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PSYCHOSOCIAL NEEDS OF FAMILY CAREGIVERS
OF CANCER PATIENTS

A Project

Presented to the

Faculty of

California State University,

San Bernardino

In Partial Fulfillment

of the Requirements for the Degree

Master of Social Work

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by

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ABSTRACT

Family caregivers of cancer patients receive little preparation, information, or support to perform their caregiving role. This study focused to identify the psychosocial needs of family caregivers of cancer patients in order to develop programs and implement interventions intending to improve their quality of life and quality of care for their cancer patients. Eleven caregivers of cancer patients were recruited from a caregiver support group. Two semi structured focus group interviews and two telephone individual interviews were conducted. Content analysis and inductive coding was used to code the transcribed interview data. Several areas of caregivers' lives were identified to be affected: Emotional, IADLs, Social, Spiritual, and Financial. This paper also considers how oncology units are making remarkable improvement to better serve cancer patients and their family caregivers.

ACKNOWLEDGMENTS

I wish to thank the administrative staff of Gilda's Club Desert Cities, in particular the program director and the caregiver support group facilitator for their support with this study. A special recognition goes to Dr. Shon, whose encouragement motivated me to succeed with this research project. I am also most grateful to all the caregivers whose participation made this study possible.

DEDICATION

My mother has been an inspiration throughout my life. With her actions, she has shown me that it is never too late to start something new. I must also extend my gratitude to Carolina, the kid; who helped me out with most of the editing of this research. This project has proven to me how supportive and loving a person can be. And just like the participants in this study, my beautiful wife and friend, Monica has been a significant part of this wonderful journey for the past two years. Thank you baby, I would not have done it without you. Finally, this effort is dedicated to my two children, Amanda and Enzo. Watching you grow encourages me to continue the path of my personal legend. My hope is that we all find the courage to confront our own dreams.

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CHAPTER ONE

INTRODUCTION

The contents of Chapter One introduce an overview of the population being studied, in addition to policy and practice contexts impacting their needs. An examination of the purpose of the study is further discussed. Finally, the significance of the project for social work is presented.

Problem Statement

The American Cancer Society (2009) estimates that approximately 1.5 million Americans were diagnosed with cancer in 2010. This figure adds into the already exuberating number of more than 11.4 million Americans with a history of cancer alive today. Three out of four families have at least one member who is a cancer survivor. Furthermore, over 560,000 Americans are expected to die of cancer this year, making it the second most common cause of death in the United States, exceeded only by heart disease. These statistics show that cancer is responsible for nearly 1 out of every 4 deaths recorded in the United States.

Without a doubt, a significant number of Americans have been impacted by a diagnosis of cancer. However, only recent studies begun to examine the impact of cancer on the family. The overwhelming sense of suffering in a cancer patient painfully affects the loved ones and reverberate the cancer diagnosis or recurrent cancer episodes in the entire family (Patterson & Garwick, 1994). In lieu of this, it is agreed that the chronic nature of cancer touches both patients and their families. Medical advances in cancer treatment and changing health care systems have largely moved caring for sicker people from the hospital setting to ambulatory care and to informal care at home. Non-medical family caregivers find themselves taking on roles that, just a short time ago, were carried out by trained health professionals. In recent years, the family caregiver responsibilities have substantially increased, primarily because of the toxic treatments in the outpatient units, resulting in debilitating the physical and emotional abilities of the cancer patient (Cochrane & Lewis, 2005). This increase in responsibilities has impacted the psychological, physical, social, and financial well being of the family caregiver as well.

While the caregiving experience can be rewarding and fulfilling, many caregivers encounter negative consequences. A study completed by Dobrof, Ebenstein, Dodd, and Epstein (2006) identified psychiatric illness, loss of employment opportunity and even death as some of the difficulties family caregivers may encounter. There is no doubt that emotional as well as physical challenges surface during the caregiving process. Furthermore, limited information of the overall cancer diagnosis appeared to be an added stressor to the family. Some studies emphasized on the lack of informative communication about the Medical System. Although family caregivers trusted the physician's recommendations for the treatment offered to their family member, they were not sure if the treatment provided was the most appropriate for the family member's particular diagnosis (Schubart, Kinzie, & Farace, 2007).

Family caregivers have received minimal attention by most health care professionals who are mainly concerned with the patients' physical needs. Because family caregiver may assume their role under unexpected circumstances, such as facing end of life issues, preventative education, and guidance regarding coping strategies are highly desired. In order to provide the best care to the cancer patient, psychosocial needs of family caregivers must be addressed.

Organizations providing support services to caregivers are trying to understand the uniqueness role of each caregiver. This study examined caregivers' psychosocial needs by conducting focus group interviews with family caregivers of cancer patients at Gilda's Club Desert Cities. It was important to conduct this study, so caregivers' needs are recognized and supported, in addition to develop interventions to enhance the quality of life of caregivers of patients with cancer.

Policy Context

Cancer costs billions of dollars per year. The National Institutes of Health estimated the 2008 overall annual costs of cancer to be $228.1 billion. The direct medical costs, total of all health expenditures was $93.2 billion. American business is losing $18.8 billion each year due to lost productivity to illness. The cost of lost productivity due to premature death and caregivers taking time off work to care for their family member with cancer is calculated to be $116.1 billion. One of the major costs of cancer is cancer treatment. But lack of health insurance and other barriers to health care prevent many Americans from even getting good, basic health care. An early release from the 2008 National Health Interview Survey reported that about 24% of Americans ages 18 to 64 and 13% of children in the United Sates had no health insurance for at least part of the year. The need for intervention for caregivers should be anticipated before the caregiver burnout becomes a crisis. Therefore, it is critical to focus investigation on family caregiver needs as well.

Policy Practice

Effective practice strategies for family caregivers caring for cancer patients should include improving attention to the caregiver's own health. Family caregivers primarily focus on the family member's care and neglects his or her own health, thus physical and psychological well-being is detrimentally impacted. Health providers need to understand that patients and their family caregivers respond as a unit, resulting in both having needs for help from health care professionals. Studies showed that when caregivers' needs were not addressed, their mental and physical health was at risk, thus cancer patients may suffer from inadequate care from an unprepared family caregiver (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). For most family caregivers, navigating through the medical system could be challenging. Communication with the physician or other health care practitioners is crucial to determine the adequate care and delivery of resources. In addition, it is important that health care professionals and the caregivers involved discuss information about resources, to limit the financial impact of cancer.

Purpose of the Study

The purpose of this study was to examine caregivers' psychosocial needs in order to develop supportive programs and implement proper interventions intending to improve their quality of life and quality of care for their loved one's affected by cancer. According to American Cancer Society (2010) it is estimated that two of every three American families will at some time have at least one family member diagnosed with cancer. Advances in cancer treatment have led to increased survivorship, which in turn has led to caregiving demands that may last for several months to years.

Family caregivers, like cancer patients themselves, have diverse needs and health concerns. In caregiving for patients with cancer at home involve caregiver burden and strain. Complex symptoms management represents a challenge for patients and their family members. Extremely high physical and emotional demands are placed on caregivers, putting them at risk for increased distress when their loved one suffers from uncontrolled symptoms (Tamayo, Broxson, Munsell, & Cohen, 2010). Caregiver needs and access to resources vary based on many factors, including gender, age, culture, education, economics, and demographics (Baider & Bengel, 2001). Furthermore, family caregivers have several needs ranging from informational, social, financial and personal care that are not fully acknowledged by health care professionals.

To examine caregivers' psychosocial needs, a qualitative study was conducted. A semi-structured interview guide was developed to use in soliciting in-depth interviews with eleven caregivers at Gilda's Club Desert Cities Caregiver support groups. The interview employed a focus group format and telephone interviews that provided interaction data resulting from discussion among participants (e.g. questioning one another, commenting on each others' experiences) to increase the depth of their experiences and their reflections on what did or make it easier to live with the cancer diagnosis. The questions covered different areas of the caregiving role, such as their experience with healthcare professionals and their social network as well.

Significance of the Project for Social Work

It is hoped that this study can improve social work on many aspects. At the micro level, understanding psychosocial needs of family caregivers should provide participants a personal awareness of their own health, addressing own fears when caring for a cancer patient, and improving in exchanging communication with health care practitioners regarding the best medical treatments for their loved ones.

At the macro level, the findings of this study can aid social worker practitioners, such as educators and administrators, strengthen the profession by the conceptualization of their functions and the consequences of their interventions. Continual training in order to identify weaknesses in the service delivery process should improve current knowledge and provide the basis for the development of possible programs to the family caregiving population (Dobrof et al., 2006).

In terms of social work practice within the agency level, this study can enhance the need for better communication and caregiver education, specifically in the identification of cancer symptoms in patients and medication administration. Addressing psychosocial needs of caregivers should provide family caregivers a great understanding of factors affecting their quality of life and through the utilization of specific researched proven methods; health care practitioners can offer treatment to prevent burnout in family caregivers. Within the social work policy spectrum, this study can demonstrate that cancer affects society in general. Billions of dollars are spent each year, in order to treat patients and their caregivers. Reducing barriers to cancer care is critical in the fight to eliminate suffering and death due to cancer.

It is crucial to undertake this study due to the lack of studies conducted on psychosocial needs of family caregivers. Therefore, identifying psychosocial needs in the family caregiver can help better understand some of the stressors this vulnerable population encounters when caring for their loved ones affected by cancer.

CHAPTER TWO

LITERATURE REVIEW

Introduction

A reasonable amount of empirical data has been conducted in the recent years identifying caregivers' psychosocial needs. This chapter was divided into four subsections: psycho educational needs, psychological and physical needs, financial needs and theories guiding conceptualization.

Psycho-Educational Needs of Caregivers

Caring for a cancer family member in the home affects different aspects of the family caregiver's needs. The need of acquiring information pertinent to the patient's care is imperative for the caregiver in order to provide adequate treatment in the home. In an early study conducted by Grahn and Danielson (1996) involving cancer patients and their significant others found that patient education was a powerful intervention. It should be noted that caregiver involvement in the cancer process was a new way of thinking; therefore, it was slowly recognized by health care professionals. The findings also showed the views of what many caregivers and cancer patients thought that psycho-education should have emphasized, which it was that health care professionals need inform, support and educate patients and their significant others about what they want to know, rather than what the staff members thought patients needed and ought to know. Furthermore, Hudson, Aranda, and Hayman-White (2005) surveyed 160 caregivers supporting a dying person at home. The results indicated that the overwhelming majority of family caregivers wanted preparatory information early in the caregiving experience. Another study conducted by Hudson, Thomas, Quinn, Cockayne, and Braithwaite (2009) on Psycho-educational interventions demonstrated that by becoming knowledgeable of patient symptoms, the family caregiver's quality of life increases. In this study 96 caregivers attended a three consecutive weekly session. Participants completed all questionnaires before and after the conclusion of classes. The results showed caregivers' significant improvements in levels of preparedness, competence, rewards, and less unmet information needs about their role. In addition, family caregivers reported that the program was useful, applicable, and accessible. These findings point out that family caregivers can be trained, not only to assume the role of supporting a relative with a life-threatening illness but also to assist them to accept the fulfilling positive aspects of caring for an ill relative.

Northouse, Katapodi, Song, Zhang, and Wood (2010) analyzed psycho-educational, skills training and therapeutic counseling interventions offered to family caregivers of cancer patients. Twenty-nine randomized clinical trials published from 1983 to 2009 were examined. The results indicated that although these interventions reduced caregiver burden, improved ability to cope, increased self-efficacy, and improved aspects of quality of life, they were not successful in reducing caregivers' depression. They found that some studies evaluated depression beyond 6 months of follow up and reported non-significant effect.

Psychological and Physical Needs of Caregivers

Carter (2002) described caregiver sleep and depression using caregiver narratives. Forty-seven caregivers of patients with advanced stage cancer were interviewed. The study indicated that Caregivers described severe fluctuations in sleep patterns over time that affected caregiver depressive symptoms. The author concluded that due to the high demands of caregiving for a chronically ill relative, caregivers suffer progressive sleep deprivation that affects their emotions and ability to continue as caregivers. The study found that it is important for health care professionals to recognize the severe sleep problems experienced by caregivers and respond with interventions to increase sleep quality and decrease depression.

Soothill, Morris, Harman, Francis, Thomas, and Mcllimurray (2001) indicated that caregivers with unmet psychosocial needs were more likely to be in poor health or to be caring for a patient who has reached the end of life stage in the cancer journey. The authors collected responses from 195 caregivers with a survey instrument composed of 48 item psychosocial needs inventory, varying from personal care needs, social network of caregivers, financial burden, emotional distress and physical burden. The study also conducted 32 face-to-face interviews. This study found that the caregiver's health was jeopardized when caring for a cancer patient was their altruistic behavior as they tended to put the needs and interest of patients above their own.

Vivar, Canga, Canga, and Arantzamendi (2009) reported the psychosocial impact of cancer recurrence of cancer survivors and family members. The study indicated that family members also experience the cancer illness. The family caregiver emotional health becomes a distress when a recurrence episode occurs. Some of the main characteristics caregivers experience the loss of hope, the family to face the uncertainty of the cancer illness again, and concerns about death. Results from the study suggested that caregivers' psychological disturbance should be equally considered important by health care practitioners. Providing treatment to caregiver's emotional state has been found to beneficial for patients with cancer as well. Moreover, Houldin (2007) conducted a qualitative study on fourteen caregivers of newly diagnosed colorectal cancer. The study found that participants focused on coming to terms with the disruption of the disease in their lives, attempting to deal positively with the effects of the illness, and maintaining a sense of normalcy in family life. Other findings in this study indicated that some caregivers suffered silently, concerned with the progression of cancer resulting in a great deal of emotional distress affecting their health.

Financial Needs of Caregivers

Upon the cancer diagnosis, patients and family caregivers display a disbelief reaction. As a result cancer has completely changed the family dynamics. Family caregivers need to joggle between work and caring for the ill relative. In a study conducted by Schubart, Kinzie, and Farace (2008) interviewed 25 family caregivers of adult brain tumor patients and found that financial problems were reported by all families, including issues around employment, difficulty understanding insurance and other benefits, in addition to inadequate earnings to meet all the family needs. Loss of job was a major factor identified in this study. One caregiver reported to struggle with bills and mainly relied on charity from church parishes. Furthermore, to identify financial strains associated with terminal cancer, Hanratty, Holland, Jacoby, and Whitehead (2007) examined Twenty-one studies published in English between 1980 and 2006; financial stress was reported in 14 papers. An interested finding in the examination of the data was found in one study from the USA (McGarry & Schoeni, 2005). It explored the effect of financial strain on patient treatment choices. The finding indicated that patients experiencing financial problems were likely to choose care at being comfortable, rather than extending their lives.

Dumont, Turegeion, Allard, Gagnon, Charbonneau, and Vezina (2006) conducted a cross sectional study of two hundred twelve family caregivers to determine the extent of psychological distress in family caregivers of advanced cancer patients. This study revealed that financial constrains experienced by the primary caregiver triggers psychological distress. Consequently, family caregivers need to take a leave without pay or even quit their jobs in order to care for their loved ones. The data indicates that there are additional expenses in medication, supplies, technical support and home care services that are not fully covered by health insurance. Furthermore, the World Health Organization (2000) conducted a study which found that many caregivers suffer from long term financial strain that profoundly affected their lifestyles. This appears to be related to time consuming role of caregiving, wage losses, difficulty in navigating the healthcare system, and transportation cost to and from the clinic, resulting in limited earning opportunities for caregivers.

Theories Guiding Conceptualization

Due to the complexity of their role, family caregivers experience high physical and emotional demands. A current approach addressing both the challenges and opportunities in providing assistance to support caregivers is based on the Caregiver Identity Theory (CIT) described by Montgomery in press (DHS, 2010). The essential argument of the model is that the caregiving career is a series of transitions that result from changes in the caregiving environment; this process includes changes in the relationship between the caregiver and the care recipient, changes in the health of the care recipient, and changes in care activities. According to the theory, the caregiving responsibility surfaces out of an existing familial relationship, typically a daughter, husband, or wife. As the amount and intensity of care recipient's needs increase over time, a change in the relationship between them and their caregiver takes place. This result in altering the caregiver's behavior, in addition to the expectations associated with their familial role.

The CIT identifies five possible phases of the caregiving role. The initial phase begins when a caregiver unconsciously performs activities that are not part of the familial role. Phase two occurs when the caregiver recognizes that these activities are beyond the normal scope, and they accept their new role. In phase three, the caregiver role becomes the primary function. When this role is assumed, caregiver tasks increase far beyond the initial familial responsibility. At this stage, the relationship becomes dominated by the amount and intensity of the tasks involved. Phase four is characterized by caregiving continuing to dominate the relationship; however the caregiver is considering the option of nursing home placement. Phase five is achieved when the care recipient is moved to a different location, placing the primary responsibility of care to formal care providers. The consequence of this change is the return of the caregiver to his or her original familial (e.g. daughter, spouse) role.

At the core of the CIT is the notion that caregivers will experience distress while engaging in activities that are inconsistent with how they view their caregiver role. As a result, this distress will encourage caregivers to open up and seek help. Participating in support groups is a useful way for caregivers to assess their own behaviors. By learning how others cope with their discrepancies and normalizing their emotions, caregivers can recognize that they are adequately providing care for their loved ones (Montgomery & Kosloski, 2009).

Summary

As identified in the literature, different psychosocial needs were discussed and examined throughout Chapter 2 of this study. A recent trend of empirical data can be found on the subject of family caregivers but psychosocial interventions for this vulnerable population continue to be limited in research. With the growing cancer survivor rate, it is imperative that more research is conducted to develop the necessary programs to better meet caregiver and patients' needs.

CHAPTER THREE

METHODS

Introduction

This chapter covered the methods used in carrying out this study. This section examined the study design, sampling, data collection, interview instrument, procedures, and protection of human subjects during the conduction of the study. Finally, data analysis was studied.

Study Design

The purpose of the study was to examine the psychosocial needs of family caregivers who are providing care for a loved one with cancer. Given the stunning large number of cancer diagnoses and the advances in cancer treatment, caregiving demands have dramatically increased lasting for several months to years. The focus of the study was to obtain caregivers' perspectives and experiences in their caregiving role. Identifying the needs of caregivers can enable healthcare professionals to develop interventions to enhance the quality of life, and well being of caregivers of patients with cancer.

The study employed a qualitative research method. Due to time restrain, two in-depth focus group interviews with nine family caregivers were conducted, as well as two telephone interviews with family caregivers from Gilda's Club Desert Cities Caregiver support groups were made. The use of focus group interaction, observations and telephone interviews of family caregivers attending the caregiver support group provided the study interaction data resulting from discussion among participants, an account of caregivers' experiences and their reflections on what did or make it easier to live with the cancer diagnosis.

The design allowed the study to identify and determine the importance of learning caregivers' needs in their social, psycho-educational, psychological, physical and financial context. Due to the limited number of participants of diverse cultural and ethnic backgrounds, this study did not portray the general family caregiver population of cancer patients. Furthermore, the family caregivers in this study were recruited from a single support group, therefore, their experiences with the health care system or other support programs did not apply to other locations. The research question included identifying psychosocial needs of family caregivers caring for cancer patients.

Sampling

Participants for this study were recruited from Gilda's Club Desert Cities caregiver support group. Gilda's Club (2011) is a non-profit organization providing networking and support groups, workshops, education and social activities for everyone living with cancer along with their families and friends.

Due to the small sampling frame, eleven family caregivers participated in this study. The inclusion criteria was that participants were caring for a cancer patient or had previously cared for a loved one affected by cancer. Furthermore, participants needed to be at least eighteen years or older. No restriction on caregiving length of time was imposed, but participants needed to be the primary source of daily care to the recipient. The study selected an availability convenience sampling strategy to maximize accessibility of participants. This sample was selected to provide further knowledge in better understanding caregiver needs at the

Gilda's Club Desert Cities Caregiver support groups, so proper interventions can be implemented.

Data Collection and Instruments

Exploratory data was collected from focus group meetings and telephone interviews about their caregiving tasks, access to information, and support needs across the course of the cancer diagnosis affecting their loved one. A semi-structured interview guide was designed by the researcher. The interview guide consisted of ten open-ended questions attempting to solicit the most comprehensive responses from participants. The demographic section included questions on gender, ethnicity, age of caregiver, age of recipient, relationship to the recipient and the stage of illness of the patient. The questions in the interview guide were developed based on the researcher prior knowledge and understanding of caregivers' roles. These questions covered the areas of interest by identifying specific psychosocial needs of family caregivers.

Furthermore, participants were asked to describe their social support system, in addition to questions on how they cope with the daily stressor of caring for a loved one affected by cancer. Moreover, to determine the level of quality of care they provide to their loved ones, participants were asked on how well informed they felt about treatment and medication delivery. The interview further included questions on financial barriers in addition to soliciting participants' experiences with the health care professionals (See Appendix A).

Prior to the interview, a review of the guide was conducted with the Gilda's Club Desert Cities Program Director to perceive if participants can relate to the questions and made corrections to the instrument. Two focus group interviews were completed during caregiver support group meetings at Gilda's Club Desert Cities. Two telephone interviews were accomplished as well. A Focus Group Moderator Guide was utilized during the interview process (See Appendix D). This guide compromised the introduction and questionnaire sections assisting the examiner with the course of the interview.

Lambert and Loiselle (2008) explained that by conducting focus group interviews, the primary goal is to use interaction data resulting from discussing among participants to increase in-depth information on how participants cope with daily caregiving tasks. Another benefit of focus group interviews is that the group interaction can emphasize participants' similarities and differences and give rich information about the range of their perspectives and experiences.

By having the researcher present during the interview, probing or clarifying concerns was provided on the spot. However, a limitation observed with focus groups is that the interaction among participants can create biases, as the individual response of a member may be influenced by another member's personal belief.

Procedures

With the assistance of Gilda's Club Desert Cities Program Director and the Caregiver support group facilitator, approval to complete the study at Gilda's Club Desert Cities was obtained. Following the consent, the interviewer attended their caregiver support group meetings to conduct two focus group interviews, and two telephone interviews as well.

Due to time restriction for the study, eleven family caregivers agreed to participate. A moderator (the researcher) was present for each focus group interview.

Data was collected between January and March 2011. Interviews took approximately one hour each. The interview sessions were audiotape and transcribed by the researcher. Written notes were taken during the interview and compared with transcription for accuracy. After completion of the interviews, participants were asked if they may be contacted at a later time, if problems arise.

Protection of Human Subjects

Participants were protected by obtaining informed consents (see Appendix B) from every person participating in the study. Participants were also informed that every possible effort was taken to protect their confidentiality, in addition to assuring them that involvement in the research was voluntary. Participants were assigned a random number from one to eleven in order to avoid association that could be made to the participant's identity and the data collected from that interview. The data was locked in a file cabinet and shredded upon completion of the study. In addition, a debriefing statement (see Appendix C) was provided by the interviewer with contact numbers to call in the event, of any problems or questions that may arise as a result of the research conducted. Upon completion of the study, the author informed participants the availability of the report at Gilda's Club Desert Cities.

Data Analysis

This study used qualitative data analysis techniques. Based on the information gathered in the literature review section, open-ended qualitative questions eliciting elaborative responses relevant to identifying psychosocial needs of family caregiver was used to guide the development of the interview instrument by the researcher (see Appendix A). A journal was used during data analysis to record the process of the study. Data from audio-taped focus group interviews and hand written recorded telephone interviews were transcribed verbatim and coding method was developed for organizing the data in specific categories, identifying similarities and differences and interpreting relationship among categories.

Recording was useful for the study, because the researcher was able to document the direct words from participants' responses, thus misinterpretation was avoided. The categories identified in the study were the caregivers' psychosocial needs, including social, psycho-educational, psychological, physical, and financial needs.

Descriptive statistics including frequency distribution, means and standard deviation was used to summarize the characteristics of demographic variables.

Summary

This chapter presented the methods used in conducting this study. Issues relating to the study design, sampling, data collection, interview instrument, procedures, and protection of human subjects were examined. This chapter concluded with the measures that will be used to process and refine data analysis.

CHAPTER FOUR

RESULTS

Introduction

This study was designed as an exploratory research to examine caregivers' psychosocial needs in order to develop supportive programs and implement proper interventions intending to improve their quality of life and quality of care for their loved one's affected by cancer. Chapter four begins with the demographic information of the participants. It also presents participants' insight about their roles as caregivers for a loved one affected by cancer.

Demographics

Of the eleven caregivers that participated in the study, six were males (55%) and five were females (45%). The most prevalent ethnicity identified was Caucasian with 64%, followed by Hispanic at 18% and Asian American at 18%. The range for age was 38 to 73 years and the mean was about 61 years (60.8181, SD = 11.205). The relationship between participants and care recipients were as follow: Three wives (27%), five husbands (46%), one daughter, one partner and one friend adding up to

27%. The range for the number of years providing care was 1 to 7 years, the mean was 2 years.

Multiple types of cancer were represented in the study. About 37% were Metastatic cancer. The second most diagnosed type of cancer was Leukemia at 27%. Ovarian cancer affected two participants (18%). However, breast cancer was identified by one participant (9%), as well as one throat and tongue cancer diagnosis was reported.

Findings

Be advised that "n" stands for the total number of entries for each question, and does not represent the number of respondents.

Table 1 displays the respondents' comments to question number eight: "What are the primary needs and concerns of your loved one affected by cancer?" all eleven respondents answer this question. Using content analysis, six main themes were revealed: 1) emotional (n = 10 entries), 2) instrumental activities daily living (IADL) (n = 5 entries), 3) physical (n = 8 entries), 4) social (n = 2 entries), 5) education (n = 3 entries), and 6) financial (n = 2 entries).

The second half of this question, "And how do you currently meet these needs and address these concerns?" all eleven respondents answered this question. There were three themes recognized: 1) emotional (n = 10 entries), 2) IADL (n = 5 entries), and 3) social (n = 2 entries).

Table 1. Open-Ended Responses to, "What are the Primary Needs and Concerns of Your Loved One Affected by Cancer?"

Themes for Question #8 (n = 30 entries)			
Items	Emotional	IADL	Physical
What are the primary needs and concerns of your loved one affected by cancer?	33.3% (n = 10)	16.6% (n = 5)	26.7% (n = 8)
	Social	Education	Financial
	6.7% (n = 2)	10% (n = 3)	6.7% (n = 2)

Themes for Question #8 second part (n = 17 entries)			
Items	Emotional	IADL	Social
"And how do you currently meet these needs and address these concerns?	58.8% (n = 10)	29.4% (n = 5)	11.8% (n = 2)

Some representative examples of responses that illustrate emotional needs of the care recipient include: "My husband has a lot of stress and he always looks angry...I think he is depressed...I noticed him to be quiet...He keeps things to himself" (Participant 7, Personal Interview, January 2011). A male participant reports, "I think my wife needs to talk about how she feels...I think that would be healthy for both of us" (Participant 11, Personal Interview, January 2011).

The physical needs of care recipients were reported to be the second most important concern. A 62-year-old male explains, "My wife is under a lot of pain, taking the right medication at the right time is extremely important" (Participant 3, Personal Interview, January 2011). Other typical responses that illustrate physical needs include: "He easily gets tired" (Participant 9, Personal Interview, January 2011) or "she has poor balance and has become forgetful since chemotherapy started" (Participant 11, Personal Interview, January 2011).

There were five IADL responses identified. A 54-year-old female best describes it, "My mother cannot do anything for herself...Doing laundry, preparing meals, cleaning the house, and buying groceries are the most important things she needs help with now" (Participant 8, Personal Interview, January 2011).

Additional theme for "responses to unmet needs" = being available to help meet cancer patient's psychosocial needs. Three categories emerged from this question. Some responses demonstrating how caregivers assisted their loved ones emotionally were: "I am there always, whenever he needs me" (Participant 5, Personal Interview, January 2011) or "I give him love and understanding" (Participant 2, Personal Interview, January 2011).or "I keep a positive attitude" (Participant 11, Personal Interview, January 2011). A 38-year-old female gave an interesting response, "I am intimate with my husband because I know that can make him feel better" (Participant 7, Personal Interview, January 2011).

A 50-year-old male best summarizes how he meets his wife's IADL needs "I do all the house chores...I even help her shower when she is tired" (Participant 11, Personal Interview, January 2011). To describe how social needs of a cancer patient are met, a 69 year old female caring for her terminally ill husband responds, "I used sense of humor...we laughed all the time...Being a good company, just listening" (Participant 2, Personal Interview, January 2011).

Table 2 shows the participants' remarks to question nine: "How would you describe your current relationship with your loved one?" All eleven participants responded. Two themes were identified: 1) Positive effect on the relationship (n = 10 entries), 2) Negative effect on the relationship (n = 5 entries). Two sub-themes emerged from each category. Loving and strong surfaced under positive effect on the relationship. On the other hand, frustration and strain were identified under negative effect on the relationship.

Table 2. Open-Ended Responses to, "How Would you Describe your Current Relationship with Your Loved One?"

Themes for Question #9 (n = 15 entries)		
Items	Positive effect on the Relationship	Negative effect on the Relationship
How would you describe your current relationship with your loved one?	66.7% (n = 10)	33.3% (n = 5)

Seven participants described their relationship as being loving, or being very much in love with their spouse. One participant said, "My relationship with my wife is outstanding...after 38 years of marriage I am very much in love with her" (Participant 5, Personal Interview, January 2011). Another male caregiver explains, "Our relationship is strong as it makes us appreciate the little things we used to take for granted...our relationship is stronger now" (Participant 11, Personal Interview, January 2011). A female participant caring for a friend who recently passed describes, "We remained very good friends until the end when she passed" (Participant 4, Personal Interview, January 2011). On male participant also explains, "Our relationship is stronger than ever...This tragedy has brought us closer to each other...Makes us rely on each other...We fight cancer together" (Participant 6, Personal Interview, January 2011).

By the contrary, negative feelings were also reported by several participants. A 62-year-old male describes, "It is difficult as her illness has caused some strains in our relationship...We easily become upset" (Participant 3, Personal Interview, January 2011). Another male caregiver adds, "Our intimacy has been affected but that takes a back seat to curing the cancer" (Participant 11, Personal Interview, January 2011). Two female participants best described some representative examples of responses that illustrate how cancer has put strains in their relationship: "Our relationship is good, but lately there has been a lot of frustration from my part because he is not saying how he feels...I care for him and I want him to know how I can help him" (Participant 7, Personal Interview, January 2011). A second female participant caring for her mother explains, "Our relationship has ups and downs...we are very independent individuals...we butt heads all the time" (Participant 8, Personal Interview, January 2011).

Table 3 displays the respondents' comments to question ten inquiring about participant's social support, "Are there people in your life that you can rely for emotional support? Who are they?" The most noted response (17) was that emotional support was given by either a family member, such as sisters, sons, mothers, and sister in law or by close friends and people from church. Only one participant, a 67 year old male who has been caring for his partner for the past three years describes "I use Gilda's Club for emotional support...They are my family" (Participant 1, Personal Interview, January 2011).

The second part of question ten asked, "How do they support you?" All eleven participants responded. Four themes emerged from this inquiry: 1) emotional (n = 7 entries), 2) social (n = 2 entries), 3) physical (n = 1 entry), 4) financial (n = 2 entries).

Table 3. Open Ended Question: How do they Support You?

Themes for Question #10 second part (n = 12 entries)				
Items	Emotional	Social	Physical	Financial
How do they support you?	58.3% (n = 7)	16.7% (n = 2)	8.3% (n = 1)	16.7% (n = 2)

Emotional responses include, "Talking...understanding my situation." One female participant explains, "I am seeing a psychologist monthly to help me cope with all of this" (Participant 9, Personal Interview, January 2011). Another female describes, "I am dating a gentleman, he provides me a great deal of support by just listening and talking" (Participant 8, Personal Interview, January 2011).

Some representative examples of responses that illustrate social support include: "I like to go to the movies or out to dinner...I do it when I can"

(Participant 4, Personal Interview, January 2011). A male participant describes, "Whenever I have a chance, I play golf" (Participant 11, Personal Interview, January 2011). Physical responses were best described by a male caregiver, "Our friends from church help us with cooking, transportation and house chores" (Participant 10, Personal Interview, January 2011).

Two responses that represent financial support include: "My son helps us with paying for some of our monthly bills" (Participant 5, Personal Interview, January 2011). A female caregiver reports, "I thank my mother for being there for us...She pays for our son's school monthly...That really helps us a lot since I am not working and my husband is on disability" (Participant 7, Personal Interview, January 2011).

Table 4 displays the participants' comments to question eleven, "What are the most important caregiver tasks?" All eleven participants responded. Three themes emerged from this inquiry: 1) emotional (n = 5 entries), 2) IADL (n = 14 entries), 3) finances (n = 1 entry).

The second part of the question, and how do you cope with them? Provided ten responses: 1) Emotional (n = 9 entries), 2) Physical (n = 1 entry).

Table 4. Open Ended Question: What are the Most Important Caregiver Tasks?

<table>
<tr><th colspan="12">Themes for Question #11 (n = 20 entries)</th></tr>
<tr><th colspan="3">Items</th><th colspan="3">Emotional</th><th colspan="3">IADL</th><th colspan="3">Finances</th></tr>
<tr><td colspan="3">What are the most important caregiver tasks?</td><td colspan="3">25%
(n = 5)</td><td colspan="3">70%
(n = 14)</td><td colspan="3">5%
(n = 1)</td></tr>
<tr><th colspan="12">Themes for Question #11 second part (n = 10 entries)</th></tr>
<tr><th colspan="4">Items</th><th colspan="4">Emotional</th><th colspan="4">Physical</th></tr>
<tr><td colspan="4">How do you cope with them?</td><td colspan="4">90%
(n = 9)</td><td colspan="4">10%
(n = 1)</td></tr>
</table>

Some examples illustrating emotional responses include: "I provide emotional support to my wife by being there for her" (Participant 11, Personal Interview, January 2011). Another participant describes, "Providing emotional support is very important...But it is hard because my partner refuses all help...He thinks he can take care of himself without my help" (Participant 1, Personal Interview, January 2011). A sixty year old man also reports, "I do not have to cope on providing care for my wife...It is my job, something I have to do" (Participant 6, Personal Interview, January 2011). An interesting response was given by a thirty-eight year old woman caring for her husband, "I need to be emotionally strong for him...Show him that I can handle it, so he will not worry" (Participant 7, Personal Interview, January 2011).

Fourteen IADL responses were given by participants. The most common answers provided include: "Giving medication, being knowledgeable on how to do it" (Participant 2, Personal Interview, January 2011). A response that illustrate how complex and difficult caregiving can be was presented by a 69 year old wheelchair bound woman caring for her terminally ill husband, "Following up on Doctor's recommendations and complete house chores are critical and important...And I get all the help I can" (Participant 9, Personal Interview, January 2011). A husband describes, "Transportation to medical appointments and making sure she takes the right medication...I cope by being there for her" (Participant 5, Personal Interview, January 2011). Another husband also reports, "Attend all medical visits, provide medication dispense, complete house chores...I cope by staying healthy, so I can focus on her healing" (Participant 4, Personal Interview, January 2011).

Table 5 shows participants' remarks to question twelve inquiring about how caregiving has affected participants' well-being. All eleven participants provided at least one response. Using content analysis, four main themes were revealed: 1) emotional (n = 14 entries), 2) physical (n = 7 entries), 3) work (n = 1 entry), 4) not affected at all (n = 2).

Table 5. Open Ended Question: Describe how Caregiving has Affected your Well-Being?

Themes for Question #12 second part (n = 24 entries)				
Items	Emotional	Work	Physical	Not at all
Describe how caregiving has affected your well-being?	58.3% (n = 14)	4.2% (n = 1)	29.2% (n = 7)	8.3% (n = 2)

Some emotional responses demonstrating how participants have been affected with caring for a loved one with cancer are: "I am worried...feeling vulnerable and uncertain". A woman responds, "I feel out of control...I just finish school but I am not concerned with that now...I know I don't look pretty anymore but I don't care" (Participant 7, Personal Interview, January

2011). A 51 year-old male reports, "I am overwhelmed...I constantly cry to release tension" (Participant 10, Personal Interview, January 2011). On the positive side, a female participant caring for her mother describes, "Eventhough, I have a lot of stress caring for my mother and work, I am also happy that I can do this for her". (Participant 8, Personal Interview, January 2011).

Several physical responses were identified. A 62 year-old male reports, "I lost 30 lbs in one year...forgot to eat and unable to sleep". (Participant 3, Personal Interview, January 2011). Another male participant responds, "I am tired more often...Also I am drinking more than what I used to". (Participant 11, Personal Interview, January 2011). A wheelchair bound female replies, "Caregiving has wiped me out physically...I am tired from being emotionally charged" (Participant 9, Personal Interview, January 2011). A daughter caring for her mother reports, "I feel like an old lady sometimes...my life is passing me by" (Participant 8, Personal Interview, January 2011).

Table 6 explains participants' comments to question thirteen examining ongoing challenges caregivers meet. Four themes emerged were revealed: 1) medication (n = 5 entries), 2) emotional (n = 8 entries), 3) IADL (n = 8 entries), 4) Physical (n = 2).

Table 6. Open Ended Question: What Daily Challenges do you have as the Caregiver of a Loved One Affected with Cancer?

Themes for Question #13 (n = 23 entries)				
Items	Emotional	IADL	Physical	Medication
What daily challenges do you have as the caregiver of a loved one affected with cancer?	34.8% (n = 8)	34.8% (n = 8)	8.7% (n = 2)	21.7% (n = 5)

Some emotional responses that illustrate caregivers' ongoing challenges were: "I have to be patient and relax for my mom" (Participant 8, Personal Interview, January 2011). A 62-year-old man describes, "Dealing with fear, trying to maintain hope" (Participant 3, Personal Interview, January 2011). Another participant reports, "He does not want help...I watch him suffer...He won't let me do anything for him" (Participant 1, Personal Interview, January 2011).

Others found it challenging to dispense medication for their loved one. A 69-year-old female describes, "Lack of nursing skills...I am not familiar with the medication" (Participant 2, Personal Interview, January 2011). Another woman responds, "I have to make sure he takes his medication on time" (Participant 7, Personal Interview, January 2011). A difficult situation surfaced when a 69 year-old wheelchair bound woman describes, "He is becoming more forgetful...I constantly have to remind him to take his medication...My fear is that I can forget too" (Participant 9, Personal Interview, January 2011).

Some examples that illustrate IADL responses were: "Completing house chores, making sure he eats all the time...coordinating medical appointments...preparing meals, running daily errands" (Participant 11, Personal Interview, January 2011).

Table 7 displays respondents' remarks to question fourteen inquiring about community resources beneficial to caregivers. All eleven participants responded. Three themes were identified from this question: 1) financial (n = 3 entries), 2) emotional (n = 1 entry), 3) education (n = 5 entries). Question fifteen was prepared as a follow up inquiry, "What type of information or help do you need from such programs and services." Two themes were revealed: 1) education (n = 6 entries), 2) financial (n = 6 entries).

Table 7. Open Ended Question: What Programs and Services would be most helpful to you as the Caregiver of a Loved Affected with Cancer? And, Open Ended Question: What Type of Information or Help do you need from Such Programs and Services?

Themes for Question #14 (n = 10 entries)			
Items	Emotional	Education	Financial
What programs and services would be most helpful to you as the caregiver of a loved affected with cancer?	20% (n = 2)	50% (n = 5)	30% (n = 3)

Themes for Question #15 (n = 12 entries)		
Items	Education	Financial
What type of information or help do you need from such programs and services?	50% (n = 6)	50% (n = 6)

One participant describes the importance of emotional support, "I find it crucial to talk to others about caregiving issues...It helps me reduce stress" (Participant 2, Personal Interview, January 2011). A 73 year-old male caring for his wife reports, "Financial assistance is very important after diagnosis...Have a social worker in the hospital providing resources and referral" (Participant 5, Personal Interview, January 2011). A woman caring for her ill mother describes, "Attending psycho-educational classes...Having to communicate with others in similar situations" (Participant 8, Personal Interview, January 2011). Two participants did not provide a response. One of them responds, "I can't think of anything, our experience have been good overall" (Participant 6, Personal Interview, January 2011).

Some example of responses illustrating the type of information or services from such programs were: "Need help on financial guidance...assistance on how to navigate the health care system...how to deal with insurance companies" (Participant 5, Personal Interview, January 2011). A male participant responds, "Gas mileage reimbursement can be helpful" (Participant 10, Personal Interview, January 2011). Another male participant provided a more deep understanding of the problem, "The medical system is so messed up...you are financially destroyed, even if you have insurance...the problem is systematic...hits people severely...it's doubtful social services can meet the real needs of patients and their caregivers" (Participant 3, Personal Interview, January 2011).

Other caregivers thought that providing education was most beneficial. A 54 year-old female participant reports, "To learn new techniques on how to help my mom...watch out for signs and symptoms" (Participant 8, Personal Interview, January 2011). Another participant explains, "Learning about the dos and don'ts on how to handle life with cancer...caregiver experiences about the challenges of cancer" (Participant 11, Personal Interview, January 2011).

Table 8 shows participants' comments to question sixteen inquiring of their knowledge about cancer. All eleven participants provided a response. Using content analysis, two main themes emerged from this question and were revealed: 1) Proactive (n = 9 entries), 2) Passive (n = 2 entries).

Table 8. Open Ended Question: Do you Feel you are Well Informed About the Type of Cancer Affecting your Loved One?

Themes for Question #16 (n = 11 entries)		
Items	Proactive	Passive
Do you feel you are well informed about the type of cancer affecting your loved one?	81.8% (n = 9)	18.2% (n = 2)

Some examples of responses that demonstrate a passive approach to understanding cancer were given by two participants, "I feel confused at times...I really don't know what cancer is" (Participant 1, Personal Interview, January 2011). The other response was given by a 69 year-female caring for her husband, "I am not really informed...perhaps I need to know more" (Participant 2, Personal Interview, January 2011).

On the contrary, the vast majority of participants (9) had a proactive approach about to being informed about the type of cancer affecting their loved ones. One 73-year-old male responds, "Once, I spent two hours with the oncologist talking about my wife's type of cancer and stage" (Participant 5, Personal Interview, January 2011). Another male participant explains, "I frequently talk to

Doctors so I can be well informed...I have done my own research also...It helps that my wife is a register nurse and can explain the medical terminology" (Participant 11, Personal Interview, January 2011). A 51-year-old man describes, "I think I am well informed, and when in doubt, I immediately ask the oncologist" (Participant 10, Personal Interview, January 2011). Also, a female participant responds, "I read books about my mom's cancer, and research it in the internet" (Participant 8, Personal Interview, January 2011).

Table 9 illustrates participants' comments to question seventeen asking about their positive encounters with the medical providers. All eleven participants answered this question. Two main themes were identified: 1) Positive (n = 20 entries), 2) Negative (n = 2 entries).

Table 9. Open Ended Question: In Dealing with the Cancer Diagnosis, Please Tell Me About your Positive Experiences with Medical Providers?

Themes for Question #17 (n = 22 entries)		
Items	Positive	Negative
In dealing with the cancer diagnosis, Please tell me about your positive experiences with medical providers?	90.9% (n = 20)	9.1% (n = 2)

Most participants indicated that they had a productive and positive experience with their medical practitioner. Some examples that illustrate their responses were: "Everyone has been cordial and friendly...all my questions were answered" (Participant 2, Personal Interview, January 2011). A 62-year-old male responds, "Most have been competent and somewhat caring...Some have been exceptional...Nurses have more sense of the real implications of procedures than the surgeons do" (Participant 3, Personal Interview, January 2011). Another male participant describes, "Great experience...Oncologists have been on board with how my wife wants her treatment plan to be" (Participant 5, Personal Interview, January 2011). A 50-year-old man caring for his wife who is currently undergoing chemotherapy describes, "Our experience with the health professionals have been nothing than positive...The Gynecologist, The Oncologist and the Chemotherapy unit have been phenomenal in helping us adjust and cope" (Participant 11, Personal Interview, January 2011).

A 69 year-old woman best summarizes, "Everyone has been supportive of my husband's needs...he was referred to a Leukemia research project by our oncologist...He had a fantastic experience" (Participant 9, Personal Interview, January 2011). In contrast, one participant replies, "I can't recall a positive experience...No sensitivity from medical staff" (Participant 1, Personal Interview, January 2011).

Table 10 shows respondents' comments to question eighteen exploring on barriers participants experienced in receiving services. All eleven participants responded this question. Using content analysis, four main themes were revealed: 1) Financial (n = 2 entries), 2) Communication (n = 2 entries), 3) Staff unqualified (n = 3 entries), 4) No barriers (n = 5 entries).

The second part of question eighteen asked: "How did you deal with it?" Three themes were identified:

1) Delegating (n = 2 entries), 2) Changing health care practitioners (n = 2 entries).

Table 10. Open Ended Question: Please, Tell Me About the Barriers of Challenges in Receiving Services you thought You Needed, What Were They?

Themes for Question #18 (n = 12 entries)				
Items	Financial	Communication	Unqualified	No Barriers
Tell me about the barriers of challenges in receiving services you thought you needed, what were they?	16.7% (n = 2)	16.7% (n = 2)	25% (n = 3)	41.6% (n = 5)

Themes for Question #18 second part (n = 4 entries)		
Items	Delegate	Changing Healthcare Practitioners
How did you deal with it?	50% (n = 2)	50% (n = 2)

Some examples illustrating financial responses given by participants were, "Financial assistance has been a challenge...I feel I have be begging for it" (Participant 1, Personal Interview, January 2011). Another male participant describes, "Constant hassles with finances and insurance procedures...it never stops" (Participant 3, Personal Interview, January 2011).

Others viewed sensible communication a challenge as part of the treatment. On male participant explains, "Many surgeons and oncologists misuse statistics and say very hurtful things" (Participant 6, Personal Interview, January 2011). Another male caregiver describes, "Well, there was one oncologist who was cold and told us that my wife had only three years to live...there was nothing he could do...definitively, no sensitive skills...very blunt" (Participant 11, Personal Interview, January 2011).

Unqualified staff was an important barrier identified by these participants. A 73 year old male describes, "It took a long time to get diagnosed...we were uncertain on what to do...not knowing was a bad situation to be" (Participant 5, Personal Interview, January 2011). Another 63 year old man responds,

> When you deal with cancer, you want things to move along...you feel that everything should have a level of urgency...so, when the receptionist messed up with the referral, there is a lot of anxiety

> especially when you see your wife in pain.
>
> (Participant 6, Personal Interview, January 2011)

A good number of participants (5) responded that they had no barriers or challenges experienced in receiving services.

As a way to deal with these barriers, participants' responds were: "I have limited patience...I let other family members deal with it" (Participant 3, Personal Interview, January 2011). A male participant describes, "We changed medical teams...we have a new oncologist who has put my wife in chemo...giving us hope to beat this terrible illness" (Participant 11, Personal Interview, January 2011).

Table 11 displays respondents' comments to question nineteen examining the impact of the participants' religious faith. All eleven participants provided an answer. Using content analysis, three themes emerged from these responses: 1) Important (n = 12 entries), 2) Strength (n = 4 entries), 3) Not important (n = 3 entries).

Table 11. Open-Ended Responses to, "What is the Impact of having a Religious Faith in Caring for Your Loved One?"

Themes for Question #19 (n = 19 entries)			
Items	Important	Strength	Not important
What is the impact of having a religious faith in caring for your loved one?	63.2% (n = 12)	21% (n = 4)	15.8% (n = 3)

Some participants do not find faith to be a significant support when caring for their loved. In fact, one male participant describes, "I don't particularly have much of a religious faith...however, I always believe in a higher power...I don't think having faith or not makes me weaker or stronger" (Participant 6, Personal Interview, January 2011). Another participant replies, "I don't have a religious faith" (Participant 1, Personal Interview, January 2011).

Examples illustrating participants' responses to have a religious faith as an essential support were: "It is very important to have faith and believe in the higher power...it provides comfort and resignation when needed" (Participant 4, Personal Interview, January 2011).A 73-year-male describes the impact of faith, "My wife believes that the Lord will heal her" (Participant 5, Personal Interview, January 2011). Another participant reports, "Faith in Jesus Christ is very important when dealing with cancer...It provides me with comfort...I go to God for guidance" (Participant 9, Personal Interview, January 2011). Another male participant describes, "It makes the biggest difference in our lives...God is in charge and we are doing everything we can...he gives us comfort" (Participant 10, Personal Interview, January 2011).

Others find faith to provide them with strength. Some examples that illustrate how they can be strong for their loved ones were: "God is my strength...it helps go forward, so I can show my husband how strong I am for him" (Participant 9, Personal Interview, January 2011). A 38-year-old female describes her dilemma, "I always believe in God, but his mother never really enforced it...He is very skeptical...I want to tell him to believe in God but I don't want to cause more stress...My faith is very strong as it helps me be strong for him too" (Participant 7, Personal Interview, January 2011). A 69 year female explains, "Having a strong faith gives me a hopeful attitude...I try to pass it on to my husband" (Participant 7, Personal Interview, January 2011).

Summary

This study was designed as an exploratory research to examine caregivers' psychosocial needs as a way to develop supportive programs and implement proper interventions intending to improve their quality of life and quality of care for their loved one's affected with cancer. Chapter four started with the demographic information of the participants. The chapter concluded with participants' perceptions and attitudes about their roles as caregivers for a loved one affected with cancer.

CHAPTER FIVE

DISCUSSION

Introduction

The information collected in this study can help understand what family caregivers for a loved one affected with cancer are facing on the daily basis, so their needs can be recognized and supported, in addition to develop interventions to enhance their quality of life. Our focus was to examine how the caregivers' psychological/emotional, physical, financial and social status has been affected while providing caregiving. We also wanted to know how they perceived the delivery of services by the health care practitioners.

It is acknowledged that caregivers of cancer patients play an important role in the cancer treatment, and the need to provide support for the patients as well as their caregivers is recognized. The evidence from this study showed that the impact of cancer diagnosis is equal to or even more devastating for family members as it is for patients. This suggests that although family caregivers do not experience the physical side effects of cancer, they suffer from its psychological implications.

The sample consisted of eleven participants, nine of them had a spousal relationship, one was a daughter and one was a friend of the care recipient. The youngest participant was 38 years old and her older counterpart was 71 years old. They have been providing care for their loved ones between 1 to 7 years. Approximately 64% of the participants were Caucasian, 18% were Hispanic/Latino, and 18% were Asian American. Different types of cancer were represented in this study. About 37% of cancer was metastases, 27% were leukemia, 18% were ovarian cancer, 9% was breast cancer and 9% was throat and tongue cancer.

The prevailing response given by the participants in this study referred to how their psychological/emotional state was affected. Recognition of the psychological needs of the caregivers is an essential first step to enhancing their quality of life and well-being. All eleven participants reported to have been emotionally distressed since cancer entered into their lives. Responses such as being constantly worried and concerned, becoming easily upset and uncertain about the future was given. Also noteworthy, they indicated that addressing their emotional needs, as a way to cope with their psychological distress is highly important.

One significant finding that came from the study was that caregivers described the cancer diagnosis affecting their relationships, resulting in a complete changed of family dynamics. One-third (33.3%) of negative feelings were reported, as one participant noted, "It is difficult as her illness has caused some strains in our relationship." Being angry and easily upset was also accounted. On the contrary, the 66.7% of the responses given described their relationship to be positive and strong. These findings may indicate a high level of loyalty and commitment from the caregiver to continue to provide care for their loved ones when necessary.

Over one-third (34.8%) of caregivers reported to be suffering silently, worried that a shared future may not exist. Worth mentioning was that caregivers showed a strong desire to contain distress and avoid thinking about the worst possible scenario. Many caregivers opted to hold on to a positive view of the disease as a way to avoid causing more distress on their loved one and to meet with the caregiving daily demands as well. These findings support previous research about caregivers' tendency to put the needs and interests of patients above their own (Morris & Thomas, 2001).

Meeting instrumental activities of daily living (IADL) was considerably discussed in this study. When respondents were asked "What are the most important caregiver tasks?" 25% of the responses had an emotional connotation, compared to 70% referring to IADL and only 5% referring to finances. These findings show that caregivers identify giving medication, managing side effects, managing symptoms such as pain and fatigue as very important learning needs. Furthermore, more than 29% of responses given by the participants described being physically affected by losing weight, unable to sleep, feeling tired at all times. One participant reported to have increased alcohol consumption as a way to cope with his wife's disease. These findings are significant because it shows their difficulty and bio-psychological effects of caring for their loved one.

Another significant finding in this study was presented when participants were asked about services helpful to their needs. One-half (50%) of responses given by our participants considered education to be essential in the delivery of services for treatment. These caregivers believed that understanding how to navigate the healthcare system and finding out about different community resources could help minimize anxiety and fear after diagnosis. Also noteworthy was that nine participants had a proactive approach to their loved one's disease. They acknowledged that being informed about treatment modalities and patient warning signs could help them provide better care for their loved one. These findings are consistent with previous literature, which emphasizes in becoming knowledgeable of patients symptoms, so the family caregiver's quality of life increases (Hudson et al., 2009).

In this study, spirituality was examined as well. Participants found that having a religious faith served as a coping technique. More than 63% of the responses identified it to be important and 21% was considered to be strong as it offered comfort and guidance to move forward in their loved one's cancer across the trajectory of illness. Healthcare practitioners must recognize the use of spirituality as a way to connect with caregivers and promote emotional well-being.

Social support appeared to be a crucial aspect in the caregiving process. These participants recognized that having someone to talk to and venting their frustration was beneficial as a way to cope with caregiving tasks or unexpected health deterioration. However, only two caregivers in this study admitted to have a family member or a friend to help them care for their loved one, so they can participate in other activities. The rest of caregivers reported that they felt it was their duty to care for their loved one, in addition to being unaware of respite services. These findings suggest that community based programs continue to struggle in expanding their services, making it available to the general population.

Finally, the participants in this study perceived their experience with the healthcare practitioner to be positive and productive. The majority of caregivers (percentage or descriptor like "more than one-half" or "approximately 75%," etc.) indicated that the medical team has been accommodating, exceptional, and helpful when they needed them. This suggests that health practitioners are striving to provide the best coordination of care, education, support, positive attitude, and caring approach to the patients and their families.

Limitations

A pragmatic limitation in this study was that its sample was largely homogeneous; it failed to include people from low literacy and low socioeconomic status, as well as people of different cultures and ethnic backgrounds. Additionally, a larger sample size would have allowed comparisons across diverse caregiving backgrounds. Similarly, the study did not make a distinction between the different stages of cancer in order to compare the level of care across the caregiving roles.

Another limitation was that in addition to having a small sample size, the study employed a convenience sample rather than random sample; therefore, this study cannot be generalized because the participants were recruited from a single support group, Gilda's Club Desert Cities. Their experiences with the health care system or other support programs may not apply to other demographic areas. Gilda's Club Desert Cities is a comprehensive cancer support center located in the city of Palm Springs with only one site in California. Cancer patients and their caregivers that reside in other cities cannot benefit from these services due to long travel.

Gilda's Club is an excellent example of the quality and quantity of support services that can be provided to individuals living with cancer and their caregivers. This researcher would suggest that it serves as a model for other localities to consider helping meet the unique biopsychosocial needs of these populations.

Recommendations for Social Work Practice, Policy and Research

Some recommendations for this target population would be to conduct studies examining caregivers' self care behaviors and physical health outcomes that follow. As indicated in this study, caregivers often place patients' needs above their own and as a result, they spend less time on activities promoting physical wellness or cancer screening. Over time, this could have harmful consequences on their health.

There is also a larger need to carry out research aimed to educate multidisciplinary teams from cancer institutions across the nation in improving care for oncology family caregivers. This would require the support of clinicians encouraging potential participants to take part in the study.

Conclusions

It is obvious that a diagnosis of cancer affects patients and their families. Family caregivers have received minimal attention by most healthcare providers who are focused primarily upon the physical needs of the patient. Due to medical advances in cancer treatment in recent years, the family caregiver responsibilities have substantially increased making this an important topic to examine and explore. Results from this study confirm the obligation to examine psychosocial unmet needs of caregivers of cancer patients. Caregivers have clear ideas about interventions intending to improve their quality of life and quality of care for their loved one. This study also suggests that healthcare practitioners in oncology units are making progress in providing the best service possible.

APPENDIX A

INTERVIEW MANUAL

Interview Manual

Demographic Questions

1. What is your age?
2. What is your gender?
3. What is your ethnicity?
4. How long have you been a caregiver?
5. What is your relationship to the care recipient?
6. What is your loved one's age?
7. Can you tell me what type of cancer does your loved one have and what at what stage they are at?

Interview Questions

8. What are the primary needs and concerns of your loved one affected by cancer? And how do you currently meet these needs and address these concerns?
9. How would you describe your current relationship with your loved one?
10. Are there people in your life that you can rely for emotional support? Who are they? How do they support you?
11. Can you identify the most important caregiver tasks? How do you cope with them?
12. Please describe how caregiving has affected your well-being?
13. What daily challenges do you have as the caregiver of a loved one affected with cancer?
14. What programs and services would be most helpful to you as the caregiver of a loved one affected with cancer?
15. What type of information or help do you need from such programs and services?
16. Do you feel you are well informed about the type of cancer affecting your loved one?

17. In dealing with the cancer diagnosis. Please tell me about your positive experiences with medical providers?
18. Please tell me about any barriers or challenges you experienced in receiving the services you thought you needed? What were they? How did you deal with it?
19. What is the impact of having a religious faith in caring for your loved one?

Developed by Graziano Mauriz

APPENDIX B

INFORMED CONSENT

Informed Consent

You are invited to add your opinions to a study of psychosocial needs of family caregivers caring for cancer patients. This study is being conducted by Graziano M. Mauriz, an MSW student under the supervision of Dr. Herb Shon, Assistant Professor of Social Work at California State University, San Bernardino. The study will be approved by the School of Social Work Sub-Committee of the CSUSB Institutional Review Board.

Purpose: To identify psychosocial needs of family caregivers.

Description: If you take part in this study, you will be asked to participate in a personal interview describing your caregiving experience.

Participation: Participation is completely voluntary, and you are free to skip any questions you do not want to answer.

Confidentiality: The information you give will remain confidential and no record will be made or kept of your name or any identifying information. The data from the interviews will only be seen by the researcher; the results will be conveyed to Gilda's Club and others in group form only.

Duration: The interview should take between 1 to 2 hours.

Risks: There are no foreseeable risks to taking part in the study and no personal benefits involved.

Benefits: Your opinions will benefit organizations providing services to caregivers to plan programs that better match caregivers' needs.

Contact: If you have any questions or concerns about this study you can contact Dr. Herb Shon (909) 537-5532.

Results: The results will be available at CSUSB Pfau Library Thesis Room in the third floor after December 2011.

By marking below, you agree that you have been fully informed about this interview and are volunteering to take part.

Place a check mark here ____________________ Date ____________

APPENDIX C

DEBRIEFING STATEMENT

Debriefing Statement

The study you have just completed was designed to examine the psychosocial needs of family caregivers who are providing care for a loved one with cancer. This study was also intended to explore social work knowledge of related interventions and issues regarding caregiving for a cancer patient.

Thank you for participating in this study and for not discussing the contents of the interview guide with other people. If you feel uncomfortable or distressed as a result of participating in the study, you are advised to contact Cancer Care Assist at (800) 813-4673 or Family Caregiver Alliance at (800) 445-8106. If you have any questions about the study, please feel free to contact Professor Herb Shon (909) 537-5532. If you would like to obtain a copy of the findings of this study, please contact Professor Herb Shon at (909) 537-5532 after December 2011.

APPENDIX D

FOCUS GROUP MODERATOR GUIDE JANUARY 2011

Focus Group Moderator Guide January 2011

Introduction

1. **Opening Comments.**
   Welcome to the focus group discussion to assess the needs of the caregivers of cancer patients. This project has been approved by the School of Social Work Sub-Committee of the California State University San Bernardino Institutional Review Board.
2. **Introduction of Moderator.**
   My name is Graziano Mauriz; I am a Social Work graduate student at the California State University San Bernardino. I will be conducting today's focus group discussion. In this capacity, I will ask you questions and direct the group discussion so that everyone has the opportunity to discuss his or her opinions.
3. **Focus Group Objective.**
   The primary reason for today's group discussion is to determine the needs of individuals and families who are faced with the responsibility of caring for a loved affected with cancer. The opinions you express today will be used to develop programs and services to assist you.
4. **Reminder of Confidentiality.**
   As we discuss your opinions today, each of you should feel free to say anything you feel like saying. The discussion will be tape recorded so that we can be sure to record all of the opinions discussed today. However, any information or opinions you express will remain completely confidential. Individual names will not be associated with individual opinions at any time. At the end of the discussion, all of the opinions discussed today will be grouped together for a final report.
5. **Focus Group Rules.**
   Every person here today has been invited to participate in this group discussion because his or her opinions are important. As a result, it is important to follow these four simple rules during our discussion today:
   A) Only one person should speak at a time.
   B) When one person is talking, please do not talk separately with the persons sitting next to you. Instead, please express your opinions with the entire group.
   C) There is no such thing as a right or wrong answer. Please be sure to discuss any opinion you have. Do not worry about what other people will think. Every person has the right to his or her own opinion.
   D) This group discussion will take about 1 hour to complete. During this time, we must all continue the discussion without interruptions.

Warm Up Questions

6. **Introductions.**
   Now that we are ready to begin, let us take a few minutes to go around the room and please answer questions 1 to 7 from the Interview Guide.

At this time, I will allow approximately ten minutes for the focus group participants to introduce themselves. Everyone takes a turn.

7. **Introduction of General Topic.**
   Thank you very much for attending today's group discussion. As mentioned earlier, I am currently assessing the needs of individuals and families who are the caregivers of a loved one affected with cancer. The opinions and comments you provide today will benefit organizations that provide services to caregivers to plan future programs that better match caregivers' needs.

General Questions (General Attitudes and Barriers)

8. What are the primary needs and concerns of your loved one affected by cancer? And how do you currently meet these needs and address these concerns?

Specific Questions (Attitudes and Barriers)

9. How would you describe your current relationship with your loved one?
10. Are there people in your life that you can rely for emotional support? Who are they? How do they support you?
11. Can you identify the most important caregiver tasks? How do you cope with them?
12. Please describe how caregiving has affected your well-being?
13. What daily challenges do you have as the caregiver of a loved one affected with cancer?
14. What programs and services would be most helpful to you as the caregiver of a loved one affected with cancer?
15. What type of information or help do you need from such programs and services?
16. Do you feel you are well informed about the type of cancer affecting your loved one?
17. In dealing with the cancer diagnosis. Please tell me about your positive experiences with medical providers?
18. Please tell me about any barriers or challenges you experienced in receiving the services you thought you needed? What were they? How did you deal with it?
19. What is the impact of having a religious faith in caring for your loved one?

Wrap Up and Close

20. Thank Participants and End Focus Group.

Thank you for your participation in today's group discussion. The information you have provided is very important and I look forward to using it to develop the types of programs and services that will make easier your life as caregivers.

Adapted from Alzheimer's Association of Los Angeles Riverside and San Bernardino Counties. (2002, November). *Asian and Pacific Islander dementia care network project.* Retrieved from http://www.alz.org/national/documents/C_EDU-APIDementiaCare.pdf

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