Caregiver Burden of Formal Caregivers of Elderly Patients in Home Settings

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In partial fulfilment of the requirements for the award of the Degree of

M.Sc. Counselling Psychology

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Certificate

This is to certify that the Dissertation entitled “**Caregiver Burden of Formal Caregivers of Elderly Patients in Home Settings”** is an authentic work carried out by Kadija Nitin Abdul Salam under the guidance of **Dr. Pramod S K** during the 4th semester of M.Sc. Counselling Psychology programme in the academic year **2023 – 2025.**

Dr. Pramod S K

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Declaration

I, **Kadija Nitin Abdul Salam**, do hereby declare that the Dissertation titled **"Caregiver Burden of Formal Caregivers of Elderly Patients in Home Settings"**, submitted under partial fulfillment to the Department of Counselling Psychology, Loyola College of Social Sciences (Autonomous), Sreekariyam, under the Supervision of **Dr. Pramod S K**, Assistant Professor, Department of Counselling Psychology, for the award of the degree of Master of Science in Counselling Psychology, is a bonafide work carried out by me and no part thereof has been submitted for the award of any other degree in our University.

Kadija Nitin Abdul Salam

Place: Sreekariyam

Date:

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Abstract

This study aims to explore the caregiver burden of formal caregivers of elderly patients in home settings. Caregiver burden is the adverse effects perceived by caregivers on their emotional, social, financial, physical and spiritual functioning. The study adopts a qualitative approach to get an in-depth understanding of the burden faced by the formal caregivers. Six participants were selected through snowball sampling from the district of Trivandrum. A semi-structured interview schedule was used to collect data from the participants. The qualitative phenomenological approach was followed, and thematic analysis was used to bring out the themes and narratives from the transcripts of the participants. Findings show, the demanding aspect of the role of being a formal caregiver of elderly patients in a home setting was balanced by the financial stability that the job provided. Due to previous personal experiences with caregiving of their own family members or possession of individual coping skills and traits, the discharge of objective caregiving tasks became easier for the formal caregivers. Physical discomfort associated with the tasks of caregiving was managed at the home setting level by the caregivers. The formal caregivers were empathetic to their patients' difficulties and saw them like their own family members. The formal caregivers gave a positive meaning to their roles and believed that they were doing an invaluable service by taking care of the elderly. This mitigated the effects of physical caregiver burden. They were able to view their physical difficulties as part of their job. They expressed an expectation that society would look at the roles of formal caregivers in home settings more favourably. Recommendations include incentives, motivation and appreciation for all the good and efficient work done by them, necessary arrangements for the caregivers to keep in touch with their families and friends.

Keywords: Caregiver burden, formal caregivers, elderly patients, home settings, personal experiences, positive meaning

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Chapter One

Introduction

Caregiver Burden of Formal Caregivers of Elderly Patients in Home Settings

According to the WORLD SOCIAL REPORT 2023: LEAVING NO ONE BEHIND IN AN AGEING WORLD by the United Nations, the number of people aged 65 years or older worldwide is projected to more than double, rising from 761 million in 2021 to 1.6 billion in 2050. The number of people aged 80 years or older is growing even faster.

In 2021, 1 in 10 people worldwide were aged 65 or above. In 2050, this age group is projected to account for 1 in 6 people globally. Population ageing is a global phenomenon, and the number of people over 60 years of age has been rising rapidly across the world. India, too, is witnessing an exponential growth in the number and proportion of elderly people, coupled with a decreasing fertility rate (less than 2.0) and increasing life expectancy (more than 70 years). The elderly in India currently comprises a little over 10% of the population, translating to about 104 million, and is projected to reach 19.5% of the total population by 2050.

This phenomenon of population ageing impacts all aspects of society and has numerous health, social, and economic implications, including changes in labour and financial markets, shifting disease burden, rising dependency ratios, evolving family structures, and altered consumption patterns. Moreover, medical expenses are more than double for this population segment as older people are likely to consume more healthcare services. While catering to the needs of the elderly population of this size is challenging, it also presents an opportunity for the growth of the senior care industry, which is presently estimated at USD 7 billion (` 57,881 crore) - SENIOR CARE REFORMS IN INDIA Reimagining the Senior Care Paradigm A POSITION PAPER (Gopal et. al 2024).

About 22.8% of Kerala's population will be senior citizens by 2036 as against the projected national average of 15%, according to the UN Fund for Population Activities' India Ageing Report 2023.This global increase brings challenges for families, especially for caregivers of elderly patients, including both formal and informal caregivers.

Starting early 21st century, home healthcare services for the elderly began to sprout in various metropolitan areas. According to a published newspaper article (The Times of India, 2014, June), these agencies offered a suite of services from palliative and geriatric care, companionship, emergency services, routine medical visits, and ‘concierge’ services that ran errands for seniors and accompanied them on outings. Each set of services are preset and packaged, and in metropolitan areas with a rising number of senior citizens, such services are not only being sought after by adult offspring who live in distant locations but also those who reside in the same city. This is largely due to adult children leading busy professional lives and finding themselves unable to tend to their aging relatives.

Multiple Challenges Faced by the Elderly

In a review titled Caregiving for Older Adults in India: The Role of Kinship and Non-kinship Networks by Jyotsna M. Kalavar, Jamuna Duvvuru, & Eric Thomas Jr India is witnessing an aging revolution in unprecedented ways. This review explores the changing trends in the care of the elderly. The current dynamics of family, culture, economics, and social provisions are not entirely favorable for the well-being of old adults. Recommendations for alternatives in all these areas are provided to improve the elder care scenario in the country.

Alienation is more likely to be experienced by men than women among older adults as the latter participate actively in the kitchen and social demands of the family (Kattakayam, 2002). However, Jamuna (2003) reported that elderly women in cosmopolitan cities are end up feeling more socially alienated than their counterparts in the rural areas. Such alienation stems from urban living that primarily affects the elderly who feels disempowered when their adult children leave the nest for better life opportunities, leaving behind an emotional vacuum that is further challenged by crimes against the elderly (Nair, 2014).

Caregiving

According to Ultimate Care (Licensed Home Care Agency), published in March 14th, 2025, Caregivers play a crucial role in providing assistance and support to individuals who are unable to care for themselves fully. Whether it's due to age, illness, or disability, caregivers offer physical, emotional, and practical help to enhance the quality of life for those in need.

Caregivers offer a range of services, including personal care, companionship, medication management, meal preparation, and transportation. Caregivers not only help with physical tasks but also provide emotional support, compassion, and companionship to enhance their clients' well-being.

For individuals with chronic illnesses or disabilities, caregivers often become a lifeline, enabling them to maintain their independence and live comfortably in their own homes. The support provided by caregivers can contribute to improved mental health, increased social engagement, and a higher overall quality of life for those receiving care.

Caregivers can be categorized into different types based on their relationship to the care recipient and their level of formal training. The four main types of caregivers are formal caregivers, informal caregivers, professional caregivers, and family caregivers.

Types of Caregivers

Formal Caregivers: These caregivers receive formal training and are employed by home care agencies, nursing homes, or assisted living facilities. They provide professional care and follow specific caregiver job descriptions and caregiver responsibilities.

Informal Caregivers: Informal caregivers are typically family members, friends, or neighbours who provide care out of love and a sense of duty. They may not have formal training but play a crucial role in supporting their loved ones.

Professional Caregivers: Professional caregivers are individuals who have received specialized training and certification in caregiving. They may work independently or be employed by home care agencies, hospitals, or other healthcare organizations. They provide skilled care and follow specific caregiver roles.

Family Caregivers: Family caregivers are relatives of the care recipient who take on the responsibility of caregiving. They provide care out of love and personal commitment, often sacrificing their own time and resources to support their family member.

Individuals and families make informed decisions when choosing the most suitable caregiver for their specific needs. Factors generally considered include the level of care required, the caregiver's qualifications, availability, and the dynamics of the caregiver-recipient relationship.

Caregivers play an invaluable role in society, providing essential care, support, and compassion to individuals in need. Whether they are formal caregivers, informal caregivers, professional caregivers, or family caregivers, their dedication and commitment have a significant impact on the lives of those they serve.

Formal Caregiving

Home healthcare services emerge as a pivotal resource offering indispensable assistance to caregivers and their dependents. Trained healthcare professionals proffer a spectrum of services encompassing medical care, aid with daily living activities, emotional reinforcement, and companionship. These services are tailored to cater to the specific needs of each individual, ensuring personalized care conducive to their health and welfare.

Formal caregivers were defined as those who provided paid care (e.g., paid health-care assistants, long-term care workers, etc.) while informal caregivers referred to caregivers who provided unpaid care (e.g., family members, relatives, etc.).

Formal caregiving is the term used to describe people who are paid for their services and have received formal training and education in providing care. Some formal caregivers are licensed and regulated by a regulatory body, such as nurses. Formal caregivers may come into your home through a home care program or provide respite care at an overnight facility or long-term care residence.

Roles and Responsibilities

Personal Care. Formal caregivers assist with activities of daily living (ADLs) such as bathing, dressing, grooming, and toileting. They ensure the comfort and hygiene of the individuals under their care.

Medical Assistance. Depending on their training and qualifications, formal caregivers may provide basic medical assistance, such as administering medication, monitoring vital signs, and assisting with medical equipment.

Companionship. In addition to physical care, formal caregivers provide companionship and emotional support to their clients. They engage in meaningful conversations, offer companionship during meals, and participate in activities that promote mental stimulation and social interaction.

Household Support. Some formal caregivers also assist with light housekeeping tasks, meal preparation, and running errands to ensure a safe and comfortable living environment for their clients.

Coordination of Care. Formal caregivers may work closely with healthcare professionals, such as nurses or doctors, to ensure continuity of care. They may communicate important information about their clients' health conditions and collaborate in developing care plans. It's important to note that the specific roles and responsibilities of formal caregivers may vary depending on the setting in which they work and the needs of their clients. Formal caregivers play a crucial role in providing professional care and support to individuals in need. Their expertise and training make them well-suited to address the unique challenges that arise in caregiving situation.

However, the duties undertaken by them require continuous commitment and may take a toll on their physical, emotional and social well-being.

Caregiver Burden

Zarit and colleagues (1986) defined caregiver burden as “the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical and spiritual functioning.” Caregiving burden has negative impact on the well-being of caregivers, including increased mortality, poorer self-care, social isolation, depression, anxiety and financial stress. A recent review suggested that caregiver burden can be the most compelling problem affecting caregivers of chronically ill elderly patients. The burden of caregiving also has negative impact on the well-being of care recipients, such as abandonment and institutionalisation of the care recipient.

Caregiving is a highly individualized experience, as such carers may experience burden due to care demands exceeding resources (e.g., financial, physical), lack of social connections, and/or having multiple conflicting responsibilities (Liu, Heffernan, and Tan, 2020).

Caregiver burden is also associated with poor self-care, sleep deprivation, and adverse health behaviours, such as alcohol and substance use (Adelman, Tmanova, Delgado, Dion, and Lachs, 2014; Webber, Davies, Leach, and Bradley, 2020). Notably, high level of caregiver burden is also negatively associated with care recipient's physical and mental health (An, Fu, and Yuan, 2019; Buck et al., 2020; Yang, Pan, Allen, and Hendrix, 2019).

Elderly Patients

Ageing, an inevitable process, is commonly measured by chronological age and, as a convention, a person aged 65 years or more is often referred to as ‘elderly’. However, the ageing process is not uniform across the population due to differences in genetics, lifestyle, and overall health. Thus, chronological age fails to address the heterogeneity observed among the ‘elderly’, particularly in regard to their pharmacotherapy needs where pharmacokinetic and pharmacodynamic factors necessitate individualisation of regimens. However, there are no concrete definitions of ‘elderly’ that appropriately characterise this patient population; in using the generic terms ‘elderly’ and ‘older persons.

According to the United Nations, an old person is defined as a person who is over 60 years of age. However, families and communities often use other socio-cultural referents to define age, including family status (grandparents), physical appearance, or age-related health conditions.

Home Setting

Home Setting is the participant's primary place of residence or the residence where the participant is receiving home care.

Home Care according to the Ministry of Social Justice and Empowerment under the office memorandum is Health care or supportive care provided by a professional care giver in the individual home where the patient or client is living. Compared to Institutional care, home care is less expensive and more satisfying to the individual and his family.

In this study Home Setting refers to the participant's primary place of residence or the residence where the participant is receiving home care.

Statement of the Problem

The problem of terminal illnesses or long-term ill health of the rising elderly population demands more and more care-giving services in today’s complex modern globalised world. Families are forced to seek employment across transnational borders often to meet the rising cost of living as well as health care. Ironically, family members may be battling their own health issues or health issues of their children. Thus, more and more families are hard-pressed to seek the help of agencies that provide formal caregivers like home nurses to ensure that their elderly are being taken care of in their absence. Formal caregiving roles exact a burden on the caregivers who often have to put the needs of the terminally ill recipient whom they are taking care of, first. With the rise in the percentage of the elderly population of the world the demand for the services of well-trained formal caregivers is increasing. Research to find solutions to reduce the burden of care-giving experienced by formal caregivers is highly invaluable in this respect. This qualitative study aims to better understand the caregiver burden of formal caregivers of elderly patients and gain valuable insights into their lived experiences. The insights so gained will inform efforts to develop solutions, policies, plans and programmes in this respect.

Objectives

1. To explore the physical impact of caregiving on formal caregivers of elderly patients in home settings.
2. To identify the emotional effects of caregiving on formal caregivers of elderly patients in home settings.
3. To identify the challenges experienced by formal caregivers of elderly patients in home settings.
4. To understand the coping strategies used by formal caregivers to relieve caregiver burden.
5. To explore caregivers' perceptions and attitudes towards their caregiving role.

Need and Significance of the Study

The rising numbers in the elderly population are facing health issues. The Longitudinal Ageing Study of India (LASI) launched in 2016 by the Ministry of Health and Family Welfare is a full-scale national survey and a seminal study on the status of the ageing population in India. The report has provided several valuable insights into the process and impact of ageing in India. The key highlights of the report are given below

Physical Health

- Every fourth Indian over 60 years and every fifth Indian over 45 years reported having poor health.

- 75% of the elderly have one or more chronic diseases.
- 40% of the elderly have one or other disabilities.
- 1 in 4 has some kind of multi-morbidity.
- Diabetes is more common among senior citizens in urban India.
- Cancer prevalence is on the rise and is higher in urban India.

Mental Health

- Around 20% of the elderly in India have mental health issues
- The prevalence of probable depression among the elderly is ten times higher than the self-reported prevalence of diagnosed depression, implying a greater burden of undiagnosed depression

This implies the need for more and more caregiving services. Informal and formal caregivers play an important role in providing care to them. Though there is increasing research on caregiver burden, studies on caregiver burden of formal caregivers tending to elderly patients in home settings are less. This study aims to explore the caregiver burden of formal caregivers who care for elderly patients in home settings, the physical and emotional well-being of the caregivers, the challenges faced by them and the strategies they employ to reduce their caregiver burden. Their views on their role of caregiving will provide valuable information to improve the quality of caregiving experience for caregivers. Working towards solutions to alleviate caregiver burden thus emerges as a critical priority given its impact on carers and care-recipients' holistic health.

Chapter Two

Review of Literature

Review of Literature

This chapter presents a comprehensive overview of the existing literature related to caregiver burden. It includes a theoretical review that outlines key conceptual frameworks relevant to the caregiving experience, followed by an empirical review highlighting previous research findings on the physical, emotional, and psychological impacts of caregiving. The review also explores the roles, responsibilities, and coping strategies of caregivers, providing a foundation for understanding the context and significance of the present study.

Theoretical Review

Pearlin's Stress Process Model

This model elaborates on the stress and coping framework by distinguishing between primary stressors (direct caregiving tasks) and secondary stressors (consequences of caregiving, such as financial strain or social isolation). The model also emphasizes the role of appraisal (how caregivers perceive their situation) and coping strategies in mediating the relationship between stressors and outcomes.

Self-Determination Theory

This theory suggests that caregiver well-being is influenced by the satisfaction of basic psychological needs (autonomy, competence, and relatedness) within the caregiving context. For example, caregivers who feel autonomous in their caregiving role and supported by healthcare professionals are more likely to experience positive mental health outcomes.

Acceptance Theory of Family Caregiving

This theory focuses on the caregiver's acceptance of the caregiving role and its associated responsibilities. It suggests that caregivers who anticipate and accept the possibility of decline in their care recipients are more likely to adapt to the role effectively.

Conceptual Models of Caregiving Process

These models, like the Model of Carer Stress and Burden, integrate elements of stress and appraisal models to understand how caregiving stress develops over time, particularly in the context of neurodegenerative diseases.

Factors Influencing Caregiver Burden

Objective Burden

This refers to the tangible tasks involved in caregiving, such as providing personal care, managing medications, and assisting with daily activities.

Subjective Burden

This encompasses the caregiver's emotional and psychological response to the caregiving experience, including feelings of stress, anxiety, depression, and social isolation.

Financial Resources

Insufficient financial resources can exacerbate caregiver burden.

Social Support

A lack of social support can increase feelings of isolation and burden.

Multiple Responsibility Conflict

Caregivers often juggle caregiving responsibilities with other roles, such as work and family obligations.

Patient Factors

The severity of the care recipient's illness, their functional limitations, and the presence of challenging behaviors can significantly impact caregiver burden.

Caregiver Factors

Individual characteristics, such as personality traits, coping skills, and pre-existing mental health conditions, also play a role.

Consequences of Caregiver Burden

Decreased Quality of Life

Caregivers may experience a decline in their physical and mental health, social life, and overall well-being.

Increased Risk of Depression and Anxiety

Caregiver burden has been linked to higher rates of depression and anxiety.

Health Deterioration

Chronic stress associated with caregiving can lead to physical health problems.

Reduced Care Provision

In severe cases, caregiver burden can impact the quality and quantity of care provided to the care recipient.

An understanding of these theories and factors, help researchers and healthcare professionals develop targeted interventions to support caregivers and mitigate the negative consequences of caregiver burden.

Empirical Review

As the population of India is expected to overtake China by 2028 (United Nations, 2015), a noteworthy change has been the country's share of older adults. According to the United Nations (2015), there has been a six-fold increase from 20.3 million in 1950 to more than 116 million. It is projected that the proportion of Indians aged 60 and older will rise from 7.5% in 2010 to 11.1% in 2025 (Mane, 2016).

In the study by Narayan et al. (2015), caregiving was not understood as a separate role but was included in the role and responsibilities of a family member. The 'caregiver' is an individual who is primarily responsible for the physical, emotional and financial care of the elder person (Johanna et al., 2017).

The study, ''Goodness and Kindness": Long-Distance Caregiving Through Volunteers During the COVID-19 Lockdown in India by Roy and Ayalon (2020) found that traditional caregiving models ceased to function in the new COVID setup. Relatives of older adults turned to strangers and volunteers in an effort to provide urgent care to their older family members. This study explores the role of volunteers in meeting the immediate needs of older adults during the lockdown. A pan-India group of volunteers was formed during the lockdown on a popular social media website to connect people of all ages in need of help with those able to offer assistance.

The Longitudinal Ageing Study of India (LASI) 2021 report, a full-scale national survey and a seminal study on the status and determinants of the ageing population in India by the Ministry of Health & Family Welfare, highlights that 75% of the elderly have one or more chronic diseases. 24% of the elderly have at least one Activities of Daily Living (ADL) limitation, and 48% reported at least one Instrumental Activities of Daily Living (IADL) limitation. One in three reported having depressive symptoms, and 32% reported low life satisfaction. In terms of social protection, only 18% reported being covered by any health insurance, 28% are aware of any concession for senior citizens, and 24% reported problems in providing documents to avail services. The report highlights that 70% of the elderly population is dependent for everyday maintenance, and 78% is living without any pension cover. Thus, the need for services of informal and formal caregivers are invaluable.

Mittal, Chaudhary and Simar (2025) conducted a cross-sectional survey to assess the dependency level of the elderly and the challenges faced by their caregivers. A total of 1265 elderly and 1000 caregivers were enrolled consecutively from an urban locality. The elderly were interviewed using the Lawton Independent Activities of Daily Living Scale to assess their dependency levels, while the caregivers were interviewed using the Zarit Caregiver Burden Scale to assess their burden related to caregiving. Significant association was found between the elderly's dependency level and their age, gender, education, occupation, and number of illnesses. It was also observed that an increase in the independence status of the elders reduces the caregiver's burden. The caregiver burden increases with the dependency level of the elderly, highlighting the need for adequate support for caregivers.

Caregiver Burden of Informal and Formal Caregivers

A review of studies on caregiver burden shows that informal caregivers experience more caregiver burden than formal caregivers.

Oh et al. (2024) examined differences in care burden between formal and informal caregivers of dependent older adults in Korea according to care-related characteristics, and whether care time had a moderating effect on the relationship between care-related characteristics and caregiver burden. Using the Korean version of the Zarit Burden Interview, they found that caregiver burden was higher for informal caregivers than formal caregivers.

Shiba et al. (2016) studied the associations of informal (e.g., family members and friends) and formal (e.g., physician and visiting nurses) social support with caregivers' burden in long-term care and the relationship between the number of available sources of social support and caregiver burden. They conducted a mail-in survey in 2003 and used data of 2998 main caregivers of frail older adults in Aichi, Japan. A validated scale to assess caregiver burden was used. They found that, after controlling for caregivers' sociodemographic and other characteristics, informal social support was significantly associated with lower caregiver burden, while formal support was not. Evaluating the associations by specific sources of social support, informal social supports from the caregiver's family living together and from relatives were associated with lower caregiver burden, whereas formal social support was associated with lower caregiver burden only if it was from family physicians. Compared to caregivers without informal support, those who had one support and two or more supports had significantly lower burden. This association was not observed for formal support.

Chandana N., James, Kokilavani C., & Padmasree P. (2024) conducted a cross-sectional questionnaire-based study to estimate the perceived level of caregiver burden in families of elderly in a selected urban community in Chittoor district Andhra Pradesh, to identify the association between selected socio-demographic characteristics of the caregivers and the level of caregiver burden. The caregivers of 50 elderly people categorized as mild and moderate dependents as per the Katz index of Independence were included in the study. The Zarith caregiver burden scale was used to evaluate their perceived level of caregiver burden. Thirty-two (64%) caregivers were found to experience a mild to moderate perceived level of caregiver burden. The majority of the caregivers suffer from a mild to moderate perceived level of caregiver burden. They experience more burden when they hold additional responsibility of caring for the elderly.

Piedrahita , Arroyave, Restrepo and Ceballos (2021) studied the Prevalence of caregiver burden syndrome in formal caregivers of institutionalised patients with psychiatric illness. A descriptive cross-sectional observational study was carried out in a population of formal caregivers with mental illness institutionalised at either of the two facilities of Clínica del Oriente, La Ceja and El Carmen de Viboral. A survey with sociodemographic, clinical and work-related variables, and the Zarit Burden Interview was done. The researchers found that the prevalence of caregiver burden syndrome in formal caregivers was lower than found in studies on informal caregivers.

Manee, Alnaser, Alqattan, and Almutairi (2025) conducted a Comparative Study of Burden of Care, Anxiety, and Well-Being Among Family Caregivers of Elderly with Dementia in Kuwait. Using the Zarit Burden Interview, the Hospital Anxiety and Depression Scale, and the World Health Organization-Five Well-Being Index they found that family caregivers experienced significant levels of burden of care and anxiety when caring for the elderly with dementia. A multidimensional holistic approach is needed to provide family caregivers of the elderly with dementia with valuable interventions.

Strategies and Coping Mechanism of Caregivers

Studies further show that caregiver's burden is connected to their ability to adapt to their caregiving role, and burden increases with the need for help with daily tasks.

Garlo, O'Leary, Van Ness, and Fried (2010) examined caregiver burden over time among caregivers of patients with advanced chronic disease. Caregivers of 179 community-living persons age ≥ 60 years with advanced cancer, heart failure (HF), or chronic obstructive pulmonary disease (COPD) were studied. Caregiver burden was assessed using a short-form of the Zarit Burden Inventory (ZBI) to measure psychosocial distress. High burden was associated with caregivers' need for more help with daily tasks and desire for greater communication with the patient. Caregiver burden was common among caregivers of patients with cancer, HF, and COPD. High burden was associated with the caregiver's report of need for greater help with daily tasks but not with objective measures of the patient's need for assistance, such as symptoms or functional status, suggesting that burden may be a measure of the caregiver's ability to adapt to the caregiving role.

In a qualitative phenomenological study on the Experiences of formal caregivers of elderly inpatients with physical disabilities in China, the views and experiences of formal caregivers caring for older inpatients with physical disabilities were explored (Sun et al., 2024). Using purposive sampling, twelve formal caregivers were chosen in a tertiary comprehensive hospital in Hangzhou. Coding reliability thematic analysis was used to guide data analysis and categorize, based on Lazarus and Folkman's theory of transactional coping. Four themes emerged from the data analysis: (1) Caregiving Threats. (2) motivations. (3) Responsibility Management. (4) Fear. They found that despite facing significant pressure at work, formal caregivers of elderly inpatients with physical disabilities possess the drive and various coping strategies to excel in their role. Identifying caregivers' experiences of care can help improve resilience to stress and maintain stability in formal caregivers.

Influence of Socio-demographic Factors on Caregiver Burden

Certain studies highlight the influence of socio-demographic factors like the educational level of caregivers on caregiver burden.

In an observational study by Menon et al. (2022), caregiver burden in older Indian patients with cancer from a tertiary care center was studied. 127 Caregivers of patients aged 60 years and over with a diagnosis of cancer were assessed for caregiver burden using the Zarit Burden Interview. The factors that significantly impacted caregiver burden scores were the presence of psychological issues in the patient and the caregiver's educational level. Caregiver burden was low among caregivers of older Indian patients with cancer seen at a single center. Caregivers of patients with psychological disorders, and those who had less schooling, reported higher caregiver burden.

Mahintan, Kamsika. M, Thuvaraha. M, Piyarathna. H.D.C.J. (2022) studied the influence of sociodemographic factors on the degree of burden and coping mechanisms among primary caregivers of people diagnosed with dementia at the Mental Health Unit, Teaching Hospital Jaffna. This descriptive cross-sectional study was conducted on 99 primary caregivers recruited using data available at the Mental Health Unit of Teaching Hospital Jaffna. Data was gathered over the phone using interviewer-administered Zarit Burden Inventory (ZBI), Ways of Coping – Revised Scale (WOCS-R) and sociodemographic questionnaires. They found that among primary caregivers, females, caregivers with no formal education or only up to grade 05, those not in marital life, and those unemployed or in domestic work are more at risk of experiencing more burden. Educational level of caregivers and duration of caregiving have a huge impact on the choice of coping mechanisms.

In a cross-sectional study by Nirmalasari and Sari (2025) to identify the burden among 180 family caregivers of chronic disease patients, the Caregiver Reaction Assessment-Indonesian Version (CRA-ID) was used. The results of the research showed a significant relationship between caregiver burden and age, but no relationship was found between gender, marital status, relationship with patients, caregiver education, caregiver job, and income. Age was significantly related to caregiver burden in caring for family members who suffered from chronic diseases. Health services were expected to provide adequate information for caregivers about caring for chronic disease patients to reduce caregiver burden.

Health of Caregivers

Research on the mental health of caregivers, both formal and informal, sheds light on the quality of life of the caregivers. Ensuring that caregivers have good sleep and no malnutrition reduces caregiver burden.

In a study on Mental Health of Caregivers of Elderly Patients: The Impact of Psychotropic Drugs on Quality of Life, Anxiety, Depression, and Stress, Castro and Santos (2023) aimed to assess the self-perception of formal and informal caregivers of elderly patients regarding burden, quality of life, anxiety and depression, stress, and the impact of psychotropic drugs. The questionnaire was disseminated in nursing homes and caregivers' associations. The questionnaires used were the Sociodemographic Questionnaire, the Depression, Anxiety and Stress Scales, the Zarit Scale, the Satisfaction with Medication Treatment Questionnaire and Quality of Life. Around half of the respondents admitted taking some psychotropic drug, namely selective serotonin reuptake inhibitor (s) or benzodiazepines. Caregivers who use medication report being moderately satisfied with it, and global satisfaction was correlated with the convenience and effectiveness of the medication. Caregivers also demonstrate that being a caregiver has a high impact on their quality of life, and informal caregivers are those who report a more severe state of depression, anxiety, and stress. The study highlighted the need to assess mental health status and the impact of pharmacotherapy on the quality of life of caregivers of elderly patients.

Aydin, Tanriverdi, Pasin and Sekerci (2025) studied, The Relationship Between Caregiver Burden with Insomnia and Malnutrition in Caregivers of Older Hospitalized Patients. The sample included 100 caregivers selected through purposive sampling between March 2024- January 2025. Data were collected on personal information, caregiver burden (assessed using the Multidimensional Caregiver Burden Inventory [MCBI]), nutritional status (evaluated using the Mini Nutritional Assessment Test [MNA] and the Healthy Eating Attitude Scale), sleep status (assessed using the Epworth Sleepiness Scale and the Insomnia Severity Index [ISI]), and muscle strength (measured by a handgrip dynamometer). They found that caregiver burden was associated with poor nutrition and sleep disturbances. Thus, reducing caregiver burden may improve insomnia and malnutrition. Moreover, addressing sleep and nutrition problems in caregivers suffering from insomnia or malnutrition may contribute to a reduction in overall caregiver burden.

Zhu, Li, and Fan (2025) explored caregiver burden and its influencing factors in cancer patients undergoing palliative PTBD from both caregiver and patient perspectives. A cross-sectional study was conducted on caregiver-patient dyads who underwent palliative percutaneous transhepatic biliary drainage (PTBD) from January to December 2023 at a tertiary hospital in western China. The Zarit Caregiver Burden Interview (ZBI), the Chinese version of the Family Resilience Assessment Scale (FRAS), the Self-Perceived Burden Scale (SPBS), and the Hospital Anxiety and Depression Scale (HADS) were used to assess outcome variables. Sociodemographic data and PTBD-related characteristics were also collected. The researchers found that Caregivers of cancer patients undergoing palliative PTBD had a considerable burden, which was influenced by factors from both the caregiver and patient perspectives. It is imperative for healthcare providers to develop interventions that target the modifiable influencing factors identified to support these caregivers effectively.

Effect of Therapy on Reducing Caregiver Burden

Pashazade, Momtaz and Raheb (2022) investigated the effect of Cognitive-Behavioural Therapy (CBT) based social work intervention on the extent of care burden among the formal caregivers of the elderly. This research was a quasi-experimental study with a pretest-posttest-follow-up design. Participants received seven 90-min intervention sessions (CBT-based social work). The intervention protocol was validated by the Agree form using expert opinion evaluation. Using a validated Zarit caregiver burden interview scale (short-form), they found that the CBT-based social work intervention with the dimensions of identifying and accessing supportive resources, modifying attitude, and relaxation training can reduce the burden of care in physical, psychological, and general aspects among the study subjects. Therefore, more use of this intervention by specialists can affect the care burden of formal caregivers. The present research results also highlight the necessity for the attention of nursing home officials, social policymakers, and professionals active in the field of elderly care.

Research Gap

A review of the literature shows that most existing studies focus primarily on the caregiver burden of informal caregivers (such as family members) and formal caregivers working in institutionalized settings like hospitals or nursing homes. There is a noticeable lack of research that explores the lived experiences of formal caregivers who provide care in home-based settings. Most studies rely on quantitative tools, such as the Zarit Burden Interview, which measure the extent of burden but fail to delve into the emotional, physical, and contextual realities that shape the caregiving experience.

This study aims to address this gap by exploring the physical and emotional aspects of caregiver burden, the challenges faced by formal caregivers in home settings, the coping strategies they adopt to reduce their burden, and how they perceive their caregiving role. By using a qualitative phenomenological approach, the study seeks to capture the depth and richness of their lived experiences, which remain underrepresented in current literature, especially in the Indian socio-cultural context.

Chapter Three

Methodology

Methodology

This chapter presents the methodology adopted for the study. It includes definitions of key concepts, the research questions, the research approach and design, details of the study population, sampling method, inclusion and exclusion criteria, sample size, tools and procedures for data collection, the method of data analysis, and ethical considerations.

Definition of Concepts

Operational Definitions

1. Caregiver burden- The physical, emotional, financial, and social strain experienced by caregivers of elderly patients in their role of caregiving.
2. Elderly Patient- A person aged 60 years or more facing one or more illnesses that make them dependent on formal caregivers.
3. Formal caregiver- Formal caregivers are defined as those who receive payment from families of elderly patients to provide care for them in the home setting.
4. Home Setting - It refers to the elderly patient's primary place of residence where they receive care services by a formally employed caregiver.

Research Questions

1. How does caregiver burden affect the physical well-being of formal caregivers of elderly patients in home settings?
2. How does caregiver burden affect the emotional well-being of formal caregivers of elderly patients in home settings?
3. What are the challenges contributing to caregiver burden among formal caregivers of elderly patients in home settings?
4. What strategies do formal caregivers of elderly patients in home settings use to cope with caregiver burden?

5. How do formal caregivers of elderly patients in home settings perceive their caregiving role?

Research Approach

This study uses the qualitative approach to explore the factors of caregiver burden, challenges faced by formal caregivers of elderly patients in home settings and the strategies employed by them to reduce their burden.

A qualitative approach refers to a method of investigation that focuses on understanding and interpreting individuals' experiences and behaviours through in-depth interviews and observations, rather than relying on external representations or experimental conditions.

Research Design

The phenomenological research design is used in this study. Phenomenology is a design that allows for interpretation of an individual's experiences as well as synthesis of the features that comprise the experiences (Fourie & Murphy, 2011). This study aims to understand the lived experiences of formal caregivers of elderly patients, especially how they perceive and make sense of caregiver burden.

Lived experience refers to the personal and subjective understanding of an individual's direct, first-hand involvement in everyday events and situations. It encompasses not only the events themselves, but also the emotions, perceptions, and interpretations that shape an individual's unique perspective. This concept is often used in qualitative research to explore how individuals' experiences, influenced by factors like identity, culture, and social context, shape their understanding of the world.

Population

Formal caregivers (paid/non-family) providing home-based care to elderly patients.

Sampling

In this study, Snowball Sampling was used. Private agencies that provide home care services did not permit the researcher to speak with their formal caregiver employees despite requests. Therefore, the participants for this study were identified through this sampling method.

Snowball sampling, also known as chain-referral sampling, is a non-probability sampling technique where existing study participants help recruit future subjects from among their acquaintances. This method is particularly useful when studying hidden or hard-to-reach populations. In this study, a formal caregiver of a known family referred the next participant, who referred further formal caregivers.

Inclusion Criteria

The participants who met the following criteria were selected for the study.

1. Formal caregivers who have been giving care to elderly patients in home settings for one year.
2. Formal caregivers who reside with the elderly patient in their home setting.
3. Formal caregivers who are caring for elderly patients with one or more illnesses that make them dependent on formal caregivers to meet their daily needs and activities.
4. Formal caregivers recruited through private agencies by the families of elderly patients.
5. Formal Caregivers who do not have trained certification.

Exclusion Criteria

The following categories of formal caregivers were excluded from the study since they provide short-term specialised services

- Registered nurses
- Certified nursing assistants
- Physiotherapists

Sample Size

Six participants were identified through reference from formal caregivers.

Tools for Data Collection

Socio-Demographic Data Sheet was used to collect the sociodemographic details of the participants. A semi-structured interview schedule was used to collect data for each participant. A semi-structured interview is a qualitative research method used to gain an in-depth understanding of the respondent's feelings and beliefs on specific topics.

Data Collection

Data was collected from six participants through snowball sampling. Verbal consent was taken from these participants. A semi-structured interview method was used to collect the data. The interviews were recorded, and detailed field notes were taken.

Data Analysis

In this study, thematic analysis was used. Thematic analysis involves the systematic coding of data, where researchers assign labels or codes to segments of text representing specific ideas or patterns. These codes are then organized into potential themes. The process is iterative, allowing for constant refinement and development of themes as the analysis progresses.

Thematic analysis encourages reflexivity, prompting researchers to be aware of their own perspectives, biases, and potential influences on the interpretation of data. This self-awareness contributes to transparency and helps ensure that the analysis is grounded in the participants' experiences rather than the researchers' preconceptions.

The sociodemographic data and verbatim interview transcripts of all participants are included in the appendices (see Appendices A–H).

Ethical Consideration

Verbal consent was taken from all the participants before conducting the semi structured interview after communicating with them the purpose of the study and affirming that full confidentiality would be maintained and the data collected would not be used for any other purpose other than this study.

Chapter Four

Results and Discussion

Results and Discussion

This chapter outlines the different themes in the responses of the participants. It also explains the narratives of the participants.

Results of Participant 1

Research Question 1: How does caregiver burden affect the physical well-being of formal caregivers of elderly patients in home settings?

Theme 1.1: Physical Strain from Care Duties

Evidence:

- "I get shoulder pain from transferring the patient onto the wheelchair and the bed…"
- "I also have some difficulty while carrying her because of the weight."

Narrative

Caregiving in a home setting places a significant physical demand on the body, particularly during tasks such as lifting or transferring the patient. One caregiver shared, *"I get shoulder pain from transferring the patient onto the wheelchair and the bed,"* illustrating how routine care procedures can result in muscular discomfort. This reflects the ongoing physical toll of caregiving, which is intensified by the lack of assistive equipment in many home environments.

Theme 1.2: Use of Pain Relief Methods

Evidence:

- "I put some ointment on and feel better."
- "When I get body pain, I use ointment and I sleep to get a good rest."

Narrative

To manage the bodily pain that comes with caregiving, caregivers rely on simple, self-administered relief strategies- *"I put some ointment on and feel better,"* suggests a quick and familiar remedy for muscular aches. This reveals how caregivers tend to self-manage their pain rather than seek formal medical help, possibly due to financial constraints, time limitations, or normalization of physical discomfort as part of their work.

Research Question 2: How does caregiver burden affect the emotional well-being of formal caregivers of elderly patients in home settings?

Theme 2.1: Emotional Distress from Patient's Condition

Evidence:

- "I feel really sad and upset seeing the pain the patient goes through."
- "Once, she was in a really bad state… I felt really bad and upset… very difficult and upsetting to see."

Narrative

Caregiving often evokes strong emotional responses, especially when caregivers witness the suffering of the patients they care for. The participant expressed, "I feel really sad and upset seeing the pain the patient goes through," highlighting the emotional toll of being closely involved in another person's health struggles. Another reflection- "Once, she was in a really bad state… I felt really bad and upset… very difficult and upsetting to see," reveals the emotional burden of observing physical decline and helplessness. These responses suggest that formal caregivers in home settings can be deeply affected by their patients' conditions, despite their professional roles.

Theme 2.2: Emotional Reward and Connection

Evidence:

- "Once she kissed my hand, and it made me tear up. I kissed her hand in return and told her I love her a lot."
- "I like what I am doing and I have no issues."

Narrative

Despite the emotional hardships, many caregivers experience moments of deep emotional fulfillment and connection. One caregiver recalled a touching moment, “Once she kissed my hand and it made me cry. I kissed her hand in return and told her I love her a lot,” reflecting the mutual affection and emotional bonds that can form over time. Another reflection, “I like what I am doing and I have no issues,” suggests an overall sense of job satisfaction and emotional acceptance of the caregiving role. These reflections indicate that caregiving can also be emotionally rewarding, providing a sense of purpose, appreciation, and human connection.

Theme 2.3: Social Stigma Toward the Job

Evidence:

- “A lot of people look at this job with disgust… People should never underestimate those who perform this job.”

Narrative

Emotional challenges also stem from how society views caregiving as a profession. One caregiver shared, “A lot of people look at this job with disgust… People should never underestimate those who perform this job,” shedding light on the social stigma and devaluation associated with caregiving work. Such stigma may negatively impact their self-esteem and emotional well-being, even when they find personal meaning in their work.

Research Question 3: What are the challenges contributing to caregiver burden among formal caregivers of elderly patients in home settings?

Theme 3.1: Physical Risk in Handling the Patient

Evidence:

- “Once… the wheelchair slipped and I grabbed her tightly and that was very scary.”

Narrative

One of the critical challenges caregivers face in home settings is the physical risk involved in managing the patient's mobility, especially without professional-grade equipment or assistance. A caregiver recalled a frightening incident: "Once… the wheelchair slipped and I grabbed her tightly and that was very scary." This account highlights the immediate physical danger and the constant vigilance required during routine caregiving tasks. It reflects how caregivers not only bear the responsibility for the patient's safety but must also react swiftly in moments of crisis, sometimes risking their own well-being in the process.

Theme 3.2: Emotional Impact of Medical Emergencies

Evidence:

- "Her sugar went so low, she wasn't responding… She was admitted in the ICU… very difficult and upsetting."

Narrative

Medical emergencies present another major challenge, causing intense emotional stress and anxiety for caregivers. The participant described a distressing episode: "Her sugar went so low, she wasn't responding… She was admitted in the ICU… very difficult and upsetting." The unpredictability of such incidents, combined with the emotional attachment caregivers often develop, leads to emotional overwhelm and fear. These emergencies require the caregiver to switch between emotional roles—both as a professional responder and a concerned companion—often without immediate medical support in the home setting. This dual burden contributes significantly to their psychological strain.

Research Question 4: What strategies do formal caregivers of elderly patients in home settings use to cope with caregiver burden?

Theme 4.1: Use of Physical Remedies

Evidence:

- “I use ointment and I sleep to get a good rest.”

Narrative

To manage the physical toll of caregiving, caregivers often turn to simple, self-soothing practices aimed at relieving body pain and fatigue. One caregiver shared, “I use ointment and I sleep to get a good rest,” highlighting how bodily discomfort is treated with readily available remedies and rest. These strategies reflect a practical, self-reliant approach to physical recovery, likely influenced by limited access to professional medical support or time constraints. The use of ointments and sleep indicates that caregivers recognize the importance of bodily rest, even if it is minimal or delayed due to the demands of their role.

Theme 4.2: Limited Reliance on Emotional Support

Evidence:

- “I talk to my daughter but I don't really feel the need to talk to anyone…”

Narrative

When it comes to emotional relief, caregivers tend to rely minimally on external support systems. The participant stated, “I talk to my daughter but I don't really feel the need to talk to anyone…” suggesting that while some communication exists, it is not actively sought for emotional processing. This response reflects a low reliance on emotional outlets, which may stem from cultural expectations, internalized resilience, or the belief that emotional expression is unnecessary.

Research Question 5: How do formal caregivers of elderly patients in home settings perceive their caregiving role?

Theme 5.1: Caregiving as a Natural Extension of Past Experiences

Evidence:

- "I took care of him [husband] for 7 years… By taking care of him, I started to like caring for people."

Narrative

For some caregivers, the role of caregiving is not merely an occupation but a continuation of deeply personal life experiences. One participant reflected, "I took care of him [husband] for 7 years… By taking care of him I started to like caring for people." This insight shows how previous caregiving experiences, especially within the family, shape a caregiver's identity and foster a lasting emotional connection to the work. These individuals often embrace caregiving as an extension of who they are, rather than viewing it as just a duty or profession.

Theme 5.2: Caregiving as a Source of Livelihood and Gratitude

Evidence:

- "I didn't have money before and now I do. I am also able to pay off my debts."
- "I am very thankful to God that I am able to work."

Narrative

Beyond its emotional significance, caregiving is also perceived as a path to financial stability and gratitude. A caregiver shared, "I didn't have money before and now I do. I am also able to pay off my debts," emphasizing the economic empowerment that the role provides. Also "I am very thankful to God that I am able to work," pointing to a deep sense of spiritual gratitude and fulfillment. These perspectives suggest that caregiving is not only about service but also about economic survival and thankfulness for opportunity, especially in contexts where job options are limited.

Theme 5.3: Personal Fulfillment and Sense of Purpose

Evidence:

- "I would like to do more of this work."

- “I also feel a positive energy because of all of this.”

Narrative

For many caregivers, the role provides a profound sense of fulfillment and meaning. One participant stated, “I would like to do more of this work,” expressing not just contentment but an eagerness to continue. Another comment, “I also feel a positive energy because of all of this,” revealing the inner joy and vitality that caregiving can bring. These narratives indicate that caregiving, despite its burdens, is experienced by some as a calling that enriches their emotional and spiritual lives, offering a strong sense of purpose and personal growth.

Participant 2

Research Question 1: How does caregiver burden affect the physical well-being of formal caregivers of elderly patients in home settings?

Theme 1.1: Physical Fatigue from Daily Care Tasks

Evidence:

- “I also clean her room after a day's work and that makes me tired.”

Narrative

Despite expressing affection for the patient, the caregiver acknowledges that the physical labor involved in her daily routine, including personal care and household tasks, leads to tiredness. These responsibilities demand constant movement and attention, resulting in physical fatigue at the end of the day.

Theme 1.2: Health Impacts from Exposure

Evidence:

- “I got an allergy when I exposed myself to urine... I began using gloves and a mask.”

Narrative

Caregiving also poses direct health risks, particularly when safety precautions are not initially taken. The caregiver recounts developing an allergy due to exposure to bodily fluids, underscoring how hands-on care can lead to medical issues. This experience prompted her to adopt protective measures, such as using gloves and masks.

Research Question 2: How does caregiver burden affect the emotional well-being of formal caregivers of elderly patients in home settings?

Theme 2.1: Emotional Frustration Due to Patient's Non-Cooperation

Evidence:

- "When she doesn't listen, the entire schedule goes out of place and I get tense."
- "Sometimes, she refuses to eat and it makes me annoyed."

Narrative

The caregiver describes emotional strain when routines are disrupted due to the patient's resistance or aggression. The refusal to eat not only delays caregiving tasks but also triggers feelings of tension and annoyance, indicating the emotional impact of managing unpredictable behaviors.

Theme 2.2: Emotional Bond and Maternal Identification

Evidence:

- "I love her so much. I see her like my own mother."
- "Doing this has made me happy because I feel like I am taking care of someone that reminds me a lot of my own mother."

Narrative

Despite difficulties, the caregiver shares a deep emotional bond with the patient, often seeing her through the lens of her own mother. This identification brings a sense of warmth, attachment, and personal meaning to the work, which seems to help her endure the challenges.

Theme 2.3: Relief Through Family Support

Evidence:

- "Yes, I do share what happens with my family and it gives me some calmness and peace."

Narrative

The caregiver copes emotionally by talking to her family, which provides a valuable outlet for stress. This informal emotional support network offers calmness and peace, acting as a buffer against emotional burnout.

Research Question 3: What are the challenges contributing to caregiver burden among formal caregivers of elderly patients in home settings?

Theme 3.1: Managing Aggression and Dementia Symptoms

Evidence:

- "She has dementia. She is violent. If it was someone else, they would have left by now."
- "She doesn't listen to me sometimes."

Narrative

Caring for a patient with dementia presents significant challenges, particularly when the patient exhibits aggression or fails to cooperate. These moments test the caregiver's emotional endurance and patience, especially when working alone without clinical backup.

Theme 3.2: Disrupted Routine and Delayed Self-Care

Evidence:

- "When she doesn't listen, the entire schedule goes out of place and I get tense… I need to feed her as well as eat myself."

Narrative

The caregiver struggles to maintain her own routine when the patient refuses food or medicine. These delays affect her ability to care for herself, including basic needs like eating and resting, resulting in emotional frustration and stress.

Theme 3.3: Feeling Undervalued as a Professional

Evidence:

- "I also feel that she wouldn't have behaved the same way with her own children but does so because it's me."

Narrative

There is an underlying feeling of inequality in the caregiver-patient dynamic. The caregiver senses that she is sometimes treated unfairly, possibly due to not being a family member, which adds an emotional burden of feeling disrespected or undervalued.

Research Question 4: What strategies do formal caregivers of elderly patients in home settings use to cope with caregiver burden?

Theme 4.1: Protective Measures to Prevent Health Issues

Evidence:

- "I began using gloves and a mask."

Narrative

After facing physical health issues, the caregiver adopted preventive strategies, such as wearing gloves and a mask, showing a proactive approach to maintaining her health and reducing burden.

Theme 4.2: Sharing with Family as Emotional Relief

Evidence:

- "Sharing things with my family gives me some relief."

Narrative

The caregiver actively manages emotional stress by communicating with her family, which helps her process difficult experiences and stay emotionally grounded. This strategy offers her a sense of relief and calmness, even without formal counselling or peer support.

Research Question 5: How do formal caregivers of elderly patients in home settings perceive their caregiving role?

Theme 5.1: Caregiving as a Moral Responsibility Rooted in Patience

Evidence:

- “I look after the patient like my own mother.”
- “Once a person is sick, especially someone old, they start to act like a kid... You cannot say anything back to them.”

Narrative

The caregiver sees her role as a moral duty, deeply rooted in patience, love, and empathy. She draws on her personal values and previous caregiving experience to justify the need for emotional self-regulation and gentleness.

Theme 5.2: Awareness of Proper Care Practices

Evidence:

- “You need to know what has to be fed to them, how to give them a bath… if it’s cold or hot water…”

Narrative

Beyond emotional commitment, the caregiver views her role as requiring technical knowledge and attentiveness. She emphasizes the importance of skill, awareness, and sensitivity in caregiving tasks, particularly hygiene and nutrition.

Theme 5.3: Caregiving as Life-Altering and Personally Rewarding

Evidence:

- “It has changed how I take care of people.”
- “I feel happy that I am able to take care of elderly and help them get better.”

Narrative

The caregiving role has had a transformational impact on the caregiver’s outlook. She describes it as personally meaningful, leading to emotional growth and a deeper understanding of human care. This positive meaning provides emotional reward and fulfillment in the midst of hardship.

Participant 3

Research Question 1: How does caregiver burden affect the physical well-being of formal caregivers of elderly patients in home settings?

Theme 1.1: Physical Fatigue and Body Pain

Evidence:

- “I get body pain because of carrying the patient.”
- “I already have knee pain and that makes it a bit difficult for me to do my job.”

Narrative

The participant experiences significant physical strain, particularly due to patient handling. Body aches and pre-existing knee pain are worsened by the repetitive physical effort required in caregiving. These physical challenges are seen as part of the job, but they underscore the demanding bodily labor that comes with caregiving in home settings.

Research Question 2: How does caregiver burden affect the emotional well-being of formal caregivers of elderly patients in home settings?

Theme 2.1: Emotional Irritation and Distress

Evidence:

- “I feel sad and irritated when they don't eat their food, spit their food and don’t sleep on time.”
- “I also get angry when the patient's family orders me around.”

- “I was really upset because I was feeling tired as I did not get a good amount of sleep…”

Theme 2.2: Emotional Fulfillment and Spiritual Peace

Evidence:

- “I feel a sense of peace, blessing, fulfillment, and positivity.”
- “Taking care of others brought goodness in my life.”

Narrative

Emotionally, the caregiver experiences a mix of frustration and deep personal fulfillment. Moments of stress arise from patient behavior and lack of rest, but these are balanced by a sense of inner peace and spiritual reward. Caregiving is described as both emotionally taxing and transformative—shaping her outlook on life and imbuing her role with purpose.

Research Question 3: What are the challenges contributing to caregiver burden among formal caregivers of elderly patients in home settings?

Theme 3.1: Personal and Family Strain

Evidence:

- “I have two girls and I cannot take care of them because I am working most of the time.”

Theme 3.2: Physical Exhaustion and Sleep Disruption

Evidence:

- “I did not get a good amount of sleep as the patient kept making a lot of noise and I needed to wake up multiple times…”

Narrative

The caregiver faces challenges not only at work but also in balancing her responsibilities at home. Being away from her children creates emotional strain. At the same time, physical exhaustion and disrupted sleep due to patient needs amplify her vulnerability. The combination of these pressures reflects the intersection of professional and personal burdens.

Research Question 4: What strategies do formal caregivers of elderly patients in home settings use to cope with caregiver burden?

Theme 4.1: Use of Physical Remedies

Evidence:

- "When I get body pain, I use ointment…"

Theme 4.2: Inner Strength and Patience

Evidence:

- "I just manage and be patient."

Narrative

To relieve the burden of care, the participant adopts simple, practical solutions like using ointment for body aches. However, her main coping tool is a mindset of calm endurance and patience. This emotional regulation, rather than external support, appears to be her primary strategy—reflecting an internalized form of resilience rooted in faith and responsibility.

Research Question 5: How do formal caregivers of elderly patients in home settings perceive their caregiving role?

Theme 5.1: Caregiving as a Livelihood and Life Anchor

Evidence:

- "I pray for the patient because I had a huge debt and I got to pay off a lot of it by helping her. She made my life easier for me."
- "I get to live my life because of them."

Theme 5.2: Caregiving as a Moral and Spiritual Calling

Evidence:

- “I have learnt how to live my life morally and peacefully.”
- “Taking care of others brought goodness in my life.”

Narrative

The participant views caregiving not just as a job but as a life-changing opportunity. It has given her financial relief, moral clarity, and a sense of spiritual alignment. She expresses gratitude and humility, seeing caregiving as a path to peace, purpose, and redemption. This meaning-making process reflects a strong emotional investment in the caregiving identity.

Participant 4

Research Question 1: How does caregiver burden affect the physical well-being of formal caregivers of elderly patients in home settings?

Theme 1.1: Mild Physical Strain

Evidence:

- “I get knee pain due to strain but otherwise I am okay.”

Narrative

The caregiver experiences minor physical discomfort, such as knee pain, possibly due to strain from daily tasks. However, she generally considers herself physically healthy and not significantly affected by her caregiving duties.

Research Question 2: How does caregiver burden affect the emotional well-being of formal caregivers of elderly patients in home settings?

Theme 2.1: Emotionally Stable and Unaffected

Evidence:

- “I feel fine as there is not much for me to do.”
- “No, that hasn’t happened.” (in response to feeling emotionally overwhelmed)

Narrative

Emotionally, the caregiver reports feeling stable and unaffected by stress. She attributes this to the simplicity of her tasks and the manageable nature of her caregiving role, stating that she has not faced any emotional overwhelm.

Research Question 3: What are the challenges contributing to caregiver burden among formal caregivers of elderly patients in home settings?

Theme 3.1: Perception of Low Difficulty

Evidence:

- “I don't find it challenging as the task at hand are quite simple.”

Theme 3.2: Minor Health-Related Challenge

Evidence:

- “I get knee pain due to strain…”

Narrative

This caregiver does not perceive her work as challenging, as the duties involved are straightforward. While she does experience some minor health issues like knee pain, they do not significantly hinder her caregiving.

Research Question 4: What strategies do formal caregivers of elderly patients in home settings use to cope with caregiver burden?

Theme 4.1: Use of Social Support for Relief

Evidence:

- “Talking to my family does give me relief…”

Theme 4.2: Perception of Low Burden

Evidence:

- “...but since I don't have many tasks to perform, I am of good health.”

Narrative

The caregiver finds support through conversations with her family, which helps her feel emotionally relieved. However, she does not actively seek stress management strategies as she does not perceive herself to be burdened in the first place.

Research Question 5: How do formal caregivers of elderly patients in home settings perceive their caregiving role?

Theme 5.1: A Source of Independence and Income

Evidence:

- "...we are able to gain money for ourselves and not beg others."
- "It is a means of earning and it makes us independent."

Theme 5.2: Fulfilling and Meaningful Work

Evidence:

- "Yes, it is fulfilling as you get to help others and earn for yourself."

  "Yes, it is rewarding because we are able to earn for ourselves and live our lives. I also like this job."

Narrative

The caregiver sees her role as both dignified and empowering. She takes pride in earning independently through caregiving and views it as a respectable means of self-sufficiency. For her, the work is not only financially rewarding but also personally fulfilling.

Participant 5

Research Question 1: How does caregiver burden affect the physical well-being of formal caregivers of elderly patients in home settings?

Theme 1: Physical Strain Related to Patient Weight

Evidence:

- ‘’It’s only when we have to carry heavy patients and help them on to a wheelchair, that we tend to get physical pain.”

Narrative

The caregiver shared that she generally does not feel any specific physical discomfort unless the patient is physically heavy and needs to be lifted or assisted onto a wheelchair. These tasks often lead to body pain and physical fatigue. She highlighted that the extent of physical strain directly depends on the physical condition and needs of the patient being cared for.

Research Question 2: How does caregiver burden affect the emotional well-being of formal caregivers of elderly patients in home settings?

Theme 2: Emotional Impact of Disrespect and Misunderstanding

Evidence:

- ‘’ Yes, I have. There are times when families have treated me like I have not done enough for the patient, and this has upset me. In some homes, the families of the patients don't like it if I sit in the room when guests come to see them.”

Narrative

While the caregiver did not report frequent emotional overwhelm, she recounted feeling upset when families questioned her dedication or treated her as if she had not done enough. She particularly recalled being asked not to sit in the patient’s room when guests visited, which made her feel disrespected. Despite such moments, she appeared emotionally resilient and continued with her duties without significant emotional distress.

Research Question 3: What are the challenges contributing to caregiver burden among formal caregivers of elderly patients in home settings?

Theme 3.1: Difficulty in Handling Physically Demanding Patients

Evidence:

- ‘’I find it very challenging when the patient is heavy to carry. In some places that I have worked the patients had excess weight.”

Theme 3.2: Lack of Respect from Family Members

Evidence:

- ‘’There are times when families have treated me like I have not done enough for the patient, and this has upset me. In some homes, the families of the patients don't like it if I sit in the room when guests come to see them.”

Narrative

The primary challenge faced by the caregiver was dealing with physically heavy patients, which strained her body. Another significant challenge was the occasional lack of recognition and respect from the patient’s family. These situations left her feeling emotionally distressed, especially when her work ethic was questioned or when she was excluded from social interactions within the household.

Research Question 4: What strategies do formal caregivers of elderly patients in home settings use to cope with caregiver burden?

Theme 4.1: Self-Medication for Physical Symptoms

Evidence:

- ‘’If I do get body pain, headache or feel unwell, I take tablets to feel better.”

Theme 4.2: Emotional Support Through Peer Sharing

Evidence:

- ‘’Yes, I do. I share almost everything with my co-worker/friend.”

Narrative

To cope with the burden of caregiving, especially physical symptoms like pain and headaches, the caregiver resorts to taking tablets for relief. Emotionally, she shares her experiences and concerns with a co-worker friend, which seems to help her feel supported and understood. These practical and social strategies help her manage both physical and emotional aspects of her role.

Research Question 5: How do formal caregivers of elderly patients in home settings perceive their caregiving role?

Theme 5.1: Caregiving as a Source of Satisfaction

Evidence:

- ‘’Yes, it has. I’ve never felt like this was a difficult job for me as I feel satisfied taking care of the elderly. ‘’

Theme 5.2: Need for Recognition and Proper Work Conditions

Evidence:

- ‘’What I would like to say is, the families of the patient must view the caregivers like a member of the family. Caregivers must provide the best care possible to their patients. They must be provided all the necessary materials to give utmost care.”

Narrative

The caregiver expressed a sense of satisfaction in her caregiving duties, noting that she never found the job particularly difficult and felt fulfilled while caring for elderly individuals. However, she emphasized the importance of being treated like a family member by the patient’s household and having access to proper materials like gloves and hygiene supplies. Although she doesn’t describe the work as personally rewarding, she acknowledged that both patients and families often appreciate and like her, which reinforces her sense of purpose.

Participant 6

Research Question 1: How does caregiver burden affect the physical well-being of formal caregivers of elderly patients in home settings?

Theme 1.1: Physical Strain Due to Patient’s Weight Gain

Evidence:

- “While helping her sit up, I get a muscle pull on my back sometimes which gives me pain.”
- “Earlier, she used to not be that heavy but now… she has gained more weight.”

Theme 1.2: Physical Health Managed Proactively

Evidence:

- “I have hypertension and so I make sure to take my own tablets and go to bed on time.”
- “I don’t feel much struggle emotionally or physically… I try to take my tablets and keep that in check.”

Narrative

The caregiver experiences physical strain, particularly due to the patient’s increasing weight. Sitting the patient up often causes back pain, yet she manages her own health conditions like hypertension diligently by taking medication and ensuring rest. Her awareness of self-care plays a vital role in maintaining her physical well-being while delivering intensive care.

Research Question 2: How does caregiver burden affect the emotional well-being of formal caregivers of elderly patients in home settings?

Theme 2.1: Emotional Conflict During Patient Resistance

Evidence:

- “Sometimes, she doesn’t drink water or chew the food… I get angry.”
- “Sometimes, she gets angry and I calmly show some love…”

Theme 2.2: Emotional Fulfillment from Role

Evidence:

- “I wanted to care for other mothers and bring them back to good health.”
- “I am happy I get to take care of elderly and help them get better…”

Narrative

Emotionally, the caregiver experiences moments of frustration, especially when patients resist basic care like eating or drinking. However, these are tempered by deep fulfillment—rooted in her personal loss and her desire to “give back” the care she couldn’t provide to her own parents. Her role provides a sense of purpose and healing.

Research Question 3: What are the challenges contributing to caregiver burden among formal caregivers of elderly patients in home settings?

Theme 3.1: Emotional and Logistical Strain of Timing and Compliance

Evidence:

- “It is a bit difficult when trying to make sure everything is done on time.”
- “I might also have to force her to eat sometimes when she refuses to eat.”

Theme 3.2: Guilt and Unresolved Grief as a Motivator and Burden

Evidence:

- “I had a lot of tension because I couldn't care for my mother so I wanted to care for other mothers…”

Narrative

While the caregiver does not cite major daily challenges, she identifies the stress of staying on schedule and dealing with patient non-compliance. On a deeper level, her motivation comes from unresolved grief, which adds emotional complexity but also fuels her dedication to caregiving.

Research Question 4: What strategies do formal caregivers of elderly patients in home settings use to cope with caregiver burden?

Theme 4.1: Emotional Venting and Support Network

Evidence:

- “I feel a lot of relief when I share things with my friends.”

- “I have a close friend… she helps me understand how to provide the best care possible…”

Theme 4.2: Self-Care and Medication Management

Evidence:

- “I try to take my tablets and keep [hypertension] in check.”
- “I tend to take leave when I get sick or if I really need to.”

Narrative

To manage stress, the caregiver relies heavily on social support, particularly a trusted friend who shares experience and advice. She also prioritizes self-care through medication and allows herself leave when needed, showing a balanced approach to managing both emotional and physical demands.

Research Question 5: How do formal caregivers of elderly patients in home settings perceive their caregiving role?

Theme 5.1: Caregiving as Redemption and Emotional Healing

Evidence:

- “I always wished to take care of other old ladies… because I could not care for my own mother.”
- “This gives me a sense of peace.”

Theme 5.2: Source of Independence and Livelihood

Evidence:

- “I feel rewarded as I am able to be independent, take care of my own life as well as the lives of my children.”
- “It’s with my earnings that our entire family is moving forward.”

Theme 5.3: Role Guided by Empathy and Long-Term Commitment

Evidence:

- “I plan on doing this job till I can and till God gives me good health.”
- “No matter how angry we get, we cannot take it out on them… We need to be careful and take care of them with love.”

Narrative

The caregiver views her role as both a spiritual and practical journey. It allows her to heal from childhood trauma, earn a stable income, and contribute meaningfully to society. Guided by empathy and a strong moral compass, she sees caregiving not as a burden but a lifelong mission filled with personal significance.

Interpretation and Discussion

A look at the various themes reveals that the formal caregivers of the elderly in home settings experience considerable physical discomfort, like body pain and muscular aches. The objective burden of caring for the elderly patient impacts the physical health of the formal caregivers.

It was interesting to know that the participants felt empathetic to the elderly patients despite the demands of the caregiving role. Being able to view them as their own family members helped them to cope and adapt to their caregiving roles.

It was seen that the formal caregivers had previous experiences with handling their family members who either suffered from a chronic disease or they identified certain strengths in themselves, for eg: ‘’I was the only one patient with my mom”…etc, which proved useful in their current experience as a formal caregiver. Caregiver Factors like individual characteristics, such as personality traits, coping skills, and pre-existing mental health conditions thus influence caregiver burden in a positive way.

Patient factors like the degree of illness of the elderly patient and refusal to cooperate by the patient act as challenges faced by the formal caregivers in home settings. Studies have shed light on the association between the level of illness and caregiver burden. The severity of the care recipient's illness, their functional limitations, and the presence of challenging behaviours can significantly impact caregiver burden. Manee, Alnaser, Alqattan, and Almutairi (2025) found that family caregivers experienced significant levels of burden of care and anxiety when caring for the elderly with dementia.

Multiple responsibility conflict could be seen as one of the themes that emerged. The caregivers' duration of job is 24/7, where they are unable to give time to their own families and cannot attend various family functions impacting their caregiver burden in a negative way.

With regards to coping mechanisms, the formal caregivers of the elderly patients in home settings rely upon their own family networks to relieve the stress of caregiving or caregiver burden.

Inspite of the demanding nature of their job, the formal caregivers gave positive meaning to their role as caregivers and they took satisfaction by looking at their role as a rewarding experience. Sun et al., 2024 found that despite facing significant pressure at work, formal caregivers of elderly inpatients with physical disabilities possess the drive and various coping strategies to excel in their role. Identifying caregivers’ experiences of care can help improve resilience to stress and maintain stability in formal caregivers.

The formal caregivers in this study wished that society would look at their roles in a more favourable manner since they believed they were providing invaluable service to the care of the elderly in society who were chronically ill.

All the participants were thankful that the caregiving role provided them with financial stability. It was due to financial difficulties in their homes that all participants opted for this demanding job.

Theoretical Interpretation

The Pearlin's Stress Process Model (Pearlin et al. 1981) emphasises the role of appraisal, i.e., how caregivers perceive their situation and coping strategies in mediating the relationship between stressors and outcomes. The caregivers in this study perceived their situation as an invaluable service on their part for care of the elderly in society. This positive meaning helped them to cope with the caregiver burden that they experience in their roles. Thus, it helped them to mitigate the primary stressors of care-giving and its outcomes.

Self-Determination Theory suggests that caregiver well-being is influenced by the satisfaction of basic psychological needs (autonomy, competence, and relatedness) within the caregiving context. Autonomy-The need to feel a sense of choice and ownership over one’s actions and decisions. Competence-The need to feel effective and capable in one’s pursuits. Relatedness- The need to feel connected and belonging to others.

In this study we found that the caregivers were able to relate to their patients at a personal level by considering them as members of their own family. This positive meaning gave value to their tasks acted as an intrinsic motivation to sustain their efforts at caregiving. This could be considered as a positive impact on caregiver burden.

Acceptance Theory of Family Caregiving:

This theory focuses on the caregiver's acceptance of the caregiving role and its associated responsibilities. Acceptance is a process that unfolds across different stages of caregiving. It suggests that caregivers who anticipate and accept the possibility of decline in their care recipients are more likely to adapt to the role effectively. Acceptance influences various outcomes such as caregiver burden, the quality of care provided and the strength of family relationships. Caregivers who accept their role are more likely to manage challenges effectively and maintain positive connections. In this study all the caregivers had accepted their role of caregiving and associated caregiver burden as part of their job. Earlier personal experiences with caregiving also contributed to their ability to accept the caregiver burden associated with their roles.

Chapter Five

Summary and Conclusion

Summary and Conclusion

This chapter outlines a summary of the findings of the study and the conclusion. The limitations of the study and implications of the findings are discussed. Valuable suggestions hailed by previous researchers relevant to the findings of this study are also detailed.

Summary of Findings

Various themes emerged from this qualitative study. The demanding aspect of the role of being a formal caregiver of elderly patients in a home setting was balanced by the financial stability that the job provided. Due to previous personal experiences with caregiving of their own family members or possession of individual coping skills and traits, the discharge of objective caregiving tasks became easier for the formal caregivers. Physical discomfort associated with the tasks of caregiving was managed at the home setting level by the caregivers. The formal caregivers were empathetic to their patients' difficulties and saw them like their own family members. The formal caregivers gave a positive meaning to their roles and believed that they were doing an invaluable service by taking care of the elderly. This mitigated the effects of physical caregiver burden. They were able to view their physical difficulties as part of their job. They expressed an expectation that society would look at the roles of formal caregivers in home settings more favourably.

Conclusion

A review of literature revealed that the caregiver burden experienced by informal or family caregivers was greater than that experienced by formal caregivers. The findings of this study bring out how formal caregivers in home settings perceive their caregiving experience as positive and are able to look at it in a balanced way. Emotional empathy with the elderly patients and the financial stability of the role of caregiving offers a balance to the physical discomforts experienced.

Previous personal experiences and individual coping skills helped them to relate to their patients at a personal level as well. The ability of the formal caregivers to perceive their experience as a rewarding contribution and invaluable service gave meaning to their role as caregivers. Thus, we may say that though caregiver burden exists, the formal caregivers give positive meanings to their caregiving experience, and this impacts their caregiver burden in a positive way.

Implications

The findings of the study shed light on the need to work on the following areas:

1. To build awareness in society regarding the role of untrained formal caregivers in home settings in a favourable manner.
2. To start programmes that ensure health support services for the formal caregivers in home settings.

Limitations

The limitations of the study are as follows:

1. The method of Snowball sampling brings with it its limitations. The initial participants have a strong influence on the resulting sample. If they refer people from their social networks, the sample may be biased toward certain characteristics. Since the initial participant was a female, subsequent participants who were referred were also females.
2. The study has a small sample size of 6 participants.
3. The study is limited to the city of Trivandrum.

Suggestions

Priya K.P. et al (2021) in their article titled ‘’Care of caregivers – who is responsible?” summarizes the importance and/or role of caregivers, their problems and recommendations to identify, manage and prevent caregiver burden. They stressed the involvement of various stakeholders namely medical and para-medical colleges through training and medical education, hospitals, physicians, psychiatrists and/or psychologists, research organizations, governments and their policies are the need of the hour.

The involvement of various stakeholders to improve the status of the formal caregivers in home settings is an invaluable suggestion. Some other suggestions among many put forward by Priya K.P. et al (2021) in their article titled ‘’Care of caregivers – who is responsible?” are also important and will contribute to strengthening the job of formal caregivers at multiple levels. These include,

1. The need to implement routine workshops, training of doctors and nurses to provide empathic care to the caretakers.
2. Care coordination and advance care planning services available to patients should be made available to caretakers.
3. Empathetic counselling has to be a part of the Undergraduate medical and paramedical curriculum.
4. The imperative need for routine mental health assessment and examination of caregivers who have played the role of being chronic caretakers.
5. The caregivers should be referred to Psychiatrist and psychologists on a routine basis by the treating physician for their evaluation. Special clinics for caregivers to be held once a month - once a quarter.
6. Employers need to ensure regular breaks, vacations for the formal caregivers.
    - Incentives, motivation and appreciation for all the good and efficient work done by them.
    - Necessary arrangements for the caregivers to keep in touch with their families and friends.
    - To make sure that education of the caregivers is not hampered
    - To protect the caregivers from physical and sexual abuse

Role of government

A Separate department should be initiated to create job opportunities to employ caregivers. This can create more employment opportunities.

- A wide publicity of the toll-free number should be made available
- Provision of such service in both rural and urban areas
- Streamline the salary of the caregivers
- A national policy on the role of caregivers, their health and risks should be drafted based on evidence.
- Family care leave should be made available for both public and private sector employees for a total of 60 days per parent in the entire service.

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Appendix A

Sociodemographic Data Sheet

Gender:

Age:

Marital status:

Educational level:

Income:

Children:

Support provided by them or not?

Living with

Family, rented, or own house

Appendix B

Semi-Structured Interview Schedule

Background

1. Can you tell me a bit about yourself and how you became a caregiver?
2. How long have you been caring for elderly people in home settings?
3. What is the illness of the patient being taken care of?

Experience of Caregiving

4. Can you describe a typical day in your caregiving role?
5. What kinds of tasks or responsibilities do you usually perform?
6. How do you feel—physically and emotionally—after a day of caregiving?

Challenges and Burden

7. What are some of the biggest challenges you face in your caregiving work?
8. How does caregiving affect your own health or well-being?
9. Do you find it difficult to take care of your own needs? (like rest, eating, or family time?)
10. Have you ever felt emotionally overwhelmed? Can you describe a time that stood out?

Support and Coping

11. Do you have anyone to talk to about your work—like friends, family, or coworkers?
12. What helps you manage the stress or burden of caregiving?
13. What do you wish others understood about your work?

Meaning and Reflection

14. Has caregiving changed how you see yourself or life in general?
15. Despite the difficulties, is there anything meaningful or rewarding about what you do?
16. Is there anything else you'd like to share about your experience?

Appendix C

Sociodemographic Data and Verbatim Interview Transcript of Participant 1

Gender- Female

Age- 50 years

Marital Status- Widow

Educational Level- 10th grade

Income- Rs 20,000 per month

Number of Children- 1 girl

Do they provide support? No

Residence - Own house

Conversation	
Interviewer	Can you tell me a bit about yourself and how you became a caregiver?
Interviewee	My husband is an auto driver and my daughter did D Pharm. She is married. My husband was unwell for 7 years, had kidney problems and was a sugar patient and lost his eye sight. I took care of him for 7 years and had to make sure his medicines were given on time as he was a sugar patient. By taking care of him I started to like caring for people. I also needed a job for income but I also have a mind to do this. I didn’t go for work for a year in 2021 and after that I went to take care of a cancer patient who had a bag fit to collect motion. I gave 10 months of care, after which he passed away. Finally I came here where I am currently working in the month of June, 2024.
Interviewer	How long have you been caring for elderly people in home settings?
Interviewee	3 years

Interviewer	What is the illness of the patient being taken care of?
Interviewee	She has Parkinson's and has also had an operation in her leg because she had a fall and broke her thigh bone.
Interviewer	Can you describe a typical day in your caregiving role?
Interviewee	In the morning at around 7:00 a.m, I wake her up, give her thyroid tablets and water, then I give her a glass of protein. I then brush her teeth, wipe her with a cloth in warm water, and change her diapers. From 8 am to 9 am, I give her food and insulin. Afterwards I give her fruit juice. At around 12 pm she sleeps and then I change her diapers again and prepare her for lunch. Later she might sleep again or I sit her in her wheel chair or she might watch some tv. I give her water if she asks me for it. At 4 pm, I give her tea and again change her diaper. Later on, I take her to the sit out so she can get some fresh air. She also has physiotherapy every alternate day. I then give her dinner at night, change her diapers again and get her ready for sleep. At 2 am, I change her diaper again and also change her position. From 3 am to 4 am, once again I do the same.
Interviewer	What kinds of tasks or responsibilities do you usually perform?
Interviewee	Physiotherapy, I put ointment for her and place ice packs when necessary.
Interviewer	How do you feel physically and emotionally after a day of caregiving?

Interviewee	I get shoulder pain from transferring the patient onto the wheel chair and the bed but I put some ointment on and feel better. I feel really sad and upset seeing the pain the patient goes through. No one should go through a situation like this.
Interviewer	What are some of the biggest challenges you face in your caregiving work?
Interviewee	The most difficult challenge for me is when I take her for a bath. I need to transfer her from the wheel chair to a chair and once when I was doing that, the wheel chair slipped and I grabbed her tightly and that was very scary.
Interviewer	How does caregiving affect your own health or well-being?
Interviewee	I get shoulder pain sometimes. There is no infection so it doesn't spread from her. I also have some difficulty while carrying her because of the weight.
Interviewer	Do you find it difficult to take care of your own needs? (like rest, eating, or family time?)
Interviewee	I do get time to do my own things. After taking care of her, I get enough time for my own needs.
Interviewer	Have you ever felt emotionally overwhelmed? Can you describe a time that stood out?
Interviewee	Once, she was in a really bad state. Her sugar went so low, she wasn't responding. I felt really bad and upset during that time. She was admitted in the ICU and she was in a critical condition. It was very difficult and upsetting to see.

Interviewer	Do you have anyone to talk to about your work—like friends, family, or coworkers?
Interviewee	I talk to my daughter but I don't really feel the need to talk to anyone because I like what I am doing and I have no issues.
Interviewer	What helps you manage the stress or burden of caregiving?
Interviewee	When I get body pain, I use ointment and I sleep to get a good rest.
Interviewer	What do you wish others understood about your work?
Interviewee	A lot of people look at this job with disgust and undermine those who performed this job. People should never underestimate those who perform this job. Others must see it in a positive light and with good intention.
Interviewer	Has caregiving changed how you see yourself or life in general?
Interviewee	Yes, very much. I didn't have money before and now I do. I am also able to pay off my debts. I am very thankful to God that I am able to work. I also feel a positive energy because of all of this.
Interviewer	Despite the difficulties, is there anything meaningful or rewarding about what you do?
Interviewee	Yes. What is rewarding is being able to support her. Once she kissed my hand and it made me tear up. I kissed her hand in return and told her I love her a lot.
Interviewer	Is there anything else you'd like to share about your experience?

Interviewee	Nothing much. I would like to do more of this work.

Appendix D

Sociodemographic Data and Verbatim Interview Transcript of Participant 2

Gender- Female

Age- 45

Marital Status- Married

Educational Level- 10th grade

Income- Rs 23,000 per month

Number of Children- 1 girl

Do they provide support? No

Residence – Rented

Conversation	
Interviewer	Can you tell me a bit about yourself and how you became a caregiver?
Interviewee	I used to take care of women post delivery. My daughter at the time was doing her degree and I had stopped because of it and stayed home to take care of her. I have also worked in tribal schools for five years as a sweeper. My family had some financial issues and like that I came into this job. I didn't want to come for this.
Interviewer	How long have you been caring for elderly people in home settings?
Interviewee	It's been 1year since I started working as a home nurse. I have four sisters and a brother. Out of all of them, I was extremely patient with my mom. The elderly will have many personalities. They might show anger. There are caregivers who give care just for money. It will depend on the caregivers patience. I look after the patient like my own mother. I don't answer back when they get mad. Even when I feel sad, I remember my mother and stay patient. We will also age

	one day.
Interviewer	What is the illness of the patient being taken care of?
Interviewee	She has dementia. She is violent. If it was someone else, they would have left by now. I even told the patient's family that I would leave but they said that if she did no one else would come in place of her and that her condition would get worse and would end up in the hospital and need further medication. The patient likes me sometimes but at other times she gets angry. She was taken to the psychiatrist and she now takes medication. Since then, there has been no violence. But for more than a month now, she has been angry, forgetful and asks me how many daughters she has?
Interviewer	Can you describe a typical day in your caregiving role?
Interviewee	I take her to the bathroom, clean her and change pampers. I give her food and juice. I then help her take a bath in hot water. I give her tea afterwards. At around 1 pm, I give her lunch. At 4:30, it’s tea time again. From 7:30 to 8 pm, I give her dinner and tablets. A glass of milk is also given to her. At 10 am, I give her oats as well and at 10:30, I give her insulin. I prepare all her food as I am aware of the quantity she eats.
Interviewer	What kinds of tasks or responsibilities do you usually perform?

Interviewee	Nothing apart from what I have mentioned earlier.
Interviewer	How do you feel physically and emotionally after a day of caregiving?
Interviewee	I love her so much. I see her like my own mother so I joke around with her and it's not that difficult for me but I also clean her room after a day's work and that makes me tired.
Interviewer	What are some of the biggest challenges you face in your caregiving work?
Interviewee	It’s most difficult when the patient is angry. She doesn’t listen to me sometimes. When she doesn’t listen, the entire schedule goes out of place and I get tense. I need to feed her as well as eat myself. Sometimes, she refuses to eat and it makes me annoyed as I can only move forward to do the rest of the tasks after she is done and I have also eaten. I feel sad and angry at times because of this. I also feel that she wouldn’t have behaved the same way with her own children but does so because it’s me.
Interviewer	How does caregiving affect your own health or well-being?
Interviewee	I got an allergy when I exposed myself to urine. In the beginning, I used to not wear gloves or a mask while cleaning her and changing her diapers. Once this happened to me, I began using gloves and a mask.
Interviewer	Do you find it difficult to take care of your own needs? (like rest, eating, or family time?)
Interviewee	No I don’t. I call my family after I am done with all my duties.

Interviewer	Have you ever felt emotionally overwhelmed? Can you describe a time that stood out?
Interviewee	Yes. I feel upset when she refuses to eat her food because only if she does, can I give her medicines and do the next thing.
Interviewer	Do you have anyone to talk to about your work—like friends, family, or coworkers?
Interviewee	Yes I do share what happens with my family and it gives me some calmness and peace.
Interviewer	What helps you manage the stress or burden of caregiving?
Interviewee	I have taken care of heart patients, sugar patients for 3 months and more and sometimes I cannot even sleep so it's a very difficult task but I manage somehow. Sharing things with my family gives me some relief.
Interviewer	What do you wish others understood about your work?

Interviewee	I wish people understood the importance of patience when doing this job. Once a person is sick, especially someone old, they start to act like a kid, sometimes even become violent. You cannot say anything back to them so you need to know how to be patient. You also need to know about what has to be fed to them, how to give them a bath and if it's cold or hot water that needs to be used while doing so. You never know if some caregivers use hot or cold water when giving a bath if the patient and the caregiver are all by themselves. In the case of the previous patient that I took care of, two ladies who worked there before me used to pull the patient up using the bedsheet due to her weight and this caused the formation of blisters in her skin so we need to also be extremely careful. You need to show love and care.
Interviewer	Has caregiving changed how you see yourself or life in general?
Interviewee	Yes it has. I feel that some people would have lived longer, if they were taken care of well. It has changed how I take care of people. Patients need to experience a change of some sort. They need to feel they are improving. Doing this has made me happy because I feel like I am taking care of someone that reminds me a lot of my own mother.
Interviewer	Despite the difficulties, is there anything meaningful or rewarding about what you do?
Interviewee	I feel happy that I am able to take care of elderly and help them get better.
Interviewer	Is there anything else you'd like to share about your experience?

Interviewee	Yes, I would like to send a message to people, to do their duty and not get angry and that it's always better to provide care with family around as the story changes if it's just the patient and the caregiver.

Appendix E

Sociodemographic Data and Verbatim Interview Transcript of Participant 3

Gender- Female

Age- 60 years

Marital Status- Married

Educational Level- 4th grade

Income- Rs 22,000 per month

Number of Children- 2 girls

Do they provide support? No

Residence - Rented

Conversation	
Interviewer	Can you tell me a bit about yourself and how you became a caregiver?
Interviewee	I have worked as a maid since I was 13 years old. I got married at 18 years of age. I am facing some financial difficulties. It's been four years since I divorced my husband. For more than a year, I have been paying debt. The debt is from a loan my husband took to keep our house. I am working to finish off the debt. This is how I started to go for home nursing. I have worked in GIGI, Govind hospital, taking care of patients for 8 years.
Interviewer	How long have you been caring for elderly people in home settings?
Interviewee	It's been a few years now.
Interviewer	What is the illness of the patient being taken care of?

Interviewee	She has a lot of health issues and has done many surgeries. She is also a sugar patient. Before coming here, I had to take care of a patient in a hospital who was in the ICU. He was a military personnel and required the help of a ventilator. His bones were disintegrating and they hadn't found out. There was another patient who had pneumonia and was paralysed on one side.
Interviewer	Can you describe a typical day in your caregiving role?
Interviewee	If the patient is bedridden, I wake up at around 6 or 7 am and change their diaper. I wipe them clean with some lukewarm water and Dettol. Their skin is very soft due to old age, so it must be done carefully, in order to not hurt them so they don't get an infection. Then I carefully dress them up. I mostly use a front open dress as it will be easy to put on and remove. When giving the patient a headbath, I place their head upright on a pillow by slanting the pillow. Later on, I give the patient food. I make sure that the spoon and utensils are cleaned well before using them. I also take care of the quantity of food and medication that need to be given. I also make them do small exercises by moving their arms and legs slowly in different directions. You need to have good patience to take care of them. I am living for myself through them. I do my work with a mindset to do better.
Interviewer	What kinds of tasks or responsibilities do you usually perform?
Interviewee	I change their diapers, give them food, give them a bath, make sure they're given their medicines on time and the other things I mentioned earlier.
Interviewer	How do you feel physically and emotionally after a day of caregiving?

Interviewee	I feel sad and irritated when they don't eat their food, spit their food and don't sleep on time. This makes it very difficult. I cannot sleep sometimes because of noises the patient might make. I also get angry when the patient's family orders me around. I get body pain because of carrying the patient.
Interviewer	What are some of the biggest challenges you face in your caregiving work?
Interviewee	I have some family problems. I have two girls and I cannot take care of them because I am working most of the time. This makes me really tense as there is no one to look after them.
Interviewer	How does caregiving affect your own health or well-being?
Interviewee	I tend to get sick in between or get a fever. I already have knee pain and that makes it a bit difficult for me to do my job. I believe I'm able to keep working with strength because of God.
Interviewer	Do you find it difficult to take care of your own needs? (like rest, eating, or family time?)
Interviewee	No I don't, I get enough time to call my family and speak to them once I'm done with all my work.
Interviewer	Have you ever felt emotionally overwhelmed? Can you describe a time that stood out?
Interviewee	There was this one time where I was really upset because I was feeling tired as I did not get a good amount of sleep as the patient kept making a lot of noise and I needed to wake up multiple times to attend to the patient's needs. Later on, I also felt a little dizzy because of it.

Interviewer	Do you have anyone to talk to about your work—like friends, family, or coworkers?
Interviewee	No, I don't talk about any of my work with my family. I do all this to support myself.
Interviewer	What helps you manage the stress or burden of caregiving?
Interviewee	When I get body pain I use ointment, otherwise I just manage and be patient.
Interviewer	What do you wish others understood about your work?
Interviewee	I want people to understand that you must behave with lots of patience to take care of the patient. You need to also have a positive mindset and show kindness. You must also take care of the patient like one of your own. I get to live my life because of them. I believe everyone needs to remember that while doing their job.
Interviewer	Has caregiving changed how you see yourself or life in general?
Interviewee	Yes I've had so many changes in my life. I feel a sense of peace, blessing, fulfillment, and positivity. Taking care of others brought goodness in my life. I'm able to take care of my life because of them.
Interviewer	Despite the difficulties, is there anything meaningful or rewarding about what you do?
Interviewee	I have learnt how to live my life morally and peacefully.
Interviewer	Is there anything else you'd like to share about your experience?

Interviewee	I pray for the patient because I had a huge debt and I got to pay off a lot of it by helping her. She made my life easier for me.

Appendix F

Sociodemographic Data and Verbatim Interview Transcript of Participant 4

Gender- Female

Age- 63 years

Marital Status- Widow

Educational Level- 3rd grade

Income- Rs 20,000 per month

Number of Children- 2 girls and 1 boy

Do they provide support? Yes

Residence – Rented

Conversation	
Interviewer	Can you tell me a bit about yourself and how you became a caregiver?
Interviewee	I used to sell rubber when I was a kid and I also worked as a maid from when I was young. It's been five months since I came here. Money is the main reason for me to take up this job.
Interviewer	How long have you been caring for elderly people in home settings?
Interviewee	Two to three years.
Interviewer	What is the illness of the patient being taken care of?
Interviewee	She had a heart operation done. And I was assigned to take care of her after the operation.
Interviewer	Can you describe a typical day in your caregiving role?

Interviewee	I wake up early in the morning and I prepare breakfast at around 8 or 9 am. We have lunch by 1 pm. Both me and the patient prepare food together. We have dinner at 9 or 10 pm and then go to bed.
Interviewer	What kinds of tasks or responsibilities do you usually perform?
Interviewee	I mainly help in preparation of food and help her take her medicines on time and provide emotional support.
Interviewer	How do you feel physically and emotionally after a day of caregiving?
Interviewee	I feel fine as there is not much for me to do.
Interviewer	What are some of the biggest challenges you face in your caregiving work?
Interviewee	I don't find it challenging as the task at hand are quite simple.
Interviewer	How does caregiving affect your own health or well-being?
Interviewee	I get knee pain due to strain but otherwise I am okay.
Interviewer	Do you find it difficult to take care of your own needs? (like rest, eating, or family time?)
Interviewee	No I do not. I get enough time for them.
Interviewer	Have you ever felt emotionally overwhelmed? Can you describe a time that stood out?
Interviewee	No, that hasn’t happened.

Interviewer	Do you have anyone to talk to about your work—like friends, family, or coworkers?
Interviewee	I do share things with my family.
Interviewer	What helps you manage the stress or burden of caregiving?
Interviewee	Talking to my family does give me relief but since I don't have many tasks to perform I am of good health.
Interviewer	What do you wish others understood about your work?
Interviewee	I want others to understand that by taking care of others, we are able to gain money for ourselves and not beg others. It is a means of earning and it makes us independent.
Interviewer	Has caregiving changed how you see yourself or life in general?
Interviewee	Yes it is fulfilling as you get to help others and earn for yourself.
Interviewer	Despite the difficulties, is there anything meaningful or rewarding about what you do?
Interviewee	Yes it is rewarding because we are able to earn for ourselves and live our lives. I also like this job.
Interviewer	Is there anything else you'd like to share about your experience?
Interviewee	No there isn't.

Appendix G

Sociodemographic Data and Verbatim Interview Transcript of Participant 5

Gender- Female

Age- 42 years

Marital Status- Widow

Educational Level- 7th grade

Income- Rs 22,000 per month

Number of Children- 3 girls

Do they provide support? Yes

Residence - Own house

Conversation	
Interviewer	Can you tell me a bit about yourself and how you became a caregiver?
Interviewee	I’ve only studied till 7th grade. I used to go rope making and after that I went for cleaning work in Technopark. It was during this time that I also began to go for home nursing. My mom used to also go for the same job and her experiences inspired me to do the same.
Interviewer	How long have you been caring for elderly people in home settings?
Interviewee	It’s going to be about 10 years.
Interviewer	What is the illness of the patient being taken care of?
Interviewee	The patient has diabetes, blood pressure and kidney problems. She also has memory issues and keeps repeating things.

Interviewer	Can you describe a typical day in your caregiving role?
Interviewee	In the morning, I help her brush her teeth. I then help clean her up and change the sheets. I give her food then I give her the medicines she's supposed to take in the morning. This might include gas medications. Later I clean their room and wash their clothes
Interviewer	What kinds of tasks or responsibilities do you usually perform?
Interviewee	As I mentioned, the tasks that I do mainly include cleaning their rooms, taking care of them, giving them their food and medications on time.
Interviewer	How do you feel physically and emotionally after a day of caregiving?
Interviewee	I don't have any feelings as such because our main aim while doing this job is to take care of them. It's only when we have to carry heavy patients and help them on to a wheelchair, that we tend to get physical pain.
Interviewer	What are some of the biggest challenges you face in your caregiving work?
Interviewee	I find it very challenging when the patient is heavy to carry. In some places that I have worked the patients had excess weight.
Interviewer	How does caregiving affect your own health or well-being?
Interviewee	It will depend on the patient we give care to, if the patient is heavy, I tend to get body pain.

Interviewer	Do you find it difficult to take care of your own needs? (like rest, eating, or family time?)
Interviewee	No, I have not faced any difficulties in taking care of my own needs.
Interviewer	Have you ever felt emotionally overwhelmed? Can you describe a time that stood out?
Interviewee	Yes, I have. There are times when families have treated me like I have not done enough for the patient, and this has upset me. In some homes, the families of the patients don't like it if I sit in the room when guests come to see them.
Interviewer	Do you have anyone to talk to about your work—like friends, family, or coworkers?
Interviewee	Yes, I do. I share almost everything with my co-worker/friend.
Interviewer	What helps you manage the stress or burden of caregiving?
Interviewee	If I do get body pain, headache or feel unwell, I take tablets to feel better.
Interviewer	What do you wish others understood about your work?
Interviewee	It is important to use gloves while cleaning the patient. Some caregivers don’t understand its importance. They must also ensure the patients room and bathroom is always kept clean.
Interviewer	Has caregiving changed how you see yourself or life in general?
Interviewee	Yes, it has. I’ve never felt like this was a difficult job for me as I feel satisfied

	taking care of the elderly.
Interviewer	Despite the difficulties, is there anything meaningful or rewarding about what you do?
Interviewee	I have not felt it as rewarding, but the families and patients tend to like me and appreciate me for the work I do.
Interviewer	Is there anything else you’d like to share about your experience?
Interviewee	What I would like to say is, the families of the patient must view the caregivers like a member of the family. Caregivers must provide the best care possible to their patients. They must be provided all the necessary materials to give utmost care.

Appendix H

Sociodemographic Data and Verbatim Interview Transcript of Participant 6

Gender- Female

Age- 42 years

Marital Status- Divorced

Educational Level- 10th grade

Income- Rs 20,000 per month

Number of Children- 1 boy and 1 girl

Do they provide support? No

Residence - Rented

Conversation	
Interviewer	Can you tell me a bit about yourself and how you became a caregiver?
Interviewee	The reason I began working as a caregiver was because I lost both my mother and father when I was four years old. Me and my brother grew up with our grandparents. My elder sister had married when my mother was still there. Later when she passed my father had remarried to take care of us. We grew up with financial difficulties. Our grandparents educated us till 10th grade. I always wished to take care of other old ladies and care for them because I could not care for my own mother. I wanted to look after other old mothers and fathers as I couldn't do that for my own parents. I like doing it and I will do it. I had a lot of tension because I couldn't care for my mother so I wanted to care for other mothers and bring them back to good health. I wanted to get their love and care as well so I came into his job. Now to tell you about myself, I am someone with a social mind and I always like to stay happy. I am someone with a happy mind. I don't like to get tense. I like

	to eat food, listen to music and travel. These are my hobbies. I have a lot of friends and I talk to all of them with a cool mind. I don’t like fighting with others for any reason. I want to work well, educate my children and bring them to good positions. I don't want my children to suffer like my mom did. I want to live in a good manner. Mentally, I do have a lot of tension but I like to keep saying that these are not problems in my life and move forward. I do face some financial difficulties so I want to live a better life or come into a better life and I want to educate my children well and get them jobs. Like that I have many wishes.
Interviewer	How long have you been caring for elderly people in home settings?
Interviewee	I started working as a caregiver from 2019 onwards. I really like the job and I plan on doing this job till I can and till God gives me good health.
Interviewer	What is the illness of the patient being taken care of?
Interviewee	The patient I take care of now had a stroke and her right side is completely paralyzed. She cannot get up or do anything. She also had bed sores on her back but now it has all healed. She had physiotherapy and now she can sit up and eat food. Earlier, feeding was done through a tube but now she can eat herself. Even though she can’t move her right hand and leg, her condition is much better now.

Interviewer	Can you describe a typical day in your caregiving role?
Interviewee	I do most of my work from 9 am to 6 pm. I give her food at the right time in the case of breakfast, lunch and dinner. I make sure I wake her up at the right time and give her medicines on time as well. Once I am done with all these tasks including changing diapers, cleaning her, I put her to bed and I also go to bed. I have hypertension and so I make sure to take my own tablets and go to bed on time. I don't find it that hard as once I am done with all of my responsibilities I get enough time for rest. I don't need to give her a bath daily as she has pneumonia. I wipe her clean using wipes on a daily basis and also change her dress. When changing her underpass or diapers, I use Dettol and make sure it's cleaned really well to prevent infection.
Interviewer	What kinds of tasks or responsibilities do you usually perform?
Interviewee	One of the main tasks is to sit her up a lot of the time because only then can her spine and muscles be stronger and she will be able to stand on her own. I must also make sure I give her water to drink on time. I also need to put a belt on her legs and hands to support and strengthen her muscles. She calls me when she needs to go to bed and I also change her diapers when required.
Interviewer	How do you feel physically and emotionally after a day of caregiving?
Interviewee	I don't feel much struggle emotionally or physically. When I do, it's usually because of my own health as I have hypertension. I try to take my tablets and keep that in check.
Interviewer	What are some of the biggest challenges

	you face in your caregiving work?
Interviewee	It is a bit difficult when trying to make sure everything is done on time. I need to remember to give her water on a timely basis as it's extremely important for her well being. I might also have to force her to eat sometimes when she refuses to eat.
Interviewer	How does caregiving affect your own health or well-being?
Interviewee	Earlier, she used to not be that heavy but now after giving her eggs, protein rich foods, juices containing carrot and orange, she has gained more weight. While helping her sit up, I get a muscle pull on my back sometimes which gives me pain. Nothing else affects my health.
Interviewer	Do you find it difficult to take care of your own needs? (like rest, eating, or family time?)
Interviewee	In some places, I did find it difficult but in the place I am currently working, I have enough freedom to take care of my own needs. It's only when I wish to go somewhere else that the patient's family asks me to stay because I take care of her really well. I tend to take leave when I get sick or if I really need to. I might take leave for a week or a few days.
Interviewer	Have you ever felt emotionally overwhelmed? Can you describe a time that stood out?
Interviewee	Yes, there are times I have felt anger. Sometimes, she doesn’t drink water or chew the food. She might simply leave it in her mouth and not chew it. If they need to get better, then it’s important they have food so when they do this, I get angry. But, lately it’s not been this way. Sometimes, she gets angry and I calmly show some

	love which helps reduce her anger.
Interviewer	Do you have anyone to talk to about your work—like friends, family, or coworkers?
Interviewee	Yes I have a lot of friends who I share everything with. I have a close friend B, who I share everything with. She has taken care of a patient who I also took care of and she helps me understand how to provide the best care possible as she has more experience.
Interviewer	What helps you manage the stress or burden of caregiving?
Interviewee	I feel a lot of relief when I share things with my friends.
Interviewer	What do you wish others understood about your work?
Interviewee	You need to take care of the patients with love and empathy. People need to remember that one day we are all going to be old. No matter how angry we get, we cannot take it out on them because they are already ill. We need to be careful and take care of them with love.
Interviewer	Has caregiving changed how you see yourself or life in general?
Interviewee	Yes, it has. I am happy I get to take care of elderly and help them get better so they can live better lives. I was never able to take care of my mother so this gives me a sense of peace.
Interviewer	Despite the difficulties, is there anything meaningful or rewarding about what you do?

Interviewee	I feel rewarded as I am able to be independent, take care of my own life as well as the lives of my children. It’s with my earnings that our entire family is moving forward.
Interviewer	Is there anything else you’d like to share about your experience?
Interviewee	Everyone needs to understand the importance of patience and love while taking care of the elderly. They are already sick and old so it's important to shower love and provide utmost care to help them heal.