HOPE, RELIGIOSITY AND PERCEIVED SOCIAL SUPPORT AMONG NAGA CANCER PATIENTS AND THEIR PRIMARY CAREGIVERS IN RELATION TO PSYCHOLOGICAL DISTRESS

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

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Submitted

In partial fulfillment of the requirement of the Degree of Doctor of Philosophy in Psychology of Nagaland University

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DECLARATION

I, **SASHIRENLA MOLLIER,** hereby declare that the subject matter of the thesis titled, is the record of work done by me, that the contents of this Thesis did not form basis of the award of any previous degree to me or to the best of my knowledge to anybody else, and that the thesis has not been submitted by me for any research degree in any other University or Institute.

This is being submitted to the Nagaland University for the degree of Doctor of Philosophy in Department of Psychology.

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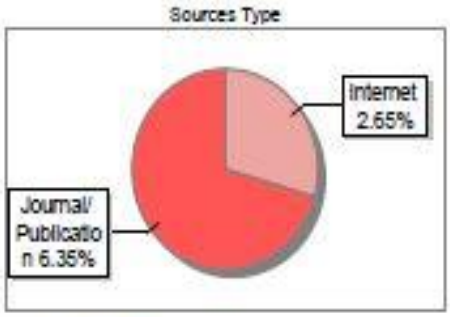

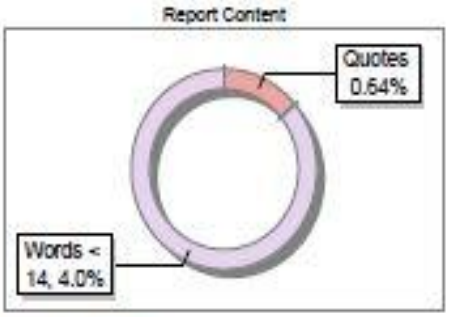

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ABSTRACT

Nagaland is also seen to have enormous growth of cancer patients ranking among the top five leading causes of death in the State. The study was conducted among Naga cancer patients and their caregivers to find the level of hope, religiosity and perceived social support and explore it relation with psychological distress specifically depression, anxiety and stress. Following purposive sampling method the present study collected Data from a total of 320 participants which comprised of 160 Naga cancer patients undergoing treatment and their primary caregivers (n=160). Tools used were Herth Hope Index (HHI), the Duke University Religiosity Index (DUREL), Berlin Social Support Scale (BSSS) and Depression, Anxiety and Stress Scale-21 (DASS-21). The analyses of data were done using SPSSv21 and test of normality was carried out using Shapiro Wilk test of normality which indicated non-normal hence non-parametric test was considered for the study. The statistical techniques used for analyzing were simple percentage, Spearman's correlation coefficient, Mann-Whitney U Test, Kruskal Wallis H Test and Chi Square. The effect of socio-demographic characteristic, annual family income, differences in the level of stage, and availing of counselling were explored.

Result shows that more than half of the patient participants were found to have symptoms of depression (53.1%) and anxiety (71.2%) while stress was also reported by a notable number (38.7%). A majority of caregiver participants were also found to have symptoms of anxiety (63.7%) while depression (39.4%) and stress (22.5%) were also reported by a notable number of the respondents. The levels of hope and perceived social support of were indicated to be high among majority of the respondents while also indicating engagement in religious activity (Organisational and Non-Organisational) by majority.

Spearman's correlation coefficient was used to find the association between Hope and psychological distress which indicated significant negative correlation; Hope and depression (r= -.569, p< 0.001), Hope and anxiety (r= -.443, p< 0.001) and Hope and stress (r= -.450, p< 0.001). Chi Square test indicated significant correlation between ORA with depression (X^2=51.321), anxiety (X^2=50.722) and stress (X^2=74.300) and NORA with depression (X^2=41.175). No significant association was observed between NORA with anxiety and stress of cancer patients. Relationship between Perceived social support and psychological distress levels was also determined by Spearman's correlation coefficient indicating significant negative association of Perceived social support with depression (r= -.164, p< 0.05). No correlation of Perceived social support with anxiety (r= -.105, p< 0.05) and stress (r= -.143, p< 0.05) was indicated.

Prevalence of psychological distress reported among respondents indicated no significant difference in gender among cancer patients. Kruskal Wallis H test determined effect on psychological distress by annual family income which indicated that there is significant annual family income effects for depression (X^2 = 7.863, p< .05) and stress (X^2 =4.248, p< .05) but not for anxiety (X^2 = 4.24, p> .05). The effect of stage of cancer was also determined by Kruskal Wallis H test which indicated that there is a significant effect of stage of cancer in stress level (X^2 = 8.695, p< .05) yet no significant effect on depression (X^2 = 7.328, p> .05) and anxiety (X^2 = 5.344, p> .05) was shown. However post hoc test for stress did not indicate any pair wise differences. Mann Whitney test was applied to evaluate psychological distress between those who reportedly sought counseling services and those who did not. Result indicated no significant difference between the two groups.

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CHAPTER 1

INTRODUCTION

1.1 Cancer

Cancer is a worldwide menace affecting people of any gender, age and race, rich and poor alike. National Cancer Institute (2021) defines cancer as a disease in which some of the body's cells grow uncontrollably and spread to other parts of the body. It is a disease causing a biological disturbance and there is no organ in the human body in which cancer cannot develop thus it is considered to be one of the major leading causes of morbidity and mortality worldwide which is distressing for both patients and their care takers (Haun et al., 2014). Cancer is life threatening, fear, despair and dejection associated, and its diagnosis is perceived by many to be their death sentence. World Health Organization (2022) report cancer as a leading cause of death globally accounting for nearly 10 million deaths in the year 2020 and reported that breast, lung, colon and rectum, prostate, skin and stomach were the most common types of cancer. With varieties of cancer types, the disease is also typically labeled into different stages. Staging is a way of describing the size of the cancer and how far it has grown. It is important to label cancer into a stage as it helps understanding which treatment is to be sought. Generally cancer is categorized into five stages: stage 0 - which usually means that there is no cancer, only abnormal cells with the potential to become cancer; stage I - which usually means that a cancer is small and contains only within the organ it started in. In Stage II cancer, the tumour is larger but hasn't started into the surrounding tissues, stage III usually means the cancer is larger and has grown into nearby tissue and lastly, stage IV, which is also called advanced or metastatic cancer in

which cancer has spread to other parts of the body. The stage of cancer determines the severity of the disease and every individual diagnosed with cancer is labeled with a stage.

1.1.1 Causes of cancer

Cancer arises from the transformation of normal cells into tumour cells in a multi-stage process that generally progresses from a pre-cancerous lesion to a malignant tumour (WHO, 2022). There are certainly many factors that cause cancer. According to WHO and American Cancer Society (2016) some of the factors that cause cancer are;

a) Genetic factor in which cancer can be inherited from parents through a process called germ line mutation. This cause is said to play a role in about 5 to 10 percent of all cancers.
b) Exposure to certain factors in the environment such as excessive chemicals, radiations, UV rays, etc. can lead to cause cancer.
c) Behavioural factors such as smoking, use of tobacco and alcohol, unhealthy diet and physical inactivity, etc also causes cancer.
d) Chronic infections with certain viruses, bacteria and parasites and exposure to viruses such as Human Papilloma Viruses (HPVs), Epstein - Barr virus (EBV), Hepatitis B and C both, etc. are also found to develop cancer.

Though the causes may be common to all races, the prevalence rate may vary. For example, worldwide, infections are linked to 15% to 20% of cancers, however the percentage of cancer developed due to various infections are shown to be higher in developing countries and lower in developed countries. Thus it may be presumed that though a particular cause of cancer may be seen to be very common, it could be affecting most commonly only to certain group of race or countries. These different causes lead to various types of cancer worldwide commonly, breast, colon, lung, skin, stomach, prostate, blood, oral, melanoma, nasal cancers, etc.

1.1.2 Treatments available for cancer

Various types of cancer treatments are available but the type of treatment one should undergo or receive will depend on the type of cancer one has and also how advanced it is. Some of the available cancer treatments are;

a) Surgery: It is one of the oldest methods which is usually done in order to prevent cancer. In this method, the tumor and nearby tissues are removed from the body.

b) Radiation therapy: It is one of the most common treatments for cancer. It uses high doses of radiation to kill cancer cells and shrink tumors. It may be used with other treatments such as surgery, chemotherapy, hormone or targeted therapy.

c) Chemotherapy: In this treatment, medicines or drugs are used to kill and treat cancer cells by keeping it from growing and dividing into more cells.

d) Hormone Therapy: The drug used in this therapy travel throughout the body to target and find the hormones and slows or stops the growth of breast and prostate cancers.

e) Immunotherapy: It is a therapy that boosts or changes how a person's own immune system works so it can find and attack cancer cells.

f) Stem cell or bone marrow transplant: It is a procedure that restore blood forming stem cells in cancer patients who have had destroyed by very high doses of chemotherapy or radiation therapy.

g) Targeted therapy: In this therapy, drugs or other substances are used to precisely identify and attack certain types of cancer cells that grow, divide and spread.

The treatments provided to a cancer patient may vary from person to person and it is of the knowledge that some people will have only one treatment, but most people have a combination of treatments. The treatment cost would vary on the type of cancer, age of the

patient, type of hospital, cancer stage, etc., yet on an average, the minimum cost of cancer treatment in India is estimated to start from Rs. 90,000/- to a maximum cost of Rs. 27,50,000/- . Moreover many may have to face one or many side effects such as appetite loss, diarrhea, fatigue, bleeding, hair loss, fertility issues, memory or concentration problems, sleep, urinary or bladder problems, etc. These side effects may also vary from person to person even among people receiving the same type of cancer treatment.

1.1.3 Cancer in India

India the most populated country in the world is seen to have a large number of cancer patients. It was estimated that in 2022 India had more than 14.1 new cancer cases and over 9.1 lakh deaths due to the disease and breast cancer was the most common (WHO in The Economic Times, 2024). In terms of cancer incidence rate, the highest in India is observed in the North-East region. Some of the common causes of cancer in India are due to smoking, alcohol and tobacco use, infections, unhealthy diet with low fruit and vegetable intake, pollution, etc. and the leading type of cancer is tobacco related cancer, followed by gastro intestinal tract, breast, cervix uteri, corpus uteri and ovary, lymphoid, etc. The number of people with cancer is increasing at an alarming rate and mortality is high. Though efforts are being made to sensitize people about its causes and treatments and also trying to march forward in providing cheaper and better medications or facilities in all parts of the country, the rate of cancer is still seen to be high owing to the lack of awareness regarding the disease, unhealthy lifestyle, genetic factors, poor immune system, delayed diagnosis, etc.

1.2 Nagaland and its people

Nagaland, the 16th State of the Indian Territory inaugurated on 1st December 1963, lies in the corner of the North-East region bordering Myanmar on the East, bounded by Assam in the West, Arunachal Pradesh on the North and Manipur in the South. The State consists of sixteen administrative districts, inhabited by 17 major tribes each with distinct custom, traditions and language. Majority of the Naga population are non-vegetarian and almost every tribe extensively consume both fresh and dried meat, fish, and fermented products such as soya bean and bamboo shoot. Other commonly consumed food items are ghost peppers, ginger, garlic, snails, worms, insects, larva, wild animals and birds, etc. The locally grown herbs are also used as what is commonly termed *local medicines* and similarly, frogs, worms, various plants and wild animals are consumed as medicinal. Though for many reasons modern lifestyle has ushered in, the traditions of Nagas still remain to a certain level and many practices are still preserved and followed. In almost every Naga house however modern, the kitchen is seen to have a traditional touch and not anyone ignores in building a fireplace where one can cook, smoke various food items, and also to keep the house warm and homely. Majority of the population uses fire for cooking. Only 43% of the population is reported to use clean fuel for cooking (Indian Council of Medical Research-National Centre for Disease informatics and Research, 2012-2016). Chewing betel leaf and nuts with or without tobacco is also favoured by many especially among the rural population. The prevalence of other tobacco use (both smokeless and smoke form) is also very high among the Nagas. It is reportedly shown by National cancer registry programme India (2020), that in report for 2012-2016 43.3% of the population above the age of 15 years use tobacco and particularly 24% males consume alcohol while its use among females is negligible.

As per the 2011 census, the population of Nagaland constitutes 87.93% Christian. It is deep rooted in modern day Naga culture to perform religious practices such as attending churches, praying, meditating, reading bible, listening to sermons, singing, etc. Religion plays a very vital and strong role among Nagas and one strictly adhere to the customary rituals of the religion. People mostly rely on religion/God, being thankful for good circumstances and at bad times, seek God's guidance, help and miracles. Emotional and practical support through religious communities among the Nagas is also seen to be very strong as one support and motivate the other through prayer or biblical quotes. Additionally, Nagas are very sensible towards caring and helping one another and one rely on the other at all times noting that support system among Nagas are very strong. In the Naga culture, when someone is unwell, the practice of visiting the patient and their family members at homes or at hospitals for prayer is very common. In addition it is also common among Nagas to render instrumental support by providing monetary aid or service of errands such as transportation, meal preparation, home care, etc.

1.3 Cancer in Nagaland

Nagaland is reported to have enormous growth of cancer patients. According to a report (Morung Express, September 10, 2022) it has been indicated that about 700 new cases of cancer in the state are registered annually with the average number of deaths as 126 per year with cancer of nasopharyngeal reported to be the highest among males, followed by stomach cancer and oesophageal cancer. In females, cervix-uteri is reported to be the leading cancer followed by breast and stomach cancers. Specifically, it has also been reported that Nagaland holds top in the country and second highest in the world in the dubious distinction of having the incidences of nasopharyngeal cancer (cancer of head and neck). It has also been reported that cancer is among the top five leading causes of death in the state (Nagaland Tribune, August 8, 2022).

Overburdened with the acceptance of its diagnosis, many people are struggling in fighting against this disease emotionally, mentally, and financially. National Cancer Control Programme reports that Nagaland is one of the leading cancer prevalent states in the country with no facilities for its management, thus compelling 90% of detected cancer cases to move out of the state in search of treatment. Many Nagas live a free lifestyle having light concern in undergoing regular medical check-ups. This may be mostly so because of negligence, lack of knowledge about cancer and the importance of regular health check up and also because most people live within a limited budget provision. Due to these reasons, and possibly many other, high prevalence rate of cancer is seen among Nagas, many diagnosed only in late stage, resulting in high rate of morbidity and mortality.

1.4 Caregivers of cancer patients and caregiver burden

According to the American Cancer Society (2016), caregiver is defined as the person who most often helps the patient and is not paid to do so. They may be a spouse, parent, children, sibling, relative, or a close friend. Shim & Ng (2019) opined that this is different from a professional or formal caregiver, who is either paid or is a volunteer with no personal relationship with the person he or she is looking after. Cancer care giving is challenging and is often associated with significant burden in family caregivers (Shim & Ng, 2019). The diagnosis of cancer in one family member has practical and emotional repercussion for the entire family (Bard et al., 2014) and none can escape its experience. Cancer patients tend to require the assistance of caregivers at every point of their illness period as once diagnosed with cancer, the treatment plan becomes very strict and demanding. Patients may have to rely on their caregivers for their daily basic functioning and also for their treatment processes. As such caregivers of cancer patients play a huge role on how the patient will deal with one's illness. Sharma et al.

(2020) noted that caregivers specifically help patients with transportation, finances, personal care, emotional support and symptom management. So the busy schedule in caring for the patient might leave caregivers with no time to take care of one's own needs and might also have to turn down job opportunities, work for fewer hours, or even retire early to meet the demands of the patient (American Cancer Society, 2016). The emotional experiences and hurdles undergone by the caregivers are as tough and challenging as that of the patients since illnesses like cancer affects not only the patient but the entire family. Caregivers may be psychologically and physically strong at the beginning but it may become exhausting as the patient's health deteriorates.

1.5 Psychological distress

Psychological distress could be experienced by anyone yet it could be more serious for those who are and have experienced tragic life incidences and can be thought of as a maladaptive response to a stressful situation. It can be largely defined as "a state of emotional suffering characterized by symptoms of depression such as loss of interest, hopelessness and of anxiety such as restlessness, feeling tense" (Mirotsky & Rose, 2002). Cancer is one disease that has the potential to drain a person emotionally, physically and psychologically because of the disease severity, physical pain and uncertainty about treatment outcome. Moreover, the cost of treatment may overwhelm the financial capacity of especially those from poor families and act as a major stressor, not just for the patient, but for the entire family. Despite advances in early detection, constant research, medical upgrades, sensitizations, and modern progress in securing possible cancer treatments and cures, it still remains a deadly and the most feared disease connected to psychological distress like depression, anxiety and stress (Mallika et al., 2006).

Having the notion that cancer is deadly and life threatening, and that one would undergo interruption in life plans, emotional responses such as shock, fear, anxiety, despair, anger, etc may be experienced by individuals upon diagnosis. These negative impacts are often overlooked which could possibly lead to serious psychological problems. Taghizadeh et al., (2018) in their study on psychological distress in cancer patients noted that due to increasing number of patients, less time is spent evaluating psychological distress while it is still an imperative component in cancer patients' medical care. It should be understood that with increasing severity of the illness and untreated psychological disorders on the other hand, a patients' quality of life is likely to worsen. Thus along with treating the disease, assessment and care of psychological distress symptom is essential.

Depression is a condition characterized by low mood, a feeling of sadness, and a general loss of interest in daily activities. According to American Psychological Association (2013), those who suffer from depression experience persistent feelings of sadness, hopelessness and worthlessness most of the day, nearly every day, diminished interest in activities they once enjoyed. Depression according to Beck (1967) has three components namely cognitive bias, negative self schema and negative triad. He found that depressed people are more likely to focus on the negative aspects of a situation while ignoring the positives and is likely to interpret information about them in a negative way. He also claimed that those with depression these thoughts and actions occur automatically. Additionally, cognitive symptoms such as diminished ability to think or concentrate, recurrent thoughts of death or suicidal ideations etc are also seen to be present among those who are experiencing depression. Besides emotional and emotional changes, physical changes such as weight loss and reduction of movement are also symptoms

that are considered one of the most central indicators of depression. It is thus important that symptoms of depression be identified and possible measures be ushered in.

Anxiety may be described as feeling nervous or worried. According to APA (2013), Anxiety is a negative mood state characterized by bodily symptoms of physical tension and by apprehension about the future. Also, those who suffer from Anxiety experience symptoms such as excessive anxiety and worry and difficult to control it, restlessness, being easily fatigued, muscle tension, sleep disturbances and difficulty concentrating are also some of the symptoms. Generally anxious behaviours such as restlessness and reassurance seeking, changes in thinking, etc are common features (Stark & House, 2000). People with cancer could most likely experience its symptoms and may intensify feelings of pain, hampering with sleep habits, cause nausea and vomiting, and negatively affect quality of life (Singh et al., 2015). One of the first emotions a person would considerably experience on finding out about one's diagnosis would be anxiety together with stress. It is much more than feeling any normal tension. Cancer being understood as a life long illness, fear of not being cured or the prolonged treatments and worsening of health may increase the level of worrying more and more, leading to a psychological disorder especially when not taken into considering to treat.

Anxiety certainly can cause disruption and can be detrimental to quality of life (Stark & House, 2000). However, though the world assumes cancer to be the end for everything, there are many cancer survivors who could overcome all sorts of physical, mental and emotional issues. Every individual is different where some are emotionally stronger and have positive outlook about anything in life while some have higher levels of distress. Yet Stark & House (2000) noted that not all patients are prepared to accept referral and so there is a need to consider management of these problems within cancer care.

Stress is a feeling of emotional or physical tension and is often a trigger for depression and anxiety which are not uncommon among people diagnosed with cancer. It is a common part of life but it has been defined differently by wide number of researchers. Hans Selye (1956) defines stress as the "lowest denominator in the organism's reaction to every conceivable kind of stressors exposure, challenge and demand". The earliest contribution to stress research was Walter Cannon's description of the fight-or-flight response. Cannon proposed that when an organism perceives a threat, the body is rapidly aroused and motivated through the sympathetic nervous system and the endocrine system. This concerted physiological response mobilizes the organism to attack the threat or flee; thus fight-or flight (Tylor, 2018). Symptoms of stress include muscle tension and pain, sleep disturbances, irritability, low energy, breathing difficulty, changes in appetite, etc.

Stress is experienced by all but how one tackles a particular threatening situation determines the frequency of stress one will experience. There are medical speculations that certain psychological factors including stress may be related to cancer (Ghosh, 2015). Cancer-related stress can harmfully impact cancer outcomes in terms of response to treatment, quality of life, disease progression, and survival (Singh et al., 2015) and give rise to negative emotional states of stress such as difficulty relaxing, nervous arousal, being easily upset or agitated, irritable or over-reactive and impatient. Physical problems can include unusual fatigue, sleeping problems, frequent colds, and even chest pain and nausea. Emotionally, people under stress experience anxiety, depression, fear, and irritability, as well as anger and frustration (Ciccarelli, et al, 2017). Cognitive psychologists Richard Lazarus developed a cognitive view of stress called the *cognitive-mediational theory* of emotions, in which the way people think about and appraise a stressor is a major factor in how stressful that particular stressor becomes. He noted that there

is a two-step process in assessing the degree of threat or harm of a stressor and how one should react to that stressor. The first step is called the *primary appraisal,* which involves estimating the severity of a stressor and classifying it as either a threat or a challenge. The second step is the *secondary appraisal*, which involves estimating the resources available to the person for coping with the stressor. According to this theory, one can assume that when a person diagnosed with cancer appraises the situation or stress as a threat, negative emotions may arise that inhibit one's ability to cope with the illness. On the other hand, depending on adequacy or abundant availability of resources such as social support, money, time, energy, ability, etc the degree of stress may vary.

Cancer is perhaps the most dreaded disease of the present day and not many are able to cope with the condition in a positive way, thus hampering the lives of many. Once the diagnosis is given to a patient, not only does one have to deal with the illness alone but also with various other associated problems thus putting a lot of demands on one's life. Stress among cancer patients may occur independently but most commonly a combination with anxiety and depression is seen. The present study will therefore assess the levels of psychological distress that Naga cancer patients and their primary caregivers experience. The impact of psychological distress may vary in terms of differences in stage of cancer, gender, annual income or socio economic status and may even vary among those receiving counselling. These aspects are also very important to be examined as it impacts on the occurrence of various psychological distresses like depression, anxiety and stress. The present study thus aims to study these areas and also find out the differences and effects on psychological distress.

1.6 Positive Psychology and coping

Positive psychological factors such as hope, social support, gratitude, happiness, acceptance, etc facilitate to improve wellbeing by building resilience to cope with adversity and buffer against stressors. Studies have indicated that using psychological intervention can reduce the level of stress and improve quality of life of cancer patients. Cancer patients in order to deal with the problems that is causing the distress and regulating stressful emotions, require the assistance of coping strategies (Benson et al., 2020). These strategies are specific efforts, both behavioural and psychological that people use to combat stressful events (Khalili et al., 2013). Different people may use different strategies in order to cope with their illness and various studies (Bean et al., 1980; Benson et al., 2020; D'Souza et al., 2016; Nipp et al., 2016) have cited coping strategies which are seen to be effective in dealing with the illness and its related issues. Some of which are religion, self-distraction, planning, active coping, positive reframing, avoiding, emotional support, self blame coping, filtering of information, and transference of decision making power to the physician and oncological team. Along with a good medical care, these backed up coping strategies help patients with their physical problems, depression and anxiety and ultimately help patients in dealing with the dreaded disease (D'Souza et al., 2016). This study deals with the how positive psychological factors such as hope, religiosity and perceived social support may affect psychological distress among Naga cancer patients.

1.7 Hope

Hope is conceptualized as either an emotion-based or cognitive based category. As an emotion, it is regarded as a feeling that allows one to sustain belief in dire circumstances and hope from the perspective of cognition is regarded as a thought or belief that allows individuals to sustain movement towards goals (Lopez & Snyder, 2003). In general hope is characterized by positive feelings about the immediate or long-term future and often coupled with high motivation, optimism, and a generally elevated mood. By showing a direction, suggesting a way and strengthening one's belief in attaining meaningful goals, hope can protect people against negativity and despair. It is also considered as a positive emotion that allows individuals to sustain beliefs during challenging times. Gottschalk (in Edwards, 2009, p 487) describes hope as a positive force that propels individuals to work through difficult circumstances. It is also seen as a mediating force that weights expectations of achievement and the affective intensity of the wish or desire (Lopez & Snyder, 2003). Additionally, Dufault and Martocchio (1985) define hope as a "multidimensional life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant". With respect to the degree of specificity of hope, the authors also distinguished between generalized hope and particularized hope where, generalized hope means positive but indefinite expectation about future grounded in reality and on the other hand, particularized hope focuses on specific future outcomes.

One of the theories developed by Snyder (1994) talks about hope as a positive motivational state that is based on an interactively derived sense of successful agency and pathway and that it serves to drive the emotions and well-being of people. Here agency thinking according to the author refers to an individual's determination to achieve their goals despite

possible obstacles and is taken as important in all goal-directed thought, but it takes on special significance when people encounter impediments. While, pathway thinking refers to the ways in which an individual believes they can achieve personal goals and it involves thoughts of being able to generate at least one, or often more useable route to a desired goal. Snyder also postulated that the theory of hope addresses the role of barriers, stressors and emotions and that positive hope result because of perceptions of successful goal pursuits and negative hope typically reflect perceived lack of success.

The word 'hope' entails a positive and powerful perspective of the future. Hopeful thoughts reflect the belief that one can find pathway to desired goals and situations. O'Hara (2013) viewed hope as having both internal, subjective existence that is to be owned by the individual and an external, objective existence, which is out there somewhere. In positive psychology, hope is considered a profound feature of human life, allowing life to keep going with positivity and happiness. Slezackova (2017) states that hope can provoke efforts to seek improvement of an unsatisfactory situation, and is therefore considered a vital coping resource against despair. Hope signifies positivity, joy, optimism, brightness, etc which are all positive sensations and feelings.

According to Fredrickson (2002) negative interpretations of events produce negative emotions, while optimistic thoughts lead to positive emotion. She has also emphasized in her broaden-and-build theory the beneficial effects of positive emotions suggesting that it creates more space for intuition and creative solutions to problems and additionally have favorable effects on motivation. Thus considering hope as a positive emotion, it can contribute affirmative results in one's life. She is also of the view that hope occupies a special place among positive emotions yet is often related to difficult and challenging situations unlike other positive emotions

which typically develops when we feel comfortable and safe. Considering this view most often hope is related to difficult and challenging situations where, when an individual is undergoing some sort of crisis or distress, hope works as a motivator, keeping one to face life's challenges with positivity. Yet again one might also consider that during crisis, some people tend to lose hope completely. This might be so because of individual differences or might also depend on the situation an individual is facing. For people with terminal illness such as cancer, the role of hope becomes very important. Because of fear about an uncertain future, patients often begin looking to additional sources such as hope, for support in handling the stress of their disease (Vartak, 2015).

Hope and distress are contradictory to each other. Hope signifies positivity while distress signifies negativity. When at distress, hope leads to well-being by helping people to deal with it or it can also be assumed that those people who are always positive and hopeful have lower levels of distress. Findings of Jahanara (2017) supports this assumption which reports in their study that hope is positively related to psychological well-being and negatively correlated to psychological problems. Psychological distress, not necessarily clinically labeled, is experienced by every individual at one point of our lives in one form or the other. It is one such experience that takes a long period of time to heal and 'hope' as a positive trait can help in recovering from these problems and make way out of the difficulties experienced by giving strength to an individual. Cancer is a terrifying disease and one may believe 'death' as the most likely end result. As one battles the disease with all possibilities, maintaining hope in the face of this serious illness becomes challenging. Yet in order to win over this illness, hope can enable individuals to look beyond their current pain, suffering and turmoil (Sunkarapalli, et al., 2016) as it is considered by many as a strong force. Regardless of what is ahead in future, cancer patients

when being hopeful about one's health recovery or remission, may live their present moment positively. Developing and experiencing hope may come through in various forms and may vary according to individual differences. Afrooz et al. (2014) in their study found that the most important sources of hope include spiritual resources, family members, and medicines and treatments available for the disease. We can assume that hope is a very powerful weapon while fighting against cancer. Once despair is caused and hope is lost, developing feelings of hopelessness, suicidal threat, unwillingness to avail medications, etc. may aggravate which often may worsen the health outcome of a patient. The present study will examine the levels of hope among Naga cancer patients and their primary caregivers and will also examine the relationship that hope has with the level of psychological distress experienced.

1.8 Religiosity

Religion may be understood as a belief in and worship of a God or in a group of Gods. It is evident in every culture which involves beliefs, practices, rituals, etc though it may differ in its types. It may be organised and practised within a community, or it may be practised alone and in private. These practises are in some way derived from established traditions that developed over time within a community (Koenig et al. 2012). The act of performing these various practises may be understood as religiosity. In a more specific way, religiosity may include praying, meditating, reading scriptures, attending religious gatherings, etc. Gupta (2017) opined that religiosity includes having or showing belief in and reverence for God, as well as participation in activities such as attending services or worship regularly and participating in social activities with one's religious community. Shafranske & Maloney (1990) defined it as "representing the adherence to the practices and beliefs of an organized church or religious institution". Various opinions can be made in order to understand religiosity and its practices. Allport & Rose (1967) proposed and

identified two basic dimensions of religiosity, namely, intrinsic and extrinsic religiosity. They interpreted intrinsic religiosity as wholly committed towards an individual's beliefs that provided them with comfort in salvation. Individuals with intrinsic religiosity moves beyond mere participation in religious activities and that religiosity is evident in every aspects of their life. On the other hand, extrinsic religiosity is identified as self serving and utilitarian outlook on religion that provide believers with comfort in salvation. Individuals with extrinsic religiosity use religion as a means for their own ends, such as status, sociability, consolation, etc.

Religiosity and spirituality are two very similar concepts and may be considered as synonymous, yet they are independent of each other. Though researchers distinguish the two concepts, most tend to overlap. However, considering the differences noted by Lazar (2010), religion/religiosity is seen to be more institutionalised and formalistic whereas spirituality is a more individual and inward expression. According to this it can be understood that religiosity is more extrinsic or following religious rules outwardly e.g. praying, meditating, reading scriptures, attending religious gatherings, etc, while spirituality is more of inwardly individual oriented, e.g. having faith, trust, hope, etc. Despite its differences, these two constructs tend to support each other. Practising a religious duty may elevate an individual's level of spirituality and on the other hand one's having a sense of trust, faith, inner peace, etc may motivate one to outwardly perform religious duties. However it should also be noted that at all times and for every individual being religious does not make him spiritual or vice versa. These two constructs may be considered completely independent where one can be spiritual without being religious or being a member of an organised religion or be religious without having any peace of mind or faith. Yet one can be both religious and spiritual, which is a search by most individual.

A person diagnosed with cancer very often turns to religious practices and they rely heavily on their faith to cope with this burden. They tend to use prayers, worship and faith to cope with the suffering conditions (Shumway, 2003). The question does not always matter to which religion one may belong to when one personally believes in its practises with faith which gives a suffering person a framework for finding meaning and hope. Patients as well as their caregivers respond to stress differently but the practice itself may enhance and boost one's confidence and as Jim et al. (2015) asserted, religious practices or behaviours may possibly help manage illness and its treatment. Psychological distresses like depression, anxiety and stress are common when an individual is undergoing a life crisis or experiencing severe or potentially life threatening illnesses such as cancer. Religiosity accounts to practising religious duties and the feeling that one has a positive relationship with God can give an individual a sense of self-acceptance and belonging as well as provide a source of emotional comfort. Gupta (2017) who worked on cancer patients noted that patients felt more in control of their lives through a problem-solving partnership with God or a divine power and that when they asked God's forgiveness and also worked to forgive others they found strength and comfort from their spiritual beliefs. Being religious is a coping behaviour that many turn to during times of distress. However faithful believers at some point of time find difficult to adhere to the unseen or unfelt promises resulting in a sense of hopelessness, increased guilt and sadness, lowered self-esteem, etc. Religiosity provides a sense of control over feelings of helplessness, fear or dejection which is certainly affirmed in the literature (Guz, 2012; Weaver & Flannelly, 2005). Yet if this religious beliefs and practices become contradictory, psychological distress may likely result.

The present study will examine the levels of religiosity among Naga cancer patients and their primary caregivers and will also examine the relationship that religiosity has with the level of psychological distress experienced.

1.9 Perceived social support

Social support can be understood as ranging from actual supportive acts which are exchanged by individuals to a personality-like factor which is based in early interpersonal experiences that will influence how a person views the likelihood of whether someone is supportive (Vartak, 2015). It is usually described as the existence of people on whom we can rely, people who let us know that they care about, value, and love us. A broad definition of social support given by (Gurung, et.al, 2006) is "the experience of being valued, respected, cared about, and loved by others who are present in one's life". Six types of support has been identified by Worthman (1984) namely, (1) expression of positive effect, which include information that one is cared (2) expressing agreement, which may be with a person's feelings (3) encouraging open expression of beliefs and feelings (4) offering of advice or information (5) provision of material aid (6) inclusion in a network of mutual or reciprocal help. Worthman (1984) also opined that the different types of social support may be valuable to cancer patients at different points in their disease or treatment. When cancer patients are dealing with such a stressful condition, any or all of these types of social support is believed to be important. The feeling or knowledge that there are people to take care or support them can elevate confidence in coping with the disease.

Perceived social support is an individual's feeling of support being received from family members, friends and the community. It is shown that cancer patients have higher quality of life and lower depression when they perceive more social support (Yoo et al., 2017). Taywade (2018) noted in her study that perceived social support consists of three dimensions, namely

family, friends and significant other. It was viewed that a significant other could be a supervisor, peer, co-worker or any other person not explicitly defined but with whom the individual has a contact on a daily basis. Kaya et al. (2012) also defined perceived social support as an individual's perception of whether social network is adequately supportive or not. When an individual is experiencing a life crisis, support becomes highly expected to be received from those who has and is a part of the person's life as also suggested by Roomaney (2020) that perceived social support is assessed prospectively, referring to it as expectations that others in one's social network will be available to provide assistance when one feels too incompetent or burnout to cope with problems. When the perceived support is received from people deemed to be important, it satisfies the basic social requirements such as love, affection, self-esteem and belonging to a group. According to Rizalar (2014) this has a direct effect on one's physical and emotional health. Any person going through psychological or physical problems require social support. Though one cannot strongly stand on the notion that receiving social support from others always has a hand in doing away with distress, we sure have a guarantee that it plays an important role. Psychological and physical disturbances connected with cancer can be hardest of all to handle which can deprive patients and their caregivers the feeling of belonging and worth of living. Some studies (Kavitha & Jayan, 2014; Yoo, et al. 2017) have reported that cancer patients who receive satisfied social support show higher quality of well-being and lower levels of depression and stress. Study conducted by Kavitha & Jayan (2014) also pointed out the need of social support in breast cancer patients to reduce distress associated with diagnosis and treatment and noted that by providing social support the family can smooth the patient in promoting good psychological adjustment. Theory of social support suggests that social connections and relationships are essential for individual's physical and mental health outcomes

and is able to improve the ability to cope with stressors. Thus individuals can identify ways to receive meaningful support from various sources and various forms including emotional, informational and instrumental support. The present study will examine perceived social support among Naga cancer patients and their primary caregivers and will also examine the relationship social support has with psychological distress experienced.

1.10 Rationale of the study

Nagaland as one of the states in India is now seen to have enormous growth of cancer patients ranking among the top five leading causes of death in the State. As per population based cancer survey (ICMR-NCDIR 2012-2016), it is reported that every year, an average of 600 new cases of cancer are registered in the state. It is also reported that tobacco use is present in nearly half of the population, while about one-fourth consume alcohol and are overweight or obese and hypertensive which are highly prone to developing cancer. Moreover as the state has a shortage of tertiary cancer care facilities, cancer care becomes burdensome both logistically and financially thus adding to the woes of patients and their caregivers. Patients on learning about their illness which does not have a guarantee about its cure, might experience extreme tension, worriedness, sadness, hope in living, loss of interest, suicidal tendency, etc. which opens the way for experiencing psychological distress. Hence with the prevalence of the illness, psychological distress such as depression, anxiety and stress in particular could be prevalent among the Naga patients. Other researchers (for eg., Maharjan et al. 2018; Haun et al. 2014) who have conducted research in cancer patients in other parts of India and abroad have found significant link between cancer and psychological distress yet studies on cancer patients in Nagaland are very limited and more specifically, no previous study is seen to be conducted in the aspect of depression, anxiety and stress among Naga cancer patients and their primary caregivers. The Naga society being

culturally different from the western society and from those in other parts of India, one wonders what the level of psychological distress might be among Nagas afflicted with cancer and among their primary caregivers. One of the main objectives of the current study is to explore the prevalence of psychological distress among Naga cancer patients and their primary caregivers.

Though cancer is regarded as a life threatening illness, positive psychological factors such as hope, religiosity and perceived social support can help in coping with the illness. The relationship of these aspects with psychological distress is very important to be explored and research in this area is very limited in the literature thus there is a felt need that this area of study be researched further. The effect of socio-demographic characteristics also needs to be explored. Women and men generally respond to life situations differently thus the study felt to explore the responses to cancer treatment from a psychological perspective in terms of gender. Financial income also becomes one of the pertinent aspects for cancer treatment since it demands huge expenses for its treatment thus its effect is also felt important to be explored. Also, the differences in the stage in which a patient is diagnosed could also impact psychological distress since as the illness deteriorates more, there could be possibilities that one would experience more stress and higher levels of depression and anxiety. Above all, one very important factor that can control psychological distress of patients is seeking counselling from professionals. Thus the effect of socio-demographic characteristics was also explored as it may also have a fundamental effect on psychological distress among patients and their caregivers.

The present study is aimed to assess the level of hope, religiosity and perceived social support among Naga cancer patients and caregivers and examine it relationship with psychological distress among cancer patients. The effect of socio-demographic characteristics is

also aimed to be explored as it may also have a fundamental effect on psychological distress. No similar study has been found to be previously conducted among Nagas.

1.12 Objectives

- To find out the prevalence of Psychological distress among Naga cancer patients and their caregivers.
- To find out Hope levels of Naga cancer patients and their caregivers.
- To find out Religiosity levels of Naga cancer patients and their caregivers.
- To find out Perceived Social Support levels of Naga cancer patients and their caregivers.
- To find out the correlation (Association/relationship) between Hope and Psychological distress levels of cancer patients.
- To find out the correlation between Religiosity and Psychological distress levels of cancer patients.
- To find out the correlation between Perceived Social Support and Psychological distress levels of cancer patients.
- To find out gender difference in the prevalence of Psychological distress among cancer patients.
- To examine the effect of Annual Family Income on Psychological distress levels of cancer patients.
- To examine the effect of Stage of Cancer on Psychological distress of Naga cancer patients.
- To examine the role of obtaining counselling service on the psychological distress of cancer patients.

1.13 Hypotheses

1. There will be significant correlation between Hope and Psychological distress levels of cancer patients.
2. There will be significant correlation between Religiosity and Psychological distress levels of cancer patients.
3. There will be significant correlation between Perceived Social Support and Psychological distress levels of cancer patients.
4. There will be significant Gender difference in the prevalence of Psychological distress among cancer patients.
5. There will be significant effect of Annual Family Income on Psychological distress of cancer patients.
6. There will be significant effect of Stage of Cancer on Psychological distress of cancer patients.
7. There will be significant difference between those who sought counselling and those who did not in terms of psychological distress of cancer patients.

CHAPTER 2

REVIEW OF LITERATURE

Various studies have been reviewed by the researcher during the research period. Under this chapter, a total of 60 studies have been compiled of which, it includes studies done abroad, studies done in India and studies done in North-East India. Studies include those conducted between the years (2000 and 2024) and includes research areas within the domain of cancer and their caregiver in terms of gender, stages, annual family income, counselling, etc, and its relation with hope, religiosity, perceived social support, psychological distress (depression, anxiety, and stress).

2.1 Psychological Distress in Cancer patients

Roshid et al. (2024) aimed to assess psychological distress and its associated factors in patients with cancer undergoing chemotherapy in rural Bangladesh. Participants comprised of 415 patients with a mean age of 46.3 years. Findings show that patients with cancer receiving chemotherapy experience a high prevalence of depression and anxiety while stress was also prevalent among 22% of the participants.

Mason et al. (2019) in their cross-sectional study on 208 cancer patients of Dehradun district aimed to estimate the prevalence of psychological distress determining its association with socio-demographic factors. Prevalence of psychological distress was found to be 38.5% (anxiety/depression/both). It was also found out that it was significantly higher in female

patients, older age, patients with no formal education, unemployed and those with lower socio-economic status.

Maharjan et al. (2018) undertook a cross-sectional study to assess the level of depression, anxiety and psychological stress among 309 cancer patients from Nepal. Respondents were interviewed using structured questionnaires to collect information on depression, anxiety, perceived stress and social support. Results indicated the prevalence of psychological distress and also found out that females are severely depressed and had higher levels of anxiety and stress than males. The study also found that social support was negatively correlated with perceived stress and nearly half of the respondents were diagnosed for various levels of depression though respondents perceived social support to be high.

Mallika et al. (2016) conducted a study on "A prospective study on the prevalence of major depression, anxiety and stress among various cancer patients" with its objective to assess the prevalence and severity of depression, anxiety, and stress using Depression, Anxiety and Stress Scale (DASS) constructed by Lovibond & Lovibond (1995). 232 cancer patients were interviewed and screened. Results revealed that there is high prevalence of depression and anxiety (associated with stress) among all cancer patients, specifically those with breast cancer.

Shankar et al. (2016) aimed to screen cancer patients for the presence of depressive disorders and anxiety disorder using Patient Health questionnaire and Generalized Anxiety questionnaire. Their sample size consisted of 534 cancer patients and about half of the patients had psychiatric morbidity either in the form of depressive disorder or in the form of GAD. They suggested that there is a need for close liaison between oncologists and mental health professionals to improve the outcome of patients with various malignancies.

Singh et al. (2015) collected data from 300 cancer patients in Malwa region of Punjab using the Depression Anxiety Stress scale (DASS-21) which was then compared to normal control. Statistical significant difference was observed in mean scoring of depression, anxiety as well as stress in cancer patients when compared with control group. Specifically stress was observed more in breast cancer patients.

Cheng et al. (2024) aimed to explore the psychological distress among 237 gastrointestinal cancer patients and examine its association with quality of life among different genders through a cross-sectional study. Result indicated that a greater proportion of female GI cancer patients have clinically relevant psychological distress compared to males and found that quality of life was negatively associated with their psychological distress. The study suggested that healthcare providers should attach their attention to GI cancer patients.

Daniel et al. (2020) with the concern that breast cancer is becoming the most common cancer among women of Indian origin, aimed to review literature and improve the understanding of psychological symptoms among Indian women with breast cancer. They found that psychological concerns similar to western women but were framed by the common culture of Indian women in either country. Family structure, religion and community appear to protect against and cause distress and additionally, migrant Indian women had more problems due to language barriers. They viewed that culturally congruent care, including accessible communication and information, may help prevent and alleviate distressing symptoms whether in India or in a migrant community.

Koyama et al. (2016) did a gender difference study in cancer distress types among 101 cancer patients above the age of 16. They attempted to find out physical distress, psychological distress, social distress and spiritual distress, together with sexuality issues. Chi-square test and Fisher's exact test were performed for the association of gender with each item and the results indicated that female patients were more likely to suffer from psycho-social issues such as changes in appearance, family problems and sexuality issues than male patients, and on the other hand, male patients were more likely to have spiritual pain. Thus the study concluded stating that there was gender difference in the distress types of cancer patients.

Taghizadeh et al. (2018) conducted a study "Psychological distress in cancer patients" with patients ranging from ages 18-89 years with any stage of cancer who referred to two academic hospitals of Mashhad University of Medical Sciences in Iran. The most prevalent cause of psychological distress found among the participants was fatigue (68.8%), followed by pain (59.4%), difficulty in transportation (59.4%), anxiety (57.2%), sadness (50.4%), anger (44.5%), and depression (43.8%). The results of the study have revealed higher rates of severe psychological distress in women.

Khan et al. (2010) undertook a study to evaluate behaviour and psychosocial impacts before and after treatment of 97 women with breast cancer in Delhi. Although the extent of socio-behavioural disorders were higher in patients on postoperative adjuvant chemotherapy and radiotherapy when compared with those on postoperative adjuvant chemotherapy alone, the difference was however not statistically significant. It also reported that psychological reactions were observed in 31% of patients but after intervention, 65% showed adjustment within 4 to 12 weeks, whereas the rest showed late adjustments.

Goldzweig et al. (2009) conducted a study in which the aim was to strengthen the knowledge of oncologists concerning distress and social support among married and unmarried male cancer patients and healthy male spouses of female cancer patients. Participants were evaluated on four standardized instruments measuring psychological distress, coping, and social support. Findings indicated that 42.6% of the participants reported on a clinical level of psychological distress and was negatively correlated to social support variables among the spouses and married patients but not among the single patient groups. It reported that single male patient are at high risk for psychological distress and that male spouses were found to have high rates of distress. It pointed out that these two groups need special attention by oncologists.

2.2 Hope and Cancer patients

Nikoloudi et al. (2023) in their study "hope and distress symptoms of oncology patients in a palliative care setting", 130 cancer patients above age 18 years completed the Greek version of the Herth Hope Index (HHI-G) and the Hospital Anxiety and Depression Scale (HADS-GR). Result indicated high levels of hope and low levels of depression and anxiety and correlation showed that hope was strongly negatively correlated with anxiety and depression. Additionally there was no difference in terms of gender, marital status, educational levels, etc.

Baczewska et al. (2020) compared hope experienced by advanced cancer patients in relation to stability of their basic mood which consisted of 246 patients throughout Poland. The researchers identified that mood was one of the determinants of hope in people dying of cancer and that cheerful people had more hope than did the sad. The researchers also opined that the hope of people with a sad but unstable mood can perform a self-regulatory function.

Vartak (2015) aimed to find out the role of hope and social support on resilience among 115 cancer patients residing in Mumbai. The study was conducted using the Herth hope scale to measure levels of hope and it performed several statistical tests namely, Two-way ANOVA, frequency analysis, correlation and regression test. Results indicated that all three variables are positively correlated to each other and patients who have higher levels of hope will have higher levels of resilience.

Afrooz et al. (2014) undertook a research to investigate the nature of hope among 200 Iranian cancer patients using a convenience sampling method and Herth Hope Index. They reported moderate to high levels of hope and indicated that hope-inspiring strategies included relationship with God, praying, controlling the signs and symptoms of the disease, etc. and those with good support from their families had higher levels of hope.

Duggleby et al. (2013) collected data from 310 cancer patients to examine the relationship of hope with pain, energy, and psychological and demographic characteristics in newly diagnosed cancer patients. They found out that those patients who were 65 years of age or older had significantly less hope than those under. Gender also was a reported to be a significant factor with men having higher hope score than women.

Berendes et al. (2010) in their study "Hope in the context of lung cancer: relationship of hope to symptoms and psychological distress" aimed to examine how hope would be significantly related to major symptoms commonly experienced by lung cancer patients (i.e., pain, fatigue, coughing) and psychological distress (i.e., depression). The participants consisted of 51 lung cancer patients and Adult Dispositional Hope Scale was used to measure hope. In

their study, higher levels of hope were found to be significantly associated with lower levels of pain, fatigue, coughing as well as depression.

2.3 Religiosity and Cancer patients

Rybarski et al. (2023) in their study of how religious dimensions interplay in predicting death anxiety in 141 cancer patients show that religious struggles appear to weaken the effect of religion on death anxiety while religious comfort does not enhance. The main aim of the study was to show how various religious dimensions interplay in predicting death anxiety in patients diagnosed with cancer.

Gupta and Koradia (2017) conducted a study among 240 parents of children suffering with cancer in Jaipur, India. The study aimed to assess the level of religiosity and psychological well-being and examined the differences between mothers and fathers. Results indicated that mothers scored significantly higher in terms of levels of religiosity while fathers scored higher in terms of psychological well being.

Meisenhekder et al. (2013) compared faith attitudes versus behaviours for their relationship to mental health in cancer patients. The results indicated that importance of faith and frequency of prayer had no relationship to mental health, but concept of God was a strong correlating factor. Also, patients who perceived God as loving had higher mental health even in the presence of a poor prognosis or pain.

Gus et al. (2012) investigated the frequency with which cancer patients engage in religious and spiritual practices, the method used, the reasons for such a search, and the levels of depression and hopelessness in patients who seek spiritual assistance. 110 cancer patients were

studied and out of which 20% preferred spiritual practices and that the decision to do so is linked to their levels of depression and hopelessness.

Weaver et al. (2005) designed a study to understand the role of religion/spirituality for cancer patients and their caregivers. The study was suggestive that religion offers hope to those suffering from cancer and that it has positive effect on the quality of life of the cancer patients. They also opined that patients tend to increase their focus on religious issues and their connection to God as their cancer advances and that on the other hand, faith-based community also offer an essential source of social support.

Pargament (2002) evaluated the cost and benefits of religiousness and presented its implications for well being. It is suggested that religion is richer, more complex process than psychologists have imagined and that religious beliefs and practices appear to be especially valuable in stressful situations that push people to the limits of their resources. Wellbeing also has been linked positively to a religion that is internalized, intrinsically motivated, and based on a secure relationship with God.

2.4 Perceived Social Support and Cancer patients

Rawas et al. (2024) following a cross-sectional quantitative method aimed to measure the levels of hopelessness and social support among cancer patients using the Beck Hopelessness Scale (BHS) and the Multidimensional Scale of Perceived Social Support (MSPSS) of 300 samples. Their finding suggested that the levels of hopelessness in cancer patients were moderate and the levels of social support received by participants are high.

Salim et al. (2019) in considering the problems caused by the burden of cancer patients and their families aimed to investigate the correlation between perceived social support and

resilience in 114 family caregivers of patients with cancer. The results indicated that increased social support improves the resilience of caregivers of patients with cancer and they recommended that families and caregivers should be trained to provide timely support.

Taywade (2018) reported in her study that cancer patients who perceive high social support actively engage in overcoming a stressful situation by trying to eliminate the source of stress. The study was to investigate the relationship between copying strategies and social support among cancer patients by following incidental sampling in which 50 cancer patients of different hospitals of Nagpur city were assessed. Results also showed significant correlation between strategies and perceived social support and between perceived social support and engagement.

Somasundaram and Devamani (2016) conducted a comparative study on resilience, perceived social support and hopelessness among 60 cancer patients treated with curative and palliative care in the age range of 18-65 years in Chennai. The study revealed that participants in the curative care obtained high score on the factors of resilience, social support and low score on hopelessness than the other group. It suggested that the role of social support and hopelessness on promoting the resilience cannot be ignored.

Kavitha and Jayan (2014) assessed the role of social support on cancer distress among 235 breast cancer patients taken from Calicut Medical College Kerala. Instruments used were Berlin social support scale (BSSS) and Distress inventory cancer version-2. The study was concluded with the result that women who had high social support had less cancer distress and it thus pointed out the need of social support in patients to reduce distress associated with diagnosis and treatment.

Rizalar et al. (2014) aimed to identify the psychosocial adjustment of 100 Turkish patients with breast cancer and the effects of perceived social support on their adjustment. The study result showed that social support for patients had an influence on their psychosocial adjustment to illness and was suggestive that patients should **be accompanied by their family/relatives in treatment and care following their diagnosis and that they should be encouraged to participate in social support groups.**

2.5 Caregiver of Cancer patients

Masoume et al. (2024) in their study aimed to determine the meditational role of hope in the relationship of resilience with depression, anxiety, and stress in caregivers of children and adolescents with cancer. It was reported that hope was a mediator and female caregivers were a moderator in the relationship of resilience with depression, anxiety, and stress and that its promotion might be effective among caregivers of children and adolescents with cancer.

Osama et al. (2021) with the understanding to achieve inclusive knowledge about the outcome of caregiver burden conducted a cross-sectional, observational study. The study assessed psychological distress among caregivers of cancer patients using systematic random sampling method. Depression and anxiety were reported 53.8% and 72.7% among the caregivers and indicated psychological distress as prevalent with subsequent characteristics, i.e. females, younger and middle age, and low economic status.

Sahadevan and Namboodiri (2021) in their study aimed to find out the prevalence and determinants of depression in caregivers of breast cancer in South India using the Hamilton rating scale. The result indicated the prevalence of depression in 58.5% of caregivers where 35%, 16%, and 2% had mild, moderate and severe depression respectively.

Shim and Ng (2019) with the notion that cancer care-giving is challenging and often associated with significant burden in family caregivers, aimed to examine the associations between the caregiver burden and their levels of depression, religiosity, and religious coping patterns. Result showed that there were no significant association found between religiosity and religious coping with the caregiver burden. However they opined that the result does not mean that religious factors have no value or positive role at all in the care-giving process.

Preksha and Kaur (2016) in 225 eligible family caregivers of cancer patients of Punjab State examined the relationship of perceived social support and burden among family caregivers of cancer patients. They hypothesised that family caregivers receiving social support are likely to feel low burden. This hypothesis was accepted and was suggestive that oncology nurses should assess the social support of caregivers of cancer patients as it directly affects the burden.

Sunkarapalli et al. (2016) designed a study to determine the relationship between hope and quality of life in caregivers of cancer patients from the city of Hyderabad. Herth Hope Index and Caregiver Quality of Life Index-Cancer were administered in which the participants were from an age range of 20-40 years. The result revealed that there is no significant difference in the level of hope and quality of life and was of the opinion that various psychological counselling sessions should be administered by counsellors to both patients and their caregivers to improve their quality of life.

Haun et al. (2014) in their cross-sectional study on "Distress in cancer patients and their caregiver and association with the caregivers' perception of dyadic communication" calculated the prevalence of clinically significant distress. The 189 patients were either out or inpatients at the National centre for tumour diseases in Germany. Results found that 33% of the caregivers

and 25% of the patients exhibited significant anxiety. The prevalence of depression was lower but equally high in caregivers and patients.

2.6 Stages of Cancer and Socio-Economic status of patients on Psychological distress

Negussie et al. (2023) following a cross-sectional study aimed to assess the prevalence of psychological distress and associated factors among 386 cancer patients in Ethiopia through an interview administered questionnaire and Oslo-3 item social support scale. The result indicated that 64.5% of the respondents showed prevalence of psychological distress. Additionally it was also reported that stage of cancer, age, marital status, place of residence, social support, etc. were associated with psychological distress.

Das and Roy (2019) conducted a stage wise comparison of psychological distress and quality of life in breast cancer patients in Kolkata, West Bengal. It was conducted among 30 women, in the initial, middle and advanced stages (10 in each stage) in which, 53% were found to have symptoms of depression, anxiety and trauma which were associated with reduced quality of life. However, the three stages were not found to differ with respect to the studied variables as well as socio-demographic and clinical variables.

Huda (2019) noted that although many articles describe psychological distress, it is poorly defined in the literature. Thus the author analysed the concept of psychological distress in terms of advanced cancer patients by literature search for the years 1988-2018. The findings reported that psychological distress in terms of advanced cancer has five defining attributes, namely, anxiety, depression, demoralisation, death anxiety, and perceived inability to cope effectively. It also stated that negative psychological distress outcomes are hopelessness, low quality of life, and reduced performance status.

Kim et al. (2017) investigated the prevalence and prognostic significance of psychological distress in 229 gastric cancer patients in South Korea between November 2009 and March 2011. Among the patients, 77 of them were identified as patients with psychological distress among which, females, unemployed, lower educational background, and those with an advanced stage (Stage IV) were found to be significantly higher.

Mushtaq et al. (2017) examined the frequency of depression among cancer patients and its relationship with duration and stages of cancer with a total of 116 patients using Beck Depression Inventory (BDI). The data was analyzed by using SPSS-v19 and Chi-square test was applied to determine the significance of results. Results of the study showed that the frequency of depression was significantly high in stage III (80%) as compared to stage I (31%) and stage II (56%). The study concluded that the frequency of depression significantly increases with duration of cancer.

Alagizy et al. (2020) in their cross-sectional study conducted on women with breast cancer revealed the prevalence of depressive symptoms, anxiety symptoms and perceived stress. More specifically, among patients who were living in rural areas, 77.3% had moderate to severe depression, 81% moderate to severe anxiety, and 80% moderate to severe stress. Additionally, unemployed patients had significantly higher prevalence of moderate to severe anxiety (100%) than employed patients.

Malhotra et al. (2020) assessed inequalities of socio-economic inequalities in end-of-life suffering among advanced cancer patients from across five countries (China, Sri Lanka, India, Vietnam and Myanmar). Results indicated that patients living in low economic status households or with fewer years of education had greater suffering in several domains. Age significantly

moderated the association between economic status of the household and social suffering and between years of education and psychological, social and spiritual setting. It suggested that greater palliative care resources for patients with low SES may help reduce these inequalities.

Kumar et al. (2018) in their study assessed socio-economic status and demographic profile of patients with advanced cancer patients receiving palliative care at Saroj Gupta Cancer Centre and Research Institute (SGCCRI), Kolkata. Eighty patients were interviewed face to face with the help of a self-designed social assessment sheet. It was observed that approximately 30% of the patients interviewed had income less than 1 lakh per month while majority (60%) had income between 1 lakh and 2 lakhs. Result was thus indicative that patients with low SES had reduced coping to psychological distress as compared to patients with high SES and required referral to a psychologist.

Srivastava et al. (2016) in their study of anxiety and depression among breast cancer patients from North India found out that the prevalence was 37% and 28% respectively. The study sample consisted of 200 patients who were diagnosed from January 2013 to December 2014 and were interviewed using the Hospital Anxiety and Depression Scale (HADS). Their study result clearly shows that younger age group, low monthly income, having less financial support, low education level and being single were associated with anxiety and depression.

Chang et al. (2014) explored the association between low Socio-Economic Status (SES) and aggressiveness of end-of-life (EOL). In this national data based study of 32,800 working-age cancer deaths in Taiwan from 2009-2011, the researchers found that the aggressiveness of EOL care differed according to individual SES. Low SES terminal cancer patients were associated with more aggressive EOL care. It was reported that they were more likely to receive

chemotherapy, have frequent visits and ICU admissions, and to die in an acute-care hospital than high SES patients.

2.7 Studies on the role of Counselling

Blunt and Trigg (2024) aimed to describe perception of psycho-oncological counselling for people directly or indirectly affected by cancer and described perceived psychological distress, depression and anxiety from pre to post counselling. Respondents' expectations, experiences, and counselling outcomes were examined via pre-post-tests and thematic analysis reporting reduced anxiety, depression and distress and it was suggested that individual supportive counselling play an integral role in lives of cancer patients and family members. It was also reported that benefits of accessing counselling included reduced sympotomology, receipt of beneficial knowledge and skills, and an increased ability to manage their everyday lives.

Luque et al. (2016) aimed to analyse the effects of psychological treatments on quality of life among cancer patients and survivors. The results of the study are an analysis of scientific studies published between 1970 and 2012 that included 78 studies. The study reported that quality of life is improved by psychological interventions, especially when patients have to cope with medical treatment or with adjustment after the disease is treated. It reported that the findings of the studies support that providing psychological treatments should be considered as crucial for patient's health in cancer context.

Wu et al. (2015) analysed individual counselling as preferred treatment for depression in breast cancer survivors. The participants were asked to complete an anonymous survey asking preference and interest in three treatments for depression; individual counselling, antidepressant

medication, or social support. It is reported that over 50% preferred individual counselling than the other two. Preference was compared using Wilcoxon Signed Ranks tests.

Bleiker et al. (2005) investigated on self reported reasons for early withdrawal of genetic counselling for cancer. The primary reason reported in the study were difficulties in anticipating the consequences of genetic counselling, and worries about being unable to adequately cope with an unfavourable test result. It was shown that more of young women, those without a history of cancer, and those who were first in their family to apply were more likely to withdraw prematurely from genetic counselling for breast/ovarian cancer.

Bish at.al (2002) sought to examine the changes in psychological distress of women following cancer genetic counselling. Women attending a family cancer clinic completed questionnaires before their appointment and at 2 weeks, 6 months and 12 months after their appointment. The samples were divided into three groups (low risk, moderate risk, and high risk) in order to make a comparison. Results indicated that specific worry about developing breast cancer was reduced for all groups following genetic counselling, although perception of risk was not reported to change.

Pascoe et al. (2000) in their study aimed to estimate the prevalence of anxiety and depression within a cross section of cancer patients in the Sydney region, and to assess the satisfaction with available social support services. The study reported that the prevalence of clinically significant anxiety and depression was 11.5% and 7.1% respectively. The study also reported that majority of the affected patients were not accessing counselling or psychological treatment. However, of the majority of patients who had attended counselling or support groups reported to have been ‘extremely’ (86%) or reasonably (83%) helpful.

2.8 Cancer in North-East India

Shenker et al. (2021) in their study aimed to describe the cancer profile of the North-East India region focusing on the cancer sites that have high incidence from population-based cancer registries (PBCRs). Their findings reported that Aizawl district in Manipur had the highest incidence of cancer in men and women in Papumpare district of Arunachal Pradesh. The type of cancer that was highest reported were, oesophageal in East Khasi Hills district in Meghalaya and stomach cancer among men in Aizawl district in Mizoram. Papumpare district of Arunachal Pradesh was reported to have the highest incidence of stomach (women), liver and cervical cancers. Lung, Nasopharyngeal and gall bladder cancer incidence were reported to be highest in Aizawl, Nagaland and Assam respectively.

Oswal et al. (2020) carried out a cross-sectional study in the North East Region (NER) of India with a sample population of 1400 participants (Assam, Meghalaya and Nagaland) to assess knowledge about cancer (oral, breast and cervical). The study indicated that 59% had heard about oral cancer, 50% about breast cancer, and 31% about cervical cancer and a limited understanding of the risk factors, symptoms and signs. They suggested that the level of cancer awareness is low in the NER and that it needs to be coupled with mass media communication and interpersonal communication through frontline health workers.

Ngaihtel et al. (2019) attempted a study to get a clear picture of cancer in North East India, the gaps in providing cancer care, and a way forward for a healthier region by doing a desk review along with secondary data analysis. They reported that the survival rate is comparatively low, with higher proportion of distant metastasis cases at diagnosis. Additionally, it also highlighted that NE region lacks required infrastructure with respect to specialized treatment facilities, human resources, etc.

Lamtha et al. (2016) looked at ethnic and dietary factors in patients above 60 years with gastric cancer in Sikkim over a period of one year. The study was divided into four ethnic groups; Bhutias, Lepchas, Rias, and other groups. The study result showed that Bhutia ethnic group had a higher incidence of gastric cancer as compared to other groups. This high incidence rate was associated with a trend towards higher intake of smoked meats, fermented vegetables, salt tea, etc.

Kataki et al. (2011) in their study Nasopharyngeal Cancer (NPC) in the North-Eastern states of India noted that this type of cancer is common among the hill states of NE India particularly Nagaland, Manipur, and Mizoram. It is reported that the age-adjusted rate of NPC is recorded highest in Kohima district of Nagaland and the least common is in Assam. The study reports that the main generic risk of this type of cancer is most common among those who are presumed to be bearers of the mongoloids.

Chelleng et al. (2000) conducted a matched case-control study to identify dietary and environmental risk factors for nasopharyngeal carcinoma in Nagaland. For each of the cases identified for study, 2 apparently healthy neighbourhood controls were matched for age, sex, and ethnicity. The result of the study reported that consumption of smoked meat was found to be the risk factor for NPC and history of using herbal nasal medicine was also found to be associated.

The researcher reviewed a series of studies related to Psychological Distress, Hope, Religiosity and Perceived Social Support among Cancer patients and their caregivers. The review was also done to explore the differences/affects based on Gender, Stages of Cancer, role of Counselling, and Socio-Economic Status. The literature included studies done abroad as well as in India which provided a vast knowledge for the present study.

Majority of the studies reported that psychological distress namely depression, anxiety and stress are common among cancer patients though the level and frequency vary. Differences in terms of gender showed mixed results revealing in most studies that women experience higher distress than men. However a number of studies have also indicated no gender difference. Very few studies have been conducted among caregivers of cancer patients which adds to the importance of exploring the prevalence of psychological distress even among them as it is may be expected that caregivers also experience distress as much as the patient themselves.

Literature on the role and association of hope on psychological distress among cancer patients was found to be conducted only among a limited number, which also did not have study among Indian samples. These few studies have indicated higher levels of hope to be significantly associated with lower levels of distress. Studies on religiosity among cancer patients were identified among a few however it is very scarce. Also no studies were found to have explored the relation with depression, anxiety or stress which sheds the importance to carry out the present research study. On the other hand, literature has indicated that studies have been conducted among cancer patients to understand the role of perceived social support but direct relationship with psychological distress has not been explored. Very importantly, apart from studies of cancer incidences and risk factors, no study was found to be conducted among cancer patients of North-Eastern States of India from a psychological perspective except on studies of its incidences and risk factors.

With regard to observations in terms of the cancer stage, it was seen that stage of cancer has association with psychological distress showing symptoms of depression, anxiety and stress where some literature additionally reports that distress is more common among advanced stage cancer and the frequency increases with duration of cancer. Literature suggests that socio-

economic factors may also be considered as another risk factor of developing psychological distress among cancer patients as literature shows consistent finding reporting greater suffering and reduce coping to psychological distress of patients due to unemployment or living with lower socio economic status. Multiple suggestions provided through various studies if implemented with a deeper understanding of common psychological concerns may do justice by enhancing and maintaining cancer patients' physical as well as psychological issues. It may also be recommended that more evidence based research be conducted among caregiver distress as well.

CHAPTER 3

METHODOLOGY

This chapter presents the methodology followed by the researcher in course of the research work. It includes the sampling design, operational definition, tools used, procedures of the study, data analysis and ethical consideration.

3.1 Sampling Design

3.1.1 Inclusion criteria for cancer patients.

- Participant must be someone who has been diagnosed with cancer (any type) and is currently undergoing treatment.
- Participants must belong to Naga community.
- Must be 18 years and above in age.
- Must be able to read and understand English.

3.1.2 Exclusion criteria for cancer patients.

- Admitted in Intensive Care Unit (ICU) at the time of data collection.
- Patients who currently exhibit symptoms of mental disorders.

3.1.3 Inclusion criteria for primary caregivers.

- Participants must belong to Naga community.
- Must be 18 years and above in age.
- Must be able to read and understand English.

3.1.4 Sampling Technique

The sampling technique used for the present study is 'Purposive Sampling Method' which is a non-probability sampling method in which a researcher selects the respondents according to some pre determined criteria that is based on the typicality of the cases to be included in the sample. As proper sampling frame for the study was not available, collection of data was done using the mentioned sampling technique and identified various hospitals in Nagaland which had provisions specifically for treating cancer patients. Five hospitals across Nagaland were identified and accordingly, patients with cancer admitted in these hospitals together with their primary caregiver were then selected from these hospitals following inclusion/exclusion criteria. Besides, data were also collected from patients who were being monitored at home. These were patients availing treatment from outside the State of Nagaland or those who visit hospital only on a basis of monthly regular treatment. They were identified through the help of friends and family members.

3.1.5 Sample size

The researcher collected responses from a total of 320 participants which comprised of 160 cancer patients currently undergoing treatment and 160 primary caregivers (one for each patient). Data were collected between the years 2019-2022. The patients and their caregivers were identified on the basis of inclusion and exclusion criteria mentioned below.

3.2 Tools used

The following research tools were used by the researcher for data collection. In order to use the tools, permission was taken from all the tool/scale developers through e-mail.

3.2.1 Depression, Anxiety and Stress Scale-21 (Lovibond & Lovibond, 1995)

The Depression, Anxiety and Stress Scale 21 (DASS-21) is a scale designed to measure three negative emotional states, i.e. depression, anxiety and stress. Depression subscale assesses dysphoria, hopelessness, devaluation of life, self-deprecation, and lack of interest/involvement, anhedonia and inertia. Anxiety subscale assesses autonomic arousal, skeletal muscle effects, situational anxiety, and subjective experience of anxious affect. Stress subscale assesses difficulty relaxing, nervous arousal, and being easily upset/agitated, irritable/over-reactive and impatient.

The DASS-21 has four possible answers in terms of severity or frequency with 21 statements organized in a scale from 0 (Never) to 3 (Almost Always) in which each item of the scale contains severity ratings ranged from normal, mild, moderate, severe, and extremely severe. The scale has a high internal consistency for each of the subscales; Cronbach's alpha for Depression – 0.96 to 0.97, Anxiety – 0.84 to 0.92, and Stress – 0.90 to 0.95.

Reliability analysis for the scale with 21 items was assessed using Cronbach's alpha for the present study samples (Cancer Patients and Caregivers). The result revealed acceptable reliability for each of the subscale constructs in the study for both samples; Cronbach's alpha of Cancer patients for Depression – 0.89, Anxiety – 0.89, and Stress – 0.91; Cronbach's alpha of Caregivers for Depression – 0.85, Anxiety – 0.84, and Stress – 0.85.

In the present study, the scoring was done by following the scoring procedure as given in the DAS Scale-21, i.e., adding up the scores of the items for each of the three subscales, i.e.

Depression, Anxiety, and Stress separately and multiplying each total score by 2. This was then interpreted as per the severity rating index of the scale as shown in Table 3.1. The scores generated from this scale were taken as a measure of Psychological distress in the present study.

Table 3.1

Table showing DAS-21 Severity Rating Index

	Depression	**Anxiety**	**Stress**
Normal	0-9	0-7	0-14
Mild	10-13	8-9	15-18
Moderate	14-20	10-14	19-25
Severe	21-27	15-19	26-33
Extremely Severe	28+	20+	34+

3.2.2 Herth Hope Index (Herth, 1992)

The Herth Hope Index (HHI) is designed to measure hope in adults consisting of 12 statements that uses a Likert scaling format. Ten items on the Index is scored on an ordinal scale from 1 to 4 with a score of 1 indicating *"strongly disagree"* and a score of 4 indicating *"strongly agree"* and two items are reversed scored. Total score can range from 12-48 with higher scores representing higher hope.

The reliability of HHI is indicated high as the alpha coefficient was 0.97 and test-retest reliability after two weeks was 0.91. Criterion-related validity of HHI is indicated by the high correlation with the Herth Hope Scale (r = 0.92), the Existential Well Being Scale (r = 0.84) and the Nowonthy Hope Scale (r = 0.81) and divergent validity established with the Hopelessness Scale indicated negative relationship (r = -0.73).

Reliability analysis for HHI with 12 items was assessed using Cronbach's alpha for the present study samples (Cancer Patients and Caregivers). The result indicated acceptable reliability for each of the subscale constructs in the study for both samples; Cancer patients (r= 0.92) and caregivers (r= 0.82). The scores obtained from the data collected in the present study were calculated by adding the raw scores. The mean of the total score was worked out and interpretation was made in such a way that higher the score, higher the level of hope. The scores generated from this scale were taken as a measure of Hope in the present study.

3.2.3 The Duke University Religiosity Index (Koenig & Bussing, 2010)

The Duke University Religiosity scale (DUREL) is used to examine relationships between religion and health outcomes which have three subscales each assessing a particular aspect of religious practice or religious devotion which is. They are,

(a) *Organizational Religious Activity (ORA*) which involves public religious activities such as attending religious services or participating in other group related religious activities (prayer groups, Scripture study groups, *etc*.), (b) *Non- Organisational Religious Activity (NORA)* which consists of religious activities performed in private, such as prayer, Scripture study, watching religious TV or listening to religious radio and (c) *Intrinsic Religiosity (IR)* which accesses degree of personal religious commitment or motivation.

However, for the present study only two dimensions, i.e. *ORA and NORA* were included which both has only 1 statement each with 6 possible answers in terms of religious participation organised as ORA (1- More than once a week to 6 -Never) and NORA (1- More than once a day to 6-Rarely/Never). The scale has a high test-retest reliability (intra-class correlation 0.91), high internal consistency (Cronbach's alpha 0.78-0.91), and high convergent validity with other measures of religiosity 0.71- 0.86.

Reliability analysis for DUREL with 2 items was assessed using Cronbach's alpha for the present study samples (Cancer Patients and Caregivers). The reliability indicated by the result for each of the subscale constructs in the study for both samples are; Cancer patients (r= 0.59) and caregivers (r= 0.60). The two subscale scoring (ORA and NORA) was done independently of each other by reversing the scores of both the items. The scores generated from this scale were taken as a measure of Religiosity in the present study.

3.2.4 Berlin Social Support Scale (Schwarzer & Schulz, 2000)

The Berlin Social support scale (BSSS) measures cognitive and behavioral aspects of social support to investigate support interaction in stressful situations. It comprises of six individual scales namely; *Perceived support, Actually Provided social support, Actually Received social support, Need for social support, Support Seeking, and Protective Buffering.*

In the present study, only one subscale of the scale, i.e. *Perceived support* has been used which comprises items of emotional and instrumental support. It is a 4-point Likert type scale with a total of 8 statements and respondents rate their agreement based on possible endorsements that is, *strongly disagree (1) somewhat disagree (2), somewhat agree (3) somewhat agree and strongly agree(4).* This subscale has a high internal consistency (Cronbach's alpha .83) where validation sample were cancer patients, N=457.

Reliability analysis for BSSS with 8 items was assessed using Cronbach's alpha for the present study samples (Cancer Patients and Caregivers). The result indicated acceptable reliability for each of the subscale constructs in the study for both samples Cancer patients (r= 0.92) and caregivers (r= 0.91). Scores were obtained by adding up item responses (sum scores) and was taken as a measure of Perceived social support.

Personal Data Form developed by the researcher was used in order to obtain socio-demographic characteristics of the participants namely, name (optional), age, gender, educational qualification, marital status, annual family income, religion, whether diagnosed with any psychological disorders in the past, type and stage of cancer, and whether counseling being sought.

3.3 Operational Definition

3.3.1 Cancer patient: In this study, cancer patient is someone who has been given a medical diagnosis of cancer by a recognized practitioner and is currently undergoing treatment.

3.3.2 Primary caregiver: According to the American Cancer Society, primary caregiver is defined as the person who most often helps the patient and is not paid to do so. This definition was adopted as the operational definition for the purpose of this study.

3.3.3 Psychological distress: Psychological distress is an emotional suffering characterized by symptoms of depression, anxiety and stress. Scores obtained from Depression, Anxiety and Stress Scale-21 (DASS-21) is taken as indicative of psychological distress of the participants.

Depression: Depression is a condition characterized by low mood, a feeling of sadness, and a general loss of interest in daily activities. The participant's level of depression is determined from DASS-21 depression score.

Anxiety: Anxiety is a negative mood state characterized by bodily symptoms of physical tension and by apprehension about the future. The participant's level of anxiety is determined from DASS-21 anxiety score.

Stress: Stress is a feeling of emotional or physical tension and is often a trigger for depression and anxiety. The participant's level of stress is determined from DASS-21 stress score.

3.3.4 Hope: Hope is an emotion characterized by positive feelings about the immediate or long-term future. Score obtained from Herth Hope Index (HHI) determines the level of Hope of the participants.

3.3.5 Religiosity: Religiosity refers to having faith in the Almighty and practicing certain religious acts. Score obtained from The Duke University Religiosity Index (DUREL) determines the level of Religiosity of the participants.

3.3.6 Perceived social support: Perceived social support refers to an individual's feeling of support being received from family members, friends and the community. Score obtained from Berlin Social Support Scale (BSSS) determines the degree of Perceived social support of the participants.

3.4 Procedure

After preparing the questionnaire, the identified hospitals were visited taking prior permission from the respective authorities to carry out research in their esteemed institution. Patients who were being monitored at home were also taken prior permission from the caregiver and/or from the patient themselves. Once the patients and caregivers were identified according to the inclusion/exclusion criteria, they were given clear information about the purpose and nature of the study and informed consents were obtained. Following this, the administration was carried out by providing proper instruction on how to fill and complete the scales. After the responses were collected from each of the participants, appropriate scoring for each scale was done followed by analysis of data.

3.5 Data analyses

The analyses of data were done using the Statistical Package for Social Sciences version 21 (SPSS-21). Test of normality was carried out using Shapiro Wilk test of normality which showed that the data were non-normal hence non-parametric test was considered for the study. The statistical techniques used for analyzing were simple percentage, Spearman's correlation coefficient, Mann-Whitney U Test, Kruskal Wallis H Test and Chi-Square Test.

3.6 Ethical consideration

In order to maintain ethical principles, approval was taken from management of various hospitals to collect data from admitted cancer patients. The study also obtained ethical approval from Departmental Research Ethics Committee, Department of Psychology, Nagaland University (Reference No. NU/PSY/ETHICS-23/02). Additionally in particular written consent was obtained from all participants before participation considering the following;

a) The researcher honored the right of the participants to remain anonymous.
b) The researcher obtained informed consent from the participants.
c) The researcher treated the data obtained from the participants as confidential and participants were assured that data will be used only for research and academic purpose.
d) The participants had the right to withdraw from the study at any point of time.
e) The researcher made sure that the participants in the study were not subjected to any psychological and physical harm.

CHAPTER 4

RESULTS

The findings obtained by subjecting the data to statistical processes in line with the responses given by the respondents are highlighted under this chapter. The analyses of data were done using the Statistical Package for Social Sciences version 21 (SPSS-v21). Test of normality was carried out using Shapiro-Wilk test of normality which showed that the data were non-normal hence non-parametric tests were considered for the study. The statistical techniques used for analyzing were simple percentage, Spearman's correlation coefficient, Mann-Whitney U Test, Kruskal Wallis H Test, Chi Square Test.

4.1 Demographic details

Various demographic details (Gender, age, religion, monthly income, stage and type of cancer, and having sought counseling or not) were collected by the researcher which has been analyzed. It was reported that 100% of the respondents (patients and caregiver) belong to Christian religion. In terms of age category, cancer patients' age ranged from 23 to 80 years while the age of primary caregivers ranged from 18 to 64 years.

4.1.1 Gender

Participants in the present study comprised of 160 cancer patients and 160 primary caregivers. Among cancer patients, 66 respondents were males and 94 respondents were females. Among caregivers, 60 were males and 100 were females.

Figure No 4.1

Sample distribution of cancer patients by gender

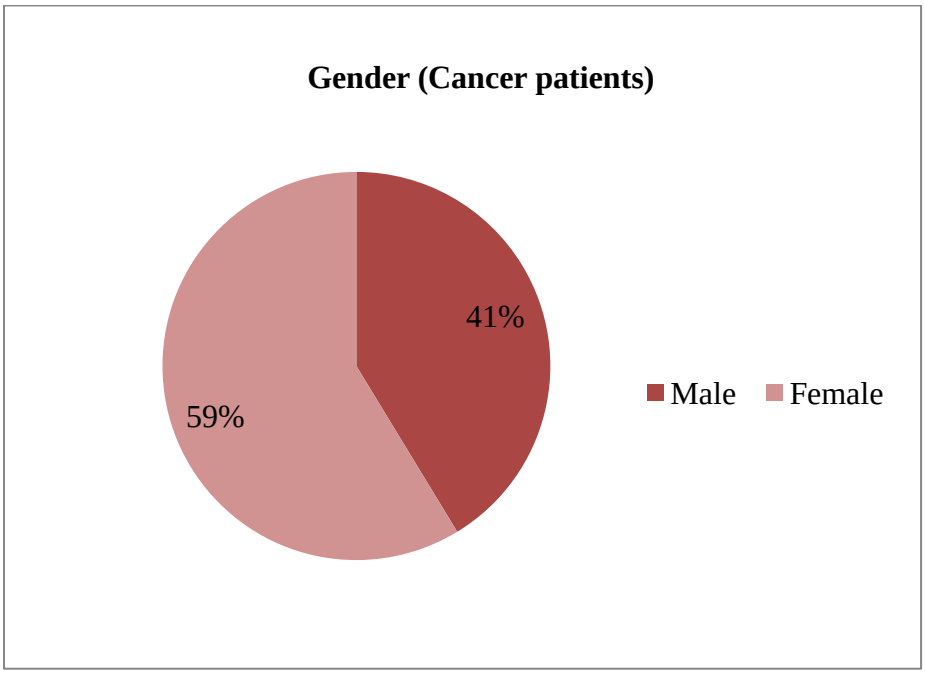
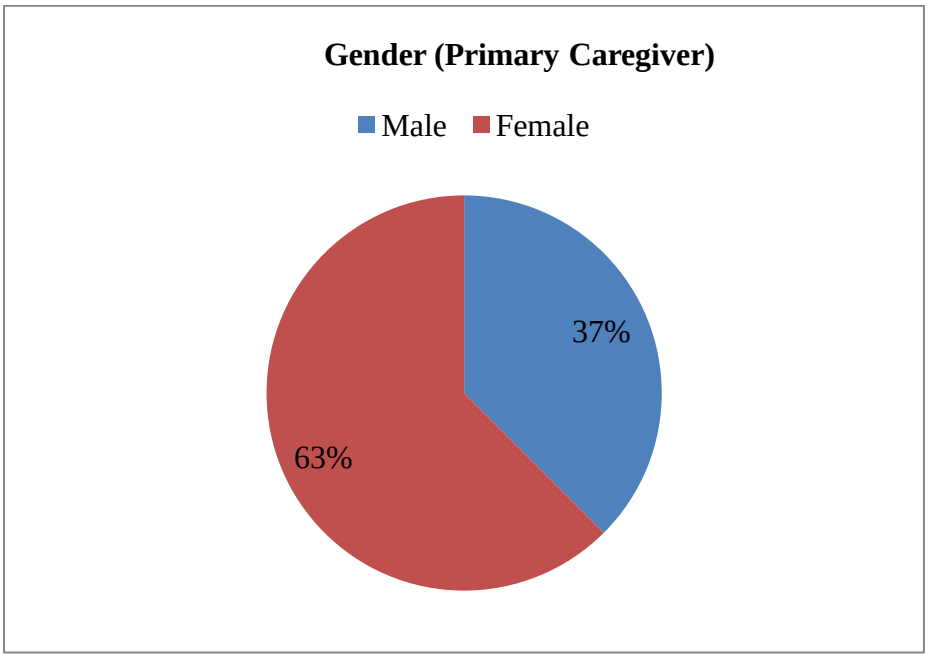


Figure No 4.2

Sample distribution of Primary caregiver by gender

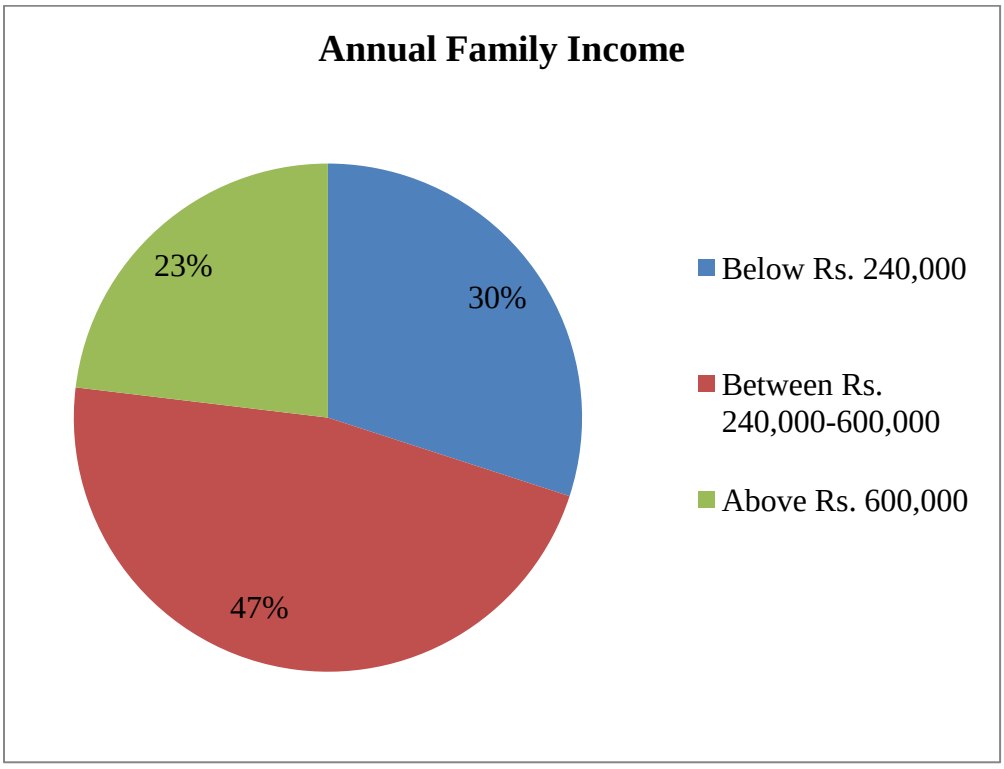


4.1.2 Annual family income.

In the present study, data on annual family income was obtained from the respondents on a basis of three categories that is, below Rs. 240,000/-, between Rs.240,000/- to Rs. 600,000/- and above Rs.600,000/- per annum as shown in figure 4.3.

Figure No 4.3

Sample distribution of cancer patients by annual family income

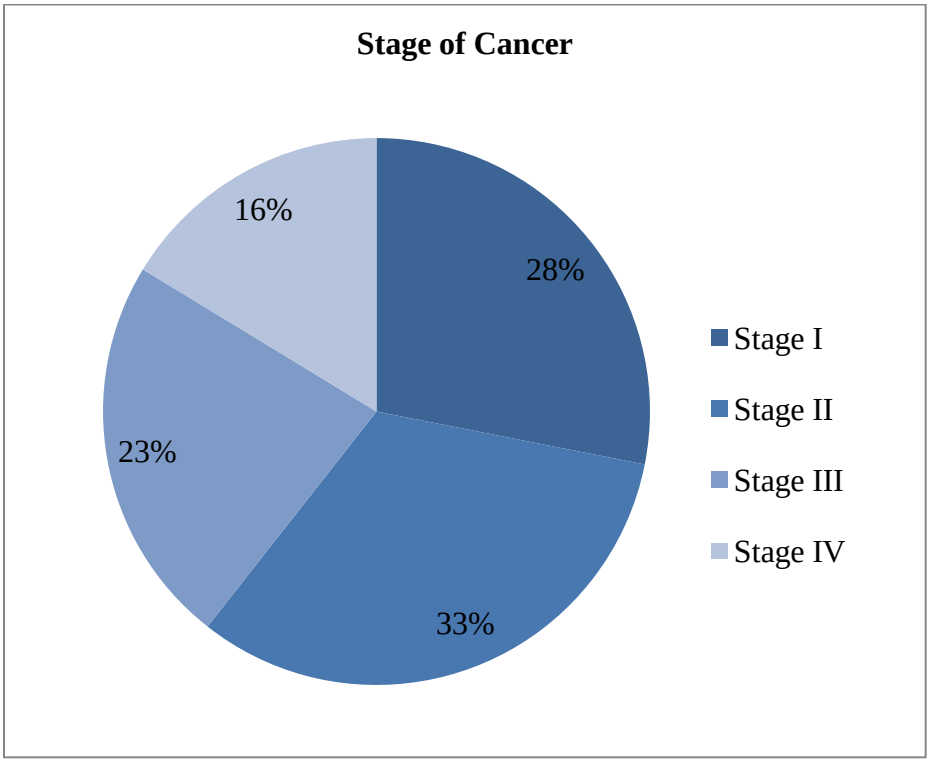


4.1.3 Stage of Cancer

Data on the stage of cancer were also collected and it was observed that 28% (n=45) of cancer patients were diagnosed with stage 1 cancer and 33% (n=52), 23% (n=37), and 16% (n=26) being diagnosed with stage 2, stage 3 and stage 4 cancer respectively (Figure no. 4.4).

Figure No 4.4

Sample distribution of cancer patients by the stage of cancer



4.1.4 Counselling

The research also considered on collecting data on whether counseling has been sought by the participants through a closed ended question as ‘yes or no’. Further investigation such as nature, type or duration of counseling was not collected. Thus this information pertains only to yes/no responses provided by the participants (cancer patients and caregiver) which can be seen in the following figures: 4.5 and 4.6.

Figure No 4.5

Sample distribution of cancer patients on seeking counseling

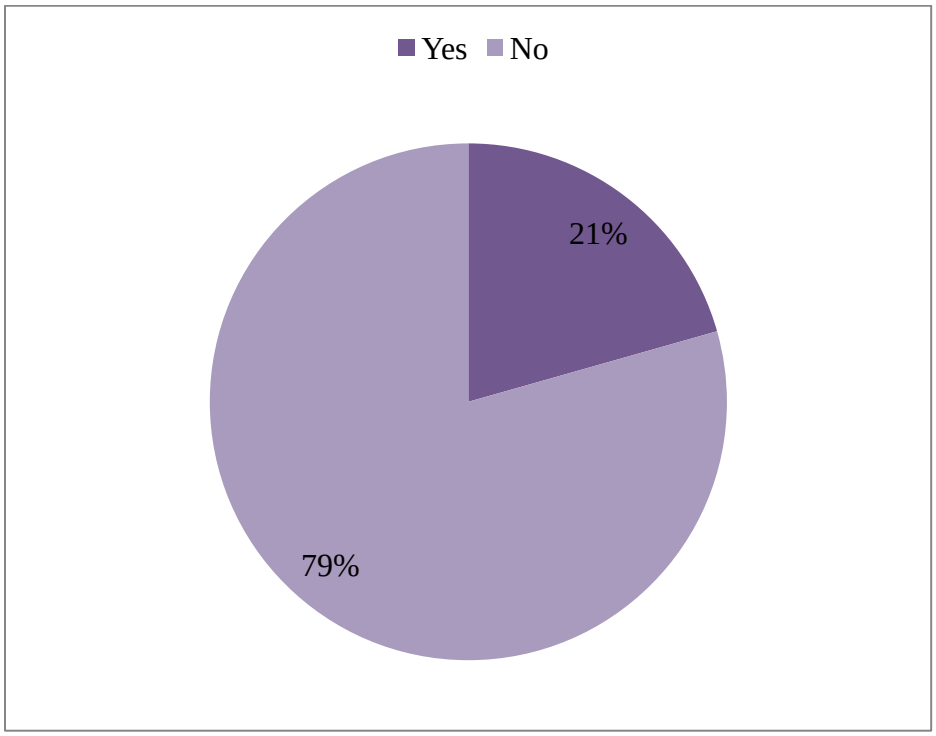


Figure No 4.6

Sample distribution of primary caregivers on seeking counseling

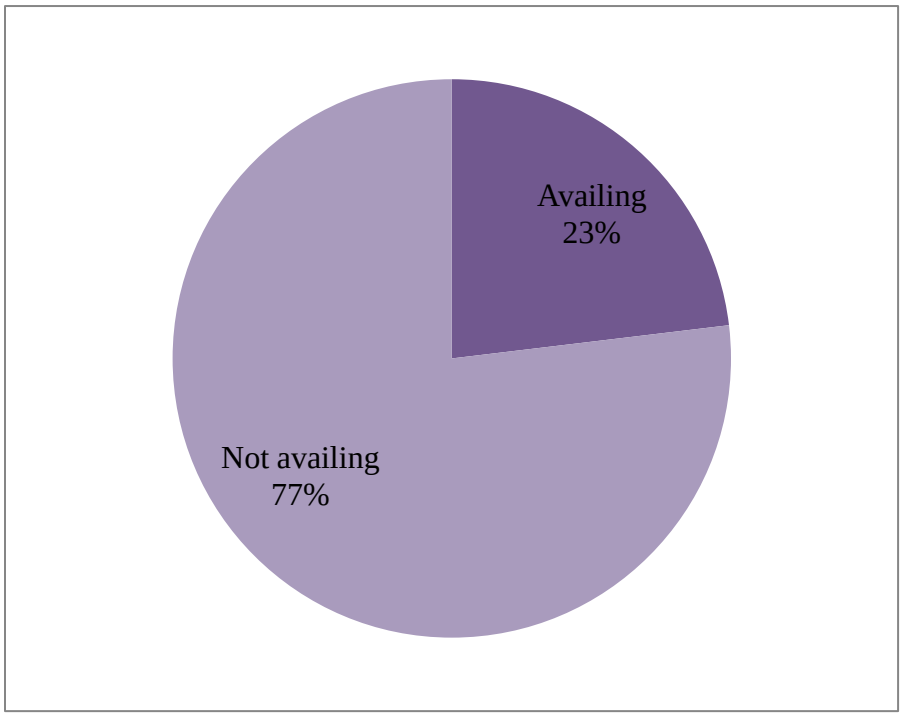


Table No. 4.1

Table showing descriptive statistics of cancer patients

Variables	Descriptive statistics						
	Mean	Median	Variance	SD	Min	Max	Range
Hope	37.41	37.53	22.77	4.77	24	48	24
ORA	2.75	2.00	7.53	2.74	1	32	31
NORA	2.94	2.00	2.68	1.63	1	6	5
Social support	28.89	30.00	14.67	3.83	3	32	29
Depression	11.74	10.00	108.68	10.42	0	42	42
Anxiety	12.96	12.00	78.89	8.88	0	40	40
Stress	13.61	14.00	71.42	8.45	0	40	40

Table No. 4.2

Table showing descriptive statistics of primary caregivers

Variables	Descriptive statistics						
	Mean	Median	Variance	SD	Min	Max	Range
Hope	39.49	38.89	14.71	3.83	29	48	19
ORA	2.21	2.00	1.61	1.26	1	6	5
NORA	2.77	2.00	2.41	1.55	1	6	5
Social support	29.45	31.00	9.49	3.08	20	32	12
Depression	7.88	8.00	40.08	6.33	0	32	32
Anxiety	9.93	11.00	41.25	6.42	0	26	26
Stress	11.24	12	45.52	6.74	0	36	36

4.2 Prevalence of Psychological distress among Naga cancer patients and their primary caregivers

In the present study, the prevalence of psychological distress among Naga cancer patients and their caregivers was assessed by examining the levels of depression, anxiety and stress using the DASS-21 scale.

The presence of psychological distress among cancer patients has been indicated ranging from mild to extremely severe. Result shows that more than half of the respondents were found to have symptoms of depression: f(%) = 85 (53.1%) and anxiety: f(%)= 114 (71.2%) while stress was also reported by a considerable number f(%)= 62 (38.7%).

Table No. 4.3

Table showing Psychological distress severity levels of Cancer Patients

Levels	Depression	Anxiety	Stress
Normal	46.9%	28.8%	61.3%
Mild	24.4%	7.5%	15.6%
Moderate	15%	30%	11.9%
Severe	1.3%	13.1%	10%
Extremely Severe	12.5%	20.6%	1.3%

The presence of psychological distress among caregivers has also been indicated ranging from mild to extremely severe. Result indicated that a majority of respondents were found to have symptoms of anxiety: f(%)= 102 (63.7%). While depression: f(%) = 63 (39.4%) and stress: f(%)= 36 (22.5%) were also reported by a notable number of the respondents.

Table No. 4.4

Table showing Psychological distress severity levels of Caregivers

Levels	**Depression**	**Anxiety**	**Stress**
Normal	60.6%	36.3%	77.5%
Mild	20.6%	5%	9.4%
Moderate	15.6%	38.8%	11.3%
Severe	1.2%	11.9%	1.3%
Extremely Severe	1.8%	8.1%	0.6%

4.3 Hope levels of Naga cancer patients and their primary caregivers

The level of hope was assessed by using Herth Hope Index (HHI) in which the lowest and highest possible scores on the scale is 12 to 48. In the present study it was found that the overall hope scores of cancer patients ranged from 24 to 48, with a mean score of 37.41 (SD = 4.77) while among the caregivers, scores ranged from 29-48, with mean of 39.49 (SD = 3.83). The mean scores of both patients and caregivers fall in the upper range indicating towards having a higher level of hope.

4.4 Religiosity levels of Naga cancer patients and their caregivers

The level of religiosity was measured using two subscales of The Duke's University Religion Index (DUREL). The first subscale (ORA- Organizational Religious Activity) measured public religious activities while the second subscale (NORA – Non-Organizational Religious Activity) measured private religious activities which both have 1 statement each with 6 possible answers. Engagement in organizational activity involved public activities such as attending religious services or participating in other group related religious activities like prayer groups, scripture study groups, etc. The involvement in organizational activities varies from engaging for more than once a week to never. On the other hand, engagement in non-organizational activity involved private activities such as personal prayer, scripture study, watching religious TV or listening to religious radio, etc. The involvement in non-organizational activities varies from engaging for more than once a day to rarely or never.

Organizational Religious Activity (ORA) and Non-Organizational Religious Activities (NORA) scores of cancer patients are shown in table 4.5. It is observed that majority of the cancer patients engage in both organizational and non-organizational activities. For ORA, the highest frequency of responses can be *observed in the response categories more than once a week, once a week, and a few times a month.* Frequencies of responses in the categories *a few times a year, once a year or less* and *never* were relatively less. This implies that majority of the cancer patients (75.7%) in the study engage in ORA frequently. Overall, a great majority (95%) reportedly engage in ORA at least sometimes. Only a small percentage of them (5%) never engage in ORA. For engagement in NORA also it can be observed that highest frequencies of responses are in the response categories of *daily, more than once a day,* and *two or more times a* week implying that majority of the cancer patients in the study also engage in NORA quite frequently. Around half of them (51.3%) engage in NORA at least once daily and a little more than three-fourth of them (77.6%) reportedly engage in NORA at least once a week. Overall, a great majority (90%) engage in NORA –frequently or infrequently. A small proportion (10%) reportedly engages in NORA rarely or never.

Table No. 4.5

Responses on ORA and NORA obtained from the sample of cancer patients.

Religious activity	Response category					
ORA	More than once a week	Once a week	A few times a month	A few times a year	Once a year or less	Never
f (%)	50(31.3%)	34(21.3%)	37(23.1%)	21(13.1%)	10(6.3%)	8(5%)
NORA	More than once a day	Daily	Two or more times a week	Once a week	A few times a month	Rarely or never
f (%)	34(21.3%)	48(30%)	23(14.4%)	19(11.9%)	20(12.5%)	16(10%)

Organizational Religious Activity (ORA) and Non-Organizational Religious Activities (NORA) scores of caregivers of cancer patients are shown in table 4.6. It is observed that majority of the caregivers engage in both organizational and non-organizational activities. For ORA, the highest frequency of responses can be observed in the response categories *more than once a week, once a week, and a few times a month.* Frequencies of responses in the categories *a few times a year, once a year or less* and *never* were relatively less. This implies that majority (83.2%) of the primary caregivers in the study engage in ORA frequently. Overall, it can be observed that a great majority (96.9%) engage in ORA at least sometimes-frequently or infrequently. Only a small percentage (3.1%) reported never engaging in ORA. For engagement in NORA also it can be observed that highest frequencies of responses are in the in response categories of *daily* and *more than once a day.* Roughly more than half of them (56.2%) engage in NORA at least once a day and a little more than three-fourth of them (79.4%) engage in NORA at least once a week. Overall, a great majority (94.4) have reported engaging in NORA-frequently or infrequently. Only a small percentage (5.6) reported never engaging in NORA.

Table No. 4.6

Responses on ORA and NORA obtained from the sample of caregivers

Religious activity	Response category					
ORA	More than once a week	Once a week	A few times a month	A few times a year	Once a year or less	Never
f (%)	61 (38.1%)	43(27%)	29(18.1%)	21(13.1%)	1(0.6%)	5(3.1%)
NORA	More than once a day	Daily	Two or more times a week	Once a week	A few times a month	Rarely or never
f (%)	37(23.1%)	53(33.1%)	22(13.8)	15a9.4)	24(15%)	9(5.6%)

4.5 Perceived Social Support levels of Naga cancer patients and their caregivers

The level of perceived social support was assessed by using Berlin Social Support Scale (BSSS) in which the lowest and highest possible scores on the scale is 8 to 32. In the present study it was found that the overall perceived social support score of cancer patients ranged from 19 to 32, with a mean score of 29.07 (SD = 3.23) while among the caregivers, score ranged from 20 to 32, with mean of 29.45 (SD = 3.08). The mean scores of both patients and caregivers fall in the upper range indicating towards having a higher level of perceived social support.

4.6 Correlation between Hope and Psychological distress levels of cancer patients

Spearman's correlation coefficient was used to find the association between Hope and psychological distress which indicated significant negative correlation. Spearman's correlation has several assumptions. These are: a) the two variables have a monotonic relationship, b) the data is measured on an ordinal or continuous scale, c) the observations are independent and the two variables represent paired observations. The data has fulfilled the assumptions of the test.

The result as shown in table 4.7 reveals negative association of hope with depression, anxiety and stress. Increase in the level of hope is associated with decrease of psychological distress of cancer patients and vice versa. The result thus supports the hypothesis of the study that assumes significant correlation between hope and psychological distress levels of cancer patients.

Table 4.7

Correlation between hope and Psychological distress levels of cancer patients

	Psychological Distress		
Level of Hope	Depression	Anxiety	Stress
	-.569 **(p=.000**)**	-.443 **(p=.000**)**	-.450 **(p=.000**)**

**p< 0.01

4.7 Correlation between Religiosity and Psychological distress levels of cancer patients

Chi Square test was used to analyze the correlation of ORA and NORA with Depression, anxiety and stress which has several assumptions. These are: a) random sampling, b) independent observations, c) mutually exclusive groups, d) should be nominal or ordinal variables, e) must have at least two categories being analyzed, f) no cell can have a value less than one and the expected value in the cells is 5 or more in at least 80% of the cells analyzed. The data has fulfilled the assumptions of the test.

Test result indicated significant correlation between ORA with depression, anxiety and stress and NORA with depression. While on the other hand, no significant association was observed between NORA with anxiety and stress. Thus the result partially supports the hypothesis of the study which assumes correlation between religiosity and psychological distress levels of cancer patients. Chi square test result and the frequency responses to ORA and NORA activities are given under the following tables.

A significant association is found between ORA with depression (X^2=51.321). Looking at the frequency distribution (Table 4.8), it can be seen that more number of participants in the normal category of depression engage in ORA more frequently *(few times a month/once a week / more than once a week).* The same trend can also be observed for the mild depression category. However, this is not so for the more severe categories of depression. For those with moderate, severe and highly severe depression, participation in ORA is observed to be less frequent.

Table No. 4.8

Frequencies and Chi square test result of ORA with Depression

Categories		ORA Response Categories							Chi Square test result
		More than once a week	Once a week	A few times a month	A few times a year	Once a year or less	Never	**Total**	
Depression Categories	**Normal**	32	16	21	4	2	0	75	χ^2 =51.321 **p=.000****
	Mild	11	7	10	8	3	0	39	
	Moderate	5	5	5	4	2	3	24	
	Severe	1	0	0	1	0	0	2	
	Ex Severe	1	6	1	4	3	5	20	

***p<0.01*

Association between ORA and anxiety (X^2=50.722) are observed. With regards to frequency distribution of ORA with anxiety, it can be seen that majority of participants with normal, mild and moderate anxieties engage frequently in ORA (*a few times a month/ once a week / more than once a week*). For those in severe and extremely severe anxiety categories, there are more or less equal number of participants practicing ORA frequently (*a few times a month/ once a week / more than once a week)* and infrequently *(a few times a year or less frequent)* categories.

Table No. 4.9

Frequencies and Chi square test result of ORA with Anxiety

Categories		ORA Response Categories							Chi Square test result
		More than once a week	Once a week	A few times a month	A few times a year	Once a year or less	Never	**Total**	
Anxiety Categories	**Normal**	19	6	15	5	1	0	46	χ^2=50.722 **p=.000****
	Mild	6	4	2	0	0	0	12	
	Moderate	16	14	12	4	2	3	51	
	Severe	4	3	5	5	3	3	23	
	Ex Severe	5	7	3	7	4	2	28	

***p<0.01*

Significant association between ORA and stress is also observed (X^2=74.300). In the table given below (Table no. 4.10), it can be seen that majority of participants with normal, mild and moderate stress engage frequently in ORA *(a few times a month/ once a week/more than once a week).* For those with severe and extremely severe level of stress, there is more number of participants who practice infrequently than those who practice frequently.

Table No. 4.10

Frequencies and Chi square test result of ORA with Stress

Categories		ORA Response Categories							Chi Square test result
		More than once a week	Once a week	A few times a month	A few times a year	Once a year or less	Never	Total	
Stress Categories	**Normal**	33	20	29	11	5	0	98	χ^2=74.300 **p=.000****
	Mild	12	4	4	4	1	0	25	
	Moderate	3	7	3	2	1	3	19	
	Severe	2	3	1	4	3	3	16	
	Ex Severe	0	0	0	0	0	2	2	

***p<0.01*

With regard to NORA and depression, a significant association is found (X^2=41.175). The frequencies in the table below (Table 4.11) show that majority of the participants fall in the normal category of depression. It is observed that more number of participants in the normal, mild and moderate categories of depression engage in NORA more frequently *(daily/more than once a day/two or more times a week).* For those with severe depression, participation in NORA is observed to be less frequent.

Table No. 4.11

Frequencies and Chi square test result of NORA with Depression

Categories		NORA Response Categories							Chi Square test result
		More than once a day	Daily	Two or more times a week	Once a week	A few times a month	Rarely or never	Total	
Depression Categories	**Normal**	19	23	11	9	8	5	75	
	Mild	12	10	4	2	8	3	39	
	Moderate	2	6	8	1	3	4	24	χ^2=41.172 **p=.004****
	Severe	0	0	0	1	1	0	2	
	Ex Severe	1	9	6	0	0	4	20	

***p<0.01*

Association between NORA and anxiety is not found to be significant. Looking at the frequency distribution (Table 4.12), it can be observed that participants in the normal category engage in NORA more frequently *(more than once a day/ daily/two or more times a week).* Most frequent engagement in NORA *(daily)* can be observed among those with normal, moderate and extremely severe categories of depression.

Table No. 4.12

Frequencies and Chi square test result of NORA with Anxiety

Categories		NORA Response Categories							Chi Square test result
		More than once a day	Daily	Two or more times a week	Once a week	A few times a month	Rarely or never	Total	
Anxiety Categories	**Normal**	17	12	10	4	2	1	46	χ^2=29.985 p=.070
	Mild	3	4	1	3	1	0	12	
	Moderate	9	14	6	4	9	6	48	
	Severe	2	8	3	1	3	4	21	
	Ex Severe	3	10	3	7	5	5	33	

No significant association between NORA and stress has been found. According to the frequency table shown in table 4.13, in the normal, mild, moderate and severe categories of stress, more numbers engage frequently in NORA. The Chi square test however, does not reveal a significant association between NORA and stress.

Table No. 4.13

Frequencies and Chi square test result of NORA with Stress

Categories		NORA Response Categories							Chi Square test result
		More than once a day	Daily	Two or more times a week	Once a week	A few times a month	Rarely or never	Total	
Stress Categories	**Normal**	24	26	15	10	13	10	98	χ^2=18.366 p=.563
	Mild	6	9	4	2	3	1	25	
	Moderate	3	5	4	3	3	1	19	
	Severe	1	7	4	0	1	3	16	
	Ex Severe	0	1	0	0	0	1	2	

4.8 Correlation between Perceived Social Support and Psychological distress levels of cancer patients

In the present study, Spearman's correlation coefficient was used to find the association between Perceived social support and psychological distress. Spearman's correlation has several assumptions which have been fulfilled. The result as shown in table 4.14 indicates negative association of perceived social support with depression. Increase in the level of perceived social support is associated with decrease in depression and vice versa. The result further indicated no association of perceived social support with anxiety and stress. The result partially supports the hypothesis of the study which assumes correlation between Perceived Social Support and Psychological distress levels of cancer patients.

Table 4.14

Correlation between Perceived social support and Psychological distress of cancer patients

	Psychological Distress		
Level of Social Support	Depression	Anxiety	Stress
	-.164 **(p=.038*)**	-.105 (p=.188)	-.143 (p=.071)

*p< 0.05

4.9 Gender difference in Psychological distress among cancer patients

Mann-Whitney U Test was used to evaluate the gender difference in the prevalence of psychological distress among Naga cancer patients. It is a non parametric test which has several assumptions namely: a) samples should be randomly selected and independent of each other, b) the variable must be continuous or ordinal c) the sample size should have more than 5 observations in each group.

Result shows that the test is not significant thus there is no meaningful difference between males and females in terms of depression, anxiety and stress (Table 4.15). In the light of the findings, the result does not support the hypothesis of the study which assumes gender difference in the prevalence of psychological distress among cancer patients.

Table No. 4.15

Sample size, Mean rank and P value in terms of gender for depression, anxiety and stress

		Mean Rank			**U/P value**		
Category	**n**	Depression	Anxiety	Stress	Depression	Anxiety	Stress
Male	66	88.48	86.87	86.29	2575.5/ 0.067	2681.5/ .143	2720/ .172
Female	94	74.90	76.03	76.44			

p>0.05

4.10 Effect of Annual Family Income on Psychological distress levels of cancer patients

In order to find the effect of annual family income on psychological distress, Kruskal Wallis H was used which has several assumptions. These are: a) each group should be independent of the other, b) should have at least five observations, c) the variables should be ordinal or continuous d) the data should be non-normal and should be randomly selected independent samples and should take a similar distribution across groups.

According to the results shown by Kruskal Wallis H test conducted to determine whether there is an effect on psychological distress by annual family income, it is indicated that there was significant annual family income effects for depression ($H = 7.863$, $p < .05$) and stress ($H = 4.248$, $p < .05$) but not for anxiety ($H = 4.24$, $p > .05$). Further post hoc test was carried out to examine pair wise comparison for annual income with depression and stress which is shown in tables 4.17 and 4.18 respectively. The hypothesis of the study which assumes effect of annual family income on psychological distress of cancer patients is supported partially. As indicated in table no. 4.16, mean rank of both depression and stress is highest for respondents with annual family income of those with *between Rs.240,000/- to Rs. 600,000/-*and is least for those with annual family income of *above Rs. 600,000/-.*

Table No. 4.16

Mean rank in terms of annual family income for Depression, anxiety and Stress

Annual Family Income	n	Depression	Anxiety	Stress
		Mean rank	Mean rank	Mean rank
Below Rs. 240,000/-,	48	78.55	81.53	73.84
Between Rs.240,000/- to Rs. 600,000/-	75	89.85	86.35	91.02
Above Rs.600,000/-	37	64.08	67.31	67.81

As shown in table no. 4.17, pair wise comparisons showed significant difference in pair by annual family income of *above Rs. 240,000/-* and *between Rs. 240,000/- – Rs. 600,000/-* (*H*=25.766, *p*<.05) for depression.

Table No. 4.17

Test statistics and P value in terms of annual family income for depression

Pairs of annual family income	Test statistics (H)	P value
Above Rs. 600,000/- -Below Rs. 240,000/-	14.471	.454
Above Rs. 600,000/- -Between Rs.240,000/- -600,000/-	25.766	**.016***
Below Rs. 240,000/- -Between Rs. 240,000/- -Rs. 600,000/-	-11.295	.555

*P<0.05

As shown in table no. 4.18, pair wise comparisons showed significant difference in pair by annual family income *above Rs. 600,000/-* and *between Rs.240,000-600,000/-* (*H*=23.209, *p*<.05) for stress.

Table No. 4.18

Test statistics and P value in terms of annual family income for stress

Pairs of annual family income	Test statistics (H)	P value
Above Rs. 600,000-Below Rs. 240,000	6.033	1.00
Above Rs. 600,000-Between Rs.240,000-600,000	23.209	**.037***
Below Rs. 240,000-Between Rs.240,000-600,000	-17.176	.133

*P<0.05

4.11 Effect of Stage of Cancer on Psychological distress of cancer patients

In order to examine the effect of stage of cancer on psychological distress of cancer patients, Kruskal Wallis H test was used which has several assumptions which have been fulfilled by the data. Results indicated that there is a significant effect of stage of cancer in stress level ($H = 8.695$, $p < .05$) yet no effect on depression ($H = 7.328$, $p > .05$) and anxiety ($H = 5.344$, $p > .05$) was found out. Further post hoc test was carried out to examine pair wise comparison for stage of cancer with stress which did not indicate any difference as shown in table no. 4.20. Thus according to the result of the study, the hypothesis of the study which assumes effect of stage of cancer on psychological distress is not supported. As indicated in table no. 4.19 mean ranks of stress is highest for respondents in *stage II* followed by *Stage IV*, *Stage I* and least among those in *Stage III*.

Table No. 4.19

Mean rank in terms of stage of cancer for Depression, Anxiety and Stress

Stage of cancer	**n**	**Depression**	**Anxiety**	**Stress**
		Mean Rank	Mean Rank	Mean Rank
Stage I	45	68.70	70.72	70.41
Stage II	52	89.41	87.29	92.88
Stage III	37	74.03	74.74	69.72
Stage IV	26	92.31	92.04	88.54

As shown in table no. 4.20, pair wise comparisons do not show difference in any pairs by stage of cancer for stress.

Table No. 4.20

Test statistics and P value in terms of pairs of stage of cancer

Pairs of stage of cancer	Test statistics (H)	P value
Stage III-Stage I	.695	1.00
Stage III-Stage IV	-18.822	.667
Stage III- Stage II	23.167	.118
Stage I- Stage IV	-18.127	.666
Stage I- Stage II	-22.474	.101
Stage IV-Stage II	4.246	1.00

4.12 Role of seeking counseling service on psychological distress of cancer patients

Mann Whitney test was applied to evaluate psychological distress between those who reportedly sought counseling services and those who did not. It is a non parametric test which has several assumptions. The data have fulfilled the assumptions of the test. The data collected pertains only to yes/no responses provided by the participants. The mean rank for depression, anxiety and stress are higher for those who did not seek counseling. However, Mann Whitney test did not reveal meaningful difference between those who sought counseling and those who did not in terms of depression, anxiety and stress (Table 4.21). In the light of the findings, the result does not support the hypothesis of the study which assumes significant difference between those who sought counselling and those who did not in terms of psychological distress of cancer patients.

Table No. 4.21

Sample size, Mean rank and P value in terms of counseling sought for depression, anxiety and stress

		Mean rank			**U/P value**		
Response	**n**	Depression	Anxiety	Stress	Depression	Anxiety	Stress
Yes	33	70.82	72.70	74.53	1905.0/	1809.0/	1958.5/
No	127	83.02	82.53	82.05	0.419	.225	.562

p>0.05

CHAPTER 5

DISCUSSION

Cancer has always been a concerning health issue worldwide claiming lakhs of life every year. It is life threatening, fear, despair and dejection associated, and its diagnosis is perceived by many to be their death sentence. Thus it is considered to be one of the major leading causes of morbidity and mortality worldwide which is distressing for both patients and their care takers (Haun et al., 2014). In the year 2022, India had an estimate of more than 14.1 new cancer cases and over 9.1 lakh deaths due to the disease and breast cancer was the most common (WHO in The Economic Times, 2024). In terms of cancer incidence rate, the highest in India is observed in the North-East region. Patients on learning about their illness might experience extreme tension, sadness, loss of interest, suicidal tendency, etc. which opens the way for experiencing psychological distress. Hence with the prevalence of the illness, psychological distress such as depression, anxiety and stress in particular could be prevalent among the patients and their primary caregivers. However positive aspects such as hope, religiosity and perceived social support may act as a coping agent with psychological distress. The present study thus focused on exploring the prevalence of psychological distress as well as it relationship with aspects such as hope, religiosity and perceived social support. The effect of socio-demographic characteristics was also explored as it may also have a fundamental effect on psychological distress among patients and their caregivers. The aim of the present study was to explore the level of hope, religiosity and perceived social support among Naga cancer patients and their caregivers and examine their relationships with psychological distress among cancer patients.

5.1 Prevalence of Psychological distress among Naga cancer patients and their primary caregivers

Despite advances in early detection, constant research, medical upgrades, sensitizations, and modern progress in securing possible cancer treatments and cures, cancer still remains one of the most feared diseases (Mallika et al., 2016) and not many are able to cope with the condition in a positive way. In the current study, depression and anxiety have been indicated among more than half of the respondents while stress was also reported among a notable number. Among primary caregivers, anxiety was reported by a majority of respondents while depression and stress was also reported by a notable number. Similar findings done among other Indian culture have also been reported in previous research studies (Mallika et al., 2016; Mason et al., 2019; Shankar et al., 2016) and it can be understood that psychological distresses are generally expected to be experienced by any individual undergoing serious health issues particularly of diseases such as cancer. In a study conducted by Swathi et al., (2023), it is indicated that depression, anxiety and stress are prevalent among chronic patients besides cancer such as cardiovascular diseases, metabolic disorders, chronic kidney disease, degenerative disorders and chronic liver disorders. Research study by Herschbach (2004) reported that the fear of disease progression is the greatest cause for psychological distress. One of the reasons could be the general perception people have about cancer as deadly and life threatening. As once diagnosis is given to a patient, not only does one deal with the illness alone but also with various other associated problems thus putting a lot of demands on one's life. Thus emotional responses such as shock, fear, anxiety, despair, anger, etc are frequently experienced by individuals upon diagnosis. These negative experiences are often associated with risk factors for psychological distress and such relationship could become more prominent while being diagnosed with a

terminal illness. Maharjan et al., (2018) who conducted study among cancer patients in Nepal also suggested high rates of depression and anxiety. Studies conducted among cancer population in Israel (Goldzweig et al., 2010) and China (Wang et al., 2020) also reported similar result. Psychological distress is endured not only by patients but also by their caregivers. However as patients remain primary to be taken care of, caregivers' health is often unintentionally overlooked and attention is provided more to the patient. The present study also reported the presence of psychological distress ranging from mild to extremely severe among a considerable number of caregivers of cancer patients. A person diagnosed with a terminal illness such as cancer requires a lot of assistance and aid at every point of their illness period (Sunkarapalli et al., 2016) and this can take a toll on caregivers of the patient. A number of earlier researches (Haun et al., 2014; Namboodiri 2021; Shahadevan & Sharma et al., 2020) have also indicated the presence of psychological distress such as depression, anxiety, stress, etc. among caregivers of cancer patients' up to a certain level. Caregivers struggle as much as the patient themselves emotionally, mentally and financially and as the patient's health deteriorates even those caregivers who initially had been psychologically and physically strong may become exhausted. This could be because of being overwhelmed with the reality of the diagnosis and eventually its treatment demanding more care giving. Cancer though considered as one of the leading factors of death, there is lack of accessible insurance policies until very recently especially in states like Nagaland. Thus having to undergo all of these relatable problems, the experience of psychological distress might be triggered to increase more.

5.2 Hope levels of Naga cancer patients and their primary caregivers

Hope signifies positivity, joy, optimism, brightness, etc which are all positive sensations and feelings. It is characterized by affirmative feelings about the immediate or long-term future and often coupled with high motivation, optimism, and a generally elevated mood. In the present study, Herth hope index result indicated that mean score of patients and caregiver was 37.41 and 39.49 respectively indicating high levels of hope. This finding is consistent with scores found in studies done among cancer patients in other parts of the world (Herth, 1990; Hsu, et.al. 2003; Rawdin et.al., 2013). The study result also align with finding of Nikoloudi et al. (2023) who found high levels of hope among cancer patients with a suggestive measure to focus on the importance of hope in patients with serious illness to improve their clinical care. Study of Kim et al. (2013) which reported a similar pattern showing high levels of hope among caregivers of cancer patients also align with the research finding. To feel positive during a dire circumstance is challenging and one feels unlikely to look forward with sanguinity and it is generally expected that due to a number of reasons most patients lose hope for longevity of survival while caregivers on the other hand may also be affected. Yet amidst such circumstance hope among Naga cancer patients is reported to be high which could be due to various reasons. Nagaland is a collectivistic society where the community plays a huge role in governing one's life. Especially during crisis situation, beyond family members there are many other who render help financially, morally, spiritually, physically, etc which help one to stay strong and have hope. Having hope even while fighting against an illness such as cancer might also be due to the impact of the society that one is living in. Chi (2007) also opined that patients upon fear of uncertain situation often begin to look for additional sources for support. This may suggest one with another understanding of having hopes while experiencing fearful situations. It may be considered that hope may play an

important role as it has a positive impact on health and acts as a protective mechanism to stress, disease, etc. (Nikolaudi et al. 2023) which acts as an effective coping strategy to get through difficult situation.

5.3 Religiosity levels of Naga cancer patients and their primary caregivers

The present study aimed to find out religiosity levels of Naga cancer patients and their caregivers. It was measured using two subscales of The Duke's University Religion Index (DUREL) that is Organizational Religious Activity (ORA) and Non-Organizational Religious Activity (NORA). Results indicated that out of the total respondents of cancer patients (n= 160), majority (95%) reported to be engaged in some kind of public or organizational religious activities out of which a large number of them engage in ORA frequently. Around three-fourth of the cancer patients have reported to be frequently engaging in ORA while amongst caregivers (n= 160) also, a great majority (97%) reportedly engage in ORA sometime or the other. A great majority (83.2%) were frequent in ORA. With respect to NORA, result shows that out of the total respondents of cancer patients (n= 160), a great majority (95%) reported to be engaged in some kind of private or non-organizational religious activities while caregivers (n= 160) also reported similar result (94.4%). Majority of patients (77.6%) and caregivers (79.4%) also reported to be engaging in NORA quite frequently, ie., at least once a week while roughly half of both patients (51.3%) and care givers (56.2) reported to be engaging in NORA at least once a day.

Analysis of study done by Khan et al. (2022) marked that patients believe in religion's comfort and particularly noted that engagement in being religious helped patient cope with the illness. The result of the present study has shown a vast majority of patients and their caregivers

to be engaging themselves in both ORA and NORA. Though the proportion may be lesser, this study result is approximately similar with the report of Gus et al. (2012) who investigated the frequency with which cancer patients engage in religious and spiritual practices. Yet another study (Boas & Nakasu, 2021) reported that there was high level rating of religious involvement. With majority being Christians in the state of Nagaland, it is firmly embedded in thought, behavior or culture to engage oneself in religious practices at all circumstances and more specifically people often turn to religious practices and rely heavily on their faith to cope with illnesses such as cancer. In a research study on cancer done by Gupta & Koradia (2017), it has been noted similarly that when stressful situation hits a family, the first thing to do is to engage in prayer and other religious activities. The present study result however does not justify that respondent engage in these activities particularly due to the diagnosis of their illness yet it marks the engagement of both ORA and NORA.

5.4 Perceived Social Support levels of Naga cancer patients and their caregivers

Perceiving and receiving social support from extended people provide huge coping mechanism during a dire situation. The present study examined to find out the levels of perceived social support of Naga cancer patients and their caregivers using the Berlin Social Support Scale (BSSS) with a higher score indicating a higher level of support, as there are no established cut-off scores for the scale. Result indicated that mean score of the BSS of patients and caregiver was 29.07 and 29.45 respectively indicating high levels of perceived social support among them. Perceiving support from another individual is considered as a feeling or knowledge that there are people to take care or support them. This thought may be able to elevate confidence in copying with sicknesses a person is battling with. In a study done by Kavitha & Jayan (2014) one can find that out of 235 cancer patients in Calicut, majority perceived moderate to high

social support which is consistent with the finding of the present study. Similarly two other studies conducted among Chinese and Saudi Arabian cultures also demonstrates a supporting result who found high levels of social support among participants (Rawas et al., 2024; Wang et al., 2020). Naga culture in itself while being observed is a socially oriented society where people render strong support at all times. Living in such societies boosts confidence of even those who have been diagnosed with terrific illness such as cancer that people around them are there to support them with moral, physical, emotional and/or financial help. Social support also allows caregivers to be strong as they are surrounded with supportive individuals, families and society in general who are there to provide help and support. In another study (Rizalar, et al., 2014) conducted among breast cancer patients in Northern Turkey by social support was reported to be high and particularly in terms of confidence support, emotional support and information support. Their study also suggested that patients should be accompanied by their family or relatives in treatment and their family should be made more aware of the fact that the patient should be physically and psychologically supported.

5.5 Correlation between Hope and Psychological distress levels of cancer patients

Cancer is a terrifying disease and as one battles the disease with all possibilities, maintaining hope in the face of this serious illness becomes challenging. Yet in order to win over this illness, hope can enable individuals to look beyond their current pain, suffering and turmoil (Sunkarapalli, et al., 2016) as it is considered by many as a strong force. Thus hope is also seen to be prevalent among other groups of individuals such as those with HIV/AIDS (Yu et al., 2024), Diabetes (Nabi et al., 2016) and Heart failure (Rustoen et al., 2005). Similarly, the prevalence of hope was also observed among participants of the present study. Further the study aimed to explore whether or not hope may have an association with psychological distress

among cancer patients which was done using spearman's correlation coefficient indicating significant negative association of hope with depression, anxiety and stress. This indicates that when hope increases, psychological distress decreases. The result thus supports the hypothesis of the study which assumes correlation between hope and psychological distress. The correlation between these two aspects may also be seen in findings of other studies (Berendes et al., 2010; Nikoloudi et al., 2023; Rajandram et al., 2011). Study conducted by Flesia et.al (2023) has also highlighted the protective role of hope on psychological distress. Similarly, Rawdin et al. (2013) have also highlighted on the negative correlation between hope with depression and anxiety. This study thus buttresses the notion given by other research findings that hope and psychological distress are negatively associated. We can assume that hope is a very powerful weapon while fighting against cancer and battling with psychological distress. Developing and experiencing hope may come through various forms and may vary according to individual differences.

Afrooz et al. (2014) in their study conducted among Iranian cancer patients found that the most important sources of hope include spiritual resources, family members, and medicines and treatments available for the disease. This finding bring to the understanding of how Naga cancer patients may also find ways of having hope during this dire situation as Nagas in general are bounded by strong support by family members and additionally abided by religious practices and spiritual support along with amenities increasing for the treatment of cancer as compared to past years. All these external factors may impact an individual's thought processes leading one to generate positive perspective about a certain situation thus in turn leading to decrease in psychological distress which can also be supportively addressed with the works of Kashani et al. (2014) who reported that creating hope was effective in reducing distress of patients suffering from breast cancer. Beck (1970) in his negative cognitive triad theory believe that when people

talk negatively to themselves of how they feel about themselves, the experiences and about believe about their future, depression is likely to occur. Thus it is important that positive feelings such as having hope and positivity be encouraged so as to allow acceleration of positive attitude toward treatment of the illness as well as ones future. Snyder's model of hope also suggests that thought processes are the crux of hope and people are likely to feel optimistic, happy and less frustrated when one is able to find out positive and realistic way in reaching out to their goals or for solving any problem. Thus it may opined that having a higher likelihood of various strategies and supports may lead to the increase of hope which further impact in lessening psychological distress.

5.6 Correlation between Religiosity and Psychological distress levels of cancer patients

A person diagnosed with cancer very often turns to religious practices and they rely heavily on their faith to cope with serious illnesses. They tend to use prayers, worship and faith to cope with the suffering conditions (Shumway, 2003). In order to examine if religiosity and psychological distress may have a relationship, the present study tried to explore this aspect. Chi Square result indicated significant correlation of ORA with depression, anxiety and stress and NORA with depression. ORA involves public religious activities such as attending religious services or participating in other group related religious activities like prayer groups, scripture study groups, etc. which involves constant interaction with other people. Being involved in social activities one directly and indirectly receives social support from other common group individuals which may result in positive coping of stressful situations. Kavitha and Jayan (2014) who conducted a study in Calicut reported that those with high social support had less cancer distress. Naga society being a Christian dominated state, religious practices are seen to be a part and parcel of life where engaging in religious activity is prioritized. Thus majority of Nagas in

general engage in various religious exercises such as prayer, reading the word of God, singing, attending churches, etc as a repetitive and patterned behavior with the understanding to find peace, solace and sense of meaning in life though the range of practices and rituals may vary from one individual to another. The religious involvement and receiving of social support from other individuals may possibly be a supporting reason for the association of ORA with depression, anxiety and stress among Naga cancer patients. Lee & Baumann (2013) suggests that several symptoms of psychological disorders can be connected with religious phenomena. It is also believed that involvement in religious practices can improve mental well being by buffering the effects of mental health issues as significant association between religiosity and psychological distress among have also been observed in several other studies across the world (Chen et al., 2023; Chong et al., 2019; Eid et al., 2020; Jokela, 2021). These findings thus indicated that engaging in religious activities improves mental health of patients. Gus et al. (2010) reported that a significant number of cancer patients engage in religious and spiritual practices indicating that the decision to do so is linked to their levels of depression and hopelessness. Koenig (2012) also suggested that religious beliefs can influence the cognitive appraisal of negative life events in a way that makes them less distressing. Similar research conducted by Meisenhekder et al. (2013) indicated that cancer patients who perceive God as loving had higher mental health even in the presence of a poor prognosis or pain though it found no relationship between frequencies of prayer with mental health. Additionally Weaver et al. (2005) also suggested that religion offers hope to those suffering from cancer and that it has positive effect on the quality of life.

5.7 Correlation between Perceived Social Support and Psychological distress levels of cancer patients

The needs of patients with cancer are different from other patients in many ways which poses great challenge and responsibility (Salim et al., 2019) leading to more negative outcome of mental health. The present study focused in finding out the effect of social support on psychological distress, Result indicated that there was negative correlation of perceived social support with depression which reveals that higher levels of social support lead to lower levels of depression. Similar findings have been reported in other populations. For example Hossenie et al., (2020) reported on association between social support for elderly and depression. In a study conducted among cancer patients being treated at national and regional cancer centres in South Korea, Yoo et al., (2017) also reported the association of higher perceived social support with depression among the cancer patients. Even in the works of Roberts et al. (1994) depression was reported to be ameliorated by social support which patient receives from spouse, friends and family members. Cancer distress is challenging yet the various findings mark that positive aspects such as social support play a role in reducing or maintaining psychological distress. The role of social support may be expected to positively affect cancer patients as in the Naga culture, emphasis on supporting each other at all times is considered as a strong communal responsibility which also helps one to raise the courage to fight against illness such as cancer when feeling incompetent and burnout to cope with it. This influential confidence that is developed by the patients helps in the reduction of worrying, feelings of hopelessness, melancholy, etc about the illness as well as other concerns that connects with the illness itself. According to the buffering hypothesis theory (Farmer & Sundberg, 2010), social support help people from the effect of stressful life events by influencing how people think and cope with the situation. The theory also

claims that social support has a significant impact on well being suggesting that individuals with available social support are less likely to have adverse reactions when faced with a stressful life situation allowing individuals to redefine the impact as less threatening. It may be suggested that patients may also be provided with domiciliary care, encourage participating in available social support groups, continuing accompany following their progressive treatment, etc.

5.8 Gender difference in the prevalence of Psychological distress among cancer patients

It has been widely documented that the prevalence of psychological distress vary in terms of gender in the general population in which generally, incidence is found to be higher among women (Bilodeau et al., 2020; Matud et al., 2014; Viertio et al., 2021). This similar trend is also observed among cancer patients showing higher prevalence commonly among women population (Cheng et al. 2024; Das & Roy, 2019; Koyama et al. 2016; Mason et al., 2019; Raineri et al., 2021; Taghizadeh et al. 2018; Wang et al., 2020). A supporting theory, the self salience theory, on the perspective of gender and mental health developed by Rosenfield et al., (2005) proposes the differences in expression of psychological distress. This perspective views that women are seen to be socializing within the private sphere of society thus resulting in internalized distress such as depression and anxiety. While on the other hand, men predispose to externalizing behaviors to substance or alcohol abuse and anti social behavior. This theory thus generally supports that women tend to be more prone to experience psychological distress than do men. Although the assumption of gender difference is extensively considered, some other studies on the other hand show no significant difference between males and females. One such result was observed from a study conducted by Csuka et al. (2024) who explored gender differences in the predictors of quality of life in patients with cancer in which showed no significant difference in gender. Additionally result of study conducted by Farooqi & Ahsan

(2009) among Pakistani cancer patients also shows evidence in support of the present finding. Their study further noted on the seriousness of cancer illness that this could be a probable reason taking a toll on both men and women quite equally. Notably a study carried out among gastrointestinal cancer patients in Iran to examine the prevalence of anxiety and depression also supports similar finding (Tavoli et al., 2007). Another similar study which was conducted by Aass et al. (1997) shows no gender difference in terms of depression however females experienced more anxiety than men. The present study which aimed to explore gender difference in the prevalence of psychological distress among cancer patients also revealed no meaningful difference between males and females. Psychological distress is prone to both male and female as the effect of distress does not discriminate gender and in general because of the frightening and potentially stigmatizing nature of cancer, both males and females may equally experience certain levels of psychological distress. Thus through the finding of the current study it can be observed that both male and female cancer patients are also seen to be experiencing psychological distress. One of the reasons could be due to the social environment that creates similar attitude toward the illness as they suffer the same complications and get treated in the same sort. At present time, domestic, economic and social burdens and roles have become almost equal between men and women which could also be another factor on the equal experience of psychological distress by both genders. It may be suggested that future research may explore more on in-depth understanding of gender on distress be explored.

5.9 Effect of Annual Family Income on Psychological distress levels of cancer patients

It is a known fact that cancer treatment face heightened economic risk and it is a far reaching problem for those diagnosed with this terminal illness. It may be expected that this burden might lead in co-occurrences of psychological distress beginning from stress, anxiety to depression. This research explored the effect of annual family income on psychological distress levels of cancer patients by running Kruskal Wallis H test which indicated that there was significant effect in terms of depression and stress however no effect on anxiety was found. It has been widely documented in other studies conducted among cancer patients of other culture that those with lower financial income or support experience more occurrence of psychological distress (Alagizy et al., 2020; Srivastava et al., 2016; Wieckiewicz et al., 2024). The financial burden of cancer treatment and care can be overwhelming as the illness demands the need of various treatment procedures. New and costly therapies with increased health care cost, wage and job losses of the patient, frequent transportation cost, etc (Iragorri et al., 2021; Zaidi et al., 2012) could be some areas of major expenses which have been seen to be associated with increased risk for depressed mood and anxiety (Battat et al., 2024; Kale & Carroll, 2015). With the state of Nagaland having a shortage of tertiary cancer care facilities, many patients are compelled to be treated from outside the state which intensify the treatment expenses. The economic stress is seen to be a common issue amongst Nagas as a larger population of people in the state is generally considered to be with average household income which is also indicated from the report of the present data showing that almost half of the respondents (n= 47%) fall under an income between Rs. 240,000/- to Rs. 600,000/- per annum. Additionally due to the lack of state's support for cancer treatment, financial burden remains alarming. Thus with the increase in financial hardship, psychological distress is experienced to some sort by cancer patients while

also affecting caregivers and other supporting individuals. While to our knowledge no research has been conducted among Naga cancer patients from a psychological perspective, some studies conducted in other areas have reported similar findings. A recent assessment conducted by Kumar et al. (2018) on socio-economic status and demographic profile of patients with advanced cancer patients receiving palliative care demonstrated that patients with low SES had reduced coping to psychological distress as compared to patients with high SES and required referral to a psychologist. Similarly lower SEC patients were more anxious and depressed as reported by Simon & Wardle (2008). Another systematic review (Sonara, 2018) shows link between the effects of socio economic status of cancer patients on depression and stress. The finding of the current study is in line with these existing literatures. It may be suggested that public be apprised of available schemes for cancer patients as well as launch more funding schemes by the state or central government or also NGOs so as to financially support and assist cancer patients for their treatment.

5.10 Effect of Stage of Cancer on Psychological distress of cancer patients

The stage of cancer signifies severity of the illness thus it may be expected that differences in the levels of cancer stage affect the psychological health as much as the physical health is affected. This assumption is found evident in some previous studies (Jan et al., 2021; Mushtaq et al., 2017; Negussie et al., 2023). However the analysis of the current study found no evidence on the effect of cancer stage on psychological distress which indicates that patients in all stages of cancer experience stress equally. Similarly to the finding can also be seen in a study conducted by Hong & Tian (2014) among Chinese cancer patients. Regardless of the stage of cancer, psychological distress may be found to be experienced by cancer patients of all cancer stage due to the knowledge of unfavorable prognosis of the illness itself. Individuals may be

diagnosed at different stages of cancer, some at an early stage yet some are unfortunately diagnosed at a more severe and advanced stage. However, irrespective of the disease duration, the shock and denial of being diagnosed with cancer seem to affect all thus resulting in experiencing distress such as depression, anxiety or stress.

5.11 The role of seeking counseling service on the psychological distress of cancer patients

Living with cancer may cause a ton of hardships and unsettled mind which may cause serious psychological issues if left untreated. Beyond improving the illness, a cancer patient may require psychosocial care through various means. Although counseling may be considered important, lesser than half of the respondents in this study reported to be availing counseling which is in line with the works of Pascoe et al. (2000) who also reported in his study that majority of patients having symptoms of depression and anxiety were not assessing counseling. One of the reasons as to why counseling is not considered important during cancer treatment could be due to the fact that Nagaland being a very socially oriented society, individual receives strong social support from loved ones which might lead to the negligence of availing professional counseling. In the present study, psychological distress was compared between those who reportedly sought counseling services and those who did not and the difference between the two groups was found to be not-significant indicating that the status of whether or not the person sought counseling has no effect on psychological distress level experienced. In addition, the services availability for professional counseling itself is quite limited as compared to other services and even those available are not widely known by a great mass in the state due to reasons such as lack of knowledge and importance of availing professional counseling. Blunt and Trigg (2024), in a study of counseling outcome examined via pre-post test analysis, had

reported that counseling reduced anxiety and depression significantly in cancer patients. The present study also has limitations in that only *yes/no* responses to whether counseling was sought or not question was considered. The nature, type or duration of counseling sought were not considered. Further, in order to understand the effect of counseling on psychological distress, a controlled experimental study would yield more insights. Future studies in this area may consider these aspects to get more understanding about the role of counseling in reducing psychological distress experienced by cancer patients.

CHAPTER 6

SUMMARY, SUGGESTIONS AND CONCLUSION

6.1 Summary

Cancer is a worldwide menace and Nagaland as one of the states in India is now seen to have enormous growth of cancer patients ranking among the top five leading causes of death in the State. Patients on learning about their illness which does not have a guarantee about its cure, might experience extreme tension, worriedness, sadness, hope in living, loss of interest, suicidal tendency, etc. which opens the way for experiencing serious psychological issues. It is imperative that the pervasiveness of the illness be explored from a psychological perspective. While there are many cancer studies conducted across other communities, this study explored the prevalence of depression, anxiety and stress. Although distress could be experienced during stressful events, feeling hopeful and perceiving and receiving support from other individuals as well as engaging in religious activities could act as a positive mediator in reducing distress. Thus the core objective of the study was also attempted to explore the level of hope, religiosity and perceived social support among Naga cancer patients and examine their association with psychological distress. This study also explored the effects of stage of cancer and annual family income and the role of counseling on the psychological distress.

Related literature review indicated on the prevalence of various psychological distresses although the level and frequency vary. Literature also provides suggestions on the importance of role played by positive constructs like hope and social support with cancer diagnosis and treatment. Although such implications and associations have been found in other cultures, no such study was found to be explored among Naga culture. It is also observed that not many

studies are conducted among caregiver of cancer patients though the prevalence of distress may be expected among them as well.

In order to examine the objectives of the study, purposive sampling method was used. Total sample size was 320 participants (160 cancer patients and 160 primary caregivers) which were identified from five hospitals across Nagaland on the basis of some inclusion and exclusion criteria. The analyses of data were done using the Statistical Package for Social Sciences version 21 (SPSS-21).

Personal Data Form developed by the researcher was used in order to obtain socio-demographic characteristics of the participants and by taking prior permission from all test/scale developers, the following tools were used for the present study.

i. *Depression, Anxiety and Stress Scale-21 (Lovibond & Lovibond, 1995).*
ii. *Herth Hope Index (Herth, K., 1992)*
iii. *The Duke University Religiosity Index (Koenig & Bussing, 2010)*
iv. *Berlin Social Support Scale (Schwarzer & Schulz, 2000)*

Obtained data showed that there were 41% (n=66) male and 59% (n=94) female cancer patients and 37% (n=60) male and 63% (n=100) female primary caregivers. It was also indicated that 30%, 47% and 23% fall within the annual family income of below *Rs. 240,000/-, between Rs. 240,000 – Rs. 600,000/- and above Rs. 600,000/-* respectively. Additionally, data indicated that 21% cancer patients seek counseling and data on stage of cancer showed that 28% (n=45) of cancer patients were diagnosed with stage 1 cancer and 33% (n=52), 23% (n=37), and 16% (n=26) being diagnosed with stage 2, stage 3 and stage 4 cancer respectively.

Result of the present study have indicated the prevalence of psychological distress i.e. depression (53.1%), anxiety (71.2%) and stress (38.7%) among cancer patients consistent with studies conducted among cancer population in Israel (Goldzweig et al., 2010) and China (Wang et al., 2020). This could be so as once diagnosis is given to a patient, not only does one deal with the illness alone but also with various other associated problems such as shock, fear, anxiety, despair, anger, etc. which could be often associated with risk factors for serious psychological distresses. The prevalence of depression (39.4%) anxiety (63.7%) and stress (22.5%).have also been indicated among caregivers similar to findings of studies (Haun et al., 2014; Namboodiri 2021; Shahadevan & Sharma et al., 2020) done previously. Caregivers may also be seen to be experiencing distress as once a person is diagnosed with a terminal illness such as cancer, one may become overwhelmed with the reality of the diagnosis as cancer care requires a lot of assistance. Amidst battling with the illness, data also showed that the mean scores of hope and perceived social support of the cancer patients are high and that majority of them also participate in ORA as well as NORA. One of the reasons could be due to the fact that Nagaland as a collectivist society bounded by very supportive community plays a huge role by rendering help financially, morally, spiritually, physically, etc.

The association of hope with psychological was examined and it was found that hope is negatively associated with psychological distress as reported in studies done in other culture (Berendes et al., 2010; Nikoloudi et al., 2023; Rajandram et al., 2011) where higher level of hope leads to decrease in psychological distress. Further, Test result of the present study indicated significant correlation between ORA with depression, anxiety and stress, and NORA with depression. While on the other hand, no significant association was observed between NORA with anxiety and stress. Although no similar supporting study could be found, this study finding

leads to the understanding that engaging religious practices such as attending religious services, group prayers, can lower psychological distress. Additionally, higher engagement in private prayer, reading the word of God, singing etc can lead to the decrease in depression. A significant association of perceived social support with depression was also indicated in the study finding thereby bringing to the understanding of how the trust in the communal support by patients help them to balance negative attributes such as depression. The result however did not indicate any association of perceived social support with stress and anxiety. In such a crisis situation although there are many people rendering support, feeling stressed and anxious about the illness and its treatment may be expected to be prevalent to some extent. This could also however be curbed if psychological treatment is incorporated alongside the illness treatment.

Though it is widely documented that the prevalence of psychological distress among cancer patients is higher among women, no meaningful difference between males and females in terms of depression, anxiety and stress was indicated in the present study result. A number of studies have also indicated how both males and females suffering from cancer experience psychological distress equally (Aass et al., 1997; Farooqi & Ahsan., 2009; Tavoli et al., 2007). Significant effect of annual family income on depression and stress among cancer patients was also indicated which shows that the financial burden of cancer treatment and care can be overwhelming and its effect can lead to the cause of experiencing distress symptoms as also supporting previous studies (Simon & Wardle, 2008; Sonara, 2018).

The study also indicated no association between cancer stage and distress which shows that regardless of the stage of cancer, psychological distress may be found to be experienced at all cancer stages. Upon examining the difference between those who reportedly sought counseling services and those who did not, no significant difference was found indicating that

the status of whether or not the person sought counseling has no effect on psychological distress level experienced.

6.2 Limitations and Suggestions

The present study employed purposive sampling as there was no sampling frame available for the target population till the time this study was conducted. Because purposive sampling is a non-probability sampling, this imposed certain restrictions in the choice of statistical tests for data analysis and it also imposes limitations in the generalizability of the study findings. The use of a modest sample size and the use of non-parametric statistics could also be considered as limitations of the present study as these are factors that can contribute to the strength of the statistical analyses. Future research may consider using larger sample size based on probability sampling if possible so that parametric statistics could be employed to add more power to the study. Variables like age, education, and type of cancer were not considered in the present study. Future researchers may consider these variables also when studying psychological distress among cancer patients as there are not many existing studies in this area.

With regard to the objective of examining the role of counseling on psychological distress of cancer patients, a controlled experimental study could have done more justice. The present study only tried a modest attempt at this by collecting self report Yes/No responses from the cancer patients as to whether or not they sought counseling services after their diagnosis as conducting a controlled experimental study was beyond the scope of this study. To get a better understanding of the role of counseling on psychological distress of cancer patients, future studies may be conducted using longitudinal controlled experimental studies.

In the present study, emphasis was given to cancer patients while looking at psychological distress in relation to the various psychological and socio-demographic factors. It is equally important to understand these dynamics among caregivers also. Another limitation of the present study is the reliance on self report measures which are subject to social desirability and other response biases. Future studies in the area may also consider these aspects while planning and conducting a study like this.

6.3 Conclusion

One of the significant observations made is the prevalence of psychological distress among a notable proportion of both cancer patients and their caregivers. The result of the study also throws light on the role that positive psychological factors such as hope, religiosity and social support can play in mitigating psychological distress in cancer patients. It may be concluded that cancer is an important physical health issue which affects the psychological health of patients and caregivers and can be financially and emotionally devastating thus attempts can be made towards psycho-oncological programs wherein oncologists and psychiatrists work as a team for raising awareness, early intervention and provide psycho-educational support. It may also be suggested to increase psychological assessment by practitioners as part of cancer management and implement specialized services to the patient as well as their caregivers in order to improve their quality of life irrespective of the stage of cancer. Based on the observations from this study, it may also be suggested that psycho-onchological treatment programs incorporate factors such as hope, religiosity and social support in order to mitigate negative emotional states.

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Appendix - I

INFORMED CONSENT FORM

Dear participant, I am conducting a research study on Naga cancer patients and their primary caregivers to find out the levels of Hope, Religiosity, and Perceived Social Support in relation to Psychological Distress. I would like you to kindly fill up this questionnaire which would require a maximum of 10 minutes. The procedure for filling up is to put a tick mark in the boxes/numbers that best describes your feelings. Your participation towards this study would be highly appreciated and beneficial for the community.

Ethical considerations: Your participation in the study is **purely voluntary,** you have the **right to withdraw** from the study at any point of time, your personal identity and information will remain **confidential** and **anonymity** will be maintained and the results of the study will be used strictly for **academic purpose.**

Consent:

I have understood the nature of the study and that participation is purely voluntary and the information provided will remain confidential. I have also understood that I have the liberty to withdraw my participation from the study at any point of the time.

Having understood everything, I voluntarily give my consent to participate in the study.

Researcher

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Signature of the Participant

Date:

Appendix - II

PERSONAL DATA FORM (PRIMARY CAREGIVER)

Instruction: Kindly fill in **ALL** the details listed under.

1. Name (Optional): …….
2. Age: ……..
3. Gender: …….
4. Marital Status: ……..
5. Tribe: ……
6. Religion: ……...
7. Educational Qualification: ……..
8. Relationship with the Patient: …….
9. Contact no.: ……..
10. Email address (Optional): ……...
11. Present Address:
    …….
12. Whether receiving any Psychological counseling: Yes/NoIf yes, kindly mention:

    ……

13. Whether receiving any Pastoral counseling: Yes/No

Appendix - III

PERSONAL DATA FORM OF THE PATIENT

(To be filled up by the Primary Caregiver)

1. Patient's Name (Optional): ……...
2. Age: …….....
3. Gender: …….....
4. Marital Status: ……..……
5. Tribe: ……..……..
6. Religion: ……..……
7. Educational Qualification: ……..
8. Annual Family Income:

   a) Below Rs. 240,000/- b) Between Rs. 240,000/- to Rs. 600,000/-

   c) Above Rs. 600,000/-

9. Type of Cancer: ……..
10. Stage of Cancer: …….
11. When was the cancer being diagnosed and at which stage?

    .....

12. Name of the Hospital in which treatment is sought.

    ……

13. Whether the patient has been diagnosed with any Psychological disorder in the past:

    Yes/No. If yes, kindly mention: ……

14. Whether receiving any psychological counseling: Yes/No
15. Whether receiving any Pastoral counseling: Yes/No

Appendix - IV

INSTRUCTIONS FOR FILLING UP THE QUESTIONNAIRE: Below are **FOUR SETS** of scales, kindly read the questions carefully before answering and make sure that you attempt ***EACH*** question.

SCALE 1 (HHI): Read each statement and place a **TICK** mark in the box that describes how

Q No.	HHI Questions	Strongly Disagree	Disagree	Agree	Strongly Agree
1	I have a positive outlook towards life.				
2	I have short and/or long range goals.				
3	I feel all alone.				
4	I can see possibilities in the midst of difficulties.				
5	I have a faith that gives me comfort.				
6	I feel scared about my future.				
7	I can recall happy/joyful times.				
8	I have deeper inner strength.				
9	I am able to give and receive caring/love.				
10	I have a sense of direction.				
11	I believe that each day has potential.				
12	I feel my life has value and worth.				

Appendix - V

SCALE 2 (DUREL): Read each statement and place a **TICK** mark in the answers that most accurately describes your usual behavior or belief.

13. How often do you attend church or other religious meetings?

    1. More than once/week
    2. Once a week
    3. A few times a month
    4. A few times a year
    5. Once a year or less
    6. Never

14. How often do you spend time in private religious activities, such as prayer, meditation or Bible study?

    1. More than once a day
    2. Daily
    3. Two or more times/week
    4. Once a week
    5. A few times a month
    6. Rarely or never

Appendix - VI

SCALE 3 (BSSS): Read each statement and place a **TICK** mark in the box that describes you.

Q No.	BSSS Questions	Strongly disagree	Somewhat disagree	Somewhat agree	Strongly agree
15	There are some people who truly like me.	1	2	3	4
16	Whenever I am not feeling well, other people show me that they are fond of me.	1	2	3	4
17	Whenever I am sad, there are people who cheer me up.	1	2	3	4
18	There is always someone there for me when I need comforting.	1	2	3	4
19	I know some people upon whom I can always rely.	1	2	3	4
20	When I am worried, there is someone who helps me.	1	2	3	4
21	There are people who offer me help when I need it.	1	2	3	4
22	When everything becomes too much for me to handle, others are there to help me.	1	2	3	4

Appendix - VII

SCALE 4 (DASS): Read each statement and place a **TICK** mark in the box that describes how much you agree with that statement

Q No.	DASS Questions	Never	Sometimes	Often	Almost Always
23	I found it hard to wind down	0	1	2	3
24	I was aware of dryness of my mouth	0	1	2	3
25	I couldn't seem to experience any positive feeling at all.	0	1	2	3
26	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
27	I found it difficult to work up the initiative to do things	0	1	2	3
28	I tended to over-react to situations	0	1	2	3
29	I experienced trembling (e.g., in the hands)	0	1	2	3
30	I felt that I was using a lot of nervous energy	0	1	2	3
31	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
32	I felt that I had nothing to look forward to	0	1	2	3
33	I found myself getting agitated	0	1	2	3
34	I found it difficult to relax	0	1	2	3

35	I felt down-hearted and blue	0	1	2	3
36	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
37	I felt I was close to panic	0	1	2	3
38	I was unable to become enthusiastic about anything	0	1	2	3
39	I felt I wasn't worth much as a person	0	1	2	3
40	I felt that I was rather touchy	0	1	2	3
41	I was aware of the action of my heart in the absence of physical exertion (e.g., sense of heart rate increase, heart missing a beat)	0	1	2	3
42	I felt scared without any good reason	0	1	2	3
43	I felt that life was meaningless	0	1	2	3