ABSTRACT

A PSYCHOSOCIAL SUPPORT GROUP FOR FAMILY CAREGIVERS OF CANCER PATIENTS: A GRANT PROPOSAL

By

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May 2015

Cancer is a growing health problem in the United States with family caregivers serving as the primary care providers of cancer patients. Research shows that family caregivers of adult cancer patients tend to experience adverse mental health effects because of their caregiving role. The proposed program, entitled the Healthy Caregiver will provide services in English and Spanish, offering group therapy support and information referrals to family caregivers of adult cancer patients. Using a cognitive behavioral therapy approach, the overarching goal of the program will be to decrease symptoms of depression and anxiety associated with the burden of caregiving. The proposed program will be hosted at St. Francis Medical Center in Lynwood, California. Funding options were explored and the Annenberg Foundation was identified as the best potential funder for this project. The actual submission and/or funding of this grant proposal were not requirements for the successful completion of this project.

A PSYCHOSOCIAL SUPPORT GROUP FOR FAMILY CAREGIVERS OF CANCER PATIENTS: A GRANT PROPOSAL

A THESIS

Presented to the School of Social Work

California State University, Long Beach

In Partial Fulfillment

of the Requirement of the Degree

Master of Social Work

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May 2015

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ACKNOWLEDGEMENTS

I would like to thank the following individuals for making my thesis project successful and assisting me at every point to accomplish my goal:

To my thesis advisor, Dr. Steve Wilson, for his guidance and support

To my thesis committee members, Dr. Julie O'Donnell and Dr. Mimi Kim, for their feedback and suggestions

To my hero, Olga L. Bustos Garcia, my god mother for saving me from giving up

To my best friend, Teresa Bustos Garcia, my mother for her continuous and unconditional support

To my guardian angel, Santiago I. Padilla Loaiza, my father for watching over me

To my siblings, Alexander, Santiago Jr., Elmer, and Rodrigo Padilla, for always believing in me

To my friends and cohort members, Mayra Maciel and Claudia Gonzalez, for their encouragement and motivation

Thank you, I could not have done it without you.

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CHAPTER 1

INTRODUCTION

Cancer is a major public health concern in the United States with nearly 20.1 million Americans diagnosed with some form of cancer in 2012 (Centers for Disease Control and Prevention, 2012). The American Cancer Society (2014c) identifies cancer as a group of more than 100 diseases. In the United States, the 10 most common types of cancer are prostate, breast, lung, colon, uterus, urinary bladder, skin, liver, kidney and thyroid (Centers for Disease Control and Prevention, 2011). Although there are many types of cancer, all cancers are described as abnormal cells growing out of control that can develop in any part of the body (National Cancer Institute, 2014b). These kinds of cancers can affect anyone regardless of age, race and gender.

According to the American Cancer Society (2014a), cancer is the second most common cause of death in the United States. It is estimated that cancer claims the lives of nearly half a million Americans each year (Centers for Disease Control and Prevention, 2011). In 2014, approximately a million new cancer cases were predicted among people in the United States, accounting for more than 4,500 diagnoses each day (Siegel, Ma, Zou, & Jemal, 2014). Given the high prevalence of cancer in the United States, the number of informal caregivers is also estimated to grow at a similar pace (American Cancer Society, 2014a). In 2009, over 65 million family caregivers in the

United States were caring for a medically ill relative, including more than a million cancer patients (National Alliance for Caregiving in Collaboration with AARP, 2009).

A cancer diagnosis can affect both the patient and his or her family. The diagnosis and course of treatment can bring considerable stress to the patient's family members in terms of uncertainty and caregiver burden (Given, Given, & Sherwood, 2011). Once a patient is diagnosed with cancer, family members often become the primary care providers throughout the trajectory of the disease (Given et al., 2011). These family members also known as informal or family caregivers are often spouses, partners, children, relatives, parents or friends who provide unpaid cancer-related care to promote the patient's quality of life (United States Department of Health and Human Services, 2014). Family caregivers of cancer patients must navigate a complex healthcare system to provide patient care and assistance with activities of daily living, make-decisions regarding the end-of-life treatment, and cope with forthcoming grief (Badr, 2014; Dumont et al., 2006; Grundfeld, et al., 2004; McLean, & Jones, 2007; Mohr et al., 2003). Given the specific needs of cancer patients, family caregivers often experience high levels of stress manifesting in physiological and psychological problems (Sercekus, Besen, Gunusen, & Edder, 2014).

A recent qualitative study with 16 adult family caregivers determined that caring for a cancer patient could lead to physical and mental health problems (Sercekus et al., 2014). These cancer caregivers reported feeling physical problems such as loss of appetite, fatigue, headaches, weight loss and existing illnesses worsened. They further stated that they had developed new illnesses such as hypertension, arthritis and skin conditions. In addition, they reported feelings of sadness, distress, shock, weakness, anxiety, irritability, hopelessness, guiltiness, fear, and depression. Findings from this study suggested that caregiving imposes a severe burden among family caregivers of cancer patients and a need for support (Sercekus et al., 2014).

Similar studies conducted in the past also indicated that family caregivers of cancer patients can develop physical problems including an impaired immune system, muscle pain, chronic fatigue, changes in appetite, irregular eating habits, weight gain, difficulty in concentration, and indigestion related to this caregiving burden and stress. It was further reported that family caregivers could develop emotional symptoms including insomnia, reduced self-esteem, restlessness, and social isolation (Brannon & Gopalan, 2006; Dimartini et al., 2004; Elcigil, Ugur, Arslan, & Sonmez, 2014; W. Lee et al., 2013; Mazaris et al., 2009; Ozkan, Ogce, Okcin, Yaren, & Demigary, 2013; Stajduhar, 2013). Additionally, family caregivers may experience depression and anxiety symptoms due to feelings of hopelessness, helplessness and constant worry about the patient (Brannon & Gopalan, 2006; Terakye, 2011). According to Schmid-Buchi, Halfens, Dassen, and Borne (2011), family caregivers may experience anxiety and depressive symptoms more than cancer patients.

The overall burden placed on family members as a result of cancer caregiving clearly impacts their physical health and mental well-being. Although several studies have shown ways to support family caregivers of cancer patients through the use of therapeutic counseling, skill building, and psycho-educational interventions, these are often delivered jointly to patients and caregivers focusing on patient outcomes only

(Badr, 2014; Cochrane & Lewis, 2005; Northouse, Katapodi, Song, Zhang, & Mood, 2010). There is clearly a growing need for evidence-based supportive programs that focus on the psychosocial needs of family caregivers to help them maintain their own physical health and mental well-being for providing the best possible care to the cancer patient (Northouse et al., 2010).

Statement of Purpose

Given the stressors faced by cancer caregiving families and a need for social support, the purpose of this research project was to write a grant to fund a psychosocial support group for family caregivers of cancer patients. The group aims to help family caregivers improve their coping skills and sense of control over their caregiving situation and reduce their sense of burden and stress by decreasing symptoms of anxiety and depression. This intervention group will follow a short-term Cognitive Behavioral Therapy (CBT) model. CBT interventions with family caregivers of cancer patients have resulted in significant improvement in mental health functioning (Carter, 2006; M. Cohen & Kuten, 2006; Sikorskii et al., 2006). The program will also provide information resources to participants as a source for additional support to the cancer caregivers.

Multicultural Relevance

Cancer affects individuals and families of diverse cultural backgrounds. In the United States, approximately 1 out of 4 individuals and 3 out of 4 families are affected by cancer (American Cancer Society, 2014b). According to the United States Census (2010a), racial and ethnic minorities groups represent one-third of the population. Dohan and Schrag (2005) suggest that cancer patients and caregivers who are members of certain groups (e.g., racial and ethnic minorities, lower socioeconomic status or recent immigrants) may be considered underserved populations in the United States. The National Cancer Institute (2011) reports that minority groups and other underserved populations are disproportionately affected by cancer due to late discovery of the disease, causing lower survival rates among patients with cancer and increased sadness and distress among family caregivers (Palos et al., 2011). The American Cancer Society (2014a) has reported that African Americans and Hispanics have the lowest survival rates in the United States when compared to non-Hispanic Whites. It is estimated that between 2010 and 2030, cancer incidence is expected to nearly double among minority groups (National Cancer Institute, 2011). Given the growing incidence of cancer among minority groups, the physiological and psychological health of these cancer caregivers will continue to be a growing public health issue (Palos et al., 2011).

Social Work Relevance

Given the diverse population in the United States, it is essential for social workers to be sensitive and competent in providing culturally appropriate services to cancer patients and their families (Colon, 2007). The National Association of Social Workers (2012) describes cultural competence as "the process by which individuals and systems respond respectfully and effectively to people of all cultures, languages, classes, races, ethnic backgrounds, religions, and other diversity factors in a manner that recognized affirms and values the words of individuals, families and communities and protects and preserves the dignity of each" (p. 10). Integrating culturally appropriate support groups in cancer care settings can be a way to improve the physical health and mental well-being of cancer caregivers. Thus, it is vital for social workers raise awareness about the negative effects of cancer caregiving for developing programs that can better support family caregivers of cancer patients.

CHAPTER 2

REVIEW OF LITERATURE

The following is a review of the literature with a focus on the roles and challenges of family caregivers who provide direct care for an adult cancer patient throughout the illness care trajectory. This chapter highlights some of the roles and responsibilities of these family caregivers during each phase of the disease. Although cancer has several phases, including diagnostic, treatment, home care, recovery, recurrence, palliative, and end-of-life care, the phases often do not occur in a sequential order (Given et al., 2011; Wozniak & Izycki, 2014). The caregiving role of family caregivers is often determined based on the patient's cancer prognosis and on their family members' willingness to accept this role (Currow et al., 2011). This chapter also creates a profile describing the characteristics of these family caregivers. Ultimately, it explains some of the negative and positive effects associated with the cancer caregiver role as well as the effects on psychosocial interventions among this population.

Overview of Cancer Prognosis

Specialized doctors estimate cancer prognosis by predicting the likely course of the disease and how much it will affect the patient (National Cancer Institute, 2014a). The prognosis determines the patient's chances of recovery and treatment options. Some factors that affect a cancer prognosis are the size, stage, and type of cancer, as well as the health status and age of the patient. While there are more than 100 different types of cancer, most cancers have been classified as stage I (one), stage II (two), stage III (three), or stage IV (four). Cancer staging is also a way of describing the size and location of the cancer. Stage I and II are considered early stages of cancer with higher chances of survival. Meanwhile, stages III and IV are considered advanced stages of cancer with lower changes of survival. Once an overall cancer stage is determined, treatment options are explored. The most common treatment options for cancer are surgery, chemotherapy, radiation, and targeted therapy. In some cancer cases, more than one treatment is required. Although cancer treatment has improved the 5-year survival rate for all cancers over the years, the disease is still regarded as a life-threatening illness (American Cancer Society, 2014a).

The patient and their family members are usually interested in learning about the prognosis to know whether the cancer is easy or more difficult to cure. It is also important to recognize that not all cancer patients choose to get cancer treatment. A large body of literature reports that family caregivers of cancer patients are greatly impacted by the illness prognosis, stage of cancer, and patients' treatment goals in terms of their caregiving roles and burden (Attner et al., 2009; Currow et al., 2008; Kozachik et al., 2001; Sharpe, Butow, Smith, McConnell, & Clarke, 2005; Sherwood et al., 2006; Silveira, Given, Given, Rosland, & Piette, 2010; Tamayo, Broxson, Munsell, & Cohen, 2010; Terakye, 2011; Wyatt et al., 2004).

Cancer Caregiving Roles and Challenges

Caregiving for a cancer patient has been described as a full-time job (Rabow, Hauser, & Adams, 2004). Family caregivers tend to take on a range of patient care responsibilities such as medication management, equipment management, symptom management, assistance with information-seeking, and transportation, as well as providing social and emotional support to the cancer patient (Deshields et al., 2012; Given et al., 2011; Kozachik et al., 2001). Family caregivers take on these cancer care activities while simultaneously sustaining their own responsibilities at work, at home, and with family (Silveira, Given, Given, Rosland, & Piette, 2010).

In Yabroff and Kim's (2009) survey, more than 600 family caregivers reported spending an average time of 8.3 hours per day providing care for a cancer patient, while 25% reported spending 16 hours or more in a period of 13.7 months. In addition, 52% of these family caregivers said they provided emotional support, while 46% said they provided tangible or logistic support as part of their caregiving role (Yabroff & Kim, 2009). According to Bakas, Lewis, and Parsons (2001), logistic tasks and coordination of care are among the most tedious and challenging tasks to carry out in cancer caregiving. Depending on the patient's cancer prognosis, these family caregivers may be involved in caring for the cancer patient during each phase or throughout certain phases of the disease (Given et al., 2011; Wozniak & Izycki, 2014).

Caregiving in the Diagnostic Phase

A cancer diagnosis brings a sudden need for diagnostic and treatment decisions, which requires the active involvement of the patient and the caregiver. Therefore, family members immediately tend to become cancer caregivers at this point. During this phase, family caregivers attempt to rapidly gather information about the diagnosis, treatment options, and chances of survival (Wozniak & Izycki, 2014). Family caregivers are expected to integrate new medical information, learn cancer-related terminology, enter a new treatment setting, and find the time to accompany the patient to medical appointments (Glajchen, 2009). In most cases, family caregivers are assigned by the patient to be the advocator and primary decision-maker throughout the entire cancer care trajectory. Making decisions about treatment choice can bring considerable stress to both the patient and the family caregiver when disagreement occurs about treatment preferences (Fried, Bradley, & Towle, 2003; Siminoff, Rose, Zhang, & Zyzanski, 2006).

In addition, family caregivers and cancer patients may face financial burden due to the numerous tasks associated with the diagnostic phase. They often become immersed in the management of medical bills and insurance paperwork (Deshields et al., 2012; Potter et al., 2010). They also tend to report loss of working hours, which can affect their income, increasing their stress and burden over time (Giovannetti, Wolf, Frick, & Boult, 2009; Robinson, Fortinsky, Kleppinger, Shugrue, & Porter, 2009; Sherwood & Donovan et al., 2008). According to the reports from the National Alliance for Caregiving in Collaboration with AARP (2009), approximately 41% of family caregivers in the United States reduce their working hours to be able to provide care for their loved ones. Thus, from the point of diagnosis, cancer can diminish the quality of life of the patient and their caregiver (Fried et al., 2003; Yun et al., 2005).

Caregiving in the Treatment Phase

Caring for the cancer patient during the treatment phase can also take a toll on the family caregiver that can cause stress and burden over their caregiving role (Given et al., 2011). Primarily, symptom management (e.g., fatigue, pain, and nausea) becomes an important caregiver activity due to the patient's cancer progression and side effects from treatment (Fletcher et al., 2008; Kurtz, Kurtz, Given, & Given, 2005; Sikorskii et al., 2006; Van Ryn et al., 2010; Wyatt et al., 2004). The complexity of care management for the family caregivers becomes greater when the cancer treatment complicates patients' preexisting health conditions and medication regimens (Given et al., 2011). According to Stenberg, Ruland, and Miaskowski (2010) and Palos et al. (2011), advanced cancer patients receiving cancer treatment require more care than those in the early stages of the disease. Because of the severity of the disease, advanced cancer patients undergo a number of treatment regimes. In some cases, advanced cancer patients decide to enroll in oncology clinical trials due to the realization that no further standardized treatments are available (Kessler et al., 2014). Cancer treatment can last from several months to many years, and it can eventually prevent the patient from returning to work and social life, which can increase the caregiver's burden and stress (Given et al., 2011; Tamayo et al., 2010; Terakye, 2011).

According to Spillers, Kim, and Hall's (2012) and Yabroff and Kim's (2009) surveys with family caregivers, cancer caregiving may last from 14 to 24 months in an active period of treatment. Throughout the treatment phase, family caregivers usually assist patients with activities of daily living, watch for secondary effects of treatment, administer medication, and schedule medical appointments (Kessler et al., 2014; Van Ryn et al., 2010). Additionally, caregivers may provide direct care demands in the areas of nutrition, physical care, housekeeping, financial support, and spiritual support (Given et al., 2011; Kessler et al., 2014). Other caregiving activities may include managing infusion pumps, taking care of wounds, and performing catheter care (Given et al., 2011). Furthermore, family caregivers are faced with undertaking patients' former roles while attempting to cope with their own feelings related to the patient's cancer prognosis and uncertainty about the future (Wozniak & Izycki, 2014). This can be highly stressful and a significant burden for the caregivers, both psychological and physiological, as it can lead caregivers to feel suspended between fear and hope about the treatment results (Wozniak & Izycki, 2014)

Caregiving in the Home Care Phase

The majority of cancer care is provided at the patients' home after they are discharged from the hospital with family caregivers planning the transition and conducting day-to-day caregiving and nursing duties (Deshields et al., 2012). Family caregivers often times report concern and difficulty performing cancer care activities (e.g., complex medical procedures and managing medical devices) at home and often request a need for information and nursing support (Potter et al., 2010). Depending on the patients' plan of care and prognosis, family caregivers may continue to transport the patients to various medical appointments for cancer treatment (radiation and/or chemotherapy) or medical check-ups. To ensure that the patient's treatment plan stays intact, the family caregiver may serve as a channel for conveying information from the cancer patient to the medical providers and vice versa (Given et al., 2011). Family caregivers often communicate with various health care professionals on a daily basis at home and in ambulatory settings regarding the patient's health status and care plan. Cancer patients may receive home health assistance, but it often does not provide enough support to the family caregiver (Longacre, Ross, & Fang, 2013). It is also sometimes assumed that the role of a cancer caregiver ends after the patient completes his or her treatment.

Caregiving in the Recovery and Recurrence Phase

Unfortunately, family members may transition in and out of the cancer caregiving role as the disease recurs. Cancer recurrence is a continued worry for cancer survivors and their family caregivers because the disease can return at any time (Kershaw, Mellon, Northouse, & Freeman-Gibb, 2007; Mellon, Northouse, & Weiss, 2006; Walker et al., 2002). The recurrence phase can have a major impact on the quality of life of cancer caregivers, leading to problems of adjustment (Hagedoorn, Buunk, Kuijer, Wobbes, & Sander-man, 2000; Mellon et al., 2006; Northouse et al., 2002). Thus, family caregivers may not always be willing to retake this cancer caregiving role (Currow et al., 2011). Cancer patients may rely on their caregiver for a long time (an average of 3.5 years after the cancer diagnosis), even after the recovery phase due to the severe long-term health effects from treatment (Mellon et al., 2006). Generally, the roles and responsibilities of the cancer caregivers shift according to the patient's health status, cancer progression, and stage of the disease (Given et al., 2011; Wozniak & Izycki, 2014).

Caregiving in the Palliative and End-of-Life Phase

Caregiving in the late stage of cancer can be one of the most stressful phases for family caregivers (Wyatt et al., 2004). Caring for a family member with advanced cancer at the end-of-life stage is often described as a challenging and traumatic experience. Family caregivers in the palliative phase are forced to anticipate the grief and loss associated with their loved one's death (Given et al., 2011). At the same time, they may continue to care for the patient emotionally, physically, medically, and financially while making difficult decisions, planning, and coordinating the end-of-life care (Wozniak & Izycki, 2014). This phase usually begins when the patient is given a poor prognosis with cancer caregivers reporting increased stress and burden throughout the entire palliative care (Grundfeld et al., 2004). This acute stress reaction may be caused by family caregivers' fear of separation and staying alone, feelings of worry related to the anticipated pain the patient will face, and a perceived lack of control over the situation and time of death (Wozniak & Izycki, 2014). Although the roles and responsibilities of the family caregiver end upon the death of the patient, the life of the caregiver continues. The way family caregivers are able to cope with the loss of their relatives depends on their own psychological and physical condition and also on their support system (Wozniak & Izycki, 2014).

Caregivers' Socio-Demographic and Psychosocial Characteristics

Family caregivers are typically employed women who are younger than the patient and often do not reside with the patient (Hagedoorn et al., 2000; Langer, Abrams, Syrjala, 2003; Robinson et al., 2009; Wagner, Bigatti, & Storniolo, 2006). According to the National Alliance for Caregiving in Collaboration with AARP (2009), family caregivers tend to be adult children providing care to their elderly parent or an elderly spouse providing care to their partner. In Pinquart and Sorensen's (2007) meta-analysis, it was found that spouses and adult children caregivers are often at greater risk for negative health effects caused by the burden and stress of caregiving. A few studies indicate that adult children, specifically adult daughters, report higher levels of burden and stress when compared to spousal caregivers due to having multiple social roles (e.g., such as caring for their children, spouse, employers, and aging parents). Such individuals are often referred to as part of the sandwich generation (Chumbler, Grimm, Cody, & Beck, 2003; Kim, Baker, Spillers, & Wellisch, 2006).

Additionally, family caregivers often have their own chronic problems. Adult children caregivers, who are women younger than 65, have reported a lack of social or personal support and tend to experience even higher levels of burden and stress that can lead to negative patient care outcomes (Bradley et al., 2009; Stommel, Given, & Given, 2002; Wyatt et al., 2004). In Navaie-Waliser et al.'s (2002) cross sectional study with 1,002 family caregivers, it was found that at least 52% of family members with specific characteristics (e.g., female, 65 years of age or older, married, and having less than a high school education) were associated with higher negative patient care outcomes. Findings from these studies include family caregivers caring for adult cancer patients.

Multiple studies have revealed a profile for family caregivers indicating that they are often employed female spouses belonging to a specific racial or ethnic minority group and a lower socioeconomic status. Researchers have further reported a correlation between these characteristics and an increased risk for caregiver burden (Pinquart, & Sorensen, 2006; Sherwood & Donovan et al., 2008). Palos et al.'s (2011) longitudinal study with 85 cancer caregivers, found that spousal relationship and lower economic status was associated with higher caregiver burden. Furthermore, the study suggested that specific characteristics (e.g., being underinsured or noninsured, belonging to a specific racial or ethnic group, having limited health literacy or having a poor prognosis) are often linked with underserved cancer populations (Palos et al., 2011).

In Longacre et al.'s (2013) study with 1,247 family caregivers, more than 100 cancer caregivers reported a need for psychosocial support. Minority caregivers reported having a greater need for psychosocial support when compared to non-Hispanic Whites. In addition, cancer caregivers living with the cancer patient reported a higher sense of burden than caregivers not residing with the patient. Findings from this study indicated that a heightened level of burden was the only significant factor linked to a greater need for psychosocial support (Longacre et al., 2013). These are all important characteristics to consider when assessing the caregiver burden and stress among family caregivers of cancer patients.

Caregiving Burden and Stress

According to Bastawrous (2013), Wozniak and Izycki (2014), and Wyatt et al. (2004), "burden" may be defined as a multidimensional concept with objective and subjective components. "Objective burden" is defined as specific happenings and activities related to caregiving, such as financial problems or personal activity limitations. "Subjective burden," on the other hand, encompasses affective responses to the caregiver experience, such as feelings and emotions related to fear, strain, and guilt (Bastawrous, 2013; Wozniak & Izycki, 2014; Wyatt et al., 2004).

The level of burden and stress experienced by cancer caregivers can indicate how prepared a family member was when taking on the caregiving role (Farace, Kinzie, & Shubart, 2008; Lawrence, Yabroff, Clauser, Davis, & Brown, 2004; Van Ryn et al., 2010). In most cases, family caregivers are seldom prepared to take the role and often lack training, education, resources, and information needed to properly care for the cancer patient (Kurtz et al., 2005; Sikorskii et al., 2006). A cross-sectional study with 104 cancer caregivers, found that having a lack of caregiving choice was greatly associated with elevated burden and stress (Longacre et al., 2013).

Caring for a family member with cancer can be a demanding and burdensome duty. Findings from Palos et al.'s (2011) longitudinal study concluded that providing care to a cancer patient, in particular a spouse, with low functionality and with grievous symptoms could increase the burden for the caregiver. The multiple demands faced while providing care to the cancer patient can cause disruption from usual personal activities that can eventually lead family caregivers to experience significant levels of distress and burden (Schumacher, Beidler, Beeber, & Gambino, 2006; Sikorskii et al., 2006; Sorensen & Pinquart, 2004; Stewart, Shumacher, Archbold, Dodd, & Dibble, 2000). This caregiving burden and stress may increase over time, and, if it stays untreated, it can have a destructive influence in the physical, social, and mental functioning of the family caregiver (Gaston-Johansson, Lachica, Fall-Dickson, & Kennedy, 2004; Nijboer et al., 2000). Cancer caregiving can also result in identity loss and role overload with various secondary stressors such as financial burden and lack of family support, which can eventually lead to mental and physical health problems that can increase mortality (Given et al., 2011; Linder et al., 2008).

Mental Health Effects

Family caregivers of cancer patients with high levels of distress can experience symptoms of helplessness, depression, anxiety, anorexia, insomnia, as well as a sense of burden and fear (Attner et al., 2009; Hudson, Remedios, & Thomas, 2010; Sharpe et al., 2005; Sherwood et al., 2006). Researchers found that the level of distress experienced as a result of cancer caregiving is rated as comparable or even higher than the one experienced by the patients (Bed-Zur, Gilbar, & Lev, 2001; Edwards & Clarke, 2004; Gilbar & Zusman, 2007; Kothamp-Mothes, Slawinsky, Hindermann, & Strauss, 2005; Segrin, Badger, Dorros, Meek, & Lopez, 2007). The level of distress experienced by family caregivers might be reinforced due to feeling unsure about accepting this new role because they are unfamiliar with the tasks they need to provide, they feel unprepared and unable to perform complex medical procedures or direct care, they find the disease difficult to cope with while still sustaining their own responsibilities, and often they feel obligated to provide emotional support to the patient and other family members (Grunfeld et al., 2004; Kothamp-Mothes et al., 2005; Wilson, Eilers, Heerman, & Million, 2009; Woodbury, & Pavalko, 2000; Wyatt et al., 2004). Family caregivers who feel unprepared for this role are more likely to report an elevated mood disturbance including feelings of guilt, anxiety, and depression (Braum, Mikulincer, Rydall, Walsh, & Rodin, 2007; Schumacher et al., 2008; Spillers, Wellisch, Kim, Mathews, & Baker, 2008).

A longitudinal study examined 200 family caregivers of advanced cancer patients and 32% met the criteria for a mental health disorder (Vanderwerker, Laff, Kadan-Lottick, McColl, & Prigerson, 2005). Anxiety and depression disorders are often link to caregiver burden and stress (Edwards & Clarke, 2004; Goren, Gilloteau, Lees, & DiBonaventura, 2014; Y. Lee et al., 2013; Park et al., 2013). According to Park et al.'s (2013) survey of 897 cancer caregivers, approximately 40% reported experiencing symptoms of anxiety, and more than 80% reported experiencing depressive symptoms. A series of studies also discovered that cancer caregiving is significantly correlated with high levels of depression during the diagnosis and end-of-life phase (Butler, Turner, Kaye, Ruffin, & Downey, 2005; Carter, 2003; Covinsky et al., 2003; Kim, Duberstein, Sorensen, & Larson, 2005; Siminoff, Wilson-Genderson, & Baker, 2010; Dodd, Fletcher, Schumacher, & Miaskowski, 2008). Researchers have found that socio-demographic characteristics (e.g., female, gender, and younger age than patient) and caregiving-related factors (e.g., patient's poor functioning status and greater caregiving burden) are associated with higher depressive symptoms among cancer caregivers (Butler et al., 2005; Covinsky et al., 2003; Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Kim et al., 2005; Wyatt et al., 2004). Additionally, anxiety and depression symptoms tend to be more commonly severe in female caregivers than in male caregivers and in cancer patients (Edwards & Clarke, 2004; Goren et al., 2014; Kim et al., 2006). It is also reported that significant levels of anxiety and depression can cause suicidal ideation (Choi et al., 2011; Sareen et al., 2005).

A recent study showed that cancer caregivers experiencing symptoms of anxiety and/or depression maybe at risk for suicide (Sanson-Fisher et al., 2013). The study surveyed 897 cancer caregivers with 17.7% reporting suicidal ideation and 2.8% attempted suicide. Among the cancer caregivers with depression, 20.4% reported having suicidal thoughts and 3.3% had attempted suicide. Of the cancer caregivers with anxiety, 31.9% reported having suicidal thoughts and 4.7% had attempted suicide. The authors also found that being unmarried, unemployed, and having a low quality of life were all contributing factors linked to suicidal ideation in female caregivers. In addition, cancer caregivers with anxiety who lost their job due to the caregiving role were the group most at risk for suicide. Financial burden was also associated with higher suicidal attempts in cancer caregivers with depression. Findings from this study suggest that early detection of anxiety and depression is vital among cancer caregivers in preventing suicidal ideation (Sanson-Fisher et al., 2013).

Physical Health Effects

The physical health of cancer caregivers can also be impacted due to the stress and burden of caregiving (Haley et al., 2003; Kim, Baker, & Spillers, 2007). High levels of burden and stress can lead caregivers to develop an impaired immune function, hypertension, and heart disease (Chang, Chiou, & Chen, 2010; Glaser, Gouin, Malarkey, Beversdorf, & Kiecolt-Glaser, 2012; Preacher et al., 2003; Roth, Haley, Howard, & Safford, 2010). In a quantitative study, it was found that spousal caregivers of cancer patients could be at risk of cardiovascular diseases even 20 years after the patient's cancer diagnosis (Zoller, Ji, Sundquist, & Sundquist, 2012). Also, family caregivers who are actively involved in strenuous activities such as bathing and dressing the patient as well as housekeeping and grocery shopping for the patient are at higher risk of developing arthritis or chronic back pain (Pinquart et al., 2006; Vitaliano, Zhang, & Scanlan, 2003).

Additionally, family caregivers' pre-existing illnesses may worsen due to the stress and burden of caregiving, as more than half of them already have chronic health conditions such as arthritis, heart disease, and hypertension (Mellon, 2002). Research also has suggested that the physical health of family caregivers can be at greater risk because they have less time to rest, increasingly use certain substances (e.g., alcohol and tobacco), engage in fewer self-caring behaviors (e.g., physical activity, healthy eating), and often fail to seek medical attention when they are ill (Riess-Sherwood, Given, & Given, 2002; Sherwood & Given et al., 2008; Travis, Lyness, Shields, King, & Cox, 2004). Overall, a prolonged sense of burden, anxiety, depression, and chronic stress has consistently been associated with health impairment and increased mortality among family caregivers (Kroger, Anackovic, Serker, & Deter, 2004; McGuire, Kiecolt-Glaser, Robles, & Glaser, 2002; Perkins et al., 2013; Preacher et al., 2003).

Caregiving Benefits and Rewards

While several studies have explored the negative aspects of cancer caregiving, some reports have focused on the positive aspects (Carver, Kim, & Schulz, 2007; Hayman-White, Hudson, & Aranda, 2005; Loke & Li, 2013; Sherwood & Given et al., 2008; Wagner, Dass, Bigatti, & Storniolo, 2011). The quality of the daily relationship between the caregiver and the patient has been identified as the central component in the positive aspects of family caregiving (Caron, Carbonneau, & Desrosiers, 2010). In Wagner et al.'s (2011) qualitative study, spousal caregivers of cancer patients reported perceiving caregiving as a form of showing love to their partner, emphasizing that it strengthened their relationship. Similar studies have revealed that family caregivers tend to report that the caregiving experience gives them a sense of purpose in life, makes them feel good about themselves, allows them to learn new skills, and strengthens family relationships (Hudson, 2006; Raque-Bogdan, Schmidt, Piontkowski, & Schaefer, 2011; Sherwood & Given et al., 2008; Tenen & Coyne, 2010). According to Carver et al.'s (2007) qualitative study, there are many benefits found in the caregiving process identified as acceptance, empathy, appreciation, family closeness, a positive self-view, and a reprioritization of values. The author specifically associates these benefits with higher life satisfaction and less mental health symptoms among family caregivers of cancer patients (Carver et al., 2007). Although there is some evidence that the cancer caregiving process can have positive rewards, these are relatively unexplored (Loke & Li, 2013). This lack of acknowledgement can limit professionals' abilities to develop psychosocial interventions that fully understand the positive aspects of cancer caregiving (Caron et al., 2010).

Effects of Psychosocial Interventions

Based on the existing literature, psychosocial interventions such as interpersonal therapy, cognitive behavioral therapy (CBT), family-based therapy, the building of coping skills, social work, and behavioral health can strengthen cancer caregivers' ability to manage care for themselves and the cancer patient (Badger, Sagrin, Dorros, Meek, &

Lopez, 2007; Empeno, Raming, Irwin, Nelesen, & Loyd, 2011; Dobrof, Ebenstein, Dodd, & Epstein, 2006; Manne, Babb, Pinover, Horwitz, & Ebbert, 2004; McMillan et al., 2006; Northouse et al., 2007; Pillail, 2012; Stenberg et al., 2009). However, more psychosocial interventions and programs targeted exclusively toward cancer caregivers need to be evaluated to increase empirical evidence (Stenberg et al., 2009). The following psychosocial interventions and programs with family caregivers show promise to improve outcomes, such as by decreasing depression, decreasing anxiety, reducing caregiver burden, and bolstering coping skills.

Interpersonal Counseling

Interpersonal counseling (IPC), also known as interpersonal psychotherapy, is a brief form of treatment used for treating psychological symptoms such as anxiety and depression. Therapy focuses on relationships and social roles. Interventions focus on areas such as role disputes, role transitions, unresolved grief, and interpersonal deficits. There is a significant amount of empirical evidence that supports the effectiveness of IPC.

According to Badger et al. (2007), psychosocial interventions such as IPC can reduce depressive and anxiety symptoms in breast cancer patients and their spousal caregivers. A study conducted by Badger et al. (2007) tested telephone-delivered psychosocial interventions with 96 breast cancer patients and their spouses with an aim to reduce their levels of anxiety and depression. Participants were randomly assigned to be a participant in one of three intervention programs: (1) attention control, (2) IPC, or (3) self-managed exercise. These interventions were delivered over a 6-week period. The attention control group received educational information about breast cancer with telephonic calls lasting less than 10 minutes. Meanwhile, the IPC group received therapeutic sessions focusing on building communication, social support, cancer education, and skills for managing symptoms of anxiety and depression with telephonic calls lasting less than 40 minutes. In the self-managed exercise group, participants were encouraged to exercise regularly or engage in lower-impact exercises (e.g., walking) with telephonic calls lasting close to 11 minutes. The study used a mixed-model analysis of variance to evaluate the effectiveness of the programs. The results revealed that depressive symptoms among breast cancer patients and their spouses decreased across all three groups. For anxiety, symptoms decreased for breast cancer patients and their spouses in the IPC and self-managed exercise groups, but not in the attention-control group. This study suggests that telephoned-delivered psychosocial interventions can be efficacious in improving the quality of life and mental health of both the cancer patient and their spousal caregiver (Badger et al., 2007).

Cognitive Behavioral Therapy

Another form of mental health treatment in evidence-based practice is CBT. This type of therapy is widely recognized as the most effective treatment for treating depression. Interventions focus on changing maladaptive thoughts, feelings, and behaviors for managing psychological symptoms.

A study conducted by Pillail (2012) examined the efficacy of CBT with male spouses of cancer patients. Ten English-speaking spouses with moderate depression were selected after completing two self-report questionnaires, (1) Demographic variables and

(2) the Beck Depression Inventory (BDI). Participants received weekly one-hour cognitive CBT sessions to decrease depressive symptoms. CBT interventions were delivered in a face-to-face format. A pre and post-test design were used before and after the intervention program. When comparing the results, the intervention group showed a significant decrease in BDI scores while the waiting list control group showed no significant changes. The study suggested that CBT might be an effective form of mental health treatment for depressed spouses of cancer patients; however, it emphasized that more evidence is needed before drawing a conclusion (Pillail, 2012).

Family-Based Intervention

Family-based interventions can also be utilized to help individuals and families deal with a mental or physical illness. Some interventions include strategic or structural family therapy. Family interventions tend to focus on increasing family engagement and members' ability to handle challenging situations related to the health problem. These types of interventions can help to improve the well-being of family caregiver as well as reduce caregiving stress and negative patient-care outcomes.

Emotional distress is significantly reported among female spouses of cancer patients, which can be related to a lack of caregiving support (Manne et al., 2004; Northouse et al., 2007). A family intervention program called FOCUS (family involvement, optimistic attitude, coping effectiveness, uncertainty reduction) was conducted with prostate cancer patients and their spouses to determine whether it could improve symptoms of distress, coping strategies, appraisal of caregiving, hopelessness, uncertainty, self-efficacy, communication, and quality of life (Northouse et al., 2007).

This clinical trial consisted of 263 patient-spouse dyads. The couples were randomized into two groups, control (standard care) or experimental (standard care and a five-session family intervention). This educative and supportive family intervention targeted hope, coping, communication, uncertainty, and symptom management between the cancer patient and his or her spouse. After a four-month follow-up, findings indicated that prostate cancer patients in the experimental group reported improved communication with spouses and less uncertainty than the control group. Spouses in the experimental group reported better communication, increased self-efficacy, improved quality of life, less uncertainty, reduced hopelessness, decreased symptoms of distress, and less negative appraisal of caregiving when compared to the control group. Northouse et al. (2007) suggested that program interventions for cancer patients should be extended to caregiving spouses to decrease distress, increase coping, and facilitate their caregiving role throughout the cancer care trajectory.

Coping Skills Intervention

Various coping skills interventions have also been identified to work with diverse populations, including cancer patients and their caregivers. Coping skills interventions primarily focus on helping others to manage, minimize, remove, avoid, or "get through" stressful situations in life. These types of interventions are also known to improve the individual's well-being and quality of life.

A study conducted by McMillan et al. (2006) examined the effect of coping skills interventions on the quality of life of family caregivers of advanced cancer patients (McMillan et al., 2006). This study recruited 354 family members caregiving for advanced cancer patients in hospice settings. Participants were randomly divided into three groups, (1) standard hospice care, (2) standard hospice care and three supportive visits, or (3) standard hospice care and three supportive visits to teach coping skills intervention. Group one received standard hospice services only. Caregivers in the group two received standard hospice services and individual supportive counseling (active listening interventions only) from nurses. Group three received standard hospice services, active listening interventions, and problem-solving methods for coping with difficult caregiving-related situations. After a one-month follow-up, findings indicated that only the group receiving the coping skills intervention showed improvement in quality of life or reported decreased burden related to the caregiving task and reduced burden of patients' symptoms. Outcomes of this study demonstrated that coping skill-building interventions might be beneficial for cancer caregivers even in the most difficult settings like end-of-life care (McMillan et al., 2006).

Social Work Support Programs

Social workers provide support to cancer patients and their families in a variety of settings and roles. In cancer settings, they are often known as oncology social workers. The following studies support the integration of social work programs among family caregivers.

Family caregivers who provide end-of-life care often experience even higher levels of stress, health problems, and a reduced quality of life (Empeno et al., 2011). A caregiver support project was studied in 2011, where social workers provided assistance to 182 family caregivers caring for a hospice patient at home (Empeno et al., 2011).

During this study, hospice social workers assessed hospice caregivers' stress and risk of burnout. Family caregivers of hospice patients with high levels of stress were referred to additional needed services despite the type of support they requested. Most caregivers requested services that provided some type of respite such as time to run errands, sleep, or spend time with family or friends. The study administered the Pearlin Role Overload Measure (ROM) to determine the impact this project had on the use of the hospice respite benefit and caregiver stress levels before and after the program. Due to challenges in reconnecting with participants throughout the follow-up period, only 123 family caregivers were included in the data analysis. Findings showed decreased stress levels, less use of respite, and fewer respite days needed. The author further suggested that caregivers of hospice patients could be at risk of becoming ill without additional supportive services (Empeno et al., 2011).

Dobrof et al. (2006) suggested that it is essential to provide social work support to family caregivers of chronically ill patients. In 2006, a hospital-based support program for family caregivers of chronically ill patients was evaluated to examine the effectives of social work interventions (Dobrof et al., 2006). Approximately 169 family caregivers participated in this study. Social workers helped these caregivers with a wide array of concerns ranging from complex to practical needs. Some practical needs of family caregivers included medical insurance coverage, home healthcare assistance, and financial planning. Complex needs included therapeutic counseling for coping with the patient's illness and numerous services needed to keep the patient at home. More than 50% of the participants with emotional problems were provided with needed resources.

An estimated 75% of cases were followed up by social workers to provide ongoing support and secure linkages to needed resources. Findings indicated that social work interventions such as psychosocial assessments, information referrals, advocacy services, and follow-up support increased caregivers' coping skills and ability to access needed resources (Dobrof et al., 2006).

Integrated Behavioral Health Care

To address the mental health needs of individuals such as cancer caregivers, current trends in health care are integrating behavioral health services in primary care settings (Hoerevitz & Manoleas, 2013). According to Gray, Brody, and Hart (2000), individuals with mental health concerns tend to seek help from primary care settings instead of from mental health settings. This integrative behavioral health approach can help eliminate mental health stigma and increase access to needed services among affected family caregivers (Hoerevitz & Manoleas, 2013; Livingston & Boyd, 2010; Vogel, Wade, & Haake, 2006). Research indicates that integrated behavioral health services have shown to be effective in decreasing depressive and anxiety symptoms and improving the quality of care of patients and their families (Arean et al., 2008; Weiss, Haber, Horowitz, Stuart, & Wolfe, 2009).

The majority of providers practicing in integrated behavioral health settings are clinical social workers (Blount & Miller, 2009). Social workers are well suited for this role as they are generalist practitioners trained in approaching health and well-being from a bio-psycho-social perspective (Hoerevitz & Manoleas, 2013). Integration of behavioral health services in primary care setting promises to treat mild to moderate mental health disorders by addressing the needs of the patients and their families across the bio-psycho-social spectrum (Hoerevitz & Manoleas, 2013).

Behavioral health social workers in primary care settings and medical providers work collaboratively to treat and reconnect the patient's mind and body by using a co-located model of care (Kiser, Lefkovitz, & Kennedy, 2001). Mental health treatment in primary care settings tends to be short term (with an average of 1-10 visits) when compared to traditional mental health settings (Pomerantz et al., 2010). In the integrated behavioral health care setting, patients are directly referred to mental health treatment by their medical providers within the same system (Hoerevitz & Manoleas, 2013). Therefore, behavioral health social workers are most likely to come into contact with patients who have not received behavioral health services in the past (Mauer, 2009). Behavioral health interventions conducted by social workers include bio-psycho-social assessments, case management, motivational interviewing, relaxation skills, psycho-education, problem-solving treatment, warm handoffs (attending a mental health crisis during patient's clinic appointment), cognitive behavioral therapy, and group work (Hoerevitz & Manoleas, 2013).

Depending on the needs of the patient population in primary care settings, behavioral health social workers can also develop and facilitate group work (Hoerevitz et al., 2013). Therapeutic groups commonly practice social work in order to treat mental symptoms such as depression and anxiety. It is well established that CBT interventions are among the most effective for treating depression and anxiety symptoms and have proven successful in primary care settings as well (Ammar, 2014; Conradi et al., 2007).

Therefore, involving cancer caregivers in CBT groups can be an effective way to decrease depression and anxiety among this population.

Conclusion

Overall, family caregivers play a significant role in the life of cancer patients throughout the cancer care trajectory. These family caregivers are constantly faced with many challenges that can lead to high levels of burden and stress, which may cause adverse effects on their overall health. A growing body of literature recognizes the importance of attending to the psychosocial needs of cancer caregivers to ensure both their and the patients' well-being (Breitbart & Alici, 2009). Developing and integrating support groups in primary cancer care settings can be a way to improve the physical health and mental well-being of cancer caregivers and a step toward helping this population.

CHAPTER 3

METHODOLOGY

Intervention and Nature of the Program

The nature of this research project is to seek funding for the development and integration of a psychosocial support group program. This support group program entitled the Healthy Caregiver will follow a short-term cognitive behavioral therapy (CBT) model and will focus on decreasing symptoms of depression and anxiety among caregivers who are providing direct care to a family member with cancer. Information resources will also be provided for participants who are seeking further support upon conclusion of the group.

Target Population

The Healthy Caregiver program will be conducted at St. Francis Medical Center (SFMC) and will seek to serve the SFMC population. SFMC is located in Lynwood, California, a diverse and underserved community. According to the United States Census (2010b) there are nearly 70,000 individuals residing in the community of Lynwood. The city’s ethnic distribution is approximately 46% Latino, 39% White, 10% African American, and 5% all other ethnicities (United States Census, 2010b). As the only comprehensive non-profit healthcare institution in the community, SFMC serves the 1.2 million residents of Southeast Los Angeles, California. SFMC service areas include the communities of Lynwood, South Gate, Downey, Huntington Park, Bell, Cudahy, Bell Gardens, Maywood, Compton and South Los Angeles. With a large population of Latinos living among these communities, the proposed program will also provide services in Spanish. The proposed program is intended for female and male caregivers who speak English or Spanish and who are members of SFMC. The goal of the program will be to serve more than 100 cancer caregivers.

Host Agency

SFMC is a non-profit healthcare institution founded in 1945 serving nearly 700,000 adults and 300,000 children. SMFC provides a full range of diagnostic and treatment services with a commitment to serving the sick and the poor. SMFC is dedicated to the values of respect, compassionate service, simplicity, advocacy for the poor and being continuously resourceful and creative. SFMC provides health care to over 500 new cancer patients each year, recognizing that cancer can affect both the patients and their love ones on several levels (St. Francis Medical Center, n.d.). Bryan Grassman, Director of Foundation Relations at SFMC supports this project and stated that this type of intervention is vitally needed among all primary caregivers across the care delivery spectrum (personal communication, September 30, 2014).

Identification and Strategies of Potential Funding Sources

To seek potential funding sources for this grant project various online strategies were utilized. Primarily, funding possibilities were explored at the federal, state, and foundation levels by conducting an online search in the world-wide-web. A search using key terms including, “cancer caregivers support funding”, “cancer caregivers programs”, “grants cancer caregivers”, “psychological support for family caregivers”, and “funding informal caregiver program” was conducted. Online databases such as the Grantsmanship Center Online and the Grants.gov websites were utilized in an attempt to locate potential funding sources for this grant project. Also, multiple websites were visited including, www.caregiving.org, www.lloydsymingtonfoundation.org, www.weingartfnd.org, www.cancer.org, www.annenbergfoundation.org, www.livestrong.org, www.cancer.gov, and www.conquercancerfoundation.org. Based on this online search three foundations were identified as potential funding sources for this grant project.

Lloyd Symington Foundation

The Lloyd Symington Foundation was identified as one potential funding source because it focuses on funding programs targeted to individuals and families facing cancer (Lloyd Symington Foundation, n.d.). This foundation funds programs that aim to improve cancer populations quality of life, alleviate physical and emotional pain associated with the cancer experience and promote a deeper connection to each individual’s essential nature. The foundation also gives funding priority to programs that promote cultural diversity as well as programs that reach out to low-income and minority populations neglected or ignored by the healthcare system. Derived from their mission statement, the Lloyd Symington Foundation serves the cancer community by supporting visionary individuals and spiritually grounded programs that offer healing at every level (Lloyd Symington Foundation, n.d.).

Weingart Foundation

The Weingart Foundation was another potential funder identified because it funds grants up to $200,000 for a period of two years (Weingart Foundation, n.d.). The foundation funds programs that deliver services in the areas of education, health, and human services. It also gives funding priority to programs that aim to increase access to services among underserved and disadvantaged populations. There are no age requirements, but programs that address the needs of low-income children, older adults and individuals affected by homelessness and disabilities are matters of particular interest for this foundation (Weingart Foundation, n.d.).

Annenberg Foundation

The Annenberg Foundation was also identified as a potential funder due to their openness in funding a range of effective project ideas (Annenberg Foundation, n.d.). This foundation awards grants in various areas including, arts, culture and humanities, military veterans, environment, civic and community, education, animal welfare, human health and wellness. The foundation funds non-profit organizations in the United States and worldwide with grant opportunities ranging from $10,000 to a maximum of $100,000. Priority is given to programs serving the five-county regions in Greater Los Angeles and grants are accepted in a continuous basis (Annenberg Foundation, n.d.).

Criteria for Selection of Actual Grant

To select a potential funder for this grant project specific criteria was reviewed. Primarily, based on the psychosocial approach of the Healthy Caregiver program the Lloyd Symington Foundation was not selected due to their focus on funding holistic programs. In addition, both the Weingart and Annenberg Foundation met the funding amount of $100,000 for this grant project. However, the Weingart Foundation was not selected given their priorities in funding programs that serve low-income populations affected by homelessness and/or disabilities. Therefore, the Annenberg Foundation was selected as the best fit for this grant project due to their flexibility in funding innovative ideas such as the Healthy Caregiver program. The Healthy Caregiver program is a new and unique idea targeting the needs of family caregivers of cancer patients in the community of Lynwood. The Healthy Caregiver program will add to the few programs available for this population. The Annenberg Foundation was also selected because it funds programs in Los Angeles County, the location for this program.

Description of Selected Foundation

Walker H. Annenberg founded the Annenberg Foundation in 1989. This family foundation believes in supporting the global community through funding non-profit organizations that are active leaders in their field of expertise. The Annenberg Foundation recognizes the complexity of social problems, and they are willing to take chances to fund new ideas despite the risk of failure. Annenberg is among the world's largest foundations and have funded over 85,000 grants all over the world. The foundation is dedicated to the core values of responsiveness, fairness, accessibility and involvement. Upon the deaths of Walker H. Annenberg in 2002 and Leonore Annenberg in 2009, the foundation has been under the direction of Wallis Annenberg and her three children focusing on its mission to advance the public well-being (Annenberg Foundation, n.d.).

Needs Assessments

In order to determine and address the needs of this population, several sources were utilized to develop a program that will best meet the needs of these family caregivers. A comprehensive literature review was conducted to assess the specific mental health needs of this population. Multiple data reports were explored in search for information on the incidence and prevalence of the problem and the population affected. The National Alliance of Caregiving in Collaboration with AARP survey reports were examined to determine the number of family caregivers in the United States. The National Cancer Institute and the American Cancer Society research studies were also study to obtain information on the cancer rate and illness trajectory. Additionally, the United States Census reports were used to establish a community profile of the city of Lynwood, California. Furthermore, if this project is funded additional steps will be taken to evaluate the need for this intervention. First, data will be collected from the host agency on the community served. Secondly, consultations with service providers and consumers of the targeted population will be conducted to further validate the need for this program.

CHAPTER 4

GRANT PROPOSAL

The following is a grant application for the Annenberg Foundation written on behalf of St. Francis Medical Center (SFMC). The purpose of this grant application is to propose a psychosocial support program for family caregivers caring for an adult cancer patient. Due to the nature of this research project, many requirements from the foundation's grant application were omitted.

Mission Statement

In the spirit of our founders, St. Vincent de Paul, St. Louise de Marillac, and St. Elizabeth Ann Seton, the Daughters of Charity Health System is committed to serving the sick and the poor. With Jesus Christ as our model, we advance and strengthen the healing mission of the Catholic Church by providing comprehensive, excellent healthcare that is compassionate and attentive to the whole person: body, mind and spirit. We promote healthy families, responsible stewardship of the environment, and a just society through value-based relationships and community-based collaboration (St. Francis Medical Center, n.d.).

Summary of Program and Services

SFMC is the only comprehensive non-profit healthcare institution serving the 1.2 million residents of Southeast Los Angeles, California, a densely populated and underserved community. SFMC located in Lynwood, California, was established in 1945 and provides a full range of diagnostic and treatment services along with a broad range of social services and educational programs. SFMC operates a 384-bed acute care hospital, five community-based health clinics, and the largest and busiest private emergency trauma services center in Los Angeles County, California. Additional services offered at SFMC include, behavioral health, family life center renaissance, bioethics program, children counseling center, heart center, health and workplace safety, imaging services, industrial and occupational medicine, intensive care and critical care unit, outreach programs, pastoral and spiritual care, primary stroke center, sweet beginnings in our family center, wound care center, skilled nursing facility, radiation oncology and rehabilitation services. The radiation oncology department at SFMC serves and provides quality care to cancer patients with a commitment that extends to cancer prevention, detection, education, and treatment. SFMC blends both a technical and compassionate approach to the fight against cancer with services such as case management, discharge planning, pain management, pastoral care, home health, and hospice. Following the SFMC mission statement, excellent healthcare is provided to the whole person physically, emotionally, and spirituality. (St. Francis Medical Center, n.d).

Needs Assessment

Every three years SMFC conducts a community health needs assessment as an effort to identify the most critical health care needs in the community. In 2013, the most recent assessment was completed and lung cancer was identified as one of the priority needs in the community (St. Francis Medical Center, 2014). SMFC provides health care to over 500 new cancer patients each year and recognizes that cancer can profoundly affect patients and their loved ones on several levels. SFMC also acknowledges the vital role family members play in caring for the cancer patient as well as the impact their caregiving role can have on their mental health. Consequently, the health and safety of cancer patients may be at risk if the psychosocial needs of their family caregivers are not addressed (Given et al., 2011; Wozniak & Izycki, 2014). Thus, SFMC is in-need of a psychosocial support program to strive to improve the mental well-being of family caregivers and the quality of care among cancer patients.

It is well documented that family members often become the primary care providers of cancer patients throughout the illness care trajectory (Given et al., 2011). Family caregivers of cancer patients tend to experience significant levels of burden and stress that can lead to severe mental health symptoms caused by the strain of caregiving (Goren et al., 2014; Longacre et al., 2013; Park et al., 2013; Sanson-Fisher et al., 2013; Vanderwerker et al., 2005). Also the most common mental health symptoms among these family caregivers are depression and anxiety, which may eventually lead to suicidal ideation and can increase to mortality (Choi et al., 2011; Linder et al., 2008; Sanson-Fisher et al., 2013). Based on these findings, the Healthy Caregiver program was developed to address the mental health needs of cancer caregivers in the community of SFMC. A community located in Lynwood, California with approximately 46% Latino, 39% White, 10% African American, and 5% all other ethnicities (United States Census, 2010b).

Project Description

The Healthy Caregiver program is a cognitive-behavioral-therapy (CBT) group for family caregivers who are providing direct care to an adult cancer patient. The purpose of the program is to provide group therapy assistance and information resources to family caregivers experiencing anxiety and/or depressive symptoms. Services will be targeted to family caregivers cared by SFMC with the behavioral health department making the referrals to the program. Potential participants will be screened individually, and a psychosocial assessment will be completed by an MSW social worker before enrollment to the group. Although the program is geared toward family caregivers within SFMC, community members who express an interest and a need for support will also be screened as potential participants.

Following a six-week CBT model, this Healthy Caregiver program will focus on decreasing symptoms of depression and anxiety. This will help family caregivers to reduce their sense of caregiving burden and stress. It will also help to increase their coping to provide participants with a sense of control over their caregiving situation. In partnership with the behavioral health department at SFMC, the Healthy Caregiver program will also provide resources for participants in need of additional support after the group concludes.

The program will conduct six English and six Spanish groups simultaneously throughout the funding year, potentially serving a total of 120 family caregivers. A total of 12 groups will be conducted with a minimum of 10 participants in each group.

Participants will meet for six consecutive sessions once a week for two hours. Upon successful completion of the group, participants will receive a gift card incentive in the amount of $50.

A social worker with a master in social work (MSW) will facilitate the group process with the help of two MSW interns who will serve as group co-facilitators. In addition to discussion of group concerns to provide mutual support, the group sessions proposed topics include:

Session 1: Introduction to caregiver burden and stress and education on anxiety and depression (discuss the positive and negative aspects of cancer caregiving, provide psycho-education on the mental health effects of caregiver strain, introduce the basic principles of CBT, and provide instructions of keep track of daily mood homework assignment).

Session 2: Cognitive restoring of maladaptive thoughts and beliefs to decrease depression and anxiety (teach techniques for identifying and responding to automatic thoughts and beliefs, practice coping self-statements, thought stopping and worry time activity, provide instructions of thought tracking homework assignment).

Session 3: CBT Techniques for coping with anxiety and depression (discuss effective coping strategies used in the past and focus on positive problem-solving strategies, practice emotional and rational role-plays for adapting new coping skills, and continue with self-monitoring of daily thoughts and mood homework assignments and suggest journaling activity).

Session 4: Coping Skills and Behavioral techniques to reduce depression and anxiety (review of homework and progress, behavioral experiments on thought testing and discovery, rehearse acting "as if" techniques, and provide instructions of a behavioral action homework assignment for acting in accordance to new beliefs and against old ones).

Session 5: Relaxation Skills and Self-Care activities that promote well-being (review of homework, discuss self-care strategies for the caregiver, and practice relaxation exercises such as guided imagery, deep breathing, and facilitate an experiential activity).

Session 6: Termination activity and provision of resources needed (review skills learned, provide information referrals, and deliver gift card incentives).

Project Goals and Outcomes

Goal 1: To help family caregivers improve their coping and sense of control over their caregiving situation as well as reduce their stress and sense of burden by decreasing symptoms of depression and anxiety through the use of group therapy.

Outcome 1: Provide group therapy to 120 family caregivers of adult cancer patients.

Activities: Acquire group materials, recruit and train three social workers (one group facilitator and two interns), arrange group space, market and advertise group, enroll and screen participants, hold 12 groups with a minimum of 10 participants each.

Goal 2: Decrease depression and anxiety symptoms among family caregivers of cancer patients through application of CBT skills with the group participants.

Outcome 2: Ninety-percent of the participants will show decrease levels of anxiety and depression as evidenced by the pre and post-tests research develop specifically for family caregivers of adult cancer patients.

Activities: Provide psycho-education, problem-solving treatment, and assign CBT homework exercises such as but not limited to journaling throughout the group therapy sessions.

Goal 3: Reduce sense of burden and stress among family caregivers of cancer patients through the application of CBT skills with the group participants.

Outcome 3: Eighty-five percent of the participants will show reduced stress and burden as evidence by the Caregiving Appraisal Scale (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989).

Activities: Provide and facilitate relaxation training, reflective activities, and self-assessment skills throughout the group therapy sessions.

Goal 4: Increase family caregivers coping skills and sense of control over their cancer caregiving situation and enhance knowledge of community resources.

Outcome 4: Eighty percent of the participants will show increase sense of control and coping as evidenced by the Perceived Stress Scale (S. Cohen, Kamarck, & Mermelstein, 1983).

Activities: Facilitate and encourage practice of appropriate coping skills (e.g., relaxation techniques, positive self-talk, and help-seeking behaviors) during group sessions and outside the group setting. Provide information resources related to the needs of the participants.

Innovative Idea

The Healthy Caregiver program is an innovative approach toward the design of mental healthcare for family caregivers of adult cancer patients. A population that is often under recognized and in greatest need of support from the healthcare system (Dohan et al., 2005; Palos et al., 2011). Bringing this program into SFMC will help raise awareness about this population within the community and the healthcare system. The program will serve as a change agent in addressing the mental health issues of these cancer caregivers. Due to the lack of available programs for this population, this will be a new service in the community impacting the quality of life of affected family caregivers.

Integrating the Healthy Caregiver program at SFMC can serve as a model of service to similar non-profit health care institutions, increasing access to mental health services among underserved cancer populations. Additionally, it can bring about systematic change in the way family caregivers of cancer patients are served in cancer care settings with similar facilities holding programs specifically directed to addressing the needs of family caregivers of adult cancer patients. Also as a member of the Daughters of Charity Health System in California, SFMC will have the opportunity to establish a new evidence-based practice among cancer communities across the state.

Program Evaluation

To evaluate the effectiveness of the Healthy Caregiver program three assessments measures will be administer before and after the intervention by the program administrator. A pre and post-test will be designed to measure the progress of the participants based on the goals of the program. The Caregiving Appraisal Scale will measure caregiving subjective burden and perceived impact of caregiving (Lawton et al., 1989). The Perceived Stress Scale will measure the participants' level of coping and control over stressful situations (S. Cohen et al., 1983). The participants will be ask to complete the pre-test and the two scales prior to the start of the group. Additionally, the participants will be asked to complete a post-test upon the conclusion of the group and the two scales after a one-month follow-up. These assessment methods will help to evaluate if the group was effective and beneficial to the participants.

Sustainability

Given the Healthy Caregiver program data and outcomes, SFMC will work to maintain the program by pooling resources to identify private and government funders with similar programmatic interests. Grant planning meetings will be held to discuss and solicit funding. To ensure program sustainability grant proposals will be submitted prior to the ending of the program funding. Additional supportive funding will be sought through community donations and previous SFMC funders. The grant management department at SFMC will focus on seeking funding opportunities at the local, state and federal level for the financial sustainability of this program.

Project Budget

The estimated cost for the Healthy Caregiver one-year program will be $73,185. Funding will cover the salary and benefits of one part-time program administrator and one part-time group facilitator. Funding will also allow for gift card incentives for the participants who attend all group sessions. Gift card incentives will be used to encourage the participation and engagement of cancer caregivers from SFMC. Other expenses such as refreshments for each group session, printing materials, technological equipment, and utilities costs haven been calculated in the final budget. Refer to Appendix A for Line-Item Budget and Appendix B for Budget Narrative.

CHAPTER 5

LESSONS LEARNED

Grant Writing Process

Research and grant writing experience are important skills to have as a social worker. Based on the requirements for this thesis project, several learning components were associated with the grant writing process. With professional guidance, a host agency was selected, funding sources were identified, a program was designed and a budget was calculated to develop a grant proposal. The topic of cancer was selected for this project based on a personal experience, but most importantly because it represents a social problem in today's society. Due to the various aspects of cancer, a brief literature review was conducted to narrow the topic idea. Given the recommendations found in the existing literature, the focus of this thesis project was on the development of a psychosocial program for family caregivers who are providing direct care to an adult cancer patient.

Selection of Host Agency

For the selection of a host agency, consultations with primary clinics in Los Angeles County, California (The Children's Clinic, Watts Healthcare Corporation and St. Francis Medical Center) were conducted to identify a need for this kind of program in their community. These communities included South Los Angeles, Lynwood and Long

Beach. Getting a hold of clinic directors was a challenged, but once consulting with them, most of their inquiries were related to the purpose, goal and target population of the proposed program. Although all three primary clinics agreed that the proposed program was vitally needed in their community, it was determined that St. Francis Medical Center located in the city of Lynwood was the best fit due to their constant contact with family caregivers of adult cancer patients through their departments in radiation oncology and behavioral health.

After obtaining permission from St. Francis Medical Center to use their name for this grant project no further contact was made. This led for the design of a program based on the findings from an extensive literature review on family caregivers of adult cancer patients. The needs assessment conducted through this in-depth literature review determined that a psychosocial support program was highly needed among this population for addressing their mental health needs.

Identifying Funding Sources

Following the completion of this comprehensive literature review, the next step was to identify potential funding sources that will support and fund this program idea. Locating a funder was a difficult process given the specific program criteria. Most funders funded programs that targeted family caregivers caring for children, older adults or individuals with Alzheimer's, which was not the intent of this program. However, after an extensive online search three potential funding sources were found at the foundation level including, Annenberg, Lloyd Symington, and Weingart. The Annenberg

Foundation was selected as the best funding source due to meeting the program's criteria; target population, funding amount, location, and the psychosocial idea.

Various online strategies were utilized to locate potential funders for this program. First a search was conducted for seeking possible grant funding opportunities at the Grantsmanship Center Online and the Grants.gov websites. Also, key words that related directly or indirectly to the program were typed in the world-wide-web, which uncovered additional grant funding sources. It is recommended to consult with the host agency to obtain information on previous funders or attend Long Beach Nonprofit Partnership workshops to consult with funders and have access the Foundation Center database online.

Program Design

Upon the selection of the Annenberg Foundation as the grant funder, a psychosocial program was designed following the foundations guidelines and utilizing the information found in the literature review. The program was titled the Healthy Caregiver and was chosen based on the purpose of striving to improve the mental well-being of family caregivers of adult cancer patients. Focusing on the mental health needs of this population, a six-week cognitive-behavioral-therapy (CBT) approach was selected as the model for this program. According to the literature, family caregivers of cancer patients tend to experience high levels of anxiety and/or depression with CBT leading as the most effective form of mental health treatment (Carter, 2006; Choi et al., 2011; M. Cohen et al., 2006; Linder et al., 2008; Sanson-Fisher et al., 2013; Sikorskii et al., 2006). In order to serve as many family caregivers of cancer patients as possible it was determined that the program will provide treatment through the use of CBT groups. Designing the six-week CBT group sessions was the most challenging and time-consuming process due to the secondary research involved in creating a clinical and evidence-based supportive program that targeted the psychological symptoms experienced by this population.

Budgeting

The budget process was also a tedious task to complete due to lack of experience in the subject. Estimating the cost for the Healthy Caregiver program was the first step, which was achieved through the help of professional advice. Also, with the help of budget template examples, the program costs were outlined in a budget-item list and described in a narrative report. Seeking professional advice and attending a budget workshop on the subject were the most helpful strategies for calculating the final budget.

Implications for Social Work Practice

Social workers come into contact with cancer patients and their family caregivers in a variety of settings and roles. Thus, it is essential for social worker to be trained in assessment and interventions skills for assisting affected patients and family caregivers with the multiple effects of cancer. Research is a required component for social workers to evaluate practice and further their knowledge about cancer populations and their problems. A growing body of literature highlights the need for psychosocial interventions among family caregivers of cancer patients, as they often report symptoms of depression and anxiety manifested by the burden and stress of caregiving (Caron et al., 2010; Empeno et al. 2011; Sercekus et al., 2014).

To support this population, social workers can perform many roles at the micro and macro level by offering clinical support, promoting psychosocial care, conducting research, and developing programs such as the Healthy Caregiver. Practicing under the six core values of social work (i.e., service, social justice, dignity and worth of the person, importance of human relationships, integrity and competence) these roles and functions can serve to enhance the quality of care of family caregivers in the healthcare system in which they are cared for. The Healthy Caregiver promises to improve the mental well-being of family caregivers of adult cancer patients, a step toward addressing this social problem.

APPENDICES

APPENDIX A

LINE ITEM BUDGET

Line-Item Budget

Expenses (Annual)	**Amount**	**In-kind**
Personnel		
Program Administrator (MSW) @ 50% PTE	$30,000	
Benefits @ 19% of PTE	$5,700	
1 Group Facilitator (MSW) @ 50% PTE	$20,000	
Benefits @ 19% of PTE	$3,800	
Total Personnel Expenses	**$59,500**	
Direct		
Program/Office Supplies @ $100 per month	$1,200	
Refreshments	$3,000	
Gift Cards to Participants @ $50 x 120	$6,000	
Room Rental		$8,200
Office Equipment; Computers, furniture, printer		$5,000
Internet/Phone Service @ $60 per month		$720
Utilities @ $40 per month		$480
Total Direct Expenses	**$10,200**	
Indirect		
Administrative Overhead @ 5 % of total cost	$3,485	
Total Indirect Expenses	**$3,485**	
Total Costs	**$ 73,185**	**$14,400**

APPENDIX B
BUDGET NARRATIVE

Budget Narrative

Personnel Expenses

Program administrator: A bilingual (Spanish/English) practitioner with a Master's in Social Work (MSW) will be hired part-time to manage the Health Caregiver program. The administrator will overlook the program and will take charge in managing the budget, conducting the evaluation, and monitoring the sustainability plan. The administrator will also work toward the recruitment of staff, interns and group participants. The administrator will train the staff and will help with the screening and enrollment of group participants. The program administrator will undertake any related administrative and management tasks and will be paid a salary of $30,000 with benefits in the amount of $5,700 during the funding year.

Group Facilitator: One bilingual (Spanish/English) MSW group facilitator will be hired part time to screen potential participants and conduct the groups. The group facilitator will also assist with the recruitment of group participants and the training of two MSW interns. The group facilitator will be paid a total amount of $20,000, with benefits in the amount of $3,800 during the funding year.

Direct Costs

Office Supplies: Approximately $100 per month ($12,000 for the year) will be spent on program materials, printing, pens, and office supplies.

Refreshments: Approximately $250 per month ($3,000 for the year) will be spent in food and beverages that will be served for the participants during each group session.

Incentives: Gift cards in the amount of $50 will be provided to each participant who completes the Healthy Caregiver program, with a total cost of $6,000 for the year.

In-Kind Resources

St. Francis Medical Center (SFMC) will provide in-kind resources including rent, utilities, and office equipment for the Healthy Caregiver program. The rent will include two rooms where the support groups will be held. The utility services will include electricity, Internet and phone services. In addition, office equipment (e.g., tables, chairs, telephones, computers, a printer) will also be provided. This sums to a total cost of $14,400.

Indirect Costs

Five percent of the total budget amount ($3,485) will be allocated to SFMC to assist with program supervision.

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