A NEEDS ASSESSMENT FOR CAREGIVERS OF THOSE WITH DEMENTIA

A Project

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by

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Division of Social Work
Abstract

of

A NEEDS ASSESSMENT FOR CAREGIVERS OF THOSE WITH DEMENTIA

by

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Alzheimer’s/Dementia is a slow and devastating illness that impacts adults at the core of who they are. It is a disease that not only affects the individuals suffering from it but it impacts the family system as well through financial, emotional, and sociological stressors. Those that identify themselves as primary caregivers are often overlooked when it comes to treatment plans which is directly correlated to the wellbeing of the individual diagnosed.

Current related research literature was reviewed. The researchers also utilized interviewing professionals in this field for additional information and insight. Personal experiences were taken into account when approaching the subject of working with this population group. One of the researchers utilized her work experience at a local skilled nursing facility and with a home health agency to conduct surveys.

Alzheimer’s/Dementia is a progressive, deteriorating disease with long-term implications. The inevitable mental incapacitation of the patient leaves the family and/or caregiver responsible for the wellbeing of this individual. This being said, the caregiver and family
members must become knowledgeable about the disease process, availability of community resources, and legal issues that are associated with this responsibility.

______________________, Committee Chair
Dale Russell, Ed.D., LCSW

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Date
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Chapter 1

INTRODUCTION

Social workers are often faced with the challenge of keeping families together. This task is particularly difficult when one of the family members is suffering from life barriers that cripple or force upon people dependence upon others. In the aging process this barrier could be considered dementia or Alzheimer’s disease. There is a societal notion that aging causes or results in memory loss. This is not altogether untrue though many early memory deficits have been misdiagnosed as senility, associating old age with intellectual decline. With the increase in dependence upon others for assistance with ADL’s (Acts of Daily Living), support systems are put in place to meet the need of a growing population that is marginalized. Family systems are the first to be utilized during this difficult time.

Family members who work but desire to keep their loved ones at home face the burden of trying to find alternate care. Not only is this difficult to do based upon the limited resources allocated in the community but this decision also brings upon multiple feelings of guilt and relational stress between the family members and those diagnosed with dementia. The lack of social supports and community resources available to family members, force social workers to be creative in intervention strategies, trying to do more with less. Family members can experience loss of wages when having to take off work to care for their family member, which adds to the unemployment and impoverished population living below the poverty line. This can push families whom “barely making it”, to prematurely place the consumer into an assisted living or skilled nursing
facility. This is especially true for caregivers who are a part of the “sandwich generation”, those between 40-60 years old who are not only the main caregiver of a parent but are also raising their own children.

**Background of the Problem**

Many studies have been done assessing the effectiveness of respite care on perceived caregiver burden. Caregiver’s experiences differ greatly depending upon what stage of dementia their loved one is in, as well as how much support the caregiver has, either formal or informal. One common theme being the majority of caregivers feel caring for their loved one is a familial responsibility. Researchers have looked at the use of respite services, support groups and psychosocial education and its impact on the caregivers overall well-being. Very little research has been done however on the caregiver’s perception of service needs, and service accessibility.

For these reasons, appropriate assessment of the caregiver’s perceived needs, should be addressed, including but not limited to, education on dementia and how to care for someone with dementia. Through this process, identification of supportive service available in specified communities and education on self-care to relieve what is referred to as “caregiver stress” should be emphasized. As social workers utilizing the empowerment approach through highlighting the stressors forced upon individuals whether those stressors are political or economic in nature, caregivers will gain the skills of balanced diet, exercise and positive ways to combat these stressors.
Statement of the Research Problem

There are approximately 5.3 million persons in the United States living with dementia, about 70% of these individuals are living at home and receiving care from family members and friends (Alzheimer’s association, 2009). Most individuals living with dementia require 24 hour care and supervision. This makes it almost impossible for caregivers to work or even care for their own immediate families. Respite care is sometimes available but can be very expensive and does not provide caregivers with emotional supports, education or coping skills. Non-medical care-giving agencies such as Senior Helpers or Bright Star cost on average $20.00 to $24.00 per hour, as they are licensed and bonded. The total monthly cost of this type of care could calculate at roughly $9,000.00 per month.

If caregiver’s needs are met to their satisfaction, their stress levels will reduce as would feelings of burden. When caregiver’s needs are met, it empowers them to be more effective in their care for the consumer and avoid premature placement in skilled nursing facilities. Adult day health centers (ADHC) have proven to be effective in relieving caregiver burden. One reason for such success is that each center is equipped with a multidisciplinary team of health professionals who conduct assessments and create individualized treatment plans to meet each client’s specific health and social needs. Caregivers feel comfortable leaving their loved ones in the care of a treatment team while they tend to their own activities of daily living. These facilities do not provide 24 hour care but do provide socialization with peers of the same population group.
Avoiding premature placement and keeping the family unit in tact is crucial as people are living longer. According to the U.S census bureau the number of Americans over the age of 65 years old will double by 2030 to over 70 million people. This is one of the many reasons caregiver’s need services that will help them to avoid burnout. When a caregiver experiences the symptoms of caregiver stress, such as social withdrawal, sleeplessness, anxiety, depression, exhaustion and irritability; the quality of the caregivers care may decline, often unintentionally. Caregiver stress can also lead to family destabilization. When the caregiver feels trapped within that role it leads to difficulty with role differentials. The caregiver may become resentful and find it difficult to identify with any other role(i.e. mother, wife, sister, son). Relationships suffer as a result, as each family member is left to take on new roles. This often changes the family dynamics, as more is expected of each family member, whom is left to find ways to complete tasks once done by the caregiver.

**Purpose of the Study**

The following Master’s project will investigate the impact of Alzheimer’s disease on the family and as a result it will ascertain the caregiver’s perceived physical, psychological and social stressors. The purpose of this study is to understand what types of assistance caregivers feel are needed in order to care for someone living with dementia. This understanding will give social workers an idea of how to intervene when working with a person with dementia as well as associated family members/caregivers. A person living with dementia is often unable to make their own decisions, thus the burden of decision making often falls on the caregiver. As social workers we often focus
on the needs of the consumer (person with dementia) without adequately supporting the caregiver.

It is hoped that caregivers will be supported through the results of this study in developing and maintaining maladaptive coping skills that will lessen their burden and bring to light where the community could increase awareness of perceived needs. In view of the concerns noted, the results should provide a measure by which advocates for the aging population can reassess the effectiveness of available programs to the older adult group and identified caregivers. The researchers also hope to describe the impact on the family of the problems associated with providing care to someone suffering from dementia. It will also ascertain the caregivers perceived physical, psychological and social stressors and to recommend interventions that social workers could find useful for working with this population group.

**Theoretical Framework**

Discussions and explanations contained in this study will coincide with the framework of an ecological perspective which has three core concepts that are pertinent to social work practice within the medical model; adaptedness, stress, and coping (Germain, 1984, p. 58). The Ecological perspective refers to the relationship between the human and their environment. There is a complex interchange between the somatic and psychological as well as environmental stressors that impact a person’s daily life. Based on the purpose of this study, the underutilization of respite care services will be analyzed under the lens of the Ecological perspective.
**Definition of Terms**

*Alzheimer’s disease.* A progressively deteriorating, irreversible dementia.

*Atrophy.* A shrinking or wasting away of a tissue or organ.

*Caregiver.* A family member or person designated to provide care and supervision of an Alzheimer’s/dementia afflicted loved one.

*Dementia.* A deterioration of mental faculties, along with emotional disturbance resulting from organic brain syndrome.

*Family.* A group of persons related by blood or marriage.

*Senile dementia.* Dementia occurring after age 65.

*Senility.* A specific type of infirmity of the mind which is frequently associated with aging.

**Justification**

It is the assumption of the researchers that dementia/Alzheimer’s are diseases that cannot be cured nor rehabilitated. Families of those diagnosed have difficulty accepting the diagnosis and those diagnosed are generally classified as older adults. The resources allocated to the caregivers and persons diagnosed with these cognitive disorders are limited primarily to the person suffering from the disease, not the caregiver. Caring for these persons may become too stressful and can cause extreme frustration and psychosocial distress.

The limitations of this study are that information is obtained from a sample of identified caregivers of persons diagnosed with Alzheimer’s/dementia. This study will not differentiate the specific respite services or favor particular modes to care for persons...
afflicted with Alzheimer’s/dementia disease. The intent of these researchers is to fully
discuss, explain and define all aspects of the research problem without jeopardizing the
ethics of the social work profession.

Statement of Collaboration

Rajeeyah Fultz and Carolyn Kluenker worked together as joint authors on this
project. Both researchers worked collectively during the process of this study. Topic
selection, data analysis, writing, and formatting were completed congruently throughout
the research project.
Chapter 2

REVIEW OF THE LITERATURE

This chapter is intended to examine pertinent information related to caregivers of persons with dementia. This chapter will examine past practices in providing direct services to caregivers of persons with dementia focusing on service delivery, services utilized, barriers to service delivery, and or utilization. The goal of this chapter is to identify gaps in services, as well as determine factors that might discourage caregivers from accepting available resources.

Due to the advancement in technology, and more assessable information regarding preventative care, people are living longer. The lifespan of persons with dementia, a disease that progressively gets worse, is increasing, which means intensified care needs over time. Presently, services that were once performed by professionals in a skilled nursing environment are now being done by caregivers, whether they are unpaid family members or hired professionals. Program’s such as home health, a program designed to re-acclimate people from hospitals into the community, where a nurse visit’s a patient weekly in their home has lessened the need for the ill to be hospitalized indefinitely. In Home Supportive Services, or paid caregiver support through programs such as Bright Star, or All about Seniors, have also implemented non-medical support such as transportation, medication management and meal preparation to support disabled adults remain in their home.

When looking at the history of social support systems, these programs are comparatively new and in many ways these changes in the health care and social services
systems have been positive. Those with incapacitating illnesses are more able to remain safely at home than before where quality of life is far greater and economic stressors placed on the government are far less. There are only two in home support systems that are paid for by the government through its social services budgeting. One is In-Home Supportive Services, also known as IHSS. Medi-cal will pay for this service as long as the individual receiving these services meets certain income criteria, is over 65 year-old, is blind, or disabled. Once again, the services provided by this support system are non-medical. With recent budget cuts, this system is losing its funding and decreasing the amount of people that it can serve. Medi-care will pay for home health which is medical support to re-acclimate into the community when someone is considered homebound post a medical procedure.

These are the only two programs funded by an outside source, adversely, taking care of family members at home often results in financial hardship for the caregiver. With an increasing life expectancy comes a higher need for support for the disabled and medically compromised population. Most caregivers in the United States identify themselves as a family member of the one whom is incapacitated. The binaries of caregiver/loved one, poses its own challenges. One such challenge with holding to the ideology that family members will carry the burden to provide support for each other is the fact that family structure has evolved along with social systems. There are some people who choose not to have children which then leads them to be dependent on the government when they are found to be indigent. Additionally, more women are deciding to peruse their careers in lieu of having children, or couples are choosing to have children later on in life. Not to
mention that family structure is subjective to the relationships built within them. It cannot be assumed that a daughter will want to reunite with her alcoholic or abusive father and provide him with 24 hour care. In order to ensure there will be enough caregivers to care for the elderly in this Country weas social workers must approach the subject from a macro level as to how these policies are made which provide social support to the aging and disabled population. We must also approach it from a mezzo level when addressing the systems that influence caregivers in how they approach the task of care-giving and the stressors that impede them from success. On a micro level, social workers must empower our caregivers to be aware of and learn from “burnout” as individuals who are influenced by culture, religion and society. In addressing these components of the care-giving task and role, the needs of caregivers will be identified and focused upon through a multitude of lenses.

It is known that caregivers of a person with dementia experience high levels of depression and burden, more so than caregivers who are caring for other chronically ill people. Due to the progressive nature of dementia, it is difficult to anticipate the needs of an individual or to know what to expect from day to day. Throughout most of the studies shared on this topic, caregivers often exhibit signs and symptoms of anxiety related to this uncertainty in day to day tasks. Those who suffer from dementia, but are still ambulatory, often are referred to as a “flight risk” or those who might elope from home without the cognitive ability to find their way back. Caregivers of these individuals will often fear for their loved one that he/she might cause self-harm accidentally whether it be in walking when he/she is unable to or starting a fire in the house by leaving the stove on.
Due to this cognitive impairment, the caregiver will take on the role of responsibility for the wellbeing of this individual. The guild associated with failure when the individual is harmed also facilitates the worsening of anxiety.

Many caregivers are not abreast of the disease process and the behaviors that a person with dementia may exhibit. In fact, the stereotypical behaviors of individuals suffering from dementia do not allude to the relational difference that will occur as a result of this disease. Bereavement, for example, is not often discussed for those family members who are living with someone suffering from this disease. The loss of a relationship with an individual due to cognitive impairment may at times feel comparatively to a death. In all actuality, this feeling is true due to the nature of the disease. The person suffering from dementia might not recognize his or her spouse or children. He/she might fall in love with someone else and forget his/her name. The role that the caregiver/family member played in the life of the demented person prior to the disease will surely change as a result of the disease process. For this reason prior interventions focused on caregiver education with the idea that a better understanding of dementia would help caregivers cope with the changes that would occur.

There has been extensive research on the well-being of caregivers in caring for people with dementia, most of this research looks at the best interventions to use with the consumer and caregiver from the researchers, and medical staff's perspective. The most common services offered being:

- Adult day Health
- Education for consumer and caregiver
• Respite care
• Facilitate family meetings
• Advanced Health Care Directives, POLST forms
• Liaison between medical staff and family
• Domestic services: light house cleaning, meal delivery
• Support groups
• Home health aids

The following literature review is focused on supportive services such as home care interventions, family based therapy, psychosocial education, respite programs, with attention to cultural variations in care-giving. Examining this literature will help to illuminate why more research focused on caregivers perceptions of what caring for a person with dementia entails, and what supports the caregiver finds useful in order to lessen feelings of depression and burden while increasing the caregivers overall well-being and ability to care for themselves and the consumer. For the purposes of this literature review, respite will be defined as temporary relief for the primary caregiver through the prearranged substitute care takers. Respite includes use of adult day health programs, in-home respite where substitute care providers come into the home to provide care, and institutional respite where the consumer stays in an institution for a short time. The goal of respite being an opportunity for the care giver to distress, rest and return to care giving responsibilities both physically and mentally recharged. The terms consumer and patient may be used interchangeably in reference to individuals living with dementia throughout the literature review.
Respite Care

In a research article by Gottileb and Johnson (2000) it was stated that research among family caregivers found respite to be one of the most desired services. For this reason, the literature focused on (1) the goals and structuring of center-based respite programs for the family caregivers for persons with dementia; (2) the timing and duration of their use by these family caregivers; and (3) their impacts on the mental health and well-being of these caregivers, as well as on the deterrence of placement in long term care facilities. Using these guidelines, the authors examined the functions that day programs serve in the long-term care system.

This research found that respite did not ameliorate the feelings of depression or burden on the caregiver; in fact it accomplished the opposite. Institutional respite, in this study, was found to be favored by caregivers but often served as a bridge to long term placement. This article adequately demonstrated the mixed emotions that go into the role of care-giving. Most caregivers appreciate respite support though feel guilty for utilizing it due to the socially held ideology that families care for one another till death. When left with a “stranger”, these feelings of guilt will often outweigh the feeling of stress that is associated with caregiver burnout. This study was conducted over the time span of twelve months which is a good portrayal of the progression of the disease and how it changes the care-giving tasks. For this reason, a short term respite option has not been the answer to relieving caregiver burden or stress. It may be one of the answers but still it leads to institutionalized support.
A similar study was conducted in Spain by Cuesta-Benjuma (2009), using grounded theory which rather than begins with a thesis, starts with data collection so that the study is not biased. The laws in Spain differ from the laws here; however, familial responsibility is a common ideology that binds our two cultures. Truthfully, the guilt associated with caregiver stress is not only linked to abandonment but to grief over a lost relationship. Participants in this study were primarily females who identified themselves as primary caregivers. Care providers participated in interviews for two years while researchers analyzed these interviews concluding that caregivers are ambivalent to accepting respite care services. The cultural expectation for women, and family, caring for their own has a great deal to do with this ambivalence.

These findings suggest the need for interventions that are specific to the individual as well as client centered. Client centered and “context specific” interventions for caregivers based on cultural, spiritual and financial systems improve sense of guilt. For example, these interventions could be tailored to the religious or cultural affiliation that the caregiver and patient identify with. For those that are catholic, calling upon the priest for communion or upon catholic social services for more community resources, would demonstrate cultural awareness. Utilizing narrative therapies to reframe a person’s belief or life story regarding help from outside sources would be beneficial for the social worker/client relationship as well as the relationship between caregiver and patient. Contextualizing guilt and its influence over one’s decisions is also conducive to the perception of this caregiver role.
Gillian Stockwell-Smith, Ursula Kellett and Wendy Moyle conducted research to explore the limiting and motivating factors that influence caregiver’s use of respite services and the ability of currently available respite services to meet the needs of both caregivers and those with dementia. Three themes emerged from the data: ‘Commitment’ characterized by reciprocity, role definition and role frustration, ‘Needing Help’ discussed in terms of trust, confidence in service, fear and resistance, and ‘Support’ discussed in relation to informal networking, misinformation and lack of knowledge.

Putnam, Pickard, Rodriguez & Shear (2010), similarly found that all caregivers in their study believed care-giving was a familial responsibility. He focused his study on the premise that people who suffer from dementia are often overlooked when it comes to client centered or “consumer directed” practice where the client directs the treatment plan. This truth is founded on the fact that those who are diagnosed lack the capacity to make significant decisions independently. The responsibility therefore falls on the family member or caregiver. This study ultimately points to crucially of this caregiver being the center of this client centered model as they are the ones providing care. The study took place in Missouri and led to caregivers identifying difficulty in acquiring: services, high stress levels, little support and a desire for stronger public policies, as the greatest challenges in care-giving.

Participants in this study also reported that surrogate decision making should be an option as this responsibility is quite significant. In the medical world this term is known as “responsible party.” This person gives informed consent for medical treatment, end of life decisions and financial obligations. As any can imagine, this role which wasn’t
asked for, can often feel as if it is a burden. A surrogate decision maker could be the public guardian through a conservator office which many family members often fall back on.

These findings are also supported by a study done by Stirling, Andrews, Croft, Vickers, Turner, & Robinson (2010). This study found caregivers felt they needed more help than they were currently receiving. The caregiver attributed stress as a result of these unmet service needs. The study found significant correlations between caregivers rated burden and felt service needs. This study linked caregiver’s perceived need with the level of stress currently observed, concluding that the higher the stress level, the greater the impaired need. The stress was not always related to the tasks associated with care-giving, but the simple cognitive impairment of the recipient. Self-awareness and “tuning in” to oneself prior to meeting someone else’s needs is proven to be beneficial in the role of care-giving as well as the quality of life experience by the recipient. Seeking therapeutic outlet such as exercise, counseling, or social relationships outside of care-giving can and will improve the quality of care provided and perceived need of the caregiver.

This exploratory study measured caregiver burden using Bradshaw’s taxonomy of need to explore the link between, what in this study is referred to normative need, expressed need, and felt need. The exploration of felt need best identifies the questions asked in the current study; “What are the perceived needs of caregivers?” This study found that caregivers may express being satisfied with available resources but in times of stress, caregivers may express they need for more help. Further, the stress does not
necessarily have to be a result of care-giving but could be due to other life situations such as, immediate family responsibilities, and work demands.

**Psychosocial Education**

A study done by Shoenmakers, Buntinx & Sélepiere (2010), was similar to the study discussed above; this study looked at the effect of home care intervention on general well-being. This study analyzed literature focusing on the effect of different types of professional dementia home care interventions. This analysis found psychosocial intervention to be “somewhat” successful in reducing caregiver’s feelings of burden, only a very slight decrease in depression was noted in this study, while multidisciplinary case management proved greater effect on the reduction of depression.

Surprisingly respite care proved to cause more burdens on caregivers, a few explanations for this finding being caregivers needing to prepare the consumer for leaving the home and/or caregivers feeling forced to discuss placement or permanent care options when coming in contact with the respite team. Caregivers may also be reluctant to accept services and feel some guilt in leaving their loved one with a stranger. One important finding of this study suggests the need to tailor psychosocial support to consumers and their caregivers.

Amanda F. Elliott, PhD, MSN, along with Louis D. Burgio, PhD, and Jamie DeCoster, PhD, discuss in their research the importance of physiological health on caregiver stress and burn out. Their research including a randomized, multisite clinical trial of those who have had a psychosocial educational intervention and those who have not, concluded that the caregivers providing self-care are better equipped to provide
quality care interpersonally, as well as to their loved one. The others who did not receive this intervention displayed fewer health-promoting behaviors; and have higher morbidity and mortality rates, more sleep problems, and higher numbers of illness-related symptoms.

The researchers in this case are attempting to prove that there is a link between interpersonal stress and perceived caregiver need. Those who find space to release stress and provide them with an environment of self-care will in the long run provide better care to those around them. Yet, the resources around them are difficult to obtain which create a further sense of stress and helplessness. Once again, on the micro level, those caregivers who are not maintaining the functionality of their lives as individuals, friends, mother, wife, etc. will not provide adequate care to the person suffering from dementia as they themselves do not have the energy to give another person.

Ducharme, Levesque, Lachance, Kergoat, Legault, Beaudet&Zarit (2011), also looked at the efficacy of psycho educational programs; their study was experimental and focused on transitioning the caregiver into that role after finding out their loved one was diagnosed with dementia. Caregivers were accessed pre-intervention and then again post intervention. The findings in this study concluded that caregivers felt more prepared and able to care for their loved one after receiving this psycho educational program. For example, the study mentioned above discussed a true story of caregivers participating in an intervention aimed at assisting families in managing behaviors and deescalating family members with dementia. The intervention was effective in raising self- awareness and confidence with redirection.
The implications for this study illustrate what is possible when a proactive psychoeducational approach to supporting the dementia patient, and their caregiver is taken. By taking opportunities to support and educate the caregiver before they reach the point of burden and burnout, caregivers are better prepared to adapt to the constantly changing and challenging duties of care-giving. This type of intervention also helps caregivers learn coping strategies which they can activate when becoming frustrated or overwhelmed. Participation in psychoeducational programs are instrumental in ameliorating self-blame and feelings of failure on the part of the caregiver.

Dennis, Gitlin, Huach, Hodgson & Winter (2010), found similar results when caregivers received education on care-giving. Although this study targets consumers and reducing the number of behaviors they experience, an important component of this trial was to assess the caregiver’s level of generalized well-being and management skills. This is critical, as this is an area that has not been thoroughly investigated. It is known that caregivers managing the behaviors of a person with dementia report more feelings of depression and distress. Further research is required to discover if there is a correlation between the caregiver’s feelings regarding their own ability to manage these behaviors, and the number along with severity of behaviors exhibited by the consumer.

Through the use of Advancing Caregiver Training (ACT) caregivers were able to learn strategies to manage behaviors, while remaining calm and less emotional or attacked by the behaviors. Through education and training caregivers learned better coping skills and therefore reported being less upset and feeling better prepared to care for their loved one and able to keep them at home. The correlation between
conceptualized knowledge and psychological well-being showed to be positive. The researchers were hoping to find that a correlation between the conceptualized knowledge and the perceived caregiver stress. Through motivational interviewing and empowerment, a social worker could improve the sense of self and decrease the amount of burden experienced by the caregivers.

This was also found to be true in a study conducted in Hong Kong by Chien& Lee (2011). This study examined how effective a six month dementia care program, the “Dementia Family Care Program” DFCP, was in assisting Chinese caregivers and their relative living with dementia. This program went beyond routine supportive services such as medical consultation and information about the illness as well as information regarding the effects of medication and treatment planning. Social Workers assisted families with appropriate referrals for financial aid and social services. Social and recreational activities were offered weekly.

In addition a case manager was assigned to each family who conducted a weekly home visit discussing issues around dementia care-giving. Main topics included self-care for caregivers, developing social relationships, sharing the emotional effects of caregiving with others, and the importance of strengthening relationships between the caregiver, the family and the consumer. The findings were that through DFCP caregivers felt less burden and consumers experienced less hallucinations and aggressive behaviors. Further research needs to be done before attempting to apply this program to different cultures.
In terms of planning interventions, exploratory research conducted by Zarit, Femina, Kim & Whitlatch (2010), identified potential risk factors that would be useful when planning an intervention for caregivers when targeting a specific outcome. This study used interviews of 67 caregivers and selected its risk factors based on the stress models of care-giving. The examined associations among risk factors included behavioral problems, family conflict, overload and depression. The stressors were identified as primary, those affecting the caregivers emotions, behavior and functioning. Secondary stressors were identified as stressors that originate from work, and personal care.

The researchers believed that primary and secondary stressors are constantly interacting with available resources. The caregivers level of stress, and availability of resources play a role in the caregivers’ depressive symptoms including failing mental and physical health. The outcomes of this study found that risk factors for family caregivers were for the most part independent of one another. This research supports the research done by Schoemakers, Buntinx and DeLepeliere (2010), that also found inconclusive results and suggested the need for tailored interventions for caregivers, including individualized needs assessments of caregivers.

An article by Mitrani and Czaja (2000), supports the idea of assessing caregivers. This study discusses how the burden, anxiety, and stress associated with care-giving have increased the number of caregivers being diagnosed with depression and anxiety. This has also increased the number of caregivers who are being prescribed psychotropic medications and utilizing more medical resources. The authors attribute the severity of
the caregivers’ depressive symptoms to the severity of the recipients’ behaviors. For example, caregivers caring for a family member who wanders, is assaultive, or asks repetitive questions would experience more symptoms of burden and stress than someone caring for a family member who did not display such symptoms.

The authors identify social support, particularly the family as a critical piece in alleviating caregivers’ symptoms of distress. Family conflict can only worsen a caregiver’s depressive symptoms. Common familial issues that arise include, poor communication, role confusion, and differing opinions on the type of care that should be provided. The authors describe ways interventions can be constructed to meet the specific needs of a family through family-based therapy. This therapy includes a host of interventions aimed at reducing burden and improving the well-being of both the recipient and caregiver. Techniques include psycho/social/educational services, and behavioral interventions. Because the focus in this study was on family-based therapy, the main interventions were focused on transforming how the families interacted with one another, it views the behavior of the family as dependent on each the behavior and role of each family member. The caregiver is seen as not only the most likely to influence change, but most motivated to work towards it. Being that the caregiver carries most of the responsibility and burden of the day to day care-giving, the caregiver would also be in the greatest need of support. The limitations of this study are that it was conducted through the use of case examples, and this study only included white and Cuban families making the results inapplicable to the population as a whole.
Giltin, Jacobs & Earland (2010), state in their article “Translation of a Dementia Caregiver Intervention for Delivery in Homecare as a reimbursable Medicare Service: Outcomes and Lessons Learned” that persons living with dementia were underserved due to lack of funding and empirical based research. To help address this problem the authors looked at whether a particular program, Environmental skill-building program (ESP), could be integrated into the home health care model. ESP services in this study were provided by a private and independently owned practice, Medicare part B was billed for the services.

What is most interesting about this study is that occupational therapists, physical therapists, and speech therapists would not only be providing the services in which they specialize, but also respite care. Nowhere in the plan are social workers, nurses or even in home aids allotted for to address the medical and psychosocial needs of the recipients. This proposal is significant in that it takes service delivery away from the professionals who are trained to deal with the complexity of life changes, and does not respect the caregiver’s role in caring for their loved one.

The purpose of this study was to explore how this program could be implemented in the homes of consumers. The findings indicated the need for more partnerships and collaboration between other disciplines. Because of requirements with Medicare, therapists are paid based upon how much time they spend with the recipient, not on training the caregivers. Further, therapists had some difficulty engaging caregivers, and encouraging them to participate in the study. This study proves that interventions must be designed to address the needs of the consumer and caregiver. It illustrates that there is no
one size fits all approach to supporting caregivers. Social workers, who have specialized training in working with diverse populations, and who are experiencing a plethora of psychosocial issues should be consulted in any planning and implementation of programs affecting such populations.

**Caregiver Perceptions**

The diagnosis of dementia can, often times, lead to depression, not only experienced by the consumer, but by the caregiver as well. The co-occurrence of Alzheimer’s disease and depression is well known and accepted, however depression is difficult to diagnose in individuals living with dementia. In this study conducted by Jeste, Lewis, Moore & Watson (2010), patients with Alzheimer’s disease who also were demonstrating behavioral disturbances were assessed for depression using single questions as to how they themselves perceive depression. Caregivers were also included in the assessment, something that has not often been done as caregivers are often seen as being unable to recognize depression in the consumer when they, the caregiver, may be experiencing depression also.

This article adds to the current literature of care-giving and dementia in that caregiver depression and level of perceived level of burden is higher when the consumer experiences depression with dementia. It also found that caregivers were less likely to identify depression in the consumer when asked if they, the caregiver, are also depressed. This identifies a need for better screening and referral processes. As noted in the literature when depression is treated caregiver burden decreases.
Andre’s Losadaa*, Maria Ma’rquez-Gonzalez, Bob G. Knight, Javier Yanguas, Philip Sayeghe and Rosa Romero-Morenof in their study, “Psychosocial factors and caregivers’ distress: Effects of familism and dysfunctional thoughts” discuss the crucial role that family plays on the caregiver perceived stress and depression. The stress is directly related to the strength this family possesses as well as the roles that are played in caregiver support. This study provides support for the importance of conceptualizing familism as a multidimensional construct with both positive and negative effects on caregivers’ emotional distress and suggests that familism affects emotional distress through dysfunctional thoughts rather than through burden appraisals.

The systems theory and importance of familial roles have significant impact on perceived caregiver need and stress. This impact will have positive influence through role differentiation and self-awareness. Someone who identifies themselves as a caregiver will in turn be able to use the strength and support of mutual aid to provide adequate care and obtain effective self-care. When the family members of the person suffering from dementia is educated about the disease process and possible stressors related to caregiver burden, it is more likely that familial stressors will be less likely to occur. With this said, as social workers, it is important to utilize the mutual aid group and educate the family members as well as caregiver about what this process might bring to the family system.

Like the study conducted by Jeste, Lewis, Moore & Watson (2010), a study conducted by Arai, Arai, Ikeda & Matsumoto (2007), looked at caregivers perceptions, in this study the focus was on caregivers perceptions of the degree of difficulty in caring for individuals with early onset dementia compared to caring for those with late onset
dementia. This study is important as the goal is to target the specific problems that caregivers experienced while caring for the consumer. Tuning in to what the perceived problems are is the first step in beginning to plan and implement interventions that can help to relieve caregiver stress and burden.

The study found that there were no significant differences between the groups. It agrees with other research in that additional resources are needed to assist caregivers with the difficulties of coping with behavioral issues and care-giving in general. The limitations to this study are that it was conducted in Japan. The familial responsibility felt by members of this community cannot be applied to all cultures and caregivers. Though the long term care insurance offered in this country appears to be one of the greatest social supports, unfortunately to qualify consumers must be over the age of 65 which does not help those with early onset dementia.

Chen, Lotus, Yang & Wang (2010), found that caregivers who also worked experienced more depressive symptoms. This study took into account the amount of support the caregiver had from family and friends as well as that of paid respite workers, coupled with the demands of the caregivers outside work. This study is important as it highlights the need for more assistance for caregivers in the home but also more flexibility at work. The limitations of this study are that it was conducted in Taiwan, were less than five percent of individuals with dementia are institutionalized, and most are taken care of by their family members.
Cultural Variations

The care-giving experience varies from caregiver to caregiver. We know that coping techniques, faith, and familial support play a role in the caregiver’s ability to care for her loved one and herself. What is not often addressed is the cultural component of care-giving. Culture influences one’s identity, it influences the way in which one sees the world. By 2050 it is expected that African Americans, Latinos, Asians and Pacific Islanders will make up more than thirty percent of the population aged sixty five and older. Therefore, it is necessary to have an understanding of one's culture in order to begin to assess their ability to cope, manage stress, or needs. On a more macro level this information is necessary in order to effectively educate health care professionals regarding what types of behaviors, and delivery of care are appropriate for varying cultures. Policy issues would be reframing policies to address culturally sensitive beliefs and rituals.

In a study conducted by Connell and Janevic (2001), which reviewed the literature pertaining to ethnic differences in dementia care-giving that was published between the years of 1996-2000, the authors found mixed findings when focused on stress and burden, depending on the scale or measurement tool used. One finding from this study that should be noted is African Americans appeared to experience greater self-fulfillment and satisfaction than did their white counterparts. African Americans were also more likely to use prayer and attend church as a means of coping with the stresses of care-giving.
Faith and spirituality is an essential part of African American culture and should be considered when working with this group. The importance of the entire family, working collectively is also important when working with this group as the caregiver caring for the demented African American is usually a family member, rather than a spouse. This is most often true for Asian dementia patients as well. It is found that in most Asian cultures, the daughter-in-law carries this duty as opposed to White demented patients, where it is usually a spouse that provides the care.

This study also found low reports of depression among Asian caregivers in contrast this same group had higher scores when answering questions regarding anger and embarrassment. This could suggest that in Asian communities mental health issues such as dementia and depression may be viewed as shameful.

Similarly to the study named above, the following article conducted by Dilworth-Anderson, Gibson & Williams (2002), also reviewed articles paying special attention to issues involving race, culture, and ethnicity. In this study rather than looking at a 4 year period, the authors review 59 articles published between 1980-2000. This study points out that the institutionalization rate among minorities is lower than whites. It is important to discern if this is due to cultural beliefs, lack of income, or if institutions such as nursing homes are not meeting the cultural needs of minorities. It is accepted that minorities underuse formal services, which begs the question. What are the perceived needs of caregivers?

The limitations of this study are that in the articles reviewed much of the data collected was done so using models which did not include concepts important to race and
culture. In assessing social support the findings of this study suggest that minorities utilize a greater pool of supports, including neighbors, church friends and fictive kin, but still desired more formal services. This study also refers to a study done by Levkoff et al. (1999), found African Americans were not satisfied with the support services received because of cultural misunderstanding that occurred. Puerto Rican caregivers were found to rarely utilize support services due to language barriers, of the services accepted by this group were home health (nursing), and domestic services such as housekeeping. Being unable to understand language is a major barrier to services. Being unable to communicate with service providers limits the patient’s and caregiver’s ability to get their needs met. The needs and wants of the family may be misunderstood due to the language barrier, just as the family’s understanding of the patient’s prognosis would be limited due to these communication problems.

According to 2010 Census data of the 308.7 million people residing in the nation, 50.5 million of these were Hispanic or Latino. Of these 50.5 million Hispanic or Latin people living in the U.S 27.8 percent live in California. We must remember that these numbers only include Hispanic and Latino’s whom filled out the Census data. This is important to note because this population is growing quickly, it accounted for more than half of the country’s growth between 2000-2010. The implications being a need for services tailor made for this group, including service providers who speak Spanish and are familiar with the social and cultural values of these very diverse group of people, which includes, Mexicans, Guatemalans, Salvadorans, Cubans, Dominicans, and Puerto Ricans.
Summary of the Review of the Literature

In sum, all of the literature reviewed agrees that care-giving is a stressful job that can cause a great deal of burden, depression and anxiety for the caregiver. It concludes that in order for a caregiver to avoid burnout the caregiver needs social supports, the tools to identify stressors, and the skills necessary to lessen the effects of these stressors their on their well-being. In order to have a better understanding of the services needed for such a growing and diverse group of consumers, research must focus on more than caregiver burden and depression. While the literature reviewed is a great starting point in understanding the approaches being used to assist caregivers and also illuminates what is missing from current research: the caregivers perceived needs.
Chapter 3

METHODOLOGY

This chapter describes the methodology used in conducting this study. The researchers were interested in the topic of care-giving and dementia because they have both worked with this population for quite some time. One of the researcher’s works in a skilled nursing facility. The other researcher has worked with consumers and their families in their own homes to avoid premature placement. Both of the researchers felt because of what they have seen in the field, there was an unmet need in terms of fully supporting the caregiver. It was important for the researchers to identify what caregivers identified their needs to be. The purpose of this research is to determine if there is a relationship between the perceived needs of caregivers of those diagnosed with dementia, the resources utilized by these caregivers, and the direct psychosocial impact of utilization of resources on those caregivers.

Study Design

The dependent variable in our study; which is also known as the client outcome variable, is “the impact on caregivers of persons with dementia whom have little resources for respite care”. This variable is being measured while introducing the independent variable, an increase in caregiver support resources, to determine if it, the poor psychosocial impact, changes.

By creating a needs assessment from the caregivers perspective, then creating a resource guide for this individual population while measuring for an increase or decrease in psychosocial distress. This would be manifested by a change in mood or behavior of
those caregivers. According to the multiple studies provided in our literature review, there have been both quantitative and qualitative analysis configured demonstrating the negative impact that limited resources have on caregivers of adults with dementia. In a research article by Gottileb and Johnson (2000), it was stated that research among family caregivers found respite to be one of the most desired services.

The independent variable in our study is the needs assessment that will be implemented after interviewing our population sample. A needs assessment is defined as systematically documenting the needs of potential clients who will likely be the recipients of a proposed intervention. In the case of caregiver support for adults with dementia, the proposed intervention would be an increase in support resources based on the needs of the caregivers from their perspective. Needs assessments can be conducted using questionnaires sent by mail or handed out at a neighborhood site, interviews by phone or face-to-face, focus groups, or other strategies. In our study, the needs assessment will be in the form of an 18 Likert Scale questionnaire, where caregivers rate the usefulness of interventions from 1-5. This questionnaire will be handed out at a public site where this population resides, a skilled nursing hospital.

**Sampling Procedures**

This study is designed to be a quantitative descriptive study. We will use non-probability convenience sampling to obtain the participants for the study in an effort to ensure we attract caregivers who work with the specific population (older adults diagnosed with dementia). These participants will be caregivers who are utilizing or seeking respite care through assisted living or skilled nursing facilities, or have their
loved one placed in a facility post-acute illness. Some snowball sampling will be utilized should we receive a low response or completion rate of the surveys (less than 10).

We intend on using SPSS to cross tabulate and to compare various questionnaire responses. We will check for statistical significance by running various statistical tests, and utilize parallel data from peer reviewed journals and online resources to compile with our research to present gathered outcomes. The data will be destroyed three years from the conclusion of the research. No identifying information of any kind will be collected from the participants. Each participant’s survey will be assigned a number, only to track how many surveys were received and handed out. Each survey will be collected in sealed envelopes; these surveys will be left in the reception area of the healthcare agencies that have agreed to participate in the survey. All the raw information collected will be kept in a locked location except when being used for this study. Only the researchers and their faculty advisor will have access to the data.

Data Collection Procedures

The researchers will survey approximately 40 persons who identify themselves as primary caregivers of someone diagnosed with Alzheimer’s/dementia. The researchers have received permission from Westview Healthcare Center to utilize the facility and family members of those who are pursuing respite care through long term care facilities. These participants must identify themselves as primary caregivers seeking assistance from the community either through education or placement. There will be no coercion and those who choose to agree will be able to find the questionnaires available in the social services office. Those who participate in the study will receive a raffle
ticket to win a fifty dollar visa gift card. Those who choose to participate then withdraw from the study will still be a candidate for the gift card. The researchers will provide envelopes for each participant to place their completed questionnaire to protect their confidentiality; this will also ensure that participation in the study is voluntary. The researchers will not attempt to bribe or persuade the families of consumers to participate in the study. Additionally, the researchers will provide a drop box that will be located behind the Director of Social Service’s desk where the participants can place their completed questionnaires. This will help to protect the anonymity of participants, as well as alleviate any pressure to participate.

There will be no conflict of interest to occur while conducting this study. Although Carolyn Kluenker is employed by the agency as the Director of Social Services, there will be no conflict of interest, or connection between her job duties and the research affiliated with this study. Rajeeyah Fultz will be primarily involved in the handling of surveys which will assist in eliminating any potential problems with role confusion. Carolyn Kluenker will not be handling surveys nor participating in the study during work hours. The researchers used the snowball sampling method, and ask this agency to refer us to other known service providers that service those who are diagnosed with Alzheimer’s/dementia. When presenting this project to the participants, the researchers made sure that the consent forms were available so participants could review them. The researchers indicate during the introduction of the subject that if they decide to participate they must read and sign the consent before they complete the questionnaire. The researchers also make sure that each questionnaire has a consent
form attached to the front of each questionnaire. Each participant will receive a copy of the consent form as well. If necessary the researchers will read the consent form to prospective participants as well as explain the document in further detail.

**Data Analysis**

The intervention that is being used is designed as a needs assessment. This assessment will be used to determine if a new intervention is needed and if the existing interventions in the community are meeting the population’s needs. Another purpose of the needs assessment will be to determine if the existing informal resources are adequate for each individual case and if the proposed intervention will be easily accessible to the population group involved. As previously stated, the structure of this assessment is a Likert Scale. The total amount of questions is 18 with an informed consent preceding its completion.

The intervention proposed will not intervene with personnel of the assigned agency. One of the researches is employed by this agency but will not be interviewing its patients and/or family members. The personnel of the agency will not be impacted by this study, nor will this study be attached to the agency as part of its policy. The rationale for the selection of our intervention is to provide the most efficient resources for this population group utilizing the client centered approach to meeting the clients’ needs from his/her perspective. The study design quantitative in nature was designed so caregivers may easily answer questions directed at towards the specific aims of the proposal; which is to gather an understanding of the deficits in pre-existing resources available, and the needs of the population.
Being an exploratory and descriptive approach to locating answers to unfounded questions while anticipating the benefits of gaining insight into this population group and the needs that are portrayed will hopefully guide the federally and state funded programs to direct their attention and expertise towards these specified areas. The strengths of quantitative research methods are that it contains important meaning inherent in the data. One advantage of quantitative data collection and analysis is that it is often the best fit for diverse and at-risk populations about which little is known. In this regard, it is often crucial to hear what they have to say and keeping it their own words avoids a tendency toward favoring majority population views and reductionism.

The population was drawn from a selection of familial caregivers whose loved one is in a skilled nursing hospital due to a sub-acute illness/injury, or following an acute medical intervention at an acute hospital. The patients at the sub-acute skilled nursing facility have altering levels of dementia that require unique approaches, interventions, and a diverse set of supportive services. Having their caregivers participate in this study will illuminate what is working, and where gaps in services exist.

**Protection of Human Subjects**

The content of the questionnaire that we be administered will consist of questions that elicit information regarding preferences in assistance with care-giving support. These questions will not require the participants to divulge any identifying information. They will be asked questions that pertain to preferences and usefulness. There is a slight chance that the participants may experience minimal discomfort due to the sensitivity of the topic. The participants will be required to sit or stand for
approximately 5-10 minutes to complete the questionnaire. For these reasons, the participants may experience minimal discomfort and or harm physically when completing the questionnaire. The questions are geared towards the caregiver’s perception of availability and usefulness of supportive services. Participants will not be asked to engage in any physically procedures other than physically filling out the questionnaire. The level of risk for this study is non-existent because we are administering anonymous questionnaires to service providers. These surveys only consist of questions that pertain to the caregiver’s ideas and perceptions. The protocol for the protection of human subjects was submitted to the division of social work, and graduate studies which found the study to be exempt from risk.

No identifying information will be collected from the participants. Each participant’s survey will be assigned a number only to indicate how many surveys are received and handed out. Each survey will be collected via sealed envelopes to be left in a designated box in the social services office at healthcare agencies that have agreed to participate in the survey. All the raw information collected will be kept in a locked location except when being used for this study. The researchers and their advisor will be the only people with access to the data. The participants will be informed that if any question is difficult for them to answer they can refuse to answer that/those questions. They will also be told that at any time should they wish to terminate their participation in the study; they are able to do so.
Chapter 4

RESULTS

This chapter presents some descriptive statistics taken from twenty-one surveys, consisting of eighteen questions. The surveys were collected from a skilled nursing facility; caregivers of persons with dementia completed these surveys. No demographic, or sociodemographic information was asked in the survey. The surveys were reviewed by the researchers, and the data was downloaded into SPSS. The researchers used SPSS to analyze the data for patterns, themes, and associated correlations. The mean and standard deviation for each of the 18 questions will be reported. The researchers also created a sub-scale which compared particular questions to identify if they were related; this was done using bi-variant correlational analysis.

Background

This project will investigate the impact of Alzheimer’s disease on the family and as a result it will ascertain the caregiver’s perceived physical, psychological and social stressors. The purpose of this study is to understand what types of assistance caregivers feel are needed in order to care for someone living with dementia. A person living with dementia is often unable to make their own decisions, thus the burden of decision making often falls on the caregiver.

The hope of this research is that caregivers will be supported through the results of this study in developing and maintaining maladaptive coping skills that will lessen their burden and bring to light where the community could increase awareness of perceived needs. In view of the concerns noted, the results should provide a measure by which
advocates for the aging population can reassess the effectiveness of available programs to the older adult group and identified caregivers. The researchers also hope to describe the impact on the family of the problems associated with providing care to someone suffering from dementia. It will also ascertain the caregivers perceived physical, psychological and social stressors and to recommend interventions that social workers could find useful for working with this population group.

Specific Findings

Our study did not find any of the 18 statements to be particularly significant. What was most interesting was the responses gathered from questions three and four. Question number three which reads “The ethnicity of the respite worker does not matter to me as long as they are qualified”, had an M= 2.29, the minimum was 1.00 and the maximum 5.00. The researchers initially questioned whether participants fully understood they question, believing the question may have been framed in a confusing way. After reviewing question number four which reads “I would prefer a respite worker of my own ethnicity and culture” it was clear that an inverse relationship was present. The mean for question four was 3.95, the minimum like question number three was also 1.00, and the maximum was also 5.00 as in question three. Please see Table 1 for a summary of this data.

The researchers also found that question seventeen which states “I find written information on dementia useful” was related to questions fourteen and fifteen which talk about perceived support. It was expected that questions fourteen and fifteen be related as they both as about support systems. It was surprising to the researchers that people who
felt like they had a good deal of social support, also utilized educational resources through written information.

Table 1

<table>
<thead>
<tr>
<th>Agree</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1</td>
<td>4.8</td>
</tr>
<tr>
<td>Strongly Agree</td>
<td>20</td>
<td>95.2</td>
</tr>
<tr>
<td>Total</td>
<td>21</td>
<td>100.0</td>
</tr>
</tbody>
</table>

M = 4.95 SD = .22

Only one participant was neutral regarding whether respite care outside of the home was useful. It was assumed that caregivers would prefer respite outside of their homes, the idea being the caregiver would be more able to rest and recharge from the physical and emotional demands of care-giving if the recipient was out of the home. It was also assumed that because of cultural differences and different views on care-giving, the caregiver would find it more difficult to have strangers in their home providing services.

As stated in the literature review, an article by Gottileb and Johnson (2000), found that research among family caregivers found respite to be one of the most desired services. Institutional respite, in this study, was found to be favored by caregivers but often served as a bridge to long-term placement.

Surprisingly, a study done by Shoemakers, Buntinx & SeLepeliere (2010), found respite care proved to cause more burdens on caregivers, a few explanations for this finding being caregivers needing to prepare the consumer for leaving the home and/or caregivers feeling forced to discuss placement or permanent care options when coming in contact with the respite team (Table 2).
Table 2

*I Find Respite Care Outside my Home Useful*

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neutral</td>
<td>1</td>
</tr>
<tr>
<td>Agree</td>
<td>6</td>
</tr>
<tr>
<td>Strongly Agree</td>
<td>14</td>
</tr>
<tr>
<td>Total</td>
<td>21</td>
</tr>
</tbody>
</table>

M=4.62 SD=.59

“The ethnicity of the respite worker does not matter as long as they are qualified” was one of the most controversial questions asked on the questionnaire. Thirteen of the twenty-one persons who completed the survey felt it “mattered” if the person providing their care was of a different ethnicity than themselves. Three people were neutral, and only five people were accepting of having a caregiver of a different ethnicity (Table 3).

Table 3

*The Ethnicity of the Respite Worker doesn’t Matter as long as Qualified*

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree</td>
<td>10</td>
</tr>
<tr>
<td>Somewhat Disagree</td>
<td>3</td>
</tr>
<tr>
<td>Neutral</td>
<td>3</td>
</tr>
<tr>
<td>Agree</td>
<td>2</td>
</tr>
<tr>
<td>Strongly Agree</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>21</td>
</tr>
</tbody>
</table>

M=2.29 SD= 1.5

The question regarding preferring a respite worker of the same ethnicity was framed similarly to the question which preceded it. However, 15 respondents stated they wanted a caregiver of their own ethnicity, in contrast to the thirteen that “cared” about the
ethnicity of their caregiver in the previous question. The way these questions were answered not only brings up questions of racism and privilege and racism, but also stresses the importance of culturally competent services. More in depth data collection must be conducted in order to identify the origin of these preferences (Table 4).

Table 4

I Would Prefer a Respite Worker of my Ethnicity

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree</td>
<td>2</td>
<td>9.5</td>
</tr>
<tr>
<td>Somewhat Disagree</td>
<td>2</td>
<td>9.5</td>
</tr>
<tr>
<td>Neutral</td>
<td>2</td>
<td>9.5</td>
</tr>
<tr>
<td>Agree</td>
<td>4</td>
<td>19.0</td>
</tr>
<tr>
<td>Strongly Agree</td>
<td>11</td>
<td>52.4</td>
</tr>
<tr>
<td>Total</td>
<td>21</td>
<td>100.0</td>
</tr>
</tbody>
</table>

M=3.95 SD=1.4

The question pertaining to participation in support groups did not show any significance though only one person “somewhat disagreed” it would be interesting to learn if this person receives strong support in other areas, therefore not feeling participation in support groups would be useful (Table 5).

Table 5

Participating in Support Groups Useful

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somewhat Disagree</td>
<td>1</td>
<td>4.8</td>
</tr>
<tr>
<td>Neutral</td>
<td>3</td>
<td>14.3</td>
</tr>
<tr>
<td>Agree</td>
<td>7</td>
<td>33.3</td>
</tr>
<tr>
<td>Strongly Agree</td>
<td>10</td>
<td>47.6</td>
</tr>
<tr>
<td>Total</td>
<td>21</td>
<td>100.0</td>
</tr>
</tbody>
</table>

M=4.23 SD=.89
Hong Kong by Chien & Lee (2011), examined how effective supportive services such as medical consultation and information about the illness as well as information regarding the effects of medication and treatment planning were in assisting Chinese caregivers and their families. In this study, Social Workers assisted families with appropriate referrals for financial aid and social services. Social and recreational activities were offered weekly. In addition a case manager was assigned to each family who conducted a weekly home visit discussing issues around dementia care-giving. Main topics included self-care for caregivers, developing social relationships, sharing the emotional effects of care-giving with others, and the importance of strengthening relationships between the caregiver, the family and the consumer. The findings were caregivers felt less burden, and consumers experienced less hallucinations and aggressive behaviors. These findings are similar to the research conducted for the present study which found support groups, written information, and educational classes; on caring for the consumer, and the caregiver to be useful.

Table 6

<table>
<thead>
<tr>
<th>I Find Educational Classes on Dementia Useful</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somewhat Disagree</td>
<td>1</td>
<td>4.8</td>
</tr>
<tr>
<td>Neutral</td>
<td>1</td>
<td>4.8</td>
</tr>
<tr>
<td>Agree</td>
<td>8</td>
<td>38.1</td>
</tr>
<tr>
<td>Strongly Agree</td>
<td>11</td>
<td>52.4</td>
</tr>
<tr>
<td>Total</td>
<td>21</td>
<td>100.0</td>
</tr>
</tbody>
</table>

M= 4.38 SD=.80
The question regarding usefulness of written information was found to be insignificant although questions that assessed the usefulness of education through written information, or classroom settings found on average ten to thirteen of the twenty-one participants “strongly agreed” that these services were in fact useful.

Table 7

<table>
<thead>
<tr>
<th>I Find Written Information Useful</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neutral</td>
<td>2</td>
<td>9.5</td>
</tr>
<tr>
<td>Agree</td>
<td>7</td>
<td>33.3</td>
</tr>
<tr>
<td>Strongly Agree</td>
<td>12</td>
<td>57.1</td>
</tr>
<tr>
<td>Total</td>
<td>21</td>
<td>100.0</td>
</tr>
</tbody>
</table>

M=4.48 SD=.68

All participants agreed that participation in classes on caring for one’s self were useful to them though no statistical significance was found (Table 8). The findings for the questions regarding usefulness of classes on caring for loved ones and helpfulness of in home aids were insignificant. Of the twenty people surveyed, eighteen either agreed, or strongly agreed that in home aids were useful. The remaining three were neutral. This may be explained by research done by Connell and Javenic (2000), that found racial and ethnic differences, cultural norms and language barriers contribute to declining the use of in home aids by minorities. Please see Tables 9 and 10 for results.
The question regarding usefulness of following my direction showed no significance. What was interesting about this question was that it is very similar to the question that preceded it; the only change in this question in relation to the usefulness of
in home aids is “If following my direction” (Table 11). This suggests that the three people who felt neutral in regards to finding an in home aid useful, either agrees, or strongly agrees that an in home aid would be useful if they themselves were allowed to instruct the aid.

Table 11

<table>
<thead>
<tr>
<th>In Home Aids Useful if Following my Direction</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agree</td>
<td>6</td>
<td>28.6</td>
</tr>
<tr>
<td>Strongly Agree</td>
<td>15</td>
<td>71.4</td>
</tr>
<tr>
<td>Total</td>
<td>21</td>
<td>100.0</td>
</tr>
</tbody>
</table>

M=4.71 SD=.46

The question regarding liking more help from family was of no significance (Table 12). Six people stated they would like more help from their family, however in the previous question which stated “I have adequate support from my family” only one person disagreed. This is interesting because it raises the question “Is adequate support enough”? The answer to this question will of course vary from caregiver to caregiver, and in many ways may be influenced by what one’s culture says about who should be doing the caregiving (Table 13). De La Cuesta-Benjumea (2010), found in her study that was conducted in Spain, that the women in her study felt guilty in regards to asking for help. In their culture it was considered a duty and honor to care for a loved one. Furthermore, the question regarding having three (3) or more people to call if the individual ever needed a break from care-giving was of no significance (Table 14).
Table 12

I Would Like More Help From Family

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neutral</td>
<td>2</td>
</tr>
<tr>
<td>Agree</td>
<td>6</td>
</tr>
<tr>
<td>Strongly Agree</td>
<td>13</td>
</tr>
<tr>
<td>Total</td>
<td>21</td>
</tr>
</tbody>
</table>

M=4.52 SD=.68

Table 13

I Have Adequate Family Support

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somewhat Disagree</td>
<td>1</td>
</tr>
<tr>
<td>Neutral</td>
<td>2</td>
</tr>
<tr>
<td>Agree</td>
<td>5</td>
</tr>
<tr>
<td>Strongly Agree</td>
<td>13</td>
</tr>
<tr>
<td>Total</td>
<td>21</td>
</tr>
</tbody>
</table>

M=4.42 SD=.87

Table 14

I Have 3 People I can Call if I Need a Break from Care-Giving

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somewhat Disagree</td>
<td>3</td>
</tr>
<tr>
<td>Neutral</td>
<td>5</td>
</tr>
<tr>
<td>Agree</td>
<td>6</td>
</tr>
<tr>
<td>Strongly Agree</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>21</td>
</tr>
</tbody>
</table>

M=3.81 SD=1.1

The research indicates that caregivers do not have much time for outside relationships due to the demands of caregiving, the stress and burden that are associated
with caregiving can also attribute to caregivers isolating themselves and causing friction in friendships. The questions regarding friendships, being overwhelmed or frustrated, and recognition of being overhelmed was of no significance (Table 15, Table 16, & Table 17). Only one person disagreed, and two people were neutral. It would be interesting to explore whether the caregivers felt this way before transitioning into the caregiver role.

Table 15

*I Have Friends who are there for me*

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somewhat Disagree</td>
<td>1</td>
</tr>
<tr>
<td>Neutral</td>
<td>2</td>
</tr>
<tr>
<td>Agree</td>
<td>11</td>
</tr>
<tr>
<td>Strongly Agree</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>21</td>
</tr>
</tbody>
</table>

M=4.14 SD=.79

Table 16

*I can tell When I am Becoming Overwhelmed or Frustrated*

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neutral</td>
<td>2</td>
</tr>
<tr>
<td>Agree</td>
<td>9</td>
</tr>
<tr>
<td>Strongly Agree</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>21</td>
</tr>
</tbody>
</table>

M=4.38 SD=.67
The majority of caregivers reported feeling that they could easily assess resources. This could be because this study was conducted in Auburn, California which is a very small city in Northern California. The city is surrounded by rural communities; there are not as many social service agencies in this community. Please see Table 18 for analyzed data results.

| Table 17 |
|-----------------|-----------------|
| **Learn how to Recognize when I am Becoming Overwhelmed** | |
| Frequency | Percent |
| Neutral | 1 | 4.8 |
| Agree | 6 | 28.6 |
| Strongly Agree | 14 | 66.7 |
| Total | 21 | 100.0 |

M=4.62 SD=.59

| Table 18 |
|-----------------|-----------------|
| **I can Easily Find Community Resources to Assist me** | |
| Frequency | Percent |
| Neutral | 4 | 19.0 |
| Agree | 3 | 14.3 |
| Strongly Agree | 14 | 66.7 |
| Total | 21 | 100.0 |

M=4.48 SD=.81

**Additional Findings**

The researcher’s assumed there would be a similar number of participants whom agreed with question six (6) “I find educational classes on dementia useful”, question number seven (7), “I find written information about dementia useful”, and question eight
“I find classes on caring for myself useful”, and question five (5) “I find participating in support groups with other caregivers useful”. The researcher’s believed that those who found education and classes useful may also find support groups useful. The results indicated no significant relationship was found. Please see Table 19 for the results to the correlated data.

The researchers also examined whether or not there were a similar number of participants who identified themselves as receiving a lot of social support, with those who found that participating in support groups was useful to them. This was done by using bi-variant correlation analysis to examine question number twelve (12) “I feel I have adequate family support”, question number fourteen (14) “I have at least three people I can call when I need a break from care-giving”, and question number fifteen (15) “I have friends who are there for me”, correlated with question number five (5) “I find participating in support groups with other caregivers useful”. Results indicated no significant relationship was found. Putnam, Pickard, Rodriguez & Shear (2010), similarly found that all caregivers in their study believed care-giving was a familial responsibility. Caregivers identified difficulty in acquiring: services, high stress levels, little support and a desire for stronger public policies, as the greatest challenges in care-giving. These findings are also supported by a study done by Striling, Andrews, Croft, Vickers, Turner, & Robinson (2010). This study found caregivers felt they needed more help than they were currently receiving. The caregiver attributed stress as a result of these unmet service needs. The study found significant correlations between caregivers rated burden and felt service needs.
Participants who agreed with questions number one (1) “I find respite care in home useful”, question number ten (10) “I find in home aids useful” and question number eighteen (18) “I can easily find community resources to assist me in caring for my loved one”, appear to utilize available services, and state they can easily access resources. Due to these statements, the researchers hypothesized that there would be a less participants that cared whether or not the person or persons who provided the services were of the same ethnic background of the recipient. The relationships between these questions approaches significance, but did not score highly enough to be considered significant.

Lastly, the researcher’s assumed those who agreed with question number nine (9) “I find classes on caring for myself useful”. Would also agree with question number sixteen (16) “I can tell when I am becoming overwhelmed or frustrated”. The logic being, those who participate in classes on self-care would learn the signs of stress and be prepared to implement coping strategies before becoming frustrated or overwhelmed. These questions were compared using bi-variant correlation analysis; results indicated no significant relationship was found.
Table 19

*Summary Table of Correlation of the Variables*

<table>
<thead>
<tr>
<th>Variables</th>
<th>Pearson's Correlation, p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participation in support groups/Class/Participation in support groups useful</td>
<td>.21</td>
</tr>
<tr>
<td>Participation in support groups/Support/Participation in support groups useful</td>
<td>.71</td>
</tr>
<tr>
<td>Ethnicity of respite worker does not matter as long as they are qualified/ Ethnicity of respite worker does not matter/Use of respite in home aid</td>
<td>.37</td>
</tr>
<tr>
<td>I can tell when I'm becoming overwhelmed/I can tell when I'm becoming overwhelmed or frustrated/Class for caring for myself useful</td>
<td>.25</td>
</tr>
</tbody>
</table>

**Summary**

This chapter looked at the perceived usefulness of particular interventions, including respite care, psychosocial education and perceived social support. The proceeding chapter will provide further interpretation of the data collected and implications for future research will be discussed.
Chapter 5

CONCLUSION, SUMMARY, AND RECOMMENDATIONS

This chapter focuses on summarizing the purpose of this study. It will discuss themes that emerged from the analyzed data in relation to the research discussed in Chapter 2, review of the literature. The implication for social work is presented in the second section. The third section focuses on recommendations. The limitations of the study are highlighted in the fourth section of this chapter followed by the conclusion.

Summary of Study

The study conducted was brought forth out of combined interest in the population group and the stressors associated with working in the field. The data collected from the study, and the literature reviewed, suggest that families experience a great deal of commonality in feelings when it comes to caring for those who are diagnosed with Alzheimers/Dementia. The degree to which these stressors are experienced can have an impact on their perceived need and ability to maintain the highest quality of life possible. The literature reviewed and data collected suggest that good coping skills and adequate support system can lessen the burden and impact that this responsibility can have on the family.

Implications for Social Work

The data collected from this study, and the literature reviewed, suggest that caregivers experience a great deal of commonality in feelings, reactions and experiences as a result of caring for someone suffering from Alzheimer’s or Dementia. The literature reviewed and the data collected suggest that good coping skills and an adequate support
system through mutual aid can lessen the negative impact that care-giving has on an identified caregiver. This implies that caregivers must adapt to new settings and coping strategies in order to manage role differential, time management, and psychological, physiological stressors commonly faced. The support networks offered by the community must also be easily accessible as well as advertised and communicated to this population group through social awareness in order to utilize all that insurance and finances will pay for.

This study can be used by Social Workers and other professionals in related fields as the basis for similar research in which the subjects of case studies such as this will be identified caregivers of those suffering from Alzheimer’s/Dementia in effort to meet the needs of a growing marginalized population. Although the researchers in this study did not account for demographics of this study group, the information regarding correlation between perceived need and identified support as well as preference on ethnicity of caregiver support could positively influence client centered approaches in the future.

**Recommendations**

As the aging population is growing in the U.S, due to the rise of the baby boomers; so must the awareness of client specific obstacles and stressors. The disease of Alzheimer’s/Dementia will affect a greater number of our population while adversely impacting those who provide direct care for these individuals. The Social Worker involved in these cases may be introduced into the family at different stages of this disease process and be involved for varied lengths of time. It is recommended that the social worker become informed and competent regarding the disease process and its
characterized behaviors associated with the disease. It is also recommended that the
social worker educate themselves regarding the impact this disease process can have on
the family system including role differentiation and psychosocial influence. This
knowledge will play a key role in treatment plans and determining appropriate
interventions for both the caregiver and the person suffering from the disease.

This study supported the premise that families need information through
psychosocial education to assist in lessoning fears and uncertainties that often accompany
the varying stages of the disease as well as its permanence. Legal and financial assistance
can be provided through the aid of the social worker while encouraging independence
through solution focused interventions and empowerment. Assisting caregivers with
effective coping skills through cognitive behavioral therapy treatments will also assist in
positively reframing client’s meaning of care-giving and the stressors associated with the
task.

Community resource referrals and appropriate linkage to the assistance programs
in the community can positively influence a person’s ability to overcome the stressors
that inhibiting them from achieving positive outcomes. Upon assessing the family
system, the caregiver is also assisting in developing a repertoire of coping skills that are
unique to the caregiver’s particular style and needs. In so doing, it is hoped that the
caregiver will develop the necessary confidence to enhance his/her ability to cope with
these psychosocial stressors.
Limitations

This study primarily conveyed the message of perceived need and its correlation to the noted burden and noted stress. This study acknowledged the impact of role differentiation and care-giving as it directly relates to quality of life of the caregiver. The limitation specifically associated with this study is the lack of demographics that are associated with the survey participants. The researchers believe that gender plays a role in identified stressors. For example, women, more so than men, are labeled as caregivers from a socioeconomic standpoint. It is most often expected that women, not men, will be the caregiver for those around them. It would have been interesting to see what the responses could have been for women as compared to men.

Cultural awareness also comes into play when discussing the aging population. If the surveyors included this in the demographics of their survey, it would have established that there are cultural differences in addressing Alzheimer's/Dementia.

Conclusion

In chapter one the researchers examined the needs of caregivers who are caring for someone with dementia. Chapter two examined the current literature focusing on studies that were conducted with demented consumers and their caregivers. In chapter three, the researchers distributed questionnaires rating caregivers perceptions of the usefulness of services offered. No significance was found in chapter four, after analyzing the data pulled from the questionnaires and entered into SPSS. The findings do suggest a need for further research and creation of services that are tailored to the unique and individual needs of consumers and caregivers.
Appendix A

Caregiver Perceived Support Scale

Please indicate how strongly you agree with the following statements by circling the number that best describes how much you agree with the following statements.
1= strongly disagree, 2 =somewhat disagree, 3 =neutral, 4= agree 5= strongly agree

1. I find respite care in my home useful 1 2 3 4 5
2. I find respite care outside of my home useful 1 2 3 4 5
3. The ethnicity of the respite worker does not matter to me as long as they are qualified 1 2 3 4 5
4. I would prefer a respite worker of my own ethnicity and culture 1 2 3 4 5
5. I find participating in support groups with other caregivers useful 1 2 3 4 5
6. I find educational classes on dementia useful 1 2 3 4 5
7. I find written information about dementia useful 1 2 3 4 5
8. I find classes on caring for my loved one with dementia useful 1 2 3 4 5
9. I find classes on caring for myself useful 1 2 3 4 5
10. I find in home aids helpful 1 2 3 4 5
11. I find in home aids useful if they follow my directions 1 2 3 4 5
12. I feel I have adequate family support 1 2 3 4 5
13. I would like my other family members to help me more 1 2 3 4 5
14. I have at least 3 people I can call if I need a break from care-giving 1 2 3 4 5
15. I have friends who are there for me 1 2 3 4 5
16. I can tell when I am becoming overwhelmed or frustrated 1 2 3 4 5
17. I would like to learn how to recognize when I am becoming overwhelmed 1 2 3 4 5
18. I can easily find community resources to assist me in caring for my loved one. 1 2 3 4 5
Appendix B

Informed Consent Form

Date:

**Study Title or Topic:** Caregiver support systems

**Researcher:** Carolyn Kluenker and Rajeeyah Fultz, MSW candidates, Graduate Program in Social Work, California State University of Sacramento

**Purpose of the Research:** To determine effectiveness of local support systems

**What You Will Be Asked to do in the Research:** Participate in survey

**Risks and Discomforts:** I do not foresee any risks or discomfort from your participation in the research.

**Benefits of the Research and Benefits to You:** You will receive a chance at the grand prize drawing for a $50.00 Visa gift card

**Voluntary Participation:** Your participation in the study is completely voluntary and you may refuse to answer any question or choose to stop participating at any time. Your decision not to volunteer will not influence the treatment you may be receiving, nature of the ongoing relationship you may have with the researcher, or the nature of your relationship with Westview Healthcare Center either now, or in the future.

**Withdrawal from the Study:** You can stop participating in the study at any time, for any reason, if you so decide. If you decide to stop participating, you will still be eligible to receive the promised pay for agreeing to be in the project. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with the researcher or Westview Healthcare Center. Should you decide to withdraw from the study all data generated as a consequence of your participation will be destroyed.

**Confidentiality:** Unless you choose otherwise, all information you supply during the research will be held in confidence and, unless you specifically indicate your consent, your name will not appear in any report or publication of the research. Your data will be safely stored in a locked facility and only the researcher and thesis advisor will have access to this information. Confidentiality will be provided to the fullest extent possible by law.

**Questions about the Research:** If you have questions about the research in general or about your role in the study, please feel free to contact Carolyn Kluenker or Rajeeyah Fultz MA candidates in Social Work, at the Division of Social Work, 6000 J St. Sacramento Ca 95815 or by e-mail swrk239@gmail.com This research has been reviewed and approved for compliance with research ethics protocols by the California State University Sacramento Human Participants Review Committee. If you have any questions about this process, or about your rights as a participant in the study, please contact Dave Russell, Thesis Advisor at drussell@csus.edu or by phone at 916-278-7170.
Legal Rights and Signatures:

I ___________________________ consent to participate in the Caregiver Support Systems study conducted by Carolyn Kluenker and Rajeeyah Fultz. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

Signature ___________________________ Date ___________________________
Participant
Appendix C

Human Subjects Review Approval Letter

To: Rajeeyah Fultz & Carolyn Kluenker

From: Committee for the Protection of Human Subjects

RE: YOUR RECENT HUMAN SUBJECTS APPLICATION

We are writing on behalf of the Committee for the Protection of Human Subjects from the Division of Social Work. Your proposed study, "Perceived Needs of Caregivers."

-X approved as -X EXEMPT ___ MINIMAL RISK ___

Your human subjects approval number is: 12-13-038. Please use this number in all official correspondence and written materials relative to your study. Your approval expires one year from this date. Approval carries with it that you will inform the Committee promptly should an adverse reaction occur, and that you will make no modification in the protocol without prior approval of the Committee.

The committee wishes you the best in your research.

Professors: Maria Dinis, Jude Antonyappan, Teiahsha Bankhead, Serge Lee, Kisun Nam, Maura O’Keefe, Dale Russell, Francis Yuen

Cc: Russell
References


