A Thesis

entitled

The Role of Recreation Therapy Protocols in Cancer Treatment and Survivor Quality of Life

by

Josie Mazza

Submitted to the Graduate Faculty as partial fulfillment of the requirements for the Master of Arts in Recreation and Leisure Studies

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The University of Toledo
December 2015
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An Abstract of

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This study sought to identify the effectiveness of recreation therapy protocols in improving the quality of life of active Cancer treatment patients and individuals considered to be in remission and/or Cancer survivors. Specifically, the current study sought to identify the effect of recreational therapy intervention participation (i.e., therapeutic arts, leisure education, and relaxation and stress management) on quality of life. The impact of diagnosis/treatment on patient caregivers is also affected. Thirty subjects participated in group intervention sessions designed to promote socialization/communication, self-esteem, creativity, and fine motor coordination. In addition three subjects provided extensive interview data detailing their caregiver experience. Results from the current study suggest that recreation therapy can provide positive therapeutic benefits when included in the Cancer treatment process.
This thesis is dedicated to my Father, who fought a tough battle, but unfortunately lost his battle to Cancer. Throughout his illness I learned how to adapt programming and find alternative choices for individuals with Cancer. I am grateful that our battle allowed me to possess the ability to serve others.
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# Table of Contents

Abstract .................................................................................................................................................. iii  
Dedication ............................................................................................................................................... iv  
Acknowledgements ............................................................................................................................... v  
Contents ................................................................................................................................................ vi  
Appendices ............................................................................................................................................. vii  

## 1. Introduction ................................................................................................................................. 1  
1.1 Statement of the Problem ............................................................................................................... 4  
1.2 Significance of Research ............................................................................................................... 5  
1.3 Purpose of Study ........................................................................................................................... 5  
1.4 Research Questions ....................................................................................................................... 6  
1.5 Definition of Terms ....................................................................................................................... 6  
1.6 Delimitations ................................................................................................................................. 8  
1.7 Limitations .................................................................................................................................... 8  

## 2. Review of Literature ..................................................................................................................... 9  
2.1 Effects of Cancer on Physical and Mental Health ......................................................................... 9  
2.2 Benefits of Recreation Therapy in Cancer Treatment ..................................................................... 10  
2.3 Benefits of Recreation Therapy Interventions .............................................................................. 12  
2.4 Victory Center Programs & Services ......................................................................................... 14  

## 3. Methods ....................................................................................................................................... 16  
3.1 Research Design ............................................................................................................................ 16  
3.2 Subjects & Subject Selection ....................................................................................................... 16  
3.3 Instrumentation ............................................................................................................................. 16
3.4 Procedure ............................................................................................................................................18
3.5 Protocol & Intervention Implementation .............................................................................................19
3.6 Statistical Design ..................................................................................................................................19

4. Result....................................................................................................................................................20
4.1 Case Studies ..........................................................................................................................................20
4.2 Caregiver Interviews ...............................................................................................................................23
4.3 Participant Goals ...................................................................................................................................32
4.4 Participant Self-Esteem ...........................................................................................................................33
4.5 Leisure Interest ......................................................................................................................................33
4.6 Leisure Participation & Value ..................................................................................................................34
4.7 Leisure Constraints .................................................................................................................................36
4.8 Quality of Life & Leisure Satisfaction .....................................................................................................37
4.9 Intervention Observations ......................................................................................................................37

5. Conclusions ..........................................................................................................................................40
5.1 Overview ...............................................................................................................................................40
5.2 Application of Recreation Therapy: Case Study I ..................................................................................40
5.3 Application of Recreation Therapy: Case Study II ................................................................................42
5.4 Application of Recreation Therapy: Caregiver Interviews ...................................................................43
5.5 Application of Recreation Therapy: Goals ..............................................................................................44
5.6 Application of Recreation Therapy: Self Esteem ...................................................................................46
5.7 Application of Recreation Therapy: Quality of Life ..............................................................................47
5.8 Professional & Research Recommendations ..........................................................................................48

References ...............................................................................................................................................51
Appendices

Appendix A. Cover Letter...........................................................................................................55

Appendix B. Leisure Interests Survey .......................................................................................56

Appendix C. Leisure Participation & Value Survey.....................................................................57

Appendix D. Post Protocol Interview Questions .......................................................................58

List of Tables

4.1 Leisure Interest ....................................................................................................................33

4.2 Leisure Environment ..........................................................................................................35

4.3 Frequency of Leisure Participation .....................................................................................35

4.4 Frequency of Meaningful Activities ....................................................................................35
Chapter 1

Introduction

When an individual is diagnosed with a terminal illness such as Cancer, the diagnosis creates a significant amount of stress and anxiety to the diagnosed individual. When diagnosed with Cancer, an individual’s life becomes limited and often the individual loses interest in continued participation in many everyday life activities due to extensive Cancer treatments (Buettner & Wang, 2011). Although sparse, research supports that the use of recreation therapy protocols in the Cancer treatment process can reduce stress and anxiety, improve leisure awareness, and contribute to a greater quality of life. (Buettner & Wang, 2011; Dawson, Knapp & Farmer, 2012; Fesner & Smith, 2002; Hillard, 2005; Krouse, 2000; Shannon, 2005; Sourby, 1997).

Rehabilitation protocols used by the Certified Therapeutic Recreation Specialist (CTRS) within both the clinical and community settings are most commonly applied in the following areas of rehabilitative services: 1) pediatrics, 2) geriatrics, 3) psychiatrics, 4) developmental disabilities, and 5) physical rehabilitation. A CTRS utilizes leisure education as well as recreation activities and/or services to assist individuals with disabilities in improving overall quality of life. A CTRS is trained to “restore, remEDIATE and rehabilitate a person’s level of functioning and independence in life activities, to promote health and wellness, as well as reduce or eliminate the activity limitations and restrictions to participation in life situations caused by an illness or disabling condition” (American Therapeutic Recreation Association, 2015, ¶, 1). Recreation therapy can be
utilized to reduce stress and anxiety, reinforce self-esteem, increase self-worth, and provide emotional and psychosocial support for patients and families during Cancer treatment and survivorship (Duke Cancer Institute, 2015). According to the Duke Cancer Institute (2015) recreation therapists of the Duke University Health System provide a variety of services including socialization, education, and pure simple fun to give patients “opportunities to create, express, and smile” (Duke Cancer Institute, 2015, ¶ 2). Further, recreation therapists assist individuals with increasing quality of life while battling the emotional and physical symptoms of Cancer.

While the implementation of recreation therapy protocols in the oncology treatment process is limited in the Toledo area, it has been introduced in other areas of the State of Ohio and across the country. One of the earliest implementations of a formalized recreation therapy program in oncology was introduced by the Duke Comprehensive Cancer Center in 1976 (Duke Cancer Institute, 2015). The center offers multiple services to patients through its department of recreation therapy. Services include: an art cart that offers opportunities for patients and families to become creative and express themselves, hospitality carts for individuals to socialize and participate in structured free time activities, a laugh mobile that brings joy to the patient through utilizing humor therapy, and a look good, feel better program that assists women with their physical appearance and self-esteem. The recreation therapy department also provides several services that assist in reducing stress, anxiety, and boredom during free time. Therapeutic arts and crafts, leisure education, and assistance in identifying community resources are also provided (Duke Cancer Institute, 2015).
Recreation therapy is also used in the oncology treatment process at City of Hope in Texas. According to interviewee Mieko, City of Hope is a cancer research facility and graduate school that treats blood-related cancer diagnoses such as Leukemia (personal communication, October 13, 2015). The facility employs occupational therapy, recreation therapy, speech therapy, and physical therapy. According to Mieko “Recreation therapy must be a doctor’s order, they determine the need for recreation therapy through an evaluation” (personal communication, October 13, 2015). In explaining the role of recreation therapy on the oncology unit, Mieko indicated that recreation therapists must monitor blood counts on each patient and if the count is less than 1.0, the recreation therapist avoids interventions on the patient due to infectious disease protocols. Within this facility, recreation therapists are a part of the treatment team and are able to utilize interventions to increase the quality of life for individuals diagnosed with Cancer. In addition Mieko indicated City of Hope provides services based on identifying goals of socialization, leisure skills, and participation (personal communication, October 13, 2015).

In the State of Ohio, Nationwide Children’s Hospital, located in Columbus utilizes recreation therapy to treat physical, mental or emotional disability caused by illnesses such as Cancer (Nationwide Children’s Hospital, 2015a). Recreation therapists are part of a psychosocial services team paired with different disciplines. The following describes the role of the recreation therapist “Our psychosocial services team will help your child understand what they are going through, assist them in coping with their new diagnosis, minimize stress and fears about medical procedures and treatments such as chemotherapy and radiation or surgery, and help siblings understand what is happening to
their brother or sister.” (Nationwide Children’s Hospital, 2015b, ¶ 1) The recreation therapist also assists the family in understanding the process of the disease.

Similar to other oncology treatment/rehabilitation centers such as the Duke Comprehensive Cancer Center, City of Hope, and Nationwide Children’s Hospital, the Victory Center, located in Toledo, Ohio, assists women, men, and children in navigating the Cancer treatment and survivorship processes (Victory Center, 2015). Opportunities that are offered to participants at the Victory Center include the following: massage therapy, Reiki, reflexology, counseling and support group sessions, Nia Fitness, belly dancing classes, aromatherapy, and crafting classes. All activities provided by the Victory Center support its mission to “provide hope and support to Cancer patients, survivors, and those closest to them” (Victory Center, 2015, ¶ 2). Activities provided by the Victory Center allow individuals to participate in leisure based opportunities to gain socialization, increase fine motor skills, and enhance creativity.

1.1 Statement of the Problem

Despite previous research addressing the benefits of implementing recreation therapy protocols and interventions into the Cancer treatment process, (see Buettner & Wang, 2011; Dawson, Knapp & Farmer, 2012; Fesner & Smith, 2002; Hillard, 2005; Krouse, 2000; Shannon, 2005; Sourby, 1997) and its use in oncology treatment in other areas of the country and the State of Ohio, its use in the Greater Toledo Area remains limited.
1.2 Significance of Research

Given the dearth in research examining the role of recreation therapy in the oncology process and the limited utilization of recreation therapy services by oncology service providers nationally and within the Greater Toledo Area, the significance of this research resides in its contribution to the professional literature addressing recreation therapy and oncology and the introduction of recreation therapy services to a local Toledo oncology service provider.

1.3 Purpose of the Study

Considering the following: 1) the use of recreation therapy protocols and interventions in oncology are limited nationally, 2) the use of recreation therapy protocols and interventions in oncology are limited locally, 3) research examining the role of recreation therapy in Cancer treatment processes from initial diagnosis through post-treatment remains limited, and 4) opportunities in the Greater Toledo area for recreation therapy to introduce protocols remain limited, the purpose of the current study is to identify the effectiveness of recreation therapy protocols in improving the quality of life of active Cancer treatment patients and individuals considered to be in remission and/or Cancer survivors. Specifically, the current study sought to identify the effect of recreational therapy intervention participation (i.e., therapeutic arts, leisure education, and relaxation and stress management) on quality of life as well as the impact of diagnosis/treatment on patient caregivers.
1.4 Research Questions

1. What are the short term goals Victory Center clients aim to accomplish in life and/or through the utilization of Victory Center recreational therapy services?

2. What are the long term goals individuals aim to accomplish in life and/or through the utilization of recreational therapy services?

3. How has the diagnosis of Cancer increased and/or decreased an individual’s self-esteem?

4. What kinds of meaningful recreational activities do individuals currently participate in or would enjoy participating in and how often do individuals participate in the activities?

5. What kinds of barriers limit or restrict clients from participating in leisure activities?

6. To what extent did participation in recreation therapy intervention services improve the individual’s quality of life?

7. To what extent did participation in recreation therapy intervention services improve an individual’s self-esteem in relation to their disease diagnosis?

1.5 Definition of Terms

Recreation Therapy

Recreation therapy is described as “a treatment service designed to restore, remEDIATE and rehabilitate a person’s level of functioning and independence in life activities, to promote health and wellness as well as reduce or eliminate the activity
limitations and restrictions to participate in life situations caused by an illness or disabling conditions” (ATRA, 2015).

**Oncology**

Oncology, is defined as “a branch of medicine that specializes in the diagnosis and treatment of Cancer. It includes medical oncology (the use of chemotherapy, hormone therapy, and other drugs to treat Cancer), radiation oncology (the use of radiation therapy to treat Cancer), and surgical oncology (the use of surgery and other procedures to treat Cancer)” (National Cancer Institute, 2015, ¶, 1).

**Intervention**

Recreation therapists utilize interventions “to improve the physical, cognitive, emotional, social, and leisure needs of their clients” (Health Professionals Network, 2015). Common recreation therapy interventions include stress management, guided imagery, relaxation techniques, biofeedback, reminiscence and social skills training.

**Caregiver**

Caregivers can be described as “the person who most often helps the person with Cancer and is not paid to do so” (American Cancer Society, 2013, ¶ 1). Spouses, partners, parents, or an adult child are considered caregivers. If family is not available, the individual may receive assistance from a close friend, neighbor, or co-worker. (American Cancer Society, 2013). Overall, a caregiver assists in supporting the emotional and physical well-being of an individual diagnosed with a terminal illness.
1.6 Delimitations

1. The study did not include random selection or assignment to recreation therapy interventions so Differential Subject Selection is a possible threat to internal validity.

2. As a result of participants engaging in interviews and face-to-face interactions, it is possible that participants provided information they deemed desirable to the researcher rather than accurate data making Reactive Effects a possible threat to external validity.

3. As a result of participants being a convenience sample of current clients using Victory Center services, results are not generalizable across other Cancer treatment environments such as clinical based oncology units or treatment centers.

1.7 Limitations

1. The number of subjects participating in the study (N= 23) did not include all clients utilizing Victory Center services. It is possible non-participating Victory Center clients may have responded differently to measures used to identify intervention effectiveness, a possible threat to internal validity.

2. Inter-Rater reliability could be a possible threat based on the qualitative nature of the interview process.
Chapter 2

Review of Literature

2.1 Effects of Cancer on Physical and Mental Health

In regard to mental health, national statistics indicate that 26% of all Cancer patients are diagnosed with mental health issues (Mesothelioma Group, 2014). Terminal illnesses such as Cancer can affect the individual as well as family and friends. Mental and physical health has a close association to the diagnosis of Cancer as the disease progresses into later stages. Symptoms associated with the diagnosis may include the following; increased fatigue, depression related to stress and anxiety, pain, malnourishment, sleep deprivation, unexplained weight loss/gain, fever, pain, change in appetite, nausea and vomiting, and skin changes (Cancer Treatment Centers of America, 2015, ¶1). These symptoms can result in limitations to an individual’s leisure lifestyle.

The family and friends or other caregivers of an individual diagnosed with or going through the Cancer treatment process can also be affected and experience some or all of the previously aforementioned symptoms associated with Cancer diagnosis/treatment (Alder & Page, 2008). For example, according to Alder and Page (2008) caregivers often assume multiple responsibilities as part of the caregiver process and at times find caring for themselves difficult due to fatigue, stress, anxiety, etc. Further, the emotional distress of caregivers can negatively impact the Cancer patient. Alder and Page (2008) comment “the emotional distress of caregivers also can directly affect the patients. Studies of partners of women with breast Cancer (predominately husbands, but also “significant others,” daughters, friends, and others) find that partners’ mental health correlates positively with anxiety, depression, fatigue, and symptom distress” (p. 4). Given that one
role of the caregiver is to provide mental and emotional support to a diagnosed loved one, and that a caregiver’s mental distress can negatively impact that loved one’s mental and emotional states, research suggests that support for caregivers should also be part of the Cancer treatment process (American Cancer Society, 2013).

Interventions that are facilitated by a CTRS can assist both a Cancer patient and his or her caregiver(s) physical and mental health. For example, Buettner and Yang (2011) demonstrated the value of Animal Assisted Therapy (AAT) in the oncology process concluding “AAT was shown to reduce anxiety and depressive symptoms in children while also increasing positive social interactions during care” (p. 26). Animal assisted therapy can be beneficial to the patient in reducing stress and anxiety while allowing the patient to interact with the other peers as well. Children tend to enjoy the company of an animal in which they are able to feel safe and secure interacting with.

2.2 Benefits of Recreation Therapy in Cancer Treatment

Cancer has the opportunity to limit one’s ability to participate in leisure interests and hobbies. Leisure activities are affected by the level of intensity and the effects of the illness has on an individual’s body resulting from the treatment the individual receives. Examining the effects of breast Cancer, Shannon (1997) found many women participating in her research cited a reduced participation in sports as a result of their Cancer diagnosis and other prevailing constraints to leisure. Results also indicated that many women held a strong obligation to the continued need to meet household obligations which decreased their levels of participation in leisure activities. Buettner & Wang (2011) also comments on constraints associated with Cancer stating that “Most of
these life-changing treatments translate into pain, loss of leisure pursuits and function, along with a dramatically reduced quality of life for months, years, or even the remainder of the patient’s life” (p. 26).

When considering oncology, an example of the implementation of recreation therapy interventions into the Cancer treatment process are the programs and services provided by Duke University’s Oncology Recreation Therapy Department. According to Duke (2015) the oncology recreation therapy department was established in 1976, further discussed, Duke (2015) states “State and nationally certified therapist use treatment interventions and music, games, crafts, and humor to optimize functioning, coping, and quality of life during treatment.” Duke (2015, ¶, 2) Duke employs five full time Certified Therapeutic Recreation Specialists (CTRS’s) and 100 volunteers that assist patients. CTRS’s provide emotional and cognitive support through interventions including stress reduction, pet therapy, communication skills, and assertive training to decrease passivity. In addition, they provide patients opportunities to explore communication techniques to cope with feelings and relationships within the family.

The Duke Cancer Institute offers an *art cart* filled with basic drawing and painting supplies to allow the patient and/or the patient’s family to express themselves through art. The *laugh mobile* is filled with old movies, comical books, whoopee cushions and rubber chickens. The *hospitality cart* is facilitated by volunteers, according to Duke Cancer Center, “Volunteers go door-to-door offering opportunities for socialization, nourishment, and activities for structuring free time to patients with Cancer and their families” (Duke Cancer Institute, 2015, ¶, 2). Services are offered free of charge
for individuals and their families to decrease the symptoms that are brought upon by the diagnosis of Cancer.

In the event that patients or family members/caregivers are unable to visit the center or participate in activities without assistance, CTRS’s and volunteers are able to make home visits to patients that are unable to participate in meaningful activities. CTRS’s and volunteers offer opportunities for socialization with the patient and the family as well as assist them in structuring their schedule to keep themselves positively engaged throughout the day.

The Center’s *look good, feel better* program assists women with their physical appearance, self-esteem, and help with other basic daily living activities. In addition, partners including the American Cancer Society and the National Cosmetology Association, donate time and items such as wigs, scarfs, hats, makeup, and beauty supplies. Overall, there are a variety of recreation therapy protocols that can be introduced into the oncology treatment process. Including AAT as previously discussed, although not limited to: musical sessions, therapeutic art and crafting, aromatherapy, guided imagery, progressive muscle relaxation, and psychotherapy.

### 2.3 Benefits of Recreation Therapy Interventions

Rehabilitative protocols used by the Certified Therapeutic Recreation Specialist (CTRS) within both the clinical and community settings are most commonly applied in the following areas of rehabilitative services: 1) pediatrics, 2) geriatrics, 3) psychiatrics, 4) developmental disabilities, and 5) physical rehabilitation. A CTRS utilizes leisure
education, as well as, recreation activities and/or services to assist individuals with disabilities in improving overall quality of life. A CTRS is trained to “Restore, remEDIATE and rehabilitate a person’s level of functioning and independence in life activities, to promote health and wellness as well as reduce or eliminate the activity limitations and restrictions to participation in life situations caused by an illness or disabling condition” (American Therapeutic Recreation Association, 2015, ¶,2).

Recreation therapy is considered when moving from pharmacological interventions to holistic interventions. One example of a non-pharmacological intervention is psychotherapy. Psychotherapy groups are facilitated by trained professionals, including CTRS’s. According to Goodheart and Lansing (1997) nonverbal psychotherapy groups such as art therapy, sand play, and movement therapy are all examples of potentially therapeutic, nonverbal expressive treatment modalities that can “provide an alternative path to self- knowledge for the patient” (p. 76). The CTRS is able to run psychoeducation groups using recreation therapy interventions that are based on coping mechanisms such as stress management and expressive art. Other therapeutic interventions also provide therapeutic benefits. Therapeutic music interventions have the ability to change an individual’s mood and the ability to calm and relax. The actual playing of an instrument can support fine motor and in some cases gross motor development (Goodheart & Lansing, 1997).

Guided imagery and progressive muscle relaxation are often used in conjunction with music therapy to create a calming atmosphere. According to Hillard (2005) end-of-life patients receiving music therapy experienced decreases in heart rates and respiratory rates with mean heart rate scores decreasing from 85.8 beats per minute before music
therapy to 77.1 beats per minute following music therapy, and respiratory rates decreasing from 19.5 to 15.4 breaths per minute after music therapy. States of relaxation can also reduce the physical symptoms that are brought upon by an illness.

Aromatherapy can be used to reduce stress and anxiety brought upon by illness or treatment processes, for example, lavender assists in relaxation. Essential oils such as lemon and orange can serve as uplifting scents that allow for increased energy. Aromatherapy can be used in conjunction with music for relaxation and stress reduction.

Therapeutic art can be used to increase creativity, range of motion, and socialization. Examining the benefits of art therapy Forzoni and Perez (2009) concluded that art therapy has the ability to reduce anxiety, evoke positive memories, and create opportunities to experience escapism. Further, art therapy interventions can expand a patient’s understanding of their feelings brought on by illness.

2.4 Victory Center Programs & Services

Similar to the Duke Cancer Institute, the Victory Center, located in Toledo, Ohio, assists women, men, and children in navigating the Cancer treatment and survivorship processes free of charge (Victory Center, 2015). Opportunities that are offered to participants at the Victory Center include the following: massage therapy, Reiki, reflexology, counseling and support group sessions, Nia Fitness, belly dancing classes, aromatherapy, and crafting classes. All activities provided by the Victory Center support its mission to “Provide hope and support to Cancer patients, survivors, those closest to them” (Victory Center, 2015, ¶ 2). Since 1996 the Victory Center has been reaching out to Cancer patients and their families in Northwest Ohio and Southeast Michigan,
providing love, support, compassion, hope, and laughter (The Victory Center, 2015). Volunteers run activity groups such as arts and crafting, game nights, bingo, dance, and ceramics to increase socialization as well as integrate individuals back into the community. Relaxation is an important aspect of the Victory Center, providing aromatherapy, yoga, aquatic therapy, and massage therapy. The calming and welcoming atmosphere allow for individuals to become comfortable with the staff and volunteers facilitating the interventions.

Healing gardens are built in conjunction with local volunteers each spring and summer for the clients at the Victory Center. Clients have the opportunity to participate in building a healing garden with other survivors and family members. Monthly activity calendars are provided with evening and weekend opportunities for survivors and their families to increase or regain their quality of life (The Victory Center, 2015).

Families are affected by Cancer diagnoses as well as the individual (American Cancer Society, 2013). The Victory Center offers short-term counseling for family members and children experiencing the difficulty of the diagnosis of a loved one. The Victory Center offers a safe haven for individuals battling Cancer. The Victory Center is a nonjudgmental place for families and individuals to participate in activities they loved prior to their diagnosis.
Chapter 3

Methods

3.1 Research Design

This study was an exploratory descriptive survey research study including case-study development, case study interviews, and both quantitative and qualitative data collection. Quantitative data was analyzed using SPSS 16.0 and reported descriptively as frequencies and percentages. Qualitative data was analyzed by identifying common issues and outcomes among non-numerical responses. Some of the individuals were interviewed as survivors; caregivers; and individuals receiving treatment. This study included three recreation therapy interventions implemented one time a month over a three-month period. Observations were made during the interventions to identify intervention effectiveness. Surveys were used to collect information on leisure interests; short term goals; long term goals; and future interests.

3.2 Subjects & Subject Selection

Subjects for the current study (N=23) consisted of a sample solicited to participate in recreation therapy interventions. Based on their current participation in Victory Center programs and services and their decision to visit the Victory Center during the dates and times in which therapeutic arts, leisure education, and relaxation and stress management protocols were being provided. Subjects were able to participate in various recreation therapy interventions.

3.3 Instrumentation

Leisure Interest Survey:
The Leisure Interest Survey for the current study was an assessment instrument used to identify study participants' current leisure participation habits, current leisure interests, and primary leisure constraint. Leisure interest categories included leisure interests, outdoor activities, art, crafting, and music. (See Appendix B)

**Leisure Participation & Leisure Value Survey:**

The Leisure Participation & Leisure Value Survey for the current study identified how study participants spend their leisure time in regard to social environment, participation frequency, meaningful activities, and leisure satisfaction. (See Appendix C)

**Post Protocol Interview Questions**

Post interview questions were separated into three categories which included leisure interests, self-esteem, and leisure participation and values. There were a total of nine questions. Leisure interests questions focused on how leisure increased the quality of life as well as how active the individual was during the day and more often during the week. Self-esteem concentrated on how self-esteem was promoted after chemotherapy treatments by participating in leisure activities, introducing new activities to promote self-esteem, and naming one activity the individual participated in during the disease process. Leisure participation questions focused on the amount of time the individual participated in the activity, how the leisure activity was increased/ decreased, and whom the individual decided to participate in the leisure activity with. (See Appendix D)

**Therapeutic Arts: Ceramics Protocol**

The ceramics protocol included the painting of various ceramic pieces to achieve the following protocol goals: providing opportunities for socialization/communication,
promoting self-esteem, providing opportunities for creativity, and increasing fine motor coordination.

**Therapeutic Arts: Holiday Crafts**

The holiday crafts intervention included creating two ornaments for the holiday season to achieve the following intervention goals: providing opportunities for socialization/communication, promoting self-esteem, providing opportunities for creativity, and increasing fine motor coordination.

**Leisure Awareness: Game Night**

The game night intervention included participating in *Apples to Apples* to achieve the following intervention goals: providing opportunities for socialization/communication, promoting self-esteem, providing opportunities for creativity, and increasing fine motor coordination.

3.4 Procedure

The Human Subjects Review Committee at the University of Toledo granted approval of the measurement instruments and gave permission to engage in the study. Participants were solicited to participate in the study in spring 2015 and were provided an informational letter indicating: participant identification procedures, confidentiality procedures, and information pertaining to the study’s purpose.
3.5 Protocol & Intervention Implementation

The protocols used within the study were implemented over a three-month span consisting of one session each month. Two sessions lasted 90 minutes each as well as an additional session which concluded at 60 minutes. Participants received leisure interest surveys at the end of the first session to collect data for future intervention planning.

3.6 Statistical Design

Data for the current study was analyzed using descriptive statistical measures and reported as mean/standard deviation and frequencies and percentages.
Chapter 4

Results

4.1 Case Studies

Case Study I: Terminal

The first diagnosis was April 17, 2013 with a 12 day stay on an oncology unit. For confidentiality purposes I will rename this patient John. John is a 61 year old man that was diagnosed with Stage-IV Lung Cancer. There is not a cure for Cancer although there are extensive treatments that are available for patients. John had multiple spots on his body affected by carcinoma. He had a spot in the middle of his lung which caused pneumonia from which he was placed into the hospital. He also had a small tumor on his 9th rib, tumors in his lymph nodes, a tumor on his scapula, and a tumor on his spine which caused a hole to form at his lumbar region. The tumors were treated although they could not be cured. The carcinomas caused pain when he coughed, sneezed, as well as unexpectedly. John’s legs and hips would go numb and he experienced the inability to walk or move his legs for short periods of time and required assistance to move. John understood the treatment process would be extensive and require aggressive chemotherapy and radiation treatments.

In regard to leisure interests John enjoyed cooking for the family, creating new recipes and cooking family favorites. John was a retired pizza maker and spent his entire life cooking for others and making others happy through his leisure interest. While battling his illness John would take trips to his cottage. While in treatment however, when he took trips to his cottage his energy levels only lasted two to three hours and 50%
of the day was consumed with fatigue. He did not engage in conversations for extensive amounts of time due to becoming fatigued. John began to use Skype as a way to communicate with his family in Italy and Canada. Conversations with relatives’ increased his positive attitude and mental health. John was participating in a form of therapy referred to as reminiscence therapy. Reminiscence therapy utilizing memories, photos, stories, and reconnecting with family and friends that an individual may have lost connection. John reconnected with family members through trips to Canada as well as speaking with family members in Sicily through social known as Skype. Reminiscence therapy allows for tangible prompts such as photos and music to bring up old memories and allow for conversations. Through observation, John utilized this form of therapy without understanding what reminiscence therapy entailed. He was able to reconnect with family prior to his final days of life.

John was re-hospitalized a week prior to Christmas Day, his chief complaint was chest pain and chronic back pain caused from the tumor on his spine. While in the hospital he did not engage in many leisure activities other than an I Love Lucy Christmas special which served as humor therapy. Limited by his illness John’s leisure activities began to significantly change and decrease. His new leisure interests included the following, watching Rachel Ray and developing new recipes to cook for his family and watching the Red Wings play hockey on Monday nights.

In the final month of John’s life he became more confused and was not oriented to person, place or things. He became increasingly delusional in conversation and thought blocked. Eventually John’s family decided to stop treatments and allow John to be at peace in his final days of life. Radiation therapy was given for comfort care only. During
his final days John returned to the comfort of his home to pass away in peace. At this time John was not tolerating food intake and family did not push eating. He found comfort and relaxation in listening to his music and being with his family. In his mind the battle was won although in reality his body was giving up. In his last days of life he was comfortable and received care from Hospice for pain management and from the family. Recreation therapy was facilitated in the home by a caregiver whom is an acting CTRS. Interventions varied depending on the severity of the symptoms presented at the time of the intervention.

**Case Study II: Survivorship**

Jane’s diagnosis occurred in fall 2008 when she was rushed to the emergency room as a result of coughing up blood in the middle of the evening. At first physicians believed it was caused by Bronchitis, however it turned out to be a more serious issue. The diagnosis was a small cell undifferentiated carcinoma, in other terms, Stage-I Lung Cancer. There was also a small mass in her fibrous tissue on her right upper shoulder causing numbness in her arm. The mass in her lymph node was approximately 4x3 centimeters in size.

While in active treatment Jane began crocheting a blanket at the beginning of treatment, she was able to finish the blanket by the end of all of her treatments. This was considered an accomplishment of completing chemotherapy forever as well as finishing the blanket. The blanket assisted in decreasing the perceived amount of time that she was in therapy by keeping herself active in her leisure lifestyle. In regards to treatment Jane tolerated the treatment well, according to her medical staff. Although she experienced fatigue for two to three days following treatment, basically she functioned and felt well.
and was able to continue working selling Avon. Chemotherapy treatment lasted six months. Today Jane is Cancer free and has been in remission for a total of six-years. She never let the diagnosis of Cancer kill her spirit. She continued to sell Avon, interact with the community, and attend her Avon meetings which assisted with increasing quality of life and promoting self-esteem.

4.1 Caregiver Interviews

Interview A

(Note: Interview response presented as grammatically expressed by interviewee.)

“My mom suffered from Leukemia for roughly eight-months. She had just finished with chemo treatments when she came down with a C-diff infection. Which, in the end, is what I believe is what finally took her life as her body just started shutting down two days after being in the hospital. But overall if I could do anything different, I would have been pushy about getting this and that done and would have got her to the hospital sooner when she came down with the infection but she fought me about going to the ER.”

Would you change anything about your caregiving experience, how do you think things may have been different?

“I might have tried to get more physical therapy tech’s in house to help her build strength and keep her motivated. Which in turn would have made her sleep better I think. Which would have helped over all.”

How many caregivers were involved in the treatment of the individual?
“At home my Aunt Helen and I did the most of the caring for her and taking her to her appointments. One Brother helped near the end with giving her massages to help with the lymphoma swelling.”

**What techniques or interventions were used to help the person you are caregiving increase the quality of life?**

“As for techniques, not sure about that one. My mom seemed to handle the treatments well except for nausea and tiredness. She saw the doctors as needed and did receive a few blood transfusions to help with her blood count.”

**What are some activities that you enjoyed participating in with the individual you were caregiving?**

“I would take her shopping. No matter how much money she didn’t have she liked to go shopping!! Or go out to Maumee Bay and eat supper by the water. We didn’t do it much but once in a while we made it out there.”

**Interview B**

(Note: Interview response presented as grammatically expressed by interviewee.)

Interviewee B was a caregiver for her Mother, Father, and Grandparents; dedicated to taking care of her loved ones.

**Would you change anything about your caregiving experience, how do you think things may have been different?**

“Yes, my Mom wished we could have gotten her to go to the Hospice facility before she did. She was receiving home health care for baths, etc. She had Breast Cancer, she found a lump in her breast and was gone nine-months later. Very
aggressive the doctor said. Comfort level may have increased. I can't really say she was in pain but seemed really happy. My Dad never got Hospice care he was doing pretty good until the end. He ended up in the hospital, this is where he died. He had Lung Cancer (he had one lung removed earlier) and fought a good fight but just got too weak and just got to the point he gave up since Mom was gone. He did last five years after her death. Grandma and Grandpa both ok I feel. Both were a lot older than my parents.”

**What techniques or interventions were used to help the person you are caregiving increase the quality of life?**

“Hospice. I really think they do a great job. I have seen both used as far as home care and facility care. Both are great and I would recommend to anyone. Used the facility care for both my Mom and my Grandma. They make them comfortable. I never experienced the comfort care until both were in the facility. It is heartwarming to know they were not suffering so much. My Mom was so happy the night before she died. She had a milkshake and was not in pain. I feel she died comfortably. My Dad was not really suffering until the last day I feel. He was making his own decisions and I feel he made the right ones. Both Grandma and Grandpa had Cancer as well but were also very old when they died. I feel they lived a great life.”

**How many caregivers were involved in the treatment of the individual?**

“Basically myself and my family and my Brother and Sister-in-law for Mom and Dad. For Grandma a lot of us- she still had three daughters in good health and all the grandchildren. My Grandpa I also took care of. He fell and broke his hip and we then found out he had a brain tumor. He died two weeks after falling. He had been good up
until that fall. Never suspected a brain tumor.”

**What was the biggest obstacle for you as a caregiver?**

“Hoping you are doing all you can for them. I had a lot of good helpers too so
that really makes a difference I believe. You know you are doing everything but you still
keep asking yourself could I be doing more?”

**How did incorporating leisure activities or hobbies help in the disease process for
the individual?**

It made them smile and enjoy themselves. Simple things made them happy.”

**What are some activities that you enjoyed participating in with the individual you
were caregiving?**

“All of them enjoyed seeing the kids. It got to a point it was too hard on the
kids but they went to see them as much as possible. All of them were ok until the end
pretty much so we saw a lot of them at their houses. Once they went to the hospital and
Hospice the kids did not go. Too hard on them. One thing we really enjoyed was my
Grandpa liked to do crossword puzzles. In the two weeks he lived after his fall we would
go to the nursing home and ask him clues to get the word. One day we were giving him
clues and he got the correct answer. I clapped and said good job. The next word he also
got and he clapped and said good job. I will remember that day forever. Also the last
night my Mom was alive she loved milkshakes, she drank that and was so happy. “

**Interview C**

(Note: Interview response presented as grammatically expressed by interviewee.)
Interviewee C became a caregiver as a teenager following her Mother’s Cancer Diagnosis. She became a comedian, a cook, and a shoulder to lean on when her Mother needed her.

**Would you change anything about your caregiving experience, how do you think things may have been different?**

“What would I change about my caregiving experience? Honestly I do not know. I was very young, a sophomore in high school, and did not know much other than how to survive and be a teenager at the same time. I made sure me and my Brother ate. I made sure the house stayed kept up on. I made sure Mom had organized rides to her appointments and her medicine on hand at all times. My Cousin helped to make sure all the bills were being paid as much as they could and on time as well as caring for my Mom. I continued to go to school while my Brother dropped out as a freshman; we have 18-months age difference. My Brother and I were completely different with the handling of Mom’s illness. I will not go into detail about him although it was basically the opposite of me. I played sports and remained active providing my own transportation. I strongly believe staying active and doing well in school gave my Mom extra strength to fight. Knowing her one child already quit going to school I am sure had a negative effect on her placing some guilt on her soul. But knowing her youngest child was excelling in school, performing great in sports and trying to remain positive and focused on her future to graduate high school and attend college I truly believe helped her to stay strong. She always told me, *I promise I will watch you walk the aisle when you graduate*, and she often reminded me how proud she was. The October prior to me graduating Mom was said to be in remission. I remember her watching me walk down the aisle from the
bleachers, screaming, *that's my daughter* and smiling big - she was stronger, happier, and a very proud Mother. With that said, maybe if I changed anything, the situation may have ended differently, and I am happy with the way it ended. I realize not everyone is as fortunate as I was while fighting Cancer with my Mom, for that I am truly blessed.”

What techniques or interventions were used to help the person you are caregiving increase the quality of life?

“I always wore a strong face in front of my Mom. My tears only fell when she was not in sight. I expressed my fears and worries to family members; they always said stay strong for your Mom, she needs your strength. “

“I recall my watching Mom’s hair falling out. She began to just stop brushing it because the reality of it coming out was too hard. It was the day she woke up with no eyebrows she realized she needed to face the reality of the consequences of her illness and it’s treatments. That day her and my Brother shaved their heads together. It was a bittersweet moment. She would not let me shave my hair because it was too beautiful and she enjoyed playing with it. I kept my hair. I would sit on the floor at the edge of the couch and let her brush it and run her fingers through; I knew how much it made her happy and allowed her to do a simple Mom task. We both enjoyed it- it seemed like it lasted forever as she played with my hair.”

“She also gained a lot of weight from the steroids. We would joke with her and say she was the strongest woman in the world. We would jokingly strike poses of body builders to make her smile. Sometimes it was the littlest sense of humor that made her smile. We realized talking about the potential negative effects of the illness would upset her and she did not like talking about it to her children or anyone else at that.”
“I also recall her eating prunes all of the time. I would go out and buy prunes often. I began eating prunes with her daily. To be honest, I have not eaten prunes since eating them with her. I did not like the taste but I did it with her for her. My idea was I cannot do chemo but I can consume prunes; I can show her I am fighting with her and willing to consume that oh-so-awful taste with her. We would often joke of the prunes on our teeth and how I would likely have diarrhea. I didn’t mind the loose bowels. My Mom was so constipated my loose bowels didn’t even bother me; I had bigger worries at the time. And I was able to keep her company while together we consumed that beautiful fruit.”

**How many caregivers were involved in the treatment of the individual?**

“Three. Myself from 15 to 18 years old, my Brother from 16 to 19 years old, and an older Cousin residing outside of our home who was 30.”

**What was the biggest obstacle for you as a caregiver?**

“I basically became the lady of the house after my Mom was diagnosed at Stage 4 Non-Hodgkin’s Lymphoma. I was barely 15 when my Mother was diagnosed with Cancer, I feel there was a lot of responsibility handed to me being she was a single Mother of two teenagers. My Father was nowhere to be found. Therefore, basically I assumed the responsibility as the homemaker. As soon as I turned 15 ½, I personally paid for and attended driving school. I wanted to make sure my Mom was able to get to every appointment and I was able to get to a store to buy food, and any other necessities. I also got back and forth to school and all of my school activities and sports. I learned how to cook, clean and care for my Mother. Although, I did have adult support, it was primarily myself and my brother caring for our Mom. Other than the spontaneous amount
of responsibility, the everyday fear of losing my Mom was the hardest. To see her so sick laying on the couch, no appetite, no motivation, barely ever awake, and then on chemo/radiation days to see her sitting in the chair basically sleeping made it harder to maintain faith everything would be okay. The biggest obstacle was to stay strong, to remind my Mom that she is a strong fighter, to hide my fears, and to continue to try be a child when forced to be an adult. Yes! It was hard; there were bad days, there were worse days, but there were also some good days. Having faith and family support helped to keep me strong, I believe that directly helped Mom to be strong and survive the fight.”

**How did incorporating leisure activities or hobbies help in the disease process for the individual?**

“Mom wasn’t able to help with much around the house. Being diagnosed at Stage-IV meant from the beginning the treatment was intense. I think she felt like I assumed all of her motherly responsibilities and felt guilty. I would find ways to seek help from her. I knew she was weak and frail but I also know as a human it is important to feel wanted and needed at times, especially as a Mother. She always loved to cook meals for us but was no longer able to. I would cook her favorite recipes and mid-meal prep ask questions on how to actually make the meal. Mom what do I combine first? What temperature should the oven be on? How many eggs? Although it may not seem like a lot she was helping me make meals by providing input. I remember saying random things like Mom, this hamburger feels so nasty on my fingers’, and we’d laugh together. Although I do not know that I always made things right- I genuinely tried.”

“She was also able to help fold laundry sometimes. Although she wasn’t able to go up and down the stairs to wash/dry or put away, we would sit together at times and
fold together and talk. Some days she would become fatigued and have to stop and lay
down to rest and feel bad. But I would always remind her I appreciated anything she was
able to do and I didn’t mind do anything at all for her. I knew when to introduce activities
and when not to. If she was displaying fatigue and weakness I would simply cater to her
and uphold all responsibilities with a smile on my face. When I could see her feeling a
little better I would find ways to allow her to help- but always asked if I could help her
perform the task to give her that sense of pride.

“Some days I would find her in the kitchen wiping (clean) counters and just
cleaning. At first I would tell her she needs to just relax I would do it. I quickly realized
how important it was to let her do things if she wanted to. It gave her a sense of pride,
independence, and Motherhood. She knew her limits. When she became fatigued she
would just stop and go rest. I would let her enjoy herself with getting things done and
keep her company and chat in the meantime- discuss my big test, tell her about soccer
practice, my experience and the high school mascot- anything a daughter would typically
discuss with a Mom.”

What are some activities that you enjoyed participating in with the individual you
were caregiving?

“Me and Mom would often play dress up. We would wear wigs and put on crazy make up
and outfits. I would dress her and she would dress me. It was always a fun silly
experience. One day my Brother joined in- man did we all laugh! “

“There were also days I would just give Mom a beauty make-over. Do her hair.
Help her with her makeup. Find a pretty outfit. She really enjoyed the days she had a full
head of hair, eyebrows and simply a smile.”
“I also enjoyed the cooking experiences with my Mom. I learned a lot about cooking young in life. I also learned how to twist up some of her recipes and even try new recipes. I began to impress her. I really enjoyed her helping me. There were multiple times she’d say, *no, you’re doing it wrong,* and show me the right way. If she was in the kitchen while I cooked I knew Mom would have input. I didn’t mind though; I enjoyed her presence.”

“Lastly, as mentioned before, I enjoyed eating prunes with her. I didn’t enjoy the taste but I enjoyed the experience. It was a Mother-Daughter bonding time for us. A time for chit-chat and jokes. She’d often say I didn’t have to and I’d remind her that I wanted to. Some things you never forget- and prunes have left an everlasting mark on my heart! I will admit- I have left the consumption of them in the past, along with her Cancer. “

“This will mark 10 years for my Mom being in remission! It’s been a long road- and we are truly blessed to still have her with us- steadily in remission.”

4.3 Participant Goals

Short Term Goals

When asked to provide their short term goals in relationship to life and/or the use of services in the community, four out of 23 participants reported the following short term goals: attending graduate school to advance a nursing career, starting an indoor garden during the winter and transferring the garden outdoors during the growing season, completing my daughter’s wedding scrapbook, and to get on with my life.
Long Term Goals

When asked to provide their long term goals in relationship to life and/or the use of services in the community, four out of 23 participants reported the following long term goals: learning to live alone, continue to invest in my retirement fund, accept life as it comes graciously, and apply for the nurse anesthetist program or pursue doctorate in nursing.

4.4 Participant Self-Esteem

When asked to comment on self-esteem in regard to leisure participation, one out of 23 participants commented on self-esteem reporting: My self-esteem was low until I finished treatment. I became self-conscious when I began to lose my hair and had to have my husband shave the rest of my hair off. I continued to crochet during my chemotherapy sessions to pass the time. I also continued to sell Avon and stay active with my work.

4.5 Leisure Interest

Ten out of 23 study participants completed the leisure interest survey. Results indicated study participants most actively engaged in music-related activities such as listening to the radio and outdoor recreation activities such as walking. Overall study participants reported engagement in a diverse repertoire of leisure activities. (See Table 4.1)

Table 4.1: Leisure Interest

<table>
<thead>
<tr>
<th>Activity</th>
<th>Currently Participate In:</th>
<th>Interested in Participating:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency (f)</td>
<td>Percentage (%)</td>
</tr>
<tr>
<td>Music:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Singing in choir</td>
<td>3</td>
<td>30.0</td>
</tr>
<tr>
<td>Listening to radio</td>
<td>10</td>
<td>100.0</td>
</tr>
</tbody>
</table>
In addition, study participants were provided the option of indicating additional leisure activities they participated in not included on the Leisure Interest Survey. Of those study participants (n= 10) providing additional leisure activities, at least one study participant indicated participating in the following: swimming, reading, singing in a choir, gardening, games, and arts and crafts.

4.6 Leisure Participation & Value

When asked to provide the type of social environment in which they most commonly engage in leisure, four out of 23 study participants indicated the following: (See Table 4.2)
Table 4.2: Leisure Environment

<table>
<thead>
<tr>
<th>Leisure Environment</th>
<th>Frequency (f)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alone</td>
<td>2</td>
<td>50.0</td>
</tr>
<tr>
<td>With Family</td>
<td>4</td>
<td>100.0</td>
</tr>
<tr>
<td>With Friends</td>
<td>3</td>
<td>30.0</td>
</tr>
<tr>
<td>Support Groups</td>
<td>1</td>
<td>10.0</td>
</tr>
<tr>
<td>Other: Significant Other</td>
<td>1</td>
<td>10.0</td>
</tr>
</tbody>
</table>

n=4
Note: Percentages do not equal 100 due to study participant’s ability to check all applicable leisure interest categories.

When asked to indicate how many days per week they participated in leisure activities, four out of 23 study participants indicated the following: (See Table 4.3)

Table 4.3: Frequency of Leisure Participation

<table>
<thead>
<tr>
<th>Number of Days Per Week</th>
<th>Frequency (f)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>One</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Two</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Three</td>
<td>1</td>
<td>25.0</td>
</tr>
<tr>
<td>Four</td>
<td>1</td>
<td>25.0</td>
</tr>
<tr>
<td>Five</td>
<td>2</td>
<td>50.0</td>
</tr>
<tr>
<td>Six</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Seven</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

n=4
Note: Percentages do not equal 100 due to study participant’s ability to check all applicable leisure interest categories.

In regard to leisure value, participants were asked to indicate those leisure activities that were most meaningful to them. Four out of 23 respondents indicated the following: (See Table 4.4)

Table 4.4: Frequency of Meaningful Activities

<table>
<thead>
<tr>
<th>Meaningful activity</th>
<th>Frequency (f)</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Socializing (family)</td>
<td>3</td>
<td>75.0</td>
</tr>
<tr>
<td>Watching Sports</td>
<td>1</td>
<td>25.00</td>
</tr>
<tr>
<td>Television</td>
<td>2</td>
<td>50.0</td>
</tr>
<tr>
<td>Going out to dinner</td>
<td>2</td>
<td>50.0</td>
</tr>
<tr>
<td>Leisure Interest</td>
<td>Count</td>
<td>Percentage</td>
</tr>
<tr>
<td>------------------------------</td>
<td>-------</td>
<td>------------</td>
</tr>
<tr>
<td>Attending plays</td>
<td>3</td>
<td>75.0</td>
</tr>
<tr>
<td>Visiting Community Centers</td>
<td>2</td>
<td>50.0</td>
</tr>
<tr>
<td>Socializing (friends)</td>
<td>4</td>
<td>100.0</td>
</tr>
<tr>
<td>Sports</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Camping</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Going to the movies</td>
<td>1</td>
<td>25.0</td>
</tr>
<tr>
<td>Gardening</td>
<td>2</td>
<td>50.0</td>
</tr>
<tr>
<td>Arts and Crafts</td>
<td>2</td>
<td>50.0</td>
</tr>
<tr>
<td>Being outdoors</td>
<td>2</td>
<td>50.0</td>
</tr>
<tr>
<td>Volunteering</td>
<td>1</td>
<td>25.0</td>
</tr>
<tr>
<td>Reading</td>
<td>2</td>
<td>50.0</td>
</tr>
<tr>
<td>Computer</td>
<td>2</td>
<td>50.0</td>
</tr>
<tr>
<td>Church</td>
<td>2</td>
<td>50.0</td>
</tr>
<tr>
<td>Educational Activities</td>
<td>1</td>
<td>25.0</td>
</tr>
<tr>
<td>Attending Concerts</td>
<td>1</td>
<td>25.0</td>
</tr>
<tr>
<td>Shopping</td>
<td>2</td>
<td>50.0</td>
</tr>
<tr>
<td>Listening to Music</td>
<td>2</td>
<td>50.0</td>
</tr>
</tbody>
</table>

n=4

Note: Percentages do not equal 100 due to study participant’s ability to check all applicable leisure interest categories.

When asked to indicate their level of leisure satisfaction on a 10-point semantic differential scale (1 = extremely unsatisfied and 10 = extremely satisfied), of the four respondents to complete the scale, all four reported having leisure satisfaction, reporting a leisure satisfaction mean of 8 with a standard deviation of 1.4.

4.7 Leisure Constraints

When asked to report their largest constraint to leisure participation, four out of 23 study participants indicated at least one of the following: work hours, financial responsibilities, cannot submerge my face in the water anymore, not knowing anyone, and lack of time.
4.8 Quality of Life & Leisure Satisfaction

When asked to report how participation in leisure activities improved their life, one study participant reported the following:

I enjoyed sewing, crocheting, and baking, hobbies that I continue to participate in today. I brought items to work on during my chemotherapy treatments and when I was finished with treatment I had an afghan finished. I am very satisfied with my hobbies, the only thing that bothers me is being alone in the home after my husband passed. My hobbies are the same as before although I have one less person to be with at home.

4.9 Intervention Observations

Therapeutic Arts: Ceramics

Study participants (n=12) engaged in Therapeutic Arts through painting various ceramic pieces to achieve the following therapeutic goals: the promotion of socialization/communication, the promotion of self-esteem, engagement in creativity, and the promotion of fine motor development. Participants were women ranging in age from mid-20s are to early 60’s.

The ceramic goal of providing opportunities for socialization/communication was achieved. The participants were engaged in conversation throughout the session and remained interactive with other peers. Self-esteem was difficult to measure based on observations of the individuals participating in the intervention. Participants appeared to enjoy painting the ceramic piece as well as showed their completed piece to the rest of the group. The individuals showed satisfaction with their art work and planned on returning home with the finished product. Self-esteem was unable to be measured and results were inconclusive. As a recreation therapist, the promotion of self-esteem was utilized within the interventions at the Victory Center although cannot be measured.
Providing opportunities for self-expression as well as creativity within the intervention was achieved. The participants used a palate of colors to decorate their ceramic piece. Fine motor skills were promoted while utilizing paint brushes of all sizes to paint the piece. The constant movement of the hand allows for an increase in fine motor skills. Overall goals set by the CTRS were achieved during the intervention excluding increased self-esteem based on inconclusive data.

**Holiday Crafts:**

Study participants (n=15) engaged in creating holiday ornaments to achieve the following therapeutic goals: the promotion of socialization/communication, the promotion of self-esteem, engagement in creativity, and the promotion of fine motor development. Participants were both male and female and ranged in age from early 20 to mid-60s. The holiday crafting intervention goal of providing opportunities for socialization/communication was achieved by observation of engagement in conversations. While painting and crafting holiday ornaments, participants shared their stories regarding their chemotherapy treatments and their journeys to survivorship.

Self-esteem was difficult to measure by observation, the individuals sharing their stories expressed a sense of pride and self-worth in survivorship which can be associated to self-esteem, however identifying increases in self-esteem was inconclusive. Opportunities for creativity was achieved, individuals were able to create their own holiday ornaments from a variety of different materials. Holiday crafting promoted fine motor coordination by the use of nail files and toothpicks to
press fabric into the Styrofoam ornaments. Individuals utilized paint brushes to create designs on the ornaments as well.

**Leisure Awareness: Game night**

Study participants (n=3) engaged in a game of *Apples to Apples* to achieve the following therapeutic goals: the promotion of socialization/communication, the promotion of self-esteem, engagement in creativity, and the promotion of fine motor development. Participants were a family of three, a Mother who was affected by Cancer, her Husband, and their Daughter. Each individual took a turn judging other family member’s cards.

*Apples to Apples* promoted opportunities for socialization and communication. Socialization and communication was achieved through social interactions by the family engaging in conversation during the game, however, the Mother’s social interaction was limited. *Apples to Apples* provided opportunities for creativity with the selection of the cards provided. The goal of improving self-esteem was deemed inconclusive due to the inability to measure self-esteem by observation. Participants created various combinations of cards and developed humorous answers to questions. Promotion of fine motor coordination was achieved as each participant was able to hold cards without the assistance of a card holder. Card holders were supplied although not utilized. Family members engaged with each other and discussed other board games they enjoyed. In addition, participants discussed various games and activities they may be interested in participating in at home which supported leisure awareness.
Chapter 5

Conclusion

5.1 Overview

The current study examined the effects and potential benefits of recreational therapy intervention within the Cancer treatment and remission/survivorship process based on two treatment case studies, three caregiver interviews, and the participation of study subjects in three group recreation therapy interventions implemented at the Victory Center located in Toledo Ohio. Overall results suggest that there are a number of different recreation therapy protocols or interventions that can be introduced into the Cancer treatment process and that the implementation of recreation therapy into the Cancer treatment process can produce positive rehabilitative results for Cancer patients.

5.2 Application of Recreation Therapy: Case Study I

Based on the terminal case study presented, as a result of a Cancer diagnosis and engagement in the Cancer treatment process the case study subject experienced considerable bouts of pain, numbness in their legs and hips limiting or preventing mobility, low energy levels, limitations to leisure as a result of re-hospitalizations, and eventual delusion in understanding and conversation. When the case study subject was not limited by the effects of Cancer and/or treatments, the case subject was able to enjoy hobbies such as watching cooking shows, watching humorous television shows, communicating with family, cooking new recipes, and listening to music.
In considering ways to reduce a Cancer patient’s pain, Martin (2006) points out that interventions including music, relaxation scripts, the monitoring of breathing, and progressive muscle relaxation can be used to directly reduce pain. Research has also suggested that recreation therapy interventions such as music therapy and aromatherapy can also reduce some of the common side effects that result from pain such as anxiety and depression (Hillard, 2005). Further, according to research conducted by Martin (2006) and Hillard (2005) recreation therapy interventions can be used to reduce the effects of pain during all phases of the Cancer treatment process including situations when end-of-life care is the only treatment alternative.

Often, the effects of the Cancer treatment process can negatively impact an individual’s self-esteem and sense of self-worth. According to the Duke Cancer Institute (2015) recreation therapy can be utilized to reinforce self-esteem and increase self-worth. Research contends that recreation therapy interventions such as reminiscence therapy may promote self-esteem through the process of connecting the positive life aspects of the past with the present (Dorset Healthcare, 2009). A recreation therapist may utilize reminiscence therapy as an intervention and involve the individual’s family. The family may use items such as photographs, music or postcards to increase memories for the family member affected by the illness. In situations in which the effects of Cancer impact the cognitive abilities of an individual, such as delusional experiences during the final stages of life, reality orientation can be used. The reality orientation process includes presenting information about time, place or person to assist an individual in understanding their surroundings and situation (Memory Matters, 2015).
To address low energy levels the CTRS could include within an intervention education related to eating a balanced diet and receiving proper nutrition, mild physical activity, or activities to reduce depression/anxiety/stress/anger, all of which have been shown to support increased energy levels (WebMD, 2009). Finally, evident from the case study was the desire of the case study subject to continue to participate in personal leisure interests. Results from the case study suggest that CTRS’s should identify with oncology patients those activities they would enjoy participating in during the Cancer treatment process and support those interests directly though intervention participation and/or leisure education.

5.3 Application of Recreation Therapy: Case Study II

When considering the experiences of the second case study subject, the effects of the Cancer treatment process were considerably less severe in regard to side effects such as such as fatigue, pain, anxiety/depression and decreased self-esteem due to physical appearance. Throughout their Cancer treatment process the case study subject continued to participate in meaningful leisure and life activities such as sewing, crocheting, cooking, baking, and working. Although the case study participant reported a decrease in self-esteem and an increase in self-consciousness due to hair loss, they also reported that the ability to participate in meaningful leisure and life activities assisted in promoting their self-esteem and reducing self-consciousness both during and after chemotherapy and radiation.

When considering the positive effects experienced by the case study subject as a result of the ability to participate in meaningful leisure and life activities, results from the
case study suggest that promoting meaningful leisure participation through the Cancer
treatment process can reduce the overall impact of treatment effects. According to Dieser
and Fox (2002) this type of leisure education can be promoted by teaching leisure and
recreation skills that support leisure awareness. Results from the case study also suggest
that developing leisure independence can assist an individual in navigating the treatment
process.

5.4 Application of Recreation Therapy: Caregiver Interviews

Caregiver case studies supported that caregivers of individuals battling Cancer
often experience many of the side effects experienced by the individual they are caring
for such as fatigue, anxiety, depression, pain, frustration, and fear as reported by Alder
and Page (2008) and the American Cancer Society (2013). Caregiver case studies also
supported that caregivers often assume multiple responsibilities as part of the caregiver
process and at times find caring for themselves difficult as support by Alder and Page

In regard to the benefits of leisure, case studies also demonstrated the importance
that leisure and recreation play in the caregiver care-receiver relationship. Caregivers
reported that engaging in activities such as trips into the community, shopping, going to
dinner, playing dress-up, doing cross-word puzzles, visiting with family, cooking, and
engaging in playful humor as part of the caregiver process assisted in reducing fatigue,
anxiety, depression, frustration, and fear for both themselves and the family member they
were caring for. In addition, participating in meaningful leisure independently can also
provide both a caregiver and care-receiver respite from the caregiver care-receiver relationship when necessary.

Caregiver respondents also provided information related to the major obstacles they faced during the caregiver process which included emotional obstacles (e.g., staying strong, hiding fear or anxiety, wondering if they were doing enough or doing things right, etc.) and physical obstacles (e.g., taking care of new or additional household duties such as cooking, cleaning, laundry, grocery shopping, etc.). All caregivers also expressed the importance of having support which has been indicated as a major part of the caregiver process (American Cancer Society, 2013).

Based on caregiver case studies and other results, the current study suggests that caregivers should be included in the development of recreation therapy interventions that are part of the Cancer treatment process both as an integrated part of the process and in terms of being provided independent support. Overall, a CTRS should consider the needs of the caregiver participating in the Cancer treatment process. Examples could be creating interventions that support positive caregiver care-receiver interactions, assisting caregivers in identifying support networks/agencies, and providing leisure education to promote leisure engagement within both the community and at home.

5.5 Application of Recreation Therapy: Goals

Short term goals identified included the following: attending graduate school to advance a nursing career, starting an indoor garden during the winter and transferring the garden outdoors during the growing season, completing a daughter’s wedding scrapbook, and getting on with life.
While recreation therapy may not be able to directly assist in the achievement of all short term goals indicated by study participants, it certainly can be applied to the achievement of reported short term goals associated with gardening, scrapbooking, and getting on with life. When considering gardening a CTRS could develop an intervention based on the creation of a healing garden. Healing gardens promote leisure independence in that the individual waters, maintains, and cares for their garden. In addition, the healing garden is designed to be a restorative piece of nature an individual can visit to decrease stress, emotionally recover, and enhance mental and physical energy. (American horticultural therapy association, 2012)

The short term goal of scrapbooking could be incorporated into a creative arts intervention which would not only allow for the completion of a scrapbook but also opportunities for creativity and self-expression. While the short term goal of getting on with life can be very broad, leisure education, “which focuses on the development of leisure related skills, attitudes, and knowledge to increase a person’s quality of life (Prvu, Navar, Yaffe & Hagar, 1999, pg. 1) could assist an individual in developing new interests and social opportunities.

Long term goals included learning to live alone, retirement investing, accepting life graciously, and applying for a nurse anesthetist program or pursuing a doctorate in nursing. Recreation therapy protocols and interventions such as reality orientation and reminiscence therapy encourage individuals to cherish memories and accept life situations as they come, in this case, both living alone and accepting life graciously. Addressing loneliness and adjusting to living alone, the CTRS may introduce animal assisted therapy into the home to decrease stress, anxiety and loneliness as supported by
Buettner & Wang (2011). Living alone could also be addressed through providing opportunities for community integration. For example the CTRS may suggest facilities such as the Victory Center which offers various support groups and meetings for individuals that battled Cancer, survivors, and their families. The support groups meet weekly and allow for guidance through the disease process for the individual and their family members. Further, support groups increase the awareness of the mental health issues the individual and their family may be experiencing during their Cancer treatment and road to survivorship (American Cancer Society, 2013).

5.6 Application of Recreation Therapy: Self-Esteem

Participants of the current study were asked to describe their self-esteem and rate how they believed their self-esteem was affected by the Cancer treatment process. Not surprisingly, study participants indicated a reduction in self-esteem through the treatment process as well as an increase in self-consciousness as a result of treatment (e.g., woman’s hair loss).

Considering that the emotional side effects of the Cancer treatment process often result in negative impacts to self-esteem and sense of self-worth, it is important that self-esteem be evaluated and addressed, as needed, by a CTRS developing interventions to assist in the Cancer treatment process, particularly considering low self-esteem has been shown to be one of strongest predictors of emotional and behavioral problems (Leary & Schreindorfer, 1995).

Although data measuring the extent to which study interventions impacted participant self-esteem was inconclusive, results did identify self-esteem as an important
element that should be addressed in the application of recreation therapy in the Cancer treatment process.

One example of a way recreation therapy could be used to promote self-esteem would be to include cognitive behavioral therapy into protocols or interventions. According to the Mayo Clinic (2015) cognitive behavioral therapy assists in promoting self-esteem through identifying and changing situations, thoughts, and beliefs that impact how an individual feels and thinks about themselves.

From a service standpoint developing programs that assist individuals with their physical appearance and other basic daily living activities, similar to the Duke Cancer Institute’s *look good feel better* program or the Victory Center’s *wig bank* could further promote self-esteem.

5.7 Application of Recreation Therapy: Quality of Life

It is well established that leisure is an important component to quality of life and that the quality of leisure experienced by an individual is impacted by the meaningfulness of the leisure they participate in and the constraints they face to leisure participation. When considering meaningful leisure study participants indicated they enjoyed engaging in arts and crafts.

According to Forzoni and Perez (2009) therapeutic art has the ability to reduce anxiety, evoke positive memories, and create opportunities for individuals to express themselves in a positive manner. Further, therapeutic art interventions can expand an individual’s understanding of their feelings brought on by illness. Depending on
limitations, therapeutic arts may also improve fine motor skills with the manipulation of the paint brushes and crafting tools needed for the intervention process.

The recreation therapy interventions introduced in the current study promoted opportunities for socialization/communication, self-esteem improvement, opportunities for creativity, and the promotion of fine motor skill development, all of which support increasing an individual’s quality of life. Further, results from the current study supported that recreation therapy can also contribute to quality of life by reducing many of the leisure constraints associated with the Cancer treatment process such as increased fatigue, depression related to stress and anxiety, pain, and sleep deprivation. Recreation therapy interventions may also decrease other physical, emotional and mental limitations that are placed on an individual’s leisure lifestyle when navigating the Cancer treatment process.

5.8 Recommendations for Professional Practice and Research

The following are recommendations for professional practice and future research based on the current study.

Recommendations: Professional Practice

- Increasing the use of therapeutic activities such as music and aromatherapy in oncology waiting rooms to benefit the mental health of the individual while waiting for treatment.
- Involving the family/caregiver in the therapeutic activities provided to Cancer patients in order to reduce factors such as stress, anxiety, or anger and to improve communication and understanding and raise the spirits of all affected by the illness.
Increased advocacy and awareness of the benefits of recreation therapy protocols and interventions in oncology processes at the national, regional, state, and local levels.

Increased opportunities for recreation therapists for continuing education through Cancer organizations with a focus on oncology and the benefits of recreation therapy and therapeutic interventions.

Increase the awareness of the benefits of recreation therapy in all stages of oncology.

Establish opportunities for clinical rotations and internships for undergraduate students on oncology units as well as outpatient chemotherapy facilities to promote recreation therapy interventions.

**Recommendation: Future Research**

- Measuring the effectiveness of therapeutic activities for individuals diagnosed with Cancer as well as the impact of activities on the family.

- Identifying the types of therapeutic activities used by oncology units and services provided (in-patient and outpatient) nationally.

- Identifying on a local level the extent to which recreation therapy is currently used in the oncology process.

- Development of assessment tools to measure outcomes of recreation therapy in within oncology in regard to self-esteem for pre and post assessment identifiers.

- Identify funding opportunities for future research in the field of recreation therapy in collaboration with the American Cancer Society for holistic, non-pharmacological interventions for individuals diagnosed with terminal Cancer.
References


Appendix A

Cover Letter

February XX, 2015

Dear Recreation Therapy Participant:

In partial fulfillment of my Master’s Degree in Recreation Administration through the University of Toledo, I am conducting evidence-based practice research to examine the effectiveness of recreation therapy protocols in Cancer survivor quality of life.

You have been selected to participate in the current study based on your use of Victory Center services. This research study is being conducted under the supervision of Dr. Eric L. Longsdorf, Associate Professor, Division of Recreation & Recreation Therapy and has been approved by the Human Subjects Research and Review Committee at the University of Toledo, SBE IRB # XXXXX.

There are no significant immediate or long-term risks associated with participation in this study. The only minimal risk includes loss of confidentiality. Please be advised however, that the surveys and interview used for the current study do not request any personal identifiers be provided. We are interested only in group-data. The results from this study will be used to measure and improve the effectiveness of the current recreation therapy protocols being used in Victory Center services.

Participation in the current study is voluntary. Refusal to voluntarily participate in the study will have no loss of benefit to which you are currently entitled or entitled in the future based on a relationship with the Victory Center or the University of Toledo. If at any time you feel uncomfortable responding to the survey questionnaire or interview you may discontinue participation without penalty or loss of benefit.

Please understand that by voluntarily selecting to complete study surveys and the interview you are providing your informed consent to participate in the study and your informed consent for any confidential information you provide in study surveys or the interview to be included in the group-data that will be analyzed. Please Note: Interviews will not be recorded.

Your choice to voluntarily participate is important to the success of the current study and will aid in further establishing evidence-based literature on the effectiveness of recreational therapy protocols.

We appreciate your participation in the current study.

If you have any questions or concerns regarding this research project please feel free to contact my graduate project advisor or myself via the contact information below.

Respectfully,

Josie Mazza
Master’s Degree Candidate
The University of Toledo
josie.mazza@rockets.utoledo.edu

Eric Longsdorf, Ph.D.
Associate Professor
The University of Toledo
419-530-2742
eri.clongsdorf@utoledo.edu
Appendix B

Leisure Interest Survey

Date Of Survey:          Age:

Please place an “X” next to the activities that you currently participate in, or would enjoy participating in the future:

<table>
<thead>
<tr>
<th>Activity</th>
<th>Currently Participate:</th>
<th>Interested in Participating:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Music:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Singing in choir</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Listening to music (radio)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attending musicals</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Art:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Painting ceramics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drawing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Baking/cooking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sewing/crocheting</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Outdoor Activities:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gardening</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exploring botanical gardens</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walks in the Park</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fishing/camping</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Leisure Time</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Board games</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cards</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bingo</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Puzzles</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Word Puzzles/ Sudoku</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If I had the opportunity to enjoy one leisure activity of my choice I would chose:

What is your biggest obstacle in participating in leisure activities?
Appendix C

Leisure Participation & Value Survey

How do YOU spend your leisure time? *(Circle All That Apply)*

<table>
<thead>
<tr>
<th>Alone</th>
<th>With family</th>
<th>With friends</th>
</tr>
</thead>
<tbody>
<tr>
<td>With support groups</td>
<td>Other:</td>
<td>Other:</td>
</tr>
</tbody>
</table>

How many days a week do YOU participate in Leisure activities? *(Circle Only One)*

<table>
<thead>
<tr>
<th>One</th>
<th>Two</th>
<th>Three</th>
<th>Four</th>
<th>Five</th>
<th>Six</th>
<th>Seven</th>
</tr>
</thead>
</table>

Meaningful activities YOU participate in include: *(Circle All That Apply)*

<table>
<thead>
<tr>
<th>Socializing (Family)</th>
<th>Socializing (Friends)</th>
<th>Arts and crafts</th>
<th>Church</th>
</tr>
</thead>
<tbody>
<tr>
<td>Watching Sports</td>
<td>Participating in Sports</td>
<td>Being outdoors</td>
<td>Educational Activities</td>
</tr>
<tr>
<td>Television</td>
<td>Camping</td>
<td>Volunteering</td>
<td>Attending Concerts</td>
</tr>
<tr>
<td>Going out to dinner</td>
<td>Going to the movies</td>
<td>Reading</td>
<td>Shopping</td>
</tr>
<tr>
<td>Attending Plays</td>
<td>Gardening</td>
<td>Computer</td>
<td>Listening to music</td>
</tr>
<tr>
<td>Visiting Community Facilities (e.g., Library, Museum, Metroparks etc.)</td>
<td>I do not have leisure interests to fill my schedule</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td>Other:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Overall, how satisfied are YOU with the activities you participate in during your leisure time?

<table>
<thead>
<tr>
<th>Extremely Unsatisfied</th>
<th>Extremely Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>
Appendix D

Post Protocol Interview Questions

1. How did participation in leisure activities improve your quality of life?
2. Do you find yourself more active in hobbies and leisure activities during the day and more often per week?

Post evaluation for self-esteem:

1. Did the participation in leisure activities increase your self-esteem after active chemotherapy treatments?
2. Did introducing various leisure activities and hobbies into everyday life assist with the disease process?
3. What is one new activity you participate in that increases your self-esteem?

Post evaluation for leisure participation and values survey:

1. How many times a week do you participate in leisure activities since the initial survey taken?
2. Has your leisure activity increased or decreased? Why?
3. What is one activity that you have added to your weekly schedule?
4. Have you begun to participate in various hobbies and leisure interests with another person, family or friends?