

THE IMPACT OF COMPLEMENTARY THERAPIES
ON CANCER PATIENT CAREGIVERS'
QUALITY OF LIFE

A Thesis Presented to the Faculty
of
California State University, Stanislaus

In Partial Fulfillment
of the Requirements for the Degree
of Master of Social Work

By
Kimberly A. Turner
May 2016

CERTIFICATION OF APPROVAL

THE IMPACT OF COMPLEMENTARY THERAPIES
ON CANCER PATIENT CAREGIVERS'
QUALITY OF LIFE

by
Kimberly A. Turner

Signed Certification of Approval page
is on file with the University Library

Dr. John Garcia
Professor of Social Work

Date

Dr. Kilolo Brodie
Associate Professor of Social Work

Date

© 2016

Kimberly A. Turner
ALL RIGHTS RESERVED

DEDICATION

To my late father, Randall L. Turner, who instilled in me my love of learning and my passion for education. It was your encouragement, your love, and your support that gave me the drive to get to where I am today. For as long as I can remember you always told me, “You can do anything you want if you set your mind to it” and now all these years later I am realizing my dream because of you.

To my mother, Patricia K. Turner, for keeping my dreams alive through all the tough times and pushing me to strive for more. I am grateful for all you have done to support me through this journey.

To all of the family and friends that have been there for me through this long and arduous process, I hope you know how much it has meant to me.

ACKNOWLEDGEMENTS

I want to give a special thank you to Dr. John Garcia, who allowed me and my fellow graduate researcher, De'zha Kendall, to join the research study at Sutter Health Memorial Medical Center. This has been a wonderful opportunity and I want to thank the cancer caregivers and cancer survivors on the research team for receiving us with open arms and open hearts.

TABLE OF CONTENTS

	PAGE
Dedication.....	iv
Acknowledgements.....	v
List of Tables	viii
Abstract.....	ix
CHAPTER	
I. Introduction.....	1
Statement of the Problem.....	1
Statement of Purpose	4
Significance of Study.....	5
II. Literature Review.....	7
Overview.....	7
Context of Cancer Patient Caregivers.....	8
Complementary Therapies	10
Quality of Life and Caregivers	12
Complementary Therapies and Quality of Life	15
Summary.....	16
III. Methodology.....	18
Overview.....	18
Research Design and Research Team.....	18
Sampling Plan	19
Data Collection	20
MMC Complementary Therapies	21
Instrumentation	22
Plan for Data Analysis	23
Protection for Human Rights	24
IV. Results.....	25
Introduction.....	25
Demographic Characteristics	26
Analysis of Participant’s Quality of Life	28

Relationship with Others.....	30
Mental Functioning.....	32
Emotional State.....	33
Attitude Towards Life.....	34
Qualitative Data Analysis	35
Summary.....	40
V. Discussion.....	42
Introduction.....	42
Major Findings.....	42
Existing Literature	44
Limitations of the Study.....	45
Implications for Future Research.....	47
Implications for Social Work Practice.....	48
References.....	50

LIST OF TABLES

TABLE	PAGE
1. Frequencies of Gender, Ethnicity, Type of Cancer, and Course of Treatment.	26
2. Frequencies of Education, Income, Residence, and Living Situation	27
3. Quality of Life Comparison	29
4. Participation in Complementary Therapies through Memorial Medical Center	30
5. Frequency of Responses for Relationship with Others	31
6. Relationship with Others CT Users Responses	37
7. Emotional State CT Users Responses	38
8. Attitude Towards Life CT Users Responses	39

ABSTRACT

The purpose of this study was to determine if cancer patient caregivers' quality of life was improved by their participation in the complementary therapies offered by Sutter Health Memorial Medical Center. This study compared two groups, caregivers that participated in complementary therapies and caregivers that did not participate in complementary therapies. The results showed that there is a difference in the overall quality of life between these two groups, with cancer patient caregivers that utilized complementary therapies reporting a better quality of life. The greatest differences were seen in their relationship with others, mental functioning, emotional state, and attitude towards life. From this study it is apparent that future research needs to utilize randomized trials with control groups to better determine the efficacy of complementary therapies in improving the quality of life of cancer patient caregivers. Social workers must educate themselves on these programs and provide these resources to their clients of diverse backgrounds.

CHAPTER I

INTRODUCTION

Statement of the Problem

In 2011, The National Cancer Institute estimated that by 2014 there will be 13,397,159 people will be living with cancer in the United States alone and it is estimated that there will be 1,665,540 new cases of cancer. They also reported that men and women in the United States have a 40.4% chance of being diagnosed with cancer at some point in their lifetime. This issue not only impacts the individual diagnosed with cancer, but also their family, friends, and other people they interact with. Many cancer patients utilize the support of a family caregiver. With advances in treatment there is a shift to patients receiving care in outpatient locations and within their own homes. (Pitceathly & Maguire, 2003). According to Bevans and Sternberg (2012), caregivers of cancer patients experience a greater burden than caregivers of patients with dementia. The mean age of a caregiver is around 58 years of age and is typically a co-resident with the patient and is more likely to be a woman than a man (Thomas, Morris, & Harman, 2002).

A study by Son et al. (2012) contributed the need for family caregivers to the increased survival rate of patients with cancer, and a trend toward outpatient treatment. Many tasks that need to be accomplished by someone other than the patient fall into the domain of at home activities making it more likely that a family member, such as a spouse, child, or parent, will be the primary caregiver (Thomas, Morris, &

Harman, 2002). This increased workload on the family caregiver has been studied and shown that it can have adverse effects evident in the caregivers' health (Bevans & Sternberg, 2012; Pitceathly & Maguire, 2003; Son et al., 2012). Bevans and Sternberg (2012) argue that, "the most obvious signs and symptoms of caregiving stress are often psychological problems, most commonly anxiety, depression, worry and loneliness" (p 400). Pitceathly and Maguire (2003) found that caregivers of cancer patients most likely display high emotional distress, but in rare cases they are known to develop psychiatric disorders. They also emphasized that a lack of support for the caregiver leads to high levels of emotional distress. Another study done by Soothill et al. (2001), shows that caregivers with significant unmet needs are more likely to be in poor health. These effects range from anxiety and depression as previously mentioned to a compromised immune system, heart disease, and in extreme cases an early death (Bevans & Sternberg, 2012).

The way to address this in the research is to lay out their needs by category and although they all have their own specific labels the main focuses are on their emotional, social and financial health (Ferrario, 2003; Soothill et al., 2001; Thomas, Morris, & Harman, 2002). The most comprehensive for the purpose of this study was Soothill et al. (2001) categories of: managing daily life, managing emotions and managing social identity and relationships. This encompasses transportation, housework, finances, feelings of guilt and support from family, friends and professionals. All of these areas are potentially impacted when a person accepts the responsibility as a primary caregiver to a cancer patient.

The issue of greater concern is the need for more research on the needs of caregivers of cancer patients as well as the utilization of this information to form resources for them. There has been a lack of attention paid to the cancer patients' caregiver's needs (Soothill et al., 2001). According to Soothill et al. (2001), before the 1980s caregivers of cancer patients were not seen as providers of assistance. This lack of acknowledgement meant that they went unrecognized for many years. Just as they are coming into the focus of research recently there needs to be more services provided to help maintain their health alongside the cancer patient they care for. There is a substantial amount of literature on the psychosocial support needs of cancer patients, but there is very little research published on the needs of caregivers (Thomas, Morris, & Harman, 2002). According to Bevans and Sternberg (2012), with the building of more evidence reporting that caregiving is a potential detriment to personal health there is more focus in research on the daily overall health of caregivers.

Bevans and Sternberg (2012) found that the level of distress reported by many of those caring for someone with cancer can be equal to or greater than that of the cancer patient. A study by Soothill et al. (2001), found that caregivers' psychosocial needs remain unmet in comparison to the cancer patients they care for. The research suggests that the creation of resources can benefit the caregiver as well as the cancer patient. Caregivers' psychosocial well-being is linked to the well-being of the cancer patients (Soothill et al., 2001). So from this point what can be done?

The resources available to cancer patient caregivers include support groups and aid in accomplishing day to day tasks, but there is a fairly recent resource known as complementary therapies that allow the cancer patient and caregiver to improve their quality of life. Complementary therapies in the context of this study consist of healing and fitness classes offered through Sutter Health Memorial Medical Center in Modesto, CA. The healing classes include: art, gardening, movement, music, photography and writing. The fitness classes include: aquatic therapy, cycling, pilates, strength & fitness, walking and yoga (Sutter Health Memorial Medical Center, 2013). The use of complementary therapies has not been thoroughly studied as it is a more recent trend. What research has been done is focused on the patients and incidentally the patient caregivers have received less attention. This is the premise of this research study, to find if there is any correlation between the complimentary therapies and quality of life in cancer patient caregivers.

Statement of Purpose

The use of complementary therapies has shown to have positive impacts on the lives of cancer patients and therefore the purpose of this study was to explore and describe the views of caregivers on the impact of complementary therapies on their quality of life. In this endeavor there was a thorough break down of the concept of quality of life into six subcategories that include: physical health, relationship with others, emotional state, mental functioning, attitude towards life, financial situation and other. This division of the term allowed the study to look at

the range of ways that these therapies have influenced the caregiver's quality of life. The study was guided by the following research question Do caregivers who have participated in complementary therapies have improved levels of quality of life in comparison to those caregivers who have not participated in complementary therapies?

The assumption that was made was that there is an improvement in the quality of life of the caregivers that have taken part in complementary therapies over those that have not utilized these therapies. If there was a change in more than one of the six subcategories then it can be assumed that the influence on their quality of life was greater. Another assumption was that the differences in the cancer patient caregiver's quality of life are correlated with their use of complementary therapies and that internal validity can be upheld.

Significance of Study

This study was pertinent to the study of social work because it has the potential to increase our body of knowledge to include not only patients, but their caregivers as well; shifting the focus to another population that is in need of services. This cognizance on the part of individual social workers can allow them to identify a potential client, gives them some of the information needed to understand the client's situation and it allows them to determine what services may be available to them.

The lack of information has limited the services that are available. Therefore this study has the ability to bring to light the range of services that could

be made available for this population. This has the potential to bring awareness to organizations and the leadership therein influencing the creation of new services and resources for cancer patient caregivers. It can demonstrate the effectiveness of services that are already in use. This would allow for organizations to make the determination if services like those that were in this study fit their clientele's needs, as well inform them of the effectiveness of these services.

From here it has the potential to spark a change in policy that could impact the availability of such services to this population. If there is an increase in the availability of similar services then there may be changes in policy to allow for an expansion of services already instituted for cancer patients to include their caregivers. It may also influence the financial backing and coverage of such programs through non-profit organizations and the inclusion of them into treatments that can be covered by medical insurance.

Social work has the ability to bring awareness to the needs of cancer patient caregivers and to inform the community and to influence organizations that have the potential to offer services, as well as to policy makers that could make these services available to as many people as possible.

CHAPTER II

LITERATURE REVIEW

Overview

With the increased survival rate of cancer patients and the conditions of cancer being categorized as a chronic illness there has been a greater need to provide cancer survivors with more long term care. There has also been a marked transition to outpatient cancer care, creating a need for more informal cancer patient caregivers. Along with this increased demand for caregiving, there has been more burden placed on cancer patients' families that volunteer as caregivers. There have been studies that show that cancer patient caregivers have many needs that go unmet. In one study it was shown that caregivers are more likely to have a higher incidence of anxiety and depression (Lai, Li, & Lee, 2011).

With the psychological and social needs that are unmet through the current course of care, there is a relatively new intervention that has been put in place known as Complementary Therapies (CTs). These CTs use a range of techniques to address the unmet needs of cancer patient caregivers. Each medical center that offers these services provide a range in the CTs, or classes, they offer for cancer patient caregivers. With this range of programs, it is hard to determine the efficacy of the CTs, and there needs to be more studies conducted on the impact that these CTs have on the caregivers.

Over the last ten years there has been an increased focus on Quality of Life (QOL) through the use of various questionnaires that are tailored to cancer patient caregivers. These questionnaires define QOL very differently and yet throughout the world they are used to measure the ability of cancer patient caregivers to maintain the same lifestyle as they had prior to providing care. Using these questionnaires and other measurement tools there have been only a few studies conducted that analyze the use of CTs and their impact the QOL of cancer patient caregivers. This chapter provides an extensive review of the context of cancer patient caregivers, complementary therapies used with this population, the impact of CTs, the definition of QOL for caregivers, and the impact that CTs have on the cancer patient caregiver's QOL. Through this review there is an analysis of what has been accomplished in the field thus far and allows for a deeper understanding of the context of this study.

Context of Cancer Patient Caregivers

According to the American Association of Retired Persons (AARP), there are an estimated 43.5 million adults throughout the United States who have provided unpaid care in the past year (2015). With the shift from inpatient care for cancer patients to an outpatient informal model there is a greater need for family caregivers to fill the role of caring for the needs of cancer patients. A cancer patient caregiver is usually a family member, either a spouse or adult child (Trudeau-Hern & Daneshpour, 2012). According to a study that collected 1,248 quantitative surveys, the average caregiver is a woman (60%), at the age of 49, and is most likely to be a child of the patient (49%) in need of care (AARP, 2015). The average period of care

lasts 4 years, and the majority of patients/recipients are women (65%) at the age of 69 (AARP, 2015). The increased dependence on informal cancer patient caregivers will only continue to increase.

Cancer patient caregivers are impacted by the cancer diagnosis and course of treatment alongside with the patients and yet their needs in many cases not assessed or addressed. The most common themes of caregiver's unmet needs include physical health, psychological wellness, social connection and spirituality (Clark, et al., 2006; Kim & Given, 2008; Kozachik, Wyatt, Given, & Given, 2006). Many of the physical health concerns pertain to the preexisting health conditions that the caregiver may have had before she or he began providing care, as well as the increased stress of caregiving responsibilities on current physical health (Clark, et al., 2006).

Caregiving for cancer patients can be defined through a range of activities and responsibilities that include, but are not limited to: helping patients with their daily living activities, scheduling and attending medical appointments, administration of medication, and emotional support through the cancer process (Soothill, et al., 2001; Thomas, Morris, & Harman, 2002). The psychological well-being is impacted by the restrictions that are placed on the caregiver's daily routine including: limited social interactions, reduced time for leisure activities, and the change in roles that are inherent in the family caregiving situation (Thomas, Morris, & Harman, 2002). The social connection is a need that is unmet because the caregivers' time is usually focused on the cancer patients and there is little time or energy to allow them to maintain the social connections they once had (Clark, et al., 2006). The spirituality

aspect pertains to the need for personal worship, the advice of a spiritual advisor and the support from people of their same faith (Soothill, et al., 2001).

The most common theme of unmet needs of cancer patient caregivers are the increased levels of distress. According to the study conducted by AARP (2015), 1 in 5 caregivers reported a high-level of “physical strain” (p.52). This is similar to the 18% that reported high financial pressure. The most significant concern reported was the high emotional stress that impacted 4 in 10 cancer patient caregivers (AARP, 2015). The need for emotional support is echoed by a number of studies and seems to be the most apparent unmet need of cancer patient caregivers (Song, et al., 2011; Alptekin, Gonullu, Yucel, & Yaris, 2010; Clark, et al., 2006).

Complementary Therapies

There has been an increased use of holistic health practices that include complementary and alternative medicine (CAM) (Kizachik, Wyatt, Given, & Given, 2006). CAM activities and treatments include: hypnosis, nutritional supplements, meditation, yoga, music therapy, guided imagery, massage, acupressure, therapeutic touch, relaxation techniques, tai chi, acupuncture, and support groups (Hamilton, et al., 2012). The term CAM has been used in various studies and it is ambiguous and different from study to study. Given the wide range of treatments there can be a division made between complementary therapies (CTs) and alternative medicines (AMs). According to Kizachik, Wyatt, Given, and Given (2006), CTs are supplementary treatments to conventional medical care that address symptom management and AMs are used to replace conventional medical care. There has been

an increased use of CTs with cancer patients, as well as with their caregivers to help meet many of their unmet needs as previously discussed.

There was a study conducted that examined the impact of music therapy on cancer patient caregiver's sleep, anxiety and depression (Lai, Li, and Lee, 2011). The participants had to be female, have normal hearing capabilities, have completed high school, be between the ages of 20 and 60, and be a caregiver for less than a year. This allowed for 34 eligible cancer patient caregivers to take part in the study. The participants went through two interventions: Music Intervention with Nursing Presence (MINP) and Recorded Music (RM) and they were randomly assigned to two groups that alternated the interventions. According to Lai, Li, and Lee (2011), there were statistically significant differences in levels of anxiety and depression. All of the participants reported that they preferred the MINP intervention and there was evidence that this method resulted in lower levels of anxiety than RM. From this study it seems that there is a positive correlation between participation in music therapy and the improved levels of participant's anxiety and depression.

For this study the focus will be on CTs that are used by cancer patient caregivers to help alleviate some of the symptoms and distress that they experience throughout the journey of cancer. The use of complementary therapies by cancer patient caregivers is a recent addition to treatment provided and the locations that provides these services are very limited. The current study was conducted at Memorial Medical Center (MMC) in Modesto, California and they offer CTs to both cancer patients and their caregivers. They divide their classes into two categories

including healing classes and fitness classes. The healing classes consist of art, gardening, movement, music, photography, and writing. The fitness classes are composed of aquatic therapy, cycling, pilates, strength and fitness, walking, and yoga (Memorial Medical Center, 2013). The healing classes are held once a week and the fitness classes are most commonly held twice a week with a range of times offered to allow for more people to take part in the CTs. The participants are allowed to take part in as many CTs as they want and there is no set limit to how many sessions can be attended by either cancer patients or their caregivers. This study focuses on the impact that these CTs have on the QOL of cancer patient caregivers.

Quality of Life and Caregivers

Quality of Life (QOL) is a term that has been used to understand the overall well-being of an individual. According to Alptekin, Gonullu, Yucel, and Yaris (2010), QOL is defined as a “subjective feeling of a person that his/her life is generally well” (p.608). In many studies QOL is broken down into numerous domains that help to better address the elements of an individual’s life that contribute to his or her life being considered “generally well.” There seem to be common domains that are addressed across studies and these include: physical health, psychological well-being, mental health, and social well-being (Clark, et al., 2006; Kim and Given, 2008; Alptekin, Gonullu, Yucel, & Yaris, 2010; Song, et al., 2011; Martin and Keats, 2014; Kozachik, Wyatt, Given, & Given, 2006). In addition to these domains there has been use of others such as: spiritual well-being (Clark, et al., 2006; Kim and Given, 2008; Kozachik, Wyatt, Given & Given, 2006), emotional well-being (Alptekin, Gonullu,

Yucel, & Yaris, 2010; Kozachik, Wyatt, Given, & Given, 2006), financial and family functioning (Alptekin, Gonullu, Yucel, & Yaris, 2010), as well as self-care and usual activities (Song, et al., 2011).

According to Kalfoss, Isaksen, Thuen, and Alve (2008), during the “past decade the use of standardized questionnaires to assess QOL in various populations has increased” (p.12). Given that there are so many different domains used to define QOL there has been a common use of the World Health Organization Quality of Life Instrument (WHOQOL-BREF) which consists of 4 domains that include: physical health, psychological health, social relationships, and environment. Physical health incorporates the individual’s daily activities, energy levels, sleep, mobility, pain, and work capacity. The domain of psychological health refers to an individual’s negative feelings, body image, appearance, memory, and concentration. The social relationship domain encompasses an individual’s social support, personal relationships, and sexual life. The domain environment is used to include physical security, access to health care, financial resources, home environment, participation in and opportunity for recreation and leisure activities, and transportation (Alptekin, Gonullu, Yucel, & Yaris, 2010). This tool has been translated into 40 languages and has been used in countries throughout the world (Kalfoss, Isaksen, Thuen, & Alve, 2008).

Another tool that is used to measure the QOL of cancer patient caregivers is the Caregiver Oncology Quality of Life questionnaire (CarGOQoL), a 75-item survey tested on 837 cancer caregivers (Minaya, et al., 2012). This tool was created by using information obtained and analyzed from interviews with 77 cancer patient caregivers.

There is also a short form known as SF36 that is a condensed version of this tool. These tools use the domains of psychological well-being, leisure and everyday activities, occupation and finances, physical well-being, and relationships to measure QOL (Minaya, et al., 2012).

For the purpose of this study, the term QOL will refer to a set of domains that were comprised by the research group which consisted of cancer survivors, cancer patient caregivers, researchers, and graduate student interns. The six domains that are used include: physical health, relationship to others, emotional state, mental functioning, attitude towards life, and financial situation. When using the domain physical health the study is concerned with the impact of caregiving on leisure time and everyday activities, as well as physical symptoms such as pain and trouble sleeping. Under the domain of relationship to others there are questions pertaining to the functioning of the family, the interactions with friends, and the attendance of social gatherings. When discussing the domain of mental functioning it is important to note that this study is looking for the impact caregiving has had on memory, concentration, and the ability to perform complicated tasks. The domain of emotional state eludes to the emotion support received by family, feelings of isolation and loneliness, as well as a sense of control over your life. In the domain of attitude toward life the survey focuses on the ability of a caregiver to maintain a positive attitude, being able to have a sense of inner peace, and a sense of faith. The last domain of financial situation incorporates financial difficulties and the impact of caregiving on the ability to work.

Complementary Therapies and Quality of Life

In research studies the QOL usually refers to a score that the participant reported on various domains, and it is an indicator of the efficacy of various complementary therapies. With the recent addition of CTs for cancer patient caregivers, there are few studies published that elude to the impact that they have on QOL. A quasiexperimental study was conducted to analyze the patterns of CT use among cancer patients and their caregivers and their impact on QOL, emotional well-being, and caregiver burden (Kozachik, Wyatt, Given, & Given, 2006). There were a total of 180 participants, comprised of 100 cancer patients and 80 family caregivers. When given the option to participate in guided imagery, reflexology, and reminiscence therapy 74 out of the 80 participated in more than one of these CTs over the course of 8 weeks (Kozachik, Wyatt, Given, & Given, 2006). They defined QOL using the following domains: physical, psychological, social, and spiritual. The results showed that there was an increased physical and social report in the participant's overall QOL (Kozachik, Wyatt, Given, & Given, 2006). With this positive correlation between CTs and QOL it seems that some cancer patient caregiver's needs are being met through these new CT programs being offered.

There was also a study conducted by Martin and Keats (2014) that examined the impact that yoga had on the quality of life of cancer patient caregivers. The participants (caregivers) were involved in a twice a week session of Vinyasa yoga that lasted a total of six weeks. This meant that the caregivers were participating in 150 minutes of exercise a week. The study targeted caregivers who reported levels of

distress, measured by scoring a five or higher on the National Comprehensive Cancer Center Distress Thermometer, and the caregivers could not have any health issues that limited their ability to increase their physical activity. The study incorporated 12 cancer patient caregivers who completed the program and they administered a pre-test and a post-test to gain an accurate measurement of the change in QOL and psychological distress. The survey administered was a qualitative open-ended assessment that allowed the caregivers to give their own responses to the questions. From the information collected from this survey, “all participants perceived improvements in their mental or physical well-being” (Martin & Keats, 2014, p.260). Some of the common themes included improvements in strength, flexibility, and physical fitness as well as improved mindfulness, increased energy, focus and relaxation. All of these are indicators that the caregiver’s QOL was impacted by the CT that was offered. It not only eludes to an impact, it shows a positive correlation between the CT and the caregiver’s QOL.

Summary

This chapter has provided an extensive overview of the literature pertaining to cancer patient caregivers, their unmet needs, their quality of life, the use of complementary therapies, and the impact that complementary therapies have on their quality of life. With a greater demand for caregivers of cancer patients there has been a documented need for more services to be provided. Research has shown that cancer patient caregivers have increased levels of anxiety and depression, are not able to maintain their social interactions, and are not able to meet their financial obligations

due to the burden that comes with caregiving. Emerging from this knowledge, there has been a creation of complementary therapy programs that address some of these needs, as well as others, to help improve caregiver's quality of life. The use of complementary therapies however range from program to program and what classes are offered and how they are administered are drastically different from one to the other. Given that these programs are relatively new there is a need to further examine their efficacy and their impact on quality of life.

CHAPTER III
METHODOLOGY

Overview

This study will be using existing data collected by a research team in collaboration with Sutter Health Memorial Medical Center (MMC) in Modesto, CA. The focus of this study is the complementary therapies that are offered to cancer patients as well as their caregivers through MMC. These programs include art, music, writing, yoga and many other activities aimed at helping the participants to gain support and strength (Sutter Health Memorial Medical Center, 2013). The purpose of this study is to describe the impacts that complementary therapies have on cancer patient caregivers' quality of life. This descriptive study broke down the concept of quality of life into six subcategories that included: physical health, relationships with others, mental functioning, emotional state, attitude towards life, and financial situation. The format of this study allowed for the following research question to be addressed: Do caregivers who have participated in complementary therapies have improved levels of quality of life in comparison to those caregivers who have not participated in complementary therapies?

Research Design and Research Team

The study utilized a descriptive design to examine complementary therapies (Rubin & Babbie, 2014). Complementary therapies are a fairly recent addition to MMC's regiment of care for cancer patients and their caregivers. With these newly

instituted programs there is a need to evaluate if they are in fact improving participant's quality of life. The study was conducted in a cross-sectional design to allow for the comparison of two distinct groups, those that have utilized complementary therapies and those that have not (Rubin & Babbie, 2014). The research group is currently composed of two professors or researchers, two student interns, three cancer survivors and three caregivers. The researchers, cancer survivors, and caregivers collaboratively created the survey that will be utilized in this study. This shift in paradigm allows for those being studied to take action for themselves (Rubin & Babbie, 2014). The research was conducted without the current student interns and their role is to aid and participate in the analysis of the data that had been collected. It is through participatory action that this team of cancer survivors, cancer patient caregivers, student interns, and researchers will be employed in the analysis of the data, as well.

Sampling Plan

The study used a non-probability sampling known as purposive sampling (Rubin & Babbie, 2014). It included responses from cancer patient caregivers that were obtained through the MMC Complementary Therapies program. These individuals comprised the "user" group. To ensure that the respondents fit the target population other measures of criteria were instituted. The respondents had to be past or present cancer patient caregivers. This included those who had been caregivers for cancer patients that had either recovered or passed away. They also had to be involved in one or more of the complementary therapies offered by MMC. This

allowed for a range of respondents, from those that were active participants in many of the programs, to those that had attended only a single class. The respondents had to be on the mailing list of the program. This may have prevented the inclusion of participants who neglected to sign in at a class, those that had neglected to submit their current mailing addresses, or those that had moved from the residence on file. With these three criteria the population totaled to approximately 400 cancer patient caregivers.

The study also included cancer patient caregivers that have not participated in complementary therapies, comprising the “non-user” group. This meant that the individual had to be a caregiver for a cancer patient that did not utilize complimentary therapies at any time. These individuals were obtained through various methods including contacting an oncology unit and attending a cancer conference. There was a need to ensure that these caregivers were similar in five demographic areas including: gender, age, race or ethnicity, socioeconomic status, and location of residence. This ensures that the two groups are comparable.

Data Collection

To obtain information from member of the “user” group an existing mailing list for the participants in the complimentary therapy classes was used that included approximately 400 people. This mailing list included every participant that had been part of the complimentary therapy classes at MMC (in Modesto, CA). The survey was mailed to each of the 400 participants and the respondents were able to return their answers by mail. The survey was mailed out and there was a reminder sent out 2

weeks later. The research team went to each of the complementary therapy sessions in existence to try to increase the sample size. The surveys that were received within a month of the original mailing date were incorporated into the study.

To assemble the information from members of the “non-user” group the research team collaboratively worked with the administration of the Sutter Gould Oncology Unit (in Modesto, CA), to collect data on caregivers that have not participated in complementary therapies. The cancer patient and their caregivers were handed a consent form and the survey from staff members of the oncology unit. When this did not yield sufficient numbers the research team also handed out surveys at a local annual cancer conference in Modesto, CA.

MMC Complementary Therapies

Complementary therapies in the context of this study consist of healing and fitness classes offered through MMC in Modesto, CA. The healing classes include: art, gardening, movement, music, photography and writing. The fitness classes include: aquatic therapy, cycling, pilates, strength & fitness, walking and yoga (“Complementary Therapy”). The healing classes are regularly held in the evenings and the fitness classes tend to be offered in the mornings with periodic evening sessions. The complimentary therapy classes through MMC are offered to cancer patients that have received medical treatment and for their caregivers. These classes are free of charge to both cancer patients and their caregivers. There are no limitations to the range of classes that an individual can take in the course of their care. Any individual can take part in as many or as few classes as they want and there

is no commitment made to continue attending. This allows the individual the freedom to decide how to take part in these free classes. The individuals are then able to participate in complementary therapies as long as they want, as of yet there is no defined end to these services. The flexibility of types of classes, times offered, and sessions allowed gives the individuals the freedom to seek out the care and support that they need throughout the journey of cancer.

Instrumentation

The survey used emerged out of a mixed method survey that was composed of a number of quantitative questions and a single qualitative question (Rubin & Babbie, 2014). This format allowed for the collection of statistical information through the use of Likert scale questions that rank the responses on a consistent continuum. This is conducted in a matrix format that allows certain questions to be lumped together to distinguish between the different areas of quality of life (Rubin & Babbie, 2014). This survey also provided the individual caregiver the opportunity to give more in-depth information in response to the open-ended qualitative question. There was also a section for additional comments at the end of the survey to allow for the individual to provide any more information they wanted to. The exact format was different for the two groups: caregivers that have participated in complementary therapies, “users” and those that have not participated in complementary therapies, “non-users.”

The survey for “users” included 51 quantitative questions on the quality of life of cancer patient caregivers and a single qualitative open-ended question. The single open-ended question allows caregivers to provide their own response to the following

question: Is there any other information you would like to share about how complementary therapies have, or have not influenced your quality of life? The survey is comprised of 51 quantitative questions that include 36 questions on the quality of life of caregivers and 15 demographic questions. The instrument will be used to gain in depth understanding of how the use of complementary therapies have increased the quality of life of cancer patient caregivers.

The survey for “non-users” included 45 quantitative questions that examined the cancer patient caregivers’ quality of life and a single qualitative open-ended question. The question posed was: Is there any information you would like to share about your quality of life? The survey has a total of 45 quantitative questions that are comprised of 32 questions that address the caregivers’ quality of life and 13 demographic questions. This instrument will allow for the comparison of the two groups’ quality of life based on the use or non-use of complimentary therapies.

Plan for Data Analysis

The surveys from cancer patient caregivers were returned to the research team to be analyzed. The target population for each group was 120 participants for the “user” group and the “non-user” group. This would accumulate to a total of 240 participants to allow for statistical analysis and comparison purposes. The quantitative questions were entered into SPSS (Statistical Software Package for the Social Sciences), and the information was then analyzed to see if there was any statistical significance in the differences in quality of life between those that used complementary therapies and those that did not. The survey’s qualitative responses

were then read, analyzed, and coded by a team of researchers, two student interns, cancer survivors and cancer patient caregivers. This process looked at the cancer patient caregivers' quality of life from the six subcategories discussed earlier and coded for any other significant commonalities among the responses. From the responses the research team will be creating a definition of each subcategory using the respondent's own words to give a more accurate picture of the impact that complementary therapies had on their quality of life.

Protection for Human Rights

The study went through two processes before the survey could be given to the participants in complementary therapies. The research team had to write a proposal to IRB. From there IRB had to approve the use of this survey through the school, California State University Stanislaus, and the hospital, MMC. Once approved by IRB through both institutions the survey was ready to be used for both cancer patients and their caregivers.

CHAPTER IV

RESULTS

Introduction

The purpose of this study was to determine if the participation in complementary therapies (CTs) by cancer patient caregivers impacted their quality of life (QOL). The study was designed to determine if CT Users have a different overall QOL in comparison to Non-CT Users. The term QOL was broken into six domains that consists of physical health, relationship with others, mental functioning, emotional state, attitude towards life, and financial situation. This chapter delves into the quantitative and qualitative data to answer the research question: Do caregivers who have participated in Complementary Therapies have improved levels of quality of life in comparison to those caregivers who have not participated in Complementary Therapies?

The demographic factors of the two groups, CT Users and Non-CT Users, is laid out in this chapter, followed by a brief overview of the overall QOL scores reported in the study. From there, each succeeding section focuses on one of the six domains. The first section analyzes the domain of physical health using the quantitative data. After this comes similar sections for relationship with others, mental functioning, emotional state, attitude towards life, and financial situation. The final component of the analysis portion is a section dedicated to the qualitative data.

Demographic Characteristics

There are two distinct groups that were accounted for in this study and these include CT Users and Non-CT Users. The Non-CT Users serve as a comparison group for the study, to be able to compare the two groups, to find efficacy of the programs offered. There were a total of 35 CT Users and 21 Non-CT Users who were included in the study. The two groups, were compared on 11 different demographic characteristics, and they were similar in all categories except for one. Between the two groups there was no statistical difference in their gender, age, racial or ethnic identity, education, living situation, location of residence, annual household income, type of cancer, stage of cancer and course of treatment for the cancer (Table 1).

Table 1

Frequencies of Gender, Ethnicity, Type of Cancer, and Course of Treatment

Demographic Characteristics	CT Users	Non-CT Users
Gender		
Female	67.6%	70%
Male	32.4%	30%
Race/Ethnicity		
Caucasian	81.8%	60%
Hispanic/Latino	9.1%	20%
African American	0%	5%
American Indian or Alaska Native	6.1%	5%
Asian	3%	5%
Other	0%	5%
Type of Cancer (may include more than one)		
Breast	37.1%	35%
Colon	17.1%	5%
Lung	2.9%	5%
Prostate	17.1%	30%
Course of Treatment (may include more than one)		
Chemotherapy	62.9%	35%
Radiation	51.4%	55%
Surgery	68.6%	55%

The average cancer patient caregiver who participated in CTs in this study was female (67.6%), Caucasian (81.8%), with a college degree (63.6%), living with their partner or spouse (71.4%), with an annual household income of \$60,000 or more (48.5%), living in Modesto, CA (71.4%), caring for a patient with breast cancer (37.1%) and the cancer patient being treated with chemotherapy (62.9%) and/or surgery (68.6%). There is a continued comparison breakdown that gives the CT Users and the Non-CT Users demographic information in Table 2.

Table 2

Frequencies of Education, Income, Residence, and Living Situation

Demographic Characteristics	CT Users	Non-CT Users
Education		
High School Diploma/GED	30.3%	38.1%
Technical or Vocational School	6.1%	0%
Associate's Degree	18.2%	19.0%
Bachelor's Degree	21.2%	33.3%
Master's Degree or Higher	24.2%	9.5%
Annual Household Income		
\$19,000 or less	9.7%	9.5%
\$20,000-\$39,999	19.4%	23.8%
\$40,000-\$59,999	22.6%	33.3%
\$60,000-\$79,999	22.6%	9.5%
\$80,000-\$99,999	6.5%	9.5%
\$100,000 or more	19.4%	14.3%
Location of Residence		
Modesto	71.4%	71.4%
Ceres	5.7%	14.3%
Turlock	8.6%	0%
Patterson	2.9%	0%
Other Location Inside Stanislaus County	2.9%	4.8%
Location Outside of Stanislaus County	8.6%	9.5%
Living Situation		
Living Alone	20%	0%
Living with Partner or Spouse (and children if applicable)	71.4%	80%
Living with One or More Adult Children	5.7%	5%
Other	2.9%	15%

There was, however, a statistical difference in the year of diagnosis for the cancer patients for whom they cared. The Non-CT Users were caring for cancer patients with a more recent diagnosis of cancer in comparison to the CT Users. The range of years of diagnosis for the CT Users spanned from 1978 to 2013 and the Non-CT Users spanned from 1990 to 2013. Within the Non-CT Users group the majority of cancer patients were diagnosed after 2009 (90%). Half of the cancer patients were diagnosed in 2013. This one demographic difference presents a confounding variable to the findings in the sense that this could explain the lower QOL scores of the Non-CT Users in comparison to the CT Users. With a more recent diagnosis there is a more recent transition into the role of cancer caregiver and this makes the year of diagnosis a confounding variable.

Analysis of Participant's Quality of Life

From the responses of the two groups, CT Users and Non-CT Users, there were statistically significant differences in four of the six quality of life domains (Table 3). There was no statistically significant differences in the physical health and financial situation. Both groups reported good quality of life scores in these areas. The CT Users reported a physical health score of 5.6 and the Non-CT Users reported a score of 6.2; these scores are considered statistically comparable. In the domain of financial situation, CT Users totaled to a score of 6.6 and Non-CT Users totaled to a score of 6.8; again there are no statistical differences in these responses. While there are no statistical differences between the two groups on these two domains, it is

important to note that both groups reported good QOL. On both domains, physical health and financial situation, lower score denote better QOL.

There were significant differences in the domains of relationship with others, mental functioning, emotional state, attitude towards life, and overall QOL. CT Users reported lower scores with an 11.8 in relationship with others, a 9.9 in mental functioning, a 22.0 in emotional state, and a 9.9 in attitude towards life. Additionally, CT Users reported an overall QOL score of 65.8. In contrast, the Non-CT Users reported higher scores with a 16.1 in relationship with others, 14.9 in mental functioning, a 33.4 in emotional state, 14.0 in attitude towards life, and an overall QOL score of 91.4. This shows that cancer patient caregivers who participated in CTs through MMC reported better QOL than those who did not.

Table 3

Quality of Life Comparison

QOL Measurement	CT Users	Non-CT Users
Physical Health	5.6	6.2
Relationship with Others*	11.8	16.1
Mental Functioning*	9.9	14.9
Emotional State*	22.0	33.4
Attitude Towards Life*	9.9	14.0
Financial Situation	6.6	6.8
Overall QOL*	65.8	91.4

* Statistically Significant Differences ($p < .05$)

MMC offers a variety of CT classes that are open to cancer patient caregivers. These CTs include: Images Cancer Art Program, Talking Photographs, Writing through Cancer, Hope Blooms Garden Club, Sounds of the Heart Music Program, Triumph Cycling, Triumph Walking, Triumph Yoga, Pilates, Moving through Cancer

Dance Program, and Strength and Fitness. The most commonly used CTs included Images Cancer Art Program (40%) and Hope Blooms Garden Club (40%). There is a full participation description of the CT use at MMC in Table 4.

Table 4

Participation in Complementary Therapies through Memorial Medical Center

Complementary Therapy Class	Response Rate
Images Cancer Art Program	40%
Hope Blooms Garden Club	40%
Writing through Cancer	23%
Sounds of the Heart Music Program	20%
Triumph Walking	20%
Triumph Cycling	20%
Moving through Cancer Dance Program	9%
Talking Photographs	9%
Triumph Yoga	6%
Pilates	0%
Strength and Fitness	0%

The percentages total more than 100% because caregivers could attend one or more CTs

There is a need to further analyze the differences in quality of life between CT Users and Non-CT Users. To do this there is a breakdown of QOL into the four domains in which there was a statistically significant difference in QOL scores. These four domains include relationship with others, mental functioning, emotional state, and attitude towards life. From these sections there will be a more complete analysis of what the differences between the two groups were.

Relationships with Others

According to the study, relationships with others is the ability to attend and participate in social activities or gatherings, form new relationships, communicate openly with others and feel supported. When comparing the two groups, CT Users

and Non-CT Users, there is a statistically significant difference in their QOL in the domain of relationship with others.

Table 5

Frequency of responses for Relationship with Others

Relationship with Others	CT Users	Non-CT Users
Cancer interferes with family life		
Very much/quite a bit	3%	10%
Not at all/a little bit	83%	60%
Satisfied with family communication about cancer		
Very much/quite a bit	60%	14%
Not at all/a little bit	25%	71%
Someone there to help when needed		
Very much/quite a bit	63%	19%
Not at all/a little bit	10%	76%
Avoid friends		
Very much/quite a bit	3%	0%
Not at all/a little bit	91%	81%
Avoid social gatherings		
Very much/quite a bit	3%	5%
Not at all/a little bit	86%	86%
Cancer interferes with social activities		
Very much/quite a bit	0%	5%
Not at all/a little bit	94%	72%
Reluctant to start new relationships		
Very much/quite a bit	6%	19%
Not at all/a little bit	94%	81%

From the responses of the CT Users and Non-CT Users there is an evident difference in two categories: satisfaction with family communication about cancer and someone there to help when needed. The majority of CT Users (38%) reported being very much satisfied with family communication, while the majority of Non-CT Users (38%) reported not being at all satisfied. In the category of having someone there to help if needed, 43% of Non-CT Users reported not at all, while 29% of CT Users reported very much. The overall QOL scores in the relationship with others

domain were 11.8 for CT Users and 16.1 for Non-CT Users. These scores are statistically significant and there is a marked difference in their responses. With a lower score, the CT Users have a better QOL in this domain and so there is a positive correlation between improved QOL and CTs.

Mental Functioning

According to the study, mental functioning is the ability to remember, concentrate, engage in complicated tasks, and make decisions. When comparing the two groups there was a statistically significant difference in their QOL in relation to their mental functioning. The quantitative data revealed that 46% of CT Users had a little bit of difficulty remembering things and 26% had no trouble at all. In contrast 38% of the Non-CT Users had a little bit of difficulty and 29% responded somewhat. When it came to having difficulty with concentrating, 37% of CT Users reported not having any trouble, while 49% had a little. When looking at the Non-CT Users 43% said they had a little bit of difficulty, while 33% reported not at all. In regards to losing interest in sex 45% of CT Users responded not at all, while 38% of Non-CT Users stated somewhat and 33% reported not at all. There was a question that addressed the caregiver's mental ability to perform complicated tasks, to which CT Users responded very much (38%) and 47% of Non-CT Users responded a little bit and 33% said not at all. When asked if they were able to assist in medical decisions regarding cancer 56% responded very much. In contrast the majority of Non-CT Users (81%) responded that were not able to assist in making medical decisions.

When looking at these two groups, CT Users and Non-CT Users, there is a statistically significant difference in their mental functioning. The CT Users reported a higher ability to perform complicated tasks and assist in making medical decisions. The CT Users overall average QOL score in this domain was 9.9 and the Non-CT Users was 14.9. The higher score of the comparison group is an indication that there was a lower QOL.

Emotional State

According to the study, the definition of emotional state is the ability to cope, manage worry, feel useful and in control, maintain a sense of intimacy and emotional support. From the quantitative data comparison there was a statistically significant difference in QOL in the domain of emotional state, with the CT Users reporting a higher QOL score. The majority of CT Users (48%) reported that their moods were not at all effected by cancer. In comparison, the Non-CT Users reported that only 30% felt their moods were not at all effected by cancer. In regards to feeling lonely or isolated, 59% of CT Users reported not at all and 50% of Non CT Users reported not at all, while 25% said a little bit. When asked if they had emotional support from their family, 33% of CT Users stated very much and 27% responded quite a bit. In regards to receiving emotional support from family, the Non-CT Users responded very much and not at all at the same interval of 29%. There were 22 CT Users (69%) and 43% of Non-CT Users that reported that they did not feel any negative effect on their sense of intimacy. The majority of CT Users felt useful to others. Of the 35 CT Users 15 (47%) responded that they were satisfied with how they were coping with cancer. In

regards to worrying about the cancer returning 40% of CT Users reported not at all. In contrast the Non-CT Users reported 21% very much, 21% quite a bit, and 26% a little bit. The majority of CT Users were not mentally overwhelmed by being a caregiver. The vast majority (71%) of CT Users did not feel at all uncomfortable about how cancer had changed the appearance of the person they were caring for and 40% of Non-CT Users responded not at all as well. When asked if they were preoccupied with the concerns of cancer 70% of CT Users responded not at all.

The differences that were most obvious were in response to: feeling useful, having control over their lives, coping with cancer, and being mentally overwhelmed with by being a caregiver? More than half of the Non-CT Users (52%) did not feel useful at all. While 48% responded that they did not feel that they had any control over their lives. When asked if they were satisfied with the way they were coping with cancer 42% responded not at all. More than half of the caregivers (52%) reported being mentally overwhelmed with the role of being a caregiver. The CT Users reported an average overall score of 22 and the Non-CT Users had a score of 33.4. The lower score of the CT Users reveals that they had a higher QOL in regards to emotional state.

Attitude Towards Life

According to the study, attitude towards life is defined as the ability to maintain a positive attitude, a sense of well-being, peace, and hope. When comparing the two groups, CT Users and Non-CT Users, there are statistically significant differences in caregiver's QOL in the domain of attitude towards life. The majority

(72%) of CT Users and (85%) of Non-CT Users reported not having lost any hope in the fight against cancer. When asked if they had accepted cancer as a part of their life, 36% responded “quite a bit,” while 21% responded very much. In contrast, Non-CT Users responded a little bit or not at all at the same rate of 35%, totaling to 70% that did not accept cancer as a part of their life. The majority of CT Users and Non-CT Users thought that cancer did not interfere with their ability to maintain a positive attitude. Half of the CT Users did not lose any sense of inner well-being or peace, while 77% of CT Users did not lose a sense of their faith. Of the Non-CT Users, 80% answered that they did not lose their sense of faith at all. There were 53% of CT Users that said that cancer very much helped them recognize what is important in life. In contrast, the Non-CT Users reported that cancer did not at all help them recognize what is important in life (5%).

When looking at these two groups, CT Users and Non-CT Users, there were some similarities, but the most obvious differences were in accepting cancer as a part of life and cancer helping them to see what was most important in life. There is also a marked difference in their overall mean scores in the attitude towards life domain. CT Users overall score of 9.9 is significantly lower than the Non-CT Users score of 14.

Qualitative Data Analysis

From the 35 CT Users that returned the survey there were 20 of them who answered the open-ended question at the end of the survey: Is there any other information you would like to share about how Complementary Therapies have or have not influenced your quality of life? From those responses the research team

coded the data into themes and then created a definition for each of the six domains. From the qualitative data there seemed to be little or no impact of CTs on QOL in regards to their physical health, mental functioning, and financial situation.

From the limited responses of the caregivers the research team constructed the following definition of physical health: According to the participants, physical health was influenced as a result of participation in complementary therapies in the sense that they were able to engage in physical activities.

In the domain of relationship with others the responses included mention of relationships formed in CT classes as well as maintaining current relationships (Table 6).

Table 6

Relationship with Others CT Users Responses

Participant	Response
#1	I was able to spend creative time with my grandmother and share in something we both love and are good at
#5	I met some nice people and some I hadn't seen in years; very good social outlet
#6	It was just what both of us needed, to be around people who understood the effects of cancer.
#10	The community as a whole is stronger when able to lean on as well as provide encouragement for one another.
#11	When I attended I met some truly wonderful and courageous people who inspired me to do what I needed to do
#13	Most of my close friends are people I met through complimentary therapies. I have met and become friends with so many good people through complimentary therapies
#14	After my spouse passed away everyone in the music group was very supportive to me and my family. Last but not least, all my new friends I have met through the complimentary therapy program have supported me.
#15	My friendship circle has greatly increased.
#27	She had invited me to attend the program with her to help support her and give us something to do together. I have made many new friends and am pleased to watch firsthand the strong sense of community this program has inspired me. This program has made me a more active member of our community.
#31	The complimentary art program has allowed me to make friends who have the same concerns I have. It also is my only social function that I do and feel comfortable at
#33	The complimentary therapy I participated in allowed me to spend time with others who have been involved in cancer and caregiving so they understand what goes on in my life. And we spend time doing something we all enjoy so there is laughter and joy.

From the responses the research team constructed the following definition for relationship with others: According to the participants, relationship with others was influenced as a result of participation in complementary therapies in the sense that they formed new and empathetic friendships, and found support and understanding by belonging to a compassionate and safe community.

In the domain of mental functioning the research team constructed the following definition from the responses of the CT Users: According to the participants, mental functioning was influenced as a result of participation in complementary therapies in the sense that they gained knowledge, completed tasks, were more cognitively aware, and acquired new skills.

The most common theme in the emotional state domain responses was the feeling of support that they received through their participation in CTs (Table 7).

Table 7

Emotional State CT Users Responses

Participant	Response
#3	I cannot imagine my life being as fulfilling without this complimentary therapy
#5	It made me feel good about being able to draw and paint.
#6	It was just what both of us needed
#10	The community as a whole is stronger when able to lean on as well as provide encouragement for one another. Without it, fear, negativity and doubt would become major players in the hearts and souls of many
#11	To not use cancer or anything else as an excuse to not live my life fully each day right where I am.
#13	Complimentary therapies gave me a new life. I do not know where or how I would be if I hadn't returned to "Sounds of the Heart" Uke group after my wife's death.
#14	After my spouse passed away everyone in the music group was very supportive to me and my family. The complimentary therapy program helped me move on into my new life. Last but not least, all my new friends I have met through the complimentary therapy program have supported me
#22	The complimentary therapies are very supportive. They have changed my life so much.
#27	The impact this program has made on my life is beyond words. This program helped me to find my center, my smile and awaken a passion for art that has lived inside me all my life, but had been buried due to life experience. I will be forever grateful for this program and the way it has enriched not only my life, but the lives of so many others.
#31	I am never judged. By going to art one night a week, I get out of the house for 3 hrs. a week worry free
#33	And you have time to think about life in general and not just concentrating on cancer and caregiving.

From the various responses the research team constructed the following definition of emotional state: According to the participants, emotional state was influenced as a result of participation in complimentary therapies in the sense that they felt supported, enriched, fulfilled, and hopeful. Participants also indicated that they were able to express themselves without judgment.

The responses that addressed attitude towards life focused on their ability to stay positive, their plans for the future, and a sense of fulfillment or enrichment (Table 8).

Table 8

Attitude Towards Life CT Users Responses

Participant	Response
#3	I cannot imagine my life being as fulfilled without this complimentary therapy.
#6	These programs are beneficial for both body and soul and should continue to be available.
#10	Without it, fear, negativity and doubt would become major players in the hearts and souls of many
#11	People who inspired me to do what I need to do no matter what.
#13	Complimentary therapies gave me a new life.
#14	It really has turned my life around by giving me something positive to look forward to every week.
#22	Without these Complementary Therapies, I would not have attempted some of the activities I now enjoy.
#27	Without a doubt my life has been enriched. I took times to rearrange my priorities. . This program helped me to find my center, my smile and awaken a passion for art that has lived inside me all my life. The peaceful, passionate and creative outlet that this program has provided for myself and others has been life changing. . I will be forever grateful for this program and the way it has enriched not only my life, but the lives of so many others. Truly I am blessed to be a part of this program. Peace. It is my deep desire to someday offer a program like this to the larger community.
#31	I feel refreshed and like I can so it again.
#33	It brings your whole life into focus and not just one part.

From these responses the research team constructed this definition: According to the participants, attitude toward life was influenced as a result of participation in complementary therapies in the sense that they felt uplifted, were able to focus on a new stage of life and move forward.

From the qualitative data there is similar evidence that there were significant differences in three of the six domains of QOL. There were little or no differences in physical health, mental functioning, or financial situation. However, there were significant differences in the domains of relationship with others, emotional state, and attitude towards life. There was also a sense that from the information the CT Users provided they had a better overall QOL than the Non-CT Users.

Summary

From the demographic data collected it was clear that the majority of caregivers in both groups, CT Users and Non-CT Users, were Caucasian females with a college education that live with their partner/spouse and children (if applicable). They reside in Modesto, CA and maintain an annual household income of \$40,000 or more, with the majority making \$40,000 to \$59,999. The majority of them are caregiving for breast cancer patients who are receiving chemotherapy, radiation, and/or surgery. The findings validate that the use of CTs through MMC did impact the QOL of cancer patient caregivers. When looking at the qualitative and quantitative data there is an increased level of QOL in the domains of relationship with others, mental functioning, emotional state, and attitude towards life. The overall

score of QOL is better for CT Users than that of Non-CT Users. There is an apparent positive correlation between CTs and QOL of cancer patient caregivers.

CHAPTER V

DISCUSSION

Introduction

This study sought to determine if cancer patient caregivers who participate in complementary therapies (CTs) had a better quality of life (QOL) than caregivers who do not participate in them. The study was conducted through a dominantly quantitative survey with a single qualitative question that allowed for the treatment group (CT Users) and the comparison group (Non-CT Users) to report their QOL. The chapter reviews major findings from the study and analyzes the findings in contrast to existing literature. From there the limitations of the study are highlighted. Next, the implications the research has for future research, as well as on the field of social work and practice are examined.

Major Findings

There were a number of major findings that were obtained through the study that need to be reviewed and discussed. There was a statistically significant difference in the reported levels of QOL between CT Users and Non-CT Users. Within the Non-CT Users group there were several areas in which they responded drastically lower than CT Users.

From the study it was apparent that the CT Users reported a higher level of overall QOL than the Non-CT Users. There were statistically significant differences in the domains of relationship with others, mental functioning, emotional state, and

attitude towards life. Within these domains the greatest difference in QOL score between the two groups was in mental functioning and emotional state. The differences in mental functioning were seen in their polar responses to whether or not they are able to perform complicated tasks and if they were able to assist in making medical decisions for the cancer patient they care for. In the domain of emotional state there were several questions that elicited polar responses from the CT Users and the Non-CT Users. When asked if their moods were effected by cancer the Non-CT Users responded that it had more impact on their moods in comparison to the CT Users. There was also a difference seen in the level of emotional support they received from their families, the feeling of being useful to other people, the feeling of having control over their lives, as well as worrying that the cancer would return. The last area within emotional state that elicited different responses was in relation to the caregivers' satisfaction with the way they are coping with cancer and the majority of Non-CT Users responded in the negative in comparison to the CT Users who responded more positively. There was no difference, however, in the domains of physical health and financial situation.

The second major finding was that there was a very similar demographic make-up of the two groups, CT Users and Non-CT Users, and with this similarity there were several characteristics that stood out. The majority of cancer patient caregivers incorporated in the study were females. They were also predominantly Caucasian with the second largest group being Hispanic/Latino. The bulk of caregivers were between the ages of 60 and 69. Most of them were highly educated,

with a college degree. Within the CT Users and Non-CT Users the majority had an associate's degree or higher and they reported a higher annual household income.

The third major finding was that there was one category within demographic characteristics that was different between the two groups. This confounding variable is that the CT Users and Non-CT Users were caring for patients with different dates of diagnosis. The Non-CT Users were caring for cancer patients that has been diagnosed more recently than the cancer patients of the CT Users. The Non-CT Users were mostly diagnosed in 2011 or later. The CT Users in contrast were mostly diagnosed before 2009. The earliest diagnosis for Non-CT Users was 1990 and for CT Users there was a diagnosis in 1978. This confounding variable is the one variable that cannot be ruled out in impacting QOL in this study.

Existing Literature

When looking at these major findings there is a need to analyze the results in relation to the current knowledge base to see if there are similarities or differences. From the study it was apparent that CT Users saw a greater impact in their QOL in areas that would be considered mental health. There seemed to be little or no difference in the physical health of the two groups, CT Users and Non-CT Users. According to Lai, Li, and Lee (2011) with the use of music intervention for cancer patient caregivers there was an improvement in levels of anxiety and depression, but there were no changes in the impact on sleep (physical health) of the participants. Similarly, Marin and Keats (2014) found that yoga used by cancer patient caregivers had a greater impact on the mental component score used to determine QOL and

overall psychological distress. It is important then to address the mental health needs of cancer patient caregivers to improve their overall QOL.

The demographic profile created by the study is also similar to what has already been shown in other studies. According to Kozachik, et al. (2006) the use of complementary therapies (CTs) were employed mostly by Caucasians (95%) that had completed high school or attended college (93%). This is very similar to the study's findings indicating a pattern that people that are Caucasian and have a higher education level are more likely to participate in CTs. The study conducted by Martin and Keats (2014) had a similar finding with 11 out of 12 participants being female and 8 of the 12 having a college degree. Half of the participants also had an annual household income of \$50,000 or more. This is in congruence with this study indicating that the gender, ethnicity, level of education, and annual household income may influence the use of CTs by cancer patient caregivers.

Limitations of the Study

The study was set up to answer the question do caregivers who have participated in Complementary Therapies have improved levels of quality of life in comparison to those caregivers who have not participated in Complementary Therapies? The study was constructed to compare two groups of cancer patient caregivers (CT Users and Non-CT Users) to be able to indicate the efficacy of the CTs and more specifically the CTs program at MMC. However, there are a few limitations to this study that need to be addressed.

The first and most prominent limitation with the study was the small sample size of 35 CT Users and 21 Non-CT Users. With this small number of participants it is easy to over exaggerate the results due to the limited volume of cancer patient caregivers providing information. With the small sample size, one cannot generalize these findings to a broader population of CT Users and Non-CT Users.

The other limitation from the study was the contribution of all CTs to the overall QOL of cancer patient caregivers. The study compared all CTs as one whole, rather than breaking it down by each intervention method or class. In relation to this there was no distinguishing between the use of one CT or participation in several CTs. These two elements limit the study's potential to target which interventions or CTs in particular are improving the cancer patient's QOL more than the others and if the use of several at a time influence it as well.

The last limitation that comes from this study is in relation to the demographic factors already discussed. With a very narrow profile of participants it is apparent that this may influence the ability to take these results and apply them to any other population. The narrow scope of participants make it difficult to predict if this method of intervention, CTs, would benefit and improve the QOL of cancer patient caregivers of diverse backgrounds. It is unclear if they will be successful in a predominantly ethnic population, with a lower educated population or a predominantly male population.

Implications for Future Research

From this study there are specific areas that need to be focused on in future research studies investigating the impact of CTs on cancer patient caregiver's QOL.

There needs to be more focus placed on increasing the sample size of participants in similar studies in the future as well. Similar to this study, Martin and Keats (2014) had a small sample of cancer patient caregivers as well. With a larger sample size there would be more accurate representations of the differences reported in both of these studies as well as in others. The larger the sample size the greater opportunity there is to gain a clearer picture of how CTs impact the QOL of cancer patient caregivers.

More importantly there needs to be more focus placed on conducting more sophisticated research study designs that will help to eliminate some of the variables in this study and others like it. This quasi-experimental design allowed for the comparison of two groups, CT Users and Non-CT Users, but because it was not randomized there were confounding variables present that could call into question the impact that CTs had on caregiver's QOL. With randomized clinical trials that include a control group there is a greater chance of gaining data that can be used to better prove the efficacy of CTs on cancer patient caregiver's QOL.

Another element that may be used in future research is to investigate each CT class offered at MMC or any other medical center that provides CTs for cancer patient caregivers. This would allow for an in-depth analysis of the individual CT classes impact on QOL. This would allow for an even greater look into the efficacy of

CTs as a whole and determine if there are certain CT classes that have more or less impact than another.

Implications for Social Work Practice

The study provides many implications for social workers in the medical profession. It is clear from this study that CTs impact the QOL of cancer patient caregivers and as such there is a greater need to make clients more aware of their availability. As a social worker there is a need to continue learning and applying evidence based practices with clients to ensure that they are receiving the information they need to be successful. With this in mind there is an apparent need to educate clients on the use of CTs and to provide them with the information they need to be able to access this resource in their communities. From the study there is a lack of diversity among participants and there is a need based on this study as well as the study conducted by Kozachik, et al. (2006), to gain a greater participation of ethnically diverse cancer patient caregivers. There also needs to be more diversity in relation to gender, education level, and annual household income that may allow for a broader scope of generalization.

There is also a need to advocate for the creation or maintenance of CTs for cancer patient caregivers in local medical centers. As social workers it is incumbent upon professionals to advocate both in policy and practice to ensure that such services are offered for their clients. The information from this study was furnished to MMC's board of supervisors to allow them to see that the CTs offered are impacting cancer patient caregiver's QOL and that they need to be provided in the future. Within the

Central Valley region of California there are very limited CTs available to caregivers and with this information it is imperative that other institutions be made aware of the need for such programs in their local medical centers to improve the care of cancer patients and their caregivers.

REFERENCES

REFERENCES

- Alptekin, S., Gonullu, G., Yucel, I., & Yaris, F. (2010). Characteristics and quality of life analysis of caregivers of cancer patients. *Medical Oncology*, *27*, 607-617. doi: 10.1007/s12032-009-9256-2.
- American Association of Retired Persons (AARP). (2015). Caregiving in the United States 2015. *Public Policy Institute and National Alliance for Caregiving*. 1-81. Retrieved from <http://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>
- Bevans, M. F., & Sternberg, E. M. (2012). Caregiving Burden, Stress, and Health Effects Among Family Caregivers of Adult Cancer Patients. *JAMA*, *307*(4), 398-403. doi: 10.1001/jama.2012.29.
- Clark, M.M, Rummans, T.A., Sloan, J.A., Jensen, A., Atherton, P.J., Frost, M.H., Richardson, J.W., Bostwick, J.M., Johnson, M.E., Hanson, J.M., & Brown, P.D. (2006). Quality of life of caregivers of patients with advanced-stage cancer. *American Journal of Hospice & Palliative Medicine*, *23*(3), 185-191. doi: 10.1177/1049909106289074.
- Family Caregivers in Cancer: Roles and Challenges (PDQ®). (n.d.). Retrieved from <http://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-hp-pdq#section/all>

- Ferrario, S. R., Zotti, A. M., Ippoliti, M., & Zotti, P. (2003). Caregiving-related needs analysis: A proposed model reflecting current research and socio-political developments. *Health and Social Care in the Community*, *11*(2), 103-110. doi: 10.1046/j.1365-2524.2003.00410.x.
- Hamilton, A.S., Miller, M.F., Arora, N.K., Bellizzi, K.M., & Rowland, J.H. (2012). Predictors of use of complementary and alternative medicine by non-hodgkin lymphoma survivors and relationship to quality of life. *Integrative Cancer Therapies*, *12*(3), 225 –235. doi: 10.1177/153473541244973.
- Kalfoss, M.H., Isaksen, A.S., Thuen, F, & Alve, S. (2008). The suitability of the world health organization quality of life instrument-BREF in cancer relatives. *Wolters Kluwer Health*, 11-22. doi: 10:109/01.NCC.0000305678.21390.f4.
- Kim, Y. and Given, B.A. (2008). Quality of life of family caregivers of cancer survivors: Across the trajectory of illness. *American Cancer Society*, 2556-2565. doi: 10.1002/cncr.23449
- Kozachik, S., Wyatt, G., Given, C., & Given, B. (2006). Patterns of use of complementary therapies among cancer patients and their family caregivers. *Cancer Nursing*, *29*(2), 84-94.
- Lai, H., Li, Y., & Lee, L. (2011). Effects of music intervention with nursing presence and recorded music on psycho-physiological indices of cancer patient caregivers. *Journal of Clinical Nursing*, *21*, 745-756. doi: 10.1111/j.1365-2702.2011.03916.x.

- Martin, A.C. and Keats, M.R. (2014). The impacts of yoga on quality of life and psychological distress in caregivers of patients with cancer. *Oncology Nursing Society, 41*(3), 257-264. doi: 10.1188/14.ONF.257-26.
- Minaya, P., Baumstarck, K., Berbis, J., Goncalves, A., Barlesi, F., Michel, G., Salas, S., Grob, J., Seitz, J.F., Bladou, F., Clement, A., Mancini, J., Simeoni, M., & Auquier, P. (2012). The caregiver oncology quality of life questionnaire (CarGOQoL): Development and validation of an instrument to measure the quality of life of caregivers of patients with cancer. *European Journal of Cancer, 48*, 904-911. doi: 10.1016/j.ejca.2011.09.010.
- National Cancer Institute. (2011). Surveillance, Epidemiology, and End Results Program Turning Cancer Data Into Discovery. Retrieved from <http://seer.cancer.gov/statfacts/html/all.html>
- Pitceathly, C., & Maguire, P. (2003). The psychological impact of cancer on patients' partners and other key relatives: A review. *European Journal of Cancer, 39*, 1517-1524. doi: 10.1016/S0959-8049(03)00309-5.
- Rubin, A., & Babbie, E. R. (2014). *Research methods for social work* (8th ed.). Belmont, CA: Brooks/Cole CENGAGE Learning.
- Son, K. Y., Lee, C. H., Park, S. M., Lee, C. H., Oh, S. I., Oh, B., ... Lee, S. H. (2012). The Factors Associated with the Quality of Life of the Spouse Caregivers of Patients with Cancer: A Cross-Sectional Study. *Journal of Palliative Medicine, 15*(2), 216-224. doi: 10.1089/jpm.2011.0305.

- Song, J.I., Shin, D.W. Choi, J.Y., Kang, J., Baik, Y.J., Mo, H., Park, M.H., Choi, S.E., Kwak, J.H., & Kim, E.J. (2011). Quality of life and mental health in family caregivers of patients with terminal cancer. *Support Care Cancer, 19*, 1519-1526. doi: 10.1007/s00520-010-0977-8.
- Soothill, K., Morris, S. M., Harman, J. C., Francis, B., Thomas, C., & McIllmurray, M. B. (2001). Informal carers of cancer patients: What are their unmet psychosocial needs? *Health and Social Care in the Community, 9*(6), 464-475. doi: 10.1046/j.0966-0410.2001.00326.x.
- Sutter Health Memorial Medical Center. (2013). Complementary Therapy. Retrieved November 29, 2014, from <http://www.memorialmedicalcenter.org/patient/cancer/therapy.html>
- Thomas, C., Morris, S. M., & Harman, J. C. (2002). Companions through cancer: The care given by informal carers in cancer contexts. *Social Sciences & Medicine, 54*, 529-544. doi:10.1016/S0277-9536(01)00048-X.
- Trudeau-Hern, S. and Daneshpour, M. (2012). Cancer's impact on spousal caregiver health: A qualitative analysis in grounded theory. *Contemporary Family Therapy, 34*(4), 534-554. doi: 10.1007/s10591-012-9211-9.