PSYCHOLOGICAL ISSUES IN HEALTHCARE PROFESSIONALS AND FAMILY CAREGIVERS OF PATIENTS WITH CANCER

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DOCTOR OF PHILOSOPHY IN PSYCHOLOGY

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DECLARATION

I, D. Asha, hereby declare that this thesis entitled — "Psychological Issues in Healthcare Professionals and Family Caregivers of Patients with Cancer" submitted by me under the guidance and supervision of Dr. G. Padmaja is a bonafide research work which is also free from plagiarism. I also declare that it has not been submitted previously in part or in full to this University or any other University or Institution for the award of any degree or diploma. I hereby agree that my thesis can be deposited in Shodganga/INFLIBNET.

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CERTIFICATE

This is to certify that the thesis entitled “Psychological Issues in Healthcare Professionals and Family Caregivers of Patients with Cancer" submitted by D. Asha bearing the Reg. No. 16CPPH01 in partial fulfilment of the requirements for the award of Doctor of Philosophy in Psychology in the Centre for Health Psychology under School of Medical Sciences is a bonafide work carried out by her under my supervision and guidance.

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Further, the student has the following publications before submission of the thesis for adjudication and has produced evidence for the same in the form of the reprint in the relevant area of his research:

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8. National Seminar on Wellbeing across Lifespan, Hyderabad, 25th -27th October, 2017
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Abstract

International research reports oncology healthcare settings to be an inherently strenuous work environment for its professionals. Healthcare professionals (HCPs) in oncology healthcare, who spend a great deal of their time planning and executing treatment plans with limited therapeutic windows, witnessing multiple agonizing deaths of patients, dealing with the seriously ill most of the time, and handling high workloads and time pressure, often experience stress, burnout, trauma and work-related psychological issues. The other important side of the picture in the cancer healthcare, is the role played by family caregivers. The support and care provided by informal caregivers or family caregivers is very critical and significant throughout the cancer continuum. Their role is crucial as family caregivers (FCGs), who take care of more than half of the patient's needs. Thus, the need to understand the psychological health of professional caregivers as well as family caregivers is essential as they form the first and second layers of care for patients with cancer. Majority of the literature has focused on the negative aspects of providing care to patients with cancer, among both formal as well as informal agents of care. Among the most common work-related psychological issues faced by oncology HCPs, burnout has been extensively studied. However, studies focused on the psychological health related to other aspects of healthcare professionals are scanty. Studies on FCGs have extensively focused on the impact of caregiving and the various psychological states of the caregivers. Although these two groups of carers have been viewed in isolation in their roles of care for the patient, the current study aims to study both these agents of care deliverers together, due to their shared care recipients. The various psychological factors that are best predictors of compassion satisfaction and compassion fatigue have been examined thoroughly in the study. The research also aims to understand the various psychological issues affecting both the professional and family care deliverers, to ensure holistic care of the patients. Thus, understanding the various psychological aspects that affect both positive as well as negative

aspects of care among HCPs and FCGs in oncology healthcare is pertinent. The study was conducted in two phases, such as phase I and phase II. Phase I of the study included the use of standardized psychological measures to acquire quantitative data from oncology HCPs (inclusive of doctors and nurses working in the field of oncology) and FCGs of patients with cancer. The first phase explored the levels of compassion satisfaction, burnout and secondary traumatic stress; perceived stress, psychological distress, well- being and coping in oncology HCPs and FCGs. The study was carried out on a total of 309 participants; 153 HCPs and 156 FCGs of patients with cancer. Based on the findings of phase I, phase II of the study was designed to acquire qualitative data from 10 HCPs and 10 FCGs of patients with cancer. The study employed an exploratory sequential mixed method, which was a quantitative-led-qualitative study design. Based on the results of phase I of the study, individual responses regarding various significant quantitative findings were captured through interviews. Questions on personal experiences and perceptions of compassion fatigue (inclusive of burnout and secondary traumatic stress) was asked. The data was collected from 10 HCPs (inclusive of oncology nurses and oncologists) and 10 FCGs for the phase II of the study. In line with the objectives of the study, there were significant correlations between compassion satisfaction, burnout and secondary traumatic stress and the other study variables. In line with the chief goal of the study, the results also found that there was a statistically significant difference between HCPs and FCGs with respect to burnout and as well as secondary traumatic stress, when controlled for the psychological variables perceived stress, psychological morbidity, well-being, problem-focused coping, emotion-focused coping, and avoidant coping. However, there was no difference found with respect to compassion satisfaction between the two groups. The novel method of establishing the best models for the prediction of compassion satisfaction, burnout and secondary traumatic stress, through the Step-up regression analysis, followed by the Max.Min Procedure yielded significant results. The findings show that the variables thus

obtained to be the best models for the prediction of compassion satisfaction, burnout and secondary traumatic stress in HCPs incrementally were perceived stress, problem-focused coping, psychological morbidity, emotion-focused coping and avoidant coping, in their mentioned order. The models thus derived through the novel Max.Min Procedure, explain the relevance of each model in incrementally explaining the dimensions of ProQoL. For instance, for developing an intervention as a future perspective, perceived stress can be considered as a significant contributor to the dimensions of ProQoL, which is then followed by problem-focused coping, psychological morbidity, emotion-focused coping and avoidant coping, representing the increasing R squared value for the variables. These findings also pave a path to helping health psychologists include the respective models as part of intervention modules to improve professional quality of life among HCPs. However, the models may also be considered to be applied in the context of FCGs as the mean values obtained for the group, although not significant were close to those obtained by the HCPs. The logistic analysis and the contingency analysis have also shown that the psychological variables perceived stress, psychological morbidity, well-being, problem focused coping, emotion focused coping, and avoidant coping predict the levels of compassion satisfaction, burnout and secondary traumatic stress in HCPs and FCGs of patients with cancer. As a part of the study, in-depth interviews done with healthcare professionals (inclusive of doctors and nurses of patients with cancer) with respect to perceptions of burnout indicated that there was a predominance of perceptions which were “job related” and “patient related”. Likewise, with respect to secondary traumatic stress, the perceptions of the healthcare professionals were mainly focused on the “work-related avoidance” and “emotions related to patients”. On the other hand, with family caregivers it was seen that, with regards to burnout, they primarily indicated “social limitations”, “financial needs”, “fatigue due to caregiving tasks”, “neglecting other responsibilities”, and “information support” as their causes of burnout; and for secondary traumatic stress, “fear of family member

dying", "uncertainty", and "sadness due to remission" were indicated as the causes. The findings of the study give an elaborate picture of the various variables such as perceived stress, problem-focused coping, psychological morbidity, emotion-focused coping and avoidant coping that are best suited to predict the compassion satisfaction, burnout and secondary traumatic stress among HCPs and FCGs of patients with cancer. The study also shows us that burnout and secondary traumatic stress were significantly higher among HCPs when compared to the FCGs. This calls for attention toward developing relevant health psychological interventions to the HCPs to deal with burnout and secondary traumatic stress. Family caregivers as a group are silent sufferers and fairly good amount of research surrounding various psychological aspects of caregivers indicates the need for interventions for this group too. Relevant psychosocial supportive interventions may be designed and implemented from a holistic health psychological perspective for a better overall functioning. This in turn results in enhanced care providing and stronger support to the patient as well.

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AC	Avoidant Coping
ANOVA	Analysis of Variance
BO	Burnout
CS	Compassion Satisfaction
EFC	Emotion-focused Coping
FCGs	Family Caregivers
HCPs	Healthcare Professionals
MANCOVA	Multivariate Analysis of Covariance
MANOVA	Multivariate Analysis of Variance
PFC	Problem-focused Coping
ProQOL	Professional Quality of Life
STS	Secondary Traumatic Stress
WHO	World Health Organisation

CHAPTER I

INTRODUCTION

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INTRODUCTION

By definition, in biological terms, cancer is a malignant growth or tumor resulting from an abnormal and uncontrollable division of cells in the body. However, in reality the meaning of this term connotes fear, pain, loss, and is extremely traumatic to individuals, families, communities and healthcare systems. The disease affects and claims tens of millions of lives around the globe. Cancer has been reported to be the second cause of death worldwide, behind cardiovascular disease (Wang, et al., 2016). By the year 2030, the WHO estimates that the incidence of cancer and cancer related deaths will exponentially increase. The estimated number of new diagnoses are expected to surge up to 21.6 million and cancer related deaths to a 12 million in year 2030 (Boyle & Levi, World cancer report, 2008). Experts predict that these numbers are expected to rise worldwide to a 29.5 million cases with a death toll of 16.4 million by the year 2040 (National Cancer Institute, 2020). Not surprisingly, these numbers are rising as predicted. Worldwide, in 2020, cancer has led to approximately 10 million deaths and the number of new cases were reported to be over 19.3 million (Sung, 2021). These alarming numbers call for a need for extensive study and research in the areas of cancer, not only of cancer pathology, cancer treatments, but also psychosocial management of one of the most feared health conditions.

Cancer and Types

The process in which healthy and normal cells mutate into cancer cells is termed as oncogenesis or carcinogenesis. Cancer originates from a single abnormal cell that has a damaged DNA sequence. It is a complex ‘multi-gene’ and a ‘multi-step’ disease. Uncontrollably proliferating in multiple rounds of mutation and natural selection this leads to the growth of abnormal cells called tumors. Cancer can be broadly divided into four types, namely, Sarcomas

(cancers arising from cells that cover the external and internal surfaces of the body), Carcinomas (cancers arising from the supporting tissues of the body), Lymphomas (cancers arising from the lymph nodes of the body) and Leukemias (cancers arising from the blood forming tissues of the body). Various environmental factors (chemicals, radiation, pollution, viral/bacterial infections), lifestyle factors (nutrition, obesity, tobacco) and factors within a biological cell (genetically inherited mutations, hormones, dysfunction of the immune system, oxidative stress) can cause the development and the progression of this disease.

Stages in Cancer

The extent of disease progression can be categorized into five stages, namely stage 0 to IV. In stage 0, also termed as carcinoma in situ (i.e. 'in place') the cancer has not spread to the nearby cells and is located in the same place where it had started in the body. It is often curable when detected at this stage. Stage I is when the cancer invades and disrupts small amounts of local tissues forming a primary lesion. Body organs or lymph nodes have not been affected in this stage. Stage II and III are where the cancer has grown deeply into surrounding tissues of the body, usually affecting the lymph nodes as well as various organs. In stage IV the tumor cells enter the bloodstream and affect other organs of the body. Staging of cancer is an essential prerequisite and acts as a guide to patient prognosis as well as designing the treatment plans, and this in turn could contribute to the patient's survival.

Factors leading to Cancer

While some cancers may be inherited, many types of cancers are caused by various external agents, called carcinogens. These can be physical (exposure to ionizing radiation and ultraviolet rays), chemical (ingesting or using chemical components such as asbestos, tobacco, alcohol, and other food and drinking water contamination) and biological (getting infected by certain types of

viruses and bacteria) carcinogens. Upon repeated or intense exposure, they can alter the genetic makeup of the cells and cause cancer. The incidence of cancer also rises dramatically with age. Additionally, the use of tobacco, following unhealthy diets, consumption of alcohol, and leading a sedentary lifestyle and oxidative stress have been established as the risk factors of a number of cancers (Vucenik & Stains, 2012). Obesity has also been linked with cancer, with studies reporting that excess body weight being linked to the increased risk of developing a wide range of malignancies (Avgerinos, Spyrou, Mantzoros, & Dalamaga, 2019).

Cancer and Treatment

There are several existing procedures to treat cancer, some of the popular ones are, Surgery, which is the removal or the abnormal cell growth, Radiation therapy, Chemotherapy, Targeted therapy, Hormone therapy, Immuno-therapy, Stem cell or Bone marrow therapy. By surgery, the tumor or the organ that is affected is removed. Chemotherapy, or treating cancer with the use of drugs is aimed at destroying cancer cells. It obstructs cell division at various stages, such as cell division, formation of new chromosomes or duplication of DNA. Radiation therapy also called radiotherapy or irradiation is a treatment which targets and destroys the genetic material of the cancer cells and shrinks the tumors through ionization. Another type of therapy which has gained popularity in the recent past is the use of targeted therapy, which includes using specific agents to destroy proteins of cancer cells. Hormone therapy is a type of cancer treatment where the growth of cancerous cells is inhibited by supplying or blocking certain hormones. This type of treatment is often an option in hormone sensitive tumors such as breast or prostate cancers. Immunotherapy is where a set of therapies or cancer vaccines are induced to generate and improve the patient's immune system to fight against the tumor. Other types of treatments include stem cell/bone

marrow therapy, hyperthermia, photodynamic therapy and the use of lasers are also used to treat cancer.

Cancer Incidence and Prevalence

Internationally, around 19.3 million new cases of cancer are registered as reported in the year 2020. Cancer related deaths worldwide were reported to be over 10 million worldwide (Sung, 2021). Breast cancer and lung cancer were among the widely prevalent types of cancer across the globe, contributing up to 12.5% and 12.2% of the total cases diagnosed, respectively. The third common type of cancer reported globally is colorectal cancer contributing around 10.7% of total cases of cancer, that is, almost 1.9 million new cases of colorectal cancer have been reported. Around the globe, the cancers most prevalent among men are lung cancer, colorectal and prostate cancers, forming 41.9% of the cancers that affect men. However, lung cancer formed 15.4% of the newly diagnosed cases of cancer among men. Other cancers reported by men were stomach and liver cancers, contributing up to 5% of the cases. In women, the most prevalent types of cancers were reported to be breast cancer, colorectal and lung cancer, contributing to 44.5% of all cancers in women. The prevalence of breast cancer and cervical cancers have shown to report 25.8% and 6.9% of the newly diagnosed cases of cancer. The fourth most reported cancer among women is cervical cancer (Worldwide Cancer Data, 2020). However, the continent of Asia reports an overall lower rate of incidence and mortality of cancer when compared to other developed continents such as North America, Oceania or Europe (Mathur, et al., 2020).

In India, cancer amounts up to 9 percent of the deaths, making it one of the main causes of deaths in the country (Mathur, et al., 2020). Recent statistics on the incidence of cancer in the country reported 1,392,179 cases as of the year 2020 (Mathur, et al., 2020). The incidence of cancer in Indian males was reported to be 679,421 that is, 94.1 persons per 100,000 are diagnosed with

cancer and 712,758 females, that is 103.6 persons per 100,000 were diagnosed with the disease as of the year 2020 (Mathur, et al, 2020). The recent statistics also reveal that 1 in every 68 males is most likely to develop lung cancer, and 1 in every 29 females is likely to develop breast cancer. The alarming estimates also predict that 1 out of every 9 Indians will develop this disease during their lifetime. The main cause of concern however is many cases of cancer in the country goes unreported, or cancer is diagnosed in the last stages and is beyond treatment.

While cancers of the lung, nasopharynx, mouth, esophagus and stomach were the most common cancers that are seen in men; breast cancer, cervix and uterine cancers are most commonly seen among women (Mathur, et al., 2021). In India, cervical cancer is reported to be the second leading cause of female cancers (Bruni, et al., 2021), and nearly two women are diagnosed newly with breast cancer for every woman that dies of breast cancer (Ferlay, et al., 2013). A new increasing trend of thyroid cancers has also been recorded among women of the country. However, with these incidence rates, it is also noteworthy that the use of tobacco is the main cause of cancer in the Indian subcontinent (Dhillon, 2018). The daily deaths caused by tobacco use in India are estimated to be more than 3,500 persons in India (Jha, Jacob, Gajalakshmi, Gupta, Dhingra, Kumar, 2008; Sinha, Palipudi, Gupta, Singhal, Ramasundarahettige, Jha, 2014).

Psychological Issues faced by Patients with Cancer

Cancer and its effects are disrupting and life altering regardless of the stage of cancer diagnosis. Cancer profoundly affects the physical, psychological, emotional, social, spiritual and interpersonal aspects of an individual's life. Despite the advances in cancer care the patients suffer a wide range of physical as well as psychological issues. An individual's life is altered beginning from the point of diagnosis, through the various treatment procedures, the process of recovery, the

underconfident rates of long-term survival, the long-term effects of the disease and treatment, and fear of recurrence or remission of the disease. This can be the cause of emotional unrest and instability in one's life. The physical effects of cancer can manifest themselves in the form of fatigue, weakness, lowered physical vitality and loss of function in many aspects of life. Other social aspects of an individual's life also take a swift decline i.e., a sudden shift in roles, activities, and priorities (Teston, Fukumori, Benedetti, Spigolon, Costa, & Marcon, 2018). As reported by the NCCN, (2017) various factors such as, becoming aware of the diagnosis, changes in treatment procedures, failure of treatment, recurrence of cancer and worsened prognosis are among the major causes of psychological distress in cancer patients. Furthermore, factors such as longer hospital stays, lowered adherence to treatment, loss of ability to carry out personal-care and unpredictable treatment outcomes have also contributed to distress among them (Gill, Costa, Hilker, Benito, 2012). During the process of treatment, the patient's increased dependence on the doctors, without much understanding of the procedures can also add to the loss of control and autonomy over what will happen to one's own body. Unlike other diseases, in cancer there is only so much that a patient can do about managing his or her disease, during and after treatment. A major part of the treatment and other aspects of care are authorized by the radiation oncologist, chemotherapists, surgical oncologists and other specialists.

The overall uncertainty that looms over the various treatment procedures and the therapeutic outcomes are also a cause of emotional distress in cancer patients. Studies have reported that decreased self-esteem, reduced self-efficacy, increased dependency, contemplation of death and leaving loved ones behind have also been listed as major threats to one's quality of life (Omran, & Mcmillan, 2018). While quality of life, in simple terms can be understood as subjective perception, in patients with cancer, this perception is threatened by disruptions in many

facets of their lives. As this poses a general threat to their sense of security and loss of equilibrium, most patients exhibit signs of emotional and psychological distress (Nikbakhsh, Moudi, Abbasian, Khafri, 2014) adjustment disorder, post-traumatic stress disorder (Cordova, Riba, Spiegel, 2017), clinical depression (Caruso, Nanni, Riba, et al., 2017) anxiety (Spiegel & Riba, 2015), the projection of negative defense mechanisms, sleep disorders and sexual dysfunction in many cases (Gregurek, Braš, Đorđević, Ratković, & Brajković, 2010). Existential questioning and negatively pondering upon the purpose and meaning of life are also common among those diagnosed with cancer. Side-effects and adverse reactions to treatments are among the major causes of physical as well as psychological distress in cancer patients. These experiences or negative responses during the illness trajectory can have significant detrimental effects on the patient's quality of life (Grassi, Spiegel, & Riba, 2017) and may remain long after the disease is gone (Kang, Park, McArdle, 2012; Barre, Padmaja, Rana, & Tiamongla, 2018).

Factors such as lack of social support, uncontrollable disease symptoms, previous history of psychiatric disorder or trauma, being aged and belonging to the female gender have been listed as some of the risk factors that can aggravate the mild symptoms of depression and anxiety into full blown clinical symptoms during the illness and treatment trajectory (NCCN, 2017). A lot of post treatment physiological changes such as amputations, loss of hair, can cause body image issues among men and women. The lack of physical strength to carry out everyday activities, development of multiple comorbidities, difficulty getting back to work-life, difficulty regaining functional activity, and sexual intimacy with their partners may be some of the other aspects being affected which can further deter the patient's quality of life (Kreitler, Peleg & Ehrenfeld 2007; Kang, Park & McArdle, 2012; Caruso, Nanni, Riba, et al, 2017). Other problems which can compromise the psychological and emotional health of the patients include poor communication

with professional care providers, mobilizing resources, difficulties in commuting to the hospitals, fiscal difficulties (Azzani, Roslani & Su, 2015). This calls for frequent psychological screening, evaluation, and interventions to monitor the extent and intensity of these symptoms and mitigate these risk factors to enhance their quality of life.

The Oncology Healthcare system in India

The healthcare system, its infrastructure, delivery and quality of the care in India is challenged by the country's vast population. India can be roughly divided into 3 socio-economic groups, namely, the upper socio-economic class, middle and the lower socio-economic class, which constitute 15%, 30% and 60% of the country's population respectively. The upper class are among those who can afford the advanced and innovative drugs and best treatments, the middle socioeconomic class can moderately afford and also co-pay a small amount for their health care; and those belonging to the lower socio-economic group struggle every day for their sustenance (Goss, et al., 2014). The healthcare system in India is managed by the public, private, modest insurance funding, out-of-the-pocket fees, NGOs, other external fundings and grants. Between the years 2017-2018, the country's public expenditure on healthcare services was 1.35% of the total GDP, according to the National Health Account Estimate report. With these numbers, the oncology healthcare system is at a further disadvantage as the treatment costs are extremely high due to the interplay of multiple specialties of medicine. These costs make the treatment highly unaffordable for the patients. The wide variations in the rates of cancer incidence and mortality, in terms of its geographic distribution within the country, the delivery of services becomes highly challenging (Bhaumik, 2013). Other factors such as patient's age, comorbidities, stage of cancer are also associated with cost of cancer care. Adding to this, the costs at various levels of treatment vary

with the types of cancers. For instance, the cost for colon cancer, prostate cancer and breast cancer varies in terms of costs of care (Simone, & Hewitt, 1999). In India's healthcare system, the administrative as well as technical support is provided by the central government, whereas the state government provides healthcare services and health education. Although the public sector in the previous years has undertaken schemes such as the Health Minister's Cancer Patient Fund in 2009 which enabled 27 regional cancer centers to provide financial assistance those patients who are below the poverty line and are affected by cancer. More recently the government of India has formed a National Cancer Grid (NCG), in 2012, which, as the name suggest, mandates the linking up all cancer centers across India. The NCG aims at reducing the disparities in the standard of patient care across the geographical topography of India, enables education and training of young personnel, encourages collaborative research and cancer policy in the country, cancer still has to be made priority for the government at all levels (Pramesh, Badwe, & Sinha, 2014). However, the country also tackles the cancer problem at the level of primary and secondary prevention, with the launch of national tobacco-control law and the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS).

Another crucial element of cancer healthcare is the range of professionals who are included in the system of care, reiterating the fact that cancer is a disease which needs the attention of multiple disciplines of medicine for the elimination of the disease and restoring the patient to productively return to the society. However, the core team of healthcare providers in cancer care, i.e. the radiation oncologists, surgical and medical oncologists, are very few in numbers when the vast cancer population of the country is considered. There are only 1250 cancer doctors in the country, as of 2017, which shows that there is one oncologist for 2000 patients. This appalling

doctor to patient ratio adds further stress to the oncology healthcare system (The Cancer Crisis in India, 2019).

The Role of Oncology Healthcare Professionals and Family Caregivers in Cancer Care

Healthcare workers can be divided into two categories, those delivering care and services to the ill directly and those delivering them indirectly. Among those providing direct care and services, are doctors and nurses, and among those providing indirect care are patient counselors, technicians, as well as those who handle medical waste. Across the world, there are approximately 59 million healthcare workers and their role is regarded as the most valuable resource for health according to WHO (Joseph & Joseph, 2016).

Doctors and nurses who provide direct care to patients, do so with the application of evidence-based practice, which can be defined as the practice of making decisions, with the help of information strongly rooted in medical knowledge supported by research and existing theories. Apart from these roles, of gaining knowledge and diagnosing and carrying out treatment plans to treat ill patients, a healthcare professional (HCP) also plays a pivotal role in activities such as practicing preventive medicine, creating awareness about prevention, and providing the public with tips to lead a healthy life.

As mentioned earlier, cancer is a combination of several diseases that need complex and multidisciplinary care, unlike other healthcare departments, which involve only a brief hospital visit or a relatively isolated medical intervention. Oncology healthcare requires the convergence of various medical, paramedical and psychosocial branches of care, to deliver holistic cancer care to the patient. For instance, the role of an oncologist (medical oncologist, radiation oncologist, and surgical oncologist) is pivotal and central in cancer care, however, equally essential are the roles

played by pathologists, hematologists, oncology nurses, radiation technicians, dieticians, patient navigators, social workers, constructive surgeons, rehabilitation specialists, mental health professionals and many more (Fleissig, Jenkins, Catt, & Fallowfield, 2006). Another important aspect in the oncology healthcare synthesis, is the informal care or the care provided by a family caregiver (FCG). The aim of cancer care at its core, is to restore a person's health to its pre-cancerous prior state, to whatever extent possible. This makes oncology healthcare an amalgamation of multiple healthcare services aiming to deliver integrated care.

While the team of oncology healthcare involves all the above-mentioned professionals, the main role is played by the core of the team, namely the doctors and nurses, that is, the oncologists and the oncology nurses. An oncologist specializes and oversees the various processes of cancer care, starting from the diagnoses to the cancer treatment. While there are broadly three main areas of treatment in oncology healthcare, namely, radiation, medical, and surgical oncology, other type of oncologists, who play a crucial role in many cancer diagnoses are geriatric oncologists, gynecologic oncologists, hematologists, neuro-oncologists, pediatric oncologists, and thoracic oncologists.

Thus, oncology healthcare can be seen as operating in three different phases, namely, acute cancer care, chronic cancer care and end-of-life- cancer care. These three phases, although distinct, may also overlap throughout the illness trajectory. These three phases of cancer include the processes of diagnosis through biopsy, pathological and histological assessment, treatment planning, managing survivorship, and end-of-life care. This is followed by the execution of treatment plans, systemic therapy, surgery, chemotherapy and/or radiation therapy. This is subsequently followed by surveillance for recurrences and screening for related cancers. Cancer care also includes end-of-life care facilities, such as providing advanced care, hospice care, and

grief support (Levit, Balogh, Nass, & Ganz, 2013). Components of high-quality cancer care essentially include planning of treatment and care procedures, offering palliative care, providing psychosocial support, prevention of post treatment, long-term effects of the disease, and ensuring family caregiver's (FCG) support. Patient-centered care is as important an aspect of providing care, equipping the patients and their family caregivers (FCGs) with disease information, provide knowledge about the prognosis of cancer, longevity of life after treatment, and potential harms and benefits of the treatment.

The role of an oncologist is to recommend tests to determine the type of cancer an individual is suffering from, explaining the cancer diagnosis, and clearly stating the stage of the disease progression and the type of cancer. An oncologist is also expected to present the various treatment options and plans to the patient and his family members, enabling the patients to make a treatment decision based on the success rates and potential harms of the treatment. Apart from this, an oncologist has to provide quality and compassionate care, aiding the patient in managing the disease symptoms and side-effects of the treatments and maintaining post treatment follow-ups.

The role of an oncology nurse is equally essential to the cancer care synthesis. Oncology nurses are trained and equipped to offer acute cancer care, deliver inpatient care, outpatient care and home-based healthcare services, as well as community services. This is possible, as oncology nurses are trained in a lot of oncology disciplines, such as surgical, medical, radiation, pediatric, and gynecological oncology. Oncology healthcare nurses are involved in direct intensive care of the patients during and post treatment, as well as providing community-based screening and prevention programs. This role is essential and has tremendous psychosocial implications in patient care. They reach a lot of individuals and provide essential information and general

awareness about the disease, disease progression, preventive measures, and procedures. To understand the role of an oncology nurse at length, it is important to understand their role in patient assessment, where nurses form the team of first line workers in cancer care playing a role in patient's physical check-ups, patient history, and other regular basic assessments. The patient's treatment plan and dosages are discussed with the nurses, to ensure patient preparedness, compliance, and a smooth flow of the procedures. Oncology nurses are important agents in imparting information and hope to patients and their caregivers who are emotionally agonized. Their role is inevitable in comforting patients and helping them maintain a sense of control and remain emotionally prepared (Northouse, 1996).

Providing health education or information to patients and their FCGs is also an essential part of oncology healthcare and is pivotal throughout the cancer trajectory (Hack, Ruether, Pickles, Bultz, Chateau & Degner, 2012; Banerjee et al., 2017). Patient education, imparted by nurses in many cases, is essential at various junctures of cancer care, such as coping with the diagnosis, preparing for long-term adjustments, basic understanding of treatment procedures and side-effects. Thus, although nurses may not play an important role in controlling the disease, they can act as a network of support for the patients and their caregivers in managing the disease. For instance, nurses play an essential part in symptom management of the patients and caregivers, before and during the course of the treatment. The physical symptoms of fatigue, vomiting and nausea are among the most common symptoms that follow rounds of chemotherapy. Controlling and helping patients manage these symptoms is also an important part of care. As oncology nurses spend a great deal of time with the patients and their family members, in terms of providing physical care when compared to other HCPs, they form an essential part of the oncology healthcare system.

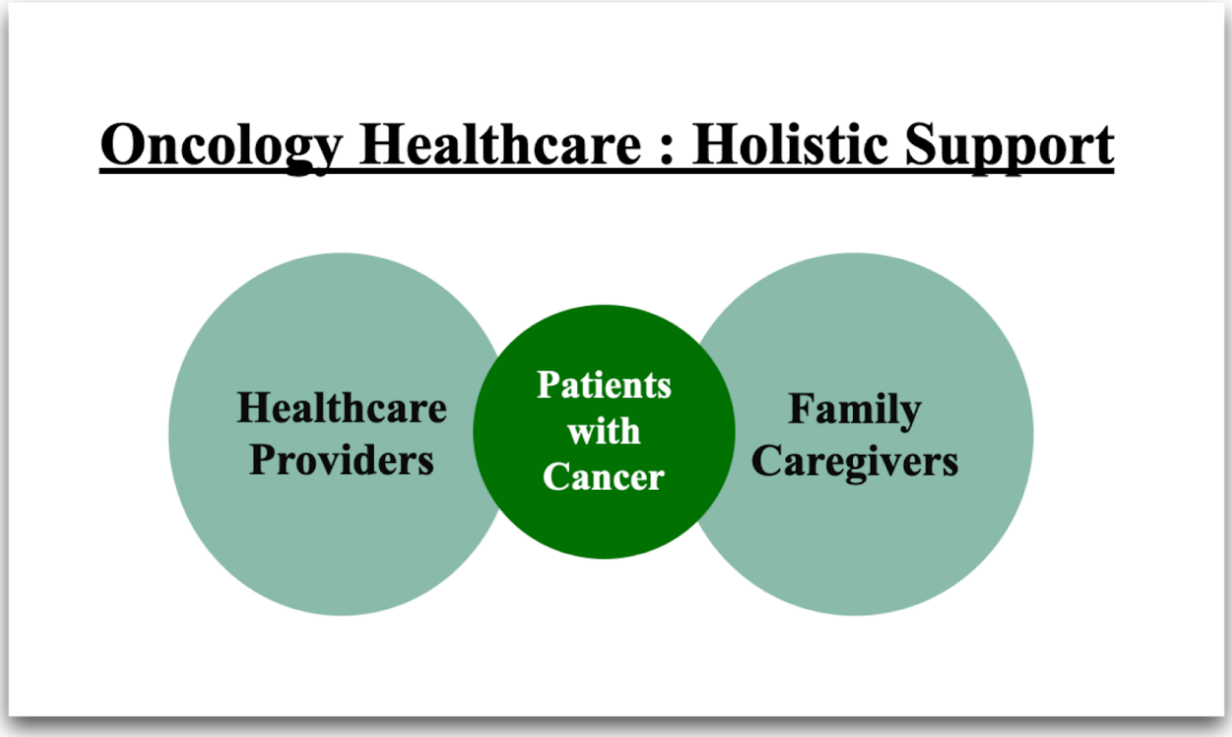
The role of a FCGs is an integral part of the oncology healthcare system. Informal caregivers can be defined as those providing a broad range of uncompensated care/assistance for an adult suffering with a serious illness. This person can be a spouse, adult child, other relative, partner or friend who shares a personal relationship with the patient (Given, Sherwood, & Given, 2011). The support and care provided by these informal caregivers or FCGs is very critical and significant throughout the cancer continuum. Their role is crucial as a FCGs, who takes care of more than half of the patient's needs (Hashemi-Ghasemabadi, Taleghani, Yousefy, & Kohan, 2016). This need, of providing personal care for patients suffering with cancer is more likely to increase with the rise in the number of new cases being diagnosed in the country and around the world. The FCGs form an essential part of the cancer care team, to support and provide direct care to those suffering with cancer. The role of a caregiver demands significant amounts of time as well as energy (Kent, et al., 2016).

Despite the mildly varying roles and responsibilities of caregiving, with respect to the disease or illness of the care recipient, the role of a caregiver largely remains universal. They are expected to quickly assume the role of a caregiver with minimal warning or preparation. Often FCGs have very little understanding of the complex roles and tasks that entail caregiving (Padmaja, Vanlalhruaii, Rana, Nandinee & Hariharan, 2016). The role played by a FCGS sometimes begins even before the diagnosis of a patient, with respect to identifying and understanding the family member's complaints regarding their health and choosing a physician for further diagnosis, which may be followed by a life-threatening diagnosis in the case of cancer. From the definite point of diagnosis, the caregiver immediately takes on a role of care towards the patient, which involves dealing with the crisis of the diagnosis, attending hospital appointments, seeking information, communicating with the healthcare staff, making decisions related to the treatment of the patient,

assisting the patient in daily activities, balancing financial resources, managing treatment and the related side effects, coping with the emotions of one's own self and that of the patient's and providing social and emotional support to the care recipients. The involvement of a caregiver is a key component in ensuring optimal treatment to patients with cancer to facilitate treatment compliance, managing the patient's emotional state, and holistic recovery of the patient. The role of the caregiver continues even after the patient is discharged from the hospital until the patient is able to return to his/her regular functional state.

Figure 1.1

Holistic Support in Oncology Healthcare System



Psychological issues faced by Oncology Healthcare Professionals and Family Caregivers of Patients with cancer

International research reports oncology healthcare settings to be an inherently strenuous work environment for its professionals (Akroyd, Caison, & Adams, 2002; Le Blanc & Schaufeli 2003; Jasperse, Herst, & Dungey, 2014; Guveli, et al., 2015). Oncology HCPs, who spend a great deal of their time planning and executing treatment plans with limited therapeutic windows, witnessing multiple agonizing deaths of patients, dealing with seriously the ill most of the time, and handling high workloads and time pressure, experience tremendous amounts of stress, burnout, trauma and work-related psychological issues (Sale, & Smoke, 2007; Girgis, Hansen, & Goldstein, 2009; Probst, Griffiths, Adams, & Hill, 2012).

The need for understanding the psychological health of professional caregivers as well as FCGs is essential as they form the first and second layer of care for patients with cancer. This is more relevant as the patients become physically and psychologically vulnerable, which may lead them to become more rigid and cause them to adopt strong negative defense mechanisms and exhibit behaviors such as noncompliance to medical care and procedures, sometimes, to the extent of completely denying the fact of being ill and even refusing treatment or help of the medical staff. These defenses can cause delays in the diagnosis of the disease and negatively affect adherence to the treatment and follow-ups. Caregivers play an essential role in helping the patients to overcome dysfunctional defense mechanisms by providing support and creating the needed alliance between the patients and physicians. However, while the professional and FCGs provide support diligently when it comes to the psychological outcomes of the continuous care may have their manifestations. Several psychological aspects of professional care providers and FCGs are hence important to be explored to design suitable support and interventions.

Components of Professional Quality of Life: Compassion Fatigue and Compassion Satisfaction

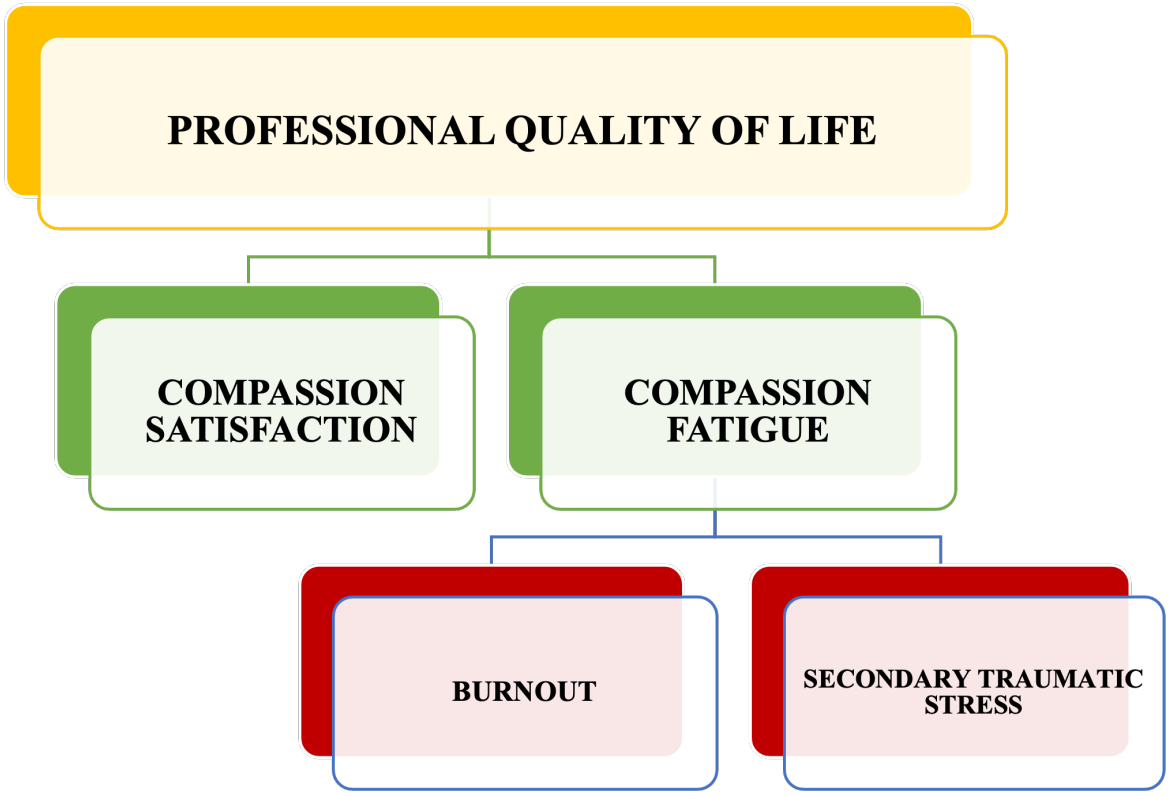
Among the most common work-related psychological issues faced by oncology HCPs, burnout (BO) has been extensively studied. Studies across the globe have reported that oncology HCPs, undergo stress and BO as a result of the nature of their work (Akroyd, Caison, & Adams, 2002; Girgis, Hansen, & Goldstein, 2009; Jasperse, Herst, & Dungey, 2014; Guveli, et al., 2015). It was reported that globally and across various medical specialties, one-thirds of the physician community are bound to experience BO at some point in their career. A recent meta-analysis, In India to understand rates of BO in the country showed that one-fourth of Indian HCPs suffer from BO (Kesarwani, Husaain, & George, 2020). However, studies focused on the psychological health of HCPs are scanty and rather focused on all the fields of medicine rather than those that have a high exposure to trauma and pain of the patients. Although the studies on HCPs working in traumatic environments such as the ICUs (Amin, Vankar, Nimbalkar, 2015; Saravanabavan, Sivakumar, & Hisham, 2019) or the emergency wards (Duffy, Avalos, & Dowling, 2015; Wilson, Raj, Narayan, Ghiya, Murty, & Joseph, 2017; Baruah, Das, Dutta, Das, Sharma, & Hazarika, 2019) have been scattered throughout the literature, studies that exclusively focus on oncology healthcare settings, which is an equally strenuous field of medicine with unpredictable patient outcomes and prognosis, has been studied poorly in Indian settings (Bhutani, Bhutani, Balhara, & Kalra, 2012; Kaur, Sharma, & Chaturvedi, 2018; Noronha, Malik, Karimundackal, Pattadath, & Sharma, 2020; Noronha, Malik, Bindhulakshmi, & Karimundackal, 2020). Increased workload increases the work burden and makes it difficult to execute timely and holistic treatments for patients with cancer. With not very clear guidelines especially in oncology healthcare, doctors are sometimes put under pressure to carry out patient treatment plans that they may not totally agree with. This further adds

to the psychological strain. Given the large population of the country and the rising need for healthcare, it is pertinent that selective focus on various specialties of medicine be given utmost importance to understand and cater to the psychological needs of the HCPs in the country.

Although the literature reporting burnout in doctors and nurses is extensive, concepts such as compassion fatigue (CF) and compassion satisfaction (CS) have not been explored in-depth (Akroyd, Caison, & Adams, 2002; Girgis, Hansen, & Goldstein, 2009; Jasperse, Herst, & Dungey, 2014; Guveli, et al., 2015). Thus, it is essential to understand the play of both negative as well as positive aspects of the nature of work, especially in oncology healthcare settings. Recently efforts have been made to understand these dual aspects, Stamm (2005) formulated and explained the concepts of CS and CF as positive and negative aspects experienced by professionals especially in the 'helping' professions, such as those in the healthcare sector, teaching, social work, lawyers, policemen, firefighters, church priests, and disaster-management site clean-up teams. Both these constructs, CS and CF, were combinedly called professional quality of life (ProQoL) (Stamm, 2010). The concept is an interplay of multiple work related as well as personal factors such as the work environment, individual factors, and being exposed to both primary as well as secondary type of trauma in the workplace. The components of ProQoL entails two aspects of work i.e., the negative aspects (CF) the positive aspects (CS) and is used to measure both the negative as well as positive affect among 'helping' individuals.

Figure 1.2

Components of Professional Quality of Life



Source: Adopted from The Concise ProQoL Manual, 2010

Joinson (1992) was the first to describe CF in an attempt to explain the apparent "loss of the ability to nurture" in nurses working in the emergency wards. The term was later adopted by Charles Figley (1995) to elaborate and describe the experiences of therapists and counselors who treated patients/clients who were victims of violent psychological or physical abuse. He called the phenomenon as the "cost of caring" and defined as "the reduced capacity or interest in being empathic or bearing the suffering of clients and (is) the behavioral and emotional state that results from knowing about a traumatizing event experienced by another person" (Figley, 1995; Figley, 2002; Adams, 2006; Boscarino, et al., 2010). The concept was also described as being identical and similar to post traumatic stress disorder, in terms of symptomatology, however, here the

individual experiences the trauma of another person, hence ‘secondary’ traumatic stress (STS) as he/she has prolonged and continuous exposure to traumatic experience of another.

Stamm (2010) has described CF to constitute two components, that is, BO and STS. Compassion fatigue as the cumulative and progressive effect of exposure to prolonged and intense levels of multidimensional stress in terms of patient care. Collectively, it is the emotional distress that is experienced by HCPs and caregivers who have an active and ongoing proximity with ill patients. The negative aspect of PrQOL is CF. Compassion fatigue is one of the major psychological issues affecting professionals and caregivers working with patients/clients who undergo physical or psychological trauma (Guveli, et al., 2015; Flannery, Ramjan, & Peters, 2016; & Sodeke-Gregson, Holttum, & Billings, 2013; Xie, et al., 2021). CF stems from investing lot of energy, empathy and involvement for a prolonged period, to those who suffer, often without experiencing much positive outcome in terms of patient improvement or well-being (Stamm, 2002). In oncology healthcare settings, this is a most commonly occurring phenomena, owing to the sudden decline in patient’s health due to various medical factors as well as increased patient mortality (Mathur, et al, 2020).

BO can be understood as an occupational stress that may affect workers in any profession. It constitutes of frustration, anger, emotional as well as physical exhaustion, and/or depression that is associated with professional life or providing care. The other negative element of CF, is STS, which is the outcome of being repeatedly exposed to indirect or second-hand experience of the trauma, pain and agony of their work recipients (Stamm, 2010; Sodeke-Gregson, Holttum, & Billings, 2013; Galiana, Arena, Oliver, Sansó & Benito, 2017). The symptoms of STS are identical to that of a person affected by PTSD (characterized by disturbances in sleep, flashes of intrusive images, constantly trying to avoid reminders of trauma), only the individual who undergoes STS

experiences the trauma of another person(s) he/she is working closely with, and this is highly relevant to professionals working in oncology healthcare settings (Najjar, Davis, Beck-Coon, & Carney Doebbeling, 2009).

On the other hand, CS, was described as the satisfaction one obtains from the work he or she performs. Compassion can be defined as the acting and feeling of deep empathy and sorrow for those suffering. Compassion satisfaction is the result of an individual's sense of altruism, and can be understood as "a sense of fulfilment or gratification that he/she derives from carrying out his/her work" (Stamm, 2010). The satisfaction plays a vital role in human services in shaping the motivation that drives them to aid others in their suffering. As Stamm describes it, there are three components to CS, they are, (i) the level of satisfaction one derives from contributing to the place of work or the society at large (ii) the level of control and competency that one experiences with respect to his/her job, (iii) the level of positive support a person receives from his/her work environment (Stamm, 2002). Along with its perils, being an oncology HCP, undoubtedly has its gratifying aspects with respect to helping fellow humans, personal satisfaction, doing one's part in bettering the society, and the like. These positive aspects tend to form a buffering layer around the professionals, acting as a protective factor, and help mitigate the onset and development of CF in these individuals. In other words, when these professional care-providers experience CS, and thus a sense of fulfilment in their work, he/she would experience less CF. Figley (1995) recognized this phenomenon in professional care-providers who are being exposed to tremendous amounts of suffering of ill patients or traumatized individuals, yet, they maintain their ability to empathize with them and help them without being emotionally overwhelmed. Recently, studies have been conducted to understand these constructs in the contexts of caregivers, due to their close encounters and the nature of their work with the affected patients (Lynch, Shuster, & Lobo, 2018).

Perceived stress

Another area which needs closer exploration is the stress perceived by HCPs and FCGs. Lazarus and Folkman (1984) have defined stress as the relationship between an individual and his/her environment, which is appraised by that person as being taxing or exceeding beyond his/her resources and having the ability to endanger their well-being. The two types of appraisals, are primary and the secondary appraisal. Primary appraisal is the degree to which a person views the situation as a challenge or a threat, while secondary appraisal is the individuals' assessment of their abilities to handle the situation and to reduce the damage or loss caused by the stressor. This is relevant because the theory also suggests that coping with stress is affected by both objective and subjective meanings an individual assigns to a stressful situation. Stress can be objective and subjective. The amount and type of impairment experienced by an individual is the objective stress and the potential emotional and psychological distress that resulted is subjective. However, according to Lazarus and Folkman, the impact of stressful events being 'objective', to an extent, can be determined by an individual's perception of the stressfulness of the event. Thus, through understanding the global stress is the first approach to understand the types of stressors faced by individuals, it is essential to measure the individual's perception of the stressful event. Understanding stress only at an objective level, implies that we are attributing the very event to be the precipitating cause of stress, rather than the cognitive mediated emotional response (subjective level) to the event. This contrasts the aspect of the stress and coping theory that proposes that there is an active interaction between the individual and their environment, involving the continual appraisal of potentially threatening event or challenging situations in light of their available coping resources. Thus, the concept of perceived stress plays a crucial role in understanding a person's response to stress, as it posits that response to a stressful event is not solely based on the intensity

of an even or any of its inherent qualities, rather it is very much so based on the perceived and contextual factors as well. It is an individual's perception regarding the amount of stress they are undergoing at a given point in time. It can be understood as the degree to which an individual perceives his or her life situations to be uncontrollable and/or unpredictable, the amount of change occurring in one's life, and how frequently he or she has to deal with the hassles of life, the perceived levels of confidence in their capacity to deal with these problems. With this said, it is essential to note that the concept of perceived stress is not merely about the frequency of stressful events taking place in a person's life, rather, it is the person's feeling about the general level of stress in their lives and their ability to handle it. Thus, studying perceived stress helps us understand the interaction between an individual, their environment and the perception of the individual of their environment (Lazarus & Folkman, 1984). Oncology HCPs are bound to experience stress in their workplace due to various factors such as lack of adequate work experience (Xie, et al., 2021) excessive workloads (Jasperse, Herst, & Dungey, 2014), interactions with patients and coping with death (Isikhan, Comez, & Danis, 2004). Studies also report a close relation of stress and burnout in HCPs (Toh, Ang, & Devi, 2012). In the case of FCGs of patients with cancer, they are overwhelmed by the multidimensionality of stress they face (Pearlin, Mullan, Semple & Skaff, 1990; Gaston-Johansson, Lachica, Fall-Dickson & Kennedy, 2004; Vanderwerker, Laff, Kadan-Lottick, McColl & Prigerson, 2005; Kim, Baker, Spillers & Wellisch, 2006; Padmaja, Vanlalhruaii, Rana & Kopparty, 2017).

Psychological Morbidity

Any amount of deviation from the 'normal' and showing differences in the psychological states such as depression, somatic symptoms anxiety and social dysfunction, can be considered

psychological morbidity. Particularly when these psychological states tend to deviate from the normal significantly and there is an effect on the capacity of an individual to carry out his or her regular functions, it can be termed as psychological or psychiatric distress/. Psychological morbidity also referred to as psychological distress is not merely poor mental health, but it is also the amount of emotional suffering that one experiences (Goodwin, Ben-Zion, Fear, Hotopf, Stansfeld & Wessely, 2013). This could result from being exposed to a variety of stressful events for HCPs and FCGs of patients with cancer. The inability to employ effective coping mechanisms to cope effectively with these stressors results in psychological distress that can manifest in a variety of adverse psychological and psychiatric outcomes (Sirois & Owens, 2021). Psychological morbidity though may appear to be a transient state having a gradual negative impact on the person's day-to-day social functioning, this distress, when prolonged for a longer period of time, can bear negative mental health implications. Studies conducted on HCPs have shown that about 37.8% of the participants experienced psychological morbidity. Psychological morbidity was related with burnout, high level of stress as well as various work-related factors as well (Zhou, et al., 2017)

Well-Being

The state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity has been defined as health (WHO, 1946). In its general sense, well-being can be understood as an extensive psychological index for measuring an individual's quality of life and it reflects his/her personal satisfaction with the conditions they are living in (Angner, 2010). Well-being improves creativity, helps a person in achieving goals with ease, aids his/her ability for decision-making, improves overall life satisfaction, enhances their quality of life, and

appeases negative emotions and feelings to promote physical and mental health in an individual (Hamid & Ghaazaei, 2013, Gao et al., 2017). According to Maccrae (2002) well-being also acts as a protective factor against psychopathology as well.

HCPs having an increased well-being can help achieve better results and act as a buffer for many negative outcomes of stress and burnout such as absenteeism and increased sick days leaves, decreased likelihood of leaving jobs as well as patient safety (Zhao et al., 2016, Hall, Johnson, Watt, & O'Connor, 2019). According to World Medical Association (WMA, 2017), physician well-being specifically has been referred to as the "optimization of all factors biological, psychological and social health and preventing or treating acute or chronic diseases experienced by physicians including mental illness, disabilities and injuries resulting from work hazards, occupational stress and burnout". As described by Bodenheimer and Sinsky (2014) factors that affect HCPs' well-being can be improved by understanding that they have a direct role in what was described as the 'Triple Aim', i.e. improving population health, enhancing patient experience, and reducing of costs. This has also further been expanded to include the fourth aim which is to improve work-life of the healthcare professionals and the staff. On the other hand, caregiver well-being is affected and influenced by many factors owing to their diverse roles which includes medical and instrumental tasks as well as delivering physical, fiscal, social and emotional support to their care recipients. This can in turn result in restriction on the amount of time that can be spent on their own personal lives such as work, leisure and other social activities (Maguire, Hanly, & Maguire, 2019).

Coping in Healthcare Professionals and Family Caregivers of Patients with Cancer

Coping was traditionally explained under a special category of adaptation which is seen among normal individuals when faced with unexpected and demanding situations (Costa, Somerfield and McCrae, 1996). One of the most popular models of coping, also called the psychological stress response process, given by Lazarus and Folkman (1984) defines coping to be a constant effort, both cognitive and behavioral an individual employs to deal with demands that are exceeding his/her resources and/or capacities. According to them, the stress-response process coping involves three main components, namely, the event or stressor i.e., the source of the stress; cognitive appraisal i.e., of process of assessment of the relevance of the stressor, the threat it poses, and the simultaneous evaluation of the available coping resources in an individual's repertoire and in their environment, and finally the coping mechanisms.

Coping mechanisms were traditionally classified into categories, such as problem vs emotion focused, functional vs dysfunctional, approach vs avoidance, engagement vs disengagement and so on. However, those suggested by Lazarus and Folkman (1984) were emotion focused or problem focused coping. They suggested that behaviors like planned problem-solving, or those actions aimed at eliminating or reducing the factor(s) of stress can be called as problem-focused coping (PFC). On the other hand, behaviors such as distancing, self-controlling, accepting responsibility, escape or avoidance, and positive reappraisal, which is an attempt to prevent or reduce the emotional pain or suffering caused by the stressor can be called as emotion-focused coping (EFC). A third set of coping strategies was proposed by Endler and Parker (1990), known as avoidant style of coping i.e., involving in activities that avoid the stressful situation. Carver, Scheier, & Weintraub (1989) proposed a combination of the above-mentioned coping categories, i.e., problem-focused coping (PFC), emotion-focused coping (EFC) and avoidant

coping (AC), and studied how individuals respond when confronted with challenging and stressful events in their lives. These various coping strategies were further studied and examined in the general population as well as various healthcare settings, such as patients, caregivers, and HCPs (Isikhan, Comez, & Danis, 2004; Northouse, Kershaw, Mood, & Schafenacker, 2005; Lauver, Connolly-Nelson & Vang, 2007; Lala, Sturzu, Picard, Druot, Grama, & Bobirnac, 2016). In recent years coping in HCPs such as physicians and nurses and FCGs of patients has been studied to understand the coping behaviors and strategies used by these groups in different life situations (Linn, Cope, Leake, & Yager, 1986; Mache, 2012, Lynch, Shusterb & Lobo, 2018).

The study attempts to understand the variables discussed in the above section with respect to the HCPs and FCGs of patients with cancer. While, variables such as burnout and stress have been researched among professionals, they have been studied sparsely among family caregivers. While variables such as well-being, distress and coping have been well researched among patients, they are less explored among the healthcare professionals and family caregivers. The following section presents the existing literature relevant to the study variables among both HCPs and FCGs of patients with cancer.

CHAPTER II

REVIEW OF LITERATURE

Chapter II

REVIEW OF LITERATURE

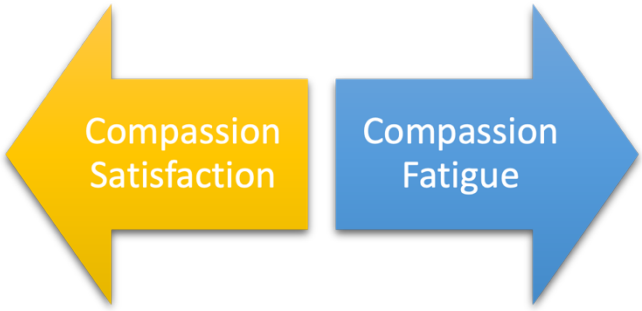
As discussed in the previous chapter, the incidence and prevalence of cancer in India and across the globe is alarming. This exponential rise in cancer cases owing most often to the advanced diagnostic procedures and awareness puts an enormous pressure on the cancer caring system, which consists of the oncology HCPs on one end and FCGs on the other end of the spectrum. This chapter includes the systematic presentation of the existing literature relevant to the study variables.

Compassion Satisfaction and Compassion Fatigue in Healthcare Professionals and Family Caregivers of Patients with Cancer

The variables CF and CS capture the negative and the positive aspects that are experienced by individuals providing care in work contexts that are characterized by pain and death. This is especially true in terms of individuals providing care to patients with cancer, inclusive of both HCPs and FCGs, as there are numerous instances of experiencing both positive as well as negative consequences of care. In the case of HCPs, this can be accounted for by the nature of their work which involves a great deal of personal interaction with the patients due to the multiple sessions of treatment and hospital stays (Vachon, 2010); and with regards to FCGs, it is due to the prolonged personal care and continued monitoring provided throughout the course of the illness, which can lead to these experiences (Lynch, & Lobo, 2012; Lynch, Shuster, & Lobo, 2018). This in turn has a toll on the patient care, the professionals themselves and the healthcare system in general (Grunfeld, Whelan, Zitzelsberger, Willan, Montesanto, Evans, 2000). It was hypothesized that the

experiences of the individuals who provide care range from CS to compassion stress and result in CF (Figley, 1995; Stamm, 2002).

Figure 2.1
The Dimensions of ProQoL representing Compassion Satisfaction and Compassion Fatigue, Positive and Negative Aspects of providing Care



As discussed in the previous section, Joinson (1992) first conjured the concept of CF and described burnout-like experiences, often seen among nurses. In many of her nurse colleagues, she observed feelings of helplessness, disengagement, anger and apathy. CF has since been defined as characterized by symptoms of BO, vicarious trauma, and STS (Thomas & Wilson, 2004).

CF was theoretically explained at length by Figley (1995). He defined it as a state of physical, psychological exhaustion and social dysfunction which occurs due to prolonged and repeated exposure to compassion stress (Figley, 1995). He poised that CF develops due to the care professional's exposure to the experiences of his or her care recipients, joined with his or her natural empathy.

Stamm (2010) later defined the construct of CF to comprise symptoms of BO as well as those of STS, to be most commonly seen among those active in the helping professions. Compassion fatigue signifies more progressed psychological disruptions, than those merely captured by the construct of BO. Although the concept of CF has been considerably well

researched among HCPs (Galiana, Arena, Oliver, Sansó, & Benito, 2017; Baqeas, Davis, & Copnell, 2021), the same cannot be said in the case of FCGs (Lynch, & Lobo, 2012; Lynch, Shuster, & Lobo, 2018).

Burnout, a concept described by Stamm (2010) to be one of the elements constituting CF, can be understood as the physical, emotional and psychological exhaustion, frustration, anger and depression that are caused by constant and prolonged exposure to stressful situations. In oncology HCPs, inclusive of physicians and nurses, BO is often the outcome of low levels of job satisfaction, deficient skills for the job at hand, lack of resources, extended periods of service, work overload, night shifts, lack of control in various aspects of the job, lack of appreciation prolonged periods of stress, poor communication and conflicts at work (Brown, Goske, Johnson, 2009; Hooper, Craig, Janvrin, Wetsel, & Reimels, 2010; Shanafelt, Boone, Tan, 2012).

While BO is the result of prolonged exposure to stressful events; STS, another component that constitutes CF, is relatively abrupt and a result of being exposed to the trauma, suffering and death of another individual (El-bar, Levy, Wald, & Biderman, 2013; Todaro-Franceschi, 2013). By definition, the trauma that one experiences from helping individuals who are traumatized or suffering can be defined as STS (Figley, 1999). Often experienced by individuals who provide care and also highly correlated with BO (Vahey, Aiken, Sloane, Clarke, & Vargas, 2004; Yoder, 2010). While both these elements of CF lead to physical, emotional and psychological exhaustion, STS closely mirrors the symptoms of post-traumatic stress, with the only difference here being, an individual is standing as the direct witness of another individual's trauma, and repeated exposure to traumatic event leads to symptoms such as being easily startled, feelings of being on the edge, avoiding situation that remind of past traumatic incidents, trouble sleeping and concentrating, irritability and an overwhelming sense of responsibility for another's suffering (El-bar, Levy,

Wald, & Biderman, 2013). This is often the case when dealing with patients with cancer. The empathy levels of the care provider towards the care recipient is hypothesized to be crucial in the care provider experiencing the trauma of the care recipient (Figley, 1995, Hinderer, VonRueden, Friedmann, McQuillan, Gilmore, Kramer, & Murray 2014). It is also suggested that with an increase in the professional's levels of empathy, there is a higher risk of developing CF. STS was significantly associated with greater exposure to death among physicians and nurses (Samson & Shvartzman, 2018). A recent review of literature gathering information from studies conducted across 11 nations, spanning from the East to the West revealed that nurses in the Asian regions reported most low levels of CS and most high levels of CF. On the other hand, lowest levels of CF and highest levels of CS were found among nurses from America and Europe (Xie et al., 2021). This might be because nurses from Asian countries reported to often experience various challenges including shortage of and misallocation of staff (Kanchanachitra et al., 2011, Khowaja, 2009, Yang et al., 2017), economically disadvantaged settings and less developed medical conditions and large population could be some of the factors leading to their higher experience of low levels of CS and high levels of CF.

CF, if persists, can lead to negatively impacting the professionals' health, including increased susceptibility to develop physical and psychological issues (Bride, Radey, Figley, 2007; Kashani, Eliasson, Chrosniak, Vernalis, 2010), more than usual consumption of substances and alcohol, lowered well-being and quality of care provided (Stamm, 2002; Shanafelt, Bradley, Wipf, Back, 2002). Moreover, when compared to other medical specialties such as intensive care unit, and nephrology, professionals working in the emergency department and oncology units were at an increased or greater risk of developing CF (Hooper, Craig, Janvrin, Wetsel, & Reimels, 2010). Studies also demonstrated that STS shares a negative relationship with CS and a positive one with

BO (Slocum-Gori, Hemsworth, Chan, et al., 2013). CF has been positively associated with psychological morbidity in HCPs (Galiana, Arena, Oliver, Sansó, & Benito, 2017). Recent reviews studying oncology HCPs, have indicated a rise in the prevalence of CF, both BO and STS, and have highlighted the increased need for interventions to help reduce their impact on them (Ortega-Campos et al., 2019).

On the other hand, CS is the positive component, which is a sense of satisfaction that an individual acquires from carrying out his or her work. According to Stamm (2002) the experience of CS is multifaceted, it includes the satisfaction one experiences by doing one's work well, sharing cordial relationships at work with workmates, having a sense of connection with their care recipients, possessing the ability to contribute to one's work and the society at large. It can be simply understood as one's 'ability to receive gratification from caregiving' (Simon, Pryce, Roff, Klemmack, 2005). There is mixed evidence regarding the intensity of CS experienced by HCPs. CS among oncology HCPs has been reported to prevail in moderate and low levels, when compared to the levels of BO and STS (Duarte & Pinto-Gouveia, 2017; Al-Majid, Carlson, Kiyohara, Faith, & Rakovski, 2018). CS can be viewed as a protective mechanism used by individuals who are exposed to components of CF and acts as a buffer to protect against the harmful effects of BO and STS (Stamm, 1999). Figley (1995) discussed that HCPs, despite being exposed to intense suffering, maintain empathy and experience lower levels of CF, because of this satisfaction and the sense of achievement due to their ability to empathize and relieve suffering without feeling emotionally overwhelmed. This is also supported by many studies which have shown an inverse relationship between the construct of CS and CF, indicating that with a rise in the levels of CS, the levels of CF (inclusive of BO and STS) stress will decrease (Slocum-Gori, Hemsworth, Chan, Carson, & Kazanjian, 2013; Alkema, Linton, & Davies, 2008). However,

recent findings suggest that despite scoring high on CF, HCPs also reported high scores on CS as well (Hinderer, VonRueden, Friedmann, McQuillan, Gilmore, Kramer, & Murray 2014; Hunsaker, Chen, Maughan, & Heaston, 2015). Studies show a significant association between the levels of CS and certain socio-demographic details such as gender, age and years of experience (Demirci, Yildirim, Ozsaran, Uslu, Yalman, & Aras, 2010; Duarte & Pinto-Gouveia, 2017; Merk, 2018).

FCGs, as discussed earlier, are an essential and an inevitable part of the cancer care system, who offer selfless services to the affected. The unpredictable nature of services provided by the caregivers in terms of the frequency and intensity of care can lead to negative outcomes such as stress, caregiver burden and CF. Although the concepts of CF and CS are well studied among professional groups, the concept has only recently been applied in the area of caregivers and is a fairly new area of research among them. Although the concept of CF is similar to the concept of caregiver burden it can be best understood as an alternative concept to it. This is because the concept of CF can capture the experiences of a caregiver during the entire process of caregiving better. This is mainly because the concept of CF encompasses two different dimensions such as BO and STS (Stamm, 2010). Compassion fatigue among FCGs can be described as a condition that occurs due to a dual process, that includes providing daily care to family members who are extremely ill or dying and at the same time being exposed to the agony and the traumatic experiences of the individuals they serve, along with experiencing their own emotional pain. Watching the distance journey of the significant person being cared, for providing support and at the same time managing the emotional pain and responsibility coupled with worry related to care provider is a complex state psychologically. The psychological response to this dual nature of stress is likely to ultimately progress to physical, psychological, spiritual, and social exhaustion.

Although a large body of research exists on the negative psychological outcomes such as caregiver burden, anxiety, depression, (Padmaja, Vanlalhruaii, Rana, Nandinee & Hariharan, 2016; Ge & Mordiffi, 2017); and positive outcomes of caregiving, like, a sense of personal growth, better health and well-being (Jones, Winslow, Lee, Burns & Zhang, 2011), satisfaction, felling gratified due to caring (Greenwood, Mackenzie, Cloud & Wilson, 2009), an effort to study these constructs in combination has been limited among FCGs. Thus, the negative aspects examined by CF in conjunction with the positive aspects of caregiving, i.e. CS (Stamm, 2010), explains the experience of caregiving in a holistic way.

Few studies which have examined CF among FCGs report significant findings, with respect to demographic details and caregiving details. A study done by Lynch, Shusterb & Lobo (2018) revealed that female caregivers scored higher on the BO and STS when compared to their male counterparts. The study also showed that various factors that could influence the caregiver's ability to carry out tasks and meet the demands of their role may be impacted and may impact the occurrence of CF. Such as employment status of the caregivers, time allocated for caregiving, caregiver's age, income and health status of the caregiver. For instance, employment status of the caregiver and the number of hours of caregiving per a week also contribute to the levels of BO and STS. As for the employment status, those caregivers who had full-time employment despite the caregiving responsibilities, had reported lower levels of BO and STS and higher levels of CS. The study also found that individuals who were involved in caregiving activities for more than 25 hours per week had experienced more BO and STS when compared to those providing care for a lesser number of hours. The age of the caregiver also seemed to contribute to the difference in the scores of CS, showing that caregivers aged 60 years and above experienced more CS. Among the other factors influencing CF and CS are the caregivers' income and health status.

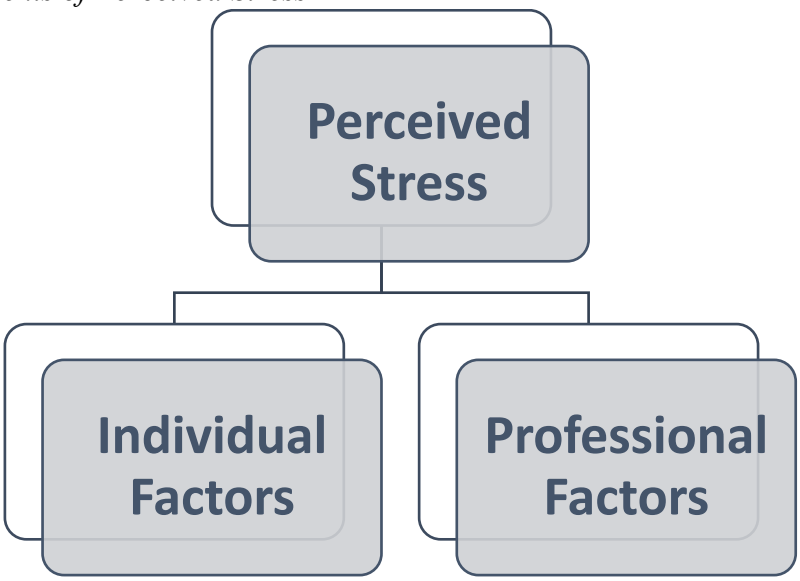
In a qualitative study conducted to understand CF among caregivers who provide care for aged family members in long-term settings, it was found that caregivers exhibited symptoms of CF. Upon examination, two main themes have emerged, according to the study such as, role engulfment, and enveloping sadness. Role engulfment included sub-themes such as 'sacrificing the self, not practicing self-care, and depleted levels of energy'. Whereas, symptoms such as 'despair, loss, experiencing hopelessness and grief' were categorized under the theme enveloping sadness (Perry Dalton, & Edwards, 2010). The scanty research in this area shows that research exploring the constructs, CF and CS among FCGs needs to be further explored as it is a fairly new and unexplored area of research.

Perceived Stress in Healthcare Professionals and Family Caregivers of Patients with Cancer

Stress in oncology HCPs and FCGs has been well studied and reported by previous research. Various factors contribute to the levels of stress in the case of oncology HCPs and can be broadly classified as individual and professional factors.

Figure 2.2

The Components of Perceived Stress



One's perception of stress, in relation to the personal aspects of his/her life, such as lack of individual capabilities, skill set and competencies, unable to effectively deal with problems at home, having a lowered sense of control over his or her life, restricted social relationships or life, can also be a few factors of stress among HCPs (Maswadi, Khader & Slaih 2019; Das, Mallick, Debnath, Biswas, & Mukherjee, 2021).

Professional factors can be work environment-related, patient-related, academic in nature, where as individual factors can be related to one's personal/family life. In oncology healthcare settings, owing to the various limiting work conditions, factors such as work overload, work timings, lack of autonomy in workplace, staffing resources, satisfaction with workplace conditions, number of inpatients and outpatients treated in a day, weekend shifts, night duties, proper assignment of work-roles, satisfaction with income, relationships with colleagues, conflicts with colleagues, problems with superiors in-charge, treatment decisions, discrimination at work place, and satisfaction with training program, in case of professionals involved in academic programs were seen as prominent factors that affect the stress levels of HCPs (McVicar, 2003; Dougherty, Pierce, Ma, Panzarella, Rodin, & Zimmermann, 2009; Pronost et al., 2012; Jasperse, Herst, & Dungey, 2014; Spiers, 2016; Leonelli, et al., 2017; as cited by Sallon, Katz-Eisner, Yaffe, & Bdolah-Abram, 2017; Maswadi, Khader, & Slaih, 2019; Hu, Jiao & Li, 2019). Other factors such as age of the HCPs, also are important, where the younger face stressors due to their work inexperience (Flynn, Hulbert-Williams, Bramwell, Stevens-Gill, & Hulbert-Williams, 2015), the older face a problem with work colleagues with regards to treatment delivery demands. In addition to the above, stress due to the gender of the professional, that is, being a female HCP, level of education, socio-economic status, marital status, being non-religious have been factors influencing

levels of stress among HCPs dealing with patients with cancer (McVicar, 2003; Sehlen, 2009; as cited by Mache, 2012; Jasperse, Herst, & Dungey, 2014; Leung, Rioseco, & Munro, 2015).

Stressors in HCPs are also affected by various patient-related factors such as being the deliverers of bad news to the patients and caregivers about the diagnosis and progress of disease, patient death and suffering, death of patient during absence of the HCPs, inappropriate prolongation of life, sudden decline in health of patient, dealing with post-op patients, relationship with the patient, strained patient-provider and/or HCP-FCGs interactions, stress due to compassion, patient and caregiver satisfaction, patients with advanced cancer, meeting patient and caregivers needs, ineffective or negligent follow-up treatment sessions (McVicar, 2003; Sehlen, et al., 2009; Ramondetta, et al., 2011; Jasperse, Herst & Dungey, 2014; Flynn, Hulbert-Williams, Bramwell, Stevens-Gill & Hulbert-Williams, 2015; Leonelli, et al., 2017; Fernández-Sánchez, 2018; Maswadi, Khader & Slaih, 2019; Hu, Jiao & Li, 2019).

Although stressors among HCPs have been categorised into individual and professional stressors, stress due to a specific event cannot be viewed separately from the stress that arises other sources such as personal or work-related stress (Lewis et al., 1994) as an individual's perceived ability to cope may be diminished and vice-versa. Moreover, elevated levels and prolonged periods of stress can lead to BO among HCPs (Toh, Ang, & Devi, 2012) making them susceptible to fatigue, insomnia, irritability, obesity, coronary diseases, diabetes; and psychological (anxiety and depression), thus compromising the overall quality of healthcare (Leonelli, et al., 2017; Grover, Sahoo, Bhalla, & Avasthi, 2018). Evidence also suggests that this can lead to an callousness and lowered levels of compassion in the HCPs, in-turn affect the interactions with the patients and caregivers, patient compliance and recovery, and patient dissatisfaction. Studies have found that

HCPs under stress were more prone to making errors of judgement, and they also showed a greater tendency to treat patients poorly (Pronost et al., 2012; à Ile-Ife, 2020).

On the other end of the caring spectrum, the FCGs, due to the nature of their often undefined roles and multidimensional nature of stressors, face difficulties from the point of diagnosis of their family member, through treatment, post-recovery which further continues until the patient is independently functional. Caregivers are affected differently based on the prognosis of the patient, disease stage, and the goals of treatment and care. Along with providing tangible patient care, caregivers also make themselves available and provide emotional and social support to the patient, often adjusting and reprioritizing their personal and/or professional commitments (Okabayashi, Sugisawa, Takanashi, Nakatani, Sugihara, & Hougham, 2008; Kulkarni, Kulkarni, Ghooi, Bhatwadekar, Thatte, & Anavkar, 2014; Kent, Mollica, Buckenmaier, & Wilder Smith, 2019). Prolonged periods of stress can thus have negative physical, psychosocial, emotional implications (Padmaja, Vanlalhruaii, Rana, Nandinee, & Hariharan, 2016; Yuen & Wilson, 2021). Previous research shows that perceived stress has been associated with various sociodemographic details such as gender, that is females being at a greater risk of experiencing stress than males, and differences in terms of age (middle-aged), level of education, low family income, degree of caregiving (providing care to the patient frequently or more often), change in employment status and the daily activities of the patient. Other patient disease aspects such as tumor grade, diagnosis and disease progression of the patient, fear of treatment outcomes, side-effects for the patient, inability to understand medical and diagnostic terminology, and duration of care have been associated with stress among FCGs (Keir, Guill, Carter, Boole, Gonzales, & Friedman, 2006; Hong, Tae, & Noh, 2012; Masa'Deh, 2017; Abuatiq, 2020). Other factors such as primary stressors during hospitalisation, faulty patient-caregiver communication patterns and maladaptive coping

mechanisms can all lead to perceiving higher levels of stress in FCGs of cancer patients (Abuatiq, 2020).

Though not thoroughly researched, evidence suggests that perceived stress in FCGs has been associated with BO, indicating that higher levels of stress can lead to caregiver burden, BO as well as STS (Hong, Tae, & Noh, 2012; Lynch, Shuster & lobo, 2018; Alliegro, 2019). Also, findings suggest that providing informal care to patients with cancer is associated with distress, depression, and fatigue (Gaston-Johansson, Lachica, Fall- Dickson, Kennedy, 2004; Kim, Baker, Spillers, & Wellisch, 2006; Keir, Guill, Carter, Boole, Gonzales, & Friedman, 2006).

Psychological Morbidity in Healthcare Professionals and Family Caregivers of Patients with Cancer

Non-specific symptoms of stress, anxiety and depression are usually referred to as psychological distress or psychological morbidity. Subjective perceptions of the global stress response can be termed as symptoms of distress (Rhodes & Watson 1987). High levels of psychological distress are indicative and can lead to psychological issues such as anxiety and depression (Cuijpers, Smits, Donker, ten Have & de Graaf, 2009). It is an area recently explored in the field of oncology, among patients, FCGs (Padmaja, Vanlalhruaii, Rana, Nandinee & Hariharan, 2016; Padmaja, Vanlalhruaii, Rana, & Kopparty, 2017), and HCPs (Davey, Sharma, Davey, & Shukla, 2019). In a recent systemic review, psychological distress as measured by general health questionnaire (GHQ) was shown to be more prevalent among those in occupational settings (including HCPs) when compared to the general population; it also increased their risk for common mental disorder (CMD) (Goodwin, Ben-Zion, Fear, Hotopf, Stansfeld, & Wessely, 2013).

It is usually expected of a medical professional to be devoid of anxieties or worries and be at a good state of mind in order to deliver quality care, to the patients. This, is however not the case as these HCPs are often affected by many factors that cause stress in the general population in addition to the inherent stressors of the demanding work and work environment. Thus they are at a higher risk of developing symptoms related to psychological morbidity or distress. Psychological distress is often an outcome of the negative aspects of the work and the constant exposure to challenging work conditions among HCPs (Dunwoodie & Auret, 2007; As cited by Veronese, Pepe, Massaiu, De Mol, & Robbins, 2017; Buhari, Ogunmodede, & Ogunmodede, 2020; Eelen, Bauwens, Baillon, Distelmans, Jacobs, & Verzelen, 2014; Chan, Ahmad, Yusof, Ho, & Krupat, 2015). A recent study has also found that many aspects of work-associated stressors were converted into psychological distress among HCPs (Davey, Sharma, Davey, & Shukla, 2019).

Among HCPs, psychological distress can affect levels of anxiety, depression, suicidality, or aggravate an underlying mental ill health and even BO (Asai, et al., 2007; Spiers, 2016). Distress was attributed to various stress inducing factors such as mentioned above as well as other sources such as systemic factors relating to increasing workloads, bureaucracy, dysfunctional relationships and abuse at work place, bullying, lack of support, and emotional isolation (Leigh-Hunt, et al., 2017). Such experiences were also reported to be key for intentions for quitting the job, having low morale and job dissatisfaction (Riley et al., 2021). Studies have also found associations of BO with increased psychological distress/morbidity (Probst & Griffiths 2007; Poulsen, Poulsen, Khan, Poulsen & Khan, 2011; Chan, Ahmad, Yusof, Ho, & Krupat, 2015). While some studies have reported the levels of psychological distress to be low among nurses when compared to doctors,

(Mache, Schoffel, Kusma, Vitzthum, Klapp, Groneberg, 2011; Ogundipe, Olagunju, Lasebikan, & Coker, 2014) there are others who have reported findings in contrast to this (Kausar, 2010).

Oncology HCPs reported much more psychological distress when compared to HCPs in other fields of medicine (Asai, et al., 2007). Psychological distress has also been linked with coping. Studies show that distress has been higher among HCPs who adopted negative coping as opposed to those who adopted positive coping to deal with distressing situations. Positive or adaptive coping was associated with fewer behavioral problems, higher self-esteem and low levels of depression symptoms (Wong, Leung & So, 2001; Loukzadeh & Bafrooi, 2013; Zhou, et al., 2017; Wang & Wang, 2019). Furthermore, factors such as acceptability and approval of others (work colleagues) have been associated with low levels of psychological morbidity (Morimoto, Shimada, & Tanaka, 2015). A study done exclusively on female doctors, revealed a prevalence of 23.8% psychiatric morbidity in the study population, and the factors such as age (being younger), relationship with colleagues, frustration and feeling angry at work, access to a maternity leave were found to be associated with psychiatric distress among them (Buhari, Ogunmodede, & Ogunmodede, 2020). Another study on radiation oncologists has reported that excessive and prolonged job stress leads to high levels of distress which in-turn can lead to errors in judgement and erosion of physician compassion, that is, leading to CF among the HCPs (Adams, Boscarino, & Figley, 2006; Imo, 2017). It was also observed that lowered levels of compassionate care from HCPs can lead to noncompliance in patients and bad treatment outcomes (Sehlen, et al., 2009).

Psychological distress among FCGs of patients has also been an extensive area of research. Research done on caregivers and non-caregivers reveals that caregivers were more significantly distressed when compared to the non-caregivers (Mackenzie, Wiprzycka, Hasher, & Goldstein, 2009), indicating an increased risk for developing clinical psychological disorders as well as

physical chronic disease (Vanderwerker, Laff, Kadan-Lottick, McColl, & Prigerson, 2005). The experience of cancer places the patients as well as the caregivers under immense psychological distress (Cassidy & McLaughlin, 2015). The impact of caring for a patient with cancer, puts the FCGS at heightened risk of developing psychological and physical disorders (Padmaja, Vanlalhruaii, Rana, Nandinee & Hariharan, 2016; Ge, & Mordiffi, 2017). The caregivers' experience of caring varies with the type and intensity of care provided to a cancer patient that varies across time.

A research study on caregivers of patients with cancer has reported that 64.7% of a study's sample experienced psychological distress and had shown symptoms of clinical disorder sufficient to render intervention. The study also found a negative relationship between psychological distress and social support received from friends or other family members, self-efficacy, resilience, optimism, and the satisfaction of communication with HCPs. Psychological distress was positively associated with caregiver burden, perceived burden and perceived stress in the study (Cassidy, McLaughlin, & Giles, 2015). Research also found that the interference of caregiving activities with valued social or personal lifestyle of the caregiver has been associated with psychological morbidity in caregivers of patients with cancer (Kim, Baker, Spillers, & Wellisch, 2006; Cameron, Franche, Cheung, & Stewart, 2002). Studies have established that the distress of caregivers of cancer patients is identical and as complex as the distress undergone by the patient himself/herself (Gaston-Johansson, Lachica, Fall-Dickson, & Kennedy, 2004; Padmaja, Vanlalhruaii, Rana, Nandinee, & Hariharan, 2016). This is very essential to understand as the risk this places on a caregiver is multifold, as along with his/her fear of losing a family member to a disease, also has to play an active role and carry out various activities demanding of a caregiver. This further puts the caregiver at a greater risk of experiencing other negative aspects of care, such as caregiver

burden, BO, STS, (Lynch, & Lobo, 2012; Lynch, Shuster, & Lobo, 2018), lowered well-being and quality of life (Padmaja, Vanlalhruaii, Rana, & Kopparty, 2017).

Coping in Healthcare Professionals and Family Caregivers of Patients with Cancer

Traditionally, coping is the third aspect of the process of stress. According to Lazarus & Folkman (1984) coping can be defined as the process of executing the response(s) after the secondary appraisal of a stressful situation. It is a dynamic process that uses various coping strategies at different stages of encountering a stressor (Stephenson, & DeLongis, 2020). The process of coping involves the use of cognitive and behavioral efforts to handle a sequence of stressful events.

Coping with stress, is a natural and an inevitable aspect of everyday life. However, coping to sudden and ongoing, unexpected, relatively traumatic incidents in one's daily life is of a particular interest for researchers. HCPs working in the field of oncology, emergency medicine, and those dealing with patients suffering from terminal illnesses, are bound to experience stressful situations as a part of the nature of their work. These stressors in-turn lead to various psycho-social symptoms such as BO, exhaustion, fatigue, depression, distress, anxiety, and CF, engendering to lowered levels of well-being and quality of life among these professionals. Ceslowitz (1989) reported that PFC was beneficial in improving one's performance as well as the health consequences of stress. A study done by Chang et al. (2006) summarizes that EFC can have negative affect on the health; it was also found that escape-avoidance coping was associated with lowered mental health among Japanese nurses.

Coping to specific stressors, such as faced by these professionals, with adaptive/positive/functional coping strategies has positive personal, professional, and social

outcomes. In HCPs coping is one of the key cognitive-behavioral aspect to alleviate psychological maladjustment among these individuals (Dorz, Novara, Sica, & Sanavio, 2003; Morimoto, Shimada, & Tanaka, 2015). A study in previous research has found that HCPs often resort to maladaptive/avoidance coping styles to deal with workplace stressors. Research conducted to enquire the coping mechanisms of emergency nurse and doctors revealed that the most frequently used coping methods among them were sleeping and smoking (Kim, Park, Lee, Cho, & Chung, 2008). In contrast, a study conducted on oncology HCPs reveals that these individuals managed stress using social support and PFC, rather than withdrawal or avoidance coping (Pronost, et al., 2012). It was found that seeking social support was positively associated with overlap of time between shift change and negatively associated to lack of time and collaboration between specialities. On the other hand, problem-solving strategies were negatively associated with number of deaths per month. Other avoidance coping strategies were associated inversely with factors such as lack of recognition and lack of inter-speciality collaboration (Pronost, et al., 2012). A study showed that adaptive coping strategies like positive reframing and active coping were positively associated with low levels of stress. Humor, neither belonging to adaptive nor maladaptive coping strategies, was associated with high stress level. Also, maladaptive coping strategies such as denial, substance use, self-blame, behavioral disengagement and venting shared a positive relationship with high levels of stress. Active coping was inversely related to stress level in HCPs (à Ile-Ife, et al., 2020). In a study conducted by Wang & Wang (2019), positive/adaptive and negative/maladaptive coping were found to be mediators in the association between perceived stress and psychological distress. While positive/adaptive coping mediated stress-distress (S-D) relationship and those HCPs who scored high on stress, had low scores on positive scores; in turn leading to increased psychological morbidity/distress. The study also indicated that higher stress

scores might make an individual to use negative coping in-turn leading to higher levels of psychological morbidity/distress. The same mediating relationship was also found between levels of BO, positive, and negative coping (Ding, et al., 2015). In addition, Partlak Günüşen, Üstün, Serçekuş, & Büyükkaya, (2019) reported that HCPs (nurses) coped with STS, a component of CF, by acquiring a new perspective on coping, that is, they actively recognized and shared positive changes to other HCPs to be examples for others who are experiencing STS.

Coping in FCGs of patients with cancer, is essentially important for the well-being of the patients, their compliance and recovery. Earlier research shows various coping patterns among FCGs and found that among the Asian FCGs of patients with cancer active coping was negatively associated with BO. Interestingly, it was also found that those caregivers who provided care 'entirely alone' also employed active coping (Hong, Tae, & Noh, 2012). While some studies found the use of dysfunctional coping mechanisms to be dominant in their sample, others found that they were minimal, for instance, Long, et al., (2021), reported that substance use was the least commonly used coping strategy among caregivers. Active coping, acceptance and positive reframing were found to be the most widely used coping strategies among them. Also, the study reported that social support was positively related with utilization of coping mechanisms, and acted as burden mitigating, and quality of life enhancing factors.

Well-being in Healthcare Professionals and Family Caregivers of Patients with Cancer

Research of well-being and positive mental health has been popularly studied in both the general population as well as the at-risk groups (Kusier & Folker, 2020). Though studies of well-being among patients have been highly prevalent in the literature, however the same cannot be stated in the case of the HCPs of these patients (Mohanty, Kabi, & Mohanty, 2019). Various

psychological issues that are negatively affecting the HCPs such as CF, stress, distress, and morbidity were reported to be high in them when they were compared to the general population (Schattner, Davidson, & Serry, 2004; Jasperse, Herst, & Dungey, 2014; Imo, 2017; Oates, Drey, Jones 2017; Oates, 2018; Mohanty, Kabi, & Mohanty, 2019). Stress has been shown to have a negative influence on the well-being and on the medical practice of professionals (Sarafis, et al., 2016). These factors in-turn have been reported to decrease the levels of well-being and diminish the positive effects of their work (Zhao, Guo, Suhonen, & Leino-Kilpi, 2016; Veronese, Pepe, Massaiu, De Mol, & Robbins, 2017; Oates, 2018). Moreover, previous studies also show that well-being plays an important role in coping and thus insulates these individuals from various potential psychological/physical issues (Huppert, 2009; Shiwani, 2009; Ahmad, et al., 2015).

In addition to the psychological issues such as stress, BO, and psychological distress, being female and having low social support were also negatively related with well-being as well as caring behaviors of the HCPs (Poulsen, Poulsen, Khan, Poulsen & Khan, 2012; Chana, Kennedy, & Chessell, 2015; Lizano, 2015; He, Turnbull, Kirshbaum, Phillips, & Klainin-Yobas, 2018; Dahlke et al., 2018). Well-being was found to be affected by levels of autonomy one experiences regarding the care he/she provides (Foster, Roche, Giandinoto, & Furness, 2020). However, it was also found that personal or trait-based factors of resilience can facilitate lowered levels of distress and thus improve well-being among the HCPs (Rothstein, McLarnon, & King, 2016; Foster, Roche, Giandinoto, & Furness, 2020; Delgado, Roche, Fethney, & Foster 2021). Oncology HCPs have also reported moderate and suboptimal levels of well-being and their well-being was predicted by resilience as well (Uzar-Özçetin, Sarıoğlu, & Dursun, 2019; Adiukwu, 2020). With relation to the occupational characteristics, recent studies show that those with a job experience of more than 1 year as a HCP showed greater levels of stress, lowered well-being and lowered satisfaction with

life (Atanes, et al., 2015). It was also found that levels of stress decrease with an increase in the number of years of work.

A study conducted by Owoc, Mańczak, Tombarkiewicz, & Olszewski (2021) showed that HCPs had high score on BO and low scores on well-being. While having higher levels of BO was attributed by the HCPs to be the main cause of making errors (self-reported errors) in their medical practice in the past three months, low scores of well-being showed that 22% of the professionals were at a risk of depression. Additionally, the study reported that 14% of the professionals admitted having suicidal thoughts. The rate of self-reported errors among these professionals was so high that a 5% of them reported to leading to the death of patients. Thus, well-being is an essential part for a HCP to fulfill his/her practice (Rose & Glass, 2006). Among those surveyed, 80% of HCPs reported that their health and well-being had a noticeable impact on the care they provide to the patients (Department of Health's Boorman Review, DoH 2009). A study conducted by Pahlevan Sharif, Ahadzadeh, & Sharif Nia (2018) showed that there was a positive association with HCPs well-being and job satisfaction (Jin & Kim, 2017) and the quality of care that they provide, indicating that the quality of the care being delivered to the patients is very much influenced by the well-being and satisfaction experienced by the HCPs. Also, positive coping strategies to manage stress promotes well-being which plays a crucial role in patient outcomes and experiences (Francis, 2013).

The health status of a caregiver, initially is similar to the general population, until the diagnosis of the illness (Maguire, Hanly, & Maguire, 2019). Being a FCG (informal) can in itself lead to decreased levels of well-being among them, due to the intensity and the nature of the tasks and several other factors (Glajchen, 2012). The wellness of a FCG of cancer patients varies across the illness trajectory (Kim, & Given, 2008). Over the years, research on caregivers' well-being has

primarily focused on the burden associated with care (Verbakel, 2014; Berglund, Lytsy, & Westerling, 2015). A meta-analysis conducted by Hodges, Humphris, & Macfarlane (2005) found that caregiver's responses to cancer were interdependent (between the caregiver and the patient) and were also affected by each other's emotional well-being, also seen in the relationship shared by HCPs and their patients. A dyadic study examining the influence of caregivers' well-being on that quality of patient care revealed that patients of caregivers with higher levels of depression, reported fair or poor perceived quality of care. Furthermore, patients of caregivers who had fair/poor self-rated health, were three times more likely to feel and report fair/poor perceived quality of care indicating that health of the caregivers is very much associated with that of the perception of quality of care of the patient (Litzelman, Kent, Mollica & Rowland, 2016).

Previous research on well-being among caregivers has linked sociodemographic factors, and found that women/females were more likely to have low level of well-being; those who had a higher level of education and were employed reported more satisfaction and well-being (Magnavita, et al., 2018; Maguire, Hanly, & Maguire, 2019). Interestingly, a meta-analysis that was conducted to bring out the differences among Asian, non-Hispanic White, African-American and Hispanic caregivers, found that Asian caregivers were at greater risk of stress, burden and psychological distress as these caregivers performed more tasks for the patient, put in more number of hours of caregiving and also used lesser formal support services than caregiver in other groups (Meyer, Liu, Nguyen, Hinton & Tancredi, 2018).

A recent study, attempting to understand if there exists an association between positive psychological appraisals, and well-being revealed that all the indicators of positive psychological appraisal such as optimism, perceived autonomy, sense of purpose, resilience and perceived social inclusion were all associated with well-being among caregivers. The study also found that despite

the caring duties, many caregivers experienced high levels of well-being, suggesting that psychological appraisals play an important and protective role among caregivers (Maguire, Hanly, & Maguire, 2019). In addition, a recent study found positive correlation between well-being and CS demonstrating that improvement of well-being increases with compassionate experiences of caregiving (Roeser, Colaianne, & Greenberg, 2018; Settineri, Frisone, Alibrandi, & Merlo, 2019). The study also showed an inverse association between BO and well-being among caregivers, findings similar to that of the HCPs (Settineri, Frisone, Alibrandi, & Merlo, 2019). Studies have also found that well-being (subjective) in FCGs of patients with cancer acts as a protective factor against psychological and physical distress (Delgado-Guay MO, Parsons, Hui, Cruz, Thorney, & Bruera, 2013; Spatuzzi, et al., 2019). Studies also show that those caregivers who had better spiritual support during the trajectory of the entire illness, showed better levels of well-being (Kim, Carver, Spillers, Crammer, & Zhou, 2011; Son, et al., 2012).

The variables and the discussion thus far demonstrate the importance of psychological health aspects of HCPs and family care deliverers which appears to be relatively less explored together. Thus, it appears important to explore psychological aspects in the contexts of both HCPs as well as FCGs.

Rationale

This study focuses on the professional and personal contributions respectively, of the HCPs and FCGs of patients with cancer. Though the two groups under research are quite different and have their own set of roles in cancer care, our study is an attempt as perhaps a first of its kind, to study both these agents of care deliverers, due to their shared care recipients. In both groups an attempt to explore same variables is done. The research aims to understand the various psycho-social issues affecting both the professional and family care deliverers, to ensure holistic care of the patients. The literature search shows a sparsity in terms of bringing together these two groups though individually the groups have been researched. The variables similarly have been studied in the groups separately or in a few combinations. The present study is thus an attempt at integrating the relevant variables to be explored in both the groups of care deliverers and identify areas where pertinent health psychological interventions may be suggested.

Research Questions

1. Is there a relationship between the dimensions of professional quality of life (Compassion Satisfaction, Burnout, and Secondary Traumatic Stress), Perceived Stress, Psychological Morbidity, Well-being, Problem-focused coping, Emotion-focused coping, and Avoidant Coping in Oncology Healthcare Professionals and Family Caregivers?

2. What are the predictors of the dimensions of professional quality of life (compassion satisfaction, burnout and secondary traumatic stress) in Oncology Healthcare Professionals and Family Caregivers?

3. Will there be a difference between the two groups of Oncology Healthcare Professionals and Family Caregivers, with respect to the dependent variables, Compassion Satisfaction, Burnout, and Secondary Traumatic Stress?

4. What is the contrasting behavior of the dimensions of Professional quality of life (Compassion Satisfaction, Burnout, and Secondary Traumatic Stress), with respect to Oncology Healthcare Professionals and Family Caregivers in light of Perceived Stress, Psychological Morbidity, Well-being, Problem-focused coping, Emotion-focused coping, and Avoidant Coping?

5. Will Perceived Stress, Psychological Morbidity, Well-being, Problem-focused coping, Emotion-focused coping, and Avoidant Coping predict the levels of Compassion Satisfaction, Burnout, and Secondary Traumatic Stress among Oncology Healthcare Professionals and Family Caregivers?

6. What does the analysis of burnout and secondary traumatic stress demonstrate in Healthcare Professionals and Family Caregivers of patients with cancer based on the qualitative responses?

Objectives of the Study

1. To examine the relationship between the dimensions of professional quality of life (Compassion Satisfaction, Burnout, and Secondary Traumatic Stress), Perceived Stress, Psychological Morbidity, Well-being, Problem-focused coping, Emotion-focused coping, and Avoidant Coping in Oncology Healthcare Professionals and Family Caregivers.

2. To examine the predictors of the dimensions of professional quality of life (compassion satisfaction, burnout and secondary traumatic stress) in Oncology Healthcare Professionals and Family Caregivers.

3. To understand the difference between the two groups of Oncology Healthcare Professionals and Family Caregivers, with respect to the dependent variables, Compassion Satisfaction, Burnout, and Secondary Traumatic Stress.

4. To extract the contrasting behavior of the dimensions of Professional quality of life (Compassion Satisfaction, Burnout, and Secondary Traumatic Stress), with respect to Oncology Healthcare Professionals and Family Caregivers in light of Perceived Stress, Psychological Morbidity, Well-being, Problem-focused coping, Emotion-focused coping, and Avoidant Coping.

5. To predict the levels of Compassion Satisfaction, Burnout, and Secondary Traumatic Stress with respect to Oncology Healthcare Professionals and Family Caregivers in the light of Perceived Stress, Psychological Morbidity, Well-being, Problem-focused coping, Emotion-focused coping, and Avoidant Coping.

6. To critically analyze the perceptions of burnout and secondary traumatic stress in Oncology Healthcare Professionals and Family Caregivers based on the qualitative responses.

Hypotheses of the study

1. There will be a relationship between the dimensions of professional quality of life (Compassion Satisfaction, Burnout, and Secondary Traumatic Stress), Perceived Stress, Psychological Morbidity, Well-being, Problem-focused coping, Emotion-focused coping, and Avoidant Coping in Oncology Healthcare Professionals and Family Caregivers.

2. Perceived Stress, Psychological Morbidity, Well-being, Problem-focused coping, Emotion-focused coping, and Avoidant Coping will significantly predict dimensions of professional quality of life (Compassion satisfaction, Burnout and Secondary Traumatic Stress) in Oncology Healthcare Professionals and Family Caregivers.

3. There will be a difference between the two groups of Oncology Healthcare Professionals and Family Caregivers, with respect to the dependent variables (Compassion Satisfaction, Burnout, and Secondary Traumatic Stress).

4. There will be a contrasting behavior in the dimensions of Professional quality of life (Compassion Satisfaction, Burnout, and Secondary Traumatic Stress), with respect to Oncology Healthcare Professionals and Family Caregivers in light of Perceived Stress, Psychological Morbidity, Well-being, Problem-focused coping, Emotion-focused coping, and Avoidant Coping.

5. Perceived Stress, Psychological Morbidity, Well-being, Problem-focused coping, Emotion-focused coping, and Avoidant Coping will predict the levels of Compassion Satisfaction, Burnout, and Secondary Traumatic Stress in Oncology Healthcare Professionals and Family Caregivers.

CHAPTER III

METHOD

Chapter III

METHOD

The plan and design of the study have been explained in this chapter. This chapter includes the general characteristics of the participants in the study, research tools administered in the study, the protocol of the study, procedures involved in data collection, and details of data analysis employed in the study.

Plan and Design

The study constituted two phases, such as phase I and phase II. The first phase (phase I) of the study included the use of standardized psychological measures to acquire quantitative data from oncology healthcare professionals (inclusive of doctors and nurses working in the oncology healthcare) and family caregivers of patients with cancer, through convenience sampling. The first phase explored the levels of compassion satisfaction, compassion fatigue (burnout and secondary traumatic stress), perceived stress, psychological morbidity, well-being and coping in oncology healthcare professionals and family caregivers. Based on the findings of phase I, the second phase (phase II) of the study was designed to acquire qualitative data from the study participants. The study employed a quantitative led qualitative sequential exploratory mixed method design.

Participants

The participants recruited for the study included oncology healthcare professionals and family caregivers. The participants were approached in various cancer hospitals located in the city of Hyderabad. The hospitals from which data was collected were one government hospital and three corporate hospitals.

Inclusion criteria for professional staff: Oncology healthcare professionals, doctors and nurses working in the field of oncology healthcare for more than a year were included in the study.

Exclusion criteria for professional staff: Oncology healthcare professionals providing palliative/end-of-life care and those with a history of mental illness were excluded from the study.

Inclusion criteria for caregivers: Caregivers who were providing care to patients with cancer for more than a year were included in the study.

Exclusion criteria for caregivers: Caregivers below the age of 18, caregivers of terminal patients i.e. those in stage IV of cancer and those individuals having a history of mental illness were excluded from the study.

Sociodemographic details of the healthcare professionals, occupational characteristics of the healthcare professionals, sociodemographic details family caregivers, caregiving experience details of the family caregivers, and patient sociodemographic and disease details are presented in the following tables.

Table 3.1

Sociodemographic Details of the Oncology Healthcare professionals

Sociodemographic Details of HCPs (n=153)		
		%(n)
Gender	Male	26.9 (42)
	Female	73.1 (114)
Age	20-29	37.18 (58)
	30-39	37.82 (59)
	40-49	13.46 (21)
	50-59	11.54 (18)
Marital Status	Unmarried	48.1 (75)
	Married	48.1 (75)
	Separated/ Widow(er)	3.8 (3)
Socio-economic Status (SES)	300,000-500,000 (per annum)	2.6 (4)
	500,001-700,000 (per annum)	51.3 (80)
	700,000-10,00,000 (per annum)	28.8 (45)

	Above 10,00,000 (per annum)	17.3 (27)

Table 3.2

Occupational Characteristics of the Oncology Healthcare Professionals

Occupational Characteristics of the Healthcare Professionals (n=153)		
		%(n)
Position at Work	Nurses	51.6 (79)
	Oncologists	48.3 (74)
Years of Experience	1-5 years	52.56 (82)
	6-10 years	22.44 (35)
	11-15 years	5.13 (8)
	16-20 years	7.69 (12)
	21-25 years	5.77 (9)
	26-30 years	4.49 (7)
	31-35 years	1.92 (3)
No. of work hours per day	5hrs	7.7 (12)
	6hrs	40.4 (63)
	7hrs	1.9 (3)
	8hrs	12.2 (19)
	10hrs	32.7 (51)
	12hrs	5.1 (8)
No. of hours of night duties	None	9.62 (15)
	1-6hrs	30.13 (47)
	7-12hrs	25.64 (40)
	13-18hrs	5.77 (9)
	30hrs	28.85 (45)
Control over work timings	Yes	37.2 (58)
	No	62.8 (98)
Choice on work timings	Accepted	44.9 (70)

	Not Accepted	55.1 (86)
Work beyond work timings	Yes	78.8 (123)
	No	21.2 (33)
No. of hours beyond work	None	21.2 (33)
	1-4hrs	69.2 (108)
	5-8hrs	9.6 (15)
Extra hours per week	None	21.2 (33)
	1-5hrs	55.1 (86)
	6-10hrs	23.7 (37)

Table 3.3

Sociodemographic Details of the Family Caregivers

Sociodemographic Details of FCGs (n=156)		
		%(n)
Gender	Male	46.8 (73)
	Female	53.2 (83)
Age	18-34	41.0 (64)
	35-49	30.1 (47)
	50-64	21.8 (34)
	65&Older	7.1 (11)
Marital Status	Unmarried	17.9 (28)
	Married	75.0 (117)
	Separated	7.1 (11)
	Widow(er)	64.7 (101)
Socio-economic Status (SES)	Below 100,000 (per annum)	64.7 (101)
	100,000-200,000 (per annum)	34.0 (53)
	Above 10,00,000 (per annum)	2 (1.3)

Table 3.4

Caregiving Details of Family Care Deliverers

Caregiver Details of FCGs (n=156)		
		%(n)
Relationship with patient	Family	94.9 (148)
	Extended Family	5.1 (8)
Duration of care	1-2 years	84.0 (131)
	3-4 years	9.6 (15)
	5 years & more	6.4 (10)
Type of care being provided	Primary	85.9 (134)
	Secondary	14.1 (22)
Change in employment status	Yes	76.9 (120)
	No	23.1 (36)
Other caregivers	No caregiver	60.3 (94)
	Close Fam/Extend Fam	39.7 (62)

The sociodemographic and disease details of the patients whose caregivers were approached are presented in table 3.5, to maintain consistency.

Table 3.5

Personal Details of the Cancer Patients

Personal Details of the Cancer Patients (n=156)		
		%(n)
Gender of patient	Male	32.1 (50)
	Female	67.9 (106)
Age of patient	20-30	6.4 (10)
	31-40	14.1 (22)
	41-50	26.9 (42)
	51-60	36.5 (57)
Cancer Stage	61-70	16.0 (25)
	Stage-I	17.3 (27)
	Stage-II	49.4 (77)
	Stage-III	33.3 (53)

Research Instruments

In this study, data was collected using a demographic data form to record the participants' details and five standardized research instruments. The study administered the following measures: Professional Quality of Life (ProQoL-V5, Stamm, 2010), Perceived Stress (Cohen, 1994), General Health Questionnaire (GHQ-12) (Goldberg, 1978), WHO-5 Well-being Index (WHO, 1998) and Brief COPE Inventory (Carver, 1997) were used in the study. A few questions in the Professional Quality of Life Scale (ProQoL-V5) were modified for the administration upon the caregivers of patients with cancer. Every research measure was translated and back translated into Telugu as per the procedure by different experts, for participants' convenience and better understanding of the

questionnaires. The instruments used in the study and their Telegu translations are appended to this document (Appendix A).

The sociodemographic details forms of the participants; the description, scoring procedures and psychometric properties of the research measures are detailed below:

Demographic Data Form

Details of Oncology Healthcare Professionals: This form was designed to gather basic demographic details of the oncology healthcare professionals as well as their occupation characteristics which are shown in Table 3.1 and Table 3.2 respectively. (Appendix A12).

Details of Family Caregiver: This form also was designed to procure basic demographic details of the caregivers, details of the caregiving experiences and patient details (also collected from the caregivers), these are depicted in Table 3.3, Table 3.4 and Table 3.5 respectively. (Appendix A13).

Professional Quality of Life (ProQoL-V5)

The Professional Quality of Life (ProQoL-V5, Stamm, 2010), was developed by Stamm (2010). It is a self-administered, 30 item scale used to measure compassion satisfaction (CS), burnout (BO) and secondary traumatic stress (STS) among those individuals who provide services and/or care to others at the time of a traumatic or stressful event or later. The questionnaire requires the participants to rate the frequency of experiencing both positive (CS) and negative aspects (BO & STS) of their work (help) as an oncology healthcare professional or caregiver, in the past 30 days. Although the scale was used among professionals, it has also adopted to be used among caregivers in previous research (Lynch, Shuster & Lobo, 2018). In this study, the scale was adopted to be administered among family caregivers of patients with cancer to explore and understand the

constructs of CS, BO and STS. The measure has been appended to this document (Appendix A2). The ProQoL is measured on a 5-point Likert scale. It measures compassion satisfaction and compassion fatigue. The compassion fatigue construct is measured by two separate subscales, burnout and secondary traumatic stress. There are three sub-scales, which have 10 items each namely, CS, BO & STS. There is no total or composite score for the ProQoL. After reversing Five-items on the scale, the raw scores for each subscale were computed. The raw scores were converted to Z scores, and then converted into 't' scores using a raw score mean of 50 and a raw score standard deviation of 10, as instructed in the scale manual. A new 't' score variable was added for each subscale. A minimum score of 10 and a maximum score of 50 can be obtained on each of the subscales. Obtaining a higher score on the subscales indicates a greater incidence of the construct being measured. The scale also allows for the categorisation of scores, low levels of CS, BO and STS for scores of 43 or less; average (medium) levels of CS, BO and STS for scores around 50; and high levels of CS, BO and STS for scores for scores of 57 and more. The subscales have good reliability and a Cronbach's alpha value of 0.88, 0.75 and 0.81, respectively for CS, BO and STS subscales.

Perceived Stress

The perceived stress scale, is a 10-item scale developed by Cohen, Kamarck, & Mermelstein (1983). It measures the perception of stressors in an individual's life (Cohen, 1994). The items of this scale were developed to measure and understand how uncontrollable, unpredictable and burdensome the participants perceive their lives to be. The items of the scale include those about daily hassles, occurrence of major events in life, and also notable changes in coping within the past one month of their lives. It is a 4-point Likert scale where 0 = Never and 4

= Very often. The scale yields a score range of 0 to 40. The scale requires items 4, 5, 7, 8 to be reverse scored to obtain a composite score of the scale. Higher the score on a scale, higher the level of stress. The Cronbach's alpha value of the scale is 0.67.

General Health Questionnaire

The questionnaire has been designed by Goldberg (1978). The instrument is a 12-item questionnaire that is self-administered which has been designed to detect psychological morbidity among the participants. The GHQ was originally a 60-item scale which was later reduced to a 12 items version to ensure feasibility of administration (Goldberg, 1988) to measure psychological morbidity. The GHQ-12 asks questions about how an individual relates to his or her personal life over the past few weeks. The items in the questionnaire are worded to comprise six positive and six negative items enquiring various aspects related to an individual's life. Scored on a 4-point Likert scale, the questionnaire yields a score range of 0 to 36. Although some studies have applied a dichotomous scoring method (0,0,1,1), this study has scored the items on a scale on 4-point Likert scale of 0–3 as this provides improved power and better scope for multivariable analysis. Higher scores indicate more distress/morbidity. The scoring suggests categories of normal (for score of 11 or 12), evidence of distress/morbidity (for scores more than 15) and severe problems with psychological distress/morbidity (for scores more than 20). While several studies report the questionnaire as a two dimensional or three-dimensional measure, the present study will be adhering to the single dimension of psychological health as prescribed by the tool developers.

WHO Well-being Index

The WHO-5 Well-being Index was developed by the Psychiatric Research Unit, Frederiksberg General Hospital, Hollered, Denmark, a WHO Collaborating Centre for Mental Health (WHO, 1998). The WHO-5 well-being index was originally derived from a 10-item scale (Bech, Gudex, Staehr Johansen, 1996) which was in turn obtained from a 28-item scale (Warr, Banks, Ullah, 1985). This short 5-item version of the scale has been widely used to measure well-being. All the 5 items on the scale are positively worded and designed to enquire about an individual's positive mood, levels of vitality and general interests. The extent of experiencing these aspects in the past 2 weeks was captured. The WHO-5 well-being index is scored on a 6-point Likert scale ranging from 0 (At no time) to 5 (All the time). A raw score ranging from a minimum of 0 to a maximum of 25 is generated and is then multiplied by 4 which gives a final composite score with a minimum score of 0 representing worst well-being and a maximum of 100 representing best well-being. The Cronbach's alpha value of the instrument is 0.84, indicative of good internal consistency.

Brief COPE

This instrument was developed by Carver (1997). The 28-items brief version has been derived from the original 60-item scale which has been developed by Carver, Scheier & Weintraub (1989). The respondents are asked to answer according to the extent and frequency of usage of the various ways of coping mentioned in the inventory. It aims to examine the various ways of coping employed by an individual in the face of stressful situations. The instrument has three dimensions, namely problem-focused coping (PFC), emotion-focused coping (EFC), and avoidant coping (AC). Each dimension is characterized by various facets of coping. For instance, PFC includes the

facets of active coping, use of information support, positive reframing and planning (Items 2, 7, 10, 12, 14, 17, 23, 25). A high score on PFC indicates the aims and efforts of an individual to change the stressful situation he or she is facing.

Likewise, EFC includes emotional support, venting, humor, acceptance, religion and self-blame (Items 5, 9, 13, 15, 18, 20, 21, 22, 24, 26, 27, 28). Greater scores on this subscale depict efforts of coping aimed at regulating and managing emotions associated with the stressful situation. Although higher or lower scores in this dimension may not be associated with psychological health or psychological ill health, the score gives us a general and wider information about the participants' coping styles.

The third sub-scale, AC entails the facets of self-distraction, denial, substance use and behavioral disengagement (Items 1, 3, 4, 6, 8, 11, 16, 19). A higher score on this subscale indicates the respondents' efforts to disengage from a stressful situation or stressor, which can be both physical and/or cognitive in nature. Low scores on this subscale are typically indicative of adaptive coping.

The Brief COPE is scored on a 4-point Likert scale where '1' = "I have not been doing this at all" to '4' = "I have been doing this a lot". The scale does not yield a composite score, rather the totals of each dimension are calculated separately. The instrument has a good internal consistency with a Cronbach's alpha value of 0.82

Procedure

The procedure followed to conduct this study is detailed in the paragraphs below:

Ethical Clearance and Identification of data collection sites: Before initiating the data collection for the pilot study, ethical clearance from the Institutional Ethics Committee, University

of Hyderabad was obtained (Appendix B1). As all the scales selected for the study were readily available in the public domain, no permissions were taken to access/buy the tools. Following the selection of research tools and the approval of the ethics committee, the tools were then translated and back translated into the regional language as necessary, Telugu, for the convenience of the participants. This was followed by identification of cancer hospitals and hospitals with oncology departments for the commencement of data collection. The investigator then sought necessary permissions from the respective hospital administrations as per their procedures and procured approvals to collect data from their healthcare staff and caregivers of patients with cancer.

Pilot Study: A pilot study was conducted to ensure the effectiveness of the design, to check the availability of the sample and to explore the feasibility of the research instruments to be used in the main study. Once the aforementioned conditions were met, the main study commenced.

Main Study (Phase I): For the main study, data was collected from 153 oncology healthcare professionals and 156 caregivers of patients with cancer.

The Process of Recruitment: The participants who met the criteria were selected from the hospitals where the permission for data collection was approved through required procedures. Convenience sampling method was used. The participants were approached by the investigator and rapport was established. Further, the investigator explained the relevance of the study as well as the participant's role in the study to the participants individually. An information sheet containing the details of the study such as its purpose, the aim, the risk of psychological discomfort which may arise during the process of research enquiry, data confidentiality and the right to withdraw from participating in the study at any given point in time, was also given to the participants (Appendix B2 and B4). For those who do not/cannot read, a detailed explanation of the above in local language was provided to seek informed consent. Once the participants

understood his/her role in the study and consented to participate in the study, they were asked to sign/give thumb impressions on the informed consent form (Appendix B2 and B4). The participants were then given or read out a demographics form, followed by the measures used in the study, namely, Professional quality of life scale (ProQoL-5), Perceived stress scale (PSS-10), General health questionnaire (GHQ-12), WHO-5 Well-being index and Brief COPE inventory.

The participants were requested to fill the questionnaires and in the case of oncology HCPs, owing to their busy schedules enough time as required for administration was given, the researcher personally administered the tools of measurement. Whenever and to whoever necessary the researcher personally read out the items and obtained responses. In the case of the caregivers, who could read and write, while some filled the questionnaires in the presence of the investigator, for some, the investigator had administered the questionnaires orally to gather the data/information as described in the preceding portion. The researcher was available throughout for any clarification. The investigator had communicated in English as well as regional languages in the process of the procurement of data. Any doubts or questions during the process of filling up the questionnaires were clarified and the participants were debriefed after the completion of the study. Owing to the pandemic conditions, it took a long time to obtain above data.

Main Study (Phase II): Basing on the results of the phase I, individual responses regarding various significant quantitative findings were captured through interviews. Questions on personal experiences and perceptions of CF (inclusive of BO and STS) was asked. The data was collected from 10 HCPs (inclusive of oncology nurses and oncologists) and 10 FCGs for the second phase of the study. The sample for the phase II was subject to availability and willingness of the respondents in the case of HCPs and FCGs. Subject mortality was also considered. Owing to pandemic conditions, it was not possible to obtain a larger sample due to practical difficulties and

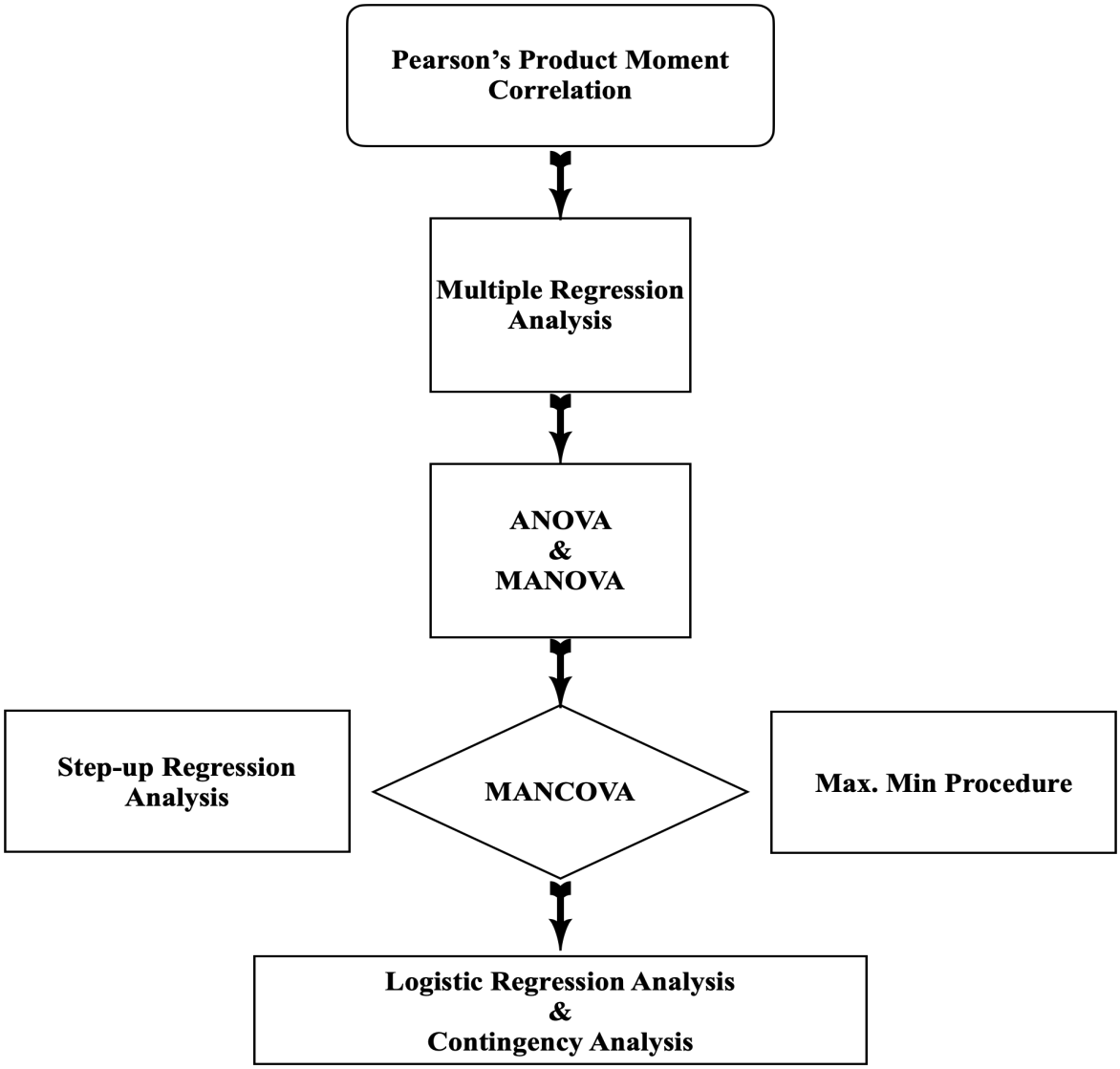
troubles of caregivers and busy schedules and nonavailability of HCPs for further qualitative assessment of phase II.

Statistical Data Analysis

Data analysis was carried out using the IBM SPSS v.25.0. Descriptive statistics and inferential statistics were computed. Pearson's product moment correlation (r), Multiple regression analysis, Analysis of variance (ANOVA), Multivariate analysis of variance (MANOVA) were also used. Furthermore, Multivariate analysis of covariance (MANCOVA), was carried out to facilitate Step-up regression analysis and Max.Min procedure. Logistic regression analysis and contingency analysis were also conducted.

Figure 3.1

Flow of the Statistical Analysis



CHAPTER IV

RESULTS

Chapter IV

RESULTS

The study initially aimed to understand the relationship between the dimensions of Professional quality of life (ProQoL) and the various psychological variables considered in the study, namely, perceived stress, psychological morbidity, well-being, problem-focused coping (PFC), emotion-focused coping (EFC), and avoidant coping (AC). Further on, multiple linear regression was conducted taking the dimensions of ProQoL such as compassion satisfaction (CS), burnout (BO) and secondary traumatic stress (STS) as three separate dependent variables and the psychological variables such as perceived stress, psychological morbidity, well-being, PFC, EFC and AC as the independent variables. The study also aimed at understanding the differences in the oncology healthcare professionals (HCPs) and family caregivers (FGs) with respect to the dimensions of ProQoL. To achieve this, the three dimensions of ProQoL, were taken as the dependent variables and the 'type of caregiver' (HCPs and FGs) as the independent variable, to compute univariate analysis, i.e. Analysis of variance (ANOVA) and multivariate analysis i.e. Multivariate analysis of variance (MANOVA).

Since the primary objective of the study was to quantify the effects of and extract the contrasting behavior of the dimensions of ProQoL, with respect to the various psychological variables such as perceived stress, psychological morbidity, well-being, PFC, EFC and AC, in oncology HCPs and FCGs, multivariate analysis of covariance (known as MANCOVA) was computed. For MANCOVA, the 'types of caregivers' (HCPs and FCGs) served as the independent variable, the dimensions of ProQoL (CS, BO and STS) were considered to be the dependent

variables and the psychological variables (perceived stress, psychological morbidity, well-being, PFC, EFC and AC as the covariates.

Derived from the R Squared values obtained from the MANCOVA, Step-up Regression Analysis was conducted to obtain the best models for the prediction of the dimensions of ProQoL, by employing the "Max.Min Procedure". The study also planned to predict the levels of CS, BO, and STS with respect to HCPs and FCGs in the light of perceived stress, psychological morbidity, well-being, PFC, EFC, and AC. Accordingly, logistic regression analysis and contingency analysis were also conducted to achieve this objective. From qualitative data, themes were evolved. The quantitative results of the study are reported in the order of the objectives, sequentially, followed by the qualitative findings.

Objective 1

For the first objective of the study Pearson's product moment correlation was employed to find out the relationships between dimensions of ProQoL and the other psychological variables considered in the study, namely, perceived stress, psychological morbidity, well-being, Problem-focused coping (PFC), Emotion-focused coping (EFC), and Avoidant coping (AC).

Table 4.1

The correlations between the dimensions of ProQoL and the other study variables in the combined sample of Oncology HCPs and FCGs (n=309)

Variables	CS	BO	STS	WB	PS	PM	PFC	EFC	AVC
Compassion Satisfaction (CS)	1	**-.542****	**-.149****	**.244****	**-.354****	**-.193****	**.332****	**.130***	**-.227****
Burnout (BO)		1	**.568****	**-.505****	**.547****	**.499****	**-.301****	-0.055	**.421****
Secondary Traumatic Stress (STS)			1	**-.377****	**.419****	**.464****	**-.179****	0.095	**.366****
Well-Being (WB)				1	-.644**	-.674**	.343**	0.028	-.269**
Perceived Stress (PS)					1	.730**	-.248**	.187**	.280**
Psychological Morbidity (PM)						1	-.445**	0.096	.400**
Problem-Focused Coping (PFC)							1	.264**	-.359**
Emotional-Focused Coping (EFC)								1	.36**
Avoidant Coping (AC)									1

Note. *= p<.05, **= p<.01, ***= p<.001.

Table 4.1 depicts the correlation between the dimensions of ProQoL, (CS, BO, STS) and perceived stress, psychological morbidity, well-being, PFC, EFC, and AC.

The variable CS had a significant negative correlation with perceived stress (r = .35, p < .01), psychological morbidity (r = .19, p < .01), and AC (r = .23, p < .01). This implies that as perceived stress, psychological morbidity and AC increase, the score of compassion satisfaction

decreases and vice-versa. The variable CS also shared a significant positive correlation with well-being ($r = .24$, $p < .01$), PFC ($r = .33$, $p < .01$), and EFC ($r = .13$, $p < .05$). This implies that as PFC and EFC increase, the scores of CS also increased.

With respect to BO, there was a significant negative correlation with well-being ($r = .51$, $p < .01$), and PFC ($r = .30$, $p < .01$), implying as well-being and PFC increase, the score of BO decrease and vice-versa; while it shared a significant positive correlation with perceived stress ($r = .54$, $p < .01$), psychological morbidity ($r = .50$, $p < .01$), and AC ($r = .42$, $p < .01$). This explains that as perceived stress, psychological morbidity, and AC increase, the scores of BO also increase. However, there was no significant relationship found between burnout and EFC.

Similar, STS had a significant negative correlation with well-being ($r = .38$, $p < .01$), and PFC ($r = .18$, $p < .01$), implying as well-being and PFC increase, the score of STS decreases and vice-versa; while it shared significant positive correlations with perceived stress ($r = .42$, $p < .01$), psychological morbidity ($r = .46$, $p < .01$), and AC ($r = .37$, $p < .01$). This implies that as perceived stress, psychological morbidity, and AC increase, the scores of STS also increase. However, there was no significant relationship found between STS and EFC.

Significant correlations were found between the dimensions of ProQoL. The results show that CS shared a significant negative relationship with both BO ($r = .54$, $p < .01$) and STS ($r = .15$, $p < .01$), suggesting that as CS increases the scores on BO and STS decrease and vice-versa. It was also found that BO and STS shared a significant positive correlation ($r = .57$, $p < .01$), implying that the increase of one variable will also increase the other.

Moreover, Table 4.1 also shows significant correlations between the various psychological variables in the study. Well-being shared a significantly negative correlation with perceived stress ($r = .64$, $p < .01$), psychological morbidity ($r = .67$, $p < .01$), and AC ($r = .27$, $p < .01$). Well-being

also shared a significantly positive correlation with PFC ($r = .34$, $p < .01$), however, there was no significant correlation with EFC. While, perceived stress shared a positive correlation with psychological morbidity ($r = .73$, $p < .01$), EFC ($r = .19$, $p < .01$) and AC ($r = .28$, $p < .01$), it was significantly negatively correlated with PFC ($r = .25$, $p < .01$). Psychological morbidity shared a significantly negative correlation with PFC ($r = .46$, $p < .01$), and positively with AC ($r = .40$, $p < .01$). While well-being shared a significantly positive correlation with PFC ($r = .34$, $p < .01$). There was no significant relationship shared between psychological morbidity and EFC. While PFC was significantly negatively correlated with AC ($r = .36$, $p < .01$) and positively with emotion focused coping ($r = .26$, $p < .01$); EFC shared a significant positive correlation with AC.

Objective 2

In order to find out the second objective, which sought to examine the predictors of the dimensions of ProQoL (CS, BO & STS) in HCPs and FCGs, multiple regression analysis was conducted by considering the dimensions of ProQoL as criterion or the dependent variables and the significantly correlated psychological variables as the predictors or independent variables.

The resulted significant model for the criterion CS is thus presented in table 4.2. It may be observed from the table 4.2, that perceived stress, psychological morbidity, Problem-focused coping (PFC), Emotion-focused coping (EFC), and Avoidant coping (AC) to be the contributors of CS. This model explained a variance of 26.7% in CS, R^2=.267, $F(6,302) = 18.36$, $p < .001$. This shows that, apart from well-being, other psychological variables such as psychological morbidity ($\beta = .38$, $p <.001$), PFC ($\beta = .26$, $p <.001$), and EFC ($\beta = .17$, $p <.001$), positively predicted CS, while perceived stress ($\beta = -.54$, $p <.001$), and AC ($\beta = -.17$, $p <.001$), negatively predicted CS.

Table 4.2

Multiple Regression Analysis for variables predicting Compassion Satisfaction

	B	***SEB***	***β***	***t***
Perceived Stress	-.81	.17	-.54	-6.96***
Psychological Morbidity	.57	.13	.38	4.39***
Well-being	.003	.027	.008	.110
Problem-Focused Coping	.63	.15	.26	4.12***
Emotional-Focused Coping	.35	.12	.17	2.95**
Avoidant Coping	-.55	.19	-.17	-2.93**
SE			5.003	
R^2			.267	
C			41.88	
F			18.36***	

Note. *1. B=Unstandardized beta coefficient, SEB=Standard Error of Beta, β= Standardised beta coefficient, t=t-test, SE= Standard Error of the estimate, R2= Variance, C=Constant, F=Fstatistic*
*2. *= p<.05, **= p<.01, ***= p<.001.*

The resultant significant model for the criterion BO is shown in table 4.3. From Table 4.3, it may be observed that perceived stress, well-being, and AC to be the contributors of BO. This model explained a variance of 40.8% in BO, R^2=40.8, F(5,303) = 41.74, p < .001. The multiple regression analysis revealed that, perceived stress (β = .34, p <.001), AC (β = .25, p <.001), positively predicted BO while well-being (β = -.21, p <.001), negatively predicted BO.

Table 4.3

Multiple Regression Analysis for variables predicting Burnout

	B	***SEB***	***β***	***t***
Perceived Stress	.56	.11	.34	4.95***
Psychological Morbidity	-.03	.13	-.02	-.26
Well-being	-.08	.03	-.21	-3.32***
Problem-Focused Coping	-.17	.14	-.06	-1.21
Avoidant Coping	.89	.17	.25	5.16***
SE			5.70	
R^2			.408	
C			37.71	
F			41.74	

Note. *1. B=Unstandardized beta coefficient, SEB=Standard Error of Beta, β= Standardised beta coefficient, t=t-test, SE= Standard Error of the estimate, R2= Variance, C=Constant, F=Fstatistic*
*2. *= p<.05, **= p<.01, ***= p<.001.*

The resulted significant model for the criterion STS is presented in Table 4.4. It may be observed from the table 4.4, that psychological morbidity and AC to be the contributors of STS. This model explained a variance of 27.6% in STS R^2=27.6, F(5,303) = 23.09, p < .001. The result of the analysis showed that, the psychological variables such as psychological morbidity (β = .25, p <.01), and AC (β = .23, p <.001) positively predicted STS, while others did not significantly predict STS.

Table 4.4

Multiple Regression Analysis for variables predicting Secondary Traumatic Stress

	B	***SEB***	***β***	***t***
Perceived Stress	.24	.13	.14	1.81
Psychological Morbidity	.44	.15	.25	2.95**
Well-being	-.038	.031	-.086	-1.22
Problem-Focused Coping	.22	.16	.08	2.95
Avoidant Coping	.86	.20	.23	4.26***
SE			5.70	
R^2			.276	
C			26.23	
F			23.09	

Note. *1. B=Unstandardized beta coefficient, SEB=Standard Error of Beta, β= Standardised beta coefficient, t=t-test, SE= Standard Error of the estimate, R2= Variance, C=Constant, F=Fstatistic*
*2. *= p<.05, **= p<.01, ***= p<.001.*

Objective 3

As a part of the third objective, the study attempted to find out the differences between the two groups of caregivers HCPs and FCGs, with respect to the dimensions of ProQoL. A one-way between groups ANOVA was computed to understand the difference between the two groups, with respect to the dependent variables (CS, BO, and STS). The 'type of caregiver' (HCPs and FCGs) was the independent variable, while CS, BO, and STS acted as the dependent variables. Separate analyses were carried out for each of the three dependent variables. Prior to conducting a ANOVA, assumptions such as criteria for normality, Levene's equality of variance and major assumptions were met. The groups were compared by means of the one-way ANOVA, in terms of the dependent variables, CS, BO, and STS. Table 4.5 shows that there was a statistically significant difference in the levels of BO F(1,307) = 4.917, $P = < 0.05$, there was a statistically significant difference in the

groups of HCPs and FCGs. However, with regards to CS F(1,307) = 1.798, *P* = > 0.05 and STS F(1,307) = 0.506, *P* = > 0.05 there was no significant difference observed between the two groups.

Table 4.5

One-way ANOVA for Compassion Satisfaction, Burnout, and Secondary Traumatic Stress for two groups (Mean, standard deviation, F, and η^2 values)

	M(SD)		F (1,307)	η^2
	HCPs	**FCGs**		
Compassion Satisfaction	50.99 (9.04)	49.61 (9.09)	1.798	.006
Burnout	52.33 (10.37)	49.83 (9.39)	**4.917***	.016
Secondary Traumatic Stress	51.03 (10.85)	50.19 (10.03)	.506	.002

Note. *$p < .05$, $\eta 2$ = Eta Squared

As the univariate analysis of ANOVA found a statistically significant difference only with respect to the dependent variable BO, a multivariate analysis, MANOVA, was also conducted to investigate the differences as MANOVA evaluates the mean differences on the dependent variables (CS, BO & STS) simultaneously. Prior to conducting MANOVA, assumptions such as criteria for normality, Levene's equality of variance and important assumptions were also met, thus suggesting the appropriateness of the MANOVA.

Table 4.6

Multivariate analysis of variance (MANOVA) of the type of caregiver in relation to the dependent variables CS, BO and STS

	F	p	ηp2
Compassion Satisfaction	1.799	0.180	0.006
Burnout	4.917	**0.027***	0.016
Secondary Traumatic Stress	0.506	0.477	0.002

Note: *$p < .05$, $\eta p2$ = Partial Eta Squared

Table 4.6 shows the results of one-way MANOVA for the type of caregiver in relation to the dependent variables CS, BO and STS. A significant effect was observed only for the dependent variable BO $F(1, 307) = 4.917$, $p < .0.05$; $\eta p2 = .016$, while the other dependent variables, CS and STS did not demonstrate a significant effect.

Objective 4

As part of the fourth objective, the study, sought to extract contrasting behaviors of dimensions of ProQoL with respect to the oncology HCPs and FCGs in the light of Perceived Stress, Psychological Morbidity, Well-being, Problem-focused coping (PFC), Emotion-focused coping (EFC), and Avoidant coping (AC).

For this study objective, initially, one-way MANCOVA was conducted by including the three dimensions of ProQoL as dependent variables (CS, BO, STS); the 'type of caregiver' as the factor variable; perceived stress, psychological morbidity, well-being, PFC, EFC and AC as covariates. The results of the MANCOVA are presented in the Table 4.7 below.

Table 4.7

Multivariate analysis of covariance for the dependent variables compassion satisfaction, burnout and secondary traumatic stress in Oncology HCPs and FCGs

Source	Dependent Variables	SS	df	MS	F	Sig.	η_p^2
Perceived Stress	Compassion Satisfaction	3064.564	1	3064.564	49.837	**0.000*** **	0.142
	Burnout	2183.157	1	2183.157	40.621	**0.000*** **	0.119
	Secondary Traumatic Stress	457.411	1	457.411	6.044	**0.015***	0.020
Psychological Morbidity	Compassion Satisfaction	967.228	1	967.228	15.729	**0.000*** **	0.050
	Burnout	60.339	1	60.339	1.123	0.290	0.004
	Secondary Traumatic Stress	1261.257	1	1261.257	16.666	**0.000*** **	0.052
Well-being	Compassion Satisfaction	10.525	1	10.525	0.171	0.679	0.001
	Burnout	746.390	1	746.390	13.888	**0.000*** **	0.044
		380.861	1	380.861	5.033	**0.026***	0.016
Problem-focused coping	Compassion Satisfaction	1051.106	1	1051.106	17.093	**0.000*** **	0.054
	Burnout	9.724	1	9.724	0.181	0.671	0.001
	Secondary Traumatic Stress	175.186	1	175.186	2.315	0.129	0.008
Emotion-focused coping	Compassion Satisfaction	558.051	1	558.051	9.075	**0.003****	0.029

	Burnout	1080.140	1	1080.140	20.098	**0.000*** **	0.063
	Secondary Traumatic Stress	62.964	1	62.964	0.832	0.362	0.003
Avoidant Coping	Compassion Satisfaction	340.855	1	340.855	5.543	**0.019***	0.018
	Burnout	1193.875	1	1193.875	22.214	**0.000*** **	0.069
	Secondary Traumatic Stress	509.516	1	509.516	6.733	**0.010***	0.022
Type of Caregiver	Compassion Satisfaction	88.500	1	88.500	1.439	0.231	0.005
	Burnout	952.912	1	952.912	17.731	**0.000*** **	0.056
	Secondary Traumatic Stress	1521.413	1	1521.413	20.104	**0.000*** **	0.063

a. R^2 = .271 (R^2_{adj} = .254)
b. R^2 = .471 (R^2_{adj} = .459)
c. R^2 = .322 (R^2_{adj} = .306)

*Note. 1. *p < .05, ***p < .001; ηp2 = Partial Eta Squared, R^2 = R Squared, R^2_{adj} = Adjusted R Squared*

In MANCOVA an overall significant main effect was observed in the model with covariates perceived stress (Wilk's Lambda = .821; F(3, 301) = 21.692; P <0.001), psychological morbidity (Wilk's Lambda = .898; F(3, 301) = 11.317; P <0.001), well-being (Wilk's Lambda = .949; F(3, 301) = 5.323; P <0.01), PFC (Wilk's Lambda = .929; F(3, 301) = 7.621; P <0.001), EFC (Wilk's Lambda = .932; F(3, 301) = 7.247; P <0.001), AC (Wilk's Lambda = .927; F(3, 301) = 7.830; P <0.001) and type of caregiver (Wilk's Lambda = .915; F(3, 301) = 9.300; P <0.001).

The results demonstrate that the covariate perceived stress has a statistically significant impact on compassion satisfaction F(3, 301) = 49.837; P <0.001; ηp2 = 0.142, burnout F(3, 301) = 40.621; P <0.001; ηp2 = 0.119, and secondary traumatic stress F(3, 301) = 6.044; P <0.05; ηp2 = 0.020.

It can be observed that the covariate psychological morbidity has a statistically significant impact on compassion satisfaction F(3, 301) = 15.79; P <0.001; ηp2 = 0.050 and secondary traumatic stress F(3, 301) = 16.67; P <0.001; ηp2 = 0.052. But did not show any impact on BO.

The results found that the covariate well-being has a statistically significant impact on burnout F(3, 301) = 13.89; P <0.001; ηp2 = 0.044, and secondary traumatic stress F(3, 301) = 5.033; P <0.05; ηp2 = 0.016. In the case of CS there was no impact observed.

The results also show that the covariate PFC has a significant impact on CS F(3, 301) = 17.093; P <0.001 ηp2 = 0.054 alone. No significant impact was found for BO and STS.

The results demonstrate that the covariate EFC has a statistically significant impact based on compassion satisfaction F(3, 301) = 9.075; P <0.01; ηp2 = 0.029 and burnout F(3, 301) = 20.098; P <0.001; ηp2 = 0.063. None were seen for STS

As shown in Table 4.7 the covariate AC has a significant impact on compassion satisfaction F(3, 301) = 5.543; P <0.05; ηp2 = 0.018, burnout F(3, 301) = 22.214; P <0.001; ηp2 = 0.069, and secondary traumatic stress F(3, 301) = 6.733; P <0.05; ηp2 = 0.022.

Table 4.8

Mean, standard error, F, and η^2 values for Compassion Satisfaction, Burnout, and Secondary Traumatic Stress for two groups

	M	***SE***	***M***	***SE***	**F (1,307)**	**ηp^2**
	HCPs		**FCGs**			
Compassion Satisfaction	49.61	0.74	50.99	0.73	1.439	.005
Burnout	53.42	0.69	48.81	0.68	**17.73*** **	.056
Secondary Traumatic Stress	53.55	0.82	50.19	0.81	**20.10*** **	.063

*Note. M = Mean, SE = Standard Error; *p < .05, ηp2 = Partial Eta Squared*

The results also show that there was statistically significant impact of the 'type of caregiver' on burnout F(3, 301) = 17.731; P <0.001; ηp2 = 0.056, and secondary traumatic stress

$F(3, 301) = 20.104$; $P < 0.0001$; $\eta p2 = 0.063$. This is also shown in Table 4.8 which shows the significant difference between the two groups of HCPs and FCGs, with the variables BO and STS. The mean values show that the HCPs have greater mean scores on the variables BO and STS when compared to the FCGs. However, there was no significant difference found in terms of CS among both the groups.

Objective 4

Step-up Regression and Max.Min Procedure for Best-fit Model Prediction

As the fourth objective sought to extract the contrasting behavior of the dimensions of ProQoL (CS, BO and STS), with respect to Oncology HCPs and FCs in light of Perceived Stress, Psychological Morbidity, Well-being, Problem-focused coping (PFC), Emotion-focused coping (EFC), and Avoidant coping (AC), the following analysis was conducted. This was conducted in order to derive the best-fit models of prediction of the dimensions of ProQoL.

The above conducted MANCOVA analysis indicated that it is worth building a model. Thus, a schematic method has been evolved to build models with one variable alone, with two variables alone, with three variables alone and so on as demonstrated in the following section by following step-up approach. Derived from the R Squared values obtained from the multivariate analysis of covariance (MANCOVA), Step-up regression analysis was conducted to obtain the best models for the prediction of the dependent variables, namely CS, BO and STS. Initially each of the covariates were entered separately into the multivariate analysis along with the three dependent variables (CS, BO and STS), and type of caregiver. The minimum of the R^2 values (from the three R^2 values) obtained for each covariate separately were taken. Then, the maximum of these (minimum) R^2 values was taken to evolve the first model. The first model was then added to the

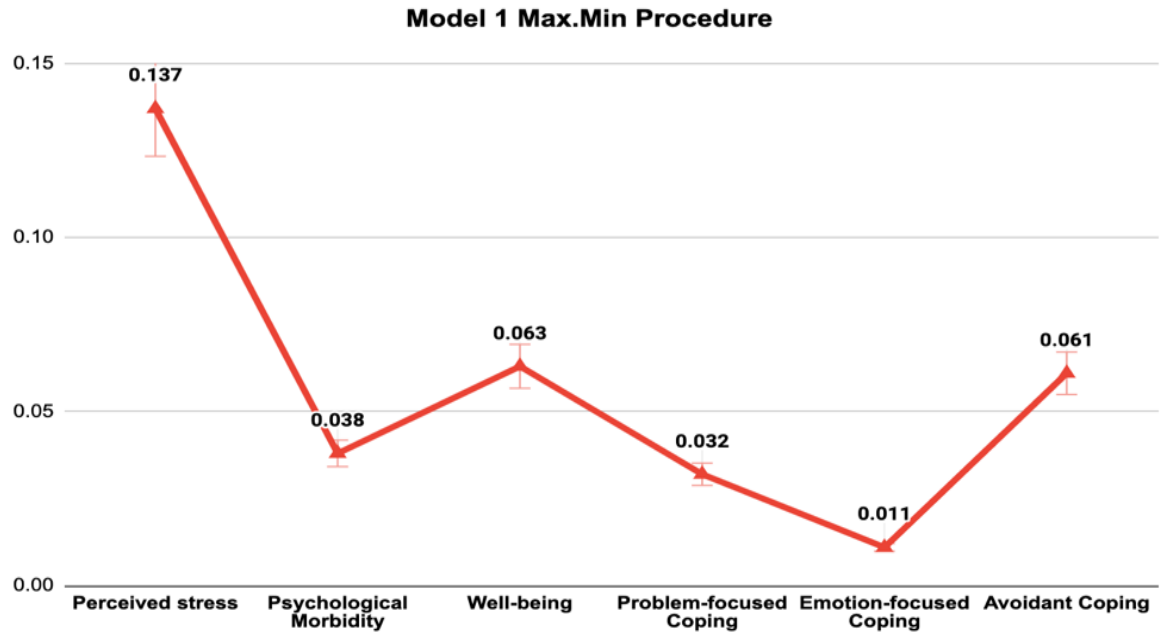
next 'minimum' of the R^2 value and analyzed to obtain the other models. Thus, six models have thus been obtained by employing the Max.Min Procedure. The MANCOVA tables for the 6 models have been appended (Appendix C1-C6).

Max.Min procedure is a procedure used in game theory. The following section describes the models derived using the Max.Min procedure.

Initially for model 1 the minimum of the R^2 value obtained for each variable in the multivariate analysis were considered and noted. The values are as follows: Perceived stress ($R^2 = 0.137$), psychological morbidity ($R^2 = 0.038$), well-being ($R^2 = 0.063$), PFC ($R^2 = 0.032$), EFC ($R^2 = 0.011$) and AC ($R^2 = 0.061$). The largest (maximum) R^2 value obtained by this process, that is, perceived stress was considered to be model 1, as shown in Figure 4.1. The multivariate analysis tables have been appended (Appendix C1).

Figure 4.1

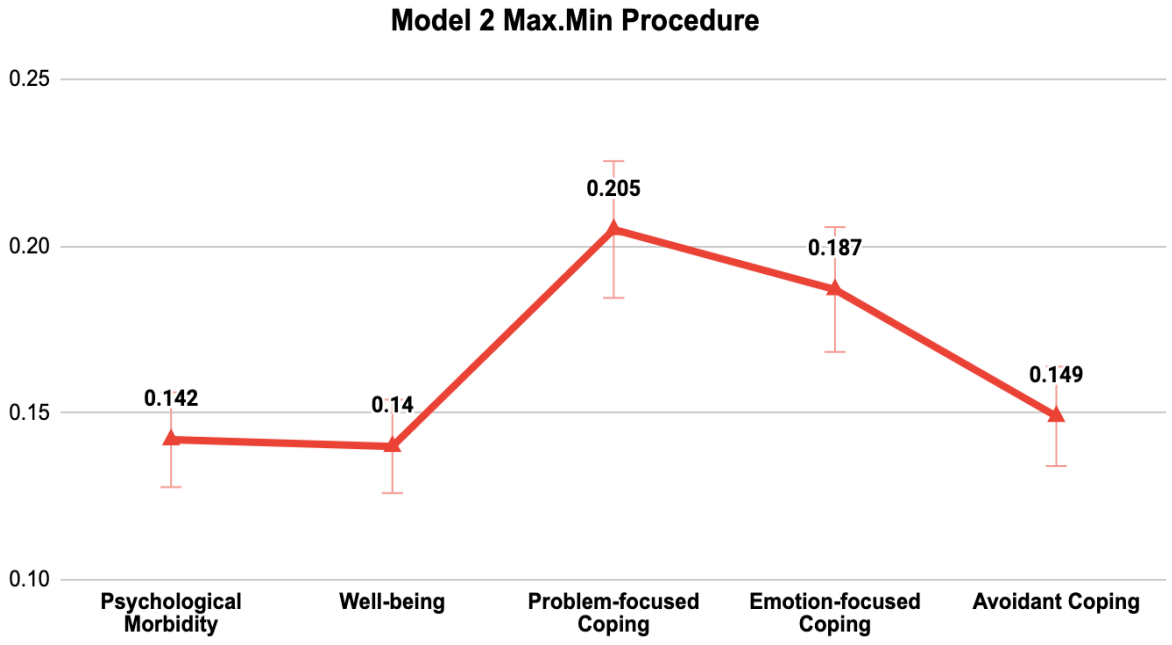
Model 1 Max.Min Procedure including the variables perceived stress, psychological morbidity, well-being, PFC, EFC and AC



To derive model 2, perceived stress (model 1 variable) was added to the remaining variables individually. The minimum of the R^2 values thus obtained (from the multivariate analysis for each variable) were considered for the construction of model 2. Multivariate analysis was conducted by adding up the variable of model 1, that is perceived stress and psychological morbidity ($R^2 = 0.142$); perceived stress and well-being ($R^2 = 0.140$); perceived stress and PFC ($R^2 = 0.205$); perceived stress and EFC ($R^2 = 0.187$); perceived stress and AC ($R^2 = 0.149$). The largest (maximum) R^2 value obtained by this process, i.e. PFC was considered to be model 2. This has been depicted in Figure 4.2. The multivariate analysis tables have been appended (Appendix C2).

Figure 4.2

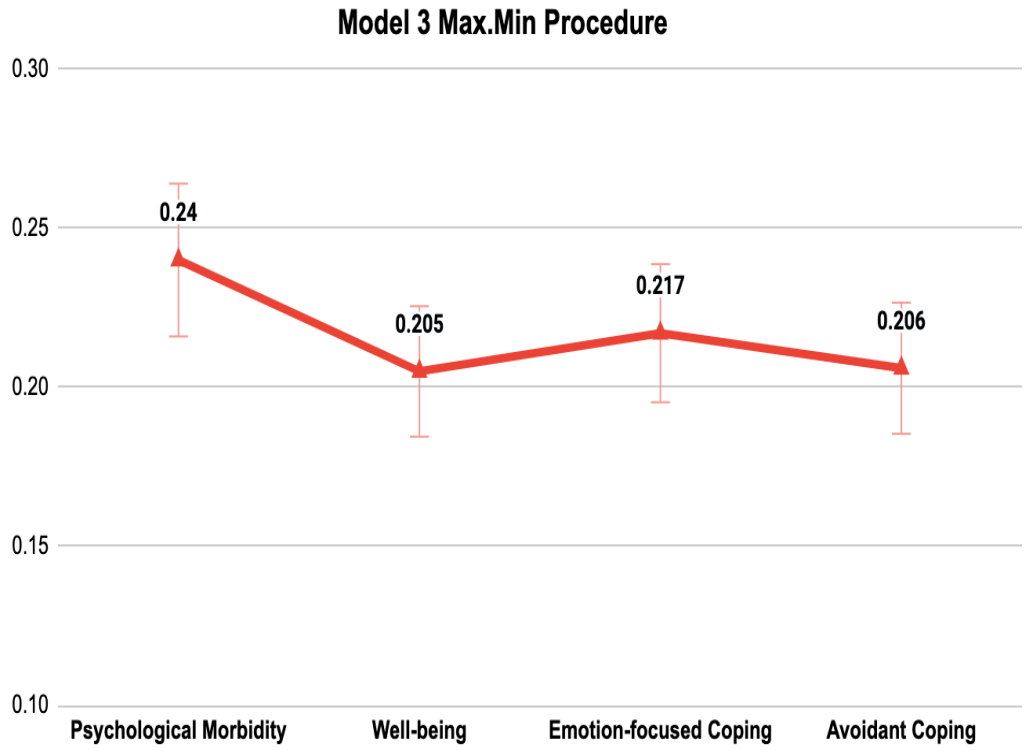
Model 2 Max.Min Procedure including the variables psychological morbidity, well-being, PFC, EFC and AC with perceived stress



Model 3 was derived by adding variables of model 1 and model 2 to the remaining variables individually. The minimum of the R^2 values thus obtained (from the multivariate analysis for each variable) were considered for the construction of model 3. The R^2 values thus derived for the variables were perceived stress, PFC and psychological morbidity ($R^2 = 0.240$); perceived stress, PFC and well-being ($R^2 = 0.205$); perceived stress, PFC and EFC ($R^2 = 0.217$); perceived stress, PFC and AC ($R^2 = 0.206$). The largest (maximum) R^2 value obtained by this process, that is, psychological morbidity was considered to be model 3. This has been illustrated in Figure 4.3. The multivariate analysis tables have been appended (Appendix C3).

Figure 4.3

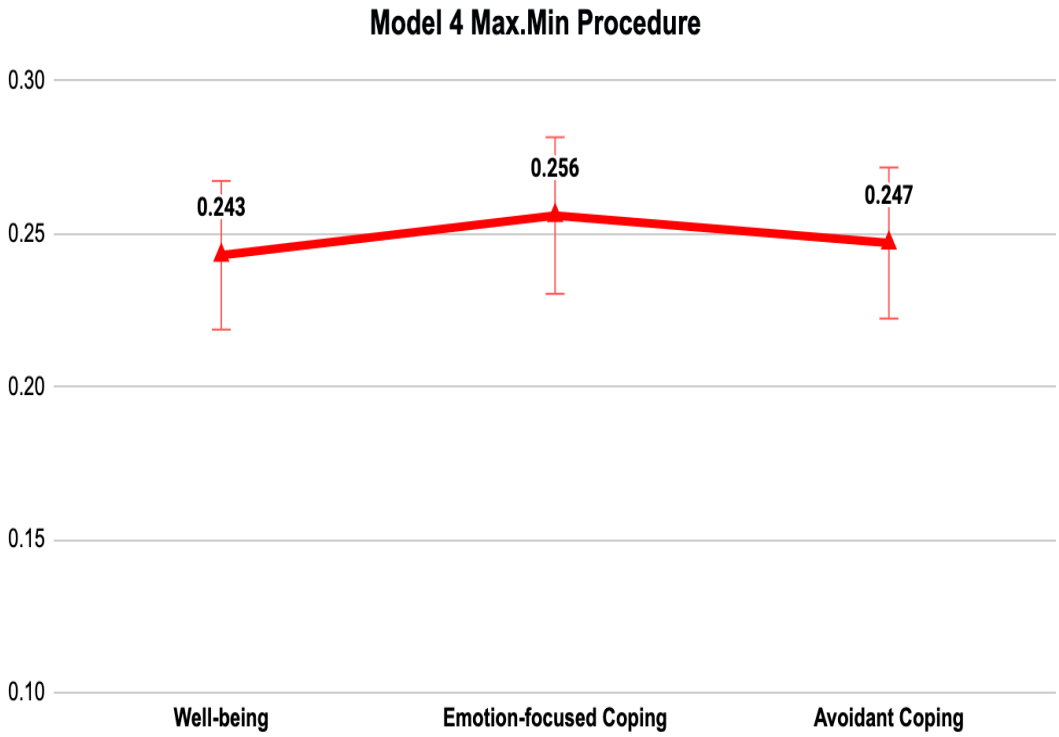
Model 3 Max.Min Procedure including the variables psychological morbidity, well-being, EFC and AC with perceived stress and PFC



Model 4 was derived by adding variables of model 1, model 2 and model 3 to the remaining variables individually. The minimum of the R^2 values thus obtained (from the multivariate analysis for each variable) were considered for the construction of model 4. The R^2 values thus derived were for the variables perceived stress, PFC, psychological morbidity and well-being ($R^2 = 0.243$); variables perceived stress, PFC, psychological morbidity and EFC ($R^2 = 0.256$); variables perceived stress, PFC, psychological morbidity and AC ($R^2 = 0.247$). The largest (maximum) R^2 value obtained by this process, that is, EFC was considered to be model 4. This has been illustrated in Figure 4.4. The multivariate analysis tables have been appended (Appendix C4).

Figure 4.4

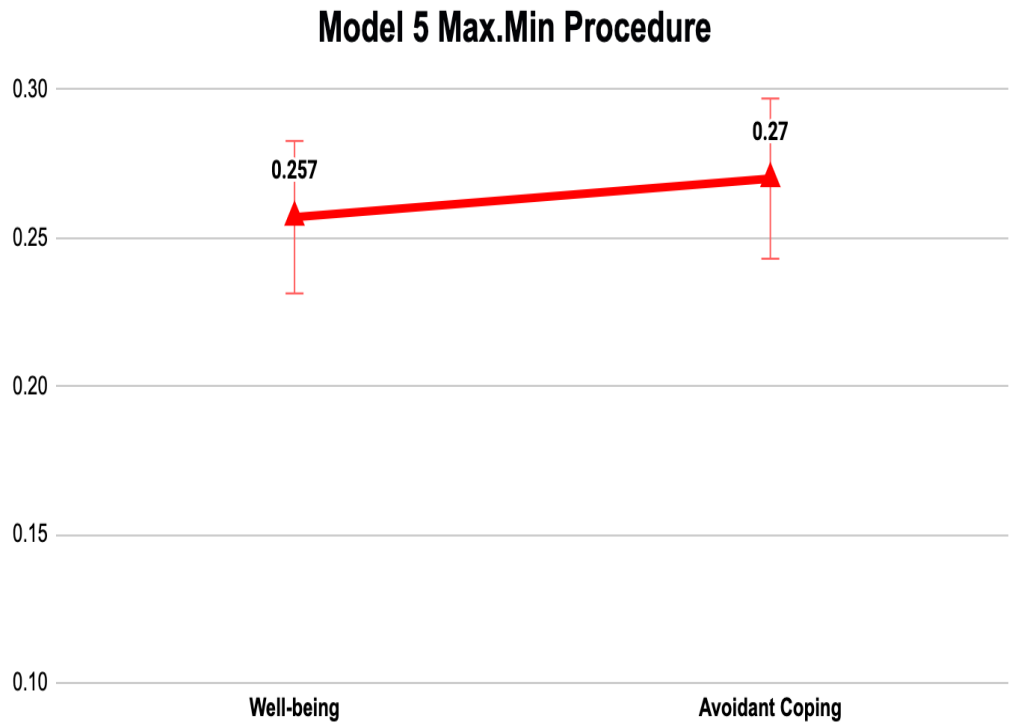
Model 4 Max.Min Procedure including the variables well-being, EFC and AC with perceived stress, PFC and psychological morbidity



Model 5 was derived by adding variables of model 1, model 2, model 3 and model 4 to the remaining variables individually. The minimum of the R^2 values thus obtained (from the multivariate analysis for each variable) were considered for the construction of model 5. The R^2 values thus derived were for the variables perceived stress, PFC, psychological morbidity, EFC and well-being ($R^2 = 0.257$); variables perceived stress, PFC, psychological morbidity, EFC and AC ($R^2 = 0.270$). The largest (maximum) R^2 value obtained by this process, i.e. AC was considered to be model 5. This has been shown in Figure 4.2. This has been depicted in Figure 4.5. The multivariate analysis tables have been appended (Appendix C5).

Figure 4.5

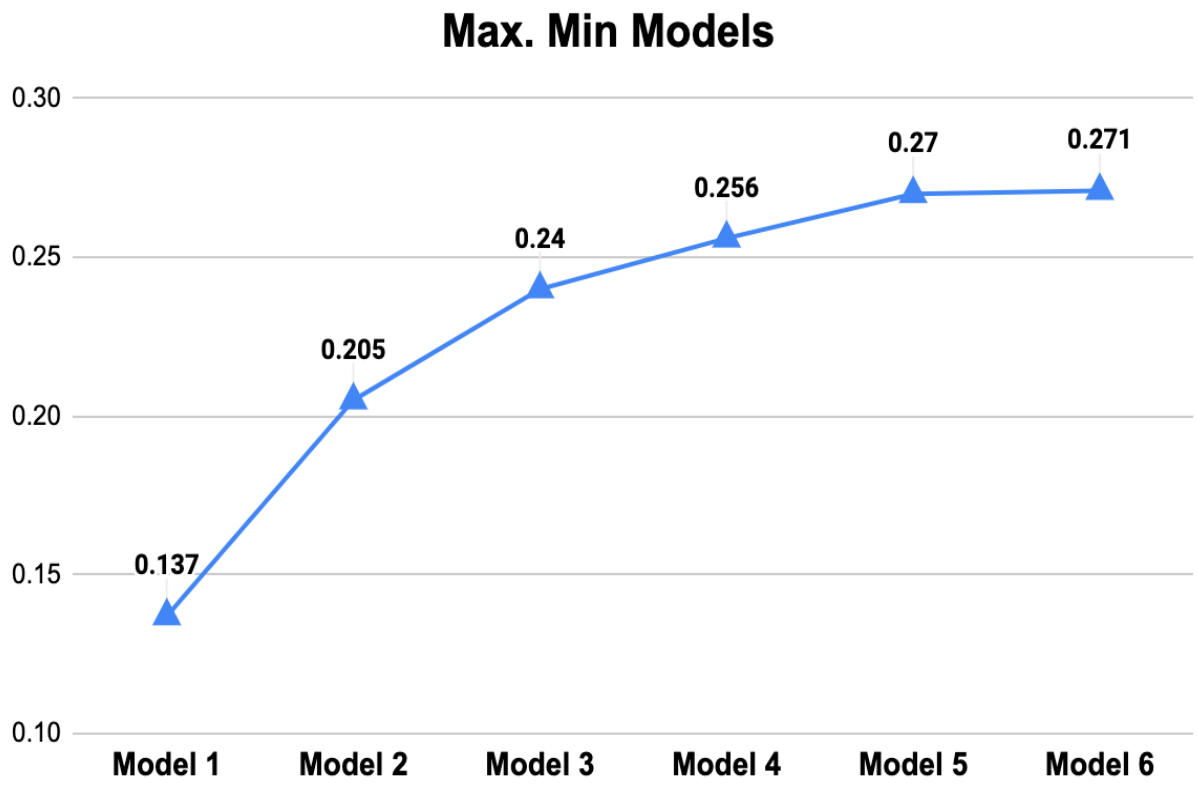
Model 5 Max.Min Procedure including the variables well-being and AC with perceived stress, PFC, psychological morbidity and EFC



Model 6 was derived by adding variables of model 1, model 2, model 3 and model 4 to the remaining variables individually. The minimum of the R^2 value thus obtained (from the multivariate analysis for the variable) were considered for the construction of model 6. The R^2 values thus derived were for the variables perceived stress, PFC, psychological morbidity, EFC, AC and well-being ($R^2 = 0.271$). Thus, well-being was considered to be model 6 (Appendix C6).

Figure 4.6

Max.Min Models for the six variables perceived stress (model 1), PFC (model 2), psychological morbidity (model 3), EFC (model 4), AC (model 5) and well-being (model 6)



The R^2 values thus derived were for the variables perceived stress ($R^2 = 0.137$), PFC ($R^2 = 0.205$), psychological morbidity ($R^2 = 0.24$), EFC ($R^2 = 0.256$), AC ($R^2 = 0.27$) and well-being ($R^2 = 0.271$). These results show that the best models evolved to predict CS, BO and STS in HCPs and

FGs are perceived stress, PFC, psychological morbidity, EFC, AC and well-being (in the mentioned order).

Objective 5

Logistic Regression and Contingency Analysis

As a part of the fifth objective, logistic regression analysis and contingency analysis were carried out to predict the levels of Compassion Satisfaction, Burnout, and Secondary Traumatic Stress with respect to Oncology HCPs and FCGs in the light of Perceived Stress, Psychological Morbidity, Well-being, Problem-focused coping (PFC), Emotion-focused coping (EFC), and Avoidant coping (AC).

Logistic Regression for the variable Compassion Satisfaction

Table 4.9 Demonstrates the independent variables that significantly predict the probability of participants belonging to the 'low level of CS' and the 'medium level of CS' category (i.e. the comparison groups) versus the 'high level of CS' category (i.e. the baseline), conditional on the predictors.

Table 4.9

Logistic Regression Analysis of Levels of Compassion Satisfaction

Low Level of Compassion Satisfaction		**B**	**SE**	**Exp(B)**	***p***
	Perceived Stress	0.345	0.061	1.413	**0.000*** **
	Psychological Morbidity	-0.274	0.065	0.761	**0.000*** **
	Well-being	-0.018	0.012	0.982	0.136

	Problem focused coping	-0.171	0.064	0.843	**0.008****
	Emotion focused coping	-0.110	0.051	0.895	**0.030***
	Avoidant Coping	0.328	0.087	1.388	**0.000*****
	[caregiving=0]	-0.070	0.497	0.933	0.888
Medium Level of Compassion Satisfaction		B	SE	Exp(B)	Sig.
	Perceived Stress	0.049	0.041	1.050	0.235
	Psychological Morbidity	-0.138	0.045	0.871	**0.002****
	Well-being	-0.029	0.010	0.972	**0.003****
	Problem focused coping	-0.096	0.050	0.909	0.057
	Emotion focused coping	0.006	0.040	1.006	0.879
	Avoidant Coping	0.030	0.067	1.031	0.649
	[caregiving=0]	-0.024	0.377	0.976	0.950

Note. *1. B -Unstandardized beta coefficient, SE -Standardized error, Exp(B)= Odds ratio;*
*2. *= $p<.05$, **= $p<.01$, ***= $p<.001$.*

As shown in Table 4.8, in the 'low level of CS' versus the 'high level of CS' category, the regression slope for the significant predictors, perceived stress, psychological morbidity, PFC, EFC, and AC is interpreted as follows:

Perceived Stress: For an increase of each unit on this variable, the odds of a case falling into the 'low level of compassion satisfaction' category (relative to the 'high level of CS') is predicted to increase by 0.345 units. The odds ratio is 1.413, indicating that with increased scores on the predictor, the odds of falling into the 'low level of CS' category change by a factor of 1.413. So, overall, these results suggest that individuals who score higher on perceived stress, are at a higher probability of falling into the category of 'low level of compassion satisfaction'. It means

that they have a lesser probability/likelihood of falling into the category of 'high level of CS' than individuals who have lower scores of perceived stress (b = .345, S.E. = .061, *P* = <0.001).

Psychological Morbidity: For an increase of each unit on this variable, the odds of a case falling into the 'low level of CS' category (relatively to the 'high level of CS') is predicted to decreases by -0.274 units. The odds ratio is 0.761, indicating that increased scores on the predictor, the odds of falling in the 'low level of CS' category as changing by a factor of 0.761. So, overall, these results suggest that individuals who score higher on psychological morbidity, are at a higher probability/likelihood of falling into the category of 'low level of CS' which means that they are at a lesser probability of falling into the category of 'high level of CS' than individuals who have lower scores of psychological morbidity (b = -0.274, SE = 0.065; *P* = 0.000).

Problem-focused Coping: The regression slope for PFC is interpreted as follows, for each unit increase on this variable, the odds of a case falling into the 'low level of compassion satisfaction' category (relatively to the 'high level of CS') is predicted to decrease by -0.171 units. The odds ratio is 0.843 indicating that with increased scores on the predictor, the odds of falling in the 'low level of compassion satisfaction' category as changing by a factor of 1.109. So, overall, these results suggest that individuals who score higher on PFC, are at a lower probability/likelihood of falling into the category of 'low level of CS' which means that they are at a higher likelihood of falling into the category of 'high level of CS' than individuals who have lower scores of PFC (b = -0.171, SE = 0.064; *P* = 0.008).

Emotion-focused Coping: The regression slope for EFC is interpreted as follows, for an increase of each unit on this variable, the odds of a case falling into the 'low level of CS' category (relatively to the 'high level of CS') is predicted to decrease by -0.109 units. The odds ratio is 1.109 indicating that with increasing scores on this predictor, the odds of falling in the 'low level

of CS' category as changing by a factor of 1.109. So, overall, these results suggest that individuals who score higher on EFC, are at a lower probability/likelihood of falling into the category of 'low level of CS' which means that they are at a higher likelihood of falling into 'high level of CS' than individuals who have lower scores of EFC (b = -0.110, SE = 0.051; *P* = 0.030).

Avoidant Coping: For an increase of each unit on this variable, the odds of a case falling into the 'low level of compassion satisfaction' category (relative to the 'high level of compassion satisfaction) is predicted to increase by 0.328 units. The odds ratio is 1.388 indicating that with increasing scores on this predictor, the odds of falling into the 'low level of CS' category as changing by a factor of 1.388. So, overall, these results suggest that individuals who score higher on AC, are at a higher probability of falling into the category of 'low level of CS' which means that they have a lower likelihood of falling into the category of 'high level of CS' than individuals who have lower scores of AC (b =-.328, S.E. = .087, *P* = 0.000).

In the 'medium level of compassion satisfaction' versus the 'high level of CS' category, the regression slope for the significant predictors, perceived morbidity, and well-being is interpreted as follows:

Psychological Morbidity: For an increase of each unit on this variable, the odds of a case falling into the 'medium level of CS' category (relatively to the 'high level of CS') is predicted to decrease by –0.138 units. The odds ratio is 0.871, indicating that with increasing scores on this predictor, the odds of falling in the 'low level of CS' category as changing by a factor of 0.871. So, overall, these results suggest that individuals who score higher on psychological morbidity, are at a lower probability/likelihood of falling into the category of 'low level of CS' which means that they have a greater likelihood of falling into the category of 'high level of CS' than individuals who have lower scores of psychological-morbidity (b = -0.138, SE = 0.045; *P* = 0.003).

Well-being: For an increase of each unit on this variable, the odds of a case falling into the 'medium level of CS' category (relatively to the 'high level of CS') is predicted to decrease by –0.029 units. The odds ratio is 0.972, indicating that with increasing scores on this predictor, the odds of falling in the 'low level of CS' category as changing by a factor of 0.972. So, overall, these results suggest that individuals who score higher on well-being, are at a lower probability/likelihood of falling into the category of 'low level of CS' which means that they have a greater likelihood of falling into the category of 'high level of CS' than individuals who have lower scores of well-being (b = -0.029, SE = 0.010; *P* = 0.003).

Contingency Analysis for the variable Compassion Satisfaction

The contingency analysis is used to determine which level of compassion satisfaction is the best predictor of the model.

Table 4.9.1

Contingency Analysis of the Levels of Compassion Satisfaction of HCPs and FCGs of patients with cancer

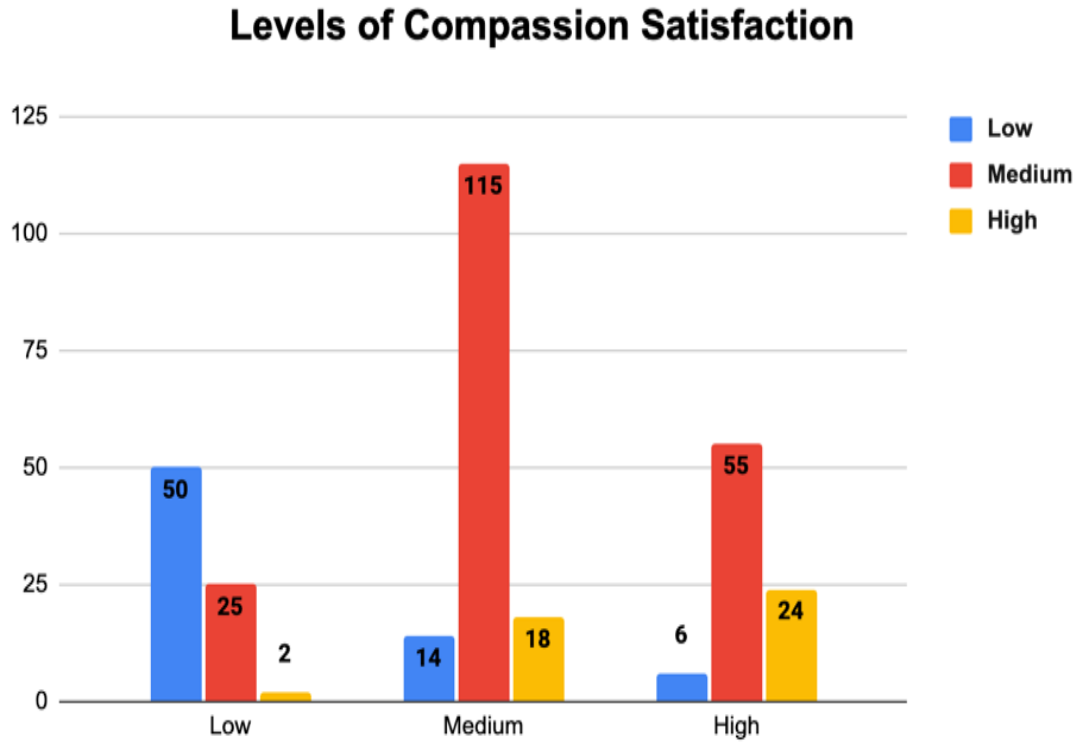
Levels of Compassion Satisfaction	Low	Medium	High	Percent of Levels
Low	50	25	2	64.9%
Medium	14	115	18	78.2%
High	6	55	24	28.2%
Overall Percentage	22.7%	63.1%	14.2%	61.2%

The contingency analysis is used to determine which level of CS is the best predictor of the model. The probability of an individual falling into one of the levels of CS has been calculated by the contingency analysis. It has also been used to determine which level of CS is the best

predictor of the model. As shown in table 4.9.1 and Figure 4.7, low levels of compassion satisfaction were correctly predicted by the model 64.9% of the time, while medium levels of CS were correctly predicted by the model 78.2% of the time, and high levels of CS were correctly predicted by the model 28.2% of the time by the model.

Figure 4.7

Contingency analysis for the levels of compassion satisfaction in HCPs and FCGs of patients with cancer



The figure 4.7 shows that the classification was accurate with respect to the medium level of CS, and equally accurate in the low level of CS. However, in the high level of CS, it is biased towards the medium level of CS. Overall, this suggests that the model is more or less accurate to classify an individual into the levels of CS. Contingency analysis has been carried out as a validation for the above done logistic regression analysis.

Logistic Regression Analysis for the variable Burnout

Table 4.9.2 demonstrations the independent variables that significantly predicts the probability of participants belonging to the 'low level of BO' and the 'medium level of BO' category (i.e. the comparison groups) versus the 'high level of BO' category (i.e. the baseline), conditional on the predictors.

Table 4.9.2

Logistic Regression Analysis of Levels of Burnout

Low Level of Burnout		**B**	**SE**	**Exp(B)**	***p***
	Perceived Stress	-0.308	0.065	0.735	**0.000*** **
	Psychological Morbidity	-0.041	0.067	0.960	0.541
	Well-being	0.039	0.014	1.039	**0.005** **
	Problem focused coping	0.014	0.070	1.014	0.845
	Emotion focused coping	0.104	0.055	1.109	**0.050***
	Avoidant Coping	-0.211	0.095	0.809	**0.026***
	[caregiving=0]	-1.668	0.591	0.189	**0.005** **
Medium Level of Burnout		B	SE	Exp(B)	Sig.
	Perceived Stress	-0.252	0.052	0.777	**0.000*** **
	Psychological Morbidity	-0.012	0.052	0.988	0.822
	Well-being	0.014	0.011	1.014	0.176
	Problem focused coping	-0.093	0.054	0.911	0.084
	Emotion focused coping	0.077	0.044	1.080	0.080
	Avoidant Coping	-0.216	0.072	0.805	**0.003** **
	[caregiving=0]	0.002	0.435	1.002	0.996

Note. *1. B -Unstandardized beta coefficient, SE -Standardized error, Exp(B)= Odds ratio;*
*2. *= p<.05, **= p<.01, ***= p<.001.*

As shown in Table 4.9.2 in the 'low level of BO' versus the 'high level of BO' category, the regression slope for the significant predictors, perceived stress, well-being, EFC, and AC is interpreted as follows:

Perceived Stress: For an increase of each unit on this variable, the odds of a case falling into the 'low level of BO' category (relative to the 'high level of BO') is predicted to decrease by 0.308 units. The odds ratio is 0.735, indicating that with increasing scores on this predictor, the odds of falling into the 'low level of BO' category change by a factor of 0.735. So, overall, these results suggest that individuals who score higher on perceived stress, are at a lower probability/likelihood of falling into the category of 'low level of BO', which means that they are at a greater probability/likelihood of falling into the category of 'high level of BO' than individuals who have lower scores of perceived stress (b = -.308, S.E. = .065, P = <0.001).

Well-being: For an increase of each unit on this variable, the odds of a case falling into the 'low level of BO' category (relatively to the 'high level of BO') is predicted to increase by 0.039 units. The odds ratio is 1.039, indicating that with increasing scores on well-being, the odds of falling in the 'low level of BO' category as changing by a factor of 1.039. So, overall, these results suggest that individuals who score higher on well-being, are at a higher probability/likelihood of falling into the category of 'low level of BO' which means that they are at a lesser risk of falling into the category of 'high level of BO' than individuals who have lower scores of well-being (b = 0.039, SE = 0.014; P < 0.01)

Emotion-Focused Coping: The regression slope for EFC is interpreted as follows, for an increase of each unit on this variable, the odds of a case falling into the 'low level of BO' category (relatively to the 'high level of BO') is predicted to increase by 0.109 units. The odds ratio is 1.109

indicating that with increasing scores on EFC, the odds of falling in the 'low level of BO' category as changing by a factor of 1.109. So, overall, these results suggest that individuals who score higher on EFC, are at a higher probability/likelihood of falling into the category of 'low level of BO' which means that they are at a lesser probability/likelihood of falling into the category of 'high level of BO' than individuals who have lower scores of EFC (b = 0.104, SE = 0.055; $P < 0.05$)

Avoidant Coping: For an increase of each unit on this variable, the odds of a case falling into the 'low level of BO' category (relative to the 'high level of burnout) is predicted to decrease by 0.211 units. The odds ratio is 0.735 indicating that with increasing scores on AC, the odds of falling into the 'low level of BO'; category as changing by a factor of 0.735. So, overall, these results suggest that individuals who score higher on AC, are at a lower probability/likelihood of falling into the category of 'low level of BO' which means that they are at a greater probability/likelihood of falling into the category of 'high level of BO' than individuals who have lower scores of AC (b = -.211, S.E. = .095, $P = 0.05$).

In the 'medium level of BO' versus the 'high level of BO' category, the regression slope for the significant predictors, perceived stress, and AC is interpreted as follows:

Perceived Stress: For an increase of each unit on this variable, the odds of a case falling into the 'medium level of BO' category (relative to the 'high level of BO') is predicted to decrease by 0.252 units. The odds ratio is 0.777 indicating that with increasing scores on this predictor, the odds of falling into the 'medium level of BO' category as changing by a factor of 0.777. So, overall, these results suggest that individuals who score higher on perceived stress, are at a lower probability/likelihood of falling into the category of 'medium level of BO' which means that they have a greater probability/likelihood of falling into the category of 'high level of BO' than individuals who have lower scores of perceived stress (b = -.252, S.E. = .052, $P = <0.001$).

Avoidant Coping: For an increase of each unit on this variable, the odds of a case falling into the 'medium level of BO' category (relative to the 'high level of BO') is predicted to decrease by 0.216 units. The odds ratio is 0.805 showing that with increased scores on this predictor, the odds of falling into the 'low level of BO' category as changing by a factor of 0.805. So, overall, these results suggest that individuals who score higher on AC, have a lower probability of falling into the category of 'medium level of BO' which means that they have a greater probability/likelihood of falling into 'high level of BO' than individuals who have lower scores of AC (b = -.216, S.E. = .072, *P* = <0.01).

Contingency Analysis for the variables Burnout

The contingency analysis is used to determine which level of burnout is the best predictor of the model.

Table 4.9.3

Contingency Analysis of the Levels of Burnout in HCPs and FCGs of patient with cancer

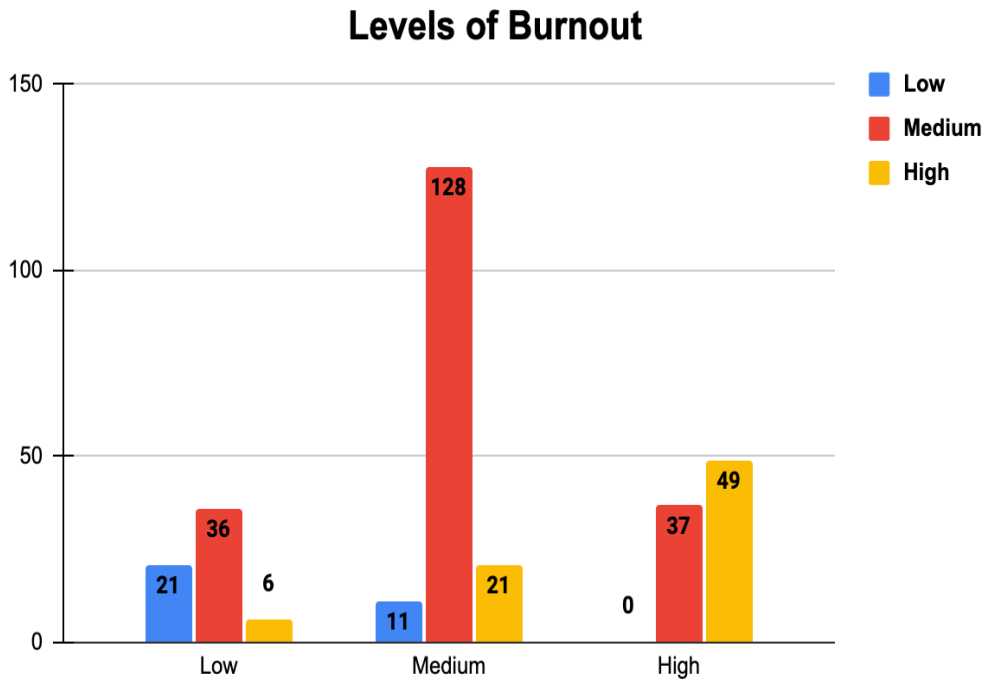
Levels of Burnout	Low	Medium	High	Percent of Levels
Low	21	36	6	33.3%
Medium	11	128	21	80.0%
High	0	37	49	57.0%
Overall Percentage	10.4%	65.0%	24.6%	64.1%

The contingency analysis is used to determine which level of BO is the best predictor of the model. The probability of an individual falling into one of the levels of BO has been calculated by the contingency analysis. It has also been used to determine which level of BO is the best predictor of the model. As shown in Table 4.9.3, and Figure 4.8, low levels of BO were correctly predicted by the model 33.3% of the time, while medium levels of BO were correctly predicted by

the model 80.0% of the time, and high levels of BO were correctly predicted by the model 57.0% of the time by the model.

Figure 4.8

Contingency analysis for the levels of burnout in HCPs and FCGs of patients with cancer



The figure 4.8 shows that the classification was accurate with respect to the medium level of BO, and equally accurate in the high level of BO. However, in the low level of BO, it is biased towards the medium level of BO. Overall, this suggests that the model is more or less well to classify an individual into the levels of BO. Contingency analysis has been carried out as a validation for the above done logistic regression analysis.

Logistic Regression for the variable Secondary Traumatic Stress

Table 4.9.4. demonstrations the independent variables that significantly predicts the probability of participants belonging to the 'low level of STS' and the 'medium level of STS' category (i.e. the comparison groups) versus the 'high level of STS' category (i.e. the baseline), conditional on the predictors.

Table 4.9.4

Logistic Regression Analysis of Levels of Secondary Traumatic Stress

Low Level of Secondary Traumatic Stress		**B**	**SE**	**Exp(B)**	***p***
	Perceived Stress	-0.096	0.050	0.908	0.055
	Psychological Morbidity	-0.219	0.061	0.804	**0.000*** **
	Well-being	0.011	0.012	1.011	0.334
	Problem focused coping	-0.020	0.063	0.980	0.750
	Emotion focused coping	-0.052	0.051	0.949	0.306
	Avoidant Coping	-0.149	0.087	0.861	0.085
	[caregiving=0]	-1.862	0.521	0.155	**0.000*** **
Medium Level of Secondary Traumatic Stress		B	SE	Exp(B)	Sig.
	Perceived Stress	-0.033	0.037	0.967	0.369
	Psychological Morbidity	-0.019	0.041	0.982	0.653
	Well-being	0.008	0.009	1.008	0.367
	Problem focused coping	0.112	0.049	1.118	**0.024***
	Emotion focused coping	-0.079	0.040	0.924	**0.048***
	Avoidant Coping	0.011	0.059	1.011	0.856

	[caregiving=0]	-0.259	0.370	0.772	0.485

Note. *1. B -Unstandardized beta coefficient, SE -Standardized error, Exp(B)= Odds ratio;*
*2. *= p<.05, **= p<.01, ***= p<.001.*

In the 'low level of STS' versus the 'high level of STS' category, the regression slope for the significant predictor, psychological morbidity is interpreted as follows:

Psychological Morbidity: For an increase of each unit on psychological morbidity, the odds of a case falling into the 'low level of STS' category (relative to the 'high level of STS') is predicted to decrease by 0.219 units. The odds ratio is 0.804, indicating that as the scores on this predictor increase, the probability of falling into the 'low level of STS' category change by a factor of 0.804. So, overall, these results suggest that individuals who score higher on psychological morbidity, are at a lower probability of falling into the category of 'low level of STS', which means that they are at a greater probability/likelihood of falling into the category of 'high level of STS' than individuals who have lower scores of psychological morbidity (b = -.219, S.E. = .065, *P* = <0.001).

In the 'medium level of STS' versus the 'high level of STS' category, the regression slope for the significant predictors, PFC and EFC is interpreted as follows:

Problem-focused Coping: The regression slope for PFC is interpreted as follows, for an increase of each unit on this variable, the odds of a case falling into the 'low level of STS' category (relatively to the 'high level of STS') is predicted to decrease by 0.112 units. The odds ratio is 1.118 indicating that as the scores on this predictor increase, the odds of falling in the 'low level of STS' category as changing by a factor of 1.118. So, overall, these results suggest that individuals who score higher on PFC, are at a higher probability/likelihood of falling into the category of 'low level of STS' which means that they are at a lesser risk of falling into the category of 'high level of STS' than individuals who have lower scores of PFC (b = 0.112, SE = 0.049; *P* = 0.024).

Emotion-focused Coping: The regression slope for EFC is interpreted as follows, for an increase of each unit on this variable, the odds of a case belonging to the 'low level of STS' category (relatively to 'high level of STS') is predicted to increase by –0.079 units. The odds ratio is 0.924 indicating that as the scores on this predictor increase, the odds of falling in the 'low level of STS' category as changing by a factor of 0.924. So, overall, these results suggest that individuals who score higher on EFC, are at a lower probability/likelihood of falling into the category of 'low level of STS' which means that they have a greater probability/likelihood of falling into the category of 'high level of STS' than individuals who have lower scores of EFC (b = -0.079, SE = 0.040; *P* = 0.48).

Contingency Analysis for the variables Secondary Traumatic Stress

The contingency analysis is used to determine which level of secondary traumatic stress is the best predictor of the model.

Table 4.9.5

Contingency Analysis of the Levels of Secondary Traumatic Stress of HCPs and FCGs of patients with cancer

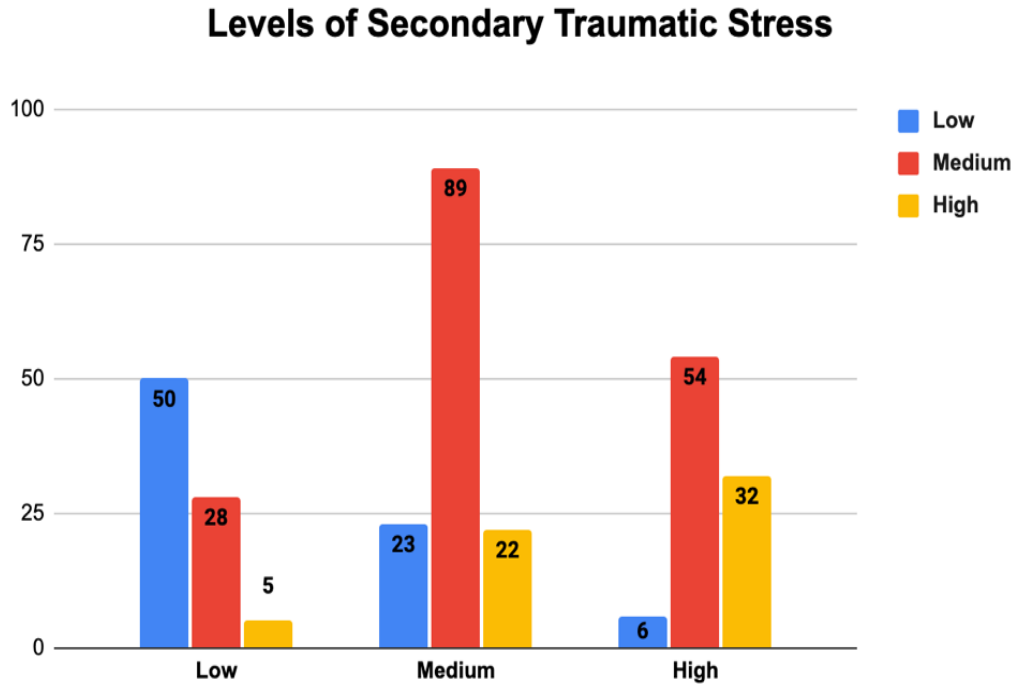
Levels of Secondary Traumatic Stress	Low	Medium	High	Percent of Levels
Low	50	28	5	60.2%
Medium	23	89	22	66.4%
High	6	54	32	34.8%
Overall Percentage	25.6%	55.3%	19.1%	55.3%

The contingency analysis is used to determine which level of STS is the best predictor of the model. The probability of an individual falling into one of the levels of STS has been calculated by the contingency analysis. It has also been used to determine which level of STS is the best

predictor of the model. As shown in table 4.9.5 and Figure 9, low levels of STS were correctly predicted by the model 60.2% of the time, while medium levels of STS were correctly predicted by the model 66.4% of the time, and high levels of STS were correctly predicted by the model 34.8% of the time by the model.

Figure 4.9

Contingency analysis for the levels of secondary traumatic stress in HCPs and FCGs of patients with cancer



The figure 4.9 shows that the classification was accurate with respect to the medium level of STS, and equally accurate in the low level of STS. However, in the high level of STS, it is biased towards the medium level of STS. Overall, this suggests that the model is more or less accurate to classify an individual into the levels of STS. Contingency analysis has been carried out as a validation for the above done logistic regression analysis.

Objective 6

The sixth objective of the study, sought to critically analyse the perceptions of burnout, secondary traumatic stress and coping in oncology HCPs and FCGs based on the qualitative responses. The themes, sub-themes and the responses on perceptions of BO in HCPs are summarised in the Table 4.9.6. As part of this, based on the results obtained from phase I, in-depth interviews were conducted among HCPs and FCGs to understand their perceptions of BO and STS.

Table 4.9.6

Perceptions of Burnout in Oncology of HCPs based on the qualitative responses

Themes	Sub-themes	Responses
Job Related	Increased work load	"Change in staffing due to the pandemic" – decreased workforce
	Lack of cooperation	"Senior staff not supportive"
	Boredom	"Monotony in tasks of the job"
	Role ambiguity	"Being asked to do administrative and technical work"
	Task overload	"We being nurses even prepare chemos like doctors, we do their tasks"
	Limitations in expansion of Knowledge	"More time spent in patient care than learning something new"
Patient Related	Limitations in taking up new challenges	"Taking fewer challenges to avoid risks in patient care" "Avoiding changing treatments mid-course, even if necessary to avoid paper work"
	Increased patient intake	"Taking more patients for Arogyashree money" "Lowered quality of care due to increased case load"

	Gradual lowering of compassion	"Gradual onset of apathy in patient care – Losing empathy" "Developing apathy towards patient suffering - Back referring patients to avoid complex cases" & "Postponing appointments"
	Irritability due to patient behaviour	"Patients irritating with repeated questions about small things"

The themes, sub-themes and the responses on perceptions of STS in HCPs are summarised in the Table 4.9.7.

Table 4.9.7

Perceptions of Secondary Traumatic Stress in Oncology of HCPs based on the qualitative responses

Themes	**Sub-themes**	**Responses**
Work-related avoidance	Avoiding work	"Taking off cases because I don't feel up to the mark in dealing with patients with severe disease"
	Limiting interaction	"Speaking briefly to patients and not getting into personal details"
	Displeasure related to current work	Thoughts of "I wish I wasn't here doing this job; I could choose to do another job and not see patients everyday"
	Feeling overloaded & avoiding too many procedures	"Not being able to explore different treatment avenues before giving up on the case" (because of work overload & too much of paper work)
Emotions related to patients	Loss of life	"Losing patients frequently makes me feel sad"
	Attachment	"I feel attached to patients"

	Breaking bad news	"I find it difficult to explain to the patient & caregivers the patient's low chances of survival"
	Dissatisfaction in being with the current state of the patient	"I feel sad about being a part of the worst part of someone's life"

The Table 4.9.8 shows us the broad themes that have emerged on the perceptions of BO and STS in FCGs upon analysis.

Table 4.9.8

Perceptions of Burnout and Secondary Traumatic Stress in FCGs of patients with cancer based on the responses

	Themes	**Responses**
Burnout	Social Limitations	"I had no choice"
	Financial needs	"Limitations of current financial situation"; "Leaving work for caregiving"
	Fatigue due to caregiving tasks	Going from one hospital to another and also taking care of all the needs of my family member
	Neglecting other responsibilities	"Not able to take care of children due to caregiving"
	Information support	"Seeking more information"
Secondary Traumatic Stress	Fear of family member dying	"When I see another patient die suddenly even after treatment, I get scared about my husband"; Having bad dreams that my family member is dying"
	Uncertainty	"Forgetting things due to fear and anxiety"
	Sad due to remission	"I feel sad we are in this state again"

CHAPTER V

DISCUSSION

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DISCUSSION

The study's main objective was to explore the various psychological factors affecting oncology healthcare professionals (HCPs) and family caregivers (FCGs). The present study tested six hypotheses on HCPs and FCGs of patients with cancer. It was observed that the mean score of the oncology HCPs was higher with respect to burnout (BO) and secondary traumatic stress (STS) when compared to the family caregivers.

Providing care to patients suffering with cancer, can have an emotional, psychological, and work- related impact on HCPs and FCGs, resulting in poor or negative consequences that possibly may affect their job with the patient. Thus, firstly, it is essential to study and understand the factors that are associated positively and negatively with ProQoL (comprising of CS, BO and STS) and secondly, to understand the factors that are predicting CS, BO and STS.

Hence the study's first objective was to find out the relationships that exist between dimensions of ProQoL (comprising of CS and CF) and the other psychological variables considered in the study, namely, perceived stress, psychological morbidity, well-being, problem-focused coping (PFC), emotion-focused coping (EFC), and avoidant coping (AC).

It was hypothesised that there will be a significant relationship between the dimensions of ProQoL and the study variables. The study found that there were significant relationships between variables of the study such as CS, BO, and STS and the other study variables such as perceived stress, well-being, psychological morbidity, and PFC, EFC, and AC. The study revealed that compassion satisfaction (CS), was positively correlated with well-being, PFC and EFC and

negatively correlated with AC. This indicated that as CS increased, there was an increase also in the well-being, PFC and EFC of the HCPs as well as FCGs. It was also seen that, with an increase in CS, perceived stress, psychological morbidity and AC decreased in the sample. These findings are similar to the findings of previous studies among HCPs as well as FCGs (Slocum-Gori, Hemsworth, Chan, Carson, & Kazanjian, 2013; Galiana, Arena, Oliver, Sansó, & Benito, 2017; Lynch, Shuster & Lobo, 2018). In addition, recent studies have also found positive correlations between well-being and CS depicting an improvement of well-being with compassionate experiences of caregiving and also that CS promotes well-being (Roeser, Colaianne, & Greenberg, 2018; Sacco & Copel, 2018; Settineri, Frisone, Alibrandi, & Merlo, 2019).

The study showed that BO was positively associated with perceived stress, psychological morbidity, and AC. This indicated that with an increase in BO, there was an increase in perceived stress, psychological morbidity, and AC. Previous studies also stated that psychological distress and maladaptive coping mechanisms are related to greater levels of BO in HCPs as well as FCGs (Lynch, Shuster & Lobo, 2018; Granek, et al., 2016).

It was seen that BO shared a negative association with well-being and PFC. It was seen that with a decrease in BO, there is an increase in the well-being and PFC increased among HCPs and FCGs of patients with cancer. this is in line with findings which also stated a negative relationship between the construct of BO and well-being among HCPs (Chana, Kennedy & Chessell, 2015; Uzar-Özçetin, Sarıoğlu & Dursun, 2019). However, no significant relationship was found between BO and EFC, was contrary to previous study findings which state that there is a positive association between BO and EFC (Meyerson, Gelkopf, Eli & Uziel, 2022).

Similarly, the study found that STS was also associated positively with perceived stress, psychological morbidity, and AC. This indicated that with an increase in STS, there was an

increase in perceived stress as supported by previous studies (Moosavian Khorasani, Vagharseyyein, Zarei & Shafiee, 2019; Amin, Vankar, Nimbalkar, & Phatak, 2015), psychological morbidity, suggested by previous research (Harker, Pidgeon, Klaassen, & King, 2016), and AC supported by previous study by Vukčević Marković & Živanović (2022). It was also seen that with a decrease in STS, well-being and PFC increased among HCPs and FCGs of patients with cancer. However, it shared a negative association with well-being and PFC. As we observed with BO, there was no significant relationship found between STS and EFC as well.

Significant relationships between the variables CS, BO and STS were also observed. The study showed that, while CS shared a significant negative relationship with BO and STS, BO shared a significant positive relationship with STS. This demonstrated that with BO, the STS also increases. This finding was in line with previous study findings (Slocum-Gori, Hemsworth, Chan, Carson, & Kazanjian, 2013).

The *second hypothesis* of the study conjectured that CS, BO and STS will be predicted by psychological variables such as perceived stress, psychological morbidity, well-being, PFC, EFC and AC in HCPs and FCGs of patients with cancer. The study found that the model was significant and explained a variance of 26.7% in CS and the variables perceived stress, psychological morbidity, PFC, EFC and AC significantly predicted CS in HCPs and FCGs of patients with cancer. This is in line with studies which state that perceived stress, psychological morbidity and AC negatively impact CS as well as lowered compassionate care provided to the patients (Sehlen, et al., 2009; Imo, 2017).

The analysis for BO showed that the model was significant and explained 40.8% variance in BO. The variables perceived stress, AC, and well-being significantly predicted BO among HCPs

and FCGs of patients with cancer. The study found that the model was significant and explained 27.6% of variance in STS and the psychological variables such as psychological morbidity and AC predicted STS in the oncology HCPs and FCGs of patients with cancer. Thus, this has been found in other studies as well, which stated that adaptive and active coping strategies were found to negatively predict BO and STS in HCPs as well as general populations (Ding, et al., 2015; à Ile-Ife, et al., 2020). Studies have also shown that BO inversely predicted well-being among FCGs (Settineri, Frisone, Alibrandi, & Merlo, 2019), as well as HCPs (Alkema, Linton, & Davies, 2008).

The *third hypothesis* propounds that there will be a significant difference between the two groups under study, i.e. the HCPs and the FCGs with respect to CS, BO and STS. The study found a significant difference with regards to the variable BO between the two groups, with mean values indicating that HCPs had higher levels of BO when compared to the FCGs. Various studies stated that HCPs of patients with cancer experienced BO (Girgis, Hansen & Goldstein, 2009; Probst, Griffiths, Adams & Hill 2012; Van Oers, 2021). However, the same cannot be said of the FCGs of patients with cancer as the research on this area appeared scanty. The experience of BO in HCPs can be explained by the fact that a HCP's daily work routine involves being exposed to aspects of pain and agony via their work, and limited psychological wellness tools which makes them more susceptible to developing BO as indicated by previous research (Samson & Shvartzman, 2018).

The *fourth hypothesis* postulates that there will be a contrasting behaviour of the dimensions of ProQoL (CS, BO, and STS), with respect to oncology HCPs and FCGs in light of perceived stress, psychological morbidity, well-being, PFC, EFC, and AC. These results indicate the contribution made by each covariate to significantly predict CS, BO and STS in HCPs and

FCGs; thus, indicating the need to include them in case of an intervention design, in order to address both CS and CF (inclusive of BO and STS) among the sample.

The results from the multivariate analysis of covariance show that covariates such as perceived stress, psychological morbidity, PFC, EFC and AC are significant contributors of CS. Hence the results suggest that an intervention designed to improve CS must include factors focusing on perceived stress, psychological morbidity, PFC, EFC and AC as they were found to be the significant contributor of CS. Likewise, in terms of BO, the results found that covariates such as perceived stress, well-being, EFC and AC are significant contributors of BO. This suggests a need to design an intervention to address BO that includes dealing with factors such as perceived stress, well-being, EFC and AC, as they were found to be the significant contributors of BO. Further with regards to STS, it was seen that covariates such as perceived stress, psychological morbidity, and AC were significant contributors of STS, indicating that intervention programs designed to address STS must include perceived stress, psychological morbidity, and AC as they significantly contribute to STS.

Finally, the results found that there was a statistically significant difference between HCPs and FCGs with respect to BO as well as STS, when controlled for the psychological variables perceived stress, psychological morbidity, well-being, PFC, EFC, and AC. However, there was no difference found with respect to CS between the two groups.

Deriving further from the results of MANCOVA, the study undertook a novel method of establishing the best models for the prediction of CS, BO and STS, through the Step-up regression analysis, followed by the Max.Min Procedure. The findings show that the variables thus obtained to be the best models for the prediction of CS, BO and STS in HCPs incrementally were perceived stress, problem-focused coping, psychological morbidity, emotion-focused coping and avoidant

coping, in their mentioned order. The models used helped predict CS and CF in the order of the variables mentioned, in the given sample of HCPs who are often under-researched. The models thus derived through the novel Max.Min Procedure, explain the relevance of each model in incrementally explaining the dimensions of ProQoL. For instance, for developing an intervention as a future perspective, perceived stress can be considered as a significant contributor to the dimensions of ProQoL, which is then followed by PFC, psychological morbidity, EFC and AC, representing the increasing R squared value for the variables.

These findings also pave a path to helping health psychologists include the respective models as part of intervention modules to improve professional quality of life among HCPs. However, the models may also be applied in the context of FCGs as the mean values obtained for the group, although not significant were close to those obtained by the HCPs.

The *fifth hypothesis* posited that the psychological variables perceived stress, psychological morbidity, well-being, PFC, EFC, and AC predict the levels of CS, BO, and STS in HCPs and FCGs of patients with cancer.

For the analysis of the levels of CS, initially a comparison was made between low level of CS and the high level of compassions satisfaction. The study found that individuals who scored higher on perceived stress and AC were more likely to score low on CS. It was also seen that those who scored higher on PFC and EFC, were more likely to score high on CS. This was in line with previous study findings which state that there is a significant association between CS and PFC (Varadarajan & Rani, 2021). However, it also contradicts the previous research conclusions regarding the relationship between CS and EFC which found that CS is explained by lower levels of EFC (Meyerson, Gelkopf, Eli & Uziel, 2022).

Those who scored higher on psychological morbidity were more likely to score high on CS. This finding contradicted previous study findings (Cassidy, McLaughlin & Giles, 2015). However, those who scored higher on PFC and EFC were also likely to score high on CS which is in line with studies on FCGs as well as HCPs (Jang & Kim, 2014; Lynch, Shuster & Lobo, 2018).

Likewise, in comparison of medium level of CS with high level of CS, it was found that individuals who scored higher on psychological morbidity and well-being had a greater likelihood of scoring high on CS as well.

While this finding is meaningful in the case of well-being, it does not appear well justified in the case of psychological morbidity. The rationale that appears is that the high level of CS and high psychological morbidity may be going together due to the sensitivity that the helpers themselves possess while providing care to the patients through the journey of disease and treatment involving witnessing of pain and suffering and having to deal with the same. The same sensitivity that is contributing towards the compassion may also be behind their psychological morbidity. Being able to be compassionate with the patient who goes through the ups and downs through the disease progression and necessary treatments, may also be the background to create a subjective vulnerability while understanding the suffering. This sensitivity which is common with both compassion leading to satisfaction, but at the same time to their own psychological vulnerability owing to the witnessing and dealing with the pain appears paradoxical but seems to be coexisting. There are studies which show that such paradoxical variables may coexist. For instance, CS has been also seen among those experiencing BO and STS (Hinderer, VonRueden, Friedmann, McQuillan, Gilmore, Kramer, & Murray 2014; Hunsaker, Chen, Maughan, & Heaston, 2015; Bos, Shen, Prescott & Brown, 2022).

The contingency analysis for CS found that the classification was accurate with respect to the medium level of CS, and equally accurate in the low level of CS. However, in the high level of CS, it was biased towards the medium level of CS. Overall, this suggests that the model is more or less accurate to classify an individual into the levels of CS, however, on the level of 'low CS' it is suggested to be cautious, as it is more likely to classify an individual into medium level of CS although they belong to the low level of CS.

For BO, in both low and medium levels Vs the high level of BO, the study found that individuals who scored higher on perceived stress and AC were at a greater risk of scoring 'high level of BO' as well. This was evident in studies that explain the concept of BO as a phenomenon that emerges due to the prolonged exposure to stress and demanding situations (Jackson & Maslach 1982), especially in the context of medical field (Vetter, Vetter & Fowler, 2018; Bos, Shen, Prescott & Brown, 2022). Previous research on HCPs (van Oers, 2021; Behrani, Nasir, Khan, Maqsood, & Sulaiman, 2020; Ercolani, et al., 2020) also showed that AC predicted BO. In comparison of 'low level of BO' with 'high of BO', it was found that individuals who scored higher on well-being and EFC, were at a higher probability of scoring low level of BO. This finding is also supported by related recent research which suggests that high levels of BO can hamper HCPs well-being and lead to issues such as depression among them (Kwan, Chan, Cheng, Leung & Lau, 2021).

The contingency analysis for BO found that the classification was accurate with respect to the medium level of BO, and equally accurate in the high level of BO. However, in the low level of BO, it was biased towards the medium level of BO. Overall, this suggests that the model is reasonably accurate to classify an individual into the levels of BO, but also suggests that caution

needs to be exercised with regards to classifying an individual into the 'low level of BO' as they are most likely to fall under the medium level of BO although they belong to the low level of BO.

For STS, in the low Vs high level of STS, the study seen that those who scored higher on psychological morbidity, had a greater risk of scoring high levels of STS; which was in line with findings of previous research (Chan, Ahmad, Yusof, Ho, & Krupat, 2015); likewise, in the medium Vs high level of STS, those who scored higher on EFC were at a greater risk of scoring high levels of STS, contrary to the findings of previous research (Lynch, Shuster & Lobo, 2018). The findings also show that individuals who scored high on PFC, were at lower risk of experiencing high levels of STS. This was in line with a previous study which stated that oncology HCPs reported to manage stress using social support and problem-solving coping (Pronost, et al., 2012).

The contingency analysis for STS found that the classification was accurate with respect to the medium level of STS, and equally accurate in the low level of STS. However, in the high level of STS, it was biased towards the medium level of STS. Overall, this suggests that the model is more or less accurate to classify an individual into the levels of STS. However, on the level of 'high STS' it is suggested to be cautious, as there is more likelihood of an individual being classified into medium level of STS although they belong to the high level of STS

In addition to the above, quantitative analysis, based on the findings an in-depth interview was conducted with HCPs and FCGs. The in-depth interviews explored their perceptions of their perceptions of BO and STS. For BO, the responses indicated that there was a predominance of perceptions which were "job related" and "patient related". The sub-themes emerged were such as "increased work load", "lack of cooperation", "boredom", "role ambiguity", "task overload", and "limitations in expansion of knowledge". The job related perceptions of BO reflected the various

aspects of lack of clarity in providing the necessary role framework and direction with regards to work roles and task assignment. The reality of the limited work force especially in oncology healthcare has been found to be a major cause for the work overload and task over load among the HCPs. Other aspects reported were related to restriction to expansion of knowledge caused predominantly due to the role ambiguity as well as work overload which seemingly does not allow a future scope for fruitful learning endeavours and expansion of the HCPs.

Under the main theme *"Patient related"* (issues), the sub-themes emerged were "Limitations in taking up new challenges", "increased patient intake", "gradual lowering of compassion" and "irritability due to patient behaviour". The participants reported that the increase in patient intake as per the directives and requirements is a major setback and perceived to cause BO as the HCPs has to compromise on the patient-centred care that needs to be provided. It was also reported that the HCPs perceived limitations in taking up new tasks and challenges as they are often occupied in providing routine care to the patients leading to a sense of monotony and boredom. Patient behaviour was also reported to be a major cause of irritability among the HCPs, again owing to the number of patients they treat in a particular point in time. They find it challenging to cater to the necessary informational needs and provide reassurances to the patient and their caregivers as expected due to the constraints of time and resources. Cumulatively all such reported factors may result in their irritability. Finally the participants also reported a gradual lowering of compassion towards the care recipients owing to the shift from providing optimum care to reaching more number of patients and providing the primary care needed for all. This can hinder the role of these HCPs in major aspects of holistic care, such as providing information regarding the treatment plans, disseminating knowledge about the myths and misconceptions related to diagnosis, treatment, and remission.

Likewise, with respect to STS, the perceptions of the HCPs were mainly focused on the "work-related avoidance" and "emotions related to patients". The participants reported work related avoidance, in terms of limiting their interaction about work, avoiding work and work conversations. They also reported coming late and leaving early from work in order to avoid the possibility of being in painful and sad situations, as they often feel they are not able to do much for the patients. It was also reported that they often feel overloaded and try to avoid changing a treatment plan as it often involves many procedures that are taxing and time-consuming, which in turn leads to a sense of dissatisfaction with regards to providing optimum care to the patients.

As part of the perceptions of STS the theme 'emotions related to patients' showed that aspects like witnessing traumatic circumstances like the loss of an otherwise healthy patient, the agony of the patients and their caregivers, forming emotional attachments with patients, breaking bad news to them and being a part of one's worst aspect of life were reported.

On the other hand, with FCGs, the interactions appeared restrained as they seem to have felt apprehensive and guilty talking about feeling burdened, 'burnt-out' or feeling overwhelmed while caring for their family member. However they reported that social limitations, financial needs, fatigue due to caregiving tasks, neglecting other responsibilities, and information support, when enquired regarding their perceptions of BO. With regards to STS, witnessing pain of their family member, fear of losing them, uncertainty around the diagnosis, progression of disease, treatment and other aspects of personal and professional life, and sadness due to remission of the disease were indicated to be the causes of STS.

Conclusion

The findings of the study give an elaborate picture of the various variables such as perceived stress, PFC, psychological morbidity, EFC, AC and well-being, that are best suited to predict the CS, BO and STS among HCPs and FCGs of patients with cancer. The study also shows us that BO and STS were significantly higher among HCPs when compared to the FCGs. This calls for attention toward developing relevant health psychological interventions to the HCPs to deal with BO and STS. Family caregivers as a group are silent sufferers and fairly good amount of research surrounding various psychological aspects of caregivers indicates the need for interventions for this group too.

Implications

The findings of the present study indicate the need to design appropriate health-psychological interventions culturally suitable for the care professionals and caregivers. The study paves an important path in expanding the health team with care providers from multiple areas including oncologists, oncology nurses, psychologists, rehabilitation specialists/occupational therapists, nutritionists and allied HCPs. Such a holistic health team approach will help in a trifold manner. It helps in strengthening the support to the patient, contributes to mutual support and cooperation within the health team and provides larger framework of the health team for caregivers to seek support and information. A more inclusive and integrative approach may involve integration of FCGs into the health support system. This support system may be customised according to the patient as well as the family needs and the social contexts of the patient.

It also points to a need to explore the psychological aspects of functioning among HCPs and FCGs. Both the groups usually fall into the range of high expectations in caregiving as they are expected

to provide utmost care to the patient who is the sufferer. The contributions of both HCPs and FCGs while are considered important, are at the same time taken for granted and sometimes remain unacknowledged. The psychological states of both these groups who deal with the pain and agony of the patient diagnosed with cancer hence also need to be explored in depth. Accordingly relevant psychosocial supportive interventions may be designed and implemented from a holistic health psychological perspective for a better overall functioning. This in turn results in enhanced care providing and stronger support to the patient as well.

Limitations and future directions

One of the major limitations of the study was that the sample was collected predominantly from one state in India. The scope of the study may be expanded across India to help explore and understand the various factors leading to negative outcomes on a larger cross-sectional sample. Based on the study findings, interventions for HCPs and FCGs of patients with cancer should also be designed and tested. The need to develop appropriate health psychological interventions to help deal with the negative as well as contribute to the positive aspects of caregiving/healthcare providing in Indian contexts is suggested.

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APPENDICES

Appendix A1

Form-A

Professional Quality of Life Scale – Healthcare Professionals

Below are some questions about your experiences, both positive and negative, as a *[helper]*. Consider each of the following questions about you and your current work situation. Tick the option that honestly reflects how frequently you experienced these things in the last 30 days.

S.No.	STATEMENTS	Never	Rarely	Some-times	Often	Very Often
1.	I am happy.					
2.	I am preoccupied with more than one patient of mine.					
3.	I get satisfaction from being able to *[help]* people.					
4.	I feel connected to others.					
5.	I jump or am startled by unexpected sounds.					
6.	I feel invigorated after working with those I *[help]*.					
7.	I find it difficult to separate my personal life from my life as a *[helper]*.					
8.	I am not as productive at work because I am losing sleep over traumatic experiences of a person I *[help]*.					
9.	I think that I might have been affected by the traumatic stress of those I *[help]*.					
10.	I feel trapped by my job as a *doctor/nurse*.					
11.	Because of my *[helping]*, I have felt "on edge" about various things.					
12.	I like my work as a *[helper]*.					
13.	I feel depressed because of the traumatic experiences of the people I *[help]*.					
14.	I feel as though I am experiencing the trauma of someone I have *[helped]*.					
15.	I have beliefs that sustain me.					
16.	I am pleased with how I am able to keep up with *[helping]* techniques and protocols.					
17.	I am the person I always wanted to be.					
18.	My work makes me feel satisfied.					
19.	I feel worn out because of my work as a *[helper]*.					
20.	I have happy thoughts and feelings about those I *[help]* and how I could help them.					
21.	I feel overwhelmed because my case [work] load seems endless.					
22.	I believe I can make a difference through my work.					
23.	I avoid certain activities or situations because they remind me of frightening experiences of the people I *[help]*.					
24.	I am proud of what I can do to *[help]*.					
25.	As a result of my *[helping]*, I have intrusive, frightening thoughts.					
26.	I feel "bogged down" by the system.					
27.	I have thoughts that I am a "success" as a *[helper]*.					
28.	I can't recall important parts of my work with trauma victims.					
29.	I am a very caring person.					
30.	I am happy that I chose to do this work.					

Appendix A2

Form-A

Professional Quality of Life Scale – Family Caregivers

Below are some questions about your experiences, both positive and negative, as a caregiver. Consider each of the following questions about you and your responsibility as a caregiver. Tick the option that honestly reflects how frequently you experienced these things in the last 30 days.

S.No.	STATEMENTS	Never	Rarely	Some-times	Often	Very Often
1.	I am happy.					
2.	I am preoccupied with more than one person in the family who needs my help.					
3.	I get satisfaction from being able to help my family member.					
4.	I feel connected to others.					
5.	I jump or am startled by unexpected sounds.					
6.	I feel invigorated (energized and strengthened) after working with my family member					
7.	I find it difficult to separate my personal life from my life as a caregiver for my family member.					
8.	I am not as productive at work because I am losing sleep over traumatic experiences of my family member with cancer.					
9.	I think that I might have been affected by the traumatic stress of the family member with cancer.					
10.	I feel trapped by my responsibility as a caregiver to my family member.					
11.	Because of my *[helping]*, I have felt "on edge" about various things.					
12.	I like my work as a helper for my family member.					
13.	I feel depressed because of the traumatic experiences of the people I *[help].*					
14.	I feel as though I am experiencing the trauma of someone I have *[helped].*					
15.	I have beliefs that sustain me.					
16.	I am pleased with how I am able to keep up with *[helping]* techniques and procedures for my family member as recommended by doctors.					
17.	I am the person I always wanted to be.					
18.	My work of helping my family member makes me feel satisfied.					
19.	I feel worn out because of my responsibilities as a caregiver.					
20.	I have happy thoughts and feelings about my family member I *[help]* and how I could help him/her.					
21.	I feel overwhelmed because my caregiving load seems endless.					
22.	I believe I can make a difference through my work in helping my family member.					
23.	I avoid certain activities or situations because they remind me of frightening experiences of the people I					
24.	I am proud of what I can do to *[help]* my family member.					

25.	**As a result of my *[helping]*, I have intrusive, frightening thoughts.**					
26.	**I feel "bogged down" by the system of treatment and support for my family member.**					
27.	**I have thoughts that I am a "success" as a *[helper] for my family member*.**					
28.	**I can't recall important parts of my work with my care receiver due to the trauma of their illness.**					
29.	**I am a very caring person.**					
30.	**I am happy that I chose to do this work toward helping my family member myself.**					

Appendix A3

Form-B

Personal life and professional life cannot be separated with relation to perception of stress. Stress tends to have a spillover effect. The questions asked below are concerned with both your personal and your professional life's feelings and thoughts during the last month. In each case, you are requested to indicate by ticking *how often* you felt or thought a certain way. A holistic response is requested when you answer these questions.

S.No.	STATEMENTS	Never	Rarely	Some-times	Often	Very Often
1.	In the last month, how often have you been upset because of something that happened unexpectedly?					
2.	In the last month, how often have you felt that you were unable to control the important things in your life?					
3.	In the last month, how often have you felt nervous and "stressed"?					
4.	In the last month, how often have you felt confident about your ability to handle your personal problems?					
5.	In the last month, how often have you felt that things were going your way?					
6.	In the last month, how often have you found that you could not cope with all the things that you had to do?					
7.	In the last month, how often have you been able to control irritations in your life?					
8.	In the last month, how often have you felt that you were on top of things?					
9.	In the last month, how often have you been angered because of things that were outside of your control?					
10.	In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?					

Appendix A4

Form-C

Please indicate for each of the five statements which is closest to how you have been feeling over the last two weeks.
Notice that higher numbers mean better well-being.
(Example: If you have felt cheerful and in good spirits more than half of the time during the last two weeks, put a tick in the box with the number 3 in the upper right corner)

	Over the last two weeks	All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
1.	I have felt cheerful and in good spirits.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
2.	I have felt calm and relaxed.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
3.	I have felt active and vigorous.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
4.	I woke up feeling fresh and rested.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0
5.	My daily life has been filled with things that interest me.	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1	☐ 0

Appendix A5

Form-D

Have you recently?

1.	Been able to concentrate on what you're doing?	Better than usual	Same as usual	Less than usual	Much less than usual
2.	Lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
3.	Felt you were playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
4.	Felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable
5.	Felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
6.	Felt you couldn't overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
7.	Been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
8.	Been able to face up to your problems?	More so than usual	Same as usual	Less so than usual	Much less able
9.	Been feeling unhappy and depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
10.	Been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual
11.	Been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
12.	Been feeling reasonably happy, all things considered	More so than usual	About same as usual	Less so than usual	Much less than usual

Form-E

These items deal with ways you've been coping with the stress in your life. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the items says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not— just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

	STATEMENTS	I haven't been doing this at all	I've been doing this a little bit	I've been doing a medium amount	I've been doing this a lot
1.	I've been turning to work or other activities to take my mind off things.				
2.	I've been concentrating my efforts on doing something about the situation I'm in.				
3.	I've been saying to myself "this isn't real".				
4.	I've been using alcohol or other drugs to myself feel better.				
5.	I've been getting emotional support from others.				
6.	I've been giving up trying to deal with it.				
7.	I've been taking action to try to make the situation better.				
8.	I've been refusing to believe that it has happened.				
9.	I've been saying things to let my unpleasant feeling escape.				
10	I've been getting help and advice from other people.				
11	I've been using alcohol or other drugs to help me get through it				
12	I've been trying to see it in a different light, to make it seem more positive.				
13	I've been criticizing myself.				
14	I've been trying to come up with a strategy about what to do.				
15	I've been getting comfort and understanding from someone.				
16	I've been giving up the attempt to cope.				
17	I've been looking for something good in what is happening.				
18	I've been making jokes about it.				
19	I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.				
20	I've been accepting the reality of the fact that it has happened.				
21	I've been expressing my negative feelings.				
22	I've been trying to find comfort in my religion or spiritual beliefs				
23	I've been trying to get advice or help from other people about what to do.				

24	I've been learning to live with it.				
25	I've been thinking hard about what steps to take.				
26	I've been blaming myself for things that happened.				
27	I've been praying or meditating.				
28	I've been making fun of the situation.				

Appendix A7

ఫారం - ఏ

ఒక డాక్టర్/నర్సుగా మీరు ఎదుర్కొనే సానుకూల మరియు ప్రతికూల అనుభవాల గురించి క్రింది ప్రశ్నలు అడగబడును. ప్రస్తుతం మీ వ్రత్తి గురించి మరియు మీ వ్రత్తికి సంబంధించిన విషయాల గురించి ప్రశ్నలు ఉంటాయి. మీరు గత 30 రోజుల్లో ఈ క్రింది పేర్కొనిన వాటిని ఎంత తరచుగా ఎదుర్కొన్నారో నిజాయితీగా "టిక్" ( ) చేసి తెలుపండి.

	వాక్యాలు	ఎప్పుడూ లేదు	అరుదుగా	కొన్నిసార్లు	తరచుగా	చాలా తరచుగా
1.	నేను సంతోషంగా ఉన్నను.					
2.	నా పేషంట్లో ఒకరి కన్న ఎక్కువ మంది గురించి ఆలోచ్నలతే నిమగ్నమై ఉన్నను.					
3.	నేను ఇతరులకు సహాయ పడగలుగుతున్నందుకు నేను సంత్రుప్తి పేందుతున్నాను.					
4.	నేను ఇతరులతే సత్-సంబంధాలు కలిగి ఉన్నను.					
5.	ఊహించని పెద్ద శబ్దాలు విన్నప్పుడు నేను ఉలిక్కి పదతాను.					
6.	నా వ్రత్తిలే నేను ఇతరులకు సహాయపడినప్పుడు నాకు చాలా ఉత్సాహభరితంగా అనిపిస్తుంది.					
7.	ఒక డాక్టర్/నర్సుగా సహాయపడే నా వ్రత్తినుండి, నా వ్యక్తిగతి జీవితాన్ని వేరు చేయడం నాకు కష్తంగా అనిపిస్తుంది.					
8.	పేషంట్లకు చికిత్స అందిస్తు వారి బాధాకర అనుభ్వాలను గురించి నాకు నిద్ర లేమి కలగడం వల్ల నేను పని సరిగ్గా చేయలేకపేతున్నను.					
9.	పేషంట్ల బాధాకరమైన స్థితి తాలూకు ప్రభావం నా పై ఉంటుందని అనుకుంటున్నాను.					
10	ఒక డాక్టర్/నర్సుగా నేను నా వ్రత్తిలో చిక్కుకుపోయినట్లు అనిపిస్తుంది.					
11	ఒక డాక్టర్/నర్సుగా నా పనిని బత్తి, ఇతర విషయాలలో నాకు చాలా చికాకుగా అనిపిస్తుంది.					
12	ఒక డాక్టర్/నర్సుగా నా వ్రత్తి అంటే నాకు చాలా ఇష్టం.					
13	క్యన్సర్ వల్ల పేషంట్లకి కలిగే బాధాకరమైన అనుభవాల వల్ల నాకు మానసికంగా క్రుంగినట్లు అనిపిస్తుంది.					
14	నేను చికిత్స అందిస్తున్న పేషంట్ల యొక్క బాధను నేను అనుభవిస్తున్నాను అనిపిస్తుంది.					

15	నన్ను నిలబెట్టే నమ్మకాలూ నాకు ఉన్నయి.					
16	నా వ్రత్తికి సంబంధించిన వివిధ వైద్యపద్ధతులు, మరియు వైద్యవిధానాలను నేను నిర్వర్తించే పద్ధతి నాకు సంతోషం కలిగిస్తుంది.					
17	నేను ఎప్పుడూ ఎలా ఉండాలనుకున్ననో అలాగే ఉన్నను.					
18	నా పని నాకు సంత్రప్తిని కలిగిస్తుంది.					
19	ఒక డాక్టర్/నర్సుగా నేను నా పని వల్ల అలిసిపోయినట్లు అనిపిస్తుంది.					
20	నా పేషంట్లగురించి, వారికి నేను చెయగలుగుతున్న సహయాన్ని గురించి నాకు సంతొషకరమైన ఆలోచనలు, భావనలు ఉన్నయి.					
21	అంతులేని నా పని భరం వలన, నేను మునిగిపోయినట్లు అనిపిస్తుంది.					
22	నేను చేసే వ్రత్తి ద్వార నేను మార్పు తీసుకురాగలనని నేను నమ్మతున్నాను.					
23	పేషంట్ల యొక్క బాధ మరియూ భయపూరితమైన సంఘటనలు గుర్తుకు తీసుకొనివచ్చె కొన్ని కార్యాలను, పరిస్థితులను నేను దాటివేస్తాను/తప్పించుకుంటాను.					
24	ఈ వైధ్యవ్రత్తిలో నేను చేయగల సహాయాన్ని గురించి నేను గర్విస్తున్నాను.					
25	ఈ వైధ్యవ్రత్తిలో నేను అందించే సేవలవల్ల నాకు అనుచితమైన మరియు భయపెట్టే ఆలోచనలు వస్తాయి.					
26	నేను ఈ వైధ్య వ్యవస్తలో నిమగ్నం అయిపోవడం వల్ల వేరే ఏ పనిని చేయలేకపోతున్నాను.					
27	ఈ వైధ్యవ్రత్తిలో నేను విజయంపొందానని అనుకుంటాను.					
28	తీవ్రఘతం (బాధ) అనుభవించిన రోగులకోసం నేను చేసే పనిలో కొన్ని ముఖ్య భాగలు నేను గుర్తు తెచ్చుకోలేకపోతుంటాను.					
29	నేను ఇతరుల ఇడ్ల చాలా శ్రర్ద చూపే వ్యక్తిని.					
30	నేను ఈ వైధ్యవ్రత్తిని ఏంచుకోవడం నాకు చాలా సంతోషంగా ఉంది.					

Appendix A8

ఫారం - బీ

మన వ్యక్తిగత జీవితంలో, వ్రత్తి జీవితంలో రెండిటిలోనూ తేడాలేకునండా ఒత్తిడిని ఎదుర్రోండం మామూలే. ఈరెండిటిలో కోన్ని సార్లు మన ఈ భాగంలో ఒత్తిళ్ళు మన జీవితంలోని మరోక భాగంపై చూపించవచ్చు. ఈ క్రింద పేర్కోనిన ప్రశ్నలు గత 30 రోజులుగా మీ వ్యక్తిగత,వ్రత్తికి సంబంధించ్చిన ఆలోచనలు, బవనల గురించి అడుగుతాయి. ప్రతి ప్రశ్నలో, మీరు ఎంత తరచుగా ఈ క్రింద పేర్కోనిన ఆలోచనలు, బవనల ఎదుర్కోన్నారొ "టిక్" గుర్తు పెట్టడం ద్వారా తేలీయజేయండి.గుర్తుంచుకోండి గత 30 రోజులుగా మీ వ్యక్తిగత మరియు పని ఒత్తిళ్ళను గురించి ఒక పరిపూర్నమైన అవగాహనతో క్రింది ప్రశ్నలకు జవాబు ఇవ్వండి.

	వాక్యాలు	ఎప్పుడూ లేదు	అరుదుగా	కొన్నిసార్లు	తర చుగా	చాలా తరచు గా
1.	గత నెలలో, అనుకోకుండా జరిగిన సంఘటనల వల్ల మీరు ఎంత తరచుగా కలత చెందారు?					
2.	గత నెలలో, మీ జీవితంలోని ముఖ్యమైన విషయాలను మీరు నియంత్రించ లేక పోయారని మీరు ఏంత తరచుగా భావించారు?					
3.	గత నెలలో, మీరు ఎంత తరచుగా భయము మరియు ఒత్తిడికి గురైయ్యారు?					
4.	గత నెలలో, మీ వ్యక్తిగత సమస్యలను పరిష్కరంచుకోగల సామర్థ్యం మీకు ఉన్నదన్న విశ్వాసాన్ని ఎంత తరచుగా అనిభావించారు?					
5.	గత నెలలో, మీ జీవితంలో మీరు అనుకున్న విధంగానే పనులు, విషయాలు ఎంత తరచుగా జరిగాయని భావిస్తున్నరు?					
6.	గత నెలలో, మీరు చేయవలసిన పనులన్నీ మీరు చేయలేక పోయినట్లు మీకు ఎంత తరచుగా అనిపించింది?					
7.	గత నెలలో, మీరు మీ జీవితంలూని చికాకులను ఎంత తరచుగా నియంత్రించగలిగారు అని మీకు అనిపించింది?					
8.	గత నెలలో, మీరు మీ పనులన్నింటిపై నియంత్రణ కలిగి ఉన్నారని భావించారా?					
9.	గత నెలలో, మీ నియంత్రించలేకపోయిన విషయాల వల్ల మీరు ఎంత తరచుగా కోపం చెందారు?					

10	గత నెలలో, మీరు అధిగమించలేని కష్టాలు మీ జీవితంలో ఎంతెత్తుగా పేరుకుపోతున్నయని ఎంత తరచుగా భావించారు?					

ఫారం - సి

క్రింది పంక్తులలో 5 వక్యాలు ఉన్నయి. గత 2 వారాలగా మీరు వీటిని ఎంత తరచుగా ఎదుర్కొన్నరో ప్రక్కన ఇవ్వబడిన బాక్సులో ‘టిక్’ చేసి తెలపండి. దీనిబట్టి మీ మానసిక శ్రేయస్సు తెలుసుకోవచ్చు. బాక్సు ప్రక్కన అంకెను గమనించండి.పెద్ద అంకె, అధిక మానసిక శ్రేయస్సును సూచిస్తుంది. (ఉదా: మీద్విప్రశ్నలో "నేను సంతోషంగా మరియు ఉత్సాహంగా ఉన్నాను" అని ఉంది. ఒకవేళ్ గత 2 వారాలలో మీకు "సగంకన్నా ఎక్కువ సార్లు" అలా ఉన్నిట్లు అనిపిస్తే, 3 అంకె ప్రక్కన ఉన్న బాక్సులో ‘టిక్’ చేయండి.

	గత రెండు వారాలగా	ప్రతీ సారి	చాలా సార్లు	సగం కంటే ఎక్కువ సార్లు	సగం కంటే తక్కువ సార్లు	కొన్ని సార్లు	అసలు ఎప్పుడూ కాదు/లేదు
1.	నేను సంతోషంగా మరియు ఉత్సాహంగా ఉన్నాను.	5	4	3	2	1	0
2.	నేను ప్రశాంతంగా మరియు విశ్రాంతిగా ఉన్నాను.	5	4	3	2	1	0
3.	నేను చురుకుగా మరియూ శక్తివంతంగా ఉన్నను.	5	4	3	2	1	0
4.	నేను తాజాగా మరియు విశ్రాంతిగా ప్రాద్దున్నే లేచాను.	5	4	3	2	1	0
5.	నా రూజువారి జీవితం నాకు ఆసక్తి కలిగించే విషయాలతో నిండి ఉంది.	5	4	3	2	1	0

Appendix A10

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మీరు ఇటీవల కాలంలో ఈ క్రింది అంశాలలో ఎలాంటి అనుభవాన్ని పొందారు?

1.	మీరు ఇటీవల చేసేపనిపై ద్రష్టి / ఏకాగ్రత పెట్ట గలిగారా?	ఎప్పుడూ కంటే చాలా బాగా	ఎప్పుడూ లాగానే	ఇదివరకటి కన్నాతక్కువగా	చాలా తక్కువ
2.	మీకు ఆందోళనచే ఎక్కువగా నిద్రలేమి కలిగిందా?	అస్సల లేదు	ఎప్పడి కన్నా ఎక్కువగా ఏమీ లేదు	ఎప్పటి కంటే ఎక్కువగా	ఎప్పటి కంటే చాల ఎక్కువగా
3.	మీరు చేసే పనులలో మీరు ఉపయోగకరమైన పాత్ర వహిస్తున్నట్లు అనిపించిందా?	ఎప్పటి కంటే చాలా ఎక్కువగా	ఎప్పుడూ లాగానే	ఎప్పటి కంటే తక్కువ ఉపయోగపడుతున్నాను	ఎప్పటి కంటే చాలా తక్కువ ఉపయోగపడుతున్నాను
4.	మీ జీవితంలో జరుగుతున్న విషయాలగురించి సమర్ధతలో తీసుకొగలుగుతున్నానని భవిస్తున్నారా?	ఎప్పటి కంటే చాలా ఎక్కువగా	ఎప్పుడూ లాగానే	ఇదివరకటి కన్నాతక్కువగా	చాలా తక్కువ సామర్థ్యత
5.	నిరంతరంగా వత్తిడికి గురి అవుతున్నంట్లు అనిపిస్తుందా?	అస్సల లేదు	ఎప్పడి కన్నా ఎక్కువగా ఏమీ లేదు	ఎప్పటి కంటే ఎక్కువగా	ఎప్పటి కంటే చాల ఎక్కువగా
6.	మీ జీవితంలో కలిగిన ఇబ్బందులను అధిగమించ లేక పోతున్నట్లు మీకు అనిపించిందా?	అస్సల లేదు	ఎప్పడి కన్నా ఎక్కువగా ఏమీ లేదు	ఎప్పటి కంటే ఎక్కువగా	ఎప్పటి కంటే చాల ఎక్కువగా
7.	మీ రోజువారీ పనులను ఆస్వాదించ గలుగు తున్నారా?	ఎప్పటి కంటే చాలా ఎక్కువగా	ఎప్పుడూ లాగానే	ఇదివరకటి కన్నాతక్కువగా	చాలా తక్కువ
8.	మీరు మీ సమస్యలను ఎదుర్కోగరిగారా?	ఎప్పటి కంటే చాలా ఎక్కువగా	ఎప్పుడూ లాగానే	ఇదివరకటి కన్నాతక్కువగా	చాలా తక్కువ సామర్థ్యత
9.	మీరు ఇటీవల అసంత్రుప్తికి మరియు నిరాశకు గురి అయ్యారా?	అస్సల లేదు	ఎప్పడి కన్నా ఎక్కువగా ఏమీ లేదు	ఎప్పటి కంటే ఎక్కువగా	ఎప్పటి కంటే చాల ఎక్కువగా

10.	మీ మీద విశ్వాసం మీరు కోల్పోతున్నరా?	అస్సల లేదు	ఎప్పడి కన్నా ఎక్కువగా ఏమీ లేదు	ఎప్పటి కంటే ఎక్కువగా	ఎప్పటి కంటే చాల ఎక్కువ గా
11.	మీ గురించి మీరు ఒక విలువలేని వ్యక్తినని అనుకుంటున్నరా?	అస్సల లేదు	ఎప్పడి కన్నా ఎక్కువగా ఏమీ లేదు	ఎప్పటి కంటే ఎక్కువగా	ఎప్పటి కంటే చాల ఎక్కువ గా
12.	మీ జీవితంలో జరుగుతున్న అన్ని విషయాలను పరిగణించినప్పతికినీ, మీరు చల వరకు సంతోషంగా ఉన్నట్లు మీకు అనిపిస్తుందా?	ఎప్పటి కంటే చాలా ఎక్కువగా	ఎప్పుడూ లాగానే	ఎప్పుడు కంటే తక్కువగానే	చాలా తక్కువ

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క్రింద ఇచ్చిన అంశాలు మీరు మీ జీవితంలో ఒత్తిడి ఎలా ఎదుర్కొంటున్నారన్న విషయాలను గురించినవి. సమస్యలని పరిష్కరించుకోవడానికి చాలా మార్గాలు ఉన్నాయి. ప్రస్తుతం మీకున్న సమస్యని ఎదుర్కొవడానికి మీరేం చేస్తుఇన్నారనేది, ఈ క్రింది అఒంశాలు ప్రశ్నిస్తాయి. వివిధ పరిస్థితులని వివిధ పద్ధతుల్లో ఎదుర్కొంటారు. మీరు మీ పరిస్థితులనెలా ఎదుర్కొన్లనే ప్రయత్నం చేశారన్న విషయంలోనే మా ఆసక్తి. ఈ అంశాల్లో ప్రతి అంశమూ ఏదో ఒక ఒత్తిడి నెదుర్కోనే పద్ధతిని సూచిస్తుంది. ప్రతి అంశం ప్రస్తావించే విషయాన్ని మీరు ఎంత వరకు పాటిస్తున్నారో మేము తెలుసుకోవాలనుకుంటున్నాము. ఎంతగా ఎదుర్కోంటున్నారు, ఎంత తరచుగా ఎదుర్కోంటున్నారనేది మాకు ముఖ్యం. ఫలానా పద్ధతి పని చేస్తుందా లేదా అని కాక మీరు అలా చేస్తున్నారా లేదా అన్న విషయాన్ని ఆధారం చేసుకుని సమాధానాలివ్వండి. క్రింద ఇచ్చిన సమాధనాల్లో ఒక దానిని ఎంచుకొడి. ప్రతి అంశాన్ని మీ మనసులో క్షుణ్ణంగా అర్థం చేసుకొని మీ విషయంలో ఎది నిజమో, ఆ సమాధానిచ్చి సూచిచండి.

	వాక్యాలు	నేను ఇలా ఎప్పుడూ చేయలేదు	నేను ఇలా చేయడం కొద్దిగా జరిగేది	నేను ఇలా చేయడం మధ్యమ పరిమాణంలో జరిగేది	నేను ఇలా చేయడం చాలా ఎక్కువగా జరిగేది
1.	నా మనసుని విషయాల మీద నుండి మళ్ళించుకోడానికి పని వైపుకి, ఈతర కార్యక్రమాలవైపుకి వెళ్ళిపోతుంటాను.				
2.	నేనున్న పరిస్థితి గురించి ఏదైనా చేయడానికి నా ప్రయత్నాలను కేంద్రీకరిస్తూ ఉన్నాను.				
3.	ఇది నిజం సాదని నాకు నేను చెప్పుకుంటున్నాను.				
4.	కోంచెం మెరుగుగా అనిపించడానికి ఆల్కహాల్ (మంధు), మాదక ద్రవ్యలని వాడుతున్నాను.				
5.	ఇతర దగ్గర్నుండి నాకు ఉద్వేగ సహకారం దొరుకుతున్నది.				
6.	విషయాన్ని తట్టుకుని ఏదైనా చేసే ప్రయత్నాలను వదిలేస్తువస్తున్నాను.				
7.	పరిస్థితిని మేరుగు పరచడానికి చర్యలు తీసుకుంటున్నాను.				
8.	ఇలా జరిగిందని నేను నమ్మట్లేదు.				
9.	నాలోని సంతోషాన్నివ్వని భావాలను తప్పించుకోడానికి ఏదో చెప్తూ ఉంటాను.				
10	ఇతరుల దగ్గర్నించి నాకు సహాయం, సలహా దోరుకుతున్నాయి.				
11	ఈ పరిస్థితి దాటడానికి ఆల్కహాల్ (మంధు), మాదక ద్రవ్యలని సేవిస్తున్నాను.				

12	పరిస్థితి మరింత సానుకూలంగా కనిపించడానికి, పరిస్థితిని వేరే ద్రక్కోణంలో చూసే ప్రయత్నం చేస్తున్నాను.				
13	నన్ను నేను విమర్శించుకుంటున్నాను.				
14	ఏం చేయాలనే విషయంలో ఒక విధానాన్ని రూపొందించే ప్రయత్నం చేస్తున్నాను.				
15	ఎవరో అర్థం చేసుకుని, సౌకర్యాన్నిస్తున్నారు (ఆధరిస్తున్నారు).				
16	పరిస్థినేదురొ్కనే ప్రయత్నాన్ని వదిలేస్తున్నాను.				
17	జరుగుతున్నదానిలో ఏదో మంచి కోసం వేతుక్కుంటున్నాను.				
18	విషయాన్ని గురించి హాస్యంగా మాట్లాడుతున్నాను.				
19	ఈ విషయాన్ని గురంచి హాస్యంగా తక్కువ ఆలోచించడానికి- సినిమాలసి వేళ్ళడం, టివి చూడతాం, చదవటం, పగటికలలుకనడం, నిద్రపోవడం, షాపీంగ్ చేయడం వొటివి ఏదో ఒకటి చేస్తున్నాను.				
20	జరుగుతున్న విషయంలో వాస్తవాన్ని అంగీకరిస్తున్నను.				
21	నా వ్యతిరేక భావాలను వ్యక్తికరిస్తున్నాను (వ్యక్తపరుస్తుంటాను).				
22	నా మతంలోనూ, ఆధ్యాత్మిక విశ్యాసాలలోనూ సాంత్వన వేతుకుంటున్నాను.				
23	ఏం చేయాలన్న విషయంలో ఇతరుల వద్ద నుండి సహాయం, సలహా కోసం ప్రయత్నిస్తున్నాను.				
24	ఏ పరిస్థితితో పాటు జీవించడం నేర్చుకుంటున్నాను.				
25	ఏం చర్యలు తీసుకోవాలో తీవ్రంగా ఆలోచిస్తున్నాను.				
26	జరిగిన విషయాలనకు నన్ను నేనే నందించుకుంటున్నాను.				
27	ప్రార్థన లేదా ధ్యానం చేస్తున్నాను.				
28	పరిస్థితిని ఎగతాళి చేస్తున్నాను.				

Appendix A12

Demographic Details (Doctors & Nurses)

Name **పేరు:** Age **వయస్సు:**
Gender: Male/Female/Transgender **లింగం: పురుషుడు/స్త్రీ/ఇతరులు**

Marital Status: Unmarried/ Married/ Divorced / Separated /Widow(er)
వైవాహిక స్థితి:
వివాహంకానివారు/వివాహితులు/విడాకులుతీసుకున్నవారు/విడిపొయినవారు/వితంతువు
Social Economic Status (SES) / **ఆర్థిక స్థితి:**

Phone Number: **ఫొను నంబరు:**

Position at work: **మీరు చెసే వ్రుత్తి:**

Area of Specialization: **స్పెసలైజేషన్/ప్రావీణ్యతారంగం:**

Years of experience : A. India (No. of Years ____) B. Abroad (No. of

Years ____)

వ్రత్తిలొ అనుభవం (సంవత్సరాలలో): (ఎ). భారత దేశంలో____ (బి). విదేశాలలో____
Unit of care: **ఆసుపత్రిలో పని చేసే విభాగం:**

No. of Working Hours Per week: **వారంలో ఎన్ని గంటలు పని చేస్తారు:**

Work timings: **పని వేళలు:**

Night duties: **నైట్ డ్యుటీలు: (ఎ). ఎన్ని రొజులు_____ (బి). ఎన్ని గంటలు_____**

Do you have control over your work timings: A. Yes B. No

మీ డ్యుటీ టైమింగ్లు మీ ఆధినంలొ ఉంటాయ? : (ఎ). ఉంటాయి (బి). ఉండవు

Is your choice over work timings: A. Accepted B. Not Accepted

మీ డ్యుటీ టైమింగ్లు మార్చుకొవడనికి మీకు అధికారం ఉంటుందా? : (ఎ). ఉంటాయి (బి). ఉండవు

Do you work beyond your official hours: A. Yes B. No

మీ నియమిత పని గొటలు కంటే మీరు ఎక్ష్టా గంతలు పని చేయాల్సివస్తుందా? : (ఎ). అవును (బి).

కాదు

If Yes, how often _____ and no. of extra hours worked _____

ఒక వేళ అవును అయితె, వారంలొ ఎన్ని రోజులు అథికంగ/ఎక్కువగా పనిచేస్తారు_____; వారానికి

ఎన్ని గంటలు పని చేస్తారూ_____

Physical Illness (if any): A. Yes B. No
మీకు ఎదేనా శారీరక అనారోగ్యాలు ఉన్నయా? : (ఎ). అవును_____ (బి). లేదు
Duration of Illness: ఏంతకాలం నుండి అనారోగ్యం ఉంది? _____

Psychological Illness (if any): A. YesB. No
మీకు ఎదేనా మానసిక అనారోగ్యాలు ఉన్నయా? : (ఎ). అవును (బి). లేదు
Duration of Illness: ఏంతకాలం నుండి అనారోగ్యం ఉంది? _____

Personal information: Smoking / Alcohol / Drugs / Others / NA
అలవాట్లు: ధూమపానం/మధ్యపానం/మాదకద్రవ్యలు/ఏమీలేదు.

Appendix A13

Demographic Details (Family Caregivers)

Name పేరు :
Age వయస్సు :
Gender : Male/Female/Transgender లింగం: పురుషుడు/స్త్రీ/ఇతరులు
Marital Status : Unmarried/ Married/ Divorced/ Separated/ Widow(er)
వైవాహిక స్థితి:
వివాహంకానివారు/వివాహితులు/విడాకులుతీసుకున్నవారు/విడిపొయినవారు/వితంతువు
Social Economic Status (SES) / ఆర్థిక స్థితి:

Phone Number ఫోను నంబరు :
Relationship to the patient :
పేషెంట్ తో గల సంబంధం :

Do you live with the patient? : Yes/No
పేషెంట్ తో మీరు కలిసి ఉంటున్నారా : అవును/ లేదు

For how long have you been providing care? _____
సంరక్షకులు గ అనుభవం _____

Occupation వృత్తి :
Has your employment status changed as a result of caregiving?
సంరక్షకులు గ ఐనందున వృతిరీచ మార్పులు : అవును/ లేదు

Physical Illness (if any): A. Yes B. No

మీకు ఎదేనా శారీరక అనారోగ్యాలు ఉన్నయా? : (ఎ) అవును_____ (బి). లేదు

Duration of Illness: ఏంతకాలం నుండి అనారోగ్యం ఉంది? _____

Psychological Illness (if any): A. Yes B. No

మీకు ఎదేనా మానసిక అనారోగ్యాలు ఉన్నయా? : (ఎ). అవును (బి). లేదు

Duration of Illness: ఏంతకాలం నుండి అనారోగ్యం ఉంది? _____

Personal information: Smoking / Alcohol / Drugs / Others / NA

అలవాట్లు: ధూమపానం/మధ్యపానం/మాదకద్రవ్యలు/ఏమీలేదు.
Number of additional caregivers, if any:
మీరు కాకుండా ఇతరు సంరక్షకులు:

Patient Details

Age వయస్సు:
Gender: Male/Female/Transgender లింగం: పురుషుడు/స్త్రీ/ఇతరులు
Stage of Cancer:
క్యాన్సర్ స్టేజి:
Time since onset:

క్యాన్సర్ నిర్ధారణ సమయం

First time occurrence/relapse: Yes/No

క్యాన్సర్ పునఃస్థితి: అవును/ లేదు

Type of treatment: radiation/chemotherapy/surgery/others:

చికిత్స రకం : రేడియేషన్/ కెమోథెరపీ / సర్జరీ/ ఇతరుకు:

Appendix B1

UNIVERSITY OF HYDERABAD

INSTITUTIONAL ETHICS COMMITTEE DECISION LETTER

IEC No. **Application No:**	UH/IEC/2018/24	**Date of review**	21-12-2021
Project Title:	Psychological Issues in Healthcare Professionals and Family Caregivers of Patients with Cancer		
Principal Investigator/ Co-PI:	PI: D. Asha CI: Dr. G. Padamaja		
Participating Institutes if any	----	Approval from Participating Institute	----
Documents received and reviewed	Protocol & ICF		
In case of renewal submission of update	----		
Decision of the IEC:	Approved Duration: One year from date of approval		
Any other Comments Requirements for conditional Approval	----		
Members Present	Dr. A.S. Sreedhar, Dr. M. Srinivas, Prof. B. R. Shamanna, Dr. M. Varalakshmi, Sri. A. Madhava Rao, Dr. Stalin Choudary, Prof. Pingali Sailaja, Dr. M. K. Aruansree and Dr. Deepa Srinivas		

Please note:

a. Any amendments in the protocol must be informed to the Ethics committee and fresh approval taken.
b. Any serious adverse event must be reported to the Ethics Committee within 48 hours in writing (mentioning the protocol No. or the study ID)
c. Any advertisement placed in the newspapers, magazines must be submitted for approval.
d. If the conduct of the study is to be continued beyond the approved period, an application for the same must be forwarded to the Ethics Committee.
e. It is hereby confirmed that neither you nor any of the members of the study team participated in the decision making/voting procedures and declared conflict of interest.

Chairman	Member Secretary	Convenor
(Dr. A S Sreedhar)	(Prof. B. R. Shamanna)	(Dr. M. Varalakshmi)

Address: School of Medical Sciences, University of Hyderabad, C. R. Rao Road, Gachibowli, Hyderabad-5000046
Tel (O): +91-040-23135470/23135471 Email: iec_uoh@uohyd.ernet.in, deanmd@uohyd.ernet.in

Appendix B2

Informed Consent Form (Healthcare Professionals)

Centre for Health Psychology
School of Medical Sciences
University of Hyderabad

Title of the study: Psychological Issues in Healthcare Professionals and Family Caregivers of Patients with Cancer

Principal Investigator: D. Asha, Ph.D. Research Scholar, Centre for Health psychology, University of Hyderabad.

About the Study: The present study attempts to understand various psychological factors related to your work-life as an oncology healthcare professional

Why Are You Approached?

The present study explores the psychological aspects highly related to doctors and nurses working in the field of oncology healthcare. Therefore, you are approached for the purpose of collecting relevant information for the study. Your role will be to fill out questionnaires or answer few questions which will be related to your work-life as an oncology healthcare professional. If and when you consent to participate in the study, you will be approached for a single session for about 15-30 minutes for information.

Confidentiality: The information thus collected will be used exclusively for research purposes and your identity will remain confidential.

Any Potential Risks?

As the present study attempts to understand the psychological factors influencing the oncology healthcare professionals, the question asked will be in the same direction. Thus, in the course of participation you may come across a question or answer choice that you may find unpleasant, upsetting or otherwise objectionable. For instance, a few of the questions may cause you to think about negative emotional states. In case of any emotional distress felt, you may feel free to withdraw your participation from the study completely An attempt will be made by the investigator to handle any such emotional distress faced After the completion of the seat, debriefing will be done In case of any doubts queries de investigator can be contacted, whose details are given below

By signing this informed consent form, you are indicating that you understand the following:

- The nature of the present research study
- Your role in the present arch study
- Your voluntary participation in the present research study

By voluntarily signing this form, you are also starting that you are over 18 years of age and consent to participate in this study.

Statement of Consent: I have read the above provided information I have asked any questions I had regarding the research and these have been answered to the best of my satisfaction

I, _____, consent to participate in the study.

Contact Information of Investigator:

D. Asha
Ph.D. Research Scholar
Centre for Health Psychology University of Hyderabad, Gachibowli,
Hyderabad-500046. Ph. No. 9866454242; E-mail: asha.benjamin1993@yahoo.com

సమ్మతి ప్రకతన పత్రం (డాక్టర్లు /నర్సులు)
సెంతెర్ ఫార్ హేల్థ్ ప్స్యాచలొగ్య
స్చూల్ ఒఫ్ మెదిచల్ సైన్సెసెస్
యునివెర్సిత్య ఒఫ్ హ్యారబదు

పరిషొదన సీర్షిక: క్యన్సెర్ వ్యథిగ్రస్థులని సెవచెసె కుతుంబసభ్యుల, వైద్య-ఆరొగ్య సమ్రక్షహ సిబ్బందికి సంబందించిన మానసిక అంశాల పరిషొదన

పరిషొకురలు: డి. ఆష, ఫిహ్.డి రిసేర్చ్ స్కలర్, సెంతెర్ ఫార్ హేల్థ్ ప్స్యాచలొగ్య, యునివెర్సిత్య ఒఫ్ హ్యారబదు

పరిషొదన గురించి: క్యన్సెర్ రొగుల ఆరొగ్య సమ్రక్షణ నిపునుదిగా/నిపుణిరలిగా మీ వ్యక్తిగత మరియు వ్రుత్తిగత జీవితం గుర్చి మానసిక మరియు సామాజిక అఒశాలపై ఈ ప్రస్తుత పరిశోధన జరుగుతున్నది

మిమ్మన్ని ఈ పరిశొధనలో ఎందుకు భాగస్వములను చెస్తున్నము?
పైన పెర్కొనినట్లు, ఈ పరిశొధన క్యన్సెర్ రోగులకు ఆఆరోగ్య సంరక్షక సెవలు అంధజెస్తున్న నెపుణులు, కుటుంబసభ్యుల మాననిక మరియు సామజిక ఆంశాల గురించి తెలుసుకొనె ప్రయత్నము. ఆ ప్రక్రియలొ భాగంగ తగిన సమాచారం పొంధటానికి క్యన్సెర్ విభగంలొ పనిచేస్తున్న డాక్టర్లు మరియు నర్సులు, కుటుంబసభ్యులు అయిన మీకు ఈ ప్రశ్నపత్రాలు ఇవ్వడం జరుగుతుంది. మీరు ఈ ప్రశ్నలకు తగిన సమధానలు ఇవ్వవల్సిందిగా కోరబడుతున్నది. మీ అంగీకారాన్ని బట్టీ మీ ఖాళీ సమయంలో ఒక 15-20 నిమిషాలకు మీ వద్ధనునండి తగిన సమాచారం సేకరించడం జరుగుతుంది.
మీరు ఇచ్చిన సమాచారం యొక్క గొప్యత: ఈ పరిశొధన విషయమై తెలిపిన మీ వృత్తి మరియు వ్యక్తిగత సమచరము కేవలం పరిశొధన పరంగా వాడబడుతుంది. మీ గుర్తింపుకి సంబంధీంచిన ఎటువంటి వివరాలైనా గొప్యంగా ఉంచబడుతాయి

పరిశోధనకు సంబంధిచిన నష్టాలు ఏమైనా ఉన్నాయా?
ఈ పరిశొధన శీర్షిక మీకు మరియు మీ వృత్తికి/సేవకి సంబంధించిన మానసిక, సామాజిక అఒశాలకు సంబంధించింది కాబట్టి, మిమ్మల్ని అడిగే ప్రశ్నలు కూడా అదే దిశగా ఉంటాయి. ఈ ప్రక్రియలో ఏవైనా ప్రశ్నలలో గానీ జవాబు ఎఒపికలలో గానీ, మీకు అభ్యంతరకరమైన్ లేదా బాధ కలిగించె ఇబ్బంది కరమైన విషయాలు ఉండే అవకాశముండొచ్చు. ఉదాహరణకి కొన్ని ప్రశ్నలు మిమ్మల్ని మీ ప్రతికూల ఉద్రెగ స్తితులను గురించి ఆలోచించేట్లు చేయగలవు. మీకెమైన ఉద్రేగకరమైన ఒత్తిడికలిగించే పరిస్థితులలో పరిశొధన నుంచి మీరు స్వేచ్చగ, పూర్తిగా వైదొలగచ్చు. మీరు అటువంటి స్థితులాగుండా వెళుతుంటే ఈ పరిశోధకురాలు మిమ్మల్ని ఆ ఒత్తడికి గురైన మానసిక స్థితి నుంది బయటకు వచ్చేందుకు సహాయం చేస్తుంది. పరిశొధన పత్రాలను నింపడం పూర్తిచేసిన తరువాత మీకు ఈ పరిశోధనకు సంబంధించిన సందెహాలు, ప్రశ్నలను, ఇతర వివరాలగురించి స్పష్టత ఇవ్వడం జరుగుతుంది. ఒక వేల మీకు ఏవైనా ప్రశ్నలలొ సందేహాలు ఉన్నచో, క్రింద ఇవ్వబడిన వివరాలద్వారా పరిశొధకురలిని సంప్రదించవచ్చు.

ఈ సమాచార-సమ్మతి పత్రంలో సంతకం చేయడం ద్వరా, మీరు ఈ క్రింద వాటిని అర్ధం చేసుకున్నరని సూచిస్తున్నరు:

- ప్రస్తుత పరిశొధన అధ్యయనం యొక్క స్వభావం/అర్ధం.
- ప్రస్తుత పరిశొధన అధ్యయనంలొ మీ పాత్ర.
- ప్రస్తుత పరిశొధన అధ్యయనంలొ మీ స్వచ్చంద భాగస్వామ్యం.

ఈ సమ్మతి పత్రంలో సంతకం చేయడం వల్ల మీరు ఈ పరిశోధనలో స్వచ్చందంగా పాల్గొంటున్నారని, మరియూ మీరు 18 ఏళ్ల పైబడి ఉన్నారని మీరు తెలీయజేస్తున్నరు.

సమ్మతి ప్రకటన: నేను పైన ఇవ్వబడిన సమాచారాన్ని పూర్తిగా అర్ధం చేసుకున్నను. పరిశొధనగురించి నాకు ఉన్న సందేహాలను, ప్రశ్నలను నేను అడిగి పూర్తిగ సంత్రుప్తి కరమైన జవబులు పొందాను.

_____, అనే నేను ఈ పరిశోధనలో పాల్గొనడానికి నా సమ్మతిని ప్రకటిస్తున్నాను.

పరిశోదకురాలి సమాచార వివరాలు:
డి. ఆష
ఫిహ్.డి రిసేర్చ్ స్కలర్,
సెంతెర్ ఫార్ హేల్థ్ ప్స్యాచలొగ్య,
యునివెర్సిత్య ఒఫ్ హ్యారబదు, గచ్చిబౌలి,
హ్యారబదు-500046.
ఫొను నంబరు: 9866454242; ఈ-మేలు: asha.benjamin17@gmail.com

పరిశోదకురాలి సంతకం

పరిశొధనలొ పాల్గొనేవారి సంతకం

Appendix B4

Informed Consent Form (Family Caregivers)

Centre for Health Psychology
School of Medical Sciences
University of Hyderabad

Title of the study: Psychological Issues in Healthcare Professionals and Family Caregivers of Patients with Cancer

Principal Investigator: D. Asha, Ph.D. Research Scholar, Centre for Health psychology, University of Hyderabad.

About the Study: The present study is done to understand the impact of cancer on family caregivers. The study attempts to assess various psychological changes that have occurred in your personal life after becoming a caregiver to a family member who is diagnosed and being treated for cancer.

Why Are You Approached?

The present study explores the various psychological aspects related to caregivers tending to their family members who have cancer. Therefore, you are approached for the purpose of collecting relevant information for the study. Your role will be to answer few questions or fill out questionnaires regarding your experience as a caregiver. If and when you consent to participate in the study, you will be approached only for a single session for about 15-20 minutes for information.

Confidentiality: The information thus collected will be used exclusively for research purposes and your identity will remain confidential.

Any Potential Risks?

As the present study attempts to understand your psychological state of mind in relation to your role as a caregiver, the questions asked will be in the same manner. Thus, in the course of participation you may come across a question or answer choice that you may find unpleasant, upsetting or otherwise objectionable. For instance, a few of the questions may cause you to think about negative emotional states. In case of any emotional distress felt, you may feel free to withdraw your participation from the study completely. An attempt will be made by the investigator to handle any such emotional distress faced. After the completion of the session, debriefing will be done. In case of any doubts/ queries, the investigator can be contacted, whose details are given below. Sometimes you may feel that you have answered few questions incorrectly, however, it should be kept in mind that there is no right or wrong answer.

By signing this informed consent form, you are indicating that you understand the following:

- The nature of the present research study
- Your role in the present research study
- Your voluntary participation in the present research study

By voluntarily signing this form, you are also stating that you are over 18 years of age and consent to participate in this study.

Statement of Consent: I have read the above provided information. I have asked any questions I had regarding the research and these have been answered to the best of my satisfaction

I, _____, consent to participate in the study.

Contact Information of Investigator:

D. Asha
Ph.D. Research Scholar
Centre for Health Psychology University of Hyderabad, Gachibowli,
Hyderabad-500046. Ph. No. 9866454242; E-mail: asha.benjamin1993@yahoo.com

Appendix B5

సమ్మతి ప్రకతన పత్రం (సంరక్షకుడు)

సెంతెర్ ఫొర్ హేల్థ్ ప్స్యాచలొగ్య
స్కూల్ ఒఫ్ మెదిచల్ సైన్సెసెస్
యునివెర్సిత్య ఒఫ్ హ్యారబదు

పరిషొదన సీర్షిక: క్యన్సెర్ వ్యథిగ్రస్థులని సెవచెసె కుతుంబసభ్యుల, వైద్య-ఆరొగ్య సమ్రక్షహ సిబ్బందికి సంబందించిన మానసిక అంశాల పరిషొదన

పరిషొకురలు: డి. ఆష, ఫిహ్.డి రిసేర్చ్ స్కలర్, సెంతెర్ ఫొర్ హేల్థ్ ప్స్యాచలొగ్య, యునివెర్సిత్య ఒఫ్ హ్యారబదు

పరిషొదన గురించి: క్యన్సెర్ రొగుల ఆరొగ్య సమ్రక్షణ నిపునుదిగా/నిపుణిరలిగా మీ వ్యక్తిగత మరియు వ్రుత్తిగత జీవితం గుర్చి మానసిక మరియు సామాజిక అఒశాలపై ఈ ప్రస్తుత పరిశోధన జరుగుతున్నది

మిమ్మన్ని ఈ పరిశొధనలో ఎందుకు భాగస్వములను చెస్తున్నము?
పైన పెర్కొనినట్లు, ఈ పరిశొధన క్యన్సర్ రోగులకు ఆఆరోగ్య సంరక్షక సెవలు అంధజెస్తున్న నెపుణులు, కుటుంబసభ్యుల మాననిక మరియు సామజిక ఆంశాల గురించి తెలుసుకొనె ప్రయత్నము. ఆ ప్రక్రియలొ భాగంగ తగిన సమాచారం పొంధటానికి క్యన్సర్ విభగంలొ పనిచేస్తున్న డాక్టర్లు మరియు నర్సులు, కుటుంబసభ్యులు అయిన మీకు ఈ ప్రశ్నపత్రాలు ఇవ్వడం జరుగుతుంది. మీరు ఈ ప్రశ్నలకు తగిన సమధానలు ఇవ్వవల్సిందిగా కోరబడుతున్నది. మీ అంగీకారాన్ని బట్టీ మీ ఖాళీ సమయంలో ఒక 20-25 నిమిషాలకు మీ వద్ధనునండి తగిన సమాచారం సేకరించడం జరుగుతుంది.
మీరు ఇచ్చిన సమాచారం యొక్క గొప్యత: ఈ పరిశొధన విషయమై తెలిపిన మీ వృత్తి మరియు వ్యక్తిగత సమచరము కేవలం పరిశొధన పరంగా వాడబడుతుంది. మీ గుర్తింపుకి సంబంధించిన ఎటువంటి వివరాలైనా గొప్యంగా ఉంచబడుతాయి

పరిశోధనకు సంబంధిచిన నష్టాలు ఏమైనా ఉన్నాయా?
ఈ పరిశొధన శీర్షిక మీకు మరియు మీ వృత్తికి/సేవకి సంబంధించిన మానసిక, సామాజిక అఒశాలకు సంబంధించింది కాబట్టి, మిమ్మల్ని అడిగే ప్రశ్నలు కూడా అదే దిశగా ఉంటాయి. ఈ ప్రక్రియలో ఏవైనా ప్రశ్నలలో గానీ జవాబు ఎఒపికలలో గానీ, మీకు అభ్యంతరకరమైన్ లేదా బాధ కలిగించె ఇబ్బంది కరమైన విషయాలు ఉండే అవకాశముండొచ్చు. ఉదాహరణకి కొన్ని ప్రశ్నలు మిమ్మల్ని మీ ప్రతికూల ఉద్రెగ స్తితులను గురించి ఆలోచించేట్లు చేయగలవు. మీకెమైన ఉద్రేగకరమైన ఒత్తిడికలిగించే పరిస్థితులలో పరిశొధన నుంచి మీరు స్వేచ్చగ, పూర్తిగా వైదొలగచ్చు. మీరు అటువంటి స్థితులాగుండా వెళుతుంటే ఈ పరిశోధకురాలు మిమ్మల్ని ఆ ఒత్తడికి గురైన మానసిక స్థితి నుంది బయటకు వచ్చేందుకు సహాయం చేస్తుంది. పరిశొధన పత్రాలను నింపడం పూర్తిచేనిన తరువాత మీకు ఈ పరిశోధనకు సంబంధించిన సందెహాలు, ప్రశ్నలను, ఇతర వివరాలగురించి స్పష్టత ఇవ్వడం జరుగుతుంది. ఒక వేల మీకు ఏవైనా ప్రశ్నలలో సందేహాలు ఉన్నచో, క్రింద ఇవ్వబడిన వివరాలద్వారా పరిశొధకురలిని సంప్రదించవచ్చు.
ఈ సమాచార-సమ్మతి పత్రంలో సంతకం చేయడం ద్వరా, మీరు ఈ క్రింద వాటిని అర్ధం చేసుకున్నరని సూచిస్తున్నరు:

- ప్రస్తుత పరిశొధన అధ్యయనం యొక్క స్వభావం/అర్ధం.
- ప్రస్తుత పరిశొధన అధ్యయనంలొ మీ పాత్ర.
- ప్రస్తుత పరిశొధన అధ్యయనంలొ మీ స్వచ్చంద భాగస్వామ్యం.

ఈ సమ్మతి పత్రంలొ సంతకం చేయడం వల్ల మీరు ఈ పరిశోధనలొ స్వచ్చందంగా పాల్గొంటున్నారని, మరియూ మీరు 18 ఏళ్ల పైబడి ఉన్నారని మీరు తెలీయజేస్తున్నరు.

సమ్మతి ప్రకటన: నేను పైన ఇవ్వబడిన సమాచారాన్ని పూర్తిగా అర్ధం చేసుకున్నను. పరిశొధనగురించి నాకు ఉన్న సందేహాలను, ప్రశ్నలను నేను అడిగి పూర్తిగ సంత్రుప్తి కరమైన జవబులు పొందాను.

_____, అనే నేను ఈ పరిశోధనలో పాల్గొనడానికి నా సమ్మతిని ప్రకటిస్తున్నాను.

పరిశోదకురాలి సమాచార వివరాలు:
డి. ఆష
ఫిహ్.డి రిసేర్చ్ స్కలర్,
సెంతెర్ ఫొర్ హేల్థ్ ప్స్యాచలొగ్య,
యునివెర్సిత్య ఒఫ్ హ్యారబదు, గచ్చిబౌలి,
హ్యారబదు-500046.
ఫొను నంబరు: 9866454242; ఈ-మేలు: asha.benjamin17@gmail.com

పరిశోదకురాలి సంతకం పరిశొధనలొ పాల్గొనేవారి సంతకం

Appendix C1

Below are the results of tests of Between-Subject Effects derived from Multivariate analysis of covariance (MANCOVA) conducted for the purpose of Step-up Regression and Max.Min Procedure (Objective 4)

Model 1 Variables

R Squared values for perceived stress

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[d]
Corrected Model	tot_cs	3464.983[a]	2	1732.492	24.189	.000	.137	48.378	1.000
	tot_bo	9861.009[b]	2	4930.505	72.820	.000	.322	145.639	1.000
	tot_sts	6990.718[c]	2	3495.359	40.182	.000	.208	80.365	1.000
Intercept	tot_cs	85790.894	1	85790.894	1197.820	.000	.797	1197.820	1.000
	tot_bo	21842.066	1	21842.066	322.590	.000	.513	322.590	1.000
	tot_sts	25167.695	1	25167.695	289.327	.000	.486	289.327	1.000
Perceived Stress	tot_cs	3317.132	1	3317.132	46.314	.000	.131	46.314	1.000
	tot_bo	9378.960	1	9378.960	138.520	.000	.312	138.520	1.000
	tot_sts	6935.448	1	6935.448	79.730	.000	.207	79.730	1.000
Caregiver	tot_cs	276.997	1	276.997	3.867	.050	.012	3.867	.500
	tot_bo	710.591	1	710.591	10.495	.001	.033	10.495	.898

	tot_sts	1088.763	1	1088.763	12.516	.000	.039	12.516	.941

a. R Squared = .137 (Adjusted R Squared = .131)
b. R Squared = .322 (Adjusted R Squared = .318)
c. R Squared = .208 (Adjusted R Squared = .203)

Note. tot_cs – Total score Compassion Satisfaction, tot_bo – Total score Burnout, tot_sts – Total score Secondary Traumatic Stress, Caregiver – Type of Caregiver [Professionals and Family Caregivers]

R Squared values for psychological morbidity

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[d]
Corrected Model	tot_cs	965.178[a]	2	482.589	6.048	.003	.038	12.096	.883
	tot_bo	8271.055[b]	2	4135.527	56.725	.000	.270	113.451	1.000
	tot_sts	8920.374[c]	2	4460.187	55.282	.000	.265	110.563	1.000
Intercept	tot_cs	104637.708	1	104637.708	1311.384	.000	.811	1311.384	1.000
	tot_bo	47510.511	1	47510.511	651.683	.000	.680	651.683	1.000
	tot_sts	43951.043	1	43951.043	544.750	.000	.640	544.750	1.000
Psychological Morbidity	tot_cs	817.326	1	817.326	10.243	.002	.032	10.243	.891
	tot_bo	7789.006	1	7789.006	106.839	.000	.259	106.839	1.000
	tot_sts	8865.105	1	8865.105	109.878	.000	.264	109.878	1.000
Caregiver	tot_cs	15.042	1	15.042	.189	.664	.001	.189	.072

	tot_bo	647.061	1	647.061	8.875	.003	.028	8.875	.844
	tot_sts	1677.294	1	1677.294	20.789	.000	.064	20.789	.995

a. R Squared = .038 (Adjusted R Squared = .032)
b. R Squared = .270 (Adjusted R Squared = .266)
c. R Squared = .265 (Adjusted R Squared = .261)

Note. tot_cs – Total score Compassion Satisfaction, tot_bo – Total score Burnout, tot_sts – Total score Secondary Traumatic Stress, Caregiver – Type of Caregiver [Professionals and Family Caregivers]

R Squared values for well-being

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[d]
Corrected Model	tot_cs	1601.145[a]	2	800.572	10.302	.000	.063	20.603	.987
	tot_bo	8619.683[b]	2	4309.842	60.055	.000	.282	120.110	1.000
	tot_sts	5921.063[c]	2	2960.531	32.719	.000	.176	65.439	1.000
Intercept	tot_cs	78969.947	1	78969.947	1016.168	.000	.769	1016.168	1.000
	tot_bo	164604.750	1	164604.750	2293.662	.000	.882	2293.662	1.000
	tot_sts	152134.579	1	152134.579	1681.365	.000	.846	1681.365	1.000
Well-Being	tot_cs	1453.293	1	1453.293	18.701	.000	.058	18.701	.991
	tot_bo	8137.634	1	8137.634	113.393	.000	.270	113.393	1.000

	tot_sts	5865.793	1	5865.793	64.828	.000	.175	64.828	1.000
Caregiver	tot_cs	93.807	1	93.807	1.207	.273	.004	1.207	.195
	tot_bo	824.788	1	824.788	11.493	.001	.036	11.493	.922
	tot_sts	1150.397	1	1150.397	12.714	.000	.040	12.714	.945

a. R Squared = .063 (Adjusted R Squared = .057)
b. R Squared = .282 (Adjusted R Squared = .277)
c. R Squared = .176 (Adjusted R Squared = .171)

Note. tot_cs – Total score Compassion Satisfaction, tot_bo – Total score Burnout, tot_sts – Total score Secondary Traumatic Stress, Caregiver – Type of Caregiver [Professionals and Family Caregivers]

R Squared values for problem-focused coping

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[d]
Corrected Model	tot_cs	2806.305[a]	2	1403.152	19.019	.000	.111	38.039	1.000
	tot_bo	2923.528[b]	2	1461.764	16.174	.000	.096	32.347	1.000
	tot_sts	1079.753[c]	2	539.876	5.079	.007	.032	10.157	.818
Intercept	tot_cs	9618.573	1	9618.573	130.377	.000	.299	130.377	1.000
	tot_bo	39959.097	1	39959.097	442.124	.000	.591	442.124	1.000
	tot_sts	32889.081	1	32889.081	309.387	.000	.503	309.387	1.000
Problem-focused Coping	tot_cs	2658.453	1	2658.453	36.035	.000	.105	36.035	1.000
	tot_bo	2441.479	1	2441.479	27.014	.000	.081	27.014	.999

	tot_sts	1024.483	1	1024.483	9.637	.002	.031	9.637	.872

a. R Squared = .111 (Adjusted R Squared = .105)
b. R Squared = .096 (Adjusted R Squared = .090)
c. R Squared = .032 (Adjusted R Squared = .026)

Note. *tot_cs – Total score Compassion Satisfaction, tot_bo – Total score Burnout, tot_sts – Total score Secondary Traumatic Stress, Caregiver – Type of Caregiver [Professionals and Family Caregivers]*

R Squared values for emotion-focused coping

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[d]
Corrected Model	tot_cs	540.565[a]	2	270.282	3.329	.037	.021	6.659	.628
	tot_bo	545.524[b]	2	272.762	2.779	.064	.018	5.558	.545
	tot_sts	380.557[c]	2	190.279	1.752	.175	.011	3.505	.366
Intercept	tot_cs	15546.384	1	15546.384	191.506	.000	.385	191.506	1.000
	tot_bo	23814.403	1	23814.403	242.630	.000	.442	242.630	1.000
	tot_sts	16210.140	1	16210.140	149.280	.000	.328	149.280	1.000
Emotion-focused Coping	tot_cs	392.713	1	392.713	4.838	.029	.016	4.838	.592
	tot_bo	63.475	1	63.475	.647	.422	.002	.647	.126
	tot_sts	325.288	1	325.288	2.996	.084	.010	2.996	.407
Caregiver	tot_cs	112.812	1	112.812	1.390	.239	.005	1.390	.217
	tot_bo	453.182	1	453.182	4.617	.032	.015	4.617	.572

	tot_sts	77.105	1	77.105	.710	.400	.002	.710	.134

a. R Squared = .021 (Adjusted R Squared = .015)
b. R Squared = .018 (Adjusted R Squared = .011)
c. R Squared = .011 (Adjusted R Squared = .005)

Note. *tot_cs – Total score Compassion Satisfaction, tot_bo – Total score Burnout, tot_sts – Total score Secondary Traumatic Stress, Caregiver – Type of Caregiver [Professionals and Family Caregivers]*

R Squared values for avoidant coping

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[d]
Corrected Model	tot_cs	1535.928[a]	2	767.964	9.855	.000	.061	19.710	.983
	tot_bo	6197.796[b]	2	3098.898	38.892	.000	.203	77.784	1.000
	tot_sts	4654.613[c]	2	2327.306	24.596	.000	.138	49.192	1.000
Intercept	tot_cs	52341.756	1	52341.756	671.680	.000	.687	671.680	1.000
	tot_bo	14784.835	1	14784.835	185.553	.000	.377	185.553	1.000
	tot_sts	16229.599	1	16229.599	171.521	.000	.359	171.521	1.000
Avoidant Coping	tot_cs	1388.077	1	1388.077	17.813	.000	.055	17.813	.988
	tot_bo	5715.747	1	5715.747	71.734	.000	.190	71.734	1.000
	tot_sts	4599.343	1	4599.343	48.608	.000	.137	48.608	1.000
Caregiver	tot_cs	227.880	1	227.880	2.924	.088	.009	2.924	.399

	tot_bo	779.674	1	779.674	9.785	.002	.031	9.785	.877
	tot_sts	164.511	1	164.511	1.739	.188	.006	1.739	.260

a. R Squared = .061 (Adjusted R Squared = .054)
b. R Squared = .203 (Adjusted R Squared = .197)
c. R Squared = .138 (Adjusted R Squared = .133)

Note. tot_cs – Total score Compassion Satisfaction, tot_bo – Total score Burnout, tot_sts – Total score Secondary Traumatic Stress, Caregiver – Type of Caregiver [Professionals and Family Caregivers]

Appendix C2

Model 2 Variables

R Squared values for perceived stress and psychological morbidity

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[d]
Corrected Model	tot_cs	3591.737[a]	3	1197.246	16.758	.000	.142	50.275	1.000
	tot_bo	10996.040[b]	3	3665.347	57.085	.000	.360	171.254	1.000
	tot_sts	9787.598[c]	3	3262.533	41.773	.000	.291	125.318	1.000
Intercept	tot_cs	82184.624	1	82184.624	1150.372	.000	.790	1150.372	1.000
	tot_bo	19563.377	1	19563.377	304.683	.000	.500	304.683	1.000
	tot_sts	21692.985	1	21692.985	277.751	.000	.477	277.751	1.000
Perceived Stress	tot_cs	2626.559	1	2626.559	36.765	.000	.108	36.765	1.000
	tot_bo	2724.985	1	2724.985	42.439	.000	.122	42.439	1.000
	tot_sts	867.224	1	867.224	11.104	.001	.035	11.104	.913
Psychological Morbidity	tot_cs	126.754	1	126.754	1.774	.184	.006	1.774	.264
	tot_bo	1135.031	1	1135.031	17.677	.000	.055	17.677	.987
	tot_sts	2796.881	1	2796.881	35.810	.000	.105	35.810	1.000
Caregiver	tot_cs	172.595	1	172.595	2.416	.121	.008	2.416	.341

	tot_bo	1190.930	1	1190.930	18.548	.000	.057	18.548	.990
	tot_sts	2081.995	1	2081.995	26.657	.000	.080	26.657	.999

a. R Squared = .142 (Adjusted R Squared = .133)
b. R Squared = .360 (Adjusted R Squared = .353)
c. R Squared = .291 (Adjusted R Squared = .284)

Note. tot_cs – Total score Compassion Satisfaction, tot_bo – Total score Burnout, tot_sts – Total score Secondary Traumatic Stress, Caregiver – Type of Caregiver [Professionals and Family Caregivers]

R Squared values for perceived stress and well-being

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[d]
Corrected Model	tot_cs	3548.397[a]	3	1182.799	16.523	.000	.140	49.570	1.000
	tot_bo	11984.312[b]	3	3994.771	65.522	.000	.392	196.565	1.000
	tot_sts	8470.384[c]	3	2823.461	34.257	.000	.252	102.770	1.000
Intercept	tot_cs	25939.284	1	25939.284	362.362	.000	.543	362.362	1.000
	tot_bo	15060.781	1	15060.781	247.024	.000	.447	247.024	1.000
	tot_sts	15065.153	1	15065.153	182.783	.000	.375	182.783	1.000
Perceived Stress	tot_cs	1947.252	1	1947.252	27.202	.000	.082	27.202	.999
	tot_bo	3364.629	1	3364.629	55.186	.000	.153	55.186	1.000
	tot_sts	2549.322	1	2549.322	30.930	.000	.092	30.930	1.000

Well-Being	tot_cs	83.414	1	83.414	1.165	.281	.004	1.165	.190
	tot_bo	2123.303	1	2123.303	34.826	.000	.102	34.826	1.000
	tot_sts	1479.667	1	1479.667	17.953	.000	.056	17.953	.988
Caregiver	tot_cs	350.142	1	350.142	4.891	.028	.016	4.891	.597
	tot_bo	1618.460	1	1618.460	26.546	.000	.080	26.546	.999
	tot_sts	1913.139	1	1913.139	23.212	.000	.071	23.212	.998

a. R Squared = .140 (Adjusted R Squared = .131)

b. R Squared = .392 (Adjusted R Squared = .386)

c. R Squared = .252 (Adjusted R Squared = .245)

Note. *tot_cs – Total score Compassion Satisfaction, tot_bo – Total score Burnout, tot_sts – Total score Secondary Traumatic Stress, Caregiver – Type of Caregiver [Professionals and Family Caregivers]*

R Squared values for perceived stress and problem-focused coping

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[d]
Corrected Model	tot_cs	5206.339[a]	3	1735.446	26.236	.000	.205	78.707	1.000
	tot_bo	10900.511[b]	3	3633.504	56.314	.000	.356	168.942	1.000
	tot_sts	7281.855[c]	3	2427.285	28.120	.000	.217	84.361	1.000
Intercept	tot_cs	11495.453	1	11495.453	173.784	.000	.363	173.784	1.000
	tot_bo	10110.782	1	10110.782	156.702	.000	.339	156.702	1.000
	tot_sts	8582.751	1	8582.751	99.432	.000	.246	99.432	1.000
Perceived Stress	tot_cs	2400.034	1	2400.034	36.283	.000	.106	36.283	1.000
	tot_bo	7976.983	1	7976.983	123.632	.000	.288	123.632	1.000
	tot_sts	6202.103	1	6202.103	71.852	.000	.191	71.852	1.000
Problem-focused Coping	tot_cs	1741.355	1	1741.355	26.325	.000	.079	26.325	.999
	tot_bo	1039.501	1	1039.501	16.111	.000	.050	16.111	.979
	tot_sts	291.138	1	291.138	3.373	.067	.011	3.373	.449
Caregiver	tot_cs	404.538	1	404.538	6.116	.014	.020	6.116	.693
	tot_bo	857.811	1	857.811	13.295	.000	.042	13.295	.953
	tot_sts	1177.956	1	1177.956	13.647	.000	.043	13.647	.958

a. R Squared = .205 (Adjusted R Squared = .197)

b. R Squared = .356 (Adjusted R Squared = .350)
c. R Squared = .217 (Adjusted R Squared = .209)

Note. *tot_cs – Total score Compassion Satisfaction, tot_bo – Total score Burnout, tot_sts – Total score Secondary Traumatic Stress, Caregiver – Type of Caregiver [Professionals and Family Caregivers]*

R Squared values for perceived stress and emotion-focused coping

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[d]
Corrected Model	tot_cs	4736.594[a]	3	1578.865	23.326	.000	.187	69.977	1.000
	tot_bo	10999.538[b]	3	3666.513	57.113	.000	.360	171.339	1.000
	tot_sts	7001.478[c]	3	2333.826	26.753	.000	.208	80.258	1.000
Intercept	tot_cs	19320.999	1	19320.999	285.441	.000	.483	285.441	1.000
	tot_bo	12654.223	1	12654.223	197.114	.000	.393	197.114	1.000
	tot_sts	8795.479	1	8795.479	100.823	.000	.248	100.823	1.000
Perceived Stress	tot_cs	4196.029	1	4196.029	61.991	.000	.169	61.991	1.000
	tot_bo	10454.014	1	10454.014	162.841	.000	.348	162.841	1.000
	tot_sts	6620.920	1	6620.920	75.896	.000	.199	75.896	1.000
Emotion-focused Coping	tot_cs	1271.611	1	1271.611	18.786	.000	.058	18.786	.991
	tot_bo	1138.529	1	1138.529	17.735	.000	.055	17.735	.987

	tot_sts	10.760	1	10.760	.123	.726	.000	.123	.064
Caregiver	tot_cs	535.364	1	535.364	7.909	.005	.025	7.909	.801
	tot_bo	1062.903	1	1062.903	16.557	.000	.051	16.557	.982
	tot_sts	1090.085	1	1090.085	12.496	.000	.039	12.496	.941

a. R Squared = .187 (Adjusted R Squared = .179)
b. R Squared = .360 (Adjusted R Squared = .353)
c. R Squared = .208 (Adjusted R Squared = .201)

Note. *tot_cs – Total score Compassion Satisfaction, tot_bo – Total score Burnout, tot_sts – Total score Secondary Traumatic Stress, Caregiver – Type of Caregiver [Professionals and Family Caregivers]*

R Squared values for perceived stress and avoidant coping

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[d]
Corrected Model	tot_cs	3774.211[a]	3	1258.070	17.758	.000	.149	53.275	1.000
	tot_bo	11750.513[b]	3	3916.838	63.446	.000	.384	190.337	1.000
	tot_sts	8622.077[c]	3	2874.026	35.082	.000	.257	105.245	1.000
Intercept	tot_cs	51845.783	1	51845.783	731.835	.000	.706	731.835	1.000
	tot_bo	6320.451	1	6320.451	102.380	.000	.251	102.380	1.000
	tot_sts	8024.354	1	8024.354	97.949	.000	.243	97.949	1.000

Perceived Stress	tot_cs	2238.282	1	2238.282	31.595	.000	.094	31.595	1.000
	tot_bo	5552.717	1	5552.717	89.944	.000	.228	89.944	1.000
	tot_sts	3967.464	1	3967.464	48.429	.000	.137	48.429	1.000
Avoidant Coping	tot_cs	309.227	1	309.227	4.365	.038	.014	4.365	.549
	tot_bo	1889.504	1	1889.504	30.607	.000	.091	30.607	1.000
	tot_sts	1631.360	1	1631.360	19.913	.000	.061	19.913	.994
Caregiver	tot_cs	136.395	1	136.395	1.925	.166	.006	1.925	.282
	tot_bo	220.582	1	220.582	3.573	.060	.012	3.573	.470
	tot_sts	473.601	1	473.601	5.781	.017	.019	5.781	.669

a. R Squared = .149 (Adjusted R Squared = .140)
b. R Squared = .384 (Adjusted R Squared = .378)
c. R Squared = .257 (Adjusted R Squared = .249)

Note. *tot_cs – Total score Compassion Satisfaction, tot_bo – Total score Burnout, tot_sts – Total score Secondary Traumatic Stress, Caregiver – Type of Caregiver [Professionals and Family Caregivers]*

Model 3 Variables

R Squared values for perceived stress, problem-focused coping and psychological morbidity

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[d]
Corrected Model	tot_cs	6103.706[a]	4	1525.926	24.063	.000	.240	96.252	1.000
	tot_bo	11425.336[b]	4	2856.334	45.333	.000	.374	181.331	1.000
	tot_sts	9803.000[c]	4	2450.750	31.296	.000	.292	125.184	1.000
Intercept	tot_cs	7180.685	1	7180.685	113.236	.000	.271	113.236	1.000
	tot_bo	6666.418	1	6666.418	105.803	.000	.258	105.803	1.000
	tot_sts	3970.138	1	3970.138	50.699	.000	.143	50.699	1.000
Perceived Stress	tot_cs	3232.056	1	3232.056	50.968	.000	.144	50.968	1.000
	tot_bo	2948.105	1	2948.105	46.789	.000	.133	46.789	1.000
	tot_sts	827.840	1	827.840	10.572	.001	.034	10.572	.900
Problem-focused Coping	tot_cs	2511.969	1	2511.969	39.612	.000	.115	39.612	1.000
	tot_bo	429.296	1	429.296	6.813	.009	.022	6.813	.740
	tot_sts	15.401	1	15.401	.197	.658	.001	.197	.073
Psychological Morbidity	tot_cs	897.367	1	897.367	14.151	.000	.044	14.151	.963
	tot_bo	524.826	1	524.826	8.329	.004	.027	8.329	.820
	tot_sts	2521.145	1	2521.145	32.195	.000	.096	32.195	1.000

a. R Squared = .240 (Adjusted R Squared = .230)
b. R Squared = .374 (Adjusted R Squared = .365)
c. R Squared = .292 (Adjusted R Squared = .282)

Note. *tot_cs – Total score Compassion Satisfaction, tot_bo – Total score Burnout, tot_sts – Total score Secondary Traumatic Stress, Caregiver – Type of Caregiver [Professionals and Family Caregivers]*

R Squared values for the perceived stress, problem-focused coping and well-being

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[d]
Corrected Model	tot_cs	5206.716[a]	4	1301.679	19.614	.000	.205	78.457	1.000
	tot_bo	12472.984[b]	4	3118.246	52.353	.000	.408	209.412	1.000
	tot_sts	8539.650[c]	4	2134.912	25.889	.000	.254	103.556	1.000
Intercept	tot_cs	9193.493	1	9193.493	138.531	.000	.313	138.531	1.000
	tot_bo	11580.147	1	11580.147	194.422	.000	.390	194.422	1.000
	tot_sts	9734.260	1	9734.260	118.042	.000	.280	118.042	1.000
Perceived Stress	tot_cs	1817.030	1	1817.030	27.380	.000	.083	27.380	.999
	tot_bo	3268.218	1	3268.218	54.871	.000	.153	54.871	1.000
	tot_sts	2515.717	1	2515.717	30.507	.000	.091	30.507	1.000
	tot_cs	1658.319	1	1658.319	24.988	.000	.076	24.988	.999

Problem-focused Coping	tot_bo	488.672	1	488.672	8.204	.004	.026	8.204	.815
	tot_sts	69.266	1	69.266	.840	.360	.003	.840	.150
Well-Being	tot_cs	.377	1	.377	.006	.940	.000	.006	.051
	tot_bo	1572.473	1	1572.473	26.401	.000	.080	26.401	.999
	tot_sts	1257.795	1	1257.795	15.253	.000	.048	15.253	.973
Caregiver	tot_cs	356.714	1	356.714	5.375	.021	.017	5.375	.637
	tot_bo	1626.081	1	1626.081	27.301	.000	.082	27.301	.999
	tot_sts	1916.233	1	1916.233	23.237	.000	.071	23.237	.998

a. R Squared = .205 (Adjusted R Squared = .195)
b. R Squared = .408 (Adjusted R Squared = .400)
c. R Squared = .254 (Adjusted R Squared = .244)

Note. *tot_cs – Total score Compassion Satisfaction, tot_bo – Total score Burnout, tot_sts – Total score Secondary Traumatic Stress, Caregiver – Type of Caregiver [Professionals and Family Caregivers]*

R Squared values for perceived stress, problem-focused coping and emotion-focused coping

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[d]
Corrected Model	tot_cs	5765.341[a]	4	1441.335	22.337	.000	.227	89.348	1.000
	tot_bo	11515.305[b]	4	2878.826	45.905	.000	.377	183.622	1.000
	tot_sts	7286.911[c]	4	1821.728	21.040	.000	.217	84.159	1.000
Intercept	tot_cs	7800.359	1	7800.359	120.886	.000	.285	120.886	1.000
	tot_bo	10391.983	1	10391.983	165.709	.000	.353	165.709	1.000
	tot_sts	7007.747	1	7007.747	80.935	.000	.210	80.935	1.000
Perceived Stress	tot_cs	2911.472	1	2911.472	45.120	.000	.129	45.120	1.000
	tot_bo	8568.817	1	8568.817	136.637	.000	.310	136.637	1.000
	tot_sts	5473.089	1	5473.089	63.210	.000	.172	63.210	1.000
Problem-focused Coping	tot_cs	1028.747	1	1028.747	15.943	.000	.050	15.943	.978
	tot_bo	515.767	1	515.767	8.224	.004	.026	8.224	.816
	tot_sts	285.434	1	285.434	3.297	.070	.011	3.297	.440
Emotion-focused Coping	tot_cs	559.002	1	559.002	8.663	.003	.028	8.663	.835
	tot_bo	614.794	1	614.794	9.803	.002	.031	9.803	.877
	tot_sts	5.056	1	5.056	.058	.809	.000	.058	.057

Caregiver	tot_cs	571.368	1	571.368	8.855	.003	.028	8.855	.843
	tot_bo	1098.222	1	1098.222	17.512	.000	.054	17.512	.987
	tot_sts	1116.466	1	1116.466	12.894	.000	.041	12.894	.947

a. R Squared = .227 (Adjusted R Squared = .217)
b. R Squared = .377 (Adjusted R Squared = .368)
c. R Squared = .217 (Adjusted R Squared = .207)

Note. tot_cs – Total score Compassion Satisfaction, tot_bo – Total score Burnout, tot_sts – Total score Secondary Traumatic Stress, Caregiver – Type of Caregiver [Professionals and Family Caregivers]

R Squared values for perceived stress, problem-focused coping and avoidant coping

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[d]
Corrected Model	tot_cs	5217.911[a]	4	1304.478	19.667	.000	.206	78.669	1.000
	tot_bo	12088.239[b]	4	3022.060	49.682	.000	.395	198.730	1.000
	tot_sts	8633.218[c]	4	2158.304	26.271	.000	.257	105.083	1.000
Intercept	tot_cs	7373.082	1	7373.082	111.162	.000	.268	111.162	1.000
	tot_bo	3250.821	1	3250.821	53.443	.000	.150	53.443	1.000
	tot_sts	2440.731	1	2440.731	29.708	.000	.089	29.708	1.000
	tot_cs	2051.065	1	2051.065	30.923	.000	.092	30.923	1.000

Perceived Stress	tot_bo	5397.844	1	5397.844	88.740	.000	.226	88.740	1.000
	tot_sts	3935.300	1	3935.300	47.900	.000	.136	47.900	1.000
Problem-focused Coping	tot_cs	1443.700	1	1443.700	21.766	.000	.067	21.766	.996
	tot_bo	337.726	1	337.726	5.552	.019	.018	5.552	.651
	tot_sts	11.140	1	11.140	.136	.713	.000	.136	.066
Avoidant Coping	tot_cs	11.572	1	11.572	.174	.676	.001	.174	.070
	tot_bo	1187.729	1	1187.729	19.526	.000	.060	19.526	.993
	tot_sts	1351.362	1	1351.362	16.449	.000	.051	16.449	.981
Caregiver	tot_cs	332.211	1	332.211	5.009	.026	.016	5.009	.607
	tot_bo	319.456	1	319.456	5.252	.023	.017	5.252	.627
	tot_sts	484.415	1	484.415	5.896	.016	.019	5.896	.677

a. R Squared = .206 (Adjusted R Squared = .195)

b. R Squared = .395 (Adjusted R Squared = .387)

c. R Squared = .257 (Adjusted R Squared = .247)

Note. *tot_cs – Total score Compassion Satisfaction, tot_bo – Total score Burnout, tot_sts – Total score Secondary Traumatic Stress, Caregiver – Type of Caregiver [Professionals and Family Caregivers]*

Model 4 Variables

R Squared values for perceived stress, problem-focused coping, psychological morbidity and well-being

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[d]
Corrected Model	tot_cs	6164.647[a]	5	1232.929	19.440	.000	.243	97.201	1.000
	tot_bo	12632.331[b]	5	2526.466	42.653	.000	.413	213.267	1.000
	tot_sts	10317.975[c]	5	2063.595	26.846	.000	.307	134.231	1.000
Intercept	tot_cs	4727.508	1	4727.508	74.541	.000	.197	74.541	1.000
	tot_bo	7728.842	1	7728.842	130.483	.000	.301	130.483	1.000
	tot_sts	4320.902	1	4320.902	56.212	.000	.156	56.212	1.000
Perceived Stress	tot_cs	2753.274	1	2753.274	43.412	.000	.125	43.412	1.000
	tot_bo	1811.684	1	1811.684	30.586	.000	.092	30.586	1.000
	tot_sts	456.674	1	456.674	5.941	.015	.019	5.941	.681
Problem-focused Coping	tot_cs	2385.791	1	2385.791	37.618	.000	.110	37.618	1.000
	tot_bo	271.104	1	271.104	4.577	.033	.015	4.577	.569
	tot_sts	43.306	1	43.306	.563	.453	.002	.563	.116
Psychological Morbidity	tot_cs	957.931	1	957.931	15.104	.000	.047	15.104	.972
	tot_bo	159.347	1	159.347	2.690	.102	.009	2.690	.373
	tot_sts	1778.325	1	1778.325	23.135	.000	.071	23.135	.998

Well-Being	tot_cs	60.941	1	60.941	.961	.328	.003	.961	.165
	tot_bo	1206.995	1	1206.995	20.377	.000	.063	20.377	.994
	tot_sts	514.975	1	514.975	6.700	.010	.022	6.700	.732
Caregiver	tot_cs	186.441	1	186.441	2.940	.087	.010	2.940	.401
	tot_bo	1749.877	1	1749.877	29.542	.000	.089	29.542	1.000
	tot_sts	2499.633	1	2499.633	32.519	.000	.097	32.519	1.000

a. R Squared = .243 (Adjusted R Squared = .230)
b. R Squared = .413 (Adjusted R Squared = .403)
c. R Squared = .307 (Adjusted R Squared = .296)

Note. *tot_cs – Total score Compassion Satisfaction, tot_bo – Total score Burnout, tot_sts – Total score Secondary Traumatic Stress, Caregiver – Type of Caregiver [Professionals and Family Caregivers]*

R Squared values for perceived stress, problem-focused coping, psychological morbidity and emotion-focused coping

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[d]
Corrected Model	tot_cs	6501.656[a]	5	1300.331	20.869	.000	.256	104.344	1.000
	tot_bo	12208.277[b]	5	2441.655	40.270	.000	.399	201.350	1.000
	tot_sts	9821.134[c]	5	1964.227	25.020	.000	.292	125.099	1.000
Intercept	tot_cs	5367.108	1	5367.108	86.136	.000	.221	86.136	1.000
	tot_bo	7448.714	1	7448.714	122.851	.000	.288	122.851	1.000

	tot_sts	3700.444	1	3700.444	47.135	.000	.135	47.135	1.000
Perceived Stress	tot_cs	3535.417	1	3535.417	56.739	.000	.158	56.739	1.000
	tot_bo	3404.139	1	3404.139	56.144	.000	.156	56.144	1.000
	tot_sts	845.292	1	845.292	10.767	.001	.034	10.767	.905
Problem-focused Coping	tot_cs	1628.878	1	1628.878	26.142	.000	.079	26.142	.999
	tot_bo	99.584	1	99.584	1.642	.201	.005	1.642	.248
	tot_sts	26.398	1	26.398	.336	.562	.001	.336	.089
Psychological Morbidity	tot_cs	736.316	1	736.316	11.817	.001	.038	11.817	.929
	tot_bo	692.972	1	692.972	11.429	.001	.036	11.429	.921
	tot_sts	2534.223	1	2534.223	32.280	.000	.096	32.280	1.000
Emotion-focused Coping	tot_cs	397.951	1	397.951	6.387	.012	.021	6.387	.712
	tot_bo	782.941	1	782.941	12.913	.000	.041	12.913	.948
	tot_sts	18.134	1	18.134	.231	.631	.001	.231	.077
Caregiver	tot_cs	249.592	1	249.592	4.006	.046	.013	4.006	.514
	tot_bo	1517.950	1	1517.950	25.035	.000	.076	25.035	.999
	tot_sts	2082.261	1	2082.261	26.523	.000	.080	26.523	.999

a. R Squared = .256 (Adjusted R Squared = .244)
b. R Squared = .399 (Adjusted R Squared = .389)
c. R Squared = .292 (Adjusted R Squared = .281)

Note. *tot_cs – Total score Compassion Satisfaction, tot_bo – Total score Burnout, tot_sts – Total score Secondary Traumatic Stress, Caregiver – Type of Caregiver [Professionals and Family Caregivers]*

R Squared values perceived stress, problem-focused coping, psychological morbidity and avoidant coping

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[d]
Corrected Model	tot_cs	6268.194[a]	5	1253.639	19.874	.000	.247	99.369	1.000
	tot_bo	12265.692[b]	5	2453.138	40.586	.000	.401	202.931	1.000
	tot_sts	10329.703[c]	5	2065.941	26.890	.000	.307	134.451	1.000
Intercept	tot_cs	6168.435	1	6168.435	97.787	.000	.244	97.787	1.000
	tot_bo	2877.442	1	2877.442	47.606	.000	.136	47.606	1.000
	tot_sts	1688.196	1	1688.196	21.974	.000	.068	21.974	.997
Perceived Stress	tot_cs	3101.337	1	3101.337	49.165	.000	.140	49.165	1.000
	tot_bo	2692.895	1	2692.895	44.553	.000	.128	44.553	1.000
	tot_sts	724.258	1	724.258	9.427	.002	.030	9.427	.864
Problem-focused Coping	tot_cs	2106.796	1	2106.796	33.399	.000	.099	33.399	1.000
	tot_bo	184.909	1	184.909	3.059	.081	.010	3.059	.414

	tot_sts	81.571	1	81.571	1.062	.304	.003	1.062	.177
Psychological Morbidity	tot_cs	1050.283	1	1050.283	16.650	.000	.052	16.650	.982
	tot_bo	177.453	1	177.453	2.936	.088	.010	2.936	.401
	tot_sts	1696.486	1	1696.486	22.081	.000	.068	22.081	.997
Avoidant Coping	tot_cs	164.488	1	164.488	2.608	.107	.009	2.608	.363
	tot_bo	840.356	1	840.356	13.903	.000	.044	13.903	.961
	tot_sts	526.703	1	526.703	6.856	.009	.022	6.856	.742
Caregiver	tot_cs	43.489	1	43.489	.689	.407	.002	.689	.131
	tot_bo	451.679	1	451.679	7.473	.007	.024	7.473	.778
	tot_sts	1176.234	1	1176.234	15.310	.000	.048	15.310	.974
Error	tot_cs	19113.283	303	63.080					
	tot_bo	18314.097	303	60.443					
	tot_sts	23279.088	303	76.829					
Total	tot_cs	807054.197	309						
	tot_bo	837120.371	309						
	tot_sts	825150.497	309						
Corrected Total	tot_cs	25381.477	308						
	tot_bo	30579.789	308						

	tot_sts	33608.791	308					

a. R Squared = .247 (Adjusted R Squared = .235)
b. R Squared = .401 (Adjusted R Squared = .391)
c. R Squared = .307 (Adjusted R Squared = .296)

Note. *tot_cs – Total score Compassion Satisfaction, tot_bo – Total score Burnout, tot_sts – Total score Secondary Traumatic Stress, Caregiver – Type of Caregiver [Professionals and Family Caregivers]*

Appendix C5

Model 5 Variables

R Squared values for perceived stress, problem-focused coping, psychological morbidity, emotion-focused coping and well-being

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[d]
Corrected Model	tot_cs	6531.557[a]	6	1088.593	17.441	.000	.257	104.644	1.000
	tot_bo	13208.910[b]	6	2201.485	38.274	.000	.432	229.642	1.000
	tot_sts	10320.425[c]	6	1720.071	22.306	.000	.307	133.834	1.000
Intercept	tot_cs	3876.462	1	3876.462	62.106	.000	.171	62.106	1.000
	tot_bo	8299.170	1	8299.170	144.285	.000	.323	144.285	1.000
	tot_sts	4125.875	1	4125.875	53.504	.000	.151	53.504	1.000
Perceived Stress	tot_cs	3052.212	1	3052.212	48.900	.000	.139	48.900	1.000
	tot_bo	2163.572	1	2163.572	37.615	.000	.111	37.615	1.000
	tot_sts	451.553	1	451.553	5.856	.016	.019	5.856	.674
Problem-focused Coping	tot_cs	1588.991	1	1588.991	25.458	.000	.078	25.458	.999
	tot_bo	58.990	1	58.990	1.026	.312	.003	1.026	.172
	tot_sts	45.295	1	45.295	.587	.444	.002	.587	.119
Psychological Morbidity	tot_cs	760.044	1	760.044	12.177	.001	.039	12.177	.936
	tot_bo	263.343	1	263.343	4.578	.033	.015	4.578	.569

	tot_sts	1755.192	1	1755.192	22.761	.000	.070	22.761	.997
Emotion-focused Coping	tot_cs	366.911	1	366.911	5.878	.016	.019	5.878	.676
	tot_bo	576.579	1	576.579	10.024	.002	.032	10.024	.884
	tot_sts	2.450	1	2.450	.032	.859	.000	.032	.054
Well-Being	tot_cs	29.901	1	29.901	.479	.489	.002	.479	.106
	tot_bo	1000.633	1	1000.633	17.396	.000	.054	17.396	.986
	tot_sts	499.291	1	499.291	6.475	.011	.021	6.475	.718
Caregiver	tot_cs	276.736	1	276.736	4.434	.036	.014	4.434	.555
	tot_bo	2045.558	1	2045.558	35.563	.000	.105	35.563	1.000
	tot_sts	2456.813	1	2456.813	31.860	.000	.095	31.860	1.000

a. R Squared = .257 (Adjusted R Squared = .243)
b. R Squared = .432 (Adjusted R Squared = .421)
c. R Squared = .307 (Adjusted R Squared = .293)

Note. tot_cs – Total score Compassion Satisfaction, tot_bo – Total score Burnout, tot_sts – Total score Secondary Traumatic Stress, Caregiver – Type of Caregiver [Professionals and Family Caregivers]

R Squared values for perceived stress, problem-focused coping, psychological morbidity, emotion-focused coping and avoidant coping

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[d]
Corrected Model	tot_cs	6861.888[a]	6	1143.648	18.650	.000	.270	111.897	1.000
	tot_bo	13656.394[b]	6	2276.066	40.617	.000	.447	243.700	1.000
	tot_sts	10449.080[c]	6	1741.513	22.709	.000	.311	136.255	1.000
Intercept	tot_cs	5434.053	1	5434.053	88.613	.000	.227	88.613	1.000
	tot_bo	3463.331	1	3463.331	61.804	.000	.170	61.804	1.000
	tot_sts	1788.980	1	1788.980	23.328	.000	.072	23.328	.998
Perceived Stress	tot_cs	3465.054	1	3465.054	56.505	.000	.158	56.505	1.000
	tot_bo	3269.550	1	3269.550	58.346	.000	.162	58.346	1.000
	tot_sts	801.508	1	801.508	10.452	.001	.033	10.452	.897
Problem-focused Coping	tot_cs	1059.001	1	1059.001	17.269	.000	.054	17.269	.985
	tot_bo	5.011	1	5.011	.089	.765	.000	.089	.060
	tot_sts	159.089	1	159.089	2.075	.151	.007	2.075	.300
Psychological Morbidity	tot_cs	977.842	1	977.842	15.946	.000	.050	15.946	.978
	tot_bo	224.928	1	224.928	4.014	.046	.013	4.014	.515
	tot_sts	1733.996	1	1733.996	22.611	.000	.070	22.611	.997

Emotion-focused Coping	tot_cs	593.694	1	593.694	9.681	.002	.031	9.681	.873
	tot_bo	1390.702	1	1390.702	24.817	.000	.076	24.817	.999
	tot_sts	119.377	1	119.377	1.557	.213	.005	1.557	.238
Avoidant Coping	tot_cs	360.231	1	360.231	5.874	.016	.019	5.874	.676
	tot_bo	1448.117	1	1448.117	25.842	.000	.079	25.842	.999
	tot_sts	627.946	1	627.946	8.188	.005	.026	8.188	.814
Caregiver	tot_cs	78.715	1	78.715	1.284	.258	.004	1.284	.204
	tot_bo	609.514	1	609.514	10.877	.001	.035	10.877	.908
	tot_sts	1237.403	1	1237.403	16.136	.000	.051	16.136	.980

a. R Squared = .270 (Adjusted R Squared = .256)
b. R Squared = .447 (Adjusted R Squared = .436)
c. R Squared = .311 (Adjusted R Squared = .297)

Note. tot_cs – Total score Compassion Satisfaction, tot_bo – Total score Burnout, tot_sts – Total score Secondary Traumatic Stress, Caregiver – Type of Caregiver [Professionals and Family Caregivers]

Model 6 Variables

R Squared values for perceived stress, problem-focused coping, psychological morbidity, emotion-focused coping, avoidant cooping and well-being

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power[d]
Corrected Model	tot_cs	6872.413[a]	7	981.773	15.966	.000	.271	111.761	1.000
	tot_bo	14402.785[b]	7	2057.541	38.284	.000	.471	267.988	1.000
	tot_sts	10829.941[c]	7	1547.134	20.444	.000	.322	143.107	1.000
Intercept	tot_cs	4063.182	1	4063.182	66.077	.000	.180	66.077	1.000
	tot_bo	4199.508	1	4199.508	78.139	.000	.206	78.139	1.000
	tot_sts	2164.067	1	2164.067	28.596	.000	.087	28.596	1.000
Perceived Stress	tot_cs	3064.564	1	3064.564	49.837	.000	.142	49.837	1.000
	tot_bo	2183.157	1	2183.157	40.621	.000	.119	40.621	1.000
	tot_sts	457.411	1	457.411	6.044	.015	.020	6.044	.688
Problem-focused Coping	tot_cs	1051.106	1	1051.106	17.093	.000	.054	17.093	.985
	tot_bo	9.724	1	9.724	.181	.671	.001	.181	.071
	tot_sts	175.186	1	175.186	2.315	.129	.008	2.315	.329
Psychological Morbidity	tot_cs	967.228	1	967.228	15.729	.000	.050	15.729	.977
	tot_bo	60.339	1	60.339	1.123	.290	.004	1.123	.184

	tot_sts	1261.257	1	1261.257	16.666	.000	.052	16.666	.983
Emotion-focused Coping	tot_cs	558.051	1	558.051	9.075	.003	.029	9.075	.852
	tot_bo	1080.140	1	1080.140	20.098	.000	.063	20.098	.994
	tot_sts	62.964	1	62.964	.832	.362	.003	.832	.149
Avoidant Coping	tot_cs	340.855	1	340.855	5.543	.019	.018	5.543	.651
	tot_bo	1193.875	1	1193.875	22.214	.000	.069	22.214	.997
	tot_sts	509.516	1	509.516	6.733	.010	.022	6.733	.735
Well-Being	tot_cs	10.525	1	10.525	.171	.679	.001	.171	.070
	tot_bo	746.390	1	746.390	13.888	.000	.044	13.888	.960
	tot_sts	380.861	1	380.861	5.033	.026	.016	5.033	.609
Caregiver	tot_cs	88.500	1	88.500	1.439	.231	.005	1.439	.223
	tot_bo	952.912	1	952.912	17.731	.000	.056	17.731	.987
	tot_sts	1521.413	1	1521.413	20.104	.000	.063	20.104	.994

a. R Squared = .271 (Adjusted R Squared = .254)
b. R Squared = .471 (Adjusted R Squared = .459)
c. R Squared = .322 (Adjusted R Squared = .306)

Note. *tot_cs – Total score Compassion Satisfaction, tot_bo – Total score Burnout, tot_sts – Total score Secondary Traumatic Stress, Caregiver – Type of Caregiver [Professionals and Family Caregivers]*

Appendix D

eXplorations
E-journal of the Indian Sociological Society

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Paper Acceptance letter

28/12/2022

To,

D. Asha

Dr. Gadiraju Padmaja

Dr. Sivender Alapati

Dear Author (s):

We are pleased to inform you that your paper ***Compassion Satisfaction, Compassion Fatigue, Perceived Stress and Coping among Family Caregivers of Patients with Cancer in India*** is accepted for publication in Explorations for upcoming issue (ISS e-journal, ISSN: 2581- 5741).

Editor,

Prof Nagaraju Gundemeda

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Original Article

Knowledge, attitude, and practice of radiation oncologists during COVID-19 pandemic

ABSTRACT

Background: Cancer care hospitals are taking measures to reduce the spread of COVID-19. Doctors and health-care workers might be suffering from burnout. Measures taken to reduce overcrowding in hospitals might be making access to essential cancer care difficult. The study aims to understand changes in practice, levels of burnout, and other psychological aspects in radiation oncologists working in a regional cancer center during the COVID-19 pandemic.

Methods: Data were collected through online Google Forms. The participants who were included in the study were doctors working in the department of radiation oncology. A 25min survey consisting of multiplechoice questions related to the changes at work during COVID19, and standardized questionnaires assessing fear of Covid 19 and burnout. The Oldenburg Burnout Inventory (OLBI) was used in this study to assess burnout. The Fear of COVID-19 Scale was used to assess fear induced by the COVID-19 pandemic.

Results and Conclusion: Out of 71 professionals who participated in this study, most of them belonged to the category of residents (84.5%) and the rest were consultants (15.5%). Rescheduling of the patients' radiation treatment to convenient time slots to avoid overcrowding, preferring hypofractionated radiotherapy, and the use of telephonic consultations to prioritize outpatient appointments were the most commonly used measures. The results have shown that 62% of the doctors have experienced symptoms of exhaustion and disengagement, indicating a presence of burnout. However, aspects related to fear of COVID have been revealed to be less prevalent among the participants.

KEY WORDS: Burnout, COVID-19, fear, hypofractionation, psychological, radiation oncology, radiation therapy, radiotherapy, rescheduling, telephonic consultation

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INTRODUCTION

The COVID-19 pandemic is causing widespread stress on health-care settings worldwide, including cancer care hospitals. The health-care system is changing to accommodate increasing COVID-19-infected patients while doctors and health-care workers might be suffering from burnout.[1] It has been seen that oncology health-care professionals are experiencing higher levels of burnout during the pandemic when compared to professionals dealing with COVID-19 patients.[2] It has been reported that doctors are concerned about contracting the infection themselves and are worried about possible harm to their families and communities.[3]

Measures adopted to reduce the spread of infection such as issuing a nationwide lockdown, temporary suspension of public transport, and measures targeting the reduction of overcrowding at hospitals have made access to essential cancer care difficult.[1]

In India, as of this write-up, about 1.4 million cases of COVID-19 are confirmed, and in the state of Telangana, the numbers are about 57,000. Every year, about 18 million patients are diagnosed with cancer worldwide causing nine million deaths.[4] Data suggest that around one million people are diagnosed with cancer in India every year. Telangana, with a population of about 35 million, has its crude annual incidence rate for all cancers at 72.6 per lakh population.[4] About 60% of all patients require radiation therapy

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during their treatment, and this requires multiple hospital visits.[5]

Measures were taken to ensure a reduction in the spread of infection based on guidelines. Masks were made compulsory for all patients and doctors entering the outpatient block. Mandatory temperature checks were performed at the entrance of the hospital, and patients could enter with only one accompanying person. This regional cancer center is a 500-bedded cancer hospital with 5 units operating within the department of radiation oncology staffed accordingly. Three linear accelerators and a brachytherapy unit are operational under this department. The radiation oncology department also has multiple inpatient wards for patient stay when the treatment team deems it necessary. Cancer care is changing to accommodate lesser time spent at the hospital, and to reduce overcrowding and exposure, guidelines for the same are also emerging.[6] Considering these changes in clinical practice and lifestyle of doctors in our hospital, we tried to understand the extent of the same.

METHODS

The study design and protocol were reviewed and approved by the institutional ethics committee. The data were collected from a single regional cancer center (RCC) in Telangana, Hyderabad. Radiation oncology professionals, inclusive of PG students, senior residents, and consultants of the hospital were recruited for this study through online methods.

Participants and procedure

In this study, 71 participants were selected from a tertiary (regional) cancer care center employing purposive sampling method (almost all personnel interviewed). After verbal informed consent was obtained from the participants of the study through phone calls, data were collected through online Google Forms. The participants who were included in the study were PG residents (60.6%), senior residents (23.9%), and consultants (15.5%) working in the department of radiation oncology. The radiation oncology staff were asked to answer a 25-min survey consisting of sociodemographics, multiple-choice questions related to the changes in their work experience during COVID-19, and standardized questionnaires to assess the psychological effect that COVID-19 has had on them. The study was conducted between August 7, 2020, and September 30, 2020.

Materials

The form specifically designed for doctors consisted of two sections. The first section consisted of general sociodemographic details and a forty-item questionnaire that assessed various aspects related to the changes in cancer care since the onset of the pandemic. The questions were partially adopted from various studies done during the COVID-19 period (Jereczek-Fossa *et al*., 2020; Wu, 2020; and Kang, *et al*., 2020).[2,7,8] Various aspects such as management of clinical and outpatient activities, management of patients and clinical practice, management of medical personnel, attitudes toward COVID-19, and exposure to COVID-19 were included in the questionnaire.

The second section included standardized questionnaires to assess the impact of COVID-19 and the psychological states of the professionals working in radiation oncology. The recently developed scale, Fear of COVID-19 Scale [FCV-19S], by Ahorsu *et al*. (2020)[9] was used to assess fear induced by the COVID-19 pandemic. It is a seven-item scale requiring the participants to indicate their level of agreement with the statements. It is a unidimensional, five-point Likert scale with a scoring assigned to be: strongly disagree = 1, disagree = 2, neither agree or disagree = 3, agree = 4, and strongly agree = 5. The range of scores on the scale is from 7 to 35, with a minimum possible score of 1 and a maximum of 5 on each item. The scale has been found to have robust psychometric properties, with internal consistency (α =0.82) and test–retest reliability (ICC = 0.72). A higher sum score on the scale indicated a higher fear of COVID-19. Scores on the Fear of COVID-19 Scale were categorized as low and high levels of fear based on the mean which was taken as a cutoff. The scores which were found to be less than or equal to the mean were considered low fear and scores that were above the mean were considered high fear scores.

The widely used and internationally validated measure, Oldenburg Burnout Inventory (OLBI), was used in this study to assess burnout. The OLBI is a 16-item scale, with a four-point Likert scale (1 = strongly disagree and 4 = strongly agree), which measures burnout by two dimensions, namely disengagement and exhaustion. The two dimensions have eight items each; The disengagement subscale measures an individual's distancing from their work, lack of interest in work content and holding negative belief and attitudes in general towards work. The exhaustion subscale measures one's physical experience with his/her work, such as feeling tiredness, lacking time for leisure activities due to their work, and the like. As the scale developers of OLBI did not provide the cutoff scores, those recommended by Peterson *et al*. (2008) were used for this study as they predicted the best physician-diagnosed burnout. Scores $\geq$2.25 for exhaustion and $\geq$2.1 for disengagement suggested the presence of burnout; participants were also scored separately on both the subscales.

Descriptive statistics were used to summarize questionnaire results. All statistical analyses were performed with the SPSS 12.0.1 for Windows, and graphs were constructed using the Excel 2013.

RESULTS

Out of 71 professionals who participated in this study, most of them belonged to the category of residents (84.5%) and the rest were consultants (15.5%). In the sample collected, there

is an approximately equal representation of females (47.9%) and males (52.1%). The mean age of the participants of the sample was found to be 30.9. The results are elaborated in the following headings [Figure 1].

Outpatient clinics

While seeing new patients in the outpatient, doctors have admitted having spent lesser than usual time for history taking 55.9% (38) and clinical examination 70.6% (48). However, 23.5% (16) admitted to having spent the same amount of time like before on history taking and clinical examination. 36.6% (26) of the doctors said that they relied more on imaging details for staging cancer. There was a 10%–30% reduction in clinical activity in the 1st month as reported by 45.6% (32) of the doctors. It was also reported by 60.6% of the professionals that there has been a delay in the process of diagnosis of cancer patients during this period, while a 28.2% reported no such delays and an 11.3% reported to be unsure about the delays in the diagnosis.

Radiation treatment

Phone calls were made to schedule radiation treatment to avoid overcrowding in the patient waiting area (as reported by 73.2% of the doctors). A vast majority of the participants preferred hypofractionated radiation therapy over standard radiation therapy. Concerning the outpatient visits, those affected by acute radiation toxicity were treated as a priority, and most of the ordinary/regular checkups were rescheduled initially. Most of the participants have also reported having faced difficulty in referring patients to other specialties for treatment.

Characteristics	Frequency *n*=71	Percentage (%)
Gender		
Female	34	47.9
Male	37	52.1
Designation		
Residents	60	84.5
Faculty	11	15.5
Age		
21-30	48	67.6
31-40	16	22.5
41-50	2	2.8
51-60	5	7.0

Figure 1: Table showing demographic data of the sample

Safety measures

As part of the safety measures, the doctors used medical gloves (87.3%), goggles or visors (78.9%), disposable gowns (73.2%), overhead (39.4%), FFP2 masks (54.9%), surgical masks (52.1%), and overshoes (39.4%). 53.5% of the participants reported taking the COVID test, and most of them (65.8%) having taken it only once during this period. It was also reported that only 7%[5] of the doctors tested positive for COVID during this period.

As a part of the protocol to reduce the spread of infection among the patients, a large majority (81.5%) of the doctors had stopped the radiotherapy treatment in all cases when patients tested positive for COVID-19. Doctors preferred restarting treatment after 14 days beginning from the day the patients tested negative for COVID-19 (one negative swab). However, a 19.1% have started the treatment after waiting for a 30-day window, and another 19.1% of the professionals reported to have started the treatment almost immediately after the patients have tested negative only after one negative swab/quarantine. The number of patients testing positive for COVID-19, as reported by 34.4% of the doctors was between 5–10 cases during their treatment. 16.4% and 19.7% of the professionals have come across two and three positive cases, respectively. About 11.5% of the doctors have reported having had 11 or more positive cases. The results also indicated that patients with head-and-neck cancers (78%) constituted most of the patients who tested positive for COVID-19, with 42% of lung cancers and 36% of gynecologic cases. As and when the hospital staff discovered patients in treatment as a documented contact of a COVID-positive patient, a 46.3% of the doctors have suspended treatment and requested for a swab test if the patients were paucisymptomatic; however, 43.3% of the professionals reported having encountered no so such cases, whereas a 7.5% have stopped treatment immediately in such cases and a 3% of them reported to have continued the treatment, taking necessary precautions.

A vast percentage of the doctors (91.5%) reported having friends who tested positive for COVID-19, while 46.5% of them said that their neighbors tested positive for COVID-19. While more than half of the participants have attributed their willingness to work in the hospital during this pandemic owing to their responsibility of being a part of the health-care system, the remaining have obliged as they are not given an option to quit. Upon inquiry, more than half of the participants have reported that their professional, as well as personal relationships, have been affected due to COVID-19.

As opposed to earlier, there has been a major shift from holding a meeting in person, to conducting webinars as reported by 72% of the professionals, while it was also reported by 60% and 45% of the participants that there has been a decline in case presentations and multidisciplinary case discussions, respectively. Upon inquiry, more than half of the participants have reported that their professional, as well as personal relationships, have been affected due to COVID-19.

The participants also reported having faced financial losses during the pandemic. Most of the participants have also mentioned that their interactions with neighbors in their communities have also been affected because of them being a health-care professional. Quite a few of the participants had encountered difficulties in their daily commute to the workplace as compared to pre-COVID-19 times. Sixty-seven percent (46) reported that they were afraid to use the washroom in the hospital due to a fear of developing COVID-19. 19.62% (42) strongly agreed, while 32.4% (23) have agreed that they are worried about their family members contracting the infection from them.

Attitudes toward COVID-19 and fear of COVID-19

The participants were also asked questions to understand their attitudes toward the effect of COVID-19 on them. While 60% of the participants agreed or strongly agreed to feel more burned out when compared to before the crisis, 39.4% of them have disagreed or reported feeling neutral on this aspect. The participants have agreed or strongly agreed in a vast majority on being worried for themselves as well as their families being infected by COVID-19. Many of the participants (80%) have also reported to being worried about the pandemic situation going on for too long and its possible negative effects at large. Figure 1 describes the participants' attitudes toward COVID-19 [Figures 2 and 3].

Burnout

Burnout was measured by the Oldenburg burnout Inventory. Scores for the two sub-scales, namely exhaustion and disengagement were calculated. The scores indicate that 62% of the participants had symptoms of exhaustion and disengagement, indicating a presence of burnout among the majority of them. Fifteen percent of the participants were found to score high on the single subscale of disengagement and 10% on EXHAUSION only, whereas 13% of the participants showed no signs of burnout [Figures 4 and 5].

DISCUSSION

Being a teaching hospital, the questionnaire was predominantly filled by residents. Doctors admitted to having spent lesser time than usual in history taking and clinical examination. For patients who had to be examined routinely, imaging was preferred over physical examination, particularly in head-and-neck cancers.

Rescheduling of the patients' radiation treatment to convenient time slots to avoid overcrowding in treatment waiting rooms has been done, but it must be kept in mind that delay in the initiation is known to cause poor locoregional control and overall survival[10] and such delay must be avoided. Preferring hypofractionated radiotherapy where evidence suggested feasibility[6] and increased referral to pain and palliative care was reported. In the clinics, patients who were found to be suffering from acute radiation toxicities were given priority; the use of telephonic consultations to prioritize outpatient appointments was constituted as is also used in other radiation oncology departments.[11] The use of telephone to schedule radiation treatment appointments was also used. The doctors reported a decline in the caseload of up to 50%. It was found that many doctors found it difficult to refer patients to other specialties. Gloves,visors, disposable gowns and masks were the most commonly used form of personal protective equipment. FFP2 and surgical masks were used in equal measure. Similar use of PPE was seen in Italy.[7] The institute based its PPE usage on the Ministry of Health and Family Welfare recommendations.[12] A total of 7%[5] of the doctors admitted to having tested positive for COVID-19. When patients on radiation treatment tested positive for COVID-19, majority of the doctors chose to stop radiotherapy in paucisymptomatic and symptomatic patients and resume treatment after 14 days from a negative test. In case of a positive patient, for whom the treatment was suspended, and who resulted negative after two consecutive swabs, about half stated they would start or continue the treatment immediately. Other responders were more cautious and would wait for an additional 14 or even 30 days.

Head-and-neck patients were predominantly found to develop COVID-19. However, it must be kept in mind that head-and-neck cancer patients constituted a dominant portion of the cases receiving treatment in our hospital. Doctors reported difficulty traveling to the hospital, financial losses, changes in their personal lives, and a decline in academic activity.

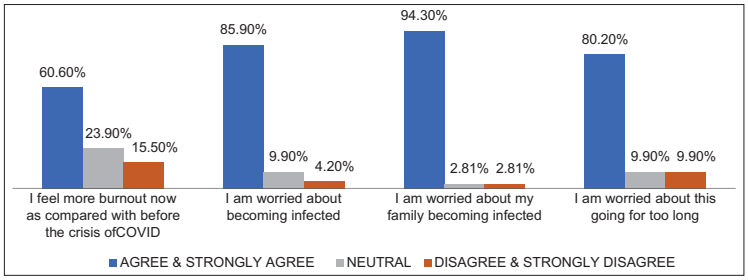

Figure 2: Description of the participants' attitudes toward COVID-19

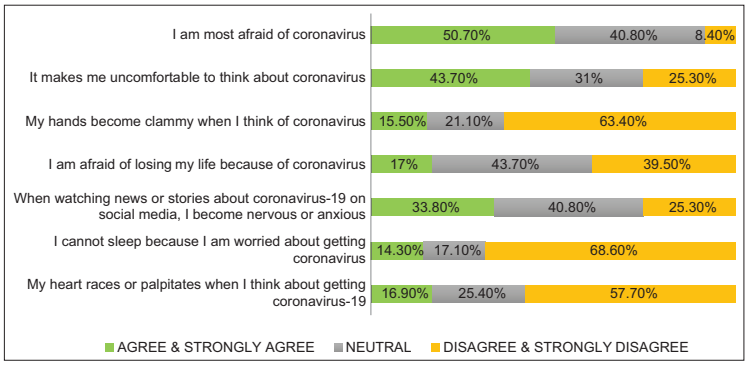

Figure 3: Item-wise distribution of responses on the Fear of COVID-19 Scale

S.No	Items	N (%)				
		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1.	I am most afraid of Coronavirus	10 (14.1%)	26 (36.6%)	29 (40.8%)	4 (5.6%)	2 (2.8%)
2.	It makes me uncomfortable to think about Coronavirus	11 (15.5%)	20 (28.2%)	22 (31%)	13 (18%)	5 (7%)
3.	My hands become clammy when I think about Coronavirus	4 (5.6%)	7 (9.9%)	15 (21%)	35 (49.3%)	10 (14.1%)
4.	I am afraid of losing my life because of Coronavirus	6 (8.5%)	6 (8.5%)	31 (44%)	20 (28.2%)	8 (11.3%)
5.	When I watch news and stories about Coronavirus on social media, I become nervous or anxious.	4 (9.9%)	17 (23.9%)	17 (40.8%)	29 (19.7%)	14 (5.6%)
6.	I cannot sleep because I'm worrying about getting Coronavirus.	7 (10%)	3 (4.3%)	12 (17%)	32 (45.7%)	16 (22.9%)
7.	My heart races or palpitates when I think about getting Coronavirus	7 (9.9%)	5 (7.04%)	18 (25.4%)	27 (38%)	14 (19.7%)

Figure 4: Item-wise distribution of responses on the Fear of COVID-19 Scale

	Mean	Median	Mode	SD	Min	Max
Oldenburg Burnout Inventory Disengagement Subscale	18.54	19.00	19	2.961	11	25
Oldenburg Burnout Inventory Exhaustion Subscale	19.03	19.00	18	2.853	13	26
Oldenburg Burnout Inventory Total Burnout Score	37.56	37.00	36	5.326	26	50
Fear of Covid-19 Scale	20.01	20.00	20	6.037	9	35

Figure 5: Descriptive statistic parameters of the Oldenburg Burnout Inventory and Fear of COVID-19 Scale for the entire sample

Our findings related to the attitudes of the participants toward COVID-19 reveal that a vast majority of them are worried about personally contracting COVID-19 and their families/close ones contracting it, which is similar to the findings of a study conducted by Wu *et al.*, 2020, Gill *et al.*, 2020.[2,13] However, the Fear of COVID-19 Scale results indicate that the participants have not experienced fear in most of the aspects measured by the scale such as losing their life to the virus, experiencing loss of sleep or physiological symptoms, and feeling anxious when exposed to news of coronavirus on social media, which indicates that the fear of COVID-19 has not been generalized to various aspects of the participant's lives.

The results suggest that the rates of burnout experienced by the participants are predominantly high, which is in line with the findings of various other studies conducted during the pandemic, indicating that oncology health-care professionals are at an increased risk of burnout, both by the nature of their work and the conditions of the pandemic.[2,14,15] The high levels of burnout can be attributed to the added burden of the pandemic to the preexisting set of difficulties unique to the oncology health-care settings. The role of psychological support which was reported by more than half of the participants as lacking for the professional staff may be one of the causes of the high levels of burnout reported in this study.

This study was done in a single institute where residents were interviewed predominantly. The results cannot be generalized to other radiation oncology settings. A larger study group involving multiple institutes in different regions might show different results. Involving more consultants and policy-making doctors might yield different insights. As the number of persons testing positive for COVID-19 increases in the foreseeable future, radiation oncology centers should learn to function under these circumstances. In this crisis, radiation oncology centers need to share experiences to conduct patient care safely and effectively.

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Conflicts of interest
There are no conflicts of interest.

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Perceptions of Health: a Developmental Trend in Indian School Children

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Perceptions of Health: a Developmental Trend in Indian School Children

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Abstract
The potential for children to be used as agents of change in health research and practice is being increasingly valued. To reach this objective, it is foremost to gauge children's perceptions about health, based on which future pathways to health promotion programs may be built which are easily comprehensible to children. Therefore, this study was conceptualised to understand the way school children perceive health and track the changes in their comprehension of health. Basing on a cross-sectional design, a sample of 667 children belonging to Class 6 to 10 from three different Indian schools were selected. These children having similar socioeconomic status and education curricula were asked to respond to an open-ended question—What do you understand by 'being healthy'? The obtained qualitative data were analysed by means of content analysis to explore categories or themes of responses. Divergence of conceptualisation was measured through calculation of entropy. The three emerged major themes—Meaning of health, Ways to be healthy, and Indices of health— represented children's health perceptions. The entropy values revealed a steep rise in the divergence in perceptions of health of Class 10 children compared to plateau in perceptions of children of lower classes. Implication and limitations of this study were also discussed.

Keywords Concept of health · Children's conceptualisation · Indian children · Content analysis · Entropy · Cross-sectional design

1 Introduction

World Health Organisation (WHO) defined health as a state of complete physical, mental, and social well being, and not merely the absence of disease or infirmity.

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Bircher (2005) has also given a holistic definition of health as a "dynamic state of wellbeing characterized by physical, mental and social potential which satisfies the demands of life commensurate with age, culture and personal responsibilities. If the potential is insufficient to satisfy these demands this state is disease."

The concept of health is interpreted in various ways—sometimes restricted to a unidimensional understanding of illness, or a partial acknowledgement of health promoting and health risk behaviour, and rarely as a wholesome understanding of the broad concept of health. Health education formally and informally begins at a young age through family, peer group, or school curriculum. Thus, children's perception of health is an important subject as it lays the foundation for their health literacy. Comprehending health at an early stage assumes great significance as the cognitive base paves the path to future health promoting or health risk behaviour. Insight into children's perceptions of health is important in view of its significant influence on various dimensions of life, particularly related to health behaviour. The understanding of the complexities of health behaviour begins at an early age (Almqvist et al. 2006; Goldman et al. 1991; Tinsley 1992) and is reflected over time in the attitudes and beliefs sustained in adulthood inadvertently affecting their wellbeing (Susman et al. 1992). According to Zaloudikova (2010), the subjective perception of health and illness has fundamental influence on the behaviour of the given person in respect to his or her own health.

Research on childrens' understanding of health and illness has concentrated more upon the age and cognitive developmental differences in children's conceptualisations of health and illness. With Piagetian theory of cognitive development as a theoretical base, studies (Kalnins and Love 1982; Bibace and Walsh 1980) have been conducted on children of different ages revealing that the concepts of health and illness mature with cognitive developmental changes. For example, children's concepts of health shift from being behavioural indicators of health (engaging in healthy practice) to describing them in abstract states (feeling good). Cognition on the concept of health with its complexities is found to follow a developmental trend well in line with Piaget's cognitive development. Williams and Binnie (2002) found a significant difference between four-year old and 7-year old children in their understanding of different ailments in terms of aetiology.

Natapoff (1982) investigated into children's concept of health by interviewing 264 children within the age group of 6 to 12 years belonging to 1st, 4th, and 7th grades. The results revealed a cognitive developmental trend in conceptualizing health. The study clearly indicated children's concept of health following Piagetian concept of cognitive development. This study found that younger children failed to understand the cause and effect relationship in the context of health, while older children conceptualised health and illness with the idea of mutual reversibility. Children above 10 years conceptualised health holistically by including mental health. The results of the study by Williams and Binnie (2002) were in line with that of Natapoff. Their study attempted to understand the children's concept of illness by interviewing 60 children belonging to age 4 and age 7. They found a significant age difference in the level of sophistication in the children's understanding of illness. However the level of understanding of children was found to improve after intervention. Goldman et al. (1991) conducted an intensive study on 27 children using a combination of interview, open-ended question and observation. The results revealed that children's concept of health represented five characteristics namely causation, identity, consequence, timeline, and cure. Further the study reiterated

developmental trend following Piaget's model (1951) in understanding children's understanding of health and illness. Children in the age group of 9 to 11 years exhibited divergent ideas on being healthy or unhealthy referring to nutrition, environment, cleanliness, and mental health (Reeve and Bell 2009). Mouratidi et al.'s (2016) study that compared two samples consisting of adults and children clearly tracked a developmental trend with younger group of children understanding health and illness from a biomedical perspective, while older children depicting multi-faceted comprehension, and adults responding from a psychosocial angle.

However, there are claims that the Piagetian approach underestimates children's understanding of illness. The criticisms of Piagetian research argues that the stage theory underestimates children's abilities such as reasoning about physical phenomenon (Baillargeon 1993) and conversion of number. Furthermore, Hergenrather and Rabinowitz (1991) proposed that it is incorrect to use Piaget's stages to plot the development of illness concepts as Piaget's stages refer to children's logic and capability for certain types of thought, not to their understanding. Carey (1985) also argued that illness and health cannot be conceptualised as a part of a domain-general Piagetian framework as children's reasoning skills are very different across domains.

Few recent studies are in line with earlier ones indicating a developmental trend while others suggested a combination of simple and complex perception (Mouratidi et al. 2016). The opportunities for accessing health information has widened in the past decade. This has a possibility of children perceiving health in a more complex and holistic way. Youssef et al. (2010) conducted a study on 472 Egyptian children in the age group of 9 to 11 years to understand their concepts of health, illness, and risk factors using 'draw and write' technique. The findings revealed a trend that was different from the earlier studies. The responses indicated a majority of children having a mixed concept of health that included biomedical and holistic definitions extending to the emphasis on healthy lifestyle. The major source of information for them was cited as media. It is very important to understand the developmental progression or trend of perception of health among children. This would enable us to design health interventions in sync with the comprehensions of children so as to optimize the intervention outcome.

Comprehending health in holistic perspective demands understanding of health protective behaviour (related to nutrition and hygiene), health promotive behaviour (related to lifestyle aspects), and health risk behaviour (abstinence of substance use, unprotected sex). In this context it is relevant to mention that as the health risk behaviour of smoking begins at adolescence (Global Youth Tobacco Survey Collaborative Group 2003) or triggered at childhood when a family member is a chronic smoker (Leonardi-Bee et al. 2011), it is very essential that they understand the statutory warning on cigarette packets. However, a study by Borzekowski and Cohen (2013) revealed that a large percentage (62%) of children did not comprehend the warning on cigarette packets. The study had revealed that Indian children had the lowest level of comprehension compared to children from China, Brazil, Pakistan, Nigeria, and Russia. Most of the research in this area of children's conceptualisation of health and illness has studied children from developed countries. Thus, as pointed out by Skelton and Croyle (1991), there is a dire need for research examining the issues among children in developing countries.

Research in the past has classified children's perceptions of health into three basic categories: (a) biomedical, (b) psychosocial, and (c) healthy lifestyle representations

(Campbell 1975; Natapoff 1982; Piko and Bak 2006; Zaloudikova 2010). These categories match the categories specified in the official definition of health given by the World Health Organisation (WHO 1948). The biomedical category comprises representations of biological and medical processes related to health or the absence of specific diseases and symptoms (Campbell 1975; Natapoff 1982; Piko and Bak 2006; Reeve and Bell 2009; Zaloudikova 2010). The psychosocial category includes perceptions of healthy and cheerful humans (Piko and Bak 2006), able to enjoy joyful activities (Natapoff 1982; Piko and Bak 2006; Zaloudikova 2010). The lifestyle categories refers to activities that could potentially affect an individual's health, e.g. specific eating habits and exercise (Piko and Bak 2006; Youssef et al. 2010; Zaloudikova 2010). Previous findings suggest that children define health by incorporating all its different dimensions (Onyango-Ouma et al. 2005; Reeve and Bell 2009; Youssef et al. 2010). Piko and Bak (2006) conducted a study on 128 primary school children (8 to 11 years) to understand children's beliefs of health, illness, health promotion and disease prevention. An equal percentage of children seem to hold biomedical and biopsychosocial concept of health. The study indicated that children's concepts were found to have reference to their past experience. Children in the age group of 9 to 11 years exhibited divergent ideas on being healthy or unhealthy referring to nutrition, environment, cleanliness, and mental health (Reeve and Bell 2009).

Children's perception of health has been studied by adopting various methods. A number of researchers have preferred to adopt projective methods such as auto-documentation using small notebook and camera (Reeve and Bell 2009), drawing pictures (Onyango-Ouma et al. 2005) and use of vignettes (Buchanan-Barrow et al. 2003; Williams and Binnie 2002). There are also studies that used semi-structured (Myant and Williams 2005) and in-depth interview (Marin 2010; Fernandes et al. 2014), questionnaires (Wahl et al. 2012), or knowledge tests (Cordingley et al. 2012). All the methods have their inherent strengths and weaknesses. While the projective methods may work better with younger age groups, subjectivity involved in scoring and interpretation is a factor to be considered too. On the other hand, the questionnaire, scales, other forms of measure that suit the older age groups may not be of help when the study aims to compare the younger age groups with that of the older. Hence, the method that meets the purpose of comparing different age groups may be open-ended question(s) with clear instructions. However, the responses need to be treated with rigorous qualitative and quantitative analyses in order to protect objectivity and scientific rigour. The present study used an open-ended question.

1.1 Research Questions

The study attempted to answer to two research questions. First, how do school children conceptualise 'health'? Second, does the concept of health show a progressive change across age?

1.2 Objectives

Health habits are formed in childhood and sustained thereafter. Pre-adolescence and adolescence are critical stages for inculcating desirable health behaviour. This demands the right perception and cognition of health. It is of research interest to examine the

progressive changes in conceptualising the meaning of 'being healthy' across ages during the pre-adolescence and adolescence period. The objectives of this study were formulated in the following ways—(i) understand the way high school children in India conceptualise 'health' and (ii) track the changes in comprehending 'health' among Indian school children from Class 6 to Class 10.

2 Method

2.1 Research Design

The design of the study fits into a qualitative framework. The methodology of data collection followed a single open ended question where the responses were put through content analysis following thematic approach. The data were analysed using descriptive statistics. The study involved an innovative method of quantifying the complexity of the concept of health by applying a new formula to measure complexity through entropy.

2.2 Participants

Following a cross-sectional design, the sample was drawn in two stages. In *first* stage schools were identified based on purposive sampling. Two inclusion criteria were followed to identify the schools. First, the schools must be catering to the children from low socioeconomic status. Second, the curriculum of the schools must be similar. Following these two criteria, one Social Welfare Residential School that catered to the students from socially marginalised sector, run by the State Government, one school that is run by a private Cement Industry in a remote district majorly catering to the needs of the children from neighbourhood tribal hamlets, and one school run by a Christian Missionary for the children coming from socioeconomically backward families were included.

In *second* stage, all the children in these schools from Class 6 to Class 10 were included as participants of the study. The initial total sample consisted of 712 children of which 402 were boys (56.46%) and 310 were girls (43.54%). After dropping the participants whose written responses were either illegible or did not make any meaning, the final sample was 667 participants. This sample consisted of boys (55.77%) and girls (44.33%). They belonged to Class 6 (22.03%), Class 7 (23.24%), Class 8 (23.54%), Class 9 (21.74%) and Class 10 (9.44%). The age range of the children is between 11 to 16 years.

2.3 Procedure

The procedure explains data collection, content analysis method, and method of calculating "entropy" for measuring the complexity of the concept of health. Informed consent was taken from the Principals of the selected schools and class teachers of the classes concerned. All participants consented to participate. The participants were assembled in their classes and were provided with a lined sheet of paper. One side of the paper sought the demographic details, such as name, age, gender, and Class; and on the other side a question—"What do you understand by 'being healthy'?"— was printed. No time limit was specified to complete the answer. The students were

instructed to give a descriptive answer to the question in the way they perceived health and they were asked to write their responses in English or the two local languages—Hindi and Telugu, in the limited space of six lines provided in the sheet. The descriptive responses of participants were manually analyzed using content analysis, thematic approach. The responses were independently handled and coded by the investigators. The verbatim responses of each participant were read and re-read several times to gain a holistic picture of the responses. Memos of specific meaning units were noted down in the margin of the response sheets. These units of information were carefully examined and similar responses were collated under different sub-themes or categories on the basis of inductive process. Three broad themes, viz, meaning of health, ways to be healthy, and indices of health emerged out of content analysis. Under each theme the sub-themes were identified.

One method of measuring the extent of divergence in response is through calculation of entropy. The concept of entropy originates from Physical Sciences that are broadly interpreted as the degree of disorder. The method of measuring response divergence of conceptualizing 'diabetes' was used by Padhy et al. (2018), and also was used in measuring the diversion in conceptualizing HIV/AIDS among students was used by Nagpal et al. (2017). Applied in the context of responses, to the issue of understanding of 'being healthy', entropy is operationally defined as the extent of variations in the responses of children belonging to a particular Class/Grade.

2.3.1 Mathematical Derivation of Entropy

Step 1: After the responses were categorised, the ratio of responses for each of the three major themes was calculated for a particular Class of students using the following formula. It suggests the probability of response occurrence; to be more specific the ratio of responses to the theme (*P*).

$$\boldsymbol{P} = \frac{\boldsymbol{Number\ of\ responses\ per\ theme}}{\boldsymbol{Total\ number\ of\ responses\ of\ each\ class\ of\ students}}$$

Step 2: This ratio was logarithmically evaluated to convert the value into easily interpretable friendly scale. The output value after logarithmic transformation is denoted as 'I'. In this context, '*I*' refers to the information of the response occurrence. The treatment applied is expressed as

$$\boldsymbol{I} = \boldsymbol{-\log}\ (\boldsymbol{P})$$

Step 3: Now the value is ready for evolving a score indicating absolute entropy, denoted as '*E*. The entropy was computed using the formula.

$$\boldsymbol{E} = \sum (\boldsymbol{P} \times \boldsymbol{I})$$

The value of absolute entropy in this study is derived as a sum of logarithmic values of the three themes. The formula is expressed as

$$\boldsymbol{E} = \mathbf{P_m I_m} + \mathbf{P_w I_w} + \mathbf{P_i I_i}$$

Where,

m Meaning of health;
w Ways to be healthy;
i Indices of health

This value of absolute entropy indicates divergence of ideas of each Class. Simply, it is the abstraction of the distribution of responses across themes for each Class. Higher value of entropy indicates higher divergence of conceptualisation of 'being healthy' for a Class of student. In case of convergence or uni-dimensionality of ideas, the entropy is indicated by a low value, or even '0'. The composite score of entropy is the measure of complexities with which the idea of being healthy is construed. The composite value of entropy is implicitly affected by the size of the Class of students which is not uniform in the sample studied. Therefore, an attempt is made to neutralise the varying sample size in different classes of students. Towards this end the entropy value is divided by the Neutralising Ratio between the class size and the total sample. The ratio between sample size in a Class and the total sample is calculated using the following formula to derive a Balancing Factor denoted as B_F.

$$B_F = \frac{\textbf{Sample size of a Class of students}}{\textbf{Total sample size of students}}$$

Step 4: The final score of entropy neutralised for varying samples of different classes, denoted as E_n (Neutralised entropy) is calculated by the following formula.

$$E_n = E/B_F$$

3 Results

The results are discussed from qualitative angle of content analysis as well as quantitative angle, where divergence of response for each Class was calculated by computing entropy values.

3.1 Qualitative Analysis

By following the thematic approach of content analysis as described under the 'method' section, three broad themes emerged, namely 'meaning of health', 'ways to be healthy', and 'indices of health'. Each theme had revealed sub-themes under which the responses converged. These themes and their corresponding sub-themes are presented in Table 1A. These themes and sub-themes are for the whole sample.

Under the first theme, i.e. 'meaning of health', health was described as a multidimensional concept— living a good life, good genetic loading, health as an asset, having health awareness, no physical or mental illness, and as God's gift. The sub-themes under this category ranged from health as a divine blessing or genetic loading over which there is no control of the individual to leading a good life or possessing knowledge of health where the individual has a definite role to play.

The second theme refers to 'ways of being healthy' where all the sub-themes connoted a line of behaviour on the part of the individual to be healthy. The sub-themes included a number of action points indicating a definite role of the individual by adhering to a balanced diet, adequate water intake, indications of healthy habits, maintenance of personal and environmental hygiene or simply health promoting behaviour like exposure to sunlight and avoidance of health risk behaviour such as keeping off from junk food.

The third theme relates to 'indices of being healthy'. The sub-themes referred to were from a broad spectrum of biopsychosocial indicators such as physical strength, ideal body mass index, ability to work hard, longevity of life, and agility as biological/physical indices. Peace, effective coping, enjoying leisure time, and good cognitive skills as psychological indices. Enjoyment of life, success, high academic performance, perfectionism, and community involvement were the psychosocial indicators.

As Table 1 gives a picture of the overall sample without categorizing them into classes, Table 2 presents the sub-themes that were common to different classes along with a model response (only when more than 30% of the Class responded to corresponding sub-theme it was included under 'Common Theme/Sub-theme').

It may be observed from Table 2 that defining health as 'absence of disease' was a predominant common response from students across classes. Similarly under the theme of *Ways to be Healthy* students belonging to all classes mentioned the sub-themes emphasizing on having a balanced diet, avoiding junk food, practicing physical exercise and yoga, maintaining good sleep and personal hygiene. Interestingly, students of Class 7 were exceptions in emphasizing the need for environmental hygiene. With reference to the theme on *Indices of Health,* students of all classes mentioned being active and energetic as a predominant feature. The ability to play well was mentioned only by students of Class 6, 7, and 8.

While it is necessary to present the themes and sub-themes common to the classes, it is equally significant and relevant to throw light on the themes, sub-themes, and responses unique to each Class. Table 3 presents the sub-themes and responses unique to different classes. The responses were considered as unique only when 1 to 5% in the Class responded corresponding to a particular sub-theme.

It may be observed from Table 3 that the students of Class 6 were unique in the response revolving around food and beverage. The responses were related to eating the right quantity (no overeating) at the right time (eating on time) in the right way (chewing well). Typically the unique response related to *Index of Health* as 'good digestion'. The unique responses of Class 7 featured avoidance of oily food under the theme of *Ways to be Healthy* and good academic performance as an Index of Health. The table indicates that the sub-themes of children of Class 8 were psychosocial in nature. The unique sub-themes were ability to 'adapt to situations', 'having healthy interpersonal relations' and 'coping with stress'. Students of Class 9 had unique sub-themes such as adequate rest and sleep as *Ways to be Healthy* and the longevity of life as an index of health. Students belonging to Class 10 uniquely mentioned about mental health and corresponding positive affect state, and internal peace as *Indices of Health.* Further they suggested regular health check up as a measure to be healthy.

Based on the common and unique responses of children of different classes, the class-specific definition of 'being healthy' is inferred in the following way. While

Table 1 Themes, sub-themes, and specimen responses of participants

Themes and Sub-themes	Sample Responses
1.Meaning of health	
God's gift	Health is a gift given by God (Boy, Class 9)
Genetic contribution	Healthy body is given from family (Boy, Class 6)
Health as an asset	Health is considered bigger than wealth (Boy, Class 8)
Multidimensional concept	Health is nothing but being physically fit, mentally strong and being moral, spiritual and intellectual (Girl, Class 10)
Living a good life	I understand that being healthy means having a good life (Boy, Class 6)
Awareness of diseases	We should be aware of diseases and behave in a proper way (Boy, Class 9)
No physical or mental illness	Not having any illness is being healthy(Boy, Class 6)
2.Ways to be healthy	
Balanced diet	Eating fruits and taking balanced diet is good for health (Girl, Class 8)
Adequate water intake	Drink plenty of water (Girl, Class 8)
Avoidance of junk food	Avoid fried snacks, oily food, and junk food. They make a person put on weight and lead to digestive problems (Boy Class 6)
Healthy habits	We should brush our teeth twice a day, wash hands before eating and go to sleep timely (Girl, Class 9)
Environmental hygiene	We should maintain clean surroundings (Girl, Class 8)
Personal hygiene	I understand that being healthy requires us to keep our body clean by bathing, brushing our teeth, washing our hands and wearing clean clothes (Girl, Class 7)
Exposure to sun	We should wake up before sunrise, we take vitamin D from sun (Girl, Class 7)
Yoga and exercise	We should exercise daily and do yoga in the morning (Boy, Class 7)
Sleep hygiene	We should sleep and wake up early and on time daily (Boy, Class 7)
Avoidance of smoking	Some people smoke which is not healthy(Girl, Class 8)
Adequate rest	We should take proper rest and sleep (Boy, Class 9)
3.Indices of health	
Enjoyment of life	Being healthy helps us enjoy our life(Boy, Class 8)
Ideal body mass index	Good figure according to age and height(Boy, Class 7)
Peace	Being peaceful is a sign of health (Girl, Class 10)
Strength	Being very strong is healthy (Boy, Class 7)
Success	Health is important for success (Girl, Class 8)
Ability to work hard	If one is healthy one can work hard (Boy, Class 6)
Playing	If we are able to play outdoor games, then we are healthy (Girl, Class 10)
High academic performance	We are able to write exams and do well because we are healthy (Girl, Class 6)
Effective coping	Can solve all problems if one is healthy (Girl, Class 8)
Leisure time	A healthy person can enjoy leisure (Boy, Class 8)
Agility	You can do all activities quickly when you are healthy (Girl, Class 7)
Perfectionism	Being perfect in work is healthy (Boy, Class6)
Longevity of life	Being healthy will ensure a long life (Boy, Class 9)
Community involvement	To be healthy we need personal care as well as community involvement (Boy, Class 9)
Good cognitive skills	If we are healthy, we can think fast and clearly (Boy, Class 8)

Table 2 Common Themes, sub-themes, and specimen responses of participants across different classes

Themes and Sub-themes	Classes	Sample Responses
1.Meaning of Health		
Absence of disease	6,7,8,9,10	"A healthy person cannot have diseases" (Boy, Class 10)
2.Ways to be healthy		
Balanced diet	6,7,8,9,10	"It is important to follow a balanced diet for healthy life" (Girl, Class 8)
Avoiding junk food	6,7,8,9,10	"To stay healthy a person must avoid junk food" (Boy, Class 7)
Physical exercise & yoga	6,7,8,9,10	"Should do exercise and yoga which will make one healthy and active" (Girl, Class 9)
Adequate sleep	6,7,8,9,10	"Sleeping early and waking up early keeps you healthy" (Boy, Class 8)
Personal hygiene	6,7,8,9,10	"Take personal care of yourself. e.g. comb hair, brush" (Boy, Class 6)
Environmental hygiene	6,8,9,10	"Keeping surroundings neat and clean for staying healthy" (Girl, Class 8)
3.Indices of health		
Active & energetic	6,7,8,9,10	"Being energetic & active in all classes" (Girl, Class 7)
Ability to work hard	6,8,9,10	"If one is healthy, he/she is able to do anything" (Boy, Class 10)
Playing well	6,7,8	"To be healthy, we should always play games" (Boy, Class 8)
Fit & strong	6,7,8	"Keeping body fit is important to be healthy and do any work" (Girl, Class 7)

inferring the definitions the priorities on aspects (based on the percentage of responses) were also taken into consideration.

Class 6 children defined 'being healthy' mostly in terms of consumption of healthy diet that includes drinking milk and adequate water, being fit and strong, following personal hygiene, practicing yoga and exercise for physical fitness so as to be free of diseases.

Similarly, the children of Class 7 defined 'being healthy' in terms of a nutritious and balanced diet and avoidance of oily food, being fit and strong through exercise, leading to a disease free state indicated by good academic performance.

The children of Class 8 described 'being healthy' in terms of a nutritious and balanced diet, through maintenance of personal as well as environmental hygiene, regular exercise, ability to do any work, being fit and strong, having energy and being active, ability to adapt to situations, maintaining good interpersonal relations, coping well with stress, and maintaining a disease free state.

Class 9 children had a comprehensive definition of 'being healthy' i.e. consumption of nutritious and balanced diet, a state of no disease, sustained through personal and environmental hygiene, and regular exercise and yoga with an outcome of long life.

Children of Class 10 also described being healthy as adherence to nutritious and balanced diet along with observing personal and environmental hygiene, being active in their work, including psychological factors such as mental health, positive affect state, having a peaceful mind, along with behavioural factor such as preventive healthcare.

Table 3 Unique sub-themes under themes, and specimen responses of participants across different classes

Class	Themes and Sub-themes	Sample Responses
6	Ways to be healthy	
	Eating on time	"Eating on time is very good for health" (Girl)
	No over eating	"If we have to stay healthy we should not over eat" (Boy)
	Chewing well	"We should chew food properly, for proper digestion" (Boy)
	Drinking lot of milk	"Drink milk everyday to stay stronger" (Girl)
	Drinking lot of water	"Drinking plenty of water is very important" (Girl)
	Not being fat/not over-weight	"Being fat is dangerous" (Girl)
	Indices of health	
	No indigestion	"For healthy digestion we should eat good food" (Boy)
7	Ways to be healthy	
	Avoiding oily food	"We should be avoiding oily food because it is bad for our health" (Boy)
	Indices of health	
	Good academic performance	"Studying without any tension and doing well in exams" (Boy)
8	Indices of health	
	Ability to adapt to situations	"If we are healthy, we can adapt to changes nicely" (Boy)
	Maintaining good interpersonal relations	"Interacting well with others can make us have a happy mind" (Boy)
	Coping well with stress	"If we are healthy we will have the ability to adapt to stress in life" (Boy)
9	Indices of health	
	Living longer	"If we are healthy, we can live a long life" (Boy)
10	Indices of health	
	Mental health and positive affect state	"A healthy person is a happy person" (Girl) "Not just being physically strong but being mentally strong is complete health" (Girl)
	Peaceful Mind	"When we are healthy, we have a peaceful mind (Girl)
	Preventive Action	"To be healthy, we have to go for regular health check-ups" (Boy)

It may be observed that though factors like nutrition and balanced diet are common, the classes differed in their emphasis and additional factors.

3.2 Quantitative Analysis

The purpose of quantitative analysis is to compare the conceptual complexity on 'being healthy' across the classes. In order to compare the children from Class 6 to Class 10 on the divergence of responses across the three themes, the percentage of responses of each Class of students across the three themes is presented in Table 4.

The table while presenting the number of responses also presents the mean responses per Class. It is observed from the mean scores that the mean number of responses across themes for Class 10 is 3.22 as against the mean number of total responses ($M = 2.79$). This can be compared with the mean number of responses of 6th

Table 4 Summary of frequency of responses under themes across classes

Class	N	Responses categorized into theme			Total responses	Mean of responses
		Theme1 Meaning of health	Theme2 Ways of being healthy	Theme3 Indices of health		
6	147	79 (21.70%)	169 (46.43%)	116 (31.86%)	364	2.48
7	155	83 (17.93%)	215 (46.43%)	165 (35.64%)	463	2.99
8	157	103 (22.54%)	239 (52.30%)	115 (25.16%)	457	2.91
9	145	114 (30.32%)	203 (54.00%)	59 (15.69%)	376	2.59
10	63	50 (24.63%)	120 (59.11%)	33 (16.26%)	203	3.22
Total	667	429	946	488	1863	2.79

N = Sample size

Class ($M = 2.48$) which is lower than the total mean ($N = 2.79$). The results also reveal that the percentage of responses under theme 2, i.e. *ways of being healthy* increased from 46.43% (Class 6 & 7) to 59.11% (Class 10). This shows that larger percentage of children responded with the antecedent of health. In case of theme 3—*indices of health* the percentage ranged from 15.69% (Class 9) to 31.86% (Class 6). On the contrary, in case of the theme *meaning of health* the responses ranged from 17.93% (class7) to 30.32% (Class 8). This indicates that it is more common among children to conceptualize health in terms of causal action and parameters indicating health than in abstract terms of 'meaning of health'.

3.2.1 Computation of Entropy to Examine the Extent of Divergence in Response and Class-Wise Conceptualisation

The concept of 'being healthy' is subjective. Hence, children may hold different schema of the concept. Higher the variation across themes, higher is the entropy.

In order to meet the objective of examining if the responses across classes showed a progressive developmental trend in perception of health, the frequency of responses under themes were plotted. The convergence or diversity in conceptualisation based on the frequency of responses under different themes was observed by calculating the disorderliness or entropy. The steps of mathematical process of detailed derivation of entropy are explained under Method section.

Using this process, the derived Response Ratio, Balancing Factor, Absolute and Neutralised Entropy across five classes of students are presented in Table 5. The Neutralised Entropy values are plotted as line graph in Fig. 1.

Both Table 5 and the graph revealed a significant spurt in response divergence between Class 9 ($E_n = 1.969$) to Class 10 ($E_n = 4.373$). Surprisingly, the entropy score at Class 6 was found to be higher ($E_n = 2.074$) with a marginal declining trend thereafter till Class 9. This needs to be interpreted with reference to their curriculum of Biological or Human Sciences across classes.

Table 5 depicts the sample size for each of the classes, along with B_F, i.e. or Balancing Factor which is a correction for class size. The significant highlight of the table is the depiction of divergence or disorderliness of responses, i.e. the

Table 5 Response ratio, balancing factor, absolute and neutralized entropy across five classes of students

Class ($N = 667$)	R	B_F	E	E_n
6 ($n_1 = 147$)	2.476	0.220	0.457	2.074
7 ($n_2 = 155$)	2.987	0.232	0.448	1.928
8 ($n_3 = 157$)	2.911	0.235	0.444	1.886
9 ($n_4 = 145$)	2.593	0.217	0.428	1.969
10 ($n_5 = 63$)	3.222	0.094	0.413	4.373

R, Response ratio; B_F, Balancing Factor; E, Absolute Entropy; E_n, Neutralized Entropy

respondent's tendency to respond variedly in response to the question posed to them, indicated by E_n. In short it refers to the spread of responses of a class across the themes. According to Neutralised Entropy values, there was a slight drop from Class 6 ($E_n = 2.074$) to Class 7 ($E_n = 1.928$), and a slight further reduction in Class 8 ($E_n = 1.886$). This pointed out to an 'unstable stagnancy' in cognition of the respondents belonging to middle school, as the values could not be predicted as drastic changes. For Class 9, there was an increase in Neutralised Entropy scores as compared to Class 8 ($E_n = 1.969$). The surprising element in the observation of this trend was reflected in the radical jump of divergence of health-related schema in the respondents of Class 10 ($E_n = 4.373$). This phenomenon is illustrated in the line graph in Fig. 1. In the figure, it is observed that the developmental trend line was a plateau for Class 6 to Class 9 with an upward steep for Class 10.

Among other computations it is of relevance to note the probability of response by any random child in a class. This is suggested by the Response Ratio (R) value. A randomly selected child of Class 6 was expected to have a schema of 'being healthy' that was expressed in an average of 2.476 meaningful statements. Similarly, 'being healthy' was conceptualised and expressed in an average of 2.987, 2.911, 2.593, 3.222 statements by Class 7, Class 8, Class 9, and class10 respectively. This is different from the entropy value because the explanations may not be divergent in nature cutting across different themes. However, it indicates the ability of the child to explain 'being healthy' in more than one way.

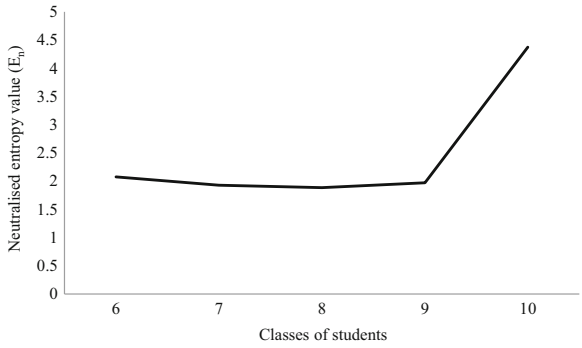

Fig. 1 Line graph plotted with neutralized entropy values showing developmental trend in conceptualization of 'health' among Indian school children ($N = 667$)

4 Discussion

The major findings of the study indicate two broad aspects related to children's concept of being healthy. The first one refers to the thematic concentration and the second relating to developmental trend indicating a progressive increase in the complexity of the concept.

The content analysis and the emergence of the three themes subscribed to and strengthened the qualitative approach. The three themes have indicated that Indian children included the abstract concept of health (meaning of health), behaviour orientation to be healthy (ways to be healthy), and the outcome indices of being healthy (symptoms of health) into their schema of health. This implies that the children conceptualised 'health' in its complexity, close to the holistic definition of health proposed by Bircher (2005).

The three themes evolved out of the responses—*meaning of health, ways to be healthy* and *indices of health* have also been included in different independent research findings in the past. The themes being abstract indicate some level of complexity ranging from physical strength and fitness to psychosocial aspects (Almqvist et al. 2006). The low percentage range of response in this theme indicated low level of awareness. This is expected because conceptualizing health in abstract terms is much more difficult than in terms of antecedents and consequents. This finding is in line with that of Motakpalli et al. (2013) that suggested a low awareness of disease and health risk behaviour among rural children in Mangalore, India. However, the difference between Motakpalli et al. (2013) study and the current findings are that the former specifically referred to health risk behaviours and also limited to rural children. Further the method adopted in their study was an assessment of personal hygiene using a scoring system.

The sub-themes listed under the second major theme of 'ways of being healthy' pointed at health promoting and health risk behaviours. The sub-themes such as adherence to balanced diet, food chart, and physical exercise concur with the earlier findings of Protudjer et al. (2010) which stated that children's concept of being healthy referred to healthy eating and physical exercise as significant components. Larger percentage of children's responses across classes falling into this category is also in expected lines since the sub-themes classified under this are related to actions for being healthy.

The biopsychosocial indices of being healthy that were enlisted under the theme of healthy indices corroborated with the earlier findings which indicated that children's concept of being healthy included ability to work, participate in daily activities and attaining the derived goals (Nordenfelt 2007; Schramme 2007; Almqvist et al. 2006). The percentage range of responses under this theme was also found to be relatively lower compared to *'ways of being healthy'*. Such percentage variations across the themes suggest that the level of awareness indicated by any tool is dependent on the type of question. Thus it contributes to the argument that using an open-ended question to measure awareness avoids such limitations in measurement that is imparted by the type of question.

The commonality of themes and sub-themes suggest the most popular ideas about health that are prevalent across classes. Children's most popular beliefs were limited to the biomedical aspect of health, i.e. absence of disease. Similar polarization of the

concept of health by children has been reported in various studies (Piko and Bak 2006; Myant and Williams 2005). Other common concepts of health circled around good diet, hygiene, and rejuvenating sleep which signified the children's positive attitude towards basic actions to maintain good health. Observable characteristics such as being active and energetic, and ability to do any work as the indicators of health were identified by all the classes. However, younger children from lower classes focused on indicators like playing, being fit and strong, and academic performance indicating the simplicity in understanding of health as related to their own day to day activities. The overall picture about the commonality of themes and sub-themes shows the concrete qualities children understand about health. Abstract yet important features of health such as good mental health, psychosocial factors such as social relationships seem to be absent across the classes. The unique sub-themes interestingly bring out the progression in the comprehension of health in the children as their exclusivity in defining health shifts from *'ways to be healthy'* to markers of good health. This can be interpreted as the shift in their cognition from merely remembering and following instructions about how to maintain good health (probably from their caregivers, teachers, or curriculum) to self observation of markers or indices of good health which also includes psychosocial aspects (maintaining good interpersonal relationships, having a peaceful mind, good mental health and positive affect, etc.) as they move higher up the classes.

Another of the contributions of this study is measuring the concept of health with its complexity. Computation of 'entropy' across the classes enabled the investigators to measure the degree of complexity in the schema of health as held by children. Rather than merely counting the number of responses, the concepts that spread across the themes indicated by higher values of entropy projects the complexity of the schema, which in turn is an assessment of presence or absence of a developmental trend in conceptualizing health. The results though indicated a developmental trend, it almost showed a plateau between Class 7 and 9 and then onwards a steep upward slope. Similarly in a study of children's concept of diabetes there was spurt in conceptual knowledge of diabetes for Class 10 (Padhy et al. 2018). However in conceptualizing HIV/AIDS, there was a gradual increase in the neutralised entropy from Class 6 to Class 8 and then a sudden jump from Class 9 to Class 11 (Nagpal et al. 2017).

The developmental trend was found to be somewhat erratic. The findings that indicated a relatively higher entropy score at Class 6 which showed a slight downward slope at Class 7 and 8 followed by a negligible pick up in Class 9 which then showed a significant sudden upward slope between Class 9 and Class 10 needs to be interpreted in relation to the curricular inputs. With these objectives the textbooks of Biological Science followed by these schools were examined. The contents related to health were searched. This exploration revealed that Biological Sciences are taught as a distinct course only from Class 8. In Class 6 the science text in the very first chapter explains the "dos and don'ts" of the food consumed. There is no focus on health in the science text of Class 7. Though there is a focus on 'illness and avoidance of health risk behaviour' in Class 8, that is listed as the last chapter which was not yet covered at the time of data collection. Again in Class 9 the focus of science curriculum was on plant sciences than on human health. However, the Biological Sciences in Class 10 have a wide range of chapters focusing on health. Thus, the entropy line seems to correlate with the school curriculum.

In the light of the present findings it can be inferred that children in this study had a complex concept of health and involved a cognition that includes abstraction such as 'God's gift' to concrete actions as well as the consequences of being healthy. This can be further strengthened and enhanced with a curriculum that is more systematically organized along the stages of cognitive development. The concept of entropy may be useful for the researchers who adopt quantitative content analysis for understanding the divergence of response pattern.

4.1 Limitation and Conclusion

Despite its high utility in comprehension of children's perception of *health*, this study is limited to a particular academic curriculum of schools and students belonging to the lower socioeconomic group. A comparison of this group with the children from higher socioeconomic status and following a different curriculum would have given an insight whether the conceptual complexity is related to SES and school curriculum. Also, there should be further opportunity for children to clarify their answers and follow-up.

Nevertheless, the Indian school children are found to perceive health in multi-dimensional terms organised around its meaning, health promoting or risk behaviours, and indices of health. A developmental variation in children's operationalisation of the dimensions of health is mostly attributed to exposure of health curriculum taught in their schools. This study paves a future direction of research to design the school science curriculum to promote better conceptualisation of perception of health and subsequent risky or healthy behaviour, so as to enhance health promoting behaviours in children.

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Compliance with Ethical Standards

Conflict of Interest Nil

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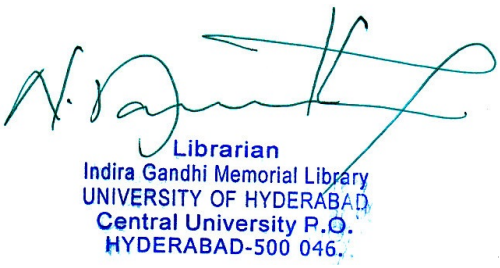

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