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Los Angeles

Deciding to Seek Help among Family Members Caring for  
Veterans with Diabetes Mellitus and Co-morbid Illnesses

A dissertation submitted in partial satisfaction of the  
requirements for the degree Doctor of Philosophy  
in Social Welfare

by

Nancy Yasue Takahashi

2016

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# ABSTRACT OF THE DISSERTATION

Deciding to Seek Help among Family Members Caring for  
Veterans with Diabetes Mellitus and Comorbid Illnesses

by  
Nancy Yasue Takahashi

Doctor of Philosophy in Social Welfare  
University of California, Los Angeles, 2016  
Professor Lené Faye Levy-Storms, Chair

Studies suggest that strict control of diabetes is dangerous for older adults with chronic illnesses. Since Veterans have a higher prevalence of diabetes and other chronic ailments, caregivers need a better understanding of how restrictive diabetes control may be detrimental. Furthermore, the critical role of caregivers in the management of diabetes supports the need to understand how they experience the help-seeking process. In order to develop effective programs and policies, researchers must understand what triggers caregivers to seek help. At this time, limited understanding exists on how help-seeking takes place among caregivers of Veterans.

This study utilized Grounded Theory and interviewed caregivers (N=25) of Veterans who were diabetic with other co-morbid illnesses. The recruitment of caregivers took place at the West Los Angeles Veterans Administration (VA). A semi-structured interview was used to understand the help-seeking process. The transcripts were analyzed to develop a theoretical model.

The study findings suggests that help-seeking is a complex phenomenon. Two themes emerged: (1) Knowing what you do not know and (2) Help means different things to different

people. The first theme suggests that caregivers provide care to Veterans until they reach a crisis point in which their resources (instrumental and financial), physical and mental well-being are compromised. Therefore, caregivers experience a multitude of factors before they come to realize “what they don’t know”. The type of assistance the caregiver needs (informational, instrumental, emotional, spiritual or financial support) depends on how it is defined by the caregiver - “help means different things to different people”. Help-seeking, therefore, occurs based on what kind of assistance the caregiver needs. The study also shows that informal and formal networks are critical in facilitating the help-seeking process and provides insights into two different types of caregivers (proactive and overwhelmed, passive and overwhelmed).

This study provides a foundation for understanding the help-seeking process of caregivers of Veterans and suggests that the VA needs to bring forth policy changes to reduce the risk for hypoglycemia and caregiving burden. Furthermore, the study findings can be used to develop social work interventions and encourage future research on understanding the phenomenon of help-seeking among caregivers.

The dissertation of Nancy Yasue Takahashi is approved by:

Theodore J. Hahn  
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University of California, Los Angeles  
2016

To my parents, Mitsuru and Takako Takahashi  
my husband, Anthony Cannizzaro II and my son, Anthony Cannizzaro III

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why research on Veterans and their caregivers is so important. Dr. Torres-Gil, thank you for the incredible guidance you have provided me. You were always there for me whenever I needed advice from you. Again, I am grateful for the wonderful individuals on my dissertation committee.

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Sasaki D, **Takahashi N**, Feil D. Qualitative Study of Medical Students' Awareness of Hypoglycemia. UCLA Conference on Aging (2012).

Damron-Rodriguez, JA, Goodman C, Ranney M, Won Min J, **Takahashi N**. (2011). The State of Gerontological Social Work Education in California: Implications for Curricula Evaluation. Journal of Social Work Education.

Labor Force Study of Adult Protective Services & In-Home Supportive Services. Preliminary Selected Data. Presented with Ailee Moon, Steve Wilson, Catherine Goodman, and **Nancy Takahashi** for Aging Initiative Committee Meeting, Los Angeles, California, May 1, 2008.

Sherman, S., **Takahashi, N.Y.**, Kalra, P. (2008). Care Coordination to Increase Referrals to Smoking Cessation Telephone Counseling: A Demonstration Project. The American Journal of Managed Care, 14(3), 141-148.

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## CHAPTER 1 BACKGROUND

*This chapter provides an overview of the major concepts in the proposed study. The first discussion concerns the dangers of hypoglycemia (low blood sugar) among older diabetic Veterans, followed by a case study illustrating the caregiving burdens placed on family members. The next discussion elaborates on caregiver burden, help-seeking, utilization of community resources, and the role of informal/formal networks in help-seeking. The chapter concludes with the problem statement, research questions, implications for policy and clinical social work.*

### Hypoglycemia among Physically Frail Older Adults

The management of diabetes involves a complicated regimen of medicines, finger pricks, diet and exercise to prevent the possibility of hyperglycemia (high blood sugar) from occurring (DeCoster 2008). If untreated, hyperglycemia can lead to a diabetic coma (DeCoster 2008). Hypoglycemia (low blood sugar) is also equally dangerous, because it can cause a diabetic coma and potentially be fatal among older adults (DeCoster 2008). Among physically frail older adults, hypoglycemia leads to increased mortality, macro vascular disease (e.g., heart disease) and occurrences of diabetic coma (UK Prospective Diabetes Study Group 1998; Gerstein et al, 2008; Patel et al, 2008). In these studies, “vulnerable or frail” elderly represents someone that is 75 years and older or 65 and older with limited life expectancy and/or high medical burden/functional disability (UK Prospective Diabetes Study Group; 1998; Gerstein et al, 2008; Patel et al, 2008). Intensive control of diabetes is dangerous for older adults (60 years and older) with multiple chronic illnesses (UK Prospective Diabetes Study Group; 1998; Gerstein et al, 2008; Patel et al, 2008). The prevalence of hypoglycemia is especially high among older adults with cognitive impairment (Feil et al, 2010).

Studies from the VA (Veterans Affairs) support previous findings on the dangers of hypoglycemia among older physically frail Veterans with co-morbid illnesses, such as dementia (Feil et al, 2010). A study consisting of 497,900 diabetic Veterans (65 years and older) show that Veterans with cognitive impairment are more likely to be prescribed complex diabetic regimens (insulin and/or oral medicine) than unimpaired patients (Feil et al, 2010). Furthermore, cognitively impaired diabetics have more episodes of hypoglycemia than those cognitively unimpaired (Feil et al, 2010). Despite achieving control of diabetes, many Veterans in the study were placed on complex (perhaps unnecessary) diabetes care regimens by their healthcare providers. Various reasons exist as to why older, frail diabetic Veterans experience hypoglycemia, including aggressive treatment of diabetes, polypharmacy (using multiple medicines) and older age (Feil et al, 2010). However, despite studies suggesting the dangers of hypoglycemia, Veterans continue to be placed on complex diabetes care regimens.

Preliminary findings from the main study (associated with the proposed study), *Individualizing Diabetes Care in Older Veterans*, suggest that healthcare providers do not discuss with Veterans and caregivers the dangers of hypoglycemia. In fact, healthcare providers may be inadvertently placing Veterans at-risk for death and macro vascular disease due to their continued tight control of diabetes. Many caregivers in the study know the dangers of hypoglycemia due to previous hypoglycemic episodes experienced by their loved one. Therefore, caregivers voice their concern and question whether it is necessary to continue the burden of having to manage a complex diabetic regimen for their loved one. Caregivers describe the burden of diabetes caregiving and the demanding responsibilities associated when caring for a frail older adult. The following is a case study of a caregiver experiencing the burden of caring for a diabetic Veteran who is at-risk for hypoglycemia.

## The Case of Mrs. Robinson

### *Mr. Robinson - A Frail Older Veteran At-Risk for Hypoglycemia*

Mrs. Patricia Robinson is a 69-year-old spouse of a 75-year-old Veteran who has type 2 diabetes mellitus, depression, hypertension and cardiovascular disease. He is also in the early stages of dementia. Mr. Robinson has been a diabetic for over 15 years. He has been taking insulin shots and oral medications to manage his diabetes during this time. Recently, Mr. Robinson's VA doctor increased the dosage of oral medication and insulin. In the past month, Mr. Robinson has fallen three times inside his home. He also complains of dizziness, weakness, headaches and irritability – signs of hypoglycemia. Mrs. Robinson also began to notice that her husband's blood sugar runs low (70) before he goes to sleep. Despite telling her husband's VA doctor about these problems, he feels no change should be made to Mr. Robinson's diabetes care regimen.

### Why Mrs. Robinson Began to Care for Mr. Robinson

Five years ago, Mrs. Robinson began to notice that her husband would mix up his medication and forget to give himself insulin shots. He was no longer performing finger pricks (to check his blood sugar levels) and refuses to adhere to a strict diabetic diet. There were times, when Mr. Robinson would put himself at risk for hypoglycemia and administer insulin shots before he had eaten anything for the day. At times, Mrs. Robinson felt that he was in denial of having diabetes and had become stubborn in his refusal to take care of his diabetes. She also noticed that Mr. Robinson had become apathetic and felt there was “no need” to take medications since he no longer had the desire to live. She has spoken to husband's VA physician about these problems. However, the doctor does not offer any suggestions and tells Mrs. Robinson that she must continue to maintain a “strict diabetes care regimen” for her husband.



### The “24/7” Nurse to Mr. Robinson

Mrs. Robinson has been married to Mr. Robinson for 30 years. However, she feels the nature of their relationship has changed from husband-wife to caregiver-patient. She describes herself as a “24-hour nurse”, because she must constantly monitor Mr. Robinson. She must manage her husband’s medication, diet and make sure that he does not fall and injure himself. She is most concerned that her husband’s recent falls may eventually lead to a broken hip. She also feels there is more tension and arguing due to her husband’s denial of being ill, worsening depression and refusal to “do anything” to take care of his health. She describes high levels of stress, because “he cannot do anything for himself”. Therefore, she must monitor Mr. Robinson’s medications, check his blood sugars, prepare food, and take him to medical appointments at the VA.

### Mrs. Robinson and Help-Seeking

As a wife, Mrs. Robinson feels that it is her spousal obligation to take care of Mr. Robinson. Therefore, she does not feel there is a “problem” in her current situation. Mrs. Robinson tries to tell her husband’s VA doctor the difficulties that she is encountering in her caregiving situation. However, she feels the VA doctor minimizes her caregiving role. Mrs. Robinson realizes that seeking assistance from the VA healthcare providers is futile. She believes the high levels of stress are just a “part of life”. Although she regularly takes Mr. Robinson to the VA, his doctor and none of the healthcare professionals (nurses, social workers, nurse practitioners) have discussed little about what to expect as a caregiver. For example, nobody at the VA has discussed with Mrs. Robinson about what to do when Mr. Robinson refuses to adhere to the diabetes care regimen. She feels the stress and burden of caregiving is what any “good wife” would accept and seeking help through community resources, such as support groups and respite care would be unacceptable. Mrs. Robinson says, “Well I guess I just have to grin and

bear it”.

### Prevalence of Diabetes among Older Adults & Economical Cost to Society

Mrs. Robinson’s situation is just one of thousands of stories of family caregivers, who experience the burden of caring for an older adult with diabetes mellitus and other comorbid chronic ailments. Mrs. Robinson’s story is common in the United States, since diabetes is a significant health care problem. Nearly 25 million and 800,000 (8.3%) of the US population are affected by diabetes (Center for Disease Control 2011). Compared to the general population of older Americans (65 years and older), the prevalence of diabetes in the VA is 27%, higher than the general population prevalence of 18% (CDC, 2011). Those 75 years and older are the fastest growing group of Americans with diabetes (Boyle et al, 2001). Diabetes is also the major cause of disability, morbidity and mortality among older adults (American Diabetes Association 2012).

Diabetes is an expensive disease to society. The total estimated cost of healthcare for patients with diabetes was \$174 billion in 2007 (American Diabetes Association 2012). Self-management of chronic diseases such as diabetes can have substantial healthcare savings. The Stanford University Chronic Disease Self-Management Program (CDSMP), developed by Dr. Katie Lorig, is the most well known self-management proven to reduce cost through reduction in hospitalization and outpatient visits (Gordon et al, 2007; Schneider 2002). One study found a two-year savings of between \$390 and \$520 per participant based on reduced hospitalizations and outpatient visits; using CDSMP cost \$70 to \$200 per patient (Gordon et al, 2007; Schneider 2002). Improved healthcare utilization includes fewer emergency room visits, hospitalizations, inpatient days, and/or outpatient visits. In the first year, visits to doctors and emergency rooms dropped by 8 percent, while patients spent 40 percent less time in the hospitals (Gordon et al, 2007; Schneider 2002). Furthermore, effective glucose control reduces the complications from

diabetes and improves quality of life (Berlowitz et al 2003; Sorenson et al, 2002; Mazzone 2009; Ray, Seshasai, Wijesuritya 2000).

What happens when the older adult is no longer able to manage his/her diabetes due to functional and cognitive impairment? Among older Veterans, diabetes is one of many chronic illnesses commonly found within this population. VA patients tend to be older, poorer and sicker with more chronic illnesses (Agha, Lofgren, VanRuisyk & Layde, 2000; Selim et. al, 2004). Furthermore, complications from diabetes (i.e., neuropathy of the legs and feet, blindness, limb amputation, renal disease and cognitive impairment) place caregiver burden upon family members (American Diabetes Association 2012). Since VA patients are sicker than the general population, the expected increase in the incidence of diabetes will place caregiving burden upon family members.

One must remember the many cases similar to that of Mrs. Robinson at the VA, where caregivers must contend with the burden of caring for a Veteran at-risk for hypoglycemia. Additional burden is further placed on the caregiver when the Veteran experiences hypoglycemia, such as falls and fall-related injuries. Therefore, many caregivers feel they are “24/7” nurses for their loved one.

### **Why Diabetes is the Core Illness of the Proposed Study**

In the proposed study, the author examines the phenomenon of help-seeking in the context of diabetes and comorbid illnesses (cognitive impairment, dementia, depression). However, diabetes is the main focus of the study because in the current VA healthcare system, healthcare providers continue to place frail, older Veterans at-risk for hypoglycemia (Feil et al, 2010; Feil et al, 2011). Despite studies suggesting that a less restrictive diabetes care regimen is appropriate for frail, older adults, Veterans and caregivers may experience unnecessary burden

due to the strict diabetes care regimen (Feil et al, 2011). Thus, Mrs. Robinson's story is common among VA caregivers. However, as in the case of Mr. Robinson, many Veterans suffer from multiple co-morbid illnesses. Therefore, the author examines the phenomenon of help-seeking in the context of other chronic illnesses with the main focus placed on diabetes.

Preliminary findings from the main study suggest that caregivers often describe the challenging nature of the diabetes care regimen due to its complexity. Mrs. X (from the main study) describes the diabetes care regimen as “creating an additional layer of complication to an already complicated situation” (personal communication, May 2012). Complications from diabetes such as neuropathy (weakness) of the leg and foot combined with the risk for hypoglycemia is disconcerting to caregivers. Mrs. B says it is the “constant vigilance of making sure hubby doesn't fall that is stressful “(personal communication, June 2012). The Feil study (2010) supports current study findings suggesting that diabetes caregiving is a demanding responsibility due to the complex diabetes care regimen.

The author examines diabetes caregiving in the context of other commonly associated illnesses (e.g., cognitive impairment, dementia, depression). Since diabetes caregiving adds a “complicated layer to an already complicated situation”, a discussion must ensue on cognitive impairment, dementia and depression in conjunction with diabetes. Older diabetics often have co-morbid illnesses, which increases the likelihood of needing a caregiver to assist with their diabetes care regimen.

***Type 1 & Type 2 Diabetes:*** Four different classifications of diabetes (gestational, pre-diabetes, Type 1 and Type 2) exist. The most common forms of diabetes are Type 1 (diagnosed in childhood) and Type 2 (adult onset) diabetes. Type 2 accounts for 95% of all diagnoses in the United States (DeCoster 2008). Diabetes is an incurable disease consisting of a complex

treatment regimen. The diabetes care regimen often requires a complicated combination of oral medications and/or insulin, diet, physical exercise and stress management (ADA 2012).

***Diabetes & Cognitive Impairment:*** Numerous studies show that diabetes associates with cognitive impairment and accelerates cognitive decline in older adults (Stewart 1999; Fontbonne & Berr 2001; Wu et al, 2003; Hassing et al, 2004). Several longitudinal studies show diabetes as a strong factor for cognitive decline (Wu, Tang, Kwok 2004; Logrtoscino, Kang, Grodstein 2004; Okerke et al 2008). Persons with diabetes (type 1 or type 2) have twice the risk of developing dementia and cognitive impairment as those without diabetes (Fontbonne 2001; MacKnight 2002; Cukieman 2005). Type 2 diabetes is strongly associated with cognitive impairment and dementia (Velayudhan et al, 2010).

***Diabetes, Vascular dementia and Alzheimer's.*** Dementia is one of the most expensive diseases among the elderly population in the United States costing \$100 billion per year for those with Alzheimer's disease (AD) (Qaseem et al 2007). Dementia is a prevalent condition affecting the oldest old (85 years and older). Prevalence for those 85 and older is believed to be over 40% (Pogach 2004, Pani 2008,). In 2000, 4.5 million Americans were affected by AD (Herman 2007). Prevalence of dementia doubles every 5 years after age 60 which suggests more family members will provide care to their loved one (Pogach 2004;Herman 2007;Pani 2008,).

Dementia is a severe pathological form of brain ageing (Raffaitin et al 2009). Dementia describes a variety of cognitive and behavioral symptoms including memory loss and disturbance; impairment of abstract thinking, reasoning and judgment; mood and personality changes and aphasia (difficulty remembering words or completely unable to speak, read, or write), apraxia (loss of ability to carry out learned or purposeful movement), or agnosia (loss of ability to recognize objects, persons, sounds, shapes, or smells) (Phillips & Phillips 2011). All

dementia is progressive and worsens with time. The four main types of dementia are: (1) Alzheimer's Disease (most common form of dementia) (2) Vascular dementia (commonly affects people with diabetes due to association with hypertension) (3) Fronto-temporal dementia (4) Lewy body dementia (Phillips & Phillips 2011). Vascular dementia is the most common form of dementia affecting older adults with diabetes (Jolley, 2009).

***Diabetes and Psychosocial Challenges:*** Diabetes presents numerous psychosocial challenges for patients and family caregivers. The potential complications from diabetes include blindness, kidney failure, peripheral neuropathy, limb amputation and heart disease (DeCoster 2003). Diabetes also brings forth emotional challenges for the individual and family members. Patients and families face a “literal torrent of affect” throughout their lifetime with diabetes (Rolland 1984). During the course of the illness, patients and families experience an “emotional roller coaster” from onset to the end of the individual's life (Rolland 1984). Diabetes has a strong influence on the emotions experienced by individuals and families (Spritito 1992; Merbis, Snoek, Kane & Heine 1996). Some of the common emotions experienced by diabetics are fear, irritation, sadness, anger, anxiety, and guilt (DeCoster 2003). Fear is a common emotion among diabetics. Diabetics fear the possibility of losing their eyesight or limbs if diabetes should worsen (DeCoster 2003).

Sadness is the second most common emotion among diabetics. Many describe feeling “low”, “down”, “depressed” regarding long-term complications from diabetes (e.g., increased mortality, kidney failure, impotence) (DeCoster 2003). Others describe feeling sad realizing that there is no cure for diabetes and the possibility of losing control over the diseases (DeCoster 2003). Anger over strict treatment regimens is another emotion among diabetics. Diabetics will generally feel anger over treatment issues (i.e., strict diet plans, exercise, insulin injections and

oral medications) (DeCoster 2003). Some describe getting angry towards family members because they “harp on” eating sugar-free foods when they do not want to (DeCoster 2003). Since diabetes is a life-long chronic illness, diabetics and their family members are subjected to a range of emotions, potentially leading to caregiver stress.

***Diabetes and Depression.*** Depression is commonly found among diabetic older adults, which further complicates the caring situation for family members (Iwata & Munshi 2009). Having depressive symptoms is a risk factor for developing type 2 diabetes (Golden et al 2008) and that diabetes is associated with an increased risk of depressive symptoms (Maraldi et al 2007). Thus, a bidirectional association exists between diabetes and depression (Iwata & Munshi 2009). Furthermore, depression in older adults with diabetes has a substantial impact on mortality, quality of life and healthcare costs to society (Finkelstein et al, 2003). A 3-year prospective cohort study shows that older patients with diabetes and minor depression had a 1.7 fold increase in mortality; and 2.3 fold for those with major depression (Katon et al, 2005). Furthermore, patients with diabetes and depression had a significantly lower score in the Short Form Health Related Quality of Life Questionnaire (SF 36) than those with diabetes but no depression (Katon et al, 2005). Depression can also stem from the individual having a complicated illness with a strict treatment regimen.

Unfortunately, studies on caregiving of older adults with diabetes remain limited. Although a higher incidence and prevalence of diabetes exists among older Veterans compared to the general population, few studies examine the family caregiving experience of Veterans with diabetes. The next section includes a discussion on the psychological and physical impact caregiving can have on family caregivers.

## Diabetes and Caregiving Burden

***General Overview of Caregiving:*** According to the National Caregiver Alliance, approximately 34 million informal caregivers (16% of population) provide unpaid help to community-dwelling older adults (50 years and older) in the US. Seventy-eight percent of community-dwelling adults rely on informal caregivers for their care needs (Thompson 2004). According to the Administration on Aging, informal caregivers are primarily spouses, adult children and other relatives and friends. Family caregivers continue to be the major providers of everyday long-term care to community-dwelling older adults (Feinberg, 2002). According to the National Caregiver Alliance, nearly one-quarter of US caregivers aged 65 years and older provide care for their spouse. In a national sample of US caregivers who lived with the care recipient, nearly 62% were primary caregivers (Kennedy and Walls, 1997). At the national level, there are approximately 600,000 Veterans with dementia who are cared by their family members (Levine 2010). Caregiving stress and burden can place the caregiver at risk for psychological and physical health problems (Change et al, 2009). On average, caregivers provide care for 8 years and one-third provide care for more than 10 years (MetLife Act Study 1999).

Informal caregivers also provide a majority of in-home care for their family member. Caregivers provide 80% of home care service to persons age 50 and older (Schumacher & Marren, 2004). Furthermore, caring for an older adult with a chronic illness and/or disability is burdensome and stressful contributing to poor psychological health for the caregiver (Schulz et al, 2001, Kiecolt-Glaser et al, 2003). Caregiving stress and burden can lead to depression, deterioration in health status, increased healthcare service use, and higher morbidity and mortality (Bass et al, 1994).

Since caregiving is not a short-term responsibility, Aneshensel (1995) describes it as a “career”. The caregiving career describes the “evolving character of caregiving” (Aneshensel,



1995, p.19). Although there are different descriptions of how a caregiver career may look, essentially, it is an “evolution of the role-related responsibilities across time” (Aneshensel, 1995, p.19). Thus, unsurprisingly, on average, caregivers provide care for their family members for at least 8 years. The concept of caregiving career, allows people to understand that caregiving does not emerge suddenly. Instead, the “career” is gradually developed just as an occupational career. The concept of caregiving as a career allows individuals to view caregiving as a sequence of events leading up to the present time (Aneshensel 1995).

***What is Caregiver Burden?*** The term caregiver burden first appeared in the 1960s, when it was used to describe the burden perceived by family members when caring for a mentally ill relative living in the same residence (Grad & Sainsbury 1963). Since the first introduction of caregiver burden, there have been different interpretations of this term. Caregiver burden has been described as “a state resulting from the action of taking care of a dependent or elderly person, a state which threatens the physical and mental health of the caregiver” (Zarit et al, 1980). Other researchers describe burden as the impact that care has on mental and physical health, family relations, the job and financial problems of the caregiver (Pearlin et al, 1990; Gaugler et al, 2000). The concept of burden was eventually refined to include subjective and objective burden. Subjective burden refers to the attitudes and emotions (such as anxiety or depression) assessed by the caregiver that is associated with caregiving (Carretero et al, 2009). Objective burden, on the other hand, refers to the activities associated with caregiving, especially in relation to the physical and behavioral changes of the care recipient (i.e. family member) (Carretero et al, 2009). Although caregiver burden continues to be a commonly used term, there is still heterogeneity regarding its meaning and use within the literature (Friss 2002).

From a theoretical perspective, caregiver burden has been explained from the

psychological perspective of stress and coping (Gaugler et al, 2000). Perhaps the most commonly cited model used to understand caregiver burden is the Pearlin Stress Process Model. In this model, caregiver burden presents as a process. According to the Pearlin Stress Process model, caregiving stress relates to five factors: (1) background and context of caregiving (2) objective primary stressors (care demands and care provided) (3) subjective primary stressors (role overload and relational deprivation) (4) secondary stressors (role strains and intrapsychic strain) and (5) social support and coping (Pearlin et al, 1990, Aneshensel et al, 1995). The care demands (objective primary stress factor) influences the caregiver by causing negative emotional reactions (subjective primary stress factors) (Carretero et al, 2009). The primary stressors can also influence the caregiver's life (secondary stressor). Examples of this could be the negative effect the care demand may have on the social relations and employment situation (role tensions). The caregiver's assessment of these negative consequences can lead to feelings of lowered self-esteem, expertise, sense of self or competency (intrapsychic tensions) (Pearlin et al, 1990, Aneshensel et al, 1995).

Understanding how to prevent caregiver burden is important, since caregivers are pivotal in allowing frail older adults to live within the community. However, when caregiver burden is high, the caregiver's mental and physical health is compromised which may lead to the deterioration of the care recipient's care (Schulz et al, 1995; Schulze & Rossler 2005; Cooper et al, 2007). Caregivers may feel they are no longer able to care for their family member and nursing home placement and in some cases, elder abuse may occur due to high caregiver burden (Pearlin et al., 1989, 1990; Aneshensel et al., 1995; Pearlin and Skaff, 1995; Havens, 1999; Mockus Parks and Novielli 2000). Institutionalization of a family member by the informal caregiver does not resolve caregiver burden. Although caregiving at-home may have ceased,

additional stressors may appear due to nursing home placement (Pearlin et al., 1989, 1990; Aneshensel et al., 1995; Pearlin and Skaff, 1995). In fact, the caregiving role continues to persist for informal caregivers after their family member is institutionalized, especially for older adults with dementia (Dempsey & Pruchno, 1993; Naleppa, 1996; Aneshensel et al 1995). A study of informal caregiver involvement one year after institutionalization of a loved one, suggests that family involvement persists and that dissatisfaction is related to staff care within the nursing home (Levy-Storms & Miller-Martinez, 2005). Although the stress of at-home care no longer exists, the caregiving role of family members persist through their involvement with nursing home care (Levy-Storms & Miller-Martinez, 2005).

Since negative ramifications (such as elder abuse and institutionalization) occurs because of high caregiver burden, researchers need to understand what aspects of the informal caregiving process is difficult and burdensome. Doing so allows healthcare professionals to intervene before caregiver burden becomes overwhelming. The following section discusses how caring for a family member with diabetes can lead to caregiver burden and strain.

***Diabetes and Caregiver Burden & Strain - General Population:*** Although based on limited research, informal caregiving for a family member with diabetes can lead to caregiver burden. A study of nationally representative sample of community-dwelling older adults in the US shows that diabetes is associated with higher physical impairments and that family members spend a substantial amount of time providing help with diabetes treatment, such as help with medications and with functional limitations due to complications of diabetes (Langa et al, 2002). Older adults with diabetes are more likely than those without diabetes to report needing help with at least one ADL or IADL (28% of those without diabetes compared to 40% of diabetics) (Langa et al, 2002). Walking across the room was the most common ADL limitation cited (46%

of diabetics), whereas “grocery shopping” (36% of diabetics) was the most commonly reported IADL limitation by diabetics (Langa et al, 2002). The reason why diabetics require assistance walking across the room or grocery shopping may result from impairment of lower extremities from neuropathy or amputations (Langa et al 2002). Diabetics taking insulin were twice as likely to report a functional limitation for a given ADL/IADL compared to non-diabetics (Langa et al, 2002).

Older adults with diabetes also receive more weekly hours of informal caregiving than non-diabetics. According to the study, diabetics that took oral medication received 10.1 hr./week of informal care compared to 14.4hr/week of diabetics on insulin (Langa et al, 2002). Thus, family caregivers spend a substantial amount of time managing the diabetes care regimen and the functional disabilities resulting from the disease (Langa et al, 2002). Increased hours were also associated with a greater number of medications by the diabetic older adult (Langa et al 2002). Caregivers were likely to spend more time monitoring and assisting in the provision of medication as the number of medicines increased.

Langa’s findings support previous studies regarding the heavy caregiving responsibilities experienced by caregivers. In an earlier study, informal caregivers frequently helped with daily diabetes care and instrumental activities of daily living (IADLs; e.g., shopping, cleaning, and cooking) (Silliman et al, 1996). Another early study suggests that 25-50%of caregivers assist their family member with at least one IADL (Silliman et al, 1996). Family caregivers also schedule medical appointments, provide transportation, perform or assist with activities of daily living (ADL) and monitor the care recipients’ health status between medical appointments (Wakefield et al, 2012). From earlier studies, education should be provided to caregivers when the opportunity exists (Silliman et al, 1996; Langa et al, 2002).

Furthermore, the study suggests that compared to non-diabetics, diabetics were likely to have other co morbid illnesses such as heart disease, stroke, visual impairment, arthritis, urinary incontinence and dementia (Langa et al, 2002). These co-morbid illnesses were predictors of disability, which led to about one-third of the increase in informal caregiving associated with diabetes (Langa et al 2002). The Langa study is the first to quantify the weekly informal caregiver hours provided to older adults with diabetes. The study provides an economic analysis of the cost placed upon unpaid informal caregivers. According to the study, the societal cost of informal caregiving is \$3-\$6 billion dollars - close to the total cost (\$5.4 billion) of nursing home and paid home health services in 1998 (Langa et al, 2002). This study demonstrates the specific aspects of informal caregiving that is burdensome to family members and highlights the importance of supporting informal caregivers.

Other studies support the Langa study, suggesting that caregiver burden experienced by informal caregivers is high for those caring for an older family member with diabetes. In comparison to other chronic illnesses such as dementia, cancer and mental illness, caregiver burden for those caring for a family member with diabetes is relatively stressful. In a comparative study examining caregiver burden among caregivers of cancer, dementia and diabetes patients, the researcher created a scale of intensity levels of caregiver burden ranging from 1 (least intense) to 5 (most intense) (Kim Y & Schulz R, 2008). The caregiving intensity (score of 4) was similar between caregivers of dementia and diabetes patients. Twenty-seven percent of caregivers of dementia patients scored 4 compared to 25% of caregivers of diabetes patients (Kim Y & Schulz R, 2008). Furthermore, the study suggests that disease type is a significant predictor of caregiver emotional stress. Emotional stress was significantly associated with cancer, dementia and diabetes caregiving (Kim Y & Schulz R, 2008). Additionally, diabetes

caregivers spent an average of 24 hours per week providing care (Kim Y & Schulz R, 2008). Thus, this study along with the Langa study suggests that diabetes caregiving should not be overlooked regarding the stress and burden it places upon family caregivers.

More recently, a study in England confirms the demanding and overwhelming experience of caring for an older adult with diabetes. In the study, half of the caregivers felt “overwhelmed” by their responsibilities and found it to be upsetting and an emotional strain (Sinclair et al, 2010). Sixty percent provided 20 hours or more of caregiving (Sinclair et al, 2010). Caregivers had not received caregiver assessment nor given information about caregiving and available resources. In fact, 37% wanted more information on available community resources and support groups. Forty percent never received information regarding diabetes and caregiving (Sinclair et al, 2010). In the study, caregivers described feeling overwhelmed due to their limited ability to enjoy social activities and wanted some form of respite from caregiving (Sinclair et al, 2010).

The Sinclair (2010) study confirms previous study findings on caregivers of older adults with diabetes (Sinclair et al, 2010). In many cases, the caregiver’s needs are unmet and appropriate information regarding available resources and information about the chronic illness are not given to the caregiver, thus increasing caregiver burden and stress. A limitation of the Sinclair study is that it did not examine whether caregivers seek out help and if they do how?

***Caregiver Burden & Strain - VA Population:*** There is limited information on caregiver burden and strain among family caregivers of diabetic Veterans. A study, which focused on dyads of caregiver-Veterans living in Missouri, Kansas and Illinois, suggest that VA caregivers spend more hours providing care than the general population of caregivers (Wakefield et al, 2012). In this study, a majority (61%) of Veterans were diagnosed with diabetes, followed by

heart failure (19%), hypertension (10%), depression (7%) and chronic obstructive lung disease (4%) (Wakefield et al, 2012). The mean age of Veterans was 67 years old and 59 years for caregivers; a majority (91%) of the caregivers were female family members (Wakefield et al, 2012). Informal caregivers of Veterans with chronic illnesses report a mean of 43 hours weekly of caregiving compared to 14 hours a week reported by Langa (Wakefield et al, 2012; Langa et al, 2002). Veterans may require more assistance, since they are sicker and older compared to the general population.

The Wakefield (2012) study also implies that Veterans require ongoing intensive care management. Caregiver strain among family caregivers of Veterans is associated with medication assistance; accompanying the care recipient (CR) to doctor appointments; helping CR with medical equipment, rehabilitation; use of paid help; receiving less help from family and friends (Wakefield et al, 2012). Caregiver strain was also associated with CR greater dependency in ADL and IADL, lower levels of social support, higher levels of caregiver depressive symptoms and increased caregiver age (Wakefield et al, 2012). Although the Wakefield study did not measure for caregiver burden, it is possible that caregivers are at-risk for caregiver burden due to the high number of hours associated with caregiving. Furthermore, the Wakefield study did not disaggregate findings by disease, which further limits its relevance to diabetes caregiving. However, the next chapter will include a more recent study on caregivers of Veterans with diabetes and dementia. This study specifically highlights the caregiver burden and barriers associated when caring for a Veteran with diabetes (Feil et al, 2011). Findings from the Feil study support previous studies, highlighting the demanding responsibilities associated with caregiving for a diabetic Veteran with comorbid illnesses.

## Underutilization of Formal Networks by Caregivers

To alleviate caregiver burden, community resources such as respite, emotional and educational support groups and formal care services are available. However, studies continue to document the underutilization of community resources by caregivers (Krout 1983; Caserta et al, 1987; Parker 1990; Collines et al, 1991; Fine and Thomson, 1995; McCabe et al 1995; Braithwaite 1998, 1999; Toseland et al 2002; Winslow 2003; Brodaty et al 2005). The reasons for underutilization of resources vary and may include lack of awareness, attitudes, cost, and family norms (Forney et al 2002; Toseland et al 2002; Kadushin 2004; Brodaty et al 2005; Zodikoff 2007). In some cases, male caregivers were more likely to use formal services (home health aide) instead of seeking help from informal sources (Neufeld & Harrison 1998). Female caregivers, however, were less likely to use formal services and provide direct care to the family member (Siripoulos et al., 1999).

The caregivers' belief about their caregiving role may prevent the use of formal services (Brodaty et al, 2005; Croog et al, 2006). In many cases, caregivers decide not to use community resources due to their belief that caregiving is an extension of their familial role (Graham 1983; Parker 2000). Although the care receiver may experience high levels of caregiver strain, caregivers refuse to identify their situation as "problematic" (Brodaty et al 2005). Other studies suggest that individuals refuse to accept assistance with caregiving believing what they are doing is consistent with their role as a family member (Smyth & Mildonis 1999). In addition, gender differences exist with respect to caregiving. Wives believe that caregiving is an extension of their spousal role, whereas men view caregiving as a new role (Miller & Cafasso 1992; Allen, 1994). Furthermore, men are more likely to hire help to assist with caregiving duties and "manage" the paid caregivers (Miller & Cafasso 1992; Allen, 1994). Thus, gender influences how caregivers view caregiving responsibility and whether to seek help with their situation.



Studies on attitudes toward community resources are often based on the Theory of Reasoned Action (Ajzen & Fishbein, 1980) in which attitudes present as feelings of favorableness or unfavorableness towards use of community services among family caregivers. This theory suggests that behavior is the result of interaction of the environment with beliefs, attitudes and intention of the individual to perform the behavior (Ajzen & Fishbein, 1980). An important factor, which influences caregiver attitude, is the trajectory of the chronic illness (Stommel et al, 1999). The concept of the illness trajectory first appeared in Glaser and Strauss's *Dying Trajectory* (Strauss & Glaser, 1970). The trajectory refers to the on-going and interconnected events experienced by the patient. The trajectory includes what the patient experiences and remembers of their period of illness – this is their interpretation of the series of situations or events (Strauss & Glaser, 1970). In the current study, the illness trajectory is shifted away from the patient and used to understand the experience of family caregivers.

Therefore, how a caregiver experiences the family member's illness may influence their decision to seek help. For example, a caregiver who experiences caregiver burden due to physical and cognitive decline of their family member may begin to have favorable attitudes towards receiving help from community resources (Stommel et al, 1999). In essence, the Stommel study suggests that the worsening of the illness (e.g., dementia) may lead to high caregiver burden, ultimately overshadowing any negative attitude a caregiver may have about receiving help (Stommel et al, 1999). However, how this trajectory occurs in other illnesses, such as diabetes, remains unclear as does whether the course of the illness (i.e., diabetes) changes the caregivers' perception towards receiving help. Thus, this proposed study will examine caregiver's perception and willingness to seek help through an in-depth interview and will seek to understand the help-seeking process of caregivers.

## Help-Seeking Rational Choice Approach vs. Dynamic Approach

Studies on help-seeking behavior appear in various disciplines including psychology, sociology, social work, business, education, criminal justice and medicine. Help-seeking represents a process that begins in response to a problem that cannot be solved or improved alone and involves the active pursuit of and interaction with a third party (Cornally 2011). The concept of help-seeking has its history rooted in illness behavior research. Two schools of thought exist regarding help-seeking: Rational Choice and Dynamic approach. The *rational choice approach* (based on the economics of cost/benefit analysis of an action) explores *who* seeks help whereas the social *dynamic approach* explores *when and how* individuals seek help (Pescosolido & Boyer, 1999).

***Rational choice approach:*** The rational choice approach is the most dominant form of studying help-seeking processes. According to this perspective, help-seeking presents as a voluntary and logical decision made by an individual who weighs the costs and benefits of seeking help (Pescosolido & Boyer, 1999). In many studies, researchers define the problem using the rational choice approach. Furthermore, the perspective of the individual is excluded in the rational choice approach (Armstrong, 1999). Early studies on help-seeking focused on the beliefs, attitudes, and motivations of why some individuals, for example, failed to participate in the immunization campaigns of the 1950s (Armstrong 1999; Uehara, 2001). The rational choice approach focuses on the single decision of whether one seeks help, specifically examining the psychological factors of the individual (Uehara, 2001). The rational choice approach ignores how individuals perceive an illness and the help-seeking process. Instead, the focus is on the individual and his or her beliefs and actions (Pescosolido, 1992; Pescosolido & Boyer, 1999). Thus, research questions often focus on predicting help-seeking through quantitative measurements of psychological, structural or demographic factors. Quantitative studies using the

rational choice approach often use Andersen's behavioral model of health service utilization, Azjen's theory of planned behavior and Rosenstock's health belief model (Armstrong 1999; Pescosolido & Boyer, 1999).

Critics of the rational choice approach portray it as a limited and narrow view of help-seeking. Specifically, the problem with the rational choice approach is that it : (1) conceptualizes help-seeking as discrete (either one seeks help or not) (2) limits deep understandings, meanings and processes of help-seeking and (3) compartmentalizes illness and lacks awareness of how health concerns pervade one's life (Pescosolido 2000).

***Dynamic approach.*** In the 1970s, providing a counterpart to the rational choice approach began to garner momentum among medical sociologists and anthropologists. Sociologists and anthropologists led a key shift in theorizing help-seeking by proposing the acceptance of a subjective interpretation of the problem (e.g., illness) and the concept of chronic illness as a "career" (Pescosolido & Boyer, 1999). By allowing individuals to define and interpret the problem, this allowed researchers to understand how one viewed illness, for example, as a product based on socialization, past experience and knowledge (Brown 1995; Coreil, Bryant & Henderson, 2001). This subjectivity allowed researchers to understand that perception of the problem (e.g., illness) can evolve over time during the course of the illness (Coreil et al., 2001).

Secondly, the dynamic approach brought forth the notion of help-seeking as a dynamic, on-going, and interactive process of decision making in the course of the illness career (Pescosolido, 1992; Uehara 2001). The concept of the illness career, orientated researchers to appreciate the dynamic action that individuals engage to interpret and manage the illness and connect with others over the course of the illness (Pescosolido, 1992). Thus, by examining the subjective experience, the dynamic approach recognizes the "catalogue of experiences" and the

help-seeking process during the course of an illness (Pescosolido 1992; Biddle, Donovan, Sharp & Gunnell, 2007).

### Informal and Formal Networks: Facilitator or Barrier to Caregiver Help-Seeking?

**Informal Network:** Some studies suggest that informal networks (friends and families) can play an important role in the help-seeking process (Caserta et al, 1987; Cotrell and Engel 1998; Kosloski et al 2001). When in need of help (seeking information, advice, emotional support), most individuals turn to their informal network consisting of friends and family first, before formal sources. Individuals will then turn to their neighbors and coworkers in an ever-widening ‘hierarchy of... successively less intimate lay consultants’ (Friedson, 1961, p.198). The informal network (family and friends) consists of a lay referral network (Friedson 1961) from which an individual can gather advice and information. This network can then help an individual decide whether to consult a professional, such as a doctor, nurse or social worker (Cameron, Leventhal & Leventhal 1993). Therefore, individuals generally look for help (information, advice, medical assistance) from their formal network (doctors and other professionals) when they have first sought help from their informal network (Taylor 1999; Verbrugge & Ascione 1987).

**Formal Network:** Formal network may consist of healthcare professionals (physicians and social workers) and community resources. Although there are no specific studies on formal networks and help-seeking, studies on physician-caregiver interactions may offer a glimpse into how medical encounters hinder or facilitate the help-seeking process. Studies on physician-caregiver encounters suggest that caregivers are dismayed when physicians do not recognize the difficulties of providing care (Morgan & Zhao 1993). This lack of recognition, often leave caregivers feeling minimized, overwhelmed, isolated and distressed (Feil et al, 2011).

Furthermore, caregivers do not receive appropriate information from physicians regarding community resources such as support groups (Alzheimer Association 2001).

Given the multiple roles of caregivers, physicians must be able to listen and acknowledge the caregiver's efforts in the caregiving process (Maletta 1986; Gwyther 1990). Caregivers want better communication and moral support from physicians to help cope with their situation (Chiverton 1989). Without support and encouragement from physicians and other healthcare professionals, caregivers are likely to experience caregiver strain and burden (Coe RM 1985; Adelman et al 1987; Beisecker 1989). Caregiver burden will eventually lead to poor physical and mental health for the caregiver and the patient. Furthermore, negative encounters with healthcare providers may discourage the caregiver from seeking additional help.

### Problem Statement & Justification for Study

Caregivers are pivotal in helping Veterans remain in their own home (Silliman, Bhatti, Khan, Dukes & Sullivan, 1996; Buhr, Kuchibhatla, & Clipp, 2006). Although caregiving is stressful and burdensome, studies show an underutilization of formal networks. However, there is limited information on the help-seeking process of the caregivers who care for Veterans with diabetes (Stewart & Liolitsa 1999; Lustman et al 2000; Brown et al 2003; Bell et al 2005). Unfortunately, quantitative studies do not provide an in-depth understanding of caregivers as a heterogeneous group with different needs. Furthermore, the continued underutilization of formal services suggest a need to examine the psychosocial process of help-seeking of caregivers. Understanding the basic help-seeking processes will help in the development of social work interventions and policy formulation, specifically for caregivers of Veterans with diabetes.

Caregiver attitudes, beliefs, informal and formal networks influence the help-seeking process. Some people may not seek help since they view caring as part of their duty as a family

member (Smyth & Milidonis 1999; Brodaty 2005). If researchers and social workers are to develop effective interventions to support caregivers, they need to understand caregiver attitudes and beliefs towards caregiving and help-seeking. Furthermore, what role informal and formal networks play in the help-seeking process among caregivers should be clarified (Smyth & Milidonis 1999, Brown and Alligood 2004). By developing a substantive grounded theory on the help-seeking process, researchers, policy makers and social workers can effectively design appropriate interventions to meet the needs of caregivers.

Given the expected increase of older Veterans and the incidence of diabetes, one must understand the family caregiving experiences. Although there are studies on the caregivers experience in caring for children and teens with diabetes, there is limited information on the caregiving experience of older adults (Winsock & Grecco 2006; Sinclair 2010). To address this gap in literature and understand the help-seeking process of caregivers, this study will utilize a grounded theory approach to understand how and when caregivers seek help. The research questions for this study are discussed in the methods chapter.

### Policy & Practice Implications

***Policy & Practice Implications:*** Findings from this study will add new insights into when and why caregivers seek help for their situation. As noted earlier, preventing caregiver burden is essential. There are many studies on caregiving for other illnesses such as dementia and cancer. However, few studies have examined the equally stressful situation of caring for an older adult with diabetes and comorbid illnesses. The previous section highlighted the stress and burden placed upon caregivers of diabetic older adults. Furthermore, the expected increase in the incidence and prevalence of diabetes among older adults will further require a better understanding of these caregivers.

Although studies on the needs of caregivers are numerous, federal policy on providing support for caregivers remain limited. During the nineteenth and twentieth centuries, the United States gradually transferred responsibility of elder care from the family to the government. Some of the key public policies regarding the well-being of older adults and their caregivers are the (1) Social Security Act (2) Medicare (3) Medicaid (4) Older American Act (5) Family and Medical Leave Act (6) National Family Caregiver Support Program (Torres-Gil 1992; Bookman and Kimbrel 2011).

Two policies that have a direct impact on caregivers include the Family and Medical Leave Act of 1993 (FMLA) and the National Family Caregiver Support Program of 2000. FMLA offers twelve weeks of job-protected unpaid leave with health benefits for employees that are seriously ill, and/or care for an ill parent, child or spouse (Bookman and Kimbrel 2011). Although studies of FMLA is positive, this policy is only available in companies with 50 or more workers. FMLA is restricted to only 55% of the workforce due to eligibility (Bookman and Kimbrel 2011). Additional restrictions include how employees are unpaid during their leave of absence (except in California) making it difficult for lower income employees to benefit from this policy. Other limitations include that spouse and parent define “family”. Thus, caregivers for grandparents, uncles and aunts would be ineligible.

Finally, the National Family Caregiver Support Program (NFCSP) is the first federal law to acknowledge the need to support caregivers. The NFCSP is funded by the Older Americans Act, Title III and offers referrals for services such as respite care, information, counseling, training and caregiver support groups (Torres-Gil 1992; Bookman and Kimbrel 2011). Although the NFCSP brought community resources and attention to preventing caregiver burden, funding continues to be problem. Limited funding, however, makes it difficult for NFCSP to offer

comprehensive services to assist caregivers (and hence potentially hinder help-seeking by caregivers).

Community services available to caregivers and their loved one is fragmented and uncoordinated due to funding from different state and federal policies. For example, Medicare is the main payer of inpatient and outpatient care provider to older adults, whereas Medicaid is the major payer of nursing home care (Torres-Gil 1992). Other long-term care services (e.g., respite, adult day health care, home health care, hospice, case management and social health maintenance organizations) occur through a mixture of public, private and for-profit agencies (Torres-Gil 1992). The lack of coordination and fragmented services can be bewildering and confusing to a caregiver and hinder help-seeking. The current health care system is also based on an acute illness model, not a chronic care model. The healthcare system is fragmented and does not recognize the various care transitions a chronically ill patient and caregiver may encounter. Thus, policies do not exist to treat the caregiver and care recipient as a unit.

According to Dr. Fernando Torres-Gil (1992), social policies for the aged must encourage individuals (family and non-family members) to care for one another. Specifically, reforming public and private sector policies should encourage caregiving through community-based programs and changes to work place policies, such as FMLA. Furthermore, social policies must consider providing a more “user-friendly” system of community services (Torres-Gil 1992). To seek help, caregivers are forced to wander through a daunting maze of social security district offices, area agencies on aging, health clinics, adult day-care center, and welfare departments to receive the services they need to care for their loved one (Torres-Gil 1992).

The passage of the Patient Protection and Affordable Care Act (PPAC) is a step forward in helping caregivers. Many of the PPAC provisions place the caregiver and loved one at the



center of the reformed healthcare system. The PPAC offers provisions to address issues such as developing a long-term care workforce, providing long-term care insurance, state incentives to expand home and community based services in Medicaid, programs to improve resources to help caregivers and consumers, protect seniors and people with disabilities, and improve nursing home care (Kaiser Family Foundation 2010) . Specifically, the PPAC assists caregivers through the provision of care coordination. For the first time, providers will be paid for care coordination (Kaiser Family Foundation 2010). Therefore, caregivers will no longer have the burden of having to be the care coordinator for their loved ones care. The PPAC also establishes a CMS (Center for Medicare and Medicaid) Innovation Center to test new models of care delivery focusing on both the patient and caregiver. The PPAC also offers education and training grants to Geriatric Education Centers, which provide instruction and training on caregiving, (Alzheimer’s Association 2012).

Findings from this study will provide a preliminary understanding of caregivers of diabetic Veterans that may improve the policy at the state and federal level. The study will provide insights into what triggers caregivers to seek help. Findings may suggest needed changes, for example, on how to provide more individualized education for caregivers. Furthermore, the study findings may reveal the barriers caregivers encounter during the help-seeking process. Equally important, the study findings may shed light regarding the caregiving burden of unnecessary tight glycemic control on Veterans at-risk for hypoglycemia.

At the clinical level, medical social workers represent an important link for caregivers and have the opportunity to enhance the quality of life for caregivers and patients. Since the VA is one of the largest employers of social workers, study findings suggest that social workers are an important source of assistance for caregivers seeking help. By understanding the help-seeking

process of caregivers, study findings will help medical social workers identify interventions to assist caregivers from feeling isolated and overwhelmed. Improvements may be made, for example, with the PACE (interdisciplinary clinical program) to offer better training and services to caregivers. Additional insights may shed light into the need for better clinical assessments to prevent caregiver burden among those who care for diabetic Veterans.

## CHAPTER 2 LITERATURE REVIEW

*This chapter includes an in-depth examination of relevant studies on diabetes caregiving and help-seeking. The chapter highlights the current literature gap in the help-seeking experience of caregivers of Veterans with diabetes. The author reviews studies on caregiving, help-seeking, informal/formal networks and attitudes/beliefs towards community resources.*

### Caregiving of Diabetic Veterans with Co-Morbid Illness

One of the few studies on diabetes caregiving of Veterans suggests that many family caregivers experience high caregiver burden. In the study, 21 caregivers of Veterans with dementia and diabetes were included in a focus group to explore caregiver concerns, experiences and attitudes/beliefs and barriers to care at the Veterans Administration (Feil et al 2011). The goal of the study was to understand the impact of dementia and the associated behavioral and psychological symptoms of dementia (BPSD).

Findings from the study produced three themes with several sub-themes related to the complexity of caregiving for someone with dementia and diabetes. The themes included: (1) caregivers began assisting patients with diabetes care during first signs of memory decline (2) BPSD interfered with diabetes care (2a) most burdensome BPSD are the patients' denial of diabetes and dementia (2b) reducing BPSD reduces caregiver burden (3) caregivers wanted more support from family members (3a) caregivers wanted more support from healthcare providers (Feil et al, 2011). In general, caregivers were uninformed about how to deal with BPSD, which interfered in the caregivers' ability to provide medication, insulin shots and finger pricks. Many caregivers misinterpret BPSD as personal affronts rather than symptoms of dementia and felt guilty for failing in their efforts as a caregiver (Feil et al, 2011). In many cases, caregivers must resort to making decisions on their own as to how best to manage the patient's diabetes given the

behavioral problems associated with dementia.

However, caregivers highlight the need for more information and support from the physicians (Feil, et al 2011). The study discovered that caregivers want more recognition and assistance from the patient's physician to lessen the burden of caregiving. Specifically, caregivers felt they were not provided any guidance or information regarding how to adjust the patient's care when the patient refused to adhere to the diabetes care regimen (Feil, et al 2011). Caregivers also wanted more information about diabetes and felt they were poorly informed. In fact, many of the caregivers used the focus group as an opportunity to discuss strategies in managing the patient's diabetes care.

The study is one of the first to explore the complex nature of diabetes caregiving and the obstacles caregivers encounter. Dementia caregiving is difficult; however, managing diabetes care adds another complex layer to the caregiving experience. Since the focus group was limited in its nature, it would help researchers to understand whether caregivers sought help (e.g., information, advice, etc.) from the patient's physician when there were signs of memory decline. If so, what happened and what did the caregiver do? Additionally, did caregivers seek help from the patient's physician when BPSD began to interfere with the diabetes caregiving process? Several questions arise from the Feil study and will be explored in the proposed study. The next section will review studies examining the concept of help-seeking.

### **Informal Networks & Help-Seeking: Quantitative Findings**

Studies examining the help-seeking process of caregivers with diabetes are non-existent. Studies on caregiving and help-seeking that do exist pertain to dementia or cognitive impairment. Many of these studies on help-seeking target the individual's belief and knowledge regarding dementia symptoms, especially Alzheimer's disease.

Studies on dementia care and help-seeking are quantitative in nature and use a wide variety of measures. Studies use a variation of several measures and scales to assess help-seeking behavior include such as Werner Scale, Verloff Scale and Ways of Coping Revised Questionnaire. The inconsistency in the use of help-seeking behavior measures demonstrates that complex and varied nature of the help-seeking process. Furthermore, the lack of a consistent measure to assess help-seeking behavior may indicate that researchers have yet to come to a consensus on which measure best validates and elucidates a thorough understanding the concept of help-seeking.

***Help-Seeking & Informal Network:*** The majority of studies on the topic of dementia and help-seeking focus on the individual knowledge and perception of dementia, specifically Alzheimer's disease. To examine the extent to which individuals had sufficient knowledge and awareness of Alzheimer's disease, Werner (2003) conducted a study of 150 community-dwelling adults aged 45 and older in Israel. The goal of the study was to assess knowledge of AD symptoms and its relationship to help-seeking intention. The empirical study interviewed individuals by assessing their identification of AD symptoms and by using a Likert-type scale measuring help-seeking intention. The scale consisted of potential sources of help (spouse, friend, other family members, neighbor, general practitioner, family physician, psychiatrist, psychologist, neurologist, nurse, and social worker) (Werner 2003). Individuals were then asked (based on the AD symptoms identified) who they would go to seek help. A majority of the individuals (60%) were able to accurately identify symptoms of AD (Werner 2003). Fifty-six percent of individuals said that they would seek help from spouse and their children based on the symptoms they identified (Werner 2003). This is followed by 29.4% seeking help from other family members and 24%

from friends (Werner 2003). Indeed, the study findings are consistent with previous literature and theories regarding help-seeking behavior - individuals first turn to their family and friends before going to their formal network (Werner 2003). The study further discovered individuals who were well-informed about Alzheimer's disease would seek help from professional sources (i.e., doctors) compared to those who had limited knowledge about the disease (Werner 2003). One of the reasons as to why some individuals did not seek help from professional sources are that individuals assumed that one of the early signs of AD, such as forgetting names and placement of objects are related to the normal signs of aging. This explains why individuals first decided to turn to family and friends before going to a professional source such as a healthcare provider.

However, a weakness of the Werner study is the vague use of help-seeking. It is unclear whether the author used the term to assess help-seeking for instrumental care, medical advice or general information about the AD symptoms. Therefore, it is unclear whether study subjects were seeking help from their informal network for emotional support, advice, information or assistance with daily activities.

The Werner Scale was also used in a similar study examining layperson's knowledge of AD symptoms in Brazil. In this empirical study, Blay and colleagues (2008) used a vignette describing an elderly woman with symptoms of Alzheimer's disease. The goal of the study was to understand individual perception of the source of illness and the appropriate person who can provide assistance in treating the elderly woman in the vignette (Blay et al., 2008). Nearly 500 subjects (ages 18-65) were interviewed and presented with the vignette. Using the Werner Scale, subjects were asked to identify who could best help the elderly woman. Nearly 27% of the subjects chose close family as the first source of help followed by psychologists (15%), self-help

group (12%) close friend (9%) and religious leader (3%) (Blay et al, 2008). The findings are consistent with literature on help-seeking, which suggests that individuals, especially older adults turn to their informal network of family and friends before receiving assistance from a formal network (Cantor 1983, 1991; Horowitz 1985; Litwak 1985; Sutor & Pillemer 1990). Another explanation as to why individuals chose “close family member” as a source for help as opposed to a healthcare professional may suggest that subjects perceived the symptoms described in the vignette as a common part of aging (Blay 2008). Furthermore, the choice of choosing family and friends suggest that subjects also saw the need for daily assistance for someone suffering with Alzheimer’s disease, which highlights the important role informal networks play in dementia care.

Additional studies examine help-seeking about individual awareness of knowing whether he/she has Alzheimer’s disease. A study of 169 adults (40-60 years old) in the Northeast was conducted to understand whether familiarity with the AD increased the likelihood of seeking help (Hodgson & Cutler 2004). Help-seeking was compared between two groups of subjects: Individuals living with a parent with AD and a matched group with no parental history of AD. Help-seeking was adapted from an instrument developed by Veroff, Kulka and Douvan (1981). Subjects were asked to indicate which individuals (family, friends, neighbors, co-workers, healthcare professionals, and other professionals) they were likely to talk to when they have concerns about their health (Hodgson & Cutler 2004). Subjects were also asked about seeking help through informational resources such as family, friends, internet and agencies (Hodgson & Cutler 2004).

The Hodgson & Cutler study suggests that a majority of the subjects turn to their informal network first before going to their formal network. The finding is consistent with

previous studies since many individuals with personal concerns of having AD will want to turn to their family and friends for emotional support and advice. Only a third of the subjects said they would seek help from their formal network (specifically a physician) regarding concerns of having AD (Hodgson & Cutler 2004). Again consistent with previous studies, one reason is that individuals may confuse the early stages of AD as part of the normal part of aging. However, the most robust finding is that subjects with parental history of AD were more likely to seek help (from informal, formal and informational sources) compared to those with no parental history of AD (Hodgson & Cutler 2004).

Indeed the Hodgson & Cutler (2004) study provides a better understanding of what factors predict help-seeking. However, given the empirical nature of the study one cannot understand the process by which individuals sought to seek help from their informal and formal sources. For example, it would be helpful to understand how decisions were made and who in their informal network were influential for them to seek help. It is also important to understand when caregivers sought help and why.

***Dementia Caregiving & Help-Seeking:*** One of the first studies to examine help-seeking among dementia caregivers suggest the important role of primary care providers in assisting with the help-seeking process. In this study, Smyth and Milidonis administrated a structured survey to 120 caregivers who were caring for a loved with Alzheimer's disease. The purpose of the empirical study was to understand the relationship between service use, normative beliefs about help-seeking and experience of caregiving (Smyth & Milidonis 1999). Normative beliefs for the study were measured by using the Belief in Caregiver Independence, Concern for Family Opinion and Preference for Informal Care. The main outcome from the study was that caregivers



who were concerned with the opinion of other family members about seeking formal assistance were most likely to experience caregiver burden despite the nature of the relationship between caregiver and care recipients. Thus caregivers who were most concerned with how they were viewed by other family members in the use of formal assistance were least likely to seek help from community services.

As presented in the Werner and Blay articles, informal social networks are important factors in understanding help-seeking behavior. This is especially true in culturally diverse communities. Valle and colleagues used composite scores from the Ways of Coping Revised questionnaire (WOC-R) to explore social network help-seeking behaviors of 89 dementia caregivers (Latino and Euro-American) in San Diego County. For the study, only six from the 67-item WOC-R was used for the study (Valle et al, 2004). These items are used as part of a structured questionnaire, along with satisfaction with support, caregiver distress, and size of support networks (Valle et al, 2004). The six items from the WOC-R are scored on a four-point Likert scale. Some of the questions asked study participants to: “asked someone respected for advice”, “talked to someone about how you were feeling”, “talked to someone who could do something” and “talked to someone to find out about the situation” (Valle et al, 2004).

Findings from the Valle study suggest that compared to Euro-Americans, Latino caregivers were less likely to turn to their social support network (informal social network). Furthermore, Latino caregivers were also less likely to turn to formal networks, such as doctors and nurses during times of distress. The findings suggest that help-seeking behaviors are deeply influenced by cultural values, such as a strong sense of filial obligations (Talamantes et al, 1995). Caregivers in this study felt that caregiving tasks were expected as part of their familial role, which explained why they did not seek help from their informal or formal network.

Although the studies discussed on caregiving and dementia provide important insights, they do not provide researchers with a theoretical framework explaining the help-seeking process of caregivers. Furthermore, these studies do not address the added complexity of how multiple co morbid illnesses, such as diabetes and dementia complicates the caregiving process.

### Caregivers & Help-Seeking: Qualitative Findings

Studying help-seeking from the perspectives of caregivers is relatively new. The Brown and Alligood (2004) study is the first to call attention to the importance of understanding help-seeking from the perspective of the family caregivers using a grounded theory method. In their qualitative study, Brown and Alligood examined the different help-seeking behavior of female caregivers whose spouses were diagnosed with dementia. Thus, the study sought to capture the interactions, thoughts and feelings associated with patterns of help-seeking. The study uses a grounded theory approach and guided by Margaret Newman's Theory of Health as Expanding Consciousness, the researchers discover three categories of help-seeking behavior among the female caregivers. According to this theory, illness is seen as a facilitator in patterns of person-environment interactions reflecting patterns of expanding consciousness (Newman 1992). The three patterns of help-seeking consist of : (1) avoiding - strategy in of no action in which the caregiver neither reaches out (for help) or within but ignores, minimizes or denies problems (2) shouldering - assumes the burden than seeking help (3) facing - involves acknowledging the need for help and seeks it (Brown & Alligood 2004). Help ranged from seeking medical advice to needing assistance with the daily care of their husband at home. The authors conclude that caregivers' decision to seek help is based on a cyclical pattern where consequences of caregiving determines future choices of continuing care at home or seeking help from formal services (Brown & Alligood 2004). Furthermore, the study suggests that several caregivers were in denial

of needing help, but through the encouragement of healthcare professionals such as physicians, they were able to realize their burden and seek help they needed (Brown & Alligood 2004).

A significant recommendation from the study is that healthcare professionals are crucial in assisting caregivers receive help. In many of the stories, the realization that a “problem” existed came too late (Brown & Alligood 2004). The researchers suggest that healthcare professionals can help in encouraging caregivers to seek and receive the help they need. They conclude that elders see healthcare professionals frequently due to their chronic illnesses, spending 10% - 15% of their lives with a chronic illness (Brown & Alligood 2004). Thus, the frequent interaction between healthcare professional and caregiver allows an opportunity for the healthcare professional to make an assessment to determine the needs of the caregivers and providing referrals to services.

One of the major limitations of the Brown and Alligood study is that majority of the participants were non-Hispanic White older adults. Furthermore, the study did not include additional information regarding their caregivers experience and perception of their contact with healthcare professionals, especially when the healthcare provider was helpful or not.

### Formal Networks & Help-Seeking

The concept of help-seeking behavior is often treated as an independent or dependent variable using the rational approach to understanding help-seeking. Most studies on help-seeking in older adults are on mental health, especially depression and schizophrenia (Angermeyer & Matschinger 1999; Lauber et al, 2001; Riedler-Heller, Matschinger & Angermeyer 2005). However, findings from these studies cannot be understated. These studies suggest that formal networks (i.e. healthcare professionals) can hinder or facilitate the help-seeking behavior for caregivers by providing advice and support (Angermeyer & Matschinger 1999; Lauber et al,

2001; Riedler-Heller, Matschinger & Angermeyer 2005).

Several studies suggest that during medical visits, caregivers feel physicians do not recognize or validate the caregiving role of family members. When physicians do not recognize the burden they experience, caregivers feel minimized and isolated (Feil et al, 2010).

Additionally, caregivers report that physicians are unaware of their worries and feelings of grief and distress (Schoenmaker et al 2009). Although caregivers often accompany the care receiver to medical visits, healthcare professionals are trained mainly to focus on patient care and not on the caregiver. As noted earlier, caregivers take on a multitude of roles (Beisecker 1989, Coe RM 1985, Adelman et al 1987). Unfortunately, healthcare professionals such as physicians are not trained to consider the “help-seeking family caregiver as a possible patient” and provide them with guidance on where to receive help (Schoenmakers et al 2009).

**Physicians:** Physicians may indirectly contribute to the underutilization of community services by caregivers. One problem is that physicians have limited knowledge of community services and agencies that may provide formal assistance or other support services for caregivers. A Canadian study of 142 physicians, show that 75% had not attended continuing education regarding caregiver needs in the past 3 years prior to the study (Yaffe 2002). The same study also found physicians heavily relied on the social services department regarding information on community services to address the needs of caregivers (Yaffe 2002). This suggests physicians had limited understanding and awareness of the available social services available to the caregivers (Yaffe 2002). Furthermore, the study also revealed that physicians who believed caregivers might be reluctant to use community services admitted to having no knowledge about the services offered (Yaffe 2002). Caregiver dissatisfaction and unmet needs during the caregiver-physician encounter is associated with limited physician knowledge about caregiving

issues and community services (Yaffe 2002).

To encourage help-seeking among caregivers, a study was conducted in Germany, which consisted of an experimental group consisting of doctors educated and informed about caregiver support groups and caregiver counseling (Donath et al 2010). Furthermore, physicians in the experimental group were asked to explicitly discuss and recommend the use of support services whereas physicians in the control group did not have any discussions with the caregivers. In the experimental group, the utilization of support services increased by four fold (counseling) and five-fold (support groups) when compared to the control group (Donath et al 2010). The findings suggest that when physicians have a discussion with caregivers regarding support services, and validate their role, they are more likely to use those services. One year later, caregivers continued to use the support services given the benefits they received from attending the support groups and counseling.

Given the empirical nature of the Donath study, there are limitations since researchers were not able to ascertain the thoughts and feelings of the caregivers. Specifically, it would help researchers to understand from the caregiver's perspective how it made them feel to have a physician recognize the burdens of caregiving and recommend support services. Furthermore, a qualitative perspective could explain how caregiver's distress were alleviated by attending these services and their relationship with the physician.

The Donath study is the only one so far to examine how physicians can facilitate the help-seeking process for caregivers. However, most studies suggest that physicians do not recognize or validate the caregiving role of family members, leaving many to feel demoralized. This raises the question as to how a negative caregiver-physician encounter may influence the help-seeking process. How do caregivers internalize the help-seeking process? Do caregivers

become discouraged or are there other healthcare professionals in their formal network that facilitates and encourages the help-seeking behavior? These questions are explored in the current study.

***Social Workers:*** Social service departments play an important role in the healthcare delivery system and the Yaffe study substantiates findings from another study. An Australian survey of 1259 community-dwelling dementia caregivers show that those who used community services such as respite care or support groups were in contact with a social worker (Brodaty et al 2005). This study suggests that social workers and other healthcare professionals are an important link to coordinating services for caregivers seeking help (Brodaty et al 2005). Although some may see the primary care provider as the central person for coordinating all care for the patient and caregiver, it is usually not the case (Bruce & Paterson 2000).

The aforementioned studies suggest that social workers can have a positive impact in assisting caregivers in the desire to receive help. However, it is important to understand from the perspective of the caregiver their interaction and communication with social workers within a healthcare system. This can shed light as to how having contact with a social worker can possibly modify any misconceptions they have regarding the current caregiving burden. As noted by Brown and Alligood it is possible that a social worker was able to ameliorate the caregiver's misconception about seeking help. This is addressed in the current study.

## CHAPTER 3 THEORY

*This chapter provides the author's philosophical orientation (symbolic interactionism) for the proposed study. A discussion on justifying why symbolic interactionism is appropriate in utilizing the dynamic approach to help-seeking is provided. The three stage model is introduced and its relevance to help-seeking.*

### Symbolic Interactionism

Influenced by pragmatism, George Herbert Mead laid the foundations of symbolic interactionism during the 1900s. Known for his works in *Mind, Self, and Society*, Mead argued that humans are social beings shaped by society (Meltzer, Petras, & Reynolds, 1975). He described how social processes influence individuals as they come to know themselves and others as they perceive, interpret and encounter uncertainties and ambiguities in life. Specifically, Mead argued that meaningful communication requires the ability to engage in role taking and use of shared symbols (Meltzer 1967).

However, it is Mead's student, Herbert Blumer who advanced symbolic interactionism by drawing on the works of John Dewey, William James, Charles Peirce, William Thomas and Charles Cooley (Charon 2010). Blumer proposed three core tenets of symbolic interactionism: 1) people act toward something based on meanings they ascribe to it (2) meanings are products of social interaction, and (3) meanings are modified through an individual's interpretive process (Fine 1993). Blumer claimed that people interact with each other by interpreting or defining each other's actions instead of simply reacting to each other's actions (Blumer 1962). An individual's "response" is not made directly to the actions but on the meaning, which they attach to the particular action. Therefore, human interaction is mediated by the use of symbols, ascertaining the meaning of one another's actions (Blumer 1962).

Charon suggests there are five central tenets to symbolic interactionism. These include: (1) humans must be understood as social beings...ongoing social interactions leads us to do what we do (2) humans are thinking beings; humans are thinking animals always conversing with ourselves as we interact with others (3) humans define the situation they are in; definition arises from ongoing social interactions and thinking (4) cause of human action is a result of what is occurring in our present situation; social interaction, thinking, definition of the situation takes place in the present and the past enters into our actions because we think about it and apply it in the definition of the present situation (5) humans are active beings in relation to their environment; they are actively involved in what they do and form own action (Charon 2010). Thus, Charon describes humans as active agents of action based on how they define and perceive the situation.

Symbolic interactionists believe that an objective reality exists but it is socially defined. Reality is “social” and what we see “out there” is developed through social interactions we have with each other (Charon 2010). Thus, we *define* the situation “as it exists” and the definition is dependent upon the social interactions we have with each other (Charon 2010). For example, when Stokowski (1952) studied the physiological experience of physical pain, he concluded the pain was defined differently by individuals depending on their ethnic group (reference group) (Stokowski 1952). Thus, physical pain is interpreted differently by individuals depending on how they are socialized to experience pain by their reference group.

The notion of the how a situation is defined is relevant to this study since help-seeking behavior is initiated when the caregiver perceives a problem (see Figure 1). However, how the problem is defined is dependent on the caregivers’ interpretation of the situation. The caregivers’ interpretation of a situation being problematic is dependent on his/her socialization with other



individuals in his/her reference group such as family or friends. Although a particular caregiving task may cause distress to the caregiver, he/she may not interpret it as a “problem” perhaps due to feelings that the caregiving task is a family obligation that is to be fulfilled by the family caregiver. How a situation is perceived is important because symbolic interactionists believe that individuals will decide to act based on his/her interpretation of the situation (Charon 2010). Therefore, if a caregiver does not view a particular aspect of caregiving to be a problematic, he/she is unlikely to seek help.

Another important tenet of symbolic interactionism is the understanding of social objects. Human and non-human action is based on the understanding of social objects. Social objects are defined according to their use for people involved in a situation...“meaning arises from how the individual is prepared to act toward it” (Blumer 1969, p68-69). Mead, Blumer and other symbolic interactionists believe that social objects are defined according to the “line of action” and individual is about to take (Charon 2010). Some examples of social objects include the self, other people (doctors, social workers, and friends, family), ideas and perspectives (e.g., belief in god) (Charon 2010). Objects are thus not static and intrinsically defined. Instead, human actors define them and use them to achieve their goals in a situation and change them according to changing goals (Charon 2010).

***Human Action (Decision to Act):*** Symbolic interactionists believe that humans act according to their definition of the situation (Charon 2010). Understanding how a definition is created requires researchers to focus on the “social interaction with others and the thinking within the actor as he or she acts overtly” (Charon 2010, p.114). Taking this position requires the researcher to view the individual (or the actor) as someone who is in charge, an active, living, problem-solving individual who will act based on his definition and perception of the situation at

hand. Thus, the symbolic interactionist perspective is conducive for the proposed study. The three-stage model (see Figure 1) is based on how the caregiver (actor) perceives the situation and whether the decision to seek help will take place.

Using a symbolic interactionist perspective requires understanding human action as a “stream of action”. Symbolic interactionists believe that action is continuous, a constant and never-ending process (Charon 2010). The stream of action is complex in which the actor never stops acting along this stream. Instead, one act leads to another, overlap and there are no lines separating one act from another (Charon 2010). This stream of action is analogous to a water stream in which the action never stops though the direction may change. However, barriers such as rocks may change the direction of the flowing water, yet the action never stops. This is also true with human actions. Like rocks in the analogy of the water stream, other individuals may enter into the actor’s lives. The social interaction between the actor and other individuals may redirect the actor’s action in a different direction. Thus, in the proposed study one of the goals is to understand how caregivers seek help during the course of their family member’s illness (i.e. diabetes). The “act” to seek help, however, may change due to the social interaction the caregiver has with his or her informal and formal network. Furthermore, the proposed study will not simply examine the decision to seek help (or not) at one fixed point in time. Instead, the author will try to understand (retrospectively) the caregivers’ help-seeking process during the course of the family member’s illness (i.e. diabetes). Thus, the author will inquire about the various events, which led the caregiver to seek help.

Symbolic interactionism also assumes the decision to act are based on the interaction between the self (the actor) and interaction with others (Charon 2010). Thus, decision-making is an ongoing process. Many decisions are made to cause an actor to go in a particular direction

(e.g., seeking help). Thus, “decision-making is constantly being influenced by our interaction with others and with the self...what others do in relation to us makes the difference in the decisions we make; defining goals and objects along the stream, we also make a difference” (Charon 2010, p.117).

The symbolic interactionist perspective, thus, assumes that individuals define the situation and act according to those definitions (Charon 2010). Actors define goals and plan to achieve those goals. Human action, therefore, unfolds around those goals. Actors are “thinkers, planners, schemers” (McCall and Simmons 1966). Each act in the ongoing stream of action consists of a goal, social objects and involves the decisions made by the actor (Charon 2010). Thus, each act may differ during this stream of action depending on the goals and social interactions. For example, a caregiver may say that early during her experience as a caregiver, her decision to not seek help was based on her goal to appease her family member. However, she may later change her goal to find respite from caregiving, seek help and hire a paid caregiver to help her achieve this goal. Furthermore, her decision to hire a paid caregiver may be based on her social interaction with friends, family (informal network) and healthcare professionals (formal network). These individuals may influence the caregiver to perceive the caregiving situation differently than what she had previously thought. The definition of the situation is the “result of ongoing action with the self (thinking) and interaction with others (Charon 2010, p.123).” One must also not forget the self consists of attitudes and beliefs toward the caregiving situation and help-seeking.

Since the proposed study plans to examine the attitude, beliefs as well as informal and formal networks as part of the decision making process, the symbolic interactionist perspective is an ideal philosophical orientation for the study. Furthermore, symbolic interactionism is ideal

since this is also consistent with the dynamic approach discussed earlier. In the next section, the dynamic approach will be discussed in conjunction with the three stage decision-making model.

### Understanding Help-Seeking from a Dynamic Approach

As discussed earlier, help-seeking behavior research has two divergent perspectives: rational choice approach (based on economics) and the dynamic approach (based on sociology and symbolic interactionism). The study will use the dynamic approach to understanding help-seeking among caregivers. In accordance with symbolic interactionism, individuals are seen as a social product and human action arises from social interactions (Pescosolido 1992). Thus, the decision to seek help is simply not based on mental calculations on cost/benefit of taking the action to seek help. Instead, the dynamic approach examines the decision to seek help as a product of social interactions consisting of individuals from social networks (Pescosolido 1992). Thus the decision to take a particular action, choice or decision is a social processes whereby interactions of individuals influence decision-making, define the situation and whether something should be done or not (Pescosolido 1992). As noted earlier, the definition of a situation (or a caregiving problem) is socially constructed. Thus, individuals in the caregivers' informal (family, friends, peers) or formal network (healthcare professionals) may influence how a situation (or caregiving problem) is perceived by the caregiver. Furthermore, individuals in the informal or formal network can either hinder or facilitate the help-seeking process. Sociological studies on help-seeking shows that "pathways to care" friends, relatives, clergymen are critical actors in the social process of individuals seeking help (Clausen & Yarrow 1955). These actors not only influence help-seeking but are advisors and caregivers providing emotional support for distressed caregivers (Janzen 1978). Thus, the dynamic approach recommends that help-seeking models include examining the important role of social networks of family, friends, peers and

healthcare professionals (Pescosolido 1992).

### Three Stage Model of Help-Seeking

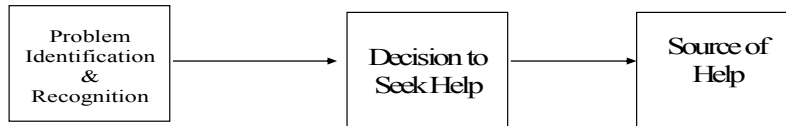
To understand the help-seeking process of caregivers, this study will utilize a three stage model of help-seeking (see Figure 1). Since the early 1970s, help-seeking has been conceptualized as a decision-making process (Zola 1973; Goldsmith et al, 1988; Cauce et al, 2002; Murray 2005; Liang et al 2005; Eiraldi et al, 2006). Literature reviews and examination of help-seeking models consistently show that common to all models is a three stage process, which begins with problem recognition, decision to act and selecting a source of help (Butcher & Crosbie 1977; Shapiro 1984; Greenley & Mullen 1990; Murray 2005; Cornally 2011).

The three-stage process model proposed by Gross & McMullen illustrates the three main stages (see Figure 1) of help-seeking, which has been used in a variety of disciplines to understand help-seeking (Gross & McMullen, 1982; Cornally 2011). First, the individual must perceive that a problem exists. However, what is considered a problem can vary from person to person (DePaulo 1983; Cornally 2011). The problem must be perceived by the individuals as amenable to help; the individual must believe that obtaining help will alleviate the problem (DePaulo, 1983). In some instances, an individual may seek help immediately after recognizing a problem, while others may delay seeking help until “it’s too late” (Cornally 2011).

The second phase consists of making the decision to seek help. In this phase, the individual has accepted that a problem exists and decides that help is needed to alleviate the situation. The individual assess whether the problem can be fixed by depending on oneself or

**FIGURE 1**

**Conceptual Model of Help-Seeking by Caregiver**



seeking outside help (DePaulo 1983). Furthermore, the decision to seek help is influenced by social networks, significant others and beliefs and attitudes about the source of help (Rosenstock 1965; Gourash 1978; Wilcox & Birkel 1983). The decision to seek help consists of various factors such as deciding whether seeking help is financially feasible and the potential stigma attached to seeking help. In some instances, individuals may refuse to seek help due to the negative attribution from others. From a symbolic interactionist perspective, the perception of others can have a powerful effect on the self-concept, since the self develops and is maintained through social interactions. For example, studies show gender influences whether one decides to seek help. Dementia caregiving research shows that women are more likely to provide most of the direct care and then seek help from friends, families, or formal services; whereas men were more likely to be, “care managers” and obtain formal care services (Brown & Chen 2008). One reason behind this is that women felt it was their spousal obligation to provide as much of direct care for their husbands and not doing so would make themselves look like “bad wives“(Brown & Chen 2008).

Finally, the third phase consists of source selection. In this phase, service selection is

defined as where or whom individuals turn to after identifying a problem and deciding to seek help (Cauce et al 2002). In this phase, an individual decides whom to turn to for help (i.e. community resources). Based on the perception of the problem, an individual will determine what type of help is needed before contacting the source of help (Liang et al 2005). Again, friends, families, peers and healthcare professionals can play an important role in helping the individual decide on which type of service to obtain help.

As noted earlier, the three stage model is used in various disciplines such as education, business, mental health and domestic violence to name a few. This three stage model is used in domestic violence literature, for example, to examine the variation in differences of how an abusive situation is perceived. For example, a study on the help-seeking patterns of African-American, Korean-American, and Caucasian found a difference on whether domestic violence is viewed as a problem depending on the cultural orientation of the individual (Moon 1999). For the proposed study, the three stage model is helpful in understanding not only how decisions are made but also the variation in the perceptions caregivers may have about their situation.

The purpose of this study is to generate grounded theory on how caregivers of Veterans seek help. Therefore, hypothesis and theories are not be tested a priori given the nature of the study. The three-stage model is left simplistically since theory will be generated through collected data. The study examines how informal and formal network influences problem recognition, decision to seek help, and use of community resources during the course of an illness (see Figure 1). Depending on one's beliefs toward caregiving, the caregiving tasks may or may not be viewed as a problem. Informal and formal networks may influence how the caregiver perceives or interpret the problem.

## CHAPTER 4 RESEARCH METHODS

*This chapter includes a discussion on the author's rationale for using a grounded theory approach to studying help-seeking. The author discusses a description of data collection and analysis utilizing a grounded theory approach. Furthermore, the author discusses the issue of rigor in grounded theory and potential limitations.*

### Research Design and Rationale

**Qualitative Paradigm:** The study utilizes a qualitative research design to understand the help-seeking process of caregivers. Furthermore, the goal of the study is not to test a hypothesis as in the case of quantitative studies but to generate an understanding of the phenomenon from the perspective of the caregivers. A qualitative paradigm serves well in understanding the process and experience of help-seeking from the eyes of the caregivers. The research questions are:

1. How do caregivers seek help during the course of their family member's illness?
  - a. What is the role of informal and formal networks in the help-seeking process?
2. At what point during their caregiving careers do caregivers seek help?

A qualitative research design allows researchers to understand the experience and perception of individuals who are part of the phenomenon of interest (Patton 2002). The main assumption in the qualitative approach is that the phenomenon is best understood by examining how the individuals (e.g., caregivers) experience the phenomenon of interest (help-seeking) (Patton 2002). Caregiving is a dynamic and non-linear process (Levy-Storms 1996). Thus, utilizing a qualitative approach is appropriate since this facilitates an understanding the



complexity of caregiving through the eyes of the participant. Qualitative research presumes an insider's (emic) perspective in which hypotheses are not tested but generated through collected data. Thus, the focus is not to quantify the phenomenon of interest but to understand how caregivers view and experience it. Qualitative research, such as grounded theory aids in examining how participants experience the phenomenon and, what it means to them (Guba and Lincoln, 1994). Furthermore, qualitative research may lead to hypotheses, whereas quantitative research tests hypotheses (Guba and Lincoln 1994). Grounded theorists also view human beings as active agents in their lives and world, rather than passive agents (Charmaz 2006). The notion of human agency, emergent processes, social and subjective meanings, problem-solving practices relocates to the foreground (Charmaz 2006).

Since help-seeking is a social process, collecting this information in a specific measure may be difficult. Furthermore, evidence on help-seeking among caregivers of Veterans with diabetes remains limited. Thus, utilizing a grounded theory method allows the author to develop a substantive theory "grounded" in the information provided by the caregivers. In grounded theory, two different types of theory may emerge: substantive and grand theory (Chiovitti and Priari 2003). According to Strauss and Corbin (1990), grand theory emerges from exploring a phenomenon in various contexts whereas substantive theory emerges by studying a phenomenon in a specific situational context. Since the study examines help-seeking among caregivers of Veterans receiving care from the geriatric, primary care and diabetes clinic at the WLA-VA, the emerging theory will be substantive. However, based on the findings from the proposed study, a future study may seek to develop a grand theory by including caregivers from different VA medical centers and clinics in California. Therefore, the grounded theory approach buttresses the philosophical orientation of symbolic interactionism and the dynamic approach to help-seeking.

***Why Grounded Theory?*** The author utilizes a grounded theory method because the purpose of the study is to generate a hypothesis and develop a theory to understand when and how caregivers seek help. The intent also is to understand the conceptual relationship of attitudes, beliefs, informal, formal networks and help-seeking in the context of diabetes and co-morbid illnesses. Other qualitative methods, such as phenomenology and narrative analysis, may also be conducive to the proposed study. However, phenomenology aims to describe the meaning of the lived experiences of several individuals about a concept or phenomenon (Creswell 1998). The goal of phenomenology looks to understand “what it’s like to experience” the phenomenon (Creswell 1998, p.55). Thus, a phenomenological study would examine what it means to be a caregiver of a Veteran with diabetes. Data analysis would consist of looking at how caregivers make meaning of their situation by examining statements and themes of meanings.

Similarly narrative inquiry examines how people create meanings of a phenomenon through narratives (Clandinin & Connelly 2000). Researchers using narrative analysis examine the meaning study participants attach to an event (Clandinin & Connelly 2000). Narratives are powerful, because they allow the sharing of knowledge hidden in constructed and perceived memory (LeGoff 1992). These memories are recollections of events as experienced by the subject. These events provide an in-depth understanding of how subjects perceived the phenomenon. Furthermore, researchers doing narrative analysis focus on capturing the emotions of the events described infused with the latent meaning being communicated by the study participant (LeGoff 1992). Thus, story collecting consists of allowing study participants to provide narratives of the past, present, future and understand the phenomenon through the meanings people assign to them (Klein & Myers 1999).

However, the goal of the study is different from those of phenomenology and narrative analysis. This study intends to examine when and how caregivers seek help in the context of the caregiving situation and develop a theory. The proposed study will examine how concepts of attitudes, beliefs, informal/formal networks and the illness trajectory converge in the help-seeking process. Thus, the goal is to generate a hypothesis as to when and why help-seeking occurs in relation to the aforementioned concepts.

***Constructivist Grounded Theory:*** The study uses a grounded theory methodology to generate a theory on help-seeking of caregivers. Grounded theory has three schools of thoughts: (1) Glaser often referred to as “classical” grounded theory (2) Corbin and Strauss and (3) Constructivist Grounded Theory proposed by Kathy Charmaz. The study utilizes a constructivist grounded theory to develop a theoretical understanding of how help-seeking behaviors occur among caregivers of Veterans with diabetes. Before discussing constructivist grounded theory, one must first understand the differences between the three different methods of grounded theory.

Grounded theory was initially conceived by Barney Glaser and Anselm Strauss. The publication of their book, *The Discovery of Grounded Theory: Strategies for Qualitative Research* (Glaser & Strauss 1967). Considered to be classical grounded theory, the Glaserian approach aims to answer “why” questions (Charmaz 2006). According to Charmaz, classical grounded theorists “seek explanation and predication at a general level...” (Charmaz 2006, p14). In classical grounded theory, the research is neutral and is not acknowledged in the co-creation of the research data. Thus, the classical grounded theorists “emphasize generality, not relativity and objectivity, not reflexivity” (Charmaz 2006, p8). Glaser also proposed that researchers should enter the field “*tabula rasa*” to avoid bias from any studies or articles about the topic in

question (Charmaz 2006).

In Strauss and Corbin, *Basics of Qualitative Research* (1990, 1998) provided a structured guide on how to do qualitative research. Although Strauss and Corbin provided guidance on how to effectively do qualitative research, it muted the social constructionist elements of the grounded theory method” (Charmaz 2006, p 10). The Strauss and Corbin’s approach to grounded theory also did not address the role of the researcher in the production of the research data. Kathy Charmaz revisited grounded theory by proposing a social constructionist perspective. In her proposed grounded theory method, there are four central tenets: (1) research process is treated as a social construction (2) scrutinize the research decisions and directions (3) improvise methodological and analytic strategies throughout the research process (4) collect sufficient data to discern and document how research participants construct their lives (Charmaz 2006). Furthermore, using constructionist grounded theory requires responding to emergent questions, new insights, and further information and simultaneously constructing the method of analysis (Charmaz 2006). The researcher in the constructionist perspective is considered a co-creator (with the research participant) of the research data. Therefore, reflexivity of the researcher is central to the constructionist grounded theory method (Charmaz 2006). Since the researcher is the “instrument” of data collection and analysis, reflexivity is important and enhancing credibility of the study findings (Beck 1993, Glesne, 1999; Merriam, 1998; Russell & Kelly, 2002; Stake, 1995). Through reflection, researchers become aware of what allows them to see, as well as what may inhibit their seeing (Russell & Kelly). The importance of reflexivity will be discussed later in this chapter regarding standards of rigor in grounded theory methods.

## Data Collection & Data Analysis

Data collection took place at the West Los Angeles VA Medical Center. The WLA-VA

Medical Center was chosen as the study site, since it is one of the largest inpatient and outpatient medical centers in Southern California. The inclusion criteria for the proposed study included the following: (1) Caregiver provides care for a Veteran who is 65 years or older (2) Veteran is diagnosed with diabetes (3) Veteran receives majority (50% or more) of healthcare services from the VA (4) Caregiver is a family member (spouse, daughter, son, nephew/niece, cousin) (5) Caregiver manages diabetes care for family member and has been (6) Providing care for at least 2 years. Caregivers who were cognitively impaired or who did not speak English were excluded from the study.

The author uses purposive sampling for the study. Purposive sampling focuses on a small group of individuals with characteristics that is of interest to the researcher (Patton 2002). There are several types of purposive sampling: (1) Maximum variation sampling (2) Homogenous (3) Typical case (4) Extreme case (5) Critical case (6) Total population (7) Expert sampling (Patton, 1990; Kuzel, 1999). Since the author is interested in a sample of caregivers who had been caregiving for two years of Veterans with diabetes, a homogenous sample was used. Homogenous sampling consists of units (i.e., caregivers) who share the same (or very similar) characteristics or traits (e.g. a group of people that are similar in terms of age, gender, background, occupation, etc.) (Patton, 1990; Kuzel, 1999).

During the course of the study, the author used theoretical sampling to ensure the saturation of categories. When saturation of categories was reached and the experiences of the study participants were illuminated, sampling ceased. The author was mindful that theoretical sampling was not about representing a population but as it pertains to conceptual and theoretical development (Charmaz 2006). The author collected data from 25 caregivers from the WLA-VA Medical Center.

Recruitment took place at the WLA-VA Medical Center during a six-month period. The proposed study recruited caregivers from the following clinics: diabetes, geriatric and outpatient. The rationale for recruitment from these clinics was that a majority of older Veterans with diabetes are enrolled in one of these three clinics. Furthermore, older patients from these clinics tend to be sicker and frailer which in many cases require family caregiving. Based on discussions with the principal investigator of the main study, recruiting from these clinics helped to ensure a homogenous sampling.

The author obtained IRB approval from the VA and UCLA before the study began. Before obtaining consent from the caregiver, the author discussed the background and purpose of the study, main research questions and study design. Participants were informed of the voluntary nature of participation. Participants were also informed that no identifying information would be collected. In addition, the author informed the subject that she will audio-record the interview. The author proceeded to obtain consent (verbal or written).

### Semi-Structured Interview

The in-person interview took place at the WLA-VA and lasted 30-60 minutes. Due to the caregivers' busy schedule, the author (after consulting with the principal investigator of the main study), believed that a 30-60 minute interview would be most feasible. However, the author also informed caregivers that she might contact them in the future with additional questions and clarifications of the responses provided. The interview was retrospective, in-depth, and semi-structured using an interview guide (see Appendix 1). All interviews occurred in a private office. With the permission of the study participant, the interviewer recorded the conversation. Questions were open-ended to encourage discussion of the caregivers experience and understand their how they sought help. First, the author introduced the topic of the study and briefly

discussed the purpose of the study. She proceeded to ask questions and used probes for the caregiver to elaborate on their responses. During the course of the interview, the author observed the facial expressions, body language, and attention to any discomfort/comfort the participant may display.

Prior to each interview, the author wrote memos regarding her thoughts and feelings about the interview questions. Memo writing was used to keep track of insights and analytical ideas as they occurred during data collection and analysis (Hutchinson 1986). Memoing provided an opportunity for the author to be reflexive regarding any biases she may bring to the interview. Since constructive grounded theory “takes the lead of the respondent”, the author also wrote memos on any additional topic areas that need to be included in the interview guide (Charmaz 2006).

### Zarit Burden Scale

The Zarit Burden scale was used to assess for the level of burden experienced by the caregivers. The Zarit Burden Interview is a commonly used caregiver self-report measure by researchers (Zarit, Reever & Bach-Peterson, 1980). The newly revised version contains 22 items. Caregivers were asked to self-report his/her level of caregiver burden using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always).

### Standards of Rigor

**Credibility:** Lincoln and Guba (2000) believe that qualitative research should be judged on the “trustworthiness” of the findings. Trustworthiness relates to the credibility of the findings (Carpenter-Rinaldi 1995). To enhance credibility the author utilized the four strategies suggested by Beck (1993) throughout the data collection and analysis phase of the study (see Appendix 2).

Data analysis took place concurrently with data collection to identify when saturation occurred. The transcripts were analyzed using line-by-line coding. Initial coding utilized the words described by the caregivers to remain close to the data. The preliminary codes allowed new ideas and inquiries led by the caregivers (Charmaz 2006). The author looked for tacit assumptions, explicated implicit actions and meanings, crystallized the significance of the points, using a constant comparison method and identified gaps in the data (Charmaz 2006). To prevent bias, the constant comparison method validated the researcher's interpretations by comparing one piece of data to another (Strauss and Corbin 2008). This method facilitated the inductive and deductive pattern of thinking and validated the constructs emerging from the data. The emergence of theory resulted from the constant interplay between the data and the researcher developing conceptualizations (Strauss and Corbin 2008).

After line-by-line coding finished, the author used focused coding. Focused coding requires researchers to use the most significant and/or frequent codes to sift through the data (Charmaz 2006). This level of coding required the author to make decisions about which initial codes made the most analytic sense. Again, these codes included the words utilized by the caregivers. In fact, using the caregivers own words at all levels of coding adds to the credibility of the findings (Strauss and Corbin 2008).

After focused coding was completed, theoretical coding occurred. Glaser first conceptualized theoretical coding as "how the substantive codes may relate to each other as hypotheses to be integrated into a theory" (Glaser 1978, p72). Theoretical codes specify possible relationships between categories developed during focused coding (Charmaz 2006). These codes helped to tell an analytic story about the phenomenon of interest. Thus, theoretical codes moved the analytic story towards a theoretical direction (Charmaz 2006).



Allowing the caregivers to lead the process of inquiry also meant the possibility of research and interview questions changing. As suggested by Beck (1993), enhancing credibility means the interview questions may change depending on the incoming data provided by caregiver. There are two levels of checking during the theory construction process. First, as codes developed (through line-by-line and focused coding), the author slightly changed the interview questions due to areas of importance highlighted by the caregivers. Secondly, the relationship between theoretical codes was checked by questioning their relevance to the caregivers' meaning of help-seeking (Beck 1993). Thus, caregivers were asked to participate in the refinement, development and revision of the emerging theoretical structure (Chiovitti and Prian 2003).

Discussing the author's own construction of the theory and acknowledging how it affected the inquiry is important to enhancing credibility (Chiovitti and Prian 2003). Thus memo writing, maintaining a personal journal and monitoring how literature was used (see Appendix 2) in establishing credibility of the findings. During data collection and analysis, the author maintained a journal to document thoughts and ideas about the research process. She documented and reflected on the stocks of knowledge and bias she brought to the research process (Charmaz 2006). Doing so helped to illuminate ways in which the researcher's own assumptions and behavior may be affecting the inquiry.

As noted earlier in this chapter, the author wrote memos (i.e., post comment interview sheet) to facilitate new findings and relish information that is not supported by the interviews. To enhance credibility, the author wrote personal journals (i.e., memos) to reflect on the emerging theoretical constructs emerging from the data Hutchinson (1986), especially during the phase of raising focused codes to conceptual categories (Charmaz 2006). In the analytic memos, the author discussed conceptual categories and gave them a conceptual definition. Doing so allowed

the author to go beyond the code as a descriptive tool and synthesize the data. In the memo, the author: defined the category, explicated the category, specified the conditions under which the category emerged, described its consequences and discussed how this category related to other categories (Charmaz 2006). Once theoretical saturation arose, data collection ceased.

The analytic memos provided the basis for creating the results section of the dissertation. Memoing assisted in making the analysis stronger, clearer and theoretical (Charmaz 2006). Theoretical sorting contributed to the emerging theory. Furthermore, this facilitated theoretical integration of the categories (Charmaz 2006). The author sorted and integrated the memos by title of each category, compare categories, and considered how the categorical order reflected the studied experience. She also considered how their order fits the logic of the categories and the best possible balance between the studied experience, categories and theoretical statements about them (Charmaz 2006).

For visual representation of the integration of the categories, the author diagramed the categories to further the theoretical development of the help-seeking process by caregivers. This was done in Atlas.ti. Diagramming helped in the emergence of a grounded theory on the phenomenon of help-seeking among caregivers of diabetic Veterans. The theory that emerged from the data analysis is an interpretation since it is dependent on the researcher's view. Constructivist grounded theorists acknowledge that theory is a co-creation between the researcher and participants (Charmaz 2006). Various researchers may come up with similar ideas, but how it is viewed theoretically may differ (Charmaz 2006).

Finally, discussing the role of the literature review in grounded theory must occur. Since the purpose of this study is to generate a substantive theory on help-seeking by caregivers, the use of sensitizing concepts, such as the three-stage decision making model and previous literature are "points of departure" which formed the interview questions (See Appendix 1). However, the author

carefully listened, analyzed the data during the data collection phase, and pursued other topics the respondents deemed as crucial (Charmaz 2006).

***Auditability:*** Auditability refers to the ability of another researcher to replicate the methods and conclusions achieved by another researcher (Carpenter Rinaldi 1995). Furthermore, auditability exists when another researcher is able to follow up the audit (or decision) of all the decisions made by a researcher at every stage of the analysis (Beck 1993). To ensure auditability, the author approached the transcribed interviews with such questions as (1) What is happening in the data? (2) What does the action in the data represent? (3) Is the conceptual code part of the caregivers' vocabulary? (4) In what context is the code used? (5) Is the code encompassed by a broader code? (6) Are there codes that reflect similar patterns? (Strauss and Corbin 2008). These questions were asked in the identification, development and refinement of the codes. Furthermore, the author wrote memos to describe her thoughts and steps undertaken.

Enhancing auditability also included describing how and why the study participants were selected (Beck 1993; Strauss and Corbin 2008). As noted earlier, the recruitment of caregivers were determined by theoretical sampling. Thus, recruitment ceased when no new information emerges from the interviews (Morse et al 2002).

***Transferability:*** This refers to the probability that the study findings will have meaning to others in similar situations (Carpenter Rinaldi 1995). This criterion of fittingness involves how applicable the working hypothesis from the study fits into other contexts other than the one from which the study was based (Beck 1993; Guba and Lincoln 1994). The first strategy is to describe demographic characteristics of the study participants and setting (Beck 1993). This information allows the reader to understand the context in which the theory and categories were developed (Beck 1993). The author collected demographic characteristics of the caregivers (age, gender, education, etc.). She also examined the characteristics of the different clinics in which

recruitment took place. Information about the demographic characteristics and setting will allow researchers to determine the transferability of findings (Beck 1993).

## CHAPTER 5 RESULTS

*This chapter presents the findings from the study. The discussion includes the profile of the caregivers and the Veterans, followed by a discussion on the experiences of the caregivers.*

### Participants Profiles

The purposive sample included 25 caregivers and Veterans. Spouses or a family member (daughter, son, nephew or niece) were caring for more than half of the Veterans. Anyone who was providing at least 50% of the Veterans' care at home was considered a caregiver. On average, the caregivers had been providing care for 7 years to Veterans that were aged 65 years or older. Caregivers were on average 56.7 years old and 88% were female. The average age for Veterans was 75 years old and 96% were male (Table 1).

**Table 1: Participants Profile**

|                                | Caregiver                         | Veteran                          |
|--------------------------------|-----------------------------------|----------------------------------|
| <b>Age</b>                     | 39-77 (MEAN = 56.7, STDEV = 12.9) | 65-89 (MEAN = 75.4, STDEV = 8.4) |
| <b>Male</b>                    | 3 (12%)                           | 24 (96%)                         |
| <b>Relationship to Veteran</b> |                                   |                                  |
| Spouse                         | 11 (44%)                          | -----                            |
| Daughter/Son/Niece/Nephew      | 13 (52%)                          |                                  |
| Sister/Brother                 | 1 (4%)                            |                                  |
| <b>Education</b>               |                                   |                                  |
| <12 years                      | 3 (12%)                           | 5 (20%)                          |
| Completed high school          | 11 (44%)                          | 11 (45%)                         |
| College or beyond              | 11 (44%)                          | 9 (36%)                          |
| <b>Race</b>                    |                                   |                                  |

|           |          |          |
|-----------|----------|----------|
| Caucasian | 19 (76%) | 20 (80%) |
| Black     | 4 (16%)  | 4 (16%)  |
| Hispanic  | 2 ((8%)  | 1 (8%)   |

\*STDEV – Standard Deviation

### *Health Status*

Caregiver self-rated health ranged from “fair to poor”. A majority of the caregivers (48%, n=12) indicated their health to be fair, while 20% (n=5) only perceived their health to be poor. Nearly 24% (n=6) perceived their health to be good, while 8% (n=2) viewed their health as excellent. According to the caregivers assessment of the Veterans’ health, forty-eight percent (n=12) of the Veterans were in poor health. Forty percent (n=11) of the Veterans were in fair health, while only 8% (n=2) were in good health.

### *Burden Level*

Caregivers completed the Zarit Burden Interview. The instrument provided a score to assess the burden level of the caregiver. The score ranged from 0 (no burden) to 88 (severe burden). In this sample, the mean score for the caregivers was 54.1 (Standard Deviation = 13.2, 29-76). On average caregivers experienced moderate to severe burden.

## Three Stage Model & Proposed Model

### *Original Help-Seeking Model*

The original help-seeking model suggested a linear process in which individuals were assumed to (1) Identify the problem (2) Make a decision to obtain help and (3) Identify a help source. To reiterate, the three stage process model proposed by Gross & McMullen illustrates the three main stages (see Figure 1) of help-seeking (Gross & McMullen, 1982; Cornally 2011). First, the individual must perceive that a problem exists. The problem must also be perceived by

the individuals as amenable to help; the individual must believe that obtaining help will alleviate the problem (DePaulo, 1983). In some instances, an individual may seek help immediately after recognizing a problem, while others may delay seeking help until “it’s too late” (Cornally 2011).

The second phase consists of making the decision to seek help. In this phase, the individual accepts that a problem exists and decides to seek help to alleviate the situation. The individual assess whether the problem can be fixed by depending on oneself or seeking outside help (DePaulo 1983). Furthermore, the decision to seek help is influenced by social networks about the source of help (Rosenstock 1965; Gourash 1978; Wilcox & Birkel 1983).

Finally, the third phase consists of choosing the source of help. In this phase, service selection is defined as where or whom individuals turn to after identifying a problem and deciding to seek help (Cauce et al 2002). In this phase, an individual decides whom to turn to for help (i.e. community resources). Based on the perception of the problem, an individual will determine what type of help is needed before contacting the source of help (Liang et al 2005). Again, friends, families, peers and healthcare professionals can play an important role in helping the individual decide on which form of assistance to seek.

### *Proposed Model*

The study findings suggest that the help-seeking process for caregivers is non-linear and complex. The proposed model (Appendix 3) suggests that caregivers endure a multitude of issues before identifying a need for help. Initially caregivers rely on themselves in the provision of care. Within the “self-reliance on providing care” category, caregivers rely on themselves to manage the diabetes care regimen of the Veteran (Appendix 3), meaning they solely manage most or all of the diabetes care regimen. They also find themselves “managing the caregiving situation” to the best of their ability (Appendix 3). While relying on their will and desire to help the Veteran,

caregivers encounter challenges in which they may be inadequately prepared. With limited knowledge and experience, caregivers try to manage the situation to the best of their ability. In this category, caregivers manage their caregiving situation based on previous experience or what they learned from family and friends. In other instances, caregivers created inventive ways to care for the Veteran. For example, one caregiver said:

“My uncle hates to get fingerpicks. So I realized that the best time to prick his fingers is when he’s watching TV. You know when he’s distracted. Otherwise, I wouldn’t be able to do this. He’s just won’t let me do this if he’s paying attention”.

Other caregivers realized that the best way to manage their caregiving situation is by planning ahead, especially for caregivers of Veterans living with dementia. Many of these caregivers mentioned the challenges of caring for someone with both dementia and diabetes. One caregiver shared her story of dealing with an uncle who did not want to take diabetes medication. She describes how he would become belligerent whenever she would try to give medication. Therefore, she devised a plan to have the medication laid out for him on the kitchen table for breakfast:

“I wake up around 5AM before school and get breakfast ready. I make sure to make something that he’ll eat, like hash browns and eggs. I also leave the meds for him next to his plate. When he’s eating, I remind him to take his meds. He doesn’t complain and takes it. It’s the only I can get him to do this.”

“Self-reliance on providing care” and “managing caregiving situation” were not mutually exclusive. It was not unusual to find instances in which caregivers relied on themselves in the midst of managing the caregiving situation. One of the caregivers described how she would find strength within herself and would identify creative ways to manage her father’s diabetes care:



“Sometimes I want to try cry, because I’m so tired from work and family. But that’s when I have to just tell myself to stay strong and move on. I figured out that I’m pretty savvy when it comes to things. Like when my dad gets feisty about not taking his meds, I just tell him that mom’s not happy with you. You know you don’t want to make mom cry from heaven!”

Although caregivers identified strategies to manage the caregiving situation to the best of their ability, such strategies, in turn, could lead to a constellation of other issues such as encountering additional caregiving challenges, caregiving emotions, and lack of knowledge and negative (or positive) reactions to the caregiving situation (Appendix 3). This cluster of categories gradually influenced the caregivers to realize that a problem exists within the caregiving situation, thus, leading them to seek help. The first theme to arise from this study is “Knowing what you don’t know”.

### **Theme 1: Knowing what you don’t know**

Caregivers often find themselves reaching a point in which they are overwhelmed and realize they are not prepared to attend to the complex needs of the Veterans. Many Veterans have a multitude of comorbidities complicating the diabetes caregiving experience. Furthermore, many experience neuropathy, vision or limb loss due to diabetes. Caregivers do the best they can to care for the Veteran. However, while in the midst of the caregiving, caregivers begin to encounter challenges, such as the Veterans’ behavioral or medical issues for which they are unprepared to undertake. Encountering difficult situations in which the caregiver has limited knowledge leads to an array of negative emotions, including frustration, anger and distress. Caregivers eventually reach a breaking point in which they come to “know what they don’t

know”. In many cases, caregivers simply do not have enough knowledge or information on how to care for a Veteran with complex diabetic needs.

The first theme, “Knowing what you don’t know”, consists of core categories fundamental to answering the research question. These categories include: (1) Caregiving challenges (2) Caregiving Emotions (3) Lack Knowledge – Diabetes & Caregiving and (4) Responses to Caregiving Situation. Four categories encompass “problem identification” from the original three stage model. Caregivers come to realize a problem exists when several of the categories overlap one another. Caregivers reach a point in which they are overwhelmed and understand that they need help. Below is a discussion on the dimensions of the first theme.

### *Caregiving Challenges*

The category of “caregiving challenges” consist of codes ranging from Veterans experience with hypoglycemia to caregivers lacking awareness of resources available at the VA, which all describe the challenges to caregiving such as hypoglycemia. Caregivers tell stories of Veterans fainting or being rushed to the emergency room due to low blood sugar. Veterans experiencing light-headedness or fainting soon after taking diabetes medication often preceded hypoglycemia according to caregivers. One caregiver described how an increase in the dosage of insulin (prescribed by the PCP) led to a hypoglycemic episode. This caregiver described the fear of not knowing why her father had collapsed:

“I did what the doctor told me to do. I gave him insulin and before you know it, I found him on the floor. He was complaining of feeling faint and weak. I didn’t know what to do. I called 911. When they arrived, they said his blood sugar was really low, something like 70”.

This caregiver later describes that her father was assigned a new PCP. The new doctor had given her father an increased dosage of insulin. Caring for her father was a challenge since

she did not know how to properly control his blood sugar and prevent a hypoglycemic episode. She describes the experience as being “stressful” and “frightening”.

Another related category is “caregiver believes tighter control of diabetes is best”. Since many of the caregivers lack knowledge about the dangers of hypoglycemia, they may find themselves inadvertently inducing hypoglycemic episodes. Caregivers discuss how the Veterans’ primary care provider (PCP) would recommend a low Hemoglobin A1C (i.e. 7 or below), so they tend to believe that the lower the blood sugar the better. This often means doing several finger pricks during the day which may prove to be challenging. Since fingerpricks can be uncomfortable, caregivers describe the challenges associated with them:

“I was told by the doctor that I should check my father’s blood sugar three to four times a day. The doctor said his blood sugar should be something like 7 or below. So, I make sure to check his blood after every meal. But it’s hard because dad doesn’t like to feel the needle pinch him. He always complains about it hurting him. But I have to do it regardless”.

Other challenges to caregiving consist of Veterans experiencing mental health, behavioral problems or suffering from other chronic illnesses such as dementia. Since dementia often co-occurs with diabetes, many of the caregivers described their challenges:

“I don’t know where to begin. Sometimes my uncle is so unpredictable because he doesn’t recognize me. I mean I’ll go up and tell him, you need to take your medicine. He will scream and push me away. I mean what I am supposed to do when you have someone who is this difficult? He refuses to take his medicine and then argues with me. He also can’t remember who I am and why he needs to take all of this stuff! It’s so frustrating. Sometimes, I just feel like giving up!” Another caregiver describes how her uncle’s inability to remember can be a hindrance to caregiving. She describes her need to constantly monitor him while eating:

“I have to be careful with my uncle. When he takes his glimepiride, he has to eat, you know. Otherwise, he’ll get real dizzy and such. One time he forgot that he ate, but told me that he had a snack, so I gave him the medication. Before you know it, he’s complaining about the room spinning and feeling weak. Later on, I found out that he didn’t eat anything. That’s why the blood sugar got real low. I mean it’s tough to, you know, keep an eye on him. I gotta make sure that he eats otherwise, his blood sugar can get real low...too low.”

Caregivers also have trouble with Veterans being in denial of having diabetes. One caregiver described how her husband carelessly ate anything high in sugar:

“It’s aggravating because my husband doesn’t think he has diabetes. Even though the doctor has told him several times the need to eat a low sugar diet, my husband doesn’t think it’s important to him. I don’t know he’s just stubborn. It’s hard to get him to believe that he needs to be careful. I just don’t know what to do. I mean what do you do?”

Caregivers experience frustration with Veterans regarding the diabetes regimen and feel unprepared to deal with realities of dealing with Veterans that refuse to adhere to the diabetes care regimen. Furthermore, many caregivers lack the knowledge of how to care for someone with a multitude of chronic illnesses. In many instances, caregivers are not aware of services available to them such as the VA Caregivers’ Hotline.

### *Responses to Caregiving Situation*

The caregivers’ response to the caregiving situation reflect the demanding nature of the being a caregiver. Most of the caregivers experience “worsening physical and mental well-being” given the multiple needs of the Veteran. Since most of the Veterans have several co-morbidities along with diabetes, many caregivers become physically and mentally exhausted. One caregiver complained that during the five years she has been caregiving, her mental and

physical health has deteriorated. As an elderly woman in her 60s, she experiences bouts of depression and anxiety. She described how her diabetes worsened due to having limited time to manage her own health:

“You know, what’s so funny is that I also have diabetes. I can’t believe that here I am taking care of my father and my diabetes gets worse. I don’t have time to go to the doctor and such because my father comes first. I want to make sure that he doesn’t lose a leg or go blind if the diabetes gets out of control. Who knows, I may end up that way.”

Caregivers describe their experience as being *stressful* from their need to monitor the Veterans’ diabetic diet, blood sugar and their risk for falls (due to hypoglycemia). A caregiver describes being on “night patrol” because her father had a tendency of experiencing low blood sugar during the night. He had fallen several times in the bathroom, and the caregiver worried that one day he may fracture his hip. She complained:

“It’s hard to get a good night’s sleep. I mean I have to wake up 5 AM to get my children ready for school. But I’m up all night making sure that dad doesn’t fall over and hurt himself in the house.”

Furthermore, caregivers describe their situation as “demanding” and “stressful”, given their fear of the dyscontrol of diabetes. Caregivers described in detail the need to carefully monitor the diet, check the Veterans’ feet for infections, and provided daily checks on the blood sugar and appropriate medications:

“I wake up in the morning around 7 and make sure to cook him oatmeal or something healthy like that. He forgets a lot, so I make sure to wake him up about 10 so I can get his blood sugar in the morning before he eats. I lay out all his medications; he takes about 10 every morning because he has high cholesterol, blood pressure, and check it again after

he eats. Then I cook lunch for him and take him outside for exercise. He likes to walk, so I walk with him. He can't see well so I make sure that I'm with him all the time. I can't leave him alone. Then I go home and recheck his blood before dinnertime. I mean, it's a lot of work. The doctor said that he wants his blood sugar checked 3-4 times/day. Caring for a diabetic is demanding and stressful. I don't want his sugar to go too high".

In the study, many Veterans lost their eyesight or the use of limbs due to the progression of diabetes, which, in turn, adds to caregiver stress. This creates an additional burden since this requires "constant vigilance" of the Veteran. Several of the Veterans suffer from foot neuropathy and blindness. This leaves many caregivers needing to provide constant monitoring of the Veteran due to their risk of falling. A caregiver remarked, "When I'm at work, I worry about my dad because I'm afraid that he may trip and fall over a rug or table. He can't see well anymore. When I get home, I make sure to keep a close eye on him. Plus, he doesn't feel anything under his foot. The doctor said that diabetes killed all the feelings in his foot. One time, dad stepped on a nail and he didn't even know it."

The need to constantly monitor the Veteran takes a toll on the "quality of life" of the caregivers. The caregivers complained how they have little time for themselves and a social life. One caregiver said, "I didn't think things would be this way. I don't go out with friends anymore, because I'm home taking care of my husband. I can't take him with me, because he can't walk very far. My life has changed ever since he got worse from diabetes." She was one of many of who describes how the progression of diabetes requires more time from the caregivers and little time for themselves. The demanding nature of caregiving further diminishes any social life the caregivers previously had.

Some caregivers found "fulfillment" in caring for the Veterans. A daughter of a Veteran

says that she “feels closer than ever to dad because I get to spend lots of time with him”. She was one of the few who was able to maintain an optimistic view of her caregiving situation. Although caregiving has taken a toll on her physically and mentally, she was able to respond to the caregiving situation with optimism.

### *Caregiving Emotions*

The caregivers experience a wide array of emotions. Caregivers find the caregiving experience to consist of a mix of emotions. One of the benefits of caregiving is the feeling of “joy” in knowing they are helping their loved one. The wife of a Veteran says, “I know that my husband needs me. I just feel happy that I’m able to help him. I know that he would do the same for me too if I was in his situation”. Such a sense of reciprocity may occur because family members described how they were providing care in return for the love they had received from the Veterans.

At the same time, caregivers also expressed feeling “frustration or anger” with their caregiving situations. Caregivers feel frustrated towards the Veteran as well as themselves. One of the caregivers remarked, “I get upset at my father because he doesn’t take his diabetes medicines like I tell him too. I’m also upset at myself. I mean I feel that I’m not doing a good enough job for him. Somehow I feel that I’m at fault for his stubbornness”. Another caregiver also described how she felt frustrated because she doesn’t have enough information about diabetes and dementia: “I don’t know much about diabetes. I heard about dementia but didn’t think it would happen to dad. It’s so crazy because there’s so much going on. Gosh, I’m doing what I can but it’s just so crazy.”

Feelings of “guilt and sadness” over the need to make sure the Veteran maintains a restrictive diabetic diet may also arise. Believing that strict diabetes control is best, caregivers

limited the kinds of food the Veteran can eat. However, this left many caregivers feeling guilty. A caregiver said, “Sometimes I feel guilty when I’m eating candy near my dad. He always wants some, but I can’t give it to him because his diabetes may get worse. Sometimes, I feel sad too because I can’t enjoy certain kinds of food with my dad”. Other caregivers allowed the Veteran to “cheat” and have morsels of sugary foods. However, this often leads many caregivers to feel guilty. Since the Veterans’ doctor recommends a strict diet, many of the caregivers knew that allowing their loved ones to “cheat” would leave them feeling guilty:

“My husband’s VA doctor told him that he can’t have any kind of candy or anything sugary because it’s going to make the diabetes worse. I don’t want him to die from diabetes, so I make sure not to give him anything sweet. There are times when I just feel sorry for him and allow him to have a stash of chocolates in his room. He loves it. But I also feel guilty thinking that I could be making the diabetes worse.”

#### *Lack of Knowledge – Diabetes & Caregiving*

Limited information and knowledge about diabetes and caregiving may compound the caregiving situation. As mentioned earlier, providers at the Veterans Administration tend to focus on strict diabetes care. However, many caregivers lack information regarding what an appropriate Hemoglobin A1C and blood sugar levels should be for an elderly person, and the dangerous consequences of hypoglycemia. Nearly half of caregivers said “no” to whether they knew the meaning of low blood sugar. A caregiver stated, “All I’ve been told is that you gotta have the blood sugar levels low, you know like 100 or something like that. I don’t know what you mean by low blood sugar.” In some instances, caregivers had personal experience with hypoglycemic episodes. In some cases, the Veteran had to be taken to the Emergency Room due to dangerously low blood sugar. A caregiver said,



“I had to call 911 because my dad fainted and his face turned white. I was scared because I didn’t know what to do. The ambulance guys said that he had a really low sugar reading, something like 50. I don’t remember but I remember that experience because I was scared. It was the first time, I saw what can happen when you get a low blood sugar.”

As in many cases, the caregiver gave an extra dosage of insulin without knowing the dangers of hypoglycemia.

Additionally, caregivers did not know how to care for a Veteran who had “diabetes and dementia”. Since dementia can cause behavioral problems, many caregivers do not know how to handle difficult behavior related situations. One of the caregivers said,

“I just don’t know what you’re supposed to do when someone becomes combative because he doesn’t want to take his medicine. My uncle was always feisty, but since he developed Alzheimer’s, I think he became more combative. He would attack me if I tried to give him his medicine. I just don’t know what to do. It’s just overwhelming!”

Lacking information about how to handle Veterans with behavioral problems adds an additional layer of burden to the caregivers. Many are forced to develop strategies to deal with behavioral problems on a short-term basis. A caregiver said, “For now, the best thing I could do is make sure to give him his [diabetes] medicine with his food. He likes to eat it with roast beef. Lately, I’m noticing that he doesn’t eat much food anymore, especially meat. I’m not sure how long I can keep doing this.”

The caregivers also lack information regarding the complications of diabetes, which causes constant worrying. They describe symptoms of neuropathy, such as “limited foot sensation” and “weakness in the legs”. They know something is wrong, but do not understand exactly why the Veteran is experiencing these symptoms. A caregiver best describes this

experience as “being in a black hole. You see bad things happening to your husband, but you don’t know why. The doctor just says to keep an eye on his sugar levels. But I don’t know why he’s feeling weak or falls over things”. She continues, to say that “...not knowing much about caregiving and diabetes is a scary because you know something has to be done, but you don’t know what to do”.

### *Problem Identification*

Caregivers do the best they could given their circumstances. Encompassed by a variety of issues compounding the caregiving situation, many caregivers simply reach a breaking point. Although they struggle to maintain their ability to care for the Veteran on their own, many come to realize that they simply did not have the knowledge or the capacity to continue with their caregiving. Throughout the interviews, caregivers realize a problem exists with their caregiving situation when they experience caregiving challenges, the emotions of caregiving, understanding they lack knowledge and the array of responses to the situation (Appendix 3). Some caregivers realize the need for help by explaining a time when they sought assistance from family or friends. One caregiver stated:

“I knew that I couldn’t keep doing this for long. I mean I was taking care of my mother for almost 4 years and I couldn’t understand what I was doing wrong or what I was supposed to do. I thought her diabetes was under control, but she would fall inside the house. This didn’t seem right. I always got sick and took time from work. I was getting upset and angry at god all the time. All this was something that I couldn’t take it anymore. I got to realize that there were things that I didn’t know about caring for my mother. I guess I knew what I didn’t know.

I knew I had to get some advice from friends or my sister. I just knew something had to happen.”

In this case, the caregivers’ desire to seek help is influenced by a moment in which she realizes “knowing what you don’t know”. Other stories emerged of caregivers coming to grips with problems in their caregiving situation. One of the caregivers, mentioned:

“I knew I was in trouble because I always felt tired and frustrated. I would take it out on my wife, and our marriage was crumbling. I was just getting tired of taking care of my dad. It’s tough caring for someone who has lots of problems, but just seeing him weak from the diabetes was sad for me. Dad didn’t care anymore about his diabetes and refused medicine. I didn’t know why he would get feisty and complain about the medication and insulin. So, I started reading books and talking to doctors. I knew I wasn’t doing something right”.

In this situation, the caregiver seeks informational help because he has little information regarding caregiving. Furthermore, he began to respond to his caregiving situation by taking his frustration on his wife. Additionally, he experiences the challenges of dealing with a Veteran who was experiencing the complications of diabetes but also had become resistant to taking medication. The caregiver, therefore, realizes that a problem exists that in fact, that he “knows what he didn’t know”.

Other caregivers demonstrate a need for respite from caregiving, financial and/or spiritual assistance. Often caregivers need different types of support. One caregiver described how she needs respite from caregiving as well as a need for financial and spiritual support:

“Taking care of my brother takes whole lotta of time from the day. He can’t use his hands because he had a stroke. I have to make sure to give him insulin and check his blood sugar.

He can't walk well because he some kind of problem with his legs...It's got something to do with diabetes. There's so many things that I gotta do that it'd be nice to get some help...you know someone to help me with these daily chores. I'd like to hire someone but it costs money. Sometimes, I just pray and ask god to help me”.

She further described the difficulty of finding help with her caregiving situation because of the confusing information provided to her by the VA. She discussed how conflicting information further made her realize how much she does not know about resources available to her:

“I heard some people at the hospital [VA] tell me I could get some kind of help, something like Medicaid for my brother. They gave me some information and brochures, but I don't understand what all this means. They got so many things that it's just a maze for me. Then I heard someone tell me about Medicare. I don't know where to begin. I still don't understand any of this!”

This particular caregiver is confused and overwhelmed with the information provided to her. This is compounded by her exhaustion from her caregiving responsibilities. Although she is seeking help, she still requires additional assistance to help her understand the resources available.

Although a majority of the caregivers experienced exhaustion and confusion while caring for a Veteran, there was a case in which this was not necessarily true. A negative case analysis was conducted in which the experience of a particular caregiver was compared with those of the other caregivers. In this particular case, the caregiver's experience was inconsistent with those of the other caregivers interviewed for the study. She was able to fully comprehend the dangers of hypoglycemia and successfully manage the caregiving responsibilities on her own. After conducting a negative case analysis, it made sense that the caregiver was able to successfully

care for her husband. She had worked as a nurse for 15 years and was involved in caring for patients with diabetes. Given her experience, she made sure to have discussions with her husband's doctor about his care and to ensure that his diabetes care regimen was appropriate. Therefore, she was fully aware of how to care for her husband. She was atypical since she did not encounter the same conditions (as noted in the theoretical framework) as most caregivers.

### Theme 2: "Help Means Different Things to Different People"

The second theme reflects the different types of help individuals seek. Once a caregiver knows a problem exists, he or she seeks assistance while respecting the wishes of the Veteran (Appendix 3). Caregivers respect the wishes of the Veterans but make sure that family members or friends provide care. Veterans feel uncomfortable of having "strangers" provide any assistance to them. A 65 year-old caregiver describes wanting to have her neighbor help care for her uncle so she can get a "break" from caregiving but refuses to do so because her uncle feels uncomfortable. She described a conversation she had with her uncle:

"I remember telling my uncle that I want to have a friend – a neighbor come and cook and give him his medicines while I get a break from my daily responsibilities. He completely refuses to have anyone else inside the house. He complains that "strangers" may steal things and doesn't want them near him. Oh well, I guess I have to put up with and do all the care myself. I want him to feel comfortable in our home"

In reviewing the data, it is also clear that caregivers are proactive or passive in their help-seeking behavior (i.e., "help-seeking type). Caregivers are classified as being "Proactive and overwhelmed" or "Passive and Overwhelmed". An example of the former is a 70-year-old caregiver of her husband. She described seeking information regarding how to care for someone with diabetes and dementia:

“I always look out for any kind of studies where I can learn to help my uncle. I joined...an Alzheimer’s project so that I can learn more about the disease. You know I learned that it’s normal for people with Alzheimer’s to act out and such. So, I realized what my uncle wasn’t strange or anything”

She also describes seeking out information from VA staff. She stated, “Whenever I have a question, I ask doctors, nutritionists, psychologist and such about my uncle. They’re so nice!” However, despite being proactive in her effort to obtain help, she describes being stressed and overwhelmed with her caregiving responsibilities. She says, “My uncle is so difficult. You need to make sure that he eats, so his sugar don’t go too low. Sometimes he forgets, and I give me him insulin. It’s just tiring. It’s stressful!”

On the other hand, some overwhelmed caregivers do not seek assistance right away. However, these caregivers initiate help-seeking based on their interaction with informal and formal network. An elderly caregiver mentions, “I know there’s things like In-Home Supportive Services (IHSS), but I’m just too tired to fill out the application”. In other situations, caregivers describe the need for assistance, such as instrumental help, but are unsure of where to go since they have found it to be a futile process. Another caregiver described her attempts, “I went to the VA to get help with maybe getting some adult day care for my husband. All I got was the run-around. I just gave up because it just seemed pointless for me to get any assistance for him”.

The term “help” had different meanings to caregivers. Some perceive help as informational, psychosocial, spiritual, instrumental or financial support (Appendix 3). How a caregiver defines help influences their interaction (i.e. communication) with their formal and/or informal network (Appendix 3). Discussing the kind of help the caregiver needs commonly took place within their informal network (i.e., family or friends). A caregiver described a situation

where she reached out to her friends for instrumental and informational help:

“I have good friends. They saw how I was having trouble with my dad and how stubborn he is with me. I asked them if they could lend a hand, you know, when I need it. They (friends) help me clean the house and give him medication. They also gave me some books about caregiving because I couldn’t find any good information on the internet about these things”.

The formal network is only used when the caregiver feel their friends or family cannot help answer their questions. Caregivers communicate with their formal network when information regarding diabetes is needed. Caregivers commonly ask the VA provider (nurses or doctor) clinical questions regarding diabetes. A daughter of a Veteran, who experienced hypoglycemia, asks her father’s doctor what to do when he becomes “light-headed”:

“I needed to know what to do when my dad got light-headed, dizzy. Most of my friends, family, co-workers said I should read WebMD. I felt more confident getting advice from my dad’s doctor. He said to give him OJ if dad ever got dizzy or anything. I’m glad I asked because I feel better knowing what to do in case dad’s blood sugar gets low”

Caregivers also describe wanting more advice from VA staff about their caregiving situation, but feeling uncomfortable discussing this. Most of the interactions with VA staff occur with the physicians. Caregivers describe wanting to discuss the challenges of the caregiving situation with VA staff, however feeling uncomfortable doing so. One of the caregivers said:

I remember going with my husband to his medical appointment. His doctor is nice, but I don’t feel comfortable talking to him about what’s going on at home and just how hard it is to take care of him. There’s only so much time during the appointments, so I make sure to ask him questions about his health....I’ve never been asked by the doctor about what

I'm going through. It would be nice, you know. But I don't think he has time to do that".

Another caregiver also echoed the statements of the previous caregiver. She said:

"I ask questions about my husband's diabetes and some the issues with him not wanting to eat the right kinds of foods. Yeah, there are times when I want to ask the doctor, if he knows of books or support group or something that can help. He (doctor) makes it clear that he doesn't have time to talk about this with me. I don't think he's a bad doctor.

There's so many patients that I don't think he has time for the family to ask questions that's not medically related".

Indeed, caregivers want more time to discuss with the Veterans' physician and to get specific advice on caregiving resources. However, caregivers are reluctant to do so because of the time constraints. In fact, the limited time for discussions during the medical appointments is a common barrier described by the caregivers.

"Help" for most caregivers means informational and instrumental help (Appendix 4).

According to the diagram (Appendix 4), caregivers need informational support the most, then, instrumental, psychosocial and spiritual support. Most caregivers need basic information regarding caregiving and diabetes. As stated earlier, many caregivers rely on themselves and their creativity to invent strategies to help Veterans adhere to the diabetes care regimen.

Caregivers complain that the VA does not provide enough information regarding caregiving and diabetes. This is especially true with the diabetic diet. A common complaint among caregivers is that Veterans refuse to stay away from sugary foods. Many suggest that the VA needs to provide educational classes on nutrition for caregivers. One of the most common problems for caregivers are arguments between them and the Veteran regarding the diabetic diet. Caregivers often find themselves arguing with the Veteran over the need to maintain a sugar-free diet. A 63 year-old



caregiver of a Veteran who had already lost his legs to diabetes describe the daily arguments they have. She feels that her husband is in denial and continues to eat unhealthy foods. She said:

“I’ve been married for over 20 years. I think my husband is in denial or something because he continues to eat chocolates, donuts, soda and other crap that he shouldn’t have. Somehow he’s able to get his friends to buy him food because, I guess, they feel sorry for him. But you know what, I’m the one they should feel sorry for. I mean, I have to argue with him every day because I don’t want him to eat that junk. I don’t want him to lose his eyes because the diabetes got bad. The VA should have classes for people like us. You know to educate us. When you don’t know what to do it don’t make me feel good, you know”

Caregivers commonly have arguments with Veterans because managing diabetes require a strict diet. As in the case of the 63 year-old caregiver, the need for education to help caregivers is evident. Nearly all of the caregivers describe needing some kind of information regarding diabetes and caregiving at some point.

The diagram also shows that informational support overlaps with instrumental support (Appendix 4). The need for informational and instrumental support often occurs when caregivers find themselves in difficult situations. This often occurs for Veterans who have suffered from the complications of diabetes leading to blindness and/or neuropathy. In their effort to obtain information, caregivers want to learn how to be encouraging and supportive towards the Veteran while also managing the challenging aspect of providing instrumental care. One of the caregivers mentioned:

“I don’t know what to tell my husband [when he] feels like he’s sad and doesn’t want to live anymore. He’s blind and knows that he can’t do anything without me. I bathe him

and give insulin...but it's so hard to carry him in and out of the bath and into bed. I talked to my friends about what I can do to make him feel better. You know, like what they know, books or something”.

Caregivers of Veterans who have dementia and diabetes are also in need of informational and instrumental support. Many caregivers lack information regarding the behavioral problems of a Veteran with dementia. Specifically, caregivers need information on how to manage the behavioral issues while also managing the Veterans' diabetes care regimen. Caregivers describe problems with belligerent Veterans who are verbally and physically combative because they do not want to take medicine or insulin. A 38 year-old caregiver who cares for her uncle with dementia described the painful experience of having to endure physical and verbal assaults.

“I'm sorry, but I can't stop crying when I tell you how mean my uncle is to me. He pushes me away when I try give him is insulin shots. He calls me a bitch because he thinks I'm giving him poison. I know it's the Alzheimer's but it doesn't feel good to hear this from your uncle. I don't know if this is normal or not....I can't do everything myself.”

Furthermore, caregivers who need information and instrumental assistance describe feeling “stressed”, “anxious” and “overwhelmed”. The lack of knowledge on how to care for a Veteran suffering from the complications of diabetes or dementia leads many caregivers to describe themselves of being “overwhelmed”.

“I can't tell you how frustrating and overwhelming it is when you know that you need someone to help you but at the same time you don't know why. It's like being in a Black hole because everything is mysterious but then again you feel tired and stressed because you don't know what to do.”

Caregivers in need of instrumental support also need financial assistance. Caregivers describe their need for financial assistance to facilitate instrumental care, especially caregivers who want respite care. They are open to having formal assistance from a professional caregiver. However, caregivers also want to “respect the wishes” of the Veteran. Therefore, caregivers discuss the convenience of having friends as paid help with instrumental care. Since caregivers want to “respect the wishes” of the Veteran, caregivers commonly suggest friends of the Veteran would be ideal candidates to assist with instrumental care. Caregivers do not want to burden friends; therefore, they want to obtain financial support from the VA. The need for financial support to pay for instrumental care is to also alleviate burden on the Veterans’ friend. One caregiver said:

“I’d feel better knowing my husband’s friend could get paid for taking care of him while I went shopping. Sometimes I feel like a burden on friends when I ask them to watch over him while I go shopping. Gosh, there are days when I need time to myself. I checked around at the VA but nobody seem to know if program to help caregivers get financial help with caregiving. I’d like to get paid for helping my husband.”

Psychosocial support is the third common form of help described by the caregivers (Appendix 4). In most cases, caregivers want emotional support from friends, family and other caregivers. Caregivers describe getting psychosocial support mainly from their informal network: “My friends are always there for me. They’re the “wind beneath my wings” so to speak. They understand what I’m going through and cheer me up when I need it. They just know”. Caregivers also described receiving psychosocial support by attending support groups at the Alzheimer’s Association.

“I go to this support group at the Alzheimer’s Association. We talk about the problems

we have and learn from each other on how to cope with the good and bad. I get good information but the most important part is the support. I made several friends and we encourage each other. Sometimes we talk by phone. It's like I have [my] group of cheerleaders!"

Spiritual support commonly overlaps with psychosocial support (Appendix 4). Although spiritual support sometimes mean "turning to God", most caregivers need the psychosocial support they receive from other church members. Similar to being part of a support group, caregivers describe the spiritual renewal as having a positive influence in continuing as a caregiver. Caregivers also enjoy the positive support they receive from pastors, priests and church members. One of the caregivers described that help means turning to the church:

"To me help is about getting the love and prayers from the church pastor and church friends. Sometimes when I just get so overwhelmed that I can't go on, I pray and call my church friends. They give me the emotional boost that I need. It always make me feel better knowing that you have all these people praying for you!"

As noted earlier, "help" means different things to the caregivers. Depending on how they define help determines where they obtain assistance. In most cases, however, caregivers need informational support regarding diabetes and caregiving. However, the different forms of help overlap with one another, thus, demonstrating caregivers' complex needs. "Help" is not uni-dimensional but multi-dimensional.

#### *Overwhelmed Caregivers & Need for Help*

To better ascertain the needs of overwhelmed caregivers, a diagram illustrates what differentiates this group from other caregivers that feel overwhelmed. In examining the group

who are categorized as “overwhelmed”, this group needs a combination of informational, instrumental and psychosocial support (Appendix 5). A majority of the caregivers (n=17), describe feeling overwhelmed with their caregiving situation and their need for help. As one of the caregivers described:

“The way things are right now, I’m just feeling overwhelmed with everything. I don’t know what’s going on with dad, and the doctors don’t seem to tell me anything. I’m not sure why dad keeps falling over. He says he feels dizzy at times. Then I have to work and I hate leaving him at home by himself. I wish someone could watch him while I’m out of the house or maybe help with walking and bathing....sometimes, I just talk to my friends to get some encouragement. It’s just so much for me to deal with”

This particular caregiver describes the sentiment described by those feeling overwhelmed. The caregiver lacks any understanding as to why her father experiences light-headedness and falls inside the house. The father experiences hypoglycemia, yet the caregiver does not understand any of this and requires obtaining informational support. The caregiver also describes wanting instrumental support while she is away from work. Due to the overwhelming experience of lacking information and the need for instrumental assistance, she turns to her friends for emotional support.

What differentiates the “overwhelmed” caregivers from those who describe being “somewhat overwhelmed” is that the former group consistently describe the need for informational, instrumental and psychosocial support. Individuals who are “somewhat overwhelmed” also describe the need for emotional and informational support, or the need for psychosocial and/or spiritual support. However, the combination for the need of these types of help is not as consistent as those for the “overwhelmed” caregivers. As shown in Appendix 5,

some of the caregivers in the “somewhat overwhelmed” group needed informational and instrumental support while others sought psychosocial or spiritual support. However, the need for informational, instrumental and psychosocial support is not as strong as those in the overwhelmed group.

## Chapter 6 DISCUSSION & IMPLICATIONS

*This chapter interprets and summarizes the study findings. It also examines relevant policy and social work practice implications, study limitations and future research.*

The purpose of the study was to understand the complex nature of the help-seeking process of caregivers of Veterans with diabetes. The 25 caregivers in this study provide care under demanding circumstances. Diabetes is a complicated illness, which requires constant monitoring and adherence to a strict diabetes regimen. Thus, caring for a Veteran can be time-consuming (Langa 2002). When Veterans suffer from additional comorbid illness this can increase caregiver burden. In this study, over half of the Veterans had more than three comorbid illnesses besides diabetes. As in previous studies, Veterans in the study had limited ADL and IADL, which required greater dependence on the caregiver (Wakefield 2012). Thus, caregivers provide assistance in various everyday activities, such as bathing, walking, shopping, etc. Due to the need for everyday assistance, nearly all of the caregivers and Veterans stated that they were living together (n=24), which is slightly higher than the number of Veterans and caregivers who stated living together in a previous study (Wakefield 2012). In the Wakefield study, 82% of the caregivers lived with the care recipient.

While providing the best care they could, caregivers face the reality of not having enough information about caregiving and hypoglycemia. They receive information from the VA that is focused on tight glycemic control. The combination of these factors lead many caregivers to realize they have limited understanding of their caregiving situation and realize “what they don’t know”. They experienced an inner struggle to provide the best care and to fulfill their responsibility as a caregiver. However, as they encounter the various challenges to caregiving, they soon realize that help is necessary.

As discussed earlier, diabetes caregiving is complex and challenging (Langa 2002). Tight glycemic control adds an additional layer of complication, since it may result in hypoglycemic episodes. Caregivers believe that tight control was the only option to diabetes management. However, as the study findings suggest, many caregivers are also inadvertently leading their loved ones to experience hypoglycemic episodes. Without relevant information on the dangers of hypoglycemia, caregivers are distressed not knowing what to do when Veterans experience a hypoglycemic episode. The focus on tighter control also lead many caregivers to spend time performing unnecessary caregiving duties, such as multiple finger pricks. Although caregivers receive information that tight glycemic control is best, they are not given sufficient information about caregiving and the dangers of hypoglycemia.

Caregivers feel it was their responsibility and duty to provide the best care possible for the Veteran. Therefore, caregivers are not adverse to receiving assistance. Mainly, caregivers are interested in learning more about diabetes and caregiving to help understand how to care for their loved one. However, in this study, caregivers did not seek help in a linear fashion but encountered a multitude of complex factors before obtaining assistance. Unlike the Three Stage Decision model, caregivers encounter a web of issues before realizing they need help with their caregiving situation.

#### **Main Finding #1 – Knowing what you don't know”**

The sense of family responsibility supports previous research from other studies in which family members feel a sense of “in-debtedness” to caring for their family member (Wakefield 2012). Family members feel that it is their duty to make sure the Veteran is comfortable with the care he/she is receiving. This explains why nearly all of the Veterans lived with their caregivers. During the initial stages of caregiving, the caregivers rely on themselves to manage the caregiving situation, which aligns with previous research studies (Wakefield 2012, Caron and



Bowers 2003). At this point in the caregiving process, the caregiver focuses on maintaining the medical, emotional and psychological well-being of the care recipient (Caron and Bowers 2003). As shown in the three stage decision model (Appendix 3), caregiving generally starts with the caregiver “relying on themselves” to provide and manage the caregiving situation.

Previous studies speculate that during the early stages, caregivers provide direct care to help maintain the relationship between the caregiver and care recipient. In many cases, this takes place because the caregiver wants to avoid disrupting the relationship. Instead, the goal of the caregiver is to maintain things as “the way they had always been” (Caron and Bowers 2003). Although many of the caregivers have been providing care for several years, they want to make sure the Veteran is aware that things were not going to change. In fact, the caregivers in this study are intent on not giving up this sense of “normalcy” for the sake of the Veteran.

During this period of time in which the caregiver is directly providing care and managing the caregiving situation, they report little interest in seeking help. This confirms the placement of “self-reliance on providing care” and “managing caregiving situation” early in the three stage model. The unlikelihood of caregivers’ to seek help at this point in the stage is supported by previous studies (Caron and Bowers 2003). Although caregiving may be burdensome and stressful, the caregiver focus is to avoid any kind of conflict between themselves and the care recipient by ensuring that nobody else except for the caregiver provides care. In the study, caregivers state that they want to be involved in providing direct care because they feel it provides the Veteran the sense of “security” knowing that they are being appropriately cared for by their loved one. In this study, the caregivers are not necessarily averse to receiving assistance, such as formal services, however they feel obligated to help the Veteran know that things are not going to change, which aligns with previous caregiving research (Wakefield 2012).

Often caregivers find themselves wanting to be the sole caregiver to the Veteran. Caregivers feel they “owe it” to the Veteran to do the best they can to provide assistance. Although 96% of the study participants are family members, those who are non-family also shared the same sentiment. Caregivers also feel they must do what is best for the Veteran, even if it means they shoulder the burden as the sole caregiver (Aligood 2010).

As shown in the three stage model (Appendix 3), caregivers in this study continue providing care on their own, until they encounter a multitude of issues leading them to see that a problem exists with their caregiving situation. However, unlike the study participants in the Caron and Bowers (2003) study, these caregivers are intent on making sure the Veteran is cared by a mixture of family/friends and formal services. Although many of the Veterans experienced blindness, limb loss or other complications due to diabetes, the caregivers were not interested in placing the Veteran in an assisted living facility or nursing home.

The desire to provide direct care to the Veteran continues as diabetes worsened. For the caregivers they find fulfillment (one of the caregiving emotions identified in this study) in being able to care for the Veteran. Caregivers also want what is best for the Veteran. In the three stage model (Appendix 3), the caregiver experiences an intrapsychic conflict as he/she begins to realize that they may not be able to provide the best care for the Veteran. As the complications of diabetes worsens and the Veteran experiences hypoglycemia, caregivers began to realize a need for help.

In the three stage model, “problem identification” occurs when the caregiver experiences several interrelated events. These events include caregiving challenges, caregiving emotions, responses to the caregiving situation and lack of knowledge regarding diabetes and caregiving. The study suggests these events occur due to a combination of factors that may be related to the

nature of the illness, the desire to do what is best for the Veteran, and the VA's focus on tight control of diabetes. In the study, caregivers do not experience these events in any specific order. However, the caregiver experiences an amalgam of these episodes that lead them to realize a problem exists.

As diabetes worsened, the complexity of the illness led to emotional strain for the caregiver. As demonstrated in this study, diabetes caregiving causes emotional stress for the caregivers such as sadness, guilt, frustration and anger (Kim Y & Schulz R, 2008). Furthermore, caregivers experience various emotions proving that caring for a loved one with diabetes can be overwhelming (Sinclair et al, 2010). The emotions experienced by the caregivers support previous studies that describe diabetes as an emotional roller coaster (Rolland 1984).

However, in this study, fear is a common emotion for the caregivers. Major causes of fear for caregivers are twofold. One reason is the fear of the dyscontrol of the Veterans' diabetes. With messages from VA healthcare providers saying "tight control is best", caregivers fear the Veterans' diabetes will worsen without constant monitoring (i.e., frequent fingerpicks). However, despite the caregivers' concern, they are unaware of the negative implications of tight control. Caregivers are inadvertently inducing hypoglycemic episodes for the Veterans. In the study, caregivers describe hypoglycemic episodes where they are scared and unaware of what is happening. Furthermore, their lack of knowledge about hypoglycemia adds to the "emotional roller coaster" for the caregivers. Many caregivers describe the fear of not knowing what is happening to their loved when a hypoglycemic episode occurs.

Despite the negative emotions experienced by the caregivers, their willingness to do what is best for the Veteran continues. For many caregivers, this means they want to provide the best care possible. They are open to utilizing community resources or other services, if it means it

would improve the care for the Veteran. However, the caregivers feel obligated to provide care to the Veteran to the best of their ability, and in doing so, a sense of fulfillment arises. Other caregiving issues, however, overshadow the sense of fulfillment including: caregiving challenges, lack of knowledge, emotions and the demanding nature of their situation. For caregivers, this means they experience anywhere from moderate to severe levels of caregiver burden. A previous study found that caregivers describe the demanding nature of their situation and its negative impact on caregiving burden (Wakefield 2012).

As shown in the three stage model (Appendix 3), caregiving challenges represent a common part of the caregivers' lives. One of the major challenges caregivers encounter is related to their internalized belief that "tight blood sugar control is best" and the consequential issue of hypoglycemia. Unknown to the caregivers, their belief in "tight blood sugar control" induce hypoglycemic episodes. Unfortunately, due to the lack of knowledge, the caregivers do not understand why their loved ones are experiencing hypoglycemia. The lack of communication and information provided to the caregivers from the healthcare providers support previous study findings (Schoenmakers et al 2009, Beisecker 1989, Coe RM 1985, Adelman et al 1987). The caregiving challenges are due to the lack of guidance or information regarding how to adjust the patient's diabetes care regimen (Feil, et al 2011).

The progression of diabetes also adds to the complexity of the caregiving situation. For many caregivers, it is difficult to observe their loved ones experience the negative consequences of diabetes such as vision, limb loss and neuropathy. In addition, caregivers must contend with the associated sense of denial that their loved ones experienced. For many caregivers, the Veterans' denial of having diabetes proved to be overwhelming which further complicated the diabetes care regimen. While caregivers struggle to adhere to the VA's recommended strict

diabetes care regimen, they also have to deal with the Veterans' unwillingness to cooperate. This further adds to the caregiving strain, since caregivers are unprepared or uninformed on how to deal with these caregiving challenges. Furthermore, caregivers also provide care to Veterans that have associated co-morbidities, such as dementia. In this study, caregivers encountered the challenges of having to care for Veterans with behavioral problems associated with dementia such as those in the Feil Study (2011).

Consequently, caregivers have a myriad of responses to their caregiving situation. For many the progression of diabetes leads to a need for constant monitoring of the Veterans' physical well-being. In the study, caregivers often discuss the need for "constant vigilance" because of their concern that the Veteran is at-risk for falls. The need for constant monitoring confirms previous studies of caregivers experience (Faes et al, 2010). However, the current study sheds new light into the difficulties of caring for a frail Veteran suffering from diabetes, especially neuropathy. Many of the caregivers are concerned their loved one may experience a fall due to the "lack of sensation" in the Veterans' foot. Adding to the complexity of the situation is that many of these Veterans are being tightly controlled for blood sugar by their healthcare provider. As one of the caregivers stated, "I'm damned if I do and damned if I don't. My father has no feelings under his feet, but then again I have to worry of him falling because he gets light-headed from his blood sugar getting too low". This statement exemplifies why caregivers feel there is a need to be constantly worried about their loved one.

The experience of the caregivers in this study support many of the findings from previous studies, such as experiencing worsening physical and mental health. Due to the strict diabetes care regimen, and the constant distress of not knowing how to care for the Veteran, many caregivers describe mental and physical problems. These findings support other studies which

suggest that caregiving can have negative impacts on the physical and mental well-being of their caregivers (Schulz 1995, Vitilano 2003, Pinquart 2010, Schulz 2008).

### *Reaching a Crisis*

When caregivers conclude, “knowing what they don’t know”, it is a crisis point. Caregivers struggle to maintain the best care possible for the Veteran. However, the caregivers reach a point of “problem identification”. At this point, the caregiver is encompassed by a myriad of factors in which s/he begins to realize the need for additional resources. For example, a caregiver has reached a “crisis” in which they experience a depletion of resources (Levy-Storms, 1996). Others suggest a caregiving crisis occurs when there is a sudden onset leading to emotional and instrumental caregiving tensions (Sprangers, Tempelaar, van den Heuvel, & de Haes, 2002). At this time, no consistent definition exists of “family caregiving crisis”.

In this study, many of the caregivers experience a crisis when they realize a problem exists. As the proposed model suggests, during the problem identification stage, caregivers experience a compilation of emotions and caregiving challenges supporting existing literature (Sprangers, Tempelaar, van den Heuvel, & de Haes, 2002). Furthermore, it may be more than emotions and instrumental tensions. For example, a lack of knowledge about caregiving and the caregivers’ response to the situation may lead them to perceive that a crisis exists.

In the theoretical model, problem recognition can be viewed as a crisis point which triggers the caregiver to seek help. A crisis triggers caregivers to make decisions regarding their caregiving situation. In some cases, caregivers place their loved ones in nursing homes such as when caregivers experience strain and depleted family caregiving resources and capacities, which leads to additional stress on caregiving relationships (Chen 2014, Levy-Storms, 1996). For this study, caregivers are reluctant to place their loved ones in a nursing home. However, their

sense of duty and the desire to care for the Veteran at home led many to seek help, because they reached a crisis point. According to the proposed model, caregivers would initiate help-seeking, although “help meant different things to different people”.

### **Main Finding #2 – “Help means different things to different people”**

According to the proposed model (Appendix 5), there were two different types of caregivers:

(1) Proactive and overwhelmed (2) Passive and overwhelmed. Those that are proactive and overwhelmed initiate help-seeking on their own. For example, a 70 year old caregiver of her husband discussed seeking help by participating in research studies because she felt the knowledge gained from these studies helped her understand how to deal with caring for someone with both diabetes and Alzheimer’s. The caregivers’ experience of feeling “overwhelmed” exemplifies the depletion of caregiving capacity and, therefore, leading the caregiver to decide that help was needed (Chen 2014). In this case, the caregiver proactively sought information about caregiving from research studies and other VA staff (i.e., nurses, psychologists). Other caregivers may be passive about initiating help. In some instances, the caregivers initiate help-seeking, however, discover that obtaining help (i.e., instrumental help) from the VA was a “futile” process due to the bureaucracy. In this group, caregivers are also “overwhelmed” and do not proactively seek help. One of the reasons why this occurs is that caregivers felt “too tired” to seek help. For example, one of the caregivers explained that she was exhausted from her caregiving duties, and had “little energy” to complete an application for IHSS. However, despite being passive about seeking help, many of the caregivers did eventually seek help after interacting with their informal or formal network.

How “help” is defined by the caregivers determine their interaction with the informal and formal network. As in previous studies, caregivers will initially rely on their informal network before seeking help from their formal network. The informal network consists of family and

friends from which an individual can gather advice and information (Friedson 1961). Furthermore, the network help caregivers decide whether they should seek help from a professional, such as a doctor, nurse or social worker (Cameron, Leventhal & Leventhal 1993). Individuals generally look for help (information, advice, medical assistance) from their formal network (doctors and other professionals), when they have first sought help from their informal network (Taylor 1999; Verbrugge & Ascione 1987).

Here, caregivers discuss with family and friends regarding their need for help before going to the formal network. However, what previous literature did not identify was that help could be defined differently by the caregivers. For caregivers needing emotional or instrumental or help, they often turn to their family and friends. The informal networks are also used to facilitate obtaining help on spiritual and financial assistance.

On other hand, caregivers use the formal network when they feel that informational help is needed regarding how to care for the Veteran. This occurs when the caregivers feel they need additional information from healthcare providers. However, caregivers feel their interaction with the VA primary care provider is limited due to time constraints. Although caregivers want to discuss caregiving issues with the provider, they are reluctant to do so. Unfortunately, caregivers feel that much of their needs are not addressed during the medical visits.

Their unmet needs are consistent with previous studies. Earlier studies on physician and caregiver communication suggest that caregivers feel that when physicians do not recognize their burden, they feel minimized and isolated (Feil et al, 2010). Caregivers also feel that physicians lack awareness of their worries and distress (Schoenmaker et al 2009). Although caregivers take on a multitude of roles, physicians fail to consider the “help-seeking family caregiver as a possible patient” and provide them with guidance on where to receive help (Schoenmakers et al



2009, Beisecker 1989, Coe RM 1985, Adelman et al 1987).

### Theoretical Implications

This study provides an expansive understanding of the help-seeking process of caregivers and its meaning to them. It adds to the three stage model by providing a comprehensive understanding of what initiates caregivers to seek help (i.e. problem identification) and how individual's definition of help determines their decision to get help. To better understand the help-seeking process, the study used the dynamic approach (based on sociology and symbolic interactionism to understand caregivers' behavior). The dynamic approach views help-seeking as a product of social interactions (Pescosolido 1992). Thus, the decision to take a particular action, choice or decision is a social process, whereby, interactions of individuals influence decision-making regarding their situation (Pescosolido 1992).

Caregivers will first attempt to care for the Veteran on their own. However, once the challenges of caregiving becomes overwhelming, it triggers caregivers to understand that they need more resources to continue providing adequate care to the Veteran. They reach a "crisis" point in which they realize the lack the information and knowledge to successfully care for the Veteran. They also feel the physical, mental and emotional strain of continuing to provide care for the Veteran. Triggered by this "crisis", caregivers turn to their informal (family, friends, peers) or formal network (healthcare professionals) which, in turn, influences how a caregiver perceives a situation (or caregiving problem). Furthermore, individuals in the informal or formal network can either hinder or facilitate the help-seeking process. Sociological studies on help-seeking shows that "pathways to care" friends, relatives, clergymen play critical actors in the social process of individuals seeking help (Clausen & Yarrow 1955). These individuals can facilitate the help-seeking process by providing assistance (i.e. emotional support) or advice on what kind of help the caregiver should obtain (Janzen 1978). Thus, the dynamic approach

recommends that help-seeking models include examining the important role of social networks of family, friends, peers and healthcare professionals (Pescosolido 1992).

By utilizing the dynamic approach on the three stage model, help-seeking becomes a dynamic and interactive process of decision-making. The concept of help-seeking orients researchers to understand the dynamic action that individuals engage to interpret and manage their caregiving situation and connect with others (Pescosolido, 1992). Thus, by examining the subjective experience of the caregivers, the dynamic approach recognizes and illuminates the experiences of the help-seeking process during the course of the Veterans' illness (Pescosolido 1992; Biddle, Donovan, Sharp & Gunnell, 2007).

According to the study findings, caregivers desire to seek help is triggered when a "crisis" occurs. The crisis leads caregivers to realize that a problem exists: "Knowing what I don't know". This phenomenon can be explained by crisis theory. According to crisis theory, any changes may lead to caregiving crisis, which requires restructuring of family caregiving patterns (Schulz, Gallagher-Thompson, Haley, & Czaja, 2000; Levy-Storms, 1996; Biegel & Blum, 1990). Furthermore, caregivers experience "situational changes" that pertain to unpredictable crises" such as the illness of elderly parents. Various situational changes result from sudden onset of illness. An illness such as diabetes, dementia, stroke, dementia, may lead to family caregiving crises (Biegel, Sales, & Schulze, 1991). The declines in family caregiving resources and capacities leads to changes in caregiving arrangements. In some instances, these dire situations may lead to the institutionalization of their loved ones (Levy-Storms, 1996).

Thus, with crisis theory considered, caregivers in this study experience a crisis when changes occur in caregiving resources, caregiving relationships, and a perceived gap between the Veterans' needs and available caregiving resources. Caregivers often find themselves identifying

a need for help because they experience a decline in their abilities and resources to care for the Veteran. Caregivers may feel that they are no longer able to respond to the Veterans' increasing caregiving needs. This "crisis" triggers the help-seeking process because they desire to re-establish the caregiving equilibrium with the right type and amount of help.

Theoretically, this study examines the role of formal and informal networks in the help-seeking process for caregivers. The study expanded the three stage model by revealing that obtaining assistance is dependent on how the caregiver defines "help". As the study suggests, the definition of help held various meaning to the caregivers. By examining the initiation of the help-seeking process from a crisis theoretical perspective, one is able to understand the context of *when and why* caregivers use their informal and formal networks. Consistent with previous literature, caregivers will turn to their informal network (family and friends) to obtain advice and psychosocial support (Friedson 1961). When caregivers need help to manage and maintain the caregiving equilibrium, they turn to their formal network, which consists of the VA healthcare provider, nurse or social worker (Cameron, Leventhal & Leventhal 1993). Therefore, individuals generally look for help (information, advice, medical assistance) from their formal network (doctors and other professionals) when they have first sought help from their informal network (Taylor 1999; Verbrugge & Ascione 1987). The problem is that VA providers mainly focus on the *medical* needs of the Veterans. Unfortunately, the medical visits (due to limited time) does not include discussions about caregiving and available services. Thus, the underutilization of community resources may be due to the caregivers' lack of awareness and knowledge of available VA services.

### Methodological Implications

From a methodological perspective, a rich and in-depth understanding of the help-seeking process of caregivers has emerged. Unlike previous studies that have utilized a quantitative

measures and tools to understand help-seeking, this study *characterizes the context of when, how and why caregivers seek help*. By providing an expansive understanding of what psychological, physical, and social triggers contribute to caregivers seeking help, this study expands on previous studies' methods and, in doing so, identified how caregivers define help.

*An in-depth understanding of how help is perceived by the caregivers*

As discussed earlier, most of the studies on help-seeking have utilized a quantitative approach. One of the problems with this approach is that the definition of help-seeking continues to be inconsistently used among the research studies (Rickwood 2012). The lack of consensus of what help-seeking means and how it should be measured points to the complex nature of this phenomenon (Cornally 2001, Rickwood 2012). This lack of consensus of how help-seeking should be examined remains a problem. This creates an opportunity to examine help-seeking from a grounded theory perspective allowing the caregivers to describe what takes place when they initiate help-seeking.

Most of the literature on help-seeking utilized measures to assess future help-seeking intentions, recent and past help-seeking experiences. The problem with these measures is that it does not provide an understanding of *how* individuals perceive help-seeking and *what* triggers them to obtain assistance. For example, one of the most commonly used tool is the General Help-Seeking Questionnaire (Rickwood 2012); it assesses future help-seeking intentions, recent and past help-seeking experiences. It measures the intentions to seek help by listing help sources and asking participants to indicate how likely they would seek help from that source (Wilson et al, 2005). One of the limitations of this tool is it does not assess how individuals perceive help and what triggers them to obtain it.

By using a qualitative approach, this study provides a basis for understanding what

“help” means to the caregivers and how it motivates them to seek the help they need. In this study, “help” cannot be simply broke down into quantitative and predefined measures. Instead, the meaning of help can mean different things to various caregivers, depending on their loved ones’ perceptions. Also, previous quantitative studies were unable to specify the type of assistance sought, for example, what form of assistance was sought in terms of information, advice, and general support (Rickwood 2012). In this study, individuals may seek assistance to obtain informational, instrumental, psychosocial, spiritual or financial support, which, in turn, provides a deeper understanding as to when caregivers seek assistance and why.

### *Patterns of Help-Seeking*

Quantitative studies on help-seeking commonly use some kind of conceptual framework to understand the strength of associations between certain variables, such as behavior and intentions. One of the most commonly used frameworks is the Theory Planned Behavior (Fishbein and Ajzen 2010). According to this theory, behavior is a rational decision influenced by intentions. Attitudes, norms and perceived behavioral control all affect intentions (Fishbein and Ajzen 2010). However, the strength of the association between attitudes, intentions and behavior is weak, especially the relationship between intention and behavior (Armitage & Connor 2001; Hardeman et al, 2002).

The study findings provide an insightful understanding on how other factors such as caregiving emotions, caregiving situation, caregiving challenges and lack of knowledge can also influence intentions to seek help. Unlike the quantitative studies that examine the association between intention and behavior, this study provides an additional element of understanding how a “crisis” triggers a caregivers’ decision to seek help. Instead, this study shows that caregivers reach a “crisis” point when they realize their need for help.

## Policy-Relevant Implications

### *Educating providers about hypoglycemia*

One of the major implications from this study suggests that we need to consider revising VA policies regarding strict diabetes control. According to the US Department of Veterans Affairs and Defense (2010) glycemic control is based on a risk-stratified approach which focuses on tight control (HbA1c < 7%) for patients with life expectancy of 10-15 years or more and absent/mild microvascular complications. However, the adoption of these policies is in contrast to what the American Diabetes Association (ADA) and American Geriatric Society (AGS) recommends which is the avoidance of tight glycemic control in older adults with comorbidities.

Unfortunately, there continues to be a focus among VA healthcare providers that tight glycemic control is best. A recent study confirms that providers are unnecessarily placing Veterans at risk for hypoglycemia. Using a national cohort of Veterans treated for type 2 diabetes, researchers discovered that more than 50% had been tightly controlled at HbA1c levels < 7%, despite clear guidelines that recommend higher glycemic goals (Thorpe et al, 2015). Furthermore, 75% of these patients had been provided medications that further exacerbated their risk for hypoglycemia (Thorpe et al, 2015). In addition, risk factors for tight control in older patients (especially with dementia) were identified to include age  $\geq 75$ , weight loss, chronic lung disease and anemia (Thorpe et al, 2015). This suggests that providers and patients may not understand that changes in appetite and weight, advancing age and other comorbidities may not require an intense diabetes care regimen (Thorpe et al, 2015). In some instances, patients may no longer need diabetes medication. The Thorpe study confirms findings from the current study which suggests that VA providers are unnecessarily placing frail older Veterans at-risk for hypoglycemia.

The VA needs to institute policies that promote more awareness of the risk of hypoglycemia and educate providers, patients and caregivers about the risks of tight control among frail Veterans. Although previous studies, such as the Action to Control Cardiovascular Risk in Diabetes (ACCORD) and Action I Diabetes and Vascular Disease Preterax Diamicron Modified Release Controlled Evaluation (ADVANCE) trials also showed that frail older adults were at risk for hypoglycemia due to intensive glycemic control (Bonds et al 2010, Zoungas et al 2010), few providers seem to realize the dangers of tight control. Educational seminars for providers need to focus on individualizing treatment plans (according to life expectancy, preserving quality of life and reducing hypoglycemic episodes). They also need to be educated on considering medications that may reduce the risk for hypoglycemia. Furthermore, emphasis also need to be placed on training physicians on the importance of screening and identifying Veterans who may be at-risk for hypoglycemia. For example, clinical reminders could be implemented identifying patients who are at-risk for hypoglycemia. Since the Thorpe (2015) study found that VA providers were prescribing a high frequency of medications that could lead to hypoglycemia, the VA could consider implementing quality measures to monitor the use of certain medications that may increase the risk for hypoglycemia.

#### *Establishing Programs for Caregivers of Veterans with Diabetes*

Caregivers from the current study are interested in receiving assistance from formal networks (such as paid in-home assistance from Medi-Cal), however, the lack of coordination between the VA and non-VA entities (such as Medi-Cal) made it difficult for caregivers to receive the assistance they desired. As noted earlier, caregivers proactively seek assistance but the lack of coordination between services is bewildering and confusing. Although there are VA Caregiver Support Services available for the caregivers of Veterans, few in the study were aware

of this resource. With the exception of the GRECC clinic, caregivers did not receive the assistance they needed to help navigate the social service system. As one of the caregivers cited, “I’m just too tired to look for these services on my own”.

Indeed, social policies must consider providing a more “user-friendly” system of community services (Torres-Gil 1992). The VA could consider policies that would utilize social workers to work with this population of frail older Veterans and their caregivers. Currently, programs exist for caregivers of Veterans with Alzheimer’s and for those who served Post 9/11. Since the population of frail older adults with diabetes are likely to increase, the VA could consider implementing a program that provides care coordination and education for this group of individuals. Social workers could provide support, information about caregiving and providing coordination to other services that caregivers may need. Indeed, this would reduce the caregiving burden of having to seek assistance within a confusing and fragmented system.

#### *Unique needs of Veterans from Different Eras & Implications for Caregivers*

The majority of Veterans in the study were from the Korean War. Only a small handful of the Veterans served during World War II. This brings forth the question of whether programs targeting Veterans and their caregivers from different eras would be appropriate. Since the cohort in this study consisted of frail and older Veterans, most of the caregivers concern were regarding the physical well-being of the Veteran. However, if the study cohort consisted of Veterans from the Vietnam War, for example, caregivers are likely to have encountered matters relating to PTSD, along with diabetes. The National Vietnam Veterans’ Readjustment Study suggests that 25% of Vietnam War Veterans have PTSD (Kulka et al, 1990). Spouses of PTSD-diagnosed Veterans tend to assume most of the responsibility for household tasks (e.g., finances, time management, and house up-keep) and the maintenance of relationships (e.g., children, extended



family) (Nelson 1996). Another study examined the relationship between PTSD severity and the experience of caregiver burden in female partners of Vietnam Veterans with PTSD (Beckham et al, 1996). Study findings suggest that high levels of caregiver burden included psychological distress, dysphoria, and anxiety. Another study reported that partners of Veterans with PTSD experienced greater burden and had poorer psychological adjustment than partners of Veterans without PTSD (Calhoun 2002). The studies suggest that caregiver burden increased with PTSD symptom severity. That is, the worse the Veteran's PTSD symptoms, the more severe the caregiver burden.

A recent RAND study suggests that caregivers of Veterans Post 9/11 have unique needs. Post-9/11 military caregivers tend to be younger, caring for a younger individual with a mental health or substance use condition, employed, and not connected to a support network. They are more likely to use mental health resources and services, and to use them more often. Seventeen percent of civilian caregivers reported spending more than 40 hours per week providing care (8 percent reported spending more than 80 hours per week); 12 percent of post-9/11 military caregivers and 10 percent of pre-9/11 military caregivers spent more than 40 hours per week

In addition, Traumatic Brain Injury (TBI), often called the signature wound of OEF (Operation Enduring Freedom) and OIF (Operation Iraqi Freedom) is associated with a host of long-term adverse health outcomes, including unprovoked seizures, decline in neurocognitive function, dementia, and adverse social function outcomes, such as unemployment and diminished social (IOM 2009). Currently, the VA provides services to caregivers of Post 9/11 which includes financial assistance, mental health services, respite care and a VA caregiver training provided by Easter Seals (<http://www.caregiver.va.gov/>).

However, what is needed are specific caregiver training programs. These programs can provide specific training on communication and interpersonal skills on how to care for Veterans. This is especially relevant given the unique needs of Veterans from different eras. In the current study, one of the most common caregiving issues was related to behavioral problems of Veterans with dementia. For example, training programs could teach caregivers evidence-based strategies on how to effectively care for the Veteran. These could include verbal and non-verbal communication techniques such as using positive statements, eye contact, affective touch and smiling (van Weert 2005; Levy Storms 2008). Additionally, behavioral strategies could be used to facilitate interpersonal communication between the caregiver and Veteran. Kohler proposed several strategies that can be used by caregivers. Some of these strategies include using positive regard, approaching the care recipient in a calm manner, and using touch to gain a person's attention (Kohler 2004). These techniques could help lessen caregiver burden and assist in redirecting behavioral problems to facilitate the management of the Veterans' diabetes care regimen.

Similar to the caregivers in the study, caregivers of Veterans from other campaigns are also in need of informational support to help build their caregiving skills. For caregivers of Veterans from the Vietnam War and Post 9/11, they will need to develop skills to manage diabetes along with other issues related to PTSD and TBI. Caregivers of Vietnam Veterans often contend with the challenges of their loved ones struggling with PTSD. An additional challenge is the issue of Agent Orange Agent and the possible correlation with the development of diabetes. In the main study, Veterans discussed their belief that Agent Orange had led to the development of diabetes. Several of these Veterans, therefore, were distrustful of the services provided by the VA. This can be problematic for caregivers, since this may preclude them from

seeking help. For these caregivers, effective communication strategies and information regarding the availability of resources is important.

The RAND study confirms that caregivers of Post 9/11 Veterans need to learn caregiving strategies to alleviate caregiving burden (Ramchand 2006). These caregiver training programs could teach important interpersonal, behavioral and communication skills to facilitate the management of their caregiving situation. Since communication is an important aspect of the caregiving relationship, caregivers could utilize perspective-taking techniques that are effective for care recipients who suffer from mental and physical ailments (Lobchuk 2005). These behavioral and communication techniques could teach caregivers the importance of viewing the caregiving situation from the perspective of the care recipient. This can further help alleviate conflict regarding the caregiving situation and allow the caregiver to understand how to best interact with the Veteran. Since the next generation of caregivers are savvy technology users, online training programs could be available allowing opportunities for social support within the virtual world.

Findings from this study provides a preliminary understanding of caregivers of diabetic Veterans and the need for policy reform within the VA. The study shed insights into what triggers caregivers to seek help. Moreover, changes need to be made to provide more education for VA providers, caregivers and patients regarding diabetes and hypoglycemia.

### Organizational Implications

This study demonstrates that diabetes management is complicated and challenging for caregivers of Veterans. The findings from this study are unique to caregivers of Veterans of diabetes since most of their concern focused on the issue of hypoglycemia. Although most of the Veterans had other comorbid illnesses, the main concern of caregivers related to issues of falling and other hypoglycemic related events. An additional problem is the lack of shared decision

making between the providers, caregivers and Veterans. The lack of communication between the caregivers and healthcare providers proved to be problematic in ensuring the diabetes care regimen was conducive to meeting the needs of the Veteran and caregiver.

#### *Valuing the Caregiver and Patient Dyad – Model of Care*

At the organizational level, policies could encourage providers to view the patient-caregiver dyad as a unit. Since many of the caregivers feel they are not provided enough information regarding hypoglycemia, the VA may consider creating appointments that include a discussion with the patient and provider. Longer medical appointments could be provided to allow caregivers to discuss their concerns about the diabetes care regimen. These appointments can allow VA providers to facilitate discussion about individualizing a treatment plan for glycemic control. Furthermore, it can also serve as an opportunity for caregivers to become educated about various aspects of caregiving, including the dangers of hypoglycemia. Healthcare providers could provide caregivers with a treatment plan and specific instructions on how to prevent hypoglycemia from happening. It can also serve as an opportunity for VA providers, patients and their caregivers to work as a team to identify a treatment plan that is mutually beneficial for all the individuals involved.

Another suggestion is to utilize the Shared Medical Appointment (SMA) model. Studies suggests that this model can improve the quality of care of Veterans with chronic illnesses (Kirsch 2007). In this program, patients were assigned to a 1-2 hour appointment. They interacted with a team of healthcare providers comprising of a general internist, nurse practitioner, pharmacist, clinical health psychologist and nurse. The program also consisted of patients participating in a group education class during their appointment. The purpose of the classes were to educate the patients and facilitate social support. A similar approach can be used

for caregivers and diabetic Veterans. The caregivers and Veterans could be seen by the physician to review and answer questions regarding the medical care of the Veteran. Another group of providers (nurses and social workers) can provide more in-depth evaluation and consultation regarding the psychosocial aspects of caring for the Veterans. This can also facilitate discussions regarding the caregiving situation and address the caregivers' concern facilitating shared decision-making. Finally, by having caregivers and Veterans attend an educational class on caregiving and diabetes this can provide needed informational and emotional support. As in SMA, the model of care would utilize existing personnel, however, it would be redesigned to ensure that caregivers and Veterans are provided with in-depth evaluation and consultation.

When caregivers and Veterans are treated as a dyad, this also raises the issue of conflicting opinions. For example, a caregiver and Veteran may disagree on how diabetes and the caregiving situation should be managed. As noted earlier, caregivers want to respect the wishes of the Veteran and often forgo seeking assistance with their caregiving situation. However, by redesigning the model of care to include a discussion between the caregiver and Veteran, a healthcare provider can facilitate discussions regarding this matter. The SMA model could allow for in-depth discussion between a social worker, Veteran and caregiver regarding their disagreement to identify a solution. Resolving disagreements regarding the caregiving situation is important. This can be problematic if the discrepancy between the caregiver and Veteran limits the opportunity to obtain needed help with the caregiving situation. One study shows that discrepancy between the caregiver and care recipient can lead to increased caregiver stress (Lyons, Zarit, Sayer & Whitlach 2002). Thus, a redesigned model of care could facilitate

in-depth discussions with the social worker regarding the needs of the caregiver and care recipient – decreasing the risk of caregiver stress.

### *Organizational Change and Provider Behavior*

Changing provider behavior to prevent unnecessary tight glycemic control requires organizational change. Studies show that multiple factors influence the prescribing behavior of healthcare providers. Some organizational behavior experts suggest, “*Prescribing can be regarded as a function of the patient, prescriber and environment*” (Spinewine, Schmader, Barber, et al 2007). A systematic review of studies utilizing interventions to change provider prescribing behavior suggest that the following are considered to be the most effective: academic detailing, clinical reminders, performance feedback, physician profiling, local opinion leaders, drug utilization review, local census guidelines and multi-faceted interventions (Sketris, Ingram & Lummis 2009). Creating substantial provider change, therefore, may require the use of variety of interventions, which targets the healthcare providers’ knowledge about the dangers of tight control and prescribing behavior. One suggestion may be to utilize a multi-faceted intervention, which includes the use of a local opinion leader who advocates and encourages the use of a less restrictive diabetes care regimen. The local opinion leader could provide educational sessions to healthcare providers on diabetes care among the frail elderly. Furthermore, the VA could also utilize clinical reminders to identify frail elderly patients at-risk for hypoglycemia. The use of the clinical reminders, didactic session and other interventions such as drug utilization reviews could help to create change in the prescribing behavior of physicians.

It is also important to understand that change in provider behavior requires organizational change. The VA will need to encourage more shared decision-making and awareness among

providers, patients and caregivers regarding hypoglycemia. Furthermore, leadership (change agents) need to be actively involved in these change efforts (Armenakis, Harris & Mossholder 1993). Their active participation and persuasive communication can help providers understand that the VA is committed to ensuring that dangerous hypoglycemic episodes are prevented in the frail elderly population.

### Social Work Implications

*Assessment for identifying individuals who are at the “crisis” point.*

One of the major contributions of this study is the identification of factors that trigger caregivers to seek help. We know that caregivers reach a crisis point in which they come to the realization of “knowing what you don’t know”. The culmination of these factors (caregiving challenges, caregiving emotions, responses to caregiving situations and lack of knowledge regarding diabetes and caregiver) lead caregivers to realizing that they need help. The identification of these factors can be used to assess caregivers and provide an intervention before they reach a crisis point. This information is important because it allows social workers to be proactive in educating caregivers about the full range of VA services available to them. Furthermore, social worker can assist in providing care coordination to facilitate services between the VA and other community resources.

This study also identifies the different types of caregivers and how “help” can mean different things. In this study, caregivers are proactive and overwhelmed or passive and overwhelmed. The identification of these two groups of caregivers can facilitate establishing interventions that are unique to each group. Understanding what differentiates the overwhelmed group compared to those who are slightly overwhelmed may allow social workers to understand and assess the needs of caregivers feeling burdened. Informational support is important in both

groups of caregivers. However, caregivers that require informational, instrumental and psychosocial support need informational support, because they view their situation as being difficult and challenging. Furthermore, social work assessments can address the caregivers' burden and include interviews with the Veteran and caregiver to determine what form of assistance is suitable to the situation. Since "help" can mean different things to caregivers, social workers could facilitate assistance with various forms of help (i.e., informational, instrumental, emotional, spiritual and financial support). Social work assessments, such as the biopsychosocial assessment, can be used to determine what services would help to meet the needs of the caregiver and Veteran. The interventions may include education about caregiving and coordination with VA Caregiver Services. Equally important, the assessments can target caregivers for case management who are at-risk for becoming mentally and physically overwhelmed with the caregiving situation. Case management can provide the caregiver with the referrals to a range of VA and other community resources that can help alleviate caregiving burden.

*Support groups for caregivers of Veterans with diabetes*

Furthermore, caregivers need more support groups. Since many of the caregivers lack knowledge or information regarding caregiving (especially the dangers of hypoglycemia), these support groups can provide an opportunity for informational support. Furthermore, these support groups can provide emotional support providing the caregivers an opportunity to discuss their experience. Social workers can also consider incorporating a holistic approach by including other sources of support (i.e., spiritual) that caregivers may already be using. Support groups could address the needs of "proactive and overwhelmed" or "passive and overwhelmed caregivers". For those in the former group, the support groups can provide an opportunity to discuss some of



the barriers they encounter while proactively seeking help. The latter group could involve discussions on how they can initiate help when they feel overwhelmed with their caregiving situation.

Social workers can also use these opportunities to understand caregivers concern and facilitate discussions with VA healthcare providers. For example, in the outpatient clinic at the West Los Angeles VA, some of the support groups utilize these sessions as an opportunity to discuss their concerns with a team of primary care providers. Support groups for caregivers can also use this model to discuss, for example, their concern with the strict diabetes care regimen. Since informational and emotional support represent two major forms of “help” identified by the caregivers, support groups using this model could be effective in providing the assistance caregivers need.

#### *Educating Veterans and Non-Veterans about Hypoglycemia*

Although this study mainly focused on caregivers, there are implications for Veterans and non-Veterans. One of the major findings from this study is that many caregivers and providers are unaware of the dangers of hypoglycemia. Since the medical community has focused on tight control of diabetes, there has been limited information provided to patients about the dangers of hypoglycemia. According to the American College of Endocrinology, a recent study suggests that many patients have limited information about hypoglycemia (2011). The national survey indicates that most of the participants could not recognize the symptoms of hypoglycemia. Therefore, the results suggests that educational efforts need to be committed towards educating the public about the dangers of hypoglycemia.

Social workers are in a position to educate and help patients understand the dangers of hypoglycemia. This effort should not only be targeted towards Veterans but non-Veterans as

well. Educating patients about hypoglycemia can also empower patients to take part in shared decision-making regarding their diabetes care regimen.

### Limitations and Further Research

The study interviewed caregivers of Veterans with diabetes and other co-morbid illnesses that received care from the Primary Care, Diabetes and Geriatric Clinic at the West Los Angeles VA. Caregivers provided information regarding their experience seeking help. Since this was a study specifically focusing on the experience of the caregivers, future research should interview Veterans and the caregiver as a dyad in better understanding their perceptions of help-seeking. In the current study, caregivers mentioned a desire to respect the wishes of the Veterans. It would be interesting to examine the conversations caregivers have with Veterans when a need arises to seek help and how decision are made to obtain the needed resources.

The study also did not include the perception of the VA healthcare providers in the caregivers' help-seeking process. Interviewing VA healthcare providers may provide an understanding of their perception of help-seeking and what they believe are the barriers and facilitators in this process. Since help-seeking is a social process, future studies could study the interactions between the caregivers, Veterans and healthcare providers. Equally important, future studies can also examine the interactions between caregivers and the informal network. Since previous studies indicate that individuals will seek help from the informal network prior to seeking help from a formal network, studying the underlying process of how this occurs could be valuable and help understand how informal and formal networks can be utilized to create an intervention regarding specific issues related to caregiving. The new concepts that emerged from this study could be investigated quantitatively by expanding the scope to other medical centers to understand the potential variation in need of caregivers and what barriers they face in the help-

seeking process. Additionally, future studies could compare experiences of caregivers of Veterans of other comorbid illnesses with those of caregivers of Veterans with diabetes. A deeper understanding of how services for caregivers could emerge to address the specific caregiving issues about the Veterans' illness. Future studies should also examine whether general differences in the help-seeking process exist among elderly and younger caregivers. This also raises the question of whether the younger generation of caregivers (for example those caring for Post 9/11 Veterans) are more likely to reach a crisis point earlier or later than those caring for frail Veterans. In addition, future studies should inquire how caregivers of Veterans from different eras differ in seeking help. For example, are there differences in the use of the informal and formal network?

There are also implications for future studies to utilize the theoretical concepts in surveys. For example, a survey research study could examine which of the four components (lack of knowledge, responses to caregiving situation, caregiving emotions and caregiving challenges) seem to predict the likelihood of understanding that a problem exists. At this time, we can only presume that a constellation of these factors come together to trigger a caregiver to understand that a problem exists. Survey research can also examine what kind of barriers exist to obtaining the help needed by the caregiver (informational, emotional, spiritual, financial support). The survey can examine how these barriers may contribute to caregiver burden.

Finally, the study did not consider the racial/ethnic differences in the help-seeking process. Since the Veteran and caregiver population continues to become more ethnically diverse, future studies should investigate whether ethnic differences exist in the help-seeking process. Furthermore, studies can consider cultural differences and how this may manifest in a caregivers' decision to seek help. Findings can help the VA to design caregiver services that are

culturally sensitive and address the specific needs of the Veterans and caregivers. This can also help to understand if there are also ethnic differences in the types of assistance they need and how individuals access the informal and formal networks when needing help.

## **Summary**

The results of this research study clearly shows that help-seeking is a complex and multifaceted process. Caring for a Veteran with diabetes has always been and remains to be a complicated and daunting task. However, these dedicated caregivers from this study have committed themselves to ensuring the best care possible for their loved ones. The problem is that caregivers find themselves having limited knowledge about diabetes care and excessive burden from the complex nature of the diabetes care regimen. Furthermore, the VA healthcare providers focus on tight glycemic control and limited shared-decision making leaves many Veterans vulnerable to hypoglycemia. Unfortunately, caregivers find themselves overwhelmed having to deal with the consequences of caring for Veterans who is at-risk for hypoglycemia.

In the help-seeking process, caregivers experience a multitude of factors before they come to realize “what they don’t know”. While trying their best to care for the Veteran, caregivers inevitably reach a crisis point in which they realize that they need help. The type of assistance the caregiver needs (informational, instrumental, emotional, spiritual or financial support) depends on how it is defined by the caregiver. Informal and formal networks play a crucial role in facilitating the assistance needed by the caregivers. However, more studies may help understand how this social process occurs among the various stakeholders (Veterans, caregivers, friends, families and VA providers). This study also discovered two different groups of caregivers (proactive and overwhelmed, passive and overwhelmed). Again, future research

could aim to understand the complex nature of these groups and how ethnic differences may play a role in the help-seeking process.

This study provided a foundation regarding the help-seeking process of caregivers of Veterans with diabetes. The study findings revealed that the VA would need to bring forth policy changes at the organizational and clinical level to reduce the risk for hypoglycemia and caregiving burden. This study also highlights how the findings can be used to develop social work interventions and the need for future studies in understanding the phenomenon of help-seeking among caregivers.

## APPENDIX 1

### Interview Guide –Caregivers of Veterans with Diabetes

**Introduction:** Thank you for your willingness to participate in this study. The main purpose of this interview is to understand your experience as a caregiver and learn more about your attitudes, beliefs regarding caregiving seeking help when needed. Furthermore, I want to understand how you made decisions during your time as a caregiver to seek help and if there were times when you decided not to seek help. At any point during the interview, please let me know if you need clarification with the questions I ask.

**Potential ice-breaker:** please tell me little about yourself and your relationship with [Mr./Mrs. XXX]?

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### *Interview Questions*

#### **Background: Caregiving Situation**

1. When was [Mr./Mrs. XXX] first diagnosed with diabetes?
2. When did you first begin to manage diabetes care for [Mr./Mrs. XXX]?
  - a. What led you to begin caring for [Mr./Mrs. XXX]? (probe: was there forgetfulness by [Mr./Mrs. XXX])?
    - i. Could you describe what was happening with [Mr./Mrs. XXX]?
    - ii. How did you react to this?
      1. How has this experience changed your life?
      2. How has becoming a caregiver affected your life?
      3. What about your relationship?
        - a. How has caregiving affected your relationship with [Mr./Mrs. XXX]
    - iii. How was your relationship with [Mr./Mrs. XXX] prior to you becoming a caregiver?
3. Please describe your caregiving situation?
  - a. What's a typical day like for you?

- b. What was it like for you when you first began caring for [Mr./Mrs. XXX]?
4. What do you do for [Mr./Mrs. XXX]
- a. What does he/she need the most?
  - b. How has your caregiving responsibilities changed since you began providing care?

### **Attitudes & Beliefs towards Caregiving & Help-Seeking**

5. How would you describe your thoughts and feelings regarding your current caregiving situation?
- a. What happened when you first began to care for [Mr./Mrs. XXX]?
  - b. How do you feel about being a caregiver?
  - c. How has your feelings changed since you began caring for [Mr./Mrs. XXX]?
  - d. Some days can be worse than others? What do you think?
6. How would you describe your thoughts and feelings seeking help with your caregiving situation?
- a. What happens if you need help?
  - b. What do you do?
  - c. What concerns you the most?
  - d. Have you talked to anyone about your concerns for needing help?
  - e. How has the course of the illness changed your thoughts and feelings with regards to help-seeking?

### **Problem Recognition**

7. What do you do when you need help?
- a. Who can you turn to for help?

- b. What would you suspect would happen if you ask for help?
- c. What are you most concerned about?

### **Decision to Seek Help**

8. Please describe what happened when you decided to seek help? If no help was sought, why?
  - a. What were your thoughts and feelings when this happened?
  - b. What was the role of your informal and formal network?
    - i. Please describe the conversation you had.
  - c. At what point during your family member's illness did you decide to seek help?

### **Help Source**

9. When you made the decision to get help, please tell me how you decided to choose the kind of help you needed?
  - a. Could you tell give me an example of what happened?
  - b. Can you tell me more about your decision to seek help?
  - c. What has happened to your caregiving situation since you made this decision?
10. Did you have any difficulty or problems getting help (eg, respite care, support group, paid caregiver, etc)?

### **Basic Demographic Information**

- Age, gender, educational background, etc



## APPENDIX 2

### Standards of Rigor – Grounded Theory

| <b>Standards of Rigor in Grounded Theory</b> | <b>Suggested Methods</b>   |
|--|--|
| Credibility                                  | 1) Let participants guide the inquiry process<br>2) Check the theoretical construction generated against participants' meanings of the phenomenon<br>3) Use participants actual words in the theory<br>4) Articulate researcher's personal views and thoughts about the phenomenon through (a) post comment interview sheets (b) personal journal (c) monitoring the literature was used |
| Auditability                                 | 5) Specify the criteria built into the researcher's thinking<br>6) Specify how and why participants in the study were selected   |
| Fittingness                                  | 7) Delineate the scope of the research in terms of the sample, setting and the level of the theory generated<br>8) Describe how the literature relates to each category which emerged in the theory  |

Beck, CT (1993). Qualitative research: the evaluation of its credibility, fittingness and auditability. *Western Journal of Nursing Research*, 15, 263-266.

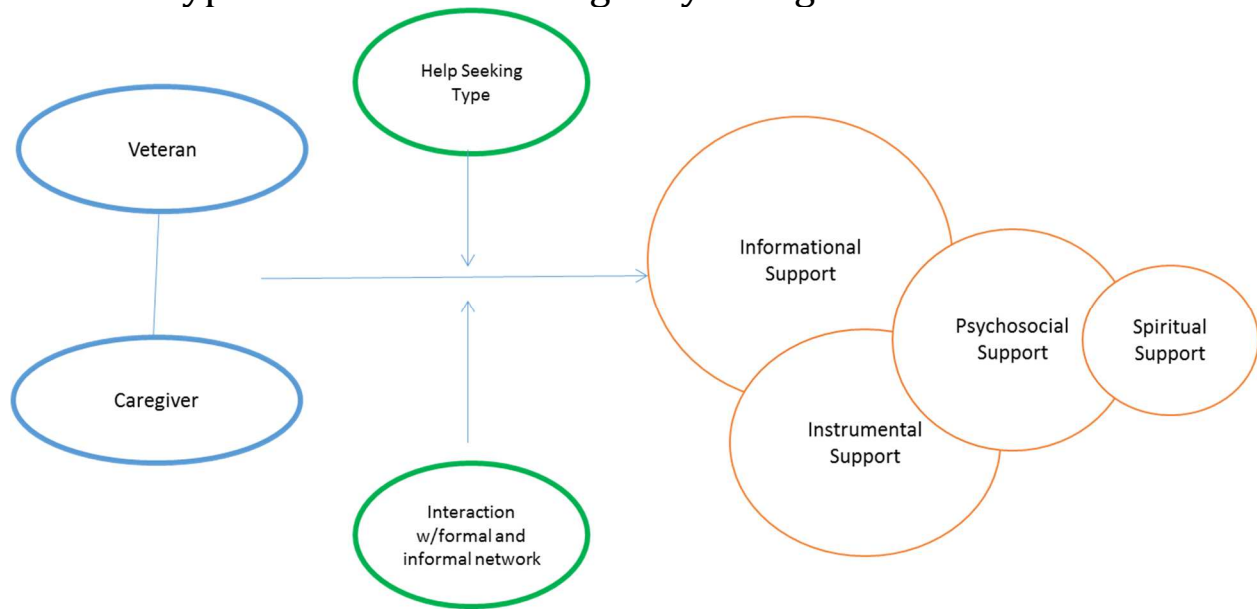
# APPENDIX 3

## Proposed Model from Study Findings



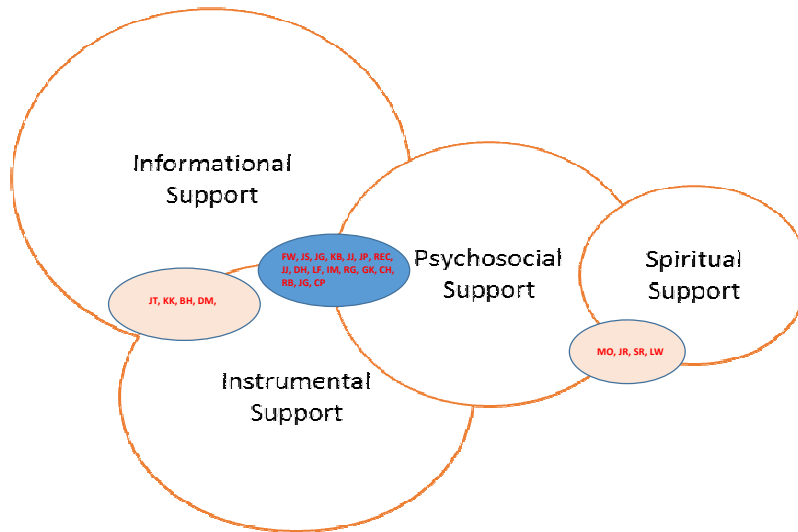
## APPENDIX 4

### Various Types of Assistance Sought by Caregivers



# APPENDIX 5

## Overwhelmed Caregivers - Need for Assistance



Blue – Overwhelmed  
Pink – Slightly overwhelmed  
\*\*Diagram includes assigned caregiver initials

The subject's initials were changed for the study

## REFERENCES

- Adelman RD, Greene MG, Charon R. The physician-elderly patient-companion triad in the medical encounter: the development of a conceptual framework and research agenda. *The Gerontologist*. 1987; 27(6): 729-734.
- Administration on Aging (AOA), United States Department of Health and Human Services. Family caregiving fact sheet: What we do makes a difference, Washington, DC: United States Department of Health and Human Services, 2003.
- Agha, Z., Lofgren, R. P., VanRuiswyk, J. V., & Layde, P. M. (2000). Are patients at Veterans affairs medical centers sicker? A comparative analysis of health status and medical resource use. *Archives of Internal Medicine*, 160, 3252–3257.
- Alzheimer's Disease Study. Communication gaps between primary care physicians and caregivers. Washington DC: American Alzheimer's Association, May 2001.
- American Diabetes Association. *Winning at Work-Diabetes Facts*. 2011. Available at: <http://www.diabetes.org/in-my-community/programs/winning-at-work/winning-at-work-diabetes.html>. Accessed May 20, 2012.
- American Geriatrics Society. *Choosing Wisely: Five Things Physicians and Patients Should Question*. New York, American Geriatrics Society, 2013
- Aneshensel C.S., Pearlin L.I., Mullan J.T., Zarit S.H. & Whitlatch C.J. (1995) Profiles in Caregiving. Academic Press, San Diego.
- Aneshensel, C. (1999). Mental illness as a career: sociological perspectives. In *Handbook of the sociology of mental health* (pp. 585-604). New York, NY: Springer.
- Angermeyer, MC & Matschinger H (1999). Whom to ask for help in case of a mental disorder? Preferences of the lay public. *Social Psychiatry and Psychiatric Epidemiology*, 34, 202-210.
- Angermeyer, MC, Breier P., Dietric S., Kenzine D & Matschinger H (2005). Public attitudes toward psychiatric treatment. An international comparison. *Social Psychiatry and Psychiatric Epidemiology*, 40, 855-864.
- Armenakis A, Harris S & Mossholder K (1993). Creating readiness for organizational change. *Human Relations*, 46(6): 681-703.
- Armitage CJ, Connor M. Efficacy of the theory of planned behavior: a meta-analytic review. *Br J Soc Psychol*. 2001;40:471–499.
- Armstrong, D. (1999). Social theorizing about health and illness. In G. Albrecht, R. Fitzpatrick, & S. Scrimshaw, *The Handbook of Social Studies in Health and Medicine* (pp. 24-35). Thousand Oaks, CA: Sage.

Bass DB, McClendon MJ, Deimling GT, et al. The influence of diagnosed mental impairment on family caregiver strain. *J Gerontol B Psychol Sci Soc Sci* 1994; 49:S146-S155.

Beck, CT (1993). Qualitative research: the evaluation of its credibility, fittingness and auditability. *Western Journal of Nursing Research*, 15, 263-266.

Beckham, J. C., Lytle, B. L., & Feldman, M. E. (1996). Caregiver burden in partners of Vietnam War Veterans with posttraumatic stress disorder. *Journal of Consulting and Clinical Psychology*, 64, 1068-1072

Beisecker AE: The influence of a companion on the doctor-elderly patient interaction. *Health Communication*. 1989;1:55-70.

Bell RA, Smith SL, Arcury TA, et al.: Prevalence and correlates of depressive symptoms among rural older African Americans, Native Americans, and whites with diabetes. *Diabetes Care* 2005, 28:823–829.

Berlowitz DR, Glickman M, Ash AS., Friedman R, Hickey EC, Kader, B. Hypertension management in patients with diabetes: The need for more aggressive therapy. *Diabetes Care*. 2003;26:355-359.

Biddle, L., Donovan, J., Sharp, D., & Gunnell, D. (2007). Explaining non-help-seeking amongst young adults with mental distress: a dynamic interpretive model of illness behaviour. *Sociology of Health & Illness*, 29 (7), 983-1002.

Biegel, D. et al (1991). *Family caregiving in chronic illness*. Newbury Park, CA: Sage.

Blay SL, Furtado A, Peluso TP (2008). Knowledge and beliefs about help-seeking behavior and helpfulness of interventions for Alzheimer's Disease. *Aging and Mental Health* 12(5), 577-586.

Blumer, H. (1969) *Symbolic Interactionism; Perspective and Method*. Englewood Cliffs, NJ: Prentice-Hall

Bookman A, Kimbrel D (2011). Families and Elder Care in the Twenty-First Century. Retrieved June 20, 2012 from [www.futureofchildren.org](http://www.futureofchildren.org)

Bonds, DE, Miller ME, Bergenstal RM et al. The association between symptomatic, severe hypoglycemia and mortality in type 2 diabetes: retrospective epidemiological analysis of the ACCORD study. *BMJ* 2010; 340:b4909.

Boughton, B (2011). Patients With Diabetes Lack Knowledge About Hypoglycemia. Retrieved from <http://www.medscape.com/viewarticle/740881>

Boyle JP, Honeycutt AA, Narayan KM, et al.: Projection of diabetes burden through 2050: impact of changing demography and disease prevalence in the U.S. *Diabetes Care* 2001, 24:1936–1940.

Braithwaite V. 1998. Institutional respite care: breaking chores of breaking social bonds.

*Gerontologist* 38(5): 610–617.

Brodaty H, Thomson C, Thompson C & Find M (2005). Why caregivers of people with dementia and memory loss don't use services. *Intl J Geri Psy* 20, 537-546.

Brodaty H, Griffin D, Hadzi-Pavlovic D. 1990. A survey of dementia carers: Doctors' communication, problem behaviours and institutional care. *Aust N Z J Psychiatry* 24: 362–370.

Brotman SL, Yaffe MJ. Are physicians meeting the needs of family caregivers of the frail elderly? *Can Fam Phys* 1994;40:679±85.

Brown AF, Mangione CM, Saliba D, et al.: Guidelines for improving the care of the older person with diabetes mellitus. *J Am Geriatr Soc* 2003, 51:S265–S280.

Brown, P. (1995). Naming and framing: The social construction of diagnosis and illness. *Journal of Health and Social Behavior*, 34-52.

Brown P, Holmes A, Mitchell R. 1990. Family caregivers' experiences and consequences associated with caring for family members with dementia. *Aust J Ageing* 9(2): 44–48.

Bruce D, Patterson A (2000). Barriers to community support for the dementia carer: a qualitative study. *Int J Geriatr Psychiatry* 15(5): 451-457.

Bruce JM, McQuiggan M, Williams V et al. (2008). Burden among spousal and child caregivers of patients with mild cognitive impairment. *Dementia*, 25, 385-390.

Buhr, G. T., Kuchibhatla, M., & Clipp, E. C. (2006). Caregivers' reasons for nursing home placement: Clues for improving discussions with families prior to the transition. *Gerontologist*, 46, 52–61.

Butcher R, Crosbie D. *Pesioned off; a Study of the Needs of Elderly People in Cleaton Moor*. York, UK: University of York, 1977.

Calhoun, P. S., Beckham, J. C., & Bosworth, H. B. (2002). Caregiver burden and psychological distress in partners of Veterans with chronic posttraumatic stress disorder. *Journal of Traumatic Stress*, 15, 205-212.

Cameron L., Leventhal EA & Leventhal H (1993). Symptom representations and affect as determinants of care seeking in a community-dwelling adult sample population. *Health Psychology*, 12, 171-179.

Carretero S., et al. (2009). The informal caregiver's burden of dependent people: Theory and empirical review. *Arch Gerontology and Geriatrics*, 49, 74-79.

Carpenter Rinaldi D (1995). Grounded theory research approach. In *Qualitative Research and in*

*Nursing: Advancing the Humanistic Imperative*, JB Lippincott Company, Philadelphia, pp 145-61.

Caserta M, Lund D, Wright S, Redburn D. 1987. Caregivers to dementia patients: the utilisation of community services. *Gerontologist* 27(2): 209–214.

Cauce AM, Paradise M, Domenech-Rodriguez *et al.* Cultural and contextual influences in mental health helpseeking: A focus on ethnic minority youth. *Journal of Consulting and Clinical Psychology* 2002; 70: 44–55.

Centers for Disease Control. *National Diabetes Fact Sheet*. Atlanta, Ga: U.S. Department of Health and Human Services. 2011. Available at: [http://www.cdc.gov/diabetes/pubs/pdf/ndfs\\_2011.pdf](http://www.cdc.gov/diabetes/pubs/pdf/ndfs_2011.pdf). Accessed May 20, 2012.

Chang HY, Chiou CJ, Chen NS. Impact of mental health and caregiver burden on family caregivers' physical health. *Arch Gerontol Geriat* 2009; May 13, Epub ahead of print.

Chappell N, Penning M. 1996. Behavioural problems and distress among caregivers of people with dementia. *Ageing Soc* 16(1): 57–73.

Charon JM (2010). *Symbolic interactionism: an introduction, an interpretation, an integration*. Tenth ed., Prentice Hall, Boston.

Chen L. 2014. Deciding to Institutionalize: Caregiving Crisis, Intergenerational Communication, and Uncertainty Management for Elders and Their Children in Shanghai. *Journal of Gerontological Social Work*. 58:128–148

Chiverton P, Caine ED: Education to assist spouses in coping with Alzheimer's Disease: A controlled trial. *Journal of the American Geriatrics Society*. 1989;37(7): 593-598.

Chiovitti RF, Prian N. Rigour and grounded theory research. *Journal of Advanced Nursing*, 44(4), 427-435.

Clandinin DJ, Connelly FM (2000). *Narrative Inquiry: Experience and Story in Qualitative Research*. San Francisco: Jossey-Bass Publishers.

Clausen, John A., and Miriam Yarrow. 1955. "Paths to the Mental Hospital." *Journal of Social Issues* 11:25-33.

Coe RM, Prendergast CG: The formation of coalitions: interaction strategies in triads. *Sociology of Health and Illness*. 1985; 7:236-247.

Cohen CA. Caregivers for people with dementia: what is the family physician's role? *Can Fam Phys* 2000;46:376±80.

Cohen D, Luchins D, Eisdorfer C, et al. Caring for relatives with Alzheimer's disease: The mental health risks to spouses, adult children, and other family caregivers. *Behav Health Aging*



1990; 1:171–82.

Collins C, Stommel M, Given C, King S. 1991. Knowledge and use of community services among family caregivers of Alzheimer's disease patients. *Arch Psychiatr Nurs* 5(2): 84–90.

Connell CM, Boise L, Stuckey JC, Holmes SB, Hudson ML. (2004) Attitudes toward the diagnosis and disclosure of dementia among family caregivers and primary care physicians. *Gerontologist* 44: 500-7

Corbin J & Strauss A (1988). *Unending work and care: managing chronic illness at home*. San Francisco: Jossey-Bass.

Coreil, J., Bryant, C., & Henderson, J. (2001). *Social and Behavioral Foundations of Public Health*. Thousand Oaks, CA: Sage.

Cornally N, McCarthy G (2011). Help-seeking behavior: a concept analysis. *International J of Nursing Practice*, 17: 280-288.

Creswell J (1998). *Qualitative Inquiry and Research Design: Choosing among the Five Traditions*. Thousand Oaks, CA: Sage

DeCoster, V (2008). Diabetes Treatments. *Journal of Gerontological Social Work*, 50: 105-29.

DeCoster, V (2003). The emotions of adults with diabetes: a comparison across race. *Social Work in Health Care*, 36(4), 79-99.

Dempsey, N. P., & Pruchno, R. A. (1993). The family's role in the nursing home: Predictors of technical and non-technical assistance. *Journal of Gerontological SocialWork*, 21(1/2), 127-145.

DePaulo BM, Nadler A, Fisher JD (1983). *New Directions in Helping*. New York: Academic Press

Department of Veterans Affairs; Department of Defense. VA/DoD Clinical Practice Guideline: Management of Diabetes Mellitus (DM). Version 4.0. Washington, DC, Veterans Health Administration, 2010

Donath C et al (2010). Effects of general practitioner training and family support services on the care of home-dwelling dementia patients. *BMC Health Services Research*, 10, 1-14.

Eiraldi RB, Mazzuca LB, Clarke AT, Power TJ. Service utilisation among ethnic minority children with ADHD: A model of help-seeking behaviour. *Administration Policy of Mental Health and Mental Health Service Research* 2006; 33: 607–622.

Feil, D, Lukman R, Simon B, Vickrey B (2011). Impact of dementia on caring for patients' diabetes. *Aging & Mental Health* 15(7), 894-903.

Feil , D et al, (2010). Increased risk of hypoglycemia in older patients with dementia and cognitive impairment: aligning outcome measures with safety. *J Amer Ger Soc*, (forthcoming)

Feinberg LF. The state of the art: Caregiver assessment in practice settings, San Francisco, CA: Family Caregiver Alliance, 2002.

Fine M, Thomson C. 1995. Three Years at Home: The Final Report of the Longitudinal Study of Community Support Services and Their Users, SPRC Report and Proceedings No. 121. Social Policy Research Centre, University of New South Wales: Sydney.

Finkelstein EA, Bray JW, Chen H etal. Prevalence and costs of major depression among elderly claimants with diabetes. *Diabetes Care* 2003, 26:415-420.

Fine, G. (1993). The sad demise, mysterious disappearance, and glorious triumph of symbolic interactionism. *Annual Review of Sociology*, 19, 61-87.

Fishbein M, Ajzen I. *Predicting and Changing Behavior: The Reasned Action Approach*. New York, NY: Psychology Press (Taylor and Francis); 2010.

Fontbonne A, Berr C, Ducimetiere P, et al.: Changes in cognitive abilities over a 4-year period are unfavorably affected in elderly diabetic subjects: results of the Epidemiology of Vascular Aging Study. *Diabetes Care* 2001, 24:366–370.

Friedson, E (1961). *Patients' views of medical practice*. New York: Russell Sage.

Friss, L., 2002. The State of the Art: Caregiver Assessment in Practice Settings. Family Caregiver Alliance, San Francisco.

Garand L, Dew MA, Eazor LR, et al. (2005) Caregiving burden and psychiatric morbidity in spouses of persons with mild cognitive impairment. *Int J Geriatr Psychiatry* 20, 512-522.

Gaugler, J.E., Kane, R.A., Langlois, J., 2000. Assessment of family caregivers of older adults. In: Kane, R.L., Kane, R.A. (Eds.), *Assessing Older Persons: Measures, Meaning and Practical Applications*. Oxford University Press, New York, pp. 320–359.

Glaser M, Rubin S, Dickover M: The caregiver role: review of family caregiver-physician relations and dementing disorders. In: Stahl SM, ed. *The legacy of Longevity - Health and Healthcare in Later Life*. London: Sage, 1990: 321-337.

Gerstein HC, Miller ME, Byington RP, et al. Effects of intensive glucose lowering in type 2 diabetes. *N Engle J Med* 2008 Jun 12;358(24): 2545-2559.

Golden SH, Laze M, Carnethon M, et al. Examining a bidirectional association between depressive symptoms and diabetes. *JAMA* 2008, 299: 2751-759.

Goldsmith HF, Jackson DF, Hough RL. Process model of seeking mental health services: Proposed framework for organizing the research literature on help-seeking. In: Goldsmith HF

(ed.). *Needs Assessment: It's Future*. University of Michigan, MI, USA: National Institute of Mental Health, 1988; 49–93.

Gordon C, Galloway T. Review of findings on Chronic Disease Self-Management Program (CDSMP) outcomes: Physical, emotional, & health-related quality of life, healthcare utilization and costs. National Council on Aging. 2007.  
[www.healthyagingprograms.org/resources/Review\\_Findings\\_CDSMP\\_Outcomes1.8.08.pdf](http://www.healthyagingprograms.org/resources/Review_Findings_CDSMP_Outcomes1.8.08.pdf)

Gourash N. Help-seeking: A review of the literature. *American Journal of Community Psychology* 1978; **6**: 413–423.

Grad J., Sainsbury P. Mental Illness and the family, *Lancet* 1963; 544-547.

Greenley J, Mullen J. Help-seeking and the use of mental health services. *Research in Community and Mental Health* 1990; **6**: 325–350.

Gross AE & McMullen PA: Models of the help-seeking process. In: *New Directions in Helping*. New York: Academic Press, 1983: 47-67.

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). Thousand Oaks, CA: Sage.

Gwyther LP: Clinician and family: a partnership for support. In: Mace NL, ed. *Dementia Care: Patient, Family and Community*. Baltimore: Johns Hopkins University Press, 1990: 193-230.

Hamilton KE, Milne A, Chenery A & Tilbrook C (2010). Help-seeking in relation to signs of dementia: A pilot study to evaluate the utility of the common-sense model of illness representations. *Psychology, Health and Medicine* 15(5), 540-549.

Hardeman W, Johnston DW, Bonetti D, Wareham NJ, Kinmonth AL. Application of the theory of planned behavior in behavior change interventions: a systematic review. *Psychology and Health*. 2002;17: 123–158.

Hassing LB, Grant MD, Hofer SM, et al.: Type 2 diabetes mellitus contributes to cognitive decline in old age: a longitudinal population-based study. *J Int Neuropsychol Soc* 2004, 10:599–607.

Haug MR (1996). Elements in physician/patient interactions in late life. *Research on Aging*, 18(1), 32-51.

Havens, B., 1999. Home-based and Long-term Care. World Health Organization, Geneva.

Hodgson LF & Cutler S. (2004). Help-seeking for personal concerns about developing

Alzheimer's Disease. *J App Gero*, 23(4), 385-410.

Hutchinson S (1986). Grounded theory in method. *In Nursing Research: A Qualitative Perspective* (Munhall PL and Oiler C). Appleton-Century Crofts, Norwalk CT.

IOM (Institute of Medicine). 2009. *Combating Tobacco Use in Military and Veteran Populations*. Washington, DC: The National Academies Press.

Intensive blood-glucose control with sulphonylureas or insulin compared with conventional treatment and risk of complications in patients with type 2 diabetes (UKPDS 33). UK Prospective Diabetes Study (UKPDS) Group. *Lancet* 1998, Sept 12;352 (9131):837-853.

Iwata I & Munshi MN (2009). Cognitive and psychosocial aspects of caring for elderly patients with diabetes. *Current Diabetes Reports* 9:140-46.

Janzen, John M. 1978. *The Quest for Therapy in Lower Zaire: Medical Pluralism in Lower Zaire*. Berkeley: University of California Press.

Jolley D (2009). The epidemiology of dementia. *Practice Nursing* 20(suppl 6): S4-S6.

Jordan CM, Oei TPS. Help-seeking behaviour in problem drinkers: A review. *British Journal of Addiction* 1989; **84**: 979-988.

Katon WJ, Rutter C, Simon G, et al: The association of co morbid depression with mortality in patients with type 2 diabetes. *Diabetes Care* 2005, 28:2668-672.

Kennedy J, Walls C. A national profile of intra-household ADL/IADL assistants: Population estimates from the 1992 and 1993 Surveys of Income and Program Participation, Champaign: Department of Community Health, University of Illinois at Urbana, 1997.

Kiecolt-Glaser JK, Preacher KJ, MacCallum RC, Atkinson C, Malarkey WB, Glaser R. Chronic stress and age-related increases in the proinflammatory cytokine IL-6. *Proc Natl Acad Sci* 2003; 100: 9090-5.

Kim Y, Schulz R. Family Caregivers' Strain: Comparative analysis of cancer caregiving with dementia, diabetes and frail elderly caregiving. *J Aging and Health*, 20(5), 483-503.

Klein HK, Myers MD. A set of principles for conducting and evaluating interpretive field studies in information systems, *MIS Quarterly* 1999, 23(1): 69.

Kohler S. *How to communicate with Alzheimer's: a practical guide and workbook for families*. Venice: Granny's Rocker Publishing; 2004.

Kosa J & Robertson L (1975). The social aspects of health and illness. In J. Kosa, I.Zola & R. Ekert (eds). *Poverty and health: A sociological analysis* (p.80-134). Cambridge, MA: Harvard University Press.

Krout J. 1983. Knowledge and use of services by the elderly: a critical review of the literature.

*Int J Aging Hum Dev* 17(3): 153–167.

Kulka, R. A., Schlenger, W. E., Fairbank, J. A., Hough, R. L., Jordan, B. K., Marmar, C. R., et al. (1990a). *The National Vietnam Veterans Readjustment Study: Tables of findings and technical appendices*. New York: Brunner/Mazel.

Lai, D. W. L. (2007). Validation of the Zarit Burden Interview for Chinese Canadian caregivers. *Social Work Research*, 31, 45-53.

Langa et al (2002). Informal caregiving for diabetes and diabetic complications among elderly Americans. *Journal of Gerontology*, 57(3): S177-S186.

Lazarus RS & Folkman S (1984). *Stress, Appraisal and Coping*. Springer, New York.

Lauber C, Nordt C, Falcato L., & Rossler W (2001). Lay recommendations on how to treat mental disorders. *Social Psychiatry and Psychiatric Epidemiology*, 36, 553-556.

LeGoff J (1992). *History and Memory*. New York: Columbia University Press.

Levine C, Halper D, Peist A, et al, Bridging troubled waters: family caregivers, transitions and long-term care. *Health Aff* 2010; 1: 116-24.

Levy-Storms L, Miller-Martinez D. Family Caregiver Involvement and Satisfaction with Institutional Care During the 1<sup>st</sup> year of Admission. *J App Gero*, 2005, 24, 160-74.

Levy-Storms, L. (1996). The predictors of institutionalization in context: A crisis perspective. *Family Perspective*, 30, 63–83.

Levy-Storms, L (2008). Therapeutic communication training in long-term care institutions: Recommendations for future research. *Patient Education and Counseling*, 73, 8-21.

Liang B, Goodman L, Tummala-Narra P, Weintraub S. A theoretical framework for understanding help-seeking process among survivors of intimate partner violence. *American Journal of Community Psychology* 2005; 36: 71–83.

Lobchuck M. Concept analysis of perspective-taking: meeting informal caregiver needs for communication competence and accurate perception. *J Adv Nurs* 2006 May; 54(3): 330-41.

Logroscino G, Kang JH, Grodstein F: Prospective study of type 2 diabetes and cognitive decline in women aged 70-81 years. *BMJ* 2004, 328:548.

Lustman PJ, Anderson RJ, Freedland KE, et al.: Depression and poor glycemic control: a meta-analytic review of the literature. *Diabetes Care* 2000, 23:934–942.

Lyons, K. S., Zarit, S. H., Sayer, A. G., & Whitlach, C. J. (2002). Caregiving as a dyadic process: Perspectives from caregiver and receiver. *Journal of Gerontology: Psychological Sciences*, 57B, P195–P204

Maletta GJ, Hepburn K: Helping families cope with Alzheimer's: the physician role. *Geriatrics*. 1986;41(11): 81-90.

Maraladi C, volpato S, Penninx BW, et al. Diabetes mellitus, glycemc control, and incident depressive symptoms among 70-79 year old persons: the health, aging and body composition study. *Arch Intern Med* 2007, 167: 1137-144.

Mazzone, T. Hyperglycaemia and coronary heart disease: The Meta picture. *The Lancet*. 2009;373:1737-1738.

McCabe B, Sand B, Yeaworth R, Nieveen J. 1995. Availability and utilisation of services by Alzheimer's disease caregivers. *J Gerontol Nurs* 21(1): 14-22.

Meltzer, B., Petras, J., & Reynolds, L. (1975). *Symbolic Interactionism: Genesis, varieties and criticism*. Routledge.

Merbis, M. A. E., Snoek, F. J., Kanc, K., & Heine, R. J. (1996). Hypoglycemia induces emotional disruption. *Patient Education and Counseling*, 29: 117-122.

MetLife Juggling Act Study. Balancing caregiving with work and the costs of caregiving, Westport, CT: Met Life Mature Market Institute, 1999.

Mockus Parks, S., Novielli, K.D., 2000. A practical guide to caring for caregivers. *Am. Fam. Physician* 15, 2215-2219.

Montgomery RV & Kosloski K (2009). Caregiving as a process of changing identity: implications for caregiver support. *Generations*, 33(1): 47-52.

Morgan DL & Zhao PZ (1993). The doctor-caregiver relationship managing the care of family members with Alzheimer's Disease. *Qualitative Health Research*, 3(2), 133-164.

Morris R, Morris L, Britton P. 1988. Factors affecting the emotional wellbeing of the caregivers of dementia sufferers. *British J Psychiatry* 153: 147-156.

Morse et al (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*. Retrieved August 10, 2012 from <http://www.ualberta.ca>

Murray C. Young people's help-seeking; an alternative model. *Childhood* 2005; 12: 479-494.

Naleppa, M. J. (1996). Families and the institutionalized elderly: A review. *Journal of Gerontological Social Work*, 27(1/2), 87-111.

National Alliance for Caregiving and AARP. Caregiving in the U.S., Bethesda: National Alliance for Caregiving, and Washington, DC: AARP, 2004.

National Institutes of Health. Most people with diabetes do not meet treatment goals. *NIH News*. 2004. Available at: <http://www.nih.gov/news/pr/jan2004/niddk-20.htm>. Accessed May 20, 2012.

Nelson, B. S., & Wright, D. W. (1996). Understanding and treating post-traumatic stress disorder symptoms in female partners of Veterans with PTSD. *Journal of Marital and Family Therapy*, 22, 455-467

Newman MA (1992). Window on health as expanding consciousness. In M O'Toole (Ed), *Miller-Keane encyclopedia and dictionary of medicine, nursing & allied health* (5<sup>th</sup> ed, p650). Philadelphia: WB Saunders.

Okereke OI, Kang JH, Cook NR, et al.: Type 2 diabetes mellitus and cognitive decline in two large cohorts of community-dwelling older adults. *J Am Geriatr Soc* 2008, 56:1028–1036.

Patel A, MacMahon S, Chalmers J et al. Intensive blood glucose control and vascular outcomes in patients with type 2 diabetes. *N Engl J Med* 2008 Jun 12;358(24): 2560-2572.

Parker G. 1990. *With Due Care and Attention: A Review of Research on Informal Care*, 2nd ed. Occasional Paper No. 2. Family Policy Studies Centre: London.

Pearlin L.I., Mullan J.T., Semple S.J. & Skaff M.M. (1990) Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* 30(5), 583–594.

Pearlin, L.I., Skaff, M.M., 1995. Stressors in adaptation in late life. In: Gatz, E.M. (Ed.), *Emerging Issues in Mental Health and Aging*. APA Press, Washington, DC.

Pearlin, L.I., Turner, H.A., Semple, S.J., 1989. Coping and the mediation of caregiver stress. In: Light, E., Lebowitz, B. (Eds.), *Alzheimer's Disease Treatment and Family Stress: Directions for Research*. U.S. Government Printing Office, Washington, DC, pp. 198–217.

Pescosolido, B. (1992). Beyond rational choice: The social dynamics of how people seek help. *The American Journal of Sociology*, 97 (4), 1096-1138.

Pescosolido, B., & Boyer, C. (1999). How do people come to use mental health services? Current knowledge and changing perspectives. In A. Horwitz, & T. Scheid (Eds.), *A Handbook for the Study of Mental Health: Social Context, Theories and Systems* (pp. 392-411). Cambridge: Cambridge University Press.

Pescosolido, B. (2000). Rethinking models of health and illness behaviour. In M. W. Kelner (Ed.), *Complementary and Alternative Medicine* (pp. 175-194). Amsterdam, The Netherlands: Hardwood Academic Publishers.

Phillips S & Phillips A (2011). Dementia a growing problem for older people with diabetes? *Practice Nursing* 22(10): 526-531.

Pinquart M. Correlates of subjective health in older adults: a meta-analysis. *Psychol Aging* 2001;16 (3):414–26.

Rabins P, Mace N, Lucas M. 1982. The impact of dementia on the family. *JAMA* 248(3): 333–335.

Raffaitin C, Gin H, Emapana JP (2009). Metabolic syndrome and risk for incident Alzheimer's disease or vascular dementia; the Three-city study, *Diabetes Care* 32(1): 169-74.

Ramakers IH et al, (2009). Characteristics of help-seeking behavior in subjects with subjective memory complaints at a memory clinic: a case control study. *Int J Geri Psy* 24: 190-196.

Ramchand, Rajeev, Terri Tanielian, Michael P. Fisher, Christine Anne Vaughan, Thomas E. Trail, Caroline Batka, Phoenix Voorhies, Michael Robbins, Eric Robinson and Bonnie Ghosh-Dastidar. Key Facts and Statistics from the RAND Military Caregivers Study. Santa Monica, CA: RAND Corporation, 2014. <http://www.rand.org/pubs/presentations/PT124>.

Ray KK, Seshasai SR, Wijesuriya S et al. Effect of intensive control of glucose on cardiovascular disease outcomes and death in patients with diabetes mellitus: A meta-analysis of randomized controlled trials. *The Lancet*. 2000;373:1765-1772.

Rickwood D. Promoting youth mental health through computer-mediated communication. *International Journal of Mental Health Promotion*. 2010;12:31–43.

Rickwood D. Conceptual measurement framework for help-seeking for mental health problems. *Psychology Research and Behavior Management*, 2012; 5: 173-183.

Rolland, J. S. (1984). Toward a psychosocial typology of chronic and life-threatening illness. *Family Systems Medicine*, 2, 245–262.

Rosenstock IM. Why people use health services. *The Milbank Memorial Fund Quarterly* 1965; 44: 94–127.

Schneider, Ellen. Chronic Disease Self-Management Program (CDSMP): Evidence-based Chronic Disease Self-Management Program for Older Adults. National Council on Aging. 2002. [www.healthyagingprograms.org/resources/EBSummary\\_CDSMP\\_Overview.pdf](http://www.healthyagingprograms.org/resources/EBSummary_CDSMP_Overview.pdf)

Schoenmakers B, Buntinx F & Delepeleire B (2009). What is the role of the general practitioner towards the family caregiver of a community-dwelling demented relative. *Scan J of Psy Health Care* 27, 31-40.

Schumacher, K. L., & Marren, J. (2004). Home care nursing for older adults: State of the science. *Nursing Clinics of North America*, 39, 443–471.

Schulz R, Beach SR. Caregiving as a risk factor for mortality: The Caregiver Effects Study. *JAMA* 1999;282:2215±19.



Schulz R, Beach SR, Lind B, et al. Involvement in caregiving and adjustment to death of a spouse: Findings from the caregiver health effects study. *JAMA* 2001; 285: 2132–3129.

Schuz R, et al. Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. *Gerontologist* 1995;35(6):771–91.

Selim, A. J., Berlowitz, D. R., Fincke, G., Cong, Z., Rogers, W., Haffer, S. C., Kazis, L. E. (2004). The health status of elderly Veteran enrollees in the Veterans Health Administration. *Journal of the American Geriatrics Society*, 52, 1271–1276.

Selvin E, Coresh J, Brancati FL: The burden and treatment of diabetes in elderly individuals in the U.S. *Diabetes Care* 2006, 29:2415–2419.

Shapiro G. Help-seeking; why people don't. *Research on the Sociology of Organisations* 1984; 3: 213–236.

Silliman RA (1989). Caring for the frail older patient: the doctor-patient-family caregiver relationship. *Journal of General Internal Medicine*, 4, 237-241.

Silliman, R., Bhatti, S., Khan, A., Dukes, K., & Sullivan, L. (1996). The care of older persons with diabetes mellitus: Families and primary care physicians. *Journal of the American Geriatrics Society*, 44, 1314–1321.

Sinclair AJ, Ames DG, Randhawa G, Bayer AJ (2010). Caring for older adults with diabetes mellitus: characteristics of carers and their prime roles and responsibilities. *Diabetic Medicine*, 27, 1055-1059.

Sketris I, Ingram E, Lummis HL (2009). Strategic opportunities for effective optimal prescribing and medication management. *Can J Clin Pharmacol* 16 (1) Winter 2009:e103-e125

Smyth KA & Milidonis MK. (1999). The relationship between normative beliefs about help-seeking and the experience of caregiving in Alzheimer's Disease. *J App Geron* 18(2), 222-238.

Sorensen, S, Engelgau, M, Thompson, T et al. CDC cost effectiveness of intensive glycemic, intensified hypertension control, and serum cholesterol level reduction for type 2 diabetes. *JAMA*. 2002;287:2542-2551.

Spinewine A, Schmader KE, Barber N, et al. Appropriate prescribing in elderly people: How well can it be measured and optimised? *Lancet* 2007 Jul 14;370(9582):173-84.

Spirito, A., Ruggiero, L., Coustan, D., McGarvet, S., & Bond, A. (1992). Mood state of women with diabetes during pregnancy. *Journal of Reproductive and Infant Psychology*, 10: 9-38.

Sprangers, M. A., Tempelaar R., van den Heuvel, W. J., & de Haes, H. C. (2002). Explaining quality of life with crisis theory. *Psycho-Oncology*, 11, 419–426.

Stewart R, Liolitsa D: Type 2 diabetes mellitus, cognitive impairment and dementia. *Diabet Med* 1999, 16:93–112.

Strauss A, Glaser B (1970). *Anguish: A Case History of a Dying Trajectory*, London: Martin Robertson,

Straus J, Strauss A (2008). *Basics of Qualitative Research*. Thousand Oaks: Sage Publishing

Talamantes MA, Lawler WR & Espino D (1995). Hispanic-American elders: caregiving norms surrounding dying and the use of hospice services. *Hospice Journal*, 10, 35-49.

Taylor SE (1999). *Health Psychology*. Boston: McGraw Hill.

Thompson RL, Lewis SL, Murphy MR, et al. Are there sex differences in emotional and biological responses in spousal caregivers of patients with Alzheimer's Disease? *Biol Res Nurs* 2004; 5: 319–30.

Thorpe CT, Gellad WF, Good CB, Zhang S, Zhao X, Mor M, Fine MJ. Tight glycemic control and use of hypoglycemic medications in older Veterans with type 2 diabetes and comorbid dementia. *Diabetes Care*, 2015;38(4): 588.

Uehera, E. (2001). Understanding the dynamics of illness and help-seeking: event structure analysis and a Cambodian-American narrative of "Spirit Invasion". *Social Science and Medicine*, 52, 519-536.

Valle R, Yamada AM, Barrio C (2004). Ethnic differences in social network help-seeking strategies among Latino and Euro-American dementia caregivers. *Ageing and Mental Health* 8(6), 535-543.

Van Hout et al (2006). Do general practitioners disclose correct information to their patients suspected of dementia and their caregivers? *Ageing Ment Health* 2006; 10: 151-5.

van Weert JCM, van Dulmen AMS, Peter MM, Ribbe MW, Bensing JM. Effects on snoezelen, integrated in 24 h dementia care, on nurse-patient communication during morning care. *Patient Educ Couns* 2005;58:312–26.

Velayudhan L, Poppe M, Archer N, Proitsi P, Brown RG, Lovestone S (2010). Risk of developing dementia in people with diabetes and mild cognitive impairment. *Br J Psychiatry* 196: 36-40.

Verbrugge LM & Ascione FJ (1987). Exploring the iceberg: Common symptoms and how people care for them. *Medical Care*, 25, 539-569.

Veroff J, Kulka R & Douvan E (1981). *Mental health in America: Patterns of help-seeking from 1957-1976*. New York: Basic Books

Vitaliano PP, et al. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychol Bull* 2003;129(6):946–72.

Wakefield BJ, Haynes J, Boren SA et al (2012). Strain and satisfaction in caregivers of Veterans with chronic illness. *Research in Nursing & Health*, 35, 55-69.

Werner P (2003). Knowledge about symptoms of Alzheimer's disease: correlates and relationship to help-seeking behavior.

Wilkinson D, Stave C, Keohane D, Vincenzino O. The role of the general practitioners in the diagnosis and treatment of Alzheimer's. *J Int Med Res* 2004, 32, 149-59.

Willoughby J. & Keating N. (1991). Being in control: the process of caring for a relative with Alzheimer's disease. *Qualitative Health Research*, 1, 27-50.

Wilcox BL, Birkel RC. Social network and the help-seeking process: A structural perspective. In: Nadler A, Fisher JD, DePaulo BM (eds). *New Directions in Helping: Applied Perspectives on Help-Seeking and Receiving*, Vol. 3. New York: Academic Press, 1983; 235–251.

Wilson CJ, Deane FP, Ciarrochi J, Rickwood D. Measuring help-seeking intentions: properties of the General Help-Seeking Questionnaire. *Canadian Journal of Counseling* 2005; 39:15-28.

Wu JH, Haan MN, Liang J, et al.: Impact of diabetes on cognitive function among older Latinos: a population-based cohort study. *J Clin Epidemiol* 2003, 56:686–693.

Wu AM, Tang CS, Kwok TC: Physical and psychosocial factors associated with health-promoting behaviors among elderly Chinese with type 2 diabetes. *J Health Psychol* 2004, 9:731–740.

Wysocki T, Greco P. Social support and diabetes management in childhood and adolescence: influence of parents and friends. *Curr Diab Rep* 2006; 6: 117–122.

Zarit, S.H., Reever, K.E., Bach-Peterson, J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980, 20, 649–654.

Zarit, S. H., Reever, K. E., Back-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist*, 20, 649-655

Zola IK. Pathways to the doctor—from person to patient. *Social Science and Medicine* 1973; 7: 677–689.

Zoungas S, Patel A, Chalmers J et al. Severe hypoglycemia and risk of vascular events and deaths. *N Eng J Med* 2010;363:1410-1418.