EVIDENCED BASED SUPPORT SERVICES FOR INFORMAL CAREGIVERS OF INDIVIDUALS WITH DEMENTIA IN THE UNITED STATES, INDIA, AND NEPAL

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A Thesis

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ABSTRACT

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The world is graying rapidly due to increased life expectancy. Because people are living longer, they are facing a number of health issues. Dementia is one of the leading health problems that are affecting numerous older persons around the globe. It is expected that the number of people living with dementia will double every 20 years. Dementia is a progressive disorder that demands assistance and support for most activities of daily living. Caregivers (usually family members) are taking care of persons with dementia and this is a demanding task. Caregivers often suffer from physical, emotional, social, and financial problems as a result of caregiving. Services, programs, and interventions are essential to support caregivers in order to improve both their physical and psychological well-being. The primary purpose of this study was to investigate the different support services that are available in the United States, India, and Nepal. This study also compared support services/programs to determine the best type of programs for developing countries such as India and Nepal. For this study, articles that met specific criteria were reviewed. All of these articles described evidenced-based programs that were beneficial in improving caregivers' experience including measures of caregiver's bother, burden, depression, and negative health.

This study also revealed that there is a treatment gap for individuals with dementia in India, and Nepal. Due to the lack of resources and inadequate infrastructure, dementia is still stigmatized in most parts of these countries. There are very limited services both for the person with dementia and their caregivers. This was especially evident in Nepal, where the number of individuals with dementia is not proportionate with the number of trained health professionals.
Additionally, the government is not taking any specific steps that would benefit people with dementia and their caregivers. This study concludes with recommendations for services and interventions that were found to be effective for caregivers and would be culturally acceptable and affordable in both India and Nepal.
DEDICATION

To my mother,
Janaki Hamal

Thank you seems very little when it comes to you. Although it was not easy for you, you constantly encouraged me to pursue my dream. I will always embrace the values and morals you taught me. You were and always will be my source of inspiration. I love you and miss you.
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CHAPTER I. INTRODUCTION

Dementia, also known as "neurocognitive disorder" is a chronic and progressive neurodegenerative syndrome characterized by deterioration in intellectual and social functioning that requires medical, social, and/or mental health interventions at different points of life (Jha & Sapkota, 2013). Dementia is not a disease itself but a group of symptoms that are caused by other diseases or conditions. Dementia is a global issue. The number of older persons (i.e. age 65 years and older) is increasing worldwide and dementia is becoming an increasingly challenging global public health problem (Gallagher-Thompson et al., 2012). Dementia is associated with a progressive loss of memory and it also affects language, judgment, and the planning abilities of an individual and leads to impairment in activities of daily living, and social interaction (Das, Pal, & Ghosal, 2012). It is the most common cause of cognitive impairment in older adults (Skinner, 2009). Not only does dementia impact the personal, familial, and social life of the affected person, but also loved ones who care for a person with dementia are affected. The costs related to dementia (e.g. health care) also imposes severe financial burdens on the nation and caregivers especially when caregivers must reduce the number of paid hours that they can work to provide care. In the United States, the health care expenditures for dementia care are expected to reach $1.1 trillion by 2050 (Mitchell et al., 2012). Although prescribed medication may reduce the symptoms of dementia, there is no known cure and the duration of the illness can extend up to 20 years, with averages of 8 to 10 years (Lee & Casado, 2011). It is an overwhelming condition not only for the affected person but also for family members, friends, and relatives. There is substantial increase in care needs as the disease progresses (Lee & Casado, 2011).
Prevalence of Dementia

Dementia affects mostly the older adult population (Shaji, George, Prince, & Jacob, 2009). At the present time, 13% of people aged 65 years and older, and 43% of those 85 years and older in the United States have been diagnosed with Alzheimer's disease (Ambrose, 2013). Also, in the United States, it is the fourth leading cause of death. It is estimated that approximately 5.1 million Americans currently have Alzheimer's disease, and worldwide, it is estimated that 30 million persons have some form of dementia. This number is expected to rise to over 100 million by 2050 because of increases in life expectancy (Ghatak, 2011). Due to increases in life expectancy and declines in fertility, it is also expected that the majority of older people will be living in Asian countries in the 21st century (Wai-Chi Chan, 2011). The rate of growth of individuals living with dementia will be the highest in India, China, South Asia, and western Pacific regions and lowest in the developed regions (Das, Pal, & Ghosal, 2012). The World Health Organization's (WHO) report highlighted the serious consequences of dementia in developing countries (Jha & Sapkota, 2013). However, countries like India and Nepal lack good longitudinal studies that document the incidence of dementia, making it more complex to identify the true trend of the disease. In India the prevalence of dementia is 0.8-3.5% of the total population (1.27 billion) (Brijnath & Manderson, 2011), and in Nepal there may be 135,000 people (out of 26.6 million people) living with dementia (Jha & Sapkota, 2013). As there is little awareness about the disease and its consequences for both patients and caregivers, coupled with an absence of supportive health and welfare services in developing countries, the societal burdens of dementia is substantial and increasing (Subedi, Tausig, Subedi, Broughton, & Williams-Blangero, 2004).
Caregiver Burden

Caregiver burden is defined as “a multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual” (Kim, Chang, Rose, & Kim, 2012, p. 846). Caregiver burden threatens the physical, psychological, emotional, social, and functional health of caregivers (Kim et al., 2012). Worldwide, family members are the major source of care providers for persons with dementia. In the U.S. among non-institutionalized persons who need assistance with activities of daily living, two out of three depend solely on family and friends, and only 25% supplement family care with services from paid providers (Santo, Scharlach, Nielsen, & Fox, 2007). The progressive declining nature of dementia presents challenges for both the patient and caregivers. Caregivers of persons with dementia have to provide care not only related to physical health conditions and functional impairments, but they must also deal with symptoms related to dementia (e.g., compromised memory, judgment, orientation, communication), as well as problematic behaviors (e.g., wandering, incontinence, agitation, sleeplessness) (Li, 2012). When compared to caregivers of individuals without dementia, caregivers of person with dementia provide more assistance, report higher levels of caregiving stress, and experience more negative impacts on their families, jobs, and leisure activities (Li, 2012). The prevalence of depressive symptoms among caregivers is found to be high in virtually many published studies. Depending upon the methodology and measures used, the incidence of depression has been reported to average 30% to 50% (Gallagher-Thompson et al., 2012). Deterioration in behavioral health and loss of memory is common as dementia progresses. It has been reported that caregivers of people with dementia spend an average of 1.6 hours daily assisting with personal care and a total of 3.7 hours assisting with instrumental activities of daily living (e.g., cooking, driving, shopping). These hours may increase to 7.4
hours per day if supervising time is included (Prince et al, 2012). In the United States, one in five persons is an informal caregiver and 79% of these caregivers are caring for someone aged 50 or older (Giunta, 2010). Caregivers of persons with dementia frequently suffer from depression, exhibit maladaptive coping strategies, and express concern about their poor quality of life (Kim et. al, 2012). Because of the lack of awareness or availability of professionally provided services, much of the growing burden of care will have to be absorbed by family and other informal systems of caregiving (Monahan, 1994). In the U.S. about 80% of adults requiring long term care live at home or in the community, and unpaid family caregivers provide 90% of their care (Collins, & Swartz, 2011).

The same system of familial caregiving is common in developing countries. In the developing regions of the world, almost all persons with dementia are cared for by family members within the home, and this situation is unlikely to change in the near future as institutional care is neither affordable nor culturally acceptable (Shaji, George, Prince, & Jacob, 2009). Additionally, due to widely accepted notions of the family as being endlessly capable and supportive caregivers, governments of developing nations continue to accord a low priority to the needs of older people and their caregivers (Shaji, Smitha, Lal, & Prince, 2003). There are very few support programs for older adults and their caregivers in these countries, and awareness about dementia is limited both in the general community and among health care professionals. One of the possible reasons for limited services is that dementia is often perceived as being part of the "normal aging process," and family members rarely utilize health care services (Dias et al., 2008). Because of this, family members of a person with dementia are compelled to provide continuous supervision and meet all the caregiving needs and demands, which is actually
making them vulnerable to depression, poor health, and decreased or (non-existent) social engagement.

Purpose of the Study

The purpose of the study was to compare the evidenced-based support services/interventions for caregivers of people with dementia that are available in the United States, India, and Nepal. It was the goal to provide recommendations about support services that would address the unmet needs of caregivers in Nepal.

Definition of Terms

The following terms are used in this study,

*Dementia*: serious loss of cognitive ability, that influences overall functioning of an individual (Das, Pal, & Ghosal, 2012).

*Alzheimer's Disease*: the most common form of dementia.

*Informal caregivers*: family member, friend, unpaid caregiver, neighbor, or any person who provides care and assistance to a person with disability.

*Evidence-based support services*: programs that are effective in promoting health, which are supported by some scientific evidence. It involves identifying, assessing, and implementing services and strategies that are found to be effective in various outcome measures.

*Adult-Day Care(ADC)*: provides care and companionship for adults who need assistance and supervision during the day. It also supports the health, nutrition, daily living needs, and social support of the adults.

*Community-based Services*: provides services related to health, nutrition, and activities in a community setting.
Partners with Dementia Care (PDC): a care coordination program that integrates and provides to medical and non-medical services, while providing information, coaching, and emotional support (Bass et al., 2013).

Consumer-Directed Services: provides individuals with freedom and independence to choose the person or services to meet their needs (Masters, 2006).

Psychoeducation: a therapeutic approach that may include education and various activities to improve the health with a cognitive impairment person.

Role Training: a training programs that provides information, linkage, and role coaching to participants (Hepburn, Tornatore, Center, & Ostwald, 2001).

Care Condition (ICC): a comprehensive program that enhances caregivers' skills so that they may cope with the stress of caregiving by providing relaxation training, strategies to increase everyday pleasant activities, cognitive restructuring, improvement in communication skills, and counseling. (Kajiyama, 2013).

Education/Information Only Condition (EOC): a condition, where education/information regarding dementia and caregiving is provided.

Multicomponent Intervention: combination of various interventions such as home services, individualized care, assessment, education, training, and information.

Polarity Therapy: provides gentle pressure on energy points of the participants (Korn et al., 2009).

Enhanced Respite Control Condition (ERC): provides respite care for the person with dementia and a choice of activities for the caregiver (Korn et al., 2009).
General Health Questionnaire (GHQ): a questionnaire to assess general well-being and distress.

Person with Dementia (PWD): person suffering from dementia.

Project CARE: a multicomponent group intervention for caregivers of people with dementia.

Neuropsychiatric Symptoms: behavioral and psychological signs and symptoms of dementia (e.g., mood disorder, anxiety, aggression, sleep disturbances, inappropriate behaviors).

Resources for Enhancing Alzheimer's Caregivers' Health (REACH): a multi-component intervention that provides individualized assessment of caregiver needs (Elliott, Burgio, & DeCoster., 2010).

Activities of Daily Living (ADLs): routine activities that people perform everyday (e.g., eating, bathing, dressing, toileting).

Instrumental Activities of daily Living (IADLs): activities that require certain amount of physical strength, planning, and organizational skills (e.g., cooking, shopping, housekeeping, financial management).
Dementia

Dementia is the most degenerative neurologic disorder of the brain. It is usually found in persons age 65 and older and is the most common cause of cognitive impairment in older adults. It is a progressive condition, which not only causes physical limitations, but also affects memory, perception, thought, reasoning, and speech. It is not a disease itself, but a group of symptoms that are caused by other diseases or conditions. Dementia develops when the parts of the brain associated with cognitive functioning are impaired which can be caused by diseases (Alzheimer's disease, Parkinson's disease) that results in degeneration or loss of nerve cells in the brain or due to metabolic causes (endocrine disorders, heavy metal exposure). It can affect the ability to perform previous familiar tasks, to remember recent events, and to learn new skills. In other words, persons affected with dementia progressively lose their autonomy. A person with dementia lives an average of eight years after onset, but some individuals with dementia can live for twenty years or more from the onset of symptoms (Skinner, 2009). In most cases, dementia is not treatable. However, dementia with treatable causes such as metabolic abnormalities, infections, nutritional deficiencies, emotional problems can be cured if diagnosed correctly. Dementia in general accounts for 4.1 % and 40 % of total disease burden among people aged 65 years and 85 years and older respectively (Mitchell et al., 2012). It was estimated that approximately 35.6 million people were affected with dementia in 2010 and numbers are expected to double every twenty years (Jha & Sapkota, 2013).
Global Aging

Around the world, many older adults progressively lose their autonomy and become dependent on others due to chronic age-related illnesses. One of the most common is dementia and dementia continues to be one of the major health problems (Morrow-Howell & Mui, 2013). Although it is primarily associated with aging, because of its devastating impact on family members, its effects are truly intergenerational (Cox, 1999). Globally, the world's population is aging rapidly with estimates of one in five people over 65 years of age by 2030. In the year 2030, there will be more older adults over the age of 60 than children under the age of 15 (Morrow-Howell & Mui, 2013). In many developed countries (e.g. Japan, United States, United Kingdom), life expectancy is now approaching 80 years and it is expected to slowly increase. Fertility rates are decreasing in most countries around the world, and it is estimated that the global fertility rate will drop below the global replacement rate for the first time by 2020 (Morrow-Howell & Mui, 2013). Globally, oldest old (80 years of age and above) are the fastest growing segment of the population. This changing trend is creating tremendous challenges in society, and it will lead to increased health care costs and economic burdens. Similarly, the number of persons afflicted with dementia is expected to increase, and this will ultimately increase the demand for caregiving. (Mitchell et al., 2012). Dementia is quickly becoming the chronic disease of the 21st century with an ever-growing aging population. The impending social and economic impact from dementia is immeasurable.

Caregiving

Currently, the provision of care to persons with dementia is taking place within the home and/or community setting rather than in institutional settings. Family members are expected to
assume the responsibility of providing care to the affected person and within almost every
country family members are providing care to the majority of persons affected with dementia.
Approximately 80% of care is provided by family members to the person with dementia,
however, the amount of care and time spent providing care may differ depending upon the
severity of dementia (Bekhet, 2013). Providing care to the person with dementia can be
extremely stressful, challenging, and time-consuming. Although family members may assume
the responsibility of caring for the person with dementia willingly and may find it to be a great
source of satisfaction, eventually, they may find it more difficult to manage and may experience
emotional and physical stress (Feinberg & Newman, 2006).

Caregiving Trends in the United States

Similar to other countries, American families also provide the bulk of the care and this
care is often based on social norms, psychological preferences, and economic capacity of the
older population. Society expects adult children to assume the responsibility of their older
parents. Additionally, economic capacity of older adults determine whether the care should be
provided by family members or by formal caregivers. Due to greater longevity of the general
population, family members today provide more care to older adults for longer periods of time
than ever before in U.S. history (Singer, Biegel, & Ethridge, 2010). Approximately, 30% of the
U.S. adult population provides care to old, frail or disabled persons (Morrow-Howell & Mui,
2013). Women can be expected to spend more years caring for older parents than rearing their
own children (Morrow-Howell & Mui, 2013). In the U.S., most caregivers are spouses,
daughters, and daughters-in-law. Because of the increased cost of institutionalization, there is
transfer of caregiving of older adults from public health services to unpaid family members, in
which family members will be absorbing greater eldercare demands. The increased graying of
the older population will increase the number of persons with dementia as dementia affects mostly older adults and eventually increase the number of informal caregivers and caring for persons with dementia will be a major public health problem. More than five million Americans have dementia and by 2050 this number is expected to reach 13 million (Mitchell et al., 2012). Also, in 2009, it was the sixth-leading cause of death, however, this ranking is expected to increase every year. In 2011, the health care expenditures for dementia were $183 billion and are projected to reach to $1.1 trillion by 2050 (Mitchell et al., 2012). Almost all people with dementia are cared for by their family members, friends, or relatives, at least in the earlier stages of dementia. It is reported that seven out of ten persons with dementia live at home and 75% of the care they receive is provided by family members, friends, or relatives and the duration of caregiving can cover as long as 20 or 30 years (Tompkins & Bell, 2009). However, the length, amount, and intensity of care amongst caregivers may vary depending upon the severity of dementia. Caregiving to the person with dementia may lead to substantial physical, psychological, and social costs to caregivers. The majority of caregivers experience high levels of stress and many report poor health. Many caregivers have reduced their work hours or have taken a leave of absence while providing care (Singer, Biegel, & Ethridge, 2010). As the disease progresses, caring for the person with dementia usually becomes more difficult and persons with dementia require constant supervision and assistance with routine activities.

It is well documented in the literature that caregivers of person with dementia experience heavy burden and depression than caregivers of other chronic illnesses. This burden and depression require health services for the caregivers (Hepburn et al., 2005). There is lack of health services as compared to the increasing number of persons with dementia (Liebig, Koenig, & Pynoos, 2006). In order to provide effective care to the person with dementia, caregivers
should first be in a good state of health physically, mentally, socially, and financially. Various interventions and services such as respite care, day care centers, education, and training are found to be effective in alleviating caregivers' burden and improving their overall well-being. Effective services not only reduce caregivers' burden but also provide various coping skills (Lahaie, Earle, & Heymann, 2013). It is essential to address the needs of caregivers who are providing care to persons with dementia, so that both the affected person and caregivers can have positive health and well-being.

Caregiving Trends in India

Within the culture of India, people are expected to live in a joint family and traditionally, the next generation family members assume the responsibilities of caring for older adults (Dias et al., 2008). However, due to urbanization and migration, family dynamics have become disrupted and as a result, older adults are left alone with little or no support from family members (Dias et al., 2008). Additionally, demographic changes such as increased life expectancy and decreased fertility rates are leading to negative influence such as loneliness, depression, stress, and lack of social support among older adults (Prince et al., 2012). In India, primarily children are the caregivers. Sons are especially expected to take care of their parents. However, due to demographic transitions and modernization, the majority (70%) of caregivers are women and are mostly wives, daughters and daughter-in-laws (Dias, Samuel, Patel, Prince, Parameshwaran, & Krishnamoorthy, 2004). Due to culture and tradition, family members are obligated to take care of old, frail, and disabled persons in the family. The World Health Organization has estimated that the aging population is dramatically increasing in developing countries, and dementia is becoming an epidemic among older generation (Das, Pal, & Ghosal, 2012). Because of the increasing aging population, the burden of dementia is expected to rise in India, and persons with
dementia are also expected to receive care from their family members. Unfortunately, there is a lack of awareness about dementia among the general Indian population as well as among health care professionals (Shaji, Smitha, Lal, & Prince, 2003). Systematic awareness about dementia is very limited (Shaji, Smitha, Lal, & Prince, 2003). Because of poor awareness there is poor recognition of dementia, which then delays the diagnosis of dementia. Dementia is still stigmatized and often considered "a normal part of aging," and thus, it is often neglected by most family members. There is need to estimate the burden of dementia in the community, identify risk and protective factors for dementia, and plan and develop measures and services to provide social benefits to the affected person and their caregivers. Awareness about dementia is lacking among general physicians, para-medical professionals, and the public (Das, Pal, & Ghosal, 2012). Accurate trends of the disease cannot be determined because there is a general lack of studies in this field and a scarcity of basic and clinical research on dementia (Shaji, Smitha, Lal, & Prince, 2003).

In India, most of the older adults with dementia remain unidentified, thus, they do not receive a proper diagnosis and they often have no access to treatment and/or services due to the lack of adequate health services. There remains little help from health care services sectors to person with dementia and their caregivers. There is also a huge treatment gap for persons with dementia and there is limited services for sufferers and their caregivers. Therefore, caregivers have to take full responsibility to look after the affected person. Also, due to tradition, long-term facilities and day-care centers are not well accepted by both the person with dementia and his/her family members. With limited knowledge and skills, lack of resources, and increasing needs and demands of persons with dementia, caregivers are facing tremendous burdens related to caregiving. They lack needed information, and most of them do not know where to seek help
when problems arise. Caregivers in India are experiencing strain primarily due to behavioral and psychological symptoms of dementia and resultant incontinence (Das, Pal, & Ghosal, 2012). Their burden is exacerbated when there is little or no emotional and financial support from other family members, relatives, and friends. Because caregivers have to assume multiple roles, the majority of the caregivers experience burden, depression, loneliness, anxiety, anger, and physical symptoms (Dias, Samuel, Patel, Prince, Parameshwaran, & Krishnamoorthy, 2004). They literally have no time for their personal activities or life as they have to provide round-the-clock supervision.

Caregiving Trends in Nepal

In Nepal, generally older adults depend upon their children, particularly sons, for support and security in their old age (Chalise & Brightman, 2006). A 2010 status report on elderly people in Nepal showed that more than 80% of older adults are living with their children. Culturally, sons are expected to take the full responsibilities of their parents. The study further showed that unlike Western countries where daughters, married or not, usually provide care for their parents, only 2.7% of the older adults in Nepal are living with their married daughters because of cultural taboos that prevent parents from living with their married daughters (Chalise, 2006). Advancement in medical technology and improvements in public health have increased the life expectancy in Nepal from 57 years to 65 for males and 62 years for females (Shrestha & Dahal, 2007). Because of which the number of older adults is increasing and thus, there is more pressure on society to be prepared for this change. According to the 2001 census report, Nepal's older adult population constitutes 6.5% of the total population of the country and during the years 1991-2001, the annual older adult population growth rate was 3.39% as compared to the national population growth rate of 2.3%. Population growth rate is 2.3% whereas economic growth rate is
Due to changes in social structure, the historical practices of providing care to older adults, the living arrangements with joint family, and familial responsibilities towards older adults are being affected, which is in turn affecting the living conditions of older adults. Lack of higher education and employment opportunities in the rural areas have led to an outflow of young adults to urban areas and to foreign countries. According to the United Nation Population Division (Geriatric Center Nepal, 2009), over 1200 young people leave their homes each day for education and career goal purposes. This in turn leaves older adults behind. Changes in sociological conditions (e.g., the absence of children or changes in attitudes of children after they get married and start a family in a new social environment) are also putting older adults at risk for isolation, loneliness, depression, and financial burden. Until recently, the Nepali traditions and values ensured care for their older members. But now, the nuclear family is replacing the traditional multi-generational family structure. This shift leads to potential isolation among older adults (Pun, Pandey, Pokhrel, & Subedi, 2009). The expected reciprocity by older adults during their old age is decreasing as they are receiving less support from their children (Chalise & Brightman, 2006). Records suggest that the main cause of the increase in population aging in Asian countries is due to declines in fertility and increases in life expectancy rather than decreases in mortality. As a result, the older adult population in the future will increase at an even quicker rate.

Social, economic, and demographic developments have all caused changes at the individual, familial and societal levels, all of which influence the lives of older populations (Shrestha & Dahal, 2007). There is evidence that Nepalese individuals are dissatisfied when they live apart from their children (Status reports on elderly people in Nepal, 2010). However, many older (approximately 60%) adults in Nepal are fortunate to continue to live with their adult
children (Status reports on elderly people in Nepal, 2010). Particularly in Nepal, the availability of care and support from a spouse or child is essential to the well-being of older adults. There are adults who are taking care of their parents and taking on these responsibilities. As older adults are living longer, caregiving demands are also increasing. Many older adults are suffering from dementia and family members are facing multiple challenges associated with caregiving. Additionally, many family members do not know that they are caring for the person affected with dementia as it is often considered "a normal part of aging" (Jha & Sapkota, 2013). The burden of caregiving is related to the provision of constant supervision, the increasing needs of persons with dementia, lack of knowledge and skills, little or no support from other family members and friends, and very limited services for persons with dementia and their family members all are adding to the stress and burden of caregivers (Jha & Sapkota, 2013). There is poor awareness about dementia and its associated problems both on the local and national level. Additionally, there is no epidemiological survey for dementia and no evidenced-based services of continuing care and support for people diagnosed with dementia and their caregivers. The government is seeking to address the needs of older adults using a welfare approach, in which diagnostic service and basic education and information about dementia is provided to those seeking help at secondary care and teaching hospitals. Broader issues of population aging such as dementia are not among the major priorities for policy development by the government at this time, despite projections of a significant increase in the percentage of older adults within the next 40 years (Geriatric Center Nepal, 2010). The financial, technical, and human resources are not sufficient to provide high quality analytical information to support evidence-based policy development (Chalise, 2006).

Experience of Caregivers of Persons with Dementia
Caregivers of persons with dementia experience burden and stress associated with caregiving, which is well documented in the literature (Hepburn, Lewis, Narayan, Center, Tornatore, Bremer, & Kirk, 2005). It is painful to watch someone slowly deteriorate. Providing care to the person with dementia can be very costly to caregivers' health. As the disease progresses, there are increasing demands for assistance and constant supervision, which can become overwhelming. Caregivers frequently report depression, anger, chronic fatigue, burden, poor self-rated health, and physical and financial problems (Cox, 1999). Approximately 50% of caregivers of persons with dementia are found to suffer from depression (Skinner, 2009). It is also reported that depression in caregivers may also lead to depression in the persons with dementia. Factors such as problem behavior and increased needs of persons with dementia, lack of knowledge and skills related to caregiving, lack of support from family and friends, family disharmony, social isolation, burden and stress associated with caregiving, compromised personal and professional life may lead to depression among caregivers (Nichols, Martindale-Adams, Greene Burns Graney, & Lummus, 2009).

Caregivers of persons with dementia face not only the problems of meeting multiple physical demands of the affected person but also economic and psychosocial stressors as they experience financial problems and heavy burden associated with caregiving. In addition, caregivers may become physically and mentally exhausted because of providing total care to the person with dementia. Caregivers may experience reduced self-care and health risk behaviors such as poor diet, inadequate rest and sleep, and decreased exercise. These may lead to negative health outcomes such as depression and stress associated with caregiving. It is also reported that caregivers of persons with dementia visit health professionals frequently, use more medications, and have more health problems than other people of their same age. Because of the disruption of family routines, structure and
dynamics of family, many caregivers become isolated from their family and friends (Eisdorfer, Czaja, Loewenstein, Rubert, Arguelles, Mitrani, & Szapocznik, 2003). Additionally, the majority of caregivers must make work related adjustments in order to meet the needs and demands of care recipients.

Caregivers of persons with dementia assume heavy burdens when they provide the necessary care and support. Compared to caregivers of individuals without dementia, the type of care and support provided by caregivers of persons with dementia are more physically and emotionally challenging, which eventually disrupts work, family, and social life as they have to sacrifice their personal and professional life in order to provide care (Wilks & Croom, 2008). Due to caregiving obligations, the majority of employed caregivers report missed work time and many experience financial hardships. It has been reported that on a five-point scale, where five is the highest score of stress, approximately 41% of caregivers of person with dementia rate their emotional stress at least a four when compared to 31% of all other caregivers (Wilks & Croom, 2008). Caregiver stress has become a gerontological concern because caregiving is an age-related issue because many caregivers are also older adults. It is estimated that over half of the caregivers of person with dementia are 50 years of age and older and 14% of caregivers are above the age of 65 (Giunta, 2010). Therefore, the older the caregivers, the likelihood is that they too will experience poorer physical and mental health and as a result, this can lead to poor quality of care for the person with dementia.
Support Services Available in the United States, India, and Nepal

Although, family members are the major source of care providers all over the world, social services agencies, nursing homes, and government programs especially in the United States are contributing to a large extent to help persons with dementia and their caregivers. There are various services available in the United States, India, and Nepal that are working to promote health and reduce burden of caregivers of persons with dementia. Even though these services/interventions may or may not be evidenced based, these services/interventions are developed specifically for caregivers of persons with dementia to meet their needs and demands associated with caregiving. Services/interventions designed to support caregivers can prevent and decrease symptoms of depression, stress, burden, and other physical or mental health problems experienced by caregivers of persons with dementia (Giunta, 2010). Additionally, utilization of support services by caregivers increases their caregiving hours and delays institutionalization of a person with dementia (Gaugler, Kane, Kane, & Newcomer, 2005). So, it is essential to make people aware about the services that are available in their own community. Brief descriptions of each of these services/interventions are provided below:

National Family Support Program

National Family Support Program works in partnership with Area Agencies on Aging and local community service providers. This program is funded by Older American Act. This program provides information, assistance to caregivers in accessing services, individualized counseling, group support, caregiver training to improve coping skills, respite care, and supplemental services (Giunta, 2010).
In-Home Care Services

In-home respite care service provides respite to caregivers and allows people with dementia to stay in their own homes. Services may range from personal care (bathing, dressing, toileting), companion services (supervision, visiting), homemaker or maid services (housekeeping, shopping), to skilled care services to help with medical services and other medical needs.

Adult day centers

Adult day centers provide a safe environment for persons with dementia and respite services for caregivers. Various activities such as nutrition, health services, therapy, counseling, transportation, art programs, and social interaction are delivered through these centers. Adult day services may be very beneficial for full-time caregivers, caregivers with a day-time job, and for the person with dementia because they provide opportunities to be social and active.

Residential Facilities

Residential facilities provide caregivers an extended break or vacation by providing options to the person with dementia to stay overnight, a few days, or a few weeks in a supervised and safe environment. Different types of residential facilities provide different levels of care.

Multi-Component Intervention

Resources for Enhancing Alzheimer's Caregivers Health (REACH) is an example of a multicomponent intervention. It was funded by the National Institute on Aging (NIA) and the National Institute on Nursing Research (Wisniewski et al., 2003). It provides multiple interventions to enhance the health of caregivers and persons with dementia such as information
and referral services, educational materials (written or oral), counseling, social support services, skill training intervention, telephone-support group/individual calls, behavior care, and family support services.

Individual and family Counseling

Individual and family counseling is a healthy and positive way to empower oneself. This is a therapeutic service primarily provided by trained practitioners for treatment of caregivers depression and management of stress. It is a collaborative process that helps caregivers to build upon strength and improve their coping skills. One of the common form of this type of service is solution-focused therapy.

Psychoeducational Programs

Psychoeducational programs teach a specific set of skills such as cognitive, behavioral, and social over a specific period of time in a small group or in one-to-one sessions. "Coping with Caregiving", "Savvy Caregiving", "REACH out" are some examples of psychoeducational programs that teach coping skills in a healthy structured format (Gallagher-Thompson et. al, 2012)

Specialized Skill Training Programs

This program focuses on specific skills and it provides training to improve these skills. Behavior management and in-home modifications are some examples of specialized skill training programs. These help caregivers by providing training on making the home safe for the person living with dementia by providing training on home modifications, managing difficult
behavior of persons with dementia, dealing with frustration, managing sleep disruption, and encouraging caregivers to exercise to reduce the stress associated with caregiving.

Psychotherapy

Cognitive Behavioral Therapy (CBT) is a common form of psychotherapy. It was developed over 30 years ago to treat depression, but it has been found to be effective in reducing stress and the burdens of providing care to persons with dementia (Gallagher-Thompson et. al, 2012). It requires highly trained, specialized staff and is found to be more expensive than other forms of psychotherapy. It is highly effective even with persons suffering from significant mental illness who would not likely benefit from support group programs or skill training interventions.

Telephone/Videophone Consultation and/or Treatment

Telephone/Videophone consultation is provided by professional practitioners either through telephone or videophone. Mainly counseling, information, and support services are provided to reduce caregiver burden and to promote optimal coping.

Internet Based Service Delivery Program

The Internet is widely used to deliver support services for caregivers. A number of psychoeducational intervention programs are delivered through this format. Characteristics of these programs include an online discussion forum, information on national and local resources, classes via telephone or videophone, psychoeducational information, and a telephone support system (Gallagher-Thompson et. al, 2012). iCare is an example of an Internet-based program, in which information about dementia is given through Internet.
Online Support Group

Online support groups such as PatientsLikeMe, QuitNet, and CureTogether help caregivers to self-organize and disperse with anonymity. Not only do these support groups provide opportunities to share personal experiences with caregiving, but they assist caregivers in developing solutions to their problems through suggestions and information. In 2005, "Aging in Asia" was formed by the Gerontological Society of America for academics to disseminate information and collaborate from all Asian countries (Gallagher-Thompson et. al, 2012).

DVD Products

DVDs and videos have also been found to be effective in delivering information and services as well as skill training to caregivers of a person with dementia to reduce the burdens associated with providing care. There are many DVDs/videos related to dementia caregiving that were developed by the National Institute on Aging, the Alzheimer's Association, and many other commercial production companies. DVDs are available for purchase or loan.

Alzheimer's and Related Disorder Society of India (ARDSI)

The ARDSI is one of the main resources for caregivers with dementia in India. It is involved in dementia and caregiving awareness activities, training for professionals and/or family members of persons with dementia, developing supportive services, and undertaking research related to dementia. ARDSI sites are established in most of the cities of India.
Dignity Foundation

   This organization mainly works in the general area of senior care, but it also provides
dementia specific services such as Day Care Centers in different cities of India. It also operates a
helpline for persons with dementia and their caregivers.

Dementia Day Care and Respite Care

   There are ten dementia day care centers in India that provide assistance, care, and short-
term/long-term stay for persons with dementia. These centers are run by ARDSI and other
organizations like Dignity Foundation.

HelpAge India

   HelpAge works directly with older adults and assists them in fighting isolation, poverty,
and neglect. HelpAge India facilitates emergency responses, and provides counseling for
caregivers and persons with dementia. HelpAge India also operates dementia help lines in 16 cities
whereby they address questions and inquiries and provide referral services.

Portal for Old Age Solutions

   Portal for Old Age Solutions provides comprehensive information related to health,
nutrition requirements, entertainment, recreation, networking, and assistive devices for the aging
population.
Dementia Helpline

A dementia helpline is present within each and every city of India. The helpline provides information, addresses questions and concerns related to caregiving and provides referral services.

Palliative Care Resources

Palliative Care Resources help caregivers to evaluate options and make decisions when a patient approaches end-of-life. Indian Institute of Palliative Care provides such services.

Alzheimer's and Related Disorders Society of Nepal (ARDSN)

This Organization is working towards raising awareness about dementia, supporting people with dementia and their family members, and providing dementia training to doctors and nurses of Nepal. Education and training intervention is delivered for half hour sessions, 5 days a week for caregivers of persons with dementia. It also runs a dementia helpline that provides information and guidance about dementia and providing care for the caregivers. It also assesses if the person with dementia qualifies for any government or non-government benefits (Jha & Sapkota, 2013).

So, given these trends, experiences of caregivers of persons with dementia and various services/interventions available in the United States, India, and Nepal, a systematic review of the literature was conducted to compare the evidenced-based services between the United States, India, and Nepal and to provide recommendations about services that can be affordable and acceptable in Nepal.
CHAPTER III. METHODOLOGY

Articles for this systematic review were collected by using various databases i.e. EBSCO Academic Search Complete, PsycINFO, MEDLINE, and, CINAHL. Articles reviewed were limited to publications between January 1990 to December 2013, so that a maximum number of published articles could be included and considered for the study and also to cover all articles published recently in India and Nepal. Keywords used for the search were dementia, dementia caregivers in the United States, India, and Nepal, informal caregivers, caregiver burden, support services for caregivers, respite care for dementia caregivers, interventions for dementia caregivers, day-care services for older adults, community-based services, cognitive impairments in Nepal. These keywords were used alone and in combination.

The main goal of the study was to compare the evidenced-based support services between the United States, India, and Nepal, so the search included published literature from all of the three countries. Because of the extensive research about the support services of caregivers in the United States, compared to India and Nepal, most of the articles included were conducted in the United States. Reference sections of articles were also examined to acquire additional articles that were not discovered during the search process. All publication selected were written in English. Articles were included if the following criteria were met: a) articles discussed evidenced-based support services, b) caregivers were taking care of persons with dementia, c) any one of the outcomes of caregivers such as stress, depression, burden, pain, overload, bother, quality of life, coping strategies, psychosocial morbidity, caregivers knowledge, caregiving hours and social support were measured, d) studies were in the United States, India, or Nepal. Articles were included for any types of caregivers including spouses, co-residing adult children, adult children living separately, daughters-in-law, relatives, or friends. Also, articles comparing users
and non-users of support services were included. Studies that included pharmacological interventions, or those that primarily addressed only caregivers' evaluations and preferences of support services were excluded because these studies did not include any type of evidenced-based interventions. Articles with study designs such as cross-sectional, randomized controlled trial, meta-analysis, qualitative study, longitudinal study, and pre-post designs that showed comparisons and cause and effect relationships were included. Articles consisting of case studies, case series, and/or editorials that provided only the description of support services were excluded from the study as those articles did not measure any type of caregivers' outcomes. Articles meeting all the criteria also needed to contain human samples of not less than 15, to be included in this study because less than 15 human sample in a study would be very less in number to generalized the result.

Each article was initially reviewed by inspecting the article's title and abstract to determine if they were applicable to the research question. One hundred eight articles were subsequently selected based on the review of the title and abstract, and these articles were fully reviewed to determine if they met the inclusion criteria. Out of 108 articles of those reviewed 19 articles met the criteria and were found to be evidenced-based (i.e. presented interventions and services that provided measure of outcomes of interventions). Of these 19 articles, 12 were randomized controlled trials, 2 were qualitative studies, 1 quasi-experimental, 1 pre-post designs, 1 longitudinal study, 1 survey and 1 cross-sectional study. Subjects of all these articles were informal caregivers who were caring for persons with dementia. Articles focused on the outcomes such as depression, burden, strain, knowledge, role overload, self-rated health, quality of life, and anxiety, and two articles addressed institutionalization of dementia patients. Studies were conducted either within the home settings or community settings. Articles differed in the
focus of the intervention such as Partners with Dementia Care (PDC), psychoeducation, role training, Internet-based training, icare therapy, adult-day services, multicomponent intervention, polarity therapy, and home-services.

Table 1 presents the brief description of articles that met the inclusion criteria. The following data are presented from each study such as authors, date of publications, study objectives, study population, study location, study design, brief description of intervention or support services, and findings of the study.
Table 1. Characteristics of reviewed articles

<table>
<thead>
<tr>
<th>Author (s)Year</th>
<th>Study Objective</th>
<th>Sample</th>
<th>Setting</th>
<th>Design</th>
<th>Description</th>
<th>Finding</th>
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<tbody>
<tr>
<td>Beisecker, Wright, Chrisman, &amp; Ashworth. (1996)</td>
<td>To determine the perceived benefits and barriers to the use of ADC</td>
<td>104 caregivers</td>
<td>Home</td>
<td>Qualitative</td>
<td>52 users and 52 non-users of ADC were interviewed by telephone</td>
<td>Barriers: negative feelings towards ADC, staffing, and poor nutrition. Benefits: respite, emotional relief, and good health</td>
</tr>
<tr>
<td>Gaugler et al., (2003)</td>
<td>To assess the effectiveness of ADC services in reducing caregiver's hours</td>
<td>400 caregivers</td>
<td>Community</td>
<td>Longitudinal</td>
<td>Interview was conducted with participants at baseline, at three months, and after one year.</td>
<td>ADC users reported greater reductions in role overload as it provided respite to family caregivers</td>
</tr>
<tr>
<td>Zarit, Stephens, Townsend, &amp; Greene (1998)</td>
<td>To assess the effectiveness of use of ADC services in reducing caregiving-related stress</td>
<td>428 caregivers</td>
<td>Community</td>
<td>Quasi-experimental</td>
<td>G1: used substantial amount of adult day services and G2: used small amount of respite services</td>
<td>G1 showed significant reduction in stress compared to the G2</td>
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ADC= Adult Day Center, G= Group
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<tr>
<th>Author(s)</th>
<th>Study Objective</th>
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<tbody>
<tr>
<td>Cox. (1999)</td>
<td>To identify the experiences of respite use by African American and white caregivers of people with dementia</td>
<td>228 African Americans and white caregivers</td>
<td>Home</td>
<td>Interview(Pre-post test)</td>
<td>Telephone interview before and after 6 months of respite use</td>
<td>No change in levels of anxiety or depression but both group had significant reduction in their feelings of burden</td>
</tr>
<tr>
<td>Santo, Scharlach, Nielsen, &amp; Fox. (2007).</td>
<td>To examine the association of caregivers' differential utilization of respite and counseling support services with different situational stress processes</td>
<td>1,643 caregivers</td>
<td>Community</td>
<td>Randomized Controlled Trail</td>
<td>G1: respite users, G2:counseling users</td>
<td>G1: more likely to seek community services to alleviate their care related distress. G2:increase in confidence and were more likely to seek out information about services</td>
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Table 1 (Continued)

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<th>Author(s)</th>
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<th>Setting</th>
<th>Design</th>
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<tr>
<td>Gaugler, Kane, Kane, &amp; Newcomer. (2005)</td>
<td>To determine effectiveness of utilizing community-based services on institutionalization</td>
<td>4,761 caregivers</td>
<td>Community</td>
<td>Survey</td>
<td>Caregivers were interviewed about the services they had used in past 6 months</td>
<td>Caregivers utilizing services earlier in their caregiving careers were more likely to delay institutionalization</td>
</tr>
<tr>
<td>Robinson, Buckwalter, &amp; Reed. (2013)</td>
<td>To examine differences between users and non-users of community services</td>
<td>241 Caucasian caregivers</td>
<td>Community</td>
<td>Cross-sectional</td>
<td>Cross-sectional data on use of community services were collected from caregivers at baseline</td>
<td>Users were less depressed, provided more hours of care per week, and received increased social support</td>
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<td>Author(s)</td>
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<tr>
<td>Masters. (2006)</td>
<td>To assess the benefit of consumer-directed services in extending caregiving role</td>
<td>112 caregivers</td>
<td>Community</td>
<td>Randomized Controlled Trial</td>
<td>G1: voucher for consumer-directed services G2: voucher for traditional aging services. ADC, respite</td>
<td>G1 were more likely to extend their caregiving role than G2</td>
</tr>
<tr>
<td>Gonyea, O' Conner, &amp; Boyle.</td>
<td>To test the effectiveness of the project CARE to reduce caregiver distress related to neuropsychiatric symptoms</td>
<td>80 caregivers</td>
<td>Home</td>
<td>Randomized Controlled Trial</td>
<td>G1: five weekly sessions of techniques about managing neuropsychiatric symptoms and G2: psycho education</td>
<td>Compared to G2, G1 displayed significant reduction in caregiver distress related to neuropsychiatric symptoms</td>
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<tr>
<td>Author(s)</td>
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<tr>
<td>Elliott, Burgio, &amp; DeCosters.</td>
<td>To examine the effectiveness of REACH intervention in caregiver (CG) self-reported health, burden, and bother</td>
<td>495 caregiver and care recipient dyads</td>
<td>Home</td>
<td>Randomized controlled trial</td>
<td>G1: REACH intervention through nine in-home and three telephone sessions over 6 months. G2: two brief “check-in” telephone calls</td>
<td>G1: better self-rated health, sleep quality, emotional, and physical health which led to less burden and bother</td>
</tr>
<tr>
<td>Belle et al. (2006)</td>
<td>To assess the effects of a structured multicomponent intervention on QOL and depression in caregivers and on rates of IP of care recipients</td>
<td>212 Hispanic, 219Caucasian, and 211 African-American caregivers and their care recipients</td>
<td>Home</td>
<td>Randomized Controlled Trail</td>
<td>G1: education and strategies about caregiving through 12 in-home and telephone calls.G2: 2 brief &quot;check-in&quot; telephone calls during the 6-month period</td>
<td>G1: experienced significantly greater improvement in quality of life and depression</td>
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</table>

REACH= Resources for Enhancing Alzheimer's Caregivers Health, QOL= Quality of life, IP= Institutional Placement
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<th>Author(s)</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Hepburn, Tornatore, Center, &amp; Ostwald. (2001)</td>
<td>To examine the effectiveness of role-training intervention in ameliorating the adverse outcomes</td>
<td>94 caregivers/care receivers dyads</td>
<td>Community</td>
<td>Randomized Controlled Trial</td>
<td>G1: 14-hour training program provided information, linkage, and role coaching G2: general information about dementia.</td>
<td>G1 reported improvements in burden, depression, care giving roles and responsibilities</td>
</tr>
<tr>
<td>Kajiyama. (2013)</td>
<td>To determine the effectiveness of the online ICC in reducing stress, bother, depression, and poor life quality</td>
<td>150 family caregivers</td>
<td>Home</td>
<td>Randomized controlled trial</td>
<td>G1: ICC) G2: EOC for a 3-month period</td>
<td>Improvements in perceived stress were significant for the ICC but not the EOC</td>
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ICC = iCare Condition, EOC = Education/information Only Condition
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<tr>
<th>Author(s)</th>
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<tbody>
<tr>
<td>Korn et al.</td>
<td>Compare the effectiveness of PT, to an ERC to reduce stress and depression and improve QOL</td>
<td>42 American Indian and Alaskan Native family caregivers</td>
<td>Community</td>
<td>Randomized Controlled Trial</td>
<td>G1: 8-sessions of gentle pressure on energy points</td>
<td>G1 improved significantly more than ERC on stress, depression, QOL and bodily pain</td>
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<tr>
<td>(2009)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>G2: ERC</td>
<td></td>
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<tr>
<td>Eisdorfers Et. al.</td>
<td>To assess the effect of a family therapy and technology-based intervention on caregiver depression</td>
<td>225 White Americans and Cuban American caregivers</td>
<td>Community</td>
<td>Randomized controlled trial</td>
<td>G1: SET</td>
<td>G2 reported decreased levels of depression</td>
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<td>G3: MSC</td>
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PT= Polarity Therapy, ERC= Enhanced Respite Control, SET= Structured Ecosystem Therapy, CTIS= Computer-Telephone Integrated System, MSC= Minimal Support Control
Table 1 (continued)

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<tr>
<th>Author(s)</th>
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<th>Setting</th>
<th>Design</th>
<th>Description</th>
<th>Finding</th>
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<tbody>
<tr>
<td>Bass et. al (2013)</td>
<td>To assess the effectiveness of PDC to improve the caregivers unmet needs, three types of caregivers strain, depression, and two support services</td>
<td>486</td>
<td>Home</td>
<td>Randomized Controlled Trial</td>
<td>G1: access to PDC G2: received the same educational material but did not have access to PDC</td>
<td>G1: significant improvements in outcomes representing unmet need, three types of strain, depression, and two support services</td>
</tr>
<tr>
<td>Dias et al. (2008)</td>
<td>To develop and evaluate the effectiveness of a home based intervention in reducing burden</td>
<td>81 families with caregivers and care recipients dyads</td>
<td>Community</td>
<td>Randomized Controlled Trial</td>
<td>G1: information on dementia, guidance on behavior management, and a single psychiatric assessment.</td>
<td>Significant improvement in GHQ (improved caregiver mental health), and decreased caregivers' burden</td>
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PDC= Partners in Dementia Care, GHQ= General Health Questionnaires
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<tr>
<th>Author(s) Year</th>
<th>Study Objective</th>
<th>Sample</th>
<th>Setting</th>
<th>Design</th>
<th>Description</th>
<th>Finding</th>
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<tbody>
<tr>
<td>Tompkins &amp; Bell. (2009)</td>
<td>To examine the association between psychoeducational training, respite grant and their combination in relieving psychosocial stressors</td>
<td>367 caregivers</td>
<td>Home</td>
<td>Randomized-controlled trial</td>
<td>G1: psychoeducational training G2: respite grant G3: both</td>
<td>G3 reported lower levels of depression, increased support service use, and increased support group usage</td>
</tr>
<tr>
<td>Hepburn et al., (2005)</td>
<td>To assess the effectiveness of a psychoeducational intervention to relieve dementia caregiver distress</td>
<td>215 caregiver/care recipient dyads</td>
<td>Community</td>
<td>Randomized Controlled Trail</td>
<td>G1: A six-week psycho educational program G2: basic education about dementia</td>
<td>G1 reported improvement in caregiving attitude and decrease in caregiver distress</td>
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</table>
CHAPTER IV. ANALYSIS OF RESULTS

An analysis of the reviewed literature revealed that the support services/interventions that are available for caregivers were effective in improving outcome measures. As expected, interventions and services were beneficial to the caregivers. The goal of the study was to compare the evidenced-based support services/interventions for caregivers of persons with dementia between the United States, India, and Nepal. Data were collected by searching the literature published between January 1990 to December 2013. Keywords such as dementia, caregivers of persons with dementia in the U.S., India, and Nepal, respite for dementia caregivers, informal caregivers, caregiver burden, support services for caregivers, adult-day services for caregivers, and interventions for dementia caregivers were used to search the literatures. Articles were included from the United States and India. There was no article that studied any evidenced-based support services in Nepal.

Bass et al., (2013) conducted a study to assess the effectiveness of Partners in Dementia care (PDC), a care coordinated program in improving caregivers' unmet needs, depression, strain, and utilization of support services. Caregiver strain (role captivity, physical strain, relationship strain), depression, use of support resources (family members, friends, neighbors, and relatives), and respite and emotional support services were measured. Results showed that caregivers in the PDC group demonstrated significant improvements in all the outcome measures when compared to the control group, who did not have access to PDC but received the same educational materials. Additionally, improvements were more evident soon after the six months of interventions than that of twelve months. A study conducted by Beisecker, Wright, Chrisman and Ashworth (1996), users and non-users of Adult Day Centers (ADC) were surveyed by telephone. They were asked about the perceived benefits and barriers to the use of ADC programs. The
benefits of ADC use were coded in seven categories: caregiver (respite, physical and emotional health), patient (socialization, self-esteem, physical health), staff (empathy, sensitivity, qualification), program (stimulating activities), facility (pleasant atmosphere, accessibility), convenience (convenient hours, flexibility, transportation), and cost (Beisecker et al., 1996). More users (100%) than non-users (89%) stated benefits of ADC use ($t = -2.35, p<.05$). Also, users of ADC indicated that ADC use benefited both the patient and caregiver. However, both users and non-users indicated that the caregivers benefited more than patients. A similar study was conducted by Gaugler, Jarrott, Zarit, Stephens, Townsend and Greene (2003) to assess the effectiveness of ADC in reducing caregiving hours (e.g., time that caregivers spent on the patient with activities of daily living/instrumental activities of daily living, managing behavioral problems and memory problems) and whether caregivers stress and negative mental health over time was alleviated. Participants were selected from 45 ADCs with face-to-face interviews conducted at baseline or immediately prior to the ADC use, three months later, and one year later. Caregivers were asked to identify the total numbers of hours spent per day assisting or managing ADLs/IADLs, and behavioral and memory problems at each interview. Results suggested that caregivers using ADC reported decreases in the numbers of hours of managing memory problems and hence, felt decreased role overload. Also, their level of stress and negative mental health (e.g., levels of depression, worry, and anger) were reduced. So, both studies indicated that caregivers using ADC have decreased stress and improved psychological well-being.

A study was conducted by Masters (2006) to assess the benefits of consumer-directed services in extending caregivers roles. In this study, participants in the treatment group were given vouchers, with which they could purchase any goods or services that they believed would
be helpful. However, participants in the control group could utilize the voucher only for
traditional services such as respite and ADC. Caregivers in the treatment group were also
assisted by the care manager and were provided with educational materials to assist them with
caring. Results of the study showed that participants in the treatment group indicated that the
services they utilized extended their caregiving role. However, participants of both groups were
satisfied with the services they received. Elliott, Burgio and DeCoster (2010) conducted a study
to assess the relationship between changes from baseline to after an intervention of a
multicomponent program, REACH, in caregiver's self-reported health (sleep quality, physical
and emotional health), bother, and burden. Participants in the treatment group received
individualized interventions that were based on the needs identified at baseline and five
structured telephone group support sessions. Participants in the control group received
educational materials and two brief telephone calls. Participants in the treatment group reported
significant improvement in self-reported health. Also, there was a subsequent reduction in
caregiver burden and bother at six month follow-up. Similarly, Gonyea, O' Conner and Boyle
(2006) examined the effectiveness of a caregiver based multicomponent behavioral intervention,
Project CARE, in reducing caregiver distress related to neuropsychiatric symptoms of persons
with dementia. Caregivers in the treatment group received five weekly sessions of techniques for
managing neuropsychiatric symptoms. They were also offered other techniques such as
relaxation and were involved in a group sessions where they could share their experiences and
personal challenges. Respite services were provided for caregivers who needed these services.
Conversely, control group caregivers received basic psychoeducation, in which they received
only general information on aging and Alzheimer's disease, home safety tips, techniques for
improved communication, and support. As was predicted, compared to the control group, the
treatment group reported significant reductions in distress and were confident in managing neuropsychiatric symptoms. So, it was found out that Project CARE is effective in reducing caregiver distress related to neuropsychiatric symptoms.

In order to identify the experiences of respite, Cox (1999) conducted a study with African American and Caucasian caregivers of persons with dementia. This study also compared the relationship of race to the utilization of respite services. Interviews were conducted for approximately 40 minutes with caregivers who were accepted into the respite program. Follow-up interviews were conducted after six months. African Americans were more likely to use the respite programs, while Caucasian caregivers stopped the program after six months of use because after six month of service use, they were confident in their role and were more likely to provide care by themselves. Caucasian caregivers indicated decreased time providing care but there was no change for the African American caregivers. Additionally, Caucasian caregivers were more satisfied with the services they received (p<.001) as respite service they received were helpful to them. A study by Hepburn, Tornatore, Center and Ostwald (2001), assessed the effectiveness of role training interventions in alleviating adverse outcomes associated with caregiving. Family caregiver dyads were randomly assigned to role training (beginning immediately) or to a wait list control group (received training after five months). The role training workshops consisted of five main components: information provision (information about dementia), concept development (framework for understanding the progressive effect of dementia), role clarification (information on caregivers role such as care recipient's safety, comfort) belief clarification (information to beliefs about caregiving), and mastery-focused coaching (information to put what was taught into practice) that were delivered in group settings for seven weeks in 2-hour sessions weekly. Compared to the wait-list control group, caregivers
attending the workshops showed significant improvements in outcomes such as depression, burden, and were able to manage behavioral problems of the care recipients. They also expressed belief in their caregiving work.

Dias et al., (2008) conducted a study in India to discover the effectiveness of a home care program in supporting caregivers of persons with dementia. Caregiver dyads were selected and randomized either to a treatment group or to a waiting list group (received services after six months). Home care intervention consisted of providing basic education about dementia, education about behavioral problems and ways of managing these problems, support to the caregiver, referral services as needed, networking of families to form support groups, and advice on government schemes regarding benefits of older adults. The control group received only information and education about dementia and received interventions after six months. Treatment group caregivers reported significant improvements in mental health and reductions in burden as measured in the General Health Questionnaire. There was also a reduction in the rate of a death among patients of the treatment group. To assess the effectiveness of psychoeducation interventions on caregivers' distress, Hepburn, Lewis, Narayan, Center, Tornatore, Bremer and Kirk (2005) conducted a study. Partners In Caregiving (PIC) is a psychoeducation program that consisted of two multi-session multidisciplinary interventions. The first version consisted of developing basic day-to-day caregiving strategies and the second one consisted of a decision-making framework in which participants were taught about identifying and using values and preferences of persons with dementia so that evaluation and decisions can be made regarding day-to-day caregiving. For both programs homework was assigned whereby participants practiced learned skills and strategies. Follow-up coaching that taught managing immediate situations, brainstorming, and implementing solutions was delivered. Both programs were
conducted for six weeks for two hours each week. Outcomes such as distress, burden, role captivity, and negative health were measured. Results indicated that the psychoeducational program helped caregivers to alleviate distress related to providing care and improved their caregiving attitude. Improvements were more significant for the decision-making framework group, which demonstrated the improvement of personal differences.

A psychoeducational intervention was also assessed by Tompkins and Bell (2009). They conducted a study to examine the effectiveness of three interventions (i.e. psychoeducational intervention, a respite grant, and their combination in relieving caregivers' psychosocial stressors). Participants were assigned to the Savvy Caregiver Program (SCP), where participants were assigned to an academic-based caregiver psychoeducational program, or received a respite voucher. The voucher provided $1000 to use for any type of respite services, or to a combination group, where they received both forms of interventions. The SCP participants received a caregiver manual consisting of an introduction to dementia, caregiver self-care, the anchors of enjoyable involvement, and strengthening family as a caregiving resources and an educational CD, consisting of a 12 hour session of acknowledging the disease, developing emotional tolerance, and taking control. Training was conducted for six months. Results reported that the SCP group was highly satisfied with the training and participants were more confident in their role, and gained valuable knowledge related to caregiving. Follow-up results showed that they also used the manual and educational materials after six months of training in implementation of their day-to-day caregiving activities. The respite voucher receiving group members were able to purchase the services they needed and hence, felt less depressed and utilized support services available in the community areas. However, all three groups reported reductions in depression and increased support service use.
It has been found that the quality of life of caregivers of persons with dementia decreases as the dementia progresses (Brodaty, Green, & Koschera, 2003). Quality of life in caregiving is essential not only to be able to deliver desired support and assistance to the care recipients, but also to live a physically and mentally healthy lives. In order to assess the quality of life of caregivers, Belle et al. (2006) conducted a study. The goal of the study was to assess the effectiveness of multicomponent interventions on caregivers' quality of life and depression. The primary outcome-quality of life consisted of caregiver burden, depression, self-care, social support, and behavioral problems of care recipients. The secondary outcomes were caregiver depression and institutionalization of care recipients. Intervention provided caregivers with education, strategies for enhancing healthy behavior and for reframing negative emotional responses, skills to manage behavior problems of care recipients, and stress associated with caregiving. Interventions were delivered for six months in 12 sessions (9 in-home and 3 telephone sessions). The control group received educational materials and two brief "check-in" telephone calls at three months and five months. Results showed that the multicomponent intervention was successful in improving the quality of life of caregivers in the intervention group as measured by indicators of depression, burden, self-care, and care recipient's behavior problem.

A study by Robinson, Buckwalter and Reed (2013) examined differences between users and non-users of community services among caregivers of persons with dementia. Data were collected from both groups about the use of community services at baseline and analyzed several years thereafter. Outcomes such as social support, depression, problem behavior, and caregiver burden were measured. For this study, caregivers were divided into three groups: caregivers using community services (caregiving assistance and respite) for two hours or more per week, caregivers using community service (respite only) for two hours or more, and caregivers using
less than two hours per week of community services (non-users). Results demonstrated that those using only respite services were more depressed than those using both services. Caregivers receiving both types of community services reported significant improvements in use of social support and managed problem behaviors of person with dementia confidently. However, they were found to be more burdened than any of the two groups, which indicated that even though they improved in other outcomes their levels of burden was not reduced when utilizing both the services.

Santo, Scharlach, Nielsen and Fox (2007) conducted a study to examine if caregivers' differential utilization of respite and counseling support services was associated with different situational stress processes. It was hypothesized that the utilization of particular types of caregiver support services is linked to their specific caregiver needs. This study highlighted the fact that the utilization of support services by caregivers can be understood as coping strategy as a response to stressors inherent in the care situation. Two types of stressors (primary and secondary) were assessed. Variables of primary stressors included ADLs and IADLs care needs of recipients' behavioral, memory, and mental health problems and if ADL assistance was provided by caregivers. Secondary stressors were assessed by asking if there is any family conflict, financial strain, physical/mental health problem, sleep disturbances, and work-related changes due to caregiving. Caregivers were divided into respite users, counseling users, and those who used neither services. Findings suggested that respite service users were more likely to assist in ADLs and problem behavior and were more likely to seek use of support services, thereby alleviating their burden and stress. However, they also reported physical health problems related to caregiving. Counseling service users were more likely to report mental health problems related to caregiving. They also inquired about information regarding support services as they
developed more confidence and were more expressive about their problems. Secondary stressors did not make any significant contribution. As hypothesized, this study found associations between different stressors and types of services utilized by caregivers (i.e. caregivers with higher levels of physical stress symptoms and more physically demanding situation were likely to seek respite services, and caregivers with higher levels of interpersonal stress symptoms and more emotionally demanding situation were more likely to opt for counseling services).

A study by Gaugler, Kane, Kane and Newcomer (2005) examined whether utilizing community-based services early in one's dementia caregiving career delays institutionalization of persons with dementia. For this research, two types of community-based services, (in-home assistance and adult day services) were analyzed. Caregiver dyads were asked about services they had used in the past six months and about the frequency with which they used these services. Primary objective stressors such as ADLs/IADLs, problem behavior of care recipients, burden as primary subjective stressors, utilization of resources such as family or friends, and global well-being such as depression were measured. Results showed that caregivers utilizing in-home assistance and community-based services helped in delaying institutionalization. Also, caregivers who utilized any of the services were more likely to assist in ADLs/ IADLs and reported decreased burden related to caregiving during their caregiving career.

A study was conducted by Korn, Logsdon, Polissar, Gomez-Beloz, Waters and Rýser (2009) to examine the effect of Complementary and Alternative Medicine (CAM) therapy in stress reduction among American Indian and Alaskan Native family caregivers. Two interventions were used Polarity Therapy (PT) and Enhanced Respite Control (ERC). The PT group received gentle pressure on energy points for eight sessions, and the ERC group received respite for the person with dementia and choice of activities ( music therapy, yoga, swimming,
and sauna) for caregivers. The primary outcomes (stress, sleep quality, quality of life, and worries) were assessed. Secondary outcomes (bodily pain, general health, vitality, and mental health) were assessed. Both groups improved from baseline to post-treatment. However, the PT group had a significant reduction in levels of stress and depression. Also, compared to the ERC group, the PT group had significant improvements in general health, vitality, and bodily pain. The results indicated that PT is highly effective in reducing stress among caregivers of persons with dementia.

Caregivers' distress was also assessed by Kajiyama, Thompson, Eto-Iwase, Yamashita, Di Mario, Marian Tzuang and Gallagher-Thompson (2013). This study determined the effect of an Internet-based online iCare training intervention in reducing caregivers' distress, and stress related symptoms. Primary outcome (stress), and secondary outcomes (depression, bother, and perceived quality of life) were assessed. Caregivers were randomly assigned to the iCare Condition (ICC) and Education Only Condition (EOC) for three months. ICC included an introductory section, six modules, and a summary of future actions. The introductory section included general information on dementia. Module 1 contained information on dealing with stress, Module 2 contained information learning how to relax, Module 3 contained information on pleasant activities, Module 4 contained information on learning new communication skills, Module 5 contained information on managing difficult behaviors, Module 6 contained information on learning healthy habits. The summary consisted of planning for the future regarding anticipating problems and identifying resources. All interventions were delivered through video clips that described how to perform the various skills presented. Actors were used to portray different stressful situations that are common for most caregivers, followed by more effective ways of handling those situations. EOC caregivers were exposed to a website
containing information about dementia. Booklets of various health agencies were also provided.

ICC showed greater improvements in perceived stress than the EOC. Also, secondary outcomes
such as depression, bother, and perceived quality of life were improved in caregivers using ICC.

Zarit, Stephens, Townsend and Greene (1998) conducted a study to assess the
effectiveness of use of adult day services in reduction in caregiving related stress. This study
used a quasi-experimental design. Caregivers in the treatment group utilized substantial amount
of adult day services and caregivers in the control group did not use any adult day services
throughout the study. However, they used only small amount of respite services. Primary
appraisals (overload and strain), and two measures of well-being (depression and anger) were
measured. Results were analyzed at three months and after one year of study. Result at 3 months
indicated that caregivers in the treatment group showed significant reductions in depression,
overload, strain and anger when compared to control group. Findings at one year showed that
caregivers in the treatment group had significantly improved in all of the measured outcomes
than that of control group. These results demonstrate that use of adult day services by caregivers
of persons with dementia results in lower levels of caregiving-related stress and better
psychological well-being than those caregivers not utilizing adult day services.

Eisdorfer et al. (2003) conducted a study to evaluate the effect of family therapy and
technology-based interventions on depressive symptoms of caregivers. This study was conducted
at the Miami site of Resources for Enhancing Alzheimer's Caregiver Health (REACH) program,
which investigated the efficacy of Structural Ecosystem Therapy (SET)-a structural family
therapy intervention, SET+ Computer-Telephone Integrated System(CTIS), and Minimal
Support Control(MSC) on caregivers. The goal of SET was to identify and restructure specific
interactions within the family that may be linked to caregivers' burden. In SET, information and
guidance were provided for different aspects of caregivers such as identifying specific interactions within the family, identifying caregivers' problems, identifying resources available to the caregivers, and identifying community support services available and accessible to them. SET+CTIS facilitates linkages of the caregivers within the family and support services outside the home. It included both the caregivers and family members. MSC consisted of biweekly telephone-calls for the first six months and monthly calls for next six months. Caregivers in the SET+CTIS group reported decreased levels of depression when compared to the other two intervention. SET+CTIS was found to be effective for Caucasian Americans as well as Cuban American caregivers. Also, because of training with computer-telephone technology (information provided through computer or telephone), caregivers in the SET+CTIS group were able to participate in family conferences and online support groups, which helped them share their experiences and challenges associated with caregiving (Eisdorfers et al., 2003).
CHAPTER V. DISCUSSION

Globally, most of the persons with dementia are cared for by family members, friends, and relatives, who are also referred to as "informal caregivers." Dementia caregiving is a global experience (Gallagher-Thompson et al., 2012; Giunta, 2010). Caregiving is typically considered to be a family responsibility in almost every country of the world. Caregivers experience multiple problems such as poor physical and mental health, burden, bother, stress, financial strain, decreased socialization, and early institutionalization of a person with dementia. There is extensive research on various support services and interventions to help caregivers. Development of services and/or interventions to support caregivers has gained increasing interest due to the rapid growth of the older population and the increased cost of providing custodial care (Beisecker, Wright, Chrisman, & Ashworth, 1996). Support services are expected to assist caregivers and alleviate stress and symptoms associated with caregiving (Winslow, 2003). The primary reason for developing any support services or intervention is to promote the quality of life of caregivers and increase the duration of caregiving, thereby preventing early institutional placement of persons with dementia. Government and many social service organizations of developed countries are focusing on developing specific programs and interventions that would significantly benefit caregivers.

The goal of this study was to compare the support services for informal caregivers caring for persons with dementia in the United States, India, and Nepal. Literature was assessed for evidenced-based support services and promising services were found to be available mostly in the United States. Programs/interventions that were effective in promoting caregivers' health such as REACH, National Family Caregiver Support Program, psychoeducational and psychosocial interventions, various types of respite such as in-home services, adult day services,
and respite grant, family therapy, polarity therapy, community-based services and multicomponent interventions were found to be available in the United States. Also, Internet-based support programs, educational DVDs, role training, telephone-computer intervention, and online-support groups were found to be effective in improving caregiver outcomes. However, there are barriers between the caregivers and available services. Historically, little has changed in the caregiver community and caregivers still continue to experience tremendous burdens related to providing care (Robinson, Buckwalter, & Reed, 2013). Lack of information and guidance are the main barriers of accessing support services. Also, caregivers wait too long to seek help and find support services. Beisecker et al. (1996) and Li (2004) identified multiple barriers to accessing support services by caregivers of persons with dementia. Negative feelings towards support services and staff (e.g., inadequate staff, improper behavior of staff), lack of convenience related to services (e.g., program availability, hours of operation, location of program), cost of services, patient concerns (e.g., patient unhappiness, physical health, safety, functional level, behavior), caregivers knowledge and feeling, fear and guilt associated of using services, programming (e.g., lack of nutrition both in quality, and quantity, lack of exercise), facility (e.g., lack of cleanliness of the facility, inadequate space, and unpleasant environment) were reported as barriers for using services by caregivers. However, caregivers are more likely to use services when there are benefits to persons with dementia as well (Gaugler, Kane, Kane, & Newcomer, 2005)

Application to Nepal

The World Health Organization states that about 75% of the estimated 1.2 billion aged people 60 years of age and older will reside in developing countries, and it is estimated that the number of people with dementia will almost double every 20 years and will be 81.1 million
people in 2050 (Das, Pal, & Ghosal, 2012). In developing countries such as Nepal, the older population is increasing rapidly. According to the Central Bureau Statistics of Nepal, (2011), the population of those aged 60 years of age and older was 2.2 million, accounting for 8.3% of total population of Nepal (Jha & Sapkota, 2013). These older adults are at high risk of dementia in the coming years as dementia affects mostly the older adult population.

The main goal of this study was to provide some recommendations of promising support services and interventions that would benefit not only caregivers but also policy makers and organizations working with aging populations in Nepal. To date, there has been no epidemiological survey of dementia in Nepal. However, the process of data collection and survey regarding the total number of persons with dementia is going on. Most Nepalese reach later adulthood after living a lifetime of poverty, deprivation, inadequate access to health services, and poor nutrition (Yarger & Brauner-Otto, 2014). Traditionally and culturally, older adults are expected to live with their sons. However, due to demographic transitions and urbanization, most older adults are living by themselves, thus, suffering from loneliness, depression, and poor health (Prince et al., 2012). Nepal is not at all prepared for the challenges associated with dementia and problems of caregiving. There is a treatment gap for persons with dementia because there is a lack of resources, services, and infrastructures both for the person with dementia and caregivers in Nepal. People with dementia and their caregivers attend clinics or hospitals, which often involves a long journey and long waiting lists for assessment or treatment, which is often focused on acute rather than chronic conditions (Dias et al., 2008). There are few professionals who are trained to diagnose and manage dementia and related disorders. Lack of knowledge and skills among practitioners are key factors for lack of recognition of dementia in Nepal (Subedi, Tausig, Subedi, Broughton, & Williams-Blangero, 2004). Another factor would be an inadequate
infrastructure and trained human resources that are essential to developing programs, services, and interventions to support people with dementia and their caregivers. Unfortunately, dementia related programs are not a priority for the government of Nepal at this time (Jha & Sapkota, 2013). Public policy to specifically address the needs of persons with dementia and their caregivers is lacking. Poor awareness, scarcity of basic and clinical research on dementia, and inadequate social benefits are making problems more challenging. Also, programs such as adult day services, long-term care facilities, and nursing homes for persons with dementia are neither culturally acceptable not affordable in the present context of Nepal as adult children are expected to take care of their older parents till they die.

Recommendations

First, a grass root movement is needed to raise public awareness about dementia in Nepal. General information, health education, counseling, workshops, conferences, trainings, group talks, distribution of pamphlets, flyers, and newsletters would help reduce stigma about dementia and improve knowledge about the disease and would provide awareness on the available services. Also, actively promoting awareness through social media such as radio, television, newspaper and a social network sites would help to spread information to a large population at a single time. Secondly, government, policy makers, and organizations working with the aging populations should make significant investments in developing and disseminating research, policy, services, interventions, and programs that are feasible and accessible to people with dementia and their caregivers. Provisions should be made to train practitioners, nurses, social workers, and other health care professional so that early detection and diagnosis can be made.
The Government should understand that although the initial cost to start these services are high, it will definitely pay off later in terms of improved physical and mental health for both the person with dementia and their caregivers, increased resources (infrastructure and manpower), delayed institutional placement, and lowered health care cost. Additionally, Government should be more conscious and should take a leading role in establishing a national coordinating body that works towards developing policies and strategies on aging. Programs that contribute to attitude change towards older adults and dementia should be considered. The Government should be prepared to meet the upcoming challenges of an increasing number of older adults and its related problems.

Barriers to Accessing Services

As caregiving is considered the primary responsibility of the family in Nepal, services and programs such as adult day services, nursing homes, residential facilities, and long-term care facilities for persons with dementia may not be acceptable at this time. Also, due to low literacy, many older adults lack knowledge about technology so, implementation of technology-based programs such as Internet-based training, coaching, online group support, telephone information/education will take a much longer time to implement in Nepal. However, respite programs such as in-home services (assisting in bathing, cooking, overnight stays) and other services such as family and individual counseling (stress management program), training, workshops, support groups, psychotherapy such as psychoeducational program, psychosocial therapy, and specialized skill training (problem behavior management) will be very beneficial to caregivers. These programs would be both feasible and acceptable to the caregivers and will reduce burden, stress, bother, and depression associated with caregiving in Nepal. Also, it is important to note that because of the limited existing financial resources in Nepal programs must
be sustainable. Finally, barriers to accessing health services should be identified and reduced. It was evident from this research that most older adults and caregivers in Nepal do not seek medical health services until it is too late, which is more common in rural areas of Nepal (Subedi et al., 2004). Most caregivers do not realize that they also need support and/or respite. Caregivers often neglect their own health care needs until they are very sick. Because there is stigma associated with a diagnosis of dementia many caregivers have to bear misunderstanding and discrimination from the society. This in turn can make them less expressive about their own problems. Illiteracy, lack of knowledge of services and what they can actually do for them, lack of transportation, lack of communicating skills, and cost are the barriers that are preventing caregivers from services (Jha & Sapkota, 2013).

Limitations

There are several limitations of the study. First, and foremost, all the articles were reviewed by a single person, hence chances of bias and inaccuracy are possible. Second, the number of articles reviewed were less in number (i.e., only 19 articles were reviewed) and were mostly conducted in the United States. Third, actual comparison of services between the United States, India, and Nepal could not take place because of the lack of literature in this area from India and Nepal. In India only one article describing evidenced-based support services was found, and there were no publications related to this field from Nepal. Hence, the objective of the study was not fully met. However, it provided an overview of support services and interventions that are available in the United States, which may prove to be very beneficial for other countries like India and Nepal.
Conclusion

This study provides an insight on different types of programs and interventions that are beneficial to caregivers of persons with dementia that would improve their quality of life and overall wellbeing. All the reviewed articles in this study provided evidenced-based interventions that were effective in alleviating outcome measures such as depression, stress, burden, bother, and negative mental health and improving knowledge, skills, self-esteem, and both physical and mental health of caregivers. Belle et al. (2006) found multicomponent intervention effective in delaying institutionalization of persons with dementia. This study also investigated the services that are available in India and Nepal and found that both India and Nepal are just emerging in this field. Nepal lacks much of the information and awareness about dementia and it is unfortunate to know that there are only two organizations: ARDSN and Aging Nepal, that are working towards addressing older adults with dementia and their caregivers. Because of the limited resources and services, Nepal is facing treatment gaps for persons with dementia. The looming epidemic of dementia needs to be addressed effectively. Nepal's Government needs to be proactive by establishing policy for services for persons with dementia and their caregivers. The Government needs to develop resources (both human resources and infrastructure), promote awareness and research, provide skill training to current practitioners, provide public education about dementia, work closely with other organizations, facilitate the establishment of dementia clinics in general and teaching hospitals, and assist in developing and implementing services, programs, and interventions that are not only helpful to persons with dementia and their caregivers but also feasible in terms of cost and access. It is hoped that this study with a review of the literature on various support services for caregivers will help inform individuals about
evidence-based support interventions that can, and should be implemented in countries like Nepal to forestall the upcoming challenges associated with dementia.
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