ABSTRACT

SUPPORT GROUPS FOR CAREGIVERS OF OLDER ADULTS WITH END STAGE RENAL DISEASE:

A GRANT PROPOSAL

By Mayra Ramirez

May 2015

The purpose of this grant proposal was to obtain funding to provide support groups for caregivers of older adults who have been diagnosed with End Stage Renal Disease (ESRD) in the Los Angeles area. The purpose of the support groups was to increase caregivers' level of emotional well-being as they would have a social support system in place. The caregivers would also receive psychoeducational services relating to ESRD to better understand how they could care for their loved ones.

An extensive literature review was conducted to identify effective interventions for the target population and to locate potential funders. The support groups were designed to enhance the quality of life for both caregivers and/ or their care recipients as they learn coping strategies. The actual submission of this grant was not a requirement for the successful completion of the project.

SUPPORT GROUPS FOR CAREGIVERS OF OLDER ADULTS WITH END STAGE RENAL DISEASE:

A GRANT PROPOSAL

A THESIS

Presented to the School of Social Work

California State University, Long Beach

In Partial Fulfillment

of the Requirements for the Degree

Master of Social Work

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May 2015

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ACKNOWLEDGEMENTS

I want to thank my family for supporting me throughout my academic years and graduate studies. My mother, Martha, and my father, Refugio, thank you for supporting and motivating me to continue pursuing my passion. Also thank you to all my siblings, for encouraging me in every way possible: Ulices, Arturo, Octavio, and Iliana, you all are golden! Also, thank you to my amazing support system, and my amazing friends who empowered me when I needed it the most, as completing this project was very challenging for me.

I would also like to thank my EOP counselor, Harrelson Notah, for guiding me in the social work path since my freshman year of my undergraduate degree and for his continuous support now. His direction, linkages to resources, and support throughout the years have helped me plenty. Also, I would like to thank my advisor, Dr. Nagai, for her patience and support throughout this project. Lastly, I would like to thank Sara Sgarlata for her support and valuable knowledge for this project.

My heart goes out to all individuals with chronic kidney disease and to those loving caregivers who attempt to provide the best quality of care for them.

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CHAPTER 1

INTRODUCTION

This introductory chapter consists of four sections. The first section includes an overview of the issue. The second section describes the purpose statement. The third section provides conceptual definitions. Finally, the fourth section addresses the social work and multicultural relevance.

Overview of the Issue

Chronic Kidney Disease (CKD) had a prevalence of about 10% of the adult population in the United States (Centers for Disease Control and Prevention [CDC], 2014b). Age and medical conditions are two recognized factors for CKD. Adults diagnosed with diabetes or high blood pressure were at a higher risk for CKD than adults without those issues (CDC, 2014b). The likelihood of a person developing CKD increases after 50 years of age (CDC, 2014b). Just like many illnesses that target older adults, CKD at its terminal stage is more common among adults over 70 years of age (CDC, 2014b). When symptoms of kidney failure develop, it is considered End Stage Renal Disease (CDC, 2014b). In 2011, the CDC (2014b) estimated that 113,136 patients in the United States commenced treatment for End Stage Renal Disease [ESRD].

A study conducted by Makara-Studzińska and Koślak (2011) was composed of 523 participants. In the sample, there were 323 participants with ESRD and 200 participants who did not have ESRD or kidney failure. Researchers used the Beck

Depression Inventory to measure depressive symptoms among the participants (Makara-Studzińska & Koślak, 2011). Their study found a high prevalence of depression in patients with ESRD. Makara-Studzińska and Koślak identified more depressive symptoms in ESRD patients than those without kidney failure. Makara-Studzińska and Koślak indicated that 30-50% of those undergoing dialysis treatment experienced depressive symptoms. Not only are the patients affected due to their diagnosis, but the well-being of the caregivers of the patients with ESRD would also be affected.

There is wealth of research on caregivers. The National Alliance for Caregiving (NAC] and American Association of Retired Persons (AARP; 2004) estimated 21% of the adult United States population as caregivers. The NAC and AARP national study (2004) was composed of 200 African American, 200 Hispanic, and 200 Asian American caregivers in the United States. This study found that although caregivers reported experiencing some strain in their well-being, higher rates of caregiving burden and stress were correlated with longer hours spent with the recipient of care (NAC & AARP, 2004). Some of the most common stressors caregivers endured were psychological, physical, and financial burdens (Garlo, O'Leary, Van Ness, & Fried, 2010). In Wilson-Genderson, Pruchno, and Cartwright’s (2009) study, a two-factor model was used to compare experienced caregiving burden to the influence of their well-being and also the well-being of patients with ESRD they provided care to. The researchers conducted interviews via phone with caregivers and patients with ESRD. After the caregiving burden was identified, caregivers were examined on how this burden affected their well-being. Wilson-Genderson et al. indicated an association between the caregiving burden and the affect of the patients and caregivers. Thus, negative affect experienced by both caregivers and patients were strongly associated with caregiver burden rather than caregiver satisfaction (Wilson-Genderson et al., 2009).

Another issue caregivers face includes balancing time for their personal well-being, and care for the patients (NAC & AARP, 2004). As caregivers often neglect their self-care, caregivers may also juggle multiple roles as parents, providers for their homes, and so forth. In the NAC and AARP's (2004) study, a finding suggested that 76% of individuals who were providing care also worked outside their caregiving duties. Some effects that caregivers reported while employed included being late to work, calling out sick, and leaves of absence to care for their family member (NAC & AARP, 2004). Caregiving may impact individuals in other areas of their life such as the work environment.

Research is rare on ESRD caregivers; however, there are many similarities they share with caregivers of those with chronic illness. Ramsay et al. (2012) study found high levels of stress and depression in chronically ill patients. Researchers also found the caregivers of chronically ill patients were experiencing similar symptoms as the patients with chronic illness. This study focused on different interventions practitioners could use to assist caregivers to alleviate depressive symptoms and stress (Ramsay et al., 2012). The qualitative study consisted of 12 focus groups in Georgia. The participants of the study had to meet the criteria of being a former caregiver who spent time with the recipient two times per week and assisted the recipient with daily activities such as transportation and medical management (Ramsay et al., 2012). The findings suggested that caregivers needed support programs in the group setting. In addition, the participants suggested that such programs should be facilitated by former caregivers, healthcare professionals, or clergy representatives (Ramsay et al., 2012). The data suggest that caregiver support groups should be utilized as a component of a support program for caregivers.

Purpose Statement

The purpose of this project was to develop a grant proposal and identify a funding source to create support groups for caregivers of older adults who have a diagnosis of ESRD in the Los Angeles area. This project was designed to: (a) assist caregivers of ESRD patients by allowing them to process their feelings in order to enhance their emotional well-being, (b) increase the knowledge about chronic kidney disease and its fifth stage, and (c) provide resources and referrals if and when necessary.

In these support groups, caregivers of patients with ESRD will address their emotional well-being and identify coping strategies for caregiving stress. As previously described, caregivers face unique challenges that non-caregivers do not face as they juggle multiple roles in their lives and have stress that comes with care taking (NAC & AARP, 2004). In these support groups, caregivers would be allowed to discuss these issues with other caregivers who may be experiencing similar problems. These support groups were designed to provide a supportive network for caregivers of patients with ESRD to prevent caregivers from neglecting their needs. Patients with CKD were found to face different issues compared to others who suffer from other terminal illnesses, such as prevalence in certain populations, causal factors for the illness, comorbid issues, and higher risks for other chronic illnesses (Gayomali, Sutherland, & Finkelstein, 2008). It would benefit caregivers to receive psychoeducation on such topics. In order to ensure the continuity of care of caregivers, this program will offer both psychoeducational and supportive interventions as well as referrals when necessary.

Conceptual Definitions

Chronic kidney disease (CKD) is the condition in which a person’s kidneys are damaged to the point of not being able to filter blood (CDC, 2014b).

End stage renal disease (ESRD), otherwise known as kidney failure or stage 5 of CKD, occurs when a patient’s kidneys discontinue processing waste (CDC, 2014b). Waste cannot be removed from one’s blood any longer (CDC, 2014b). The terms ESRD, kidney failure, and Stage 5 of CKD are used interchangeably in this project.

Older adults will be used to describe all adults 55 and older in this project. Although there are different sub-categories that each age-span could be broken down in, the term older adults would be used for all adults 55 and older (Haight & Gibson, 2005).

Support groups in this project refer to caregiver support groups. These caregiver support groups are established to help caregivers cope with stress of caregiving (Haight & Gibson, 2005).

Social Work and Multicultural Relevance

When social workers work with the ESRD population, race and culture play an important role particularly when working with African American and Hispanic populations. These minority populations are most at risk to develop ESRD (CDC, 2014b); therefore, social workers should be aware of possible cultural barriers or challenges they encounter such as language and socioeconomic status (National Association of Social Workers [NASW], 2008). Social workers should be knowledgeable with coping mechanisms of these minority populations. African

Americans compared to Caucasians were 3.5 more prone to develop ESRD than Caucasians (CDC, 2014b). Hispanic individuals compared to Caucasians were 1.5 times more at risk than non-Hispanics to develop ESRD (CDC, 2014b).

Several major principles of the NASW Code of Ethics that this project focused on included the empowerment of individuals who have been underserved, marginalized, or live in poverty (2008). Another Code of Ethics principle that this program focused on was dignity and respect of a person, as individuals should be treated with respect (NASW, 2008). Social workers are intended to treat all potential participants in a respectful matter. All individuals should have the right to their own self-determination (NASW, 2008). If participants decide to be part of the projected support groups, they should be treated with dignity and be allowed to leave the group at any time. The proposed program also addresses the Code of Ethics regarding services, and clients will be referred to appropriate services, as needed (NASW, 2008). The Code of Ethics also indicates that social workers must provide competent services. The social workers responsible for the support groups would have sufficient knowledge related to CKD, ESRD, older populations, and caregiver stressors and burdens associated with caregiving.

CHAPTER 2

LITERATURE REVIEW

The following literature review examines the nature of Chronic Kidney Disease (CKD) and its fifth stage, otherwise known as End Stage Renal Disease (ESRD). First, there is an overview of psychosocial effects upon patients with ESRD. Second, it includes how the psychosocial needs were neglected among caregivers of patients with ESRD, including the needs of lesbian, gay, bisexual, transgender, and queer (LGBTQ) caregivers. In this literature review, end of life issues and grief are further examined, including the responsibilities of caregivers and cultural issues, as well as the roles and responsibilities of caregivers and cultural issues. This literature review focuses on African Americans and Hispanics due to their high prevalence of ESRD.

Chronic Kidney Disease (CKD)

Overview of CKD

The Centers for Disease Control and Prevention (CDC) found kidney disease to be the ninth leading cause of death in the United States (2014b). The primary causes for kidney disease are diabetes and high blood pressure (CDC, 2014a). The CDC (2014b) found that about 1 in every 3 adults who has diabetes also has CKD. Other environmental risk factors have been correlated with such health conditions in California. Individuals residing in California may have multiple symptoms, which put them at further risk for other types of chronic conditions (California Department of Public Health

[CDPH], 2013). California's ethnic demographics indicate that about 48% of the population is Hispanic and about 8.3% are African American. Besides race, there are other barriers such as poverty that may put them more at risk for health inequities (CDPH, 2013). The CDPH (2013) identified that Latinos and African Americans are approximately twice as likely than Caucasians to have incomes below the poverty level, which contributes to the health inequity. The CDPH also found that approximately 1 in 8 Latinos and 1 in 9 African Americans have diabetes. African Americans 3.5 more at risk for developing CKD stage 5 or end stage renal disease, than their Caucasians counterparts (CDC, 2014b). Hispanics are approximately one and a half more at risk to develop CKD stage 5 than non-Hispanics (CKD, 2014).

Stages of Chronic Kidney Disease (CKD)

People with CKD may not have apparent symptoms; therefore, they must be further assessed trough urine and blood tests (CDC, 2014b). The glomerular filtration rate (GFR) is the tool utilized to indicate the stage of CKD (National Kidney Foundation, 2015). The CKD has five stages that are measured by an individual's GFR (The Renal Association, 2013). A GFR of 90 or higher would indicate a person has stage 1 of CKD. During stage 1, kidney function tends to be normal, however, treatment for this stage includes observation and blood pressure control. During stage 2 of CKD, the GRF level must be in between 60 and 89 indicating that kidney function appeared to be mildly affected. There are two phases of stage 3: (a) stage 3A would indicate a GFR of 45 to 59 and (b) stage 3B has a GFR of 30 to 44. The third stage indicates when the kidneys start to have moderate impairments. During stage 4, a person's GFR is measured between 15 and 29 and his or her kidney's experience a severe reduced level of function. Lastly, an individual’s GFR would need to be 15 or lower to have stage 5, which indicates there is severe kidney failure. The fifth stage of CKD can be prevented, as it is most diagnosed in kidneys with severe impairment. During stage 5 of CKD, hemodialysis treatments and kidney replacement are offered (The Renal Association, 2013). When kidney failure is present, CKD is considered at stage 5 and is called ESRD (ESRD; CDC, 2014).

End Stage Renal Stage (ESRD)

Overview of ESRD

There are two types of dialysis treatments for ESRD patients, which are hemodialysis and peritoneal dialysis (National Kidney Foundation, 2014). One of the most common treatment methods for ESRD patients is hemodialysis (United States Renal Data System [USRDS], 2011). Hemodialysis treatment consists of the cleansing of an individual’s blood by using a machine that has a filter known as artificial kidney or dyalizer (National Kidney Foundation, 2014). When the patients undergo treatment, they usually attend hemodialysis three times per week for about 4 hours per day (Griva, et al., 2013). When in treatment, patients can also receive continual nutritional management, medication, and recommendations for exercise (Griva et al., 2013).

The Centers for Disease Control and Prevention estimates that about 113,136 people started treatment for ESRD in 2011 (CDC, 2014b). Hypertension or diabetes was listed as a linked factor to seven of every ten new cases of ESRD (CDC, 2014b). After individuals have been diagnosed with ESRD, they can survive by either dialysis treatment or a kidney transplant (American Kidney Fund, 2014). This kidney dysfunction is considered to be permanent (American Kidney Fund, 2014). Since diabetes and hypertension are causal factors, one way to prevent ESRD is to have individuals monitor their own health (American Kidney Fund, 2014). This may include exercising on a regular basis, having a balanced diet, and consistent follow-ups with a person's primary physician (American Kidney Fund, 2014). The next section will discuss the psychological effects among patients with ESRD.

Psychological Effects Among Patients with ESRD

Tyrrell, Paturel, Cadec, Capezzali, and Poussin (2005) conducted their research on 51 participants who were 70 years or older and attended an outpatient dialysis center in Grenoble, France. A psychologist assessed the participants of the study. The following tools were used in the study: Montgomery-Asberg Depression Rating Scale (MADRS) and Mini Mental Status Examination (MMSE). Three factors that were studied in the research were cognitive abilities, depressive mood, and quality of life satisfaction. The result showed that older adult ESRD patients were frequently in a depressed mood or could suffer from cognitive impairment. The research also indicated that cognitive impairment and depression may be overlooked or neglected with this population. The researchers recommended using a trained psychologist or psychiatrist to assess psychological functions and cognitive capacities (Tyrell et al., 2005).

In addition to depressive symptoms, patients with ESRD also face other challenges such as personal losses. One qualitative research study in Texas examined 26 Mexican American women with ESRD between the ages of 33 and 55 (Tijerina, 2009). In this study, the patient's perspectives of dialysis treatment and the consequences of treatment on the disease were examined. The study indicated that common themes among patients with ESRD were losses in personal freedom, positive body image, functional capability, ability to maintain social roles, and independence. Other patient concerns included the uncertainty of being a dialysis patient and the implications it would have on the future. For example, patients worried about completing their daily life activities as a result of their condition. In addition, the researcher addressed the patients' marital conflicts and difficulty in relationships with their children. Patients noted another theme that was associated with the death of others as a result of failing to survive treatment (Tijerina, 2009). Another factor that was important was the needs of the caregivers. Caregiver needs were not mentioned in the previous study. Caregivers are essential as they may be family members of patients and undergo the burden of caregiving (NAC & AARP, 2004).

Needs of Caregivers

Pereira and Rebelo Botelho (2011) suggested personal and family needs of caregivers become neglected when taking on the caregiving role. Most of the caregiver's time is devoted to the dependent person, who may be a family member (Pereira & Rebelo Botelho, 2011). The NAC and AARP (2004) identified the unmet needs of caregivers that included not having enough personal time, stress, and difficulty in balancing roles and responsibilities in their homes. The Family Caregiver Alliance (FCA), reported that it was not unusual for caregivers to experience mild or serious depression as a result of caregiving (2014c).

Psychological and Social Needs of Caregivers

The caregiving role is known to be stressful as caregivers may suffer from burn out and they may neglect caring for themselves (Wilson-Genderson et al., 2009). A predictor of emotional stress for caregivers is living in the same home as the person they look after (NAC & AARP, 2004). Other issues caregivers experience are personal strain in their lives and social isolation (Limpawattana, Theeranut, Chindaprasirt, Sawanyawisuth, & Pimporm, 2013). Caregivers may also experience resentment if they feel that they do not have a choice in taking on the caretaking role (NAC & AARP, 2004). Often, family members fall into the role of caregiver involuntarily.

Unfortunately, family caregivers are reported to be less likely than non-caregivers to engage in self-care or preventative healthcare measures (FCA, 2014c). Family caregivers compared to non-family caregivers are at higher risk of developing depression (FCA, 2014c). Approximately 20% of family caregivers suffered from depression and 60% of the caregivers of the California's Caregiver Resource Center displayed clinical signs of depression (FCA, 2014a).

Although the data indicated that family caregivers develop depressive symptoms, the FCA (2014d) made the distinction that caregiving was not a causal factor for depression. Instead, it emphasized that the strain may come from caregivers sacrificing their own physical and emotional needs in attempt to provide the best care for their loved ones. As a result, caregivers may have feelings of anger, exhaustion, anxiety, frustration, and isolation toward their loved ones or toward themselves. Some caregivers may also experience guilt for having such feelings (FCA, 2014e).

Needs of Lesbian, Gay, Bisexual, Transgender, and Queer Caregivers

A study composed of women between the ages of 31 to 91 who identified as LGBTQ caregivers was conducted (Valenti & Katz, 2014). The researchers outreached the participants from local agencies in Los Angeles that serve the LGBTQ population via mail, email, and telephone, and conducted both qualitative and quantitative studies. A quantitative approach was used to measure the demographic data, and a qualitative approach was used to examine participants' perceptions of services and challenges for their loved ones. The study's instrument was a survey that measured caregiver stress due to discrimination by the health care system, support services, the government, and society in general. Participants also received follow up phone interviews. The study found that these participants feared future discrimination and challenges with health care providers. The study also indicated that the participants required health care professionals who were knowledgeable and supportive of LGBTQ issues (Valenti & Katz, 2014). Not only is it important to discuss the issue of LGBTQ caregivers' needs, but also informal caregivers who are often family members who are caring for their loved ones.

Roles and Responsibilities of Caregivers

Informal Caregiving

An informal caregiver is known as the person who unpredictably takes the caring role of an individual who has been diagnosed with a mental illness or a physical condition (Pereira & Rebelo Botelho, 2011). As a result, an informal caregiver unlike a paid professional assumes the responsibilities of caring for an individual (Pereira & Rebelo Botelho, 2011). Pereira and Rebelo Botelho (2011) suggested that an informal caregiver experiences situational transition taking on this new role. Not having choice to care for an individual has been a predictor of stress and burden for caregivers (NAC & AARP, 2004).

Family Caregiving

Although an informal caregiver is not necessarily associated with being a family member, the Emblem Health and the NAC (2010) stated that approximately 86%

caregivers are related to the patient. A family caregiver is defined as the person who is related to the individual and has the responsibility to assist in the daily care of another person. The majority of family caregivers tend to be women, as Emblem Health and the NAC (2010) indicated that 66% of women were family caregivers. Family members and friends provide the longest-term care in the United States. It is estimated that 58% of care recipients who are 50 years or older live at home and 20% of those individuals live with their caregivers. As a result, the government annually saves costs, because they are not paying for older adults to receive caregiving services outside their home. Family and informal caregivers contribute to an estimated cost of 375 billion dollars per year for their services, thus saving the government from paying those costs (Emblem Health & NAC, 2010). Unlike an informal caregiver, a formal caregiver receives financial compensation for his or her services to the care recipient.

Formal Caregiving

When an informal caregiver is unavailable to take care of a patient, a paid caregiver may be hired. Paid caregivers may include professionals such as personal care attendants and direct workers (Lindquist, Cameron et al., 2012). Formal caregivers are hired to help individuals with home activities (Lindquist et al., 2012). Whether a caregiver is formal or another type, caregivers have a wide range of caregiving responsibilities.

Caregiving Responsibilities

As older adults may experience more chronic health conditions, additional assistance is required of daily activities (Limpawattana et al., 2013). Caregiving responsibilities may include assistance with instrumental activities of daily living

(IADLs) such as providing transportation, taking care of household chores, preparing finances, cooking meals, assisting with medications, and managing services for care recipients (NAC & AARP, 2004). In addition, caregivers may also provide assistance with activities of daily living (ADLs). Examples of ADLs include helping patients get out of bed, getting dressed, bathing, assisting with bathroom functions, and feeding. According to the NAC and the AARP (2004), caregivers on average spend 21 hours per week looking after a person. The caregivers who spend the greatest amount of time with patients tend also to live with them. These caregivers may share poor health conditions, a lower income, or have a high school education or less (NAC & AARP, 2004).

Care recipients with ESRD, compared to those without ESRD need more assistance with daily activities. Welch et al.'s (2014) study investigated issues regarding caregiving and in home dialysis. This qualitative study was conducted in a Midwestern city in the United States. Seventy-eight participants were recruited from a daily home dialysis center. The study utilized interviews and recorded audio as their tools. This study identified that patients with ESRD may need the following caregiving services: (a) transportation, (b) meal preparation assistance, (c) management of appointments, and supplies, and (d) symptom management. Although this study focused on in home dialysis caregivers rather than outpatient dialysis caregivers, both caregivers have similar responsibilities (Welch et al., 2014). Another finding was that patients stated group therapy or support groups were beneficial for them. The researchers further inferred that caregivers may need help with dealing with negative emotions and behaviors of the person they look after (Welch et al., 2014). To add, due to CKD being a comorbid condition, patients overall functional abilities may be compromised and increase the level of burden for their caregivers (Gayomali et al., 2008). Patients with ESRD tend to be visually impaired, are unable to drive, have ambulation issues, and are at higher risk for mood disorders (Gayombali et al., 2008).

Death and Loss Issues

ESRD is an example of a chronic illness where care recipients could receive services that may prolong life but do not guarantee a good quality of life (Song et al., 2009). ESRD is known to be the last stage in CKD (CDC, 2014b). Patients with ESRD often go through a period of chronic illness before they die (FCA, 2014a). Both caregivers and care recipients explore further options and make choices (FCA, 2014a).

Types of Losses

There are various forms of losses that a caregiver of a patient with ESRD could experience. A caregiver may experience different types of losses before the care recipient dies. Caregivers may miss out on their own independence, control over their lives, freedom, lose sleep, lose relationships, experience family disharmony, or loss of companionship (FCA, 2014e). The Family Caregiver Alliance (2014d) states that caregivers need to identify their losses to acknowledge their grief over these losses. Feelings of grief can then lead to sadness, depression, guilt, and sleeplessness (FCA, 2014e). The FCA (2014a) recognizes that receiving assistance from a support group can help individuals through their grieving process and could engage them in therapeutic processes such as writing in journals, meditation, and relationship exercises (FCA, 2014a).

Psychological Impact

Another factor of burden for caregivers of patients with ESRD is comorbidity due to their chronic illness (Gayomali et al., 2008). Although the mortality rate for people with ESRD has declined in the two decades, it continues to be significant especially for individuals who are in between the ages of 30 and 50 who are expected to live one third less than those individuals who do not have ESRD (United States Renal Data System, 2014). According to the United States Renal Data System (2014) about 54% of ESRD patients receiving hemodialysis treatment survived after a 3-year period following the onset of ESRD. Caregivers who care for people with ESRD are likely to go through the end of life phase due to the mortality prevalence. Caregivers can go through change after their care recipients with ESRD have died. Pruchno, Cartwright, and Wilson-Genderson's (2009) qualitative study was composed of 315 couples including ESRD patients, and their wives who provided care for them. The purpose of this study was to gain a better understanding of end life practices for patients with an ESRD diagnosis. The instrument used in this qualitative study was phone interviews. The participants were contacted for a baseline interview and then an annual follow up interview. If the care recipient died, their spouses would be contacted for interviews. The study found that going from caregiving to widowhood was complicated for the caregivers. Caregivers often experienced depressive symptoms following the death of their loved one with ESRD (Pruchno et al., 2009). The study suggested that depressive symptoms among caregivers may be higher after the death of their loved one with ESRD than before their death. The study also indicated that the participants who had higher levels of caregiving stress experienced more relief after the death of their spouse than participants with lower levels of caregiving stress (Pruchno et al., 2009).

Cultural Issues

ESRD impacts different ethnic groups. According to Land and Guada's (2011) study, caregiver burden varies among different cultures and ethnic groups. Practitioners should be aware of culturally sensitive practices when providing services to assist caregivers with relieving their stress. The burden of caring has been associated with amount of time caregivers spend with caring for recipients and living with them (NAC & AARP, 2004). Moreover, African American and Hispanic caregivers are more likely to spend 8 hours or more per week providing care (NAC & AARP, 2004). Hispanic caregivers also reported living with the person they cared for compared to caregivers of other ethnicities (NAC & AARP, 2004). Caregivers experienced burden living with the care recipient (NAC & AARP, 2004).

African American Population

African Americans compared to Caucasians are at greater risk of developing ESRD (CDC, 2014). Tanyi and Werner's (2007) qualitative study was composed of 58 participants from Minnesota. There were 31 African American and 27 Caucasian women participants. All of these participants had ESRD and were undergoing dialysis treatment. It appeared that African American women coped more spiritually than Caucasian women. As a result of their spirituality, African American women were more content with their lives and were positive about their future than their Caucasian counterparts (Tanyi & Werner, 2007).

As there are growing numbers of African American individuals with ESRD, it is highly likely that their informal caregivers may be family members. In another study, 125 African American with ESRD were participants in a randomized controlled study in Pennsylvania. The ESRD patients in the study were required to provide a decision maker or surrogate to meet the criteria of the study. The study's tool was the Sharing Patients' Illness Representations to Increase Trust (SPIRIT) intervention that addressed communication on end of life issues (Song et al., 2009). The SPIRIT intervention approach was used to examine the patterns of communication between surrogate decision makers and ESRD patients. The SPIRIT intervention was about an hour-long interview process with the surrogate. One of the study's findings suggested that there was effectiveness in dyad congruence regarding the surrogate's decision-making abilities. Another important consideration is African American informal caregivers and how they find purpose in caretaking.

A qualitative study in the United States recruited 300 African American participants who were providing unpaid care for older adults (Sheridan, Burley, Hendricks, & Rose, 2014). These caregivers were part of a 60-90 minute interview held at their homes. Time dependence, developmental, social, and physical burden were found to have high significant scores of burden in this study for African American caregivers (Sheridan et al., 2014). This study also indicated low levels of distress in these African American caregivers. This study also supported that spirituality and religion were important resources for these participants. This suggested that African American caregivers that participated in the study found it rewarding to look after someone else (Sheridan et al., 2014).

Hispanic Population

Mexican American s living in the United States are six times more likely to be diagnosed with ESRD than non-Hispanic Caucasian-Americans; this is primarily due to higher incidences of type two diabetes among this population (as cited in Tijerina, 2009). Tijerina's (2009) qualitative study also suggested that an approach social workers may find useful working with Mexican Americans in treatment for ESRD is the social constructivist approach. According to Tijerina (2009), this strategy could be beneficial for social workers to understand how patients undergo treatment and create meaning of their reality.

The importance of seeking outside support from family members may be more of a westernized notion than in other cultures. For instance, seeking support from professionals may vary in different cultures. A study conducted with Hispanic participants indicated that initially, they were suspicious of professionals and were hesitant to confide in them (Shatell, Hamilton, Starr, Jenkins, & Hinderliter, 2008). Hispanics were also more likely to adhere to services if the professional spoke their same language (Shatell et al., 2008). An interpreter would not help the situation, as the client's focus would be on trusting the interpreter rather than the practitioner. It also suggested that if there was an interpreter, the focus should not be to them because then clients begin trusting interpreters more than on practitioners (Shatell et al., 2008).

In another study on participants of Mexican descent Koerner, Shirai, and Pedroza (2013) examined to understand caregivers' religious and spiritual beliefs and how these beliefs helped or impeded their caretaking abilities. The study was composed of 58 caregivers of Mexican descent in Arizona. The finding of this study indicated that the participants believed that their spirituality was very valuable in helping them manage their caregiving responsibilities (Koerner et al., 2013).

In a similar study composed of 66 Mexican and Catholic caregivers, it was found that religiosity had both positive and negative impacts on caregiver mental health and caregiver burden (Herrera, Lee, Nanyonjo, Laufman, & Torres-Vigil, 2009). Caregivers who identified as having more religiosity were less likely to perceive caregiving as a burden. Furthermore, participants who reported less religiosity reported worse mental health outcomes. This study also identified that poor mental health is correlated to caregiver burden (Herrera et al., 2009). Not only is it important to address unique needs of caregivers of at risk populations, but also how to refer caregivers for appropriate supportive services.

In order for caregivers to address their unmet caregiver needs, they must be referred to the appropriate supportive services. Montgomery, Jung, and Rowe (2011) highlighted the importance of identifying resources for caregivers to appropriately refer them to supportive services to address their neglected needs. There are different kinds of supportive services. In a study by Donorfio, Vetter, and Vracevic (2011), the researchers compared differences between three different support approaches which included a home –based literature group, caregiver support group and a creative movement group. The study was composed of 16 women caregivers. This study supported that caregiver support groups are the most dominating interventions for treating caregiver stress and burden. To add, Donorfio, et al., (2011) supported previous literature that indicated that caregiver support are beneficial in relieving caregiver burden and stress.

Overall, this extensive literature review explored the nature and prevalence of chronic kidney disease and end stage renal disease in the United States. It also expanded on caregivers’ roles and responsibilities toward their loved ones. It also made the differentiation between informal and formal caregiving. Through this research, it was found that caregivers have psychological and social unmet needs that may be disregarded due to their role of caretaking. Different types of caregiving styles were explored as well. Lastly, the more at risk populations, African Americans and Hispanics, were explored. This literature review indicated the need for caregivers to have a support program to relieve caregiving stress.

CHAPTER 3

METHODS

Interventions and Nature of the Problem

This project was designed to establish support groups for individuals who are caregivers for older adults diagnosed with end stage renal disease (ESRD) in the Los Angeles area. There are 6 groups in a period of 12 months. The total enrollment for each group may not exceed 15 participants to ensure group cohesion. The support groups will be closed groups; this is intended to build group cohesion between group members, as it will be both a psychoeducational and processing group. There will be two groups; one group will be held in Spanish and the other in English.

The groups will consist of weekly one-hour meetings for a total of 12 meetings each. The weekly group meetings will be held on Mondays from 11 am to 12 pm. It may be convenient to have the groups at these times, because this may be the time within the hours of hemodialysis treatment that caregivers may have available to partake in a support group. The support groups will be held at El Centro de Ayuda (ECDA), host agency of this project. This location is selected to ensure the convenience of the participants due to its proximity, a walking distance from the White Memorial Hospital and other dialysis centers. It can save caregivers gas and driving time. Taking proximity into consideration can be strategic because it may encourage potential members to attend if the location may be at a fair range for potential participants.

Target Population

The target populations for the support groups are caregivers of individuals who have a diagnosis of ESRD or kidney failure, who are over 60 years old, and who are undergoing dialysis treatment or waiting for a kidney transplant. This project targets caregivers who are at least 18 years old, who reside in the Los Angeles area, and who speak English or Spanish. Informal, formal, and family caregivers of patients with ESRD also meet the criteria as a specific caregiver title will not be enforced in the criteria for the groups.

Due to the finding that two known vulnerable populations to ESRD are African Americans and Hispanics (CDC, 2014), the proposed groups will be offered in both Spanish and English; however, persons from any ethnic and racial groups, as well as religious, class, and sexual orientation, are welcomed. To be part of any group, the caregiver must be caretaking for an individual with chronic kidney disease stage 5 or end stage renal disease (ESRD). The groups are targeting caregivers of a specific population but will also be unique by being provided in two languages.

Host Agency

El Centro de Ayuda (ECDA) is located in Boyle Heights which is part of Los Angeles County. Boyle Heights is one of the oldest areas in Los Angeles, that has a history of large Mexican populations in the United States (ECDA, n.d.b.). ECDA's mission is to promote individuals emotional, social, academic, and economic self-sufficiency through an array of human services (ECDA, 2013). ECDA provides a wide range of services to the East/North-East Los Angeles community of individuals with low socio-economic status (ECDA, n.d.b). ECDA was established in 1981 and began as a

Substance Abuse Treatment Center (SATC) and evolved to ECDA in 1996 (ECDA, n.d.b). ECDA has a history of providing psychoeducational and processing support groups in both English and Spanish languages (Sara Sgarlata January 28, 2015). Currently, ECDA does not provide support group for caregivers, however they do provide an array of psychoeducational groups such as parenting, female domestic violence for batterers, male domestic violence for batterers, drug diversion and anger management groups that are offered in both languages (ECDA, 2013). Although the population being served may primarily be Hispanic, ECDA does not exclude individuals and attempts to welcome individuals in need of services and also provides English services as well (Sara Sgarlata, January 28, 2015).

With the support from Sara Sgarlata, Program Coordinator at ECDA, the following information of the agency was gathered (personal communication, January 28, 2015). EDCA had provided mental health services under the supervision of a marriage and family therapist and offered services for individuals with substance abuse, domestic violence batterers, and parenting but also support groups for victims of domestic violence and for individuals who lost loved ones. When a new supervisor joined ECDA's billing system services changed. The program was no longer billing for Medi-Cal and transitioned to a fee for service program. The program coordinator highlighted that some support groups were no longer offered such as the grief groups. It was suggested that they were no longer offered due to funding and not to lack of need in the population.

Identification of Potential Funding Source

This grant writer conducted an Internet search for local, state, and federal potential funding candidates. The Foundation Center database was utilized to find potential funders for this grant. In the foundation center database some of the key words to identify potential grantors included: *support groups, older adults*, *adults*, *minorities, and*, *kidney disease*. In search for support group funders, two foundations were identified. The first foundation identified was the Action Council of Monterey Council. This organization focused primarily on economic and social justice. The Action Council of Monterey Council provides fiscal sponsorship to new programs to maintain sustainability (Action Inspiring Change, 2015). This organization's population of interest for developed program included women, children, youth, and minorities in the Monterey County (Action Inspiring Change, 2015). Although this organization promoted services for minorities, it was not found to also support older adults or caregivers. The second was the May and Stanley Smith Charitable Trust. This organization's identified focused populations for supportive services included children and youth, the elder population, adults and families, and people with disabilities. The May and Stanley Smith Charitable Trust also funds programs in California (May & Stanley Smith Charitable Trust, n.d.).

Criteria for Actual Grant

The May and Stanley Smith Charitable Trust was selected as a potential funder for this project. One of the identified populations this granter supports is the elderly population (May & Stanley Smith Charitable Trust, n.d.). The May and Stanley Charitable Trust focuses on issues among the elderly population and support services (May & Stanley Smith Charitable Trust, n.d.). It also highlights the importance of informal and formal caregiving at both the individual and community levels (May & Stanley Smith Charitable Trust, n.d.).

The May and Stanley Smith Charitable Trust promotes assisting the identified populations with supportive services. This grant would allow older adults with ESRD to be better cared for by their caregivers as they would receive support and also provide support to them. To add, this granter's guidelines include funding innovative programs (May & Stanley Smith Charitable Trust, n.d.). The purpose of the May and Stanley Smith Charitable Trust matches with the purpose of this project, which includes providing supportive services through caregiver support groups for the elder population.

The May and Stanley Smith Charitable Trust and the host agency, El Centro de Ayuda (ECDA), have similar characteristics in their mission statements. ECDA's mission includes the ability to promote social, emotional, academic and economic self-sufficiency through a range of human services (ECDA, 2013). Similarly, the May and Stanley Smith Charitable Trust's mission includes supporting organizations that help their targeted populations such as elders, in improving quality of life, promotes self-sufficiency and help individuals reach their highest potential in life (May and Stanley Smith Charitable trust, n.d.).

Description of Selected Foundation

The May and Stanley Smith Charitable Trust was established in 1989 (May & Stanley Smith Charitable Trust, n.d.). The trust's stewards envisioned a community in which a persons' strengths, richness, and well-being, would be recognized and further motivated, and empowered (May & Stanley Smith Charitable Trust, n.d.). The trust has strategic plan guidelines from 2014. The plan attempted to focus, enhance, and provide significant positive changes to individuals and communities.

Needs Assessment

The literature review found that the particular ethnic groups such as African Americans and Hispanics are more prone to developing ESRD (CDC, 2014b). The reason for developing both Spanish and English groups was due to this finding that these populations are more at risk than their Caucasian counterparts. The literature review also indicated that caregivers are faced with burden and stress in their daily living and have difficulty in managing multiple roles (NAC & AARP, 2004). To add, other individuals are faced with informal caregiving in which they were not presented with the option to be a caregiver, making their role more stressful (NAC & AARP, 2004). The proposed program was designed to address these concerns and reduce their stressors. In Pereira and Rebelo Botelho's (2011) study, the researchers indicated that caregivers had a tendency to neglect their personal needs when caregiving. This proposed program was also designed to address personal unmet needs of caregivers through support groups.

Proposed Budget

The proposed financial budget for this project is approximately $100,550 for one year. However, only nine months of the year will be used to provide caregiver support groups for three different cycles. There will be three months between those cycles that will be used for outreach and group related activities. The grant funds will be used to develop two unique support groups for caregivers of patients with ESRD. The personnel expenses include the salaries of two part-time master's level social workers ($17, 472 annual salary + $3,319.50 PTE benefits x 2 workers= $41,583). The master's level social workers will be responsible for developing two different curriculums, one for Spanish speaking participants, and one for English-speaking participants that are culturally sensitive. One social worker will be bilingual. The master's level social workers must also be knowledgeable and have experience on older adults with chronic illness. These master's level social workers will be supervised by a program coordinator who will also be a master's level social worker already employed at the host agency. The program coordinator services to the program will be in-kind, however the program coordinator will receive ten percent of the FTE. The program executive director will be responsible for overseeing the program and will receive ten percent of the FTE. Both the program coordinator and the executive director will receive ten percent of their full-time equivalent for their participation in this project. An outside evaluator will be responsible for an annual program evaluation and will receive five percent of the FTE. An estimated $14,860 will be used to cover direct cost of the program such as office supplies, computers, supplies, phone lines, internet, printing, training, and rent (See Appendix A).

Evaluation

There will be different tools used to measure the group's purpose such as pre-tests and post-tests during the first and last sessions. The entrance and exit interviews for caregivers will also be conducted. In addition voluntary satisfaction surveys will be given to caregivers to complete at the end of the program. The pre-test and post-test will measure caregiver's wellbeing and overall knowledge of ESRD, including caregiver roles and stress. Similarly, a post-test will be given to caregivers of the group to complete once they have culminated 12 sessions of the caregiver group. Pre-tests and post-test will be used to compare the scores and based on the responses, improve the program. The entrance and exit interviews and satisfaction surveys will give caregivers an opportunity to provide their input of the group.

To determine the success of the program, attendance and completion rates will also be recorded. There will be attendance sheets that will record presence of group participants that will then be transcribed to ECDA’s database. For purposes of future funding and the continuation of the program, there will be an attendance tracking record of all group participants that will begin during the first entrance interview until the exit interview.

CHAPTER 4

GRANT PROPOSAL

Proposal Summary

This grant project seeks $100,550 in funding from the May and Stanley Smith Charitable Trust fund. The purpose of this proposal is to receive funding for two 12-week support groups for caregivers that will be provided at El Centro de Ayuda (ECDA), in the city of Los Angeles, for three different cycles. There will be a total of 6 groups offered throughout the year with two groups going on at a time (one Spanish and one in English). At the beginning and after the first and second cycles, one month will be used strategically for program evaluation, recruitment for new participants, and intake appointments for potential participants. The two support groups in each cycle are designed for caregivers of older adults with a chronic kidney condition, end stage renal disease (ESRD). These support groups may not exceed more than 15 participants each to ensure group cohesion. The two groups will provide supportive psychoeducational interventions based on the current and best evidenced based practices for group settings. One group will target English-speaking caregivers, and the other will target Spanish-speaking caregivers. The curriculum for each group will be modified to address culturally sensitive topics, such as spirituality in different cultural groups, that allow group members to express and process their feelings in a safe environment.

Introduction

El Centro de Ayuda (ECDA) is a grassroots agency established in 1981 and, although it was originally a substance abuse treatment center, this agency developed other programs over the years. ECDA acknowledged the importance of partnerships and had collaborated with private, public, and non-profit organizations to develop effective programs in the community. ECDA had worked collaboratively with agencies like the Gang Reduction and Youth Development and Plaza de la Raza. ECDA had received numerous awards in the last years for their performance (ECDA, n.d.a). On June 2013, ECDA received the Four-Star award for outstanding contractual performance for their family source center program. To add, ECDA has been awarded with a four-start performance award for the last three consecutive years (EDCA, n.d.b). ECDA has also received awards such as the California Award of Performance Excellence.

ECDA's mission is to provide human services to assist individuals in the following areas: social, emotional, academic, and self-sufficiency (ECDA, 2013). Similarly, the May and Stanley Smith Charitable Trust, the selected funder of this project, promotes independence and strives to allow individuals to reach their full potential. The funder's other area of interest includes providing direct services (May and Stanley Smith Charitable trust, n.d.). ECDA has experienced providing direct services to the community since its establishment (ECDA, n.d.b). The May and Stanley Smith Charitable Trust also funds supportive services for older adults (May and Stanley Smith Charitable trust, n.d.). This grant is primarily addressing the issue of older adults and is created to obtain funding for caregiving support groups.

Needs Assessment

The Centers for Disease and Prevention (2014b) indicated that African Americans and Hispanic populations are more at risk for ESRD. Therefore, the special issues that Latinos and African Americans face should be brought too the forefront as they may have problems concerning with service providers who do not understand their culture. Because African Americans and Hispanics tend to have higher risks of ESRD (CDC, 2014b) than Caucasians, the need to provide services for them was emphasized. Focusing on the needs of African American and Hispanic caregivers with ESRD was a highlight of this grant proposal and the hope was to inspire cultural sensitivity to health professionals providing services for them.

Emblem Health and the National Alliance of Caregiving (NAC; 2010) indicated that about 86% of caregivers are related to the individuals they looked after. Family caregivers were reported to engage in less self-care practices and were more likely to avoid routine doctor check-ups (Family Caregiving Alliance, 2014). The support groups that this grant proposal is advocating for will address topics of self-care and provide a safe environment for individuals to self-disclose. Another purpose of the support group is to provide caregivers with psychoeducation about CKD stage five. It may be beneficial for caretakers to have that information so they could provide the best quality of care for their loved ones.

Limpawattana, Theeranut, Chindaprasirt, and Sawanyawisuth (2013) indicated that due to the increase of illnesses in older adults, they would require additional assistance with their daily activities. Gayomali, Sutherland, and Finkelstein (2008) identified an association between various comorbid conditions with CKD, which were linked to increased caregiver burden. ESRD patients tend to: (a) be visually impaired, (b) be unable to drive, (c) be at higher risks for mood disorders, and (d) have ambulation issues (Gayomali, et al., 2008). If caregivers are allowed to process these experiences in a support group, they are better able to handle stresses of caregiving (Donorfio, Vetter, & Vracevic, 2011).

Caregivers should also be educated on the comorbid conditions ESRD patients may be experience. This could help caregivers in their daily interactions with the family members they look after. The NAC and AARP (2004) indicated that caregivers' responsibilities include assisting with IADLs and ADLs. It may improve caregivers' empathy for family members they look after.

Program Objectives

The goal of these support groups is to increase caregivers' ability to cope with stresses of caring for patients diagnosed with ESRD.

In order to achieve this goal, the following objectives will be accomplished.

Objective 1: The support groups will improve the caregiver's emotional well-being by 10% as evidenced by a pre-test and post-test and satisfaction surveys.

Objective 2: Increase the participant's knowledge of ESRD by 15% by measuring scores on pre and post-tests.

Objective 3: To recruit 15 participants for each group and 70% of the participants will complete the group as evidenced by the attendance record and number of completion certificate given.

Timeline

Month 1

1. Hire two MSW social workers.

2. MSW social workers will meet with ECDA’s MSW coordinator for weekly supervision.

3. Develop the Program and curricula for Spanish and English groups.

4. Outreach by distributing flyers of the new support groups and advertise the groups on El Centro de Ayuda’s website.

5. Screen referrals.

6. Schedule interviews for initial assessments.

7. Conduct initial assessment evaluation for caregivers upon commencement.

Month 2

1. Commence the first support group for caregivers.

2. Conduct pre-test and entrance.

3. MSW social workers will continue to meet with MSW coordinator for weekly supervision.

4. Train MSW interns for caregiver group.

5. Allow MSW interns to co-facilitate the groups.

6. MSW social workers will continue to meet with MSW coordinator for weekly supervision.

Month 3

1. Continue caregiver support group.

2. MSW social workers will continue to meet with ECDA's MSW coordinator for weekly supervision.

3. Continue support group outreach.

4. Screen referrals for the next cycle of support groups.

Month 4

1. Continue support group for caregivers.

2. MSW social workers will continue to meet with EDCA's MSW coordinator for weekly supervision.

3. Continue support group outreach through community outreach fairs and website.

4. Begin initial assessments for caregiver groups.

5. Terminate the first cycle of caregiving groups.

6. Conduct the post-test and exit interviews for group participants and allow them to complete a satisfaction survey.

Month 5

1. MSW social workers will continue to meet with ECDA’s MSW coordinator for weekly supervision.

2. Evaluate and improve the program based on the results of tests, interviews, and survey.

3. Continue screening referrals.
4. Schedule appointments for caregivers initial assessments.
5. Conduct caregiver’s initial assessment for caregivers support groups.

Month 6

1. Commence new cycle of caregiver support groups.

2. Conduct the pre-test and entrance interview for the second cycle of groups.

3. MSW social workers will continue to meet with ECDA’s MSW coordinator for weekly supervision.

4. Distribute support group flyers to the community for outreach.

Month 7

1. Continue caregiver’s support group

2. MSW social workers will continue to meet with ECDA’s MSW coordinator for weekly supervision.

3. Distribute flyers for continued outreach.

Month 8

1. Terminate the second cycle of caregiver support groups.
2. Conduct the post-tests.
3. Schedule exit interviews for individuals who completed the group.
4. MSW social workers will continue meeting with ECDA's MSW coordinator for weekly supervision.

Month 9

1. Continue scheduling the exit interviews.
2. Conduct exit interviews with group participants and allow them to complete a satisfaction survey.
3. Evaluate and improve the program based on the results of tests, interviews, and survey.
4. MSW social workers will continue to meet with ECDA's MSW coordinator for weekly supervision.
5. Begin scheduling initial assessment appointments.

Month 10

1. Commence the last cycle of the for caregiver support groups.
2. Conduct the pre-test and entrance interview for the cycle of groups.

3. MSW social workers will continue to meet with ECDA’s MSW coordinator for weekly supervision.

4. Continue distributing support group flyers to the community for outreach.

Month 11

1. Continue caregiver support group.
2. MSW social workers will continue to meet with ECDA’s MSW coordinator for weekly supervision.
3. Continue outreach services for caregiving group.
4. Continue screening referrals for caregiver support group.
5. Commence scheduling new appointment for the new cycle of support groups.

Month 12

1. Terminate the last cycle of caregiver support groups.

2. Conduct the post-test and exit interviews for caregiver support groups and allow caregivers to complete satisfaction surveys.

3. MSW social workers will continue to meet with ECDA’s MSW social workers for weekly supervision.

4. MSW social workers will evaluate the program.

There will be different ways to assess whether the above objectives have been met. For example in objective 1, group members will have an commencement interview in which they will complete a pre-test that measures emotional wellbeing and overall knowledge of ESRD before the beginning of the group. The group members will be allowed to take the pre-test 15 minutes before the interview with the MSW social workers. Participants will then partake in a dialogue interview that will be used to screen the potential group members for the criteria of the group. After completing 12 sessions, the participants will be evaluated with the post-test. When the group terminates, participants will take a post-test that will re-evaluate their emotional wellbeing and their general ERSD knowledge 15 minutes prior to their exit interview. The exit interview will be the final dialogue between the MSW social workers and the participants, where they will be able to express any final thoughts about the group that was not addressed in the post-test and final closure if necessary. After caregivers conclude exit interviews, they will be allowed and encouraged to complete a satisfaction survey that will serve to measure overall quality of the support groups. The satisfaction questionnaire will include questions about their emotional well-being. They will also be evaluated after they have completed the 12 sessions. The survey will include several demographic questions such as age, gender, ethnicity, and type of caregiver. It will also include “yes” or “no” questions for example, “This program helped me relieve daily stress as a caregiver”, “I learned coping skills to help with my burden and stress in this support group”, and “I am able to manage multiple roles I have because of everything I learned in this group”. On the survey members will also be given extra space to explain their answers.

Objective 2 will be measured with the pre and post-tests that will be completed during the initial and exit interviews. The pre and post- tests would include “yes” or “no” responses and to further explain. Examples of questions regarding emotional well-being include, “Do I put other people’s needs before mine?”. Another question would be “I tend to stress over my multiple roles." A third question could be "I cannot get other things done when I am caregiving.", and lastly, "I often feel depressed when I place other's needs before my own."

The pre and post-tests will also have a specific section regarding issues of ESRD. Participants will be asked five general questions about ESRD related issues such as the different stages in CKD, the at risk populations, the daily living activities, chronic illness', its correlation with depression, and different types of losses.

An attendance sheet will be used to track whether objective 3 was met. The sheet will allow the facilitators to keep record of participant's attendance and date of completion. For every group session, the group members will have to sign-in. Participants will only be permitted to sign-in within the first 15 minutes of group.

The group has different purposes, however the overall purpose is to improve wellbeing of caregivers or participants. Unmet needs identified caregivers in other studies include: no time for themselves, difficulty in managing physical and emotional stress and, juggling multiple roles (NAC & AARP, 2004). To add, it was noted that when individuals take the caregiving role they might neglect their personal and familial needs (Pereira & Rebelo Botelho, 2011). Since caregivers may not consider their own wellbeing, the groups are intended to provide caregivers the opportunity to express their feelings about their experiences in caregiving.

Methods

The research conducted by Ramsay et al. (2012) suggested that caregivers may benefit from support groups. This proposed project is designed to provide support groups for caregivers who are caring for individuals diagnosed with ESRD. To add, the researchers suggested that group facilitators should have prior experience with the population served. Such workers could be former caregivers, healthcare professionals, and or clergy representatives (Ramsay et al., 2012). This grant will provide funding to hire individuals with this background to provide quality support for these caregivers. Another study supported professionals that spoke the same language as clients were able to foster a deeper connection (Shatell et al., 2008). Facilitators of the groups are required to have prior knowledge of the population, be culturally competent, and be able to speak the same language as the caregivers.

Evaluation

The support groups will be evaluated for their success rate in reducing caregiver stress, attendance, and retention. The measurement tool that will be used will be ECDA's pre and post-test that will be completed before the initial and exit interviews followed by a satisfaction survey once participants have completed their 12 week sessions. ECDA's current surveys will be updated to measure the program objectives. ECDA currently uses pre and post-tests by having an intake interview when the group members commence the services and an exit interview before receiving their completion certificate. The interviews also allow members to express what they liked or disliked about the support group. The interviews for the intended caregiver support groups will be conducted after participants complete their satisfaction surveys. During the interviews, participants will be able to voice their concerns and disclose if their needs have been met.

The overall success of the program will also be evaluated by three factors: participant registration, participant attendance, and participant completion. The registration numbers will indicate whether caregivers in the community want to be part of this support or whether more advertising or outreach are needed. Good numbers of attendance will determine whether this program will continue to be subsidized. If members are attending regularly, they may be benefit from the group. A lack of attendance would be a good cause for group facilitators to follow-up on what is occurring with the quality of services. Finally, a large number that have completed 12 weeks of support groups would suggest that many participants have benefitted from this program. If there is a 70% or more completion rate, the group will be determined to be successful. A high number in attendance would suggest that this program should continue to be funded by other grant funders.

Budget

A total of $100,550 will be requested for one year of funding for this program. This will cover the salary and benefits of an executive director, a program coordinator, two social workers, a program evaluator, and other expenses.

Personnel Costs

Executive Director: The executive director will receive 10% of the full time equivalent salary for overseeing the entire program (10% FTE of $82,626 = $8,263). The executive director's responsibility is to supervise the entire program.

Program Coordinator: The program coordinator would be an MSW social worker who will receive 10% of full-time equivalent of $55,000 group facilitators (10% FTE of $55,00 = $5,500). The program coordinator's responsibility is to supervise the newly hired MSW social workers.

Social Workers: There will be two master's level social workers with a yearly salary of 20, 633.50 each including part-time equivalent benefits. Their salaries and benefits are (2 employees @ $42/hour x 8 hrs/week x 52 weeks = $34,944, with $6,639.00 in part- time equivalent benefits). The social workers will be responsible for a newly developed curriculum with modules based on the best evidence-based practices that are culturally sensitive and conducting the pre-test and post-test during both commencement and exit interviews. They will collaborate and work with master's level (MSW) interns but will not supervise them as ECDA already provides supervision for MSW interns. The total personnel expense including benefits is $70,496.

Program Evaluator: An outside evaluator will be contracted to perform a program evaluation per year. The outside program evaluator's salary will be $850 (5% FTE @ $17,000). The purpose of the use of an outside evaluator is to maintain credibility, integrity, and reduce the risk of a biased evaluation for this program.

Non-Personnel Expense

The total cost for direct expenses is $14,860 and will cover office supplies ($200 per month x 12 = $2,400), expandable equipment ($1,000), program supplies ($500), phone and Internet ($100 per month x 12 = 1,200), printing ($200), trainings ($160), and rent ($600 x 12 = $7,200). In addition, there would be indirect expense for this program. The total amount for indirect expenses is $15,239. Indirect expenses for this program include administration, human resources, payroll, accounting, and supervision (@10% of the overall cost of the program = $8,253). The evaluation ($6,876/year) and liability insurance ($110/year) are also indirect expenses. The total amount of indirect expenses would total $15,239.

The two assigned MSW interns and the two volunteers will demonstrate program financial savings as they are not paid positions. The interns and volunteers will be recruited from ECDA's internship program that trains and prepares master's level interns and also includes volunteers. MSW Interns will be allowed to co-facilitate and conduct pre and post interviews after the MSW staff have trained them. The funding will cover $160 for four hourly trainings for the interns and volunteers (Appendix A).

CHAPTER 5

DISCUSSION

Lessons Learned

Although chronic kidney disease is the ninth leading cause of death in the United States (CDC, 2014), there was scarcity of literature that discussed the final stages of the disease. It was also challenging to find research articles concerning caregivers' experiences looking after their family members with ESRD. This writer gained much knowledge about grant writing for support groups for caregivers of individuals with CKD and ESRD. The grant writer assessed that there was a need given the scarcity of support groups offered to this population in Los Angeles and limited research of such interventions. After finding all the appropriate data to support the caregivers' needs, the grant writer was motivated to develop a grant proposal for this endeavor. At first, the grant writer thought Spanish groups would be more appropriate but, after learning about the prevalence of ESRD in African Americans in the United States (CDC, 2014), there would also be a need for English-speaking groups.

Analysis of Process

One of the challenges with writing this grant proposal was the limited research on caregiver burden, particularly for caregivers of ESRD patients. Considering that ESRD is a chronic illness at its terminal stage, this writer found relevant research about caregivers caring for patients with chronic and terminal illness. However, there were many studies that explained the correlation between caregiving and stress.

One issue that surprised this grant writer was the ESRD patients' and caregivers' reliance on spirituality (Tanyi & Werner 2007; Sheridan et al., 2014; Koerner et al., 2013). This writer assessed that there should be more studies addressing this phenomenon within this population. Also, studies regarding spirituality healing versus social support in support groups should be compared. It should be further investigated if these populations would benefit more from spiritual interventions rather than support groups when dealing with caregiver stress and burden.

The literature review primarily focused on both caregivers who were caring for individuals with terminal illnesses and ESRD. Due to the limited research of ESRD caregivers, studies about patients were found to gain a better understanding of the daily functions of caregivers given that they would provide care for these individuals. It was important to find information about the actual population with ESRD because it provided insight to what it would be like to care for an individual experiencing ESRD. Through different studies, unique ADLs and IADLs were identified due to patients' comorbidity and their tendency for blindness and inability to drive. With this solid information and a several of studies that identified burden in the caregiving populations (Gayomali et al., 2008), this writer was able to construct a needs assessment for the purpose of this grant proposal.

Strategies to Enhance the Project and Recommendations

This grant writer assessed that the proposed grant could be improved by talking with professionals who work directly with caregivers with ESRD. As previously stated, professionals such as social workers were not contacted due to their busy work loads.

This grant writer understood that caregiver support groups are not the only type of supportive services that caregivers can benefit from; however, it was found to be the most prominent type (Donorfio, et al., 2011). This grant writer assessed that more research should investigate more interventions that would assist ESRD caregivers fulfill their unmet needs. Thus, this grant proposal did not go over different treatment modalities such as counseling and other types of groups such as self-help groups. Investigating more supportive services will ultimately assist ESRD caregivers. If there is more research for this population, grant writers could be more effective in addressing more specific needs.

Implications for Social Work and Multicultural Practice

Social workers working with ESRD patients have different responsibilities including assisting patients and families cope with their illness (Davita, 2015). Additionally, social workers educate individuals on how to adjust to changes of treatment (Davita, 2015). As social workers continue to work with the ESRD population, they are providing supportive services to address client's wellbeing. Since ESRD patients are receiving direct services from their social workers, caregivers of these patients should also be provided with supportive services to improve both the caregiver and patient well-being. The Code of Ethics 1.01, states the commitment that social workers work towards enhancing their clients' wellbeing National Association of Social Workers [NASW], 2008).

Also, the Code of Ethics on cultural competence, there are underlying issues regarding diversity and oppression that should be highlighted when working with underserved populations. Due to the higher prevalence of African Americans and Hispanics with ESRD, social workers are more likely to work with African Americans and Hispanics that experience having ESRD or their caregivers. The proposed groups are expected to provide linguistically relevant services for these populations. Based on previous studies it is known that Hispanics people have distrust self-disclosing to service providers. Social workers should be competent in building rapport with such clients to provide them with optimum support. In other studies, it was noted that African Americans caregivers were more spiritual compared to the general population. Social workers can use this knowledge to address spirituality for African Americans in all support group sessions.

The proposed support groups are intended to benefit caregivers of patients with ESRD. As a result of caregivers addressing their unmet needs, patients may receive better quality of care from their caregivers. Due to the lack of literature of this specific population of caregivers, it would be difficult to influence policy to mobilize the existence of these support groups. In the future, there should be more research conducted working with the ESRD population and finding interventions that help ease caregiver stress, as beneficiaries of these groups would be both caregivers and their patients they care for that suffer from ESRD.

Conclusion

Despite the challenges in having personal communication with social workers, adequate research was found to develop a needs assessment for this population. The introduction of this grant proposal provides a general overview of the issue of caregiver burden and stress among ESRD patients. The literature review consisted of studies that provided more information on individuals with ESRD and their emotional needs, on caregivers' responsibilities, and issues of loss. The grant proposal included the nature of ESRD and how it has affected caregivers. The grant proposal consisted of requesting funds from the Smith and Stanley Charitable Trust to support the existence of this program to build support groups for this population at ECDA.

Overall, this grant proposal includes a wide range of information and studies that correlate to why ESRD caregivers would benefit from support groups. The goals and objectives of the support group were meant to address emotional needs and provide psychoeducation for caregivers. These goals were meant to serve caregivers and their family members with ESRD and provide both with tools to enhance their overall wellbeing.

APPENDIX BUDGET

Appendix

BUDGET

SALARIES	
Project Director Supervision @ 10% of FTE of $82, 626	$8,263.00
1 Program Coordinator (MSW) @10 % of FTE of $55,000	$5,500.00
2 Social Workers (MSW's) PTE 100% $42 per hr x 8 per week x 52 weeks	$34,944.00
1 Program Evaluator @ 5% of $17,000	$850.00
Benefits @ 26% of FTE	$14,300.00
Benefits @ 19% of PTE	$6,639.00
TOTAL SALARIES AND BENEFITS	$70,496.00
DIRECT EXPENSES	
Office Supplies @ $200 per month	$2,400.00
Expandable equipment (Computers and printers)	$1,000.00
Program supplies (Curriculum and art equipment)	$500.00
Phone and Internet @ $100 per month	$1,200.00
Printing @ $200 per month	$2,400.00
Training @ $40 per hour (4 one-hour trainings)	$160.00
Rent for space (Group room and 2 office rooms) @ $600 per month	$7,200.00
Total Direct Expenses	$14,860.00
INDIRECT EXPENSES	
Administration, HR, Payroll, Accounting and Supervision @10 %	$8,253.00
Evaluation @ 10%	$6,876.00
Liability Insurance @1.6%	$110.00
TOTAL INDIRECT EXPENSES	$15,239.00
TOTAL PROGRAM EXPENSES (IN-KIND donations not included)	$100,550.00

REFERENCES

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Action Inspiring Change. (2015). *Program incubation*. Retrieved on February 15, 2015 from http://www.actioncouncil.org/program-incubation/

American Kidney Fund. (2014). *End stage renal disease.* Retrieved on December 1, 2014 from http://www.kidneyfund.org/kidney-disease/kidney-failure/end-stage-renal-disease/

California Department of Public Health. (2013). *The burden of chronic disease and injury: California burden of disease and injury report 2013.* Retrieved on January 12,2015 from http://www.cdph.ca.gov/programs/Documents/BurdenReportOnline %2004-04013.pdf

Centers for Disease Control and Prevention. (2014a). *Diabetes public health resource. R*etrieved on September 30, 2014 from http://www.cdc.gov /diabetes/ projects/ kidney_ day.htm

Centers for Disease Control and Prevention. (2014b). *National chronic kidney disease fact sheet, 2014*. Retrieved on September 30, 2014 from http:// www.cdc.gov /diabetes/pubs/pdf/kidney_factsheet.pdf

Davita. (2015). *Social workers: Helping patients at the dialysis center*. Retrieved on February 12, 2014 from http://www.davita.com/treatment-options/hemodialysis/in-center-hemodialysis/social-workers:-helping-patients-at-the-dialysis-center/t/5598

El Centro de Ayuda. (n.d.a). *Combined federal campaign 2014 application for local independent organizations and members of federations; attachment a, el centro de ayuda.*

El Centro de Ayuda. (n.d.b). *A needs assessment [unpublished document]*.

El Centro de Ayuda. (2013). *About us*. Retrieved on February 2, 2015 from htt://elcentro deayuda.org/index.php/about-us

Emblem Health & The National Alliance for Caregiving (NAC) (2010). *Care for the family caregiver: a place to start*. Retrieved on December 1, 2014 from http://www.caregiving.org/data/Emblem_CfC10_Final2.pdf

Family Caregiver Alliance. (2014a). *Advanced illness: holding on and letting go.* Retrieved on December 8, 2014 from https://www.caregiver.org/advanced-illness-holding-on-letting-go

Family Caregiver Alliance. (2014b). *Caregiver depression: a silent crisis.* Retrieved on December 8, 2014 from https://www.caregiver.org/caregiver-depression-silent-health-crisis

Family Caregiver Alliance. (2014c). *Caregiver health.* Retrieved on December 8, 2014 from https://www.caregiver.org/caregiver- health

Family Caregiver Alliance. (2014d). *Depression and caregiving.* Retrieved on December 8, 2014 fromhttps://www.caregiver.org/depression-and-caregiving

Family Caregiver Alliance. (2014e). *Grief and loss.* Retrieved on December 8, 2014 from https://www.caregiver.org/grief-%20and-loss

Garlo, K., O'Leary, J. R., Van Ness, P. H., & Fried, T. R. (2010). Burden in caregivers of older adults with advanced illness. *Journal of the American Geriatrics Society*, *58*(12), 2315-2322.

Gayomali, C., Sutherland, S., & Finkelstein, F. O., (2008). The challenge for the caregiver of the patient with chronic kidney disease. *Nephrol. Dial. Transplant*. *23* (12), 3749-3751.

Griva, K. K., Ng, H. J., Loei, J. J., Mooppil, N. N., McBain, H. H., & Newman, S. P. (2013). Managing treatment for end-stage renal disease – A qualitative study exploring cultural perspectives on facilitators and barriers to treatment adherence. *Psychology & Health*, *28*(1), 13-29.

Haight, B., & Gibson, F., (2005). *Working with Older Adults: Group Process and Techniques. 4th edition*. Sudbury, Massachusetts: Jones and Barlett Publishers.

Herrera, A. P., Lee, J. W., Nanyonjo, R. D., Laufman, L. E., & Torres-Vigil, I. (2009). Religious coping and caregiver well-being in Mexican American families. *Aging and Mental Health*, *13*(1), 84-91.

Koerner, S. S., Shirai, Y., & Pedroza, R. (2013). Role of religious/spiritual beliefs and practices among Latino family caregivers of Mexican descent. *Journal of Latina/o Psychology*, *1*(2), 95-111.

Land, H., & Guada, J. (2011). The Latina Caregiver Burden Scale: Assessing the factor structure for rapid clinical assessment. *Social Work Research*, *35*(2), 95-106. doi:10.1093/swr/35.2.95

Limpawattana, P., Theeranut, A., Chindaprasirt, J., Sawanyawisuth, K., & Pimporm, J. (2013). Caregivers burden of older adults with chronic illnesses in the community: A cross-sectional study. *Journal of Community Health: The Publication for Health Promotion and Disease Prevention, 38*(1), 40-45.

Lindquist, L. A., Cameron, K. A., Messerges- Bernstein, J., Friesema, E., Zickuhr, L., Baker, D.W., & Wolf, M. (2012). Hiring and screening practices of agencies supplying paid caregivers to older adults. *Journal of the American Geriatrics Society, 60*(7), 1253-1259.

Makara-Studzińska, M., & Koślak, A. (2011). Depression symptoms among patients with end stage renal disease and among primary health care patients. *Archives of Psychiatry and Psychotherapy*, *13*(3), 5-10.

May & Stanley Smith Charitable Trust. (n.d.) *Adminitrust*. Retrieved January 25, 2015, from http://www.adminitrustllc.com/may-and-stanley-smith-charitable-trust/

National Alliance for Caregiving (NAC) and American Association of Retired Persons (AARP) (2004). Caregiving in the U.S. Bethesda, MD and Washington, DC.

National Association of Social Workers. (2008). *Code of ethics of the National Association of Social Workers.* Retrieved on October 2, 2014 from http://www.socialworkers.org/pubs/code/code.asp

National Kidney Foundation. (2014) *About chronic kidney disease*. Retrieved on September 30, 2014 from http://www.kidney.org/kidneydisease/aboutckd

Pereira, H., & Rebelo Botelho, M., (2011). Sudden informal caregivers: The lived experience of informal caregivers after an unexpected event. *Journal of Clinical Nursing*, *20*(17-18), 2448-2457.

Prevention and Health Promotion. *The Burden of Chronic Disease and Injury. California Burden of Disease and Injury Report 2013.* Retrieved on February 10, 2015 from: http://www.cdph.ca.gov/programs/Documents/Burden ReportOnline%2004-04-13.pdf

Pruchno, R. A., Cartwright, F. P., & Wilson-Genderson, M. (2009). Effects of marital closeness on the transition from caregiving to widowhood. *Aging and Mental Health*, *13*(6), 808-817.

Ramsay, C., Reisinger Walker, E., Ramsay, R., Compton, M., & Thompson, N. (2012). An exploration of perceptions of possible depression prevention services for caregivers of elderly or chronically ill adults in rural Georgia. *Community Mental Health Journal 48*(2), 167-178.

Schwab, T., Meyer, J., & Merell, R. (1994). Measuring attitudes and health beliefs amongst Mexican Americans with diabetes. *Diabetes Educator, 20*, 221-227.

Shattell, M., Hamilton, D., Starr, S., Jenkins, C., & Hinderliter, N. (2008). Mental health service needs of a Latino population: A community-based participatory research project. *Issues in Mental Health Nursing*, *29*(4), 351-370.

Sheridan, M. J., Burley, J., Hendricks, D. E., & Rose, T. (2014). "Caring for one's own": Variation in the lived experience of African American caregivers of elders. *Journal of Ethnic and Cultural Diversity in Social Work: Innovation in Theory, Research and Practice*, *23*(1), 1-19. doi:10.1080/15313204.2013.849642

Song, M., Ward, S. E., Happ, M. B., Piraino, B., Donovan, H. S., Shields, A., & Connolly, M. C. (2009). Randomized controlled trial of SPIRIT: An effective approach to preparing African American dialysis patients and families for end of life. *Research In Nursing & Health*, *32*(3), 260-273. doi:10.1002/nur.20320

Tanyi, R. A., & Werner, J. S. (2007). Spirituality in African American and Caucasian women with end-stage renal disease on hemodialysis treatment. *Health Care For Women International*, *28*(2), 141-154.

Tijerina, M. S. (2009). Mexican American women's adherence to hemodialysis treatment: A social constructivist perspective. *Social Work*, *54*(3), 232-242.

Tyrrell, J., Paturel, L., Cadec, B., Capezzali, E., & Poussin, G. (2005). Older patients undergoing dialysis treatment: Cognitive functioning, depressive mood and health-related quality of life. *Aging and Mental Health, 9(4),* 374-379.

United States Renal Data System (USRDS). (2011). *USRDS 2011 Annual data report: Atlas of chronic kidney disease and end-stage renal disease in the United States*. Bethesda, MD: National Institute of Health, National Institute of Diabetes and Digestive and Kidney Diseases. Retrieved on September 30, 2014 from http://www.usrds.org/adr.aspx

United States Renal Data System (USRDS). (2014). *Annual data report: An overview of the epidemiology of kidney disease in the United States*. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases.

Welch, J. L., Thomas-Hawkins, C., Bakas, T., McLennon, S. M., Byers, D., Monetti, C., & Decker, B. S. (2014). Needs, concerns, strategies, and advice of daily home hemodialysis caregivers. *Clinical Nursing Research*, *23*(6), 644-663.

Wilson-Genderson, M., Pruchno, R. A., & Cartwright, F. P. (2009). Effects of caregiver burden and satisfaction on affect of older end-stage renal disease patients and their spouses. *Psychology and Aging*, *24*(4), 955-967.

Valenti, K., & Katz, A. (2014). Needs and perceptions of LGBTQ caregivers: The challenges of services and support. *Journal Of Gay & Lesbian Social Services: The Quarterly Journal Of Community & Clinical Practice*, *26*(1), 70-90.