CHALLENGES AND COPING STRATEGIES AMONG CAREGIVERS OF PERSONS WITH BREAST CANCER

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SUBMITTED BY

Name: Vysakh Suresh

Exam Code: 91520402

Candidate Code: 91521115025

Subject Code: SW 2.4.5

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CERTIFICATION OF APPROVAL

This is to certify that this dissertation entitled **“Challenges and Coping Strategies among Caregivers of Persons with Breast Cancer”** is a record of genuine work done by **Mr. Vysakh Suresh**, fourth semester Master of Social Work student of this college under my supervision and guidance and that it is hereby approved for submission.

Date: 16 August 2023

Thiruvananthapuram

Dr Anjali U.S

Research guide

Department of Social Work

Loyola College of Social sciences

Sreekariyam, Thiruvananthapuram

Recommended for forwarding to the University of Kerala

Rev. Dr. Sabu P Thomas S. J.

Head, Department of Social Work

Loyola College of Social sciences

Sreekariyam, Thiruvananthapuram

Forwarded to the University of Kerala

Dr. Saji P. Jacob

Principal

Loyola College of Social Sciences

Sreekariyam, Thiruvananthapuram

DECLARATION

I, **Vysakh Suresh**, do hereby declare that the Dissertation titled "**Challenges and Coping Strategies among Caregivers of Persons with Breast Cancer**" is based on the original work carried out by me and submitted to the University of Kerala during the year 2021-2023 towards partial fulfillment of the requirements for the Master of Social Work Degree Examination. It has not been submitted for the award of any degree, diploma, fellowship or other similar title of recognition before.

Candidate Name: Vysakh Suresh

Place: Thiruvananthapuram

Date: 16 August 2023

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Vysakh Suresh

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LIST OF ABBREVIATIONS

WHO – World Health Organization
DNA - Deoxyribonucleic Acid
ICMR - Indian Council of Medical Research
BRCA - Breast Cancer Gene
HSV - Herpes Simplex Virus
MHC - Major Histocompatibility Complex
CD - Cluster of differentiation
QOL - Quality of Life
GLOBOCAN - Global Cancer Observatory: CANCER TODAY
PBCR - Population Based Cancer Registries
RCC - Regional Cancer Centre
ASR - Age Standardized Rates
CQOLC - Caregiver Quality of Life Index - Cancer
CI - Confidence Interval
NSCLC - Non small cell lung cancer
NCI - National Cancer Institute
HNC - Head and Neck Cancer
CA 125 - Cancer Antigen 125 test

ABSTRACT

Cancer is a large group of diseases that can start in almost any organ or tissue of the body when abnormal cells grow uncontrollably, go beyond their usual boundaries to invade adjoining parts of the body and/or spread to other organs. A neoplasm and malignant tumour are other common names for cancer. Cancer is the second leading cause of death globally, accounting for an estimated 9.6 million deaths, or one in six deaths, in 2018 (WHO, 2018). Breast cancer is the most frequently diagnosed cancer and the most frequent cause for cancer-related deaths in women worldwide. Breast Cancer, like most other diseases has significant impact on both the patient as well as the caregiver. Caregiving for individuals diagnosed with breast cancer imposes significant challenges on caregivers, who play a vital role in providing physical, emotional and psychological support throughout the patient's journey. The study "Challenges and Coping Strategies among Caregivers of Persons with Breast Cancer" gives details about the various social and psychological challenges faced by the caregivers along with the coping strategies that they made use of.

The study adopted a case study research design to gain an in depth understanding of the experiences, challenges and the coping strategies used by the caregivers in which the patient were availing treatment from the Regional Cancer Centre, Thiruvananthapuram. The information was collected through a semi-structured interview guide.

The study brought to light the various challenges faced by the caregivers. These included psychological challenges such as consternation, fear and anxiety, depression, stress, sleeplessness, emotional distress and guilt. They also faced social challenges including changes in role, changes in daily routine, disruptions in social life, job issues and loneliness. The study found out how factors such as the caregivers' economic background, nature of occupation and the level of social support influenced the challenges faced by them. The participants of the study made use of different coping strategies such as problem focused coping, emotion focused coping and avoidant coping in order to deal with the challenges faced.

As a result of the findings obtained from the study, the researcher was able to establish a number of social work interventions to specifically address the challenges faced by

the caregivers during their journey of supporting the patient during a challenging period.

CHAPTER I: INTRODUCTION

INTRODUCTION

1.1 OVERVIEW

According to World Health Organization (WHO), Cancer is a large group of diseases that can start in almost any organ or tissue of the body when abnormal cells grow uncontrollably, go beyond their usual boundaries to invade adjoining parts of the body and/or spread to other organs. The latter process is called metastasizing and is a major cause of death from cancer. A neoplasm and malignant tumour are other common names for cancer. Cancer is the second leading cause of death globally, accounting for an estimated 9.6 million deaths, or one in six deaths, in 2018 (WHO, 2018).

Cancer is characterized by uncontrolled cell growth and acquisition of metastatic properties. In most cases, activation of oncogenes and/or deactivation of tumour suppressor genes lead to uncontrolled cell cycle progression and inactivation of apoptotic mechanisms (Sarkar, 2013). Cancer changes the lives of the patient and their loved ones, causing both physical and psychological suffering, as well as negative social and spiritual experiences (Lewandowska et al., 2020).

The 30 trillion cells of the normal, healthy body live in a complex, interdependent condominium, regulating one another’s proliferation. Indeed, normal cells reproduce only when instructed to do so by other cells in their vicinity. Such unceasing collaboration ensures that each tissue maintains a size and architecture appropriate to the body’s needs. Cancer cells, in stark contrast, violate this scheme; they become deaf to the usual controls on proliferation and follow their own internal agenda for reproduction. They also possess an even more insidious property—the ability to migrate from the site where they began, invading nearby tissues and forming masses at distant sites in the body. Tumors composed of such malignant cells become more and more aggressive over time, and they become lethal when they disrupt the tissues and organs needed for the survival of the organism as a whole (Weinberg, 1996).

Cancer causes great psychosocial distress among patients. Distress affects an individual depending on their culture and how the illness is perceived by the patient. During the illness, many common psychological problems such as depression, anxiety and an increased risk of suicidal behaviour arise, leading to intense emotions and troubling thoughts that affect the individual in multiple ways leading to poor quality of life (Wajid et al., 2021). Lung, prostate, colorectal, stomach and liver cancer are the most common types of cancer in men, while breast, colorectal, lung, cervical and thyroid cancer are the most common among women (WHO, 2018).

Early detection of cancer increases the probability of better treatment outcomes. Screening programs and increased awareness about the signs and symptoms can prevent major complications. However, in India, most of the cancers are detected at an advanced stage (Murthy et al., 2011). From the diagnosis and as the disease progresses the persons with cancer depend on others to meet their needs. Often times the family members step into the role of the care giver. This study aims to understand the challenges and coping strategies among caregivers of persons with cancer with specific reference to breast cancer.

1.2 BACKGROUND

1.2.1 CANCER

Cancer is a group of diseases that is characterized by uncontrolled cell growth, which affects healthy body functioning, leading to fatal outcomes for the individual (National Commission on Macroeconomics and Health, 2005). Cancer is a complex disease evolved due to multiple genetic changes leading to uncontrolled proliferation of cells with metastatic ability (Kotebagilu et al., 2018). Cancers are linked to changes that happen in the genetic component of the cell which is deoxyribonucleic acid (DNA). Each gene within the DNA codes for specific enzyme or protein. Two essential genes that are vital in cell proliferation are protooncogenes which are involved in normal cell growth and; tumor suppressor genes which produce protein that control cell growth. On the other hand, excess and impaired cells are also removed from the body in a process called apoptosis or programmed cell death, thus, maintaining a balance. Mutations in these genes promote uncontrolled cell proliferation.

Cancer begins when a cell breaks free from the normal restraints on cell division and begins to follow its own agenda for proliferation. All of the cells produced by division of this first, ancestral cell and its progeny also display inappropriate proliferation. A tumor, or mass of cells, formed of these abnormal cells may remain within the tissue in which it originated (a condition called in situ cancer), or it may begin to invade nearby tissues (a condition called invasive cancer). An invasive tumor is said to be malignant, and cells shed into the blood or lymph from a malignant tumor are likely to establish new tumors (metastases) throughout the body. Tumors threaten an individual's life when their growth disrupts the tissues and organs needed for survival. The process of cancer development is a multistage event involving inactivation of tumor suppressor genes, activation of oncogenes and altered expression of non-coding ribonucleic acids (Cooper et al., 2000; Ragusa et al., 2017). Cancer is caused by both internal factors (such as inherited mutations, hormones, and immune conditions) and environmental/acquired factors (such as tobacco, diet, radiation, and infectious organisms) (Anand et al., 2008). Hence in simpler terms, cancer is a group of more than 100 diseases that develop across time and involve the uncontrolled division of the body's cells.

A. PREVALENCE OF CANCER

- **GLOBAL CONTEXT:** The global cancer burden is estimated to have risen to 18.1 million new cases and 9.6 million deaths in 2018. One in 5 men and one in 6 women worldwide develop cancer during their lifetime, and one in 8 men and one in 11 women die from the disease (WHO, 2018). According to the World Health Organization, Cancer is a leading cause of death worldwide, accounting for nearly 10 million deaths in 2020. Breast and lung cancers were the most common cancers worldwide, contributing 12.5% and 12.2% of the total number of new cases diagnosed in 2020. Colorectal cancer was the third most common cancer with 1.9 million new cases in 2020, contributing 10.7% of new cases (World Cancer Research Fund International, 2020).
- **INDIAN CONTEXT:** In India it is estimated that around 2.25 million people are living with the disease. Over 11, 57,294 lakh people are registered every year by new cancer. There are almost about 7,84,821 cancer-related deaths. Risk of dying from cancer before the age of 75 years is 7.34% in males and 6.28% in females (ICMR, 2020). The cancer incidence rate is detected highest in Kerala, followed by Mizoram, Haryana in India. In 2016, Cancer incidence rate in India was 106.6 per 1lakh people, while in Kerala it is 135.3 per 1 lakh people. Even mortality and disability rates due to cancer are high in the southern state (Indian Council for Medical Research, 2016).

B. TYPES OF CANCER (NATIONAL CANCER INSTITUTE):

There are more than 100 types of cancer. Types of cancer are usually named for the organs or tissues where the cancers form. Some categories of cancers that begin in specific types of cells:

- Carcinoma: Carcinomas are the most common type of cancer. They are formed by epithelial cells, which are the cells that cover the inside and outside surfaces of the body.
- Sarcoma: Sarcomas are cancers that form in bone and soft tissues, including muscle, fat, blood vessels, lymph vessels, and fibrous tissue (such as tendons and ligaments).
- Leukemia: Cancers that begin in the blood-forming tissue of the bone marrow are called leukemias. These cancers do not form solid tumors. There are four common types of leukemia, which are grouped based on how quickly the disease gets worse (acute or chronic) and on the type of blood cell the cancer starts in (lymphoblastic or myeloid). Acute forms of leukemia grow quickly and chronic forms grow more slowly.
- Lymphoma: Lymphoma is cancer that begins in lymphocytes (T cells or B cells). These are disease-fighting white blood cells that are part of the immune system. In lymphoma, abnormal lymphocytes build up in lymph nodes and lymph vessels, as well as in other organs of the body.
- Multiple Myeloma: Multiple myeloma is cancer that begins in plasma cells, another type of immune cell. The abnormal plasma cells, called myeloma cells, build up in the bone marrow and form tumors in bones all through the body. Multiple myeloma is also called plasma cell myeloma and Kahler disease.
- Melanoma: Melanoma is cancer that begins in cells that become melanocytes, which are specialized cells that make melanin (the pigment that gives skin its color). Most melanomas form on the skin, but melanomas can also form in other pigmented tissues, such as the eye.

C. STAGES OF CANCER

Most types of cancer have four stages: stage I to IV (American Society of Clinical Oncology)

- Stage 0: This stage describes cancer in situ, or static. Stage 0 cancers implies that the cancer is still located in the place they started and have not spread to nearby tissues. This stage of cancer is often curable and surgery is usually sufficient to remove the entire tumour.
- Stage I: This stage is usually a cancer that has not grown deeply into nearby tissues. Neither has it spread to the lymph nodes or other parts of the body. It is often also called early-stage cancer.
- Stage II and Stage III: In general, these 2 stages are cancers that have grown more deeply into nearby tissue. They may have also spread to lymph nodes, with indication of lymphadenopathy, but not spread to other parts of the body.
- Stage IV: This stage means that the cancer has spread to other organs or parts of the body. It may be also called advanced or metastatic cancer.

1.2.2 BREAST CANCER:

Breast cancer is the most frequently diagnosed cancer and the most frequent cause for cancer-related deaths in women worldwide. Globally, breast cancer accounted for 2.08 million out of 18.08 million new cancer cases (incidence rate of 11.6%) and 626,679 out of 9.55 million cancer-related deaths (6.6% of all cancer-related deaths) in 2018 (Bhattacharyya et al., 2020). Breast cancer is the most common cause of cancer in women and the second most common cause of cancer death in women in the U.S (Sharma et al., 2010). From being fourth in the list of most common cancers in India during the 1990s, breast cancer has now become the first.

The classic symptom for breast cancer is a lump found in the breast or armpit. Doing monthly breast self-exam (BSE) is a great way to be familiar with the breasts' texture, cyclical changes, size, and skin condition. The general alerting features of breast cancer are such as swelling or lump (mass) in the breast, swelling in the armpit (lymph nodes), nipple discharge (clear or bloody), pain in the nipple, inverted (retracted) nipple, scaly or pitted skin on nipple, persistent tenderness of the breast, and unusual breast pain or discomfort. In Advanced stage (Metastatic) of disease, underarm lymph nodes are present with other symptoms such as bone pain (bone metastases), shortness of breath (lung metastases), drop in appetite (liver metastases), unintentional weight loss (liver metastases), headaches, neurological pain or weakness (Sharma et al., 2010).

A. TYPES:

Different kinds of breast cancers are identified where the cells multiply at different rates and based on the area, rate and extent of spreading; it is classified in to following types:

- **Angiosarcoma:** Bruise-like lesion is seen over the breast skin which is affected with angiosarcoma. Mainly, this type of cancer is formed in the lining of blood vessels and lymphatic vessels.
- **Lobular Carcinoma in Situ (LCIS):** It is formed in the linings of lobules, which are the glands that produce milk. Invading process is nil in LCIS type of breast cancer.
- **Inflammatory Breast Cancer (IBC):** It is due to the lymphatic vessel blockage caused by the cancer cell accumulation leading to inflammatory symptoms such as redness or swelling.
- **Invasive Lobular Carcinoma:** This type of cancer occurs in the lobules and the cancer cells have the ability to spread to lymph nodes.
- **Paget’s disease:** accumulation of cancer cells around nipples causes paget’s disease. Ducts present in the nipple area are affected first, followed by its move to main nipple part.
- **Recurrent Breast Cancer:** This type of cancer occurs to a woman whose cancer cell presence is not identified for a particular period of time and later on it occurs again in any one of the breasts.
- **Dual Carcinoma:** Dual Carcinoma, a noninvasive form of breast cancer occurs due to the formation of cancer cells in milk ducts.
- **Male Breast Cancer:** It is the rarest form of cancer that occurs mostly in breast tissues of adult old aged men.
- **Multifocal:** Normal tumor cells multiply and it is non-invasive.
- **Multi-centric:** Tumor cells are grown in different areas in a breast.
- **Metastatic:** This tumor cell spreads to nearby surrounding tissues and invades the cells present in other body parts.

B. CAUSES*:*

- **A previous history of breast cancer:** A woman who has had breast cancer has an increased risk of getting breast cancer in the other breast.

- **Significant family history:** If several members of patient's family have had particular types of cancer, patient may have an increased risk of developing breast cancer.
- **Genetic causes:** Family history has long been known to be a risk factor for breast cancer. Both maternal and paternal relatives are important. The risk is highest if the affected relative developed breast cancer at a young age, had cancer in both breasts, or if she is a close relative. First-degree relatives, (mother, sister, daughter) are most important in estimating risk. Several second-degree relatives (grandmother, aunt) with breast cancer may also increase risk. Breast cancer in a male increases the risk for all his close female relatives. BRCA1 and BRCA2 are abnormal genes that, when inherited, markedly increase the risk of breast cancer to a lifetime risk estimated between 40 and 8S%. Women who have the BRCA1 gene tend to develop breast cancer at an early age. Some syndromes such as Wiskott-Aldrich and Beckwith-Wiedemann syndrome are known to alter the immune system. One theory suggests that the cells in the bone marrow, the stem cells, become damaged or defective, so when they reproduce to make more cells, they make abnormal cells or cancer cells. The cause of the defect in the stem cells could be related to an inherited genetic defect or exposure to a virus or toxin.
- **Hormonal causes:** Alteration in hormonal level may precipitate breast cancer. It could be attended by starting and stopping of periods (Menstrual Cycle), Pregnancy in early age, Hormonal replacement therapy, Use of oral pills etc.
- **Life style and dietary cause:** Sedentary life style, high dietary intake of fat obesity particularly in postmenopausal women may cause breast cancer. The use of alcohol is also another one cause of breast cancer. The risk increases with the amount of alcohol consumed. Women who consume two to five alcoholic beverages per day have a risk about one and a half times that of non-drinkers for the development of breast cancer.
- **Environmental cause:** There is known to be a slight increase in risk in ladies who work with low doses of radiation over a long period of time-for example, X-ray technicians.
- **Infections:** Epstein-Barr infection and HIV, the infection that causes Helps, have been connected to an expanded gamble of fostering tumours, like Hodgkin and non-Hodgkin lymphoma. Potentially, the infection modifies a cell somehow or another.

That cell then, at that point, recreates a modified cell and, ultimately, these modifications become a malignant growth cell that replicates more disease cells.

C. MANAGEMENT

Management of Breast cancer is multidisciplinary and has come a long way. In the past, the widely used treatment option was mastectomy followed by adjuvant chemotherapy for locally advanced Breast Cancer, triple-negative breast cancer and HER2neu expressing tumours (human epidermal growth factor receptor 2). At present, it includes a loco-regional approach (targeting only the tumour with the help of surgery and radiation therapy) and a systemic therapy approach that targets the entire body. The systemic therapy includes endocrine therapy for hormone receptor-positive disease, chemotherapy, anti-HER2 therapy for HER2 positive disease, bone stabilising agents, polymerase inhibitors for BRCA (breast cancer gene) mutation carriers and, recently, immunotherapy. However, the majority of patients still undergo primary ablative surgical procedures.

Gene expression profiling in hormone receptor-positive disease is also a promising option but has financial implications (Mehrotra & Yadav, 2022). Breast cancer is a histologic diagnosis made according to standardized pathologic criteria. The most common breast cancer histology is invasive ductal carcinoma (50%-75% of patients), followed by invasive lobular carcinoma (5%-15% of patients), with mixed ductal/ lobular carcinomas and other rarer histologies making up the remainder of patients (Harris, 2014).

Following approaches are to be made for the management of breast cancer (Sharma et al., 2010). They are as follows;

- **Surgery:** Depending on the stage and type of the tumor, lumpectomy (removal of the lump only), or surgical removal of the entire breast (mastectomy) is performed. Standard practice requires the surgeon to establish that the tissue removed in the operation has margins clear of cancer, indicating that the cancer has been completely excised. If the removed tissue does not have clear margins, further operations to remove more tissue may be necessary. This may sometimes require removal of part of the pectoralis major muscle, which is the main muscle of the anterior chest wall. More recently, the technique of sentinel lymph node (SLN) dissection has become popular, as it requires the removal of far fewer lymph nodes, resulting in fewer side effects. Advances in sentinel lymph node mapping over the past decade have increased the accuracy of detecting sentinel lymph node from 80% using blue dye alone to between 92% and 98% using combined modalities. Surgery for breast cancer consists of two main options.

In **breast-conserving surgery**, only the tumor and an area of normal tissue surrounding it are removed. Breast-conserving surgery includes the following:

- Lumpectomy: A small amount of surrounding normal tissue is removed. Wide excision: Also called as partial mastectomy in which somewhat larger amount of the surrounding normal tissue is removed
- Quadrantectomy: About one fourth of the breast is removed.

In **mastectomy**, all breast tissue is removed.

- **Radiation Therapy:** Radiation therapy involves using high-energy X-rays or gamma rays that target a tumor or post-surgery tumor site. These radiations are very effective in killing cancer cells that may remain after surgery or recur where the tumor was removed. In addition to this treatment implanted radioactive catheters (brachytherapy), similar to those used in prostate cancer treatment, can be used. However, this treatment option has been superseded by electron beam radiotherapy to the breast scar. Radiation therapy for breast cancer is usually performed after surgery and is an integral component of breast-conserving therapy. The dose of radiation must be strong enough to ensure the elimination of cancer cells. Treatments are typically given over a period of five to seven weeks, performed five days a week. Each treatment takes about 15 minutes.
- **Chemotherapy:** It is the use of anti-cancer drugs to treat cancerous cells. Specific treatment for the breast cancer will be based on; overall health, medical history, age (whether menstruation is there or not), type and stage of the cancer, tolerance for specific medications and procedures etc. Chemotherapy treatments are often given in cycles; a treatment for a period of time, followed by a recovery period, then another treatment. Chemotherapy can be given before surgery to shrink the tumor and sometimes make breast conserving surgery possible rather than a mastectomy. Many times, it is given after surgery and may be given every three weeks or every two weeks in a "dose dense" fashion.

- **Gene Therapy:** It is generally accepted that cancer arises because of an accumulation of multiple molecular genetic defects that culminate in a cellular phenotype characterized by unregulated growth. Based on the knowledge, a variety of gene therapy strategies have been developed as potential new therapies for cancer. Current knowledge of proto-oncogene and tumor suppresser genes in the genesis of malignancy has stimulated the development of gene therapy tactics directed at ablating or restoring such genes, respectively. In other strategies, cancer cells are endowed with the ability to convert a systemically delivered prodrug to a toxic metabolite, or a target for destruction by replicating viral vectors conversely transfer of drug resistance genes into normal cells may provide chemoprotection during high dose antineoplastic treatment. Finally, immune system modulation can activate anticancer drug defence mechanisms.
- **Oncogenes Inactivation:** Several oncogenic proteins have been identified and associated with various malignancies. The most commonly applied approach in clinical trials to date has been use of antisense strategies. Transcription of oncogenes also can be inhibited by using adenoviral gene E1A, which interfere with the transcription of erbB-2, a strategy useful in treating cancer that over express this oncogenic protein, such as breast and ovarian cancer.
- **Cell-Target Suicide:** A conversion of a pro drug to a toxic metabolite by genetically engineering tumor cells is an attractive way to create an artificial difference between normal and neoplastic tissue. This can be achieved by the expression of a gene that confers a dominant, negatively selectable phenotype to the cancer cells, such as cell death imparted by expression of a prodrug – metabolism enzyme. Greater selectively in killing malignant cells will be obtained by transferring a gene that is not normally found inhuman beings (e.g., HSV--thymidine kinase), rather then by overexpression an endogenous gene. The prototype for this approach utilizes the HSV-1 Thymidine kinase gene given to combination with produg ganciclovir in a manner distant from mammalian thymidine kinase. Phosphorylated ganciclovir is ultimately incorporated into DNA and inhibits DNA synthesis and transcription.
- **Immunomodulation:** Various cytokines can enhance immunity against cancer cells, and this observation has stimulated the development of gene- based approaches to modulate the immune reaction in malignancy.

- **Ectopic Cytokine Expression:** A variety of cytokine have been shown to decrease tumor growth when ectopically expressed in tumor cells or in their microenvironment. Some immunostimulatory agents do not alter the growth rate of the tumor initially, but lead to immunity against tumor growth if the animal is later challenged with wild type tumor cells.
- **Immune enhancement**: One such approach is to express on the surface of cancer cells highly immunogenic molecule, such as allotype MHC antigens. It has been long known those additional "costimulatory" pathways distinct from the T-cell are needed to achieve T cell activation. The molecules B7-1 (CD 80) and B7-2 (CD 86) stimulate one such pathway. The B7s, whose expression normally is limited to antigen presenting cells and other specialized immune effector cells, engage specific receptors on the T cells surface in concert with antigen binding to the T-cell receptor.

D. CHALLENGES FACED BY PERSONS WITH BREAST CANCER

A cancer diagnosis can influence the emotional health of patients, families, and caregivers. Normal sentiments during this life changing experience incorporate tension, trouble, and despondency. Jobs at home, school, and work can be impacted (American Cancer Society, 2011). The rate of survival of breast cancer patients has been significantly enhanced with improvements and availability of therapy. However, women with breast cancer who have undergone chemotherapy, radiotherapy, biotherapy or hormonal therapy, surgery, and reconstructive surgery may face numerous psychosocial and physical issues and as well as a compromised overall quality of life (Sapkota et al., 2016). After the initial treatment and the adjuvant therapy, most of the women encounter weight gain, musculoskeletal pain, hot flashes, nausea, and itching around the genital area. The sexual desire of breast cancer survivors is also highly affected after therapy and may experience fatigue, loss of nipple sensitivity, vaginal dryness, and scarring (Chang et al., 2016). Psychological problems such as sadness, anxiety, and depression owing to therapy, recurrence, and bodily disfigurement stay constant after diagnosis and cure. Some of the significant psychological issues include:

- Anxiety about relapse: Numerous survivors stress that their disease will return eventually.

- Misery/Grief is a characteristic consequence of misfortune. Misfortune can incorporate one’s wellbeing, sex drive, fruitfulness and actual autonomy.
- Depression: It is assessed that 70% of disease survivors experience discouragement sooner or later.
- Self-perception: Cancer survivors who have encountered removals, deformation or a significant change in actual capability can experience the ill effects of an absence of confidence. A negative self-perception can influence one’s longing for closeness and social cooperation (American Cancer Society, 2011).

Besides, the lack of support and communication from their partners, family, and friends reduced their social integration. Survivors of breast cancer are also at high risk of secondary health issues such as cardiovascular disease, cessation of the menstrual cycle, and poor bone health (osteoporosis). Other common issues are low physical activity and poor dietary habits, which are associated with recurrence of breast cancer. The majority of breast cancer survivors are unable to re-join their respective occupations due to their inability to work. This is associated with a high financial burden because the resources to pay consultation fees, medical bills, and medications become limited, therefore they show poorer medication adherence (Altice et al., 2016). As the survival rate of breast cancer is increasing, the long-term social, physical, and psychological issues are also becoming very common among them.

1.2.3 CAREGIVERS

The term ‘caregiving’ is simply derived from the two separate words connotes the act of giving out care or extending care to an external body. Caregiving can simply be defined as the process or act of rendering care services to other people, who as a result of illness or disorder, have a deficit in or have lost the independent capabilities of carrying out certain fundamental activities on their own. The caregiver is the active person who renders the care to the passive care recipient who is on the receiving end. It is usually an ongoing process, which involves execution of duties and routines by somebody who has taken the sole responsibility of ensuring the fundamental activities of the individual in need of care (Schulz & Patterson, 2004).

A. TYPES OF CAREGIVING

The act of caregiving can be categorized into two major types based on the source of care being rendered (Schulz & Patterson, 2004):

- **Informal caregiving:** Informal caregiving signifies a form of caregiving that is less structured and in which the caregivers are not paid for the services rendered. Often, informal caregiving occurs in a family setting involving parents, grandparents, siblings, children, cousins, spouses, in-laws, and other relatives. In some cases, it could involve friends, neighbours, and good Samaritans.
- Informal caregiving can be categorized into primary caregiving and secondary caregiving. In primary caregiving, the primary caregiver lives with the individual in need of the care and substitutes for the deficient activities or tasks such as bathing and feeding. They bear most of the recipient's burden of care in terms of emotional, financial and physical support. In secondary caregiving, on the other hand, the secondary caregiver usually does not live with the care receiver but gives support and assistance in form of finances, visits, and transportation to and from the hospital.
- **Formal caregiving**: As the name implies, formal caregiving is a planned and structured form of caregiving where the caregivers are employed and get paid for the services they render. These caregivers are mostly professionals such as nurses, doctors and other professional health workers who are trained to carry out services. Depending on the severity and specialty of the illness, formal caregivers are usually in demand alongside informal caregivers for home care services.

B. CAREGIVERS OF PERSONS WITH CANCER

Cancer is a chronic illness that leads to profound and long-lasting physical, social, emotional, and spiritual changes in those diagnosed with it (Kim & Yi, 2015). Advances in cancer treatment and current trends toward outpatient cancer treatment enables care to be implemented in the home setting, and the engagement of family members to assume important roles as caregivers (Rha et al., 2015). The disease also affects the caregivers who play a pivotal role in the health care requirements of patients with cancer, starting from the process of diagnosis to follow-up.

The roles of caregivers have diversified and include many responsibilities, including the management of infusion pumps or intravenous lines at home in an attempt to reduce the length of the hospital stay of patients with cancer (Papastavrou ey.al., 2009). Family caregivers (FCs), who are major but unpaid care partners, are affected most by meeting multi-dimensional needs of cancer patients. They play a pivotal role in monitoring treatment, managing treatment-related symptoms, and providing emotional, social, and spiritual support to their family member with cancer (Kim & Yi, 2015). Caring for a loved one with cancer is associated with both positive and negative psychological well-being (Ekwall & Hallberg, 2007).

Caregivers who are in strong relationships with ample support may find that their relationship grows stronger through the intimacy of caregiving, while those for whom the relationship is more complicated and who lack adequate support for the intensity of this role may experience significant caregiver burden (Chen et al., 2009). Increased caregiver burden increases the risk for depression and anxiety. Cancer caregivers bear the burden of care, which affects their health and well-being, but their persistent efforts despite numerous issues play a vital role in improving the patients' outcomes and quality of life. While cancer caregiving is a meaningful experience, it is also associated with deteriorating quality of life (QOL), greater psychiatric sequelae, and increased risk of mortality for the caregiver (Lim et al., 2017).

1.3 STATEMENT OF THE PROBLEM

In 2020, there were 2.3 million women diagnosed with breast cancer and 685 000 deaths globally. As of the end of 2020, there were 7.8 million women alive who were diagnosed with breast cancer in the past 5 years, making it the world’s most prevalent cancer. There are more lost disability-adjusted life years (DALYs) by women to breast cancer globally than any other type of cancer. Breast cancer occurs in every country of the world in women at any age after puberty but with increasing rates in later life (World cancer report, 2020).

Both globally and on the Indian scene, breast scene is dismal with more than 20% increase in breast cancer since 2008 with 1.7 million new cases diagnosed in women in 2012; and there were 6.3 million women alive with breast cancer in the previous five years. Breast cancer is also the most common cause of cancer deaths among women (521,817 deaths in 2012) and the most frequently diagnosed cancer among women in 140 of 184 countries worldwide. It now represents one in four of all cancers in women. For the first time, breast cancer is the leading cancer in Indian women and cause of cancer death, surpassing cervix uteri cancer, despite cervical cancer considered more common in rural India, and almost 80–85% of India is rural India (Saranath & Khanna, 2014).

Cancer mortality in India has doubled from 1990 to 2016. India’s cancer incidence is estimated at 1.15 million new patients in 2018 and is predicted to almost double as a result of demographic changes alone by 2040 (Dhillon et al., 2018). Cancer is the second and fourth leading cause of adult death in urban and rural India, respectively (Banthia, 2004). According to a report by the Indian Council for Medical Research on the ‘Burden of cancers in India’, seven cancers accounted for more than 40% of the total disease burden: lung (10.6%), breast (10.5%), oesophagus (5.8%), mouth (5.7%), stomach (5.2%), liver (4.6%) and cervix uteri (4.3%).

As breast cancer incidences have been increasing on a higher trend all over the world and specifically in Kerala, we also see an increase in number of family members stepping into the role of caregivers. It is known that long term caregiving has significant impact on the physical, psychological and economic aspects of the individuals for which they may employ various coping strategies. Hence, this study aims to understand the challenges faced by the caregivers and the coping strategies used by them in order to understand the social work implications in this context.

1.4 SIGNIFICANCE OF THE STUDY

Studies show that the number of cancer cases, both globally and in India are rising at an alarming rate. With the increase in the number of cancer patients, the number of person’s taking care of them also rises. The people with cancer experience various challenges from the time symptoms appear and even after the treatment is over. Throughout this journey they need the support of others, especially their family members to help them navigate through life. These family members often times, step into the role of the ‘primary caregiver’. Studies show that caregivers experience many challenges as part of their role as the caregiver. As per the Global cancer data 2020, in India, Breast Cancer accounted for 13.5% of all cancer cases and 10.6% of all deaths. The survival rate of patients with breast cancer is poor in India as compared to Western countries due to earlier age at onset, late stage of disease at presentation, delayed initiation of definitive management and inadequate/fragmented treatment as nearly

60% of Breast cancer cases are diagnosed at stage III or IV of the disease (Mehrotra & Yadav, 2022).

This study specifically focuses on the challenges faced by the caregivers of persons with breast cancer as it has one of the highest rates of prevalence among all cancers in Kerala. This would help in designing appropriate interventions for them.

Caregivers have been described as hidden patients who also need attention so as to be protected from both physical and emotional harm. Interventions to reduce burden are important in directly curtailing care-giver distress and promoting overall wellbeing whilst the care recipient also benefits secondarily from such interventions (Wright et al., 2008). This study also tries to understand the caregiver’s coping mechanisms. The findings of this would help not only to design interventions for caregivers but also understand the different ways in which people cope with their issues and to determine which of the strategies could be modelled. This study would also facilitate further research in this area and contribute to the subject matter of social work.

1.5 CHAPTERIZATION:

The coming chapters will be dealing about:
Chapter I: Introduction
Chapter II: Literature Review
Chapter III: Methodology
Chapter IV: Case Description/ Narratives
Chapter V: Thematic Analysis and Interpretations.
Chapter VI: Findings, Suggestions and Conclusions
Bibliography
Annexure

CHAPTER II: REVIEW OF LITERATURE

REVIEW OF LITERATURE

2.1. OVERVIEW

Review of the literature is an essential part of academic research. The review is a careful examination of a body of literature pointing toward answer to the research question. It includes scholarly journals, scholarly books, authoritative databases etc. It is a crucial aspect of the planning of a study. It provides an overview of historical perspective, development, deviations and new departure of research in that area and guides to identify the methods appropriate to the present problem under investigation.

To give a theoretical background this study has reviewed various journal articles and books based on different themes/areas. The studies conducted in the areas are evaluated, at the end of the chapter in order to identify the gaps in the literature.

2.2 THEMES

The following themes are discussed in this chapter:

- 2.2.1: Prevalence of breast cancer
- 2.2.2: Challenges faced by the persons with breast cancer
- 2.2.3: Challenges faced by Caregivers of persons with cancer
- 2.2.4: Challenges faced by Caregivers of persons with breast cancer
- 2.2.5 Coping strategies used by patients with breast cancer
- 2.2.6: Coping strategies of caregivers of persons with cancer

2.2.1. PREVALENCE OF BREAST CANCER:

Ghoncheh et al., (2016) conducted a study to understand the Incidence and Mortality and Epidemiology of Breast Cancer in the World. This study aimed to investigate the incidence and mortality of breast cancer in the world using age-specific incidence and mortality rates for the year 2012 acquired from the global cancer project (GLOBOCAN 2012) as well as data about incidence and mortality of the cancer based on national reports. It was estimated that 1,671,149 new cases of breast cancer were identified and 521,907 cases of deaths due to breast cancer occurred in the world in 2012. According to GLOBOCAN, it is the most common cancer in women, accounting for 25.1% of all cancers. Breast cancer incidence in developed countries is higher, while relative mortality is greatest in less developed countries.

In a study conducted on the “Epidemiology of breast cancer in Indian women”, it was found that the age adjusted incidence rate of carcinoma of the breast in India, was found as high as 41 per 100,000 women for Delhi, followed by Chennai (37.9), Bangalore (34.4) and Thiruvananthapuram District (33.7). A statistically significant increase in age adjusted rate over time (1982–2014) in all the PBCRs namely Bangalore (annual percentage change: 2.84%), Barshi (1.87%), Bhopal (2.00%), Chennai (2.44%), Delhi (1.44%) and Mumbai (1.42%) was observed. Mortality-to-incidence ratio was found to be as high as 66 in rural registries whereas as low as 8 in urban registries. Besides this young age has been found as a major risk factor for breast cancer in Indian women. Breast cancer projection for India during time periods 2020 suggests the number to go as high as 1797900 (Malvia et al., 2017).

In a study titled “Epidemiology of Breast Cancer in India” the findings indicate that among females the most common site of cancer is the cervix, with the second most common site being the breast. Among the females suffering from cancer, the cervix was affected in 40%, whereas the breast was affected in 18%. The most common histologic type of breast cancer was the infiltrating duct carcinoma. The relative frequencies of cancer of the breast and cervix varied widely among different religious communities of Western India. In Hindu women, the breast was affected in 13% and the cervix in 48%. In the Parsee women the breast was affected in 49% and the cervix in only 11%. The socioeconomic and demographic characteristics of the community differed greatly. The observed differences in the incidence of breast cancer are believed due to certain unknown factors and also to habits and customs prevalent in the community (Paymaster & Gangadharan, 1972).

Asthana et al., (2014) conducted a study titled “Breast and Cervical Cancer Risk in India An Update” with the objective to compute risk of breast and cervical cancers using updated data from different cancer registries of India and study of its trends. Data on incidence rates of breast and cervical cancers were obtained from six major cancer registries of India for the years 1982-2008 and from the recently initiated cancer registries, North Eastern Registries of India with a total of 21 registries. Annual percent change in incidence and risk in terms of one in number of women likely to develop cancer was estimated for both the cancers in various registries. The findings indicate that annual percentage change in incidence ranged from 0.46 to 2.56 and −1.14 to −3.4 for breast and cervical cancers respectively. Trends were significant for both cancers in the registries of Chennai, Bangalore, Mumbai and Delhi except Barshi and Bhopal. North East region showed decrease in risk for breast and cervical cancers whereas increasing trend was observed in Imphal (West) and for cervical cancer in Silchar.

In the study titled “Incidence and pattern of distribution of cancer in India; A secondary data analysis from six population-based cancer registries”, conducted by Shetty et al., (2020) conducted with the aim to analyze the Indian National Cancer Registry report of 2020 to determine whether there has been a change in the trend of cancer incidence, it was found that lung and oral cancers were found to be the leading cancer types among men, and breast and cervix uteri cancers among women. The mean relative proportions showed that oral, breast, and cervical cancers still constitute the major bulk of this disease in India. For this study, six population-based cancer registries (PBCR) with the highest number of patients were selected from each zone of the country. From these, a total of 1,87,891 patients were included in the study to ensure a pan-India representation. The relative proportion of oral, breast, cervical, lung, ovarian, endometrial, and prostate cancers was determined from these PBCRs. The mean of these values for each of these cancer types from the six PBCRs was considered the mean proportion of these cancer types across the country.

Mathew, A., Sara George, P., M C, K., G, P., K M, J. K., & Sebastian, P. (2017). conducted a study titled, “Cancer Incidence and Mortality: District Cancer Registry, Trivandrum, South India” where people residing for a minimum period of 1 year in Trivandrum were considered as residents. The major sources for cancer incidence were the RCC, the physical location of the registry, and the Government Medical College Hospital, Trivandrum. The medical records from nearly 75 potential data sources (hospitals and diagnostic laboratories) were reviewed at regular intervals to data on incident cancer cases. The study found out that Total cancer incidence (CRs) rates were 161 and 154 (ASR: 142.2 and 126) and mortality rates were 66 and 49 (ASR: 54 and 37) per 105 males and females respectively. Common cancers in males were lung (ASR: 19), oral cavity (ASR: 15), colo-rectum (ASR: 11.2), prostate (ASR: 10.2) and lymphoma (ASR: 7) and in females, breast (ASR: 36), thyroid (ASR: 13.4), cervix-uteri (ASR: 7.3), ovary (ASR: 7) and colo-rectum (ASR: 7). Nationally, the highest CRs for breast, prostate, colo-rectum, corpus-uteri and urinary bladder cancers and low incidence of cervix-uteri cancer were observed in Trivandrum.

2.2.2 CHALLENGES FACED BY THE PERSONS WITH BREAST CANCER

Forbair et al., (2006) studied, Body image and sexual problems in young women with breast cancer. The purpose of this study was to determine the frequency of body image and sexual problems in the first months after treatment among women diagnosed with breast cancer at age 50 or younger. A multi-ethnic population-based sample of 549 women aged 22–50 who were married or in a stable unmarried relationship were interviewed within seven months of diagnosis with *in situ,* local, or regional breast cancer. The findings of the study shows that Body image and sexual problems were experienced by a substantial proportion of women in the early months after diagnosis. Half of the 546 women experienced two or more body image problems some of the time (33%), or at least one problem much of the time (17%). Among sexually active women, greater body image problems were associated with mastectomy and possible reconstruction, hair loss from chemotherapy, concern with weight gain or loss, poorer mental health, lower self-esteem, and partner's difficulty understanding one's feelings. Among the 360 sexually active women, half (52%) reported having a little problem in two or more areas of sexual functioning (24%), or a definite or serious problem in at least one area (28%). Greater sexual problems were associated with vaginal dryness, poorer mental health, being married, partner's difficulty understanding one's feelings, and more body image problems, and there were significant ethnic differences in reported severity.

In the study titled “Concern about aspects of body image and adjustment to early-stage breast cancer” Carver et al., (1998) found that the Concern about body integrity did not strongly predict emotional distress, but it related to adverse impact on social and recreational activities in the follow-up period, to deterioration in feelings of sexual desirability, and to feelings of alienation from the self (feeling "not like yourself anymore").

Daniel et al. (2020) The study’s goal was to investigate the psychological distresses experienced by Indian women with breast cancer in Kerala, South India, before and after treatment, and to better understand what contributed to reduce or exacerbate these distresses. The data revealed three significant trends. The key issue was extensive psychological suffering. This includes feelings of worry, guilt, rage, and melancholy in response to the disease and physical side effects of therapy, as well as concerns with body image, particularly hair loss and sexuality.

Baucom et al., (2006) in their study Psychosocial Issues Confronting Young Women with Breast Cancer found that younger women with breast cancer experience a lower quality of life after cancer compared to older women. In part, this lower quality of life results from the effects of medical treatment. The effects of surgery and removal of the breast result in more negative feelings regarding body image, particularly for young women. With systemic treatment, many younger women experience the sudden onset of menopause, with the attendant symptoms of hot flashes, decreased sexual desire, and vaginal dryness. These physical effects along with a variety of relationship issues contribute to a high level of sexual concerns for young women. From a psychosocial perspective, breast cancer affects both females and their male partners. Both partners experience psychological distress including depression and anxiety.

Ganz et al., (1996) studied “Breast cancer survivors: psychosocial concerns and quality of life”. The aim of the study was to describe the psychosocial concerns and quality of life of breast cancer survivors evaluated 2 and 3 years after primary treatment. A sample of 139 breast cancer survivors who had been interviewed during the first year after primary treatment participated in a mailed survey at 2 years (N = 69) and 3 years (N = 70) after initial surgery. A random sample of these survivors were also interviewed in person. The mailed questionnaire included standardized instruments to assess quality of life (QOL), rehabilitation needs, and psychological distress. Additional survey questions were developed to examine post-surgical recovery, employment and insurance problems, social support, and existential concerns. The in-person interviews expanded on these questions and systematically compared these patients' rehabilitation needs to those which existed at the time of an interview 1 year after surgery. The findings show that the breast cancer survivors demonstrated higher levels of functioning in many dimensions (role functioning, social functioning, pain, and general health) than the patients with chronic medical conditions. In spite of relatively good physical and emotional functioning on this generic measure of health status and quality of life, these breast cancer survivors reported a number of important and severe rehabilitation problems that persisted beyond one year after primary treatment.

Especially frequent were problems associated with physical and recreational activities, body image, sexual interest, sexual function, and problems with dating for those who were single.

The findings of the study titled “Depression and body image following mastectomy and lumpectomy”, conducted by Lasry et al., (1987) showed that the total mastectomy patients showed higher levels of depression and less satisfaction with body image. Partial mastectomy patients did not display any measurable increase in fear of recurrence. Patients undergoing radiation therapy showed surprising increase in depressive symptoms.

2.2.3 CHALLENGES FACED BY CAREGIVERS OF PERSONS WITH CANCER

Mor, V., Masterson-Allen, S., Houts, P. & Siegel, K. (1992) in their study titled, “The changing needs of cancer patients at home: a longitudinal view”, examined the psychosocial impact of cancer on patient’s primary caregiver. Data was collected through telephonic interview, which contained a broad array of measures of functional health, mood state, health and social service use and social support from family as well as friends. Level of emotional distress was found to be relatively constant across age groups. Younger caregivers (younger than 65 years) reported more disruption compared with approximately half of the older caregivers (older than 65 years). Majority of caregivers reported reduced socialization with friends, neighbours and acquaintances as a result of the patient’s illness regardless of age.

Ferrell.B., Grant.M., Borneman.T., Juarez.G.,Veer.A., (2005), in their study “Family Caregiving in Cancer Pain Management” aimed to describe the experience of pain management from the perspective of family caregivers of patients with cancer amidst the current healthcare environment. The investigation reveals disruption to family caregiver quality of life in the areas of physical, psychological, social, and spiritual well-being. There is a continued need for education regarding cancer pain management. Comparison between patients and family caregivers demonstrated that pain impacts both the patient experiencing it and their caregivers.

Osse, B. H., Vernooij-Dassen, M. J., Schad, E., & Grol, R. P. (2006). Conducted a study on the topic “Problems Experienced by the Informal Caregivers of Cancer Patients and

Their Needs for Support”. This study explored caregivers' problems and their needs for professional support. Seventy-six caregivers of cancer patients with advanced disease were given a comprehensive needs assessment questionnaire, the Problems and Needs in Palliative Care questionnaire-caregiver form, listing 67 potential problems in their quality of life and their role of caregiver and 9 items concerning informational needs. The results of this study reveal that the "Top 20" list of the problems and needs reported by caregivers includes fears and emotional burdens; for the most part, caregivers did not need any more professional attention than they were already receiving. Many, however, needed support for managing patients' symptoms and wanted professional attention for the availability and coordination of services.

Kulkarni, S. S., Patil, C., Anap, Y. S., Tanawade, P. K., Watve, P. J., & Pawar, A. S. (2021). in their study “Quality of Life of Primary Caregivers Attending a Rural Cancer Centre in Western Maharashtra: A Cross-Sectional Study” aimed to understand the Caregiver QOL Index—Cancer (CQOL-C) score of the primary caregivers and to find the significant predictors affecting CQOL-C. this cross-sectional study was conducted among the caregivers attending a rural cancer center in western Maharashtra. A pretested and predesigned questionnaire using the CQOL-C scale was used to interview the caregivers from December 2019 to June 2020. The data using Statistical Package of Social Sciences (SPSS) software. Univariate analysis was done using Student’s t-test and a multivariate model was generated using linear regression analysis of the data. The findings show that, the mean total CQOL-C score was 44.15 ± 17.24 (confidence interval [CI]: 41–47.3). About 71% of the caregivers reported moderate-to-severe hampering of their QOL. The mean CQOL-C scores in caregivers of patients with and without recurrent cancer were 58.24 (CI: 51.66–64.81) and 40.58 (CI: 37.35–43.80), respectively ($p < 0.001$). The mean CQOL-C scores in caregivers of patients with and without metastatic cancer were 56.68 (CI: 51. 13–62.22) and 39.80 (CI: 36.45–43.14), respectively ($p < 0.001$). The mean CQOL-C score in caregivers of patients with hematological malignancies was 60.03 (CI: 58.88–61.17) which was significantly higher compared with other sites ($p = 0.0257$). The majority of the caregivers in this study have moderate-to-severe detrimental QOL.

Morgan, M. A., Small, B. J., Donovan, K. A., Overcash, J., & McMillan, S. (2011) conducted a study titled “Cancer patients with pain: the spouse/partner relationship and quality of life” which explained that receiving a diagnosis of cancer has a profound impact not only on patients, but also families. A spouse/partner is particularly affected not only because of fear and uncertainty of a life-threatening illness1, but also, they must manage changes in role, pain, and financial threats in treatment costs and lost earnings. These changes can have a profound effect on quality of life for both parties and research has shown that patients' and partners' psychological adjustments are interrelated.2 A partner's adjustment to the patient's diagnosis of cancer is a critical component of how the patient adjusts to the disease.

Braun, M., Mikulincer, M., Rydall, A., Walsh, A., & Rodin, G. (2007) in "Hidden morbidity in cancer: spouse caregivers" said that spouse caregivers of cancer patients have been found to be adversely affected by the illness in physical and psychological areas. Their emotional distress may be as high as or even higher than that of the patients themselves. Caring for spouse caregivers may be important not only to relieve their distress but also because this may have positive effects for their ill spouses. With regard to the latter, spousal support has been found to buffer against patients' distress.

Ajith, Karthik; Sarkar, Sonali,; Sethuramachandran, Adinarayanan; Manghat, Sreeja; Surendran, Gayathri. (2023) in the article "Myths, beliefs, and attitude toward cancer among the family caregivers of cancer patients: A community-based, mixed-method study in rural Tamil Nadu" explained that Caregivers' beliefs and attitudes about cancer treatment can affect the outcome. Patients had sought care from alternative medicine before resorting to allopathy medicine. Even though they believed in modern medicine, they followed religious worships also. They believed that visiting religious institutions and giving offerings to God can cure the cancer. Family members' support was believed to be important for cancer patients. Majority of the participants had favourable attitude toward the cancer patients. however, some considered caring for a patient as burden in terms of time, energy and money.

Jasbir Bisht, Priyanka Rawat, Ujala Sehar, & P. Hemachandra Reddy (2023). Caregivers with Cancer Patients: Focus on Hispanics. The lives of patients and their families become even more unsettled when the patient has a progressive illness, terrible symptoms, or an uncertain survival possibility. Huiwen and colleagues' study also found rural–urban disparities in caregivers of older adults with advanced cancer. Caregivers are at risk of caregiving burden, specifically those from rural areas and with a lower education. Serge Dumont and colleagues' study found that family caregivers of patients in the advanced stages of cancer live through a high level of psychological distress, which grows significantly as the patient loses autonomy. In addition, a high distress index was considerably linked to the caregiver's burden, the patient's young age, the patient's indications, the caregiver's young age and gender, a poor perception of their health, and disappointment with emotional and tangible support.

Khan, M. Z., Qamar, N., Ahmad, S., & Siddique, A. (2021). Impact of Cancer on Quality of Life & Depression among Caregivers. According to the study there was a significant association between the time from the diagnosis of cancer and the Quality of Life (QoL) of spouse as those spouses who cared for patients who had cancer for a longer time had more negative effects on their QoL. Cross tabulation done between caregivers' QoL one year ago and current QoL status of caregiver showed that there was a significant decline in the QoL of the caregivers.

Muhammad Noman Khan Wazir., Sara Abbas., Susan Saadat Kakakhel., Haseeba Mukhtar., Nowsher Yusuf & Fakhria Wahid (2021), in a study "The Psychological Impact of Cancer on Caregivers, A Review." aimed to quantifiably measure the stress faced by the caregivers and its association with the diagnosis/prognosis of the different cancer types and find out opportunities for helping the caregivers cope better in their difficult time. It used a Qualitative research design with a sample size of 160 and made use of Chi square and one-way ANOVA tests which were carried out on Statistical Product and Service Solutions (SPSS) software. The results showed a much higher level of anxiety/stress reported by the caregivers studied, compared to the general norm. Keeping a life-threatening diagnosis, a secret from the patient and avoiding discussions of disease progression further add to a caregiver's sense of burden, isolation, and responsibility. Higher scores of stress in the female sample and in the uneducated groups were also found.

Reddy & Anitha, (2015) in their study "An exploratory study of psychological factors affecting quality of life of caregivers in palliative care cancer patients." studied the relationship between Quality of life and select psychological correlates of caregivers of cancer patients in palliative care, demographic variables and its effect on Quality of life of caregivers of cancer patients in palliative care. It used Between Group design with a sample Size of 160 with the samples collected using purposive Sampling. The caregivers caring for 6 types of cancer patients namely, Lung cancer, Oesophageal cancer, Gastrointestinal cancer, Breast cancer, Lymphoma and Cervical cancer were taken for the study. The study found out that there was an escalation in caregiver's anxiety, depression, and psychological distress as the patient's functional status declined and the patient slips to palliation or nears death. Higher level of caregiver's experience of stress significantly impacted their quality of life and this affected their role as caregivers. Caregivers of patients with higher level of symptom distress showed negative impact on their health and high level of burden thus affecting their quality of life.

Fujinami, R., Otis-Green, S., Klein, L., Sidhu, R., & Ferrell, B. (2012) conducted a study titled "Quality of Life of Family Caregivers and Challenges Faced in Caring for Patients with Lung Cancer" attempted to understand the changes in Quality of life of caregivers of patients with lung cancer and enable palliative care intervention delivered by advanced practice nurses for patients and families living with NSCLC. (Non-small cell lung cancer). It made use of two composite caregiver case studies were selected from a National Cancer Institute (NCI)–funded program project to provide perspective of the complex issues faced by FCGs (Family Care Givers) caring for patients with NSCLC. The study found out that one of the caregivers did not share his concerns with his wife which contributed to a sense of isolation and loneliness for them both. Also, the QOL of the patient with lung cancer and the QOL of the FCG affected each other.

The study, "Challenges encountered by family caregivers of prostate cancer patients in Cape Coast, Ghana: a descriptive phenomenological study" by Owoo, B., Ninnoni, J. P., Ampofo, E. A., & Seidu, A. A. (2022). was a qualitative study based on descriptive phenomenology, involving a purposive sampling of family members considered family caregivers by the patient. The caregivers were involved in care for more than 8 hours a day and were aged above 18. Data collection was done using a pretested in-depth interview guide to conduct face-to-face interviews (one on one) of twelve participants. The study disclosed that the majority of the participants expressed many misconceptions about the condition. Some participants reported that cancer might be contracted due to immoral behaviour or punishment from God, which is consistent with the finding of a study by Kuan Lee Wai. Such beliefs resulted in fear/ panic and further decreased the support network. Lack of effective communication between healthcare personnel and family caregivers was an important issue, mainly because it could lead to errors and poor patient outcomes. Lack of preparedness for caregiving was a significant concern among all the participants. It was also found that family caregivers often felt unprepared to provide care, and had inadequate knowledge to deliver proper maintenance, and received little guidance from the formal health care providers.

“Burden of caregiving: A study of caregivers of adult cancer patients” (Bhardwaj, 2010) aimed to demographic characteristics of the patients with cancer and their caregivers, develop a burden assessment scale to empirically measure the burden of caregiving, examine the quality of life of the patients with cancer, the nature of caregiving burden on the primary caregivers of cancer patients, coping mechanisms adopted by the caregivers and to suggest social work intervention strategies to help families to effectively manage the burden of caregiving. The study was a quantitative study which used non-probability sampling method (purposive sampling), with a sample size of 100 patient-caregiver dyads. It was found that in majority of cases, caregivers had negative feelings after hearing about the diagnosis. They were worried, depressed, irritated, insecure, and wondered why it happened to their family member. A few of the patients and caregivers also experienced positive change in their life – they turned more religious, more patient and had lesser temper tantrums.

The study “Effect of Cancer Patients’ Activity Level and Psychosocial Factors on Caregivers’ Quality of Life” by Padmaja & Vanlalhruaii, (2018) intended to assess the level of psychological states and perception of the interpersonal relationship among cancer patients (BC & HNC) and their family caregivers and assess the quality of life of family caregivers, find out the differences in the levels of psychological states, interpersonal relationship, and quality of life among caregivers, categorized on the basis of patients’ activity levels, find out indicators of family caregivers’ quality of life, understand agreement or disagreement in perception of the interpersonal relationship between cancer patients (BC & HNC) and their family caregivers as well as to categorize family caregivers of cancer patients based on their levels of QOL and to examine the differences in indicators of their quality of life. The study used Quantitative method using 270 pairs (248 finally selected pairs) of patients with Breast Cancer (BC), Head and Neck Cancer (HNC) and their family caregivers. It was observed that the mean scores of patients on all four of the psychological states that is distress, depression, anxiety, and somatization were higher than that of their family caregivers. Also, on all the components involved in the interpersonal relationship between patients and caregivers such as mutual communication, mutual relationship, availability and providing comfort, attention and support, and mutual care, reciprocation may not be practically possible. As a result, while patients perceived the above components and perceived better interpersonal relationship, family caregivers did not perceive the same to the same extent.

2.2.4 CHALLENGES FACED BY CAREGIVERS OF PERSONS WITH BREAST CANCER

Coristine, M., Crooks, D., Grunfeld, E. & Stonebridge, C. (2003) conducted a study titled, “Caregiving for women with advanced breast cancer”, aimed to describe the psychosocial impact on caregivers of women with advanced breast cancer. Data was collected through five focus group discussions held with bereaved caregivers i.e., spouse caregivers and non-spouse caregivers who were either close friends or relatives. Non-spouse caregivers experienced much burden compared to spouse caregivers as they were not able to negotiate the care-related roles with patient and struggled to satisfy the wishes of the patient.

Grunfeld, E., Coyle, D., Whelan, T., Clinch, J., Reyno, L., Earle, C. C. et al. (2004), the researchers in their study titled, “Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers”, examined the psychosocial, occupational and economic impact of caring for a person with terminal illness. The researchers studied the 89 caregivers of women with advanced breast cancer using standardized instruments of anxiety, depression and burden. Findings reported that over half of the caregivers (52%) were patient’s spouse or partner. Caregivers were more anxious, depressed than the patients and had higher level of burden. Sixty nine percent (69%) of employed caregivers reported some form of adverse impact on work like missing work because of caregiving responsibilities. The finding suggested that caregivers’ depression and perceived burden increased with decline in patients’ functional status.

Zahlis, E. H., & Lewis, F. M. (2010). “Coming to grips with breast cancer: the spouse's experience with his wife's first six months”. Spouses viewed the breast cancer diagnosis as unexpected, sudden, and emotionally overwhelming. They felt helpless to save themselves or their wives from what was happening. Every aspect of their daily lives and function was impacted, including job performance and social times with friends. They struggled to understand why such a thing would happen. Spouses described themselves as not being able to take on more than they were already doing, physically, or emotionally. They were exhausted from caring for her, taking care of the family, experiencing pressure from others to do things differently, going to work, and lacking sleep from being up with their wife during the night. The breast cancer altered the couple’s relationship. For some spouses, the experience brought them closer together and they approached the breast cancer as a team. For other spouses, and at other times, the breast cancer challenged their relationship as a couple in new ways and created friction between them. The breast cancer also altered and challenged their parenting.

Fletcher, K. A., Lewis, F. M., & Haberman, M. R. (2010) conducted a study “Cancer-related concerns of spouses of women with breast cancer” according to which spouses attribute specific illness-related demands to the early diagnosis and treatment period of their wives' non-metastatic breast cancer. During the first seven months, spouses are concerned about their wives' well-being, the potential success or non-success of medical treatment, and what to do to support and protect her from the stressors from breast cancer and treatment. Spouses fear for their own future, their children's future, and they fear cancer recurrence and progression, even during active treatment for the disease.

Tao, L., Hu, X., Chen, H., Xiao, S., & Zhang, X. (2022) conducted a study “Factors influencing the burden on spousal caregivers of breast cancer survivors” which found that spousal caregivers experienced a high degree of burden, higher than it was recorded in studies conducted in Eastern China, possibly due to differences in regional economic status. As hypothesized, it was found that higher individual resilience, family resilience, and social support might reduce spousal caregivers’ burdens. The relationship between family resilience and caregiver burden was partially mediated by breast cancer survivors’ individual resilience.

2.2.5 COPING STRATEGY USED BY PATIENTS WITH BREAST CANCER:

The study titled “Challenges, Coping Strategies, and Social Support among Breast Cancer Patients in Ghana” aimed to explore the challenges, coping strategies, and support systems among women diagnosed with Breast Cancer in Ghana. A descriptive cross-sectional study was conducted from February to August 2017 at the Komfo Anokye Teaching Hospital (KATH), Ghana. A systematic random sampling technique was used to select 202 women with a confirmed diagnosis of Breast Cancer. Coping strategies of women with Breast Cancer were assessed using the Brief-COPE. The associations between sociodemographic characteristics, social network/support, and coping strategies were assessed using linear regression models. The findings show that the most and least adopted active coping strategies were religious coping and humors, respectively. Self-distraction and substance use were the most and least adopted avoidant coping strategies, respectively. Spouses and children offered the most support to women with Breast Cancer; having support from 5 or more sources was associated with higher mean active coping (beta [β] 1.14; 95% CI 0.66 to 1.62) and avoidant coping (β 1.46; 95% CI 0.98 to 1.94), as compared with having <2 sources of social support (Benson et al., 2020).

Khalili et al., (2013) studied "Coping strategies, quality of life and pain in women with breast cancer". This was a cross-sectional study which held in Seyed-AL shohada hospital and two private offices in Isfahan, Iran. Target population was women with confirmed diagnosis of breast cancer in a recent year and between 18 and 60 years old. Data were collected via3 questionnaires (Brief cope, EORTC QLQ-C30 and Brief pain Inventory). The results show that the most common coping strategies were religion, acceptance, self-distraction, planning, active coping, positive reframing and denial.

Hajian et al., (2017) conducted a study titled "Coping Strategies and Experiences in Women with a Primary Breast Cancer Diagnosis". The aim of this study was to explore the experience of coping behavior and the main strategies that women use in dealing with a breast cancer diagnosis. Purposive sampling was used for recruiting participants with breast cancer, and data collection was conducted by semi-structured, in-depth interviews. The findings suggest that three dominant themes that emerged from the interviews were emotional turmoil, avoidance, and logical efforts.

2.2.6 COPING STRATEGIES OF CAREGIVERS OF PERSONS WITH CANCER

The study "Burden and Coping Strategies Among Caregivers of Cancer Patients Receiving Palliative Care at Home" (George & John, 2018). assessed the burden and coping strategies adopted by caregivers of cancer patients receiving palliative care at home in a selected community, Idukki district, Kerala. A descriptive cross-sectional study was conducted among sixty caregivers of cancer patients using nonprobability convenient sampling technique. Sociodemographic Performa was used to collect demographic characteristics of caregivers of cancer patients. Structured rating scale was used to assess the burden and coping strategies adopted by caregivers of cancer patients. Collected data were analyzed using descriptive and inferential statistics. Results show that fifty percentage of caregivers experienced moderate burden and (48.30%) experienced severe burden. The mean score of overall burden was (67.20%). Highest caregiver burden was reported in ‘physical’ domain, and least in ‘spiritual’ domain. Majority of the caregivers (82.00%) adopted average coping, and (18%) adopted good coping. Mean score of overall coping was 51.4, (61.20%). Caregivers used ‘confrontive’ coping (80.80%) more frequently, and ‘escape avoidance’ (43.30%) less commonly in order to overcome caregiver burden. No statistically significant correlation was found between burden and coping strategies among caregivers of cancer patients receiving palliative care at home.

A study conducted by Long et al., (2020). studied “Coping strategies and social support among caregivers of patients with cancer: a cross-sectional study in Vietnam.” examined the relationships between types of coping strategies utilized and social support among cancer caregivers. cross-sectional study conducted in three main cancer hospitals in Vietnam. The 28-item Brief COPE Inventory (BCI) Scale and the Multidimensional Scale of Perceived Social Support (MSPSS) were utilized. Descriptive statistics and multivariate linear regression were performed. It was found that active coping, acceptance and positive reframing were the most used coping strategies among participants, while substance use was the least commonly used. The level of social support was positively correlated with the utilization of coping mechanisms. Receiving high social support and utilizing positive coping strategies enables caregivers to mitigate their caregiving burden, control the situation and enhance their own quality of life.

Karabulutlu E. Y. (2014). studied “Coping with stress of family caregivers of cancer patients in Turkey.” sought to to determine the attitude of coping with stress of family caregivers of cancer patients. This study was conducted as descriptive research at the Medical Oncology Clinic and the sample group comprised of 127 family caregivers. In the collection of the data, the Personel Information Form and Attitude of Coping with Stress Inventory were used. The coping attitude used most frequently by family caregivers was active planning, and the least used coping attitude was avoidance isolation (biochemical). There was no significant statistical difference between the coping attitude depending on the descriptive characteristics of the family caregivers ($P > 0.05$).

Antony, L et al., (2018). Conducted a study titled “Stress, Coping, and Lived Experiences among Caregivers of Cancer Patients on Palliative Care: A Mixed Method Research”. According to the study, sixty-two percent of the patients were dependent on caregivers for all activities of daily living. Assessment of stress revealed that 82% of the participants had moderate stress and 18% had severe stress. Participants adopted both negative and positive coping. There was a significant negative correlation ($r = -0.722$, $P = 0.001$) between stress and coping. Palliative caregiving is stressful, challenging and can impact the caregiver's physical, emotional, psychological, and social well-being.

2.3 RESEARCH GAP

The review of literature shows that number of cancer cases in the world is increasing at an exponential rate. Various studies are conducted in India and all over the world to identify the prevalence and the rate of increase of cancer cases. The studies also look into the challenges – physical, psychological and social – of the persons with cancer. As people with cancer increases, the number of persons stepping into the role of a caregiver also increases. There have been various studies conducted on caregivers’ burdens and issues faced by them when caregiving is done. However, when comparing to the international studies, Indian studies on this issue is limited. And along with it, we see a number of resilience and coping mechanisms adopted by both the patients and the caregivers to overcome the torment they have been facing by being in such a position. Although there are studies focusing on the challenges of caregivers of persons with cancer, studies focusing on interventions for them is limited. This study, aims to understand the challenges of the caregivers and to suggest interventions for them from social work perspective so that their quality of life can be improved and they can live a dignified life.

CHAPTER III: METHODOLOGY

METHODOLOGY

3.1 OVERVIEW

This chapter deals with the methodology adopted for this particular study. The chapter discusses the orientation of the research (epistemological and ontological), the topic under study, the design employed to the study topic and the tool used for data collection. An attempt is made to narrate the methods and techniques used to identify the cases. This chapter also includes method through which, the data will be analyzed and interpreted in order to arrive at certain findings, suggestions and conclusions.

3.2. TITLE OF THE STUDY

The title of the study is **"CHALLENGES AND COPING STRATEGIES AMONG CAREGIVERS OF PERSONS WITH BREAST CANCER".**

3.3. RESEARCH QUESTIONS

General Research Question:

- What are the challenges faced by caregivers of persons with breast cancer and their coping strategies?

Specific Research Questions:

- What are the psychological challenges faced by the caregivers of persons with breast cancer, as part of their role as a caregiver?
- What are the social challenges faced by the caregivers of persons with breast cancer?
- What are the coping strategies used by caregivers of cancer patients?
- What are the possible social work implications/ interventions to cope with the psycho-social challenges faced by the caregivers.

3.4 DEFINITIONS OF CONCEPTS:

3.4.1 CANCER

- **Conceptual:** According to World Health Organization (WHO), Cancer is a large group of diseases that can start in almost any organ or tissue of the body when abnormal cells grow uncontrollably, go beyond their usual boundaries to invade adjoining parts of the body and/or spread to other organs.

- **Operational**: In this study cancer refers to breast cancer, in persons undergoing treatment at Regional Cancer Centre (RCC), Thiruvananthapuram.

3.4.2 CAREGIVER:

- **Conceptual:** A person who give care to people who need help taking care of themselves. Examples include children, the elderly, or patients who have chronic illnesses or are disabled. Caregivers may be health professionals, family members, friends, social workers, or members of the clergy. They may give care at home or in a hospital or other health care setting (National Cancer Institute).
- **Operational**: In this study, a caregiver is a family member taking care of the person with breast cancer, undergoing treatment at Regional Cancer Centre (RCC).

3.4.3 CHALLENGES:

- **Conceptual**: A situation needing great mental or physical effort in order to be done successfully, or the situation that requires great effort (Online Cambridge dictionary, 2021).
- **Operational:** In this study, challenge refers to the psychological, social, financial problems faced by the family members of persons with breast cancer undergoing treatment at RCC as part of their role as a caregiver.

3.4.4 COPING STRATEGIES:

- **Conceptual:** Coping strategies refer to the specific efforts, both behavioral and psychological, that people employ to master, tolerate, reduce, or minimize stressful events (Taylor, 1998).
- **Operational:** Coping strategy in this study refers to the measures taken by the primary caregivers of persons with breast cancer, undergoing treatment at RCC to master, tolerate, reduce, or minimize stressful events and its impact.

3.5 PILOT STUDY:

Pilot study was conducted with one caregiver of person with breast cancer patient who visited RCC, Thiruvananthapuram for clinical/follow up examination. The researcher also interacted with the patient. The pilot study was conducted in order to determine the feasibility of the study. After the pilot study, it was understood that respondents were keen and ready to share their experiences openly.

3.6 PRE-TEST:

The pre-test was done by collecting information from one caregiver of person with cancer. A semi structured interview guide consisting of 19 questions and demographic details seeking answers to the research questions was used for data collection. The researcher collected the data from the participant through face-to-face interview. Based on the pre-test, appropriate modifications to the tool were made to get appropriate information from the participants.

3.7. RESEARCH DESIGN:

According to Alan Bryman (2012), a research design provides a framework for the collection and analysis of data. A choice of research design reflects decisions about the priority being given to a range of dimensions of the research process. According to Creswell (2003), qualitative research seeks to collect an in-depth insight into human behaviour and the causes that direct that behaviour. Qualitative research has its heredity in social science and is more concerned with finding out why people behave as they do. Since this study aims to understand the challenges of the caregivers of persons with cancer, each case has to be studied in depth to get deeper understanding, hence, this study adopted a qualitative approach.

As this study requires in-depth, multi-faceted explorations of complex issues in the caregivers' real-life settings, case study design was selected for the present study.

3.8. RESEARCH TOOL:

The interview schedule was prepared to find out the socio-demographic profile of caregivers. It also included closed questions, dealing with the socio-demographic profile like age, occupation, type of family of the caregivers. The researcher used semi-structured interview guide to collect the data from participants. Appropriate modifications were made to the semi-structured interview guide based on the pretest.

3.9. RESEARCH SITE:

The cases identified for the purpose of the study included caregivers of person with breast cancer, undergoing treatment at Regional Cancer Centre (RCC), Thiruvananthapuram. The Regional Cancer Centre (RCC), Thiruvananthapuram established in 1981, is an internationally recognised centre providing state-of-the-art facilities for cancer diagnosis, treatment, palliation and rehabilitation and conducting a wide range of research on various type of cancers. This state-owned premier cancer care hospital and research centre is one among the six centres instituted in India under the 'National Cancer Control Programme' of the Ministry of Health and Family Welfare, Govt. of India (Regional Cancer Centre, 2012).

3. 10 SAMPLING STRATEGY AND SELECTION OF PARTICIPANTS:

Five caregivers of persons with breast cancer, undergoing treatment at Regional Cancer Centre (RCC) were selected for the study a based on specific criteria. Convenient sampling, a type of sampling technique involves choosing people who are easy for the researcher to reach and get in touch with, was selected for this study. A Convenience sample is one that is simply available to the researcher by virtue of its accessibility. While convenience sampling provides good response rates, it may be difficult to generalize the findings. (Bryman, 2012).

3.11 INCLUSION AND EXCLUSION CRITERIA

INCLUSION:

- The study included the caregivers of persons with breast cancer.
- The study only included the primary caregivers
- Caregivers of patients undergoing treatment at Regional Cancer Centre, Thiruvananthapuram.

EXCLUSION:

- The study excluded caregivers of person with cancer other than breast cancer.
- Secondary and formal caregivers are excluded from the study.

3.12. DATA COLLECTION:

The data was collected from five caregivers of persons with breast cancer, a semi structured interview guide was used as the tool, through which the researcher was able to get in-depth understanding of the challenges faced by the caregivers of breast cancer patients. The data was collected through face-to-face interview with each participant. Interview with each participant lasted about three to four hours. The researcher also interacted with the patients to gain better understanding of their condition and to understand how they perceive their situation, their relationship with the caregiver and the challenges faced by the caregivers from their perspective. The data was initially collected in Malayalam and thereafter translated into English.

3.13. DATA ANALYSIS:

The data collected was analysed on the basis of different themes using the data collected from participants and categorized under definite sub themes. For data, recorded interviews were transcribed into verbatim. The researcher tried to identify, analyse and interpret qualitative data patterns. The transcripts were analysed thematically. Themes were generated and identified through an iterative process.

3.14. ETHICAL CONSIDERATION:

- An informed consent was obtained from all the participants prior to data collection after informing them about the study and the purpose of the study.
- The participants were assured full confidentiality of information and that the participant details will be maintained by the researcher.
- The participants were assured that the collected data will only be used for academic purposes.
- Before recording the interviews, consent was taken from the participants.
- The participants were permitted to withdraw from the study at any point in time.

3.15 LIMITATIONS AND SCOPE OF THE STUDY

LIMITATIONS

- Limited number of participants

- The caregivers of those undergoing treatment at Regional Cancer Centre only were selected.
- Only the primary caregivers are considered in this study.

SCOPE

- This study would help to understand the challenges faced by the caregiver of persons with specific reference to breast cancer.
- This study would also give an insight into the coping strategies – both positive and negative- adopted by the caregivers, which could be replicated or modified to help the participant caregivers as well as other caregivers going to similar issues.
- The findings of this study would help in proposing social work interventions that would improve the quality of life of the caregivers.
- This study could also support and facilitate further studies in these areas.

CHAPTER IV: CASE DESCRIPTION/NARRATIVES

CASE DESCRIPTION

CASE 1

The first participant Mrs ‘A’ is a 63-year-old Christian woman belonging to a lower-class family in Ernakulam. She is the mother of the breast cancer patient. She had completed her 12th standard. Her family consists of herself, her daughter (‘Y’38 years old), son-in-law and 2 other daughters who are married and their children. As all her daughters are married, they all have separate homes. She has a family history of cancer as her own husband had died of bone cancer a few years ago. The family used to stay in Ernakulam. It was about one year ago when her daughter was diagnosed with breast cancer. Mr Y was living with her husband in Muscat and was working as a nurse there when she started experiencing mild pain in her arms. She thought of it as a result of her tedious work and ignored it. However, it was after Mrs Y noticed a lump in her left breast, that she decided to get a check-up. On conducting the tests (Including CA 125 test), it was found that she had third stage breast cancer. As a result of the breast cancer diagnosis, Mrs Y had to leave her job as a nurse in Muscat. As the cost of treatment would be very high there and her husband would require to quit his job in order to care for her, she decided to return to Kerala for her treatment. Her husband continues to work, thus requiring Mrs A to take care of her daughter.

Detailed check-up was done at a cancer hospital near their home. When Mrs Y was diagnosed with cancer, it was a big shock to the entire family, including Mrs A. Mrs A reported *“I could not believe that my daughter had cancer and it took me some time to accept the fact. I kept praying to God that my daughter gets better soon. I didn’t want her to experience what her father went through”*. Soon, it was decided to take treatment from the Regional Cancer Centre (RCC), Thiruvananthapuram (another district). Mrs Y now undergoes 5 rounds of radiation a week (Monday-Friday) and chemotherapy sessions along with regular tests. The radiation and chemotherapy sessions have resulted in side effects such as extreme fatigue, hair loss, vomiting and joint pains. It has also affected the appetite of Mrs Y.

Mrs A says *“Whenever I see her in this state it reminds me of the sufferings my husband had to endure. I was with him throughout his treatment. I know it is very painful and the treatment takes a toll on the patients but I am hopeful that my daughter will be able to overcome it.”*

While undergoing treatment at the Regional Cancer Centre, Mrs Y and Mrs A stay at the De Paul Cancer Care Centre, Kumarapuram, Thiruvananthapuram. Due to 5 rounds of radiation from Monday to Friday, the duo stays in Thiruvananthapuram the whole time, visiting home occasionally.

The cancer diagnosis and the subsequent caregiving has had a significant impact on the daily life of Mrs A. She used to be a housewife and spent time with her friends who lived nearby. They would go to church regularly but now she spends all her time caregiving for her daughter and stays with her. She is responsible for taking care of her daughter, washing her clothes, providing her medicine, helping her when she suffers from side effects of medication and providing her emotional support. According to her: *"Now that I am in Thiruvananthapuram I am always in a room. I miss my home and the comfort of having my neighbours around. I feel solitude as I don't know anybody in Thiruvananthapuram except my daughter."*

Although she is the primary caregiver, she is supported by her son in law who sends in money regularly and her daughters who inquire about and visit them from time to time. Although they are not able to be present with her and her daughter throughout the treatment, their emotional support and prayers have been a strength to her. She says:

"I understand their position, they have to take care of their family, their children, so they would not be able to come and stay with us. But I know they care. They pray together as a family for my daughter. I know they pray for us and I take comfort in knowing that. I believe their prayers have helped us to get this far".

Since the cancer treatment began, Mrs A has noticed certain behavioural changes in Mrs Y. She feels that Mrs Y has now become very aggressive and occasionally feels very low. Mrs Y feels very warm due to the medication she takes which makes her very irritable and she lashes out Mrs A. This behaviour has not strained their relationship in any way as Mrs A understands these are due to the medication, but she still feels sad that in spite of her efforts, her daughter still feels uncomfortable. She also experiences certain issues such as sleeplessness and as a result frequent headache. She says:

"I worry about her and her future. I know her treatment is going on and she will be able to overcome this situation but as a mother I worry. All these thoughts pop up in my mind during the night. I find it difficult to sleep properly, she has been married for 7 years now. They do not have kids. I do not know after all these treatments if she could

have kids in future, also there is a high chance of relapse in such cases. I have met many people who thought their cancer is cured but after few years they relapse".

Mrs A also experiences certain physical issues as a result of her role as the caregiver. She has body pain whenever she exerts herself. She is taking medication for diabetes. Although she has to be very particular about her diet and medicines, she hasn't been able to take care of herself like she use to before. She also admitted that she has occasionally shown her frustration on her daughter but then she apologized quickly. This has started affecting her health. She feels bad for her daughter occasionally and wonders why she got breast cancer. Despite of the physical issues she faces, Mrs A actively wants to help her daughter during her treatment. She feels content that she is there for her daughter whenever she needs her.

Mrs A said that her family is her main strength during these times. She feels blessed to have a family that loves and supports each other. Her relationship with her daughter has become stronger after the treatment started. Before Mrs A did not stay with her daughter, after the diagnosis, she spends her entire time with her daughter, they got to share their life and experience with one another on a deeper level. She also revealed: "*I feel very depressed whenever I think about my daughter. Sometimes I cry alone. I don't know why God has given her cancer. I just hope she gets well as soon as possible".*

She exclaimed that she did not think much of what others thought about her situation as she was fully focused on her daughter's treatment and that she did not consider it as a burden. She believes that whatever happens is God's will and God will protect her daughter.

According to Mrs A, she does not have much time to deal with the stress or emotions that she faces as a caregiver. Having already cared for her husband with cancer, she says she is used to the burdens of caregiving. Because of the financial problems that they face, Mrs A has said that she started managing her finances more carefully and stopped unnecessary spendings. For her, the burden of caregiving is not intolerable but hopes that her daughter's condition would improve soon. According to her: *"As soon as the cancer diagnosis was made, I realized that we will have lot of expenses in treatment. That is why I decided that we will cut our expenditure on other things and would take a small loan for her medical expenses. When we go home, my daughters would help me with caregiving, providing me with some relief."* She is also very religious and is grateful for whatever she has. She attends religious service at De Paul Cancer Care Centre which has provided her support during the time of stress and burden. She said that “Everything is in God’s hands”. She uses a positive approach which can be understood by the fact that she is hopeful that her daughter’s condition improves soon and does not consider taking care of her daughter a burden. She said: *“I always try to be positive and hope that in spite of the challenges that we are facing, things will get better sooner. I also try to be positive so that my daughter doesn’t became depressed because of me”.*

CASE 2

The second participant is Mr ‘S’ a 40-year-old Hindu man belonging to a financially lower class family. He is the husband of a breast cancer patient Mrs ‘T’. The family consists of Mr S, his wife, and 2 daughters. Mr S’s mother had died a long time ago while his father died a year ago. One of the daughters has completed her 12th standard and pursuing NEET while the other daughter is currently doing her 8th standard. The family comes from Anchal in the Kollam district. Mr S had completed his education till 10th standard. Mr S is an auto-rickshaw driver who plies his trade in Anchal while his wife is a homemaker. Mr S met Mrs T in school and later had a love marriage about 20 years ago. Mr S described his wife as a warm person with a kind personality who was loved by family, friends and neighbours.

It was one and a half years ago that Mrs T was diagnosed with breast cancer. Before the diagnosis, Mrs T had felt some pain in her breasts and felt a lump on her right breast. When she remarked to her husband that she might have cancer, Mr S scolded her for even talking about cancer. However, subsequent tests proved her fears true. Mr S said

“It was as if our whole life shattered in a moment. We could not believe it at all. Both of us were shocked and it took time to process everything”.

As Mr S felt that there were not good enough hospitals in Anchal and Kollam, they decided to take treatment from the Regional Cancer Centre, Thiruvananthapuram.

When the cancer was diagnosed, it was a huge shock and moment of sadness for the entire family. Mr S stated that while his elder daughter understood the gravity of the situation, the younger daughter did not know the exact details of her mother's condition. The treatment of Mrs T had changed everything in the life of Mr S and Mrs T. Mr S, an auto-rickshaw driver was the sole breadwinner of the family as his wife was a homemaker who took care of her daughters. But the diagnosis and the treatment has forced Mr S to spend his time with his wife.

Mr S stated: *"My wife has radiation 5 times a week. So, I have to stay with her the entire week. It's not worth to travel to Anchal and drive auto for one day. Because of this, I haven't driven auto for many months. This has caused us a lot of financial loss."*

He says that due to Mrs T's treatment he could not drive auto-rickshaw any more. Mrs T has radiation treatment 5 times a week, chemotherapy and several injections and various tests. These all make her very tired physically and mentally. Mr S also remarked that the only time he gets is during the weekend (when there are no treatment procedures or tests) but not worth travelling to Anchal and plying his trade for one day and coming back the next day. Due to this, there exists a severe financial crisis for the family. The family which is already poor has been forced to take loans and deposit his wife's and daughters' ornaments in banks to get some money. The family lives in a house in a 4 cent plot and does not have any wells or the money to construct one.

Even Mr S's daughters have become emotionally distressed at the plight of their mother. Currently, the daughters are being taken care off by his wife's mother. According to him, the doctors informed that the cancer had not spread to other parts of the body. Mrs T's cancer is currently in the 3rd stage.

Mr S has noticed several changes in his routine since the diagnosis occurred. According to him, he had become hopeless with his wife's condition and the fact that the family's financial condition was very poor. He also did not even bother about his physical appearance and felt very depressed. He said that in front of his daughters and wife, he did not show his sadness in order to prevent them from being sad themselves. His social life had almost become non-existent. He said:

"My interactions with family and friends became confined over mobile phone. But talking to them over the phone is much different than being with them. Both of us did not have much knowledge about her condition, treatment and other procedures and felt that we were at the mercy of the doctors. The fact that we are away from our daughters and all the relatives and friends made us feel lonelier."

Mr S said that Mrs T felt she had become a burden on the family as her condition had caused trouble to Mr S as well as her daughters. Even Mrs T's mother had grown depressed after the diagnosis was made and the fact that she could not visit her daughter due to her own illnesses made her more despondent. According to Mr S, he was ready to do whatever possible to help his wife in the situation but was feeling hopelessness. After becoming a caregiver, he could not devote much time to his daughters which made him feel slightly guilty.

According to Mr S: *"I feel guilty as I sometimes feel that I cannot take care of my wife as much as I should be. My own state sometimes makes me think I am not taking care of her properly. I also feel guilty of not giving time for my daughters."*

Mr S stated that many of his fellow auto-rickshaw drivers had come together and provided financial help for his wife's treatment. He had 3 siblings, but their own financial condition was worse than his and therefore he could not ask them for help. Even with the financial help and the loans he had taken, he felt that the situation could not be sustained without taking even more loans. Till now, he had avoided taking loans from private individuals and institutions, wanting to avoid debt trap. But he mentioned how taking loans from legitimate sources required documents and a lot of paperwork.

As far as the expectation of future is concerned, Mr S explained that they are worried about the financial aspect of the situation. They neither possess much money nor property to sell off to raise money. Both husband and wife also don't know about what will happen in the treatment and whether after the treatment the cancer will reoccur. Mr S said the longer the treatment continues, the greater will be the financial difficulty for them.

Mr S explained about the stress and frustration that he feels as not only being the caregiver, but also due to the fact that their financial condition is poor. He said:

"All time I worry about my wife and my daughters. Its difficult to see what can I do in this situation".

He remarked that as a husband, it is his duty to take care of wife when she is ill but it is not easy. Mr S also explained that how he has trouble sleeping sometimes and has started to neglect his own health. He said "I have diabetes and blood pressure but due to taking caring of my wife, I have sometimes forgotten to take my medicines. It does not feel like a priority.”

Mr S said that even though he feels a lot of worry and frustration, he does not take any action to control his emotions. According to him, only God knows what will happen but the future looked bleak. He also said: *“I try not to display my frustration or sadness in front of my wife or daughters so as to not make the situation even more negative. But I really feel hopeless”*

Even though he tries to take the situation off his mind, it is very difficult. The emotional support that he gets from his relatives and fellow auto-rickshaw drivers make him feel supported but he thinks it is not enough. He said he has trouble coping with the situation. According to him: *“I try to take my mind off this situation by watching TV shows and browsing internet on my phone, but it is not effective. Also, I have started to drink more, but it gives me relief only for some time”.*

CASE 3

The third participant is Mrs R, who is a 45 year old Hindu woman and the sister-in-law (husband’s sister) of the breast cancer patient (Mrs Q). Mrs R’s family consists of her husband, her parents and 2 children. She had completed her undergraduation and is now a government employee working in Wayanad while her husband is involved in business. The elder son is undergoing his Masters while the younger son has just completed his 12th standard. The family resides in Wayanad district of Kerala. The family did not have any history of cancers of any kind.

It was in March 2022 (1 year and 3 months ago) that Mrs Q was diagnosed with breast cancer. Initially, she felt a lump on her breast as well as some pain. While the pain was initially attributed to an injury that she had sustained on her breasts, subsequent tests showed that she had breast cancer. This was a moment of huge surprise to her and her family and was completely unexpected. Initially, the doctor informed Mrs Q’s husband about the cancer diagnosis which he then proceeded to tell to his wife. It was only after some days that the news was delivered to other relatives including Mrs R. After this, Mrs Q’s husband sought the help of his sister (Mrs R) to provide help in caregiving for Mrs Q. Initially, the family was in Wayanad and Mrs R was able to help in caregiving. But when Mrs Q sought treatment from the Regional Cancer Centre in

Thiruvananthapuram, Mrs R had to take leave from her job in order to continue caregiving for the patient. She said that Mrs Q has become slightly melancholic since her diagnosis and subsequent treatment. She explained that with the chemotherapy and radiation, Mrs Q's physical health has not been great and she displays side effects such as nausea, vomiting, fatigue and irritability. Mrs Q has also been advised to avoid certain foods, including grapes and red meat. The patient did not have any other health issues. Mrs R has been caregiving for the past 4 months and says that it has not been a burden to her.

According to Mrs R, the doctors said the patient has a second stage breast cancer which required surgery along with chemotherapy and radiation treatment. Mrs Q had one surgery and required another one. Mrs R had started to provide caregiving ever since the first surgery, since Mrs Q's husband had a job and could not take time off to provide caregiving to his wife. Mrs Q and her husband had 2 children, both of whom were very young. They were currently with their paternal grandparents.

The caregiving had a significant impact on the daily routines of Mrs R. She worked as a government employee and in order to take care of Mrs Q, she had to take an extended leave from her job. Apart from that, she had to leave her home and her family and stay with the patient in Thiruvananthapuram for her medical treatment. She also said that: *"Even though I have not felt too much stress, since I came to Thiruvananthapuram my sleep has become disturbed and my appetite has gone down".*

Mrs R said: *"I miss my 2 sons and my husband and feel lonely sometimes but I take my responsibility as a caregiver seriously".* She also said that she knew the situation that her brother and his wife were in and she did not hesitate when her brother asked her for help. She said:

"My brother and his wife were in trouble and I felt I could be of some help for them during such a traumatic time. This is why I chose to help my sister-in-law"

When she started caregiving, she initially struggled with it as she had no experience of caregiving. But as she got used to it, it became progressively easier especially as her bond with Mrs Q became stronger. According to her, she had been moderately positive and only worried about her brother's and his wife's mental health as they are sad. She also thought that Mrs Q tried to hide her frustrations and sadness from others. However, over the course of caregiving, Mrs Q had come to trust Mrs R and would always share her thoughts and what she felt to her. In other words, Mrs Q had started to confide in Mrs R. While before the diagnosis, both of them had a cordial relationship, due to caregiving, they had become closer.

Mrs R explained that her relationship with her own family and friends hasn't undergone much change since she started caregiving. Though, her interactions with them had reduced as she lived far away from them. She also said that she missed being with her 2 sons and would go home when her leave expires at the end of the month (June).

According to her: *"I am worried what would happen after I leave as her husband has a job and therefore would require someone else to provide caregiving. I also feel slight guilt that I have to leave her, but with my leave expiring, I have no other choice."*

Mrs R said that her husband was initially hesitant when she was approached for caregiving and then when she had to take leave and go to Thiruvananthapuram. But then he accepted her decision especially as Mrs Q's husband was struggling to find anyone for caregiving. Her 2 sons were also sad to see her leave them to go and take care of Mrs Q.

According to Mrs R, she had to provide caregiving most of the time as all her relatives are in Wayanad. Only occasionally do relatives and friends come to visit Mrs Q and they leave the same day. Thus, she had to cope with the caregiving duties. However, her husband and her children call her daily and this provides her emotional support and reduces her loneliness. Mrs R stated that *"I started reading a lot about caregiving including medication management, medical terminologies, and how to care for a cancer patient which has helped me a lot in caregiving. As our bond became stronger, I have felt a bit more comfortable to take care of her"*

Mrs R stated that she has not felt too much stress or frustration as a caregiver but still makes use of both yoga and meditation. She stated that she had undertaken a course in yoga and used it whenever she got the time to do so. According to her: *"Even though I am busy taking care of her, whenever I get time, I make sure to practice meditation and yoga. These have helped me a lot, something that I practiced even before starting taking care of my sister-in-law."* She also said that talking to Mrs Q was itself a stress relieving exercise for her. Till then, she was not worried about the financial position of her sister-in-law as they came from a financially well off family and much of her medical expense was covered under medical insurance schemes. However, if the medical expenses were to increase, it could eat into their savings. One thing that bothered Mrs R was about the mental condition of her brother and his wife. Both tried to portray themselves as calm in front of others, but based on her conversations with Mrs Q, she knew that they were anxious about Mrs Q’s health and the future.

Mrs R also talked about not trying to think too much about the cancer and treatment of her sister-in-law. She also revealed that thinking about Mrs Q’s condition, she felt a lot of gratitude about her own good health. “*I can’t even imagine being affected by cancer and how it would impact me and my family.”* She also stated: *“Both of us would talk about various topics such as cooking, gardening, TV shows and other things to avoid boredom and it also helped us to shift their focus away from the problems that we faced.”*

CASE 4

The fourth participant in the study is a 52 year old Hindu man (Mr G), who is the husband of the breast cancer patient (Mrs H - 48 years old). The family consists of the husband, wife, a daughter and the parents of the husband. The parents of Mrs H are taken care by their other children with Mrs H occasionally visiting them. Mr G is a bank employee working in Kottayam while his Mrs H is a housewife. Mr G had completed his schooling and undergraduation in Kottayam before getting a job in a bank. The marriage between Mr G and Mrs H was an arranged marriage which occurred 26 years ago. Their daughter is currently doing her postgraduation in chemistry from a college in Ernakulam. Mr G described his wife as a god-fearing, religious person and he was also very religious. Except a distant relative, their family did not have any other cases of cancers of any kind.

In January 2022 (1 year and 5 months ago), Mrs H started complaining about swelling of breasts and pain along with changes in the texture of the surrounding skin. When the problems failed to subside, it was decided to visit a doctor in Kochi. After having the mammogram done, the doctors diagnosed Mrs H with breast cancer in the second stage. This was something which caused a lot of shock and frustration for the couple. The news was even more disturbing for their daughter and required both the parents to console her for a long time. Mr G said

"When we came to know about the diagnosis, I could not even believe for a few days that what was happening was real. It took a lot of time to take it all in. Our daughter was inconsolable for a long time and seeing her made us even more sad".

The news was also communicated to other relatives and friends of the couple. It was then decided to take treatment from the Regional Cancer Centre, Thiruvananthapuram.

Now, Mr G and Mrs H live at Lourdes Matha Cancer Care Centre in Kochulloor in Thiruvananthapuram and have treatment at RCC, Thiruvananthapuram. Mrs H has chemotherapy, injections and radiation treatment along with periodical tests. She had not yet been prescribed any surgeries. As a result of treatment, Mrs H suffers from hair loss, fatigue, loss of appetite and headaches. She also suffers from anaemia which actually was even before the cancer diagnosis. For this, she has been taking Vitamin B supplements along with some dietary modifications. Mr G stated that he helps her during the time of side effects and is involved in caregiving. Mr G described his wife as an incredibly positive character and stated that she rarely complains about her condition and only about the pain or fatigue she suffers after chemotherapy or radiation therapy. According to him, his wife has not changed much since her treatment started and still prays a lot.

Mr G was a bank employee who works in ESAF Bank branch in Ernakulam. As a result of the cancer diagnosis and treatment of his wife, he had been forced to take a leave from his employment. He also stated that he had been looking for a caregiver who could take care of his wife as he will have to return to his job sooner or later. The caregiving has had a big impact on his work life as well as social life. About his daily routine, he said

"I used to go to work from 9 till 6 at the bank, then come home, spend some time with friends in the neighbourhood, have conversations with wife and parents and occasionally go out for walks or dinner with family. Now the entire routine had changed and I am all day involved in caring for my wife. But I have never considered it to be a burden. Sure, it is a difficult time for both of us but we have to accept whatever our fate is and work without any complaints. Even if we were to get depressed it will not help the situation anyway."

The fact that he took a leave from his job does not bother him, but knows he has to find a person to help his wife as he would eventually have to go back to work.

Mr G admits that his social interactions had naturally diminished as he stayed with his wife the entire time. He was not able to go out with his friends but completely accepted the situation. On being asked whether he feels any isolation, he replied that he sometimes feels so. He exclaimed that *“I am somewhat worried about my daughter’s mental state as she is far away from her parents and wonder whether her mother’s health would affect her studies”.*

Mr G said that as soon as the news of the diagnosis was made, a large number of friends and relatives visited the family and expressed their sympathies. They provided emotional and monetary support. It was only from close relatives that they took any money. According to him their daughter decided to skip her classes for a few days and many of her friends inquired for her.

As far as caregiving is concerned, Mr G admits that he alone does most of the work. He is responsible for washing his wife’s clothes, providing her medicine, handling paperwork, helping her deal with side effects of treatment etc. However, he is not bothered by his work and feels whatever God has provided must be accepted. He also appreciates the fact that even though Mrs H’s friends and their other relatives cannot come regularly to stay in Thiruvananthapuram owing to the large distance, they still come occasionally and call both of them regularly. He also feels that his friends lend an ear whenever he talks about his problems which makes him feel grateful.

As far as his stress is concerned, Mr G stated that *“When the diagnosis was made, both of us felt very confused as we didn’t expect such a thing ever. But as days passed, we accepted it and tried to be as positive as possible.”* He though admits that caregiving for his wife was a new experience and it has sometimes been tricky.

According to him: *“I have received advice regarding caregiving from my friend’s wife, who is a nurse and also accept suggestions from others. I do sometimes wish that someone would have been with me to help me and I worry whether I am able to satisfy my wife as a caregiver.”*

Regarding the negative emotions that he experienced, Mr G said: *“I have accepted whatever occurs as something given by God. If I am not positive, then it would affect my wife’s health. But I do worry a lot about her health and whether I am caring for her well enough. I have also felt sadness for what my daughter is going through this time and the fact that I cannot meet her regularly.”*

He also mentioned that though his parents are managing themselves, he feels guilt that neither he nor his wife are with them. He said: "*My parents used to manage with me and my wife. Now that we are not with them, they have to manage by themselves. I do feel guilty but I know I cannot do anything about it."*

Mr G also said that as his experience in caregiving increased, he felt more and more comfortable with it. Mr G and Mrs H are both extremely religious and pray everyday after waking up and in the evenings. According to Mr G, it is something that has provided a lot of power to both of them to face their challenges. They also accept that in life both positive and negative things occur and they have to face them.

He said *"Without God, I don't think we would have been able to face these challenges. Even though many people question us about how God would allow my wife to get cancer, we simply ignore such questions. Whatever good or bad happens, if we believe in God, it would help us"*

Mr G also mentioned that in order to distract himself from the problems that he faces he meditates every day, prays alone or with his wife, call and talk to his friends, and practice gratitude for all things he has including financial stability, caring friends and family.

CASE 5

The fifth participant Case 'E' was a 43-year-old, Hindu female from Ernakulam district in Kerala. Her family consisted of herself, her two children aged seven and ten, and her younger sister who was diagnosed with breast cancer fourteen months back. She had completed her education till 8th standard. Mrs E was now a daily wage worker. Both her parents had passed away. Her father also had blood cancer and was undergoing treatment at Regional Cancer Centre (RCC). Her sister was the one taking care of her father when he was sick. Mrs E was separated from her husband. She was the sole breadwinner of the family. Mrs E had been taking care of her sister since her diagnosis with breast cancer.

Mrs E's sister was 35 years old. She was working as a housekeeper at two different homes to meet ends meet. She started experiencing symptoms about two years back. She would come home every day and complain about severe back pain and pain in the arm. She would use ‘tailam’ ayurvedic oil and sometimes take painkillers. She avoided going to the hospital as it would be an additional expense.

Mrs E says *“I would ask her to go to a hospital every day. I would have taken her to the hospital. But she never says anything. She would keep saying I feel better or it is because of the work. After a point she said everything was fine with her. She was feeling better. It wasn’t until the pain got very severe that she decided to seek treatment”.*

The responsibility of the entire house was now on Mrs. E’s shoulder. She had to take care of both her children and her sister. She was the one accompanying her sister to the hospital. The initial diagnosis was done at clinic near their home. They were then referred to Regional Cancer Centre (RCC). Mrs. E’s sister had been undergoing treatment at RCC for the past one year.

She underwent two surgeries and is currently on radiation and chemotherapy. The relation between the two sisters was always cordial as they were each other’s support system. The treatment only made their relationship stronger. Mrs E said *“All we have is each other. We have been very close since our childhood. Through all the difficulties in life we have stood by each other. Whatever comes, I will be there for her. It is difficult for me to balance everything, but if I don’t take care of her who will? She has struggled a lot in her life. She took care of our father while I was trying hard to earn. Now I will support her in any way possible”.*

Mrs. E, having seen her father go through cancer treatment and eventually succumbing to it, knows very well how cancer diagnosis and treatment affects a person physically and mentally. Her sister feels frustrated that she has now become a burden for Mrs E as she has to now take care of her young children and her. She keeps talking about wishing death, which makes Mrs E feel bad. Her sister has become more irritable and sadder since her diagnosis. She feels that instead of contributing to the family she is draining them financially. Mrs E also finds it draining when her sister feels frustrated as she has to put in more energy to make her feel better. She says *“I am doing my best to make her better. I feel sad that she feels that she is a burden to me. I am struggling but I would never consider her as a burden to me. After all I do, when she says such things, I wonder what else can I do? I feel hopeless at times”.*

Mrs E had been struggling to meet ends meet. She was unable to go for work as she was the primary caregiver. She was a daily wage worker. So, she got paid only on the days that she got work. All her savings were about to get exhausted. They had already exhausted all the saving of her sister. She was worried about the entire family's future. She sadly stated *"Whatever we had we have already used it all. I am worried about the future. I have two young children. I don't know what I will do with them. As any other mother, I also wanted to educate them, I wanted them to get good jobs and have a good and secure future, unlike my own. Today, standing here, all of that feels like a dream".*

She was unable to attend to the needs off her young children. When Mrs E had to come to Thiruvananthapuram along with her sister, her children stayed with the neighbors. They took care of their food. Even though they were young, they were able to manage with the support of their neighbors. She said *"Although both of them are very young, they understand the situation and act accordingly. They have never demanded anything from me. They have been taking care of themselves and also support me whenever possible. I feel sad that I am not able to provide them with the kind of childhood they deserve. But I am thankful to God for giving me two children who are very understanding and good".*

She shares that since she started her role as a caregiver her health has also started deteriorating. She felt tired as she got no rest. When she is taking care of her sister during the treatment, she has to assist her in all her daily activities. When she goes back home, she has to go for work, take care of her sister and children and complete all the household chores. She is worried to get herself checked as there is no one to take care of her if she is also sick.

She shares *"I am also experiencing some physical issue such as body pain. But I don't have the time to get it checked. I think it is because I exert myself a lot these days. In a way it is good that I don't get time to get myself a checkup. If God forbid something comes up in the tests, I'll be shattered. There's nobody to take care of me. I don't know if something happens to me, what would my family do".*

She added *"Both my body and mind are affected. I keep thinking about the future. It worries me. I stay awake at night thinking about my children. Who will take care of them if something happens to my sister and me? I don't know what will happen to my sister. She never lived her life. She lost many years caring for our father, now she is suffering from the same illness".*

Mrs E feels anxious about the future and finds it difficult to maintain sleep. She tries to keep herself busy to keep such thoughts away. She also mentioned that she has kept all her worries within her as she has nobody to vent her frustrations to.

"I have nobody to whom I can share by pain and sadness. I don't want to talk about my troubles to my sister or my children as I don't want them to become sad. So I try to act more positive in front of them. I have accepted that I cant do much in this situation."

The support from her neighbors and her firm belief in God are the two things giving her strength to move forward in life. Her neighbors are kind to provide her children with food and take care of them whenever necessary. They also provide her children with clothes and books occasionally.

She says *"After everything I had to go through in my life, I still feel that God is with me. Otherwise, I would not have survived this far. There are times when I question the point of life, but I know God keeps me moving forward. Praying helps me to feel positive. I don't have anyone else to share my sorrows with".*

CHAPTER V: THEMATIC ANALYSIS AND INTERPRETATION

THEMATIC ANALYSIS AND INTERPRETATION

5.1 OVERVIEW

Qualitative data analysis is the process in which we move from the raw data that have been collected as part of the research study and use it to provide explanations, understanding and interpretation of the phenomena, people and situation which we are studying. Thematic analysis emphasizes on pinpointing, examining and recording patterns or themes within the data available. The analysis covers the socio-demographic profile of the participants as well as the following themes: psychological challenges, social challenges and the coping strategies used by the participants involved in the study.

5.2 PROFILE OF THE CASES

Personal Profile of the Caregivers

Table 5.1

Personal Profile of Caregivers

Cases (Care Giver)	Age	Sex (Caregiver)	Relation to the patient	Education	Family Status	Religion	Occupation
1	63	Female	Mother	12th standard	Lower	Christian	Housewife
2	40	Male	Husband	10th standard	Lower	Hindu	Auto-rickshaw driver
3	45	Female	Sister-in-law	Degree	Middle	Hindu	Government employee
4	52	Male	Husband	Degree	Middle	Hindu	Bank employee
5	43	Female	Sister	8th standard	Lower	Hindu	Daily Wage

The profile of the participants gives a basic idea about their socio-economic background. The researcher conducted 5 case studies among them were 2 males and 3 females. 3 participants were from lower economic background while 2 were from middle class economic background. 2 participants had completed their undergraduation while 1 had completed schooling. Out of these, 4 participants were earning salary or wages while 1 participant was a housewife.

5.3 THEMATIC ANALYSIS

✓ Theme 1: Psychological Challenges

The psychological challenges faced by the caregivers of breast cancer patients include fear and anxiety, depression, stress, sleeplessness, emotional distress and guilt. From the data collected, it was found that all the participants faced psychological issues. All the cases reported that they were shocked by the cancer diagnosis and found it difficult to accept the situation. A few participants also expressed frustration with the situation and wondered why the patient had cancer. Based on the first theme, the following sub themes can be analysed.

➢ Sub Theme 1: Consternation

All the participants said that the cancer diagnosis was completely unexpected and could not believe it. It took time to accept the fact that their relative had breast cancer.

Case 1 stated: *"I could not believe that my daughter had cancer and it took me some time to accept the fact. I kept praying to God that my daughter gets better soon. I didn't want her to experience what her father went through"*.

Case 2 said*: "It was as if our whole life shattered in a moment. We could not believe it at all. Both of us were shocked and it took time to process everything"*.

Case 4 stated: *"When we came to know about the diagnosis, I could not even believe for a few days that what was happening was real. It took a lot of time to take it all in. Our daughter was inconsolable for a long time and seeing her made us even more sad"*.

When an unexpected event like a cancer diagnosis occurs, it is difficult for both the cancer patient as well as the caregiver to accept the situation. It is only after some time that they can fully understand the reality of the situation.

Zahlis, E. H., & Lewis, F. M. (2010). "Coming to grips with breast cancer: the spouse's experience with his wife's first six months" had talked about how spouses viewed the breast cancer diagnosis as unexpected, sudden, and emotionally overwhelming. In this study too, the caregivers as well as the patients found it sudden and unexpected and found it overwhelming.

- <u>Sub Theme 2: Fear of future</u>

The participants said that they were fearful of the future. One participant was worried how her daughter's treatment would proceed and whether there could be a relapse. Another caregiver was worried about how they would be able to manage the finances for the treatment in the future. The participants were anxious what would happen in the future. The two participants who took leave from their jobs and had to return were worried regarding who would take care of the patients once they returned to their jobs.

Case 1 said: *"I worry about her and her future. I know her treatment is going on and she will be able to overcome this situation but as a mother I worry. All these thoughts pop up in my mind during the night. I find it difficult to sleep properly, she has been married for 7 years now. They do not have kids. I do not know after all these treatments if she could have kids in future, also there is a high chance of relapse in such cases. I have met many people who thought their cancer is cured but after few years they relapse".*

Case 2 mentioned: *"All time I worry about my wife and my daughters. It's difficult to see what can I do in this situation".*

Case 3 recalled: *"I am worried what would happen after I leave as her husband has a job and therefore would require someone else to provide caregiving. I also feel slight guilt that I have to leave her, but with my leave expiring, I have no other choice."*

Pattern Matching and Rival Explanations

Table 5.2

Fear of future of caregivers

Case	Common fears	Other fears	Rival Explanation
1	Fear of patient's health and the impact of breast cancer	Fear of relapse	Fear of relapse is an issue which is faced by many caregivers and patients. However, in this study, only Case 1 mentioned this fear.
2 &5		Fear regarding financial sustainability	The patient and the caregiver belong to an economically weaker group. Therefore, they will have more concerns regarding the finances as compared to more well-off families.
3		Fear of who would provide caregiving after the participant leaves for her job	The caregiver took leave from her job to care for the patient. With the leave expiring, she was worried about who would take her place.

It can be seen that that the reasons for the fear of future varies from caregiver to caregiver. Depending on each caregiver the fear may be of relapse, economic sustainability or regarding who would provide caregiving once they leave.

- Sub Theme 3: Guilt

Among the participants, two of them stated that they felt guilt as a result of caregiving for the cancer patient. However, the reasons for guilt were different for them both. One participant stated that he felt guilty because he was not taking care of his wife properly. He also felt that he was not devoting time for his daughters. The other participant said that he felt guilty as had to leave his parents while taking care of his wife, but could not do anything in the situation.

Case 2 stated: *"I feel guilty as I sometimes feel that I cannot take care of my wife as much as I should be. My own state sometimes makes me think I am not taking care of her properly. I also feel guilty of not giving time for my daughters."*

Case 4 said: "*My parents used to manage with me and my wife. Now that we are not with them, they have to manage by themselves. I do feel guilty but I know I cannot do anything about it."*

Table 5.3

Reasons of guilt faced by caregivers

Case	Reason for guilt
2	Feeling of not taking care of patient properly
4	Having to leave parents at home while taking care of patient.

Feelings of guilt can be seen in caregivers due to varying reasons. In the study, two participants displayed guilt for varying reasons.

- Sub Theme 4: Hopelessness

In the study 2 participants who belonged to a lower class family stated that they felt hopeless in the current situation. One participant was struggling with the treatment expenses and was starting to feel depressed and hopeless about the future situation. Another participant was struggling with both health issues and financial issues.

Case 4 recalled *"I try not to display my frustration or sadness in front of my wife or daughters so as to not make the situation even more negative. But I really feel hopeless.*

Case 5 remarked *"I am doing my best to make her better. I feel sad that she feels that she is a burden to me. I am struggling but I would never consider her as a burden to me. After all I do, when she says such things, I wonder what else can I do? I feel hopeless at times".*

When experiencing a negative situation like caring for a family member with cancer, some caregivers face feelings of hopelessness. They may be facing situation in which they cannot see any solutions, leading to feelings of hopelessness.

- <u>Sub Theme 5: Sleeplessness</u>

In the study, two participants stated that they have experienced sleeplessness since they started caregiving for the breast cancer patients. One participant said that she struggles with sleep and it leads to headaches. The other participant stated that even though she does not feel much stress, her sleep has become disturbed ever since she started caregiving.

Case 3 mentioned: *"Even though I have not felt too much stress, since I came to Thiruvananthapuram my sleep has become disturbed and my appetite has gone down".*

Case 5 said*: "Both my body and mind are affected. I keep thinking about the future. It worries me. I stay awake at night thinking about my children. Who will take care of them if something happens to my sister and me?*

Taking care of a breast cancer patient places a lot of emotional and physical burden on the caregiver. This can lead to issues such as reduced sleep and sleeplessness.

- <u>Sub Theme 6: Depression</u>

From the study, it was found that two participants said they were feeling depressed due to the situation that they were facing. The first participant mentioned that she felt depressed whenever she thought about her daughter (Cancer patient) and would cry. The other participant was depressed by his wife's condition and due to their financial struggles.

Case 1 stated: "*I feel very depressed whenever I think about my daughter. Sometimes I cry alone. I don't know why God has given her cancer. I just hope she gets well as soon as possible".*

The caregivers who said they were depressed said that they felt sad regarding the condition of the patient. Another caregiver, who was from an economically weak family also had the problems managing the expenses which caused him distress and depression.

- ✓ **Theme 2: Social Challenges**

The social challenges faced by the participants of the study included changes in role, changes in daily routine, disruptions in social life, job issues and loneliness. These problems can be seen as interconnected. All the participant are from different districts and had to leave their homes and family for providing caregiving and this has led to many social challenges. The following sub themes can be analysed.

- ➢ Sub Theme 1: Role changes

All the participants experienced changes in the role in the aftermath of the diagnosis and becoming a caregiver. The participants included a housewife, bank employee, government employee, daily wage worker and auto-rickshaw driver. All had to experience role changes when they started caregiving for their family member.

- ➢ Sub Theme 2: Social Life

The participants revealed that their social life had been disrupted as a result of the caregiving for the cancer patient. They had lost touch with their relatives, neighbours and friends, stopped pursuing leisure activities and were devoted to taking care of the cancer patient. This is perhaps the biggest social challenge faced by the participants.

Case 2 stated: *"My interactions with family and friends became confined over mobile phone. But talking to them over the phone is much different than being with them. Both of us did not have much knowledge about her condition, treatment and other procedures and felt that we were at the mercy of the doctors. The fact that we did not know of many people in Thiruvananthapuram made us feel lonelier."*

Case 4 said: *"I used to go to work from 9 till 6 at the bank, then come home, spend some time with friends in the neighbourhood, have conversations with wife and parents and occasionally go out for walks or dinner with family. Now the entire routine had changed and I am all day involved in caring for my wife.*

- Sub Theme 3: Loneliness

Participants also stated that by leaving their families and caregiving can be a tough experience which makes them feel lonely. By giving up their hobbies and leisure activities, interactions with friends, family and neighbours and without physical help, the participants are socially isolated. The first participant stated that she used to go to church and spend time with friends. Another participant who was an auto-rickshaw driver also used to daily interact with fellow drivers and friends. Yet another participant wished if he had someone who could help him with caregiving.

Case 1 noted: *"Now that I am in Thiruvananthapuram I am always in a room. I miss my home and the comfort of having my neighbours around. I feel solitude as I don't know anybody in Thiruvananthapuram except my daughter."*

Case 2 remarked: *"My interactions with family and friends became confined over mobile phone. But talking to them over the phone is much different than being with them. Both of us did not have much knowledge about her condition, treatment and other procedures and felt that we were at the mercy of the doctors. The fact that we are away from our daughters and all the relatives and friends made us feel lonelier."*

Case 3 said: *"I miss my 2 sons and my husband and feel lonely sometimes but I take my responsibility as a caregiver seriously"*

Mor, V., Masterson-Allen, S., Houts, P. & Siegel, K. (1992) in their study titled, "The changing needs of cancer patients at home: a longitudinal view", examined the psychosocial impact of cancer on patient's primary caregiver. In the study, majority of caregivers reported reduced socialization with friends, neighbours and acquaintances as a result of the patient's illness regardless of age. Thus, it can be seen that living away from family members, friends and neighbours while taking care of the person with breast cancer can lead to feelings of loneliness.

- Sub Theme 4: Job Issues

In the study, four participants stated that they used to go to work before the cancer diagnosis was made. In the case of the participant who was an auto driver, he was forced to stop driving auto as he became involved in caregiving. The other 2 participants who worked as private bank employee and government employee, had to take temporary leave from their jobs to provide caregiving. A daily wage worker whose sister had breast cancer also struggled to earn income as she was not able to work anymore.

Case 2 reported: *"My wife has radiation 5 times a week. So, I have to stay with her the entire week. It's not worth to travel to Anchal and drive auto for one day. Because of this, I haven't driven auto for many months. This has caused us a lot of financial loss."*

Case 4 stated*: "I used to go to work from 9 till 6 at the bank, then come home, spend some time with friends in the neighbourhood, have conversations with wife and parents and occasionally go out for walks or dinner with family. Now the entire routine had changed and I am all day involved in caring for my wife."*

Table 5.4

Impact of Caregiving on Occupation

Case	Occupation	Impact
1	Housewife	
2	Auto-rickshaw driver	Unable to drive auto-rickshaw for income
3	Government employee	Temporary leave from employment
4	Bank employee	Temporary leave from employment
5	Daily wage worker	Unable to work while caring for patient

Four participants were involved in occupation when the cancer diagnosis of their relative was made. It can be observed that two participants with jobs in the informal sector (auto-rickshaw driver and daily wage worker) had to completely stop their work to take care of the breast cancer patient. Their condition was worsened by the fact that their economic condition was poor as compared to the other three participants. The other two respondents who worked in the formal sector (government employee and bank employee) had to take temporary leave from employment. But since they had to return to their jobs after their leave got over, they had worry about who would provide caregiving in their absence. In conclusion, caregiving has a great influence on the job status of the caregiver.

These findings are consistent with the results of a study conducted by Grunfeld, E., Coyle, D., Whelan, T., Clinch, J., Reyno, L., Earle, C. C. et al. (2004), the researchers in their study titled, "Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers" had mentioned that a majority of employed caregivers reported some form of adverse impact on work like missing work because of caregiving responsibilities.

- Sub Theme 5: Economic challenges

All the participants mentioned that as a result of the cancer treatment, the cancer patient and the family had to cope up with expenses for chemotherapy, radiation, drugs and surgery. One participant said that the patient was availing medical insurance which gave them some financial respite, but it was not enough. It was observed that the 3 patients who belonged to lower class families faced the greatest economic challenge. It was also seen that financial concerns of the caregivers also led to rise of psychological distress.

Case 1 stated *"As soon as the cancer diagnosis was made, I realized that we will have lot of expenses in treatment. That is why I decided that we will cut our expenditure on other things and would take a small loan for her medical expenses".*

Case 2 said *"My wife has radiation 5 times a week. So, I have to stay with her the entire week. It's not worth to travel to Anchal and drive auto for one day. Because of this, I haven't driven auto for many months. This has caused us a lot of financial loss."*

Case 5 remarked *"Whatever we had we have already used it all. I am worried about the future. I have two young children. I don't know what I will do with them."*

The economic challenge faced by the caregivers also had a relation to factors such as nature of occupation and family background. Those from lower economic background and those working in the informal sector faced more economic challenges as compared to the caregivers from higher economic background and having a job in the formal sector (where they could avail leave).

Cross Case Synthesis

Table 5.5

Economic Challenges

Case	Economic Background	Occupation	Economic Challenge
1	Lower	Housewife	Financial problems, low income of family. Dependent on son-in-law's income.
2	Lower	Auto-rickshaw driver	Severe problems - has taken many loans and cannot earn while taking care of wife.
3	Middle	Government employee	Financially well off. But worried about possible treatment expenses in future
4	Middle	Bank employee	Financially well off. Stated no economic problems
5	Lower	Daily wage	Severe problems – caregiver earns low wages and is worried about treatment expenses. Patient is poor as well.

Morgan, M. A., Small, B. J., Donovan, K. A., Overcash, J., & McMillan, S. (2011) conducted a study titled “Cancer patients with pain: the spouse/partner relationship and quality of life” which explained that receiving a diagnosis of cancer has a profound impact not only on patients, but also families. A spouse/partner is particularly affected not only because of fear and uncertainty of a life-threatening illness, but also, they must manage changes in role, pain, and financial threats in treatment costs and lost earnings. The results of the study also showed how the cancer diagnosis had an impact on the caregivers’ roles, financial threats due to treatment expenses and loss of earnings due to job disruptions.

- ✓ **Theme 3: Coping Strategies**

The coping strategies used by the participants can be broadly classified into: Problem Focused Coping, Emotion Focused Coping and Avoidant Coping. It could be observed that different participant used different strategies to cope with the stressors faced as caregivers of breast cancer patients.

- ➢ Sub Theme 1: Problem Focused Coping.

Problem Focused coping is a type of coping strategy that focuses on actively addressing and managing the specific problems or stressors that one encounters. It involves taking practical steps to directly deal with the root causes or demands of a stressful situation. Three participants of the study could be observed to use practical measures to help in their coping. One participant decided to manage their finances and take the help of her daughters in caregiving, which gave her some relief. The other participants either too advice from others regarding caregiving or started reading about it to reduce their caregiver burden.

Case 1 stated: *“As soon as the cancer diagnosis was made, I realized that we will have lot of expenses in treatment. That is why I decided that we will cut our expenditure on other things and would take a small loan for her medical expenses. When we go home, my daughters would help me with caregiving, providing me with some relief.”*

Case 3 said: *“I started reading a lot about caregiving including medication management, medical terminologies, and how to care for a cancer patient which has helped me a lot in caregiving. As our bond became stronger, I have felt a bit more comfortable to take care of her.”*

Case 4 mentioned: *"I have received advice regarding caregiving from my friend's wife, who is a nurse and also accept suggestions from others."*

In this study, 3 participants were seen to take measures to resolve problems faced in caregiving. The methods included cutting down on expenditure, reading about caregiving and taking advice regarding caregiving from others. These coping strategies were designed to address the problem rather than deal with the emotions or distracting from the issue. Thus, problem focused coping come under positive coping.

- Sub Theme 2: Emotion focused coping

Emotion focused coping is a type of coping strategy that involves managing and regulating one's emotional response to a stressful or challenging situation. Instead of directly addressing the problem itself, emotion focused coping aims to regulate the emotions associated with the stressor to promote emotional well-being. Four participants made use of emotion focused coping. Two participants mentioned that they try to adopt a positive mindset for coping and also to ensure that their loved ones don't get depressed. Another participant made use of yoga and meditation in order to control their emotions. Two other participants considered the situation as something given by God and tried to accept it.

Case 1 remarked: *"I always try to be positive and hope that in spite of the challenges that we are facing, things will get better sooner. I also try to be positive so that my daughter doesn't became depressed because of me".*

Case 3 said: *"Even though I am busy taking care of her, whenever I get time, I make sure to practice meditation and yoga. These have helped me a lot, something that I practiced even before starting taking care of my sister-in-law."*

Case 4 mentioned: *"I have accepted whatever occurs as something given by God. If I am not positive, then it would affect my wife's health."*

Case 5 stated *"After everything I had to go through in my life, I still feel that God is with me. Otherwise, I would not have survived this far. There are times when I question the point of life, but I know God keeps me moving forward. Praying helps me to feel positive. I don't have anyone else to share my sorrows with".*

The study involved participants who tried to cope with their emotional challenges as a caregiver in a number of ways. These included adopting a positive attitude, making use of yoga and meditation and accepting the situation as something given by God and trying to face it.

- Sub Theme 3: Avoidant Coping

Avoidant coping refers to set of strategies employed to avoid or escape from a stressor or a challenging situation. Instead of actively addressing the stressor or seeking solutions, avoidant coping involves minimizing or denying the problem, distracting oneself from the situation, or suppressing emotions associated with it.

In the study, two participants admitted to using avoidant coping. One of the participants, an auto-rickshaw driver, said that he used to watch Tv and use phone to distract himself. He had also started to drink more. Another participant stated that she and the cancer patient would discuss various topics to rid boredom and also to shift their focus away from the problem.

Case 2 said: *"I try to take my mind off this situation by watching TV shows and browsing internet on my phone, but it is not effective. Also, I have started to drink more, but it gives me relief only for some time".*

Case 3 stated: *"Both of us would talk about various topics such as cooking, gardening, TV shows and other things to avoid boredom and it also helped us to shift their focus away from the problems that we faced."*

Cross Case Synthesis

Table 5.6

Types of Coping used by Caregivers

Case	Problem Focused coping	Emotion Focused Coping	Avoidant Coping
1	Financial Management	Try to be positive	

2			Watching television and browsing internet. Substance use.
3	Reading about caregiving to help the patient better	Practice meditation and yoga	Talk about various topics to shift focus away from the problems
4	Received advice on caregiving from a nurse	Having belief in God to make things better	
5		Belief in God to provide emotional support.	Resigned acceptance

Out of the three participants who belonged to lower economic class family, only one mentioned financial management to cope with the financial crisis they faced. It could be observed that taking advice regarding how to provide caregiving was used to improve the quality of caregiving. Only a single participant admitted to using practices like yoga and meditation to control their emotions. Two participants said their belief in God was something which provided emotional support to them. One of them also accepted the situation as it is, but said nothing can be done. Case 2 remarked that he did not have the time to take care of his own health and was worried about his financial condition. Incidentally, he used only avoidant coping which was not successful for him. Case 3, an educated woman with a government job admitted to using various coping strategies in her role as caregiver and had the least fear of future. Her only worry was about leaving her role as caregiver after she went back to her job.

Jia H., Uphold C. R., Wu S., Reid K., Findley K., Ducan P. W. (2004). “Health-related quality of life among men with HIV infection: effects of social support, coping, and depression” divided coping responses into positive and negative. Positive coping refers to direct rational problem-solving, while negative coping refers to avoiding, withdrawing, or denying the problem. It can be seen that the participants used both type of coping in their role as caregiver of breast cancer patient. The positive coping strategies used by the caregivers included financial management, being positive, reading about caregiving, use of yoga and meditation etc. negative coping strategies used included use of substances and accepting the situation and believing that nothing can be done to change it.

Table 5.7 - Positive and Negative Coping Strategies

Case	Positive Coping Strategy	Negative Coping Strategy
1	Financial Management Positive Approach Attending religious service	Lashing out at daughter occasionally before apologizing to her.
2		Watching Television and browsing internet Alcohol use
3	Reading about caregiving Practicing meditation and yoga Discussing diverse topics with patient	
4	Receiving advice regarding for improving caregiving Belief in God for emotional support	
5	Belief in God for emotional support	Resigned acceptance regarding the situation

5.4 SUMMARY OF THE CHAPTER

The analysis of the data collected reveals how the participants of the study faced various psychological challenges such as shock, fear of future, guilt, hopelessness, sleeplessness and depression. In the case of some problems, all participants faced the issue while in the case of other problems only some faced the issue. They also faced social challenges such as role changes after becoming the caregiver, change in social life, loneliness, employment issues and economic problems. Some issues, such as role changes and change in social life were common to all participants of the study while other issues were faced by one or more participants. It could also be seen that the economic problems faced by the caregivers had some relation to the nature of employment as well as the economic class they belonged to. Finally, the researcher focused on the coping strategies adopted by the participants which were broadly classified into problem focused coping (directly focusing on problems faced as caregiver), emotion focused coping (strategies to address the negative emotions faced in as a result of caregiving) and avoidant coping (measures to avoid or shift focus from the stressors or emotions). The participants of the study made use of these types of coping strategies to deal with the psychological and social challenges they faced.

CHAPTER VI: FINDINGS, SUGGESTIONS AND CONCLUSIONS

FINDINGS, SUGGESTIONS AND CONCLUSIONS

6.1 FINDINGS

A) RESEARCH QUESTION 1: What are the psychological challenges faced by the caregivers of persons with breast cancer, as part of their role as a caregiver?

- All the caregivers experienced psychological challenges. The psychological challenges faced by the caregivers of breast cancer patients include fear and anxiety, depression, stress, sleeplessness, emotional distress and guilt.
- All the participants experienced consternation (distress as a result of unexpected event) due to the cancer diagnosis and found it difficult to accept the reality of the situation.
- Participants expressed fear of future. However, the reason for the fear was different for different participants. The reasons for fear included worry about the patient's health and possible relapse, arranging for finances for meeting treatment expenses, worry about who would take care of patient once the caregiver returned to their jobs etc.
- Participants also felt guilt as a result of caregiving for the breast cancer patient. The reasons for guilt differed from participant to participant and included feelings of not taking care of family members or leaving parents at home while taking care of the cancer patient.
- In the study, participants stated that they felt hopeless in the current situation. The reasons for feelings of hopelessness included struggles with meeting the treatment expenses and having both health issues and financial issues. In the study, it was the participants from the lower economic background who expressed hopelessness.
- In the study, participants stated that they have experienced sleeplessness since they started caregiving for the breast cancer patients.
- From the study, it was found that participants were feeling depressed due to the situation that they were facing. This feeling was due to factors such as thinking about the plight of the cancer patient and worries about managing the treatment expenses.

B) RESEARCH QUESTION 2: What are the social challenges faced by the caregivers of persons with breast cancer?

- The participants experienced changes in the role in the aftermath of the diagnosis and becoming a caregiver.
- The participants revealed that their social life had been disrupted as a result of the caregiving for the cancer patient. They had lost touch with their relatives, neighbours and friends, stopped pursuing leisure activities and were devoted to taking care of the cancer patient. This is perhaps the biggest social challenge faced by the participants.
- Participants also stated that by leaving their families and caregiving can be a tough experience which makes them feel lonely. By giving up their hobbies and leisure activities, interactions with friends, family and neighbours and without physical help, the participants are socially isolated.
- In the study, the participants who had jobs had to adjust to changes. The participants either had to stop working or take temporary leave from their jobs.
- The participants mentioned that as a result of the cancer treatment, the cancer patient and the family had to cope up with expenses for chemotherapy, radiation, drugs and surgery.
- The economic challenge faced by the caregivers also had a relation to factors such as nature of occupation and their family background. Those from lower economic background and those working in the informal sector faced more economic challenges as compared to the caregivers from higher economic background and having a job in the formal sector (where they could avail paid leave).

C) RESEARCH QUESTION 3: What are the coping strategies used by caregivers of cancer patients?

- The broad classifications of the coping strategies used by the participants of the study included Problem Focused Coping, Emotion Focused Coping and Avoidant Coping. It could be observed that different participant used different strategies to cope with the stressors faced as caregivers of breast cancer patients.

- The problem focused coping strategies used by participants included cutting down on expenditure, reading about caregiving and taking advice regarding caregiving from others. These coping strategies were designed to address the problem rather than deal with the emotions or distracting from the issue.
- The emotion focused coping strategies used by participants included adopting a positive attitude, making use of yoga and meditation and accepting the situation as something given by God and trying to face it.
- The avoidant coping strategies used by the participants included watching television and browsing internet to distract from the problem, drinking more alcohol than before and discussing random topics to shift their focus.

6.2 SUGGESTIONS:

- Awareness much be spread through various media about cancer specifically the increase in rate of breast cancer. Women can be taught on how to conduct self-examinations which would help them to seek treatment early. As with any cancer, early diagnosis and treatment helps in better prognosis.
- “Breaking the bad news” if done in a sensitive manner can help both the patients and their caregivers come to term with the reality in a better way. Giving them time to process the information and clarifying doubts can help people to feel in control over their situation thus reducing the trauma they might go through.
- Once a person is diagnosed with cancer, both the person as well as their caregiver should be educated about the diagnosis and the prognosis. This helps them to get a complete picture of their situation, clarify doubts and to make informed decision for future. A social worker can help them by giving them relevant information and facilitate them in their decision-making process.
- Both the patient as well as the caregiver can be taken as individual cases and a social worker can help in improving their psycho-social functioning. A social worker can provide psychological support such as providing counselling or referring to specialized professional as required. Social worker can also help the clients in social adjustment in various ways such as through environment modification, connecting them with community resource, resource mobilization etc. The social worker can also help the patients and caregivers to have an open conversation with one another and with the medical team.

- The caregivers can be educated about the impact of caregiving on their own health and various strategies to improve their health can be taught. Importance of taking care of oneself in terms of their own mental and physical health should be emphasized. They must also be encouraged to keep some time aside for themselves so that they do not feel fatigued.
- Emphasis should be given on helping the caregivers use positive coping mechanisms so that they are able to cope with their challenges in a constructive way. This would help the to build confidence in themselves and also reduce their feeling of guilt.
- Support groups can be formed for the caregivers so that they do not feel lonely. A support group would help them be in company of people with similar issues as them, where they would be free to share their concerns and get to learn from each other's experiences. Support group can also be educational or the members involved.
- The social support system should be strengthened so that such person receive support from within their communities itself so that the caregivers do not have to quit their jobs altogether. Certain policies can be formulated or new schemes can be introduced so that the caregivers get some type of financial assistance during their time as a caregiver, when they cannot go for work.
- Social Worker can act as a bridge between the caregivers and other resource providers within the hospital and the community. The concerns of the caregivers can be voiced by the social worker with various stakeholders to make the caregiver's life better.
- Social Worker can conduct further research in the area of breast cancer from various dimensions to understand the complexities – physical, psychological and social – associated with the disease and suggest interventions to facilitate better psychosocial functioning of those concerned.
- Educating the general public on the causes of cancer and the ways to prevent it is very important so that they can take appropriate actions. Making appropriate lifestyle changes is an important step in ensuring better health. After all, "prevention is always better than cure".

6.3 CONCLUSION:

Cancer is a large group of disease that can start in almost any organ or tissue of the body when abnormal cells grow uncontrollably, go beyond their usual boundaries to invade adjoining parts of the body and or spread to other organs. It not only changes the lives of those affected with it but also has a significant impact on the caregivers who dedicate their life intaking care of their loved ones with Cancer. The findings of the study shows that the caregivers experienced challenges in their physical, psychological, economic and social aspects of their lives as part of their role as a caregiver. Along with the pressure associated with taking care of a person with cancer, the challenges faced in various aspects of their lives in turn made the caregivers' lives difficult. It was found that to deal with their challenges the caregivers employed coping strategies – both positive and negative ones. As the cancer rates are increasing at an exponential rate, the number of people stepping into the role of a caregiver are also increasing. While the health care system focuses on the persons with cancer, their caregivers are not given due attention. As this study shows, the caregivers face many challenges and adopt various coping strategies to handle these challenges. It is important that they also receive additional support so that they can not only support their loved ones but also live a dignified life themselves.

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ANNEXURE

SOCIO - DEMOGRAPHIC DETAILS

1. Name:
2. Age:
3. Sex:
    a) Male
    b) Female
    c) Transgender
4. Religion:
    a) Hindu
    b) Christian
    c) Muslim
    d) Others

5. Level of Education:
    a) Illiterate
    b) Primary
    c) SSLC
    d) Upto 12th
    e) Degree and above

6. Type of family:
    a) Joint family
    b) Nuclear Family

7. Marital status:
    a) Unmarried
    b) Married
    c) Divorced/Widowed

8. Employment status:

    a) Employed
    b) Unemployed

9. Financial Status:
    a) APL
    b) BPL

10. Relation with the patient:

11. Stage of breast cancer of the patient:
    a) Stage 1
    b) Stage 2
    c) Stage 3
    d) Stage 4

12. Time since diagnosis:

    1 Year to 3 years

    3 Years to 5 years

    5 Years to 10 Years

    Above 10 years

13. Years of caregiving:
    a) 1 Year to 3 years
    b) 3 Years to 5 years
    c) 5 Years to 10 Years
    d) Above 10 years

14. Do you have any other family member who has ever been diagnosed with cancer?

Psychological challenges faced by caregivers as part of their role as caregivers

- How has the diagnosis and caregiving impacted your daily routine?
- Explain the changes that you have noticed after becoming the caregiver of the patient and how has it affected your mental health?

- How did you feel after the cancer diagnosis was made?

Social challenges

- How do you describe your relationship with others (family and friends) prior to and during the role as a caregiver?
- How do the people around you perceive your situation?
- How has your role as a caregiver affected your social life?
- Do you receive help in caregiving from others? If yes, how has it helped you in your life?

Coping strategies

- In what ways are you trying to deal with your stress as a caregiver?
- How do you deal your emotional issues as a part of overcoming your stress?
- What all measures do you take to shift your focus from the problem when you are stressed?