



A Study on Psycho Social, Emotional and Spiritual Needs of Caregivers in Home Care Settings

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ABSTRACT

Social work in oncology settings are in a developing stage comparable to other branches of medicine such as psychiatry. Yet it is important and necessary for social workers to engage in this particular field and broadening the understanding of cancer clients various psycho social, financial, emotional and spiritual issues. Palliative care is a branch of medicine that generally deals with end of life or patients suffering from terminal illness such as severe heart problems, neurological disorders and cancer. This branch focuses on providing treatment that helps the patient to ease the pain and has the philosophy of "Quality of Death". In the western countries, social workers are an integral part in various palliative care settings and established procedures of working in the palliative care settings are laid down by National Association of Social Workers. In India palliative care was introduced very late and gained importance during 1990's and the involvement of social workers in palliative care in India is also very minimal. The researcher finds that due to the lack of literature on palliative care social work of India and particularly in the field of cancer is the reason that the practice of palliative care social work is minimal in oncology settings. There are many literatures addresses the psycho social and emotional issues of clients with cancer while undergoing the treatment and during the recovery process. Yet there are no literatures on caregiver focussed psycho social, emotional and spiritual issues. This study will be addressing the same and try to bring interventions from social work. This study will also act as a preliminary study in creating literature of palliative care social work with regards to cancer setting.

Keywords: Palliative care, Oncology, Social Work and Mental Health

1. Introduction

"Health is a state of complete physical, mental and social well being and not merely the absence of disease or infirmity" An important implication of this definition is that mental health is more than just the absence of mental disorders or disabilities (WHO, 1948). It is indispensable to explain about disease which is one of the important components that affect health, even though it is not the only component to be taken care of. Disease can be explained as any harmful deviation from the normal structural or functional state of an organism, generally associated with certain signs and symptoms and differing in nature from physical injury. Though it is complicated to draw the boundary between health and disease, the concept of disease can be understood through the signs and symptoms with a proper pre analysis of normality of a person.

The diseases can be divided into two based on the transmission ability such as communicable and non communicable diseases (Burrows & Scarpelli, 2023). As per World Health Organisation (WHO), Non communicable diseases (NCDs), also known as chronic diseases have the tendency to be in longer duration and it can be a result of a combination of genetic, physiological, environmental and behavioural factors. Some of the main types of non communicable diseases are cardiovascular diseases such as heart attacks and stroke), cancers, chronic respiratory diseases (such as chronic obstructive pulmonary disease and asthma) and diabetes.

The data from WHO also emphasises that people belonged to low and middle income countries are prone to have NCD diseases and more than three quarters of global NCD deaths, which is 31.4 million occur in those countries. Some of the risk factors mentioned by WHO for the increase spread of non communicable diseases are unplanned urbanisation, globalisation of unhealthy lifestyles and population ageing. These are called metabolic risk factors and can lead to many NCDs particularly cardiovascular diseases that have the high tendency in premature deaths. Cancer is one of the major life

threatening non communicable diseases in the world and in particular to India, the cases are rising in alarming manner. According to the Indian council of Medical Research- National Cancer Registry Programme (ICMR- NCRP), the number of cancer cases in the country is projected to go up from 14.6 lakh in 2022 to 15.7 lakh in 2025 (Cancer cases India, 2023).

The union government of India has a National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular diseases and Stroke (NPCDCS) under National Health Mission to address the issue.

As per revised guidelines of NPCDCS 2013-2017, the common cancers of India are breast, cervical and oral cancer. Apart from the above mentioned risk factors for non communicable diseases, the NPCDCS also mentioned some major factors such as tobacco use, alcohol use and physical inactivity as life style behavioural risk factors. The biological risk factors are overweight, high blood pressure and raised blood sugar. There are certain non modifiable risk factors such as age, sex and heredity also associated with the occurrence of NCD's.

For any diseases that can be communicable or non communicable, the psychological and social components should be taken into consideration for the treatment of a client. In Oncology there are two major types of treatment such as cancer directed and non cancer directed treatment. In the cancer directed treatment, the treatment will be targeted directly through a specific therapy which modifies controls, removes or destroys cancer tissue. In the non cancer directed treatment, there are five major types such as Surgery, Radiotherapy, Chemotherapy, Immunotherapy and Hormone therapy. Palliative care is also known as supportive care which is required in the terminal cases of Cancer, AIDS etc. and can be provided relatively simply and inexpensively. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources. It can be provided in tertiary care facilities, in community health centres and even in patients' homes. It improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement.

In both of the treatment procedures, the palliative care plays a role as non curative and removing the obstructing tissues. Yet in the oncology settings, the palliative care emphasises more on the psychological and social components of the terminally ill clients. This research study will explore the psycho social, emotional and spiritual needs of caregivers in home care settings and a comprehensive study of the home care team approach in the treatment of clients. Additionally from the research findings, the researcher will be explaining the role of social worker and the interventions that can be brought from the field of social work to the department of palliative (Home Care).

2. Research Methodology

Research Design-Descriptive; the design of the research was descriptive since it involved the assumption that the psychosocial, emotional, spiritual needs of caregivers in home care settings can be addressed by the skills and efficiency of social workers.

Type of Research- The research was done qualitatively and the data was collected through primary data collection by using overt observation and semi structured interview as the methods of data collection and secondary data from journals and research in the field of oncology social work and palliative social work.

The researcher used the **Purposive Sampling process** for data collection; Sampling Plan- The estimated sample size of the participants was N=10

Inclusion Criteria:

- Primary Caregiver
- Caregivers of the client with terminally ill cancer' and the clients must be receiving treatment from Rajiv Gandhi Cancer Institute.

Exclusion Criteria: Other family members were excluded, even though they came under the category of caregivers.

Ethical Complications: Confidentiality was strictly maintained and the informed consent was received from the participants during the data collection.

Objectives of the research

- To study the psychological and social needs of the caregivers.
- To assess the spiritual needs of the caregivers.
- To understand and study the homecare team's approach.
- To suggest the suitable social work intervention for the caregivers.

1. Working definitions of the research study

Cancer- According to World Health Organisation (WHO) Cancer is defined as 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.

Clients- As per the National Association of Social Workers (NASW) in its code of ethics, clients are used inclusively to refer to individuals, families, groups and communities.

Caregivers- Although there is no single definition for caregiver due to its applicability in different context, the definition from marian Webster dictionary will be the operational definition for the study. The meaning of caregiver is a person who provides direct care (as for children, elderly people, or the chronically ill)

3. RGCIRC- History of the organisation

Indraprastha Cancer Society and Research Centre, is a “not for profit organization”, formed under the Societies Registration Act 1860 and it had set up Rajiv Gandhi Cancer Institute and Research Centre, a standalone oncology care centre, in Delhi, in 1996. The founders of the society are a group of socially responsible selfless philanthropists, who had no financial resources but by their hard work and sheer determination, were able to, initially, raise money for running the hospital. Quality, affordability and easy access, for the patients suffering from cancer were the main motivating factors for setting up of the Hospital. RGCIRC is a great example of a “not for profit organization” supplementing government efforts in the area of healthcare. Rajiv Gandhi Cancer Institute and Research Centre is today counted amongst Asia’s premier exclusive cancer centres that offer unique advantage of cutting edge technology, put to use by renowned super specialists. This potent combination of man and machine ensures world-class cancer care to not only patients from India, but also from the neighbouring SAARC countries and others. The institute is fortunate to have touched the lives of more than 2.75 Lakh patients since inception in 1996. RGCIRC has been consistently ranked amongst India’s Best Oncology Hospitals, and has been the recipient of many awards, including National Business Leadership & Service Excellence Award 2017 for Best Oncology Hospital in India, Indywood Medical Excellence Award 2017, Most Trusted Hospital in Oncology 2017 by India Today (Reader’s Digest)

4. Organisation Objectives

RGCI & RC is committed to bringing the benefits of cutting edge technology to its patients.

The Institute offers best in class techniques such as whole-body robotic surgery, Intraoperative Brachytherapy, True Beam (the next generation Image Guided Radiation Therapy), PET- MRI fusion, High Frequency Ultrasound, Tomosynthesis (first-of-its-kind revolutionary 3D mammography machine), Nucleic Acid Testing (for safest possible blood), and advanced diagnostic and imaging techniques, including Digital PET CT, Circulating Tumour Cell testing, liquid biopsy, and Next Generation Sequencing. The institute has established Molecular Laboratory for gene profiling, Biorepository (Tissue Bank) for clinical and research purpose and a dedicated Cath Lab for cancer patients has been started to do all interventional radiology procedures, few such as portal venous embolization, carotid artery embolization, TACE, TARE etc.

The Institute offers super specialized tertiary care services in Medical, Surgical and Radiation Oncology by dedicated Site-Specific teams and super specialists at RGCI & RC practice an organ specific multi-disciplinary approach to cancer diagnosis and treatment, with the Tumour Board acting as a second opinion clinic for cases that are more critical than others.

In line with the RGCI & RC quality policy, “to do things right first time and every time” the safety of our patients is of paramount importance. The institute is committed to providing the highest-quality, safest care for all patients. The institute’s approach to patient care reflects our commitment to safety, effectiveness, patient centeredness, timeliness, efficiency and equity.

4.1 Vision

- To Provide Affordable Oncological Care of International Standard and Help
- To Eliminate Cancer from India through Research, Education, Prevention & Patient care

4.2 Mission

- To be the premier cancer care provider in India and be the preferred choice of Patients, Care Givers, Faculty and Students
- By offering comprehensive services at an affordable price and excellence of our personnel leveraging best technology

4.3 Goals

- The institute hold their patients in high esteem and works with ethics and compassion.
- The institute care and function with mutual respect, trust and transparency
- The institute delivers accurate diagnosis, correct advice and effective treatment.

4.4 Regarding client specific goals

- Hold patients in high esteem
- Transparency
- Proper Diagnosis
- Proper Treatment and Correct advice to the patients

4.5 Regarding staff (Medical & Paramedical)

- Teamwork
- Mutual respect and Trust

The major cancer treatment options are surgical treatment, chemotherapy, radio therapy and hormone therapy. But today various immunological therapies, as well as smart drug delivery methods, are also being used for targeted drug delivery and quicker cure. There are many varieties of cancer treatment drugs available in the market today.

The drugs are used in combination with other cancer treatment options for faster and better results. Cancer therapy is customised or personalised as per the patients. That's why its treatments vary from person to person. The treatment option may be influenced by the cell type, location of tumour, distribution and the patient's condition and other illness symptoms. Even the pros and cons of a treatment on a particular patient are assessed beforehand.

4.5 Department of Pain, Palliative and Home Care

At RGCI, a robust Pain and Palliative Care services are integrated with oncology care ever since its inception. The department comprises of Pain, Palliative and Home care services managed by three consultants and a home care team with a qualified doctor, palliative care nurse and a medical social worker.

The Department offers comprehensive care for all chronic pain problems, symptom management, home care services, bereavement counselling (online in covid-19 times) with a face to face support maintaining confidentiality which offers caregivers to express their thoughts and worries, planning end of life, support to children and their parents. The benefits of patients are many and some of the important services are for

- Low back pain with sciatica
- Nerve entrapments
- Neck and Arm pain
- Neuropathic pain and post stroke pain

The home care team recognizes and provides optimum patient care where it is at most needed i.e. in patient's home according to the needs of patients and their families. The team pledges to provide supportive services to the patients with incurable illness, regardless of age, race and religion. The service is available throughout Delhi NCR and it will be done through free of cost for patients registered with RGCI & RC

In the department, the role of home care team involves

- A qualified Doctor, a Nurse & Medical social worker / Counsellor visit at their door step
- Clinical assessment
- Symptomatic treatment and providing patients and families an opportunity to talk and understand how to manage predictable symptoms at home efficiently and not to panic.
- Nursing care & Procedures
- Educate caregivers to use easy homemade sterile dressings for wound care.
- Health education to patient and relatives
- Counselling and Emotional support for patients and family members to help reconcile psychosocial and spiritual issues.
- Work towards improvement of quality of life in their own environment and provide comfort to patient and their family
- The doctors and nurse become confidante and clinician, friend and counsellor, all at once to the patient as well as the caregivers.
- Knowledge to caregivers about preparation of home based mouth wash, Vaseline gauge and bed sore dressing ointment.

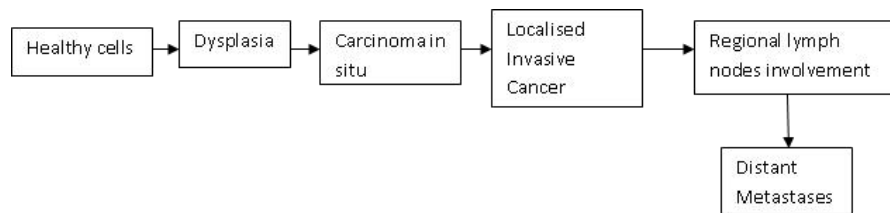
5. REVIEW OF LITERATURE

5.1 Cancer

Among the non communicable diseases, cancer is a life threatening disease and it is increasing in a rapid manner in India due to the change in lifestyle habits. Cancer is referred as a disease in which some of the body's cells grow uncontrollably and spread to other parts of the body. It can start almost anywhere in the human body. The cell division process is about forming new cells by replacing the old ones. Sometimes this process will break down and abnormal or damaged cells grow and multiply.

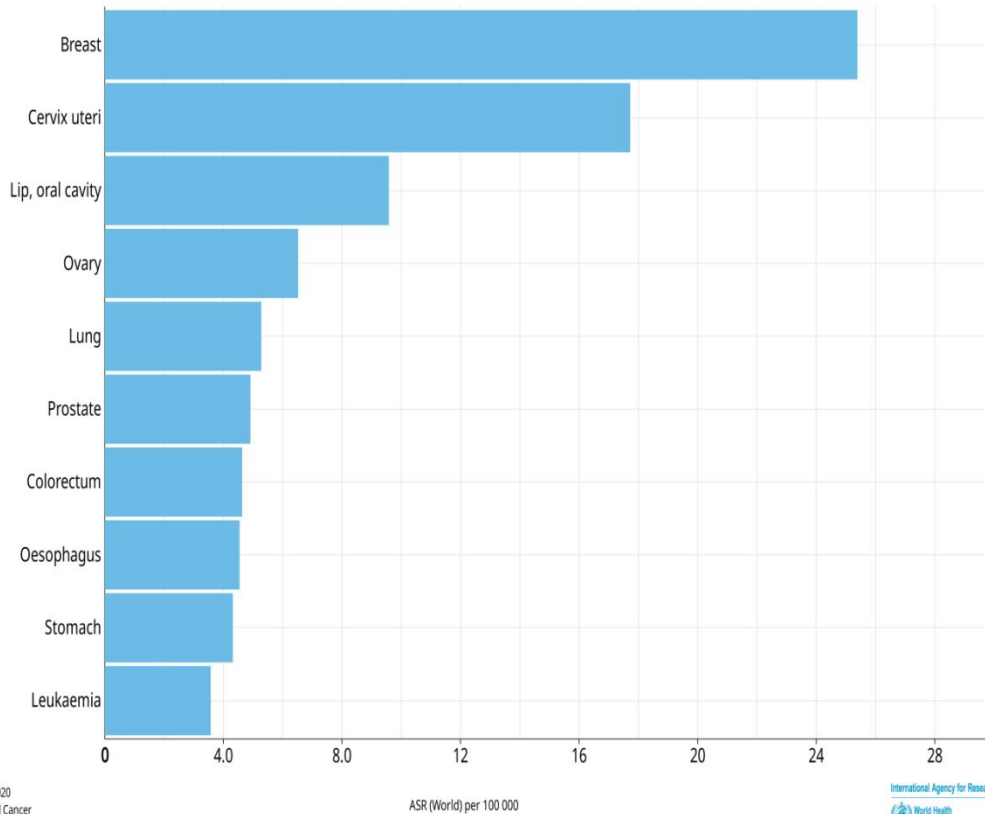
These cells may form tumours, which are lumps of tissue and those can be cancerous or non cancerous. Cancerous tumours spread or invade into other tissues and form new tumours called **metastasis** (What is cancer, 2021).

A **tumour** is said to be benign when its characteristics are considered relatively harmless suggesting that it wouldn't spread to near-by or distant areas, can be operated easily and doesn't risk the patient's life significantly. **Malignant tumours** are collectively referred to as cancers, derived from the Latin word crab, because they involve the tissues in a manner similar to a crab.



Malignant tumour can invade and destroy adjacent structures and spread to distant sites (metastasize) to cause death (Cancer, n.d). As per the (Globocan, 2020), a global cancer observatory to analyse the spread of different type of cancers in various countries found that the top three and most common type of cancers are Breast, Cervix uteri and Lip, oral cavity. These findings can be compared with NPCDCS findings of most common cancers that are prevalent among people in India. Additionally on the cancer registry data it is estimated that there will be about 800,000 new cancers cases in India every year. At any given point there is likely to be 3 times this load that about 240,000 cases. Cancer sites associated with tobacco form 35 to 50% of all cancers in men and about 17% of cancers in women. These cancers are amenable to primary prevention and can be controlled to a large extent (Varghese, n.d).

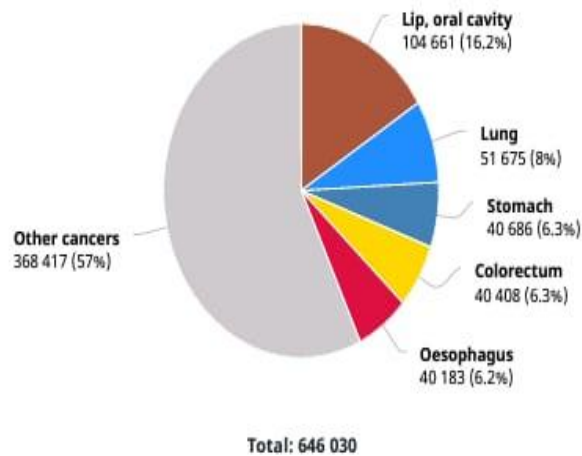
Estimated age-standardized incidence rates (World) in 2020, India, both sexes, ages 0-84 (excl. NMSC)



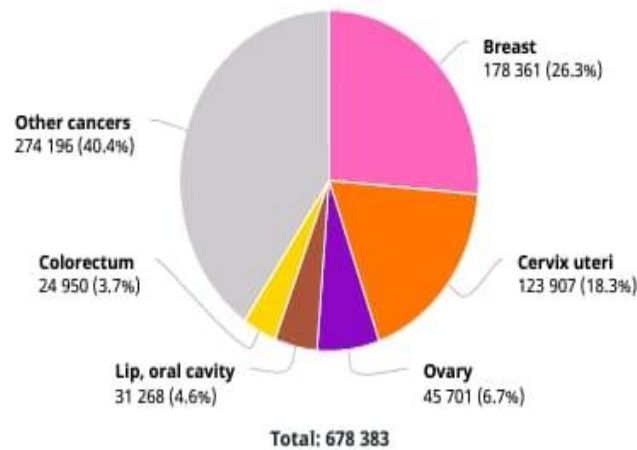
Summary statistic 2020

	Males	Females	Both sexes
Population	717 100 976	662 903 415	1 380 004 378
Number of new cancer cases	646 030	678 383	1 324 413
Age-standardized incidence rate (World)	95.7	99.3	97.1
Risk of developing cancer before the age of 75 years (%)	10.4	10.5	10.4
Number of cancer deaths	438 297	413 381	851 678
Age-standardized mortality rate (World)	65.4	61.0	63.1
Risk of dying from cancer before the age of 75 years (%)	7.4	6.7	7.1
5-year prevalent cases	1 208 835	1 511 416	2 720 251
Top 5 most frequent cancers excluding non-melanoma skin cancer (ranked by cases)	Lip, oral cavity Lung Stomach Colorectum Oesophagus	Breast Cervix uteri Ovary Lip, oral cavity Colorectum	Breast Lip, oral cavity Cervix uteri Lung Colorectum

Number of new cases in 2020, males, all ages



Number of new cases in 2020, females, all ages



Source: Globocan, 2020

5.2 Breast Cancer

Though breast cancer has different types such as various forms of tumours, a generalised description of breast cancer is explained in the WHO classification of the tumours of the breast. Worldwide the invasive breast carcinoma is the most common carcinoma and in India it accounts for nearly 26.3% of women cancer patients. The probable occurrence of breast cancer increases with age and the prognosis for patients with this disease is very good, if it is detected in an early stage. When it comes to the origin of breast cancer, it has multiple factors just like any non communicable diseases that may have a combination of different factors such as diet, reproductive factors and hormones. The epidemiological data clearly proved that the breast cancer is a disease of affluent “western lifestyle” which is a high calorie diet rich in animal fat and proteins combined with a lack of physical exercise. Yet in India some of the other risk factors are also responsible such as obesity, alcohol, prolonged exposure to radiation and exogenous hormones are also responsible (Lakhani et.al 2011).

Breast cancer is a heterogeneous disease and it encompasses a variety of entities with distinct morphological appearances and clinical behaviours. In recent years, it has become evident that this diversity is the result of genetic alterations (Badve et al., 2011). One of the prominent forms of Breast Cancer is Triple Negative Breast Cancer and it is caused through the absence of Estrogen receptor (ER), progesterone receptor (PR) expression and no over expression of HER2 is typically associated with a poor prognosis, due to the aggressive tumour phenotype. The recurrence pattern of TNBC also differs from other biological subtypes of cancer.

A protein found inside the cells of the female reproductive tissue, some other types of tissue, and some cancer cells. The hormone estrogen will bind to the receptors inside the cells and may cause the cells to grow (NCI Dictionary, n.d). [Progesterone receptor](#) (PR) belongs to the super family of [steroid receptors](#) and mediates the action of [progesterone](#) in its target tissues (Recouvreur et al., 2013) and HER2 is a protein that helps breast cancer cells

grow quickly. Breast cancer cells with higher than normal levels of HER2 are called HER2-positive. These cancers tend to grow and spread faster than breast cancers that are HER2-negative, but are much more likely to respond to treatment with drugs that target the HER2 protein (Breast Cancer- HER2 Status, n.d).

5.3 Cervix Uteri

Globally, cervical cancer continues to be one of the most common cancers among females, being the fourth most common after breast, colorectal, and lung cancer. GLOBOCAN 2020 estimated that, worldwide, there were approximately 604 000 new cases of cervical cancer, with 342 000 deaths annually. The majority of new cases and deaths (approximately 85% and 90%, respectively) occur in low-and middle-income countries (LMICs), where it is the third most common cancer among women (Bhatla et al., 2021). The cervix is the lowermost part of the uterus and is a cylindrical structure composed of stroma and epithelium. The ectocervix, which projects into the vagina, is lined by squamous epithelium. The endocervical canal, which extends from the internal os to the external os, is lined by columnar epithelium. Almost all cases of cervical carcinoma originate from the ecto-or endocervical mucosa in the transformation zone, the area of the cervix between the old and new squamocolumnar junction. This type of cancer is a rare long term outcome of persistent infection of the lower genital tract by one of about 15 high risk Human Papilloma Virus (hrHPV) types, which is termed the necessary cause of cervical cancer. The reason to say persistent infection is because of the presence of the same type specific HPV DNA on repeated sampling after 6-12 months. Studies showed that more than 80% of women followed over time will acquire at least one hrHPV infection, which shows the pervasive nature of the virus and its transmission. Yet only one tenth of all infections become persistent and these women could develop precancerous lesions. The knowledge of HPV epidemiology by stating the fact that a viral infection should be the necessary cause of the infection helped the countries to come up with strategies to tackle the spread of cervical cancer. The two important strategies are

- HPV vaccination
- Screening for precancerous lesions.

The World Health Organisation under the global strategy to accelerate the elimination of cervical cancer as a public health problem proposed a percentage strategy of vaccine and treatment that is 90%-70%-90%

- 90% of girls fully vaccinated with two doses of HPV vaccine by the age of 15 years;
- 70% of women screened using a high-performance screening test at the age of 35 and 45 years; and
- 90% of women detected with cervical lesions to receive treatment and care

5.4 Lip, Oral Cavity

Thomson (2019) explained that the Oral Squamous Cell Carcinoma (SCC) arises from the mucosal lining of the mouth, accounts for over 95% of all oral cancer cases and it is not only one of the most frequent head and neck malignancies but also one of the commonest cancers to affect the male population worldwide. The presence of cancer is clinically as non healing ulcerative lesions due to epithelial destruction and subsequently irregular, raised, invasive and ultimately painful tumour masses due to continued growth. The scientific study of the factors responsible for the malignant transformation of Oral Squamous Cell Carcinoma (SCC) is the excessive consumption of tobacco products, alcohol misuse and betel quid. The betel quid is more specific to the South Asian region that the mixture is consumed with or without tobacco by wrapping it with betel leaf. The attribution of oral cancer is mainly coming from the usage of tobacco and it can be either smoking or non smoking tobacco usage associated with higher dose dependent. There are various harmful carcinogens found in tobacco such as the aromatic hydrocarbon benzopyrene and tobacco specific nitrosamines (Anatharaman et.al. 2011).

When it comes to the role of alcohol consumption as a factor in the development of Oral Squamous Cell Carcinoma (SCC), it accounts for nearly 7 to 19% of oral cancer cases and it is based on the amount of consumption per day. The consumption of alcohol further leads to the DNA damage because it is metabolised in the body to the known carcinogen acetaldehyde resulting in damaging the epithelial cells (Marron et. al., 2012).

Though these are the known factors for the risk in developing oral cancer, people who didn't overexpose to the above factors are also developing cancer. This shows that there are certain additional risk factors are also involved in developing the oral cancer. They are

- Poor diet and Nutrition
- ageing
- an impaired immune response
- low socio economic status
- short stature
- manual occupations and poor oral health

Though these are certain additional risk factors, their role is obtuse and studies are undergoing to prove these factors as an additional one (Diajil and Thomson, 2016).

6.5 Palliative Care and Social Work

As per the World Health Organisation, Palliative care defines as *“an approach that improves the quality of life of patients and their families facing the problem associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”* (WHO, 2016) Compared with the definition of health, the palliative care includes the spiritual component of client’s and caregivers.

As per **United Nation’s committee on economic, social and cultural rights**, Palliative care is considered as **human right to health** under general comment 14- sub clause 34; *which is that states are obliged to respect the right to health by, inter alia, refraining from denying, or limiting equal access for all persons to preventive, curative, and palliative health services* (CESCR, 2000).

Generally palliative care treatment includes diverse range of disorders and conditions such as **cardiovascular diseases, cancer, respiratory, HIV/AIDS, diabetes, Parkinson’s, neurological illness, other chronic mental illness, spinal cord injuries and drug resistant tuberculosis** (Rajagopal and Venkateswaran, 2003).

In India there is a National Programme on Palliative Care (NPCC) under National Health Mission which defines *Palliative care as a supportive care which is required in the terminal cases of Cancer, AIDS etc. and can be provided relatively simply and inexpensively*. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources. It can be provided in **tertiary care facilities, in community health centres and even in patients’ homes**. It improves the **quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement**. The Ministry of Health & Family Welfare constituted an expert group on Palliative care which submitted its report ‘Proposal of Strategies for Palliative Care in India’ in November, 2012. On the basis of the Report, a palliative care note for 12th Five Year Plan was formulated. No separate budget is allocated for the implementation of National Palliative Care Program. However, the Palliative Care is part of the ‘Mission Flexipool’ under National Health Mission (NHM).

According to the National Association of Social Workers (NASW), *“clinical social work practice is the professional application of social work theory and methods to the treatment and prevention of psychosocial dysfunction, disability, or impairment, including emotional and mental disorders. The practice works with the goal of enhancement and maintenance of psychosocial functioning of individuals, families, and small groups.”*

Palliative care social work (PCSW) has developed primarily as a specialist health related form of clinical social work and has been recognized and recommended as a necessary and appropriate part of palliative care. The goal of palliative care and social work is one and same that to improve the overall quality of life of those who are suffering from any kind of problems (Payne, 2007).

Palliative and end of life care is a growing area of practice, and social workers may require knowledge and often unprepared to deal with the complex issues it encompasses (Csikai & Raymer 2003; Christ & Sormanti, 1999). Therefore certain standards are designed to enhance social workers’ awareness of the skills, knowledge, values, methods, and sensitivities needed to work effectively with clients, families, health care providers, and the community when working in end of life situations. The standards are

Ethics and Values: The values, ethics, and standards of both the profession and contemporary bioethics shall guide social workers practicing in palliative and end of life care. The NASW Code of Ethics (NASW, 2000) is one of several essential guides to ethical decision making and practice.

Knowledge: Social workers in palliative and end of life care shall demonstrate a working knowledge of the theoretical and biopsychosocial factors essential to effectively practice with clients and professionals.

Assessment: Social workers shall assess clients and include comprehensive information to develop interventions and treatment planning.

Intervention/Treatment Planning: Social workers shall incorporate assessments in developing and implementing intervention plans that enhance the clients’ abilities and decisions in palliative and end of life care.

Attitude/Self-Awareness: Social workers in palliative and end of life care shall demonstrate an attitude of compassion and sensitivity to clients, respecting clients’ rights to self-determination and dignity. They shall be aware of their own beliefs, values, and feelings and how their personal self may influence their practice.

Empowerment and Advocacy: The social worker shall advocate for the needs, decisions, and rights of clients in palliative and end of life care. The social worker shall engage in social and political action that seeks to ensure that people have equal access to resources to meet their biopsychosocial needs in palliative and end of life care.

Documentation: Social workers shall document all practice with clients in either the client record or in the medical chart. These may be written or electronic records.

Interdisciplinary Teamwork: Social workers should be part of an interdisciplinary effort for the comprehensive delivery of palliative and end of life services. They shall strive to collaborate with team members and advocate for clients' needs with objectivity and respect to reinforce relationships with providers who have cared for the patient along the continuum of illness.

Cultural Competence: Social workers shall have, and shall continue to develop, specialized knowledge and understanding about history, traditions, values, and family systems as they relate to palliative and end of life care within different groups. Social workers shall be knowledgeable about, and act in accordance with, the NASW Standards for Cultural Competence in Social Work Practice (NASW, 2001).

Continuing Education: Social workers shall assume personal responsibility for their continued professional development in accordance with the NASW Standards for Continuing Professional Education (NASW, 2002) and state requirements.

Supervision, Leadership, and Training: Social workers with expertise in palliative and end of life care should lead educational, supervisory, administrative and research efforts with individuals, groups, and organizations. These are the standards that a social worker must follow while engaging in the field of palliative and end of life care. (Palliative and End of life Care, 2004) Though palliative care was introduced in India during 1980's, the department gained attention in major medical as well as non medical fields such as social work. Social Work as a discipline empowers, advocates, assists and research about issues of the people. Since the palliative (Home care) involves the components of psycho social and emotional well being of the clients and caregivers, the role of social workers are indispensable.

6. RESEARCH FINDINGS

7.1 General Information

7.2 Respondents and Sex

In order to maintain the anonymity of the respondents, their names are not mentioned in the information. The respondents are codified from **R1-R10** and cross tabulated with their respective Sex.

Respondents	Sex	Age
R1	Male	37
R2	Male	36
R4	Male	56
R6	Male	49
R3	Female	41
R5	Female	40
R7	Female	63
R8	Female	74
R9	Female	59
R10	Female	42

Although all respondents are caregivers of terminally ill patients, some of the observed types of client's cancers are oral and breast cancer and that was found among four clients.

7.3 Age and Sex

The average age of male caregivers from the calculated responses is 44.5 years and for the female caregivers it is 53.16 years.

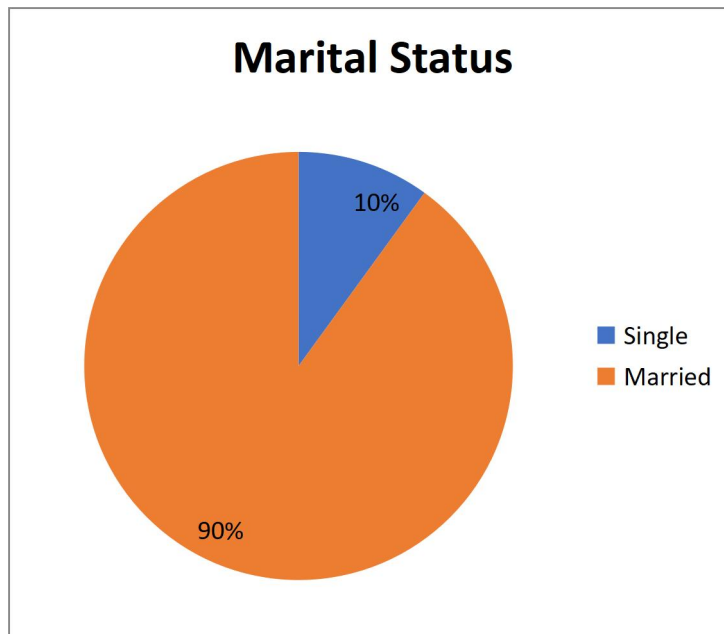
Age	Sex
37	Male
36	Male
56	Male
49	Male

AVG= 44.5

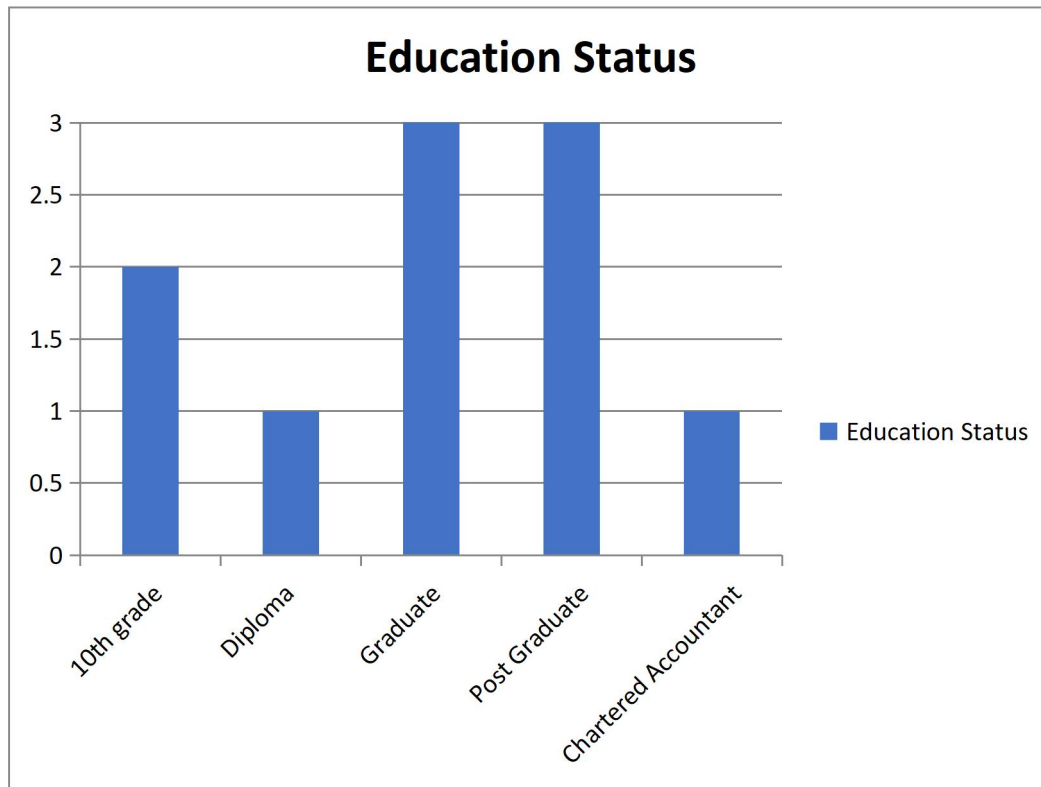
Age	Sex
41	Female
40	Female
63	Female
74	Female
59	Female
42	Female
AVG= 53.1667	

7.4 Marital Status

As per the calculated data, 90% of the caregivers are married; whereas the remaining 10% of the caregiver is single.

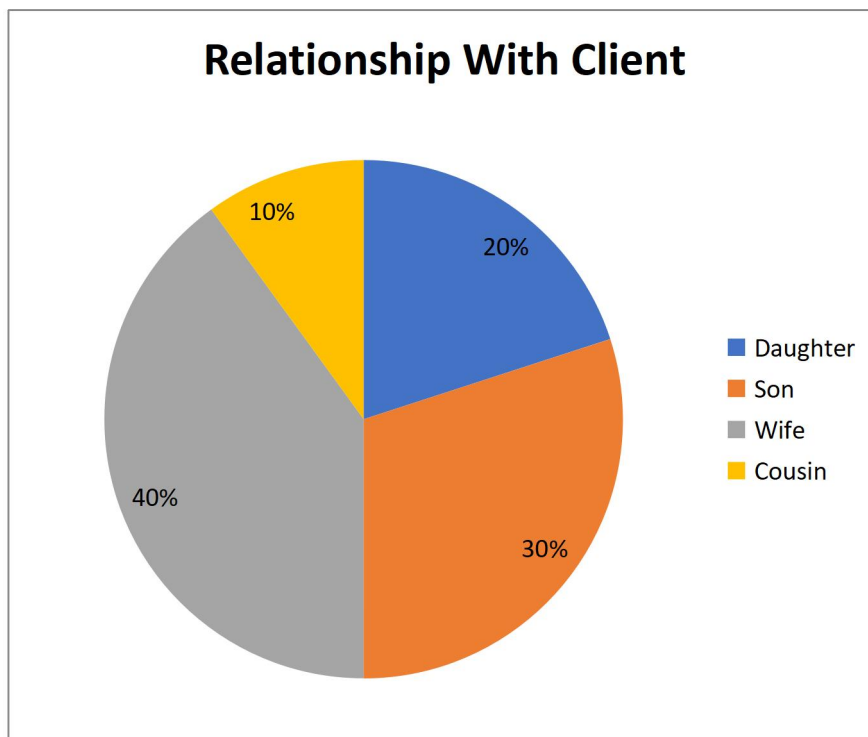


7.5 Education Status



From the chart we can infer that 2 out of 10 respondents are 10th grade pass students, 1 of them has a diploma, 3 of them are graduate, 3 of them are post graduate and 1 of them are chartered accountant.

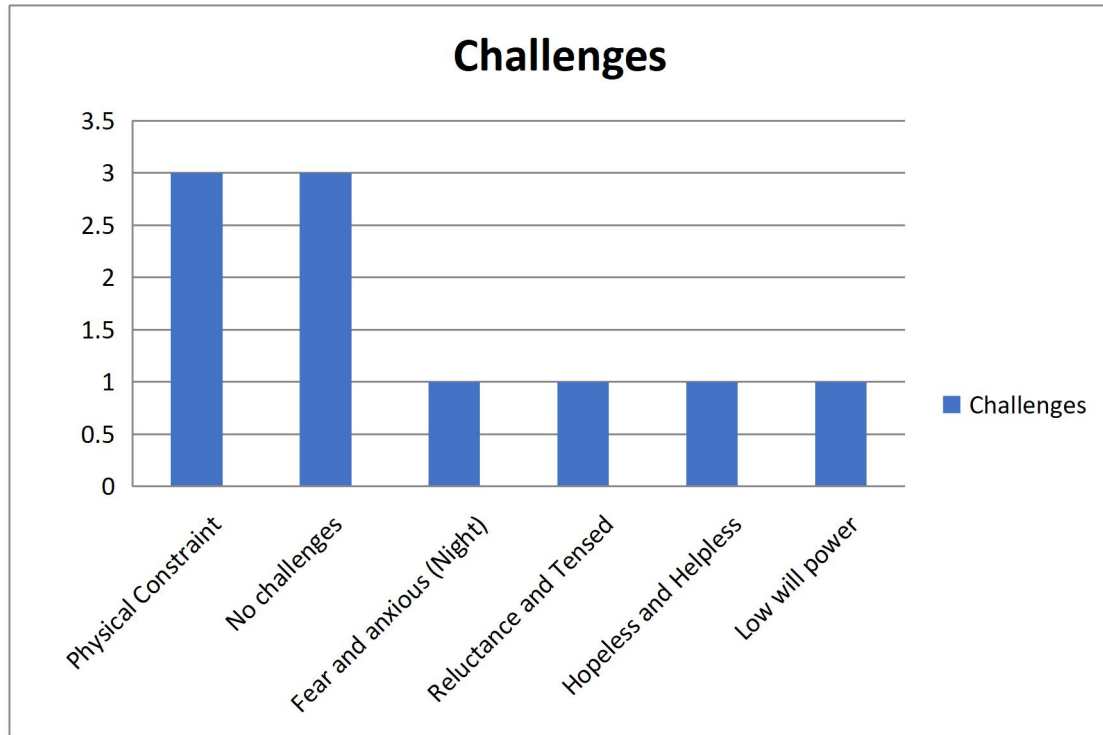
7.6. Relationship with the Client



As per the calculated data, the researcher was able to categorise the caregiver's relationship into four such as daughter, son, wife and cousin. 40% of the caregivers were wife of the client's, 30% were son of the clients, 20% were daughter of the clients and 10% were cousin of the clients respectively.

8. Psycho Social

8.1 Psycho Social Challenges by Caregivers



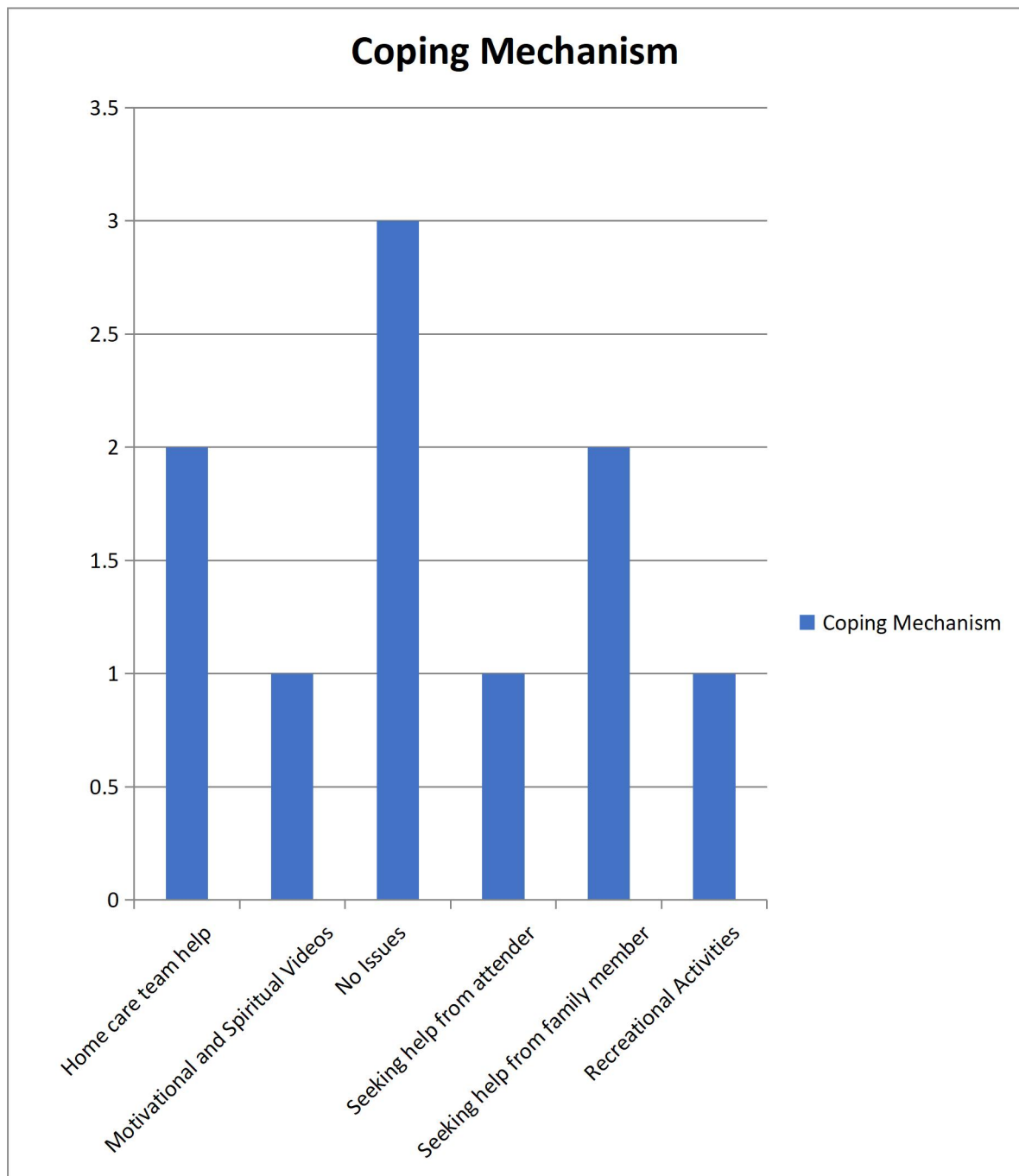
From the graph, we can infer that there are various psychosocial challenges for the caregivers in taking care of the client such as two of them had physical constraints. The respondent R1 has physical constraint and said *“I am in high stress now days and not able to concentrate on my work. Since there is no woman in the home, my mother lacks a person to share all her physical needs and a space to talk”*.

The respondent R5 said that **her own health is also deteriorating since she is not eating well. There is a lack of family and emotional support and she is not able to spend time for herself in terms of mental health. Additionally she is facing issues in taking care of the client.**

The other challenges faced by the caregivers are fear and anxious (Night), Reluctance and tensed, Hopeless and Helpless, Low will power and feeding the client along with physical constraints.

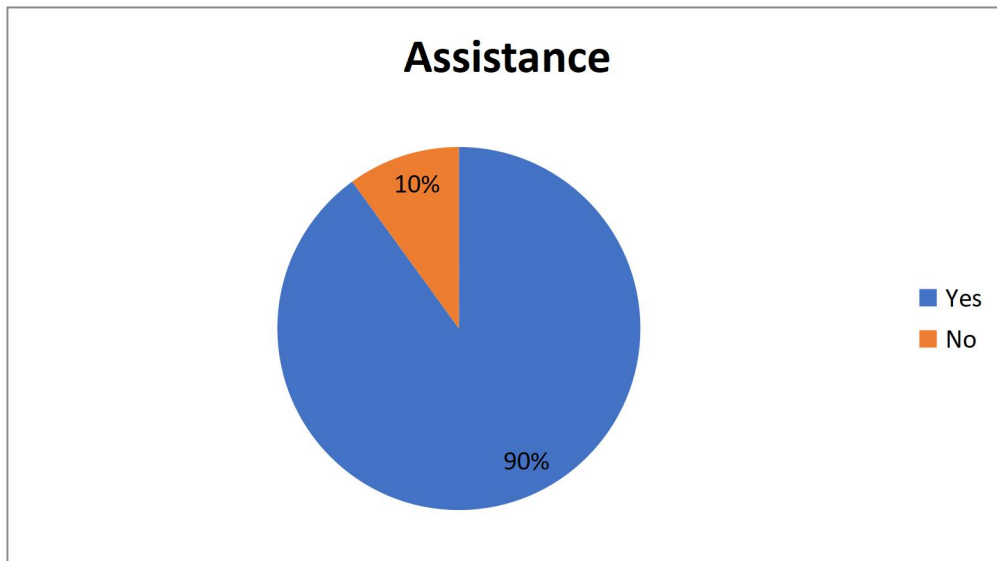
Three respondents said there are no challenges in taking care of the client.

8.2. Coping Mechanism of caregivers



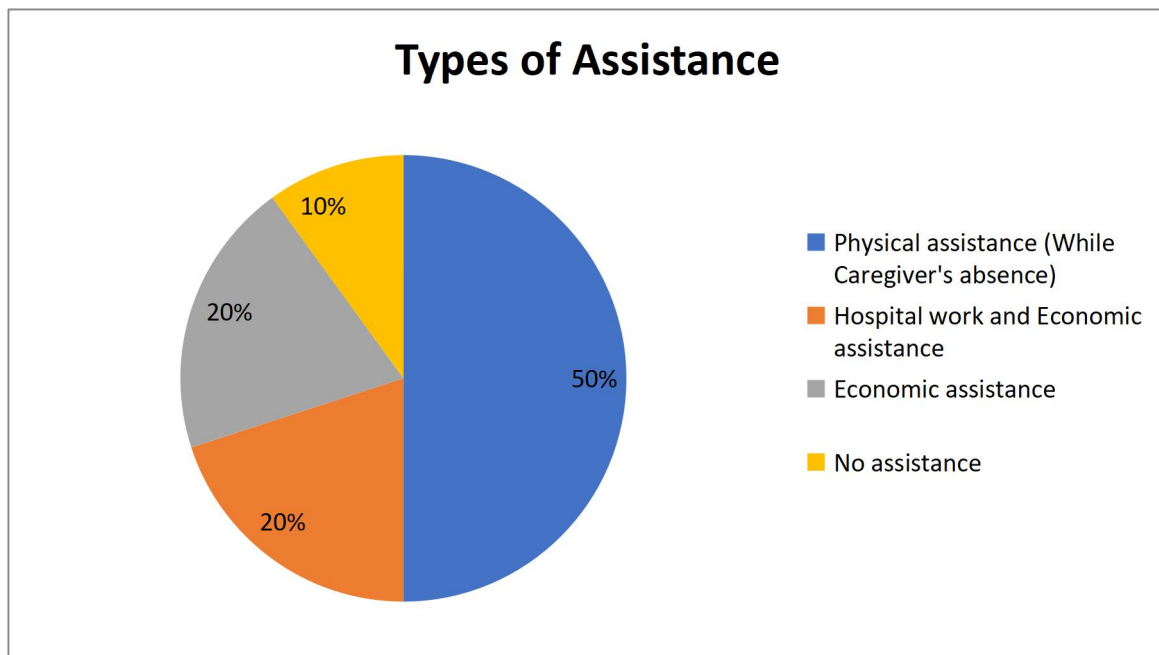
In order to tackle the psychosocial challenges, most of the caregivers are seeking help from family members and attender. The Home care team which comprises of a physician, nurse and a social worker of Rajiv Gandhi Cancer Institute and Research Centre also helps the caregivers in coping up with psycho social issues. One of the caregivers also uses the motivational and spiritual videos as a tool to cope up with the issue. Another caregiver said about recreational activities for relaxation like playing games.

8.3. Assistance of all sorts received by caregivers



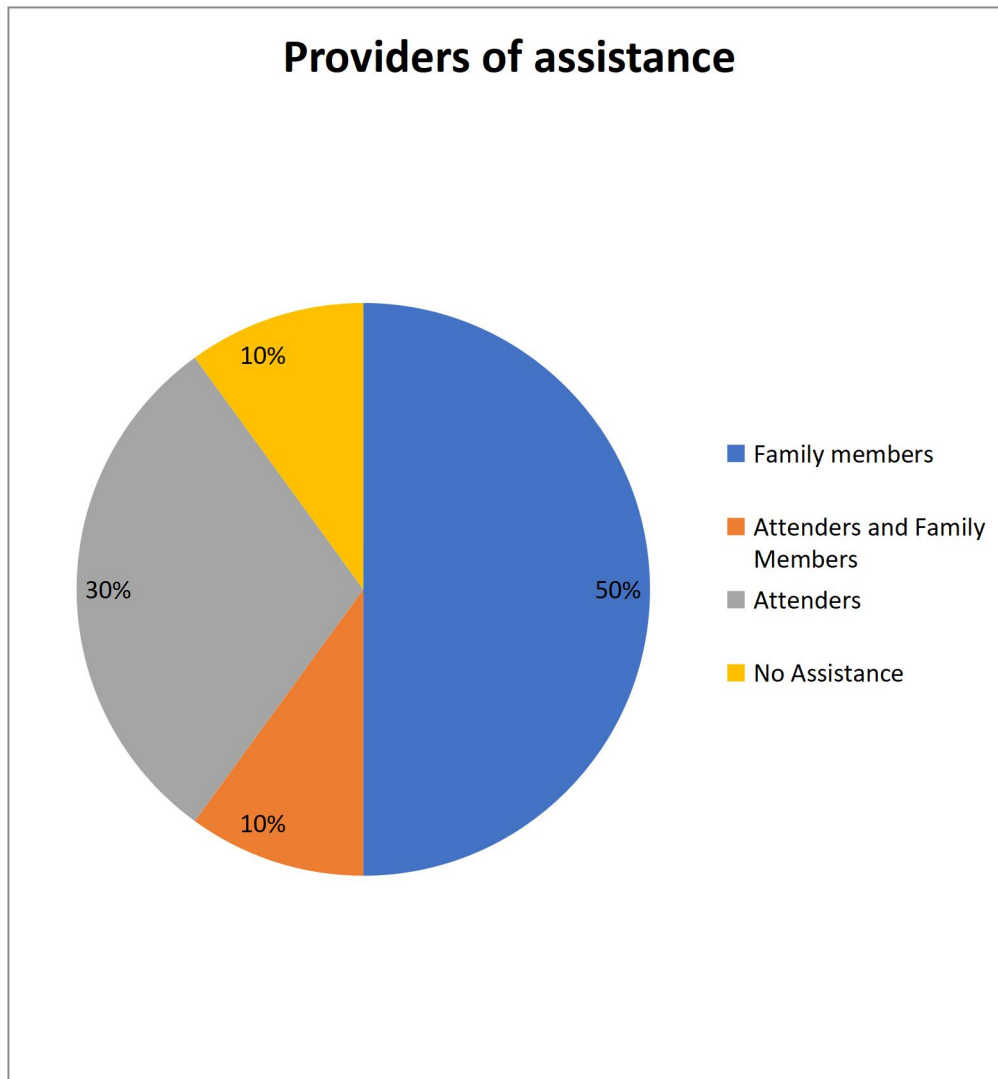
Almost 90% of the caregivers are receiving assistance in taking care of the client.

8.4. Types of Assistance received by caregivers



From family members and attenders, the caregivers are receiving three major types of assistance in taking care of the client such as 50% of Physical assistance, while the caregiver is not able to take care of the client due to various reasons such as work. 20% of the assistance is in the form of managing the hospital work and economic assistance together. 20% of the assistance is focussing only in the economic assistance for the caregiver. Lastly the remaining 10% of the caregiver require no assistance.

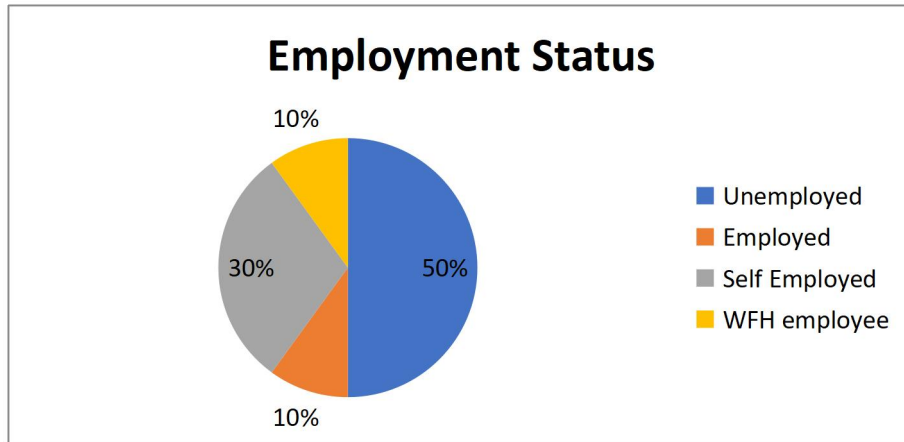
8.5. Providers of assistance



Nearly 50% of the family members are assisting the caregivers in taking care of the client, 30% of the caregivers are appointing the donor based on the needs and 10% of the caregivers are appointing attender as well as taking help from family members, The respondent R3, said that *"I am struggling to maintain the work life balance along with taking care of the client and so I require help from both attender and family members simultaneously"*. The assistance actually helps the caregiver a lot because she added *"My immediate caregiver is my grandmother and she also accepted the eventual passing of the loved one and she is 95 years old. Additionally Home care team is providing all the necessary support and I am in contact with the senior palliative care physician in case of emergency. Last 10% of the caregiver requires no assistance"*.

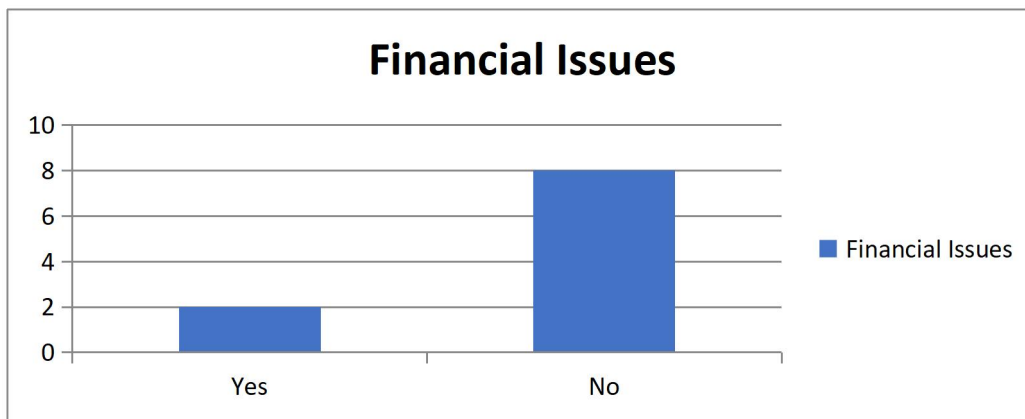
9. Financial

9.1. Employment Status of caregivers



Nearly 50% of the caregivers are unemployed, 30% of the caregivers are self employed which includes business, 10% of the caregiver is employed and the remaining 10% is also employed in a Work from Home (WFH) setting.

9.2. Financial Issues



From the chart, we can infer that eight caregivers had no financial issues in taking care of the client. Yet two caregivers said that they had financial issues. The respondent R2 said *"I recently got terminated from the office due to lack of concentration and started a work from home job. Now days the expenses of treating the client is more than the income and so I am struggling financially in taking care of the client."* The other respondent R9 also had financial issues but only during sudden expenses. She said, *"We have spent nine lakhs in total for the treatment that got covered in the insurance and my husband's pension money. Yet now a day's sudden expenses are arising such as medical tests and hospital visits, which act as a burden for us."*

9. Emotional

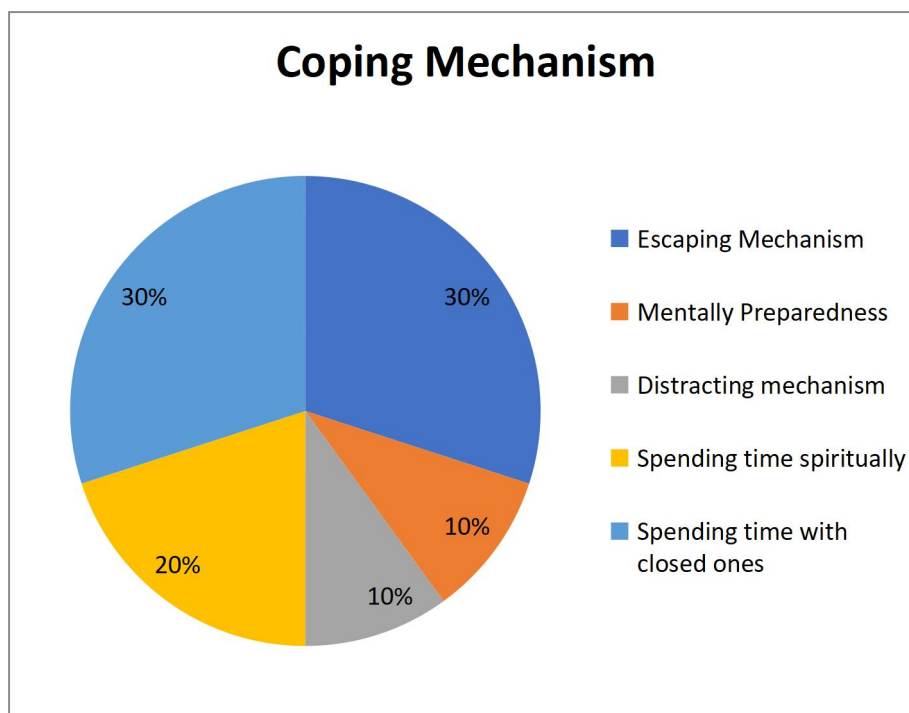
9.1. Emotions of the caregivers



In order to analyse the caregiver's emotional state while taking care of the client, the responses were taken into the aspect of negative effects because of the nature of the emotions. Coming under the category of negative effect, the caregivers shared emotions such as disheartened, guilty, stressed, tiredness, worry, and fear with the common element of sadness.

The respondent R3 said *"My grandmother is the immediate caregiver after me in taking care of my father. The hardest part is she is 95 years old and my dad is 70 years old. She felt disheartened when she got to know about the illness. Although I am mentally prepared to handle the issues, it is difficult for her to see his son's health getting deteriorated."*

92. Coping mechanism of caregivers for emotional issues



The emotional issues of the caregivers while taking care of the clients were mentioned in the diagrams of 4.1. The above diagram explains various coping mechanism of caregivers to handle the emotional issues such as 30% of the caregivers are spending time with their closed ones, 20% of the caregivers are spending time spiritually by listening to chalisa and devotional songs, 10% of them are mentally prepared. It is important to note that 30% of the caregivers have escaping mechanism and suffer a lot. It is indispensable to bring interventions for such caregivers from the field of social work.

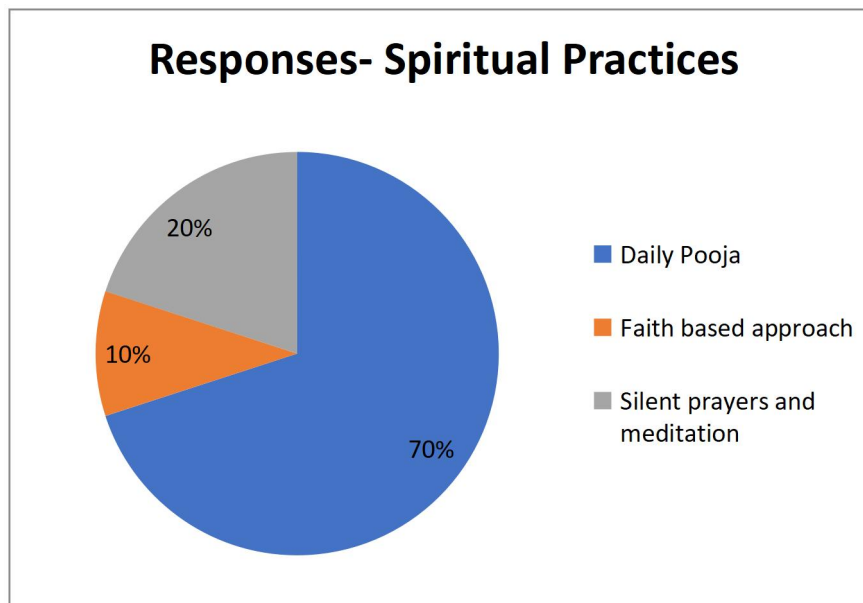
Some of the responses shared by the caregivers are

The respondent R2 said *“I am not able to share the emotional turmoil to anyone and always keep inside myself than bursting out in front of the client”*.

The respondent R5 said *“I am taking care of the household from morning to evening and taking care of the client as well, it is emotionally draining me every day and my children are also not listening to me and so it is very hurtful. During night time I become mentally fatigue and constantly worrying about my husband’s health conditions.”*

13. Spiritual

13.1. Spiritual activities

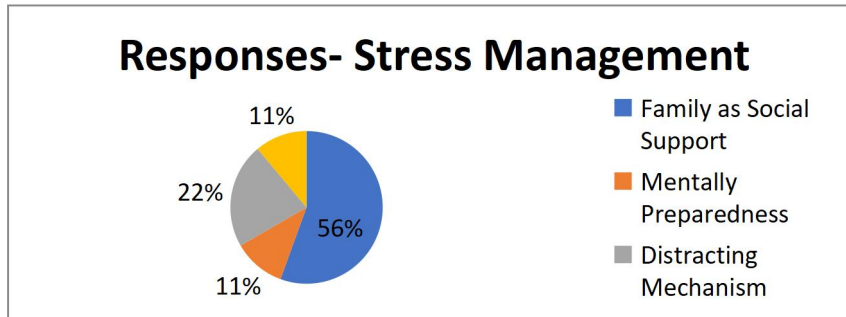


The respondents were asked the question of whether they are spiritual or not and all of them responded that they are spiritual. From the above chart, we can infer that there are different types of activities such as 70% of them are doing daily pooja and 20% of them are doing silent prayers and meditation. 10 of them are having their own faith based approach. This data shows about the role of spiritual practices in taking care of caregiver’s mental health.

The respondent R2 said *“It is a faith based approach and when there is no hope for me, it is the last resort. Yet I am not much religious and rarely engage in any pooja activities. My mother is the only religious and spiritual person”*.

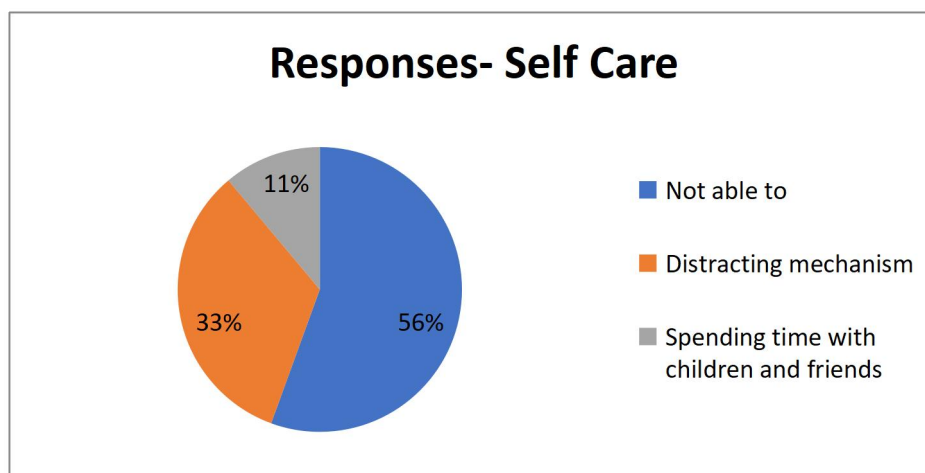
The respondent R8 said *“I am following a strict fasting for the god and continuously chanting the chalisas and mantras in the morning. I have a fixed diet and always pray to the god to ease the pain of my husband. I recommend to you as well; take good care of your parents, if they get any diseases and also devote yourself spiritually. It will help to keep your mind in peace from day to day stress and also prepares you for bereavement”*.

13.2. Stress Management



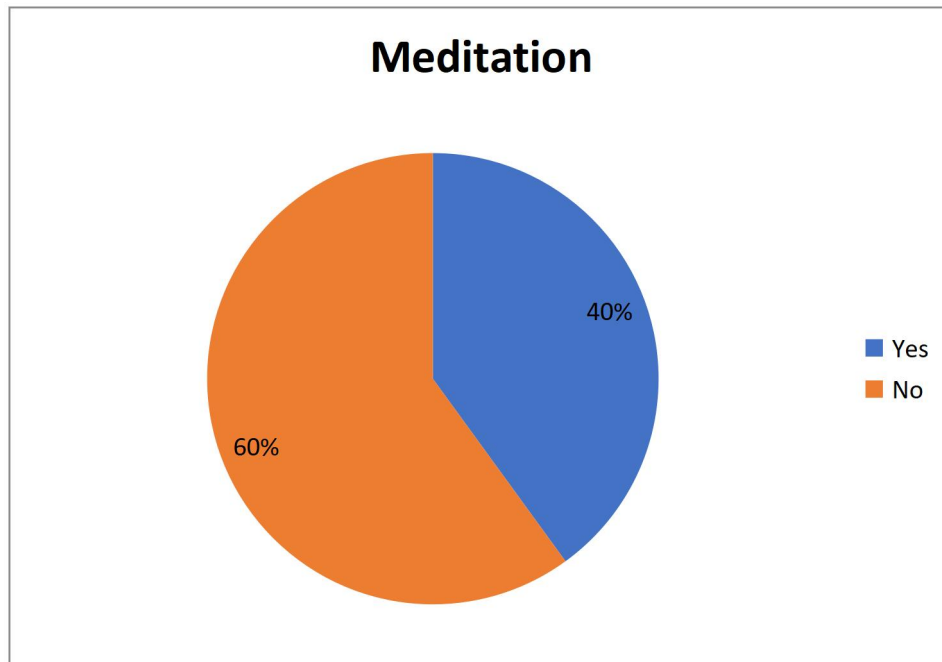
When the caregivers were asked about handling the day to day stress, nearly 56% of them said family is acting as a social support in managing the stress and it also proves the importance of creating a social capital. Around 22% of them have a distracting mechanism by engaging themselves in other activities and 11% of them are seeking spiritual help for stress management. As mentioned by the respondent R8 in 13, spiritual activities may help a person to handle day to day stress and 11% of the responses are corresponding with her view.

13.3. Self Care



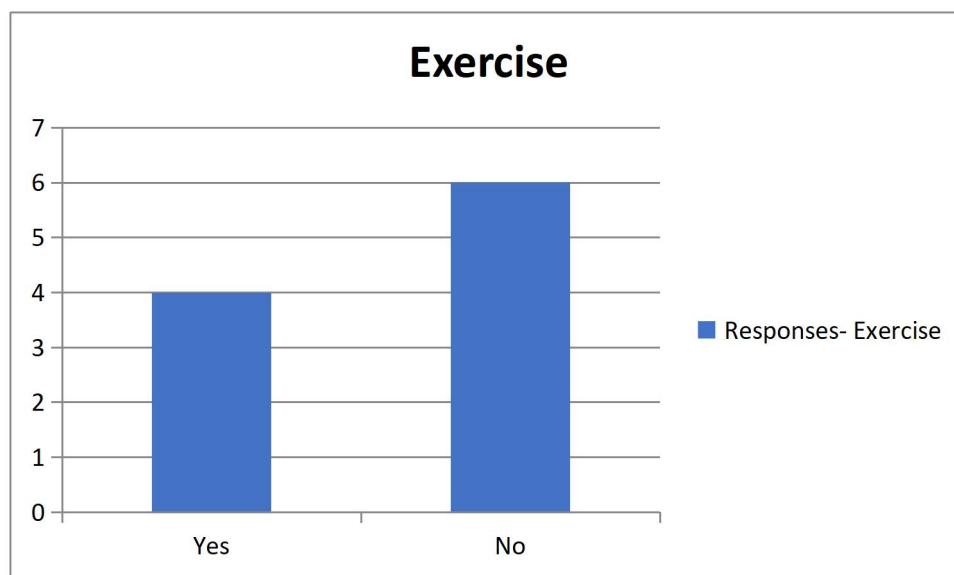
When the caregivers were asked about taking care of him/her self, 56% of them said, they were not able to take care of themselves; this proves the above fact of needing family as support system to help them. 33% of them have distracting mechanism and 20% of them are taking care of them by spending time with children and friends when they felt they are not able to take care of themselves.

13.4. Meditation



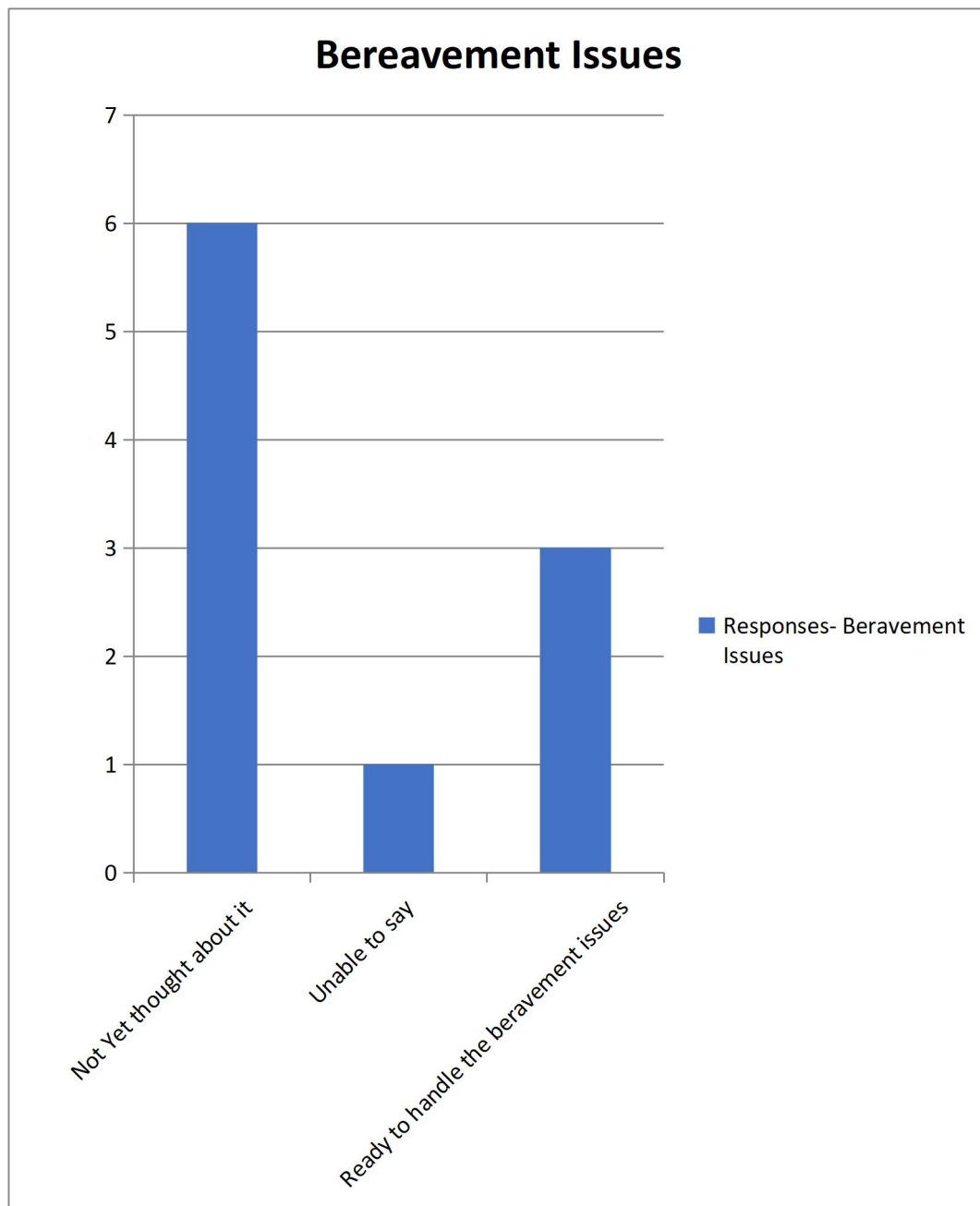
Most of the caregivers are not doing any meditation or yoga practices like nearly 60 percentage and 40% of them are doing meditation while performing pooja in home.

13.5. Exercise



Out of 10 caregivers, only 4 of them are engaged in regular exercise tasks and 6 of them are not performing due to various reasons such as employment, taking care of the caregiver without any attender's help and taking care of the household. This continuous engagement made the caregivers unable to allot a particular time for exercise.

13.6. Bereavement issues



One of the important parts in the study is to find out the caregiver's response in handling the bereavement issues and only 3 of them are ready to handle the bereavement issues and 6 of them are still in process of handling and not yet thought about it. This shows an uncertainty in handling the bereavement issues after the passing of loved ones, since many of them had emotional and psycho social issues.

14. Interventions from Social Work

Social Work is an eclectic discipline that derives theories from various subjects and practices those theories in various settings such as community, hospitals, nongovernmental organisation and social action based movements as well. There are various methods of practicing social work and the primary methods are case work with individuals, group work and community work whereas the secondary methods are research in social work practice and social action. Often times the methods will be merged and practice together. This particular social work research work is also a practice and will be merging with other practice methods such as group work. The researcher will be providing interventions for psycho social, emotional, and spiritual issues of the caregivers in detail. These interventions can be done by the upcoming social work trainees from the palliative care department.

14.1. Psycho Social

The responses provided by the caregivers such as being highly stressful and own health issues because of the care giving are leading to psychosocial issues for them. Health is a cohesion of physical, emotional, psychological well being not the mere absence of any disease or infirmity. The responses such as highly stressful is leading to physical distress as mentioned by the respondent as physical constraint and own health deterioration because of the care giving leads to mental health issues. This proves the above point of health and its necessity of cohesive functioning of the three elements.

The social workers can address the issue through group work method. Konopka (1963) explained that Social group work is a method of social work which helps individuals to enhance their social functioning through purposeful group experience and to cope more effectively with their personal group community problem. Although every caregiver's issue is different from each other, it will be very useful when the issues are approaching through group work method because of the existence of certain common issues among all the caregivers along with the individual issues. There are various types of groups in group work practice based on the needs, membership and interests of the individuals such as voluntary groups such as joining a political party or a religious group. The membership is voluntary in nature and individuals are joining based on his/her interest. With regards to group work in health care settings, it will be called as treatment groups and among the treatment groups, there is a sub group called therapy groups.

In the therapy groups in order to address the substance use deaddiction and rehabilitation, there is a process of forming anonymous support groups to address the issues of individuals and solving it through therapeutic approach. There is no need to reveal any personal information, if the caregiver wishes not to do so.

Caregivers anonymous can be formed by the social worker from palliative care department. It can act as a space where all the caregivers can meet together in a month and discuss about the issues. This should be supervised by a trained professional from the psycho-oncology department because the department currently has social work trainees only and so therapeutic approach must be done through supervision. Germain (1973) developed the ecological perspective from the person in environment approach to address the issues of individual to macro level issues.

“The present thinking on the ecological approach suggests that the primary premise explaining human problems is derived from the complex interplay of psychological, social, economic, political and physical forces. Such a framework accords due recognition to the transactional relationship between environmental conditions and the human condition. This perspective allows the practitioner to effectively treat problems and needs of various systemic levels including the individual, family, the small group, and the larger community”.

Taken from Germain (1973), an ecological perspective in social work

The social worker must develop an understanding about caregivers' issues by using the above perspective. Additionally one of the therapy models can also be used during the group work of caregivers facing psychosocial issues which is Gestalt Psychotherapy. Gestalt therapy facilitates problem solving through increased self-regulation and self-support by the caregiver themselves. As therapy goes on, the caregivers and the therapist turn more attention to general personality issues. (Here the psychosocial issues will be addressed) By the end of successful therapy the caregiver directs much of the work and is able to integrate psychosocial problems solving by themselves. Yontef, 1993

Though the caregiver anonymous can meet in weekly basis, it should definitely meet atleast once in every month. This due to the fact that caregivers are taking care of the clients and nearly 50% of them employed as well. The meeting will keep the therapy in progress and also make the caregivers to prepare for the forthcoming bereavement as well.

14.2. Emotional

When it comes to the emotional issues of the caregivers, there is a diverse set of emotional issues that the caregivers are facing while taking care of the client. One common negative effect emotion that found among all the caregivers was sadness. In order to explain the reason for expressing such negative emotions, the identity control theory can be used. It was developed by Peter Burke to identify various positive and negative emotions by developing a theoretically based measurement system to capture the meanings of the self in a role (Burke, 1980). The idea was formulated and it is based on traditional symbolic interaction views, that people choose behaviours, the meanings of which correspond to the meanings in their identity. There are four main components in theory Identity standard, Input, Output and Comparator.

Identity standard- it is about self meaning and roles of self given as per the standards of society and relevant culture. For our research purpose, the identity standard is the expectation from caregiver to be ready for the forthcoming loss than worrying about the situation. The caregiver tries to be up to the standard and engage in practice to face the coming situation. i.e. the passing of loved ones; **Input-** These are the activities where the caregiver tries to do but often not able to and so people notice the negative effects of emotion and may or may not help the caregiver to cope up with the situation. As per the findings, some of the caregivers are facing emotional turmoil and emotionally draining. Additionally they didn't have coping mechanism than an escaping mechanism; **Comparator-** can be a social work researcher who studies the expected emotions as per the identity standard and compare it with inputs; this will lead to the discrepancy between the identity standard and input of negative emotions. **Output-** it is the discrepancy found by the comparator.

While identity processes themselves, within the scope of ICT, are psychological, dealing with the perceptions and emotions of an active agent, these are necessarily set within the context of a social structure of relations between individuals, groups, and institutions, and within a context of an existing culture. Thus it is very important for the social worker researcher to identify the negative emotions of the caregivers from home care settings and

analyse through ICT by taking the social structure and culture of the particular family into consideration. This can be done in a larger level by developing a proper tool for assessment. As per the findings, the caregivers are spending time spiritually, with their closed ones and for the caregivers having escaping mechanism; the spiritual belief of them must be strengthened.

14.3. Spiritual

As mentioned about the strengthening of spiritual belief in the 14.2, the responses received about the spiritual beliefs must be understood. All the caregivers have spiritual beliefs and majority of them or involved in daily pooja based on their own faith. Yet the associated factor of meditation was not practiced by 60% of the caregivers. Although associating meditation with spiritual practices is difficult due to diverse methods of meditation practice, the meditation process yield positive responses in emotional regulation and stress management. Yet in order to strengthen the assessment of spiritual practices of the caregivers, the researcher proposes a spiritual audit for assessing the belief of caregivers. Trent Hospice Audit Group is a research group working primarily on developing the audits for palliative care since 1990's. They developed a spiritual assessment for patients and nurses in London (Bradshaw, 1996 & Walter, 1997). Since social workers are specialised in conducting the social audit which is assessing the social responsibility of any business by involving the not only the stakeholders but also everyone who is being benefitted or affected by the business. Likewise the spiritual audit of Trent Hospice can be used by the social worker to assess the spiritual well being of the caregivers by modifying some elements into the Indian context.

There are five categories provided by the audit group to find the spiritual well being as well as distress of the caregivers:

- Spiritual matters are the most important thing in life and give immense support.
- I am interested in the meaning of life and spiritual matters and take comfort from this.
- I am comfortable with my own philosophy and meaning of life, and spiritual matters do not affect me one way or another.
- Spiritual considerations considerably interfere with my life.
- I feel so troubled by spiritual matters that they are totally taking over my life.

When we compare the responses with the categories, we can find similarity such as response about own faith and it aligns with own philosophy and meaning of life. As mentioned, the social work trainees can take certain components from the audit and develop a tool like a questionnaire to assess the spiritual well being.

The meditation is one of the important components in the spiritual part of the research study and this particular part will be providing valuable suggestions to cope with emotional and spiritual well being.

In the book of Psychology in the Indian Tradition, a detailed description about the neuro physiological aspects of the meditation done by R K Wallace found that a fourth state of consciousness of transcendental has a possibility of existence and it is prevalent high among the Zen, Yoga or transcendental meditation. Vahia et.al (1973) found that a therapy based on yogic practices helps the patients to ease from the day to day stress and emotional regulation.

The hospital is already providing a space for patients and caregivers to conduct their own spiritual activities in a separate room. Likewise among the activities of caregiver's anonymous, a therapy based on yogic practices can be developed by the psycho-oncology department and the social worker can provide the factual input in creating such model for the caregivers.

All the interventions mentioned above are practice based social work ones and these interventions can be done by receiving supervision from both psycho oncology and palliative care department with the supervision from the professional social worker.

15. Conclusion

The study tries to explore the psychosocial, emotional and spiritual issues of the caregiver in homecare settings of oncology. In Rajiv Gandhi Cancer Institute and research centre, there is an interdisciplinary team for homecare visits consists of a senior palliative care physician, a head nurse, a nurse and a social work trainee. As per the registry data from RGCIRC, there were nearly 683 visits were done by the homecare team from July 2020 to December 2022. The least visits were done during the time of pandemic and the number increased drastically over a period of time. This data shows the need for the home care team and the social work trainee can also assist the team by working on the above interventions and try to implement by working together with the team. The study will act as a preliminary study of social work research in the field of palliative (Home Care) in oncology settings and further detailed study can be done by incorporating and considering the limitations of the current study.

15.1. Limitations of the study

- The sample size is very less and so it is difficult to analyse various caregivers in different settings within the stipulated amount of time.
- There is no benchmark set for the income level, which also lead to unidentification of diverse issues based on different economic level.

15.2. Conflict of Interest: NIL**16. References**

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