CAREGIVERS’ EXPERIENCE IN PROVIDING CARE FOR THE BED-BOUND ELDERLY

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DECLARATION

I **Akshay Kishore,** hereby declare that this dissertation titles **"CAREGIVERS' EXPERIENCE IN PROVIDING CARE FOR THE BED-BOUND ELDERLY"** is a record of genuine work done by me under the guidance of **Dr. Sonny Jose** and no part of this has been produced before any university for the award of degree, diploma certificate, to be the best of my knowledge and belief.

AKSHAY KISHORE

CERTIFICATE OF APPROVAL

This is to certify that the work embodied in this dissertation entitled **“CAREGIVERS’ EXPERIENCE IN PROVIDING CARE FOR THE BED-BOUND ELDERLY”** has been carried out by **Akshay Kishore**, of Semester-IV of Masters of Social Work under my supervision and guidance that is hereby approved for submission.

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ABSTRACT

Caregivers‘ are at risk of experiencing caregiver burden. It is therefore important to determine the caregiver burden of caregivers who provide care to bedridden elderly and related factors. The aim of this study is to determine the caregiver burden of caregivers who provide care to bedridden elderly and the factors that impact their burden. This study assessed the level of stress experienced by caregivers of the bed bound elderly and determined the association of caregiving burden with different characteristics of the quality of care provided for the bed bound elderly.

The the study is qualitative in nature. Multiple case study design was used with selected respondents purposively selected. The research questions posed enquired about the experiences faced by the caregivers of the bed bound elderly and the coping mechanisms adopted by them to provide quality of care for the bed bound elderlies, it also looked into the aspect of community resources or supporting schemes to easen the caregivers burden. The study is woven around the caregiver burden themes - physiological challenges, psychological challenges, social challenges, financial challenges and problems faced on a daily basis.

The overall findings of the research indicate that the caregivers are facing challenges due to physical, psychological, social and financial constraints. Most of the caregivers are unaware about the resources and provisions they are entitled to receive from the government and none of them felt the need to undergo professional training to be a caregiver, thus they lack knowledge and find it stressful in emergency situations. Some of the caregiver‘s experience compassion fatigue due to the long hours of care provided for their loved ones. Financial burden is another major stressor in providing quality care for the bed bound elderly. On the whole there is a need to develop a supportive network for the caregivers which can be arranged from the family or community itself and thereby ease the burden for the caregivers.

CONTENTS

CHAPTER I

INTRODUCTION

1.1 OVERVIEW

The following chapter will outline the introduction about the current study on *"Caregivers' Experience in providing Care for the Bed-bound Elderly"*. This chapter begins with an introduction in which the researcher gives the reader an idea about the caregivers' experience in delivering care for the bed-bound elderly. The chapter introduces the concepts such as caregiving, needs of the bed-bound and goes on to explain the statement of the problem and significance of the study, followed by research questions. Finally, this chapter concludes with a section summary.

1.2 INTRODUCTION

With progress in health care and development, the average life expectancy (LEB) is bound to improve leaving a lot many human beings to age and eventually left more bed-bound. This burgeoning numbers also pose an increasing burden to old age care (IAR, 2018). The present study focuses on the challenging life of caregivers of the bed-bound elderly population and is undertaken to generate a new framework for finding community resources for the group under study. The caregivers who take care of the bed-bound patients have to assist them all the time, since the patient is immobile and it is always tilted to be a full-time job. Relevant studies indicate that most of the caregivers are daughter-in-laws or daughters, and usually it is imposed on them forcefully or circumstantially. Underestimate for their services and more than often taken for granted such carer-givers are often regarded unthankfully as ―unpaid workers‖.

Caregiving

This study tries to investigate any core relation of caregiving strategies adopted by the primary caregivers in providing quality services for the bed-bound elderly, in all the three different social strata. So far there are no specific studies done specially on evaluating from different classes of the same society. Caregiving is a complex health care activity. From an informal family level activity, it is becoming a major part of health care. There is a growing awareness of the mental health aspects of caregiving both in the economically rich, low and middle (income) countries. It is this aspect of addressing the emotional dimensions of caregiving, in addition to importance to care receivers and to utilize the caregiving situations to address the prevention of mental disorders, promotion of mental health, and fight stigma of mental disorders that will be discussed in this study.

In India, caregiving is largely by the family members as there are extremely limited alternative institutional facilities and welfare supports for those with long-standing illnesses such as mental disorders, chronic illnesses such as diabetes and cancer. In addition, in India, most families prefer to care for the ill person at all stages of illness. However, the larger societal changes in the country are placing significant demands on the caregivers. Two of the changes making caregiving difficult are living in urban areas and living in nuclear families. The lack of a supportive community in urban areas and the limited resources in a nuclear family make caring a demand on the caregivers and places their mental health at risk.

Caregiving can be a genuinely rewarding experience, the caregivers often face common challenges that leave them overwhelmed, anxious and/or intimidated by their duties. Some of the challenges family caregiver faces are (American Senior Communities, 2020):

1. Managing their time - Caregivers often find they have less time for themselves and other family members. They often spend so much time on caregiving duties that they end up sacrificing the things they enjoy, like hobbies or vacations. Or, they have trouble balancing work schedules around caregiving.
2. Emotional and physical stress - most caregivers experience health related issues such as their health has gotten worse as a result of caregiving. Caring for chronic conditions like dementia or Alzheimer‘s disease seem to cause the most emotional stress. The physical demands of caregiving can also take a toll, when the duties include lifting and helping with mobility.
3. Lack of privacy - A caregiver often reports feeling a lack of privacy in the home once they‘ve taken on a loved one, especially in a smaller space. It can be difficult to set boundaries to get away from constant interactions.

4. Financial strain - Because most caregivers are unpaid, they can start to feel some financial strain, especially when caregiving takes them away from a paying job. The longer the caregiver has been providing care, the more financial strain they feel.
5. Sleep deprivation - Lack of sleep can be a big issue for a caregiver, as often the loved one‘s sleep-wake cycle can be mixed up. Sleep deprivation can take a huge toll on a caregiver who is already feeling the strain of being burned from both ends.
6. Being afraid to ask for help - Many caregivers feel ashamed to ask for help from others. They feel they must assume the full caregiver burden as that asking for some assistance may be a sign of weakness. The caregiver in turn starts to feel guilty that they aren‘t providing the best care that they could.
7. Depression and isolation - A caregiver is often at high risk for depression. Oftentimes, caregiving duties take up so much of their time that they no longer maintain social connections outside of the home.

Gender differences in the caregiving experience

A number of studies have suggested that the experience of caregiving differs among men and women. Gender-specific differences in the provision of care for those with dementia or physical illnesses have been found to exist in several areas.

Duration spent on caregiving: Gender-differences in the time spent on caregiving have been considered in several reviews and studies on the subject. Some of them have concluded that despite conflicting reports, the bulk of the evidence indicates that women devote greater time to caregiving for the elderly, compared to men. Explanations based on the gendered nature of paid work have argued that women are more likely to care for the elderly because they are less likely to be employed outside home. Women‘s work roles are viewed as being centered in the home and may reflect a greater sense of family obligation among them. This increases the likelihood of women spending more time providing care. Time-intensive care among women is also more likely in those societies and cultures, which endorse the traditional value of the woman as the natural caregiver. There is also considerable agreement that gender differences in the time spent on caregiving are confounded by several other variables such as kinship (spouses *vs* children), and cultural or ethnic influences. Regarding the duration of caregiving, there is far greater consensus that gender does not have an impact on total duration of caregiving.

Types of tasks: A distinction has been made in this literature between tasks associated with personal care such as bathing, dressing and managing incontinence, and tasks associated with management of everyday living. Some studies have found that women are more likely than men to provide assistance with tasks related to personal care, while others have not reported similar gender differences. Female caregivers are more likely than men to carry out these tasks. Gender differences have not been found in tasks associated with everyday living. Gender differences in the types of tasks also appear to be influenced by several mediating variables such as the patient‗s gender and disability levels, kinship, caregivers‗ marital and employment status, family composition, social class, and race or ethnicity.

Role-strain and Role-conflict: Caregiver role-conflicts refer to the perceived difficulties in fulfilling the caregiver-role, and the negative consequences emanating from this role. Female caregivers often have to play multiple roles such as wives, daughters, mothers, or employees. The pressures of enacting these conflicting roles may create difficulties for women. Roleconflicts and role-strains may manifest in many ways. Role-conflicts arise when conflicting and incompatible demands are made of the caregiver himself/herself. Role-strain occurs when one is unable to meet the expectations and obligations of multiple roles. Role-overload sets in when these competing demands overwhelm the person‗s ability to carry out his/her role. This might lead to role-captivity, which refers to the caregivers‗ feelings of being trapped in their roles. Role-conflicts give rise to several adverse consequences for caregivers such as physical problems, fatigue, burnout, depression and other emotional disturbances, and feelings of resentment towards the patient. Many studies have found that female caregivers of the elderly with physical problems or dementia experience greater role-strain and role-conflict than male caregivers. Women appear to experience greater interference and limitations in their work and social life because of their role as caregivers. They are generally believed to experience greater role-strain due to the more intense care they provide. Greater role-strain in women produces more frequent health problems, a less positive outlook on life, and a greater need for external support.

Satisfaction with Caregiving: This is a relatively sensitive topic when compared to other parameters. Some studies report that women are less satisfied, while a similar number of studies have found no differences in satisfaction between male and female caregivers. However, it can be concluded that when women tend to have multiple responsibilities at home along with caregiving, they tend to feel guilty and incomplete due to the quality of outcome, which leads to dissatisfaction.

Reasons for Caregiving: Several authors have identified emotional and social connectedness of women towards their patients, as well as their sense of family obligation as the basis for their nurturing approach to caregiving. Women appear to be more concerned about the emotional well-being of the people they provide care for. This attachment often motivates them to engage in caregiving. A greater sense of responsibility towards the patient, altruism, and self-sacrifice has also been found to characterize women‗s attitudes to providing care. However, studies of male caregivers have suggested that caregiving among men is also driven by a similar sense of affection, commitment, and family responsibility.

Essentials needed for Bed-bound Elderly

Being bedridden can be difficult for both the elderly, as well as for the caregiver and family members. If there is a loved one at home who is confined to the bed, there are various products termed under bedridden patient care equipment that can be used to make their everyday life more comfortable, and also make it easier for the caregiver to assist the elderly. These pieces of equipment for bedridden people allow them to have better comfort which facilitates better recovery. Some of the equipment‗s used for bed-bound elderly care are as follows (Valerie Paxton, 2011):

Bed pads and under pads: - A bed pad or under-pad is a type of underlining that you can place under the main mattress on the bed. These are especially helpful to soak up any wetness that can occur as a result of accidental spills, urine leak due to incontinence or water spill during a bath or sponge routine. The bed pads and under-pads can be easily washed and are easy to dry, and can also be reused for a long period of time.

Bed-rope ladder: - is a type of equipment that is placed on the bed and can help the bed-bound person sit up from a lying down position, without too much assistance and can use the different rungs of the ladder to pull himself or herself up to a sitting position.

Pressure-relief mattress: - is a type of mattress that is specially designed for bedridden patient care equipment. It is a very soft mattress and helps to spread the entire body‗s weight evenly. It also helps to prevent and ease any bedsores, making it important for anyone who has to spend a considerable amount of time in bed.

Bed-pan: - is a type of toilet pot for bedridden person that is used to help to pass urine while still in bed. This type of equipment (also commonly known as a bed toilet for elderly) allows easy passage of urine for the bed-bound and bed-bound elderly does not have to be taken out of the bed to go to the bathroom. These are easy to use and are discreet too, thus providing comfort and privacy.

Hospital Bed: - are beds used in hospitals, and can also be used at home. The bed has rails on the sides that can be lowered and put up as required. A pressure relief mattress is specifically designed for such types of beds and comes in three sections that are joined together. It makes it easier to have the foot, middle and head part of the bed to be raised separately, depending on the patient‘s need.

Food-table: - is used to serve food to the patient on the bed, without the need to move the bedbound around. It comes with a flat surface that serves as the table and is in part like a trolley with wheels that can be moved around.

Adult Diapers: - These come in various forms such as pant form or regular diapers, disposable or cloth ones and with a varying amount of absorbency. It is important to check that the diaper is the right fit, as else it could cause leakage and result in diaper rash and sores.

Cotton and Wet Wipes: - It is always good to keep a few rolls of cotton as well as a few packs of wet wipes near a bed-bound elderly. These can come in handy to take care of accidental spills or bleeding and help clean the patient instantly.

Bedside Commode: - is a type of toilet that can be moved around the bed. Since it does not have the feature of running water, it can be kept anywhere and makes it easier for the bed-bound to use. The commode looks like a chair that has a toilet seat attached to it. It also comes with a container that is placed under the seat and can be removed after each use for cleaning. Complete hygiene should be maintained.

Wheelchairs: - There are different types, such as manual and electric. While selecting one should make sure to check its weight and the type of seat it has, so that it is easy to move it around from one place to another, and is also comfortable for the bed-bound to use.

Ventilator: - It is a type of machine that helps the bed-bound elderly to breathe easily by sending oxygen to the lungs. It is used for persons who have lung failure and cannot breathe naturally. It comes attached to a tube that can be placed near the nose to assist in breathing and can also come with the option of having a breathing cup that is placed over the nose and mouth. It is a piece of important equipment for bedridden patients as it is medically used.

There is a host of equipment available that can make one be comfortable while being in bed, and also make it easier for the caregiver to assist on a daily basis, but most of these equipment entail an extra cost, and only those who belong to high income category can easily access these services; for the rest, it should cost an eye and a hand.

1.3 STATEMENT OF THE PROBLEM

In India, there is an increase in the proportion of the aged *vis-a-vis* a decrease in the proportion of the young. It is estimated that the population of senior citizens in India would be around 19% of total population by the year 2050 (India Ageing Report-2017). The growing number and share of older people in all societies are also posing an increasing burden to old age care, especially in settings wherein there is limited institutional, human, and financial resource capacity to meet the basic needs of older people and where social safety nets do not exist (International Aging Report - 2015).

Low- and middle-income countries differ from high income countries with regard to readiness or resources available to provide health care for an aging population. In India the small-family norm means that fewer working, younger individuals are called upon to care for an increasing number of _economically unproductive‘ elderly persons. Moreover, it is the legal and moral responsibility of family members to support the elderly at an older age (Ministry of Social Justice and Empowerment). In India as per 2011 census, while the national old dependency ratio is 142, and in Kerala it is 196 due to higher life expectancy at birth. The old-age dependency ratio shows an increasing trend in Kerala and is highest among Indian States (Elderly in India 2016, Ministry of Statistics and Programme Implementation, GOI). Kerala, interestingly termed an _emigration pocket‘ of India, the emigration narrative is so common that for every 100 households, 29 households experienced an emigration event in 2011. Given that emigration from Kerala has been traditionally male-dominated, majorly to the Gulf, and involves emigrant men leaving behind _Gulf wives' – the term used for left-behind wives of migrants to the Gulf (Osella & Osella, 2008; Zachariah & Rajan, 2013) – along with older parents (Desai & Banerji, 2008), the burden of care giving is bound to be genedered, i.e., wrested more on women.

Long-term care (LTC) is something that is needed for bed-bound elderly, comprising everyday tasks such as bathing, toileting, feeding, medical administration, etc. This type of care, not intended to cure someone, is needed for the rest of their life. The need for LTC impacts the entire family, and providing such care can be time-consuming, stressful, and exhausting for a familial caregiver. Such demands on a full-time basis in the long-term takes them away from their own obligations including their children, their spouses, and their job. This casts a huge burden on the primary caregiver, and this is more so where emigration is an almost an every household feature. The present study is undertaken in this context, with the purpose to understand and document the life and challenges encountered by the primary caregiver while delivering care for the bed-bound elderly in Kerala.

1.4 SIGNIFICANCE OF THE STUDY

The study pivots round the challenging life of caregivers of the bed-bound elderly population. This study is expected to expose their psycho socio-economic challenges experienced by them during the face of delivering the care for elderly, it also looks into the coping strategies or techniques adopted by the different class groups of caregivers in the society. The advantage of the present study will help to generate a new framework for finding community resources for the underprivileged needy caregivers and also to extend a support network for them from their own community and legislation. So far there are no specific studies done specially on evaluating from different classes of the same society. The researcher believes that this study will help to project the best effective practices adopted by the caregivers in delivering quality care for the bed-bound elderly. This study will also document the availing governmental services and program in regards to the caregivers of bed-bound elderly, by which such information can be provided for those in need of such services.

1.5 CHAPTERISATION

The study follows the below given chapters in the sequence provided below:

Chapter 1- Introduction

Chapter 2- Review of Literature

Chapter 3- Research Methodology

Chapter 4- Case Studies

Chapter 5- Analysis and Discussion:

Chapter 6- Findings, Suggestions and Conclusion

1.6 CONCLUSION

The researcher was motivated to take up this topic due to the cases he encountered during the field work and also interactions with some of the caregivers made him realize the intensity of the pressure they experience on a day to day life. The researcher has conducted the study of caregivers as various themes such as psychosocial aspects affecting the caregivers and their coping strategies adopted to tackle these challenges and to understand the best practices among them. This research will also look into the available community resources which can be suggested to support these caregivers.

CHAPTER II

REVIEW OF LITERATURE

2.1 Introduction:

The present chapter review studies related to the concepts relevant to the study on the caregivers‘ experience, in providing care for the special category termed as bed-bound elderly‖ Hence, one looks at the limitations arriving out of disabilities affecting the elderly, especially the bed-bound elderly, the caregiving, the caregiver, the psychological aspects involved in caregiving and its consequences on the persons involved primarily in caregiving.

Disability:

Disability is a gap between a person‘s capability and the environment's demands (Verbrugge,1990). The change in muscle strength can reduce the physical ability of older adults, especially, in women where the decline in strength occurs most dramatically after the onset of menopause (Jamuna,1995). Some studies state that women get diseases more often but their survival is better than men. In epidemiological terms, women experience greater morbidity but lesser mortality (Mc Clean, 1984). Some of the health problems among Indian elderly women reported being arthritis, hypertension, diabetes, gynecological problems, cancers, anemia, and respiratory problems (Pathak,1975, Ramamurti & Jamuna,1992).

Many studies stated that common health problems seen in aged persons are locomotor problems e.g., osteoarthritis, rheumatic arthritis, vision problems, e.g., cataract, glaucoma, trachoma and hearing impairment, hypertension, chronic bronchitis, diabetes, heart stroke, genitourinary problems, dental and emotional problems, etc. Need assistance from the family members with respect to aging, risk factors should be considered as continuous rather than dichotomous entities. So, elderly care recipients require assistance in daily living activities and instrumental daily living activities due to physical impairment, and also sometimes cognitive impairment. Many studies revealed that older females would be particularly vulnerable to mental disorders because the mental health among elderly women is frequently related to low economic status, widowhood, and social isolation (Jamuna, 1991). All these conditions can make normal daily activities beyond the older person‘s ability to perform needs assistance from family members. Caregivers, who primarily are involved in caring for the elderly are primary caregivers. Families of older adults mainly get caring from family members only, especially, from women, in the family, in any nation (Preston,1984).

Over the past two decades, much attention has been brought to the impacts of caregiving by both social and health practitioners (Pinquart & Sorensen, 2003 a & b &2005). This concern for family caregivers has prompted many aging institutes to designate caregivers as one of the top priorities for social and behavioral research and has led to the creation of numerous fragments for family caregivers (Montgomery, 2007).

Caregivers:

The general consensus in the literature is that, most often, one family member serves as the primary source of an impaired elderly person, although others in the network of family and friends may serve as secondary caregivers. This role of primary caregivers is not uniformly embraced by all potential caregivers, nor is it experienced in the same manner by those who assume the role (Acton & Kang, 2001, Anhensel, Pearlin, Mulan, Zarit & Whitlatch, 1995 Miller & Lawton, 1997; Sorensen, Pinquart & Duberstein, 2002). There is a hierarchy in the selection of primary caregivers that is linked to sex, generation, and geography, when available, a spouse provides the majority of care. In the absence of a spouse, a daughter is most likely to assume the role. Daughters are twice as likely as sons to become the primary caregiver (Campbell MartinMathews, 2003).

Damron Rodriguez & Lubben (2007) elicited that informal caregivers are ―on the clock‖ as formal caregivers are. Time commitment of informal caregivers requires that they respond to unpredictable demands at all hours of the day and night, such as incontinence. Family caregivers have often been referred to as the ‗backbone' of long-term care because most patients are cared for at home by relatives, usually spouses, and these play a key role in care. (Feinberg Pilsuk, 1999).

The crucial role of the sex in the hierarchy of obligation to elderly family members is reflected in the fact that after spouses and daughters, it is the daughters-in-law and not sons who are the next lines of the resort (Ory, 2002). The caregiver role tends to fall to the person with the fewest competing responsibilities, including obligations to the spouse, children, and employees (Brody, 1990; Stern, 1996; Steve O'Donnell, 1989).

Geography also influences the selection of the primary caregivers, in that adult children who live closer to parents are more apt to assume caregiving responsibilities. However, offspring who live distance often provide assistance with financial and legal matters and arrange for the provision of direct care by paid caregivers. Caregivers who are poor health themselves, who have limited functional resources, little or no flexibility at work, and minimal support from others while providing significant amounts of care are most likely to experience serious, adverse impacts of caregiving on their physical and mental health (Lero, 2007). Caregivers‘ self-rated health was found to have a significant influence on caregiver burden such that the poorer the self-rated health, the greater the perceived burden (NAC AARP, 1997, Iecovich, 2011).

High rates of widowhood among the older population and sharing of caregiving responsibilities by siblings, children greatly outnumber spouses as active caregivers (Spillman and Pezzin, 2000). The prevalence of different types of relatives (e.g., spouse, daughter, daughter-in-law, or son) has also been found to differ by ethnicity and income (Dilworth-Anderson & Gibson, 2002).

Daughters and more distant relatives are more prevalent as caregivers in Hispanic and Black people than they are in White people but this trend is moderated among higher-income groups (Laditka & Laditka, 2001). Among Asian groups, sons are more frequently identified as caregivers who assist with instrumental activities of daily living (IADLs) and daughters-in-law are more prevalent as caregivers who provide assistance with household tasks and personal care (Youn, Knight, Jeong & Benton, 1999).

Diversity of Care Tasks:

Caregivers not only differ in terms of their relationship to the care receiver but also in the manner in which they embrace and experience the caregiving role. That is, caregivers differ in what they do it, how long they do it. In general, the closeness of the familial relationship is directly linked to the amount, type, and duration of care provided. As a rule, relatives who are more closely related to the care recipient provide greater amounts of care, as measured by the types of assistance provided, the time spent performing care tasks, and the length of time they are willing to persist in the caregiving role. Hence, spouses tend to provide more care than adult children, and adult children tend to provide more care than do siblings, nieces or nephews, or grandchildren (Delgado & Tennstendt, 1997).

Caregivers provide a variety of tasks for their senior family members/friends and those who are not engaged in eldercare activities are often surprised by the nature and extent of these necessary tasks. Activities associated with elder care include assisting with household tasks, bills, taking them to doctors or other appointments, and assisting with shopping and food preparation, as well as lifting and moving. Approximately, one in four caregivers provides basic personal care in the form of assistance with dressing, bathing, walking, feeding, and toileting. A small percentage provides assistance with wounds and injections (Decima, 2002).

Many individuals may willingly provide care and support to close friends and family members and derive satisfaction from doing so, it has been shown that caregiving can result in significant personal costs to caregivers and to their families costs that can compromise the quality of care provided and the sustainability of family and friend caregiving networks. Significant health consequences, guilt, depression and anxiety; marital/family conflict and more limited opportunities for social interactions with others, sometimes leading to isolation; increased out of pocket expenses; and employment-related costs (absenteeism, reduced hours, work-family conflict, having to quit work or turn down opportunities, are evident in various studies of caregivers (Lero, 2007).

The emotional consequences of caregiving are believed to be widespread. Caregiver strain/burden may be experienced as a sense of being tied down, lack of time for oneself, difficulty in getting a break (Kuuppelomaki, 2004). Common outcomes in literature are feelings of guilt, anger, anxiety, and depression. Depression is the main and largest contributor to caregiver burden and mediated the effects of other variables, such as patient symptoms and social support (Grov, Gossa, Sorebo & Dahl, 2006). One out of four employees experiencing high levels of caregiver strain (physical, financial, or mental stress and sometimes more than one also), primarily as a result of eldercare responsibilities (Duxbury & Higgins, 2005).

Many factors can influence caregivers' health, well-being and difficulties combining work and elder care and one of the most significant predictors of caregiver strain among employees is the number of hours spent each week providing care to an elderly dependent, which reflects a combination of care needs and the lack of other supports. Many caregivers report that a key task is checking in or monitoring the needs and emotional well-being of care recipients (Pyper, 2006).

There is also substantial evidence that within groups of caregivers who have the same relationship to the care recipient, care activities differ by sex (Delgado & Tennstedt, 1997; Mathews, 1995

Montgomery& Kamo, 1989). There is also some evidence that husbands and wives differ in their style of care. Wives are apt to be concerned with the emotional well-being of their husband and frequently undertake tasks intended to maintain continuity of the husband‘s identity. Husbands, in contrast, are more apt to approach caregiving using a management style primarily focused on the physical needs of the wife (Pinquart & Sorensen, 2006).

Few differences in helping behaviors have been reported between daughters and sons assisting parents who have minimal need for assistance. There is, however, strong evidence of differences between daughters and sons when they are assisting parents who have significant functional or cognitive impairment. When parents are severely impaired, daughters provide more hours of care than do sons, performing on a regular basis). Although daughters often seek assistance from their immediate family members, including their husbands and children, they tend to receive less assistance from siblings or distant kin than do sons (Cicirelli, Dwyer & Coward, 1992; Mitteleman, 2003).

Impart, these differences, in care patterns, reflect a difference between sons and daughters in the duration of the caregiving role. Fewer sons than daughters are willing or able to continue in the duration of the caregiving role when the functional level of their parent declines to a level that requires assistance with activities of daily living (ADLs), such as dressing and bathing. Consequently, as a group daughter are more apt to be caring for parents with greater needs for assistance, and the care recipient is more likely to be residing with a daughter than with a son (Brody, Litvin, Hoffman & Kleban, 1995). There has been some speculation that this pattern reflects social norms and taboo (Montgomery & Kamo, 1989) but there is also evidence that these patterns are related to stronger normative ties between mothers and daughters (DilworthAnderson & Gibson, 2002).

In India, after marriage, the daughter resides at the parents-in-law‘s house and the daughter-inlaw leads the role of the caregiver, as son is the responsibility to take care of the elderly parents, which is a normative practice (Jamuna, 2002).

Psychological Behaviour of the Care Receiver:

Looking from a psychological perspective, dependency may be a form coping or means of attaining ―passive control over one‗s environment‖ and pointed out that this perspective is ―consistent with Goldfarb‗s (1969) typology where an older patient may seek control over those around him or her by exhibiting passive and dependent behaviors. In this way care recipients, who may otherwise be perceived as work or helpless, may effectively gain power or influence over caregivers upon whom they are dependent. Passive Dependent behavior may be used by care-recipients to gain attention. Dependency is not simply influenced by biological, but also environmental and societal conditions. The gerontological literature addresses a wide range of dependencies including structured, mental, physical, economic, social, emotional, cognitive, real, pseudo, or neurotic dependencies, analyzed from different perspectives be it at the behavioral, personal situations, or interpersonal level. Sensory disability means persons with vision disability may lead the elderly to feel the tension. Hearing disability of aged people, who are unable to hear normal sounds, creates uneasiness both in the care receiver and also in the caregiver (Kahana &Young, 1990).

Consequences of Caregiving:

An extensive study exists on both positive and negative outcomes of caregiving. The large majority of research that has examined outcomes has been guided by a stress model. The conceptual framework identifies four domains, this makes up the stress process: the background and the context factors include the demographic and ascribed characteristics of the caregiver, the relationship between caregiver and care receiver, and aspects of the social and service delivery environment that frame the context in which care is provided, in common, four factors related to Pearlin‗s stress process are caregiving context; primary stressors; secondary stressors, and potential mediators. Primary stressors are conditions and characteristics of the care receiver that translate into the care tasks and responsibilities that are assumed by the caregiver. These include the care receiver‗s cognitive status, problematic behaviors, and the need for assistance with ADLs and IADLs. Primary stressors may impact negatively on the caregiver and lead to secondary roles and intrapsychic strains. That is to say, primary stressors may produce secondary strains that translate into a subjective sense of role overload and relational deprivation. The secondary strains on the caregiver include constraints on their aspects of the care giver‗s life, including family and occupational role and social and recreational activities, and intrapsychic strains such as loss of self-esteem, loss of self, role captivity and lowered sense of competence. Family conflicts that arise due to caregiving are understood as secondary stressors resulting from the care demands that serve as primary stressors, e.g., cognitive impairment and problematic behaviors. Family is a central arena for secondary role strains. Family conflict and other secondary stressors can directly impact caregiver stress, while also mediating the effect of primary stressors. Thus, the entire stress process occurs in the context of background demographic characteristics (age, gender, socioeconomic status, caregiver-care-receiver relationship, living arrangements and role of family conflict and its role as a potential mediator of caregiver strain. In view of Pearlin‘s model, the elder‘s illness and resulting care activities are seen to occur within the context of uniquely meaningful and continuing family relationships and family member‘s chronic illness or impairment can disrupt existing relationships and signs of family dysfunction resulting in increased distress in leading to caregivers burden in family members who have primary caregiving responsibilities (Pearlin, 1990).

The outcomes of the caregiving stress process may include care depression, a subjective sense of stress or anxiety, and change, in turn, can prompt caregiver physical and mental health. These in turn can prompt caregivers to leave the caregiving role. In general, the negative impact of caregiving can be grouped under four general headings: infringement on time and lifestyle, impacts on the caregiver-care receiver relationship, mental health, and physical health. (Scharlach, Li & Dalvi, 2006).

The bed-bound elderly is elderly who stay in bed for short or long periods for various reasons, including chronic illnesses, old age, and disability. The bed-bound elderly cannot perform selfcare and medical care partially or completely and need the help of others. The bed-bound elderly is usually cared for by family members, paid caregivers, and/or health professionals (Handicap International, n.d.; Vieira, 2015). Family caregivers are defined as relatives and friends who provide care free of charge to individuals with chronic or debilitating conditions (Collins & Swartz, 2011; Sanuade & Boatemaa, 2015). Family members play important roles in the care of the sick and those unable to take care of their own needs. Providing care adversely affects the health and quality of life of the caregiver (Bauer & Sousa-Poza, 2015; Jeong, Myong, & Koo, 2015; Rha, Park, Song, Lee, & Lee, 2015). Caregivers are likely to spend less time with their family and friends, experience increased levels of emotional stress, and neglect self-care activities such as getting a good night's sleep, exercising, and healthy eating (Collins & Swartz, 2011).

Caregivers are at risk of caregiver burden (Chang, Chiou, & Chen, 2010; Chiou , 2009; Roopchand-Martin & Creary-Yan, 2014). Caregiver burden is defined as a multidimensional response to perceived stress and negative assessments that derive from providing care to a sick person (Kim, Chang, Rose, & Kim, 2012). The risk factors that have been identified in the literature as affecting caregiving burden include being female, having a lower level of education, living in the same house with the care recipient, providing care for long hours, having depression, being socially isolated, being under financial stress, and having no choice but to be a caregiver (Adelman, 2014). The caregiver burden threatens the physical, psychological, emotional, and functional health of caregivers (Bauer & Sousa-Poza, 2015; Etters, Goodall, & Harrison, 2008; Ma, Lu, Xiong, Yao, & Yang, 2014). Moreover, caregiver burden is known to be a significant predictor of quality of life (Jeong , 2015; Rha , 2015). Researchers have found that caregiver burden is affected by many factors related to providing care. The health of both caregivers and care recipients impacts strongly on caregiver burden (Rha , 2015; Sanuade & Boatemaa, 2015).

The health of persons receiving care and their degree of dependence affect caregiver burden (Abdollahpour, Noroozian, Nedjat, & Majdzadeh, 2012; Conde-Sala, Garre-Olmo, Turró-Garriga, Vilalta-Franch, & López-Pousa, 2010; Zaybak, Güneş, Günay İsmagloğlu, & Ülker, 2012). Furthermore, caregiver burden affects the level of well-being of the caregiver and, as a consequence, reduces the caregiver's ability to provide good care (Collins & Swartz, 2011; Sanuade & Boatemaa, 2015). Chang (2010) found that the mental health and caregiver burden of care providers were related to the health problems experienced by caregivers. Women make up the large majority of caregivers in family settings (Jeong, 2015; Rha, 2015; Yıkılkan, Aypak, & Görpelioğlu, 2014).

Whereas some research has identified gender as a significant predictor of caregiver burden (Brodaty, 2014; Etters, 2008; Sousa, 2016), some have found no correlation between gender and caregiver burden (Orak & Sezgin, 2015; Roopchand-Martin & Creary-Yan, 2014; Sanuade & Boatemaa, 2015).

Chiou (2009) reported that caregivers with poor social support and family functions have a higher level of caregiver burden and that perceived social support is a better indicator of caregiver burden than the social support actually received. Furthermore, studies have shown that living in the same house with a bed-bound elderly (Adelman, 2014; Conde-Sala, 2010) and having a direct role in that bed-bound elderly's physical care (Sanuade & Boatemaa, 2015) increases caregiver burden. Professional healthcare providers have an important impact on the health and well-being of caregivers (Yıkılkan, 2014).

Nurses may engage in training primary caregivers and support caregivers by aiding in carerelated activities. Thus, nurses have an important role to play in lessening the caregiver burden of care providers (Schulz & Sherwood, 2008).

Nurses are best positioned to make early diagnosis of caregiver burden and to help caregivers avoid/minimize the adverse effects of caregiving (Etters, 2008). Nurses should observe caregivers during their home visits and evaluate them in terms of caregiver burden risk (Etters, 2008; Yıkılkan, 2014).

When a caregiver burden is identified, the perceptions of caregivers regarding the burden that they are taking on may be eased with appropriate interventions (Etters, 2008). Thus, for all of the above-stated reasons, it is important to identify caregiver burden and its related factors, to ensure that caregivers receive support, and to develop, organize, and implement caregiver-burden prevention programs.

Providing regular support to a friend or a relative can entail a number of responsibilities, which, taken together, can create stress and undermine the health of caregivers. Increased life expectancy and better management of chronic care, both positive developments, have nevertheless lengthened the period of commitment for caregivers, affecting their quality of life over the long-term. The responsibilities of care can include meal preparation, cleaning, running errands, helping the care recipient dress and take medication, scheduling appointments, providing transport, and assisting with physical therapy. The intensity of this workload depends in large part on the conditions surrounding the care recipient. The recipient‘s distance from the caregiver, illness type, and geographic/cultural context all play a role in shaping the caregiver‘s experience, and her or his health. Caregivers have, for example, reported skipping doctor‘s appointments, with 57 percent saying that they prioritize the care recipient‘s needs over their own. Fifty-one percent say that they do not have enough time to take care of themselves, and 49 percent say that they do not do so because they are too tired. Additionally, 29 percent say that they experience difficulty managing emotional and physical stress. Caregiving can also pose challenges to mental health. Significantly, 49 percent of caregivers said that they do not feel that they had a choice in taking on their responsibility. Given the challenges of caregiving and the fact that it often comes as an unsought responsibility, it is perhaps not surprising that four in 10 caregivers say that they consider their caregiving activities to be highly stressful, with 38 percent ranking their stress level as four or five on a five-point scale (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Chiou, Chang, Chen, & Wang, 2009).

A study found that the caregiving burden of unemployed caregivers was higher than that of their employed counterparts, indicating that outside employment reduces caregiver burden. A prior study reported that the caregiver burden of employed caregivers is of a lower level compared with that of unemployed caregivers (Sanuade & Boatemaa, 2015).

Another study found that self-employed caregivers had lower caregiver burden scores (Roopchand-Martin & Creary-Yan, 2014). As caregivers who hold jobs outside the home cannot serve as primary, full-time caregivers, their caregiving time is shorter than that of caregivers who are not employed, which may explain why employed caregivers have a lower caregiver burden. Chiou (2009) found that caregiver burden increases as the duration of caregiving. No difference was found in caregiver burden based on employment status. The caregiver burden of caregivers who live in squatter houses or apartments was shown to be higher than those who live in private houses, indicating that living in a private house reduces caregiver burden. This result indicates that physical circumstances may affect caregiver burden. Istanbul is one of Turkey's most densely populated and most expensive cities. Accordingly, it is likely that people who live in private homes in Istanbul are of a relatively high socioeconomic status. As caregivers at higher economic levels care for their elderly in more comfortable physical conditions and are more likely to employ outside help, their caregiver burden may subsequently be less (Yeşil, Uslusoy, and Korkmaz, 2016).

Caregivers of elderly with higher levels of education were found to have higher burdens of care than those of the elderly with low levels of education. As elderly with higher levels of education

have higher life expectancies, they likely have greater expectations from their caregivers. This may increase the burden of care of their caregivers. This study found that the elderly was most commonly dependent on their caregivers for bathing and least dependent for feeding, with results showing that the degree of bed-bound elderly dependency was a significant predictor of caregiving burden. As bed-bound elderly dependency lessened, caregiver burden increased. Concurrently, the caregiver burden of individuals caring for the elderly who were partially dependent because of continence or feeding issues was higher than the burden of those caring for dependent elderly. This outcome suggests that the caregivers of partially dependent elderly may not have been able to accept the additional dependency-related burdens. As bed-bound elderly dependency increases, caregivers tend to feel that the elderly actually do need them and therefore accept the situation, leading to lower levels of perceived caregiver burden. In a study by
Taşdelen and Ateş (2012), as bed-bound elderly dependency grew in terms of ADL, the caregiver's emotional burden lessened, which is consistent with the results of this study. However, contrary to the results of this study, other studies have shown that caregiving burden increases as bed-bound elderly dependency rises (Abdollahpour, 2012, Kim, 2012, Zaybak, 2012).

It is important that further qualitative studies be conducted to discover the reasons for these outcomes, so that appropriate interventions may be designed to lessen the burden of caregiving. Other studies have also found that most caregivers are women (Rha, 2015; Unver, Basak, Tosun, Aslan, & Akbayrak, 2016 Yeşil, 2016). Whereas the univariate analysis revealed a higher level of caregiver burden in female caregivers compared with male caregivers, the multiple regression analysis did not reveal a significant relationship between gender and caregiver burden. Similar to the results of this study, other studies have not detected any significant relationship between gender and caregiver burden. However, other studies still have pointed to female caregivers having greater levels of caregiver burden than their male counterparts (Sanuade & Boatemaa, 2015; Sousa, 2016; Unver, 2016). These results reveal that the burden of caregiving in women may be affected not only by gender but also by normal responsibilities such as housework and childcare, by personal characteristics, by employment status, and by other relevant factors. Although the burden of caregiving was found to be higher in caregivers aged 56 years and above, age was found not to be a significant determinant of this burden. Similarly, other studies have shown age not to significantly impact the burden of caregiving. Despite this, it is still believed that the older a caregiver is, the higher the caregiving burden may be because of age-related health problems and physical limitations. It was found that caregivers with 2 or more years of caregiving experience had a higher level of caregiver burden than those with durations of care of 1–6 months and 1–2 years (Orak & Sezgin, 2015; Roopchand-Martin & Creary-Yan, 2014; Sanuade & Boatemaa, 2015).

Similar to the results of this study, Çetinkaya and Karadakovan (2012) found that longer caregiving durations were positively associated with higher caregiver burden. A study by

Yıkılkan (2014), caregivers who cared for their elderly for more than 3 years had higher levels of depression and anxiety than caregivers with shorter caregiving durations. Regression analysis showed that the duration of caregiving was not a significant predictor of the burden of caregiving. This finding is an important outcome, as it shows that caregiver burden is associated with more than only the duration of the caregiving. It may be that long-term caregiving results in Caregiver Burden in Caregivers VOL. 27, NO. 3, JUNE 2019 7 higher caregiver burden because of the increases in frequency and severity of physical, mental, and social problems. The caregiver burden of caregivers who were required to meet all of the needs of their elderly was higher than that of caregivers who met only the financial needs or provided psychological support to their care recipients. Multiple regression analysis found no significant relationship between areas of care and caregiver burden, found that those caregivers who met all of the needs of their elderly had a higher level of caregiver burden (Mollaoğlu, Özkan Tuncay, and Kars Fertelli, 2011).

Moreover, Sanuade and Boatemaa (2015) found that caregivers who provided only financial support and caregivers who received outside financial and physical support had lower levels of caregiver burden. Caregivers who provide the elderly with only financial or psychological support are not primary caregivers. In these types of cases, the main caregiver is usually another member of the family, and the caregiver's burden is less compared with those who must meet all of their elderly' needs. The cross-sectional approach used limits its generalizability to similar populations only. In addition, the self-report nature of data collection potentially limits the accuracy and generalization of results. The relatively large sample size is a strength of this study. Future studies should consider more complex variables dealing with caregiving as predictive variables (e.g., caregiver-perceived social support, coping strategies, daily care hours, having help available at home, and number of caregivers). Furthermore, in line with the results of this study, it is recommended that experimental studies be carried out to evaluate the effectiveness of nursing interventions that are carried out to reduce the caregiver burden of individuals who provide care to the bed-bound elderly (Aysun Bekdemir, June 2019).

The burden of care was also associated with caregiver stress, but after adjustment, the number of hours per day spent caring for the bed-bound elderly and not the bed-bound elderly's dependencies in ADLs was significant. Stress scores increased, on average, four points when caregivers reported caring for the bed-bound elderly 8 or more hours per day. Caregivers who spend long hours with the elderly may be less able to meet their own needs for socialization. Indeed, the principal component analysis of the stress score indicated that isolation was a prominent variable in the first three factors that explained 85% of the total variance of the score. Our findings are consistent with those published in a recent British study of the caregivers of bed-bound elderly. In that study, nearly half reported that caregiving had affected their social lives. Recent U.S. studies also document the restriction of social activity or isolation caused by caregiving and the importance of a social network in caregiver health (Chiou, 2009).

Women who spent more than 8 hours each day caring for their elderly and who identified themselves as being in poor health were at high risk for caregiver stress, with stress scores (range: 6–30) that were over 11 points higher, on average, than male caregivers who spent less than one hour caring for elderly and who perceived their health to be excellent. Although the majority of caregivers in our unselected group were not seriously stressed by caring for their older relatives, 25% of caregivers had scores of 15 or greater, levels that might be associated with clinical depression or anxiety. Several of the factors that we identified as associated with caregiver stress are potentially modifiable. For example, assistance can be found for caretakers, and elderly' depression and hearing impairment can be treated (Norman A. Desbiens, 1 April 2001).

Positive Outcomes of Caregiving:

Although, widespread agreement exists that caregiving has negative consequences for many caregivers. Positive outcomes were also observed including a sense of mastery, positive affect, and an improvement in the quality of the dyadic relationship between the caregivers and the care recipients (Beach, Schulz, Yee & Jackson, 2000).

There is also growing evidence that feelings of caregiver satisfaction or gratification may be linked to subjective meanings attributed to the caregiver‘s role. One of the relationships between loss of self and self-gain is that some caregivers may feel that they have grown as a result of their experience does not protect themselves from suffering a loss of identity (Skaff and Pearlin, 1992).

29 studies that focused on positive gains; she argues for research that focuses on the positive aspects of caregiving. She suggests that understanding the positive gains may enable professionals to work more effectively with families and may enhance theories of caregiving adaptation and well-being. These findings support the proposition that there are uplifts in the caregiving experience that may prevent the stress of caregiving from dominating all spheres of life. (Kramer, 1997).

Love and intimacy appraisals were not related to burden, but were associated with improved psychological well-being. Similarly, in a qualitative study conducted and found that predominant themes of caregiving meaning included gratification and satisfaction, family responsibility and reciprocity and friendship and company (Braithwaite, 2000).

Caregivers who view caregiving as a fulfilment rather than a ―sacrifice‖ commonly ―felt good about fulfilling an obligation‖. Burrac Weiss opposes Beever and Muller (1992) notion that caregiving often leads to ego ―despair‖ as opposed to ―ego integrity‖. Healthy caregivers have been found to benefit more than frail elderly caregivers. Maton (1987) found that healthy caregivers support the act of providing care itself. Frail caregivers that were unable to perform certain caregiving duties tended to view a sense of failure and helplessness in their ability to deliver care. It is important that studies regarding caregiver burden maintain an awareness of the benefit of care giving in order to maintain a non –biased view that the act of caregiving is not necessarily a negative experience (Mutchler & Buller, 1994).

Use of emotion-focused coping strategies found associations with negative outcomes, with caregivers being less able to regulate their negative emotions compared to controls (RuizRobledillo and Moya-Albiol, 2013).

Caregivers using fewer positive strategies (e.g. engaging in pleasant activities and seeking social support) and greater negative coping strategies (e.g. self-blame and avoidance) reported poorer psychosocial outcomes and adjustment compared to non-caregivers (Mausbach, 2013).

Providing long term care to elderly relatives is associated with a variety of negative consequences for caregivers. The physical and psychological, work related stress associated with caregiving roles have received considerable attention in the recent Gerontological literature (Horowitz, 1985).

Caregivers on average exhibit greater levels of psychiatric symptoms such as depression, demoralization, on self-report measures than appropriate comparison groups. There is also some support for increased clinical psychiatric illness requiring professional intervention among some caregivers (Cohen & Eisdorfer, 1988; Gallagher, 1981).

Several studies revealed that caregivers find certain behaviors of care receivers to be particularly stressful. These include the patient's lack of impulse control, anger, self-absorption, inability to show enthusiasm, poor coordination, poor concentration, paranoia, withdrawal, aggression, repetition of words/actions, bizarre behavior, severe mood swings, verbal or physical aggression, sleeplessness, wandering and sun downing (Lisa Nirenberg, 2002).

Sherwood, (2005) stated that the care recipient‘s mental and functional status and regency of providing care demands predicted depressive symptoms. Health care practices only can assist the caregivers with new demands stemming from care receivers mental and functional status to decrease the stress. Care giver‘s emotional aspect, vitality and mental care are the most affected dimensions. The most affected caregiver‘s burden scale dimensions were general strain and environment also (Angelica, 2006).

Care recipient‘s activities of daily living (ADLs) impairment being a woman caregiver living with care receivers, reporting poorer quality of relationship with anxiety disorder due to care recipient‘s irritability nature. High rates of depressive symptoms in family caregivers at a risk for psychological morbidity and should be treated energetically (Cooper, 2007). The effect of caregiving stress has consistently been documented and includes psychological consequences (Bullock, 2004; Pickett-Schenk, 2006). Depression is the most commonly observed as a psychological consequence of caregiving (van-Wijingarden, Scheme & Koeter, 2004).

Researchers review that family caregiving has been associated with elder care with adverse health effects on the caregiver, including difficulty in sleeping, frequent headaches and weight loss or gain (van Exel ,2005). Extremely high levels of stress may lead to self-neglect, elder abuse and granny dumping (Lund, 1993).

Gupta.R, (2007) stated the psychological consequences of caregiving creates constant fatigue, feeling overwhelmed by the problems in caring the elderly, getting discouraged by role of caregiving, experiencing hatred of life changes caused by role of caregiving and feeling that at this time of life he or she should not be in apposition of caring for the elders. Research studies testify that there is a link between caregiving stress and increased risk of depression and anxiety (Cooper, Balamurali & Livinston, 2007; Dunn Burbine Bowers & Tantleff-Dunn, 2001; Majerwitz, 2007; Pinquart & Sorenson, 2003).

Family caregivers who experience negative feelings due to caregiving have been found to report such as depression, poor health by report, guilt and worry (Cohen, 2002; Sethi, 2011). Indeed, higher levels of stress of caregivers appear to be potential contributors to symptoms of depression and anxiety (Beach, Schultz, Yee & Jackson,2000, Cooper , 2007; Garand, Dew, Eazor, Dekosky& Renolds,2005), and at risk of four mortality in older caregivers (Schulz & Beach,1999) and constant stress in overtime (Vedhara, Shanks, Anderson& Lightman, 2000).

Sleep disturbances, depression and anxiety seen in various caregiver groups (Brummett, 2006; Flaskerud, Carter& Lee, 2000; Mc Curry, Logsdon, Teri & Vitiello, 2007; Wilcox & King, 1999). Sleep quality and feeling of isolation, are mediators in the relationships between care giving strain and burden and psychological morbidity and considered as potential mediators (Phillips, 2009). Sleep quality predicts depression (Livingston, Blizard& Mann, 1993) and to improve sleep quality resulted in psychological morbidity in caregivers (Carter, 2006).

A negative impact of caregiving on the mental health of caregivers is substantiated in a population based on study in which differences in well-being between caregivers, as a group and non-caregivers were demonstrated. Intimacy and love in the relationship between caregiver and care recipient have been associated with lower levels of minor psychiatric symptoms and burden (Braithwaite, 2000) and the quality of relationship between care recipient and caregiver who is the parent may have an influence on ability to satisfy family function. It has also been suggested that depressive symptoms, anger and resentment may be experienced by caregivers in very close or enmeshed families if they have taken on the caregiving role to confirm to family rules (Schofield, 1998).

Negative Consequences of Caregiving

Physical health problems: Physical disability of care recipients affects the caregiver‘s health, work and finances. Physical disabilities would consider loco motor / orthopedic disabilities. The relationship of health outcomes to care giving is an important both in itself and is as much as it affects the caregiver's capacity to provide ongoing care to the care recipient with functional impairments (Summer & Shields, 1987). Providing care to frail elderly, persons can involve a considerable amount of physical labour, supervision, and vigilance. Heavy lifting and turning, frequent bedding changes, dressing, toileting, bathing and an increased amount of cleaning, washing clothes can put physical strain on caregivers. Researchers noted that violence and aggression mostly occur while providing personal care that require physical contact such as bathing, dressing etc. (Ware, Fairburn & Hope, 1990).

Health related outcomes associated with providing care to the functionally impaired elderly, illness effects are assessed using measures of self-reported health, presence of particular illness, use of health and medical services and objective physiological measures (Schulz 2000).

Researchers have shown that numerous demands, including greater assistance in ADLs or IADLs of care recipients, longer care giving duration and more hours of care are associated with poor adjustment of caregivers (Pinquart & Sorensen, 2003, Schulz, 2005).

Negative effects of caregiving on the health of caregivers have also been established, as well as decreases in the rate of wound healing. Women have been found to be less likely to engage in preventive health behaviours such as time for rest and exercise, when compared to men(Burton, 1997). In addition, cardiovascular changes such as increase in blood pressure have also been found. Lack of time to devote to self-care and preventive health behaviours due to long term negative health outcomes for caregivers, in addition to direct effects of objective burden and depression (Vitaliano, Young & Zhang, 2004).

B. Mental health and Psychological problems: Psychological disability of care recipient affects the certain factors that predict caregiver‘s distress such as the presence of patient‘s behavioral problems. Certain factors predict care giver‘s distress such as the presence of a patient's behavioral problems, the nature of the support and ability to cope with difficult situations. A 1992 study by the Carers National Association found that one of every two caregivers had financial burdens and two of every three caregivers were ill themselves and many studies document depression, marital problems, stress, fatigue, and social problems. Family caregivers of older adults provide care and support in health, emotional and financial domains, particularly who are frail or suffer from chronic illness (Aswey & Kleinpeter, 2002; Koh & Mc Donald, 2006).

Many findings generally indicate that providing high levels of care to dependent relatives, whether they are chronically ill (Manjoney & McKegney, 1978) or acute ill (Herz,1976) mental ill adults (Lefton, 1962) produces difficulties for caregivers. The majority research studies have shown that because of the burgeoning demands for care represented an increased number of frail elders since 1960 about the experience of caregivers of the elderly affects the psychological health of caregiver (Barer & Johnson , 1990 ; Given & Given,1991). Emotional strain is generally felt to be the most prevalent and difficult aspect of caregiving (Cantor, 1983). Impacts on mental health have been variously conceptualized as care distress, burden strain, depression and psychological wellbeing. Care stress or strain is linked to both the functional level of elder and the activities of the caregiver (Chappell & Reid, 2002).

In general, the demands of assisting with personal care and dealing with problem behaviours of the care recipient and the need for constant supervision are stressful and lead to psychological distress, changes in social activities and negative feelings about caregiving (Levensque, Cosette & Laurin, 1995; McKinlay,Crawford & Tennstedt, 1995; Montgomery, 1989). Increase in depression and anxiety have been reported by caregivers (Schulz , 1997; Schulz, O‘Brien, Boodwasa & Fleissner, 1995) and increased psychotropic drug use by caregiver, reflecting negative psychological effects of caregiving (Sleath, 2005).

Caregiving Burden

Caregiving burden is commonly identified as ―a state resulting from the necessary care of an impaired older adult that threatens either the physical or psychological wellbeing of the caregivers‖ (Zarit, Reever & Bach, 1980; Zarit, Todd & Zarit, 1986).

Caregivers must deal with responsibilities of looking after a loved one and the emotional loss resulting from the care recipient‘s deterioration. Ory, 1999 stated that 44% of caregivers reported that their caregiving activities caused physical strains, and one quarter reported that caregiving was emotionally stressful. The provision of care for an older person with limited functional abilities can have a number of harmful outcomes including less time for work and leisure, less of privacy, constricted social networks, deteriorating relationships with the care recipient and other family members stress, anxiety, depression and even a possible 54 deterioration of the care giver‘s physical health (Aneshensel, 1995; Neal, 1993; Ory, 1999).

A number of studies have addressed the research question about the specific factors that lead to caregiving burden and stress. Within the care giving dyad, burden is related to characteristics of both caregiver and care receiver. In addition, the nature of the caregiving role, such as tasks and demands also influence perceived burden. However, mitigating factors buffer the impact of burden such as resources and social support within the existing literature on caregiving burden (Kramer & Kipnis, 1995; Miller, 2001; Monahan & Hooker, 1995).

However, while daughters-in-law were more likely to have a higher level of burden (Kim, 2001; Lee, 2002), the spouses of impaired elders experienced a higher degree of burden (Franks & Stephens, 1996; Miller & Guo, 2000; Monahan & Hooker, 1995).

The nature of the caregiving role, including the associated tasks and demands is also related to perceived burden (Barush & Spaid, 1989; Hannappel, Calsyn & Allen, 1993, Stull, 1994).
Several studies reported correlations between the care recipient‘s level of impairment, including functional and cognitive disabilities and caregiving burden (Kim & Lee, 2003; Lee, 2002; Yoon, 2003).

The ability of the caregiver to assume care demands has also been studied. Research has consistently shown that health status and the responsibility for additional dependents other than the elder care recipient, were significantly related to caregiver burden (Biegel & Schultz, 1999; Bullock,Crawford & Tennstendt, 2003; Burns & Robins, 2000; Call, Finch, Huck & Kane, 1999; Pratt , 1985; Thomas , 2002). Family caregivers who were less capable, due to their own health or rival responsibilities, report high levels of burden (Choi, 1993).

Research on social supports has also investigated how both formal and informal support impacts on caregiver burden. A consistent finding is that support, whether formal or informal attenuates burden. Caregivers who use formal services, such as in-home nursing and respite care report lower stress levels (Miller et al, 2001; Monahan & Hooker, 1995). In addition, a lack of social support generally increases role-related stress for care providers. Caregivers who report little support from

55 family members other than the care recipient have reported more intense burden (Clipp & George, 1990; Franks & Stephen, 1996; Kim, 2001; Kim & Lee, 2003; Yoon, 2003).

Caregivers may initially lack care giving skills, information and knowledge regarding community resources and stress management skills (Chipperfield, 1994). Bass (1990) found that regular exercise, proper nutrition and the improvement of relationship skills are positive methods for coping with caregiver burden. A common misconception about caregivers' burden is that the severity of burden is strongly related to the severity of the elderly bed-bound elderly‘s disabilities. Zarit‘s two-year longitudinal study found that caregiver burden decreased as the care receiver‘s health declined. It was concluded that caregiver‘s psychosocial and physical burden decreased because they had learned to manage caregiving duties more effectively and had established daily routines (Zarit 1986).

Hirst and Metcalf (1986) studied caregiver learning needs and found that burden can be reduced by providing the caregiver with information on the care receiver‘s impairment and the severity of the impairment. Smith, (1991) experience with counselling caregivers found that , in addition to medical and resource information needs caregivers also have ― psycho social needs".
Psychosocial needs include learning better coping skills, counselling, and skills to ―ventilate distressful feelings‖. Psychosocial burden is a major cause of caregiver burnout. Psychosocial burden is more debilitating than financial or physical burdens. Wright (1991) found that denial, anger, guilt, depression and frustration are emotions frequently experienced by caregivers suffering from psychosocial burden. Greenberg, (1992) conquered Wright, and stated that
―Symptoms of depression, anxiety, feelings of helplessness, lowered morale and emotional exhaustion all have been associated with caregiving (Orondecker, 1991).

The functional problems (i.e., eating, sleeping etc.,) can place a high degree of burden upon the care giver‘s time and psychosocial wellbeing (Beever & Miller, 1992). The frail or sick care receiver may also wander at night, refuse food, or have difficulty in eating, all contributing to social burden experienced by the caregiver (Orondecker, 1991). Caregiving commonly leads to significant decrease in the care giver‘s social activities. Caregiving may isolate the main care provider ―from previous, current and potential sources of social and emotional support such as relatives, friends, hobbies and community support groups (Miller & Montgomery, 1990).

Conflict between family members regarding care (i.e., institutionalization versus home care) causes stress and tension that further isolates the main caregivers from family support systems. This isolation further contributes to the care giver‘s burden (Gottleib, 1991).

Caregivers that are employed as they report experience greater levels of physical burden. Complementary formal services such as home care for physical tasks such as lifting, bathing, transferring and toileting, can reduce the risk for physical strain and or injury of the caregivers (Herlitz, 1997).

Employed caregivers may experience higher levels of physical burden; however employment has been found to reduce emotional burden. Employment has been found to reduce social isolation and offers a distraction from the worries associated with caregiving (Stull, 1994).

Beever and Miller, (1992) contend that the role change from being a marital partner to a caregiver causes the caregiver to develop role confusion. A sense of despair, dread and helplessness overwhelms the caregiver and robs them of the chance to fully develop ego integrity during the final part of their life stage. Ego integrity versus despair was a concept developed by Eric Erickson. Ego integrity versus despair is considered to be the final developmental life stage where individuals search for the meaning that their life has had. The individual accepting the self and all of humanity characterises ego integrity. The individual being disdainful or bitter towards the self and society characterizes despair. Caregiving may be considered as a role, as those who engage in it seem to identify themselves with the tasks involved (Longress,_1990).

Reducing Caregiver Burden

Singer (2005) studies supported the pivotal role of ―support systems" in meeting both physical and emotional caregiver needs in defusing the negative and positive outcomes of caregiving. National reports of Germany, Italy, Poland and, 57 based on interviews, Haff and Hamblin(2011) pointed out the necessity of caregivers to pursue or ask for help when needed and importance of supporters in having both knowledge of the care context and an appreciation for the care offered as a prerequisite to being able to truly offer caregiver emotional support. Caregivers may pursue assistance leading to an alleviation of physical and or emotional burden, by such means as seeking out advice or information for care tasks, health promotion or counselling resources, and the setting aside of dispersing time where possible. Caregiver well-being and health have been found to be influenced by the quality of resources available to assist caregivers in coping with stress (Dilworth-Anderson, 2004 Byrd, 2011).

The increasing research evidence regarding ―the crucial role of families, their care commitments, and their ensuing need for support. They likewise note an increasing awareness that caregivers need be supported as a necessary precondition to mobilize careers in the future. Thus, when the informal resources of family and one‗s support networks are not sufficient to alleviate undue burden, the availability of public resources may be the only remaining hope of assistance for struggling caregivers in the present and safeguard for the availability of caregivers in future. Casado, van Vulpen & Davis (2011) reviewed that associating behavioural problems of care recipients with negative effects on caregiver well-being including psychological and emotional distress, increases in caregiver burden and risk of illness, and general health problems (Johansson & Sundstorm, 2006).

Physical and Psychological Health and Well-being of Caregivers

Early research of caregiver burden mostly focused on the impact of family and informal care settings of mentally ill relatives transitioning from institutions back into the home. These studies did not generally look at the physical or mental health outcomes of caregivers. But since that time, researchers have gathered an increasingly large pool of evidence that for some caregivers, particularly those providing car to chronically ill family member (Pinquart & Sorensen,2003, Schulz, O‗Brien, Bookervale & Fleissner,1995; Roth , 2009;Chang ,2010), there may be psychological and as well as physical consequences(Chang,2010). For a half a 58 century now, exposure to stress has been associated with a number of physical and psychological problems. Among the health consequences that may be associated with caregiving are decreased levels in preventive health behaviours, immunity, and risk of mortality (Butler, 2005). Recent research supports the physical-psychological health link connection, which proposes that mental health influences caregivers‗ physical health (Chang, 2010; Knight & Losada, 2011; Savundranayagam, 2011).

Knight & Losada pointed out that psychological burden is associated with negative physical outcomes for caregivers, including lower antibody and higher stress hormone counts. They argued that these negative outcomes may cause mortality among caregivers reported strain (Knight &

Losada, 2011). Some researchers suggested that the most significant negative and pervasive (Stuart & Hansen, 2006) consequence associated with caregivers may be in the emotional or psychological domain. Based on research, Ravies, (1990) documented a variety of potential psychological outcomes for caregivers, including increased levels of depression, anxiety, helplessness, hopelessness, emotional exhaustion, low morale, and distress, feelings of isolation, guilt and anger. In particular, potential sources of stress include competing demands, children rearing and employment (Stuart & Hansen, 2006).

Stressors evoked in social relationships in general have been found significantly related to levels of psychological well-being. The convenience samples can provide consistent evidence of stronger effects on the mental health of caregivers caring for individuals with dementia (Knight& Losada, 2011). Badler, (2005) reported high correlations of both caregiver burden and depression with study measures including, isolation, knowledge of caregiver tasks, caregiver task difficulty, and family support, and they found that demographic variables (like age, gender, education and employment) do not predict depression, but ―suggest that caregivers across age, gender, and education categories are vulnerable to caregiver burden and depression but their sample was relatively small. Chiriboga, (1990) found that strong correlation between both care-specific and general caregiver stressors, particularly those perceived as a hassle and related to work and social relationships, were strongly correlated to indices of wellbeing. 59 Caregiver wellbeing and health have been found to be influenced by several factors, including caregiver and care receiver demographic characteristics, care related stress levels, and quality of resources available to assist caregivers in coping with stress (Byrd, Spencer & Goin, 2011).

Caregiver research identifies possible adverse effects of stress upon both the psychological and physiological health of caregivers. Saldana, (1999), reviewed that rural caregivers, in particular, as being susceptible to poorer psychological and physical health outcomes due to stress resulting from relative isolation and decreased available support, cited associating behavioural problems of care recipients with negative effects on caregiver wellbeing, including psychological and emotional distress, increase in caregiver burden and risk of illness, and general physical health problems. The link between caregiver and care-recipient well-being however, is not well established, especially in countries with more family-oriented care structures, which is typical of Eastern Countries (Keith, 2013).

Caregiver Interventions in Western Countries

Caring for a disabled family member can be challenging, potentially impacting caregivers‘ health, mental health, work, social relationships, and quality of life. To alleviate caregiver stress, enable caregivers to better cope with the demands of caring for a loved one, and improve caregiver and care recipient outcomes, many interventions have been developed. However, although programs supporting caregivers have proliferated, there exists limited research regarding their 64 effectiveness. The National Family Caregiver Support Program (Older Americans Act Amendment of 2000) examined and identified five service areas. 1. Information to caregivers about available services; 2. Assistance to caregivers in gaining access to these services; 3. Individual counselling, organization of support groups, and caregiver training to assist caregivers in making decisions and solving problems relating to their caregiving roles; 4. Respite care to enable caregivers to be temporarily relieved from their Caregiving responsibilities; and 5. Supplemental services, on a limited basis, to complement the care provided by caregivers. In general, a variety of caregiver support services are useful in alleviating caregiver strain and helping caregivers to provide care. The magnitude of their utility, however, is impacted by a variety of factors: (1) the outcome chosen for measurement; the caregiver‘s background characteristics, including their psychosocial strengths and vulnerabilities; and (2).the care recipient‘s type and level of impairment. Interventions in one service area, though useful, have not been found to be as effective as programs utilizing more than one intervention. The success of these multi-component caregiver interventions may be associated with services that address a wider variety of caregiver concerns for diverse groups of caregivers. The key is to find the best combination of services to meet the diverse nature of caregiver needs and experiences (Older Americans Act Amendment of 2000). Making meaningful decisions about one‘s caregiving situation is difficult, unless adequate and complete information is available. Indeed, some consider information, advice, and referral to be the most needed caregiver services (Friss, 1990), for even when services are available, many caregivers remain unaware of them (Maslow & Selstad, 2001).

However, it is important to note that the need for information goes beyond how and where to get help. Information regarding health conditions and their implications, care needs, costs of care, and how to plan for future care needs also is important for caregivers (Feinberg, 1997). As a result, most caregiving interventions strive to increase the caregiver‘s knowledge of available 65 services, the recipient‘s disease, and caregiver challenges and solutions (Kennet, Burgio, & Schulz, 2000).

Caregiving affects a caregiver‘s work and family finances, such as balancing a job and providing care to family members. Financial costs refer to direct momentary costs related to paying for the caregiving expenses while some are related to the forgone financial or monetary costs in employment due to one having to perform a caregiving role. Not all the financial costs could be measured by momentary values as some costs are subjectively indicated by individuals as perceived financial costs (Haddock, Zimmerman, Lyness, & Ziemba, 2006).

However, studies that have been done on the effects of information-only services have not shown evidence of Caregiver Support Interventions positive mental or physical health-related outcomes. NFCS Programme on intervention studies revealed that using information-only as the ―usual care‖ or control condition, suggests that while increasing caregiver‘s knowledge is important, it is not a sufficient intervention in and of itself. Assistance Gaining Access to Services Information about available services does not necessarily translate into caregiver service utilization. Program and service planners, along with policy-makers, must consider five key elements when analyzing why caregivers may not be using services: availability, accessibility, appropriateness, acceptability, and affordability. First, services needed by family caregivers must be available in their community. Second, these services must be accessible. A caregiver may find difficulty arranging for respite care if the respite worker must commute an hour, or if the nearest adult day care centre increases the caregiver‘s daily commute to work by an additional hour. Support groups or counselling services must be located conveniently enough for the caregiver to arrange for a respite worker and make the appointment within a reasonable amount of time. Service accessibility applies not only to physical location of services, but to the structure of service delivery as well. Working hours must be such that the caregiver can reasonably utilize the formal support network. Third, offered services must be appropriate to the caregiver‘s needs (Kennet, 2000).

There may be a plethora of counselling and support group services in a particular locale, though caregivers may have a more dire need for education and training relating to their relatives‘ mental or physical limitations. Fourth, services must be culturally appropriate and acceptable to the caregiver. Service providers must understand that the cultural position towards familial responsibility and requesting help from those outside the family can be dramatically different from culture to culture. Cultures hold differing expectations about family responsibilities and appropriate sources of support for caregivers. The 66 value placed on individuality as compared with familial consensus or elder/leader authority varies across cultures. This can result in differing perceptions regarding the utilization of formal services. Furthermore, services must be linguistically accessible in terms of native language, as well as in terms of level of education within that native language. Fifth, services must be affordable to caregivers (GallagherThompson, Arean, 2000).

Caregiver consideration of the affordability of services will not only include financial costs, but also costs in terms of time, effort, potential loss of confidentiality, and potential family conflict. Service utilization and behaviour change recommended by service providers, or expected by agencies in order to receive services, have direct and indirect costs. Caregivers must be able to reconcile the perceived costs of service utilization with the perceived benefits. Services with narrow selection criteria or high costs/co-pays significantly undermine the availability and accessibility of formal services for many caregivers. Minimizing such costs increases the likelihood of caregiver service utilization. It is important to note that simply being provided a brochure or phone number may not be as beneficial as actual linkages to services, in a study by (Weuve, Boult, and Morishita, 2000).

Caregivers who were provided a detailed care management plan and linked directly to services reported less caregiver burden than a control group, which was only provided written information and service referrals. In fact, though the control group was provided detailed literature, many in the control group could not recall that they received any information or could not find the literature. Caregiver Support Interventions Another study by Braun and Rose (1994) evaluated the impact of case-managed in-home care on caregivers, which included the direct linking to, or providing of, services to the experimental group. Caregivers receiving the services reported a decrease in time caregiving, a decrease in burden from caregiving, and a decrease in time-off from work for caregiving duties (Cole, Griffin, & Ruiz, 1986).

Though there is little research evaluating how effectively caregivers are assisted in utilizing services, there exists a strong implication from these two studies that directly linking clients to services, either through on-going case management or as a ―linkage‖ activity, increases the utilization of services and has a positive impact on caregivers. 67 Additionally, caregiver and family needs typically vary across the course of a disease as well as in response to life changes. Information and services useful at one point may not be helpful at another; further suggesting that periodic or ongoing assistance is often warranted. Counselling, Support Groups and Training: Counselling services offered to caregivers vary greatly. Counselling may include, but is not limited to, traditional psychotherapy, individual problem-solving, couples counselling, group counselling, and family treatment. Counselling, whether conducted in an individual, group, or family format, typically strives to relieve caregiver depression and/or anxiety, resolve pre-existing personal problems which complicate care giving, mollify conflicts between the caregiver and recipient, and/or improve family functioning (Casado, vanVulpen, and Davis, 2011).

Many studies have examined the effectiveness of these various types of counselling services. In 1996, Bourgeois, Schulz, and Burgio did a comprehensive review of over 100 Alzheimer‘s disease caregiver intervention studies and found that individual Family Caregivers in California counselling interventions have shown positive outcomes for narrowly defined problems. Group counselling, however, failed to yield a similar magnitude of effects. These differences between individual and group counselling were related to variations in individual caregiver goals and needs. Daughters and daughters-in-law of frail elderly parents have been found to make greater gains in psychological functioning and wellbeing when receiving individual counselling than group counselling; group interventions, however, produced greater improvements in caregivers‘ social supports (Toseland, Rossiter, Peak, & Smith, 1990).

These results suggest that the types of problems and issues specific to an individual caregiver might be the most appropriate intervention determinant (Toseland , 1990). Other studies have looked at family counselling approaches with caregivers. The effectiveness of family counselling is being evaluated in Miami with Cuban American and Caucasian caregivers. This program, the Family-Based Structural Multisystem In-Home Intervention, provides family counselling that tries to identify existing problems in communication and to produce changes in interaction patterns that allow the caregiver to harness available family and community resources. The focus of change is not just the individual or the 68 environments, but rather the transaction between the two, which is viewed as embedded within larger social and cultural systems. Preliminary data suggest that this intervention, when combined with technological support that links family caregivers to other family members and community resources, yields positive mental health outcomes, especially for Cuban American caregivers (Czaja & Rubert, 2011).

Other researchers have looked at the relative effectiveness of psychotherapy or counselling based on different theoretical orientations, finding that caregivers with Caregiver Support Interventions particularly high levels of emotional distress, depression or anxiety can benefit from various approaches. For example, GallagherThompson and Steffen (1994) found that psychodynamic therapy and cognitive behavioural therapy were effective in significantly reducing clinical levels of depression in a sample of 60 family caregivers caring for a person with dementia. This same study also found that psychodynamic counselling proved to be more effective with caregivers who had more recently become caregivers, but cognitive behavioural counselling therapy was more effective with those who had been caregivers for a longer period of time (Coon, Schulz, & Ory, 1999).

Caregivers and the Bed-bound Elderly in India and Kerala

An extensive review was essential to develop a broad knowledge base for the study as well as to identify the deficits in the existing literature related to the research question. It is very essential for the development of the conceptual framework for the study. ―Aging and elderly‟ has already been recognized as an important area of research in developed countries. But, in developing countries like India, it is a growing field. In that, research relating to bed-bound elderly is very rare. Most of the research related to the aged considered elderly as a single group and hence, adequate representation was not given to the bed-bound elderly. There is also dearth of literature related to the care and support of the elderly, especially to the bed-bound elderly. Care of the elderly, in many situations, was studied in the context of specific conditions like Alzheimer‟s disease, Diabetes mellitus, Stroke, depression etc. The review of literature relating to the present study has attempted to address the caregiving to the bed-bound elderly in the physical, psychological, social and economic aspects. Attempts have been made to assimilate a broad knowledge base from national as well as international literature (Lopez, Lopez-Arrieta & Crespo, 2005).

Family caregivers are usually spouses, children, siblings, relatives or friends throughout the world. Haekyung (1993) conducted a study on caregiver burden for impaired elderly among 169 family caregivers of non-institutionalized elderly in South Korea. The elderly were of 60-86 years and

98% had limitations with at least one ADL. The age of caregivers was between 16-82 years with average age 51.8 years. Women dominated in caregiving (87.6%). One third were wives of the elderly, 23.7% were daughters- in- law, 14.8% were married daughters and 8.9% were others. Among the caregivers, 89.3% were married, 7.1% were never married, 3% were widowed and 0.6% were divorced. Less than one third-had part time or full-time job. Results from Spain also showed that the majority of the informal caregivers were women. The study was carried out among 111 caregivers of elderly whose mean age was 59.7 years. Majority of the caregivers were women (82%). A considerable percentage was married (73.9%) and had secondary education (50.4%). Most of the informal caregivers were children (66.7%) and spouses (25.2%) of the care recipients. The reason for caring was „own initiative" for 48.6% and

„feeling of obligation" for 29.7%. About 16% of caregivers reported that they were thinking of sending their elderly to old age homes. Their previous relation was one of fondness for 45% of caregivers. The emotional relationship remained the same as before for 60%, it improved for 21.6%, but worsened in 19%. Using the data from Chinese Longitudinal Healthy Longevity Survey, Wu and Schmmele (2008) analysed the living arrangements among the Chinese bedbound elderly. The study was conducted among 2514 women and 1857 men aged 80 years and above. Their findings revealed that 12.5% of bed-bound elderly were living with a spouse only and 14.9% were 29% living alone. The most common living arrangement was living with children and grandchildren (63.4%). Nursing home residents were 7.4% only (Haekyung, 1993).

The Singapore National Caregiving Survey (Chan, 2010) analysed the profile of the informal caregivers of bed-bound elderly. They defined the primary informal caregiver as family member or friend involved in providing care or ensuring provision of care. The survey covered both the bed-bound elderly and their caregivers. Nearly 47%of the bed-bound elderly belonged to 75-79 years and the percentages showed a steady reduction with advancing age. The percentage of female bed-bound elderly was 66%. The majority of primary informal caregivers were daughters (32%), sons (28%) or wives (14%). Most of the caregivers (41.2%) belonged to 50-64 years followed by less than 50 years (33.8%) and majority were females (58.8%). Their educational level showed an upward trend where 12.3% had no formal education and 35.3% had higher than secondary education. Analysing the caregiving situation of bed-bound elderly in India, the HelpAge India survey (undated) findings on ―Economic and Health Status of Bed-bound elderly‖ revealed that

majority of the bed-bound elderly were living with sons (70.5%), daughters (9.8%) and spouse (5.6%). A vast majority of them were getting help from sons (70%) in case of healthrelated matters. Daughters in law (53.9%) and daughters (28.9%) were in line next. Help from spouses was reported by 21.7%. At the same time, 26.9% of bed-bound elderly reported that they have to take care of themselves in ill health. Sons were the prime caretakers among 48.5% of bed-bound elderly, spouse in 12.2%, followed by daughters and daughters in law (10.7% each). For carrying out daily routines like washing clothes, eating etc, and majority were depending on daughters- in- law (60.4%), and son (50.3%). The study findings also revealed a positive outlook of the bed-bound elderly regarding their caregivers as many have reported that their spouses, sons, daughters-in-law, and daughters were always willing to take care of them. Survey on the Situation analysis of elderly in selected states of India (2011) published by _Ministry of Statistics and Programme Implementation‟, gives a detailed and evidence-based description about the living arrangements for the elderly of India across selected socio demographic characteristics.
Among the study participants, all elderly except 6% were co-residing (Alam, 2012).

The Government of India announced the National Policy for Senior Citizens in the year 1990. The policy and plans were put in place by the central and state Government for the welfare of the older persons. Many incentives were introduced; pensions, travel concessions, income tax relief, medical benefits and many more schemes are covered in the document. The senior citizens should be made aware of these policies and schemes, introduced by the Government. With the intention of extending the awareness to the senior citizens, plans were formulated and the details have been elaborated (Government of India, 2011).

The proportion of elderly who were living alone was more among the 70-79 age categories and less among the 80+. In the bed-bound elderly segment, only 11.8% were living with a spouse. The most common living arrangement for the bed-bound elderly was with children and grandchildren (51.2%) followed by with spouse, children and grandchildren (20.9%). The most common reason for living alone in the 80+ age was either no children or children living away (55.8%). The reasons for living alone were family conflict (19.3%) or their preference to be independent (20.7%). About four percent of elderly changed their living arrangement after the age of 60 due to varying reasons like death of spouse, migration of children, marriage of children, economic dependency, family conflict etc. Rajan and Sanjay Kumar (2003) found that the average household size of the Indian elderly was 2-3 in 26.9% of families, 4-5 in 38.2% and more than six in 29.1% (Lopez, Lopez-Arrieta & Crespo, 2005).

When living arrangements of elderly were analysed, they found that 79.1% of elderly were living with their children. This was similar with widows (76.7%) and widowers (59.2%). When asked about the preferred living arrangement, 72.5% of elderly preferred to live with their children. Self-rated health is a strong predictor of the health status, especially among the elderly.
Australian Institute of Health and Welfare‟‟ has published a report (2007) about 31 the health status of their aged population. As per the report, health status was rated as excellent by 38.8% of the aged among the 65-74 age group and 31.3% of the aged above 75 years. Gender wise comparison revealed a better health status among the females. The proportion of elderly reporting fair and poor health showed a higher trend with advancing age. On the whole, the older population of Australia described a positive attitude to health. Ischemic heart disease and cerebrovascular diseases were the two leading causes of morbidity reported among the elderly. About 56% of the elderly had at least one form of disability and the proportion was found to be increasing with advancing age. It was 39% for the 60-74 year age and 82% for the 75+ age group. Severe disability limitation was observed among 41% of the elderly. Arthritis was the leading cause for disability in the majority (50%), followed by hearing disorders (43%), hypertension (38%), heart disease (30%) and stroke (23%) (Tiwari , 2010).

Joshi, Kumar and Avasthi (2003) conducted a survey among 200 elderly above the age of 60 years in urban and rural populations in North India in order to study the morbidity and its relation with disability and psychological distress. The „PGI Health Questionnaire‟‟ and „Rapid Disability Rating Scale-2‖ were the instruments used. Findings revealed that 88.9% were suffering from illnesses and 42.5% were having 4-6 morbidities. Eighty eight percent of elderly had disabilities of varying levels and 66% reported psychological distress. The most prevalent health problems were anemia, dental problems, hypertension, airway problems and cataract. The study findings showed that the disability was increasing with more number of health problems. The major determinants identified were age, locality, caste, education and occupation. A similar study was conducted in Bengaluru, among 356 community dwelling urban elderly of 65 years and above to determine the prevalence of health related 32 disabilities (Srinivasan & Thomas, 2010). They used the ―International Classification of Functioning, Disability and Health Checklist version 2.1a (ICF)‖ of WHO to measure disability. Eighty five percent of the participants reported to have health problems where diabetes and hypertension were equally present in both genders. The physical health and emotional health were reported to be high among the majority of them. On analysis of the ICF scale, 43% of the elderly did not report any disability, 27% reported mild disability and 31% reported severe disability (L. Joshi, Kumar and Avasthi, 2003).

Difficulties experienced by Caregivers of Elderly

The role of the family in the care and support of the elderly is established beyond doubt. The impact of caregiving on the caregivers‟ daily lives is an area of interest among researchers. There are many studies highlighting the positive and negative impact of caregiving many of which are relating to the elderly with chronic ailments like Alzheimer‟s disease or other cognitive impairments. A lot of studies have identified that the caregivers of persons with dementia were suffering from high levels of stress, depression or psychological morbidity.

Schultz, O‟Brien, Bookwala and Fleissner (1995) reported that about one third of caregivers of dementia were suffering from high levels of stress, depression or other psychological morbidities than non-caregivers of comparable age. Findings from earlier mentioned study by Haekyung (1993) on caregiver burden revealed that the caregivers ―family income (p.05), emotional strain, social problems or practical problems‖. But when the difficulties were analysed in terms of satisfaction with caregiving, the satisfied group reported that caregiving was demanding, female gender and role conflict. The caregiver‘s views on difficulties due to living with elderly were collected by Audinarayana (2012). Among 418 caregivers, half of them were of opinion that it may affect the family budget and family vacation plans. About 35% expressed the feeling that the time spent with friends will be affected. Other views expressed were relation with spouse will be strained‟ (21%), not able to spend time with relatives (20.6%) and spouse ―(20.3%) and difficulties in doing the work around the house‖ (Haekyung, 1993).

Nearly seven percent of the caregivers had the feeling that relation with children and time spent with children will be affected. About 88% of caregivers reported that they consulted with the elderly in family 69 decisions and 92% expressed that the elderly were informed about the family decisions. Nearly one fifth of the caregivers viewed that taking care of elderly is a burden and this opinion was more from the female caregivers and the gender differentials were significant. Less than 10% of the caregivers expressed difficulty that the elderly were complaining about the attitude of the family members. When the caregivers were asked about their opinion regarding sending the elderly to old age homes, only 6.7% expressed that it was better to keep the elderly in old age homes. The reasons for this were financial burden, strain on family relations, no time to look after the elderly, children away from home etc. When the caregivers were asked about their willingness for sending the elderly to old age home, eight percent expressed their willingness. Data were collected from 1363 caregivers of elderly above the age of 65 years with at least one functional limitation (Takaji, Wagner & Davey, 2013).

Among them 40.2% were caregivers of elderly aged 85 years and above. The data was from the 2004 wave of the National Long-term Care Survey (NLTCS). The caregivers were mainly adult children (64.4%) and the rest spouses. About 50% of bed-bound elderly were not receiving any support for ADL and 24.3% were not receiving support for IADL. Poor self-rated health was reported by 21.3% of adult children caregivers and 31.8% of spouses. The amount of physical strain among the caregivers had significant association with rural residence, poor self-rated health among the bed-bound elderly, number of ADL and IADL disability among the bed-bound elderly, female caregivers, and poor self-rated health among the caregivers, sole caregiver, and average caregiving hours (Venkatorao, Ezhil, Jabbar and Ramakrishnan, 2005).

The emotional strain was associated with a number of ADL and IADL disabilities, female caregivers, poor self-rated health among the caregivers, sole caregiver, length of caregiving period, and average caregiving hours. Findings from the above studies clearly indicated that the caregivers are experiencing varying degrees of stress and difficulties. The physical work of caring, different role demands and personal relationships, cognitive impairment in the elderly etc. are identified as factors contributing to difficulties. More difficulties are reported among caregivers who are women, having higher income, lacking social support and caring for a person with more disabilities and cognitive impairment (Anita, Manjula & Jose, 2014).

Studies on Family Burden, Distress and Emotional Well-being in Care Givers

In the West, studies have found that the burden of family caregivers of the bed-bound elderly does impact their financial, physical, emotional and psychological health, (Hirst, 2005). However, in India, this is not received due attention and very few studies (Mridula & Prabhu, 2008) have attempted to determine the relationship between burden of family caregivers, family distress and emotional distress. Studies on the burden of family caregivers, family distress and emotional distress in India have been conducted since the past few decades. Early studies indicated that the mentally ill persons were perceived as a financial liability and as a source of disturbance to family life (Sathyavathi & Golam, 1976).

Kulhara and Wig (1978) found that females were able to function adequately in their role as 28 housewives but that the illness was more disabling for other people, as it affected their education. Burden was perceived by family members mainly in the areas of finance, interpersonal relationships and physical and mental health of the caregivers (Muralidhar & Shariff, 1981). In a study by Giel et al (1983) as part of the WHO Collaborative Study on Strategies for Extending Mental Health Care, 259 families from four developing countries (Colombia, Sudan, India and the Philippines), were evaluated with regard to the social burden faced as a family member was bed-bound (Thara R).

State of the Elderly

According to the National Sample Survey Organisation (NSSO) Report 2004, the sex ratio of the ageing population in rural areas is 985 females per 1000 males, while in urban India, it is 1046 females per 1000 males. The 2001 census reported that 75% of the elderly live in rural areas, of which 48.2% are women—55% of whom are widows. The dependency ratio is 12.5 in rural India and 10.3 in urban India. Of the rural elderly, 67% are dependent on others. It is estimated that 6.7% senior citizens are confined to bed or home. The dramatic increase in human life expectancy over the years has resulted not only in a very substantial rise in the number of older persons but a major shift in the age group of 80 and above. According to the demographic profile, the overall population of India will grow by 40% between 2006 and 2050, whereas the population of people aged 60 years and above will increase by 270%, and those in the age group of 80+ by 500%. It is important to remember, however, that the extended period of life is, in most cases, riddled with emotional, financial and health problems.

The vast majority of the 80+ population lives in rural areas that have the least facilities for the necessary special health and family care. It has also been found that the perception of those in the 80+ age group regarding their problems changes rather drastically as they grow older. For example, young and middle-aged olds (60–79 years) may be more concerned about their economic needs and the need to remain fit and independent, while those above 80 are often sick, frail, physically weak, vulnerable to crime, dependent on others, and frequently in need of urgent support measures. They are also often excluded from the social and economic spheres of everyday life. Therefore, this group should not be treated as part of a homogenous group of all older persons. Oldest Old (80+) women are an especially vulnerable group. An overwhelming portion of this group are widows who, in India, suffer multiple miseries—being women, being widows, being poor, leading longer, more agonizing lives than men. The ageing of the 80+, with numerous morbidities, needs urgent attention. This section of people suffers more on account of disability, chronic disease, terminal illness, dementia and depression, accidents, falls, nutritional deficiencies, loneliness, etc. Furthermore, they are subjected to elderly abuse, sharpened by neglect and isolation, which makes them financially and emotionally dependent on their families and others. It is important to ensure that they are financially self-sustaining. Their pension needs to be improved and there should be a provision of free medical aid, particularly for those who are exempt from paying income tax. There are currently about 10 million elderly people in the 80+ category in India, and this number is expected to rise to around 53 million by the year 2050. The data on living arrangements of the Oldest Old in rural areas suggests that most of them live with the families of their adult children. They depend on their children to take care of them during ill health. However, the children are almost never helpful and, in many cases, the Oldest Old have to depend on their spouses. As a result, many of them face insufficient food intake and many reports economic abuse by their family members. The 80+ year old population segment is the fastest growing of the ageing population and this trend is expected to continue (State of elderly in India, 2014).

India�go's Oldest Old population has been estimated at around 80, 38,718, out of which 20, 22,345 live in urban areas (Census 2001). According to the NSS 52nd round, 63% of the elderly in India were found to be illiterate. This is likely to have a bearing on their economic activities. Poverty and loneliness further add to the problem of elderly care, rendering senior citizens even more vulnerable. Traditionally, in India, the most common form of family structure has been the joint family. The extended family consists of at least two generations living together and this arrangement has usually been to the advantage of the elderly as they enjoy special status and power. But with growing urbanization and dependency on the availability of jobs, children are increasingly opting out of the extended family setup, leaving behind an ‗empty nest‘ and establishing their own nuclear families. In the coming years, the elderly population will grow phenomenally in number, while the family size will reduce. In the absence of traditional caregivers, given the disintegration of the joint family and women moving out of the household, the elderly are already a vulnerable group in need of care and attention.

CHAPTER III

RESEARCH METHODOLOGY

3.1 INTRODUCTION

It is very vital to choose the right research methodologies and methods for a research work or thesis because it is our research on which our entire dissertation will rest on. Our research decides the kind of methodologies to be used that will underpin our work and the methods we use to collect data from various sources.

The following chapter will outline the method that was employed in the current study. This chapter begins with the title of the study. Then research design is well explained with what exactly case study means, followed next by the various aspects of methodology including the objectives, the concepts, the pilot study, sampling and sources of data. Next, describe the tool for data collection, method used to collect data which were used to analyze the study data. Finally, the chapter will conclude with chapterizations and limitations of the study.

3.2 TITLE OF THE STUDY

CAREGIVERS‘ EXPERIENCE IN PROVIDING CARE FOR THE BED-BOUND ELDERLY

3.3 RESEARCH QUESTIONS

The following are the questions considered as part of the present study:

1) What are the psycho-social-economic and physical challenges faced by the primary caregiver of the bed-bound elderly?
2) What are the different strategies adopted by the caregivers and documenting the best practices?
3) What are the services available for supporting the bed-bound elderly?

3.4.<u>DEFINITION OF CONCEPTS</u> - (Theoretical and Operational)

1. ELDERLY

Theoretical Definition:

Elderly refers to ages nearing or surpassing the life expectancy of human beings, and is thus the end of the human life cycle. (The free Dictionary)

Operational Definition:

A man or a woman, completely bed-bound and above the age of 60, in need of assistance in undertaking activities of daily living (ADL).

2. CAREGIVER

Theoretical Definition:

An adult who provides assistance with at least two instrumental activities of daily living or at least one activity of daily living to an individual who is at least 50 years of age. (*Journal of Gerontology*)

Operational Definition:

A woman or a man, who is basically a primary caretaker of the bed-bound elderly.

3. CAREGIVING

Theoretical Definition:

Characterized by attention to the needs of others especially, those unable to look after themselves adequately; professionally involved in the provision of health or social care, attention to the needs of a child, elderly person, etc. (Miller, 2001)

Operational Definition:

The act of providing care to a sick bed bound elderly person.

4. CAREGIVER EXPERIENCE

Theoretical Definition:

Caregivers typically experience both negative and positive feelings simultaneously (Kramer, 1997, Walker, 1995).

On the one hand, caregiving activities may interfere with caregivers' daily routines; cause physical, emotional, and financial strain; and eventually exhaust their energy (Pinquart & Sörensen, 2003). On the other hand, caregivers can acquire satisfaction from helping their family members (Marks, Lambert, & Choi, 2002).

Operational Definition:

Caregiver's activities or personal challenges in relation to caregiving in a holistic way, which include their physical, psychosocial, economical, and daily routine.

5. COPING STRATEGY

Theoretical Definition:

A coping strategy is a conscious effort to solve a personal or interpersonal problem that will help in overcoming, minimizing, or tolerating stress or conflict. (Psychology Applied to Modern Life)

Operational Definition:

An action, a series of actions, or a thought process used in meeting a stressful or unpleasant situation or in modifying the caregiver's reaction to such a situation.

6. PSYCHO-SOCIAL-ECONOMICAL

Theoretical Definition:

The psychosocial approach looks at individuals in the context of the combined influence that psychological factors and the surrounding social environment have on their physical and mental wellness and their ability to function, which also looks upon the financial aspects of their life.

Operational Definition:

For the purpose of the psychosocio-economic aspects were considered to be as follows: Psychological: Caregivers who experience a mental stress, compassion, burnout, fatigue or neglect towards everything.

Social: When the caregiver cuts off the social circle, it can be mainly because of lack of selfcare.

Economic: Health expenses for caring the elderly is one of the prominent economic factors.

3.5 RESEARCH STRATEGY

According to Robert K Yin, the case study method is an empirical enquiry that investigates a contemporary phenomenon within its real-life context, when the boundaries between phenomenon and context are not clearly evident, and in which multiple sources of evidence are used (Yin, 1984). The researcher chose this method as it would help in gathering experiences directly from the subjects with detailed explanations. This is a method in which feelings and emotions are captured by the researcher using observation. Multiple case study design is used as 9 cases are taken and analysed. Idiographic case study approach is also applied here, that involves in-depth interviewing. It recognizes and probes the distinctive complexity of each participant (Breakwell, Hammond and Fifeschaw, 2000). Being exploratory in nature, the researcher takes a grounded theory approach to identify various aspects concerning adjusting and living of the caregivers.

3.6 PILOT STUDY

A pilot study is done by the researcher to understand the feasibility of the topic and it is a very sensitive and qualitative case study research. The researcher went to Poonthura Community Health center and interacted with the Medical Officer as well as the palliative care nurse for initial discussion and to check the availability of the respondents.

3.7 SAMPLING STRATEGY

The units selected for the study consists of caregivers of bed-bound elderly. In units were chosen purposively based on the below give inclusion criteria:

- The respondent should be providing care for a completely bed bound elderly with chronic and serious illness.
- The bed bound elderly should have reached the age limit of 60 years old.
- Preferred caregivers who had been looking after the bedridden elderly for at least a year.

3.8 SOURCES OF DATA

Primary Data: The present study focuses mainly on primary data collected directly from the Caregivers.

3.9 TOOLS OF DATA COLLECTION

Interview Guide: The interview guide was put together by the researcher keeping in mind the research objectives and the themes that were identified under each of these objectives, so as to get relevant responses from the respondents to justify the researchers‘ objectives.

3.10 DATA COLLECTION

Nine cases were taken for this particular research study and the respondents were the people who reside in Trivandrum and the closest kin as well as the primary caregiver of the bed-bound elderly. The researcher collected the data through phone interview, firstly the researcher approached Poonthura Community Health center and got in contact with a palliative care nurse, with her help collected basic information about the bed-bound elderly‘s registered under their care and contacted the caregivers. The details were collected by building rapport and then through phone interviewing within 2 months of time.

3.11 DATA ANALYSIS

The researcher has collected the data received through the interview guide from various respondents into case documents. The responses received from the respondents have been classified by the researcher on the basis of themes related to the research questions envisaged at the inception of the study. The analysis done by the researcher involves categorizing the content generated based on themes and grouping responses under the predefined themes generated from review of literature.

3.12 CHAPTERISATION

This is done on the basis of segregating the work into the following chapters:

Chapter 1- Introduction: The chapter outlines the statement of the problem, significance/relevance of the study, the research objectives and operational definitions used in the research document.

Chapter 2- Review of Literature: This details the various literatures reviewed by the researcher in the form of books, journals, research papers and online documents, for gathering information on and formulating an understanding of the research topic.

Chapter 3- Research Methodology: This includes the details of the research design, pilot study, sampling data sources and tool of data collection, data analysis, mechanisms and limitations of the study.

Chapter 4- Case Studies: This chapter starts with an introduction and then gives detailed study of each respondent case scenario.

Chapter 5- Analysis and Discussion: This includes the socio-demographic details of the case studies conducted by the researcher. The research analysis has been classified under various themes defined by the researcher with respect to the research objectives.

Chapter 6- Findings, Suggestions and Conclusion: It lists out the findings of the researcher based on research analysis.

3.13 LIMITATIONS OF THE STUDY

The study cannot be called a complete representative case study due to the number of respondents. The researcher should have chosen a heterogeneous population with varied cultural and personality traits. However it was not that sort of representation that the researcher was aiming. The purpose of the research was a projection of the sufferings of the caregivers and to highlight the best practices adopted in caregiving which will be able to document and suggest to others implement the same or to educate and to link with the available services.

During this study one of the major challenges was the lockdown declared by the government due to the COVID- 19 pandemic. The researcher was not able to visit the respondent‘s home and personally observe their environment as the elderly‘s are categorized under high risk and most vulnerable. However, the palliative care nurse and the medical officer at Poonthura CHC, helped the researcher to identify the respondents and gave secondary information for the study. The other limitation of the study was it had to be completed in a stipulated time.

3.14 CONCLUSION

The researcher utilized case study method and purposive sampling effectively to collect data. The study focuses mainly on primary data collected directly from the caregivers. The researcher collected data through the interview schedule from different respondents into case documents. The received data from the respondents have been classified on the basis of variables that have been defined with respect to the research questions.

CHAPTER IV

VIGNETTES

4.1 CASE 1

Mr. Alex (name changed), 70 years old is staying with his family, wife and only son. They belong to a high-income family. Alex has been bed-bound for 5 years, it was reported that he had a stroke 7 years ago and he managed to recover through physiotherapy and treatment, but later his condition deteriorated and became completely bedridden. The primary caregiver of Alex is his only son, Mr. Abin (name changed), who is 47 years old and also the breadwinner of the family. Abin has a bachelor degree and he is currently working at a shop in Muttathara. Abin is the respondent of this interview, he said that he mostly looks after his bed-bound father as his mother is also having old age-related health issues. He is not married, so he stays with his parents at their family house in Valakkadavu. He informed that when he goes to work, he has arranged a paid helper for his father and she also assists his mother for the household.

The caregiver informed that he had not undergone any training for caring for the bed-bound elderly but he knew the needed basics which was shared by the palliative care nurse who visits them for regular catheter change. Unfortunately, due to the present situation, the palliative care nurse is unable to visit them on the due date and this is something that is worrying the family. Abin informed them that they buy all the medicine from the drug store and he does not buy it from the government hospital as he was informed by their consultant to stick on to the same brand of medicine which is not available in government supply. All the medical expenses as well as household expenses are met by Abin with his salary. He also said that both his parents do not receive any pension and he also informed that he does not get any sort of financial aid from anyone. His mother who is 67 years, also helps in looking after the bed-bound elderly.

The respondent informed that he does not have much difficulty with caring for his bed-bound father, but there was an incident when the air-bed which was provided for the bed-bound elderly became damaged and developed pressure sores which was difficult for them to heal. Abin‟s mother is also having health issues and she is taking treatment for her hypertension and diabetes. He had not reported any difficulty in caring for his bed-bound father during night and thus he is able to have good sleep over night. His mother too gets adequate time to sleep during night as well as in the afternoon and both of them have enough time for their personal care. However, they haven't had any vacation for the past 5 years, but they visit their relatives and attend social gatherings held in and around the city, but they don't spend too much time for this gathering as they had to come back before the servant finishes her duty.

Abin does not share any particular worries or experience of caregiver burden during the interview. However, it was understood that he experienced financial burden on his shoulder as he is the only earning member of the family. He is very much relieved that he is getting support from the palliative care nurse and also with a servant at home they are able to balance the workload. Since his father had a stroke, they have not tried any alternative medicines such as Ayurveda or Siddha medicines, for him and also he believes that his father's condition cannot be revised with any alternative medicine.

The respondent said that they wash the bed-bound elderly twice a week, while Abin and the servant are available at home and on other days the servant just provides a sponge bath for the elderly. Abin‘s mother helps him with feeding and toileting the bound eldrely, so it seems that they share their works, which do not provide much strain for the caregivers. It was also reported that it takes almost 4 hours in a day to clean the bed-bound elderly.

The equal division of shared workload technique is helping Abin and his mother, they both get quality time for themselves and to manage the dependent bed-bound elderly. They feel more relaxed with the help from their paid servant, she almost covers the majority of the household work. So the caregivers' burden or burn out experience is not present in this family.

4.2 CASE 2

Sherifa is 75 years old and she is completely bedridden. She had a long history of cardiac problems and also had undergone *angioplasty* and *hysterectomy*. She also had a history of stroke and for the past 6 months she is completely bedridden and there is no sign of responses. She also had a medical history of *tuberculosis*. She had been taking treatment for *hypertension* and *diabetes*. She is on a ryle tube for feeding her meals and on a catheter for draining urine. She has been taken care of by her son Mr. Ali Akbar and his family. Ali is 47 years old, he resides at *Cheriathura* with his mother, wife and 3 children, and they belong to a high income family.

Ali is the respondent of this interview, he said that she develops pressure sores on her back and they are trying their best to heal it. She had pulled out her ryle tube 2-3 times which can lead to complication, so they tied her hands to prevent further complications. He said she gets respiratory infections occasionally and that she needs extra attention to manage it. Ali shared that, last week he found difficulty in falling asleep at night as she keeps on crying in distress and violently moves in the bed, during this time he hardly gets 1-2 hours of sleep. The whole family including his wife and other relatives supports him with caring for the bed-bound elderly, they even take shifts at night so that everyone gets adequate time to sleep. Ali is the only breadwinner of the family and he is completely healthy, he had only been admitted in hospital when he once met with an accident. He does get personal time for his daily routines as he receives help from his family and he had not reported of having any stress while caring for his mother. Infact, he considers it his sole duty to take care of his sick mother.

Sherifa is receiving palliative care from the *Poonthura Government Hospital* and the palliative care team visits them regularly. Ali used to contact them when necessary and they also provide regular monthly home visit checkup for his mother. In the worst scenario, if the bed-bound elderrly need to be transferred to a hospital, then he had to arrange for an ambulance for the transport. He also informed that they had not tried any alternative medicine for his mother's condition, since her condition is very bad and she is going through the end of life care. Ali meets the expenses for medicines and treatments from his earnings and also depends on Sherifa‘s old age pension. Unfortunately for the last 3 months he doesn't receive the pension because of her condition. The only support he gets from the government is the palliative care service and the medicines they provide.

Ali said that it takes almost 30 minutes to clean the bed-bound elderly every day. He cleans his mother every evening with a warm wet towel to prevent further bed sores and applies medicine on the sites and he gives her a bath thrice a week. Ali informed that he received help from his wife, daughter and his mother‘s sister for cleaning and feeding her. She is fed through the Ryle‘s tube and she can only consume liquid food through this tube. The bed-bound elderly is on diaper and catheter, since she is completely bed-bound it's hard for her to make her sit on a commode chair for toileting. He has provided the bed-bound elderly with a water bed to prevent further bed sores.

He says he gets enough family time with his family members and spends quality time with his children. His social life is partially affected by his current responsibility as one has to stay home and look after the bed-bound elderly. So this family manages to go out by taking turns and he also tries not to travel far from home. He manages his daily routine and caring responsibilities altogether without any barriers as he receives help from his family members and always keeps an eye on his mother.

4.3 CASE 3

Ismail is 61 years old and he had been diagnosed with Degenerative myelination disorder for the past 28 year, and had been a known case of paraplegia. He needed a caregiver for all his activities and thus he depends on his sister Suhara, who is 56 years old and she is married and has two children. They all live at Beemapally, at her family house and they belong to a middleincome family and her husband is the only earning member of the family. Suhara is the respondent for this interview, and she was ready to open for the interview.

Suhara informed that her brother is not married as he had health issues at a very young age and she had to take his responsibility as soon as their parents passed away. She said that she gets adequate sleep during the night as she does not need to check on him during those hours. Ismail is on a catheter for urine drain and this is a great help for her as she doesn't need to change his clothes frequently. Suhara has health issues due to being a caregiver, she experienced severe back and joint pains, and she also had inflammation on her eyes for which she is undergoing treatment.

Ismail is registered as a palliative care patient under *Poonthura Government Hospital* and the team from the hospital visits him monthly and supplies his medicine.she had also not tried any alternative medicine for the bed-bound elderly. Ismail is not availing disability pension, however Suhara used to receive caregivers' pension, but since 4 years she is not receiving. She reports that she is unable to follow up because of her current responsibility. Other than palliative care service they are not receiving any support from community groups or government schemes.

Suhara said that she received help from her son who is 25 years old for bathing and cleaning Ismail. Her strategy is that she bathes him once in 2 weeks and on the other days cleans him with a wet towel. Ismail cannot sit up on bed on his own while having food so he needs support from other family members to sit up in bed and to have his food. She said that she changes positions of Ismail in bed to prevent bed sores and that should be done every 2 hours, fortunately Ismail does not report to have any bedsore. Suhara said, Ismail passes motion once in 4 days with the help of medicine and she uses old cloths as a diaper. She spends almost 2 hours a day cleaning and toileting him. Ismail is taken to the washroom in a wheelchair when he is getting a proper bath and during this task her son will also help her to lift Ismail. She also reports that due to her constraints she does not take Ismail out of his room every day, even though he can sit in a wheelchair. She only takes him out when he needs medical attention, like taking him to the hospital.

She says that she has no worries in providing care to her brother and is able to manage her responsibility, but she feels sad to watch him suffer like this for such a long time. Some elements of compassion fatigue were present in her as she talked about leaving the bed-bound elderly stay in his room forever. Even though she says that she gets adequate help from family, in deep enquiry it was reported that she is the one who does the household chores, and cleaning Ismail when he passes motion, but verbally she has not reported to have any stress. She also says that she does spend quality time with her family members but her social life is affected due to her current responsibility. She is only able to attend nearby functions and used to avoid the majority of the functions. She even asks her other family members to represent her for certain unavoidable ones. Moreover, if she needs to go to hospital she makes sure one of her children stays home and in the worst scenario she asks her neighbours to have a look at Ismail.

She explained: *I'm able to do everything so far... but the hardest part while caring for him is to witness his pathetic situation and that hurts me so much... I even sometimes cry for him and wish God would show mercy on him...*

4.4 CASE 4

George (name changed) who is 101 years old, had been bedbound for 5 years due to old age issues. He is registered for palliative care service and they had put him on a catheter for urine drain. He is partially bed-bound, so he can sit on his bed and move on the bed by himself, but still he needs assistance from his caregiver for all the activities like taking a bath, toileting and sometimes feeding. George and his wife stay with his son and family. They live in a rented house at Kamaleshwaram and George has been taken care by his daughter-in-law, Ancy (name changed) who is 49 years old. They belong to a high-income family and George‘s son is the breadwinner of the family. George‘s wife (97 years old) is also having old age issues but she is not bed-bound, so she can do her activities by herself.

The respondent of this interview is Ancy, the daughter-in-law. She informed that she gets adequate sleep during the night, approximately 7 hours a day. She reported that some days it's difficult for them to sleep as George shouts at nights because he feels unsafe and scared. Ancy has health issues, she is a thyroid patient and experiences difficulty in breathing when her condition worsens. She is on regular medication and she also expresses her physical pains over her knee and joints. George and his wife are receiving old age pension, but Ancy has not received caregivers‘ pension. They tried to manage the medical bill from this pension and they don't have much medical expense as George is only on his blood pressure medication. When enquired about alternative treatment, it was reported that they have tried it before, but since the bed-bound stage they have stopped all other treatment.

Ancy reported that she gets adequate personal time for her daily routines but she complaints about having difficulty attending functions due to her present responsibility. She explained:
―*During my daughters’ marriage I was not able to go out to invite the people and also I was not able to get involved with the arrangements as I expected… I needed to stay at home with my father-in-law... that was the time when I felt so sad that I was holding back my responsibility for my daughter.*‖Ancy stated that her social life is very much affected with her responsibilities, she alone does the household and also need to do laundry of her mother-in-law‘s and she expressed that her children stays with their husbands, so they don't provide any support.

Ancy says that she and her husband bathe George only when he is very sick, otherwise she manages it herself and George does not insist on taking bath every day. Ancy reports to spend 2 hours a day feeding, bathing and toileting the bed-bound elderly. George is not on a diaper, so when he wants to pass motion they transfer him to a commode chair and then they clean him. Ancy also informed that sometimes he defecates on the bed unconsciously, and she then needs to change and clean everything. She said that her husband helps in cutting the nails for George as she finds it difficult. Ancy reports that she does not have any burden or stress in looking after George, but she gets full body pain after doing household work. She says that she feels sad for her father-in-law‘s present condition as he was very active in the past, which affects her emotionally.

4.5 CASE 5

Jose (name changed) is 69 years old and 4 years back he had a stroke episode and had been quadriplegic since then. He needs a full-time caregiver for all his activities. Retty (name changed) his wife, 65-year-old is the primary caretaker and they reside at *Kuzhivilakam.* Jose retired as a government employee, so he is receiving his employment pension. They belong to a middle-income family and they don‘t have children, they have appointed a day time housemaid for support.

Retty informs that she gets 7 hours of comfortable sleep during night. Retty reports that 12 years back she had undergone surgery for breast cancer and is also taking medication for diabetes and hypertension. She states that she had survived her cancer, but continues with her yearly checkup at Regional Cancer Center and receives her medicines for diabetes and hypertension from the government hospital at *Valiathura*.

Retty is worried about her husband‘s condition, he is completely bed-bound without any movement of his body parts, so she needs to change his position for cleaning and toileting. Even though he lies on an air bed, sometimes he developed bed sores and she struggle so hard to heal it. Retty cleans and bathes Jose on the bed itself, she lays a rubber sheet as bedspread and washes him. She receives help from her servant who visits daily to help her with household chores and in changing the sheets. Retty bathed him twice in a week and on other days she cleans him with a hot towel. She informs that she places a large piece of cloth and lays some newspaper under him for toileting and it is the easiest method for her. She feeds him with semi liquid food which makes it easier for him to swallow. She informs that it almost takes 3 hours a day in cleaning and toileting the bed-bound elderly. The respondent informs that she often feels tired and worried while doing these activities: *"My age is not good to be a caretaker… I do have health issues and after cleaning him I feel so tired, I also have joint and knee pain which makes it difficult for me to care for him… since I get help from my servant, I am somehow managing things."*

The respondent informs that the only source of income they have is the retirement pension of Jose and she meets all her expenses from it. They get their medicines from the *Government CHC* at *Poonthura*. Jose is also registered for palliative care service from this hospital. They have their relatives living close to them, so they get support during emergencies or in getting things done.

Their niece helps them with getting money from the ATM counter. Her servant will buy groceries for them as Retty is also experiencing old age issues.

The respondent informed that she don‘t attend any functions or go out often. She tries to stay at home because of her age as well as her responsibility of being a carer. It is difficult for her to imagine a time when she also suffered such serious illness. She says that even though she does not go out she finds time for herself. She is able to do her daily routine and she finds it very helpful for appointing a servant.

4.6 CASE 6

Yesudas is 60 years old, 3 months back he had a stroke which made him bedridden and he does not communicate as a defect of his condition. He needed full time care because of his health concern and he is on a ryles tube and catheter for support. His son Shimayon is the primary caretaker and the respondent of this interview. Shimayon is 35 years old, he is the breadwinner of the family, he follows his father's path as a fisherman. He stays with his family which includes his wife, 3 children and his parents and they settled at *Poonthura* and they belong to a middleincome family.

Shimayon says he stays awake until 12 am in the morning looking after his bed-bound father, he is given his last feed of the day around this time and then he goes to sleep. Shimayon says he gets around 6-7 hours of sleep every day and sometimes has to wake up at night to check the bed-bound elderly. Shimayon says he is on his healthier side and does not have any chronic health issues. He reports that his mother is also having age related health problems and his wife had delivered their 3rd child last week, so the family is going through many stages now.

Yesudas is registered as a palliative care patient at Poonthura government hospital, and he did his major treatment from Government Medical College and he buys his medicine from government supply. The respondent said that the bed-bound elderly does not receive any pension and Shimayon tries to manage all the expenses from his earnings. He also added they plan for alternative treatment for the bed-bound elderly, unfortunately he developed bed sores and they have to drop the plan. Furthermore, the doctors recommended physiotherapy for the bed-bound elderly and they couldn't proceed due to the bed sore and deteriorating health.

Shimayon elaborated his concern and worry about the bed-bound elderly trying to pull out the ryles tube sometime and twice Shimayon brought a doctor home to insert the tube back. It is dangerous for the bed-bound elderly to pull out the ryle tube without the expert's help as it may lead to internal bleeding. Shimayon says he gets personal time for his daily routines as he receives help from his family members and he says that he does not feel or have stress in his life while caring for his father, but they don't go for other social functions, because there is plenty of things to manage at home, like having a newborn and with a bed-bound dependents at home, all the other family members have hand full work to complete in a day.

The respondent informs that the bed-bound elderly is on diapers for passing motion, but lately due to his bed sore in the buccal area, the doctor had asked them to keep it open and use clothes as alternative. The respondent also informs that the bed-bound elderly get a proper bath once in a week, as they make him sit in a chair and transfer to the bathroom. It takes lots of effort so Shimayon needs help from his family members to carry the bed-bound elderly. Since the bedbound elderly got bed sore that should be cleaned every day and apply medicines on it for fast healing, he is also on waterbed as recommended by his doctor to avoid further complications. The palliative care nurse had monitored them in cleaning the wounds and putting medicines on it, and it is really hard for the family to take the bed-bound elderly to hospital as they need to hire an ambulance for shifting to the hospital. Currently this family is giving their best shot to take care of the bed-bound elderly, but sometimes it drains their energy with other activities happening at their home.

4.7 CASE 7

Anwar is 62 years old and diagnosed with Alzheimers and has become bed-bound since 7 years. He was running his own business earlier and showed some symptoms of Alzheimers. At first, he had some impaired memory, and everyone thought it as a normal phenomenon, later he developed difficulty in dealing with money. This time the family understood the seriousness as they witnessed some loss in the business. Though he started his treatment, the symptoms proceeded to worsen, he started to forget the daily activities like, riding the bike, toileting etc. He needs a complete caregiver now, and his wife, Fathima is the primary caretaker and they live at *Kamaleshwaram*.

Anwar was taken to *Sreechitra Hospital* for medical help and later transferred to *Al Arif Hospital, Valakkadavu*. He is now registered under a palliative care unit; they regularly visit him twice a month for follow up as he is on a catheter and ryle tube. They buy the medicines from the *Government Medical College* as they can only afford it from government dispensaries. Anwar‘s brother supports them financially for medical expenses, as they don't receive any financial support from government schemes or groups. They have tried *Ayurveda* long back when he was conscious and used to recognize people, but Anwar became violent and they stopped it. They didn't get any training for caring for the bed-bound elderly, but the palliative care nurse informs them regarding changing the position to avoid bed sore.

The respondent reports that some days Anwar behaves violent and makes loud noises and she is unaware about the reason. She also said that her son resigned his job to help her with caring for his bed-bound elderly father, as she had major stress while doing it all by herself. Fathima says she gets adequate sleep as her son helps in looking after his father at night. Fathima does all the household work and looks after the bed-bound elderly at day times, sometimes she might not have slept at night because of him making loud noises. Even though, both Fathima and her son take turns in looking after the bed-bound elderly it is very stressful for them as Anwar does not remember his own family members.

Fathima does not have any health-related issues, she is only worried about her husband‘s condition and sometimes his violent behavior adds to her worries. She says: *“He is never a burden for me, but it broke me when the doctor said that he cannot be cured and it mentally affects me when we all are strangers for him… and we all are equally putting our efforts to comfort him”*. Fathima says she gets personal time for her daily routines, but her social life is completely affected. She does not attend any function or gatherings as she finds difficult to spare time for it. She also said that Anwas becomes more violent if no one is around him. She only leaves the house for medical emergencies or to buy the groceries and while doing so she makes sure her son or daughter is there at home to look after the bed-bound elderly. She receives support from her children, brother-in-law and his family. She says she tries to keep her children happy all the time and make them feel less tension because she is worried to have them stressed too.

The respondent informs that she gave a bath for the bed-bound elderly once in a week with the help of her son and on other days she just wipes him with a wet towel. She provides diapers for

Anwar for passing motion and sometimes she uses clothes too. She feeds him 3 times a day and he can only take liquid food through his ryle tube. He is given protein powder drink in the morning, oats in the afternoon and fresh juice or rice gruel at night.

The respondent reports that the hardest part of being a caregiver is that it makes her very emotional and sad to see her husband in this condition and she can‘t accept the fact that this happened to him really quick as he was living a normal life. Anwar used to be the breadwinner of the family and they were having good profit from their business, but because of his condition they need to sell their store and now depend on her brother-in-law. They experience a great shift in the family responsibility and role reversals and she is experiencing grief.

4.8 CASE 8

Rajan is 70 years old, he had a stroke in 2014 which made him physically weak and later he had physiotherapy and regained some strength. In 2017 he had another episode of stroke and made him bed-bound. He needs a complete caretaker and his wife, Lekshmi 65-years-old is the caregiver and the respondent for this interview. They both live at Ambalathara, they have 3 children who all are married and live separately. They belong to a low-income family and they live with the support from their children.

Lakshmi says she has hypertension and is taking medicines for it. Sometimes she feels fatigue when her blood pressure falls but she manages it by herself. She says she sometimes gets up at night and checks on Rajan, this does not affect her sleep and she get around 7 hours of sleep every day. For her health she consults with the nearby government hospital and takes proper medication for it. Ranjan is registered as a palliative care patient and the palliative nurse and doctor visits him regularly to change the catheter. The respondent informs that she has not tried alternative medicine for Rajan.

She said she experienced difficulty in moving Rajan and changing his positions by herself, she wished for a helping hand. The bed-bound elderly needs assistance in every activity, his right side is completely paralised and he does not sit or eat by himself, so Lekshmi needs to do all the activity for him. She says it is quite stressful for her to do all this alone. Her son visits her every day and they bath him once a week when he is available. She and her son shift him to the bathroom in a chair to provide a proper bath, on other days she just wipes him with a wet towel. She said that

Rajan has constipation, he passes motion only once in a week with the support of medicine, she places a clean cloth and disposes of it. She is also having old age-related issues and being a caretaker makes it worse.

Her daughter financially supports her for medicine, but they don't have any other source of income except her old age pension. She had applied for Rajan‘s old age pension as they were experiencing financial constraints. The respondent also talks about how her social life is affected due to her responsibilities. She does not get time to go out as Rajan is alone at home. She hesitates to take help from her neighbours as she does not want others to know about Rajan‘s current situation and she also feels guilty of being a burden for others. Very occasionally she goes to the temple and rushes back as soon as possible. She does not attend any gatherings, marriages or other functions.

She sometimes makes Rajan watch television while she does some household chores to make her work easier. Lakshmi said Rajan talks but does not talk about his discomforts or pain when asked about it. She says that her hardest part in her life when caring for Rajan is both physical and financial. She physically feels weak when caring for Rajan and also, she tries to look after him without seeking help from others as she doesn't like to disturb others in their life. Throughout the conversation the element of despair and helplessness was present, she even considered her situation as fate.

4.9 CASE 9

Robert is 63 years old and he has been bed-bound for 7 years, he had met with an accident which resulted in damaging his spinal cord and hip. He did beggary for his living, and he met with the accident during one of the occasions. He used to be in a colostomy and urostomy bag as an after effect of the accident, and after several surgery had a colostomy reversal and now, he can pass motion through anul opening. Adding to the misery he had a stroke episode 4 years back, which made him completely weak and bedbound. He needs a full-time caregiver for all his activities and his daughter Kochu Rani, is the primary caregiver. They belong to a low-income family and they don't have any financial support system now.

Kochu Rani is 43 years old and she is having an arthritis problem. A few months back she had the worst symptoms which made her bed-bound for weeks and currently she recovered but continues to have body pains. Her husband was the earning member of the family, but he had an attack and passed away a few days back. She is bereaving about his death and also anxious about the future. She is having weakness and body pain, but unable to go to hospital due to the religious rituals of her husbands‘ funeral.

The respondent informs that she does not get enough sleep at night as she has to wake up several times as the bed-bound elderly calls for help. She added that if she ignores him then he tries to roll out of the bed and twice he has broken his head. She says she only gets around 1-2 hours of sleep every day. She also complains about the lack of personal time for her daily routines. She explained: ―*I am also having health issues and caring for my father is not very easy… he sometimes shows tantrums and becomes very stubborn, which doubles my workload… sometimes i feel burnout and stressed with all my problems… my husband used to support me a lot, and now everything is gone”*

She gets support from her younger daughter while providing baths for the bed-bound elderly. They shift him on a wheelchair and move him to the bathroom, and if she is alone, she wipes him with a warm cloth. Robert cannot sit on his wheelchair for long, but if possible, she would shift him and take him out of his room to get fresh air. She with the help of her daughter feeds him every day. For toileting she uses an adult diaper for him and disposes it after use.

She used to meet the expenses for medicines and treatments from her husband‘s income and now she worries about the future bills. The only source of income now is the disability pension of the bed-bound elderly. A palliative care nurse and doctor visits once every month to check the bedbound elderly and supports the medical needs. During emergencies she needs to take him to the Government Medical College hospital and it is difficult since two people need to support him from both sides while travelling.

She barely gets quality time with her family as she is busy with household work and being a caregiver. She said that her social life is very much affected and she is emotionally suffering due to her husband‘s demise and also experiencing caregivers' burden. She feels that Robert is not trying himself and he troubles her more being stubborn. The hardest part in her caregiving life is the additional burden of finding financial support for the family and also her physical pain along with her husband's loss adds to her sufferings.

CHAPTER V

ANALYSIS AND DISCUSSION

The researcher used multiple case research design as a research method. The data is analyzed on the basis of the three specific research questions; i) Psychosocial economic challenges faced by the caregivers, ii) Different strategies adopted for caregiving iii) Available services for supporting the bed-bound elderly. The data is analyzed in a tabular form for the convenience and the clarity. The measurable factors are on the right side and the 9 cases follow: Case 1, Case 2, Case 3, Case 4, Case 5, Case 6, Case 7, Case 8, and Case 9. The first research question is also divided into five sub domains for analysis.

5.1) What are the psycho-social-economic and physical challenges faced by the primary caregivers of the bed-bound elderly?

In this conceptual framework the researcher looks into five life domains of the caregiver, each of which has other sub-domains which are as follows:

- Physiological Challenges
- Psychological Challenges
- Social Challenges
- Financial Challenges
- Problems Faced on Daily Basis

Domains	**Sub-domains**
Physiological Challenges	• Sleep Hours • Health Status • Monitoring of Health • Personal Hygiene

Psychological Challenges	• Stress/Frustrations • Lack of support • Other emotional problems • Compassion Fatigue/Burnout
Social Challenges	• Social support and responsibility • Time for attending social gathering or family functions
Financial Challenges	Expenses for: • Treatment • Health checkups • Diet • Buying products needed for the bedbound elderly • Availing any financial support
Problems Faced on Daily Basis	• Providing Personal Hygiene for the bed-bound elderly ○ Toileting ○ Feeding ○ Bathing • Moving the bed-bound elderly around

Analysis of Physical Aspects of the nine Cases

Criteria	**Sleep Hours**	**Health Status**	**Monitoring of Health**	**Personal Hygiene**
Case 1	6-7	Healthy	Not Required	Gets adequate time
Case 2	1-2	Healthy	Not Required	Gets less adequate time
Case 3	6-7	Back and joint pains, Inflammation on eyes	Undergoing Treatment	Gets adequate time
Case 4	7	Thyroid, Breathing difficulty, Joint pains	Undergoing Treatment	Gets adequate time
Case 5	7	Breast Cancer, Diabetes, Hypertension, Knee and Joint pain	Undergoing Treatment	Gets adequate time
Case 6	6-7	Healthy	Not Required	Gets adequate time

Case 7	6-7	Healthy	Not Required	Gets adequate time
Case 8	7	Hypertension	Undergoing Treatment	Gets adequate time
Case 9	1-2	Arthritis	Undergoing Treatment	Gets less adequate time

Observation:

Family members play important roles in the care of the sick and those unable to take care of their own needs. Providing care adversely affects the health and quality of life of the caregiver (Bauer & Sousa-Poza, 2015).

Out of nine respondents, 5 of the respondents stated that they have health issues which need to be monitored with medicines, under which 2 of them received treatments and did not even have adequate time for visiting the hospitals for their regular checkup because of their current responsibility. On enquiring the physical status of the respondents, 3 of them reported to experience body and joint pains which aggravate their burden while caring for the bed-bound elderly. They experience these pains due to carrying or shifting the bed-bound elderly for cleaning purposes. Most importantly 2 of the respondents reported that they don't get enough time for personal hygiene nore resting. On observing the situation the researcher finds that out of nine, 6 of the respondents are female caregivers and they do have multiple tasks to complete in a day, which physically burdens them and drains their energy.

Analysis of Psychological Aspects of the nine Cases

Criteria	**Stress/ Frustrations**	**Lack of support**	**Compassion Fatigue/Burnout**	**Other emotional problems**
Case 1	Experienced financial burden	Receives support from palliative nurse, Servant at home	Not faced	Yes (dealing with bed sores)
Case 2	Managing the bedbound elderly as she tries to remove the Ryle‘s tube which results in complications	Receives good support from family and relatives	Not faced	Yes (difficulty in sleeping as the bed-bound elderly cries in distress at nights)
Case 3	Looking after the bedbound elderly all alone and doing household work	Partially receives support from family members.	Faced (as she watches the bedbound elderly suffer and not able to leave the bed and stay in the room forever)	Yes (feels sad to watch the bed-bound elderly suffer)
Case 4	The end of the day she is left with body pain	Receives support from husband in bathing the bedbound elderly, Does not receives any	Not faced	Yes (is emotionally affected to see the condition of the bed-bound elderly‘s

		support from other family members		condition as he was very active)
Case 5	Due to her own health condition, In dealing with bed sores	Receives support from day time servant	Not faced	Yes, on the present condition of the bed-bound elderly, feels tired
Case 6	When the bed-bound elderly tries to pull out the Ryle‘s tube	Receives help from family members in carrying the bedbound elderly for cleaning and bathing	Not faced	Yes, it hard to take the bedbound elderly to hospital as they need to hire an ambulance for shifting to the hospital
Case 7	Yes, she had major stress while doing all work by herself	Receives full support from her son as he resigned from his job to look after the bedbound elderly and reduce the stress for her, receives support from her family	Not faced	Yes, as the bedbound elderly does not remember his own family members

		members		
Case 8	Yes, it is quite stressful for her to do all the work alone	Son visits her every day to help, Daughter financially supports her for medicine	Faced when her blood pressure falls	Yes, both physical and financial.
Case 9	Yes, due to health issues, financial burden, present life situation	Receives help from daughter in cleaning and bathing the bedbound elderly	Yes, she feels burnout and stressed with all her problems and present life condition	Yes, mentally as her husband's demise

Observation:

Chiou (2009) reported that caregivers with poor social support and family functions have a higher level of caregiver burden and that perceived social support is a better indicator of caregiver burden than the social support actually received.

Out of the 9 respondents all of them had faced different types of stress and frustrations due to financial burden in providing best care for the bed-bound elderly. The social worker observed that out of the 9 respondents, 1 reported to have a fair support system as they hire a paid caregiver during day time and his mother also helps him with some tasks, therefore they equally distribute the caregiving tasks. On the other hand, 3 respondents lack support from family which over burdens them and they experience compassion fatigue/burnout. It is considered to be their sole duty to do the caregiving as well as the household work, this burdens their experience and all of them face emotional problems in different ways. They find it helpless and grief silently and also blame their fate. According to (Sanuade & Boatemaa, 2015; Sousa, 2016; Unver, 2016) study *"female caregivers having greater levels of caregiver burden than their male counterparts. The study reveal that the burden of caregiving in women may be affected not only by gender but also* *by normal responsibilities such as housework and childcare, by personal characteristics, by employment status, and by other relevant factors"*, these factors are clearly visible in all the cases mentioned above, for example, Case 8, reports that she looks after her bed-bound husband at this age by herself, and she manages to shift the bed-bound elderly to the toilet only if her son visits them, on other times he is left to spend in his room for long hours because she is unable to move him. *Another study by the Carers National Association (1992) found that one of every two caregivers had financial burdens and two of every three caregivers were ill themselves and many studies document depression, marital problems, stress, fatigue, and social problems."*

Analysis of Social Aspects of the nine Cases

Criteria	**Family Support**	**Support from Community or Neighbors**	**Attending Social Gatherings/ Functions**
Case 1	Mother (feeding, toileting) Palliative nurse (Catheter change), Servant	No receiving	Affected (Only attend close and nearby functions)
Case 2	Wife, Daughter, Aunt (feeding and cleaning)	Not receiving	Partially affected (as one has to stay home to look after the bed-bound elderly)
Case 3	Partially receives support from family members, Son helps in bathing the bedbound elderly.	In certain scenarios seeks help from neighbors	Affected (Avoids most functions and only visits nearby or close functions)
Case 4	Husband (in bathing the bedbound elderly)	Not receiving	Affected (she was not able to fulfil her responsibility as a mother and not get involved fully at her daughters marriage due to her current responsibility)
Case 5	No family support, support received from day time servant	Not receiving	Affected (she tries to stay at home because of her age as well as her current responsibility)

Case 6	Receives help from family members in carrying the bedbound elderly for cleaning and bathing	Not receiving	Affected (they don't go for other social functions, because there is plenty of things to manage at home as they have a newborn and a bed-bound dependent at home
Case 7	Receives help from son completely, helps in bathing, toileting and feeding and also receives support from other family members	Not receiving	Affected (does not attend any function or gatherings as she finds it difficult to spare time for them)
Case 8	Receives help from son to bath the bed-bound elderly and financial help from daughter	She hesitates to take help from her neighbors as she does not want others to know about the current situation and she also feels guilty of being a burden for others	Affected (Very occasionally she visits the temple and rushes back as soon as possible. She does not attend any gatherings, marriages or other functions)

Case 9	Receives help from daughter in cleaning and	Not receiving	Affected as she is emotionally suffering due to her husband‘s demise and also experiencing
	bathing		caregivers' burden

<u>Observation:</u>

8 of the 9 respondents received some sort of family support in certain tasks, moreover only 1 respondent reports receiving help from the neighbours while she goes to visit the hospital or to buy groceries. She assigned them just to keep a check on the bed-bound elderly in her absence. Majority of the respondents' social lives are affected in different ways due to their caregiving tasks as they partially or sometimes purposely avoid situations like traveling and social gatherings because they find it difficult due to the lack of time and their current responsibility.

“Caregivers who spend long hours with the elderly may be less able to meet their own needs for socialization. Findings. In a British study of the caregivers of bed-bound elderly, nearly half reported that caregiving had affected their social lives. Recent U.S. studies also document the restriction of social activity or isolation caused by caregiving and the importance of a social network in caregiver health. (Chiou, 2009)” All the respondents also said that they have never had any entertainment or vacations in all these years due to their responsibility towards the bedbound. Respondents who had the tasks divided in their homes by the family members to look after the bed-bound elderly had less burden and did not have to seek support from the community or the neighbours. However, one respondent reports that she feels reluctant in seeking help or support from the community, as thought of overburdening her neighbours, which eventually affects her self-care.

Analysis of Financial Aspects of the nine Cases

Criteria	**Medical Expenses**	**Additional Equipment**	**Availing Government Schemes**
Case 1	By own	Air bed	No
Case 2	By own	Ryle‘s tube, Catheter, Adult Diapers, Water bed, Commode chair	Old age Pension
Case 3	By own	Catheter, Wheelchair	Received Caregivers Pension
Case 4	Old age Pension	Catheter, Commode Chair	Old age Pension
Case 5	Employment Pension	Air bed	Employment Pension
Case 6	By own	Diapers, Ryle‘s tube, Catheter, Water bed	No
Case 7	By Brother	Ryle‘s tube, Catheter, Adult Diapers	No
Case 8	By daughter, Old age pension	Catheter	Old age pension
Case 9	Disability Pension	Colostomy and Urostomy bag, Adult Wheel chair,	Disability Pension

		Diaper	

Observation:

"Financial costs refer to direct momentary costs related to paying for the caregiving expenses while some are related to the forgone financial or monetary costs in employment due to one having to perform a caregiving role. Not all the financial costs could be measured by momentary values as some costs are subjectively indicated by individuals as perceived financial costs. (Haddock, Zimmerman, Lyness, & Ziemba, 2006)"

In my study 4 respondents informed that they met the medical expenses for the bed-bound elderly from their own salary and earnings, and only one respondent informed that they meet it with the help of their relative and the other half of the respondents report to fill the expenses with the government schemes they received as old age pensions, employment pension or disability pension. All these 9 respondents are registered under the government palliative care so they receive a visit from the doctor or the palliative team from the hospital to check on them. It is a great relief for them as they don't need to carry the bed-bound elderly to the hospital frequently. Some of them depend on colostomy bags, adult diapers which are expensive and this is a great burden on their side as these are recurring expenses they have to spend a huge amount on these items. All the respondents have provided with the needed basic equipment for the bed-bound elderly, such as air bed, water bed, commode chair or wheelchairs etc. One of the respondents even said that they received the air bed from the palliative care team only when another patient died and this bed was given back to the team.

Analysis of Problems Faced on Daily Basis of the nine Cases

Criteria	**Time Spent (Personal Hygiene)**	**Bathing/Toileting**	**Feeding**	**Positioning**
Case 1	4 hours a day	Washes twice a week and provides a sponge bath every day. 30 mins for toileting	Provides solid food	Developed bed sores as result of damage of air bed
Case 2	30 minutes to clean everyday	Cleans with warm wet towel every day, Has diaper for toileting	Provides liquid food through Ryle‘s tube	Has provided with water bed to prevent bed sores
Case 3	2 hours a day	Bathes him once in 2 weeks and cleans with a wet towel on other days, Passes motion once in 4 days	Provides solid food	Potions every 2 hours to prevent bed sores
Case 4	2 hours a day	Gives bath only when the bed-bound elderly is feeling sick, transferred to a commode chair to	Provides solid food	Does not position and has not developed any sores till now

		pass motion (sometimes defecates in bed unconsciously)		
Case 5	3 hours a day	Baths him twice a week and on other days cleans with a hot towel, for toileting she places a large piece of cloth and lays some newspaper	Feeds with semi liquid food which makes it easier for him to swallow	Having bed sores even though lying on air bed
Case 6	2 hours a day	Baths once in a week, has diapers for passing motion	Feeds liquid food for easier consumption through Ryle‘s tube	Has bed sores, provides care and applies proper medication for it and now has a water bed to prevent them.
Case 7	1 hour a day	Baths once a week and on other days wipe with wet warm cloth, provides with diaper and sometimes cloth for passing motion	Feeds 3 times a day with liquid food, he is given protein powder drink in the morning, oats in the afternoon and fresh juice or rice gruel at	No bed sores, if spotted applies proper medicines and provides proper care

			night	
Case 8	1 hour a day	Baths once a week, Wipes body on all other days, the bedbound elderly has constipation, he passes motion only once in a week with the support of medicine, she places a clean cloth and disposes it properly	Provides solid food	Does not position and has not developed any sores till now
Case 9	1 hour a day	Bath‘s once a week with help of daughter and when alone, she wipes him clean with warm wet cloth, provides diapers for toileting	Provides solid food	Does not position and has not developed any sores till now

Observation:

On the whole, caring for the sick and bed-bound elderly consumes immense time as they have to spend nearly 3-4 hours a day cleaning and feeding the bed-bound eldelry. *“Researchers have shown that numerous demands, including greater assistance in ADLs or IADLs of care recipients, longer care giving duration and more hours of care are associated with poor adjustment of caregivers (Pinquart & Sorensen, 2003, Schulz, 2005)”*

In this scenario 5 respondents said that they have alternated their daily responsibilities by providing a proper bath to the bed-bound elderly only once in a week and 3 respondents offer it twice a week and 1 respondent only gives a proper bath when only needed and on the other days wipes them with a wet towel. Three of the bed-bound elderly have developed bed sores as their caregivers are not able to properly reposition them every 2 hours and this leads to pressure sores. These bed-bound elderlies need extra time to treat the sores with medications and dressing on the areas. Feeding is another task and 3 of the bed-bound elderly is on ryles tubes and they are provided with a special liquid diet. One respondent said that they provide semi liquid food for the bed-bound elderly as he finds difficulty in swallowing.

5.2) What are the different strategies adopted by the caregivers and documenting the best practices?

Criteria	**Coping Strategies**	**Task Managing**
Case 1	● They practice providing sponge baths every day for preventing bed sores.	● Household work done by servant ● Receives helps in bathing the bedbound elderly ● Support from the palliative care nurse in changing catheter
Case 2	● Irregular positioning (negative strategy)	● Family help in household work ● Receives help for cleaning and bathing ● Receives support from palliative care nurse
Case 3	● Frequently change positioning to prevent bed sores ● Not take the bed-bound elderly out of his room (negative strategy)	● Household work and caring the elderly is met by single person ● Receive very little support from family members

Case 4	● Use of commode chair for toileting.	● Household work is done by the caregiver ● Receives major help from her husband for cleaning and toileting the bed-bound elderly
Case 5	● Irregular positioning (negative strategy)	● Servants assist in household chores and cleaning the bed-bound elderly.
Case 6	● Irregular positioning ● (negative strategy) Waterbed provided for avoiding further ● complications Physiotherapy recommended by the doctor	● Support from palliative care nurse in cleaning the wounds ● Family support in household works and cleaning the bed-bound elderly
Case 7	● Frequently change positioning to prevent bed sores	● Household work done by the caregiver ● Little support received from family members in caring the bed-bound elderly
Case 8	● Engages the elderly in watching television while the caregiver doing household works	● Receives help from son for bathing ● All the household work and other caring works are done by the caregiver alone

Case 9	● Irregular positioning (negative strategy), but does not have any bedsores	● Receives support from her daughter in cleaning, bathing and toileting the bed-bound elderly.

Observation:

“Caregivers using fewer positive strategies (e.g. engaging in pleasant activities and seeking social support) and greater negative coping strategies (e.g. self-blame and avoidance) reported poorer psychosocial outcomes and adjustment compared to non-caregivers. (Mausbach, 2013)”

Out of the 9 respondents 3 showed positive coping strategies (positioning the elderly, engaging the elderly while doing household work, using a commode chair to transfer the elderly and bring some privacy). Three of the respondents practiced negative coping strategies as they don't change the position of the bed-bound elderly, which leads to bed sores. In the task managing category one of respondents said that they did not receive any help from their family members and she had to do both household and caregiving alone. Case 4 did not show any signs of bedsores because the bed-bound elderly is moved to a commode chair frequently. Case 8 experienced difficulty in positioning because she lives away from her children and she had to wait for anyone of her sons to visit them for helping with bathing the bed-bound elderly. *“Use of emotionfocused coping strategies found associations with negative outcomes, with caregivers being less able to regulate their negative emotions compared to controls. (Ruiz-Robledillo and MoyaAlbiol, 2013)”*

5.3 What are the available services for supporting the bed-bound elderly?

Criteria	**Available Services/ Schemes**	**Community Support**
Case 1	● Under Government Palliative Care Service ● Buys medicines from local drug store, ● Under consultation at Government hospital	● No support from community groups or government schemes
Case 2	● Under Government Palliative Care Service and medicines	● No support from community groups or government schemes
Case 3	● Receives Caregivers pension ● Under Government Palliative Care Service and medicines	● No support from community groups
Case 4	● Under Government Palliative Care Service and medicines	● No support from community groups or government schemes

Case 5	- Under Government Palliative Care Service, - Medicines from government dispensaries	- No support from community groups or government schemes
Case 6	- Under Government Palliative Care Service, - Buys medicines from government dispensaries	- No support from community groups or government schemes
Case 7	- Under Government Palliative Care Service, - Buys medicines from government dispensaries	- No support from community groups or government schemes.
Case 8	- Under Government Palliative Care Service and medicines	- No support from community groups or government schemes

Case 9	● Receives Disability pension ● Under Government Palliative Care Service and medicines	● No support from community groups

Observation:

"The Government of India announced the National Policy for Senior Citizens in the year 1990. The policy and plans were put in place by the central and state Government for the welfare of the older persons. Many incentives were introduced; pensions, travel concessions, income tax relief, medical benefits and many more schemes are covered in the document. The senior citizens should be made aware of these policies and schemes, introduced by the Government. With the intention of extending the awareness to the senior citizens, plans were formulated and the details have been elaborated. (Government of India, 2011)"

On observation, all of the cases are registered under the government palliative care service, unfortunately none of the respondents underwent any specific training in elderly bed-bound caregiving, they just naturally adapted to the role of responsibility. Out of the 9 respondents only one is aware about the caregiver‘s pension and they find little support with this scheme. The bedbound elderly‘s medicines are brought from government dispensaries as its availability to them at low costs and only one respondent reports buying medicines from a local drug store as the doctor has prescribed and recommended to stick with a particular brand, which is not available in government outlets. Except one respondent, none of the others received support from their community members and all the nine respondents are unaware about any local resources.

CHAPTER VI

FINDINGS, SUGGESTIONS & CONCLUSION

6.1 INTRODUCTION

The present study titled ―CAREGIVERS EXPERIENCE IN PROVIDING CARE FOR THE BED-BOUND ELDERLY‖ is a qualitative study aimed at understanding the life experiences of the caregivers, who look after the bed-bound elderly in the long-term. The study looked at the challenges - psycho-social-economic and physical; the various strategies adopted in caregiving; as well as examined the services availed or available by the caregivers in supporting and caring the bed-bound elderly in their households. The study adopted a multiple case study design. Data was generated using an interview guide from 9 cases purposely collected; the respondent should be providing care for a completely bed-bound elderly above 60 years of age, ailing with a chronic and serious illness for at least an year. The present chapter discusses the major findings based on the research questions and conclusions arrived on the basis of thematic analysis and the suggestions of the researcher to improve the quality of life of a caregiver.

6.2 FINDINGS

The findings are presented below based under three main themes and its sub-themes based on the general research questions:

Physiological Challenges

- Caregiving is a big task, especially for females when they are bound to do the household work as well as the responsibility of being a caregiver; therefore, it is a herculean task on their side to meet the daily needs, which will also physically affect their health and stress them out.
- Some of them are taking medications for their age-related health issues and these respondents face difficulty in keeping up with their regular medical follow-ups, as they are finding difficulty to spare time for hospital visits. As a result, these factors affect the quality of caregiving, since they fall behind their own health condition.

Psychological Challenges

- When the caregiver is similar to the age of care receiver, they are likely being more affected. They suffer from high levels of stress and frustration, emotional disturbances are seen affecting their health too, such as pressure to look after their bed bound spouse and no other family members (especially their children) around for support, which can be compared to _empty-nest‘ effect. Beyond that this may be regarded as an phenomena of abandonment when immediate family members leave the afflicted and the caregiver to get on with their lives. They also show signs of negative feelings which affect them from time to time such as sadness, dread, worry, helplessness and role guilt, etc. (Case 8)

- Some of the caregivers show higher levels of depression when the bed-bound elderly develop some disturbance or deteriorate their health, it forms pressure on the caregiver as it makes them feel guilty about not providing care and attention to their loved one.

- Some of the caregivers have lower levels of self-care, lack support from family which over burdens the caregivers and they experience compassion fatigue/burnout.

Social Challenges

- Social lives of the caregivers are affected in different ways due to their current responsibilities; very often they avoid social gathering and functions as they find it difficult to spare time from the caregiving responsibility. Some respondents even mention appointing another family member on their behalf to such functions. None of the respondents have reported having a _vacation‘ of any sort nor not even went to a movie theater to hang out with their family to have quality time. Instead many reported to sit together only when they enjoy a cup of tea, and respite care services are needed for such caregivers.

Financial Challenges

- Financial burden is an additional stress and this affects the emotion of the caregivers negatively. Due to financial burden they are cutting short of all the best options for the bed-bound elderly. The caregiver finds it difficult to provide the basic equipment to support the elderly due to its unaffordability. Air bed is an essential item to be used for bed-bound care, unfortunately some families find it hard to pay the electricity bill and they try to switch to waterbeds.

- Some bed-bound elderlies are left alone in their rooms because of the unavailable supporting resources, they need a wheelchair to move around and most of the hose are not wheelchair friendly which denies access to other areas inside the house and female caregivers find difficulty to carry them out of their confined space.

Problems Faced on Daily Basis

- Caregivers had to spend hours on cleaning and feeding the bed-bound elderly, they at least need to spend 3 hours every day for the elderly care and while dealing with bed-bound every caregiver should follow the skin care and hygiene of the bed-bound elderly. Moreover, they should position the elderly every 2 hours to prevent bed sores and to have good blood circulation, in failing to do so resulted in developing pressure sores.

Coping Strategies

- The common strategy adopted by the caregivers was to provide a proper bath once or twice in a week; on the other days, they wipe the bed-bound elderly with a clean, wet towel.
- Most of the respondents inform that they leave the bed-bound elderly alone in the room and they don‘t position them due to lack of time, but only one respondent provides a television in the elderly‘s room, so that she can do her household without making the elderly feel unwanted. This has also helped her to improve her self-satisfaction of being a caregiver.

Task Managing

- Majority of the respondents did not receive proper support from family members, which adds to their burden and affects the quality of care they provide, but respondents who divide the task among families, have better results with caregiving history without the bed-bound elderly displaying any episodes of bed sores. Two of the respondents belonging to high income family reports to appoint paid servants to help them during day times, which made their work more easier and stress free.

Community Support and Services/ Schemes Available

- Majority of them purchased medicines and other needed essentials for the bed-bound elderly from government hospitals and government medical outlets, where medicines are provided free of cost or purchased at affordable prices. None of the caregivers except one, were aware of the government schemes, especially the caregivers‘ pension scheme that could have been available by them
- They were reluctant to seek help and support from the community. This was a sort of self-stigma, as they felt that it may _overburden others. They preferred to confine their thoughts to themselves and suffer, this in a way affected the possibility to obtain material or emotional support or even respite care, therein affecting their self-care. This in the long run was bound to affect the bedbound elderly they cared for.

6.3 SUGGESTIONS

- All the caregivers should have given practical knowledge from health care workers in dealing with the bed-bound elderly. The palliative care nurse could introduce positioning techniques, such as using pillows to back support the elderly and to teach the caregivers to release such pressure points for elderly bed-bound.
- More professional outlook to counseling needs to be given for the caregiver to help them deal with the burnout and to handle their unsolicited guilt. Making them understand that the feeling of compassion fatigue/burnout is normal and is natural to feel, which helps in reducing mental stress of the caregivers.
- Generating and providing a network of support systems for the caregivers from within the family itself which will help to divide the task equally and no one will feel pressured. This also helps to engage young members being part of the responsibility, and instill in the present member the possibility of hope for continued care besides avoiding _burnout‘.
- Support from the community i.e. from other healthcare NGOs and other religious institutions would create a good effect in the life of the caregivers as well as the quality of care they provide. At times of bed sores, they may avail such professional help, even if their palliative care nurse is not immediately available.

- Regular and routine health check-ups, at least once in a month without delay can help identify the complications at an earlier stage for the bed-bound elderly.
- Making awareness of the various schemes available from the government in regards to caregiving. Such information can be delivered through ASHA workers or palliative care nurses or a social worker in the community.
- Recurring expenses can be reduced through alternatives such as using cloth bits instead of wipes or diapers. Cloth bits are easily available from tailoring shops, which can be used for cleaning and wiping.

6.4 CONCLUSION

Caregiving is a challenging yet rewarding occupation. The challenges lie within the physical demands and psychological burdens of caring for individuals with severe disabilities. At the same time, caregivers can reap a great deal of pride and reward for helping individuals with disabilities be able to live independently in their own home and achieve a high quality of life. Learning the self-care skills can make the whole caregiving experience less burdensome and more rewarding.

Caregivers play a crucial role in providing care to the bed-bound elderly. They are involved in providing multiple services to the elderly that make them burdened and distressed. The main perceived issues of the caregivers were providing physical care to the bed-bound elderly daily at home, economic burden related to treatment and travel and distress and discomfort due to lack of personal and social support. Availability of support systems in the community in the form of non-governmental organization, volunteers and government schemes together can take care of the economic, transport and other social issues. Treating team has the responsibility to improve the caregiver's level of preparedness to offer care at home. The findings of the study can support the caregivers in getting information about the community resource and to learn best practices adopted by their fellow caregivers.

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APPENDIX

INTERVIEW GUIDE FOR THE CAREGIVERS

General Information

Name:

Age:

Marital Status: single/ married/ divorced/ widow

Education:

Address:

Income Category: High Income / Middle Income / Poor Income

Relationship with the bed-bound elderly:

Duration of being bed-bound:

For paid caregivers

Duration of providing the service for current client:

Nature of training undergone for caring for the bed-bound elderly?

Previous experience years and nature of work in caring with bed-bound elderly client

Physiological Problems

1. Are you getting adequate sleep during the night or any time of the day?
2. How many hours are you able to sleep in a day?
3. Do you have any health concerns (specify) and are you taking proper medication for it?

Psychosocial Problems

4. Specify if there is anything particular or, that you are worried about in providing care to the bedbound?
5. Do you get personal time for your daily routine?
6. How do you describe the amount of stress in your life while caring for the bed-bound elderly?

Financial Burden

7. How do you meet the expense for medicine and treatments?
8. Is there any financial aid from any support groups or government schemes? Provide details and approximate total amount.
9. Are you considering alternative medicine or treatment for the bed-bound? (Depending on homemade remedies). What are they?

Challenges encountered in caregiving

10. Approximately how many hours do you spend in a day cleaning up the bed-bound elderly? (Toileting, Bathing, Feeding etc.)

11. Do you get any assistance from your family members while cleaning/caring (Toileting, Bathing, and Feeding etc)? (e.g. do you leave it to another person paid, another family member)

Social Problem

12. Do you get quality time with your family members? How do you manage it?
13. How is the social life of yours getting affected by the current responsibility?

14. What is the hardest part in your life because of caring for the bed-bound elderly? (Financial, Physical, Emotional)

Coping Mechanism

15. How do you personally manage your daily routine and caring responsibilities together? (household, elderly care, personal care)
16. Is there any particular strategy you adopt to make your work easier while caring for the bed-bound elderly? (such as making the elderly sit in a commode chair until all the household are done)