DISRUPTED LIVES:

A QUALITATIVE STUDY OF EXPERIENCES OF LIVING WITH CANCER PATIENTS AND THEIR FAMILY CAREGIVERS

By

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As members of the Viva Voce Committee, we certify that we have read the dissertation prepared by **Mehboobun Nahar Milky** entitled **"Disrupted Lives: A Qualitative Study of the Experiences of Living with Cancer among Cancer Patients and their Family Caregivers"** and recommend that it may be accepted as fulfilling the thesis requirement for the awardof Degree of Doctor of Philosophy.

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DECLARATION

I, hereby declare that the investigation presented in the thesis has been carried out by me. The work is original and has not been submitted earlier as a whole or in part for a degree / diploma at this or any other Institution / University.

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DEDICATION

In Loving Memory of My Mother,

whom I lost in this journey. She was the

fiercest woman I had ever known who

taught me to be strong and be myself.

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CONTENTS

SUMMARY

Cancer is a life- changing experience for both cancer patients and their caregivers. Often, people equate cancer diagnosis with death where cancer is assumed to be stealing away one's life surreptitiously, bit by bit (Lawton, 2000). Finlayson et al., (2019) indicated that the patient's awareness of a shortened life and dying, results in a myriad of emotions such as denial and uncertainty. The family caregivers too suffer, especially when their life becomes entangled with that of the patient, and the more they become aware of the prognosis of the patient and the deteriorating condition, the more is the risk of them suffering from psychological breakdown (Hinton, 1999; Adelbratt & Strang, 2000; Ciemins, Brant, Kersten, Mullette, & Dickerson, 2015; Li, Y, Xu, & Zhou, 2018). Furthermore, new developments in treatments and cancer managements indicate that people would be living with cancer for a prolonged period and it would be a vital aspect of their life courses. It is against this backdrop that this study is set where I seek to provide an understanding into the experiences of being a cancer patient and caring for one, in the urban Indian context. This study intends to give a detailed, empirically grounded understanding of what it is like to live with cancer and caring for those with cancer within the family. This was accomplished by exploring the experience of both the individual with cancer and that of their family caregiver through an analysis of their narratives. An ethnographic approach was used, involving observations and a series of in-depth interviews of eight dyads of cancer patients and their family caregivers. Thematic analysis was undertaken to identify relevant themes within the narratives. This study indicates that the experiences of living with cancer was a complex, difficult and arduous struggle. Participants said that 'living with cancer is difficult', as the impact of cancer has pervaded every aspect of their lives. Experience of cancer included several facets such as the difficult nature of cancer, the work of cancer, sufferings due to cancer and its care, and the coping strategies. Analysis revealed that participants faced disruption in their day-to-day normalcy since the moment of diagnosis.

Disruptions were observed in their perception of their self and others, and during the performances of their routine activities including the maintenance or continuance of their roles and in their social relations which led to profound suffering that induced alienation, uncertainty and emotional struggles. Living with cancer required participants to make adjustments at first, and over time and with experience, they learned to ‘negotiate’ or ‘get on with it’. The findings of this study suggest more emphasis on the individual supportive care based on the patients’ and their family caregivers’ perceived necessities and their crises. It is suggested that an increased awareness of the psycho-social difficulties of people living with cancer can contribute to an enhanced understanding of what and how people with cancer manage these in their everyday lives. Moreover, this thesis emphasises that more precedence is required not only to policy, education, and research that stresses on patient’s existential wellbeing but also to the wellbeing of the caregivers living with tensions of caring and comforting.

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Chapter 1: Introduction

Death is a universal truth, but it does not become an individual experience until it is identified and confirmed. The concern of this study is the change that occurs when a diagnosis of chronic illness, such as cancer, moves death from the general to the specific and in that circumstance how the diagnosis and the treatment regimens are perceived by individuals diagnosed with cancer and their caregivers and how they develop resilience within this phase. The purpose of this study is to develop an understanding of the experiences of a cancer patient and caregiver for one and in particular, how it affects them on an individual level which will assist the health care professionals in identifying sensitive and complex circumstances and to provide appropriate support for people affected by cancer. The qualitative method of inquiry allowed me to develop an extensive understanding of, and to reflect upon, the experiences of cancer and caregiving among the study participants. The narratives provided insights about the effects of suffering from such severity like cancer in their everyday life and on themselves and how they managed and coped with their situation.

The overall objective of this study, therefore, is to provide insights and to interpret the experiences, the expectations, the perseverance and actions of people living with cancer through analyses of their narratives and those of their immediate caregivers or significant other(s). Specifically, the aims of this study are:

1. To explore and understand the meaning(s) of suffering from the perspectives of individuals diagnosed with cancer and their caregivers
2. To explore the multiple coping strategies utilised towards developing resilience among the cancer patients and their caregivers
3. To develop knowledge about the ‘experiences’ of people living with cancer and their family caregivers

A. Structure of the thesis

This thesis presents the results of a qualitative investigation into the experiences of individuals living with cancer diagnosis and the experiences of family caregivers caring for them in their social setting. The following chapters have been organised in line with a traditional research report: background and literature review (discussed in this chapter), conceptual perspectives (chapter 2), followed by methods (chapter 3), results (chapters 4 and 5) and discussion and conclusion (chapter 6).

In chapter 2, I have explored how cancer can be perceived from a sociological stance using the concepts of disease, health, illness and subjective experiences. In this section, I have also discussed the concept of biographical disruption, suffering and coping strategies which I have used to interpret the data collected during the fieldwork of my research. Chapter 3 discusses the research methodology and the methods of inquiry. In here, I discuss the theoretical basis for the research design and justify the choices made in this research. Following that I describe the specific methods I have used to collect and analyse the collected data. In chapter 4, I present the findings related with the experiences of cancer patients focusing on their subjective understanding of the illness, its impact on themselves and their relationships, their personal difficulties and how they have managed or coped with those difficulties and changes. Chapter 5 focuses on the experiences of the family caregivers, the task of caring, their personal difficulties, perceived needs and how they managed themselves throughout the process. Chapter 6 comprises the discussion of the findings, based around the conceptual framework described in chapter two and within the context of broad domains of chronic illness, biographical disruption, suffering and coping. Along with this, the chapter also presents the summary of the thesis highlighting recommendations for practice and future research and the limitations of the study before concluding with some personal reflections gained during the course of the research.

In the following sections, I will give an introduction to the focus of this study, providing a background and outlining the review of literature. In addition, I will provide an overview of my own position within the study, and thereby maintaining the tradition of qualitative research.

I. What is cancer?

The word cancer is derived from the Latin word *canker* which is employed to define everything that corrupts, erodes, rots, and so on. The word *canker* implies ‘destruction, eating away, a spreading of evil or corruption’ (Deeley, 1979). Purandare (1997) commented that cancer is considered as an unclean disease. This is evident from the usual reaction to the mention of the name ‘cancer’ which generally, if not always, and in several societies across the world, evokes a sense of revulsion and fear. Cancer is also deemed as a ‘sinister disease’ where non-intelligent cells i.e., primitive, embryonic, atavistic cells multiply and ‘you are being replaced by non-you’ as defined by Sontag, (1991). Pugsley & Pardoe (1988) go to the extent of viewing cancer as an alien which might remain dormant inside one’s body only to be awakened from that state by a sudden shock or blow. Unfortunately, in many cases, it is not the disease but the one afflicted by it, i.e., the cancer patient who is blamed for deserving the disease by leading an ‘unclean life style’ (Purandare, 1997).

Cancer and its aetiology have a long history in the scientific and medical academia of disease (Rather, 1978). Interestingly, it is in in the palaeontological remains of dinosaurs that the initial traces of this disease are found in the form of lesion affecting bones (Benedek & Kiple, 2008). The earliest anthropological evidence of tumours and their treatment have been discovered from Egyptian mummies dating back to 2000 to 3000 B.C. discovered from various archaeological sites. It is pertinent to note that the world’s oldest recorded case of cancer comes from ancient Egypt documented on a papyrus which contains descriptions of eight cases of tumours. These tumours were recorded to have been breast cancers in women and they had treated this disease through cauterisation, which is basically the method of destroying tissues with a hot instrument so that bleeding can be prevented. It is to be noted that that there was no treatment for cancer at the time or any other way to deal with cancer besides palliation (Schwab, 2017). What is amply evident from the above discussion is that cancer is not a modern disease. In fact, Hippocrates in ancient Greece is usually credited with having named the disease cancer from *Karcinos* or *Karkinos* which refers to the Greek word for the crab. Benedek and Kiple (2008) point out the reasons for such a name given to the disease by Hippocrates is perhaps due to the crab like appearance in certain forms of breast cancer. This is a plausible reason as many breast cancer incidences have been recorded in ancient times as has been mentioned earlier in this discussion. Also, another reason for such a name could arise from the fact that the excruciating pain that the cancer patient feels parallels that inflicted on someone by the pinching of a crab (Benedek & Kiple, 2008). It is also instructive to note that other words related to cancer and its treatment such as neoplasm, oncology, tumour, etc. have their origins in Greek. *Neoplasm*, which means new growth and *oncology* referring to the study of masses of cells, have been derived from the Greek, as is the word *tumour*. Hesketh in the year 2013, mentions how that the words tumour and neoplasm are now interchangeably used and they both signify new or abnormal cell growth. The term tumour and cancer too are synonymously used, but there is a significant difference between the two. This difference is in the metastatic nature of cancer which evolves from tumour and then gains the capacity to spread to its surrounding from the original site of affliction. It is important to understand that cancer is not a modern disease and historically, the prevalence of this disease has been quite high (Benedek & Kiple, 2008). People have suffered a lot because of this disease and for centuries, especially till the latter part of the twentieth century, there was hardly any proper treatment for cancer. It was justifiably perceived as ‘knell of doom to the victim’ (Kelly & Frieson, 1950).

There are over two hundred medically differentiated types of cancer, the most prevalent being those of lungs, liver, stomach, prostate, breast, colon, rectum and cervix (Benedek & Kiple, 2008; Jemal, Torre, Soerjomataram, & Bray, 2019). All forms of cancer are characterised by abnormal cell growth which begins with the uncontrolled division of abnormal cells, and finally leads to metastasis (Schwab, 2017; Hesketh, 2013). Metastasis is the process of spreading of malignant cells to other sites in the body from the site of origin (Hesketh, 2013). A contemporary oncology textbook refers to cancer as a disease of cells of the body, characterised by “deregulated multiplication of cells with the consequence of an abnormal increase of all cell numbers in particular organs. Initial stages of the developing cancer are usually confined to the organ of origin whereas advanced cancers grow beyond the tissue of origin … invaded the surrounding tissues. At a later stage, they are distributed via the hematopoietic and lymphatic systems throughout the body where they can colonise in distant tissues and form metastasis. The development of cancer is thought to result from the damage of cellular genome, either due to random mechanisms or due to environmental influence” (Schwab, 2017).

In other words, it can be said that, cancer is a loss of control resulting in abnormal cell growth, which may acquire the potential to spread from site of origin to other sites in the body through various means. It includes tumours, may it be benign or malignant or osteoma. Cell division is a natural phenomenon in human body. It is worth stating that this process occurs as per the natural requirement of the body and the process of this cell division is slow and it happens in a naturally controlled manner. However, that is not the case with cancerous cells, where rapid, uncontrolled cell division occurs which results in the formation of a mass of excess tissues and this is known as tumour. Tumours are of two types – benign and malignant. Benign tumours could arise in any tissue, usually causing local damage, i.e. it is localised or restricted to its site of origin only, while malignant tumours invade through connective tissues into surrounding tissues. They have the tendency to spread through lymphatic routes or blood to other sites. The dispersion of cancer in this way is known as metastasis. There are other forms of cancer too. The cancer nomenclature describes the types of cells and the type of cancer involved such as osteoma, where *osteo* refers to bone and *oma* refers to any swelling or tumour (Hesketh, 2013).

Despite its antiquity, as seen from the discussion so far, cancer is perceived largely as a twentieth century phenomenon (Benedek & Kiple, 2008). Today's estimates of cancer are alarming: it is estimated that one in four men and one in five women are developing the disease, while one in eight men and one in eleven women are dying of the same globally. Every year more than 12 million people throughout the world are diagnosed with cancer (Hesketh, 2013; Jemal, Torre, Soerjomataram, & Bray, 2019). Recent statistics of cancer incidences and mortality indicates that more than 18.1 million new cases and 9.6 million cancer deaths were reported worldwide in 2018. In addition to this, in the same period, 43.8 million people with cancer were diagnosed within the previous five years. Cancer happens to be the cause of one in every six deaths worldwide (Jemal, Torre, Soerjomataram, & Bray, 2019). Information available on differences in the incidence and mortality of different types of cancer has been marked in different regions of the world and the highest number of new cases of cancer (5.6 million) for the year 2018 is from Eastern Asia where China represents 19 per cent of global population of new cancer cases and death, followed by Northern America (1.9 million) and South Central Asia (1.7 million) while the highest number of deaths is found to be in Eastern Asia (3.4 million) followed by South Central Asia (1.2 million) and Northern America

(693,000). It is pertinent to note that about one –fourth of all new cases and one-fifth of the deaths occur in the developed Europe, despite its health infrastructure being in place.

This global diversity of cancer prevalence indicates the presence of both local risk factors as well as the efficacy of cancer control measures (Jemal, Torre, Soerjomataram, & Bray, 2019). Several factors often associated with lifestyle and environment are ascribed for the observed variation in the recorded incidences of cancer among different registry populations. It is also noted that age too is an important factor for the worldwide variable of occurrence of cancer. The longer we live, the chance of one developing cancer is higher and so is the possibility of dying from cancer (Hesketh, 2013). Bray et al., estimated in 2018 that about 21 out of 100 males and 18 out of 100 females would develop cancer by the age of 57.1 years (Bray, Ferlay, Soerjomataram, Torre, & Jemal, 2018). The study of Jemal, et al., (2019) based on the population aging and growth estimated that the global burden of cancer would increase from 18.1 million new cases in 2018 to approximately 29.4 million cancer cases in the year 2040, which translates to an increase by a whopping 60 per cent. As of today, cancer of lung, liver, stomach, breast and colorectal are seen to be the major forms of cancer that are contributing to the worldwide mortality. Among these, lung cancer is the most commonly diagnosed cancer worldwide for both the sexes affecting 2.1 million individuals and causing untimely deaths of 1.8 million individuals (Jemal, Torre, Soerjomataram, & Bray, 2019). After lung cancer, the second most prevalent cancer is female breast cancer but it is the fifth leading cause of death due to its relatively favourable prognosis (Jemal, Torre, Soerjomataram, & Bray, 2019). Colorectal cancer is the third frequently diagnosed cancer variety in the world but it appears only second after lung cancer in terms of mortality (Jemal, Torre, Soerjomataram, & Bray, 2019). When it comes to occurrence, the fourth most frequently diagnosed cancer is prostate cancer followed by liver and stomach cancer (Jemal, Torre, Soerjomataram, & Bray, 2019). Cancer is either first or second leading cause of premature death globally, but with the availability of enhanced treatment, proper guidance, and early detection, the average survival rate of individuals affected by cancer has vastly improved. In the year 2018, there were approximately 43.8 million cancer survivors who were diagnosed within five years which shows that more numbers of early detections are happening leading to a rise in the numbers of cancer survivors. (Jemal, Torre, Soerjomataram, & Bray, 2019)

In the Indian context, studies show that the cancer estimates for the country are alarming and it is one of the leading causes of premature deaths (Murthy, Chaudhry, & Rath, 2008; National Cancer Registry Programme, 2013; Jemal, Torre, Soerjomataram, & Bray, 2019). According to Jain (2018), there are approximately 2.25 million people with cancer in India, and every year there is an addition of about 700000 new registered cases. Ferlay, et al., (2013) has suggested that India's cancer burden would nearly double in the next 20 years, from slightly over a million new cases in 2012 to more than 1.7 million by 2035. Similarly, Jemal, Torre, Soerjomataram, & Bray (2019) predicted that by the year 2040, there is a likely increase of 60 percent in number of incidences in India. Similarly, the absolute number of cancer deaths would rise from about 680000 to 1.2 million for the same period. For the year 2018, the number of new cases in the country is more than 1.15 million (International Agency for Research on Cancer, 2019) and the death from cancer is seven hundred eighty-four thousand eight hundred twenty-one for the same year (International Agency for Research on Cancer, 2019). Takiar, Nadayil, & Nandakumar (2010) points out that more than 80% of cancer cases in the country are in advanced stages, and palliative care[1] is essential towards quality life of these patients. Ferlay et al., (2013) has estimated that the total number of individuals in requirement of palliative care in India is about 5.4 million per year. There is probability of increased demand due to inadequate diagnostic facilities, poor therapy and limited opioid availability. Mallath, et

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[1] Palliative care is an 'approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' (Connor & Sepulveda, 2014).

al., (2014) described the burden of cancer in India through narrating the high incidences and mortality rates, regional variations, social contexts, and advocate promotion of cancer patients' interests. Kawachi, Subramanian, & Almeida-Filho (2002) stated that, the burden of cancer in India is intimately linked to the socio-economic inequalities when it comes to access to health care. They have identified rebalancing the distribution of power, resource management and social goods as the possible major criteria for India to reduce the cancer burden. The study indicated that, addressing social inequality, minimising the increasing cost of cancer treatment, political commitment and action, as well as awareness are essential to reduce the cancer burden. Ban of tobacco product and its control, developing well organised national, regional and district leaderships are also required to reduce the burden of this deadly disease. They also advocated that, policy makers should be aware of these facts if they want to adequately address the issue of dealing with and overcoming, some of the most fundamental obstacles that come in the way of provision of affordable, universal and equitable care for the general populace. Koirala (2018) discussed that, each year, in India there are over a million new cancer cases which lead to many untimely deaths and increase the burden on the affected families. The study based on data on various demographic, social and medical aspects on 251 households of Handiganur village of Karnataka indicates that, living in a joint family lowers the odds of cancer related emotional suffering. In a review article, Smith & Mallath (2019), discussed the history of growing burden of cancer in India where they described the decade-wise increase in the rate of occurrence, condition in the 20th century, population-based cancer registry, and future of cancer in India. The study points out that the growing burden of cancer and their warning remain largely unattended by the authorities and as a result the burden is increasing alarmingly through epidemiological transition.

At this juncture, it needs pointing out that this growing population of cancer survivors posits a challenge for not just the cancer survivors, but their families, health care professionals and government (Andrykowski, Lykins, & Floyd, 2008). Sometimes cancer survivors have to live with long and/ or life lasting challenges including impaired functional status, fear of recurrence, depression, pain, biological dysfunctionality, relational issues and financial hardship. This can make them more vulnerable to poor mental, physical health related quality of life.

II. Dimensions of cancer

Some long-held perceptions are not easy to let go of. This is certainly true of the common perception of cancer. It is true that on account of enhanced quality of cancer treatment in recent years, there is an increase in survival rates. However, despite this, often people equate cancer diagnosis with death. This perception has been there for ages. In the 1920s, George Groddeck, a psychoanalyst sought to investigate cultural meanings of cancer, instead of acknowledging it as a purely biological phenomenon, as was the general practice then. This is what he wrote regarding how cancer has often been equated with death.

> "… of all the theories put forward in connection with cancer, only one has in my opinion survived the passage of time, namely that cancer leads through definite stages of death. I mean by that what is not fatal is not cancer. From that you may conclude that I hold out no hope of a new method of curing cancer…" (George Groddeck, 1923. *The Book of It.*) (Sontag, Illness as a Metaphor, 1978)

The central premise in today's era of modern medicine may be an optimistic one that all diseases can be cured. However, perceptions inspired by critical diseases in different stages of human advancement, whether the ones inspired by tuberculosis in 19th century, or by cancer now, challenge this optimism. These responses of despondency and hopelessness come from the assumption that the disease is assumed to be intractable and capricious, even in an era of scientific advancement and advance medicine. Just as cancer diagnosis is perceived now in many quarters as a death sentence, so was the case with the diagnosis of tuberculosis in the 19th century. In the popular perception, cancer equates to a death sentence. The seemingly insidious nature of a disease like in a previous era parallels a similar perception about cancer now, where cancer is assumed to be stealing away one's life surreptitiously, bit by bit. Cancer is seen as a ruthless, secret invasion of one's body (Benedek & Kiple, 2008). Just as it was a general practice to conceal the facts of one being afflicted with tuberculosis earlier, the same is true of cancer now. Not just the family members, but even the doctors are sometimes reluctant to talk about cancer freely, due to the negative perceptions attached to it (Sontag, 1991). A large number of people with cancer face a similar situation. They are shunned by their relatives and friends and are often subjected to stigmatisation (Brown & Cataldo, 2013). This stigmatisation may come across as illogical to rational minds as cancer is not an infectious disease. But then again, tuberculosis is not contagious either and yet in earlier times, those suffering from it were largely shunned as well.

It is not just the body that is adversely affected by cancer. Cancer also impacts one psychologically. These adverse effects can lead to psychological trauma and other dilemmas. Susan Sontag, in her popular book - *Illness as a Metaphor*, has described some of the problems that cancer can elicit:

> '…cancer arouses thoroughly old-fashioned kinds of dread. Any disease that is treated as a mystery and acutely enough feared will be felt to be morally if not literally, contagious. Thus, a surprisingly large number of people with cancer find themselves being shunned by relatives and friends and are object of practices of decontamination by members of their household, as if cancer, like tuberculosis, were an infectious disease' (Sontag, 1978, p.6).

Sontag (1978) makes a very pertinent point regarding how cancer might not be contagious in the literal sense, but contagious in the moral sense. She argues that such a moral contagion could often result in patients being shunned and excluded from social life. She points out that in many societies, not to say the word (cancer) itself is seen as a way of avoiding moral contagion and isolation. A similar point has also been made by Stacey, a sociologist, who had her own experiences of living with a cancer diagnosis. She wrote (1997):

> "Whatever you do, don't say 'cancer'. The unspoken word, written on everyone's lips, must not be voiced".

Often, doctors also avoid using the word cancer during consultation. When discussing a diagnosis, the physician sometimes draws on seemingly innocent euphemisms such as lump, growth, wart or polyp, so that this does not evoke any stigma or intense emotional turbulence or mental pressure to either the patient or the doctor. In diagnostic accounts, people suffering with cancer and their relatives often stated that it was left to them to label the disease instead of being told so up front by the physician (Fallowfield,1990). While narrating her experiences of cancer, Stacey (1997) commented that during her visits, the word cancer almost never got mentioned directly in front of her by the medical staff. She surmised that their not speaking the particular word did not have a positive effect on her. On the contrary, it conveyed to her a sense of embarrassment and shame, and compounded her existing difficult emotional state wrought upon by the disease.

Of course, it should not be construed that the euphemisms for cancer are not without their benefits. Some medical professionals perceive that these euphemisms protect the patient from the associated dilemmas of the disease (Stacey, 1997). However, even though this method of interaction could be true in some instances, one has to also weigh in the burden on the patients of not knowing their illness or how this may adversely impact them managing their illness due to a lack of openness in communication with doctors. To make the speaker (doctor) and listener (patient / care-giver) comfortable, a group of diseases are sometimes reduced to a single one, in the public domain. Some such examples are “something nasty”, “a lump”, “the cruel C”, etc. (Stacey, 1997) One can argue that these euphemisms and abbreviations are a way to manage talking about a sensitive topic so that one could avoid the “unmentionable” and the accompanying cultural associations.

III. Psychosocial oncology and coping with cancer

Unlike in the past, thanks to the advancement in science and health care, researchers and healthcare professionals understand the impact of cancer on both the patients and their family members much better now. However, the literature is scarce on issues such as psychosocial needs, survivorship and long-term care, issues on which it is only in the recent times that significant work is getting done. The works of Watson & Morris (1985), Beckman (1989), Somerfield & Curbow (1992) emphasise on the role that psychological factors play in the onset and management of cancer. This role of psychological factors is increasingly being acknowledged since the late 1970’s. For long, it was primarily the biological well-being, i.e., matters of life and death were the focal points in the treatment of cancer (Benedek & Kiple, 2008). With the advances in medical science, not just the physical wellbeing, but the psychological process of recovery too is being considered as a significant aspect in cancer management. The relatively new discipline of psychosocial oncology, a sub division of oncology, has emerged due to this newer focus on understanding how people cope with cancer. Psychosocial oncology focuses on the psychological issues encountered by those diagnosed with cancer.

Recently, a few studies have been undertaken on cancer patients and their caregivers in India. Some of these studies indicate that cancer diagnosis and related treatments have profound psychosocial impact on patients and their family members as well as physical problems, and problems in the organisational areas of life (Arunachalam, Thirumoorthy, Devi, & Thennarasu, 2011; Chaturvedi, Shenoy, Prasad, Senthilnathan, & Premalath, 1996; Jagannathan & Juvva, 2009; Chawak, Chittem, Butow, & Huilgol, 2020). The diagnosis affects the patients physically, often by causing disfigurements. It affects the individual's self-esteem, body-image and the quality of life (Vidhubala, Ravikannan, Mani, & Karthikesh, 2006; Chaturvedi, Shenoy, Prasad, Senthilnathan, & Premlatha, 1996).

Alexander & Murthy (2020) have stated that the emotional health of a person living with cancer is compromised and have hence advocated that all stages of cancer care should include emotional health. Psychological inputs and interventions are effective in reducing distress, improving the quality of life and better survival. Mohandoss & Thavarajah (2016) reported that 0.61 per cent cancer patients committed suicide in India during the period 2001 and 2014. This rate of incidences is quite alarming as it is even higher than that of western countries (Henson, et al., 2019). The data from southern Indian states, during 2016 and 2018, indicates that the rate of suicide among terminally ill cancer patients was higher compared to the rate of suicides among the general populace (Mohandoss & Thavarajah, 2016). Sinha, Basu, & Sarkhel (2012) pointed out that, medical, social as well as psychological factors such as depression are the contributing factors towards suicidal ideation, desire for hastened death or even request for physician assisted suicide by terminally ill patients. They also underlined the importance to recognise psychological, cultural and religious dimensions to cancer care, because different Indian communities have different understanding of pain, suffering, end of life, dying and death. In general, though, Indians have a conservative attitude towards health, with a fatalistic attitude, wherein stigma, myth, beliefs in traditional healing, etc. play a prominent role. According to Alexander, et al., (2019), family plays an important role in treatment, whereas spiritual, religious activities are the primary strategies of coping. Here the concept of *karma* helps in rationalizing the situation. They also found lack of routine screening of distress, emotional health education and in some cases, appropriate referral for psychosocial cancer care to the specialist staff. They conclude that diagnosis, treatment, and the end-of-life situation are associated with emotional distress in those diagnosed with cancer and their care givers. The lacunae in these services in India can be addressed by improving measures, in simple and accessible ways such as utilization of information technology like mobile phones for proper and timely information dissemination, acknowledging and providing spiritual care as an essential component of cancer care system, etc. These measures will substantially help minimise the distress in patients and will also assist in improving quality of life and increase the life span or survival period.

Khullar, Singh, Lal, & Kaur (2018), studied the impact of cancer diagnosis on different aspects of life among the cancer patients of Punjab. Data was collected from 127 patients suffering from breast, cervix-uteri cancer. They were interviewed using a pretested, predesigned questionnaire at their residence. The analysis of data indicates modification in their daily life, loss of work and pleasure, reformed religious or spiritual activities, social support received by the patients. It is also observed that, social life has been affected after the diagnosis of cancer while social support received by the patients as well as their family remain unaffected. It was also observed that, after the onset of cancer, 72.4 per cent of them stopped working, 92.9 per cent discontinued pleasure activities and hobbies, and 70.1 per cent failed to continue routine religious practices. They argued that, the impact of cancer, its diagnosis as well as its treatment impact not just the lives of patients, but also those of their family members, relatives, neighbours and friends. They advocate that psychological and social support, apart from financial support, can help the cancer patient to cope with the hazards, trauma and in leading their life.

A cross sectional descriptive study by Bhattacharyya, Bhattacherjee, Mandal, & Das (2017), was conducted among 174 cancer patients undergoing chemotherapy at North Bengal Medical College Hospital, to find the magnitude of depression. They advocated that the treatment of cancer should be complimented by psychological interventions as an alarmingly high number of patients undergoing chemotherapy were found to be suffering from depression. They also underlined the importance of sensitising the groups of technicians attending the patients regarding this aspect of cancer care, and suggested that they be encouraged and empowered to pay a needful attention towards the mental health of patients and proper interventions by them would help in achieving the goal of a better quality of life for the cancer patients. The results of another cross-sectional survey among 210 advanced cancer patients in a Regional Cancer Centre, Hyderabad, India by Jacob, et al. (2019) on wellbeing shows that higher financial difficulty adversely impacts most of the health-related quality of life, lower wellbeing and higher pain severity. The study also suggests that the patients who are at an advanced stage of cancer, especially those from weaker socio-economic status reported low physical, functional, emotional, social, familial, and spiritual wellbeing and were identified with border line depressive symptoms.

Jagannathan & Juvva (2016) study on 75 patients aged between 30 to 60 years from Tata Medical Hospital, Mumbai, found that those suffering from head and neck cancer have a relatively high risk of developing emotional disturbance after diagnosis and treatment. They found that, the qualitative analysis indicates that after knowing their illness, the patients experienced varied emotions mainly on the bases of their knowledge of illness, duration of untreated illness and object of blame. The study also found that the patients cope with their emotions through including a positive attitude and confidence in doctors and treatment, sharing their emotions with family members and friends, and by indulging themselves in activities to divert attention. They conclude that to develop any affective intervention programme in India, it is crucial to focus on issues such as understanding of emotion, their root, coping strategies and spiritual as well as cultural orientations. Another study on head and neck cancer patients was conducted by Vidhubala, Ravikannan, Mani, & Karthikesh (2006), which found that the patients adopt both emotion oriented coping and problem oriented coping during the course of their illness. The study also found that educated individuals, and male patients who are subjected to various modes of treatment, preferred more of problem oriented coping as compared to other groups.

Alexander, et al. (2019) have stressed the need of emotional support for the cancer patients in India. In their findings, they identified the areas of concern in cultural suitability of intervention and their application as a part of routine cancer care. It is pertinent to note that in India, the research of psychological intervention in cancer care is still in a formative stage and most of these interventions are focussed on yoga with supportive counselling (Agarwal & Maroko-afek, 2018). A study conducted by Shafi, Shah, Shafi, Shah, & Khan (2019) on 169 consenting cancer diagnosed individuals (98 males and 71 females) used NCCN distress thermometer to find out the temporal variations in the level of distress over a period of time. Their study indicates that, psychiatric disorders were diagnosed among 59 per cent of the patients. These included posttraumatic stress disorder, anxiety and panic disorders. 29 percent patients were found to be suffering from depression. Only 12 per cent were not diagnosed with any disorder. The study also indicates that after counselling and psychotherapy, 45 percent of the patients under study, showed improvement in their emotional wellbeing. They concluded that, cancer had a significant impact on psychological bearing of the patients resulting in anxiety disorder, depression, psychosis, and post-traumatic stress disorder. They advocated the necessity of monitoring psychological symptoms and proper intervention in cancer patients and development of appropriate psych-oncology service. Somasundaram & Devamani (2016), in a comparative study on resilience, social support and hopelessness among 60 cancer patients in

India, found that, resilience was significantly associated with less hopelessness and high level of perceived social support. The study concluded that, psychological distress is very much common in the cancer patients under study. Chaturvedi, Strohschein, Saraf, & Loiselle (2014) observed that, communication is one of the important aspects of psycho-oncology care. They argued that, the professionals must strengthen themselves with sound knowledge of various aspects which influence communication to improve their confidence and skills. They should provide ideal information, knowledge and proper support to the cancer patients and their families. They opined that age, gender, education, socio economic condition and ethnicity play an important role in influencing patterns of communication. Cultural factors, religion, family role, language, nonverbal behaviour, perceptions of death and dying are some of the issues discussed by them in the communication. They advocated that in this era of technology, modern amenities must be used as tools for communication and we must take the help of mobile phones, WhatsApp, internet, online guidance, etc. for providing necessary information to the concerned individuals.

The diagnosis of cancer also impacts the family members of a cancer patient. In most of the cases it is found that, not only the patients but also the family members are affected by the adverse impacts of cancer. Goswami & Gupta (2018) observed that, sometimes while providing care to the terminally ill patients in India, the caregivers neglected their own needs leading to their own psychological and financial stress. Their study found that, family caregivers are generally females who are actively involved in the process of care giving, and are the worst sufferers. Their study advocates that the Government should understand the caregivers' problems sympathetically and introduce new programmes, by which caregivers can enhance their knowledge and skills. The study also stresses the need for suitable and systematic counselling provisions for the caregivers as well.

Apart from the psychosocial issues, the diagnosis of cancer also has a financial impact on patients and their families living in countries like India (Shankaran & Ramsey, 2015; Chakrabarty, Pai, Ranjith, & Fernandes, 2017). Chakrabarty et al. (2017) conducted their study on the financial impact of oral cancer on patients in low- and middle-income countries such as India. They found that in such countries, healthcare is financed by most patients through out-of-pocket expenditure, which results in increased financial stress on the family. The households' finances are adversely impacted due to income loss because of sickness or death in the family. The study of Alexander, et al. (2019), on 378 breast cancer patients of Bengaluru, during 2008 to 2017, was conducted to understand the role of immediate family in treatment, decision making and providing support to patients diagnosed with breast cancer. The findings indicated that, most of the patients (99%) had support from their family members. The cost of treatment was met through personal savings and through health insurance by 57 per cent of the studied patients' family. The rest (43%) faced difficulties and had to resolve the issue by taking desperate measures such as selling land, property or taking loan from money lenders on high interest. The study indicated that patients with higher education and coming from urban settings had better financial management.

There are a few studies which have focused on the coping strategies of the cancer patients (Vidhubala, Ravikannan, Mani, & Karthikesh, 2006; Chaturvedi, Shenoy, Prasad, Senthilnathan, & Premalath, 1996; Kandasamy, Chaturvedi, & Desai, 2011; Goswami, Gupta, & Raut, 2019). Kandasamy et al. (2011) have identified spiritual wellbeing as a crucial component of quality of life for advanced cancer care patients, and has a great bearing in relieving the physical and psychological distress of the patients. They therefore recommend the use of spirituality as a significant component in managing cancer, and specifically so, during palliation. (Kandasamy, Chaturvedi, & Desai, 2011).

A. Coping with cancer

‘Coping with cancer’ is an oft-used term in the public domain, primarily in academic discourses and also in health organisations. One of the most widely studied forms of coping, namely psychosocial coping, is defined in Lazarus & Folkman’s seminal work – *Stress, Appraisal and Coping* (1984), as the “ongoing and changing cognitive and behavioural efforts to manage specific external and / or internal demands that are appraised as taxing or exceeding the resources of the person”. According to them, the relationship between the individual and the environmental determines coping, which is a transactional process, whose functions are emotion and problem focused. Furthermore, their study advocates the coping efforts begin when the disease is perceived as threatening or challenging.

Holland and Frie (1973) commented that, responses to their diagnosis and illness are not similar among different patients, even when they all may be given similar levels of disease and toxicity of treatment. He came up with this finding from clinical and empirical evidence. These different responses are both at the levels of body and mind, i.e., physical and psychological (Holland & Frie, 1973). According to many researchers, after the diagnosis of cancer, the patients may face a number of psychological problems (Weis, 2015; Singer, 2018; Institute of Medicine, 2008). Anxiety, depression or even suicidal thoughts are possible issues that the patient may grapple with. Moreover, the patient may face difficulty in concentration as both the illness and the accompanying treatment may play havoc with their central nervous system (Singer, 2018). Those patients who may have existing psychological problems may find their problems aggravated due to the illness and its treatment. Sometimes the manner in which the illness is managed and social dynamics could be the reasons for the onset or aggravation of psychological problems in the patient

(Weis, 2015). It can be safely argued that like early diagnosis of the physical issues, if the psychological problems faced by the patient can be identified at an early stage, then it would be possible to devise more effective psychological interventions, which will enormously benefit the patient. Interventions based on cognitive-behavioural techniques are extremely beneficial in managing various cancer related problems (Institute of Medicine, 2008). Psychotherapy, family therapy, group therapy and cancer support groups become handy methods in meeting the psychosocial as well as informational needs of cancer patients (Institute of Medicine, 2008). However, researchers such as Temoshok & Heller (1984) have challenged the appropriateness of the methods employed to collect such information and have even cast aspersions on the accuracy of the information thus collected, because such approaches are deemed insufficient and inappropriate to measure the complexities involved. In this method of data collection, one major hurdle faced by the researchers is that the information gained thus is from self-report. The focus here is on identifying something objective, something essentially quintessential, something enduring within people that this method would like to identify. This sort of method to come up with possible 'coping strategies' measured against a number of variables may seem good on paper, but the major issue with this is that these variables, sometimes conflicting ones, are already predefined and categorised by social scientists.

There is no denying that intervention measures are extremely important for cancer patients to help them 'cope', as it may lead to maladaptive coping otherwise. However, the reluctance of the cancer patients, an understandable one, to talk about their problems or disclose any information to talk frankly for fear that these may result in some unsavoury prognosis of their psychosocial wellbeing, leading to them being labelled as depressed, anxious, etc. may be a reason as to why such approaches may not always be productive. So, this runs the risk of intensifying the already existing negative feelings and emotions about cancer. This will then lead to additional burdens on the patients of having to adjust and cope with the disease and its psychosocial manifestations.

It is evident from the information provided by Greer, Morris, & Pettingale (1979); Morris, Pettingale, & Haybittle (1992); Spiegel, Bloom, Kraemer, & Gottheil (1994); Zainal, Booth, & Huppert (2013); Smith, et al., (2021) that the people with cancer who adjust and cope successfully may have a better chance of surviving. Ibbotson, Selby, Priestman, & Wallace, (1994) reported that merely 20 to 50 per cent of the patients experiencing problems are actually identified, and given any sort of treatment which shows how this can be a complicated process. They also found that the problem is two-fold in nature: just as the patients show reluctance in disclosing their psychological issues, there is a hesitation on the part of the doctors and nurses to enquire about the same.

1. Attitude to cope or not to cope

Adopting a certain "attitude of mind" as is seen in the often-used metaphor of 'fighting' illness is viewed as an important strategies of 'coping' with the diagnosis of cancer, something that is often cited in the works of Herzlich & Pierret (1985); Herzlich, (1973); Greer & Watson (1987); Doan, Gray, & Davis (1993); Andrykowski, Lykins, & Floyd (2008); Smith, Saklofske, Keefer, & Tremblay (2016) urged the people to 'beat it', to 'think positively' and to adopt a 'positive attitude'. Survival can be hugely influenced by attitudinal factors such as psychological responses to cancer or one of hopelessness when faced with cancer. These can be termed as prognostic factors (Watson, Haviland, Greer, Davidson, & Bliss, 1999).

This 'positive attitude' or 'fighting spirit' is something that is recommended by physicians and psychologists. This has been proven to be a highly successful and influential measure in coping with the disease. Many studies which have used this scale have more or less endorsed the fact that the coping mechanism of ‘fighting spirit’ has a direct impact on coming out of psychological morbidity and even, survival. (Greer, Morris, & Pettingale, 1979; Maguire, 1985; Morris, Pettingale, & Haybittle, 1992; Watson & Homewood, 2008) have examined this model and have commented on how the MAC Scale is a readily available and often-used questionnaire to measure cancer coping styles. The self-report can be and usually is, treated as offering a generally accurate psychological state of the patient and that becomes the evidence that someone is ‘thinking positive’. Responses, instead of being treated or seen as variable and complex linguistic mechanisms, are rather simplistically treated as a transparent scene of one’s cognitive process of ‘the attitude’. This problematic aspect has been commentated on by Potter & Wetherell in 1998.

In 1994, Steptoe & Wardle advocated that it is expected of the patients to ‘beat it’, ‘fight it’, ‘deny it’, ‘to be anxious’ and to need support which would help them cope. Interventions are deemed essential for the patients as they are supposed to help the cancer patients cope with their illness in a better way. This can also improve their quality of life and some even go on to argue that this can significantly influence the disease process as well. It is a fact that a lot of value and significance is attached to the use of questionnaires and surveys while measuring attitudes; however, one must not lose sight of the fact that even minor or seemingly unimportant alterations in wording can lead to different and sometimes contrasting responses, eventually affecting the response patterns. In standard traditional approaches, variability hints at some form of error and hence can be deemed problematic. But for discourse analysts, variability actually provides a scope to identify and examine the phenomena of how multiple perspectives of accounts may evolve.

B. Social support

Social support is multi-dimensional and is one of the most important coping constructs. It has been formulated as a valued coping resource strategy and is highly recommended (Mangan, Taylor, Yabroff, Fleming, & Ingham, 2003; Lavallee, Grogan, & Austin, 2019). According to Freund & McGuire (2003), social support is a general term for the various resources which help people in 'coping with life' at times of crisis. Helgeson & Cohen (1996), from their review of the literatures, have discussed three kinds of major supportive social interactions that are related to the psychological adjustment to cancer. These are, 1) Emotional support, 2) Informational support, 3) Instrumental support. Emotional support involves providing empathy, love, caring, and/ or trust to another. Informational support is the kind of support where the focus is on providing information which can be helpful in coping with both personal and environmental problems. Instrumental support is another crucial support system where the focus is on helping out with practical problems, for instance, paying bills.

Cancer diagnosis, as has been discussed earlier, often results in changes in life and identity (Berman, 2012). Multiple factors such as 'coping' with treatment, family stresses, occupational disruption, pain and the threat of death can certainly pose a significant challenge all of a sudden to an individual's social identity (Gruenewald & & White, 2006). Moreover, social exclusion of the patient is a real possibility, mostly due to the various negative connotations surrounding cancer. It is pertinent to note that it is not just the patient who is affected by all this; rather the quality of life of family members and friends too who may be engaged in some form of support system or the other, is also affected. The work of Helgeson & Cohen (1996); Mesters, et al., (1997) underscore the point that emotional and social support from the family promotes good psychological adjustment. Cohen & Syme

(1985); Schwarzer & Leppin (1991); Pistrang, Barker, & Rutter (1997); Reblin & Uchino (2008); Leung, Pachana, & McLaughlin (2014); Adam & Koranteng (2020) have advocated the importance of social support as they found that this leads to less adverse reactions to stressful events such as the ones resulting from serious illness. Helgeson & Cohen (1996) have identified a positive relationship between social and emotional support, and that becomes a very important factor in the process of coping with cancer, adaptation and adjustment. Freund & McGuire, (2003) suggest how social relationships function as the mirror, i.e., one which helps to reflect the messages of self–affirmation back to us. Coping can be extremely stressful if the resource network is not readily available leading to a lack of social support, and this becomes worse when at the times of crisis, there is a dearth of supportive relationships. Bell, LeRoy, & Stevenson, (1982) have discussed how the lack of such support could result in the patient not being able to successfully cope in an 'adaptive' manner and can make the patient feel vulnerable. Several other studies conducted among cancer patients and their families supported this (Kornblith, et al., 2001; Hann, Oxman, Ahles, & Stuke, 1995; Tan, 2007; Li, Yang, & Liu, 2016). Thus, it can be clearly stated that just as the availability of social support helps provide various positives to the patient such as self-worth, a sense of stability, predictability, etc, the lack of social support, i.e., social isolation can have various adverse effects on self-worth, health and even on recovery. The studies of Cobb (1976) and Cobb & Erbe (1978) highlight this problem further. They say that if coping can be seen as successful, by implication non-coping can be attributed as a failure. Lack of social support is detrimental for the physical and psychological wellbeing of the patient and unfortunately in many instances, people with cancer state that after their diagnosis, many of their friends simply disappear from the scene. This phenomenon has been explained by researchers who attribute this disappearance to them feeling a sense of discomfort in the presence of someone with cancer, even if that someone is a friend, because of the stigma associated with the disease (Brown & Cataldo, 2013; Else-Quest, LoConte, Schiller, & Hyde, 2009). According to Goffman (1963), the reason for stigma is that an illness is perceived as a culturally or socially devaluated condition which sets apart the people affected with the illness from others and disqualifies them from social participation.

The studies of Bloom (1982); Dunkel-Schetter (1984); Beth, Meyerowitz, & Harvey, (1997); Rokach (2000); Robinson & Tian (2009); underscore the point that social support helps cancer patients enormously in adjusting to the stress of their disease. On the other hand, Atkinson, Liem, & Liem (1986) have noted that social support should not be treated as stable. This is because of the fact that over a period of time, levels of social support do not remain constant. Moreover, it has to be noted that neither social support nor stressful events are independent factors and hence when they interact with each other, the results will vary from time to time. However, when it comes to research examining the nature of social support functioning interactively, there is a paucity of research. Additionally, another problem is in the way the language that is used by medical sociologists and psychologists to label and categorise people often ends up objectifying the ill. Williams in the year 1993 advocated that one has to acknowledge:

> “That the expressive terms people use cannot be reduced to instrumental terms of ‘adjustment’ and ‘adaptation’. These concepts, staple components of the rehabilitation literature, tend to be ethically judgemental because they are unrelated to the context of the moral life of the person concerned. In order to avoid the pitfalls of judgement, we need to see coping strategies as moral practices” (Williams, 1993).

The strategies mentioned above are ostensibly for the welfare and convenience of the patients. However, one can also see that the series of prescriptive designs are framed in a way that it would help meet the requirements of health professionals and medical practitioners. But when it comes to the patients, not enough is done to analyse and examine whether and how these prescriptions and constructions could serve up as a burden for the patients (participants) and this is usually left outside the scope and confines of the analysts' concerns. A lot of research is undeniably done in coping, but in the domain of 'coping with cancer' research what is usually left unexplored is how people account for as well as talk about their social relationship. Those in the medical profession have exposure to the culture and language of cancer; so, they can put these resources to use which will shape the nature of their interaction. In this work, I intend to show how coping strategies are social and how patients orient themselves to their changing social world.

IV. Embodiments of mortality and death with a cancer diagnosis

From the above literature survey, broadly four themes can be identified, which draw on the patients' perspectives on death and mortality. A) Equating death with cancer diagnosis, B) Realisation of cancer as a reality triggers fear of death, C) Fear of mortality impacting wellbeing and D) Foreshadowing of mortality in family caregivers.

A. Equating death with a cancer diagnosis:

As pointed out by Lane (2005) the patients, when diagnosed with cancer, often equate this to death prognosis, in which they experience as if being 'consciously thrown' into an ever-present death experience. The study of Cohen & Mount (2000) describes this as a journey into 'darkness' and as a reality of the future that awaits them. Investigations mention that after the diagnosis, the patients experience a sense of anxiety and worry which are results of the realization of their new responsibilities and experiences (Landmark, Strandmark, & Wahl, 2001; Albaugh, 2003; Arman & Rehnsfeldt, 2003; Cooke, Gemmil, Kravits, & Grant, 2009; Nipp, et al., 2018). As per Landmark, Strandmark, & Wahl (2001), one of these new responsibilities is to fight a perceived vulnerability to death and to manage an uncertainty about the future. Chochinov, Hack, McClement, Kristjanson, & Harlos (2002); Farrell, Heaven, Beaver, & Maguire (2005); Cooke, Gemmil, Kravits, & Grant (2009); Singer (2018) described it as something to deal with fears of an inability to do things the way they were done before the onset of cancer. According to Kelly, et al., (2004); Mak (2005); Monforte-Rayo, Villavicencio-Chavez, Tomas-Sabado, Mahtani-Chugani, & Balaguer (2012); Rodriguez-Prat, Balaguer, & Monforte-Royo (2017); the worry stems from the concern that one would be a burden to the family. In the view of Cohen & Ley (2000); Chochinov, Hack, McClement, Kristjanson, & Harlos (2002); Andrykowski, Lykins, & Floyd (2008); and Singer (2018), the patient may develop apprehensions about the treatment and its side effects. Though empathy for the patient is a result of genuine human goodness, often the patient experiences the burden of unwanted sympathies, as viewed by Richer & Ezer (2002). The feelings of being different and also being made to feel different are sometimes accompanied by the diagnosis, as is observed by Farrell, Heaven, Beaver, & Maguire (2005) Cooke, Gemmil, Kravits, & Grant (2009) and Singer (2018). Sometimes, it goes to the extent of causing embarrassment and shame in the patient by bringing in their sexuality and relationship with others, as has been discussed by Landmark, Strandmark, & Wahl (2001); Farrell, Heaven, Beaver, & Maguire (2005) and Nipp, et al., (2018).

Some findings (Adelbratt & Strang, 2000; Cavers, et al., 2012; Loughan, et al., 2020) indicate that patients can have mixed emotional reactions which include sadness, anger, fear, and shock which keeps the patient in a conflicted position. Because, the patient is caught between the need to accurately know about the prognosis while at the same time being in a sense of denial by choosing to ‘not wanting to know.’ This aspect has been explored by Adelbratt & Strang (2000). Whereas, Johnston & Abraham (2000) Yun, et al., (2010); and Finlayson, et al., (2019) indicate that the patient’s awareness of a shortened life and dying, results in a myriad of emotions such as denial, uncertainty, partial or ambiguous awareness and at times, even active and open awareness. Patients are seen to generally try to ‘calculate the odds’ so that they can then decide on being genuinely optimistic or hopeful, accordingly. This will then help them to ‘play the odds’ to depict their prognosis favourably (Thorne S. , Hislop, Kuo, & Armstrong, 2006; Han, et al., 2009; Finlayson, et al., 2019; Arantzamendi, Gracia-Rueda, Carvajal, & Robinson, 2020).

According to Adelbratt & Strang (2000); Sand, Olsson, & Strang (2009); Cavers, et al., (2012), complete denial in some patients is an uncommon occurrence even when the awareness of death is kept at some distance. This shows the enormous psychological burden on the patient after the onset of cancer. Chochinov, Tataryn, Wilson, Enns, & Lander (2000) mention that those patients who have some already existing psychological distresses are the ones who are more prone to prognostic denial. This according to them is found more often in men than women. This sort of existential distress could also lead to physical manifestations of insomnia, panic attacks and physical discomfort (Grant, et al., 2004; Applebaum, et al., 2016; Arantzamendi, Gracia-Rueda, Carvajal, & Robinson, 2020). Sometimes the fear that the health care professionals will ‘give up’ on them becomes a troubling thought for the patients and hence the lack of hope in them (Wenrich, et al., 2001; Kirk, Kirk, & Kirstjanson, 2004; Ciemins, Brant, Kersten, Mullette, & Dickerson, 2015). There are many studies which bring to the fore how cancer is perceived as a culturally taboo topic which becomes a contributing factor in furthering the existential distress among the patients and caregivers in stark contrast to other diseases where such a taboo is not associated (Friedrichsen, Strang, & Carlsson, 2000; Kirk, Kirk, & Kirstjanson, 2004; Epstein & Street, 2007; Thorne S., et al., 2014; Takesaka, Crowley, & Casarett, 2004). At this point, it may be instructive to bring in a phenomenological study by Tobin & Begley (2008). It explored the journey of continual adaption by ten cancer patients. After receiving the initial diagnosis, their level of anxiety and suspicion of the diagnosis being life-threatening only increased when health professionals and caregivers tried to assuage their fears (Singer, 2018). They felt being labelled which put aspersions on their sense of existence. Even after they got to accept their diagnosis with time, a sense of uncertainty and anxiety continued to pervade their psyche. In fact, there is an interesting study by Hinton (1999) which says that patients may actually feel more anxious when the uncertainty of life-threatening diagnosis is not certain, but probable.

Field & Copp (1999); Parker, et al., (2001); Lokker, van Zuylen, Veerbeek, van der Rijt, & van der Heide (2012) suggests that, despite the growing research on the need to provide open disclosure to patients on their prognosis, what actually takes place is conditional disclosure where the patients are given ‘graduated dosages of truth’, mostly to ensure that the patients retain some sense of control of their experiences. How much of this information is to be negotiated is also dependent on the age, sex and education of the patient.

B. Realisation of cancer as a reality triggers fear of death:

Every individual reacts to cancer diagnosis differently, and hence living with cancer does not mean the same to all the patients. In 2006, Foley, Farmer, Petronis, Smith, & McGraw conducted an exploratory survey among 58 cancer survivors. Each of the patients was diagnosed at least five years earlier. It was observed that there were mainly four kinds of responses to cancer by them - that’s life, resentment, relinquishing control, and personal growth. More male patients than the female patients interpreted their experience as ‘that’s life’. Basically, it meant an acceptance of the disease and a process of adjustment by ‘compartmentalising’ life. For them, it was basically a matter of them ‘happening to have cancer’. However, there were some who could not reconcile to the new reality of living with cancer. They resented this invasion on their body and life, adversely impacting their future and health – physical and mental. This also led to some experiencing a complete lack of control as they were no longer in charge of their body, and even mind. For them, it was a case of ‘relinquishing control’. Lastly, there were some, mostly women who experienced a kind of ‘personal growth’. They discovered their inner strength that they did not know existed within and developed a greater appreciation of life. Thus, we see that patients show different degrees of physical and emotional preparation to cope with the fear of the unknown, especially the fear of death. The ability to define and then actualise their needs, is what develops the sense of self-efficacy in the patient (Carter, MacLeod, Brander, & McPherson, 2004; Gruenewald & & White, 2006). In a study Carter, MacLeod, Brander, & McPherson (2004) identified the presence of the sense of being self-efficient that wants to take charge of one’s life as an overarching theme in patients with cancer.

Volker, Kahn, & Penticuff (2004); Kirk, Kirk, & Kirstjanson (2004); Volker & & Wu, (2011); Rodriguez-Prat, Balaguer, & Monforte-Royo (2017) also have a similar observation when they point out how sometimes patients make an attempt at controlling timing and amount of information from clinicians. Usually, it is in the early stages that patients are more interested in the details of their prognosis compared to the later stages. In the later stages, their focus mostly shifts to routines of their daily living, leaving it to their family members to get the details on prognosis and care from health care providers. In the studies mentioned here, personal control over the dying process had a significant bearing on the patients. (Carter, MacLeod, Brander, & McPherson, 2004; Volker, Kahn, & Penticuff, 2004; Volker & & Wu, 2011). Several studies (Friedrichsen, Strang, & Carlsson, 2000; Griffiths, Norton, Wagstaff, & Brunas-Wagstaff, 2002; Mak, 2005; Berman, 2012; Leonard, Tracey, Robert, & Rana, 2017) talk about how the cancer patients feel that remaining connected with the health care professionals becomes an important tool for them in their attempt to take care of their wellbeing, especially emotional wellbeing. At the same time, some research such as the one by Johnston & Abraham (2000) which states how some patients show withdrawal symptoms wherein, they stay aloof from others including the health care professionals as a part of their coping mechanism. One of the reasons why they do this is to not burden others too much with their own grief. Thus, there are these two contrarian mechanisms employed by different patients when it comes to their methods of coping.

As indicated by Ohlen, Bengtsson, Skott, & Segesten (2002); Melin-Johansson, Odling, Axelsson, & Danielson (2008); Lehmann, Hagedoorn, & Tuinman (2015), the loss of bodily integrity and unmet relational needs are constant reminders of their uncertain life for the patients. Gurevich, Devins, & Rodin (2002); Nissim, et al., (2013); Schepisi, et al., (2019) emphasised that it is not just the nature of the illness, but the treatment intensity too that leads to further physical distress and mental agony. And when the patients manage to control the symptoms of effects of both illness and treatment at bay, then the constant awareness of death too can be kept at bay as well (Sand, Olsson, & Strang, 2009).

Loss of bodily integrity becomes a major source of one’s loss of self-worth and identity. Lawton’s (2000) ethnographic study among patients in a hospice in England has similar findings where the inability to control bodily fluids and the stink that their body emanates with the increase in the severity of the illness makes both the patients and their family members acutely aware of not just the constant disintegration of their body and self-hood but also made them acutely aware of their mortality and their body being seen as a show piece in front of others, including the well-meaning health care professionals. He also points out how much the patients abhor the idea of their body being subjected to public gaze, especially when death is imminent. What this effectively means is that the patient would no longer have the efficiency to determine his or her own self, and would rather be considering the self-worth through external factors such as what those under whose gaze the body comes, have to say or comment on the body. With time, this continues to become more and more of a tragically self-defeating, yet very real scenario wherein the patient advertently or inadvertently is reduced to an ‘object’ and as Lawton points out, the patient ends up less as a social person, and more as a ‘weight’ and not as a ‘whole’ person, with the agency of one’s self gradually shifting to the caregivers (Lawton, 2000). It is instructive to note that even though the patients under study in Lawton’s work were mostly aware of the imminent death, yet there were times when they did experience existential distress at the time of sudden physical pain, change in physical symptoms, etc, and this was found in patients who would not be evaluated as ‘palliative’. In another study by Jones, Huggins, Rydall, & Rodin (2003), too we see similar findings where it is shown that extreme and unbearable pain in cancer patients does not necessarily mean that the concerned patients necessarily crave for an early death to escape the pain. Rather, what can be said is that this excruciating pain that affects their daily life, in terms of lack of mobility and adverse impacts on mood leads to a sense of hopelessness. Such patients do naturally go through psychological distress and go through depression (Pasacreta & Massie, 1990; Lueboonthavatchai, 2007; Applebaum, et al., 2016; Ciemins, Brant, Kersten, Mullette, & Dickerson, 2015; Singer, 2018).

There are studies which point out how waiting for the diagnosis result itself can be quite stressful and even the very smell of a hospital can cause distress and death anxiety in a patient (Adelbratt & Strang, 2000; Gurevich, Devins, & Rodin, 2002; Tobin & Begley, 2008; Applebaum, et al., 2016; Singer, 2018). Despite the conscious efforts from the patients to keep death thoughts at bay, the daily routine impacted by the illness as well as the smells and sights in hospital become constant reminders of death and mortality for them (Gurevich, Devins, & Rodin, 2002). As coping strategies to deal with this ever-present shadow of death, patients seek and devise their own strategies, wherein they could either distance themselves emotionally from the fear of death or to accept the inevitability and intellectualise the experience. In the works of Richer & Ezer (2002); Armam & Rehnsfeldt (2003); Peretti-Watel, Bendiane, Spica, & Rey (2012); Al Kalaldeh, Shosha, Saiah, & Salameh (2018), I encounter instances of stories of cancer patients where they talk of ‘moving on’, and ‘will to live differently’. Richer and Ezer’s (2002) qualitative study conducted on ten breast cancer patients, enumerates on this ‘moving on’ aspect especially at the beginning of their treatment or first chemotherapy, where by accepting the new reality, they also strived to explore new meanings of their life and existence. They sought out a new balance in their life. Another qualitative study (Grant, et al., 2004) on cancer patients explore how the patients sometimes feel the need to go in search of meaning of life and peace of mind, that would help them cope with the stark reality they face, i.e., the experience of dying and how to make sense of this experience. The study was conducted in Scotland on 20 cancer patients. Kvale (2007) on the other hand contrasts this approach with another one used by the patients, which is to not delve into the search for something deep, and instead to continue with a semblance of normalcy by talking about mundane things such as families and hobbies.

When it comes to the feelings of hope, hopelessness, and the search for meaning in cancer patients, there is a burgeoning interest as is evidenced by works by several scholars (Chochinov, Tataryn, Wilson, Enns, & Lander, 2000; Curtis, et al., 2002; Mystakidou, et al., 2009; Mende, et al., 2013; Applebaum, et al., 2016). Their works talk of issues such as how the awareness of one’s mortality leads to a search for meaning and hope, while also at times leading to a sense of helplessness. When one loses hope, that in turn leads one to ponder over whether there is any meaning left in one’s life, and this adversely impacts one’s idea of purpose of life (Chochinov, Tataryn, Wilson, Enns, & Lander, 2000). Rodin, et al., (2008); Cavers, et al., (2012), Seiler & Jenewein (2019) talk of the advent of hopelessness and depression in cancer patients and even though both these factors adversely impact the psychological wellbeing of patients, how it is the former which has more chance of triggering in the patients a desire for an early death.

C. Fear of mortality impacting wellbeing:

The traditional approach to quality of life in health care has been on the body and its functioning, and not the emotional wellbeing (Kassa & Loge, 2003). But in recent decades, the focus has slowly been shifting to emotional well-being as well as social and spiritual wellbeing (MacDonald, 2001; Mystakidou, et al., 2009; Lokker, van Zuylen, Veerbeek, van der Rijt, & van der Heide, 2012; Singer, 2018). A qualitative study conducted on 21 critically ill patients shows how the patients seek to find a deeper meaning while constantly grappling with continued suffering (Mount, Boston, & Cohen, 2017). Suffering of this kind results in existential distress and can actually be therapeutic (Pelletier, Verhoef, Khatri, & Hagen, 2002; Petruzzi, Finocchiaro, Lamperti, & Salmaggi, 2013).

Unlike in the past, a more holistic approach is now given to health-related quality of life instead of solely focusing on physical health. Issues such as subjective self-worth of patients in their negotiation with the vagaries of their illness is a prime site of research. There are different ways in which researchers have looked at the critically ill patient's sense of self-worth. According to Whitehead (2003) and Tarbi (2019), one's attitude to the world is directly related to one's sense of self, whereas some considered that the sense of self results in suffering (Gregory & Russell, 1999; Sand, Strang, & Milberg,2008; Al Kalaldeh, Shosha, Saiah, & Salameh, 2018). Studies (Laubmeier, Zakowski, & Blair, 2004; Andrykowski, Lykins, & Floyd, 2008; Nissim, et al., 2013; Singer, 2018) indicate that less the distress, the better is the quality of life and existential wellbeing. Laubmeier, Zakowski, & Blair (2004) also suggest that this correlation is constant despite the variables of demography, sex, age, and nature of cancer.

Isolation is another lived experience of the people suffering from critical illness such as cancer (Rokach, 2000; Albaugh, 2003; Weis, 2015; Singer, 2018). These patients' illness resulted in completely changing their normative social roles and led to a feeling of isolation where they could not function the way they used to before the advent of the disease (Kuhl, 2002). The study further stresses on the need for the patients to be physically and emotionally connected with their family and caregivers. Unfortunately, for most patients, this desire to remain connected and achieve a sense of normalcy remains a futile endeavour. To compensate for this loss, they often try to find solace in searching for something which would help them in their coping mechanism, namely the search for meaning of life and its existence. This provides them a sense of comfort, and since the search is from within, the dependence on others is reduced, and the risk of being thwarted resulting in impeding sense of self-worth is lessened (Landmark, Strandmark, & Wahl, 2001; Yedidia & MacGregor, 2001; Lane, 2005; Ciemins, Brant, Kersten, Mullette, & Dickerson, 2015; Rodriguez-Prat, Balaguer, & Monforte-Royo, 2017; Seiler & Jenewein, 2019)

It is not just the illness that hampers the normalcy of life; some go on to argue that it is the treatment, especially an aggressive treatment which heightens the sense of trauma in the patients and becomes a major impediment in their quest to lead a ‘normal’ life (May, 2006; Richer & Ezer, 2002). In a report of a pilot survey by Lee, et al., (2005) conducted on patients who had undergone bone marrow transplantation, it was found that those who had emotional issues were the ones for whom post-transplantation distress was a high 25% who pondered taking prescription for anxiety and had sleep disturbance.

D. Foreshadowing of mortality in family caregivers:

There are many studies which show that the threat of mortality is not confined to only the patients. The foreshadowing of mortality invariably happens on the family caregivers also, who feel this threat acutely as well (Juarez, Ferrell, Uman, Podnos, & Wagman, 2008; Otis-Green & Juarez, 2012; Grant, et al., 2013; Fujinami, et al., 2015; Judkins, Laska, Paice, &

Kumthekar, 2018). Hinton (1999); Adelbratt & Strang (2000); Ciemins, Brant, Kersten, Mullette, & Dickerson (2015); Li, Y, Xu, & Zhou (2018) that at different stages of prognosis, the family caregivers too share the concerns and anxieties of the patient, in more or less an identical fashion. Stress and fatigue faced by the patient are also similar to the ones shared by the family caregivers, which severely impact their daily routines (Mangan, Taylor, Yabroff, Fleming, & Ingham, 2003; Cavers, et al., 2012; Wang, Molassiotis, Chung, & Tan, 2018; Zavagli, et al., 2019). The family caregivers also face the additional burden of trying to protect the health and self-worth of the patient (Mangan, Taylor, Yabroff, Fleming, & Ingham, 2003). The uncertainty surrounding the patient's future is one of the most stressful factors that affect the family caregivers (Mangan, Taylor, Yabroff, Fleming, & Ingham, 2003; Cavers, et al., 2012; Wang, Molassiotis, Chung, & Tan, 2018; Zavagli, et al., 2019).

In some cases, the family caregivers too suffer from depression, especially when their life becomes entangled with that of the patient, and the more they become aware of the prognosis of the patient and the deteriorating condition, the more is the risk of them suffering from psychological breakdown and depression (Hinton, 1999; Adelbratt & Strang, 2000; Ciemins, Brant, Kersten, Mullette, & Dickerson, 2015; Li, Y, Xu, & Zhou, 2018). While for terminally patients above the age 70, it is unsurprising for the family caregivers in many cases, if not all, to come to some sort of acceptance of the fate, for younger patients, it is a different scenario. There are instances when the family members, especially spouses suffer from the survivors' guilt and in fact at times express the desire to die even before the ill patient (Adelbratt & Strang, 2000).

Some studies indicate the family caregivers' frustrations at not receiving adequate health care (Eggenberger & Nelms, 2007; Hickman, Jr, Douglas, & Burant, 2012; Lavallee, Grogan, & Austin, 2019). It is the nurses dealing with the terminally ill patients who are often the points of entry for family caregivers with the health care system. The family caregivers expect the nurses to be emotionally caring to their patient, which sometimes is not the case (Eggenberger & Nelms, 2007). For the family members, getting timely information and support is of utmost importance, which in most cases, they expect from nurses. However, there are studies which suggest that despite the best efforts from nurses, the family members at times struggle to retain the information or even absorb the given information at times, and are then not confident of bothering the hearth care professionals with their queries (Dunne & Sullivan, 2000; Hudson, Aranda, & Kristjanson, 2004; Badr, 2014). According to Takesaka, Crowley, & Casarett (2004), it is usually the younger family members and women who feel a greater sense of distress at the sight of the deteriorating conditions of their loved ones (Harding & Higginson, 2003; Harding, List, Epiphaniou, & Jones, 2012; Ugalde, et al., 2019). There are studies that indicate that some family members find the hospital setting as an incongruous place for their critically ill family member to die in, wherein the focus is on quickly finding beds and hurriedly looking for medicines rather than being engaged with the actual act of palliative care, and paying attention to the patient (Dunne & Sullivan, 2000; Robinson, Gott, & Ingleton, 2014; Heckel, et al., 2020). This too can be a distressing factor for the family caregivers.

Corbin & Strauss (1985) in *Managing Chronic Illness at Home: Three Lines of Work* define managing illness “a set of tasks performed by an individual or a couple, alone or in conjunction with others, to carry out a plan of action designed to manage one or more aspects of the illness and the lives of people and their partners”. This definition is self-explanatory in terms of the roles of the family members as it is they who have to manage the illness, sometimes more than the patients themselves. They divided this set of work into three categories – illness work, everyday life work and biographical work. Illness work refers to the set of tasks done in order to address and manage cancer symptoms, side-effects of cancer treatment and other health related works such has scheduling appointments. Everyday life work involves various other activities that one has to perform in their day to day lives such as doing household chores and managing jobs. Biographical work indicates towards the efforts and tasks undertaken by the individual to manage life courses. Biographical works are performed in the context of adjusting one's illness into the biography. It often involves reorganisation and remaking one's identity and self (Williams, 1993).

Studies have indicated that often these works are considered as hard and difficult by the caregivers (May, 2006; Badr, 2014; Ugalde, et al., 2019). Care work also involves information and emotion work (Corbin & Strauss, 1988). Different types of information are required at different times in order to use the information to enhance the experience of illness. Studies on the experiences of cancer caregivers discusses their efforts to manage emotions and feelings (Thomas, Morris, & Harman, 2002; Stephens, 2005; Longacre, 2013; Kent, et al., 2016).

This review of literature suggests that chronic illness is an aspect of health that significantly impacts the lives of those diagnosed with it and those closely related with them. Cancer is a disease, that involves living in a continuous process of treatments, often with the threats of relapse. These experiences have rarely been reported in the literature in the Indian context. Cancer as a terminal disease that is lived each day, affects a person's life. New developments in treatments and cancer managements indicate that people would be living with cancer for a prolonged period and it would be a vital aspect of their life courses. It is against this backdrop that this study is set where I seek to provide an insight into the experiences of being a cancer patient and caring for one in Eastern India and contribute to the knowledge and understanding by exploring experiences of cancer patients and their family caregivers. Caregiving is intersubjective and complex life-experience as well, where relationships are co-created and expressed through actions and behaviours of concern, responsibility, and attention

(Ayres, 2000; Konstam, et al., 2003; Hanly, Maguire, Hyland, & Sharp, 2015; Oldenkamp, et al., 2016; Zavagli, et al., 2019). Issues of caregiving such as tasks, stresses and burdens of caregiving and socio-economic impact of caregiving have been studied (Thomas, Morris, & Harman, 2002; Mangan, Taylor, Yabroff, Fleming, & Ingham, 2003; Yun, et al., 2010; Otis-Green & Juarez, 2012; Robinson, Gott, & Ingleton, 2014; Wang, Molassiotis, Chung, & Tan, 2018; Zavagli, et al., 2019). What is needed is research in caregiving of cancer patients by their primary caregivers, whether parent, spouse, children or sibling. This is qualitative study of meaning and the account on the day-to-day experience of caregiving of a cancer patient by a family member wherein looking at the personal account of caregiving may provide us an understanding of the same. In this study, analysis of the experiences of cancer and caregiving is intended to provide the subjective understanding of the experiences as discrete from the objective aspects of the scenario. My interest about experiences of cancer and cancer caregiving emerged from an academic and personal experience. In the following section I would discuss my stance in this research.

V. Situating (My)self

Qualitative researchers should contemplate regarding the ways “that any one set of prescribed methodological strategies, personal knowledge, and social context creates theoretical and perceptual access influencing understanding” (Benner 1994). As a researcher, I attempt to be transparent about how I understand this situation. It is pertinent to note that for a researcher to be able to access and understand the participants’ honest and truthful voices, they must be acutely aware and acknowledge their own individual biases, preconceptions and experiences, as well as the theoretical apparatus which makes their research consequential to them in ways that help them understand both themselves as well as their participants (Benner, 1994). Benner further states that a researcher ‘can never escape her or his own taken-for-granted background or stance that creates the possibility of an interpretive foreground' (Benner, 1994). Lopez (2004) therefore enumerates the importance of background understandings which he considers as impossible and unproductive to nullify for a researcher, especially as these understandings play a crucial role in conceptualizing and investigating any study (Lopez, 2004). My personal experiences of being with a cancer patient, has led me to situate myself in the topic of existential concerns that offered me a stance in which to make an interpretation.

Uncertainty and anxiety about the future is common amongst those who are diagnosed with illnesses such as cancer, as well as among the family members of the diagnosed individual. As I was young when my mother was diagnosed with cancer, I cannot properly remember how she felt at that moment, but with time, it was evident that she was uncertain about 'herself'; she was worried about her health, her treatment and most importantly about her life. She was losing her 'usual rhythm' with the world. She was no longer at home within herself, or in the world, but drifting. She was tensed, disoriented and distorted. Physically, she was not able to engage with the world, which brings with it an awareness of actions and tasks that are no longer unselfconsciously carried out with ease, such as desires to go on a trip or performing daily chores. Realistically, she knew that she could no longer do these things, and was stuck in the house and with pain and agony. In essence, she didn't inhabit the world as she did before the disease, and became alienated from a sense of self and from her taken-for-granted life world. In this study, the participants sought to find meaning in their experience of illness, lost and disorientated as they were in a suddenly unfamiliar life-world. The everyday taken-for-grantedness of their life-world had been disrupted. Similarly, these led to a disruption in my mother's social world. Her social world changed; she began to remain isolated, didn't talk much with anyone, nor with me neither with my father; furthermore, wherever she went, family get- together or a party, everyone treated her differently. She was being sympathized while few didn‘t talk to her; perhaps they didn‘t know what to say, which further pushed her aside. I felt, before the diagnosis all these places and events were a source of joy and happiness, but then everything changed - the same place became the source of agony, and all those known faces became a remainder of her ‘altered self’ and her time left in this world. Similarly, as old familiar places became unfamiliar, new places, such as hospital, especially the doctor’s chamber, became familiar to her; at times, it provided her with the sense of certainty and comfort, about herself and her future. Furthermore, the doctors and other professional care providers played an important role in instilling confidence and assurance in her and in us; and in the same way, among the participants. Participants perceived the doctors as ‘going out of their way’ to care for them, just like their intimate relative. Kin played an important role in participants’ life; they were their primary care giver, and this role was sometimes played by a parent, a partner, by siblings and children. My mother’s need and comfort were never underestimated; whatever she wanted, irrespective of space and time, it was given to her immediately. There were several nights, when she wasn’t able to sleep, and needed a companion. we were there for her and these little things gave her something to hold onto, prevent her from drifting away. Additionally, it strengthened our interpersonal concern and provided a shelter for her and us. Likewise, the participants described the role of their family members in producing a sense of certainty, through their work, both health and emotional work, although some participants mentioned about things that made them feel that their needs were trivialized and it demoralized them about their future and were regarded as a hindering factor in providing a sense of well- being to the patients and their kin. As the participants said ‘having cancer is hard’, it is indeed really ‘hard’, because the impact of cancer was visible on all aspects of our life, but we all kept working towards making sense of this changed situation and to do that, we relied on a group of ready-made categories that are often utilised to distinguish illnesses. At first, when we came to know about the ‘cancer’, my mom was scared, and we were scared. She felt that death was lurking behind her, and considered it as her ‘death sentence’; but then over the years, her conception about it changed, and she considered it as a life-long disease, just as an illness with life-long medication. While in this study, some participants considered cancer as a ‘chronic’ illness and a few regarded it as a terminal illness, everyone mentioned about living in a constant threat of death and continuously coping with it. Similarly, several types of experiences are associated with this, such as somatic experiences, *Ma* (my mother) had to manage with the signs and symptoms of cancer and its treatment, just like the participants. In the beginning, the adverse effects of the medication weren’t visible, but with time the effects started showing.; Among the wide range of effects, pain, fatigue, nausea, mood swings and depression were the most common. Regardless of all these setbacks, *Ma* tried to maintain her functionality, but she was unsuccessful which led to frustration and aggression and she even tried to abandon her medication, in order to get rid of these symptoms. Many participants told me about similar experiences - how they struggled in maintaining their household and daily activities, and how they were adjusting with their self and were ‘moving on’.

Along with the patient, adjustments are undertaken by her/his intimate kin, especially by the primary care provider, and in my case, it was my father. I saw him juggling between work and home; he had taken up so many additional responsibilities and with time, I also shared his errands. But being in this position is tough. We had juggle between our roles, manage the household, work and the health care system. It required lots of effort, from each one of us, to sustain all this. However, on many occasions, we couldn’t manage and failed miserably, and there were many incidences where we broke down. But during those times, friends and neighbours were very helpful; they provided emotional support. As mentioned earlier, relatives played an important role in providing assistance among most of the participants. In my case, relatives were helpful in the beginning, but as time passed, intimacy with them decreased, and we were just three people, dealing with the situation. Apart from that, spirituality, faith in the Supreme Being, helped us in dealing with the event. We accepted it as part of God’s plan for us, and were optimistic about it. Like us, some participants considered it as God’s plan, while a few regarded it as a punishment and as a curse, and some showed a passive aggression against the perceived injustice of the Almighty. Like these, several other aspects of experiences with cancer have been discussed in an attempt to understand the ways people experience the illness trajectory.

Chapter 2: Conceptual Background

The review of literature suggests that chronic illness is an aspect of health that significantly impacts the lives of those diagnosed with it and those closely related to them. Cancer as an illness that is lived each day, affects a person's life, turning it upside down. Recent developments in treatments and cancer management indicate that individuals would be living with cancer for a prolonged period and it would be a vital aspect of their life courses. To understand the experiences of living with cancer, it is pertinent to contextualise the same using the available relevant concepts. The following section makes an attempt at describing the conceptual background for the current study.

I. A brief history of medicine and society

In the later stages of the nineteenth century and the early part of the twentieth, medicine was considered a profession on an upward trajectory. During that period, medicine was practised mainly in consulting rooms or at patron's homes, and hospitals were at a nascent stage yet in the process of becoming the epicentre of expertise and technology. Hospitals were primarily located in the cities serving the urban poor, while the rural population scantly availed health care services from rural general practitioners (Bradby, 2009). Although signs of the rise of medicine as a scientific discipline were evident in terms of attaining professional knowledge by learning anatomy, bacteriology and physiology in medical schools through textbooks and examination, and also from advancements in technology such as the use of a thermometer, stethoscope, X-Ray and electrocardiograph, but the doctors only held the ability to diagnose scientifically while being therapeutically weak (Bradby, 2009).

Later, the first world war (1914-1918) paved the way for technological advancement and scientific interventions to repair the damages of warfare's violence, with the prime focus on health. Along with the efforts to create 'homes fit for heroes', the techniques and innovations in treatments and healing of ballistic wounds and the psychological effects of sustained fights are the prominent medical legacies from the period (Bradby, 2009).

The second world war (1939-1945) saw a massive shift in the domains of medical care. It was during this time that penicillin was widely used to cure infections and sexually transmitted diseases among the armed forces. The invention of penicillin was considered as pathbreaking and it was hailed as a miracle drug that enhanced the capabilities of a doctor to influence the course of treatment and the disease, and the subsequent development of vaccines against polio, tetanus, diphtheria, whooping cough, measles, mumps and rubella contributed towards the same (Bradby, 2009).

The second half of the twentieth century witnessed a rapid economic expansion along with advancements in innovations and development in the field of medicine. However, this progress was also accompanied by certain catastrophic effects due to a few innovations. For instance, antibiotic resistance brought attention to assessing the role of medicine for the improvement of human health. While death from infectious diseases is now a rarity, the number of deaths due to cancer and other chronic illnesses has continued to increase despite the notable progress in screening and treatment regime, thereby maintaining the continuity with the nineteenth century and resisting the progress of the scientific medicine (Bradby, 2009).

Before proceeding further, it is important to get a clear understanding of what entails health and disease, as only the normative ‘biomedical understanding’ of the same would not suffice for the purpose of this study.

II. Defining health and disease

Attempts to describe health and disease in an objective term gravitates from the medical and scientific stances. According to Boorse (1975), health can be defined objectively in a descriptive and value free way, where health is understood in terms of ‘species-typical functioning’.

The biomedical understanding of disease discusses the objective conception of disease. In order to diagnose and treat disease, the discipline will first identify the cause by detecting signs and symptoms. Following the identification, the patient is expected to confer with the doctor’s interpretation of the disease without contesting the opinion. This model describes the instances where medicine is effective; however, it fails to consider all eventualities in the diagnosis and presentation of disease. For example, an individual may show symptoms without detection of underlying pathology or the absence of symptoms (Bradby, 2009). The lack of symptoms is a complication and it challenges the biomedical model of disease. The diagnosis of the asymptomatic condition as potentially diseased is uncharacteristic of the model since there isn’t a clear distinction between health and disease. So health is vital to understand the disease.

The biomedical understanding of health talks about health in the absence of disease. People who suffer from poor health or chronic illness may understand health in the absence of illness and as the indicator of health. However, individuals diagnosed with a chronic condition such as diabetes may perceive themselves as healthy as Whitbeck (1981) discusses health as being experienced by individuals through their ability to perform and achieve their goals. There is a range of ideas related to health, but majorly, health is understood in the absence of disease, and simultaneously it possesses a social and interactive quality (Bradby, 2009). Thus health is perceived as the ability to ward off disease, and the actions that make health possible is an isolated phenomenon.

III. Understanding heath and illness

Health is often conceptualised from the perspectives of functional competence (Whitbeck 1981, Canguilhem 2008). Canguilhem (1991) also stated that the health of an individual is affected by their relationship with their environment. Health referred to the ability of an individual to respond and address the changes in their environment. Health is felt through our everyday life experiences that 'provide[s] a means for personal and social evaluation' (Crawford, 1984). Gadamer(1996), Canguilhem (2008) and Leder (1990) suggest that health is an 'absent presence', where health is silent, forgotten and, exists in the backdrop. Health is a condition that is experienced through being involved, by being in the world, or being with others through active participation in one's everyday life. Radley and Billig (1996) emphasised that health is a phenomenon that is perceived through the accounts of others and is relational.

Herzlich (1985) stressed that one should not be confused with the subjective state of health in itself and the state of health as interpreted by medicine and doctors. Illness is the subjective experience of disease, and disease can be understood as something that compromises endurance and tolerance towards the changing environment. In a general context, the terms disease and illness are often interchangeably used; however, disease is often associated with a biological concept while illness is a social concept involving people's perceptions and reactions (Barkan, 2017).

Illness refers to the person's understanding and response towards the medical symptoms and their underlying pathology and similar understanding and responses of others related to them (Barkan, 2017). The social conception of illness is based on three elements: the medical labelling of the symptoms, response of the individual and others to this labelling, and the social, psychological, physiological and economic consequences of this labelling and the associated symptoms. In other words, illness refers to the ways in which individuals perceive and respond to the symptoms. Related to illness is illness behaviour, i.e. how individuals behave towards the symptoms. The illness experiences are varied; for instance, individuals with similar symptoms can respond differently and often external social factors shape these responses. For a few individuals, varying degrees of expressivity can lead to different consequences for their illness experience. While some symptoms may induce stigma, others symptoms may elicit empathy. Moreover, individuals with chronic illness and disabilities experience their own sets of physical and emotional complications, wherein situations like these demonstrate that illness experience is complex, dynamic and relational.

A. Illness as a social construction

For decades, anthropologists and sociologists have focused on illness. In social science, illness is considered a social construction that entails a subjective reality (Barkan, 2017). As a social construction, emphasis is upon understanding the effect of society and culture on the perception of medical symptoms and illness and how individuals labelled as ill should be regarded. Several anthropological studies of traditional societies show how culture plays a significant role in shaping the ideas related to health and illness. For instance, in some communities, men with pregnant wife experience morning sickness (Doja, 2005). There isn’t any apparent biological or medical basis behind this. Still, they experience it due to the fulfilment of their society’s expectation of being a father through a process of socialisation, thereby making their sickness a social construct. Kleinman (1980) discussed the three ‘arenas’ in which illness and healing experience occur: the popular arena (home or commuinity where the illness is defined and appropriate treatment is administered), the folk arena (space of non-medicalised healers) and the professional arena (area of biomedicine and professionalised healing). In all these arenas, the experience of illness occurs with respect to health and is a personal experience of ‘unhealth’ and suffering (Kleinman, 1980), and, thereby making illness a subjective construct that is historically and culturally informed by an individual’s relation with the body (Boorse 1975).

B. Illness taxonomies

Taxonomy of illness refers to the categorisation of illness as acute, chronic or terminal. An acute illness refers to a self-limiting disease characterised by a rapid onset of symptoms (Barkan, 2017). These symptoms may vary in their intensity and severity, which can be resolved in a short span of time, but in some cases could be life-threatening. Most acute diseases are contagious in nature, and a few examples of acute diseases include influenza, tonsillitis, appendicitis, bronchitis and breathing difficulties.

Chronic illness refers to an existing medical condition that makes the person perpetually ill (Boorse, 1975). Cardiovascular diseases, cancer, chronic respiratory disease, obesity, hypertension and diabetes are a few examples of chronic diseases. Chronic illness is majorly non-communicable and incurable, and is characterised by slow onset and protracted course where the affected may survive for several years with a proper treatment regime (Barkan, 2017).

Recognising the complexity and relativity of health, Blaxter (2004) discussed these taxonomies from a biomedical perspective and called them as ‘states’ of illness. She emphasised the individual definition of health, thereby supporting the relativeness of this concept. The concept of health was based on an individual’s own assessment and judgement of whether they are or aren’t healthy. Blaxter (2004) argued that health is dynamic, constructed, experienced and acted out. She described them in terms of health state and health status. Health state indicates the present health condition of a person, whereas the health status is a longer-term attribute. Blaxter (2004) stated that “an individual could have a long-term chronic condition, i.e. health status, but be in good health, i.e. health state and vice-versa”. In this context, individuals diagnosed with cancer, then possess a shifting status of either chronic or terminal health status since cancer is incurable and one may undergo rapid changes in their health state perhaps due to episodes of infection. And thus, the illness experience of cancer constantly cuts across the taxomnomy. As discussed earlier, cancer is characterised by uncontrolled cell growth. Depending upon the quantity of malignancy and its impact on an individual's functional ability, it can be categorised as acute, chronic or terminal.

C. Experiences of illness

Experiences of illness are subjective and are subjected to the hardships of daily life. It is about understanding what an individual diagnosed with a chronic illness such as cancer wants. Is it to be reassured, to be relieved from pain or care until recovery? Often, a person diagnosed with a chronic illness wants answers to questions such as - Why me? Why now? How to get out of this? A patient asks these questions in a desperate attempt to regain control over their life experiences that have been disrupted by the invasion of illness (Kleinmman, 1988). Several biomedical theories of causation of disease deal with the causes of infections and identify the predisposing factors for chronic disease. These theories with their sophisticated statistical techniques are fruitful when one intends to understand the characteristics of a disease in a population, but it fails to capture or explain the cause of one's suffering. Medicine only addresses suffering in the context of alleviating the symptoms associated with it. The objective and reductive approach of medicine restricts its ability to address distress brought about by the disruption to daily life, uncertainty and existential fears (Barkan, 2017). This approach does not consider the interaction between body and mind, neither the social and moral dimensions of illness nor the importance of people's reaction to one's illness. Since the experience of one's cancer cannot be extrapolated to another's, therefore the experience of illness is highly subjective and comprises social, emotional, symbolic and bodily dimensions of illness.

There are several concepts that deal with the experience of illness, such as the sick role, sickness as deviance, stigma and illness, and biographical disruption. In this study, I will be using the concept of biographical disruption to explain the experiences of cancer patients and their caregivers. Before discussing this concept, it is prudent to briefly touch upon the other concepts that deal with the experience of illness.

The sick role: The concept of sick role was introduced by Talcott Parsons in 1951 in an attempt to describe the expected behaviour from a person labelled as sick by a medical practitioner. Being a functional theorist, Parsons emphasised the need for social institutions and individuals to function efficiently to maintain society's stability and functionality (Barkan, 2017). Accordingly, when an individual is ill, she or he is dysfunctional and often unproductive, not only in terms of individual performance but also for the society as a whole; and in such a situation the individual may be viewed as a deviant unless the person performs the sick role. While performing the sick role, an individual should adhere to two important obligations; first, the person must have the desire and try to be healthy. Second, the individual should seek and follow medical professionals and their instructions. However, this concept has been criticised from several fronts. One such criticism is that as Parsons favoured the traditional, hierarchical patient-physician model. He emphasised that the sick role necessitates the patient to strive for complete recovery. This implies that an individual can achieve a full recovery, but it's often not feasible for an individual diagnosed with chronic illness. Lastly, Parsons's model failed to acknowledge the effects of social environment on the patient's perception and behaviour.

Sickness as deviance: Health and illness are not experienced as mutually exclusive. As cultural categories, they are often understood in terms of binaries such as sickness/ health, pathological/ normal, disabled/ able-bodied, diseased/ disease-free. These binaries demarcate or seclude a person from the healthy to sick, making them a separate, visible group. For instance, in the thirteenth century England, people with leprosy were isolated from the general population and had to follow specific codes of conduct such as sounding a bell warning of their approach and wearing a distinctive uniform.

Stigma and Illness: Stigma refers to a condition where an individual is perceived as unacceptable or inferior and is considered as polluted or shamed (Barkan, 2017). Goffman (1963) introduced three types of stigma: the stigma of body, the stigma of character and the stigma of a social group. Some types of stigma can be concealed in day-to-day interactions, through the use of prosthetics or clothing adjustments, to avoid discrediting the bearer's identity. Individuals with stigma often put efforts to manage their symptoms and associated stigma. For example, men diagnosed with HIV often concealed their status from their colleagues to avoid being feared of and being stigmatised (Barkan, 2017).

Biographical disruption

A diagnosis of a chronic or terminal illness, and the possibility of extension of life after the diagnosis often affect an individual's sense of self either positively or negatively, creating a new or an altered identity and this changed self is actively managed to allow the continual presentation of the self. While doing so, individuals tell stories that repair the damage done to them and attempt to reconstitute their biography as meaningful (Willams, 1984). In this study, I will be using this concept to explain the experiences of cancer patients and their caregivers.

Aspects of chronic illness such as stigma, sense of failure, and associated uncertainty are crucial to people's sense of self, which contributes to a sense of disjuncture between being healthy and being ill, that unfolds with the individual's life story. In this context, Mike Bury (1982) introduced the term biographical disruption. The term was introduced as both a ‘descriptor’ of people’s experiences of chronic or terminal illness and as an ‘explanatory tool’ to understand how individuals react and adjust to chronic illness (Bury, 1982).

Disruption occurs in various forms; first, the taken-for-granted assumptions about one’s body, self and the social world are no longer available for the individual diagnosed with a chronic illness. Depending on the type of illness, a person may face difficulties related with mobility; they may need assistance in performing daily activities such as bathing and dressing; or, they may exhibit visible disfigurement. Such situations can be considered as humiliating and often affect the individual’s conception of self, self-esteem and confidence. Second, a diagnosis of chronic illness often causes distress and brings uncertainty in the lives of the people. Third, a chronic illness may severely affect the social relations that one has. Due to the complexities and demands of illness, one may have difficulties in spending time with friends and family. Fourth, Chronic illness can make it difficult for individuals with jobs and can affect their ability to perform tasks and sometimes compel them to shift or retire. Bury (1982) emphasises that events such as chronic illnesses bring fore the suffering, pain and death, which are otherwise distant possibilities in one’s life.

As disruption has various forms, it also differs in severity and intensity among individuals. Although the pathology and symptoms of the disease matter in this context, but individuals with same diagnosis and similar symptoms may experience disruption differently. Several factors influence the degree of disruption, such as age, gender, social support and financial status.

Radley (1999) describes that for individuals with cancer, the impact of cancer begins at or near diagnosis with the involvement of medical interventions and nomenclature. Though cancer is a purely biological event, it has severe social, emotional and temporal consequences for individuals with cancer and their caregivers. The diagnosis marks the point from where disruption initiates, or as Bury (1982) puts it, ‘an interruption and alteration in a person’s life history’. The cancer diagnosis changes the individual’s sense of self and future direction, invading every aspect of their life. As cancer is often equated with death, the effects of the diagnosis on the self is quite pervasive. Sontag (1991) states that ‘in the popular imagination, cancer equals death and not just death, but a slow, painful and ‘spectacularly wretched’ death’. Charmaz (1994) explains that chronic illness brings realisation and awareness of death and how it severely disrupts self, particularly if the individual is perceived as ‘too young to die’.

Shortly after Bury’s work, Willams (1984) and Cornwell (1984) dicussed causality within a biographical framework. Willams (1984) talked about ‘narrative reconstruction’ and suggested that people diagnosed with chronic illness make continous effort to effect repair. While, Cornwell viewed illness as part and parcel of life, that one goes through , and for some individuals, it can be ‘par for the course’.

Narrative reconstruction emphasises on the way persons diagnosed with chronic illness ‘reconstitute and repair’ the break between body, self and the world by making causal connections between their illness experience and the events in the past (Willams, 1984). Williams conducted his study on individuals diagnosed with rheumatoid arthritis. He interviewed his participants or in his words, ‘seasoned professionals’, as they were deep into their illness trajectory who could provide him with insights about ‘structured self-image of the chronically sick person’. His focus was on knowing about living with illness after individuals had lived with it for some time. Cornwell’s (1984) study described how the participants perceived illness and death like any other hardship, disaster and loss. Illness and its effects were biographically anticipated and were contextual with time. In her study, participants dealt with numerous crises in their lives and considered the diagnosis as an anticipated aspect of their survival or biography.

The concept of biographical disruption has been considered helpful in understanding the experiences of chronic illness. However, it has been challenged on a few fronts. First, Bury's concept of biographical disruption was primarily focused around the initial stages of the illness diagnosis and the process of adjusting, and it doesn't completely represent one's experiences of illness in the later stages. Second, the notion of disruption suggests a negative experience (Locock, Ziebland, & Dumelow, 2009). Charmaz (1983) explored chronic illness in terms of the 'negative language of loss'. Others have argued that disruption in one's life due to chronic illness can be expressed as 'biographical flow', 'biographical anticipation', or 'biological continuity' (Williams, 2000).

Biographical disruption has been utilised in the domains of cancer. As discussed earlier, cancer is considered as a chronic illness and a cancer survivor may consider cancer as a permanent threat to life and thereby a constant cause of disruption. McCann, et al. (2010) used the concept of biographical disruption to know the experiences of female breast cancer patients. The study attempted to understand how the patients' identity shifts from being healthy to being ill as they advance through the illness trajetory and how they reinstitute their identity while being subjected to uncertainities. Literatures on biographical conceptualisations have focused on experience of chronic and terminal illness suugesting a disruption in social, relational, leisure and work activities (Sanders, Donovan, & Dieppe, 2002; Ciambrone, 2001; Taghizadeh & Jeppsson, 2012).

The concept of biographical disruption provides valuable insights into the experiences of living with cancer in understanding the critical events of their life and how the diagnosis impacts the patient's and their family caregiver's everyday life, which primarily manifests itself in suffering. Hence at this juncture, it is worthwhile to explore the concept of suffering in some detail, to better understand the experiences of living with cancer.

D. Suffering

The word suffering has emerged from Middle English word *suffrir* and the Latin word *suffer*, both meaning ‘long-suffering’ or ‘facing a burden of pain with patience’ (Anderson, 2014). In general, the word is used to indicate hardship, distress and turmoil. However, in academia, suffering refers to the perceived threat or damage to one’s sense of self, alluding to a state of distress associated with events that threaten one’s body or self-identity (Cassell, 2004; Chapman & Volinn, 2005). Suffering differs from individual to individual and varies in intensity, duration, awareness and source (Black, 2005). There are several forms of suffering: physical, mental, social and existential. Physical suffering is the distress originating from threats of injury to one’s physical state (Black, 2005). Often, physical suffering is equated with pain (Black, 2005; Carr, Loeser, & Morris, 2005; Wilson, et al., 2009). Mental suffering refers to the perceived distress resulting from threats to one’s cognitive or affective identity, including emotional suffering (Francis, 2006), while social suffering results from social collectives and/or social institutions (Das, Kleinman, Ramphele, Lock, & Reynolds, 2001; Nordgren, Banas, & MacDonald, 2011). Existential suffering, mostly understood along with mental suffering, is the outcome of conflicts with the interpretation of one’s existence (Langle, 2008). Several words are often associated with these forms of suffering; for instance, discomfort, hurt, torture, pain, extreme pain and unimaginable pain are used to describe physical suffering. Words such as stress, loss, sadness, anxiety, frustration, fear, disappointment, hopelessness, loneliness, and depression are used in the context of mental suffering, while words like social exclusion, discrimination, marginalisation, disability, shame, blindness, and bedridden indicate social suffering (Anderson, 2014).

1. *Perspectives on suffering*

The domain of suffering is quite vast and to understand suffering, knowledge is required from diverse disciplines, including social sciences, humanities, medical and professional health care. Suffering can be understood from various perspectives. Anderson (2014) identified several frames or perspectives from an analysis of similarities and variations in the texts on pain and suffering. Those frames depict suffering as a punishment, reward, craving, altruistic action, natural destiny, and also something that is manageable.

a) Suffering as punishment

From historical times, suffering is predominantly perceived as punishment. In early animist religions and several organised religions such as Christianity, Judaism and Islam, pain and suffering have been associated with higher powers (Kruse & Bastida, 2009; Dormandy, 2006). Accordingly, suffering has been considered as punishment and a sign of supreme or supernatural being and their discontent with people's attitude and behaviour. God(s) were thought to decide the nature, process and timings or duration of suffering bestowed to human beings for their actions.

b) Suffering as reward

While suffering was perceived as a punishment from the supreme being, it was also viewed as a reward (Ashwell, 2011). Suffering is seen in some religions as a sacred act, an act to appease God, and hence a desirable act. This kind of thought sometimes goes to the extent where the act of using medication can be seen as a hindrance in this spiritual process. A few researchers have pointed out how suffering is seen as an act that is to be lauded by some religious groups (Ashwell, 2011; Beke, 2011; Ghadirian, 2012). Some examples of how suffering is seen not necessarily as a punishment, but a reward can be seen from the fact that in some religions, there are some days dedicated to suffering. In the past too, one can see such examples, a prominent one being the Flagellants, a group of Roman Catholics who used to whip themselves in public, an act that was sanctioned by the Church initially and was later withdrawn (Bean, 2000).

c) Suffering as craving

The view of suffering as craving is prevalent in eastern cultures, where suffering is seen as ‘egocentric habits of mind’ (Targ & Hurtak, 2006). Buddhism advocates that ‘pain is inevitable; suffering is optional’ and ‘the origin of suffering is craving’. According to Dalai Lama (2011), Buddha has cautioned that all gratifying sensations result in craving and attachment to this causes suffering. In Western Philosophy, Socrates, in a similar line, said: “if you don’t get what you want, you suffer; if you get what you don’t want, you suffer; even when you get exactly what you want, you still suffer because you can’t hold on to it forever” (Millman, 2006).

d) Suffering from altruistic action

This perspective indicates that sometimes altruism demands a sacrifice on the part of the actor and it may put one at risk of suffering. According to Das (1997), providing assistance without consideration of the benefit or reward, often known as empathic-altruism, may require extraordinary sacrifice and is frequently regarded as an expensive exchange. These sacrifices are usually made in terms of economic value and highly valued social goods such as interpersonal relationships.

e) Suffering as natural destiny

The most prevalent perspective in modern societies is to accept seemingly random suffering as natural destiny and the belief that every human would die and decay. Death and suffering are the aspects of how universe works (Cassell, 2004; Wertenbaker, 2011). However, such views often create pessimism. If one accepts the fact that everyone eventually decays and dies as the universal truth, then that may lead to negativity in thought and be an obstacle in preventing preventable suffering. So, one needs to keep this line of thought at bay to be able to take initiatives that will lead to the preservation of human species. (Carr, Loeser, & Morris, 2005).

f) Suffering as manageable

This frame relies on the advancing technology in the fields of pain and medicine and holds the view that suffering can be addressed and prevented through medication. Pain relief medications are important in preventing suffering. However, due to widespread inequality, often large subpopulations in the developing world in need of pain management lack access. Furthermore, unaffordability of pain relief medications and the fear of addiction to pain analgesics sometimes withhold pain relief treatments and prolong the suffering of an individual (Anderson, 2014).

2. Suffering and biographical disruption

The basis of Bury’s biographical disruption is the distinction between an ill individual’s past and present lives. It emphasises the extensiveness of disruption, how the illness disrupts individuals’ lives, their understanding of their lives, the world and their place in it, and also how the taken-for-granted certainties become ambiguous. The concept also stresses how time, uncertainty, and the rippling effects of chronic illness affect personal and family life. Suffering becomes an immediate reality as the belief in life dissolves while facing death. Charmaz (1983) discussed that disruption was one of the numerous ways individuals experience illness. Like Bury, she emphasised the effects of loss and uncertainty for chronically ill people’s selves and the changing relationships between body and self. In her works, she demonstrates the relation between loss of self with suffering and how the degradation of earlier self-images, identities, and ways of being in the world contribute to it (Charmaz, 1983). She suggests that the sufferring and loss indicate uncertainty and biographical discontinuity and bring vulnerability, risk, embodiment, and emotions. Chronic illnes causes suffering that arises from tensions between body and self, which is reinforced with each disruptive episode or depleting social conditions (Charmaz, 1995).

Diagnosis of chronic illness or incurable disease brings forth an inescapable suffering. Often the sources of suffering during a chronic illness are external to the person. Suffering of an individual depends on the person's particular nature; for instance, the pain of cancer is pain indeed, but the form and the nature of suffering that occurs is due to the meanings held by a person about their pain. Different people with same disease may have varied perceptions and experiences of their illness, pain and suffering. According to Wilkinson (2005), we can address signs of distress and pain, but can never 'enter in the realms of their personal suffering', making it a unique, individual experience. When suffering occurs during a cancer trajectory, the medical notions of body, pain and disease categories seem insufficient to envisage suffering or offer a way for its respite. Moreover, disease theory or the molecular pathophysiology are often viewed as the sources of misunderstanding when considering suffering in chronic illness. The constant sources of distress are not only symptoms in themselves but are a part of chain of causation accountable for the illness that is ongoing, long-lasting, affecting every aspect of an individual's life and threatening the integrity of one's self (Cassell, 2004).

a) Suffering, social world and self-conflict

For an individual, much of the suffering ascends from the conflict between the ill person and the public existence. In this regard, suffering occurs when an individual fails to meet the universal understanding of 'approbativeness (the desire to be approved of)' and ‘emulatativeness (the desire to be considered superior)’ due to their illness (Cassell, 2004). Self-esteem and the longing to be like the ones admired are often inaccessible due to the behaviour imposed by the illness and its subsequent treatment. For instance, our culture does not sanction people consuming many medications (use of painkillers), but this is frequently necessary for individuals with chronic illness.

Cassell (2004) theorises that the conflict faced by a chronically ill person is internal. The patient’s daily action seems to be often influenced by external forces that can be termed as ‘demands of society’ in terms of rules of behavior, dress requirement as well as in verbal categories such as ‘patient’, ‘pain’, ‘cancer’, etc. But according to Cassell, the meanings of these verbal categories which are usually reinforced externally, actually are found within the patient. Thus, as per Cassell, the conflict seen in the patient, exemplified by his / her self-esteem, appropriations, etc. is mostly self-conflict.

Many times, in spite of the desire to live in the social world, chronically ill persons withdraw themselves from the public world and retreat to their private space in order to escape from physical and emotional pain and humiliation, and this conflict even persists in the individual’s thoughts. And as these conflicts grow, they reinforce the suffering by becoming the cause of constant unresolved pain, or at worst, ‘threatening to tear the person apart’ (Cassell, 2004). In addition to this, family, friends and others related to the ill individual provoke and intensify suffering by continually urging the ill individual to ‘try and be like everyone else’ (Cassell, 2004).

b) Suffering and the conflict of self with self

As discussed earlier, the conflict with the external world becomes self-conflict through internalisation due to the symbolic and linguistic categories and the continuum of movements of people, objects and relationships from the external reality to an internal world.

And these cause internal conflicts which can threaten to destroy the integrity of the person. The illness may bring forth dissension and confrontation with one’s body and other aspects of self (Cassell, 2004).

When an individual is ill, the body is often considered as being separate from other aspects of the person. Sometimes the individual behaves as if the body is their enemy. According to Scarry (1985), along with the sufferings from pain, tortured individuals also suffer from the conflicts between their principles and the weakness of their body. In here, the suffering ensues when the intactness of an individual is threatened and it remains so until the threat is resolved. For an individual diagnosed with cancer, threat is never resolved as cancer is incurable and thereby one can not restore their intactness within their body. This, sometimes, leads to the feelings of untrustworthiness and anger with the body (Cassell, 2004). With the advent of illness, body is no longer dependable; on the contrary, the body fails the person when needed most. And sometimes, this instigates the individual to inflict self-harm or punishment by hurting it, denying medications, or overwork it. Each punishment directed on the body is actually a punishment for the person as well. Sometimes, body can also be a source of humiliation. Controls over bowel movement, disfigurement from treatments and loss of physical competence can be difficult in chronic illness affecting their integrity of self and fostering humiliation and isolation (Cassell, 2004). Integrity of an individual involves all the aspects of the whole person in their individuality. The crisis or the injury to the individial that initiates suffering can occur in relation to any dimension of the person, for instance, an individual with a rigid personality might find adapting with life changes due to an illness as extremely difficult and the suffering begins with the failure of adaptation. Or, violation of trust from a reliable person may later create difficulties in placing their trust again even though it is necessary. The nature of illness or the disfigurements may make it tough for a person to live in the public world, thus affecting their relationships with friends and relatives. Individual roles, such as of a mother, teacher, and athlete, may be unfeasible to sustain, thereby rupturing their self-esteem and identity. Similarly, physical activities that one used to undertake before the event that initiated suffering might now be impossible; hopes, dreams, and aspirations for future might be seen uncertain and disappearing due to the individual's unsatisfactory present. Sometimes, repressed trauma or unconscious conflicts may resurface by the unsatisfactory present where the individual preceives the event or the illness that initiated suffering as a repetition of exploitation, reinhabiting, and as a result, finds oneself in the role of a marginalised victim (Cassell, 2004).

In chronic illness, suffering always involves self-conflict- the conflict within self and if it is severe or has lasted long enough, it never leaves and the suffering can go on. The suffering individual withdraws from the social world and sometimes from the interactions of their everyday life. And this makes it apparent as to why loneliness is a central feature of sufferring. Loneliness occurs since suffering is subjective and no one can actually understand why somebody is suffering. Loneliness is often heightened by the withdrawal from the social world and when it continues for a longer period, suffering becomes 'a way of life and may appear to an onlooker like depression' (Cassell, 2004).

c) Strategies for reducing suffering

Inner-conflict and loneliness are inevitable accompaniments of suffering. Cassell (2004) discusses four approaches that can reduce suffering. First, living completely in the present, as suffering involves anticipating a feared future. Second, suffering can be averted by completely being indifferent to what is happening, indicating towards a stance of absolute unconcern about the illness, its effect and self. The third strategy is denial. It allows an individual not to suffer in circumstances where they might otherwise live in misery; for instance, a person with disfigurement from cancer treatment might be oblivious to the stares of the onlookers. And the fourth is being flexible. The threat to the intactness and integrity of self that initiates suffering may take place in relation to any dimension of an individual. Similarly, suffering is comforted when the vulnerable aspect of the individual is replaced in importance by another feature. Though flexibility is difficult to achieve for individuals with chronic illness, but nonetheless, individuals should strive to compensate their loss with new interests and the loss must be replaced again and again.

Thus, suffering is personal, individual and may arise from physical illness and can be manifested in various forms- physical, social or emotional. It affects one's integrity of self and is often accompanied by self-conflict and loneliness. Although addressing the cause or treating the disease and its symptoms may relieve one's problems, but sometimes suffering continues unless it is specifically recognised and addressed. In the meantime, the individual moves forward (or at least makes an attempt at moving forward) through the act of coping. The coping strategy, though, varies from person to person despite similarities in their circumstances. The following section discusses the functions of coping, approaches of coping process, and coping within the context of chronic illness.

E. Coping

Effect of illness on individuals and on all those the individual is related to, is far-reaching. As discussed earlier, it affects every facet of one's life including relationships, financial conditions, and day-to-day activities. The impact of illness often calls for some alteration and adjustments on behalf of the diagnosed individual and people around them. Reactions to the symptoms and events due to illness vary considerably and so do the coping strategies. Individuals who are able to adapt and cope effectively are considered to be more successful in managing their altered situation and the associated stress (Falvo, 2005).

Coping is a broad construct consisting of many acts which are dynamic and individual specific. As a concept, coping is defined as a balancing mechanism that assists an individual in adapting to stressful events that include cognitive, emotional and behavioural efforts or strategies directed towards mitigating the situations (both external stressors and internal demands) and the associated emotional distress (Lazarus & Folkman, 1984; Moos & Schaefer, 1993).

1. The functions of coping

Several authors have discussed numerous functions of coping and have argued that understanding the functions of coping would help us know the operational mechanisms of coping (Cohen & Lazarus, 1979; Zeidner & Saklofske, 1996; Livneh & Martz, 2007). A few of them are as follows: acquring information about the demands exerted by the external environment, creating a steady psychological equilibrium that addresses the external demands of the environment through skilled behaviours, making a conscious decision based on the assessment of the acquired information, removing stressful environments, keeping a positive self-image, enhancing tolerance towards stressful events, modifying perceptions about the stressful events, and enhancing the chances of returning to pre-stress situation (Livneh & Martz, 2007).

Based on the functional aspects of coping, Lazarus and Folkman (1984) introduced two overarching funtional categories: problem-focused coping and emotion-focused coping. Problem-focused coping deals with mechanisms directed towards modifying the source of distress by altering the external environment, while emotion-focused coping is about regulating one's own emotion and accomodatinng oneself after an intital encounter with a threating situation and anticipating those situations as un-modifiable. Later in 2003, Skinner, Edge, Altman and Sherwood discussed three functionally derived adaptative mechanisms of coping, namely, coordination of environmental actions and contingencies, coordination of available resources, and coordination of preferences and available choices. The first mechanism, coordination of environmental actions and contingencies indicate towards the efforts of being effective and finding alternatives to mitigate the stress. The second mechanism talks about utilising the available resources and withdrawing from unsupportive situations. The third discusses the efforts of finding alternatives and ways of eliminating the threatening events or constraints. Skinner, et al. (2003) further emphasied that all these mechanisms of coping assist the individuals in adapting with the stress-triggering or threatening environment.

2. Approaches of coping process

Based on the assumption about the primary determinants of coping responses, coping is conceptualised using two generic approaches: dispositional approaches and contextual approaches (Holahan, Moos, & Schaefer, 1996). The dispositional approach is based on the ego-psychoanalytic model where ego processes are unconscious cognitive mechanisms that focus on emotions and are defensive in nature. This approach stresses that individuals have steady preferences for specific defence and coping strategies for addressing a conflict or threatning situation and these strategies evolve with time. On the other hand, contextual approaches, based on Lazarus and Folkman's appraisal model consider coping as a response to a particular stressor rather than a personality trait (Holahan, Moos, & Schaefer, 1996).

Often, one develops their coping strategies based on their coping resources. There are two types of coping resources: internal and external (Moos & Schaefer, 1993). Internal resources are the personal dispositions that help in adapting to stress. This adaptation is mostly psychological in nature and involves self-mastery, self- control, positive self-esteem, self-efficacy, optimisim, sense of coherence and interpersonal skills. On the other hand external resources comprise social and materialistic assets including social networks, financial resources, availability of time and presence of other stressors.

Another vital aspect of coping is its temporality. Based on the temporal context of coping there are five types: preventive or proactive, anticipatory, dynamic, reactive and residual (Folkman & Moskowitz, 2004). Preventive coping begins long before stress such as age-related illness. Anticipatory coping occurs when stress is anticipated to ensue in the near future. Dynamic (or present) coping occurs while the stress is ongoing or being experienced. Reactive coping occurs after stress has passed or has been experienced i.e., in the past. And residual coping occurs long after stress has been felt or experienced, and the individual deals with its effects.

3. Coping within the context of chronic illness

Studies related to coping with chronic illness are mostly based on the theory developed by Lazarus and Folkman (1984) where they talked about emotion-focussed coping and problem-focused coping. Emotion-focussed coping discusses the way people adopt an emotional response to stress; for example, through avoidance, denial or vigilance. And, problem-focused coping refers to the individual engagements that one makes to change or alter their situation and make it managable.

Indivduals with chronic illness cope in various ways (Falvo, 2005). Some acquire knowledge about their situation and actively confront and engage with it. Others may deny the realites of the intentsity of their illnes in order to protect themselves from stress. They might do so by ignoring medical recommendations or refusing to learn new behavioural skills, while a few cope by involving themselves in self-destructive behaviour that produces detrimental effects on their physical condition (Falvo, 2005).

Effective coping must be understood with regards to one’s personal experiences, perceptions and circumstances. Individuals often utilise those coping strategies which have been beneficial for them in the past. New strategies are developed when older strategies fail to neutralise the stress or are not fitting to the changed conditions. Through effective coping, one adjusts with their illness and it enables them to achieve positive outlook and maintain emotional equilibrium by avoiding incapacitation from fear, anger, anxiety or depression. There are a few commonly used coping strategies such as denial, regression, compensation, rationalisation and diversion that help the individual to restore equilibrium; however, overuse of these strategies can be detrimental at times (Falvo, 2005).

a) Denial

The diagnosis of chronic illness such as cancer can have a devastating impact and can provoke several responses such as anxiety. In this situation, some individuals use denial as a coping strategy where they deny to accept having the illness by refusing treatment or by denying the consequences of the illness. At an early phase of the illness trajectory, denial can be useful as it helps the individual to adjust to the traumatic situation at their own time, preventing excessive anxiety. However, if it persists for a longer period, it can prevent one from adapting and can put themselves and others at risk.

b) Regression

In regression, people revert to an early state of development and act passively or express dependency and emotionality than they usually would (Miller, 2000). This strategy can be therapeutic if employed during the early stages of the illness, especially if the treatment regime demands rest and inactivity. But when the person continues to be in a regressive state, it can interfere with adaptation and achievement of desired levels of independence and functional capacity.

c) Compensation

In compensation, people learn how to counteract functional limitations in one aspect by strengthening another. This behaviour is regarded as highly constructive when new behaviours are developed for attainment of positive goals and results. Compensation can be damaging when the developed behaviours are socially unacceptable or self-destructive.

d) Rationalisation

Through rationalisation, individuals search for socially acceptable reasons for their behaviour or justify their incompetence in performing a task or achieving specific goals. It can lessen the disappointment of the individual in terms of their performance. Still, it can also be a barrier to adjustment by interfering with the treatment regime or restricting one to attain their potential (Livneh & Martz, 2007).

e) Diversion of feelings

The most frequent strategy of coping is the diversion of undesirable feelings and emotions towards socially acceptable behaviours (Moos & Schaefer, 1993). Often individuals with chronic illness possess strong feelings of anger about their diagnosis and their situation; if this emotional energy is reconceived and directed towards positive activity, the result can be beneficial. Like other coping strategies, diversion of feelings can also negatively impact if the feelings such as anger are directed to negative behaviours.

Apart from these coping tasks, literature on coping with chronic illness discusses social coping tasks that one faces and overcomes them to maintain intergrity, a positive self-image and functionality in social roles and relationships (Miller, 2000; Kosciulek, 2007). Miller (2000) discussed the major tasks of social coping for individuals with chronic illness as maintaining a sense of normalcy and control, adjusting with altered relationships, dealing with role change, and social stigma.

Similarly, spirituality[2] and social support are considered vital in many coping studies (Brooks & Matson, 1982; Dysvik, Natvig, Eikeland, & Lindstrom, 2005; Sarason, Pierce, & Sarason, 1990). Utilising spiritual approaches can be both adaptive and maladaptive depending upon their utilisation, whether one is using those as a source of motivation and strength or is awaiting miracles and engaged in impractical thoughts. On the other hand, social support, whether in forms of perceived social support, supportive relationships or supportive networks, may affect the way individuals cope with the situation and can act as a buffer against stress (Sarason 1996).

To sum up, this section of the thesis has discussed the conceptual perspectives that have contributed towards understanding the experiences of living with cancer. The conceptual outlooks regarding chronic illness suggest that the diagnosis of a chronic illness is accompanied by a disruption in almost every aspect of an individual’s life. This disruption is

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[2] Spirtuality refers to a multifated construct that is expressed through the process of one’s belief, behaviour and experience (Miller & Thoresen, 1999). Spirituality is a broad word that comprises several layers of meanings that may vary in terms of culture, nationality and religious groups (Roehlkepartain, King, Wagener, & Benson, 2006). It is commonly used to describe the primary human need to experience meaning, purpose, and connectedness and is a central aspect to all faiths and beliefs both within and outside organised religion, that inturn enables individuals to give meaning to the experiential and personal side of their relationship to the transcendent or sacred (Hill, et al., 2001).

often associated with suffering and emotional struggles due to the illness trajectory and individual ways of coping.

Chapter 3: Methodology

In this chapter, I will discuss the methodological framework and the methods utilised while conducting this study. Considering the aim of the study and how these could be explored aptly, I chose the appropriate methodology. Researchers have cautioned about the fact that sometimes methodological choices are based on the preferences of the researchers, rather than being chosen for the aptness in answering the research question (Newell & Burnard, 2006). However, they do point out that being biased about the methodological choices promotes the completion of research projects as it might be of interest to the researcher (Newell & Burnard, 2006). This chapter will provide a discussion of the selected methodology for this study and justify the choices. Here, I would like to mention that I considered the qualitative approach as most fitting for this study from the early stage of the research. A qualitative approach backed the idea of studying the experiences of individuals in their natural setting. To give an overview of the research approach, I will proceed by outlining the nature of qualitative research and discuss different approaches in the context of the aptness for this study, and the chosen approach is then discussed in detail.

I. The qualitative inquiry

Several studies have used a qualitative approach for understanding experiences about which little is known (Denzin & Lincoln, 2005; Wertz, et al., 2011). A qualitative inquiry mainly involves an interpretive, naturalistic approach[3] towards the world, trying to understand or interpret the phenomena as understood by the individuals under study. In the context of

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[3] Studying things in their natural settings

chronic illness, disability, and death, several researchers have utilised qualitative inquiry to address the complexities and challenges faced by such individuals (Denzin & Lincoln, 2005).

Usually, a qualitative inquiry is grounded on certain philosophical assumptions, which the inquirer decides upon while undertaking the study. There are five philosophical assumptions that direct the researcher: ontology, epistemology, axiology, rhetorical and methodological assumptions. These philosophical assumptions are about the nature of reality (ontology), how the researcher knows what s/he knows (epistemology), the role of values in the research (axiology), the language of the investigation (rhetoric) and the methods utilised in the process. Along with the philosophical assumptions, there are certain 'basic set of beliefs', otherwise known as paradigms or worldview that guide the research (Creswell,1998). The four significant paradigms in qualitative research are a) positivism, where the reality is considered apprehendable, driven by natural laws and mechanisms. In this paradigm, the researcher and the researched 'objects' are viewed as independent units, and the methods used are experimental and manipulative in nature. b) Post positivism, where reality is apprehendable but imperfectly due to the flawed human mechanism and the intractable nature of the phenomena. In this paradigm, emphasis is on reductionist, logical and deterministic orientation. c) In critical realism, the reality is presumed to occur in a crystallised form, shaped by congeries of social, political, cultural, economic, ethnic and gender factors, which can be understood through an informed consciousness and a dialectical mode of inquiry. d) And in constructivism, realities are apprehendable in the form of multiple, intangible mental construction, which are experientially and socially based, local and specific in nature, and for their form and content, they depend on the individuals holding the construction. Epistemologically, this paradigm assumes that the researcher and the researched 'object' are interactively linked (emphasis is given on the context/ setting), and therefore, the findings are co-created as the investigation proceeds (Creswell, 1998). Keeping this in mind, the present study follows a constructivist approach to obtain a detailed understanding of the issue, experiences, and perspectives of the individual living with cancer (as both a patient and a caregiver).

Within qualitative inquiry, there are several approaches such as narrative, phenomenology[4], grounded theory[5], ethnography[6] and case study[7] that guide the qualitative research design. This study, in exploring experiences of cancer and its care, is based on a constructivist approach. The unexplored and sensitive nature of this domain of study, entwined with a desire for a complete, in-depth analysis of this experience, meant that qualitative enquiry based on ethnography was best fitting.

Ethnography is a qualitative research method. The term ethnography has been derived from the Greek words *ethnos* and *graphein. Ehnos* means people and *graphein* refers to writing about something; thereby it can be simply understood as description of people and/ or their culture (Neuman, 2014). We can consider ethnography as the act of gaining knowledge of a specific cultural or social setting through observation, primarily. Fieldwork and observation are the characteristic traits of ethnographic approach (Atkinson, Coffet, Delamont, Lofland, & Lofland, 2001). However, ethnography can be seen as not just the process but also the product (Allen, 2017). While doing ethnography, a researcher participates in the group to obtain an insider's perspective of the members and to gain an understanding of their experiences. In writing ethnography, a researcher develops an account of participants of the study, on the basis of the observations made, interviews and sometimes through an analysis of group documents and artifacts (Allen, 2017). Unlike the kind of observation where one can look at a group of

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[4] Phenomenological studies are about describing the meanings of lived experiences regarding certain phenomena for several individuals. Emphasis is on 'what' they (the participants) experienced and 'how' they experienced the phenomena and from that, a composite description of the essence of the experiences for all the individuals are developed (Creswell, 2006).

[5] Grounded theory is suitable when our intention is to generate a theory, that is, an analytical schema of a process or action or interaction (Creswell, 2006).

[6] In ethnographic studies, the focus is on describing and interpreting the shared and learned patterns of values, behaviours, beliefs and language as a culture-sharing group (Creswell, 2006).

[7] Case study research is about the study of an issue or problem explored or understood through one or more cases in a specific setting or context (Creswell, 2006).

people from outside, in ethnography, the focus is on direct observation of the participants from close quarters, and see what the people under observation really mean, and how they truly feel internally (Neuman, 2014).

Ethnography originated from a sense of disillusionment with Enlightenment ideals of standardisation, the kind of ideals that could be exemplified in an attempt to create ‘encyclopaedias’ of all forms of human knowledge (Gobo, 2008). However, it is instructive to note the difference between encyclopaedia and ethnography, because they make two very distinct claims when it comes to the conceptualisation and presentation of scientific knowledge. In encyclopaedias, the focus is on seeking and producing a comprehensive and sometimes comparative compendia, whereas ethnography’s focus is to seek and produce detailed, yet situated accounts of the cultures under study, wherein utmost care is taken to capture the authentic perspectives of the people under study.

In the early stages of twentieth century, one could see a kind of ethnography where colonial travellers who did not have any academic positions wrote of their accounts of the people they interacted with, during their colonial or missionary missions (Gobo, 2008). Sometimes, these glorified travel accounts were prepared by traders and explorers too, and these were then taken up by the metropolitan scholar scientists with no experience ‘in the field’ for ethnographic theorizing, which was very much in sync with the prevalent doctrine of the time which said that “empirical data collected by gentleman amateurs abroad could provide the basis for the more systematic inquiries of metropolitan scholar-scientists” (Stocking, 1992).

A major turning point in the way ethnography was done came with the intervention of Bronislaw Malinowski (1884–1942) who is hugely credited with the way modern ethnography is conducted and disseminated (Gobo, 2008). Thanks to his work, ethnography no longer looked at two distinct roles in terms of fieldwork and theorization by two different people, but made the ethnographer a figure who was expected to perform both the roles, that of someone who did the fieldwork and theorized his observations. With this, method and theory were brought together and not segregated, in ethnography. Thus, ethnography can be seen not just a set of interviews, survey, etc. but a rigorous methodological approach, where observation is critical and the experiences unfolding in the field, constantly guide the researcher (Boellstroff, Nardi, Pearce, & Taylor, 2012).

Moreover, Malinowski's focus was on the 'emic' perspective, which can be seen as a perspective from within, in which utmost focus was given to the perspectives of those people under the study. This was also a method used by American anthropologists in 1950's, and was a clear contrast to the 'etic' perspective, where the focus was on creating categories that would be helpful for the analyst or the researcher, and the primary focus was not on the participants. This is not to say that ethnographers are fully dismissive of the etic analyses, as these kind of outsider analyses can be quite informative. But it is the insider (emic) analysis which is the most important. Collecting data is important, but the focus is not on generating as much data as possible from the participants/ informants, but to ensure that one gets to know their pragmatic insights. A good ethnographic practice is to thus carefully draw on both forms of analyses, i.e., emic and etic. One of the challenges naturally for the ethnographic study is to rise above the confusion between the researcher's own etic conclusions and the participants' emic understanding. The two do overlap at times though and that also needs to be identified and acknowledged by the researcher.

Another important term for the ethnographers is 'thick description', which was introduced by Geertz, which he derived from philosopher Gilbert Ryle's works. The focus here is on 'contextual embedding', wherein it emphasises on building up a rich context, to enable meaningful interpretation of the observations made. A 'thick description' would thus enable and account for the different meanings. According to Geertz, ‘the object of ethnography’ is thus ‘a stratified hierarchy of meaningful structures that are produced, perceived, and interpreted’ (Geertz, 1973). Ethnographic research can hence be seen as a way to comprehend human actions in their cultural contexts.

In the 1920’s, researchers from the Sociology department of University of Chicago used ethnographic methodology and soon the discipline of sociology from all over the world started using ethnographic method in their research. The ethnographic practices have gone through major transformations since the 1960’s (Bunzl, 2005). For example, the belief that the researcher needs to maintain some distance from the subject to achieve some sort of neutrality, became a problematized idea and a more intimate gaze into the subject to explore their attitudes and belief systems, started to be considered as a viable and even preferred method (Nader, 1972). These shifts also influenced the way ethnographic writing and representation took place from 1970’s till 1990’s (e.g., Geertz, 1973; Clifford & Marcus, 1986; Visweswaran, 1994). The three major contentions of ethnography considered vital are, a) thrust on the participants as meaning-making actors who knowledge is considered valuable, b) giving primacy to even mundane practices, c) seeking to understand the various ways in which forms of social order help shape everyday life. This acknowledgment of and focus on the participants having important knowledge about their social worlds is not a new idea and can be traced to early sociological thought, especially Weber’s *verstehende sociologie*. This kind of orientation is extremely crucial for the researchers in sociology as it provides them with a theoretic grounding for ethnographic work. Herein, we see that those who are in the field site can supply data and core framings for those data, while keeping their own biases in check. Such an approach has resulted in several crucial studies in recent times where, we find a weaving together of grounded stories where everyday life is presented with its broad social and critical analysis (Gobo, 2008).

Subtypes of ethnography with different focus areas have now become a part of ethnography (Atkinson, Coffet, Delamont, Lofland, & Lofland, 2001). According to Howell (2013), positivist, critical and constructivist/ post-modern approaches are the three philosophical approaches that are vital to ethnography.

In Positivist ethnography, the focus is not so much on the researcher's belief systems and values as on the facts because this kind of approach stresses on the researcher remaining detached from the subject, to the extent possible (Payne & Payne, Key Concepts in Social Research., 2004). Herein, the focus naturally is to look for causes and rationales for the way people behave. The researcher here enjoys authority and power over the subject and their community which is under study (Howell 2013). It is not the subjects', but the researcher's views which are considered the most important. A frequent misconception about this kind of research is that positivist research always invariably has to use quantitative or experimental methods (Phillips & Burbules, 2000), which is not true. One can find positivism in early anthropologists, for example, Malinowski, who have used both qualitative and statistical methods, complementing each other. Positivist ethnographic research has played a significant role in furthering human knowledge, for instance the work of Darwin (Atkinson, Coffet, Delamont, Lofland, & Lofland, 2001).

For critical ethnography, the focus is not so much on forming a narrative as the best possible way of representing the participants under study and their community, especially issues faced by them such as inequality, injustice and control (Madison, 2012). This kind of approach takes recourse in the researcher's reflexivity, and tries to move away from the notion of 'authority' of the researcher, unlike the more traditional approaches such as the positivist approach. Howell (2013) points out five predominant features of critical ethnography: a) reflecting the nature of intent, b) identifying the possible fallouts / consequences, c) stressing the need for collaboration between the researcher and the researched, d) outlining the relationship between localism and generality, in the context of human condition, and e) considering the ways in which such research can bring about a sense of equity and justice and liberty. The thrust area here is to bring about a change in the often-repressive power structures by raising awareness and thus, it would not be inappropriate to argue that critical ethnography is political in its purpose (Thomas 1993). It needs to be acknowledged that critical ethnography may have some inconsistencies due to its value-laden assumptions at times, and hence, and this aspect has been pointed out by several prominent theorists. For instance, Howell (2013) underlines the inherent contradiction in this approach in trying to be open-minded while having theoretical preconceptions.

Unlike positivist approach to ethnography, Post-modern/constructivist ethnography focuses much more on the immersive experience of the researcher in the community he/she is studying, because the focus here is not to come up with one objective conclusion or reality, but the acknowledgment that multiple realities are possible which are constructed through the people's perceptions and experiences of the social world, and these realities can constantly change. The early constructivist ethnographers hence relied heavily on analysing the participants' perspectives and their views of the world around them (Schutz, 1970). And this can be done only through immersing oneself fully in the community / society of the participants (Denzin & Lincoln, 2005). For constructivist ethnographers, positivist approach is a problematic one as it does not acknowledge social complexity and fully invests itself in finding 'generalisable' laws (Crang & Cook, 2007). Instead of seeking 'generalisability', constructivist ethnography seeks to add knowledge about a culture by its use of 'thick description'. According to Geertz (1973), "What we call our data are really our own constructions of what they and their compatriots are up to." This clearly brings into focus the interpretive and subjective nature of post-modern ethnography. For nursing research, Post-modern/ constructivist ethnography is a useful approach. Because, herein, the patients' perceptions and experiences are considered crucial and through using an immersive approach such as postmodernist ethnography, one can unearth their world views and belief systems, which go well with the empathic nursing practices which can make use of such understanding to deliver care in a more effective manner (Robinson, 2013). constructivist ethnography can thus be seen a useful tool to study the experiences of individual patients or groups of patients. Coughlin's is an important study in this area where made an attempt at understanding the nurses' and patients' perceptions during the hospitalisation process (Coughlin, 2013). Through interviews and observations, the interactions and experiences of those under study – nurses, patients and families – the researcher could manage to arrive at themes and topics which positivist approach to ethnography or quantitative approaches would not have been able to achieve. The findings of such a study helped inform the way one could improve care during hospital admission.

Methodologically, qualitative research has been the favoured approach to understand the experiences of cancer patients and their family caregivers. The focus of this work is on developing an understanding and description of the experience of cancer patients and their family caregivers using constructivist ethnography through thematic analysis[8]. In the next segment of this chapter, I would be discussing the research setting, participants and methods utilised while conducting the study.

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[8] Thematic approaches are based on texts in terms of words, sentences, and topical cohesiveness with emphasis on 'what' is 'told,' rather than 'how' the 'telling' takes place. Consisting of minimally two narrative (event) clauses - even not only temporally following each other, but also as causally contingent - this approach assumes that continuously flowing events and time need to be stopped and analysed into confined units of events and event sequences in order to theorise across a number of cases. For example, Cain (1991) recognises a general cultural story of events and experiences in the lives of members of an Alcoholics Anonymous (AA) group to analyse how the common thematic elements shape the 'personal' stories of group members that new members attain as they take part in the organisation and learn to place into a patterned life story that is familiar to AA community.

II. Research method

In this study, I have used ethnography. Ethnographic research depends profoundly on fieldwork and observation. “Ethnography contributes directly to both description and explanation of regularities and variations in human social behaviour” (Spradley, 1980). Ethnography emerged within the fields of anthropology, originating from early work focused on second-hand description of foreign cultures. Later, ethnography developed to include fieldwork involving prolonged periods of fieldwork in unknown cultures (Prus, 1996). In field research, the ‘collection’ of data in situ, even of past (e.g., archaeological, historical, etc.), would allow the researcher to engage in detailed observation and/ or conversations to make information contextual to the purpose/ question/ hypothesis/ objective of the research to culminate in the (sometimes differentiated into ‘primary’ and ‘secondary’ following the logos of ‘presence’ over ‘absence’ of the sources of data) data. For people like us, the ethnographers, the term ‘field research’ is less used than ‘fieldwork’. The term fieldwork has been a continuously modifiable practice of a (reflexive) embodiment of being there with the people the way (why and how)—that the ethnographer analyses—they are, could be and actively change to be, eventual to or irrespective of the interactions with the field researcher. The practice, process and representation of fieldwork are rationalised as systematic and methodical in order to enhance the quality and accountability of research. Thus, commonly ethnography as field research is a study involving the researcher(s) ‘being there in the ‘natural’ setting of certain people or persons is contrasted to experimental research in laboratories or solely theoretical research or research relying solely on already existing / ‘secondary’ data.

A. Research Setting and Participants

The participants for this study were recruited using purposive sampling. Sampling is a vital aspect of research design. It indicates the process of identifying and choosing a set of items from a specific population for inclusion in a study. The degree of generalizability (or not) of findings is based on the researcher's sampling strategy (Payne & Payne, 2004). Based on the research objectives, I identified the study population and determined the primary inclusion criteria. The logic and strength of purposive sampling lie in selecting information-rich cases for an in-depth study. Information-rich cases are those from which one can acquire knowledge about the issues of primary importance to the purpose of the research, and thus purposeful sampling (Patton, 1990). Cancer patients and their family caregivers were the participants of this study. A family caregiver referred to the family member who is considered by the patient as most involved with her/his care The participants were selected based on their willingness to participate and their ability to communicate through insights through series of interviews. A vital inclusion criterion was that each of the patients (18 years or older) was diagnosed with cancer and were undergoing treatment and their ability to interact in Bangla, Hindi or English. The participants were Bengali, yet culturally diverse, geographically scattered from urban settings in Kolkata, West Bengal with varying socio-economic status.

Moreover, based on the research's scope and with the intention to obtain multiple perspectives on the research objectives, experiences of living with cancer were taken from both men and women, irrespective of their socio-economic status. Another influential factor was access to the locale and available time and budget as the study is based on fieldwork. Apart from these, having a prior permission to carry out fieldwork, and the network and connections due to my personal association with cancer provided the impetus to conduct this study. Care was given by a multidisciplinary team of doctors, nurses, nurses' assistants, and a social worker at the hospital setting, while at home, a family member or a close relative was responsible for the care of the patient, sometimes assisted by neighbours and friends. The research proposal was introduced to the patient and their family members. I introducing myself, then I described my purpose of being there. I had a few expressions of interest immediately and slowly, there were more offers of willingness to participation than I could accept.

The next concern is determining a sample size. Unlike probabilistic sampling, where the sample size is based on preselected parameters and objectives, non-probability samples are different in the context of determining sample size. For instance, Morse (1994) recommends at least six participants for phenomenological studies and approximately 30 to 50 participants for grounded theory studies. Creswell (2006) recommends a different range. He suggests a range between five and twenty-five interviews for a phenomenological study and 20 to 30 for a grounded theory study. On the other hand, based on sample heterogeneity, Kuzel (1992) suggests that, for a homogenous sample, a researcher can use six to eight interviews and 12 to 20 data sources 'when looking for disconfirming evidence or trying to achieve maximum variation'.

On the other hand, Guest, Bunce and Johnson (2006) suggest that sampling should continue until theoretical saturation[9] is reached. Often, theoretical saturation is considered the main criterion to justify sample size in a qualitative inquiry, especially in the context of health sciences (Guest, Namey and Mitchell, 2013). An empirical study conducted by Guest, Bunce and Johnson (2006), using in-depth interviews, documented the degree of thematic saturation and variability in the data during data analysis. They found that, after 12 interviews, the data was relatively 'thematically saturated', and sixty per cent of all codes were identified within the first six interviews, and 100 of 114 total codes (88 per cent) applied to the entire data set were already identified and developed. In a related area, Connell (2003) conducted her doctoral research among five mother-daughter dyads to understand daughters' experiences of caring for their elderly mothers. For this research, I intend to have a smaller sample size- eight patient-

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[9] the point at which little or no new information is being extracted from the data

caregiver dyads to obtain more intense and deep data.Moreover, the data is collected from those who had the desired experience to provide maximal accounts of the experience, enhancing the understanding of the research topic.

B. Ethical Considerations

A qualitative researcher has a moral responsibility to acknowledge and respect the rights, autonomy, and dignity of the participants of the study. The researcher should be straightforward while discussing the aims of the study. Furthermore, this research was complicated by the volatile nature of the study that involved cancer patients. Raudonis (1992) identifies this set of people “as unique in its vulnerability related to the ongoing deterioration of the patient’s condition”.

An account of the study, its objectives and its risks was given to the patients and their family caregivers. The right to withdraw at any time was discussed. Patients and family caregivers consented for their participation, indicating their willingness to participate. Initially, I briefed the participants with the details of the research, then described the voluntary nature of participation. They were assured that data would be kept confidential. The researcher had access to the raw data. Though, identifiying traits such as names, were substituted with a pseudonym to ensure anonymity.

C. Data Collection

Data were acquired through observation, open-ended interviews. Observation was conducted, where I tried to observe as many activities as possible, including patient care, patient-patient interaction, patient- family interaction. ln this ethnography, familiarity with the research setting helped in data collection in a typically shorter time frame (Cook, 2005). Observation of fieldwork and interviews were conducted over a two-year period. Observations were conducted on the field visits. Limiting the fieldwork to three to four visits per week agave me time to reflect, transcribe and expand field notes, and ongoing data analysis. Extensive field notes containing the details of the setting and interactions were kept. Open-ended interviews with patients and families happened as talks. I learnt the thoughts and experiences of the patients and their families regarding cancer and its care and the stories of their life experiences. My field notes became detailed and rich, containing stories of hope and sorrows, optimism and health, suffering and pain.

Semi-structured interviews were conducted with eight cancer patients and eight family caregivers. There were six male and ten female participants, varying in age from late ’20s to late ’50s. Each participant was interviewed four times. A few participants reached out to me after the interview to share thoughts or a memory that occurred to them later. Interviews were undertaken in a place of convenience for the patient and the family caregiver, often in participants’ homes, and, on several occasions, in the waiting hall, a tea shop or the park nearby. The interviews ranged in time from forty-five to ninety-five minutes. Each interview was transcribed verbatim to include detailed perspectives.

D. Data Analysis

While doing ethnography, both the data collection and data analysis are done simultaneously. As the observation period grew, I started to see patterns. I wrote memos in my fieldnotes filled with my intuitions, questions, and prompts to investigate specific ideas. Observations gave way for cautious attention at the emphasised domains in order to progress upon or negate inferences about what was emerging from the data. I frequently re-read fieldnotes from earlier observations to assess and follow up on intuitions. I began interviews with the patients first, then the family caregiver. I utilised a semi-structured guide, but saw that I am drifting from the format to follow the prompts in the conversation. I asked the participants about conversations where they participated and learnt their views regarding the same. As the interviews advanced, I asked further questions, searching for validation or refutation of some of my intuitions. While commuting back to my residence, I would be reflecting on what had been told. It was indeed an exciting period. I could sense that things were taking a shape in recognisable patterns. The final interviews presented more instances of ideas I had learnt earlier. After this occurred at least thrice, I started to consider the probability that the subject was close to saturation. During the end of the last interview, I was pleased that although there were a few more narratives to be heard, there did not seem to be fresh themes emerging. Following conclusion of the interviews, I reached out to the participants on several instances who supported me during the entire process of data collection. As with the last interviews, I gathered more narratives that reinforced what I had seen before. I was more confident in the validity of the themes that were emerging. After obtaining 78 similar themes, I believed that it was appropriate to conclude data collection. The data set consisted of 347 pages of interview transcripts. Following an interpretive approach, analysis was initiated. The interview contents were transcribed verbatim to acquire written information about the life experiences of family caregivers of patients with cancer. The transcripts were then subjected to thematic analysis. I reviewed the transcript line-by-line and recognised codes in the margins. Preliminary analysis of the transcripts produced a huge number of coded themes. At one point of time, I had around 200 codes. With time, I was able to improve these, recognising repetition and reconsidering my preliminary impressions. Finally, the data was condensed to 27 code categories. As the collection-analysis process progressed, clarity improved. I made summaries of the categories. Reading them over, I recognised relations between and among categories, and further clubbed them into broader overarching themes. Unnecessary data were removed, and the third and fourth drafts of the findings evolved.

E. Methodological Rigour

Since the early 1980s, standards for maintaining quality in qualitative research have been under constant examination, discussion, and modification (Emden & Sandelowski, 1998). For this research, I followed the model of validity by Whittemore, Chase, and Mandle (2001). According to the model, validity comprises primary criteria and secondary criteria.

Primary criteria: Credibility refers to the "relativistic nature of truth claims drawn from an interpretive approach. Authenticity refers to the precise representation of meanings and experiences as perceived by the participants and is crucial. In this study, data collection methods such as observation, open-ended interviews with patients and families, prolonged exposure in varied circumstances, clarification of impressions with participants, and recognition of researcher influence helped in acquiring credibility and authenticity of the findings and interpretations.

Observation assured exposure to varied circumstances I observed on the field visits. Fieldwork of a period of two years permitted me to see the effect of the situation and context of care. In the initial days of fieldwork, I concentrated entirely on fieldwork, making an overview of an experience of being a cancer patient and caring for one and identifying subtleties and differences that required further investigation. In the subsequent days, I started conducting interviews with the patients. This gave me the chance to explore in larger detail the experiences and perceptions of cancer and its care.

My status as a researcher provided me with the access to a diverse set of patients and families. I maximised each accessible chance to converse with patients and their families, listening to their narratives, and looking for their opinions on their experiences of cancer. These varied constructions of realities gave depth to the findings that also established the authenticity of the study.

Credibility and authenticity of a study require that the researcher be conscious of her impact on the phenomenon of interest. Initially, I recognised that patients were not discussing their experiences and perceptions in detail, or perhaps deliberately concealing certain aspects. Body language and the message in the eyes did not show genuineness, but with empathic probing and rapport, this issue was largely resolved.

Criticality and integrity refer to the researcher's acknowledgement to varying interpretations, prior conceptions, and its influence on the research. To obtain a critical self-reflection, I observed my influence and effectiveness during each visit of fieldwork. And, attention to conflicting data, repetitive checks of interpretations and familiarity with the data contributed in maintaining integrity of findings. As discussed in the segment on data analysis, I was intricately acquainted with the findings. Interpretations were considered, reviewed, and refined during the analytic process.

Secondary criteria: Explicitness is about the understanding the interpretive efforts of a researcher (Whittemore, Chase, and Mandle 2001). Each round of coding was saved in a separate file that allowed for an easy identification of code families and the codes with these families. Field notes contained detailed accounts of the setting and of the participants. Throughout data analysis and representation of the findings, detailed accounts were grouped with instances of interactions in order to provide a detailed representation of situations that hindered or enabled care. Thoroughness involves linkages between themes and the full development of ideas. This was a continuous process, that included several re-readings of the data as categories emerged and themes merged. Congruence in the findings was evident when the information stated by participants in interviews were related with observations and found to be consistent.

Sensitivity is about acknowledging and respecting the individual, their culture and social contexts, keeping in mind, the ethical considerations and concern for the participants of the study (Whittemore, Chase, and Mandle 2001). I was continually vigilant about ethical sensitivity. I asked for permission before recording observations. I remain cautious about my misgivings and have asked for advice from my peers wherever in doubt.

Personal Reflection and Reflexivity

ln qualitative study, the investigator herself influences the data collection and data analysis process. Reflexivity is about being self-aware and explicit as a researcher during the entire process of the study. (Finlay, 2002). I came to this research with years of experience of being a caregiver for my mother who was diagnosed with cancer. I have cared for my mother and have been privy to the situations that a family goes through in such a situation. Those experiences too have helped me in formulating questions that inspired this study. Knowing my partialities, I recognised the significance of entering the fieldwork with an open attitude. I retold myself repeatedly to search for possibilities in contrast to my own experience. I kept a reflective journal throughout the period of fieldwork. This allowed me to think about situations that had arisen and in self-awareness. The journal was an important means for outlining the source of ideas and the subjectivity of self-awareness. Fieldwork was filled with a feeling of excitement about the scope to learn about my stance in a new role. Despite being a caregiver, I couldn’t anticipate the emotional effect of being in straight contact with the patients nearing death. When the participants opened up about the fears that they have, I could relate to them, and I was affected by it.

> Field diary 15: 106-121 It was emotionally draining, but I am glad I could gain the insights that they offered. Experiences of cancer surely involve suffering and loss, not only for the cancer patient but for the families as well. The narratives

> have impacted my sleep, and they stayed in my mind in the days following. The participant opened up to me and was weeping. I didn’t say anything but listened to her and held her hands. She cried for a few minutes, and then she pulled herself together. Later, when I was about to leave, she said that she felt light by sharing her thoughts and feelings with me. I felt good that she trusted me, but it also made me realise that people like her, like us, go through so much, and people around us don’t even have a clue. Just an empathic ear eases one’s problem; I couldn’t stop thinking about this.

> Field diary 9: 63-68 While conversing with the participants, I felt that they were just responding to the questions and were withholding themselves. I realised that gaining trust and making connections were the most crucial aspects for the initiation of my study. I did learn from my academia that it is important to establish relationships – rapport, in order to further my work without compromising my analytical distance with the work.

1. Observer Effects

It was apparent to me that my presence and observation were having an effect on the patients and staff. On a few instances, I had the understanding that the staff are expressing themselves as too caring for the patients. One of my participants, a patient, told me that-

> It was really odd; today, she is behaving oddly; usually, she isn’t that caring. Perhaps your presence is the reason (Field diary 22: 101-173).

Being observed while doing their work made patients and their family caregivers uncomfortable, at least in the beginning. As a ethnographer this was a concern since a ethnographer always tries for acceptance in the field to that extent where she/he no longer stand out, preferably becoming unseen.

> My field diary saw a red-letter day when I understood that I had become a part of the participants' life. The participant introduced me as her daughter to a friend. When the participant was asked about me, she said- 'She is no less than my daughter' and expressed happiness (Field diary 19: 141-144).

2. Role confusion

Adler and Adler (1994) identified three membership roles for an observer: "peripheral member researcher, active member researcher, and a complete member researcher". My role was to be that of an active member researcher as I decided to bracket out my biases of being a caregiver while conducting my study. This prior decision served me well. It gave me a few parameters and relieved me from the temptations to get deeply invested than was suitable. However, the participants were pleased that I have similar experiences like them and felt more comfortable while expressing themselves.

> SM was very sad today; she was asking me about a way to avert her father's death, how I manage things? How I have made peace with it? I tried to assure her that it is difficult, but eventually, we will find a way to live with it. At that moment, I realised that I was interacting with her from the stance of a caregiver rather than a researcher. (Field diary: 20: 145-150)

With time, I became familiar with the patients and their families, I spent a lot of time with them, and that yielded me some stories of illness and pain, gratifying personal relations, and role confusion. As the participants became familiar with me, they seemed to overlook the purpose of my visit. One instance for role confusion happened when I was asked for information. Despite not having any knowledge about it, I could easily assume the possible response. One such example was with Mr. Mandal (M) and his family.

> I somehow overlooked how Mr. M and his family became close with time, and they started asking me questions and sought my support, both informational and emotional, and opinions related to their decisions about Mr. M's condition, their daughter's education as if I was a member of their family. During those conversations, it was easy to drift away from my role as a researcher and forget the research. After a few questions, I reminded them that I am not supposed to be involved in such discourses. But I felt the obligation to return their trust, and I did that. (Field diary: 18: 132-140)

Studies involving narratives of individuals is a reciprocal process. The participants shared a part of their self and their stories. It felt right to share what I learnt with them and sometimes be an active part of their lives. The issue was not with the sharing of information; it was the confusion I felt. Who am I here? Caregiver? Researcher? Both?

3. Ethical Concerns

People with cancer and their families are often regarded as a vulnerable group. Accordingly, this research was carefully structured to assure that there was informed consent. In addition, I also used process consent, where I periodically checked with participants that it was okay with them to continue with the study. The importance of process consent was visible in the following conversation.

> S looked weak and pale. I went to her and asked her if she was fine. S said she was feeling exhausted but wanted to continue as she liked talking with me. After being assured about her health, I decided to proceed. I began the interview and

> gave her clues about our last conversation. After hearing, she said that she remembers the conversation that now she hears of, but it’s all foggy. She knows that we have interacted earlier, and she wanted to continue but couldn’t as she didn’t remember clearly. (Field Diary 23: 174-187)

This interaction showed the importance of process consent. I had a prolonged interaction with S on the instance she did not remember. She had consented to participate in the study. She shared the story of her illness and her concerns and emotions. For me, this had been a memorable interaction. For S, it had elapsed for a brief moment as nausea, drowsiness, and pain shadowed her memory, but later she remembered it all.

Entering the fieldwork as a caregiver formed both a sense of relief in the situation and some confusion. The emotional effect of exposure to suffering, death and pain was unexpected, as was the uneasiness that observation elicited in a few of the participants. Despite the issues, it was a unique experience that further expanded my curiosity in this domain of study.

Chapter 4: Experiences of cancer patients:

Living with cancer is difficult

I. Introducing the participants: Cancer patients' stories

Barun

Barun was in his early sixties. Barun lived with his wife and two daughters in the city of Kolkata. Barun enjoyed spending time with them and valued his family dearly. He was usually more concerned about his daughters' well-being than himself in a natural and loving manner. Some years earlier, Barun underwent treatment for his tumour, followed by a few years without much medical intervention. A recurrence of symptoms was recognised recently when an acute situation arose. Before I met him, he had had surgeries and radiation and was undergoing chemotherapy. Curative surgery was not possible for him, and Barun was given a poor prognosis. Care was managed mainly by his elder daughter, along with the support of his wife and sometimes his younger daughter.

Kartick

Kartick was in his early sixties. He lived with his son, along with his brother's family. His wife died a few years ago, and his son is grown up. He, with his extended family, lived in his ancestral home outside the city of Kolkata. Kartick faced several adversities in his life, including losing his wife. He was a 'fighter' with many strong views. He often said- 'We will fight despite the hardships because that is the only thing left with us- the spirit to fight'. Kartick had been diagnosed with cancer five years ago. A sharp pain, frequent urination and occasional presence of red blood cells were the only indications of his illness. With due course of time, cancer affected his mobility, and he used a wheel chair to move around when required. After receiving the same diagnosis from several doctors, Kartick and his family finally had to accept the ‘shocking’ diagnosis. Care was undertaken at home by his son, with the close support of his sister-in-law, niece and brother.

Keka

Keka was a woman in her late forties. With her husband and two kids, she lived in a town away from the city of Kolkata. She was an independent woman, who taught children before her diagnosis and was accustomed to caring for her family. By the time Keka’s cancer was diagnosed, it had begun to move throughout her body. In the hope of curative treatment and advanced facilities, Keka and her family sought treatment outside the state as well. The diagnosis and the poor prognosis were a shock for her and her family. Keka’s care was mostly provided by her elder brother, her sister-in-law and her mother, along with her husband. She conveyed that her and her family’s life had changed irrevocably from the time of diagnosis, and things wouldn’t be the same again.

Priya

Priya was in her late forties. She lived with her husband, daughter, son and her father-in-law in Kolkata. She was diagnosed with cancer five years ago and had a few surgeries. Her care is mostly managed by herself or her young daughter. Priya was upset about her and her family’s condition due to her illness. She expressed a deep sense of regret at not being able to spend quality time with her children. The fact that her teenage daughter had to be burdened by the responsibility of caregiving for her was a major cause of her anguish. Also, she did not feel comfortable in her new altered body ravaged by the scars of cancer. However, she expressed a sharp sense of reliance on spirituality that helped her and her family to cope.

Santu

Santu was in his late forties. Santu and his family lived on the outskirts of the city of Kolkata. Most of the care was provided by Santu's son, along with the support from his wife and young daughter. Due to their poor socio-economic conditions, he faced several difficulties while managing his treatment and his care. Disquieting symptoms were present for a while before Santu visited a doctor. At first, he consulted a general physician, who then referred him to a specialist in the city. Treatment of chemotherapy was undertaken with little expectation of success. For Santu and his family, his impaired functionality and poor prognosis was difficult to cope with.

Sarmistha

Sarmistha was a woman in her late forties. She lived with her husband and her daughter in an apartment in the city of Kolkata. She is a homemaker. She is close with her teenage daughter- Alia, who is pursuing her college education. Sarmistha's roles as a wife and mother had been relatively uneventful in the context of health-related events, and she didn't have any close experience of severe illness or death. Sarmistha had been diagnosed with cancer six years ago. Before I met her, she had progressed to a state that required surgery and was undergoing treatment including chemotherapy. Disquieting symptoms were present for a while before Sarmistha visited a doctor. A series of pathological tests led to a reasonably rapid diagnosis of cancer. She received her diagnosis from her husband and it was difficult for her to accept it. She said- 'Actually, for a few days, I didn't accept that I am a cancer patient'. Sarmistha and her family worked together in an attempt to make the best of the situation they were in. Care was provided in the home setting with a few hospital admissions for a short period of time for treatment.

Saroni

Saroni was in her early forties. She and her husband lived in a house near the city of Kolkata. Her husband majorly provided the care. Her husband was a trader, and they had a son together. About four years ago, Saroni was diagnosed with cancer. She consulted the doctor after she felt a sharp pain while performing her day-to-day activities. Care for Saroni was provided by her husband at home, along with short hospital admissions. Due to the stress from the treatment and care work and anticipating its possible effects on her son, she and her husband decided to send their son away to a relative with the hope of attaining formal education without the additional stress due to her diagnosis. Saroni conveyed that the diagnosis had affected her life a lot, and letting go things and accepting the changed self was quite difficult. She said- ‘I was very active, fast and jolly; every one used to say- ‘Saroni, where from do you get your energy, give us some!’; I used to do all the chores, give lessons on music to kids of our locality, take my son to school, to tuition and pick him up, but now I can’t do any of these things.’

Sumana

Sumana was in her early forties. Sumana, with her husband and a son lived in a suburb in a neighbouring district of the city of Kolkata. She came all the way to the city in order to avail affordable and reliable treatment of her cancer. Some years earlier, Sumana had had surgery for cancer. During that time, disquieting symptoms had been there for quite some time, but as she was pregnant with her firstborn, the treatment was delayed. To re-confirm the diagnosis, she sought multiple opinions and at times travelled to different states. Soon after giving birth, she had her treatment, followed by a few years without symptoms. A recurrence of symptoms was recently identified and she was undertaking treatment for the same. She was upset with the recurrence and assumed that negligence from her side in maintaining her treatment regime might have led to the recurrence. Sumana’s home care was provided by her husband along with good support from her brothers’ family. She had a strong relationship with her brothers. Upon hearing Sumana’s diagnosis, one of her brothers, along with his family, shifted to her neighbourhood in order to take care of her and be there for her family. Sumana and her family worked to make the best of the time left to them and the situation they were in. The important issues with Sumana were coping with her illness, impending death and the regret of missing out on her child's childhood and not fulfilling her role as a mother.

These people, then, with their family members, are the *dramatis personae*[10] of this research which investigates the experiences of people living with cancer. They have made sense of their experience as they experienced it and narrated it as individuals. Considering these accounts both separately and together, further understanding is possible, allowing the reader to gain insight into the experiences of people with cancer at various life stages. The following sections provide interpretations of these experiences.

II. Perception of cancer: Equating death with cancer diagnosis

For decades, cancer has been considered as one of the most feared diseases, often equivalent to a death sentence. As mentioned in the review of literature, cancer as a metaphor indicates an insidious process that destroys one from within. This section discusses the perceptions of cancer among the participants. In this study, the participants perceived cancer in varied ways. Understanding the perception of cancer may be helpful in predicting the coping strategies and adjustments among cancer patients.

A. 'Caught off guard'

The perception about cancer developed during the time of diagnosis. For all the participants, the diagnosis came out to them as a 'shock' and 'unreal'. Even after the diagnosis

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[10] The Latin phrase for 'persons of the play', used to refer the characters in a dramatic work or a narrative work (Baldick, 2008).

which proved the existence of the disease in their body, it was difficult for the patient to accept the reality. For instance, Kartick said:

> I was shocked when I heard that I have cancer. I couldn't believe it; even now it is difficult for me to actually believe that I have cancer.

The fact that even after a relatively long time had elapsed, the patient still found it difficult to come to terms with the diagnosis. One of the reasons it was difficult for him to accept the diagnosis was the fact that he believed that the reason for one to develop cancer did not apply to him and his symptoms weren't suggestive of that. The conflict between the pathological aspects and his self-understanding of cancer made him anxious. He said:

> I have asked the doctors, my brother and even my son repeatedly about the diagnosis, but the answer was the same every time. I don't understand how I got cancer. l led a healthy life and I didn't and even now don't have any symptoms like people with cancer have -no tumour nor any abscess. I just had problems with urination and they diagnosed me with cancer.

Here, one can clearly see how some cancer patients have a flawed or limited understanding of the reasons for cancer. Though leading a healthy life certainly lessens the probability of getting cancer, in no way is it a guarantee for not having cancer. Here, one can also see that it is not just the reasons, but also the symptoms about which the cancer patients sometimes have some stereotypical notions. This can also be seen as a way of escaping from the reality. This feeling of cancer diagnosis as unreal is experienced by many cancer patients, because the disruption expected in their life after the diagnosis shocks them into a state where they find the coping to be an extremely difficult task. Like Kartick, for Santu, the diagnosis felt unreal as well. Santu anticipated that he was ill and would have to undergo treatment as the diagnosis process was lengthy and cumbersome, but cancer diagnosis was unexpected. He said:

> I knew it was something bad, because the doctor I was seeing, instructed me for further tests and other treatment. Actually, I was expecting something which would require an operation and I was preparing myself for that, arranging things in case I need to do it urgently. But when the doctors said I have cancer, I was shocked. It felt so unreal. I wasn't at all ready to hear that I have cancer.

Santu's experience underlines how despite the tale-tell signs such as the doctor asking for several tests, etc., a cancer patient is rarely ready for the shock of being diagnosed with cancer.

B. Cancer as 'death sentence'

All the participants associated cancer with death. The diagnosis was perceived as a death sentence and they anticipated death as imminent. The participants perceived death in a temporal context and its anticipated effect. Some talked about it as a certain death but in an uncertain time. The diagnosis of cancer created existential crisis among them. The certainty of death wasn't impersonal and distant; the diagnosis compelled the participants to face the threats of their own mortality in real times.

> Cancer is a death warrant, a painful, certain death now… Death is now imminent, no matter what we do. (Keka)

> For people like us, our lives are over. Cancer is a death sentence without any scope for plea or pardon. (Barun)

In both the above cases, we see how cancer has been perceived as not just a death sentence, but also a painful one that is certain to bring unimaginable suffering to their life till death, disrupting fully their normal life that they had lived thus far. A certain amount of abject helplessness is evident in the manner in which they exhibit a fatalistic attitude towards their life.

C. Cancer as a ‘destroyer’

While discussing the participants’ perception of cancer, a few participants considered cancer as a cause that destroyed the things they valued. In the following quotes, we can clearly discern an underlying belief in the cancer patients that that cancer takes away everything valuable from one’s life and leaves the patient and their near and dear ones with nothing but pain.

> You know cancer is a rot. It not only destroys my body, but it destroys everything in one’s life. It is rotting everything - my life, my husband’s and daughter’s life, our relations with others, or peace, happiness… everything. (Sarmistha)
>
> The sickness we all have here will kill us ultimately and it will destroy everything we value – everything. (Kartick)
>
> The family in which cancer occurs, destroys everything, every single thing, peace, happiness, comfort, etc. (Sumana)

It is amply clear from the above quotes that the cancer patients lament the fact that the disease takes away not only their physical ability, but also irreparably damages their mental state, by snatching away their peace of mind and happiness. What compounds their suffering is the realisation that it is not just them, but their family members too who get adversely affected by it. In other words, the disruption in the normative happens not just for the patients, but also for the patient’s family members, a fact that magnifies the suffering of the patients.

D. Cancer as a curse

A few participants connoted cancer as a curse. Identifying cancer with a curse is something that shows the extent to which the patients feel a sense of absolute surrender to the disease and see it in terms of ill fate and destiny, and not just another unfortunate medical condition. In the cultural milieu in which the patients belong, i.e. a largely orthodox Indian set up, the role of destiny in one's life is a commonly accepted belief. Believing cancer to be a curse falls very much within the normative behavioural framework in such a context.

> this disease, this curse- cancer; it just took everything from me. The person who is suffering from this will lose everything. There is a common saying- cancer is a disease which has no answer, the person and its family will succumb to loss… everything… life, happiness, health, wealth… (Barun)

> a curse that eats you up piece by piece, slowly and painfully. It not only kills you, but also eats up your family, family's happiness, prosperity, peace, certainty. (Kartick)

In the above quotes, we see the reasons as to why cancer is perceived as a curse. The fact that the diagnosis of cancer is accompanied by continued painful suffering on a regular basis, with a gradual loss of everything that one holds dear such as health, wealth and happiness, makes the patients draw parallels with a curse, when it comes to the nature and effects of the disease on them.

E. Cancer – 'a disease of the rich'

Many participants talked about the expenses that they incurred due to cancer treatment and perceived that cancer treatment is very expensive and not affordable by all. Many patients coming from a socio-economically poor background found the treatment too expensive. Not having a health insurance in many cases only acerbated their economic condition where they found their limited financial resources exhausted by the treatment expenses that they had to incur. It is natural then for them to perceive this as a disease of the rich, as it is only the financially well off who could afford a proper treatment of cancer. The following quotes attest to the same.

> It’s the disease of the royals; Treatment of this disease is difficult for people like us. (Sumana)

> Everything is gone, unless you are wealthy. (Kartick)

III. Living with cancer is difficult.

This section discusses what it is like to be a cancer patient living with the symptoms of cancer and side-effects from the treatment regime. All the participants described the experience as difficult. The following themes would describe how the participants experienced their illness subjectively.

A. Somatic experiences

Participants discussed a variety of physical complaints. They mostly talked about nausea, pain, fatigue, constipation and other side-effects from chemotherapy and radiation therapy. Majorly, the participants considered these conditions as a result of their treatment regime. Sarmistha described the symptoms she experienced thus:

> As soon the as the chemo started, I felt nauseous. Within a few hours, I could feel its strength. My head was dizzy. I could not move. I slept through out. For the next few days, I was very weak. I felt fatigued. I was barely walking. And later, I felt the long-term side effects. I still feel fatigued.

With time, participants became familiar with the symptoms and side-effects and they prepared themselves for that. As they got accustomed with the changes in their physical self and dietary needs, capabilities and limitations, they slowly accepted the new dietary regime. Coping with these adverse physical changes became an important aspect of their now disrupted lives. Kartick said:

> Side-effects were very harsh. I had difficulty with eating earlier. Whatever I used to eat, I would vomit it out and that had a toll on me. Now, I know what will stay within me. I just drink some milk and a biscuit, for a few days after the chemo. And then I slowly start with simple solid food.

All the participants talked about the way symptoms and the side-effects of the treatment regime affected their ability to perform day-to-day activities. There were times when they needed physical assistance for performing menial tasks such as walking to the toilet or dressing up. Women participants described how the treatment has affected their ability to perform regular household chores. Especially distressing for some of them was their inability to spend quality time with their children.

> After the medications, I started feeling weak and nauseated; carrying out my day-to-day activities was very difficult. I didn’t have the strength to cook; Many times, I went to the kitchen to cook lunch, but was feeling so nauseated that I had to return to my bed and when I woke up, it was already dinner time. (Sarmistha)

> Look at me; I can’t do anything - can’t play with my child, can’t carry him in my lap, even not able to cook delicious food for him, just because of this disease! (Sumana)

B. Living with an altered body

Cancer and associated treatment often affect the patient's physical appearance and self-perception. Patients with cancer have to face various side effects resulting from their treatments, such as loss of their breast or other body part, hair loss, loss of skin elasticity, weight gain and loss of fertility. Changes in body appearance were found to have affected the female participants more than the male counterparts. Disruption in appearance due to cancer and its treatment among the participants led to a negative body image and produced various psychosocial issues.

1. The changed body

The participants talked about their perception and experience towards their body since the diagnosis. Almost all the participants explicitly referred to the changes in their physical appearance and the loss of functional capabilities that they faced due to their illness trajectory.

a) Changed physical appearance.

The participants discussed their perception of their body after the cancer treatment. Most of the participants had a negative outlook about their appearance and talked about the visible physical changes. They often recognised their thoughts about feeling completely changed from within. The participants considered factors, such as hair loss, having no or asymmetrical breast, having a scar and changes in body weight, as major attributes that modified the way they perceived their body.

> Body-wise, I have changed drastically. I got all these [gesturing towards her scars]; earlier I wasn't able to touch these scars and would refrain myself from looking at them. Soon after the operation, when they removed the bandages, and I saw these and I was like 'what is this'!? I felt like someone had played wild with a knife over my body. At times I have to gather all my strength to look at these scars. I couldn't recognize my body. It feels like somebody has exchanged my flawless body with the one that is so ugly, devastating and monstrous. (Priya)

> My cancer has brought me to this condition. You can clearly see that I have lost my health, beauty and everything else. (Keka)

The adverse changes in their body, an effect of the disease and the treatment, made the cancer patients feel at a loss in terms of accepting this changed body. They lamented the loss of their body and physical appearance before the onset of the disease. This lamentation contributed to further suffering and pain, and called attention to their disrupted life.

All the participants considered hair loss as a traumatic experience. It was difficult for them to accept their hair loss as it evoked a feeling of loss of normalcy. Loss of hair was an especially distressing factor for women.

> I didn’t have any hair neither on my scalp nor in the other parts of the body; even the eyebrows shed off. I couldn’t recognize my body. I don’t feel normal anymore. (Priya)

Some patients considered their new physical self, after the onset of cancer as ‘ugly’, ‘horrible’, ‘disgusting’, ‘ghastly’ – words that reflected their deep dissatisfaction, almost veering towards loathing, towards their own altered bodies. Santu, diagnosed with oral cancer described his tumour and physical appearance thus:

> Because of this [pointing at his tumour near his mouth], see how disgusting it is and this horrible stink! It is difficult for me to bear this; how can I expect others to bear this ghastly thing! Even now, I am unable to look at my reflection in the mirror; it’s so dreadful. I can’t believe that I have turned this ugly. It isn’t that I was very handsome or something but at least not this ugly that people have to shift their gaze from me if they catch a glimpse of me. Look how I have turned out now…and that too just because of a disease- cancer!

A few participants mentioned about their experiences with changes that were often unseen by others, such as cessation of menstruation, numbness in limbs, difficulty in sleeping and fatigue. These changes in their body created more difficulties and contributed towards their perception of their own body image. The loss of menstrual cycle as a side effect of cancer treatment made the women feel ‘damaged from within’, akin to a sense of losing their womanhood.

> My menstruation has gone too. Soon after the beginning of my treatment, I had problems with my menstrual cycle; I was bleeding heavily, then it stopped. Earlier, when things were normal, I used to think menstruation is such an ache for us women, but now I don't like it this way. I feel damaged from within. (Sarmistha)

b) Loss of functional abilities

Apart from talking about the physical changes, most of the participants discussed their losing functional abilities, which was the consequence of the cancer treatment regime. Participants mentioned about their inability to perform day-to-day activities and their increasing sense of dependency on others.

> Since this [cancer diagnosis] I am too weak to do anything. Most of the time I am in bed. Earlier, I used to take care of household. I did everything, but now my body has betrayed me. There are days where I can't even manage to go to the bathroom on my own. My family was dependent on me, but now I am the one who is completely dependent on them. (Keka)

The loss of functional abilities leading to subsequent dependency on others, especially family members, was a cause of distress and pain for many. It was especially so for those patients who used to be independent before the onset of cancer, and were in fact the ones on whom others depended earlier. This sudden role reversal for the patients made them acutely aware of their disrupted lives.

IV. Personal suffering

This section describes the suffering of the family caregivers after receiving the cancer diagnosis of their family member. Suffering is a frequent response to the losses that occur during an illness trajectory, affecting both the patients and their caregivers (Northhouse, Laten, & Reddy, 1995). Suffering manifests on various dimensions. It occurs on a physical, emotional, psychological, spiritual and/or existential plane (Jones, 2004; Chapman & Gavrin, 1993; Northhouse, Laten, & Reddy, 1995). It alters one's life and relationship, by inflicting pain, conflict, anguish and exclusion from everyday life (Wright, 2005).

A. Suffering due to diagnosis

The experience of suffering is associated with the information about the cancer diagnosis. Diagnosis related response includes a sense of shock, disbelief, fear, disappointment and devastation.

> I was shocked. In the initial days, I was so broken and devastated that I wanted to give up; I wanted to die. (Sumana)

> When they told me about that, I felt cheated. My entire world was shattered into pieces. I didn't know anything then nor I know anything now, but I am scared… I am going to be dead in a few months, just a diagnosis turned my world upside down. I never thought that my life and my end will be this haphazard; this is disappointing. (Keka)

The shock of being diagnosed with a life-threatening and life-altering disease such as cancer had psychologically devastating impact on some patients, to the extent that it made them consider death as preferable to living with cancer. Diagnosis is the starting point for many patients, for what is considered by many of them, of endless suffering till their agonising death.

The feeling of fear, not just of death, but also of their whole world crumbling down, accentuates the feeling of hopelessness and adds to their suffering.

B. Suffering due to altered body

This theme discusses the participants' experiences with their changed bodies and the accompanying emotional reactions and thoughts.

1. Feelings and emotions:

Most of them shared intense feelings of dissatisfaction and displeasure towards their changed bodies. Often, this experience of body dissatisfaction was associated to their perception that their present body was a deviation from their past or ideal body. The altered body was perceived by them as one that could not possibly be considered as normative, and hence they had a crisis of identity and self. It was difficult for them to relate themselves to the new altered body, specifically when juxtaposed with their earlier photos which now seemed perfect to them, in retrospect.

> I don’t know this [gesturing towards her body] whatever that defined me isn’t there anymore. My body has changed, my agility, my strength, my beauty, everything is lost. (Keka)

> I don't know this body. If I show you my old pictures, then it would be easier for you to understand what I mean, how drastically I have changed! Seeing them [pictures], it would be difficult for anyone to relate this [body] with me then. (Sarmistha)

A few of the participants expressed a sense of dissatisfaction towards a specific body part which was perceived imperfect. This was associated with their missing or asymmetrical breast, surgery scars, weight loss and hair loss.

> I don’t wear saree anymore, if you wear a saree, there is a chance that it [scars] might be visible, anyways can’t wrap a saree around my waist anymore, as it hurts. Also, why I would need those beautiful dresses? I am no longer beautiful! (Priya)

> look at me, I am losing my strength, health, beauty and everything else. I am so thin, my bones are visible, I used to have long, thick and black hair but now see what’s left… I used to wear 36 inches blouse, and now I use 26-inch blouse. I don’t know this body. It seems it’s someone else. I can’t buy readymade blouses anymore; I have to tailor it… this changes you in every form. (Saroni)

> I had gone through other bodily changes, but I couldn’t cope with my bald head. (Sumana)

As can be seen from the above quotes, the loss of body parts equated to a sense of loss of identity and beauty, for the patients, especially for women. For some, more than any other body part, it was the loss of hair that was the most difficult to cope with. Losing a breast or losing too much weight led to an extremely negative perception of their body image. The inability to wear readymade dresses that some of them could do earlier but not anymore due to extreme body size (thinness) made them acutely aware of the changes that their body had gone through.

The participants also talked about an array of negative feelings that they felt while going through their treatment regime and often these lingered well beyond the treatment phase. All the participants experienced a sense of dissatisfaction towards their body after their surgery and treatment which led to negative thoughts and emotions. They mentioned about 'not feeling happy', 'ugly', 'horrible', 'damaged', 'sad', 'inadequate', 'estranged', and 'angry'.

> I am no longer beautiful. I was uglier a few months ago, now I am a tolerable sight. Now it is a decaying body with bruises, scars, and bald head! what to else say about it. (Priya)

> I am not happy with this. I can't believe that I have turned this horrendous. At times, I felt very upset… it’s so dreadful. I can’t believe that I have turned this ugly… (Santu)
>
> When I look at myself, I see a damaged body… I can’t see me. My old familiarised self isn’t there anymore (Keka)
>
> Look at me, I cannot move on my own. Only with someone’s help I can turn to the sides. taking care of me isn’t easy… In a hospital I will get someone to care for me… I can’t move on my own, I have catheter inserted in me for urination, I don’t have any control over my bowel movements. (Kartick)

Priya talked explicitly about her body. She mentioned how her body had transformed to a very different one, in the initial days of treatment. She considered her changed body as ‘ugly’, but with time, when the bruises healed a bit and she got the time to accustom herself to the changed reality, she felt a little better about her body though the dissatisfaction with the altered body continued to remain. Other patients such as Santu reciprocated the feeling in terms of their perception of their new body as ‘ugly’. His unhappiness with this new body stemmed from what he considered as a body that is ‘horrendous’ and ‘ugly’. For Keka, it was a ‘damaged’ body which made it difficult for him to reconcile with the fact that it is the same self. This loss of a sense of self because of the altered body was a major cause of suffering for many patients. For some patients like Kartick, it was not the loss of physical beauty, but the loss of functionality due to a weakened body which was the cause of their dissatisfaction with the altered body. For some patients, the altered body was almost like an alien object that did not belong to them. In the initial days, before they could get enough time to get somehow accustomed to these changes, it was difficult for them even to touch the scars and look at their own body, as both were tragic reminders to them of their harsh reality – that of a cancer patient.

> Earlier I wasn’t able to touch these scars and would refrain myself from looking at it. Soon, after the operation, when they removed the bandages, and I saw it, it seemed like… like… what is this! I felt like someone played wild with a knife over my body. There were times when I had to gather all my strength to look at it. I couldn’t recognize my body; it felt like somebody had exchanged my ‘flawless’ body with the one that is so ‘ugly’ and devastating, monstrous! Apart from the surgery, the chemo and medicines have ‘transformed’ me as well. You are seeing hair on my scalp now, but there was a time when I didn’t have any hair, neither on my scalp and nor in the other parts of the body; Even the eyebrows shed off. (Priya)

2. Loss of identity

Body image is an important aspect of self-identity. Changes in the body image due to diagnosis and the treatment regime of cancer, especially of breast, challenged the participants' personal identity and sense of self. All the participants referred to a diminished sense of self in terms of their body image, role and competence. For mothers, this was a concern and it affected them the most. Participants with kids faced a crisis within themselves as their illness challenged their motherhood and the role as their caregiver. Participants mentioned that it was difficult for them to balance the care of their children and family with their own limitations. It often made them rethink about their roles as active members of the family, a competent mother, and they experienced negative emotions such as guilt, helplessness and sadness. This was especially painful for the women with kids, who found themselves incapable of spending quality time with their kids. The sense of regret at not being able to perform the basic duties of a mother such as cooking for the child, and missing out on such precious little things such as playing with the child or carrying him in her lap, acerbated the sense of suffering. The inability to perform the role of a mother made them question their identity as a mother. It seemed to them as if cancer had robbed them of their motherhood. Similarly, for those who were independent and were the ones who used to carry the responsibility of others, it was quite difficult to accept their loss of independence due to their weakened physical self owing to the disease, where they had to depend on others for carrying out even simple menial tasks. Reconciling themselves to their new identity where they were dependent on others and were an object of pity, was a difficult task for them.

> Because of my treatment I can't do anything, can't play with my child, can't carry him in my lap; even I am not able to cook delicious food for him. Because of me, my husband is suffering a lot too; right from the beginning, he has to play both the roles of a father and of a mother to our child...I haven't been a mother to him [son], I haven't been there for him as a mother should have. I can't even take care of him. I am just merely there. I am a mother for namesake [weeping]. I am incapable of taking any responsibilities of a mother. I wish I could be there for him but I am never there- when he first said 'ma', I was lying on the bed; I wanted to pull him close to me, I couldn't. I didn't have the strength. I was not holding his hand when he took his first step, I wasn't there to pick him up when he first fell and injured himself nor was I there at gates of his school when he went there for the first time. Look at my condition; despite being there I am actually not there! I feel so helpless. (Sumana)

> Before this I was the one who looked after everything. People depended on me, but now I am a dependent in every terms. Now I have to ask help for little things also, no matter from whom, but I have to take help. I have lost my independency and when I try to do things on my own, people around me won’t let me do, they will say- leave it I will do it for you, otherwise you may get hurt. People pity me and living like that is very painful- a burden on everyone. (Barun)

Though most of the participants willingly opted for surgery and the subsequent disfigurement for their survival, but that had an effect in their body consciousness as well. Many of them considered the scar as a marker of their difference from those who are normal, and thereby separating them from 'others'. Some of them described that their scars and physical changes in their body constantly reminded them that they are 'sick' and they have cancer.

> Whenever I look at myself, my body reminds me that I am someone who is sick, someone who needs serious medical attention so that he can survive! (Santu)

> It is really difficult. When I think about this, it feels like, I am not me anymore; I am not normal. In whatever way I try to look at myself, I can't see me. My old familiarised self isn't there anymore. I don’t know this [moving her hands, showing her body] whatever that defined me isn’t there anymore. My body has changed… my agility, my strength, my beauty… everything is lost. (Keka)

The subsequent disfigurement due to the surgery and the treatment regime affected the participants' feminine identity and self-confidence of the participants diagnosed with breast cancer. A few participants mentioned that they felt incomplete, 'not a woman', and experienced negative emotions such as sadness and disgust as they considered themselves as not a complete person. Though the physical pain after surgery was excruciatingly painful, it was much more painful for them to lose their womanhood, which for them was synonymous with losing their breasts. For them, cancer robbed them of their identity as a woman forever.

> It is really difficult to accept yourself like this. Every time I cleaned myself, tears would roll down from my eyes. The physical pain after the surgery was excruciating, but the pain of losing womanhood is even more and is unbearable. With time, the wound healed and only a scar is there, but I lost my womanhood forever. I am not a woman anymore. I have learnt to live with this, but it's painful, you know. (Sumana)

A few participants talked about their changes and feelings about their sexuality. Participants mentioned about their emotional stress they felt after their surgery. Married participants were anxious about their husbands' reaction towards their changed body and its effect on their sexual relationships. In general, the participants mentioned about declining sexual intimacy due to deteriorating health, 'unattractiveness', and lack of interest. They considered the ‘disfigurement’ of their body after breast surgery as a humiliating and painful experience. This feeling of loss of womanhood was heightened by the anticipated reactions of their husbands as they did not think their husbands would be able to appreciate this new ‘disfigured’ body of theirs. So, they considered their identities as both a woman and a wife at threat, after their breast surgery. In other words, they were fearful of the loss of their two feminine identities, i.e. those of a woman and a wife.

> I won’t be a woman if I underwent that [breast surgery / removal]… and how will my husband feel? But then I had to go through it, because my life was at stake. After my surgery, when I realised what had happened to me, my first thought was about my husband. How will my husband feel about my disfigurement? I couldn't go in front of him like that. It is so humiliating and painful. It's not because I don't trust him or he is a man - not sure how I will explain this to you! After they operated on me, I was not the woman he knew. I am not his woman anymore and I couldn’t talk about this… will he accept this deformed me or not! (Sumana)

> It's uncomfortable now, I think, for both of us. I have neither the desire nor the strength, and my husband understands that. It's been a few years now like this; we are no longer interested in those activities. Moreover, we have so many other troubles to worry about; it's the least of our concerns. (Sarmistha)

Furthermore, participants revealed that this sense of loss of feminine identity aggravated because of the gaze of others. All the participants mentioned that the physical changes that occurred made them noticeable by others, making them feel exposed and vulnerable. Unlike earlier times, whenever there was a stare or a gaze at them, they considered those to be mocking of their ugliness. Interestingly, even when someone shifted their eyes from them, that act too was perceived to be because of their 'ugliness', and was hence considered hurtful.

> Now-a-days whenever I step out of my home, people stare at me. Earlier they used to look at my beauty, but now they stare and mock my ugliness. (Saroni)

> I wanted to hide from everyone. Whoever saw me, they either shifted their eyes from me or stared at me. (Priya)

C. Declining social relations

Here I will discuss the experiences of alienation from the relations, whether friendship or kinship ties, that the patients maintained earlier.

All the participants discussed the effect of cancer and the treatment regime on their social relations. In the context of parent-child relations, the participants discussed missing out on the child's growing up and inability to spend quality time with them, resulting in the disruption of the normative parent-child relationship. They expressed sadness, distress and feelings of guilt and helplessness. Sumana expressed that due to the symptoms of her cancer and treatment regime, she was not able to spend quality time with her son. Not being able to carry out the responsibilities expected of a mother made her feel that she failed in her role as a mother in raising her child. This perception of failure as a mother was accompanied by her sense of guilt at how her inability to function well physically led to the suffering of her child.

> In all this, my child is the worst sufferer. He is an innocent being. I wish I could be there for him. I am never there. When he first said 'ma' I was lying on the

> bed. I wanted to pull him close to me, I couldn’t; I didn’t have the strength. I was not holding his hand when he took his first step. I wasn’t there to pick him up when he first fell and injured himself nor was I there at gates of his school when he went there for the first time. He is very good in sports, you know; he always ranks first; Every year he brings trophies home; unfortunately, I have never seen my son running in a race. Look at my misery! Everyone desires a small, happy family with a loving kid and husband. I am lucky that I have one, but look at my condition, despite being there I am actually not there!

Though this study wasn’t designed to understand the effects of a patient’s condition upon their child, but the same can be understood from the point of view of the parent. Sarmistha told me how the diagnosis impacted her daughter immensely. In fact, this perception of suffering of her daughter due to her cancer made her feel responsible for that suffering, which in turn made the patient feel a deep sense of guilt and this too became a cause of her feeling as a failure in the role of a mother. The breakdown in communication between mother and daughter also created a distance between the two. She said:

> In the beginning, things were very volatile at home. Upon hearing about my diagnosis, she didn’t accept it and then she started behaving differently. I could sense from the way she was talking to both of us that she was very angry about this, and wasn’t letting it out, that was affecting her. I knew that she wasn’t sleeping at night, not eating properly, was losing her cool even in trivial things and it was really disturbing. She completely shut us out. All this led to physical changes in her; she lost about 7 kgs in two months. There were dark circles under her eyes, her grades started declining. People from school were complaining about her behaviour and we weren’t able to do anything. We felt helpless; I felt so helpless about all this.

Similar were the experiences of Priya who mentioned how the diagnosis has affected her daughter's life and she shared how her daughter has adapted to the new situation of being a caregiver to her. The burden of taking care of the family and managing the household had fallen on the shoulders of the young daughter, robbing her off her carefree adolescence life, and this too was a distressing factor for Priya who perceived this as her fault and a failure of her being a normal mother. She said:

> My daughter has to go through a lot. She is just fourteen years old and she has to manage the household as I am unable to do so. Because of me, she had to go through this. She understands that we need her to take care of the family.

Sumana, another mother of a young kid, shared about her son's ability to adapt and accept the demands of the situation. Though the fact that her son had matured beyond her age thanks to her sickness, was a matter of pride and satisfaction for her, there was an underlying lamentation of the fact that her disease had taken away the childhood of her son, and unlike other kids of his age who would demand various things from their parents, he 'never asks for anything'. She said:

> He is so mature you know; he never asks for anything. When I am very sick, he won't come to me. When I call him, only then he will come. Once, I asked him- why are you not coming inside my room? He said- 'Ma, I don't want to disturb you, you get well soon, then I will tell you what has happened in my school and you don't worry about me, okay ma!' See this was my kid's answer; I couldn't believe he is this mature, and that too at that tender age.

A few participants described how the anticipated physical help and financial strain due to cancer diagnosis and their treatment affected their relations with others apart from the immediate family members. The caregiving process in cancer treatment is extremely strenuous and requires devoting of a large chunk of time. For some close relatives, giving that much time for a sustained period of time becomes a difficult task. In Sarmistha's case, one finds that though some of her close relatives spent a month or so initially with her during her surgery, it was not possible for them to stay longer as they had to take care of their other responsibilities. Staying longer with the patient would seem like a burden and both the patient and the relatives realise the same. This creates a distance between them, and the normative social relations are disrupted. Instead of the warmth in the relationship, what replaces it is just a distant formality. Sarmistha said:

> … and regarding other relations, initially relatives from my side of the family were there to help us; my niece came to us, to take care of me during my surgery. She stayed for about a month and now they have all side-lined themselves. It's alright. I understand, it is our problem, our situation, and we shouldn't drag them in this, and especially when they don't want it. Things like this are an added burden to them, and they made that clear, though indirectly. We even don't tell them anything; now they call us once in a while, we talk for two- three minutes and that's how relation is surviving.

D. Emotional struggles

With the diagnosis, participants faced several emotional reactions. I have discussed a few in the previous sections. In this section, I will describe how the participants commonly express fear, anger, worry, guilt, loneliness and helplessness in general.

1. Uncertainty and helplessness

The diagnosis of cancer with the recognition that they would die in near future and the uncertainty associated with it is one of the common reasons of fear among the participants.

Uncertainty can sometimes be upsetting and it can have varied effects. Uncertainty often affects a person's day-to-day activities and/or their existence.

a) Uncertainty about future

Uncertainty about things related to their treatment, management of the household and the future is a major reason of worry among the participants. The uncertainty often leads to a sense of hopelessness about the future of the children in the family. Barun expressed his deep anguish regarding how his sickness had adversely impacted his daughters' education. The expensive treatment, especially considering the meagre socio-economic condition of the family, has taken a toll on the family's financial status, bringing in a lot of uncertainty about the future of the family members. The uncertainty of the health deterioration of the patient is intrinsically linked to the uncertainty surrounding the future of the children. The hopelessness seen on the faces of the children constantly reminds the patient of their insecure future and a sense of abject hopelessness about it.

> I am really worried about my daughters' future. The younger one is in class IX, next year she will appear for *Madhyamik* [class x examination], and the eldest isn't able to continue her studies. She has to drop her precious 2 years because of me. Though the principal of her college is considerate and hasn't struck her name out but as long as I live, she will not be able to concentrate on her studies. When I see their faces, I feel hopeless. They are going through this because of me, because of this disease. I am leaving an insecure future for my kids and wife. (Barun)

b) Financial insecurity

All the participants discussed about the importance of money and the financial strain that they incurred due to the cancer treatment and how it has affected them. This was especially true for the patients coming from a socio-economically poor background, for whom the treatment was too expensive, despite them not being able to avail private care. Some patients perceived this growing expenditure in treatment leading to financial duress for the family as a waste of money, and instead expressed the desire to discontinue the treatment as death was certain anyway. They would rather save that money for securing the financial future of their family members, especially their children. This difficult period made them realize the importance of being prudent in spending their hard earned money earlier. Financial worries became the major cause of distress for the patients.

> Money would have secured my family’s future; unfortunately, we don’t have any. (Santu)

> Another major issue is finance. If the drugs and other related things were cheaper, then it would have reduced lots of financial strain from the house. I can clearly understand what would have been the expenditure if I availed private care - there wouldn’t be any penny left for my daughter’s future sustenance! It would have been more difficult; think about life then! (Sarmistha)

> I have told them many times that I won’t survive long., Even the doctors had said so; then why to waste money? If they keep it, then it will help them in the future, when I will not be here. But they don’t listen. They say, ‘money is useful when life is there and moreover, what’s the use of the money if you aren’t there! Your life is more precious than the money’. We could understand the importance of time and money. Earlier I was very careless about time and money. I used to spend money on irrelevant and less important things. Now I think if I had more money, then my family’s future would be more secure and I might have got better treatment. (Barun)

c) Uncertainty about self

The participants expressed a sense of uncertainty about their own self. This uncertainty was in terms of their life as well as their body. They knew of a certain death due to the disease, but were unsure how long they would survive. For some, survival for a long period was not a pleasant proposition as they considered living longer as synonymous with suffering for a longer period. Apart from this uncertainty about mortality, they had a sense of lingering doubt about their own body, almost as if the body ravaged by the disease presented itself as a separate entity from their own self, and they felt like being trapped in it.

> Let’s see how long would I survive this? I hope my time runs out soon. (Kartick)

> I do not know how long this [suffering] will continue. (Sumana)

> This is my body, about which I don’t know, even the doctors don’t know what to do. The body is different from me. It’s like we are two contrasting things, being trapped in a vessel, unknown and incompatible with each other. (Sarmistha)

2. Guilt and regret

A few participants conveyed sadness about the way their situation had turned out. Mostly, participants who were parents expressed immense guilt and helplessness regarding their parenting as they were barely fulfilling their child’s need. The following extracts illustrate the guilt a parent felt when unable to fulfil their role as a parent. Herein we see the patients going through a myriad of emotions, primarily those of guilt and regret at not being able to perform the role of a ‘normal’ parent who would spend quality time with their children. Some worried about not having given a happy image of the parent to the child, while some blamed themselves for the difficult times that their children have had to go through because of their disease. The fact that their children would soon lose their parent was a major concern for many and felt a sense of guilt about it. For the patients who were mothers to young daughters, it was the inability to pass on their household skills such as cooking that filled them with a deep sense of regret about the same.

> What I regret is the image of a mother that I have given to him- that of a sick mother. I have never accompanied him for ‘pandal hopping’ (a tradition of visiting the many deities during Durga Puja festival in West Bengal). He always goes with his uncle, and sometimes his father. He doesn’t have a happy image of me. It’s this sick me and I am in such a state that I won’t even get the chance to change this. I have no say in this, you know; no matter what I do, I won’t be able to change this. (Sumana)

> I don’t understand what is my husband’s and daughter’s fault! My daughter is just 18 years old. Since childhood I have seen her; she has never harmed anyone, you know and now look, how much trouble she is in and soon she will be motherless! As a mother, that is my biggest concern- ‘Who will take care of her? Who will be her support, who will guide her? who will tell her what to do and when I won’t be there?’ Though I am partially here, at least she can call me ‘Ma’, but later I will take that away from her too. Why do things have to turn out like this? Let me tell you this. I always dreamt that she will learn cooking from me, and we, mother- daughter duo, would cook together and give feast to her father, but it won’t happen. Anyways these are unreal things. (Sarmistha)

E. Coping strategies

This sub-section focuses on the ways through which the participants are coping with their suffering; in other words, the focus is on seeing how the participants are maintaining a sense of worth and coherence during a stressful situation such as cancer trajectory. Although they are having a lot of difficulties, but they have managed and are managing their situation. In this regard, changing attitudes, optimistic thinking, spirituality and positive relationships have played an important role in them being resilient with their situation.

1. Acceptance

Narratives from the participants showed a great deal of acceptance with the situation that they were facing. A few of them mentioned that, accepting the reality was difficult initially, but later acceptance of it helped them deal with it a bit easier. Rational thinking about it helped them accept the situation.

> whatever is supposed to happen will happen… and one day we all will die; some will die soon and some later. We have to accept this and think rationally. (Kartick)

2. Fighting spirit

Some participants considered it futile to fight with the situation as they felt that they lacked any sort of control over it. Contrastingly, some of the participants showed courage and were determined to fight against the adversity as long as they could. For those who showed the resilience, the disease was a learning experience where the constant suffering only made them stronger to fight harder. The adversity brought out their resilient self and a philosophical attitude to life, where one saw life as a persistent challenge and one had to fight through tough situations till the end of life, even when presented with a certain defeat, because for these patients, fighting spirit was the only positive thing left in them.

> I am still fighting; I will fight till my last breath. I would fight and won't be scared. It's all about strength. I will fight and I will live until my time ends. That's what life is all about. (Sumana)

> We fight when there is a possibility to win, and in this case there is no chance for winning at all. But still we are fighting and yes, we will fight despite the hardships because that is the only thing left with us - the spirit to fight. (Kartick)

3. Avoidance

A few participants mentioned avoiding social situations in order to protect themselves from awkward and often hurtful questions related to their cancer and their body. The questioning or sympathetic gaze of others or the awkward shifting of their eyes were things that most patients wanted to avoid. This came in the way of their coping process and they wanted to avoid these situations by not attending any social gathering or ceremonies. Some even avoided looking at the mirror to save themselves from being reminded of their current physical condition.

> I did not look at the mirror, avoided attending ceremonies. I didn't like to be seen. At that moment I wanted to hide. Just hide from every one, who ever saw me they either shifted their eyes from me or stared at me. (Priya)

4. Social support

a) Immediate family

Participants regarded family support as important while coping with their situation. The most important aspect through which the immediate family members helped the patient cope was through giving the patient and their spouse and children, quality time. This helped lighten the otherwise sombre mood in the family. For some, the disease brought them closer to their spouses, as they got to spend more of their time together. Because of spending more time together, they could share their emotions with each other, which was not the case earlier. This helped them bond with each other. This was an upside during the adversity wrought on them by the disease. The role of a loving and understanding spouse, and a caring family is thus very important in the coping process for the patients. From a patient's perspective, this is a very crucial factor in their coping process.

> They are helpful and very caring. In this phase, they are there for my wife and daughters from the beginning. They will come by, spend time together, help them in household work and whenever they and their children are over here, the mood of the house lightens. (Barun)

> My relation with my husband has grown even stronger and deeper… we came closer. Unlike earlier times, I didn't open up with my feelings, especially my worries and concerns, but I now in a few instances I did so, and it felt good. Now---days, he spends more time with me, even his free time. I would tell him to please go, and take a nap, or watch football as he likes football very much, but he won't do that; He would sit next to me and he would talk about his office, day-to- day things and all and I like that. It makes me feel as if I am still a part of him… (Sarmistha)

A few mentioned how an understanding relation among the family members had helped in managing their own feeling and motivated them while dealing with their crisis. The bodily changes such as loss of hair was a painful experience for many patients. Certain actions of their close family members done in solidarity with the patient can generate in them a sense of being important and a feeling of being loved by them. This feeling of being loved and cared for is quite important during the process of coping.

> My brothers didn't leave me alone. My brothers would motivate me and cheer me up, but they understood that I was not feeling myself, so you know what they did! One morning, they came in front of me with their shaved heads. Both of my brothers shaved their heads, and said, 'like you sister' and then I started

> crying seeing them. Seeing me, they said- ‘silly sister of ours, it's just hair. Look, you will grow them again just like the doctor said, and we will grow them back as well. Now be fine. We are like you now, so no more being sad. That incidence made me realise that they will do anything for me. (Sumana)

> I am closer to my side of the family rather than the in-laws, and especially my brothers, and in this crisis and in future, they will be there, I know. (Keka)

For patients with young kids, their understanding of the situation and a sense of maturity in them helped in bringing positivity in them. When a mother afflicted with cancer feels that she cannot perform even simple things for their child, and yet the child manages to do those things on their own such as dressing up to go to school, then those acts lessen her sense of guilt at not being able to perform her motherly duties.

> He [son] is so small, but still, he understands the severity of my condition; when I am sick, he doesn't disturb anyone. He will eat on his own, would dress up and will go to school, after coming back he would come and sit near me; he won't even talk and when I insist, he says- ‘Ma, you take rest and get well soon and then we will talk, talk a lot.’ (Priya)

Besides physical and emotional support, immediate family members often helped the participants in making decisions related to their treatment and personal issues. When it comes to immediate family members, their just being there and helping in decision-making become quite helpful in dealing with the stress.

> He [brother] is always there when important decisions are taken. He is very sorted, though he is younger than me, but he thinks about future, consequences of a decision. It’s very helpful when he is around, whatever decision I will take, he will be there. (Barun)

b) Caring Neighbours

Apart from family, participants discussed the support provided by their neighbours during the time of crisis in different ways. In a close-knit community, the role of helpful neighbours cannot be overstated at the time of crisis such as the one that the patient and their family go through. For those patients who had helpful neighbours, they acknowledged their help as a source of strength for them and their family. They get both material help such as help in finances and getting groceries etc, as well as emotional support.

> My neighbours are good; they are very helpful. If I say they are more or less family now, it won't be incorrect. In case of any problem, if we approach them, they are the ones who have always helped us. Meghna, Ratna are always there for us. Arnab [Sarmitha's husband] told me, how they took care of him and Alia [Sarmistha's daughter] when I was in the hospital. They are really concerned about us. Even now, they come over in their free time, and ask about my health. They especially send their kids to our house, so that we feel a bit positive, and because I love them very much. (Sarmistha)

Some participants acknowledged the financial help that they received from their neighbours during financial crisis. The belief that even after the patient's death, their family would get support from the neighbours is a great source of strength and positivity for the patient.

> He used to accompany us when we visited hospital. Many times, during financial crisis, he has loaned us with money. We haven't yet repaid him you know. Whenever I talked about it, saying we will repay you soon, he would say- 'don't worry, it's alright; when you are able, return then. I don't need them now.' He is a nice man. I know he will be there with us; he would be there for my family even after I am gone and then his sons would help my son in various

> ways. They often fetch us groceries and vegetables from the weekly market. A few times they got us medicines as well. His kids are good and helpful, just like him. (Santu)

5. *Spirituality*

Spirituality played a significant role in helping the participants to cope with the suffering they were going through. A few participants relied heavily on destiny and fate in order to get along with their situation. Considering their condition as destiny and God's wish helped some participants reconcile with their present condition. It was a significant part of the coping mechanism for these patients.

A few of the participants showed passive aggression towards the supreme being for putting them in that situation. Them accusing the Supreme being of being unjust to them makes them strangely resilient in such a situation where they consider fighting with Him.

> People often say to me that, God is the ultimate controller, he decides our fate. If I ever meet him, I will surely ask him, why my kid? What is his fault that he has a mother like this, who can't even shower her love to him! If I had done something wrong, then it's okay that he is punishing me for my sins of this or previous life through this disease, but why is he punishing my innocent baby! Whatever he is doing that is wrong. He is being unjust. I will never forgive him. I am enduring everything; I will endure in future as well. (Sumana)

Some participants felt that the disease was a punishment from God for their sins such as pride in their health. Some accepted this punishment from God, but not the slow and painful manner of this punishment.

> I was very proud about my health; that's why God blessed me with this situation. (Kartick)

> If God wants to kill me, then why He isn’t doing it all at once! Why is he making me, making them suffer! Why this slow death! He can just take away my life with a snap of a finger, then why this suffering! (Sarmistha)

Some of the participants considered their suffering as punishment from the supreme being. They considered it as a result of their sins from this or the previous life. This line of thinking helped them reconcile themselves with their current situation. Though some found this punishment from God as unjust as they did not commit any sin in this life, they pondered the possibility of having committed some sins in their previous life, resulting in this harsh punishment from God. Some considered this as God’s way of testing them and their family members. Such line of thinking where God and spirituality become the central point, helped the spiritually inclined people in their coping process.

> If I had done something wrong, then it’s okay that he is punishing me for my sins of this or previous life through this disease. (Sumana)
>
> Fine. I understand. Perhaps I have committed a major sin in my life, whether in this life or in past life, and perhaps I deserve it. (Kartick)
>
> God is testing us and our family members. I don’t remember my previous life, but all I can say is that I haven’t done anything in this life that God should punish me. I don’t know what is in his mind. (Saroni)

A few participants believed in the notion of greater good and complete reliance on God, which helped them to look beyond their present suffering and gave a meaning to their situation. The belief in the notion of ‘karma’ and understanding of this predicament as the doing of God, helped many participants in finding a way of coping with their situation, as can be inferred from the following excerpts.

> I am in this condition because of my deeds- '*Karma*'… I am a sinful person; that is why God has put me here. (Priya)

> I pray to the Almighty that things turn out well, if not for me but for my family. God will remove all their pain from their life after all this is over. This is their penance for the past and the future. This is what God has written for me. This is my destiny. I am meant for suffering, and I will die in pain. (Santu)

> Why God put me in this, I don't know. Everything is his illusion. Something good might be there for us in this. God always showers his mercy on his devotees; by this he is cleaning my and my family's sins of this and previous life. Everything is his game…everything… life, death, happiness, health, wealth… everything. (Barun)

To conclude, one could say that for the cancer patients, their disease equates to a curse and a death sentence – a slow, and painful death at that. Their suffering begins from the time of the diagnosis, and despite having some knowledge about the disease and its symptoms, most of them are caught off guard at the time of diagnosis, which comes to them as a shock. For them, it is a life-altering moment, a moment that is the beginning of their disrupted lives. This disruption in life is in terms of their altered body which many of them consider as not normative. This leads to a sense of alienation of their body from their self, and they start questioning their identity as well. Not just the loss of beauty, but the lack of functionality of the body makes them dependent on others, which leads them to consider themselves as a burden on their family members. Also, apart from the physical distress, they undergo a lot of emotional struggles, such as uncertainty and hopelessness about future, guilt and regret, mostly as they consider themselves responsible for the difficult times that their near and dear ones have had to go through. However, to deal with their suffering they adopt some coping strategies such as a sense of acceptance of the disease, a strong inculcation of fighting spirit, spirituality, etc. Helpful family members and caring neighbours too play a significant role in the coping process of the patients.

Chapter 5: Being a Caregiver

I. Introducing the participants: Caregivers' stories

Abhijit

Abhijit was in his late forties and was managing his wife Saroni's care since the time of her diagnosis. Saroni required the least amount of care among all the participants. However, since Abhijit had to manage everything by himself, the tasks of caring did seem demanding. Often, Saroni would pitch in by doing little things around the house to ease Abhijit's work load. Abhijit was very caring and was particular about Saroni's likes and dislikes. Abhijit monitored his wife's health care, medications and related dietary needs. Abhijit had a son too, who was staying away for attaining higher education. Abhijit was thankful to his neighbours who often supported him while providing care for his wife.

Arnab

Arnab had been caregiving for his wife Sarmistha for six years. Arnab was in his mid-fifties and was the sole earner of the family of three. Along with their daughter, they provided care for Sarmistha at home. He was there for Sarmistha and helped her with the physical tasks that she could no longer do or have some difficulty to do for herself. He was very concerned about her health and was anxious about how to provide nutritive food in order to enhance and maintain her physical health. The initial years were difficult for him to manage, but with time and help from his teenage daughter, he improved. He learnt new skills such as cooking from his wife and neighbours so that he could provide better care to his wife. However, he expressed caring for a cancer patient as exhaustive. He mentioned that physical work does exert lots of pressure on your body. Taking care of cancer patients is really difficult; lots of things go on at the same time. Caregiving was Arnab's first priority. He would acquire detailed information of all kinds such as doctor details, treatment process, places to get medicines and good food from, possible side effects of the treatment regime and its care, etc. to ensure least trouble for his wife. There were times when he had to take leave from work in order to meet his wife's need.

Banty

The caregiving relationship of Banty and his father, Santu, grew out of the sense of responsibility a son has towards his father. Banty was the eldest son of Santu. He was in his mid-twenties and after his father's diagnosis, he was managing the household as well as his father's care. Along with his mother and young sister, Banty managed his father's care; however, he faced several difficulties as his father had increasing care needs, and they were going through a severe financial crisis. Banty had to manage his father's health and care work including bathing, cleaning and dressing his wounds, feeding him and taking him to the doctors, while his mother and sister managed cooking, doing the dishes, laundry, cleaning the house and attended to the minor needs of his father. He said 'As soon as I open my eyes in the morning, I am busy taking care of my father.'

Bikash

The caregiving relationship between Bikash and his wife Priya, grew out of the sense of religious and social obligation that a husband has towards his wife. Bikash was in his early fifties and lived with his wife, a teenage daughter, a little son and his old father. Soon after Priya's diagnosis, her sister visited them for some time to help in caring for his wife and his family. Most of the physical needs of Priya were taken care of, by his daughter while he manages her other needs. Though Bikash perceived his circumstances as difficult, time consuming and stressful, he believed that the rewards out-weighted the difficulties. Bikash was a religious person and had a deep spiritual belief. He believed that the illness trajectory and caregiving afforded a bonding and closeness with God, and a chance of a better afterlife, even though, the nature of caregiving imparted some amount of pain. He said- 'This cancer, no matter how horrible it is, it gave us a way to wash off our sins, and allowed us to gain some good deeds and we are lucky that God bestowed us with this opportunity.'

Chirantan

Chirantan was in his late forties. He was providing care for Sumana, with good support from his brothers-in-law and their family. The diagnosis of his wife's cancer came as a shock and in an inopportune time. He said- 'I was terrified; I couldn't make out what to do next.' Chirantan, in addition to attending his wife's needs and finances, also managed his child's need. The caring process was hectic and difficult. He had to balance his caregiving role with his other roles. He said- 'I have to manage both the household as well as the work.' He expressed his concerns about the financial crisis that he was going through due to his wife's treatment regime and how it was incapacitating him in doing little things for his wife and family. He said- 'As most of my income is spent on my wife's treatment, I can't take care of little requirements of her, like gifting her, taking her out for movies, things like that, things that will make her happy.'

Pinaki

Pinaki was the only son of Kartick. He was in his late twenties and was associated with a private company. He along with his uncle, aunt and cousin sister was engaged in providing care for his father. Kartick's physical needs asked for a great deal of attention, time and energy as he was confined to his bed. The experience of caregiving for Pinaki revolved around doing all he could to keep his father safe and in good mood, on a daily basis He would make sure that he spent some quality time with him apart from the care work. For Pinaki, the care work demanded lots of time from his schedule, which often affected his professional life. He had to change his job frequently in order to accommodate his father's need. It was difficult for Pinaki to observe his father's gradual physical and emotional decline. He believed that his faith, optimistic thinking, supportive family and friends sustained him in the challenging aspects of caregiving.

Sayani

Sayani was in her early twenties and was the eldest daughter of Barun. She had been managing her father's care along with the support of her mother and her younger sister. Sayani had a belief that caring for parents was part of their responsibility as children. She described her role as a caregiver as 'difficult'. Along with the physical challenges of caring, the prospect of losing her father in the near future was daunting for her. She also expressed concerns in maintaining her balance in her roles as a daughter, sister, student, and caregiver. For her, caregiving was about learning new skills and meeting the needs of her father, which, at times, affected her spontaneity and her personal decisions regarding herself. Sayani had uncertainty and worry about the future and her ability to support her mother and sister along with her father's need.

Tariq

Tariq was the elder brother of Keka. He was in his early fifties. He managed his sister's care along with his wife, mother and her sister's husband. Tariq was based in Maharashtra, a south-western state of India. Upon hearing the news of his sister's illness, he returned to West Bengal to do whatever the situation necessitated. Tariq characterised his relation with his sister as 'close'. Although she had multiple health care needs, apart from the physical needs, Tariq managed them all. He looked after her appointments and medication, regulated her diet and managed her finances.

These people are the *dramatis personae* of this research which investigates the experiences of people living with cancer. They have made sense of their experience as they experienced it and narrated it as individuals. Considering these accounts both separately and together, further understanding is possible, allowing the reader to gain insight into the experiences of people caring for family members with cancer. The following sections provide interpretations of these experiences.

II. Perception of Caregiving Experience

Providing care for a family member with cancer is difficult. When I asked the participants to share their story of being a caregiver, they began from the time of diagnosis. The diagnosis was considered as unreal. They often considered the diagnosis as a death sentence which has disrupted their life courses. Tariq said, ‘Cancer is a death sentence, no matter how many years pass.’ Similarly, Banty considered cancer diagnosis as ‘…very bad, terrifying… something that will not only kill my father but will destroy everything’. A few of the participants considered cancer as a disease based on its medical notion that cancer is a terminal illness which is incurable.

For most of the participants, whether spouse, child or sibling, caregiving for a cancer patient was about doing everything possible to prolong the patient’s life and ease their condition. After hearing the diagnosis and the treatment regime from the local doctors, Tariq took his sister to a different state to reconfirm the stage of the cancer and the suggested treatment. He said, ‘We didn’t waste any more time, and took her to Tata [Mumbai, Maharashtra]’. He perceived his role as more or less like a manager where he looked after the medication.

A few participants who were overwhelmed by the tasks of caring considered it as a ‘responsibility’ or a ‘duty’ towards the patient that comes with the relationship that they share. Spouses viewed marriage as encompassing of one’s carer role, an expected part of their relationship, whether a mutual understanding or a religious obligation. Likewise, many children having a parent with cancer considered it as an expected responsibility towards their parent. Banty said,

> I am the only son of my parents… my father's treatment, his care is mine. My father's responsibility is upon me.

Bikash, who has an ailing wife said-

> … as it is our responsibility [providing treatment and care], I will do whatever possible. I am fulfilling my duties as a husband. I have taken an oath while marrying her and I can't do anything otherwise.

Providing care or taking care of their spouse or parents was also seen as a reciprocal relation where the spouse or the parent had taken care of the carer and now the role had reversed.

> She used to take care of us, and now the role has changed. I take care of her, and have to look out for our daughter too. (Arnab)

Sayani, being her father's carer, strongly identified with her role as a caregiver. She told me about how she had managed her father's regime and how anything related to him would be undertaken after her consultation. She said- 'I manage my life, and I take care of his [father's] things. My mother and sister consult me before deciding something for him.'

The role of a caregiver was considered as demanding. Most of the participants described the demanding nature of the tasks performed. For instance, Banty had real difficulty in leaving his father unattended. He said-

> I have to take care of my father… When you have someone like this at home, you have to take care of them round the clock. There isn't any rest. I could hardly manage rest…actually forget about rest, I don't remember the time when I had a proper peaceful sleep

Chirantan also considered his caregiving role as very demanding, as he couldn’t even manage some time for himself and that had affected him personally. He said:

> A break would be good… sometimes I desperately want a break from all this, at least for a few days, where I don’t have to wake up early, do the household chores, won’t have to worry about anything- her [patient’s] health, medication or her food… just a bit of time for myself where I can just sleep and relax or perhaps read a book or watch a football match.

This demanding nature of caring induced a sense of burden among most of the participants. Abhijit said-

> I don’t have time for myself… it’s all about her care, either am taking care of her or managing the work. I do feel burdened with all this, but I can’t do anything.

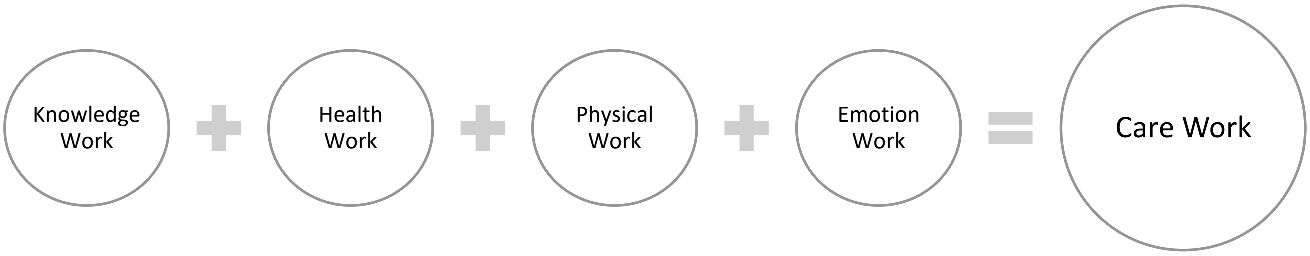
The participants considered the tasks of caring as the most challenging job, involving several tasks but at the same time considered their role as a carer as the most important aspect of their life and the patient’s life.

III. Cancer as work

During the interview process, the caregivers shared their experience of caring for a cancer patient. They mentioned about the tasks that were undertaken by them. Most of them reflected upon how it had affected their lives and shared the difficulties and their needs while caring for the patient. The re-reading of the interview contents provided a sense of what it is like to be a carer for a cancer patient. I did have some prior understanding of it due to my own experience of being a carer for my mother who was a cancer patient, but it was more vivid when the participants discussed their life as being a caregiver. From the transcripts, it was clearly understood that the participants were often struggling with life while performing care work. Care work involved various tasks of caring such as activities of daily life, household chores, symptom management, finances and needs of other members of the family. The participants mentioned that the task of caregiving had impacted multiple aspects of their life. Caring for a cancer patient required a lot of planning and effort. The treatment regime and the management of the symptoms required more efforts than usual. Cancer work influenced other day-to-day activities, asking for more efforts in accomplishment of those works. As mentioned earlier, the task of caregiving was often perceived as demanding. In order to manage with this heighted demand, a few participants even had to leave their formal education to reduce their work load.

Generally, work is understood in reference to sets of action that one undertakes to accomplish or bring about certain things (Oxford English Dictionary 1989). In this study, ‘certain things’ refer to surviving the demands of cancer and its care work. In my analysis, I have segmentized care work into four categories: knowledge work, health work, emotion work and physical work. Knowledge work referred to the work involved in acquiring, assessing and disclosing information related to cancer. Health work involved the works related with body and symptom management, including risk mitigation. Physical work was about the task related to organising treatment schedules, finances and household chore. And lastly, emotion work indicated towards the efforts that were undertaken by the caregiver to address their own and others’ emotions.

Figure 1: Care work of cancer- an overview



A. Knowledge work

Knowledge work referred to the work involved in acquiring, assessing and disclosing information related to cancer. Participants mentioned that they gathered information in order to make sense of what they were going through and what were the things they should expect in the process. During the time of diagnosis, the participants hardly had any idea about cancer. Whatever they had heard about cancer, it was from secondary sources. Initially, they learnt it from their general physician and later from the referred specialist. The participants procured information from various sources such as friends, neighbours, relatives, other cancer patients and their caregivers, health professionals and sometimes through internet. Over time, a few participants acquired information through their own experience. Tariq described how he talked with his maternal uncle seeking information when his sister was diagnosed with cancer as his uncle's spouse was a cancer survivor. He explained that, knowing someone with first-hand experience of cancer helped him in surmising what he was about to encounter next. Arnab explained how he initially went to the internet seeking information when his spouse was diagnosed, but the information and its vastness was frightening and increased his anxiety. He said that his initial searches on the internet listed symptoms and side-effects of cancer, and that through experience, he learned that side-effects and their intensity vary with time and from person to person. He slowly got over the fear of committing mistakes in his efforts to make his spouse comfortable: '… the constant fear of doing something wrong was always there; now it is still there, but it's much less, almost negligible… I have gained that skill with years now, and now-a-days, she is more comfortable with me doing her dressings and other stuff than anyone else, even a professional.'

Participants explained that they acquired the basic diagnostic and prognostic information from their physicians. A few times, participants faced conflict between expert biomedical knowledge and their own experiential knowledge, adding to confusion. Banty described how the information the oncologist gave him at diagnosis- that smoking ‘beedi’- a type of local cigarette, might have caused his father’s cancer- did not fit his own perception about the causes of cancer where he had seen many people around him living and dying normally in spite of being addicted to smoking ‘beedi’. In other words, there was non-concordance between the evidence of his experience and the evidence of the medical knowledge. Banty said:

> Doctors asked me whether he [father] smoked tobacco - ‘bidi’ or cigarettes. I doubt, it is a cause of cancer. Back in our village, everyone smokes bidi, and all of them are perfectly fine. I don't think tobacco has to do anything with it. Even I smoke, but nothing has happened to me. If tobacco were the cause, then I would surely have come across many people with my father's condition. However, I have not.

Sayani explained that initially it was difficult for her to understand the information that was appearing in front of her. But after having an idea about the things going on around her, she was able to contextualise the information about her father’s diagnosis which helped her to make sense of it herself. Eventually, she considered herself as an expert:

> Talking to doctors, nurses and other people in hospital, I think I know more of what this [cancer] is, what to do when and how to do it than a lot of people. Initially I had difficulties in taking care of my father, specifically post-surgery. I asked our clinicians, saw them when they were dressing my father’s stiches. Now I feel that I can do it better than the nurses here.

A few participants mentioned that the timing of disclosing information was important and it needed regulation. During the initial period of diagnosis, a few participants did not know what information they wanted. As they went ahead with the treatment and faced unfamiliar conditions – side effects of chemotherapy- they wanted to know about it and how to address it. Tariq said:

> As the treatment began, I kept track of what to do when and where. I looked into things, gained more information regarding what would help her [patient] and ease her pain, what food would provide her strength, what to do when she is nauseated.

Along with acquiring information, the caregivers have to regulate information disclosure. It involved a conscious decision on the part of the caregiver about what to share with whom. Before disclosure work, the caregiver analysed and then assessed the information thoroughly.

> We decided to tell him, but not in detail. We all agreed that he should know; otherwise it would be hurtful for him if he comes to know about it from others during his treatment. It is better this way that we tell him, rather than others. (Pinaki)

As the participants got familiarised with the situation, they learnt to manage or live with the restrictions imposed by the care work. They assessed the information that they procured from various sources and transformed them into knowledge.

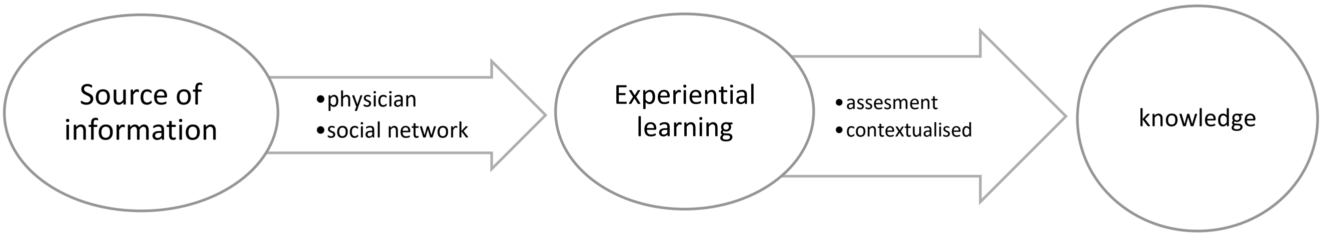


Figure 2: Utilisation of sources of information to acquire knowledge

Experience was an important source of knowledge which helped the participants to negotiate living with cancer as an individual. Information and experiential knowledge were often combined in disclosure work. Disclosure work involved assessment of the information about the experience and health condition of the individual with cancer and being its gatekeeper. Primarily, the carer, and sometimes the patient, assumed this role. Managing disclosure was about deciding who was told what and when. Participants mentioned that initially it was difficult to talk to as they didn’t know what to say and how to say it. Some participants left disclosure to other family members as it was initially too difficult for them to handle. Since disclosure exerted an emotional toll, it required planning. Abhijit told me how difficult it was for him when he had to disclose the diagnosis to his spouse for the first time:

> I learnt about the diagnosis when we were at the hospital. I was in shock. I couldn’t think properly… I asked the doctor again; he told me the same thing. It was very difficult for me. But I couldn’t tell her then, I told her later when she was physically better. I gave her minimal information, and even then, she was crying. For the first few days, she was in shock but then she accepted it and held herself quite well.

Sayani described that she was able to disclose her father’s diagnosis to other members of her extended family, but when it came to inform her younger sister, it was difficult for her and not telling her sister was a source of tension for everyone involved. She left it to her mother to ‘break the bad news’ to her sister.

As mentioned earlier, disclosure exerts an emotional toll, and it was clearly evident from the narratives of Abhijit. Arnab told me about his daughter’s reaction when she heard about her mother’s diagnosis:

> … the overall situation has affected our daughter very badly. In the beginning, she wasn't ready to accept the fact that her mum has cancer and most likely she will die because of it… she used to be very angry with everyone… even at school, she was angry; her class teacher called me once to tell me how her behaviour had changed, how she was shouting, and picking up fights with her friends, and after that she started remaining aloof from others. I could clearly see that my daughter was going through so much pain and I could not do anything. I did not know what to do. Later, I decided to talk to her. I saw a lot of changes in my daughter's behaviour; she was sad, but not angry anymore.

Pinaki mentioned that the disclosure of diagnosis had affected his family members profoundly. They were confused about whether to disclose the diagnosis to the patient as it might impact him severely. He said:

> I remember, after disclosing the diagnosis, they [family] all were silent for days. I saw my uncle weeping, my aunt was absent-minded, nobody was eating properly; we weren't talking with each other, and our biggest worry was whether to talk about this to my father or not. My aunt was saying not to reveal it as it may break his spirits, but then we decided to tell him.

Disclosure was difficult for the participants, and it took an emotional toll on both the discloser and the disclosee, but in most cases, the tension eased over time.

B. Health work

In this study, the participants mentioned about various forms of tasks that they did in order to reduce risk and effects of the cancer treatment regime for the patients. They took decision based on their knowledge and experiences that they had acquired over time. For all the participants, risk management was an important task. They focused on both physical and emotional stress of the patient and often of the other family members too. As the patients were immunosuppressed and a few of them had surgeries and tumours which required regular cleaning and dressing, a constant risk of infection always remained. The participants were vigilant and were aware of this risk. They took extra care and made decisions accordingly. Banty explained me his efforts to reduce the risk for his father:

> I have to clean the overnight-accumulated pus from his mouth. It's so smelly… like something is rotting inside, or perhaps worse than that… and it takes time… lots of time, I do it very slowly. I have to wipe it clean and then clean the feeding tube. Often the pus goes inside the feeding tube, and then there is blood… actually, there is a hole in his mouth, and blood oozes out from there. Taking care of him is very tough; I have to be careful, otherwise it may lead to further complications.

Initially, the participants were struggling in managing and reducing risk. For example, Sayani described the difficulties she initially had, and how she had overcome them through her experiential learning:

> If I am not doing it properly, he [father] may face difficulties later; He is already weak. At home I dress my father's wound, the thing that amazes me now is how I have changed in just a few months. Earlier I couldn't stand blood and other bodily fluids but now I am so used to it… even comfortable with it.

Often, along with the primary carers, other family members also prioritised the patient's wellbeing over their own leisure activities. Arnab explained how his daughter kept his mother's needs much above her own.

> Friends at her age, are enjoying their life. They are going out with friends for eating, watching movies and shopping but she rarely does that. Once in a while she would go out; otherwise, she spends most of her time in studying or with us, either taking care of her mother or helping me out.

While caring for the patients and mitigating risks, the carers consciously evaluated potential risks for the patients. For instance, Tariq described how he managed to keep people at a distance who came to visit his sister: ‘when they [relatives] heard about her cancer, they came to see her from distant places. When they reached our home, we didn’t let them see her. We told them to freshen up; then I briefed them about the cautions that they should keep in mind. I told them not to touch her, or sneeze near her. And those who already had cough and cold, I told them to maintain a two-hand distance from the bed on which she was laying. I couldn’t risk her like that, these might cause potential harm to her.’

From this study, it is observed that the caregivers were concerned about reducing risk for the cancer patient but they perceived that they were in a situation which was uncertain: ‘We don’t know what will happen’ (Sayani).

Tariq explained how his sister was vulnerable and this vulnerability had impacted them. The families felt the need of being protective towards the patient as well as the carer as risk was an issue for carers too, as Banty describes:

> My mother always tells me to be careful and cautious. I know why she is tensed. My father is in this condition and if something happens to me, then their survival will be jeopardized.

Thus, assessment and management of risk is considered as important for the carers of cancer patients and their family. In this respect, the knowledge acquired from experience and other sources were valuable. Previous experiences helped the carers learn what to be cautious about. They had been cautious about everyday activities. Risk was an issue for both the carer and the patient. Caregivers and patients were concerned about injury and managed their day-to-day activities to avoid injury. Abhijit described how pain and weakness had affected his spouse's capacity to do things:

> It's difficult for her now. She is in constant pain and that makes it difficult for her to move around. And moreover, she might hurt herself. But once in a while, I take her out in front of our house, and tell her to carefully water the plants with the pipe. She loved gardening. When she was healthy, she used to take care of her garden with so much care. She would water them in the early morning and in the evening, mend the soil, add manure, remove weed. She spent a lot of time there.

Participants were concerned with reducing the effects of cancer and its treatment. They utilised information from various sources and their experiential knowledge and with time, the participants became more skilled and efficient.

C. Emotion work

Emotion work referred to the efforts that the participants made to deal with what they felt and the feeling of those around them. Managing emotion was considered crucial for the maintenance of each other's well-being, especially soon after the diagnosis. Arnab describes the way he managed his as well as his spouse's emotion and often it required effort. He said:

> There are many nights where she would break down into tears saying- 'why this is happening with us? When will I be normal again? When will it be that, I will not be tired, will not have to think twice before starting a task?' Now she says -

> ‘it’s been so long; it would be good if I die. it is unbearable for me’. These words pierce my heart. I try to give her hope. I try to make her feel positive.

Being a caregiver for a cancer patient is difficult and there have been many incidences where participants had to actively deal with their emotions to avoid additional emotional burden on others. Often, they had to maintain a positive outlook, as Sayani said:

> I can’t express my irritation, my frustration, my pain to anyone. My family, especially my sister is there for me, but she is very young and if she sees me like this she will be devastated.

The participants were also worried about their future and most of these concerns weren’t shared with anyone. In addition to that, a few participants expressed that they had to behave in accordance to the expectation of others, maintain a ‘strong outlook’, ‘be positive’ and thus, deliberately concealed their emotions and feelings. Emotion work was a vital aspect while caring for cancer patients. It involved managing their and others’ feelings. Irrespective of the age, sex or the relation, all caregivers were deeply engaged in emotion work.

D. Physical work

Apart from the above-mentioned forms of work, participants undertook various forms of tasks on a regular basis, often demanding in nature, which required skills and management of time. Physical work was majorly related to the health care demands of cancer. They also discussed activities other than those associated to cancer. For example, physical work included household work and meeting the needs of other family members. As Sayani describes:

> I have to manage everything - my life as well as taking care of everyone, my father, mother and sister… I have to balance both the household and other works.

Often, physical work was assumed strenuous by the participants, specifically in the presence of competing demands. Abhijit mentioned that it was initially harder for him to balance the demanding nature of work, though with time, he had managed it well:

> I manage everything, from cooking, cleaning, shopping and my business as well. Initially it was difficult, but now, over the time, I have learnt how to manage. I can manage now.

Banty found that his work organisation was more difficult and complex when his father was at home:

> The real inconvenience is back at home. When he [father] is at home, it is difficult for me to manage things. There I have to take care of him and the work. I have to manage them anyhow.

Participants discussed their experience while caring for a cancer patient. Care work for a cancer patient is an integral aspect and requires a great deal of work from the family caregiver, irrespective of the nature of relation that the patient and the caregiver share. As it is observed, the work is compartmentalised into various segments such as health work, knowledge work, emotion work and physical work, that the participants undertook according to the demands of the situation.

IV. Perceived needs of the caregivers

All the caregivers participating in this study described how caring for a cancer patient is difficult and tasking. This section would discuss the needs, often unmet, of the caregivers as expressed by them. An unmet need is considered as a need that an individual identifies as important and unfulfilled. From the interview transcripts, I identified three domains related to needs- informational, psychological and social needs.

A. Informational needs

The participants discussed about the unmet informational needs in the context of cancer, its treatment regime, side effects, care options, symptom management, nutrition, and medications. The participant talked about the difficulties they initially encountered while understanding and anticipating the needs of the patients as the needs often shifted with time and situation. Arnab said-

> Caring for a cancer patient is not easy; you need to know a lot of things. Earlier I had no clue about these things. The physical work was difficult, mainly cooking. I didn’t know how to cook and more importantly what to cook. I had to make sure that she gets nutritive and light food. I didn’t know much about how to go about it; Cooking was her forte. Moreover, on the rare occasions when I cooked, it was spicy and rich, not at all suitable for her. But I managed, and it took time for me to understand how to do it efficiently. If I had known cooking earlier, then it would have been better. But still, now I can do it properly, and I prep things quite ahead so that it saves me time.

Tariq mentioned that he was really tensed about side effects from the treatment regime and he would always ask the doctors about it to gain more information and address the symptoms efficiently. He said-

> I have no understanding of the biology, what goes on with the body. It would be helpful if I had a little knowledge about it. So, whenever I get the chance, I ask the doctor about that. I would ask him about the usual side-effect that can occur, even when the doctor changes the doses of the medication by a little bit. I constantly think about what we can do to ease her pain, her nausea.

These needs were commonly associated with dealing with the treatment complications such as nausea, fatigue, insomnia, loss of appetite and pain. Tariq told how troubled he was about the physical pain that her sister was experiencing. He said:

> She was in too much pain. I told the doctor that it was unbearable for her and they gave her pain killers. It wasn't enough though. They told us to admit her so that they can reduce her pain, but that won't be helpful either. She would go through more rounds of injection and would be alone. If I knew what could be done at home to reduce her pain, then that would have been helpful.

For Banty, lack of knowledge about cancer and its cause added to the psychological burden on him and that was clearly evident when he asked me:

> Can you tell me why this happens? And is there any way to cure my father?

Many times, lack of information has aggravated the situation. For instance, Sayani said that due to her unfamiliarity and lack of awareness about the treatment regime of cancer, they took an incorrect decision which had severely affected her father's condition.

> We were under the impression that services of government hospitals were poor, but the treatment and the quality of the doctors were good. We didn't have much idea about the hospital neither about what or when to start a regime. But we decided to go ahead. And that was a huge mistake. It was all contradictory there and we ended up getting wrong treatments from the doctors and because of that my father is in this grave condition.

Difficulties associated with access to healthcare facilities that are vital for addressing their needs was a recurrent notion in the participants' narratives. The participants mentioned that they often had to navigate through various tiers of public health care system. According to the participants, the public health care facility was over-burdened and poorly resourced, that often led the participants to seek for alternatives in different states if they could afford it. Arnab described his difficulties due to lack of awareness about the place while navigating through the public hospital and what measures he took to minimise the effect of those difficulties. He said-

> If you don’t know the place and the process, then your entire day and all your energy will be lost in vain. You would be going around circles in search of the right building. It is unorganised and there are so many people here, so many wings and wards. For a person without any prior information, confusion is eminent… Before her visit, I came here alone, enquired about the process and arranged the tickets and prescriptions. I went to the department, asked the security and people around about the details of the doctors such as on which days the doctor is available for the OPD [Out-patient department], where they will do the check-up and when the OPD would begin. After doing so, I looked around the hospital campus, specifically keeping an eye on what are the other facilities available inside the campus. I located the canteen so that in case we need food, I know exactly where to go without wasting any time and causing unnecessary troubles to her [patient].

Furthermore, the lack of knowledge about symptoms, diagnosis and sometimes negligence had an impact on the treatment regime.

> I was clueless at the time of diagnosis. She was pregnant, and had cancer. I had no knowledge about it - what to do? What not to do? Whether to go on with the pregnancy or with the treatment! Things were all unclear, because of my unclear understanding of the condition. The situation was very risky; I didn’t have any clarity about it. If we proceeded with the pregnancy, then the cancer would go

> worse and if we initiated the treatment, then our first child wouldn’t survive. I was so confused and, in that confusion, we decided to delay the treatment and her condition got worse.

B. Psychological needs

All the participants discussed their psychological difficulties that they faced while caring for the patients. They felt sad, helpless, anxious and uncertain about the entire situation. For a few participants, emotional distress of the patient was a concern for them. Chirantan told that he felt helpless when his wife stopped talking to anyone. During that period, he felt the need of an expert who could quickly ease the situation and relieve him from the stress. He said:

> She wasn’t talking… I could understand that it was becoming harder for her. She wasn’t talking to me. She was bottling everything inside her. I was afraid, worried about her well-being. The way she was responding, it was not good. I could have used some help then, if only I knew some expert who knew clearly what to do.

While interacting with the participants, I realised that most of the participants were reluctant to share their feelings and emotion not only with me but with others as well. But eventually after gaining their trust through rapport, the participants shared their feeling and they felt good while doing so.

> These things that I shared - I could tell them only to you. It feels good, and I needed this. (Sayani)

> The feeling of being understood is important when you are going through a crisis like this. (Arnab)

Like Sayani, the participants felt the need to be heard and at times encouraged. They also mentioned that a good and understanding relationship among family members is crucial for them. Arnab said:

> It feels good to see her [daughter]. It gives me strength…she would spend most of the time either studying or with us, either by taking care of her mother or by helping me out.

In addition to these, the participants felt the need of the recognition of their role as a carer by themselves as well as by others.

C. Social needs

All the participants mentioned the difficulties that they were facing due to the demanding nature of the care work and how it could have been easier if someone was available to help them out. This was in the context of heath work and physical work. They also referred to long waiting hours, complicated health infrastructure and the responsibilities of managing the household. All the participants mentioned about the need of professional assistance while caring for a family member diagnosed with cancer at some point of time. Arnab said:

> I was hoping if someone could show me physically how to do it; then it would have been easier or perhaps someone could do it, any professional, but getting hold of one here is difficult… Once I have hurt her unknowingly while dressing her wound. I have added a bit more pressure or perhaps the distilled water was still warm, when I used it for cleaning; these things and no matter what, a bit of fear is always there!

Similarly, Banty and Sayani expressed the difficulties that they faced on sa regular basis in their roles as caregivers. For Banty, it was difficult to manage caregiving while having to perform his several other duties. He said:

> I have to change his shirts and towels, he is always leaking from his mouth… clean them… dry them properly in sun, give him a bath, clean his discharges. I have to look after so many other things along with his [father] care and there is no one to help me.

Similarly, for Sayani, the inability to get help from a professional carer added to her difficulties in doing her duty as a caregiver as she was not trained for such a job. She said:

> It would have been of great help if instead of me, someone trained did my dad's dressing. Then it would be one less thing to worry about; there are many things where I can use a bit of help, but unfortunately, we don't have any scope of that.

Pinaki talked about how having full time access to quality health services would help in easing their burdens. He said:

> I wish good facilities were available at affordable prices, where we would not have to compromise with hygiene, cleanliness, privacy and where 24X7 professional help in whatever form would be available. We need that and in a situation like this, one never knows when the condition would go from bad to worse!

Some caregivers talked about their need of practical help such as in cooking and cleaning the house. For them, the absence of help in such day-to-day household tasks apart from their caregiving work, left them completely exhausted. For Arnab, finishing the household chores before going to work, and then to come back and attend to the caregiving work was extremely tough on his body and mind. And Banty, exhausted by the additional household tasks apart from caregiving, lamented the fact that he did not even have a brother who could share some of these responsibilities.

> Before going to work, I would broom the house, water the plants, cut the potatoes and other vegetables, cook one curry with rice and we would eat that at both lunch and dinner. Then after returning from work, I would clean the dishes. It is too exhausting; a help would have been nice. (Arnab)

> I wish I had at least a brother, who would have taken care of my father. (Banty)

A few participants discussed how the task of caring had affected their work life. Difficulties in work place included taking days off, switching jobs, requesting colleagues to manage their work on their behalf, working remotely from home and investing less time and energy.

> They [colleagues] extended some support and financial help at the time when we went to Vellore, but I have to constantly work to repay that; I have to manage both the household as well as the work. (Chirantan)

For participants who were pursuing an academic career, they had to take a break from the same so that they could fulfil the demands of caring. Banty said:

> I had to discontinue my studies. I was to appear for High School examination but couldn't. I had so many things to do but now I don’t have enough time.

Almost all the participants described the changes that occurred in their social life since the diagnosis of cancer. They discussed how tasks of caring had left them with no time for them to engage in social activities, thereby diminishing their social interactions. Chirantan said:

> Friends! When you have a situation like this, you have to leave all your friends behind.

Likewise, Banty shared how he was no longer able to hang out with his friends as most of his time was consumed by care-giving:

> Sometimes when I am hanging out with friends, I smoke. And now I don't get the time to be with them, and neither they are close to me anymore.

All the participants described the enormous financial strain that they had to incur due to cancer diagnosis and their treatment. The lack of money sometimes made them regret the fact that they were unable to afford treatment in private hospitals for the family member with cancer, as they perceived private hospitals to be better than government hospitals in treating cancer patients, even though they were too expensive for them.

> I wish if I had more money, then I could have taken him to better hospitals. (Pinaki)

> Whatever I earn it is gone in maintaining the house hold and buying medicine and all. No matter how much I try but, I can't increase my income. I work hard but still I don't have enough money. What else could I do! If I had more money, I would have kept him in a better condition, could have taken care of my sister and my mother. If I had money, many things would have been easier. I need a huge amount of money for the treatment of my father. Now, at this point, in my pockets, there is just a hundred rupee note and a few pennies. (Banty)

> If I had more money, I could have hired a full-time maid or a governess to take care of everything, but I can't because most of my income is spent on my wife's treatment, and it’s expensive. I can't take care of even little requirements of her,

> such as gifting her, taking her out for movies, things like that…things that will make her happy, but what can I do! I am doing my best, but still it's not enough (Chirantan)

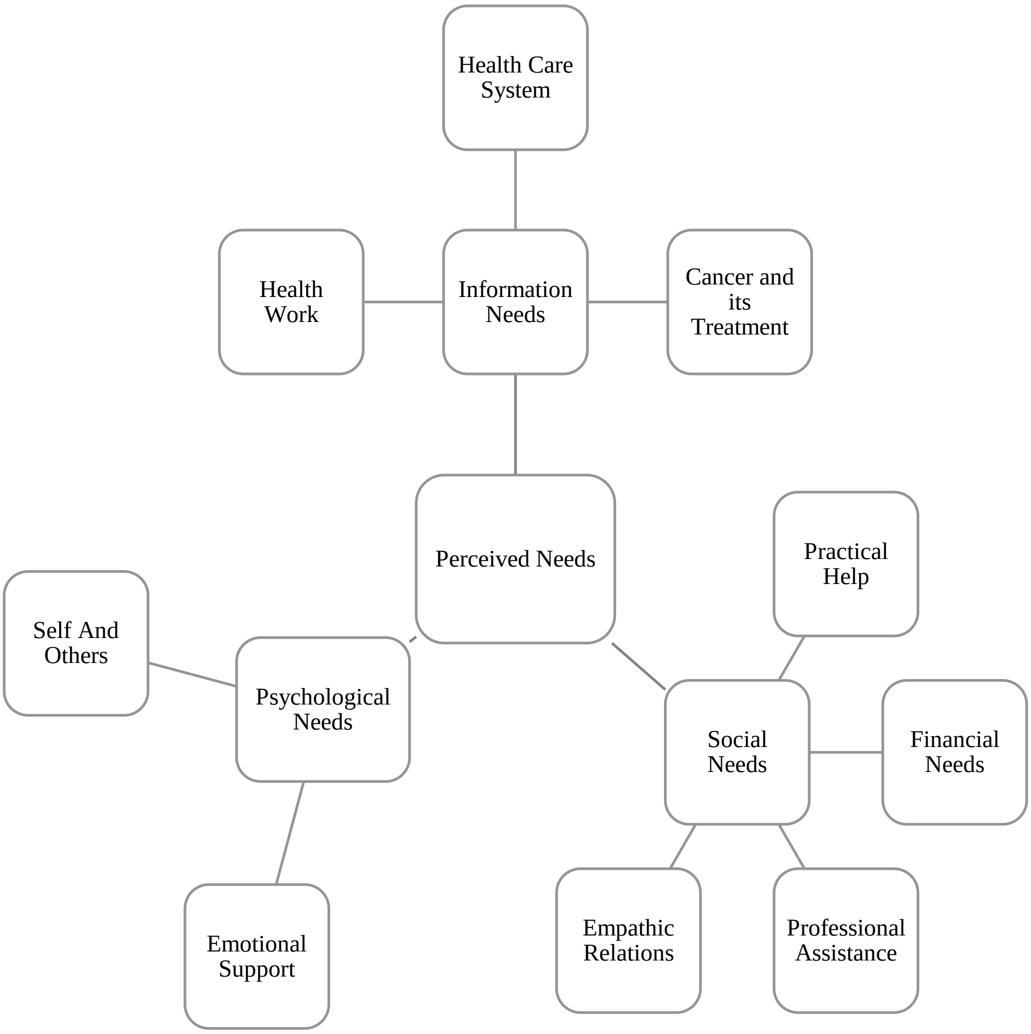


Figure 3: Perceived Needs of Caregivers

Findings from this section tell us that care givers have diverse needs and requirements and those change with time. The care givers talked about the importance of acquiring information related to cancer, its treatment and symptom management. They were also concerned about their physical well-being, especially towards the nutritive needs of the patients. The participants also highlighted the impact of their care work on themselves and their social life and stressed on the need for support, whether in instrumental, emotional, or financial form. Along with this, all the participants talked about the requirement of professional help and financial assistance while caring for a cancer patient.

V. Personal suffering and coping strategies

This section describes the suffering of the family caregivers which they underwent after receiving the cancer diagnosis of their relative. Suffering is a frequent response to the losses that occur during an illness trajectory, affecting both the patients and their caregivers (Northhouse, Laten, & Reddy, 1995). Suffering manifests on various dimensions. It occurs on a physical, emotional, psychological, spiritual and/or existential plane (Jones, 2004; Chapman & Gavrin, 1993; Northhouse, Laten, & Reddy, 1995). It alters one's life and relationship, by inflicting pain, conflict, anguish and exclusion from everyday life (Wright, 2005).

A. Suffering due to diagnosis

The experience of suffering is associated with the information about the cancer diagnosis. Diagnosis related responses include a sense of shock, disbelief, fear, disappointment and devastation.

> At first, we all were shocked. I couldn't believe it that dad has cancer. The diagnosis acted as a bomb; it destroyed everything. (Pinaki)

> I wasn't prepared for this. I was like- Is it real? Did I hear it right? I asked the doctor again- my god, that was so bad, so bad! I was terrified. I couldn't make out what to do next. It was like someone's worst nightmare coming true. I was clueless. (Chirantan)

B. Burden of caring.

As described in the earlier section, a caregiver has to face a lot of difficulties on a daily basis while caring for a cancer patient and how it contributes to their suffering. Generally, the major task of caring involves attending to the symptoms and treatment related issues, which is often considered as unending, difficult and stressful by most of the participants. The extreme difficulties involved in carefully attending to the various physical ailments faced by the patient become an arduous task, especially in the initial days of care when one is not used to the process. With time, even though the carers get used to the process, but it takes a heavy toll on their own physical and mental conditions, as it takes up a huge chunk of time disrupting their daily routine.

> When you have someone like this at home, you have to care for them round the clock… there is no rest; forget about rest, I don’t remember when was the last time that I had proper peaceful sleep! I have to clean the overnight-accumulated pus from his mouth. It’s so smelly, like something is rotting inside, or perhaps worse than that, and it takes time… lots of time. I do it very slowly. I have to wipe it clean and then, there is blood. Blood oozes out from there [orifice]. Taking care of him is very difficult, I have to be careful, otherwise it may lead to further complications. (Banty)

> If I am not doing it properly, he [father] may face difficulties later; he is already weak. I dress my father’s wound; the weird thing is how I have changed in just a few months! Earlier I couldn’t stand blood and other bodily fluids but now I can manage, struggling though. (Sayani)

Apart from managing the symptoms, the participants have undertaken various other tasks on a daily basis. These tasks were regarded as hard, strenuous and demanding. Many participants took care of household work and the needs of other family members.

> I have to look after everything... I have to balance both the household and other works majorly. (Sayani)

> I manage everything, from cooking, cleaning, shopping and my business as well. Initially it is difficult, I have learnt how to handle it. But frankly saying, I get too tired after all this. It’s tough. (Abhijit)

The task of caregiving has affected other facets of the participants’ life. Participants pursuing formal education had to face greater difficulties while tending their ailing parent. A few of them had to drop their education in order to efficiently provide care, especially in those cases where the concerned parent was the sole earning member in the family and used to manage the household.

> Before this, my life was good, it was as perfect as one can dream of. I was studying, focusing on getting a job and my father was managing the house hold and the farm, but now everything is gone. I have to leave my education so that I can sustain our family and take care of my father. (Banty)

For some participants, the tasks of caring had affected their professional life. For them, it became extremely difficult to manage both lives (those of a caregiver and a professional) as it was vital for their survival.

> We brought her home. I took a few days off from my office, so that I could take care of her, but now, I am on leave from my work or working from home most

> of the time. It's almost impossible to manage both as she needs constant care. But then I need the job as well. I can't risk losing my job amidst this. (Arnab)

C. Declining social relations

Here I will discuss the experiences of alienation from the relations, whether friendship or kinship ties, that the caregivers maintained earlier. With the caregiving work taking a huge chunk of their time, the family caregivers were left with neither the time nor the energy to continue the normative social relationships. Sometimes, it was the others who slowly severed their relations with the family of the caregiver (and the patient) for fear of being burdened by their miseries, as well.

> Friends! When you have a situation like this, everyone leaves you, even your relatives. I felt really bad. I was like a son to them and now how they are behaving like this, just because I need money and some help, and that too for my father's treatment! (Banty)

> Soon after the diagnosis, our relatives drifted away. They severed all connections with us. We are on our own. (Pinaki)

The demanding nature of the task had affected intimate relation of the caregiver such as parent-child relation and spousal relations. In the context of parent-child relations, the participants discussed missing out on the child's growing up and inability to spend quality time with them. They expressed sadness, distress and feelings of guilt and helplessness.

Arnab expressed that due to the tasking nature of the care work and other responsibilities, he wasn't able to spend quality time with his daughter. Moreover, the care work had affected his daughter's daily schedule as well. Unlike the earlier times, she now spent her leisure time caring for her mother or helping out her father in household works rather than indulging herself in her hobbies. He said:

> Friends at her age are enjoying their life. They are going out with friends for eating, watching movies, shopping and what not! But she rarely does that. Once in a while she will go out, but otherwise she would spend most of her time in studying or with us, either taking care of her mother or helping me out. I want her to be there with me, just her and me, but I am not able to manage it. perhaps a few years later it may be possible, but circumstances do not allow that now. I wish things were different. I wish I could afford help; at least that would ease the situation.

However, this study wasn’t designed to understand the effects of a caregiver’s actions upon their child, but it can be understood from the point of view of the parent. Arnab told me how the diagnosis impacted his daughter. Arnab said:

> The overall situation has affected our daughter very badly. In the beginning, she wasn't ready to accept the fact that her mum has cancer and most likely she will die because of it. She used to be very angry with everyone; even at school, she was angry, her class teacher called me once to tell me how her behaviour had changed, how she was shouting, and picking up fights with her friends, and after that she was sitting all alone.

Bikash mentioned how the diagnosis had affected his daughter’s life and how she shared his role of being a caregiver and adapted to the situation. He said:

> It [diagnosis] has affected us a lot; earlier it was really chaotic, she was sick, and wasn't able to maintain the household. I had to take care of everything. And,

> then my daughter pitched in and she learnt. Now she takes care of the basic household works, and since she is there, I can focus on important works.

Chirantan shared his son’s ability to adapt and accept the demands of the situation. He shared an incidence with me which highlighted how the carefreeness of childhood gives way to responsible maturity in a child because of the demands put on him by the situation where his mother is affected with cancer:

> A few days before his birthday, he approached saying that he wanted to invite a few friends over. To this, his mother said- ‘look, if you call your friends, we need to serve them a meal, who will cook for them! As you know I am unable to do so. Hearing this he said- ‘it's okay mom, and moreover, children ask for birthday parties, I am a big boy now, so don't worry about it'. I really felt bad; he is just 12 years old, and is saying all these things.

D. Emotional Struggles

With the diagnosis and the tasks of caring, the family caregivers face several emotional reactions. The participants commonly express fear, anger, worry, guilt, loneliness and helplessness.

The diagnosis of cancer with the recognition that the patient would die in near future and the uncertainty associated with it is one of the common reasons of fear among the participants.

> Right now, I am in a state where I don’t know what is going to happen in the next hour. Whenever my phone rings, I get scared, thinking there might be some bad news. (Pinaki)

> I don’t know what is going to happen next…you don’t know what is waiting for you out there. (Banty)

Uncertainty about things related to the patients' treatment, management of the household and the future was a major reason of worry among the participants. The uncertainty often led to a sense of hopelessness about the future of the children in the family.

> You guys are thinking about your life; your future, but when I think about my future there is nothing. I don't know what will happen to us, how we will survive this! (Banty)

> Apart from her [patient] condition and treatments, my only concern is to secure our family's future. Especially my daughter's future. (Arnab)

A few participants conveyed sadness about the way their situation had turned out. Mostly, participants who were parents expressed immense guilt and helplessness regarding their parenting as they were barely fulfilling their child's needs. The following extracts illustrate the guilt a parent felt when unable to fulfil their role as a parent.

> I am really upset with my situation. I regret about our son's upbringing. He didn't have the normal childhood, like others. (Abhijit)

> Our son's birthday is in January. For that, he came to us and said- 'Mom, are you alright! Can I call some of my friends over dinner to celebrate? Is it possible, dad!'… We were hesitant towards it. I regret this. (Chirantan)

These feelings often heightened when the care situation was difficult to manage, especially when the demands exceeded the resources available. Many of the participants felt helplessness when their patients' symptoms and their difficulties were getting harder with time, without any scope of ease.

> Sometimes I feel like running away, from all these, but then, besides me, no one is there for my family and if I leave them all, I wouldn't be able to live 'peacefully'. I have to suffer. (Banty)

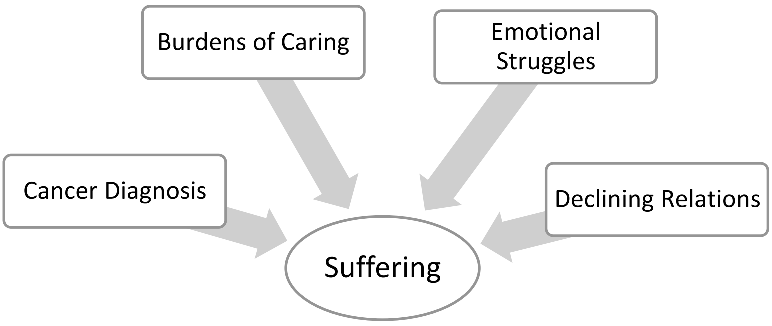
> I was hoping if someone could show me physically how to do it. It would be easier or perhaps someone could do it, anyone! Things are getting worse day by day. I feel so helpless. (Arnab)

> How will I manage everything? Neither am I capable nor do I have the strength to manage this. I am so exhausted, in every possible form. I am drained out emotionally, mentally, financially and of course, physically. (Banty)

Often, the participants mentioned about being lonely. Experiences of loneliness among the family caregivers was often seen to be linked with the constraints due to the tasks of caregiving. A few participants discussed about how their daily life was characterised by reduced freedom to have and manage their time and choice of space, by a lack of spontaneity, and with limited scope of being away from concerns. The needs of the patient were the top priority and a constant pre-occupation. Participants also talked about the losses and deprivations they faced with respect to their close relationships. The rearrangement of these relationships on both practical and emotional state due to their circumstances were sometimes perceived to heighten their loneliness. The overwhelming nature of the work of caring, declining social relations, the fear of mortality and the uncertain situation were the primary reasons for their loneliness.

> I am at the brink of losing everything. She [patient] is here, but just in flesh and blood. Then after a few months, I will be completely alone, with no one beside me. I will be stuck in my house, waiting for each day to pass and yes, I have to wait; there is no other option. I would be left behind to suffer. (Abhijit)

Figure 4: Perceived Causes of Suffering



E. Coping strategies

This section focuses on the ways through which the participants were coping with their suffering, in other words how the participants were maintaining a sense of worth and coherence during a stressful situation such as cancer trajectory. Although they were having a lot of difficulties, but they had managed and were managing their situation. In this regard, changing attitudes, optimistic thinking, spirituality and positive relationships had played an important role in them being resilient with their situation. Narratives from the participants showed a great deal of acceptance with the situation that they were facing. A few of them mentioned that, accepting the reality was difficult initially, but later acceptance of it helped them in dealing with it a bit easier. This acceptance of the situation primarily resulted from an understanding that there was no other or better option available to them.

> Let’s accept this. We can’t do anything else other than that. (Abhijit)

A few even considered it futile to fight with the situation as they felt they lacked any sort of control over it. Contrastingly, some of the participants showed courage and were determined to fight their agony as long as they could. The realization of being engaged in an unequal fight with the disease became all too evident for them, where they felt that they were in a losing battle. However, that did not deter them to show resilience and fight with all the might at their disposal, despite the seeming unfairness of it all, and the eventual defeat.

> Whatever I am going through, I will fight it till my last breath; I will never give up. I will do every possible thing to save us. (Banty)

> It's an unfair fight, where your hands are tied and then you are given a sword to fight off your enemy, who has all the advantage. We will lose. We are already pinned down; it's just that we haven't yet given up. We will be here till our last breath. I will fight this battle till the very end no matter what is the result. (Sayani)

Some of the participants displayed optimistic thinking related to the diagnosis of the patients. This was especially evident in those cases where the diagnosis was done at a relatively early stage, giving rise to hope that with adequate and appropriate treatment, they may yet win over the disease. Maintaining optimism with a hope for finding a cure too helped the caregivers to survive through the difficult phase. The absence of a sure-shot cure for cancer was a major cause of consternation for the participants. However, their belief in the power of the scientific and medical community to come up with a cure lingered in the back of their mind and helped them remain hopeful for a future cure.

> I wanted to stay positive about all this, and I think one thing is still positive- the diagnosis. I know that her detection is at an early stage; there might be some hope, and if we treat it properly, then we can get rid of it as well… Perhaps with time, we may have a cure too. (Arnab)

Strong and close family bonding also enabled coping with the situation. A few mentioned how an understanding relation among the family members had helped in managing their otherwise depressing situation. For the married participants, the role of a supportive and understanding wife was crucial in dealing with the stress of caregiving. The strength gained from such a spouse helped them a lot in their coping process.

> It gave me more courage, seeing her understanding about this and the support she gave me [teary]. Till now she has supported me in everything. I have a strong wife, you know. (Arnab)

Apart from these, spirituality played a significant role in helping the participants to cope with the suffering they were going through. The belief in spirituality many times translated into a belief in and surrender to, destiny. Though at times, this surrendering to destiny resulted in a sense of helplessness, it also made them feel that it was futile to fight with the destiny and hence, a grudging acceptance of the situation was the only way to go ahead in life. The same can be clearly discerned from the following excerpts where we see how a few participants relied heavily on destiny and fate in order to get along with their situation.

> Whatever is happening is my destiny. Whatever is destined to happen will happen eventually. (Sayani)

> Anyways, [one] can't defeat fate. (Tariq)

Passive aggression towards God was evident in some participants, where they believed in God’s hand behind their misery, but were ambivalent in their interpretation of the reasons for the same, i.e. whether it was a way of God’s love for them or it was simply God having fun with them by putting them in such situations. The belief of the many spiritually-inclined people in India in God testing those whom He loves a lot, is a reason as to why some participants consoled themselves by internalising such a belief. This became, for some participants, an effective coping mechanism to deal with the difficulties and hardships of caregiving. We can see that from the following excerpts where a few of the participants can be seen showing passive aggression towards the supreme being for putting them in that situation.

> God loves us very much, isn't it! That's why he puts me in these situations again and again. Sometimes I wonder, whether it's God's love or He is just having fun with me! [followed by a slight asymmetric smile] (Tariq)

Some of the participants considered their suffering as punishment from the supreme being. This again stems from a belief by those spiritually-inclined that every suffering that one goes through in this life is a result of God's way of punishment for their wrong doings. Even when one cannot place one's fingers on what those wrongdoings were, if any, one still believed that they must have done something wrong to deserve such a punishment from God. This too can be seen as a form of coping mechanism, where one tries to find some sort of a closure in terms of why one got to go through such a difficult situation.

> I surely did something wrong. What! That I am not aware of; otherwise why I am being punished! This is my punishment for my deeds only, nothing else. (Banty)

Most participants believed in the notion of afterlife, greater good and complete reliance on God, which helped them to look beyond their present suffering and gave a meaning to their situation. In many such cases, the suffering inflicted by the disease and its treatment were seen as not something to be despised or lamented, but as something that can actually be perceived as good since they believed that this pain and suffering would wipe out their sins of not just this life but also of their previous lives. This, they believed, would ensure that in their next birth, they would be born with a clean slate, without any sins to suffer for. This complete surrender to God and His machinations was a form of coping mechanism for these participants who considered that their present suffering are sacrifices to God that would ensure a happier and much better after life for them. This helped them gain a sense of calm and peace, and not agonise over it on a regular basis.

> We have to look past the immediate suffering. This suffering is good. Our pain will wipe our sins, both for present and past lives. Our struggles associated with this would also remove our sins, and will later result in a prosperous future. This suffering will clean our slate for our next birth. The sacrifices made here would make our lives easier there [afterlife]. (Bikash)

> Everything is God's desire. I am just entrusting my life to my 'lord'. He is the caretaker of the world; He has created this situation; hence he will rescue me. (Banty)

> By God's mercy, everything will turn out okay, I won't agonise about this. (Pinaki)

From the above discussion, it is evident that all the participants experienced sudden changes due to the diagnosis of a family member with cancer. This diagnosis and the associated treatment led to several changes in their everyday living, disrupting the 'normalcy' of their life thus far. Disruptions were observed during the performances of their day-to-day activities including the maintenance or continuance of their education and their occupation, and in their social relations. A few participants who were pursuing their education reported that they couldn't continue to do so due to fatigue, time constraints exerted by the tasks of caregiving and declining social support. Majority of the participants mentioned about the experiences of fear, worry, uncertainty, guilt, loneliness and helplessness. This indicates that the loss of normalcy due to the burdens of caregiving and lack of social support resulting in alienation are the primary reasons for these emotions.

The demanding nature of care giving also generated a sense of burden among some participants, even though they performed their role as a sense of duty for a family member. For many, it was doubly challenging not just because of the high demand it exerted on their time and health, but also due to a lack of professional help of any kind. For many, caregiving turned out to be the most challenging job of their life, and one that disrupted their lives forever. The care work consisted of knowledge work, health work, physical work and emotion work, in addition to the initial disclosure work. For the untrained caregivers, which was the case with all the family caregivers, managing these different kinds of work was a huge challenge, which they somehow managed due to their sincere desire to care for a close family member afflicted by cancer, despite the lack of expertise and training. For them, their own lived experience as caregivers was an important source of knowledge which helped them negotiate living with cancer as an individual.

The family caregivers faced several difficulties where many of their needs were unmet. Some such unmet needs are informational needs, psychological needs and social needs. The caregivers encountered difficulties in informational needs, especially in the initial days of caring, when they failed to fully understand and anticipate the needs of the patients. Their lack of knowledge about symptoms, diagnosis and sometimes negligence had an impact on the treatment regime. All the participants also faced psychological difficulties while caring for the patients. It was not just their own sadness, helplessness and anxiety but also the emotional distress of the patients that were major concerns for them. A good and understanding relationship among family members of the caregivers, went a long way in easing their psychological burden. Almost all the participants described the changes that occurred in their social life since the diagnosis of cancer. The tasks of caring had left them with hardly any time to engage in social activities, thereby diminishing their social interactions.

Faced with the initial shock and suffering by the cancer diagnosis and later the ‘burden’ of caring, declining social relations and emotional struggles, the family care givers tried to come up with various coping strategies to maintain a sense of worth and coherence during a stressful situation such as cancer trajectory. A deep-rooted belief in spiritualism among most of the participants, optimism and strong familial bonds were seen to be enhancing their ability to adjust and cope with their suffering.

Chapter 6: Discussion and Conclusion

A crucial aspect of this study involves exploring the usefulness of the ideas derived from examining the experiences of cancer patients and their family caregivers. The findings of this study regarding living with cancer as difficult add to the existing literature in the field of caring for dying people. The findings of this study underline the need for the practitioners to hone their skills in their empathetic understanding of the stories of the cancer patients and their caregivers. It is important for the practitioners to listen to their stories and the underlying meanings thereof, which will assist them in honing and improving their skills in cancer care. In the following sections, I will make an attempt at situating my findings within the existing knowledge on the study about the experiences of chronic illness. This chapter will further explore the relationships between living with cancer as 'difficult' and the existing concepts for understanding illness experience, with an emphasis on biographical disruption. The chapter will finally conclude with a discussion on the possible implications and limitations of the study.

The aim of this study was to understand the experiences of individuals diagnosed with cancer and of those caring for them. The ideation of this study was from a need to understand the experiences of cancer patients and their family caregivers, and this need was at both the personal and professional fronts for the researcher. I used ethnography for understanding the experience of illness and of caregiving. Ethnography was chosen because of its focus on the subjective experience, which it values a lot. Data were collected through observation and semi-structured interviews with the cancer patients and their family caregivers. All the participants were both willing and interested in telling their stories. However, the nature of the purposive sample limited generalization of the findings. Whether it is from investigator subjectivity, research process or design, no research is devoid of some bias or error. In this study, my personal experience of caring for my mother who was diagnosed with cancer, presented a challenge in terms of some form of subjective bias in my study. That is why, utmost care was taken from the initiation of the study process to ensure explicit depiction of the experiences of cancer patients and their family caregivers. To assure credibility and accuracy, the interviews were transcribed verbatim. Writing the transcripts and reading and re-reading the transcripts with descriptions of the experiences ensured an iterated and credible data analysis.

Data analysis was initiated as the patterns in the data were identified. The interview transcripts were reviewed line-by-line. The process of coding resulted in identifying patterns and categories, which were further refined and as deemed appropriate, collapsed, and expanded. My own shift from the stance of a caregiver to one as a researcher interested in understanding the experiences of cancer with a social gaze led me to understand stories deeply. The basis of this study was provided by the lived experiences of cancer described by the participants that included their illness stories and relationships. The experience of living with cancer, the illness stories, the work participants described, and their relationships - all provided the basis of this study. As mentioned in the introduction, cancer is many things: a medical problem, a personal problem, a social problem and it is a part of everyday life for those who have it. The stories of the participants show how living with cancer became a part of their everyday life and how cancer (as an illness) became the norm for the concerned individuals.

One can cite several accounts for the ways in which illness becomes a normal state of affairs, such as the functional aspect of health (Mcwilliam, Stewart, Brown, Desai, & Coderre, 1996), transition and adaptation (Fife, 2005; Kralik, 2002; Kralik, Visentin, & Van Loon, 2006), and normal hardship (Sinding & Wiernikowski, 2008). An individual can be termed functionally healthy when they possess the ability to fulfil their goals and ambitions while individuals with chronic illness describe ‘functional health’ when they describe health as the ability to do the things they desire to do. They consider functional health by normalising illness and recognising it as a vital aspect of their daily lives. (Mcwilliam, Stewart, Brown, Desai, &

Coderre, 1996). However, normalising illness is not a process that involves an agency; it's rather a state of being which is a reflexive one. It is often characterised by distress with varying magnitude related with the symptoms of cancer at different times. Sanderson, Calnan, Morris, Richards, & Hewlett (2011) conducted interviews with 23 people living with rheumatoid arthritis and suggested that the participants responded to the fluctuations in the symptoms and treatment. They identified various types of normality corresponding to their experiences. Similarly, participants of this study too have made adjustments in a 'repeating cycle of confronting each new phase of deterioration and improvement and incorporating it into normal daily life' (Sanderson, Calnan, Morris, Richards, & Hewlett, 2011). However, as cancer is a terminal illness, the changes and the accommodations are a 'downward' spiral of adjustment to cancer and its treatment reflected in symptoms and deterioration. The diagnosis of cancer sets the patient apart from everyone else. All the participants recall with clarity their cancer diagnosis news, which for them is a major turning point, often stimulating disruption and existential issues.

The concept of biographical disruption is a relevant concept to understand and appreciate the enormity of the impact of cancer on the patients. This concept is used to describe people's experiences of chronic illness and helps in understanding how people respond and adapt to chronic illness. The effect of illness on one's perception regarding self, future and the world has been gestated as biographical disruption (Bury, 1982). Chronic illness is a type of state which has continuing effects and lasting consequences for people's lives (Bury, 1982). In this study, the participants described their experiences of living with cancer which often disrupted their sense of self. They often experienced a sense of vulnerability and fear about the future. For most participants, their accounts began with that of their diagnosis as this was the moment when they felt that their world changed forever, for worse, in an irreversible manner. Even though many participants were experiencing symptoms indicating the possibility of something seriously wrong with them much prior to the actual diagnosis, the confirmation of the diagnosis still came as a shock and this was the point when they started to make sense of what such a diagnosis actually meant for them and their sense of self. As stated previously, some participants had been anticipating that something serious was wrong, but they did not anticipate cancer or stilled themselves into believing they did not have cancer. My subtheme in chapter four reflects this as I had interpreted this phenomenon as being ‘caught off guard’. According to Thorne (1993), the moment of diagnosis is significant for two reasons for those afflicted with chronic illness; first, they get to know the name of the disease that causes the symptoms, and secondly, they get a signal from this point what the future may hold for them. This can be seen as the moment of demarcation for the concerned individual where he transitions from his old self to a new one, from a familiar place to one that is unfamiliar and uncertain – from a normative space to one that is anything but normal. Previous studies dealing with the impact of diagnosis of cancer or other chronic illnesses have indicated the same (Bury, 1982; Charmaz, 1983). Any diagnosis has the potential to influence a person’s life, sometimes drastically and in an irreversible manner. In this study, the diagnosis was a shock for many of them. The significance of a cancer diagnosis is that it is a harbinger of a radical change to a person’s life. This point onwards, the patient perceives himself or herself as a dying human. In that moment, a person transitions from a living human to a dying human.

Most of the participants indicated towards experiencing emotional distress related to the physical manifestation of the symptoms of cancer and its treatment. A likely reason for this is that it is only when they have clearly discernible signs of the condition that the cancer patients become visible in society. The findings of Martin, et al. (2019) which brought to the fore the fears and the emotional reactions of people newly diagnosed with cancer, also support this finding. The emotional reactions of the patients and caregivers who were interviewed to the diagnosis of cancer were varied – shock, fear as well as anger and sadness. It can be argued that the reaction to the diagnosis suggest an altered perception and interpretation of meaning associated to the diagnosis. Because pre-diagnosis, the concerned individual was a person with symptoms whereas post-diagnosis, they become a person diagnosed with cancer, and this knowledge brings with it a whole set of troublesome perceptions about one's self, uncertain future, etc. Previous literature on the experiences of people with chronic illness has considered this as much more than a simple stepping over a threshold (McNulty et al., 2004). It can be clearly seen that the transformative element of this experience can be related to the biographical transformation in the patients as is seen in the analysis of data in my study where we see how the diagnosis of cancer and its treatment regime transformed the participants' sense of self. This was especially evident in those cases where the diagnosis meant the roles of individuals change, where a hitherto independent person had to depend on others who were till then dependent on him.

The findings presented in the previous chapters suggest that, being diagnosed with cancer was certainly disruptive to the normative idea of self. As a consequence of the experience of the diagnosis of cancer, the lives of people who were directly impacted by the same, changed forever in an irreversible manner (Beckman, 1989; Cooper & Watson, 1991; Singer, 2018). For the participants, the impact of this experience was a hugely disruptive one. The relative sense of security in their sense of self and the normative interaction with the world around them were brought into question by this diagnostic experience, causing them to question previous understandings about themselves and world around them.

The personal narratives of the participants which refereed to their pre-cancer self as 'beautiful', 'strong', 'normal', etc. gave way to new narratives about their own self after the diagnosis of cancer. The new disrupted self for them was the one with cancer. According to Kralik, Visentin, & Van Loon (2006), the diagnosis of cancer, often of an unexpected chronic condition, becomes an enforced transition to an ill person from a healthy one, and is this a disruptive and unwelcome factor. For those with chronic illness, Asbring (2001) described a fragmented transformation of the self, in which the concerned individuals did not identify themselves with the person they were pre diagnosis and did not even fully acknowledge their illness state that their diagnosis had suggested. Since in the findings of this study also, one finds that a cancer patient neither considers himself / herself the person he/she was before the diagnosis nor do they fully identify with their new self, the one afflicted by cancer, one can see that Asbring's (2001) findings have relevance to the person affected by cancer as well.

Many studies on chronic illness have used the concept of biographical disruption as the conceptual background (Williams, 2000; Radley, 1999; Locock, Ziebland, & Dumelow, 2009). The concept of biographical disruption is an appropriate one to study and explain the experiences of people affected by cancer as the diagnosis of cancer is perceived as a threat to one's identity. The impact of illness on personal meaning can be seen as a core assumption within the biographical account. It is a disruption to core assumptions about the world and the self. One significant assumption of the account is that identity of the self relies heavily on a narrative of the self which is continuous (Bury, 1982; Lieblich et al., 1998), because this kind of continuity helps foster emotional stability whereas anxiety is induced by disruption (Bury, 1982). For the participants, it was nothing less than a struggle to make sense of their self with cancer and thus, hinting at a rather chaotic interpretation of the experience as proposed by Kralik, Visentin, & Van Loon (2006). The data and their analysis as presented in the previous chapters clearly underline the impact of biographical disruption on several aspects of self.

The diagnosis of cancer threatened the taken-for-granted assumptions of the participants where continuity no longer remains predictable. Every single aspect of life which was seen as normative and was taken for granted is now questionable. The effect of diagnosis and the subsequent treatment forces one's attention on the body. The lived experience of many participants was characterised by a state of suffering wherein a key feature was the experience of their bodily symptoms. Several studies have discussed the relationship between embodied experience and the self in connection to biography (Finlay, 2006; Williams, 2000). Finlay (2006) highlighted the relations between body-self-world of individuals diagnosed with chronic illness. She suggested that the embodied experience of the illness was intrinsically entwined with the sense of self and the being in the world. The findings of my study are in concurrence with this notion. Reliance and confidence on the body are challenged due to the threats of death and dysfunction which are constant reminders of debility, vulnerability and mortality. The body can be seen to have continued without the volition of an individual, for instance not forgetting to breathe or start the digestion process when food is ingested. The relationship between the body and the individual self are strongly intertwined in ways which are difficult to decipher, and that is how the normativity of the relationship leads to a familiar and comforting normative co-existence of the two. However, when illness and the threat of mortality enter into the picture, this normativity is disrupted as the boundaries between the two are destabilised, leading to unknown, unfamiliar and discomforting possibilities.

The participants had not given much thought regarding their body in terms of what their body meant to them, until the time of their diagnosis. But after the diagnosis, they were forced to reflect on their body and they became aware of it in new ways. The symptoms upset the bodily experience and the balance of self is equally affected, disrupting the biographical equilibrium, suggesting a relationship between the body and self. The ever-present existence of cancer in the body and its treatment led to a sense of alienation with this new altered body, and this sense of otherness and alienation disrupted the process of embodiment, bit by bit, with time. When it came to the body-person relationship, the participants felt a sense of otherness about the body, as if it is no longer a known and familiar entity, a feeling that was also accompanied by a feeling of betrayal and invasion.

Moreover, with cancer afflicting the body, the body makes its presence felt by moving from a silently reliable presence to an almost malevolent impinging upon the consciousness and the self. The physical appearance of a body is usually a significant part of it taken-for-grantedness, and with cancer and its treatment significantly altering the body, the focus shifts even more to the body, and it is viewed as an object. The other taken for granted aspect of the body is its functionality, in terms of its mobility and intentionality. These too now become uncertain and unreliable. One becomes apprehensive about the way the rate at which the body changes for the worse, in terms of its instrumentality, as the change becomes radical at times, in terms of its deterioration. The aspects of body through which it usually becomes an instrument of relationship such as speech act, touch, looks, expressions etc. no longer function in the desired manner leading to disruptions in relationships and with it, a foreboding sense of being a burden on others, as he/she finds it extremely difficult to fulfil the commitments. As Kartick believes, he is a burden to everyone for which the changed and deteriorating body is the primary reason.

It becomes difficult for the changing body to be able to sustain the normal and existing relationships. The lack of confidence in one's own body translates into a lack of confidence in the ability to continue the relationships. The normative roles of husband, wife, daughter, son, etc that are usually sustained in embodied forms, slowly but surely get challenged due to the altering and increasingly unreliable body whose functionality gets seriously compromised due to the disease and its treatment. These changes indicate that the body has become unreliable. It has become the other, an unknown and unfamiliar object. This ensues in the individual a sense of betrayal that the body has suddenly abandoned the relative harmony in which the body and the self co-existed. The body suddenly seems like it has begun a process of separation, and almost having an agency of its own. But this body needs to be attended with due urgency on a regular basis so that the day-to-day functionality is not fully compromised. Chemotherapy leads to tiredness and nausea which ensures that it is no longer the person, but the body to which the power has shifted, and the person is helpless in front of it. The individual's sense of helplessness in his own body is all too perceptible and this helplessness leads to a sense of being a burden on others, a major concern for most participants in this study. The body ravaged by the disease and its treatment in the form of chemotherapy, surgery, radiotherapy, etc. leaves the confidence of the individual shaken as these cause undesirable changes to the body, and all these changes require some form of adjustment from the person.

The shock of being diagnosed with a chronic disease such as cancer brings in a pessimistic world view in the patients and disrupts their lives irreversibly. The shift from a rather predictable situation to one that is unpredictable and frightening, brings with it, its own trials and tribulations, which becomes a cause of suffering. This suffering entails not just the ever-present painful physical tribulations, but also other kinds of distress such as mental, social and spiritual. And it is not just the lives of the patients that are altered, but also those of the caregivers as well. Kelly (2010) emphasised that the experiences of the significant others or the caregivers were also similiarly altered. Kelly drew on Bourdieu's theory of habitus (1984), through which she compared the difficult adjustments of this new altered personhood to learning a new game with unknown rules, as an unprepared player. This work of Kelly supports my findings and my interpretation of the experiences of being the caregiver of the person with cancer and learning the processes in the illness trajectory. Moreover, the biographical disruption extends further to the caregiver since the normative roles in a relationship tend to get threatened owing to the prospect of living with a cancer patient. Esmail, Huang, Lee, & Maruska (2010) too highlighted the challenges to traditional roles in partnerships, especially when these were about the gendered roles of man being the earning member and the woman is the caregiver. The diagnosis especially impacted the family caregiver. The diagnosis of cancer was an extremely significant moment in the participants' lives in my study; the knowledge of the loved one experiencing cancer caused worry and was considered as a shock.

Being diagnosed with cancer and undergoing its treatment process can potentially affect the entire family, especially those engaged in raising young families (Singer, 2018). In my study, the capability to engage in specific roles in a sustained manner within the family was an important theme which contributed to the participants' sense of self. For the participants with cancer, the role of parent, especially that of a mother, and the role of a partner came out as the two prominent ones in the data. For those participants who were mothers, this role of theirs came out as strongly connected to their sense of identity and all of them narrated this aspect of their role while narrating their experiences of cancer. What was especially disconcerting for them was their perception of failing in their roles as mothers, especially in them failing to involve themselves productively on a regular basis in taking care of their children. These findings are very much in sync with the findings of previous studies on the impact of chronic illnesses on parenting (Barlow, Cullen, Foster, Harrison, & Wade, 1999; Grytten & Måseide, 2006). This study contributes to the existing literature on the parenting role, especially that of a mother who has cancer and their perception of themselves in that role. This failure to carry out the normal activities that are expected of a mother, due to cancer and its treatment, negatively impacts an individual's sense of self (Charmaz, 1983). The findings of my study support those of the work of Barlow, Cullen, Foster, Harrison, & Wade (1999) who explored a similar theme in case of arthritis where parents and grandparents who suffered from it had similar perceptions about their failure in fulfilling their roles as parents and grandparents, leading to a sense of pessimism and feelings of depression and guilt. Unfortunately, such issues relating to the concerns of mothers suffering from a chronic disease such as cancer failing in their mothering roles are often ignored and not even recognized by health care systems across the world. Thorne (1993), in his study has pointed out how such concerns often remain ignored.

The predominance of studies using the biomedical model often overshadows and downplays the issues such as this which are of utmost importance to people with chronic illnesses such as cancer as their lives are disrupted in many ways apart from the one seen through the prism of the biomedical angle, and this adversely impacts their sense of self and identity (Kleinman, 1995). From the data, one could clearly discern the evidence of how cancer had a huge impact on spousal relationships. The data from my study also suggests that relationship issues that arise due to cancer also adversely affect an individual’s sense of self within the relationship. The disruption within the couple relationship that thus arises due to cancer, especially from the time of diagnosis, may even lead to the couple re-evaluating their relationship. However, most of the available literature focuses on the physical dysfunction and its impact on couple relationship, and its redressal methods, largely ignoring the psychological and emotional impact of such issues on concerned individuals. All of the caregivers in this study mentioned about a marginal change in the balance of their relationship since the diagnosis. With diagnosis, the relationship between an individual with cancer and the caregiver too undergoes a change , wherein a partner, sibling or child turns into a caregiver, and the latter identity subsumes and precedes the former - from partner, child or sibling to that of a caregiver.

The data presented in the previous chapter support the experience of biographical disruption as being equally applicable to the caregivers, just as they are to the people with cancer. The changed circumstances due to the cancer diagnosis was a difficult one to accept, and demanded a significant amount of time and effort in getting somewhat used to the altered realities. The participants had to work hard to manage the complexities, constraints and difficulties brought forth by cancer. The caregiving work became a major component of their lived experience, of their day-to-day life and it can be understood in terms of knowledge work, health work, emotion work and physical work. Corbin and Strauss (1988) discuss how caregivers had to constantly change the manner in which they did things, which required them to put in a lot of additional effort. Because, they had to look after and manage situation at home, while simultaneously having to manage treatment related decisions, medications, etc. Participants in my study acquired information from different sources at varied times and combined this with their experiential knowledge. A few participants specifically pointed out how they were the most active in seeking information during diagnosis. When they received the information, they evaluated the same by drawing on from their own experiences, and their imagined future, after which they disclosed information accordingly.

This finds resonance in Hogan and Palmer's conclusions that individuals with HIV and Multiple Sclerosis have varied requirements for different types of information from multiple sources (Hogan & Palmer, 2005), which they believe, could be due to the fact that there is a requirement for varied sources of information at various stage of illness. The importance of knowledge work can be gauged from Conrad (1987)'s work wherein he emphasises how this work can be central to 'reducing uncertainty'. Participants in this study mentioned how they used the received information and experiential knowledge in their management of risk and of complications. The participants made an effort in undertaking work that was focused on maintaining their wellbeing. They invested considerable amount of time and effort in adapting to and managing restrictions on a regular basis due to the constant change in conditions, which often were unpredictable and hence they had to remain on their toes to tackle such difficult challenges. Managing the illness and working towards reducing the effects on their lives, consumed much of their time and effort. Emphasis is given on the 'processual nature of living with chronic illness, describing the experience as one that was relentless and required people to act, be vigilant, plan and learn new strategies' (Kralik, Koch, Price, & Howard, 2005). Furthermore, as cancer is life-threatening, it induces a sense of liminality, and uncertainty and even isolation (Mckenzie & Crouch, 2004; Crouch & Mckenzie, 2000). Due to this, the family members and people engaged in primary support, had only one option, i.e., to engage themselves in difficult emotion work (Thomas, Morris, & Harman, 2002) in order to protect others as well as themselves.

The care work, the various responsibilities associated with it, the unpredictable nature of the situation and the uncertainty surrounding the future, can be demanding, stressful and taxing. The primary reason behind caregiving experience being uncertain is the unpredictable nature of cancer trajectory, something that much of the literature on family caregiving for cancer patients suggests. Also evident is the disruption in daily life and a general sense of experiencing helplessness and vulnerability (Wittenberg-Lyles, Demiris, Oliver, & Burt, 2011; Harding & Higginson, 2003; Judakins, Laska, & Paice, 2018). Both the diagnosis of cancer and the subsequent treatment regime ensure endless suffering and pain for not just the cancer patients but their family members too (Mor V & Malin, 1994; Williamson, Shaffer, & Schulz, 1998; Wittenberg-Lyles, Demiris, Oliver, & Burt, 2011; Stajduhar, 2013; Harding & Higginson, 2003). All the caregivers in my study mentioned about disruptions in the day-to-day activities including the maintenance of their education and their occupation as well disruptions in their social relations. A few participants who were pursuing their education reported that they couldn't continue to do so due to time constraints and fatigue, arising due to the exertions of caregiving and declining social support. Studies such as Jensen and Given (1993) show how fatigue is one of the most common feelings in people involved in caregiving and this had a direct impact on their daily schedule. Jensen and Given suggested that there is a direct correlation between the caregiver's schedule being a burden and the intensity of the fatigue experienced. (Jensen & Given, 1993). Several studies (Fletcher, Miaskowski, Geven, & Schumacher, 2012; Savundranayagam, Montgomery, & Little, 2011) attest to the fact that caregiving work has been considered extremely strenuous by the caregivers themselves and caregiving for family members ends up causing at least one major burden, consequently resulting in major life changes. Research findings of this study suggest that most of the participants experienced uncertainty, anxiety, fear, guilt, loneliness and helplessness, similar to the findings of prior studies (Braun, Milkulincer, Rydall, Walsh, & Rodin, 2007; Mellon, Northhouse, & Weiss, 2006; Stajduhar, 2013). For the participants of my study, there was a strong sense of isolation. ‘I feel good when I am talking to you’ or ‘there isn’t anyone with whom I can talk to’ were common phrases used by the caregivers which further supported the interpretation about the caregiver requiring support which is generally not available. This indicates that perhaps the loss of normalcy due to the burdens of caregiving and lack of social support resulting in alienation is the primary reason for these emotions. In fact, there are some studies which show that it is the caregivers who experience more stress at the various stages of illness, compared to the cancer patients (Sun, et al., 2016; Sun, et al., 2015). Younger, in her article, states that suffering alienates the sufferer from himself or herself and at the same time ‘makes one a stranger, and the reaction of the others is to turn away from this stranger who now lives in a world others may be reluctant to enter’ (Younger, 1995).

Carer burden is a widely discussed topic in chronic illness literature, but in much of his literature, the focus is on the aspect of physical caring duties, whereas the issues faced by the carers in the early stages of their caring, especially the aspect of learning to live with a chronic condition is largely ignored, something that I have attempted in my study (O’connor, McCabe, & Firth, 2008; Pakenham, 2008). An overwhelming feeling of helplessness was highlighted by several caregivers in my study. This can very well be attributed to their role as a caregiver on a daily basis, physical caring activities, and the future being uncertain, and at times a sense of futility surrounding the whole exercise where the caregiver feels that the actual difference, he/ she makes in the life of the cancer patient is rather insignificant. As Bury points out, the caregiver fails to make a substantial modification in practical terms to the individual and is restricted or reduced to delivering only emotional support where both parties, i.e., the patient and the caregiver are experiencing biographical disruption (Bury, 1982). It was evident from my study that the cancer diagnosis and its symptoms affected the lives of all the participants, which required them to adopt certain coping strategies. The data from the participants suggested that their experience of uncertainty was a socially constructed and subjective experience. This experience was mostly stressful, and concerned people had to build coping strategies to lessen their distress in such an uncertain situation. For a few, this meant acceptance of their circumstances, fighting spirit, avoidance or the use of hope as a tactics to cope with the unpredictable trajectory of cancer. A sense of hope and a semblance of optimism are crucial coping mechanisms for the individuals to be able to adapt to life with a chronic illness (Grytten & Måseide, 2006; Dysvik, Natvig, Eikeland, & Lindstrøm, 2007). The deep-rooted belief in spiritualism among most of the participants, a sense of optimism and strong familial bonds are seen to be enhancing their ability to adjust and cope with their suffering. Available literature on coping with a chronic illness such as cancer support this finding and show how along with the other coping mechanisms, taking recourse in spirituality has played a major role in managing the psychological wellbeing of the family caregivers and cancer patients (Shim & Ng, 2019; Pearce, Singer, & Prigerson, 2006; Kershaw, Northouse, Kritparcha, Schafenacker, & Mood, 2004) . For caregivers in India, religious or spiritual coping has been identified as an important resource (Thombre, Sherman, & Simonton, 2010). In their study, they discuss how taking recourse in religious belief system helped the caregivers to look at illness with positive connotations and even helped them in their spiritual seeking. In my study, one finds how the Hindu philosophy of acceptance of one's *karma* and fate helped in coping with the stress of caregiving among the participants. Similar to this study's findings, another study conducted by Mehrotra and Sukumar on Indian caregivers stated that individuals used their reliance on faith to manage the demands of cancer (Mehrotra & Sukumar, 2007).

This study indicates that communication patterns and social relations such as friendships and distant affinal relations are strained due to the cancer diagnosis and its demands, similar to the findings of previous studies (Seifert, Williams, Dowd, Chappel-Aiken, & McCorkle, 2008; Garlo, O'Leary, Van Ness, & Fried, 2009; Goldstein, et al., 2004), but strong interpersonal bond with the immediate family members helped in providing support to the caregiver at the time of crisis. Studies have indicated that family members of the caregivers help in easing the burdens of caregiving by providing support, by sharing the physical, social and financial responsibilities and helping them to cope emotionally (Han, et al., 2014; Papastaravou, Charalambous, & Tsangari, 2012).

Reflective account

In Chapter One, I have delineated my position as a researcher, wherein I threw light on my own background as a caregiver which could potentially bring in some element of bias to my research because of my own lived experiences and assumptions. To minimise this possible bias, I made a conscious effort of keeping away any kind of judgements regarding the participants' accounts by adopting a position of openness (Given, 2008). It must be acknowledged that my ontological stance too has had an influence on the way I have gone about interpreting my data. Moreover, while interviewing the participants, it was my own understanding of social constructionism which guided me during the interview process. This was an important factor as it acknowledges how the social context of the participants is reflected through their construction of meaning. Keeping notes all through this entire process have been of immense help to me in having a more in-depth exploring of my experiences and understanding. Using semi-structured interviews served the purpose of my study as it provided both an underlying structure to my line of exploration while providing enough flexibility in the way conversations with the participants could take place (Smith, 2008). Though my own lived experience of a caregiver helped me during my interviews with the participants, especially in the early stages, with more time and engaged interactions with the participants, I could see a marked development in my interview skills. I could clearly discern this when I started reviewing the transcripts of my interviews. In the early interviews, I could see how my line of questions and interaction was largely guided by the initial structure / guide I had prepared for myself, and hence I could clearly see a few missed opportunities at exploring the relevant issues further in a more organic way. However, in my later interviews, this rather rigid structure gave way to a more organic and productive way of engaging with the participants, and my reliance on the guide became less rendering it less intrusive, through it did not cease to be useful. However, the data generated from the early interviews was quite useful as it was very rich in detail. Researchers have discussed how there is a potential for such interviews to be therapeutic (Morris, 2001; Holloway & Freshwater, 2007) and this was clearly evident when some of the participants told me how they found this whole exercise of being able to tell their stories in front of an empathetic listener as hugely beneficial to them, psychologically.

Limitations of the study

The design of the study was conceptualised in a way where the number of participants and the scope of exploration were limited. These may be considered as limitations of the study, but this also resulted in the kind of detailed data which had depth and richness, though it admittedly does not allow the substantiation that having a large number of subjects would have possibly had. To manage the huge amount of data generated from the participants, a dyad was considered. Limiting the family caregiver to one person may not seem to be significant especially since the kin was identified by the cancer patient as the closest to him in the family, a fact which was also confirmed by the interviews and observations. However, it needs to be acknowledged that other family members' opinions and experiences could have further enriched the study. The selection of participants too could be seen as another possible limitation of the way the study has been designed. But this was necessitated due to the intention of the study to focus on patients who had some sort of understanding of living with cancer through their own lived experiences. Moreover, the people who participated in this study may have had personal needs that they believed could be addressed through their participation in the study. It is difficult to quantify or evaluate these limitations as one is unsure as to which extent these can be considered as crucial limitations. It is important to study people with cancer, as so far only those voices which are articulate, have been studied (French, 1998). When similar studies are conducted by others, one would be able to decipher whether the experiences of the participants in study are representative of a similar group.

The relative homogeneity of a group in a small-scale qualitative study, in terms of religion, education, culture, socio-economic status, etc. is not a concern for this study as a study such as this does not require representative samples. All of the patients in the study had cancer. To exclude patients with other diseases was a conscious choice as that would have brought in whole new sets of experiences, complicating the process and the findings. So, by making this deliberate choice of exclusion, a possibly complicating issue has been evaded.

The findings of the study were limited due to several factors such as the obvious time constraints of a doctoral study, the group size and the constraints that the participants' illness itself had at several stages as well as the admittedly limited amount of time available to the researcher for data collection. If not for these restrictions, the study could have been more open.

In a country where health care services are directly affected by funding, one usually finds health care system to be constantly evolving. In a small span of time, of a couple of years, the provision of cancer treatment and palliative care in the city of Kolkata, where the data collection was undergoing, changed a number of times and at the time of writing, in the Covidian era, it is changing yet again. Any study needs to be seen in context-specific terms and when there is a change in the context in a fluid situation such as health care, the study and its implications have to be seen within that new context as well.

Additionally, the study does not claim to uncover every possible truth regarding the experience of living in the shadow of a chronic illness; rather it makes a modest attempt at revealing only some part of the truth in a given time and space. The findings of this study and their applications are limited by the design of the study which is qualitative in nature. At the same time, one could see that it is these same features which provide the richness and allow the reader to use the findings appropriately in future situations.

Implications and recommendations

This study contributes to the existing knowledge by exploring what it means for the self to be diagnosed with cancer and identify the processes that people traverse during their illness trajectory. The use of interviews during data collection enabled the participants to narrate their story and 'give voice' to their experiences of cancer (Koch, 1998; Larkin et al., 2006). Having people with cancer and the family caregivers has resulted in an enhancement of credibility of the participant accounts in the study (Elliott et al., 1999).

The interpretive process in my study has been enriched by drawing on theories from diverse disciplines such as sociology, anthropology and psychology. This has helped bring different perspectives to view the experience of being diagnosed with cancer. Moreover, as a researcher, the reflexive thought of mine can be seen to have brought all those perspectives together towards a 'fusion of horizons' (Gadamer, 1976). This study provides a meaningful insight into the experience of people who live with the disease and its daily consequences, and suggests as to how biographical disruption is relevant in entailing suffering. This study has underlined the importance and relevance of biographical disruption for caregivers, because it is the caregivers for whom the relationship with the patient changes to a caregiver relationship, and they need to construct the meaning around such a significant disruption that the diagnosis has brought about. My contention is that it is the illness which disrupts biography, and people work to cope with it. When it comes to the ‘biographical turn’ in illness literature, this study can have implications in the said field. Possible explanation for tensions between continuity and disruption has been provided by this study. And more exploration and development of this notion of normality defined as a relationship with environment may be helpful in further research towards conceptual development in the biographical illness literature.

The study has further implications for the survivorship literature. There is much biomedical research about cancer, but there is a dearth of literature when it comes to studying and investigating personal experiences of the illness. Living with cancer comes at a heavy cost, because they not only have to go through repeated cycles of invasive treatment, but also manage their everyday life which has been affected and disrupted due to cancer. There has been significant amount of literature on the work of illness, but information work has been mostly seen in the contexts of seeking, obtaining, examining / evaluating and assimilating it. The literature is especially scarce when it comes to the study of illness management in Indian setting. For instance, care work, something that has been at the fulcrum of this study, has been hardly explored in the literature thus far. The experience of caregivers has been explored in this study as part of a dyad, and this has been done as a part of the overall experience of living with cancer. The existing literature has done scant exploration of the way in which the lives of caregivers have been hugely disrupted requiring them to adapt to the ‘new normal’ through various coping strategies.

Though this study has explored the impact of cancer diagnosis and its treatment in relationships, however, further research into living with a spouse/ partner with cancer would be beneficial in identifying how partners could work together to develop joint coping strategies. This study has identified a need for further research into the effect of having a parent with cancer on the child, which could be explored from both the parent’s and child’s perceptions. Furthermore, the effect of living with a mother with cancer is an area for further research. It would be interesting to be able to interview the children of mothers with cancer once they reach adulthood to determine its impact on them. In addition to this, research into how children of parents with cancer cope themselves would also be a further area for future research.

This study builds on the existing body of knowledge that explores experiences of living with cancer. Due to the varying dimensions that contribute to cancer phenomenon, there are great opportunities for researchers of all disciplines and levels to take advantage. Based on the findings of this study, I have anticipated a few recommendations outlined in the following section. These may serve as suggestions for future research and care enhancement.

This study may be of help to health care professionals in their understanding of the kind of support that those who go through such a transitional phase may require, which will go a long way in making their interactions with the concerned individuals more empathetic and therapeutic. My study has made evident the drastic and life-altering changes to the self that happen to patients and caregivers after the diagnosis, which significantly affect them psychologically. Understanding of these altered social and psychological needs would be of great significance to the health care professionals in their dealing with persons living with cancer. It is imperative for health care professionals to try and understand the psycho-social impact of being diagnosed with cancer, which would then allow them to individualise the support to the concerned individuals. This would help rectify the current practice where the biomedical model largely ignores the psycho-social impact of cancer on concerned individuals and primarily focuses on the experience of physical symptoms. Health care professionals need to prioritise living well with the disease. People who are diagnosed with cancer and need psychological support, should be able to get it promptly and they should not be made to wait on the basis of their physical symptom profile. It is crucial for the health care professionals to realise the greater impact of cancer on the patient and the carer, and not just be fixated only on the physical aspect. They should be ready and skilled to be able to provide that support, and if need be, should consider providing / referring to additional sources of support.

In the Indian context, provisions of cancer care, for both the patients and the caregivers, are unsatisfactory. However, India has a generalised provision for delivering palliative care in several sites and with access to morphine and sources of funding. In India, hospice and palliative care services, involving inpatient provisions, outpatient clinics and home care services, are provided through non-governmental organisations, hospices, public and private hospitals, outreach clinics and volunteer networks. In India, nineteen regional cancer centres function (Rao, Gupta and Agarwal, 2016). There are only 908 palliative care centres, serving merely one per cent of a population of over 1.2 billion (Khanna and Lal, 2016). Enhancement of palliative care in the country is essential due to the present scenario of its population's health status. The GLOBOCAN project has made a dire projection for India’s cancer scenario where they estimate India’s cancer burden to double in 20 years, from just about a million new cases in 2012 to about 1.7 million in 2035. Furthermore, a study by Takiar, Nadayil and Nandakumar (2010) shows that more than 80% of cancer cases in India are in advanced stages, and hence the greater need for palliative care and pain relief for these patients (Taikar, Nadayil and Nandakumar, 2010).

Although the knowledge and experience about pain and suffering and the ways of controlling and diminishing both exist, yet palliative care in our country is not readily available to all those in need (McDermott, Selman and Clarke 2008, Khosla, Patel and Sharma, 2012; Kausal, Bhattarcharya and Singh, 2018). According to McDermott, Selman and Clarke (2008), palliative care services existed in only 16 of India's 35 states and territories, with a limited palliative care provision. To make palliative care services accessible to everyone in need in a diverse country like India, specific immediate changes in our public health care system are required. To begin with, there has to be an overhaul with the palliative care system in India with a national-level health policy. The emphasis has to be on the right to health and the right to care of the individual which are immediately required. Along with this, pain management and palliative care have to be included in undergraduate and postgraduate medical and nursing curriculum. Narcotics regulations, specifically in oral morphine, should be reassessed and included as essential drugs in the national and state level essential drug list.

Furthermore, centralised enforcement of opioid regulations will enhance the accessibility of palliative care. Thus, collective and effective efforts are required to overcome regulatory barriers, with an added emphasis on capacity building of medical and care professionals at all levels, by developing tools, conducting workshops for doctors, nurses and other health care professionals working across different settings, increasing the number of palliative care centres throughout the country for enhanced accessibility and availability, encouraging, mobilising and strengthening the local people for participating in and implementing palliative care services in their community. Moreover, it can be done by providing home and community-based palliative care, by supporting the health care professionals and family/ neighbour carers in order to deliver the care at the earliest, and effectively. A multidisciplinary team including medical practitioners, clinical nurses, technicians, allied health staff, volunteers, NGOs, social workers, sociologists, anthropologists should work together to provide care effectively. Apart from adopting and enforcing the laws and policies, general awareness is essential to achieve the goal. Furthermore, a model similar to The Neighbourhood Network in Palliative Care (NNPC) of Kerala, a sustainable community-led initiative, developed in 2001 by four NGOs and eight palliative care centres, providing outpatient and home-based palliative care in Kerala, can be used by other states to integrate self-sufficient palliative care where the community is empowered to provide sustainable care to the patients, especially those diagnosed with cancer and their families in need. It operates by (a) mobilising the community and ownership by the local community members, (b) incorporating local self-government institutions and lastly, (c) integrating palliative care in the primary healthcare system. The model emphasises on the active participation of local people in addressing the necessities of the patients and their families and establishing a nexus of medical and care professionals to support these initiatives, among other things (Bollini et al., 2004; Paleri and Numpeli, 2005; Rajagopal and Kumar, 1999; and Ajithakumari, Sureshkumar and Rajagopal, 1997). This model is cost-efficient and provides both the coverage and the quality, leading to a broader integration of the program into the mainstream health infrastructure. To provide good quality palliative care, sustainability of resources is essential. Like the NNPC model, supportive community networks sustained by volunteerism can deliver sustained and quality care to cancer patients and their families.

Keeping these in mind, one can introduce and integrate palliative care with respect to their health care delivery system. The advantage of this concept and the provision comes from its uniqueness, as it can be delivered effectively and accessibly in a community from both resource-rich and resource-poor countries through primary health care teams, especially by family doctors and community nurses and volunteers, in collaboration with palliative care specialists. Irrespective of the health care system, primary care is evident in some developing countries. Incorporating palliative care in primary care will help in identifying and addressing people with any and all forms of life-threatening illness at any point in the illness trajectory by assessing their current and future needs with systematic planning and interventions. The provisions could be improved and integrated through various collaborations.

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APPENDICES

Appendix I

Biographical details of the participants

1. Name:
2. Age:
3. Sex:
4. Religion:
5. Marital status:
6. Educational qualification:
7. Occupation:
8. Permanent place of residence:
9. Details of family:
    i. Type of family:
    ii. No of Members:
    iii. Net family income:
    iv. Any experience of past illness in the family:
    v. Profile of the family members

Sl	Name	Age	Sex	Relation	Education	Occupation

10. Diagnosis:
11. Time and place of diagnosis:
12. Insurance facility:
13. Approx. expenditure:

Appendix II

SEMI- STRUCTURED INTERVIEW GUIDE:

Patient:

- Their perception about their illness, their condition.
- How this illness has affected their daily life?
- What are the issues they are concerned with?
- How they feel about it?
- experiences with caregivers, both professional as well as kin
- How they describe their relationship with their care givers?
- What is their perception about the health care system in case of professional care? Is there any issue that should be taken care of? Their suggestions, etc.

1. Please tell us about your present state of health.
2. Is your present condition a recurrence of past illness or it is a further progression?
3. How this illness affects you? [your performances, relations, work]
4. How it affects others? [others may include family members, kin, friends, neighbors, any individuals as suggested by the participant; in terms of performing their daily activities and relations]
5. How you feel about –
    a. The situation and/or illness [cancer]
    b. What do you think you would do if it [the situation and/or illness (cancer) i.e. as mentioned by the participant] progresses further?
6. Has your view about yourself changed since you became ill?

    a. If so, how you viewed yourself earlier and how you see yourself now, kindly elaborate.
7. Has your view about your body changed since you became ill?
    a. If yes, kindly elaborate how you viewed your body earlier and how you see it now?
    b. Has your illness and/or body affected your identity?
        i. If yes, in what ways? Please describe.
8. Has your view about the world changed since you became ill?
    a. If so, kindly elaborate the way you used to view it earlier and how you see it now.
9. Is there anything else you would like to talk about that hasn’t come up or that you think is important for us to know about the experience of having cancer?
10. Kindly tell us the experience of your illness and treatment to date [or ‘illness and diagnosis’ as appropriate].
11. Could you please tell us about your entire experience, from the time when you realized that there is something wrong, to till date.
12. How did you cope with the entire situation?
    a. The diagnosis shock
    b. The treatment and procedures
    c. Other forms of crisis [physical, emotional, spiritual, existential and psychological]
13. What are the situations your carer (kin) faced in their everyday life, since the illness?
14. How did your carer [kin] cope with the situation?
    a. How s/he managed the situation (according to you)? Kindly elaborate.

        i. The diagnosis shock
        ii. The treatment and procedures
        iii. Other forms of crisis [physical, emotional, spiritual, existential and psychological]

15. When you were diagnosed, did you expect things to turn out in this way as it is now? If yes, did you think you were prepared for what was to come? If yes, please narrate how you prepared yourself? [physically, emotionally] If no, what were you expecting? How it is [participant's initial expectation] different from your lived experience?
16. Would you like to say a few words about your perception of the future?
    a. If the participants had (any) plans, explore whether they have been able to realise them [in case of prior plans] or how they will realize them [future plans]?
    b. How plans [as mentioned by the participants] have changed?
17. At this state of your condition, what are your concerns? [for instance, about yourself, family, work/ livelihood, time, after life, deeds (death)]
18. Who are the carers for you?
19. Please tell me about your relation with them. What task do these [as mentioned by the participants] individuals perform for you or on your behalf?
20. How would you describe your relation with your carers? Do you discuss your concerns with them? What are the types of concerns you discuss?
21. What affect has illness and treatment had on your relationships with others?
22. During the times of crisis, what were the types of help you required?
    a. Who helped you and/or your family?

    b. How did they help you and/or your family? Kindly elaborate, and please share a few experiences.
    c. What was their relation you and/or your family?

23. Are there times, when you felt like you needed someone?
    a. If yes, when you felt that you needed someone?
    b. Why you needed someone?
    c. In addition, did you actually have anyone at those moments?
24. What are the things in the entire process [illness trajectory] made it harder or difficult for you in terms of addressing and managing the situation?
25. Is there anything else that might have helped you?
26. Is there anything else you would like to say?

Kin – Family care giver:

- Perception about the illness and the condition of the patient
- Their relationship with the patient
- Their conception of care, values and constraints associated with caring
- Views about the system of health care, problems, ideas for improvement
- How do they imagine their role?
- What is at stake as their everyday lives are re-oriented by caregiving? How do they meet the 'conflicting' demands on their time and identity in the face of providing care full time?
- How they work to help the patient make sense of her/his condition; as well as how they console themselves regarding this situation.

- Problems faced- emotional, financial…
- Issues that should be taken care of? Their suggestions, etc.

1. What do you think about – [patient’s name] present state of health?
2. Is the present condition a recurrence of past illness or it is a further progression?
3. Please tell us how this illness has affected – [patient’s name]?
4. How this illness affects you? [your daily activities, performances, relations, work]
5. How it affects others? [others may include family members, friends, neighbors, any individual as suggested by the participant; in terms of performing their daily activities and relations]
6. Please tell us about your understanding of - [subjective perception]- The situation, illness (cancer)
7. Is there anything else you would like to talk about that hasn’t come up or that you think is important for us to know about the experience of being close with someone having cancer?
8. Kindly tell us about your understanding of care.
9. What are the things that you have to look after? [the family, patient] What are the tasks you have to perform while taking care of- [patient’s name]?
10. Do you face difficulties while taking care of –[patient’s name]?
11. If yes, what are the difficulties you face?
    i. Can you tell me certain incidences, where it was difficult to manage the situation? How you manage(d) these difficulties? Do/ Did others (family members, friends, neighbors) help(ed) in managing the situation? If yes, who are they? Through what ways they contributed in this. Please share.
12. Could you indicate some of the needs that are regarded as important by you as a carer for – [patient’s name]?

13. Please tell us about your needs (as a carer). [for instance, emotional assistance, knowledge/ hands on training on basic medical procedures, counselling, legal rights]
14. Are there other concerns that you feel needs attention? If yes, what are they?
15. Is there something that you would like to have, while you are availing care and treatment?
16. Who are the other carers along with you? What task do these [as mentioned by the participants] individuals perform? How would you describe your relation with other carers?
17. Kindly tell us your experience of – [patient's name] illness and treatment to date.['illness and diagnosis' as appropriate].
18. Please take us back to the time when you first realized there was something wrong, and bring us forward to present date? Kindly share the situations you faced. [for the entire trajectory]
19. How did you cope with-?
    a. The diagnosis shock
    b. The treatment and procedures
    c. Other forms of crisis [physical, emotional, spiritual, existential and psychological]
20. Please elaborate how others [relatives and friends] cope with the situation.
21. When –[patient's name] was diagnosed, did you expect things to turn out this way as it is now?
22. Would you like to say a few words about your perception of the future?
    a. If the participants had (any) plans, explore whether they have been able to realise them [in case of prior plans] or how they will realize them [future plans]?
    b. How plans [as mentioned by the participants] have changed?
23. At this state, what are your concerns? [for instance, about yourself, family, work/ livelihood, time, life , deeds (death)]

24. Has this [cancer and the tasks of caring] affected your relations with –[patient's name] and others? If it has, how it was prior to cancer, and how it is now?
25. What affect the illness and treatment had on your relationships? [with the patient and others]
26. What type of help you required?
27. Please tell us about the persons who helped you and/or your family? What was their relation you/ your family? How did they help?
28. Are there times, when you felt like you needed someone? If yes, when and why? Did you actually have anyone at those moments?
29. What made it harder (in addressing, managing the situation)?
30. Is there anything else that might have helped you?
31. Is there anything else you would like to share with us, which might be important for us to know?