on activity levels prior to cancer, and there may have been under or over reporting of activity participation based on memory reliance. Self-reported cognitive measures in which norms are available would be helpful for this population.

Additional limitations arose with use of ACSm. The ACSm represents a variety of activities (89 activities in four subscales) but is not inclusive of all activities individuals may engage in. When asked to list the five most important activities, some participants listed

activities that were not otherwise listed on the ACSm (i. e. hunting, four wheeling, agate hunting, meditation, social activism, and adventure). This demonstrated limits in the ACSm in representing the full spectrum of activities one might participate in. Activity participation is an important, but personal, aspect of overall QOL, leading to difficulty in measurement.

Conclusion

The primary goal of this study was to provide information to a community based cancer support center (Gilda's Club Twin Cities) on the participation levels and quality of life of their new members. A secondary goal was to collect data on fatigue and cognitive issues, two common complaints in cancer survivors. This study found participation in activities, including employment, to be altered after a cancer diagnosis. Activities requiring high physical demand and social activities were most affected, followed by instrumental activities and leisure activities requiring low physical demand. Participants in this study placed more value on activities in the social realm than any other area. Quality of life for participants in this study was lower than the norms found for both the cancer population and the general population in the US, with the exception of social well being. Fatigue, often a complaint associated with QOL, was an issue for many of the participants.

Survivorship care has become a priority in many health related initiatives and government agencies. The advancing age of the US population, advances in medical treatments for cancer, and increased health care costs will require practitioners to shift focus from traditional medical settings to community based centers in efforts to provide necessary care to a greater percentage of the population in a cost effective manner. Opportunity and need exist in community based centers to provide effective programming related to participation and activity engagement, including fatigue management, role resumption, and the necessary performance

skills to achieve personal participation goals. Occupational therapists should take the lead in supporting survivors in community based settings to achieve improved health, well being, and participation.

Implications for Occupational Therapy Practice

Although occupational therapists have been involved in caring for people living with cancer for many years (Cooper, 2006), the shift in cancer care has gone beyond palliative and hospice concepts. Cancer should now be viewed from a rehabilitation and chronic care management perspective (IOM, 2012; Stubblefield et al., 2013). Specialty certifications in oncology care exist (Oncology Rehab Partners, 2015) with new continuing education opportunities arising regularly. Organizations like AOTA (2014) and the National Comprehensive Cancer Network (Denlinger et al., 2014) support the role of occupational therapy in oncology care.

Individuals living with cancer have a variety of cancer related issues with varied levels of need. Cancer related fatigue, mild cognitive impairment, physical limitations, pain, neuropathy, intimacy and sexual issues, resumption of roles and routines, and return to work are all areas in which occupational therapy services could have a positive impact on this population. Many of these issues could be ameliorated through education, training, and self-advocacy, while some issues would require a more intensive individual evaluation of one's performance skills, performance patterns, and contextual environment.

Development of community based programs, alternative funding and reimbursement strategies, and new models of care are supported by many government initiatives. The Affordable Care Act (Abrams, et al., 2015), Healthy people 2020 (Office of Disease Prevention and Health Promotion, 2016), The Institute of Medicine (Adler & Page, 2008;, Hewitt et al.,

2006), and President Obama's Moonshot taskforce (NCI, 2016) have vested interests in improving cancer care in the US. The occupational therapy lens on biomedical and sociocultural factors that support occupational performance and participation make the profession uniquely qualified to address this chronic condition in a community based setting. The value of providing occupational therapy in community settings is to reach a wider range of clients and tap into existing resources (community site specific) in order to minimize financial and transportation barriers, to utilize the group process to the advantage of all members, particularly in areas in which there are minimal clinical practice guidelines, and to improve on overall QOL in groups of people who may otherwise not receive services. As healthcare costs continue to rise, particularly in relation to chronic illness, so do the needs for alternative solutions to decrease the burden of cancer. Occupational therapy practitioners should advocate for their role as educators, consultants, and program managers in community based programs as it is clear that activity participation and quality of life are critical issues for this population.

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Appendix A: Review of Literature

Appendix A.1: Cancer

Cancer is the general term for 100+ types of diseases that occur when abnormal cells form in the body due to DNA damage (American Cancer Society, 2014). There are over a million cancer diagnoses annually in the US, with prostate, lung, and colorectal cancers occurring most frequently in men, and breast, lung and colorectal cancers in women (excluding skin cancers for both genders) (American Cancer Society, 2014). The likelihood of a cancer diagnosis over one's lifetime is 39.6% for men and women (National Cancer Institute [NCI], 2011). As of 2014, the World Health Organization (WHO) had identified at least 100 chemical, physical, and biological carcinogens, yet, for many cancers, the exact cause is unknown (Dollinger, Ko, Rosenbaum, & Foster, 2002).

Cancer treatments have become increasingly successful, with over 60% of survivors living five or more years after diagnosis (Howlader et al., 2016). Treatment for cancer varies, dependent on type of cancer, stage of cancer, age and other factors. Common treatments include surgery (for diagnosis, treatment, and prevention), chemotherapy, radiation, targeted therapy, immunotherapy, hyperthermia, stem cell transplants, photodynamic therapy, laser treatments, and blood transfusions (American Cancer Society, 2014).

Advances in treatment have improved mortality and morbidity rates, but the side effects of life saving treatments can be devastating and long lasting. Chemotherapy and radiation side effects can produce short and long term issues, including pain, fatigue, peripheral neuropathy, appetite changes, cognitive and mood disorders, and poor eye/hand coordination. Surgical side effects can include pain, loss of range of motion, functional mobility issues, and body image issues (American Cancer Society, 2014). Side effects often have long-term consequences on a survivor's quality of life, and can lead to disability. According to the Council for Disability

Awareness (CDA) cancer was the second leading cause of new disability claims in 2013, accounting for 15.1% of new claims and 9.1% of ongoing claims (CDA, 2014). Survivorship after cancer has become the norm rather than the exception, with cancer now considered a chronic disease (Centers for Disease Control and Prevention [CDC], 2015a).

Appendix A.2: Survivorship

Treating cancer has been the subject of many national programs and research agendas for decades, primarily from a curative, prevention or biomedical perspective. Under President Lyndon B. Johnson, programs were established to help make the latest advances in biomedical research in heart disease, stroke, and cancer available to Americans (US National Library of Medicine, n.d.). In 1967, the Hospice Movement, although quite small, began to take shape and contribute to palliative care (National Hospice and Palliative Care Organization, 2016). In 1968, cancer was placed under the umbrella of chronic disease control (US National Library of Medicine, n.d.). The National Cancer Act of 1971 led to declaration of the war on cancer, and was pivotal in paving the way for government-funded research in finding a cure for cancer (NCI, 2016).

Implementing standards of care and programs for survivorship care however, is a more current trend in cancer care. By definition, a survivor is "One who remains alive and continues to function during and after overcoming a serious hardship or life-threatening disease. In cancer, a person is considered to be a survivor from the time of diagnosis until the end of life" (NCI, n.d., "NCI Dictionary of Cancer Terms"). Although the 1999 Institute of Medicine (IOM) report *Ensuring Quality Cancer Care* identified issues related to psychosocial support and the absence of a plan with goals for care, it was not until 2006 that the IOM formally addressed survivorship as a significant issue in cancer care, and recommended survivorship be viewed as a distinct phase

of treatment in the spectrum of care (Hewitt, Greenfield, & Stovall, 2006). Additionally, the American Society for Clinical Oncology [ASCO] brought attention to issues specific to survivorship in the 2004 creation of the Survivorship Task Force (McCabe et al., 2013). Since its inception, the task force has partnered with IOM and the NCCS (National Coalition for Cancer Survivorship) to bring light to the specific issues of survivors. As a result of increased attention on survivorship, the topic was added as a key component of curriculum in clinical oncology in 2005 (Muss, Von Roenn, & Damon, 2005). The CDC has had a longstanding interest in cancer care, particularly in addressing cancer prevention and control, and developed *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* to help the public health community address survivorship issues more comprehensively (CDC, 2004).

The American College of Surgeons Commission on Cancer (ACSCoC), which accredits cancer care programs, included survivorship care planning for the first time in the 2012 Cancer Program Standards (ACSCoC, 2012). Survivorship care plans are long term plans for individuals with cancer, allowing tracking of all related service, issues, and professionals involved in care. The 2016 Cancer Program Standards updated the survivorship care plan data elements based on the components outlined by the ASCO (ACSCoC, 2016). ASCO (2016) recommended survivorship care plans include not only treatment and follow up related to treatment, but also possible late or long-term side effects of treatment, healthy lifestyle management, and additional resources.

The IOM recently published *Delivering High Quality Cancer Care,* which points out the progress and gaps in cancer care since the 1999 IOM report (Levit, Balogh, Nass, & Ganz, 2013). The report detailed poor integration of palliative care, barriers in continuum of care, lack of multidisciplinary care planning, and inadequate psychosocial support as ongoing concerns in

cancer care. The report also identified issues in communication and coordination of care, care of older adults, quality and affordability of cancer care, and disparities in care, particularly for racial and ethnic minorities (Levit et al, 2013).

Cancer continues to be the subject of many national and regional priorities, particularly in the past five years. Decreasing the number of new cancer cases, as well as minimizing the disability caused by cancer, is a primary objective of Healthy People 2020 (Office of Disease Prevention and Health Promotion, 2016). The Moonshot Task Force, driven by President Barack Obama and led by Vice President Joe Biden, is listed as a key initiative by the NCI (NCI, 2015). This initiative is intended to accelerate research efforts through the National Institute of Health [NIH], Federal Drug Administration, and Department of Defense and Veterans Affairs, in efforts to prevent, detect, and treat cancer (The White House, 2016). State initiatives vary, but without exception, all states have a cancer registry program (NIH, 2015).

Survivorship has become a distinct phase of cancer care. Survivorship has often been neglected in research, education, and advocacy (Hewitt, Greenfield, Stovall, 2006) contributing to the lack of support some people feel in the post treatment phase (American Cancer Society, 2016b). In a survey of 1668 community based, adult cancer survivors living in Vermont, more than 10% of respondents identified unmet needs. In rank order, the needs were: help with stress reduction, more information on after effects of treatment, help reducing worry, help managing concerns regarding recurrence, help with the impact on relationships, help addressing problems with sex life, and more information on possible side effects (Geller, Vacek, Flynn, Lord & Cranmer, 2014). These unmet needs are in line with the 2013 IOM report *Delivering High Quality Cancer Care: Charting a new course for a system in Crisis*. This IOM report points to lack of psychosocial support, the high cost of cancer care, and fragmentation of the care system

leading to poor patient centered communication and decision-making as major issues in cancer care (Levit et al., 2013).

Appendix A.3: Consequences of Cancer: Fatigue

Common treatments for cancer, like surgery, chemotherapy and radiation, are not without some risk of adverse side effects. Silver and Gilchrist (2011) described the current state of care in the US: "In effect, the medical system creates a situation where high functioning individuals are given life-prolonging treatments and then left to struggle with how to recover from the toxic adverse effects of these therapies" (p. S7). The American Cancer Society (2016a) recognized fatigue, cognitive changes, pain, and sexual dysfunction to name just a few of the side effects of cancer treatments. Although these issues resolve over time for some survivors, many individuals are left to face long-term consequences.

Cancer related fatigue (CRF) is one of the most common side effects of cancer treatment. The National Comprehensive Cancer Network (NCCN) defined cancer related fatigue as "a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning (Berger et al., 2015, p 1014). In fact, survivors rate CRF above pain, nausea and depression in affecting daily activities and quality of life (Hofman, Ryan, Figueroa-Mosley et al., 2012).

The prevalence, incidence, and duration of fatigue are difficult to determine due to limitations in most research reports, such as small sample sizes, differing fatigue scales, and cross sectional design studies (Berger et al., 2015). In a systematic review of literature on cancer related fatigue, the incidence was found to be between 4%-91%, varying greatly due to assessment methods and populations studied (Lawrence, Kupelnick, Miller, Devine, & Lau,

2004). In an examination of the prevalence of CRF, Hofman, Ryan, Figueroa-Moseley, Jean-Pierre and Morrow (2012) found >80% of patients undergoing chemotherapy or radiotherapy reported CRF to some degree. Although most cancer survivors will live with fatigue during the course of treatment, up to 30% will have lasting, significant fatigue several years post treatment (Bower et al., 2014).

Clinical practice guidelines provide a template for healthcare providers in the screening, assessment, intervention and ongoing monitoring of fatigue in the cancer population. NCCN (2015) suggested screening should begin at diagnosis, and be performed at least annually or as indicated by symptoms. Comprehensive assessment should be performed as well as referrals to appropriate professionals. Recommendations for interventions include education, physical activity, psychosocial and mind body modalities, and as a last resort, pharmacological solutions (Berger et al., 2015).

Physical activity as a treatment for fatigue is the subject of multiple research studies, as evidenced by the 2012 Cochrane review related to the treatment of cancer related fatigue. Cramp and Byron-Daniel (2012) evaluated 56 randomized controlled trials related to exercise as a treatment for CRF. They found improvements in fatigue, either during cancer therapy or after cancer therapy, were statistically significant in those groups who participated in aerobic training, specific to those with solid tumors (predominantly breast and prostate). A majority of the studies were specific to the breast cancer population. Additional work is necessary to identify effective parameters for duration/intensity, inclusion of multiple types of cancer, and long term follow up (Cramp & Byron-Daniel, 2012).

There is evidence to support non-pharmacological treatment of fatigue beyond exercise. Saarik and Hartley (2010) led a group based support program, focused on education, goal setting,

activity pacing, increasing exercise levels, and relaxation training. The 28 survivors who participated in the four week program reported positive reductions in fatigue and coping strategies, with 35% of participants rating fatigue "mild" at the end of the program, in comparison with 0% rating fatigue as "mild" at the onset of the sessions. A recent review of literature supported these findings, and listed psychoeducational interventions, yoga, structured multidimensional rehabilitation, stress management, cognitive behavioral therapy, management of concurrent symptoms, meditation/mindfullness activities, and Wisconsin ginseng to likely be effective in managing CRF (Mitchell et al., 2014).

Treatments for cancer related fatigue may involve a variety of professionals, including occupational and physical therapists (Fialka-Moser, Crevenna, Korpan & Quittan, 2003; Saarik & Hartley, 2010; Silver & Gilchrist, 2011). Occupational therapists often provide cancer survivors with energy conservation education, modification of environmental barriers, and strategies to return to roles and activities, while physical therapists focus on improving overall strength and function to alleviate or improve CRF (Silver, Baima, Newman, Galantino, & Shockney, 2013). As evidence for the treatment of CRF through exercise and psychosocial interventions increases, rehabilitation professionals have an opportunity to develop clinical guidelines and additional treatment strategies for individuals living with CRF.

Appendix A.4: Consequences of Cancer: Cognitive Changes

Cognitive changes after cancer are a frequent complaint. Cognitive deficits during and after cancer treatment are reported by as many as 75% of the population, and can last months to years after treatment ends (Janelsins et al., 2011). Although cognitive issues are often connected to chemotherapy, there is evidence to support other causes, such as endocrine therapy and radiation (Denlinger et al., 2014; Merriman, Von Ah, Miaskowski, & Aouizerat, 2013).

Additionally, there is evidence to suggest relationships between cancer and cognition beyond treatment itself. Attentional fatigue, sleep disturbances, age, and anxiety have all been related to issues with cognition in survivors (Merriman et al., 2013). Regardless of the cause, cognitive impairment can have an impact on overall quality of life, impacting daily life in areas like work and social well-being (Von Ah, 2015).

Executive function is most often found to be the specific area of cognition affected in cancer survivors. This is the set of high-level cognitive skills responsible for cognitive flexibility, planning, organization, problem solving and self-regulation (Pascale Toglia, Golisz, & Goverover, 2014). Neuroimaging studies have noted differences in the prefrontal cortex, the part of the brain responsible for executive function, in healthy individuals as compared with those with breast cancer, particularly those breast cancer patients treated with chemotherapy (Kesler, Kent, & O'Hara, 2011).

Although there are a variety of causes of cognitive changes after cancer, chemotherapy is of particular concern. In a meta-analysis of 13 studies, chemotherapy was found to be associated with cognitive impairment, particularly in executive function and memory (Hodgson, Hutchinson, Wilson, & Nettelbeck, 2013). Individuals reported difficulty with routine tasks, such as paying bills, meal preparation and getting ready to go out (Hodgson, et. al, 2013). The conclusions of a critical summary of data related to chemotherapy induced cognitive decline found memory, executive functioning, processing speed and reaction time most affected after chemotherapy (Argyriou, Assimakopoulos, Iconomou, Giannakopoulou, & Kalofonos, 2011).

Research on cognitive deficits associated with cancer have examined differences between objective measures of cognition and the survivor's subjective cognitive complaints. Subjective complaints of cognitive issues are often not reflected in objective

assessments (Craig, Monk, Farley, & Chase, 2014; Egan et al., 2013; Hodgson, Hutchinson, Wilson, & Nettelbeck, 2013; Hutchinson, Hosking, Kichenadasse, Mattiske, & Wilson, 2012). A systematic review of 24 articles by Hutchinson et al. (2012) found a significant relationship between objective and subjective clinical findings in only eight of the articles reviewed. Psychological stress factors, including fatigue, depression, and anxiety, may contribute to subjective cognitive complaints (Craig et al., 2014; Hodgson et al., 2013; Hutchinson et al., 2012; Pullens, Vries, Van Warmerdam, Van De Wal, & Roukema, 2013). Additionally, objective testing, typically performed in a controlled environment at a specific point in time, may not reflect real life cognitive function over the course of time (Hutchinson et al., 2012). A prospective study comparing subjective cognitive complaints in women with benign breast disease (BBD) to women diagnosed with breast cancer (BC) who were preparing for chemotherapy treatments provides further insight. Both groups (BBD and BC) had very similar frequencies of complaints, but the BC group had significantly decreased satisfaction with subjective cognitive function post chemotherapy (Pullens et al., 2013).

Subjective cognitive complaints should be recognized and addressed, as they impact overall quality of life (Hutchinson et al., 2012; Pullens et al., 2013). Perceived cognitive impairment is often associated with fatigue, anxiety, and depression, which can have a significant impact on a survivor's life (Hutchinson et al., 2012). The divergence between subjective and objective measures, along with the lack of uniformity in assessing objective cognitive issues has led to difficulty in studying this phenomenon (Craig et al., 2014). Additionally, differences in the definition of cognitive dysfunction have confounded research in this area (Denlinger et al., 2014). Finally, cancer survivor's additional symptoms of depression and fatigue may make it difficult for clinicians to determine whether the cognitive complaints are

related to these, or a separate problem (Bower, 2008; Pullens et al., 2013).

The NCCN published clinical practice guidelines to help practitioners evaluate and manage cognitive dysfunction in survivors (Denlinger at al., 2014). Screening should include management of any factors that may contribute to cognitive issues, such as sleep disturbances, medications, pain or depression. Imaging may be necessary for those with unexplained deficits, to rule out brain or central nervous system involvement. Comprehensive evaluation with neuropsychological testing may be necessary, particularly due to the subtlety of perceived cognitive impairments, and the lack of screening tools available to detect these impairments (Denlinger et al., 2014).

Recommendations to manage cognitive dysfunction include a variety of non-pharmacological techniques, followed by pharmacological interventions if other treatments fail. Cognitive behavioral therapy, exercise, relaxation, and stress management are all indicated in the management of cognitive deficits after cancer (Denlinger et al., 2014). Occupational therapy is recommended, particularly for those individuals with specific limitations related to work or role performance, quality of life, and issues related to task performance, including word finding or comprehension (Denlinger et al., 2014).

Many limitations exist in research regarding cognitive changes after cancer. The exact mechanism of cognitive impairment is not clear, however, chemotherapy seems to be a factor in many cases (Hodgson et al., 2013; Wefel, Saleeba, Buzdar, & Meyers, 2010). Cognitive deficits have been reported across multiple cancer diagnoses, but the dominance of research on the breast cancer population makes it difficult to generalize the results (Argyriou et al., 2011; Hodgson et al., 2013; Hutchinson et al., 2012; Schuurs & Green, 2013). The incidence itself of cognitive

dysfunction after cancer is not clear, and may be higher and potentially longer lasting in the breast cancer population (Wefel et al., 2010).

Appendix A.5: Participation in Activities and Occupations after Cancer

Participation as a concept, particularly participation in valued activities, has been an identified as a contributor to quality of life and general well being. According to the World Health Organizations (WHO) International Classification of Functioning (ICF), participation is defined as "involvement in a life situation" (WHO, 2002, p. 10). Disability can occur due to participation restrictions, activity limitations, and/or impairments (WHO, 2002). Occupation, according to the *Occupational Therapy Practice Framework: Domain and Process (3rd ed.)* [*Framework*] refers to engagement in daily life activities, including activities of daily living (ADLs), instrumental activities of daily living (IADLs), rest and sleep, education, work, play, leisure, and social participation (American Occupational Therapy Association [AOTA], 2014). The *Framework* further identified this concept, stating, "active engagement in occupation promotes, facilitates, supports, and maintains health and participation" (AOTA, 2014, p. S4). Christiansen, Baum, and Bass (2015) discussed the importance of participation in everyday activities and occupations, with benefits in relation to well-being, self-identity, stress, and biological rhythms.

Participation in valued occupations not only contributes to overall health and wellness, but also can be beneficial in adjusting and surviving during or after an illness. The transformative benefit to participation in occupation is apparent, especially for people navigating life threatening or chronic illnesses. Occupational engagement can lead to a sense of control over one's life and a shift for those with cancer, to "living with cancer", instead of allowing a cancer diagnosis to define one's self (Vrkljan & Miller-Pogla, 2001). White, Lentin & Farnwoth (2013)

further supported the empowering nature of occupation in chronic illness, finding occupation beneficial to monitor and reveal health conditions, explain symptoms, and manage and overcome health issues. This mixed methods study, based on the interviews of 16 adults with chronic health conditions, found engagement in occupation to be central in allowing people living with chronic health conditions to find new meaning and purpose in their lives, despite changes and disruptions to their overall abilities. Reed, Hocking and Smythe (2011) provided additional insight into the importance of not only occupation, but also the meaning found in occupation. The authors, through a synthesis of literature and interviews with 12 adults who had experienced occupational disruption, described the transformative properties of occupation, and suggested the personal meanings occupations hold to be important in uncovering potential and gaining control beyond function or performance.

Cancer and treatments related to cancer have been identified as having a negative effect on participation in many realms of daily life. Areas related to employment (Brearley et al., 2011; Crist, 2013; Desiron, Donceel, Rijk, Van Hoof, 2013; Mbengi et al., 2016; Mehnart, 2011), leisure (Shipp, Mckinstry & Pearson, 2015), social activities (Hwang, Lokietz, Lozano, & Parke, 2015; Ness, Wall, Oakes, Robison, Gurney, 2006), and overall activity levels (Lyons et al., 2011; Lyons, Lambert, Balan, Hegel, & Bartels, 2013; Pergolotti, Cutchin, & Muss, 2015; Yang, Kang, Kim, & Lim, 2015) have been reported with negative consequences on a survivors life and occupational participation. Lyons (2006) summarized literature related to occupational engagement with cancer, and proposed the challenges those with cancer face: identity, social relationships, and ability to live life to the fullest. The author concluded, "occupational engagement can be a powerful vehicle to address these challenges and enhance the well being of persons with cancer" (p. 12).

Participation restrictions are evident at all stages and ages of the cancer trajectory, and with multiple cancer diagnoses. Breast cancer diagnoses tend to be the majority in many published papers related to participation, with much attention to participation in exercise (Chan, 2010; Cormie et al., 2013; Dieli-Conwright & Orozco, 2015; McNeely et al., 2006). Participation in activities as a whole has been the subject of only a few studies. Lyons et al. (2013) in a descriptive study of activity levels in older adults with cancer, found on average a 12% decrease in activity participation levels three months post treatment. Lyons et al. (2011) in a longitudinal descriptive survey reported a 25% reduction in overall activity participation amongst stem cell transplant (SCT) survivors 6 months post SCT. In a 2006 population based study of data from the 1999-2002 National Health and Nutrition Examination Survey of over 700 cancer survivors, more than half of survivors reported physical performance limitations, and roughly one third reported participation restrictions (Ness et al., 2006). The authors also found reported deficits in long-term survivors, years after diagnosis, and in those that were not elderly. Brearly and colleagues (2011), in a systematic literature review, discussed physical and practical problems encountered by adult cancer survivors. The authors identified a body of knowledge on specific issues (i.e. pain, fatigue, peripheral neuropathy, physical function, employment), but identified a lack of research in all areas, and more so in areas related to employment concerns, older survivors, and the needs and experiences of cancer survivors.

Measuring participation has been an area of difficulty in rehabilitation research. It may seem a rather concrete notion, but difficulty arises when attempting to objectify participation. There are overlapping concepts, such as activities, activity limitations, and impairments, making participation difficult to qualify (Heinemann, 2010). Participation is also dependent on

environment, personal motivations and needs, and social expectations (Heinemann, 2010), making measurement particularly challenging.

Although participation in everyday occupation after cancer has not garnered the same attention as other cancer topics, perhaps due to the emphasis rehabilitation places on physical functioning, and the complexity and difficulty in measuring participation, it warrants further exploration. It is known that those living with cancer experience participation restrictions to a greater extent than those without cancer (Ness et al., 2006) and that long term, negative consequences from cancer treatments affect everyday activities (Hwang et al., 2015; Silver et al., 2013). It has also been established that participation in occupation is necessary in coping, restoring power, and gaining a sense of self, particularly when dealing with illness or chronic disease (Lyons, 2006; Newman, 2013; Palmadottir, 2009; Palmadottir, 2010; Vrkljan & Miller-Pogla, 2001). The ability to participate, attribute meaning to occupations, recognize occupational potential and gain control of an unforeseen life circumstance can be achieved through occupational engagement. It is through recognition of participation limitations, beyond isolated physical or cognitive issues, that individuals can regain the life they want to live.

Appendix A.6: Community Based Cancer Support

Community based support services, beyond the medical model, are emerging to fill a gap in care for cancer survivors. The Institute of Medicine (IOM, 2014) has identified cancer as one of nine chronic illnesses in which care must be promoted in a community based setting, not as a substitute for quality medical management, but to provide interventions aimed at controlling, understanding, and living well with chronic disease. The issues survivors face are similar to issues faced by others living with chronic health conditions: fragmented health care, poor communication and follow up care, inadequate reimbursement for some aspects of needed care,

and questions regarding the best way to deliver care have been identified as barriers (IOM, 2014). New models of care are currently being explored to better address the full spectrum of needs of the survivor.

The gap in care between cancer patient and cancer survivor is wide, particularly in the area of psychosocial support. The IOM listed the psychosocial needs of the survivor as a significant area in which lack of support was evident (Adler & Page, 2008; Hewitt et al., 2006; Levit et al., 2013). The American Cancer Society (2014) listed the post treatment phase as a particularly difficult stage for the survivor, as support in the way of regular medical visits dwindles, and family/friends begin to visit less often. Additionally, the survivorship phase on the whole has been an area neglected in research, education, and advocacy, despite the fact that cancer survivors represent a priority population in health promotion interventions. Cancer survivors are at increased risk of developing a secondary cancer or additional chronic illnesses, like cardiovascular disease or osteoporosis (Hewitt et al., 2006).

Psychosocial health services are recommended as a standard of care and defined as "psychological and social services and interventions that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological/behavioral and social aspects of illness and its consequences so as to promote better health" (Adler & Page, 2008, p. 9). Services often encompass education on healthy lifestyle habits, disease or treatment education, stress and anxiety management, and social activities. These types of services, although discussed as necessary components to improving the overall health and quality of life of survivors, are not readily supported through health insurance (Adler & Page, 2008; Levit et al., 2013).

In response to this great need, philanthropic organizations have taken a large role in the psychosocial support of the survivor. These institutions are typically community based, group care models. The widest reaching is the Cancer Support Community. This organization began in 1982, when Harold and Harriet Benjamin recognized the lack of social and emotional support for survivors and their families, and opened The Wellness Community (TWC) in Santa Monica, CA. The late Gilda Radner, famous comedian, sought support at TWC while she lived with ovarian cancer. After her death in 1989, her husband Gene Wilder and friend Joanna Bull founded the first Gilda's Club in New York City. Additional Gilda's Club locations, founded on psychosocial support of survivors and their friends and families, have been opening their iconic red doors ever since. Gilda's Club and TWC merged their organizations in 2009, in an effort to provide a greater reach and more resources, and in response to the 2008 IOM report based on meeting the social and emotional needs of the cancer survivors. The merger resulted in the Cancer Support Community, the largest non-profit, professionally led cancer support network worldwide, providing direct service delivery, advocacy, and research related to survivorship (Cancer Support Community, 2016).

The Cancer Support Community now has 44 affiliates, 170 locations, and growing numbers of health care partners (Cancer Support Community, 2016). In addition to support in the clubhouse atmoshere, they offer online support. The Living Room is an online community dedicated to supporting adult survivors and friends and family, and Group Loop is open to teens living with a cancer diagnosis and teens living with cancer due to a friend or family member with a cancer diagnosis (Cancer Support Community, 2016).

Gilda's Club Twin Cities (GCTC) is the local affiliate of the Cancer Support Community. Located in Minnetonka, MN, GCTC opened its doors in January 2014, and has over 800

members (personal communication, Ryan Sweeney, April 26, 2016). Services at GCTC include group support in both formal and informal settings, healthy lifestyles programming, education, information and referral services, and social activities. GCTC offers all programming free of charge due to the generosity of philanthropic donations. All services are provided in a group setting, with referrals to outside organizations for those needing one on one support (GCTC, 2016).

In addition to the services provided by GCTC, the Twin Cities area is fortunate to have some additional services, free of charge, to support cancer survivors. Pathways (2016) is a community based non-profit organization providing complimentary healing methods for those facing a health crisis. The services are provided in the Pathways building in Minneapolis, MN, and include one on one bodywork sessions (acupuncture, massage) and group based art, music, movement and guided practice to allow individuals to take control of their healing journey. (Pathways, 2016). Firefly Sisterhood is a local non-profit that provides one on one support for breast cancer survivors by pairing them with a survivor who has lived with similar circumstances (Firefly Sisterhood, 2016). Additional support services, particularly for women, and those living with breast cancer, are available through the American Cancer Society (cancer.org). Local health care organizations, specifically Fairview, Hennepin County Medical Center, Mercy, Park Nicollet, St. Francis, and West Side Community Health Services (Spanish speaking only) provide free monthly support groups for specific cancers or cancer in general.

Community based organizations have been working diligently to meet the psychosocial needs of survivors, but there are still many gaps in care. Cancer and cancer treatments can leave individuals with permanent disability, and have lasting effects on physical and psychological functioning. Limits in activities of daily living, fatigue, cognitive impairment, and pain are

considered cancer-induced physical stressors, and discussed in the spectrum of psychosocial needs of cancer patients (Adler & Page, 2008). In efforts to improve care, IOM made recommendations for professional education programs to prepare licensed clinicians for not only the biomedical needs of the survivor, but also the psychosocial health needs (Adler & Page, 2008). Occupational therapists, as licensed clinicians educated and trained in both biomedicine and psychosocial health, as well as experts in group models of care, are positioned to address the cancer induced physical stressors in community based settings.

Although occupational therapists in the United States have been involved in the care of people with cancer for years, particularly in palliative care, it is just now becoming a more recognized specialty area. AOTA has published a distinct description of occupational therapy's role with regards to the subspecialty of oncology (AOTA, 2014b). Occupational therapy has been identified as integral in rehabilitation and survivorship care in three areas: physical (range of motion, strength, fatigue, endurance, mobility), cognitive (memory, problem solving, executive function, visual perception) and psychosocial (mood, caregiver issues, role competence, body image) (Silver & Gilchrist, 2011). AOTA further supports oncology and cancer care as emerging practice areas through facilitation of a listserv (AOTA, 2014a) where therapists can pose questions to one another related to assessment tools, specific types of cancers and treatment methods, and publication of fact sheets on the role of OT in cancer care.

As long-term survivorship becomes the norm, rather than the exception, research related to survivorship and follow up care is needed. Understanding the limitations faced by those dealing with cancer may help in the development of new intervention approaches for community-based settings. Insight into participation and occupation, and the barriers created by cancer and its treatments, could help those dealing with cancer live more productive and

meaningful lives. The IOM (2014) recognized chronic illness as a major public health problem, affecting productivity in economic and self care realms, and representing 75% of the 2 trillion spent annually on health care in the US. The cost of caring for cancer alone was 157 billion in 2010, with an anticipated 30% more cancer cases projected by 2020 (National Cancer Institute, 2011). As these trends continue, services and support related to participation in valued activities may be necessary provisions in a community setting. In utilizing community based cancer support organizations, the financial barrier is minimized, and psychosocial support is provided. Addressing daily life participation issues in a community setting could provide further insight into the needs of the survivor, and demonstrate the value of addressing participation and occupational needs in a community setting.

Appendix B: Methods

Appendix B.1: Research Design

This study used a cross sectional descriptive approach with self-report tools for examining the cancer population receiving services at a community based center, Gilda's Club Twin Cities (GCTC). The long-term objective was to inform a community based cancer center of self-reported participation and occupational performance and quality of life (QOL) of new members for the purpose of improving services and outcomes. Additionally, the study sought descriptive information on two specific cancer related issues, fatigue and cognition. Standard, quantitative measures were used to describe participation in life activities and QOL in the community based cancer population. A pilot version, including three community members (two survivors and one staff member at Gilda's Club) was completed prior to beginning the study. This pilot demonstrated feasibility of the number of measures proposed, allowed for an accurate account of time needed to complete the study, and helped to inform Gilda's Club staff in what was being asked of new members. The majority of this study was based on the ability of the community based cancer population to self-report on participation and occupations after cancer. Self-report is an accepted format, and is used extensively in healthcare and social science (Center for Disease Control, 2015). Approval for this was received by the Institutional Review Board at St. Catherine University (IRB ID 561).

Appendix B.2: Participants

Participants were recruited through Gilda's Club Twin Cities, a community based cancer support center, from January 7, 2016 through March 30, 2016. A sample was recruited through new member orientation at GCTC. New member meetings are the most common way for people to become GCTC members. Members of GCTC were community dwelling cancer survivors of

any age, at any stage of treatment/survivorship, with any type of cancer. Eligible GCTC members also include individuals involved in supporting a friend, family member, coworker, or significant other who is living with cancer, but this cohort was not the target population for this study. Inclusion criteria were: Diagnosis of cancer, community dwelling, new member to Gilda's Club, 18 years of age or older, and ability to read English and participate in self-report and consent. Exclusion criteria were: Those individuals who could not complete a self-report due to cognitive or literacy issues. Members meeting eligibility criteria were asked to remain after orientation to complete the self-report measures. Family members/friends were allowed to remain in the room and assist as needed with the self-reported measures. Permission to attend the new member meetings and collect data was obtained by the Gilda's Club site administrator. IRB approval through St. Catherine University was awarded. The nature of the project involved minimal to no risk to subjects, with minimal disruption to the subjects normal life experiences, therefore this study met the criteria for exempt status (Level I review).

As of 3/31/2016, Gilda's club had 866 official members. The following statistics were available regarding the population: larger proportion of female to male members (76% female, 24% male); members are living with many types of cancers, with breast as the predominant type, followed by genitourinary, hematologic, gastrointestinal, lung, brain, and multiple other types of cancers; members are also individuals supporting someone with cancer, and do not necessarily have a cancer diagnosis; age distribution is wide, with 33.7% of all members between 56-59 years of age and 31.5% between the ages of 40-55. Age of remaining members is as follows: 13.1% between 25-39, 10.3% under age 18, 9.76% over 70, and 1.7% between 18-24 (personal communication, Ryan Sweeney, April 26, 2016).

Appendix B.3: Instruments

Instruments utilized were the Activity Card Sort 2nd edition (ACS) (Baum & Edwards, 2008) and several tools from the FACIT (Functional Assessment of Chronic Illness Therapy) measurement system (Cella et al., 1993), in addition to general demographic information and information pertaining to employment. Demographics collected included: Age, sex, ethnicity, type of cancer, type of treatment (surgery, radiation, chemo, other), stage in treatment (undergoing current treatments or completed current treatment), employment status and type of work, education, marital status. Additional questions included: Did you participate in paid work prior to your cancer diagnosis? Are you currently employed in the same job you had prior to cancer? Have you reduced your hours due to cancer? To what degree has your cancer diagnosis interfered with your ability to participate in employment? (Likert scale). These additional questions served to further describe the activity levels of Gilda's Club members related to paid employment.

The FACIT instruments included the Functional Assessment of Cancer Therapy-General Version 4 (FACT-G) (Appendix D.1), with the symptom specific measures of the Functional Assessment of Chronic Illness Therapy-Fatigue Scale Version 4 (FACIT-Fatigue) (Appendix D.2) and Functional Assessment of Cancer Therapy-Cognitive Function Version 3 (FACT-Cog) (Appendix D.3) (Cella et al., 1993). The FACIT measurement system is based on FACT-G, the core questionnaire, and is targeted for populations with chronic illness, including cancer and other conditions (Cella et al., 1993). The FACT-G can be supplemented with a variety of symptom specific, disease specific, or treatments specific subscales.

FACIT instruments are well validated, commonly used self-report measures and have been used in quality of life cancer studies worldwide (Brucker, Yost, Cashy, Webster, & Cella,

2005). FACIT tools are one of the most commonly used QOL measures in cancer clinical trials (Cella, 2000). The FACT-G has a test-retest reliability of .92, and measures of internal consistency range from α =0.69 to α=0.82 (Cella et al., 1993). The FACIT-Fatigue subscale has a test/retest reliability of 0.90 and internal consistency of α =0.93 to α =0-.95 (Yellen, Cella, Webster Blendowski & Kaplan, 1997). Although limited psychometric data is available for FACT-Cog, internal consistency is reported at α =0.96 (Wagner, Sweet, Butt, Lai, & Cella, 2009).

The FACT-G (27 items) measures quality of life (QOL) in four domains: physical-well being (PWB), social well-being (SWB), emotional well-being (EWB), and functional well-being (FWB). Inclusion of the FACIT-Fatigue (13 items) and FACT-Cog (36 items) allowed for additional descriptive information on the specific issues of fatigue and cognition, two areas of interest in the cancer population. Scoring the FACT-G and FACIT-Fatigue involves adding all subscales, taking into account negatively stated items (which are reversed by subtracting the response from 4) for the total score. The exception to this is the FACT-Cog. Although there are four subscales (perceived cognitive impairments, comments from others, perceived cognitive abilities, and impact on quality of life), this symptom specific measure is best reported as a score only for the subscale "perceived cognitive impairments", as this part of the tool has undergone more development than the other subscales (J. Bredle, personal communication, January 26, 2016). Higher scores indicate higher QOL in all FACIT tools, with the exception of the FACT-Cog. A lower score indicates less perceived cognitive impairments on this scale.

The instrument utilized to measure activity level was based on the ACS. The ACS was developed to measure activity engagement in older adults in four domains: instrumental activities, low-demand physical leisure, high-demand physical leisure, and social activities

(Baum & Edwards, 2008). The ACS is intended for use as a manual card sort, and requires clients to sort 89 cards with pictures of people participating in a variety of activities into mutually exclusive categories. Three versions are available, and the categories differ based on the chosen version of ACS. The institutional version is intended to measure activities prior to a hospitalization or rehabilitation admission, and uses categories of "Done Prior to Illness/Injury or Admission", and "Not Done Prior to Illness/Injury or Admission". The recovering version requires the client to place each of the 89 cards into the following categories" "Not Done Prior to Current Illness/Injury", "Continued to Do During Illness/Injury", "Do Less Since Illness/Injury", "Given Up Due to Illness/Injury", and "New Activity Since Illness/Injury". The community living version uses the labels "Not Done Since Age 60", "Do Now", "Do Less", and "Given Up" to determine participation levels amongst older adults. The score, based on calculating the percentage of retained activities, including any new activities, reflects the occupational engagement of the client (Baum & Edwards, 2008). The community living version additionally encourages the client to disclose the five activities that are his or her favorites, regardless of whether these have been given up.

Carpenter et al. (as cited in Baum & Edwards, 2008) reported an internal consistency of the four subscales between α= .83 to .94. Test-Retest reliability indicates stable scores across several studies, with a coefficient of .89 after a one week interval (Baum & Edwards, 2008) and .79 after a two week interval (Carpenter et al. as cited in Baum and Edwards, 2008). The ACS has been established as valid in content, construct, and predictive validity in a variety of studies, with a variety of populations (Baum & Edwards, 2008). Additionally, it has been used with the cancer population in several studies (Berg, Neufeld, Harvey, Downes, & Hayashi, 2009; Lyons, Lambert, Balan, Hegel, & Bartels, 2013; Lyons, Li, Tosteson, Meehan, and Ahles, 2010).

This study utilized a modified version of ACS. The Activity Card Sort modified (ACSm) (Appendix D.4) was developed by Lyons et al. (2010) to measure activity after stem cell transplantation. Permission to utilize the ACSm was granted by the author of ACS (C. Baum, January 22, 2016, personal communication) and author of ACSm (K. Lyons, November 6, 2015, personal communication). ACSm involves using the tool as a self-report checklist, instead of manually sorting cards, and utilizes modified mutually exclusive categories (Never done prior to cancer diagnosis, Do now as often as before diagnosis, Do less or differently than before diagnosis, Not done since diagnosis, New activity since diagnosis) (Lyons et al., 2013). ACS has been validated as a self-report checklist in two previous studies (Everard, Lach, Fischer, & Baum, 2000; Lyons et al., 2010).

Scoring the 89 item checklist followed the original scoring procedure using the modified categories. The total number of activities in the "Do now…, Do less…, and Not done since…" are added and labeled as "Done previously". The label "Current activities" is attributed to the items marked by the participant as "Do now…" (recorded as one point), "Do less…" (recorded as .5 point), and "New activity…" (recorded as one point). Dividing the sum of "Current activities" by the sum of the "Done previously" provided a level of overall activity. A total score of 100 indicated the participant had retained all of the activities participated in prior to cancer, or had added new activities to make up for loss of old. A lower score indicated the level of loss of participation, and/or the lack of new activity. Of note, participants could achieve a score greater than 100 in an individual subscale or overall score, if new activities were added beyond the level at which old activities had been given up.

Appendix B.4: Procedures

New member meetings were held at GCTC, scheduled in advance, posted on the Gilda's club calendar, and facilitated by Gilda's Club staff. Meetings were held on a variety of days and times, in order to best accommodate most individual's schedules. New members were typically referred to GCTC by social workers, physicians, friends and family, or other community based cancer support services, and had reserved spots for a meeting by calling or emailing Gilda's club. Upon arrival, new members were gathered and seated in a comfortable meeting area, offered beverages, and filled out basic Gilda's club paperwork. New member meetings typically had five-eight attendees, with a range of 1-15 attendees.

The new members received a packet of Gilda's Club orientation materials, along with a written lay description of the study in the new member folder at the onset of the meeting. During introductions, a brief verbal description of the study and introduction of the investigator was facilitated by the Gilda's Club staff member. Following the new member business (typically an hour long informal presentation of services and a club tour), the staff facilitator allowed the doctoral project to be further described by the investigator. Members were then briefed on the purpose and procedure for the study including a description of informed consent, and asked to sign consent and remain in the room after the orientation, if they wished to participate. Study packets and writing materials were handed out as consent forms were turned in. Study packets included general demographics, ACSm, FACT-G, FACIT Fatigue Scale, and FACT-Cog. The investigator remained in the room to answer any questions while participants filled out materials. Participants were allowed to take study packets with them for return at a later date, and a drop box was created at the front desk at Gilda's Club. Staff members were informed of the procedure for returning completed study packets. No identifying information was asked, and

participants were assigned a number to ensure confidentiality. All completed surveys were kept in a locked file cabinet and electronic access to data was password protected.

There were a total of 19 new member meetings from January 7, 2016, to March 30, 2016. Attendance at meetings yielded 87 new members, of which 49 met eligibility requirements. The target size of the sample was 40-60 participants, based on an average of 20-30 new members participating in orientation per month. This number, however, did not take into account the number of people supporting a survivor, and was miscalculated due to that error. The number of new members living with cancer versus the number of new members supporting a person living with cancer is relatively equal (many new members living with cancer bring a significant other, friend, etc. to the meeting, as a support).

Appendix B.5: Data Analysis

Results were analyzed using SPSS software (Version 23). All data entry was checked initially by the primary investigator, and then checked again by randomly selecting seven participant's packets (20%) and utilizing a second individual to check data entry. Descriptive statistics for demographics, FACIT data (total score and subscale scores for FACT-G, total score for FACIT-Fatigue, subscale score for perceived cognitive impairments for FACT-Cog), and ACSm (total activity score and subscale scores) were obtained. In addition to descriptive statistics, the ACSm data were utilized to compile a list of activities reported as new to determine frequency and category (utilizing existing ACSm subscales) of any new activities. ACSm data were also used to identify the top three most important activities, written in by participants. Frequencies for each ACSm domain, based on the top three responses for each individual, were computed to determine which domains were most important to this sample. Data were screened and cleaned for errors by running several frequencies until all errors were addressed. Pearson's

correlations were calculated for ACSm, FACT-G, and FACIT-Fatigue. Independent samples t-tests with separate variances were used to compare variables of age, stage of diagnosis, income, married/partnered status, and post-hoc for current treatment (chemo and/or radiation) vs. not currently receiving treatment. Additional questions related to employment were analyzed for frequencies (yes/no questions) and Likert scale scores were analyzed for degree to which a cancer diagnosis has interfered with ability to participate in employment. Results were compared with normative data when available. Normative data from the general U.S. population provided a mean score of 80.1 for total FACT-G, 22.7 PWB, 19.1 SWB, 19.9 EWB, 18.5 FWB, and norms for fatigue subscale 40.1 (Webster, Cella, Yost, 2003). Normative data for the cancer population provided a mean score of 80.4 total FACT-G, 21.2 PWB, 22.3 SWB, 18.1 EWB, 18.8 FWB (Brucker, Yost, Cashy, Webster, Cella, 2005). The FACIT-Fatigue norms are known for two subsets of the cancer population; anemic cancer population mean 23.9; nonanemic cancer population mean 40.0 (Cella, Lai, Chang, Peterman, Slavin, 2002). No normative data for FACT-Cog were available.

Literature related to the areas of participation, occupation, quality of life, fatigue, and cognition in the community dwelling cancer population was summarized. This information may be used to supplement current services for Gilda's Club community members regarding occupation and participation. Resources related to this topic will be made available to the Gilda's Club staff and members through the library located on site at Gilda's Club.

Appendix C: Results

Appendix C.1: Participants

Attendance at new member meetings yielded 87 new members, of which 49 met eligibility requirements. A total of 27 eligible new members chose to participate in the study (response rate of 57%). Two surveys were not used; One member turned in an incomplete packet (less than 75% complete), and one member turned in an incomplete packet with inconsistent responses to the completed portions. Members who chose not to participate cited several reasons including: not enough time, did not feel they were appropriate due to undisclosed circumstances, too tired to participate, other plans requiring they leave immediately following orientation. This left 25 surveys for analysis. Of note, one of the 25 included surveys did not have any portion of the FACIT-Fatigue filled out, although the rest of the packet was completed.

Participant characteristics are described in Table 1. Most participants in the study were female (n = 22, 88%) and identified as white (n = 22, 88%) with Asian (n = 1, 4%), black or African American (n = 1, 4%), and more than one race (n = 1, 4%) reported. Education levels were: bachelor degree (n = 10, 40%), some college (n = 6, 24%), graduate degree (n = 4, 16%), associate degree (n = 2, 8%), high school or equivalent (n = 2, 8%), and less than high school (n = 1, 4%). The average age in the study was 57 years old, with a range of 26-82 years old. Married respondents made up 56% (n = 14) of the total, while 12% (n = 3) were widowed or divorced, and 32% (n = 8) were never married. Retired participants made up slightly less than half of all respondents (n = 12, 48%), with remaining participants described as those employed full time (n = 3, 12%), those not employed and not looking for work (n =4, 16%), those looking for work (n = 3, 12%) and those on disability (n = 3, 12%). Income levels were reported as: less

than $24,230 (*n* = 6, 24%), between $24,231-$53,657 (*n* = 8, 32%), more than 53,658 (*n* = 10, 40%) and not reporting (*n* = 1, 4%).

Table 1

Sample Characteristics (N=25)

Characteristic	N (%)
Age, years	
25-34	4 (16)
35-44	1 (4)
45-54	5 (20)
55-64	5(20)
65-74	8 (32)
75-84	2 (8)
Gender	
Male	3 (12)
Female	22 (88)
Marital status	
Married/partnered	14 (56)
Widowed	1 (4)
Divorced	2 (8)
Never married	8 (32)
Education	
Less than high school	1 (4)
High school graduate or equivalent	2 (8)
Some college but no degree	6 (24)
Associate degree	2 (8)
Bachelor degree	10 (40)
Graduate degree	4 (16)
Employment	
Full or part time	3 (12)
Retired	12 (48)
Not working	7 (28)
Disabled	3 (12)
Type of Cancer	
Breast	8 (32)
Hematologic	5 (20)
Genitourinary	5 (20)
Lung	3 (12)
Head and neck	1 (4)
Bone	1 (4)
Brain	1 (4)
Type of treatment	
Chemotherapy	20 (80)
Radiation	9 (36)
Surgery	15 (60)
Other[a]	5 (20)
None	1 (4)

Note. Type of treatment: Total percentages exceed 100% because some participants had more than one treatment.

[a]Other includes bone marrow transplant, stem cell transplant, hormone therapy, oral chemotherapy.

All cancer diagnoses occurred between 2003 and 2016 with over half (52%) reporting a diagnosis in 2015. Types of cancers reported were: breast 32% (*n* = 8), hematologic 20% (*n* = 5), genitourinary 20% (*n* = 5), lung 12% (*n* = 3), head and neck 4% (*n* = 1), brain 4% (*n* = 1), bone 4% (*n* = 1), gastrointestinal 4% (*n* = 1). Participants reported the following cancer grades: Grade 1 (*n* = 3, 12%), grade 2 (*n* = 6, 24%), grade 3 (*n* = 3, 12%), grade 4 (*n* = 7, 28%), and unknown or missing (*n* = 6, 24%). Treatment interventions reported were: surgery (*n* = 15, 60%), chemotherapy (*n* = 20, 80%), radiation (*n* = 9, 36%), no treatment (*n* = 1, 4%) with 20% reporting additional treatments including bone marrow transplant (*n* = 1, 4%), hormone therapy (*n* = 2, 8%), oral chemo (*n* = 1, 4%), and stem cell transplant (*n* = 1, 4%). Of note, totals for treatment interventions are greater than number of participants due to many individuals reporting more than one treatment. Participants who were currently undergoing chemotherapy or radiation accounted for 44% (*n* = 11).

Appendix C.2: Activity Levels

Table 2 displays the mean percentage of activities retained after a cancer diagnosis overall, and in each category of the ACSm. Overall activity levels decreased 27% among the 25 participants. The subscale of leisure- high physical demand was affected most, with a decrease of 45%, followed by a 27% decrease in social activities, a 26% decrease in instrumental activities, and a 23% decrease in leisure- low physical demand activities.

Table 2

Descriptive Statistics for ACSm (N=25)

	M % retained	*SD*	Min	Max
Instrumental	.74	.22	.41	1.04
Leisure-LPD	.77	.21	.38	1.06
Leisure-HPD	.55	.27	.13	1.00
Social	.73	.31	.25	1.61
Total	.73	.22	.38	1.09

Note. Scores displayed in percentages. Max scores may be over 100% as some participants added new activities beyond loss of previous activities. LPD= low physical demand. HPD= high physical demand.

Participation in new activities was reported by 56% (*n* = 14) of participants, with 21 different activities across all subscales listed as new. The highest frequency of new activities fell in the subscale of instrumental activities, with "going to doctor or therapy" chosen by 36% (*n* = 9) of respondents, and "resting" by 20% (*n* = 5). Volunteer work was listed as new by 12% (*n* = 3) participants. The remaining new activities listed were across all subscales, with low frequencies (only one or two participants listing them as new).

Participants were asked to identify the five most important activities to them (including things they may no longer do) by writing in answers on a list numbered one to five. Those who listed two or more responses were analyzed, for a response rate of 88% (*n* = 22). Figure 1 details the top three responses, categorized according to the best fit of the activity amongst the available ACSm domains. Activities within the social realm were identified most, with half of all respondents (50%, *n* = 11) identifying an activity within the social subscale in their number one spot. Specifically, social activities listed were spending time with friends/family, travel, and going to a place of worship. Beyond the social domain, other important activities were spread across the remaining three categories. Leisure- low physical demand examples included watching television, reading and crocheting. Important instrumental activities were specifically listed as sleeping, working, cooking, and cleaning. Walking, fishing, and being active were

examples that fit into the leisure- high physical demand domain. Additionally, some participants listed activities like hunting, four wheeling, agate hunting, meditation, social activism, and adventure.

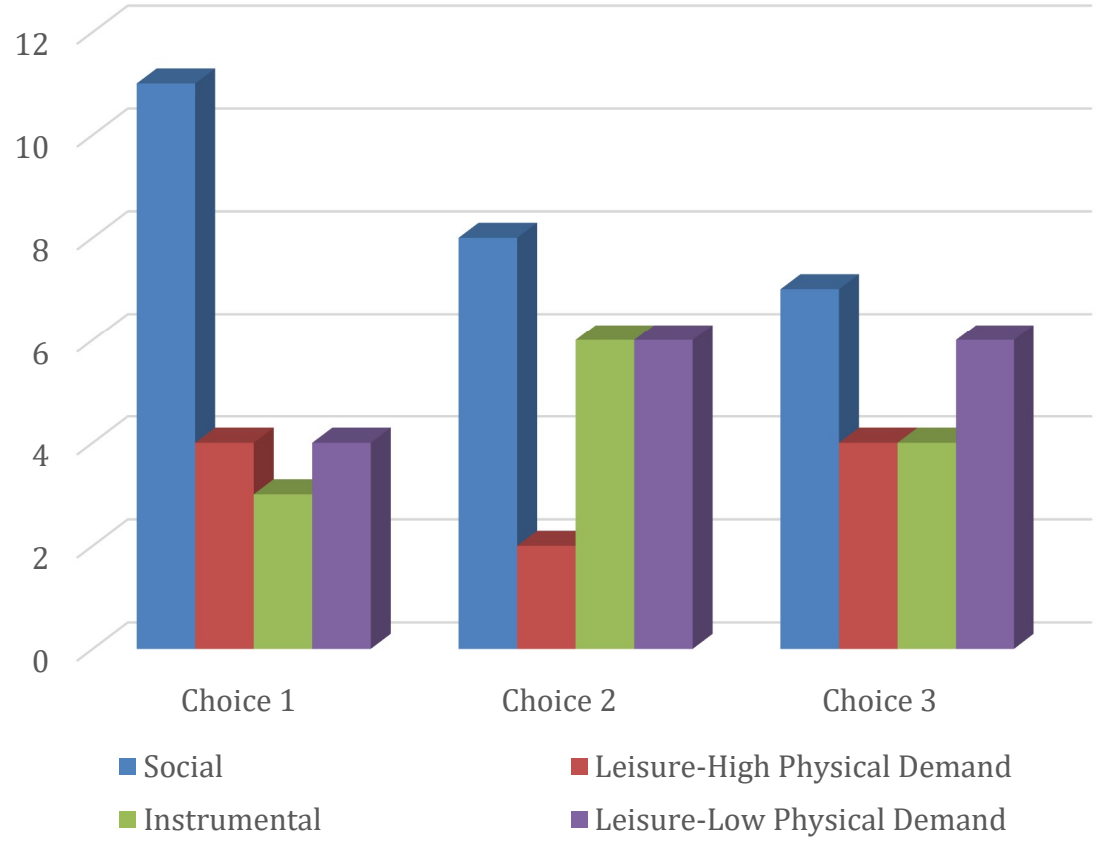


Figure 1. Important activities. Participants written answers were categorized into the appropriate domain. Social activities were listed most often in the top three most important activities. N=22 choice 1, choice 2. N=21 choice 3.

Appendix C.3: Participation in Employment

Participants responded to several questions related specifically to employment. A total of 56% (*n* = 14) participated in paid work prior to diagnosis, with 16% (*n* = 4) reporting they were in the same job they had prior to diagnosis. Of those participating in paid work prior to diagnosis, 57% (*n* = 8) reported a reduction in work hours due to cancer. All participants responded to the following statement: "Cancer has interfered with my ability to participate in paid employment". Almost half (48%, *n* = 12) strongly agreed (*n* = 6) or agreed (*n* = 6), 20% (*n*

= 5) did not know, 8% (*n* = 2) disagreed, 12% (*n* = 3) strongly disagreed, and 12% (*n* = 3) did not report.

Appendix C.4: Quality of Life

Table 3 represents the mean, standard deviation, minimum and maximum scores of perceived QoL as measured with the FACIT tools. The lowest mean subscale score of 14.44 was emotional well being, followed by functional well being at 15.89, physical well being at 16.40 with the highest mean subscale score in social well being at 19.74. The overall range of scores was wide, with a low of 19.83 overall, and a high of 101.00. The FACIT-Fatigue, a symptom specific measure, was completed by 24 participants (one participant left it blank). The mean score was 25.91 with a minimum score of 5.00 and a maximum score of 52.00. The FACT-Cog mean score was 28.64. This tool is less developed than the other FACIT tools and only the subscale of perceived cognitive impairments was used for the mean score.

Table 3

Quality of Life Psychometric Properties (N=25)

Facit Tools	*M*	*SD*	Min	Max
PWB	16.40	6.02	7.00	27.00
SWB	19.74	7.18	3.00	28.00
EWB	14.44	5.52	3.00	22.00
FWB	15.89	6.40	3.00	28.00
FACT-G Total	66.47	20.02	19.83	101.00
FACIT-Fatigue[a]	25.92	12.69	5.00	52.00
FACT-Cog	28.64	21.14	0.00	64.00

Note. PWB = Physical Well-being, SWB = Social Well-being, EWB = Emotional Well-being, FWB = Functional Well-being, Total = Total FACT-G score. Higher scores equal better QOL in all scales except FACT-Cog. Lower scores in FACT-Cog indicate less cognitive issue. FACT-Cog mean based on only perceived cognitive impairments subscale.

[a]FACIT-Fatigue *N* = 24

Histograms (Appendix C.7, figures 2-5) for the FACIT scales were bimodal or multimodal for FACT-G total, PWB, SWB, and EWB, and FACIT-Fatigue. The histogram for

FWB was approximately normal. Additionally, SWB and EWB produced a left-skewed distribution.

Appendix C.5: Correlations

Pearson correlations were obtained for all ACSm subscales and total mean score, FACT-G subscales and total mean score, and FACIT-Fatigue mean score. All correlations were positive, moderate to strong, and statistically significant ($p < .05$). Strong correlations were noted between the total mean ACSm score and the ACSm subscales ($r = .78$-$.91$), the FACT-G total mean score and FACT-G subscales (r = .72-.87) and the FACIT-fatigue total mean score and PWB, FWB, and the FACT-G total mean score (r = .79-.81). See Table 4 for specifics.

Table 4

Correlations Between Measures of FACT-G, FACIT Fatigue (FS), and ACSm

Measure	1	2	3	4	5	6	7	8	9	10	11
FACT-G											
1. PWB	1.00	.33	.44	.57	.72	.80	.58	.60	.45	.53	.62
2. SWB	.33	1.00	.51	.57	.78	.49	.44	.54	.27	.41	.50
3. EWB	.44	.51	1.00	.63	.79	.55	.47	.51	.41	.56	.56
4. FWB	.57	.57	.63	1.00	.87	.79	.72	.58	.59	.68	.70
5. FACT-G Total	.72	.78	.79	.87	1.00	.81	.69	.70	.54	.68	.74
6. FS	.80	.49	.55	.79	.81	1.00	.67	.57	.52	.67	.66
ACSm											
7. Instru-mental	.58	.44	.47	.72	.69	.67	1.00	.73	.64	.75	.91
8. Leisure-LPD	.60	.54	.51	.58	.70	.58	.73	1.00	.63	.67	.91
9. Leisure-HPD	.45	.27	.41	.53	.54	.52	.64	.63	1.00	.67	.78
10. Social	.53	.41	.56	.68	.68	.67	.75	.67	.67	1.00	.86
11. ACSm Total	.62	.50	.56	.70	.74	.66	.91	.91	.78	.86	1.00

Note. PWB=Physical Well Being, SWB=Social Well Being, EWB=Emotional Well Being, FWB=Functional Well Being, FS=Fatigue Scale, LPD=Low Physical Demand, HPD=High Physical Demand.

Appendix C.6: Group Comparisons

Comparisons were made between several groups utilizing the ACSm, FACT-G, and FACIT-Fatigue mean scores. Independent samples t tests with separate variances were used to compare age (younger vs. older), income level (higher vs. lower), partnered vs. non-partnered status, early vs. late stage of diagnosis (early- stage 1 or 2; late stage 3 or 4), and treatment status (currently in chemo or radiation vs. not currently receiving chemo and/or radiation). There was a significant difference in the means of the FACT-G subscale SWB ($p = .02$) for higher income ($M = 23.58$, $SD = 4.18$) and lower income ($M = 17.26$, $SD = 8.01$) groups. In addition, differences in the means of the FACT-G total and FACIT-Fatigue approached significance ($p = .12$, $p = .11$) in the high (FACT-G total $M = 74.08$, $SD = 13.78$; FACIT-Fatigue $M = 31.22$, $SD = 11.41$) and low (FACT-G total $M = 61.83$, $SD = 23.04$; FACIT-Fatigue $M = 22.57$, $SD = 11.41$) income groups. Differences in the means of the FACT-G subscale SWB approached significance ($p = .09$) for the partnered ($M = 22.06$, $SD = 4.70$) vs. non-partnered ($M = 16.79$, $SD = 8.83$) groups. See Tables 5-9 for specifics.

Table 5

Group Comparison Between Partnered Vs. Non-Partnered

	Partnered *N*= 14		Non-Partnered *N*= 11		
	M	*SD*	*M*	*SD*	*t*-test
FACT-G					
PWB	16.29	4.76	16.55	7.58	.92
SWB	22.06	4.70	16.78	8.83	.09
EWB	14.57	5.05	14.27	6.33	.90
FWB	15.88	5.51	15.91	7.66	.99
Total	68.80	12.34	63.52	27.31	.56
FS[a]	27.77	10.86	23.72	14.79	.46
ACSm[b]					
Instrumental	.70	.21	.80	.21	.23
Leisure-LPD	.75	.15	.81	.27	.51
Leisure-HPD	.53	.27	.58	.29	.71
Social	.70	.32	.76	.29	.65
Total	.69	.19	.79	.25	.29

Note. PWB=Physical Well Being, SWB=Social Well Being, EWB=Emotional Well Being, FWB=Functional Well Being, FS=Fatigue Scale, LPD=Low Physical Demand, HPD=High Physical Demand.
[a]Fatigue Scale Partnered *N*=13; Non-Partnered *N*=11. [b]ACSm scores reported as percentages.
*p < .05

Table 6

Group Comparison Between Current Treatment and No Current Treatment

	Current Treatment *N*= 11		No Current Treatment *N*= 14		
	M	*SD*	*M*	*SD*	*t*-test
FACT-G					
PWB	15.18	6.10	17.36	6.01	.38
SWB	20.82	7.85	18.89	6.80	.53
EWB	13.73	6.13	15.00	5.16	.59
FWB	16.94	5.42	15.07	7.16	.47
Total	66.67	18.88	66.32	21.57	.97
FS[a]	26.27	9.47	25.62	15.28	.90
ACSm[b]					
Instrumental	.75	.23	.73	.21	.82
Leisure-LPD	.75	.22	.79	.20	.68
Leisure-HPD	.56	.33	.54	.24	.93
Social	.71	.24	.74	.36	.82
Total	.73	.24	.73	.21	.97

Note. Current treatment defined as chemotherapy and/or radiation. PWB=Physical Well Being, SWB=Social Well Being, EWB=Emotional Well Being, FWB=Functional Well Being, FS=Fatigue Scale, LPD=Low Physical Demand, HPD=High Physical Demand.

[a]Fatigue Scale Lower *N*=14; Higher *N*=9. [b]ACSm scores reported as percentages.

*$p < .05$

Table 7

Group Comparison Between Lower Income and Higher Income

	Lower Income *N*= 14		Higher Income *N*= 10		
	M	*SD*	*M*	*SD*	*t*-test
FACT-G					
PWB	15.71	6.52	17.30	5.79	.54
SWB	17.26	8.01	23.58	4.18	.02
EWB	13.79	6.04	15.50	5.15	.46
FWB	15.07	6.64	17.70	6.00	.32
Total	61.83	23.04	74.08	13.78	.12
FS[a]	22.57	13.15	31.22	11.41	.11
ACSm[b]					
Instrumental	.72	.21	.80	.22	.36
Leisure-LPD	.77	.23	.80	.18	.70
Leisure-HPD	.53	.27	.62	.26	.47
Social	.71	.26	.79	.36	.56
Total	.72	.22	.78	.21	.50

Note. PWB=Physical Well Being, SWB=Social Well Being, EWB=Emotional Well Being, FWB=Functional Well Being, FS=Fatigue Scale, LPD=Low Physical Demand, HPD=High Physical Demand.
[a]Fatigue Scale Lower *N*=14; Higher *N*=9. [b]ACSm scores reported as percentages.
*$p < .05$

Table 8

Group Comparison Between Younger Vs. Older

	Younger *N*= 15		Older *N*= 10		
	M	*SD*	*M*	*SD*	*t*-test
FACT-G					
PWB	15.33	6.07	18.00	5.89	.29
SWB	18.23	17.14	22.00	7.00	.21
EWB	14.00	5.86	15.10	5.22	.63
FWB	16.13	6.15	15.53	7.07	.83
Total	63.70	19.71	70.63	20.79	.42
FS[a]	26.07	13.15	25.70	12.70	.95
ACSm[b]					
Instrumental	.75	.22	.74	.23	.90
Leisure-LPD	.75	.22	.81	.18	.41
Leisure-HPD	.57	.27	.52	.28	.70
Social	.76	.35	.68	.23	.53
Total	.72	.22	.75	.22	.81

Note. Younger defined as under age 64; older 65 and above. PWB=Physical Well Being, SWB=Social Well Being, EWB=Emotional Well Being, FWB=Functional Well Being, FS=Fatigue Scale, LPD=Low Physical Demand, HPD=High Physical Demand.

[a]Fatigue Scale Younger *N*= 14, Older *N*= 10. [b]ACSm scores reported as percentages.

*$p < .05$

Table 9

Group Comparison Between Self-Reported Tumor Type (Low Grade 1,2; High Grade 3,4)

	Low Grade *N*= 9		High Grade *N*= 10		
	M	*SD*	*M*	*SD*	*t*-test
FACT-G					
PWB	18.67	6.98	16.30	4.99	.41
SWB	18.00	8.52	20.05	5.44	.55
EWB	13.11	7.54	15.00	4.35	.52
FWB	17.44	8.62	14.83	3.88	.42
Total	67.22	28.48	66.18	13.33	.92
FS[a]	31.50	15.40	26.40	9.57	.43
ACSm[b]					
Instrumental	.79	.22	.70	.20	.36
Leisure-LPD	.73	.23	.75	.20	.83
Leisure-HPD	.58	.26	.53	.28	.68
Social	.69	.27	.79	.37	.51
Total	.72	.23	.71	.21	.94

Note. PWB=Physical Well Being, SWB=Social Well Being, EWB=Emotional Well Being, FWB=Functional Well Being, FS= Fatigue Scale, LPD=Low Physical Demand, HPD=High Physical Demand.
[a]Fatigue Scale Low Grade *N*=8, High Grade *N*=10. [b]ACSm scores reported as percentages.
*$p < .05$

Appendix C.7: Histograms

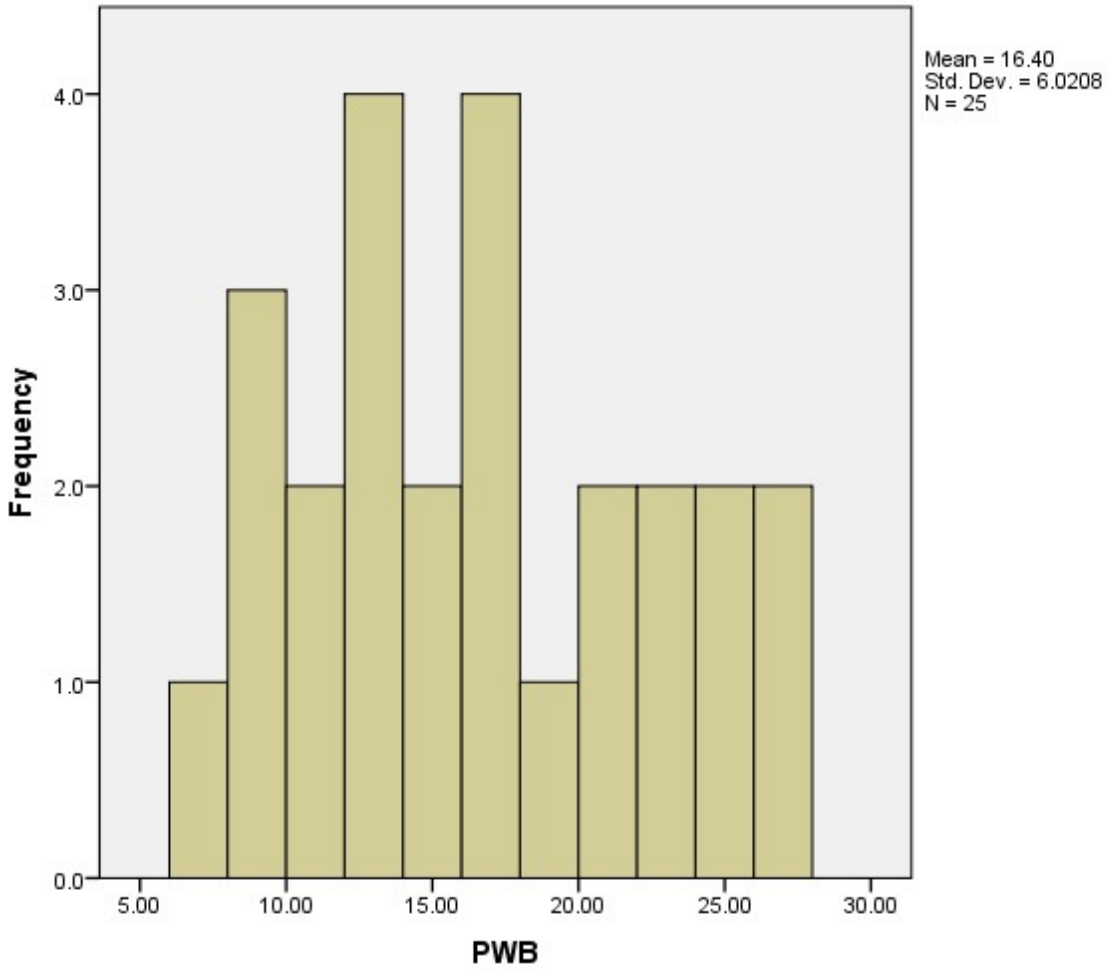


Figure 2. Physical Well Being subscale from FACT-G.

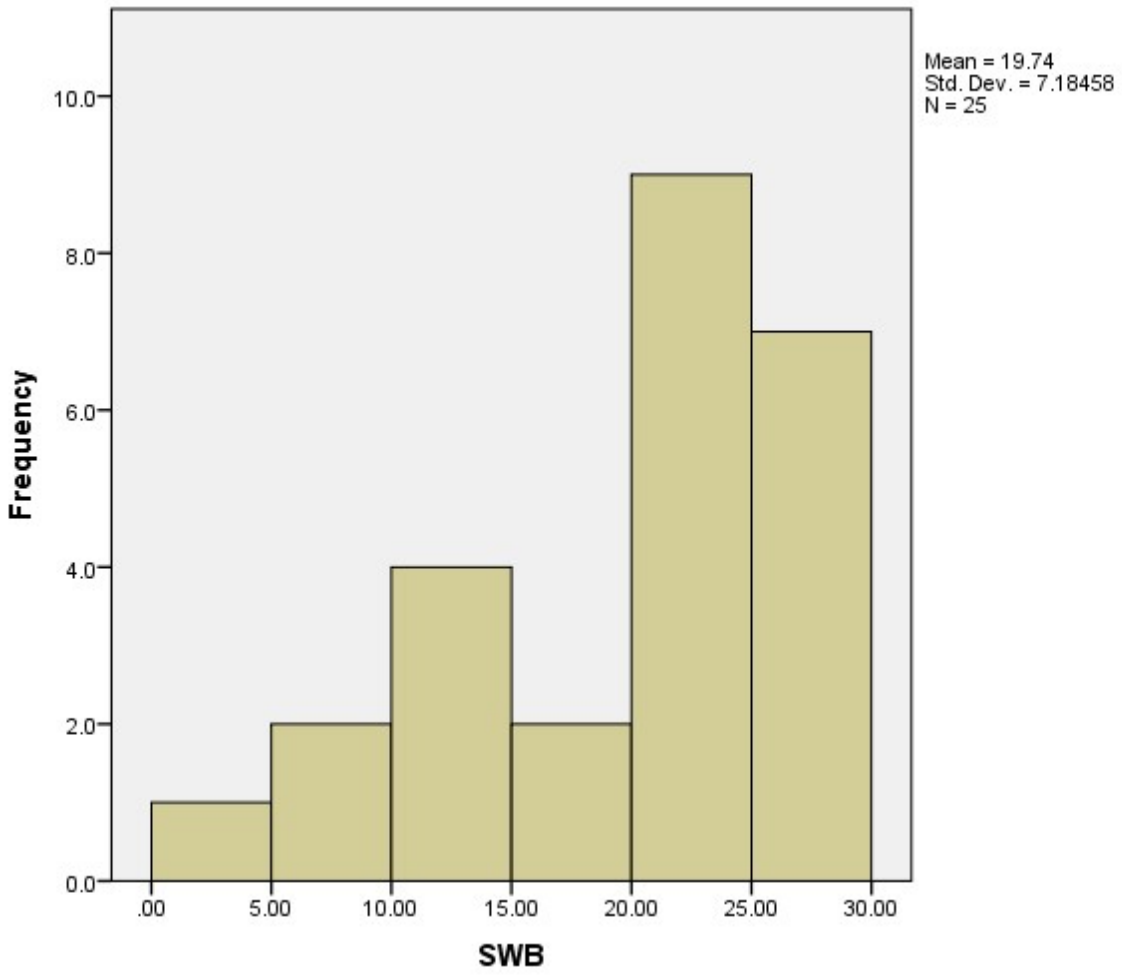


Figure 3. Social Well Being subscale from FACT-G.

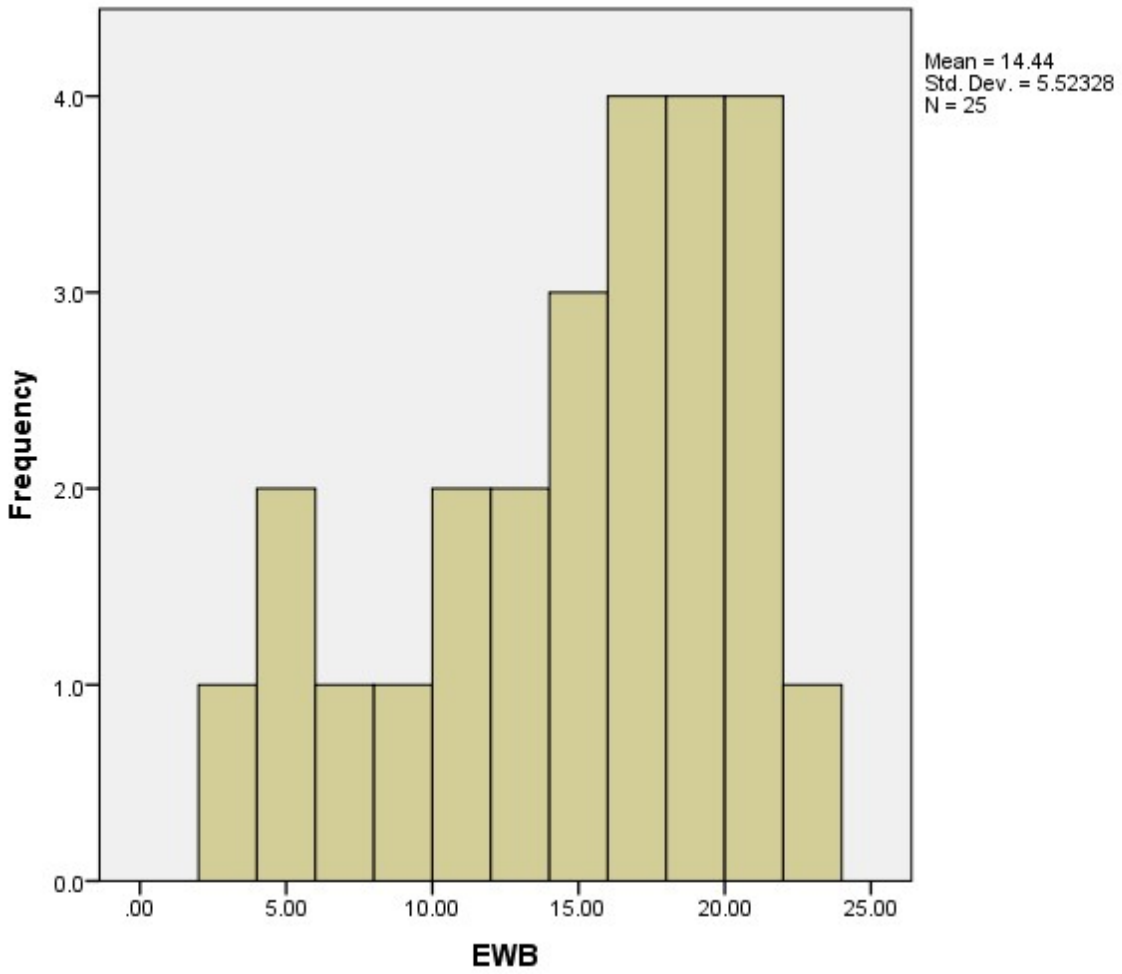


Figure 4. Emotional Well Being subscale from FACTG.

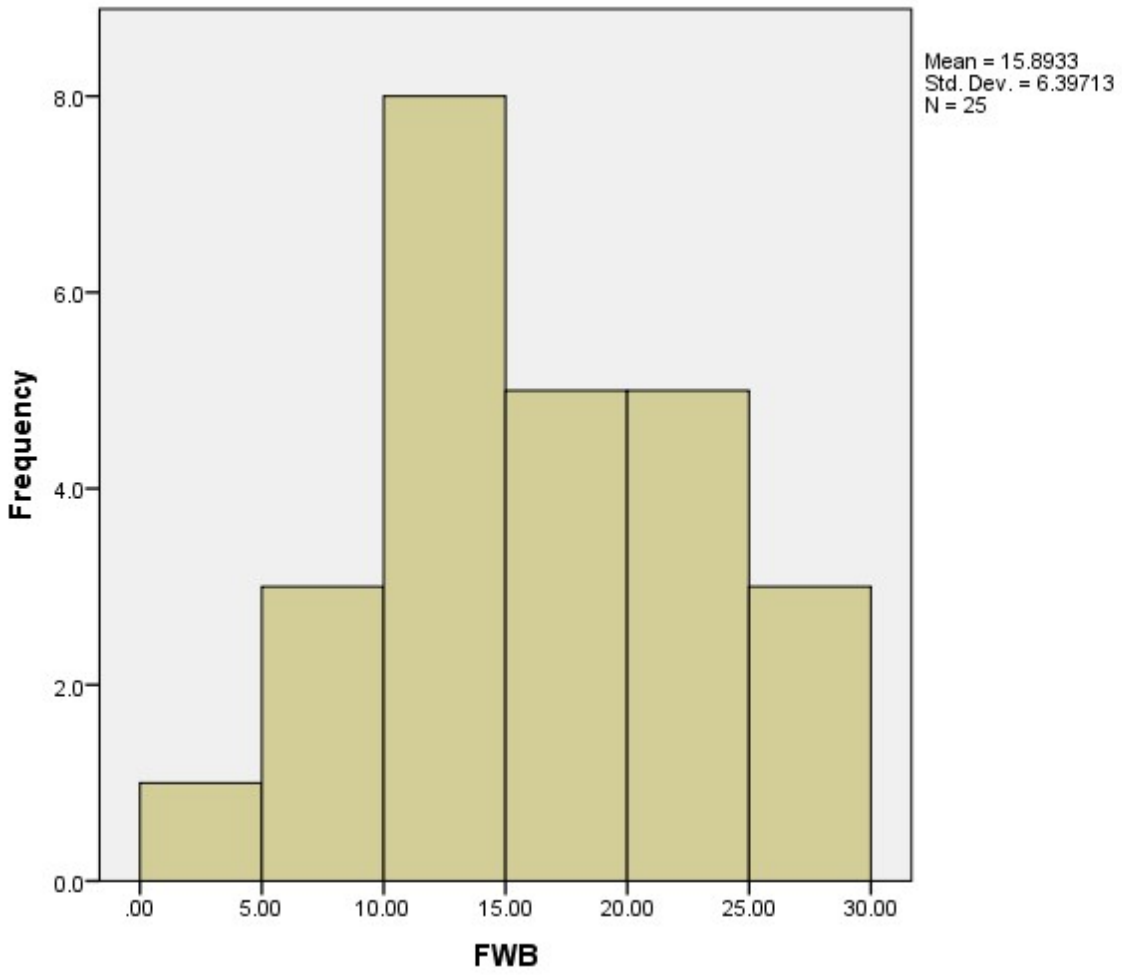


Figure 5. Functional Well Being subscale from the FACT-G.

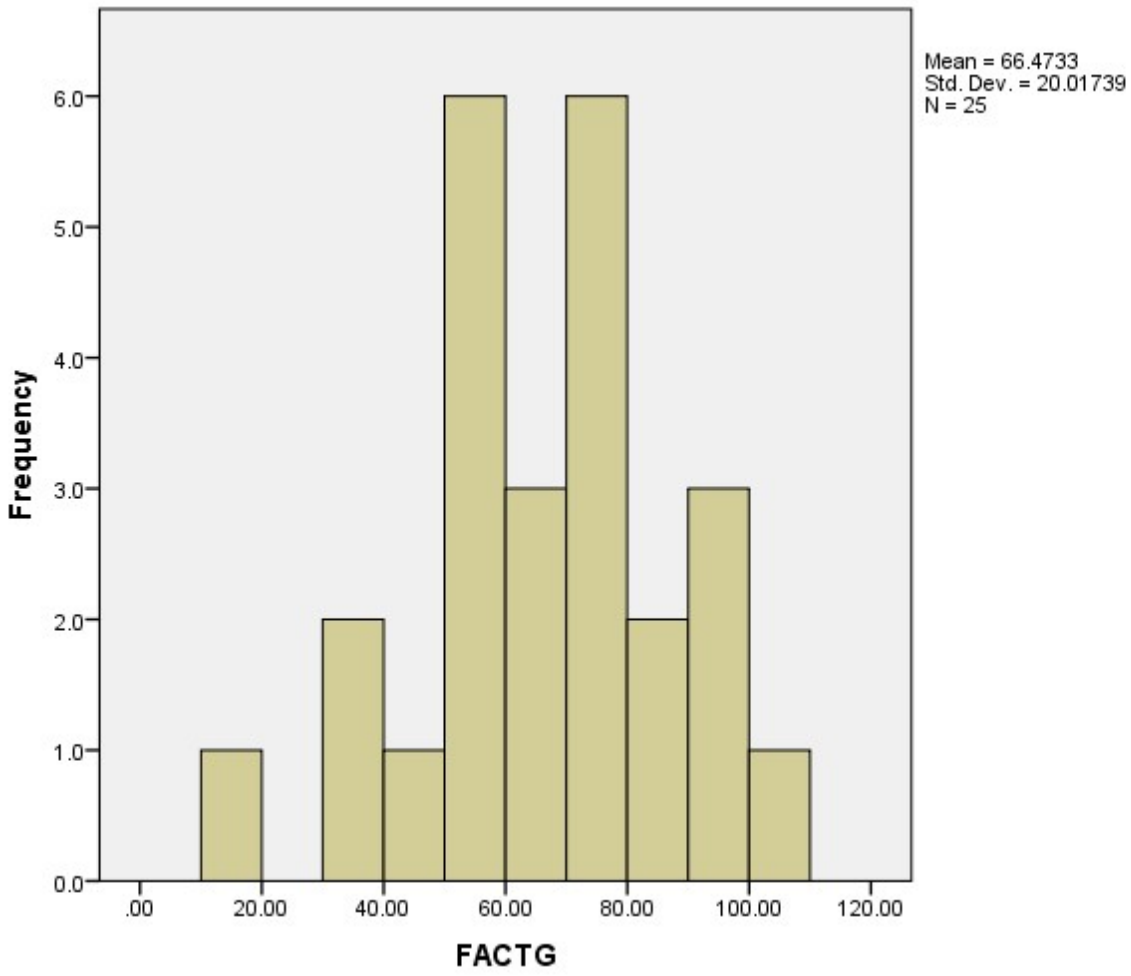


Figure 6. Total FACT-G scores.

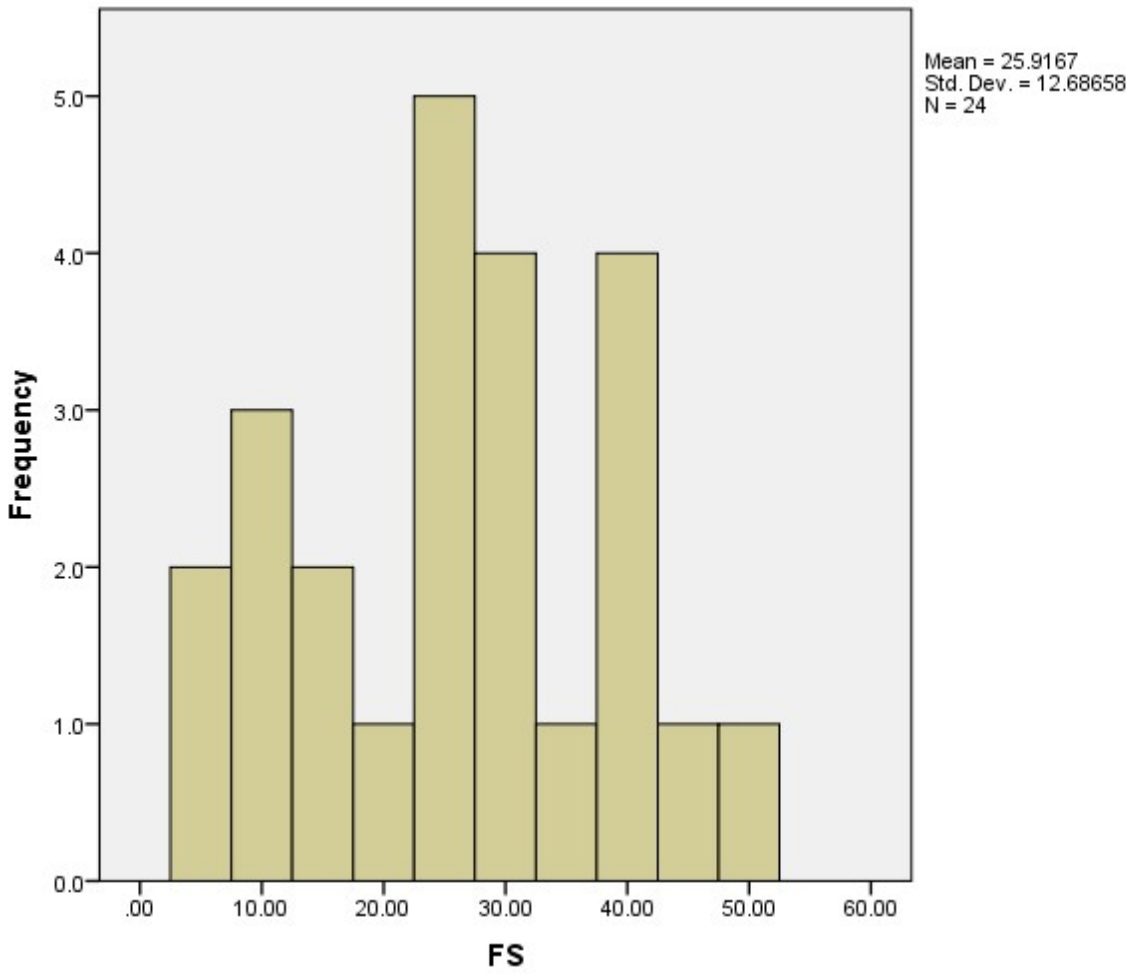


Figure 7. FACIT-Fatigue.

Appendix D: Surveys and Data Collection Tools

Appendix D.1: Fact-G, Version 4

FACT-G (Version 4)

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>.**

	PHYSICAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

	SOCIAL/FAMILY WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box* ☐ *and go to the next section.*					
GS7	I am satisfied with my sex life	0	1	2	3	4

English (Universal)
Copyright 1987, 1997

FACT-G (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>.

	EMOTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness	0	1	2	3	4
GE3	I am losing hope in the fight against my illness	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

	FUNCTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF4	I have accepted my illness	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

Copyright 1987, 1997

Appendix D.2: FACIT-Fatigue

FACIT-F (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

	ADDITIONAL CONCERNS	Not at all	A little bit	Some-what	Quite a bit	Very much
HI7	I feel fatigued	0	1	2	3	4
HI12	I feel weak all over	0	1	2	3	4
An1	I feel listless ("washed out")	0	1	2	3	4
An2	I feel tired	0	1	2	3	4
An3	I have trouble starting things because I am tired	0	1	2	3	4
An4	I have trouble finishing things because I am tired	0	1	2	3	4
An5	I have energy	0	1	2	3	4
An7	I am able to do my usual activities	0	1	2	3	4
An8	I need to sleep during the day	0	1	2	3	4
An12	I am too tired to eat	0	1	2	3	4
An14	I need help doing my usual activities	0	1	2	3	4
An15	I am frustrated by being too tired to do the things I want to do	0	1	2	3	4
An16	I have to limit my social activity because I am tired	0	1	2	3	4

English (Universal)
Copyright 1987, 1997

Appendix D.3: FACT-Cog

FACT-Cognitive Function (Version 3)

Below is a list of statements that other people with your condition have said are important. **Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>.**

	PERCEIVED COGNITIVE IMPAIRMENTS	Never	About once a week	Two to three times a week	Nearly every day	Several times a day
CogA1	I have had trouble forming thoughts	0	1	2	3	4
CogA3	My thinking has been slow.....	0	1	2	3	4
CogC7	I have had trouble concentrating	0	1	2	3	4
CogM9	I have had trouble finding my way to a familiar place.....	0	1	2	3	4
CogM10	I have had trouble remembering where I put things, like my keys or my wallet	0	1	2	3	4
CogM12	I have had trouble remembering new information, like phone numbers or simple instructions	0	1	2	3	4
CogV13	I have had trouble recalling the name of an object while talking to someone	0	1	2	3	4
CogV15	I have had trouble finding the right word(s) to express myself.....	0	1	2	3	4
CogV16	I have used the wrong word when I referred to an object	0	1	2	3	4
CogV17b	I have had trouble saying what I mean in conversations with others	0	1	2	3	4
CogF19	I have walked into a room and forgotten what I meant to get or do there.....	0	1	2	3	4
CogF23	I have had to work really hard to pay attention or I would make a mistake	0	1	2	3	4
CogF24	I have forgotten names of people soon after being introduced.....	0	1	2	3	4

FACT-Cog (Version 3)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

		Never	About once a week	Two to three times a week	Nearly every day	Several times a day
CogF25	My reactions in everyday situations have been slow.....	0	1	2	3	4
CogC31	I have had to work harder than usual to keep track of what I was doing	0	1	2	3	4
CogC32	My thinking has been slower than usual	0	1	2	3	4
CogC33a	I have had to work harder than usual to express myself clearly	0	1	2	3	4
CogC33c	I have had to use written lists more often than usual so I would not forget things	0	1	2	3	4
CogMT1	I have trouble keeping track of what I am doing if I am interrupted.....	0	1	2	3	4
CogMT2	I have trouble shifting back and forth between different activities that require thinking	0	1	2	3	4

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

	COMMENTS FROM OTHERS	Never	About once a week	Two to three times a week	Nearly every day	Several times a day
CogO1	Other people have told me I seemed to have trouble remembering information	0	1	2	3	4
CogO2	Other people have told me I seemed to have trouble speaking clearly.....	0	1	2	3	4
CogO3	Other people have told me I seemed to have trouble thinking clearly	0	1	2	3	4
CogO4	Other people have told me I seemed confused	0	1	2	3	4

FACT-Cog (Version 3)

Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>.

	PERCEIVED COGNITIVE ABILITIES	Not at all	A little bit	Some-what	Quite a bit	Very much
Cog PC1	I have been able to concentrate	0	1	2	3	4
Cog PV1	I have been able to bring to mind words that I wanted to use while talking to someone	0	1	2	3	4
Cog PM1	I have been able to remember things, like where I left my keys or wallet	0	1	2	3	4
Cog PM2	I have been able to remember to do things, like take medicine or buy something I needed	0	1	2	3	4
Cog PF1	I am able to pay attention and keep track of what I am doing without extra effort	0	1	2	3	4
Cog PCH 1	My mind is as sharp as it has always been	0	1	2	3	4
Cog PCH 2	My memory is as good as it has always been	0	1	2	3	4
Cog PMT 1	I am able to shift back and forth between two activities that require thinking	0	1	2	3	4
Cog PMT 2	I am able to keep track of what I am doing, even if I am interrupted	0	1	2	3	4

Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>.

	IMPACT ON QUALITY OF LIFE	Not at all	A little bit	Some-what	Quite a bit	Very much
CogQ35	I have been upset about these problems	0	1	2	3	4
CogQ37	These problems have interfered with my ability to work	0	1	2	3	4
CogQ38	These problems have interfered with my ability to do things I enjoy	0	1	2	3	4
CogQ41	These problems have interfered with the quality of my life	0	1	2	3	4

Appendix D.4: Activity Card Sort (Modified)

Activity Card Sort (ACS), 2nd Edition, is an 89 item measure of activity participation. In the original version, 89 cards, with photos depicting individuals engaged in a variety of occupations, are sorted according to categories, dependent on which of the three versions (institutional version, recovering version, or community living version) is utilized. The 89 activities fall into four categories: Instrumental (shopping, laundry, driving), Leisure low physical demand (spectator sports, computer use, bird watching), Leisure high physical demand (exercise, gardening, hiking), and Social (eating at a restaurant, traveling, volunteering). In the community living version, participants look through the cards and place them under one of five labels: Not Done Since Age 60, Do Now, Do Less, and Given Up). The recovering version utilizes the labels of: Not Done Prior to Current Illness/Injury, Continued to Do During Illness/Injury, Do Less Since Illness/Injury, Given Up Due to Illness/Injury, and New Activity Since Illness/Injury.

Appendix D.5: Demographics

Cancer diagnosis_____
Date Diagnosed_____
Age_____
What treatments have you had for cancer?

- ○ Surgery
- ○ Chemotherapy
- ○ Radiation
- ○ None
- ○ Other_____

Are you currently receiving chemotherapy?

- ○ Yes
- ○ No

Are you currently receiving radiation treatments?

- ○ Yes
- ○ No

Are you male or female?

- ○ Male
- ○ Female

What is the highest level of school you have completed or the highest degree you have received?

- ○ Less than high school degree
- ○ High school degree or equivalent (e.g., GED)
- ○ Some college but no degree
- ○ Associate degree
- ○ Bachelor degree
- ○ Graduate degree

Are you White (non-hispanic), Hispanic (any race), Black, Asian, or Other?

- ○ White (non-hispanic)
- ○ Hispanic (any race)
- ○ Black
- ○ Asian
- ○ Other

Are you now married/partnered, widowed, divorced, separated, or never married?

- Married/Partnered
- Widowed
- Divorced
- Separated
- Never married

Which of the following categories best describes your employment status?

- Employed, working 35 or more hours per week
- Employed, working 20-34 hours per week
- Employed, working 1-19 hours per week
- Not employed, looking for work
- Not employed, NOT looking for work
- Retired
- Disabled, not able to work

Which of the following best describes your household income?

- Less than $24, 230
- Between $24, 231-$53, 657
- More than $53,658

Did you participate in paid work prior to your cancer diagnosis?

- Yes
- No

Are you currently employed in the same job you had prior to cancer?

- Yes
- No

Have you reduced your hours due to cancer?

- Yes
- No

Please respond to the following statement.
Cancer has interfered with my ability to participate in paid employment.

- Strongly agree
- Agree
- Don’t know
- Disagree
- Strongly disagree

Appendix E: IRB Materials

Appendix E.1: IRB Approval Letter

St. Catherine University IRB *Protocol Exemption Notification*

To: Darla Coss

From: David Chapman, IRB Co-Chair

Subject: Protocol #561

Date: 12/02/2015

Thank you for submitting your research proposal to the St. Catherine University Institutional Review Board (IRB). The primary purpose of the IRB is to safeguard and respect the rights and welfare of human subjects in scientific research. In addition, IRB review serves to promote quality research and to protect the researcher, the advisor, and the university.

On behalf of the IRB, I am responding to your request for Exempt level approval to use human subjects in your research. The application **# 561: Examination of Participation and Occupation After Cancer** has been verified by the St. Catherine University Institutional Review Board as Exempt according to 45CFR46.101(b)(2): Anonymous Surveys - No Risk on 12/02/2015. The project was approved as submitted. You may begin your research at any time.

Please note that changes to your protocol may affect its exempt status. You must request approval for any changes that will affect the risk to your subjects using the Amendment Request Form. You should not initiate these changes until you receive written IRB approval. Also, you should report any adverse events to the IRB using the Adverse Event Form. These documents are available at the Mentor IRB system homepage, which can be accessed through the St. Catherine University IRB homepage. When the project is complete, please submit a project completion form.

If you have any questions, feel free to contact me or email via the Mentor messaging system. We appreciate your attention to the appropriate treatment of research subjects. Thank you for working cooperatively with the IRB; best wishes in your research!

Sincerely,

John Schmitt, PhD
Co-Chair, Institutional Review Board
ddchapman@stkate.edu

Appendix E.2: IRB Addendum for Additional Research

St. Catherine University IRB	*Amendment Approval Notification*

To: Darla Coss

From: David Chapman, IRB Co-Chair

Subject: Protocol #561

Date: 05/03/2016

The amendment to protocol **Examination of Participation and Occupation After Cancer** has been approved by the IRB Chair on 05/03/2016.

If you have any questions, feel free to contact me.

David Chapman,
IRB Co-Chair
ddchapman@stkate.edu

Appendix E.3: Letter of Institutional Support GCTC

GILDA'S CLUB TWIN CITIES
An Affiliate of the CANCER SUPPORT COMMUNITY
A Global Network of Education and Hope

A nonprofit support community for anyone touched by cancer.

November 4, 2015

This letter is in support of Darla Coss, OTD student at St. Catherine University, for the project "Exploration of Participation and Occupation after Cancer". Ms. Coss will be collecting data on this topic through our organization, Gilda's Club Twin Cities, in Minnetonka, MN. Gilda's Club is an affiliate of the Cancer Support Community, and offers support for anyone touched by cancer.

As I understand it, Ms. Coss will attend our new member meetings, which occur 5-6 times per month. This meeting serves as an orientation to our club, where we collect information on our new members, provide education on our services, and help new members identify which services/activities/events might support their life as they live with cancer. New member numbers per month range from 24-40, and are subject to change. New members are recruited through word of mouth, referred by health care providers, or find us via social media or community flyers. New members include those affected personally by cancer, and family and care providers. Ms. Coss intends on attending all new member meetings in Jan. and Feb., and may request to attend an additional month to increase the number of participants in her study to 40-60 total.

Following the regular procedure of the meeting (introduction to services, forms on interests, demographics, photo release, and member agreement), Ms. Coss will be introduced as a volunteer at the club and a student in the OTD program at St. Catherine University. At that point, she will invite new members that are living with a cancer diagnosis to participate. Those that wish to participate will stay after the meeting, and fill out forms related to demographics, activities, and fatigue/cognition. This is expected to take 45-60 minutes, and Ms. Coss will be present for the entire time to assist as needed. Members will be informed that they can discontinue participation at any time, and that the results of this study will be available in the member library by May 28, 2016.

Members will have access to bathrooms, water, coffee, soda, and snacks, and are free to have family/friends remain in the room for the entire process. Ms. Coss will provide all the forms necessary to complete her study. Gilda's Club will support this study with the above listed comforts for members, space for Ms. Coss to work, pens and paper as necessary for the club members to participate in the study, and access to staff and resources located in the club as needed.

Approval for this research is granted by the Internal Review Board at St. Catherine University. Ms. Coss is working under the direction of her advisors, Dr. Kathleen Matuska, and Dr. Julie Bass. Additional information/questions can be directed to Drs. Matuska and Bass through St. Catherine University.

Sincerely,

Allison DeCamillis, MS, ATR, LPC
Program Director

10560 Wayzata Boulevard
Minnetonka, MN 55305
612-227-2147
www.GildasClubTwinCities.org

Appendix E.4: Letter of Licensing Agreement-FACIT

FUNCTIONAL ASSESSMENT OF CHRONIC ILLNESS THERAPY (FACIT) LICENSING AGREEMENT

August 1, 2016

The Functional Assessment of Chronic Illness Therapy system of Quality of Life questionnaires and all related subscales, translations, and adaptations ("FACIT System") are owned and copyrighted by David Cella, Ph.D. The ownership and copyright of the FACIT System - resides strictly with Dr. Cella. Dr. Cella has granted FACIT.org (Licensor) the right to license usage of the FACIT System to other parties. Licensor represents and warrants that it has the right to grant the License contemplated by this agreement. Licensor provides to ***St. Catherine University*** *the licensing agreement outlined below.*

This letter serves notice that **St. Catherine University** and all its affiliates (as defined below) ("COMPANY") are granted license to use the **English** versions of the **FACT-G, FACIT-Fatigue and FACT-Cog** in one study.

"Affiliate" of (COMPANY) shall mean any corporation or other business entity controlled by, controlling or under common control with (COMPANY) For this purpose "control" shall mean direct or indirect beneficial ownership of fifty percent (50%) or more of the voting or income interest in such corporation or other business entity.

This current license extends to (COMPANY) subject to the following terms:

1) (COMPANY) agrees to provide Licensor with copies of any publications which come about as the result of collecting data with any FACIT questionnaire.

2) Due to the ongoing nature of cross-cultural linguistic research, Licensor reserves the right to make adaptations or revisions to wording in the FACIT, and/or related translations as necessary. If such changes occur, (COMPANY) will have the option of using either previous or updated versions according to its own research objectives.

3) (COMPANY) and associated vendors may not change the wording or phrasing of any FACIT document without previous permission from Licensor. If any changes are made to the wording or phrasing of any FACIT item without permission, the document cannot

be considered the FACIT, and subsequent analyses and/or comparisons to other FACIT data will not be considered appropriate. Permission to use the name "FACIT" will not be granted for any unauthorized translations of the FACIT items. Any analyses or publications of unauthorized changes or translated versions may not use the FACIT name. Any unauthorized translation will be considered a violation of copyright protection.

4) In all publications and on every page of the FACIT used in data collection, Licensor requires the copyright information be listed precisely as it is listed on the questionnaire itself.

5) This license is not extended to electronic data capture vendors of (COMPANY). Electronic versions of the FACIT questionnaires are considered derivative works and are not covered under this license. Permission for use of an electronic version of the FACIT must be covered under separate agreement between the electronic data capture vendor and FACIT.org

6) This license is only extended for use on the internet on servers internal to (COMPANY). This FACIT license may not be used with online data capture unless specifically agreed to by Licensor in writing. Such agreement will only be provided in cases where access is password protected.

7) Licensor reserves the right to withdraw this license if (COMPANY) engages in scientific or copyright misuse of the FACIT system of questionnaires.

8) In exchange for this license, (COMPANY) agrees to pay a fee of $1,500 per language, per subscale, per trial for Roman-font languages (e.g. Spanish, French, German) and $2,000 per language, per subscale, per trial for non-Roman-font languages (e.g. Japanese, Russian, Arabic). #9 IS NOT APPLICABLE AS THE FEE HAS BEEN WAIVED FOR THIS STUDY ONLY.

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Appendix E.5: Project in Lay Language for Participants

Examination of Participation and Occupation After Cancer

Darla Coss
St. Catherine University, St. Paul MN

Cancer and treatments for cancer can cause changes in a person's ability to participate in activities they want and need to do. Things like shopping, making a meal, going to a movie, or returning to work can be difficult. Darla Coss, an occupational therapist and doctoral student at St. Catherine University, is studying these issues, and would like to invite you to participate in this research. This study will help identify the needs of Gilda's Club members. Participation is voluntary. Should you choose to participate, you will be asked to sign a consent and fill out several paper surveys. This will take you 20-45 minutes. The results of this study will be available for you to read in the Gilda's Club library in May 2016. Any questions you have about this study can be emailed to dccoss@stkate.edu

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