

IMPORTANCE OF PSYCHO-SOCIAL SUPPORT TO CANCER PATIENTS AND SURVIVORS TO COPE WITH CANCER

An Assessment of Interventions by
Sanjeevani ... Life Beyond Cancer



Research Unit
College of Social Work,
Nirmala Niketan, Mumbai



Oil on Canvas by Ruby Ahluwalia

**HOW IMPORTANT IS PSYCHO-SOCIAL SUPPORT TO
CANCER PATIENTS AND SURVIVORS
TO COPE WITH CANCER?**

**An Assessment of interventions by
Sanjeevani...Life Beyond Cancer
Mumbai**

A Research Study Undertaken in joint collaboration of



**Sanjeevani...Life Beyond Cancer,
Mumbai**

and



**Research Unit
College of Social Work
Nirmala Niketan, Mumbai**

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LIST OF ABBREVIATIONS

AAY	Antyodaya Anna Yojana
ACTREC	Advanced center for Treatment, Research and Education in Cancer
ATRCTRI	Acharya Tulsi Regional Cancer Treatment & Research Institute, Bikaner, Rajasthan
CGHS	Central Government Health Scheme
CHC	Community Health Centre
DM	Doctorate of Medicine
FGD	Focused Group Discussion
FSSAI	Food safety and Standard Authority of India
GCRI	Gujarat Cancer and Research Institute, Ahmadabad, Gujarat
HIV	Human Immunodeficiency Virus
HMCPU	Health Minister's Cancer Patient Fund
IARC	International Agency for Research on Cancer
ICMR	Indian Council of Medical Research
IDI	In-depth Interview
JIPMER	Jawaharlal Institute of Postgraduate medical Education and Research, Puducherry
MGIMS	Mahatma Gandhi Institute of Medical Sciences, Wardha, Maharashtra
NCCP	National Cancer Control Program
OPD	Out Patient Department
PHC	Public Health Centre
PMNRF	Prime Minister's National Relief Fund
PPS	Probability Proportion to Size
RST	Rashtra Sant Tukdoji Regional Cancer Hospital, Nagpur, Maharashtra
SPSS	Statistical Packages for Social Sciences
SMS	Sawai Man Singh Hospital, Jaipur, Rajasthan
TB	Tuberculosis
TISS	Tata Institute of Social Sciences, Mumbai
WHO	World Health Organization





CHAPTER 1

BACKGROUND

1.1	Introduction
1.2	Cancer prevalence and existing provisions for cancer care in India
1.3	About the organization – Sanjeevani...Life Beyond Cancer
1.4	Rationale of the study
1.5	Objectives of the study

CHAPTER I

BACKGROUND

1.1 INTRODUCTION

Cancer has been on substantial rise in the past few decades and has become a big threat to human society globally. Based on GLOBOCAN estimates, about 14.1 million new cancer cases and 8.2 million deaths occurred in 2012 worldwide. By 2030, the global burden is expected to grow to 21.7 million new cancer cases and 13 million cancer deaths simply due to the growth and aging of the population. Over the years, the burden has shifted to less developed countries, which currently accounts for about 57 percent cases and 65 percent of cancer deaths worldwide (IARC, 2012).

Cancer is a life threatening disease. It is indisputably associated with a lot of fear and stigma (Dinshaw, Shastri, & Patil). The diagnosis itself and subsequent treatment of cancer can be emotionally distressing. It is still considered synonymous with death, pain and suffering (Powe BD, 2003). This seemingly terminal illness brings with itself loads of critical problems and miseries more so for the underprivileged society. Once this dreadful illness gets detected, families get caught up in vicious cycles of debts and deprivation taking a toll not only on the financial status of the household but severely affecting even their psycho-social levels. Unfortunately, its psychological impact on patients though critical has been a highly neglected aspect for health professionals involved in the treatment process. Studies clearly reflect that psychological and social aspects of the patient and family experiences are somehow not yet fully integrated into overall cancer care (Johansen & Rosberger, 2012). Myths and misconceptions about this chronic illness are also not uncommon. Review of literature also indicated that psycho-social and emotional problems occur frequently not only at the detection stage but also during the advanced and terminal stages of cancer, and need to be appropriately detected and managed (Chaturvedi, 1994). Inadequate healthcare facilities and insufficient medical experts add to their miseries. After a lot of struggle, even if they land up getting some medical treatment, their psychological need to cope up with this traumatic and distressing illness often gets the least priority. The emotional distress due to all these trepidations needs to be alleviated by providing them with some psycho-social support, in order to improve the coping ability of the patient and his/her overall quality of life.

1.2 CANCER PREVALENCE AND EXISTING PROVISIONS FOR CANCER CARE IN INDIA

Cancer incidence is rising at a steady rate in India. Although the prevalence of cancer in India is lower than in other countries, cancer ranks as the sixth leading cause of death in India (Report on Medical Certification of cause of Death 2012).

According to a 2016 report by ICMR, the estimated total burden (for the country as a whole) of cancer for the year 2016 is around 14.5 lakh new cases and likely to be 17.3 lakh new cases and over 8.8 lakh deaths due to the disease by 2020 with cancer of breast, lung and cervix topping the list. Many cancer cases in India are associated with tobacco use, infections, and other avoidable causes. Social factors, especially inequalities, are major determinants of India's cancer burden, with poorer people more likely to die due to this traumatic illness before the age of 70 years than those who are more affluent (Mallath, 2014).

The context of cancer care in India is characterized by high incidence, late detection, and lack of access to quality affordable care to majority of the populace and hence high mortality. Data reveals that barely 12.5 percent patients avail treatment in early stages of the illness, thus a huge proportion of cases report for diagnostic and treatment services in advanced stages of disease resulting in poor survival and high mortality rates (ICMR, 2014), (Dinshaw, Rao, & Ganesh, 1999).

In contrast to the growing incidences of cancer cases, there is a visible dearth of oncologists in the country. Currently there are around only 2000 medical and radiation oncologists in India - one per 5000 newly diagnosed cancer patients - and even the most basic cancer treatment facilities are non-existent in almost all remote or rural areas across the country (Sinha, 2014). The delivery of affordable and equitable cancer care is one of India's greatest public health challenges. The National Cancer Control Program (NCCP) for India was formulated in 1984 with the four major goals of primary prevention of tobacco related cancers, early detection of cancers at easily accessible sites, augmentation of treatment facilities and establishment of equitable, pain control and palliative care network throughout the country.

The existing schemes under NCCP consists of financial assistance to voluntary organizations, District Cancer Control scheme, Cobalt Therapy Installation, Development of Oncology Wings in Government Medical College Hospitals and Regional Cancer Centers.

Some of the central government schemes for cancer patients are as below:

- Prime Minister's National Relief Fund (PMNRF): Assistance from PMNRF is given to meet the expenses partially for medical treatment like heart surgeries, kidney transplantation and cancer treatment.
- The Ministry of Health & Family Welfare runs two schemes under which it offers financial assistance to poor patients. The Health Minister's Cancer Patient Fund (HMCPF) is available for patients below the poverty line. This is admissible for treatment in 27 regional cancer centers across the country.
- The Health Minister's Discretionary Grants offers up to a maximum of Rs. One lakh to poor patients to assist with a part of the hospitalization/ treatment expense in government hospitals in cases where free medical facilities are not available.

- The Central Government Health Scheme (CGHS) is applicable for retired Central Government employees & dependents, which offers coverage for cancer treatment at approved rates from any hospital, apart from the hospitals set up under CGHS.
- Indian Railway offers completely free travel to cancer patients and the attender/ bystander has to pay only 25 percent of Class II fare. Air concession of 50 percent is also offered to patients traveling for their treatment.

Some State-Specific Schemes in the country are as below:

- Aarogyasri Scheme: The government of Telangana introduced the Aarogyasri Scheme, which provides financial protection to families living below poverty line up to Rs. two lakhs in one year for the treatment of serious ailments requiring hospitalization and surgery. This scheme provides coverage for various treatments including cancer treatment (surgery, chemotherapy & radiation therapy).
- The Chief Minister's Relief Fund provides financial assistance to needy people for cancer treatment.
- Cancer Suraksha Scheme: The government of Kerala, offers the Cancer Suraksha Scheme, under which children under 18 years of age get free cancer treatment via some designated Government hospitals in the state.
- Rajiv Gandhi Jeevandayee Arogya Yojana: The state of Maharashtra offers this scheme where 971 surgeries/ procedures are covered for those holding yellow ration cards, Antyodaya Anna Yojana card (AAY), Annapurna card and orange ration card. The Scheme shall provide coverage for meeting all expenses relating to hospitalization of beneficiary up to Rs. 1, 50,000/- per family per year.

However, most of these initiatives are neither designed to address the complexity of cancer care nor take into account the need of psycho-social care for the cancer patients and their caregivers. Review of literature clearly highlights that although cancer is a psychosomatic illness, no government scheme in India emphasizes on the provision of psycho-social care to cancer patients (Mallath, 2014). This calls for an immediate need to integrate this crucial aspect into the medical line of treatment to make it more holistic for a speedy recovery phase that is mentally less torturing for all those associated with this traumatic illness.

1.3 ABOUT THE ORGANIZATION — SANJEEVANI...LIFE BEYOND CANCER

Sanjeevani...Life Beyond Cancer (henceforth interchangeably referred to as Sanjeevani), an award winning registered Public Trust, is a non-profit organisation working for prevention and early detection of cancer and providing care, counselling and rehabilitation to persons fighting cancer with focus on navigating them from disease to wellness through various activities.

Sanjeevani was founded in 2012 by Ms. Ruby Ahluwalia. Ruby, a serving bureaucrat, was diagnosed with Triple Negative (Stage 3) Breast Cancer in 2009. Having undergone the emotional stress, financial drain, physical pain and challenges associated with fighting this deadly disease, she decided to make the journey for patients fighting cancer less strenuous. A socially aware person, Ruby, after completing her treatment, started **Sanjeevani... Life Beyond Cancer** under the guidance of a Board of Mentors which comprises of eminent persons from a wide range of fields viz., Oncology, Finance, Consultancy, Chartered Accountancy, Management Education and Social sector.

Started in 2012 with one program at one centre in Mumbai, today Sanjeevani helps patients thru its nine centres spread across five states viz. Mumbai, Nagpur, Wardha (Maharashtra); Jaipur and Bikaner (Rajasthan); Ahmedabad (Gujarat); Kolkatta (Bengal); and Puducherry. We intend making all programs available across all RCCs across all States.

Sanjeevani's charter is to raise the bar of Cancer Care in India with single minded focus on navigating patients from *Dis-'ease'* to *Wellness*. **All activities by Sanjeevani are provided to patients free of cost.**

All programs instituted by Sanjeevani work towards the same objective. These being:

1. In-hospital interventions for cancer patients and their families:

Sanjeevani Counselling and Rehabilitation Centres aim to motivate and encourage patients to complete their treatment and keep a positive outlook towards treatment as well as life. The centres are manned by Sanjeevani Counselors (mostly rehabilitated cancer survivors, on payroll of Sanjeevani) who handhold the patient during and after the treatment by:

- a. Providing emotional, psychological and logistical support to patients and their relatives;
- b. Navigate patients through the whole treatment process
- c. Hand holding patients with limited family support through the treatment;
- d. Encourage patients to adhere to medical advice throughout as well as post treatment; and
- e. Facilitate better and more meaningful interaction between patients and doctors.

SCRCs Operate in Super Specialty Cancer Hospitals designated as Regional Cancer Hospitals at Mumbai, Nagpur, Wardha, Ahmedabad, Bikaner, Jaipur, Kolkata and Puducherry and last year enriched lives of over 25000 patients.

2. Rehabilitation programs for survivors:

Once the treatment at hospital is over, patients need to take charge of their lives but are faced with two challenges:

- a) The fear of recurrence of cancer; and
- b) Get gainful employment.

Wellness and Rehabilitation programs run by Sanjeevani enable and empower patients to address these needs.

2 a) Certificate Course on Onco – Care giving

This is a unique 4 months course, to train cancer survivors to become cancer caregivers. Envisaged and delivered in collaboration with Tata Institute of Social Sciences and Tata Memorial Centre, the course curriculum is designed to focus on empathetic, emotive, nutritional, paramedical, physio-therapeutic as well as spiritual aspects of oncological care.

Twin objectives fulfilled by this course are:

- a) Skill development of cancer victors resulting in rehabilitation; and also
- b) Produce a pool of professionally trained and certified care givers for cancer patients.

Three batches of the course have already been conducted at Mumbai and Ahmedabad have successfully transformed the lives of over 43 underprivileged persons, mostly cancer victors, by enabling and empowering them to embark upon their journey as Care-givers to cancer patients.

Over 90 percent have being successfully placed with organizations providing care to cancer patients.

2 b) Sanjeevani Wellness Centers

Once the treatment at hospital is over, Patients need to take charge of their lives, learn and practice new life enhancing skills enabling them to lead to a better quality of life post-treatment and hopefully reduced chance of recurrence.

To help and assist patients learn these skills Sanjeevani runs Sanjeevani Wellness Centers (adjunct to the SCRCs) that offer very well designed one month course with inputs on Psychotherapy, Nutrition, Emotional Freedom techniques, Yoga, Meditation, Music Therapy and Dance Therapy by trained faculty.

Objective of creating these spaces is to help cancer patients

- a) Deal with the side effects of modern medicine in a better way; and also

- b) Equip them with skills to take responsibility of their own health and build up their immunity systems.

Sanjeevani has been running this program at Mumbai for the past one and half year and the same has enriched live of over 350 patients.

3. Awareness Activities to help create awareness for prevention and need for early detection:

- a) Inclusion of Youth - Sanjeevani Youth Brigade,
- b) Creation of content viz., Films (www.youtube.com/sanjeevanilbc)
- c) Publishing inspirational stories of cancer victors (www.sanjeevani-lifebeyondcancer.com/Satori.pdf)
- d) Cancer awareness / detection camps,
- e) Cancer survivor/ Care givers conferences, and
- f) Can-a-thons / Can-a-rides (Walkathons / Bike rides to reflect the I-can spirit).

4. Advocacy with Policy makers / Philanthropic Organizations / Donor Groups.

Sanjeevani endeavors to represent the need for psycho social support for cancer patients' at all relevant forums.

In a nutshell, Sanjeevani endeavors to motivate and encourage cancer patients to keep a positive outlook towards life and cancer treatment in particular and enrich the lives of cancer survivors in a way that the patient feels more complete after the whole cancer experience and looks at this entire struggle as an opportunity to blossom up in life and not as a catastrophe.

1.4 RATIONALE OF THE STUDY

There is a state of sudden shock and trauma the moment cancer gets detected in one's life. The routine life comes to a sudden halt and seems as if everything has come to an end. The mere fact that someone in the family has been detected with cancer spreads a wave of uncertainty and eventually death begins to hover in the entire household. Even those who are emotionally strong collapse. The entire period from detection to recovery is marked with distress, anxiety and fear. Actually many times the cancer patients are better adjusted to others in the community but alienated from themselves. Researchers have come to conclusion that common difficulties for oncology patients are inability to express openly, emotional aggression and suppressing depressive mood. Psychological factors which might affect the occurrence of oncology diseases are stressful life events, social relationships and social support, personality traits, coping with disease, negative emotional reactions, psychiatric disorders and suppressing feelings (Gregurek, Braš, Đorđević, Ratković, & Brajković, 2010).

Medical treatment has been looked upon as the only line of treatment for cancer patients all across the globe. The scenario in India is no different. Unfortunately, their need of psycho-social support to cope up with this life threatening and traumatic illness remains completely ignored. In spite of substantial proportion of cancer patients suffering from emotional disturbances, studies have highlighted that primary care physicians fail to identify anxiety and depression in their patients (Passik & Dugan, 1998). Consequently, there is a decreased compliance to medical care, longer hospital stay, and poorer quality of life. Timely intervention could be highly beneficial and cost effective too (Ashraf & Gupta, 2004), (Payne, Hoffman, Theodoulou, Dosik, & Massie, 1999). According to a study led by Jane Beith, a medical oncologist at the University of Sydney in Australia, about 50 percent of all cancer survivors and 70 percent of young breast cancer survivors report moderate to high fear of recurrence. The fear can be so distressing that it negatively affects medical follow-up behavior, mood, relationships, work, goal setting, and quality of life. Yet, interventions to alleviate this anxiety and fear are lacking (Beith, 2017). Thus, cancer patients require not only medical treatment approach but psycho-social measures as well to cope up with associated emotional distress. Another study highlights that early recognition and management of emotional distress significantly decreases the burden on health care cost and improves the quality outcome in cancer treatment (Santre, Rathod, & Maidapwad, June 2014). Many clinicians and researchers have argued that positive feelings of hope and happiness are beneficial in treating serious medical illnesses such as Cancer (Irving, Snyder, & Crowson, 1998). Importance of hope to health care is linked with an improved quality of life (Farran, Wilken, & Popovich, 1992), less use of health care resources and better health outcomes (Herth, 1989).

Psycho-social problems are common in cancer patients. Many studies attempting to focus on the need assessment for patients with cancer have shown that almost one-third patients strongly report the need for psycho-social care covering a wide range of psycho-social needs. Most commonly reported needs include help with coping with anxiety, depression, and fear of recurrence or progression, help with better communication, and support for relatives, families, or spouses. However, the remarkable advances in biomedical care for cancer have not been matched by achievements in providing high-quality care for the psychological and social effects of cancer. Numerous cancer survivors and their caregivers report that cancer care providers did not understand their psycho-social needs, failed to recognize and adequately address depression and other symptoms of stress, were unaware of or did not refer them to available resources, and generally did not consider psycho-social support to be an integral part of quality cancer care (Weis, 2015).

Furthermore, although psycho-social needs of cancer patients are well documented in the literature, there exist barriers to the delivery of such services to the cancer patients. Psycho-social care must be delivered to every patient who needs it. However, the reality may be quite different as hospitals have often been reluctant to establish such services due to financial and other restrictions (Singer, Dieng, & Wesselmann, 2013).

With the minimal role of government hospitals in providing much needed psycho-social services to cancer patients and survivors, introducing psycho-social care into routine oncology practice attempted by Sanjeevani...Life Beyond Cancer is an important step to bridge this gap. Since 2012, Sanjeevani...Life Beyond Cancer public trust is working for the cause of helping and supporting the cancer patients and survivors across the country functioning through its nine centres across India. With the expansion of this project in different parts of the country, the organisation felt a strong need to assess the impact of the services provided by them and to identify the gaps (if any) to get concrete directions for further improvisation of the project interventions.

With increasing incidences of cancer all over the world, the role of counselors in providing psycho-social and emotional support to the patients and encouraging them to adhere to the treatment protocols post treatment becomes crucial. Consequently, it becomes imperative to assess the role of Sanjeevani psycho-social caregivers from the point of view of creating awareness amongst the beneficiaries, to judge their satisfaction levels and to understand the set of challenges faced by the psycho-social caregivers themselves in dealing with the patients who are passing through difficult traumatic conditions. Moreover, constructive inputs from the medical doctors of the respective super specialty hospitals in the form of their perspective towards the importance of psycho-social care and whether it should be integrated in the existing health system was essential to improve the program to a large scale.

This study was thus an attempt to assess the need of psycho-social support for cancer patients and to assess the interventions by Sanjeevani...Life Beyond Cancer in this direction to alleviate the sufferings of the cancer affected patients seeking treatment across nine centres of Sanjeevani.

1.5 OBJECTIVES OF THE STUDY

Broad objective of the study was to identify the gaps in existing program and assess the effectiveness of the interventions by Sanjeevani...Life Beyond Cancer across nine centres in India. More specifically the study looked at the following objectives-

1. To assess the need of psycho-social care amongst cancer patients and survivors across nine centres of Sanjeevani.
2. To assess the awareness and adequacy about psycho-social services provided by the Sanjeevani psycho-social caregivers to the cancer patients.
3. To understand the challenges faced by the Sanjeevani psycho-social caregivers in providing psycho-social services to the beneficiaries.
4. To understand the perspective of medical doctors and government hospitals towards the interventions made by Sanjeevani...Life Beyond Cancer.





CHAPTER 2

METHODOLOGY

2.1	Introduction
2.2	Research design
2.3	Sources of data
2.4	Sampling technique & Sample selection
2.5	Tools of data collection
2.6	Data processing and analysis
2.7	Limitations of the study

CHAPTER II

METHODOLOGY

2.1 INTRODUCTION

This chapter describes the research methodology used to achieve the desired objectives laid down for the study. Owing to the nature of the objectives, both quantitative and qualitative methods of research have been deployed which are discussed in detail in this chapter.

2.2 RESEARCH DESIGN

The study largely adopts Descriptive Research Design as it focuses on understanding the role played by Sanjeevani as an organization in making a difference in the lives of cancer patients. A descriptive design allows the researcher to systematically describe a situation, problem, phenomenon, service or program, or provides information about, say, the living conditions of a community, or describes attitudes towards an issue. For example, it may attempt to describe the types of service provided by an organization, the administrative structure of an organization, the needs of a community, or the attitudes of employees towards management (Kumar, 2011).

This piece of research also attempts to gain insights into the problems of cancer patients and hence the need to explore how vital is psycho-social support for cancer patients to cope with this terminal illness. This has been achieved through telephonic interviews with 250 patients and a series of Focus Group Discussions (FGDs) and In-Depth Interviews (IDIs) with the other stakeholders including patients which gives an exploratory angle to this study.

2.3 SOURCES OF DATA

Very few studies to assess the need of psycho-social care for cancer patients have been attempted in the domain of social sciences. Moreover, one of the major objectives of the study was to evaluate the impact of the interventions made by Sanjeevani to alleviate the sufferings and problems faced by cancer patients during their course of treatment. Consequently, to make the study holistic, it was conceptualized to use both – primary as well as secondary sources of data. However, primary data forms the major base of this report. It has been gathered through telephonic interviews and face to face interviews with the cancer patients, medical experts in the field of oncology working in reputed cancer hospitals of Mumbai and Ahmedabad and psycho-social care givers working with Sanjeevani from different states across the country. The secondary data has been used to substantiate and support the findings of the primary data and has been incorporated by referring to books, journals, newspaper articles, authentic websites and other relevant works.

2.4 SAMPLING TECHNIQUE & SAMPLE SELECTION

To enable a representative sample covering different types of cancer patients, data was collected telephonically from 250 patients residing across the country. The cancer patients across seven centers of Sanjeevani in four states namely Gujarat, Rajasthan, West Bengal and Maharashtra were selected using the Probability Proportional to Size (PPS) method of sampling based on key parameters of the patients like patients' age and type of cancer they were suffering from. The selection was done from database of cancer patients who were provided services by the Sanjeevani psycho-social care givers in the years 2015 and 2016 at the respective centers. However, due to high mortality rate among the elderly patients recorded in the database, PPS method had to be replaced later by random sampling of the patients from the database of patients that were alive. An attempt, however, was made to select equal number of patients from both the years to make the sample representative.

To understand the need of psycho-social support to the cancer patients and assess the awareness and adequacy about psycho-social services provided by Sanjeevani to the cancer patients, gain insights into the perceptions of oncologists about services provided by Sanjeevani and to understand the challenges faced by the psycho-social care givers, the qualitative method of data collection was effectively deployed. The data was collected from two centers of Sanjeevani viz. Mumbai and Ahmedabad through face to face interviews with eleven patients, six doctors and three psycho-social care givers using Convenience sampling technique of Non-probability sampling method. Five patients, three doctors and two psycho-social care givers were selected from Mumbai and remaining from Ahmedabad. Furthermore, six FGDs were conducted with the total participation of 56 cancer patients, three FGDs each from Mumbai and Ahmedabad. Focus Group Discussion was also conducted with the remaining twelve Sanjeevani psycho-social care givers working at different locations across India to understand their views and opinions on the aspects closely related to the objectives of the study.

2.5 TOOLS OF DATA COLLECTION

A semi-structured interview schedule was developed and administered to cancer patients across the country through telephonic interviews. As part of the qualitative data, Focus Group Discussions and In-depth Interviews with patients, doctors and psycho-social care givers were conducted based on specially designed guidelines developed to meet the study objectives. Care was taken to include those patients in FGDs and IDIs who have not been covered in the telephonic interviews. On an average around eight to ten cancer patients participated in each of the FGDs. Selection of the psycho-social care givers for the face to face interviews was done on the basis of their work duration with Sanjeevani. Those who served the organization for a longer duration were given preference. The terms 'researched' has been used for cancer patients, oncologists and psycho-social care givers while 'researcher' refers to the agency carrying out the research study. The entire

process of data collection was carried out in strict accordance with the ethical considerations of a research study. Informed consent was sought from participants and permission was ensured for usage of their data for research purpose. Measures were taken to protect confidentiality and anonymity of the participants. Provisions were also made to reduce any possible distress caused to participants as a part of data collection process

2.6 DATA PROCESSING AND ANALYSIS

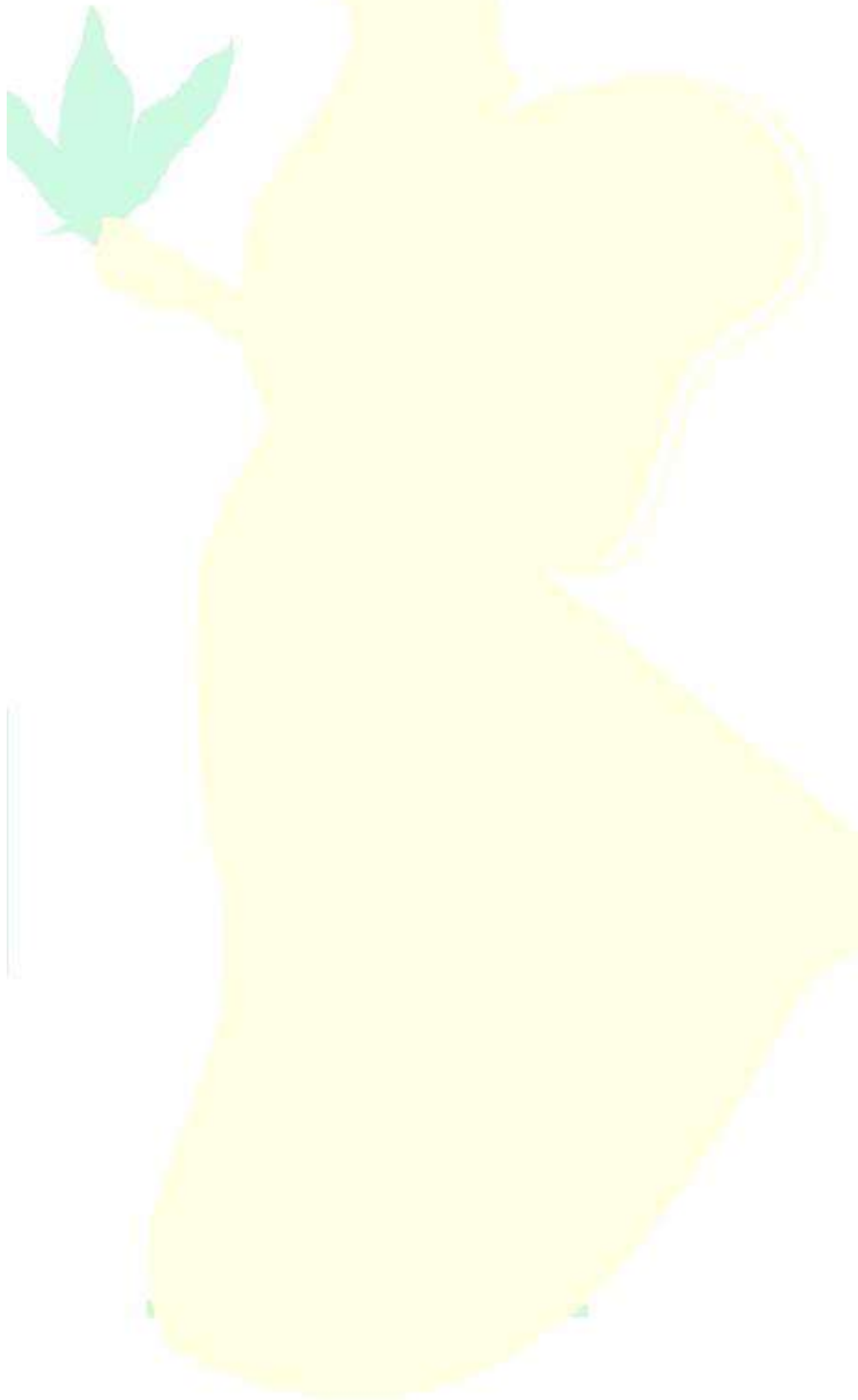
The quantitative data based on 250 cancer patients was fed into and analyzed using Statistical Package of Social Sciences (SPSS) software. As part of the qualitative data analysis, exhaustive case narratives were prepared for all 11 patients, six doctors and three psycho-social care givers as the first and most important step towards formal analysis. This further led to identification of key concepts emerging out strongly from the rich qualitative data. These concepts were then used for a within case analysis. The findings of the within case analysis were then incorporated into the cross-case analysis in order to compare the findings across the cases. Cross-case analysis was used to come up with concrete themes and patterns (hypotheses) emerging out clearly from the data. Commonality in themes across the cases helped to strengthen and validate the initial conceptualization under study. Furthermore, variations across themes helped to bring out new information leading to different perspectives in order to reinstate the initial understanding. Wherever applicable and relevant, the qualitative findings were supported by the quantitative evidences based on 250 patients interviewed telephonically to derive inferences and endorse patterns.

2.7 LIMITATIONS OF THE STUDY

There are certain situations or conditions that are beyond the control of the researcher during the entire course of the study. During this study as well, certain constraints were encountered; however they did not make any major influence either on the data collection process or on the analysis and findings. In any case, the study renders it necessary to mention them in the report.

First and foremost, although interaction with 250 cancer patients all over India was achieved through telephonic medium, the study being heavily qualitative, its findings remain confined to a set of selected cancer patients with whom personal interactions were made and so as such these cannot be generalized at large. Meeting the medical experts and interacting with them at length to understand their views was a big challenge owing to their highly busy and demanding schedule. Almost all the In-depth Interviews with the medical oncologists were conducted within the hospitals where they work. Hence, it was difficult to interact with them for adequate time. Furthermore, the medical oncologists and cancer patients were selected predominantly from Mumbai and Ahmedabad, for logistic convenience. Furthermore, cancer is a disease that changes the entire life of a person including his/her relationships with the family members and others outside the family. Hence, while interacting with such patients, it was difficult for the researcher

to empathize with their emotional state while making them open up for certain questions at the same time. The deteriorated physical state of a few patients also posed some hindrance at times. However, utmost priority was given to the comfort and treatment schedule of the patients while conducting the interviews and discussions.







CHAPTER 3

FINDINGS AND DISCUSSION

3.1	Introduction
3.2	Profile of the respondents
3.3	Perception of cancer patients about problems faced by them their expectations
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CHAPTER III

FINDINGS AND DISCUSSION

3.1 INTRODUCTION

This chapter describes the results of both quantitative and qualitative analysis of the data and presents a discussion of these results in the context of the objectives of the study. It has been divided into different sections to fulfil the requirements of the objectives. The first section deals with the profile of the respondents of this study viz. cancer patients, oncologists and the Sanjeevani psycho-social care givers. The second section attempts to put forth the problems faced by cancer patients and the suggestions given by them to tackle those problems. The third section describes the perception of the Oncologists regarding the problems faced by cancer patients and their family members and caregivers. The fourth section caters to one of the important objectives of the study to assess the need of psycho-social care among cancer patients in India as perceived by patients themselves, by doctors and finally by Sanjeevani psycho-social care givers. The following section analyzes the extent to which Sanjeevani organization has been able to help cancer patients' vis-à-vis problems faced by them. This section includes the perception of not only the cancer patients helped by Sanjeevani but also of doctors and Sanjeevani psycho-social care givers. The sixth section explains the challenges faced by Sanjeevani angels in delivering their responsibilities towards the cancer patients and their caregivers in the cancer hospitals. Finally, the last (seventh) section puts forth the suggestions provided by the oncologists and Sanjeevani psycho-social care givers in the context of the study. The entire chapter can be presented in a tabular form as below-

Section	Details of the section
3.2	Profile of respondents
3.3	Problems faced by cancer patients
3.4	Doctors' perception of the problems faced by cancer patients and their family members and caregivers
3.5	Need of psycho-social care among cancer patients in India
3.6	Impact of Sanjeevani...Life Beyond Cancer
3.7	Challenges faced by Sanjeevani angels
3.8	Suggestions provided by the doctors and Sanjeevani angels

3.2 PROFILE OF THE RESPONDENTS

Exhaustive primary data was collected from cancer patients, both in quantitative and qualitative form while data from doctors and psycho-social care givers was incorporated through interaction with them in the form of In-depth interviews and Focus group discussions to obtain a

comprehensive picture as discussed in the previous chapter. Accordingly, this section has been divided into three subsections as follows.

3.2.1 Profile of the cancer patients

For quantitative analysis, 250 Cancer patients from all across India were interviewed telephonically while interaction with those from Mumbai and Ahmedabad cancer hospitals was achieved through Focus group interviews and In-depth Interviews (IDI) for logistic convenience. For qualitative analysis, 11 in-depth interviews were conducted along with the six Focus Group Discussions (FGDs) with the cancer patients.

For telephonic interviews, the patients (N=250) were selected randomly from Tata Memorial Hospital, Mumbai (66 percent), RST Cancer Hospital, Nagpur (3.2 percent), GCRI, Ahmedabad (12.4 percent), SMS Hospital, Jaipur (10.4 percent), Acharya Tulsi hospital Bikaner (0.4 percent), Chittaranjan Hospital Kolkata (0.4 percent) and Sewagram hospital, Wardha (7.2 percent) as per the Table 1 given in the Annexure. The average age of the patients was 45 years (SD=13.2). The proportion of female patients was higher (84.4percent) than males in the sample. The patients suffering from different kinds of cancers were included in the study. Around 38.6 percent patients had breast cancer, 29.5 percent of them had gynecological cancer whereas 5.4 percent suffered from stomach cancer. About five percent had blood cancer (for more details, please refer Table 4 in the Annexure). The average household size was five members (SD=3.4) while average number of earning members per household were merely 1.71 (SD=1.4). It needs to be noted here that almost half of the patients had single earning member in their family. Moreover, almost six families (2.4 percent) with cancer patients reported that there was not a single earning member in their family as can be seen from the Table 6 in the Annexure. Out of all the patients, almost one-fourth were earning before they were diagnosed with cancer and had to discontinue it during their treatment. The cross tabulation results for earning status versus need of emotional support and counselling depict that out of the participants who reported the need of emotional support and counselling (N=190), majority (77.9 percent) of them were non-earning members. Further, a chi-square test of independence was performed to examine if there was any relation between earning status of the participants and their need for emotional support and counselling. The relation between these variables was significant. $\chi^2 (2, N = 250) = 7.8, p < 0.02$. The patients who were not earning are more likely in need of emotional support and counselling as compared to the ones who were earning. Sanjeevani as a public trust also works towards rehabilitating such cancer patients who have lost their jobs by providing them with job opportunities post completion of Oncocare certificate course and absorbing them as psycho-social care givers at various government hospitals.

For in-depth interviews, 11 patients were selected randomly from two hospitals, one in Mumbai and the other in Ahmedabad. The participants were found to suffer from different kind of cancers such as breast cancer, blood cancer, brain cancer, lung cancer, uterine cancer, cervical and ovarian

cancer. They represented a wide age range from 19 to 59 years with an average age of 41 years (SD=11.15). Among them, 64 percent were female patients and remaining were male patients. The average household size of these patients was six members (SD=3.2) while on an average two members were found to be earning per household. Among these patients, only 36 percent reported of being engaged in paid employment before the detection of cancer.

Six Focus Group Discussions were conducted with total of 56 patients from Mumbai and Ahmedabad. There was quite a variation in their ages ranging from 16 to 66 years old. However, the type of cancer for these groups remained more or less the same as mentioned above.

3.2.2 Profile of the doctors

Data based on a total of ten doctors (interchangeably referred to as medical experts or oncologists in the report) was collected to understand their opinion about the need of psycho-social care for cancer patients and their opinion about Sanjeevani interventions based on their knowledge, expertise and experience. Six of these experts were interviewed face to face. Four oncologists participated in the study through an electronic survey to put forth their opinions due to logistic reasons.

All the ten doctors interviewed for this study are experts in the field of oncology with experience ranging from 10 to 34 years. Three doctors interviewed in person were associated with Tata Memorial Hospital and ACTREC, Mumbai, another three were associated with GCRI, Ahmedabad and four more doctors, one each were associated with JIPMER Puducherry, SMS Medical College Hospital Jaipur, ATRCTRI Bikaner and MGIMS Sewagram.

3.2.3 Profile of the Psycho-social care givers

It was also felt necessary to understand the perspectives of the Sanjeevani psycho-social care givers (interchangeably referred to as Sanjeevani angels or Sanjeevani staff) regarding the need of psycho-social care and to understand their challenges in providing psycho-social services to cancer patients on a daily basis. Data based on three in-depth interviews and a Focus group discussion with the psycho-social care givers working across nine centers of the organization was collected and analyzed to meet the study objectives

In-depth Interviews (IDIs) were conducted with two psycho-social care givers from Mumbai and one from Ahmedabad. All three of them were female respondents, two of whom were cancer survivors themselves. The third respondent had lost her mother to cancer few years back which made her choose to work as a Sanjeevani angel.

The FGD consisted of 12 Sanjeevani angels excluding those who were already interviewed through IDIs. It was held at a convenient place in Mumbai. These 12 psycho-social care givers have been working across all nine centers of the Sanjeevani organization. Among them, there were three male and nine female psycho-social care givers with the age ranging from 25 to 56 years. Around one third of them had suffered from cancer in the past and have come out as cancer victors. Others were in some way connected with cancer although had not experienced the traumatic illness themselves.

3.3 PERCEPTION OF CANCER PATIENTS ABOUT PROBLEMS FACED BY THEM AND THEIR EXPECTATIONS

The hard fact of having detected with cancer breaks down a patient from within. It is difficult for many patients to come to terms with this disease as it disrupts not only their entire life but also their family members'. Cancer not only affects the body but also the emotional state and its cascading effects are felt in all walks of life. It was therefore pertinent to understand the problems faced by cancer patients at various levels in their struggle with this depressing illness. Hence, in the initial conceptualization, the researcher aimed at analyzing the problems faced by cancer patients in order to examine the need of psycho-social care among cancer patients in India. The researched were asked about all kinds of problems that they have faced since the day they were detected with cancer. The data obtained shows diverse and serious problems which have been discussed in this section. The researched patients also have suggested certain remedies to resolve their problems which are also a part of this section. The data is segregated into different categories based on the nature of the problems as below:

3.3.1 Physical problems reported by cancer patients under the study

The rigorous and painful treatment of chemo and radiation therapies are inevitable and an inherent part of life post detection for every cancer patient. These treatments are imperative and an inseparable aspect of their fight against cancerous cells in their bodies. The medications not only kills cancerous cells but also destroy healthy cells in the process rendering patients extremely weak directly hitting their immune system. In this study, almost all patients reported about the side effects of the chemo therapy and radiation treatment. Through quantitative analysis also, it was found that almost 81percent patients (N=250) reported of suffering from numerous side effects of chemo therapy (refer Table 8(a) in the Annexure). Their problems spanned from losing weight and appetite, vomiting, excessive bleeding and pain in stomach in case of women patients, loss of hair, headaches to high fever and blisters in mouth and so on. The patients are supposed to maintain a good and nutritious diet to curb these side effects; however it was reported that the mere smell of any food item also made them feel uneasy. Many women patients expressed their concern over the discontinuance of even petty household chores due to the treatment and its side effects. Gynecological issues like irregularities in menstrual cycle due to chemo therapy is a common

problem faced by women cancer patients during the treatment period. Bad health condition after few rounds of chemo therapy was also mentioned in a few cases among which one patient even thought about quitting the treatment due to the unbearable pain. She sustained only on lime juice for eight days. Looking at her condition, even her children asked her to discontinue the chemo therapy. Hence, some patients suggested that certain medicines need to be developed to help curb or ease the side effects of cancer treatment and reduce weakness among patients.

It becomes essential for cancer patients to know about the appropriate diet to be followed during and after chemo therapy and radiation to minimize their side effects. Due to the large number of cancer patients, it becomes difficult for doctors to provide diet plan or related information to each and every patient. Hence, many patients suggested that there should be more individuals like Sanjeevani psycho-social care givers who can not only provide emotional and psychological support but also provide information about diet and nutrition.

Another vital concern has been expressed over the availability of fruits and vegetables irrespective of their seasonal nature. According to the patients, people study agriculture and get engaged in research in order to artificially produce natural products. The cancer patients are normally advised by the doctors to eat good amount of fruits and vegetables to improve their immunity. However, the patients have now started questioning such unethical practices which do more harm than good for their recovery. Many vendors use banned chemicals such as Calcium Carbide to increase the shelf life of fruits. It has been scientifically proven that the calcium carbide, low-grade petroleum wax and fruit hormone injections like Ethephon are extremely hazardous. The byproduct of calcium carbide - acetylene is used in gas welding of steel goods. It has been proven to be carcinogenic. In short term it can cause discomfort to asthmatics and those with respiratory problems, but in the long run it results in cancer. If climacteric fruits like apples, bananas, plums, peaches etc., which continue to ripen after being packed, are made available in already ripe condition, they will have very little shelf life. But for this, the FSSAI authorities have allowed the use of ethylene, a gas naturally produced by fruit in closed chambers. Unfortunately, fruit sellers are not keen to use it because it involves extra expenditure. Calcium carbide, on the other hand, comes for as little as Rs. 25-30 per kilo and can ripen ten tons of fruits overnight (Deccan Herald, 2012) which then turns out to be a much cheaper alternative. Hence, suggestions that fruits and vegetables should be grown organically to not only help cancer patients but the entire public at large were voiced out strongly by cancer patients during their interaction.

3.3.2 Financial problems reported by cancer patients under the study

Despite the introduction of government funded schemes for cancer patients in India, the health care system in India remains highly privatized. Around 70 percent of health care is financed through out-of-pocket payments (National Health Systems Resource Centre, Aug, 2016). The public health expenditure in the country as a percentage of GDP fell from 1.3 percent in 1990 to

0.9 percent in 1999, with a marginal increase to 1.1 percent in 2011 (Tata Memorial Centre, Mumbai, 2014). The recent National Health Policy, 2017 aims at universal access to good quality health care services without anyone having to face financial hardship as a consequence. This would be achieved through improved access, enhancing quality and lowering the cost of healthcare delivery. It also aims at reducing premature mortality from cardiovascular diseases, cancer, diabetes or chronic respiratory diseases by 25 percent by 2025 (MoHFW, 2017). However, without adequate budgetary provisions, fulfilling these aims still seems like a distant dream for the country.

In this study, many researched patients belonged to the middle economic class and reported of being highly burdened with the escalating cost of the cancer treatment. From the in depth interaction with one of the patients, it was found that as high as five lakhs had to be spent for the treatment by a patient and he was compelled to discontinue his business due to the treatment. Another woman patient who had lost her husband some 23 years ago was looking after her household by making tiffin boxes, providing day-care services for small kids etc. Her son also earns very low salary. Hence, it becomes difficult for her when doctors prescribe medicines that are not covered under state government scheme and need to be purchased from outside. From the quantitative data as well, a similar trend was observed wherein almost 67 percent patients (N=250) reported that they were in need of financial assistance (refer Table 9 in the Annexure).

Though there are certain financial schemes of the state governments that help needy patients, these can be availed by the residents of that respective state only. Moreover, there is a dearth of cancer hospitals providing quality and affordable treatment to cancer patients in every state. Hence, patients are left with no choice but to flock to few such hospitals in other states where they do not remain eligible to avail schemes of the states other than home state. Furthermore, the quantitative data (refer Table 18 in the Annexure) suggested that more than half of the patients (N=250) were not aware about state or central government schemes that help cancer patients financially. Out of those who were aware (N=122), almost one fifth were unable to avail benefit of such schemes (refer Table 19 in the Annexure) as they were not eligible for it being residents of outside state.

It was observed through in-depth interaction with some patients that either they or their spouses had to face the disruption of their own business due to the swelling treatment expenses adding to their financial burden. Hence, all patients suggested that each state should have a hospital dedicated for cancer treatment similar to Maharashtra and Gujarat. Few patients also suggested that the government should

Quantitative data suggested that more than half of the patients (N=250) were not aware about state or central government schemes that help cancer patients financially.

undertake measures to reduce or subsidize the cost of the cancer treatment as it puts tremendous financial burden on the family members of the patients. It was also proposed that the government should help in allocating some kinds of employment opportunities to cancer patients to make them self-reliant so that they do not burden their family members further. To add to that, the cancer patients may be given monthly monetary allowance by the government to at least take care of their basic needs.

3.3.3 Health System related problems reported by cancer patients under the study

Cancer patients also reported to have faced various kinds of problems at the cancer hospitals including those related to their commute to such hospitals. For instance, it was reported by many patients that they had to visit different departments or occasionally even separate buildings in their single visit to complete the entire course of treatment. To add to their difficulties, there was no proper guidance made available to them about navigation within the hospital and the department they are supposed to visit. Cancer patients already tend to become weak because of the high intensity treatment. Over and above they are frequently made to shuttle from one to place to another within the hospital. Patients were frustrated that they were just running around the hospital all throughout the treatment without having any time left even to have food. To add to that, there is a long waiting period to undertake chemo therapy or radiation or to even collect reports owing to fewer cancer hospitals catering to the large number of cancer patients.

There is a large influx of cancer patients from all over the country to either Mumbai or Ahmedabad since the hospitals in these cities are renowned in providing quality treatment for cancer at affordable cost. Many researched patients complained about the unavailability of similar health systems within their own states. Due to poor health facilities available for cancer patients in other states, patients have no other option but to go to these states leaving their families behind. Patients flock from far away states like West Bengal, UP, Bihar, Rajasthan for their cancer treatment to Mumbai or Ahmedabad. Furthermore, the treatment of cancer spans across months rendering patients extremely frail which makes it highly difficult and sometimes even impossible for them to travel frequently. Hence, they have to find affordable accommodation in the vicinity of cancer hospitals since such stay facilities are not made available within many hospital campuses. One of the cancer hospitals in Mumbai has pioneered such stay facilities for cancer patients and their families within the hospital campus. Initiation of such facility is very commendable as it reduces patient's time and energy spent in travelling frequently to the hospital where treatment is available. It is especially useful for those patients who come for the treatment from different states. However, it was brought to attention that these hostel rooms are shared by either two or four families and have common toilet facilities. Also, the condition of the rooms and toilets is not hygienic which is precarious considering that they need to be utilized by cancer patients as these patients are particularly prone to even slightest infections due to their reduced immunity owing to the intensity of chemo and radiation therapies.

Another serious concern for all cancer patients was put forth by one of the patients. He reported of worsening the condition of the patient when they opted for treatment from private clinics. Many private clinics or hospitals do not have all the requisite machineries and infrastructure to treat a cancer patient properly. It is very crucial that cancer is detected in its early stages and the patient receives proper treatment without any delay. However, due to inadequate infrastructures in private clinics and doctors' vested interests, a lot of time is wasted which results in further deterioration of patients. The patient remarked that there is a dire need to generate awareness among cancer patients to change their perspective towards government hospitals that provide cancer treatment at an affordable cost.

It was also suggested that there should be more doctors in government hospitals as they have to attend to large number of patients. Dire need to increase the capacity of number of beds in hospitals to cater to ever increasing number of patients was also emphasized by most of the patients. A cancer patient needs to complete lot of administrative processes during their treatment at government hospitals. Hence, there should be adequate staff in such hospitals to help the patients. The cancer patients also face problems due to overcrowded public transport systems during their visit to the hospitals. To resolve this problem, few patients have requested the help from the government so that there can be some reserved space for cancer patients within all kinds of public transport systems.

The need was also brought forth on part of the hospital to make food supplements available to the cancer patients for varied reasons. A few food supplements essential to maintain patients' optimum health to undertake chemo therapy or radiation are expensive. Not all patients can afford it. Also, patients do not have sufficient energy and other resources to step outside the hospital to purchase such food supplements. Cancer patients reported of benefiting from foods that are basic in nature and those which give cooling effect to body after chemo or radiation therapy. Moreover, the patients mentioned that they feel better when such foods are consumed and hence suggested that such food items should be provided in the hospital at nominal charges for the benefit of the patients.

3.3.4 Psychological problems reported by cancer patients under the study

Cancer is perceived as an unsurmountable and the most dreadful illness among masses even today. Since the causes of this life threatening disease remain mysteriously unknown, it creates fear, anxiety and uncertainty among people. When the researched patients were detected with carcinoma in their bodies, their first few reactions were **combinations of fear, agony and concern** with respect to

There is a dire need to generate awareness among cancer patients to change their perspective towards government hospitals that provide cancer treatment at an affordable cost.

their near and dear ones. Some of them were even more **scared** after the visit to the cancer hospital. Many patients needed to be motivated to continue their treatment because of extreme side effects. Almost all the patients suffer with a **compromised immunity and excessive fatigue** during the treatment hampering their daily routine. They were not able to perform their normal routine tasks and were required to take rest throughout the day which further pushed them into **loneliness and depression**.

Another major problem faced by many patients was the **fear of relapse of cancer**. The thought of going through the trauma and the treatment all over again made them **extremely stressed and anxious**. Hence, it was emphasized that the government needs to recognize and understand the need for counseling of such patients. A strong need of dedicated counseling centers for cancer patients similar to those available for HIV patients was also voiced.

There would be many organizations that provide monetary support to cancer patients; however, there is a need of organizations that provide emotional and psychological support to patients. Cancer is a chronic disease that throws patients into all kinds of uncertainties about the present as well as the future. According to a study, younger patients and those with early stage of cancer tend to show higher **death anxiety** than older patients and those with advanced malignancies (Feroz & Beg, 1987). This makes psycho-social counseling as vital for the patients as the medical treatment.

Among the researched, there was a patient perceived as a strong figure by her family members, friends and colleagues. Her perception as a strong person could not let her share her emotions openly in front of them. When all she wanted to do was cry, she said, “*she could not afford to ‘not smile’ in front of them*”. Hence, even though they were very supportive, when she interacted with the psycho-social care giver, she could let out all her emotions and felt lot better after it. She admitted that even though cancer patients receive all support from their family members, counseling by a third person is very effective and it should be provided within all cancer hospitals.

There was another young patient who got to know about cancer when he had just passed the standard 10th examination. He had taken admission for diploma which he had to forgo due to his treatment. He had to be at home all the time as he was advised complete rest. This sudden change from his academic routine to staying at home all day made him feel very **lonely and irritated most of the times**.

“I could not afford to “Not Smile” in front of them...when ALL I wanted to do was CRY and CRY!”

.....A Cancer patient

Another concern, especially for women cancer patients, about **hair loss and change in appearance** is common as an inevitable consequence of cancer treatment. The worry about hair loss differs in its intensity and impact across patients. There were few researched patients who were constantly worried about hair loss which added to their **stress and anxiety**. There was another patient who did not worry about it as long as she survived. It implies that each patient requires personalized kind of psycho-social care at different levels catering to their diverse needs.

Cancer not only affects the patient but takes a toll on the entire family. The **discomfort** caused to family members worsens the patient's **trauma, stress and anxiety**. According to a study, the most frequently reported distressing thoughts of cancer patients seem to be that they are a burden on their family, their illness is worsening and that their illness is a punishment from God (Pai, Mehrotra, & Vidyasagar, 2003). In this study too, most of the cancer patients were found to be **excessively worried** about their family members, especially women patients who hitherto had played the role of caretaker in the family. The situation tends to worsen when patients have to go to a different state for the treatment leaving their young and old family members back at home. One of the patients found it very difficult to tell her old and ailing parents about her cancer thinking that they would not be able bear that trauma and pain. In another case, the patient lost his job due to cancer treatment and his wife had to take up the role of earning for the family to meet the financial constraints. She could not bear this pressure and after few months got separated from the patient.

The analysis of the data obtained through FGDs of cancer patients threw light on unimaginable responses by some of the patients' families after they were detected with the cancer. One of the patients who was detected with breast cancer shared that after her mastectomy operation, her mother-in-law suggested her husband to get re-married, she being perceived as useless as she could not bear another child. The patient and her husband already had a girl child; however her mother-in-law wanted her son to have a boy. To add to that, since the patient's mother-in-law perceived this as patient's fault, she wanted her son to marry the patient's sister. Though that marriage could not happen, the patient still undergoes **psychological trauma** in her house.

There was another case of a patient who had married a person who had a very young child from his first wife. The patient did not opt for pregnancy thinking she should not be biased in her attitude towards this child. However, when she was detected with the breast cancer, her husband outrightly told her that she had become useless for him and that she should go back to her parent's house. When she refused to leave, he called her parents without informing her and asked them to take their daughter back. The patient said that it was **very heart wrenching** for her to go through all this and **being left homeless without any support** after she had looked after her husband and in-

laws for so many years. In this context, the immense need of counselling for family members was emphasized by majority of the cancer patients. Apart from the personal and familial level issues, cancer patients also suffer from the **stigma** attached with this life-threatening disease in the society. It was reported during the interaction with the patients that around 90 percent people in our society think of cancer as a contagious disease which often leads to an extremely insensitive behavior towards the cancer patients. Such inconsiderate and uncaring attitude and behavior affects the mental state of cancer patients. This however has been reported on a minimal scale in this study which may be indicative of the fact that society is now slowly getting aware about the truth of this seemingly rising illness.

Thus, it is evident that the life of a cancer patient undergoes a **tremendous change** after detection of cancer and they are subjected to **countless problems**. A study conducted on cancer patients undergoing radiation treatment found that the common sources of their distress are spread across five different domains viz. financial, physical, role disruptions, interpersonal and spiritual domain (Pai, Mehrotra, & Vidyasagar, 2003). However, all these problems in the end culminate into **disturbed emotional state of the patients**. In this context, another study states that having low income or having a widowed/divorced status or even presence of physical pain are positively correlated with psychological distress (Pandey, Thomas, Ramdas, & Nandamohan, 2006). Thus, the need of psycho-social care and support for cancer patients can be clearly identified in order to enable them to effectively handle all other problems.

3.4 DOCTORS' PERCEPTION ABOUT CRITICAL PROBLEMS FACED BY CANCER PATIENTS AND FAMILY

The study also attempted to understand the doctor's perception about critical problems faced by cancer patients. When doctors were requested to share their views on the serious problems faced by the cancer patients and their family members, interestingly majority of them stated psycho-social problems as major problems faced by the cancer patients. These problems have been divided into different categories as below-

a) Psychological problems:

The doctors mentioned that patients tend to feel **frustrated** because of the disease which also leads to **anxiety and depression** in many patients. They also emphasized that these symptoms often go unnoticed which makes the situation worse. **Coming to terms with their diagnosis of cancer**, according to one of the doctors, remains the major critical issue faced by cancer patients. Secondly, even if

"I think you will never know how they are actually coping. They show that they are coping but I am sure most of them are devastated."

.....A Leading Oncologist

"They do not talk about it because they probably feel that there is no point of talking about it in front of the doctor. Maybe they talk about it in front of someone but not in front of us."

.....A Leading Oncologist

they accept, they are not ready to believe that their cancer can be cured. Most people are so nihilistic that they believe cancer to be a fatal condition and that they might never recover from it.

b) Physical Changes associated with cancer:

According to some of the doctors, physical changes such as loss of hair due chemo treatment have a huge impact on patients. One of the oncologist commented that *“I think you will never know how they are actually coping. They show that they are coping but I am sure most of them are devastated. In our medical records, their picture is taken the day when they come to TMH. Many times when you see the patient and when you open the records and see the picture of day one, you yourself can’t believe. It is hard to believe it is the same person and they know what is happening. In addition to so many other things which are going on in their bodies and in their mind, their change in appearance and how they feel about it must be terrible. They do not talk about it because they probably feel that there is no point of talking about it in front of the doctor, but I am sure they cry about it. Maybe they talk about it front of someone but not in front of us.”*

c) Effect on Interpersonal relationships:

Majority of the doctors have highlighted that cancer has significant impact on interpersonal relationships of patients.

“Inter-personal relationships do get hampered in some instances. I treat gynecological cancers. We do find that in some instances women are deserted by their husbands and no longer supported. I have had one women who was pregnant when she had the cancer. It was in a lymph node. She was a pretty young women married for two years and initially I saw that her husband and her husband’s relatives use to accompany her and then slowly they stopped. Fortunately she required chemotherapy during pregnancy which can be given safely with some drugs. She got cured and she delivered a baby daughter and now I follow her up. It is now 10 years and she is alright but she got separated from her husband that has affected her. I am just giving you one anecdotal experience. I have had such experiences with others as well. Actually I also know about the opposite. I had a very young man who had a cancer of germicidal tumor and he also got cured. He had a long standing relationship with his girlfriend who used to accompany him initially and then slowly she stopped accompanying him. When I asked he said she had also left him. This was about 10 or 12 years ago and both of these individuals are long term survivors. They are fine, but it does hamper personal relationships in such circumstances. But on the contrary I also have scores of examples where husbands and husband’s families have been enormously supportive of patients, so I can’t make a generalization.” said a doctor from Mumbai.

According to the oncologist from Ahmedabad, aspects like *“whether I should continue my relationship with my husband or not”* are very bothersome for a lady patient especially with cervix or endometrium cancer, they cannot ask or talk about it to each and every one, not even to a lady doctor. They cannot ask this query openly because it will expose their personal relations. In such

sensitive cases, it is necessary to have a psycho-social care giver around with whom she can openly interact and relieve the stress.

Another doctor from Ahmedabad mentioned that, in marital relationships if wife is suffering from breast cancer or cervical cancer, sometimes it may happen that in laws and husband are just treating them as a patient. However, the person seeks sympathy. She needs a listener. The patients' feel that they are different and now they are burden for the family. This may happen because everyone's behavior in the family would have changed towards the patient making things more difficult and circumstances more stressful.

d) Ignorance or Lack of information:

Lack of information about cancer as well as about treatment facilities and how to go about it is a major issue for majority of the patients according to the doctors. According to the doctors, prognosis is one of the major critical problem faced by cancer patients leading to fear and depression. *"How long will they live, how much time they have, this is the first question in their mind. What food they should take, should they continue their job, they should be in contact with their family members, is it infectious or what are the common queries in their mind."* were the views shared by an oncologists. Lack of adequate personnel to address information needs of patients often leads to elevated anxiety and stress amongst cancer patients, he added.

e) Process of cancer treatment:

The other problem highlighted by the medical experts was going through the whole process of cancer treatment, going to different departments, doctors, treatments and managing resources for the same and the anxiety and fear associated with this long and tedious process.

f) Discrimination and Stigmatisation:

It is recorded from all the doctors that cancer patients have to face stigmatisation and discrimination in some way or the other. Some of the doctors opined, that due to urbanisation and education, the stigmatisation has decreased, however it still exists.

Two doctors from Mumbai mentioned that they have noticed that stigmatisation is more prominent for female cancer patients especially if they have young daughters who are yet to be married. That happens especially in case of breast cancer. There is a notion that sometimes 5 percent or 10 percent of cancers could be hereditary.

"Lack of adequate personnel to address information needs of patients often leads to elevated anxiety and stress amongst cancer patients."

.....A Leading Medical Expert

This perception is strong mainly with breast cancer that if the mother has it, there are high chances that the daughter could also get it.

Some of the doctors also highlighted that the attitude of people towards cancer patients compels the patients not to disclose about their illness. *“The other thing that surprises me is that many times, highly educated people do not disclose their cancer diagnosis in the extended family or their friends. I ask them why? They say the attitude of people towards cancer patients the moment they know its cancer is bad. They look at you as you’re going to die. The whole world will start looking at them as if they are looking at a dying person and they said that it is very demoralizing. I know I’m coming to terms with my cancer diagnosis and I don’t want people to look at me like a creature which is about to die.”*

On inquiring about doctor’s opinion on areas where patients need support to cope up with cancer, aspects such as information about disease and treatment, psycho-social support, rehabilitation and logistical help was reported. Thus the discussion with doctors as well as patients strongly brought out the fact that primarily each and every cancer patient needs psycho-social support to cope up with cancer.

3.5 NEED OF PSYCHO-SOCIAL CARE AMONG CANCER PATIENTS

The notions associated with cancer as an illness are such that they induce lot of fear, anxiety and stress among patients and their family members. The word ‘cancer’ itself puts many questions on survival of a person. All the patients under study universally reported of having faced numerous critical problems when detected with cancer as elaborately discussed in the previous section. In this context, various studies also have highlighted the importance of psycho-social support for cancer patients in addition to their medical treatment to cope up with these problems. A study conducted to assess prevalence of anxiety and depression among cancer patients suggests that cancer patients require psychological treatment as well along with the medical treatment. Such early recognition and management of emotional distress caused due to cancer will also significantly reduce the burden on health care cost and it will also improve the quality of the cancer treatment (Santre, Rathod, & Maidapwad, June, 2014). Hence, this study attempts to assess the perceptions of selected cancer patients, doctors and Sanjeevani angels with regards to the need of psycho-social care for cancer patients in India

“It surprises me many times that highly educated people also do not want to disclose their cancer diagnosis among their families and friends.”

.....A Leading Oncologist

3.5.1 Through the lens of cancer patients

The study set forth an objective to assess the current need of psycho-social care to cancer patients from their perspective. In this regard, opinion was sought from 250 cancer patients all across cancer hospitals in India through telephonic interaction and from 11 patients in person through face to face in-depth interviews from two cancer hospitals in the states of Maharashtra and Gujarat out of the total nine centers where Sanjeevani is active. In this context, based on the data obtained from these cancer patients, certain themes emerged strongly which are discussed in this section.

Theme 1: The researched cancer patients strongly expressed the need of psycho-social counseling and the impact it would have on their recovery.

In line with the goals of the organization, the study conceptualized that emotional and psychological support is as crucial for cancer patients as the medical treatment in their fight against cancer. Post interaction with all these patients, this hypothesis became apparent and the above mentioned theme strongly emerged as a part of the qualitative data analysis.

From the quantitative data, it was found that over three fourth patients (77 percent, N=250) expressed the need of provision of emotional support and counseling in hospitals (refer Table 9 in the Annexure). Furthermore, qualitative data findings also highlighted that almost all the researched patients admitted the need of emotional and psychological support through counseling to deal with the traumatic situations during the entire course of illness. During the focus group discussions and an in-depth interviews, this need of psychological support through counseling emerged out strongly. During the interaction of the patients in a FGD, the patients admitted persuasively that there should be a counselor for their assistance to reduce their fears. Such support must be available in every cancer hospital. They also added that when a patient is detected with this life threatening illness, even if they have the support of their family members, it will always be better if there is someone who is familiar with that area of work and knowledge to guide the patients. Although the patients complete their treatment, they still feel a strong need of counseling in cancer hospitals to cope with this stressful illness.

Among the patients interviewed for this study, majority of the patients emphasized the need of psychological support. Moreover, it was also opined that psychological support is absolutely necessary although its importance is not recognized in India. The patients also mentioned that the trauma, the fear about cancer is much more

Over three fourth (77 percent N=250) patients expressed the need of provision of emotional support and counseling in hospitals.

Data findings also highlighted that almost all the researched patients admitted the need of emotional and psychological support through counseling to deal with the traumatic situations during the entire course of illness.

than the fear of treatment and radiation. No matter how much one is treated with medication and radiation, there is a fear one experiences not just about the future but about the present too. Cancer pushes a patient into whirlwind of uncertainties and questions to which nobody has the exact answers. Hence, psychosocial care is mainly important and relevant in initial phases after diagnosis. It was also reported by all the patients that doctors do not have adequate time to talk with each patient and hence there should be someone like counselors to help cancer patients. Another aspect that came forth during analysis is that when a person is detected with cancer, his/her family members are burdened with a moral responsibility of providing emotional support to the patient. However, more often than not, not only the patient but his/her family members also get exposed to tremendous distress and anxiety. Hence, it is crucial to have someone in hospitals apart from the family members of patients who can help patients as well as their family members or caretakers to cope up with this trauma and anxiety.

“Psychological support is absolutely necessary although its importance is not recognized in India.”

.....A Cancer patient

Majority of the patients believe that counseling in one way or the other would be extremely useful to all cancer patients. While expressing the probable impact of psychological counseling, the patients admitted that counseling will help patients in reducing their fear more effectively if they are provided with the clear information about the disease and its treatment. Another patient suggested that if all cancer patients come together and share their grief, it can make them feel better and they will regain confidence that this illness is curable. It will also help them to be positive. In one of the cases, a patient brought out an important aspect of the impact of counseling. He mentioned that if patient's mind is strong and at peace, the medical treatment will go smoothly. However, if patient is fearful and distressed the treatment will not have the desired medical impact.

“Doctors do not have adequate time to talk with each patient and hence there should be someone like counselors to help cancer patients.”

.....All Cancer patients

Further, it was hypothesized that the response by doctors during their interaction with the patients tends to influence their emotional state either positively or negatively. In other words, the interaction between oncologists and patients plays a crucial role in making an impact on the mind of patients which in turn affects their coping behavior and recovery process. The data obtained from the researched patients provides evidence in support of this hypothesis.

It was found that whenever doctors talked politely with the patients and tried to console them, the patients reported of being less fearful about the entire course of treatment. In contrast to that, when doctors could not give proper information to the patients due to lack of time or were unresponsive towards patients, it has marked negative impact on the patient. In one of the cases, when a patient approached the doctor, she was informed that she needs to be operated immediately failing which

she would not survive. After such response, the patient remembers that she could not sleep that entire night, kept weeping without any idea about what to do next. Then she consulted another doctor who assured her that there is nothing to worry about and she should go to one of the renowned hospitals for further treatment where even medical expenditure would be less. She felt relieved after talking to the second doctor who had given his comments based on the same medical reports which the prior doctor had referred. Another patient also admitted that even an occasional empathetic interaction with a senior doctor in the hospital reduced the gravity of his trauma and made him feel like his illness had ceased to exist.

This clearly brings out the fact that the response given by doctors in cancer hospitals tend to have tremendous influence on patients and it has the ability to make or break their emotional wellbeing. However, due to dearth of cancer hospitals and few oncologists in comparison to the huge number of patients, it is very difficult for the doctors to spend quality time and build a rapport with a cancer patients and fulfil their emotional and psychological needs developed due to this traumatic illness. Consequently, this highly disproportionate ratio of doctors to that of cancer patients calls for dedicated counselors in cancer hospitals to cater to the emotional and psychological needs of patients.

Based on the opinions of all the patients, the importance and need of psycho-social care through counseling is evident. The patients have also suggested that this need must be fulfilled at the cancer hospitals right from the first stage of the diagnosis for speedy recovery of the patient.

Theme 2: Irrespective of having received familial support from their families, the cancer patients tend to perceive the need for psycho-social support to deal with other myriad problems, especially at the psychological/emotional level.

At the initial stage of conceptualization, it was presumed by the researcher that the need of psychological support would be much higher for patients who do not receive emotional and psychological support from their family. However, the data obtained from the researched brings out a new dimension with reference to the initial conceptualization. It shows that despite receiving emotional support from their family members, cancer patients tend to experience psychological issues which may not be resolved with family support and hence they expect help from counselors.

“If patient’s mind is strong and at peace, the medical treatment will go smoothly. However, if patient is fearful and distressed the treatment will not have the desired medical impact.”

.....A Cancer patient

“Despite receiving emotional support from their family members, cancer patients tend to expect help from counselors.”

.....A Cancer patient

Majority of the researched patients admitted that their family members were quite supportive. They accompanied patients to hospital, guided them, motivated them and also gave strength and hope to continue the treatment for fast recovery. In spite of such support available from the family members, patients admitted having suffered many problems, predominantly psychological. In one of the cases, for example, the patient had a very loving and caring husband who was doing everything possible for his wife to help her cope up with cancer. However, his emotional dependence on the patient used to burden the patient emotionally making her excessively worried about her husband. Furthermore, cancer had cost her all her chances of becoming a mother as she had to undergo a hysterectomy to avoid the spread of the cancer in her body. The patient used to brood and mourn over this grief when she used to be alone and avoided sharing her anguish with her husband.

Another common problem shared by many patients was the fear of the relapse of cancer and the pain of going through the same trauma all over again. Irrespective of the strong support from family members, the anxiety about future keeps them haunting. Moreover, it becomes difficult to share this anguish and anxiety with their family members often as it would distress them further. It therefore calls for a strong need to have the counselors around for the cancer patients to share their anxieties and doubts more freely. These psycho-social care givers can thus empathize with them and give them hope and strength to fight with this traumatic illness.

Theme 3: In spite of firm family support, a few cancer patients expressed a strong need to counsel even the family members and caretakers by the Sanjeevani angels.

Cancer is an ailment that brings familial relationships of patients under emotional strain too. Even though, family members tend to be the first and the most important support to patient, they themselves also tend to go through lot of stress and pain. Moreover, the caregivers need to be extra careful while interacting with the cancer patients which adds to their anxiety and stress. Some support from the counselors will certainly help them ease out such tensions.

The patients opined candidly that family members also struggle equally with the patient while dealing with this traumatic disease. The entire family homeostasis is shifted on diagnosis of patient's disease. Telephonic interviews depicted that around 54.5 percent cancer patients (N=250) expressed a strong need of provision of counseling to their family members and caretakers as well (please refer Table 9 in the Annexure). Patients during the in-depth interview emphasized that counseling is necessary for family members or caregivers because once patients go back home they are with the caregivers all the time. If the caregiver himself or herself gets frustrated with the patient, it further depresses the patient leading to unwillingness to share his/her pain with the family members. This may reduce the coping capacity of the patient and consequently the process of recovery. He added that it is important to explain the various issues related to cancer and its treatment to the caregivers to enable them take better physical and mental care of the patient. In

other words, empowering the caregivers and counselling them would help the patients face this illness with more strength and support. As rightly remarked by a patient '*When you get good support from the family, you feel like a winner*'. This calls for effective counselling to the family members along with the patients.

It also emerged through the data that counseling to family members about cancer, its treatment and its side effects, and how to handle the patients at psychological and emotional level can help cancer patients deal with this illness more positively. The patients interviewed, opined that a cancer patient needs moral support, with more love and understanding the recovery would be certainly faster. Discrimination on the other hand would not only hamper the morale of the patient but also reduce his coping strength as admitted by few patients. In one of the cases, when patient got to know about cancer, her son and daughter in law started keeping distance from her thinking they might also contract the disease. After the counselor interacted with them and made them understand, they realized their folly and changed their behavior towards the patient. The patient then, with the support from her son and daughter in law faced the illness with more confidence and strength than before. Thus counseling the family members to enhance their support is extremely vital for any cancer patient to survive through this life threatening disease.

Theme 4: Despite painful cancer treatment, strong familial support and care emerges as one of the major factors that tends to encourage patients to continue their treatment.

It is well known that the cancer treatment is agonizing and distressing and hence the patient requires not only motivation but a strong will to confront and undergo such a treatment over a long period of time. In this study as well, patients mentioned about the horrifying side effects that they had to bear making the treatment intolerable. In one such case, the patient could not eat anything and was forced to sustain only on lime juice for eight days. She almost decided to quit the treatment due to these side effects. Hence, it was conceptualized that by providing emotional and psychological support to cancer patients, the counselors might be able to play a key role in the continuation of cancer treatment by the patients.

However, the data suggests that it is the strong familial support and care that emerges as one of the major factors that tends to encourage patients to continue their treatment. Many researched patients admitted that motivation from family members was major reason they became ready to undertake and continue the painful treatment and it was for them that the patients wanted to survive. One of the patient even added that since her husband is totally emotionally dependent on her, she cannot even think of escaping the treatment.

This insight reinforces the finding of the previous theme that the family members also need to be counseled to provide hope, strength and emotional support to cancer patients. This in turn would

help in reducing the rate of discontinuation of the treatment among patients enabling them to recover faster.

Theme 5: Misconceptions about cancer in the society do not hamper patient's mental state of dealing with it.

There is a stigma attached to cancer which gets reinforced in the society by the diverse myths and misconceptions about it. In this context, it was conceptualized that stigmatization and discrimination towards cancer patients may affect their emotional state of being. However, the data suggests that although many researched patients accepted misconceptions in the society towards cancer as a disease, it does not seem to have significant impact on their mental state. The patients talked about misconceptions such as cancer is contagious and non-curable etc. However, these things didn't appear as problems to them. They were more worried about psychological issues such as fear of relapse, not being able to be there for family members like before, not being able to become a mother, feeling lonely at home and so on. This again reinforces the theme that suggests the importance and need of counseling for cancer patients and their caretakers.

The researched cancer patients have expressed strong need of psycho-social care for cancer patients irrespective of their own experiences of discrimination due to cancer. It was hypothesized that patients who experience any sort of discrimination or ill behavior because they have been diagnosed with cancer would tend to emphasize more on the need of psycho-social support than other patients who have not faced such incidences. However, the data shows that irrespective of whether the patients faced discrimination or not, all of them have perceived the need of psycho-social care and support within the cancer hospitals.

To summarize, the analysis of the quantitative and qualitative data collected from the researched cancer patients has brought forth certain themes that strongly indicate that cancer patients perceive emotional and psychological support as a very important aspect of their treatment and express the need of counselors to be available within cancer hospitals. This need of psycho-social care was highlighted by the patients in spite of receiving strong support from their families. The patients even emphasized the need to counsel the families of cancer patients because they are one of the most important influences behind continuation of the treatment of cancer patients. Only with strong emotional support of the family, patients are motivated to continue their treatment despite its painful side effects. Hence, it can be concluded that the cancer patients perceive the need of psycho-social care not only for themselves but also for their caregivers who are struggling equally with the patients in their painful journey of cancer.

3.5.2 Through the lens of medical experts (Oncologists)

An attempt was made during this study to understand the perspective of medical experts in the field of cancer about the need of psycho-social care and that of para- professionals in

cancer hospitals and about barriers in delivery of cancer care services if psycho-social care is made an integral part of cancer care. Opinions were sought from six doctors from two cancer hospitals in the states of Maharashtra and Gujarat and four doctors from other parts of the country.

3.5.2.1 Opinion about need and significance of psycho-social care for cancer patients

The oncologists were asked to express their opinion on the importance and need of psycho-social care for enabling the cancer patients' to deal with the traumatic illness in a better manner. All the doctors have strongly expressed and emphasized the importance of psycho-social support for cancer patients to enhance their coping behavior and recovery process. They have also expressed a strong need of integrating psycho-social care along with medical treatment in the cancer care hospitals. According to a doctor from Ahmedabad, if a patient is getting psychological and social satisfaction, their recovery will definitely be faster. It will also improve their willpower and keep them motivated which serve as important factors for recovery. When patients begin to think - "*Since I have got this disease (Cancer), I am going to die soon*", it certainly creates a negative impact on their recovery. Another doctor from Bikaner opined that psycho-social services are as important as medical treatment in cancer patients and even more important for terminally ill patients who are in their last stage.

The doctors also opined that provision of psycho-social care will help in not only reducing treatment default and alleviate anxiety but also improve quality of life of the patients. One of the doctors from Mumbai also mentioned that doctors give prescriptions, however it is very important to give strength, hope and support to the cancer patients. According to her/him, psycho social care has to be a part of routine medical line of treatment in all hospitals. The doctor from Ahmedabad admitted that ideally, provision of psycho-social care should be there in all cancer institutes but very few have that type of built-in set-up or services. One of the doctors while emphasizing the need of psycho-social care for cancer patients mentioned that sometimes patient tend to get so badly disturbed with the illness that they may execute some irresponsible behavior and even commit suicide. So, according to her/him, psycho-social care should be provided right from the initial stage of the illness to avoid such extreme stages.

It was highlighted in the discussion that as much as one fifth of the patients abort the treatment and leave it incomplete. The probable reasons sighted for leaving the

"Provision of psycho-social care will help in not only reducing treatment default and alleviate anxiety but also improve quality of life of the patients".

....A leading oncologist

"Doctors give prescriptions, however it is very important to give strength, hope and support to the cancer patients."

....A leading oncologist

treatment midway as mentioned by majority of the doctors were fear of side effects of the treatment resulting due to lack of communication and proper guidance which manifests into anxiety and apprehension amongst patients. The other reasons sighted were lack of financial resources, lack of accommodation, lack of social and family support, a belief and feeling that their cancer will not be cured and lack of knowledge about the disease and its consequences. These ultimately make an impact on the psychological level of the patients and their family members which again bring out a strong need of psycho-social support to deal with these problems.

3.5.2.2 Opinion about need to counsel immediate family members/care givers and sensitise them about psycho social care for patients

Almost all the doctors emphasized the need to counsel immediate family members/care givers of cancer patients and also sensitize them about psycho-social care needs of the patients. One of the doctor from Mumbai commented that *“More than the patients, I feel the caregivers need more psycho social support. There is a need to talk to caregivers and sensitize them to keep the patients strong and motivated at home. For the patients who are married, more support is needed for the one who is more affected depending on who is stronger. Most of the times, it is the spouse who falls weak and cannot cope up with the trauma. The cancer patient himself/herself is very strong and is usually less affected. It is the weak partners of the two who need more emotional support. The weak spouse breaks down and it is she/he who needs psycho-social support more than the patient themselves.”*

Another doctor from Ahmedabad had slight difference of opinion. She/he remarked that psycho-social care is undoubtedly important for cancer patients. However the patients actually are looking for sympathy from their spouse and family members. In cases where the family members are not supportive, help from some external source does not solve the purpose. Patients expect support, importance, and due respect from their own family members. The doctor further emphasized that counselling is needed more to the immediate family members than the patient. She/he feels that family members should be counseled and motivated to continue with the normal life as before. She/he added that we have to motivate the relatives also to take care of patients. If caregivers are better equipped it will be more helpful for the patients in coping up with cancer.

“More than the patients, I feel the caregivers need more psycho social support. There is a need to talk to caregivers and sensitize them to keep the patients strong and motivated at home.

.....A Leading Oncologist

3.5.2.3 Opinion about need of psycho-social caregivers like Sanjeevani

It is apparent from the previous theme that all the medical practitioners in the field of oncology have emphasized the significance and need of psycho-social support to cancer patients. When they were questioned about ways of providing such care, the need of psycho-social caregivers like Sanjeevani emerged out strongly.

Theme 1: All doctors have openly recognized the need to encourage Para Professionals (like Sanjeevani) to support the interaction between doctors and patients.

The medical experts from Mumbai, while highlighting the need of para professionals like Sanjeevani opined that there is a need to train a cadre of individuals, not necessarily doctors but belonging to parallel health units who can be a part of the team. In many other countries they have cadre of individuals called ‘nurse practitioners’ who are not doctors but are trained to handle specific aspects of any particular health care problems like cardiac, oncology etc. They can take on a large fraction of responsibilities that currently fall on doctors. This will result in improvement in patient experience. Moreover, waiting time of the patients will reduce and they will get more time to spend with the health care professionals. This will also promote group decision making the interaction more meaningful and also an improvement in work flow. So counselors, other health care professionals, trained nurses, trained oncology nurses, trained cardiac nurses are required in the health system.

Theme 2: Higher influx of patients leading to inadequate time and interaction with the doctors emerges as one of the important reasons for the need of para professionals like Sanjeevani to cater to psycho-social needs of the patients.

The doctors have themselves highlighted the fact that lack of time with doctors coupled with higher influx of patients leads to communication gap between doctors and patients. It also gets difficult for the doctors and hospital staff to address the psycho-social problems of patients with the interaction time of merely 2-3 minutes per patient. As mentioned by the doctor from Ahmedabad, the number of patients in their centre is huge and so even if they wish to, they don't have much time to counsel each and every patient for small but important things like diet, psychological support and their relationship with their family members etc. There are many misconceptions regarding these things. “*All these are very important part of a normal routine life and a patient should go back to their normal routine life as soon as possible which is very important for their speedy recovery*” added the medical expert.

The doctor thus expressed the need for para professionals like Sanjeevani, who are professionally trained in this field to develop a rapport with the patients. They can counsel each and every patient, and can communicate things to patients which the doctors do not have time for. On similar lines,

doctors from Mumbai mentioned that the counselors can serve as an effective bridge between the patients and the doctors. In his/her opinion, since the volume of patients is very high, the doctors cannot really give justice to each and every patient in terms of psychological attention and comfort. In such scenario, the counselors would play a crucial role. So, more support from NGOs like Sanjeevani is required. The doctor also honestly added that they are incomplete without such NGOs. They need other people to support them and they are happy to have the Sanjeevani psycho-social care givers sharing their load. The doctor remarked that government is already helping people with financial support. For over half the proportion of patients, government is taking care of their medical expenses. But the number of counselors is limited and the volume of patients is too high. The doctor from Bikaner pointed out a very important fact that even if there are sufficient oncologists, they cannot replace the role of para- professionals. Medical practitioners neither have adequate time nor the expertise for providing professional counseling to the traumatized cancer patients.

The doctors also called attention for need of a multidisciplinary approach to cancer treatment and added that the role of paraprofessionals is certainly significant to help the doctors. However they should strictly work under the guidance of the doctors (either oncologists or oncophysicians).

It was also highlighted by the oncologists that counselling will benefit patients in many different ways such as catering to basic information needs of patients and also help them in dealing with anxiety and depression. The oncologist from Mumbai mentioned that *“Things as simple as - where is the CT scan room, where to take an appointment, where to make a payment, when, where and how to meet the doctor are their requirements on a very practical and fundamental level. Then things like, what is my prognosis, what is the outcome, what is the likely cost of treatment, what is the chance that I will suffer from significant side-effects, what are the chances that the side-effect will last for a long period of time also need to be addressed properly. So all of that are basic information needs of patients and in such cases the counselor can provide factual information, actually correct evidence based information and if you provide information to an individual, then to some extent their anxiety reduces. They at least know what is coming and they know the good or bad, they know what is happening. Then after all this is taken care of, a good counselor can also deal with problems of anxiety and depression which is common amongst patients and often also goes unrecognized.”*

During the interaction, the medical expert from Ahmedabad admitted that if aspects of psycho-social care are being taken care of by para professionals, it will be of

“Things as simple as - where is the CT scan room, where to take an appointment, where to make a payment, when where and how to meet the doctor, are their requirements on a fundamental level. In such cases the counselor can provide factual information, and if you provide information to an individual, then to some extent their anxiety reduces.”

.....A Leading Oncologist

great help for the doctors as they can have more time and give more focus on their precise medical treatment which is their expertise.

Thus the interaction with the doctors clearly bring out the need and significance of having para-professionals in the form of psycho-social care givers like Sanjeevani staff to help the cancer patients face this traumatic experience by reducing their fear, distress and motivate them for continuing the treatment while letting medical professionals focus on their line of medical treatment.

3.5.2.4 Opinion about barriers in delivery of psycho-social care services

Diverse factors emerged on inquiring about perception of the medical experts about barriers in delivery of psycho-social care services for cancer patients particularly if it needs to be made an integral part of cancer care.

Lack of recognition about importance of psycho-social care amongst medical professionals was sighted as one of the major barrier by most of the doctors. A medical expert from Mumbai said that *“In India, the biggest barrier is the fact that most medical professionals do not yet recognize the importance of psycho-social care as an integral part of cancer treatment.”* Another doctor from Ahmedabad remarked that they have a whole team of psychiatrist, psychologists and counselors available in the OPDs every day, but the concept of referring patients to counselors is not much known to the doctors. No cancer specialist thinks that the patient needs psychiatric help or counselling. She/he also added that there are times counselors are sitting in the OPD but nobody refers the patients to them. Lack of space and privacy in hospital settings was also sighted as a barrier in providing psycho-social care services by majority of the doctors. *“I think in Tata Memorial Hospital, if another 100 counselors are appointed, where will they be accommodated? Where will they talk to patients, where will they make their notes? If they are made to sit in the corridor, what if some patient begins to cry? Is it correct if patients break down in the corridors without any privacy?”* remarked one of the doctors from Mumbai.

The other impediment recorded was dearth of trained counselors, who can provide quality psycho-social care support to patients. The number of patients is rapidly increasing while the number of counselors are limited. As a result, they cannot spend adequate required time for psycho-social counseling with the patients based on their need.

Thus to summarize, all of the oncologists expressed strong opinion for the need of psycho-social care along with the medical treatment for cancer patients in

“In India, the biggest barrier is the fact that most medical professionals do not yet recognize the importance of psycho-social care as an integral part of cancer treatment.”

.....A Leading
medical expert

India. According to them, such service would help in instilling confidence and positive outlook among patients that would result in their speed recovery. They further highlighted the need to counsel even family members of the patients and found it equally necessary and important as family is the first point of support for patients. The oncologists also threw light upon certain barriers in delivering psycho-social care to cancer patients and their families such as lack of recognition of its importance in the medical treatment on part of doctors, infrastructural constraints of hospitals, increasing number of cancer patients and the dearth of oncologists as well as counselors. To resolve these barriers, the oncologists have recognized the importance of para professionals like Sanjeevani who can assist the doctors in providing psycho-social treatment to cancer patients leaving them with more time to focus on their core medical expertise.

3.5.3 Through the lens of Sanjeevani psycho-social care givers

All the psycho-social care givers, in one voice, admitted that psycho-social support is extremely important to cancer patients. They also unanimously opined that it is AS IMPORTANT AS the medical treatment. According to them, even if patient takes medication he will not respond to it if he is depressed and has lost hope. The psycho-social care givers opined that the patients feel positive and tend to gather mental energy to face this disease when interacted with them. *“Just one gentle touch of reaffirmation saying ‘aap thik ho jaoge’ works wonders!”* remarked one of the Sanjeevani angels. Another psycho-social care giver had a very strong opinion that psycho-social care is more important than medicine. *“If mental health of the patients is not appropriate, they would not consume medicine. So motivation is crucial for them to continue their medical treatment.”* he added.

When the patients come to the hospital for the first time, they are tensed and helpless and cannot control their tears, admitted the psycho-social care givers. However, after the interaction, the patients feel relieved and content which highlights the need of presence of psycho-social care givers for cancer patients within the hospitals. While interacting with all psycho-social care givers in a FGD, one of them shared that he had built a good rapport with an elderly patient. The patient was informed by the doctor that she would not survive for long as her cancer was in its advanced stage. However, the patient had tremendous willpower and survived till many years later. The patient also gives part of the credit to the psycho-social care giver for her strong support and care. It is extremely crucial to instill hope in them and so the psycho-social care and role of the counselor becomes extremely crucial, asserted the Sanjeevani staff. They also added that the patient may not respond to the treatment in full capacity in the absence of a counselor. Such

“Just one gentle touch of re-affirmation saying ‘aap thik ho jaoge’ works wonders!”

.....Sanjeevani
Psycho-Social
Caregiver

instances have made the psycho-social care givers recognize the need of psycho-social care for cancer patients even more strongly.

The psycho-social care givers voiced the fact that they need to work in close co-ordination with the medical experts in the cancer hospitals as a part of their job. Consequently it was imperative to understand the rapport they shared with these medical experts and the kind of expectations they had from the latter. Moreover, an attempt was also made to understand their opinions about the need of the doctors to act as psycho-social supporters to cancer patients to some extent. When these questions were posed for discussion during the focus group discussions, there were diverse set of reactions and responses. One of the psycho-social care giver candidly admitted that she shares a very professional relationship with the oncologist she works with. She acknowledged that the doctors are always on their toes and it is incorrect to disturb them frequently with petty doubts. The doctor directs those patients who need counseling to her only because he is sure and confident she would be able to help the patient. However, she expects the relationship with the doctor to develop in such a way that the counselors must feel free to ask them anything without hesitation. She also strongly opined that doctors are not in a position to give psycho-social support to the patients. *“Doctors don’t have time to counsel the patients. They are more into disease management and their medical line of treatment. Moreover, psychological counseling is not something which can be done in a minute or two. It takes a little longer time to bring out the emotional issues in the patient.”* She strongly suggested that doctors should instead build the capacity of the counselors whenever possible in terms of orientation about medical terms involved in the treatment, associated side effects etc.

Another psycho-social care giver in the group shared completely contrast views. According to her, even if the doctor speaks positive to the patients for a minute or two, it makes a lot of difference to the already devastated patients. *“‘Aap thik ho jaoge’ assured by the doctor will be far more effective than our counselling”!* She feels. Another psycho-social care giver expressed a similar opinion. She said *“When the doctors give hope, the patient recovers by almost 50 percent. ‘One or two consoling statements from the doctor are equivalent to half an hour of our counselling.’* Her expectation from the doctor was that she/he must speak well with the patients for at least two minutes if not more.

Majority of the psycho-social care givers unanimously agreed to the fact that conduct of the doctors needs to be more amicable with the cancer patients. There are chances that doctors may behave unfriendly with the patients due to excessive load and complexities of their job responsibilities. However, the patients look up to

“Doctors don’t have time to counsel the patients. They are more into disease management and their medical line of treatment. Moreover, psychological counseling is not something which can be done in a minute or two. It takes a little longer time to bring out the emotional issues in the patient.”

.....Sanjeevani
Psycho-Social
Caregiver

“The patients should feel satisfied with the doctors instead of complaining about them to us. Moreover, counseling them after doctors’ positive interaction makes double impact!”

Sanjeevani
Psycho-Social
Caregiver

the doctors as ‘life savers’ and so it becomes extremely important for them to give time and a patient ear to their problems, miseries and doubts. However, due to time constraints, medical experts are able to spend no more than two minutes with every patient irrespective of his/her emotional need. Consequently the patient hesitates to ask any queries or doubts to the doctors which they, more often than not, get clarified from the psycho-social care givers sitting outside the doctors’ cabin.

A psycho-social care giver complained about the doctor saying he doesn’t even direct the patients to her. *“In spite of repeatedly requesting they say “we don’t have time”! This is not done”*. Another psycho-social care giver opined that doctors must direct the patients to them only after talking to them for a few minutes and not without that. *“The patients should feel satisfied with the doctors instead of complaining about them to us. Moreover, counseling them after doctors’ positive interaction makes double impact!”* A psycho-social care giver from the same group stated that patients tend to get scared and anxious after reading the names of complex tests. She suggested that the doctors must at least tell them that the psycho-social care giver sitting outside will help understand the terminologies and procedures better.

A contradictory viewpoint was put forth by psycho-social care giver from Ahmedabad. She was happy to state that they receive very good co-operation from the doctors. Moreover, the doctors also schedule special appointments during lunch time with patients who wish to talk to them. The patients feel happy which in turn makes the job of counselor easy. She said *“This increases our confidence level and we work with more dedication. Moreover, when doctors express confidence and trust in us in front of the patients, we feel good and the patient also feels confident about us.”*

Another psycho-social care giver from West Bengal also shared a similar experience. He said doctors don’t have time to talk to patients. They simply direct them to him. He also added that he has been successful in developing a good rapport with the oncologist who now trusts him a lot to the extent that the doctor is accompanied by him everywhere during his ward visits which creates jealousy among few fellow staff.

It shows that the response given by doctors to patients is not uniform across different hospitals. This makes it necessary that counselors must be made available in all cancer hospitals not just to cater to the needs of cancer patients but to make the job of oncologists easier.

“Just as a hospital needs doctors, nurses and other staff, it needs a counselor”

-unanimous opinion of all the psycho-social care givers during the discussion.

“Being a cancer survivor increases the moral responsibility to help the patients in the best possible way.”

.....Sanjeevani psycho-social care giver who is a cancer survivor

When asked about the extent to which doctors are dependent on the psycho-social care givers, most of them asserted that doctors have started depending heavily on them. Absence of even one day from the hospital creates a chaos and confusion both among doctors as well as patients. *"Just as a hospital needs doctors, nurses and other staff, it needs a counselor"* was the unanimous opinion of all the psycho-social care givers during the discussion.

Sanjeevani management has been successful in deputing the cancer victors themselves as psycho-social care givers in most of their centers. When they were asked about the difference it is making being cancer survivors, they replied that they are far more sensitive towards the cancer patients. They also added that they are able to understand what the cancer patients are passing through in this difficult journey. A psycho-social care giver asserted that being a cancer survivor himself increases the moral responsibility to help the patients in the best possible way. Reaching out proactively to help the patients comes naturally. It becomes easier to understand and relate with the confusion faced by a patient once diagnosed with cancer. Empathizing with them makes the patient open up more easily and share his/her problems.

Another Sanjeevani angel shared her views saying most of the cancer patients are negative and believe firmly that they are not going to survive. It makes a lot of difference when the patients are given their own example as cancer victors. That makes the patient believe that cancer is curable and they would be able to come out of it. When they see the cancer victors healthy and helping others, the patients gain tremendous strength and confidence. A third psycho-social care giver emphatically said *"Patients have hundreds of questions in their mind during treatment. They are confused. They also tend to have problems at family front. We can judge all such problems merely looking at the patients just because we have been through this experience before and we also know how to make them express it openly. Being a cancer survivor really helps."*

Although not all the psycho-social care givers are cancer victors, those who have gone through this difficult phase of life are indeed able to make a marked contribution to the welfare of the cancer patients especially on the psychological front. Hence, the cancer victors can be given an opportunity to regain their

"Patients have hundreds of questions in their mind during treatment. They are confused. They also tend to have problems at family front. We know how to make them express openly just because we have been through this experience before. Being a cancer survivor really helps."

.....Sanjeevani
psycho-social
care giver who is
a cancer survivor

employment status after appropriate training to cater to the psycho-social need of cancer patients within cancer hospitals.

3.6 IMPACT OF THE ORGANIZATION – SANJEEVANI...LIFE BEYOND CANCER

This section deals with another key objective of the study which relates to assessing the awareness about psycho-social care services provided by Sanjeevani among the cancer patients and to identify the impact of such services on the patients. The main purpose was to identify how far the organization has been able to achieve its goals, to help patients in resolving their problems and to identify the gaps for improvement. In this context, this section brings forth the emergent themes from the cross-case analysis of the data collected through interviews.

3.6.1 Perspectives of cancer patients regarding interventions by Sanjeevani

3.6.1.1 Awareness about psycho-social care services provided by Sanjeevani

As mentioned in the previous chapters, Sanjeevani caters to the needs of cancer patients in terms of information, guidance and providing psycho-social support to them in nine hospitals across different states in India since 2012. This section attempts to analyze how successful Sanjeevani has been in meeting its goals and whether the organization has left a mark on the minds of cancer patients'. In other words, this study in line with one of its objectives makes an attempt to understand the visibility of the organization amongst its service users. Based on Quantitative data, On inquiring about nature of help provided by Sanjeevani staff, around 77 percent of participants reported that they were helped in understanding about and navigate through hospital services, 65percent reported that they received chemo counselling, 45percent reported of receiving help in knowing about government schemes for getting financial help, 44 percent reported that they were encouraged to continue the treatment, 31 % received help in coping up with anxiety and trauma, Around 23percent reported of receiving help in understanding role and importance of wellness clinic activities, 15percent of the participants reported that they received help in dealing with personal relationships.

After analyzing the data collected from both the quantitative and qualitative tools, the following analytical themes emerge out strongly.

Theme 1: In most of the cases, patients tend to remember the psycho-social care givers and their services more than the name of the organization.

Through the quantitative data, it was found that only 31 percent (N=250) patients remembered the name of the organization from whom they received help in the hospital during their treatment (refer Table 10 in the Annexure). In contrast, almost 76 percent (N=250) patients could either remember

name of the psycho-social care givers or could describe them correctly (refer Table 11 in the Annexure). A similar picture emerged from the interaction with the patients during the in-depth interviews and focus group discussions as part of the qualitative analysis. Majority of the patients mentioned that remembering the name Sanjeevani was difficult for them. However, because of the rapport they had developed with the psycho-social care givers and the crucial psychological support they received from them which motivated them to continue the treatment, they automatically remembered the Sanjeevani staff, in some cases even after the treatment was over. It is thus apparent that the organization is able to make a positive impact through its care givers and their services on the mind of cancer patients but need more efforts to popularize the name ‘Sanjeevani...Life Beyond Cancer’ among the masses.

Theme 2: Among the patients who remember the services provided by psycho-social care givers, many of them admitted that psycho-social care givers approached them proactively to provide help (without them asking for it).

It was observed that in many cases, psycho-social care givers approached the patients themselves in order to help them in the hospital. The quantitative data also confirms this emerged theme as almost 62 percent respondents (N=181) replied that they were approached by the psycho-social care givers in the hospital (refer Table 12 in the Annexure). The patients mentioned that the psycho-social care giver used to meet each and every patient in the hospital every day. In one case, the psycho-social care giver just approached the patient seeing her sad and started talking to her in general without revealing her identity. That patient admitted that she felt better after talking to her, reason being it was just a stranger being nice to her than an appointed counselor performing her duty. The proactive support provided by the Sanjeevani psycho-social care givers is proving important and useful as reported by the cancer patients.

3.6.1.2 Impact and Adequacy of psycho-social care services provided by Sanjeevani

It was pertinent to examine whether the services provided by Sanjeevani as perceived by the patients were adequate to fulfil their psycho-social needs and also whether they were able to make an impact on the patients. Certain themes that emerged from the analysis of the qualitative data are discussed in the following section. These themes are further supported by the quantitative data obtained from the patients wherever applicable.

Theme 1: In majority of the situations, psycho-social care givers have a tendency to explain more about diet and food habits to the patients than psychological support during their interaction.

In the initial stage of the study, it was conceptualized that the key role of the Sanjeevani psycho-social care givers is to provide emotional and psychological support to cancer patients. The other

roles for the psycho-social care givers included hand holding of patients with limited or no family assistance and supporting them through the treatment and facilitating better and more meaningful interaction between patients and doctors.

The discussion with the patients brought out the fact that the interaction between psycho-social care giver and patient in every hospital focus predominantly on diet and nutrition. Almost every patient reported that she/he was explained about the diet to be followed during and after chemo therapy sessions and the care to be taken in order to avoid infections. Psycho-social care givers were found to suggest simple home based precautionary and remedial measures such as use of lime juice or frozen lime or a particular form of a mixture of ground pulses and cereals, locally called as 'sattu' etc. to improve immunity and avoid infections. They also had warned about certain things such as pickle that are harmful for cancer patients undergoing treatment. However, relatively less patients reported of receiving support at the psychological level such as counseling for reducing patients' stress, fear or anxiety, helping him/her come to terms with the illness, helping him/her cope up with trauma etc. among other psychological aspects. The data obtained from quantitative study also confirms to this emergent theme. Almost 65 percent patients (N=250) reported of receiving information about diet whereas this figure is reduced to almost half i.e. 31 percent patients who reported of being helped by psycho-social care givers in coping up with their fear and anxiety (refer Table 15 in the Annexure).

Although the support provided by the Sanjeevani staff is predominantly related to diet and nutrition guidance, such information seems to be important to patients as it is not provided by their doctor or other hospital staff in adequate details. As pointed out by one of the patients “ *no matter how much research one does about things like what should cancer patient eat or avoid and how much one reads online, when it comes from a lady who has gone through cancer and who eats like us, who lives like us, such information definitely helps.*” The patients also expressed concern about lack of awareness among cancer patients regarding dietary habits which makes the role of counselor very important for them. Patients mainly from villages are benefitted more due to such information provided by psycho-social care givers. The patients also admitted that the communication between doctors and patients has improved because of the psycho-social care givers.

Thus, the information about diet and food habits given by psycho-social care givers has undoubtedly sensitized the cancer patients for improving immunity and better recovery. However, since the key objective of the organization is to provide emotional and psychological support to cancer patients, it is important that the psycho-social care givers prioritize their roles and devote more time on providing psycho-social support to the cancer patients.

Theme 2: Despite the nature of help provided by psycho-social care givers is more in terms of provision of information related to diet, exercises, government schemes etc., patients tend to perceive this help more from psychological point of view.

One of the interventions of the organization is to help cancer patients with regards to nutritional support. Hence, patients are given guidance about dietary practices to be followed during and after the cancer treatment both in the wellness center and in hospitals. Along with that, psycho-social care givers are also found to provide information about exercises that could be beneficial to specific patients and about government schemes that help reduce the financial burden of cancer treatment for poor patients.

When the study attempted to find the impact of such interactions of the psycho-social care givers and patients, it was hypothesized that the impact of such provision of information would entail changes in patients' dietary habits or improvement in their physical conditions due to changes in dietary habits. However, the qualitative data suggested that patients seemed to perceive such interactions more from psychological point of view. The patients felt good that someone was there to talk to and listen to them, and to clarify such things. They also felt peaceful after interacting with the counselor who had given them all necessary information about diet and other things including activities in wellness center. The patients found psycho-social care givers as someone close to them and to whom they can go with any query since they are usually approached by the Sanjeevani angels themselves.

It is evident that even if the psycho-social care givers initially tend to provide information about diet and nutrition without immediately getting into psychological counseling, the cancer patients feel a sense of belongingness and security. They tend to feel assured about the help that will be available to them once they enter the hospital. The patients tend to perceive and look up to the psycho-social care giver as someone who can reduce their fear and instill hope of getting cured. This clearly brings out the importance of having someone other than the medical staff in the hospitals to interact with the patients and provide them support to cope up with this traumatic illness.

Theme 3: In situations where psycho-social care givers provided emotional support to patients in addition to provision of information, patients reported of having a marked change towards their overall attitude towards cancer.

Cancer is commonly perceived as a terminal disease that induces fear, stress and anxiety among patients. At times, patients get traumatized to an extent that this fear or anxiety turns into depression. The data from National Crime Records Bureau (NCRB) shows that in the decade from 2005 to 2015, 13 cancer patients below the age of 18 years committed suicide whereas that number soared to 128 for those in the age group of 19 to 30 years. The number of suicides further increased

to 219 among cancer patients above the age of 30 years (NCRB, 2015). In such contexts, the role of counselor in the cancer hospitals becomes imperative. An attempt was made to understand the impact of psycho-social counseling provided by Sanjeevani psycho-social care givers on the cancer patients. The psycho-social care givers were found to provide emotional support to some of the patients in select cancer hospitals across the country. Some patients reported that psycho-social care givers were empathetic towards them and they were talking to patients and trying to understand their health condition and details about their treatment. Some of them asserted that psycho-social care givers provided them with the hope and strength to continue with treatment despite its painful nature and adverse side effects. In one case, the patient was scared of radiation procedure and hence psycho-social care giver stood beside her bed till the procedure was complete. It reduced her fear to a large extent and gave her the feeling that she was not alone during her journey against cancer. The patients also remarked that psycho-social care givers used to motivate them and instill a sense of hope and faith that cancer is curable. This was found to reduce their fear substantially. The quantitative data obtained from patients (N=250) through telephonic interviews also confirms to this theme as almost 74 percent patients reported of having an attitudinal change after their interaction with psycho-social care givers (refer Table 16 in the Annexure).

Data shows that almost 74 percent patients reported of having an attitudinal change after their interaction with psycho-social care givers.

There was a case where the patient admitted that merely by talking to the psycho-social care giver, she felt like there was someone of her own in that hospital; more so since she belonged to another state. The patient endorsed that there has been a lot of change in her after talking to the psycho-social care giver in terms of gaining confidence that cancer is not such a serious illness and with proper care and treatment, she can be cured. The patient thus reported of having developed a positive attitude towards cancer since her interaction with the psycho-social care giver. In another case, the patient reported of always been crying at the hospital until she spoke to Sanjeevani staff for the first time. Although the psycho-social care giver spoke with her in a very casual and normal way, it made the patient smile and relieve her anxiety to some extent. The patient revealed that they both did not even know each other before. The patient's parents and her brother and sister too tried giving her hope but coming words of courage from a stranger proved special for her. She admitted that it made her feel better and the interaction was far more effective. In the absence of the psycho-social care giver for a day, the patients were actually found searching them in the hospital. Merely the presence of psycho-social care givers and their smiling faces instilled a sense of happiness and hope among patients every time they visited the hospital for treatment or follow-up.

During one of the interactions with a patient, the psycho-social care giver advised the patient to be happy, to start enjoying and to meet everyone and interact with them so that she will feel better and positive which would in turn help in her recovery. Post interaction, the patient sensed some difference in her attitude and behavior. Earlier when the patient visited the hospital for treatment, she never spoke to anyone. She used to sit alone. It was awkward for her to even speak to her children. But now she has started interacting openly with her children. They all mingle around and watch television together. Now she also gets out of the house and talks to everyone. This makes her feel good.

The above discussion thus highlights the importance and influence of psycho-social care on cancer patients. Positive interaction with the patients result in overall improvement in their mental frame and attitude towards the illness as well as towards the family members and community at large.

Theme 4: The amount of time spent by the psycho-social care giver with the patients tends to have an impact on their emotional and psychological set up.

The study made an attempt to analyze the time spent by psycho-social care givers with their patients and the impact of that interaction on those patients. From the qualitative data, it was found that the time of interaction with the patients varied from 5 minutes to about 40 minutes. From the quantitative data, it was found that the average time spent by the psycho-social care givers with each patient was around 15 minutes (refer Table 14 in the Annexure). This variation may be attributed to extent of discussion required to resolve the problems faced by patients including psycho-social support.

Furthermore, it was also observed that in situations where the psycho-social care givers get to spend more time in building rapport and relationship with the cancer patients, the psychological impact of this interaction on patients was more. In all the cases discussed in previous theme, psycho-social care givers had spent sufficient time with the cancer patients which resulted in substantial psychological impact. From the prior discussion, it is clear that the interaction between psycho-social care givers and patients focus on provision of information regarding diet, exercises, government schemes etc. along with some emotional and psychological support to cancer patients. As brought out clearly in one of the themes before, patients even perceived this interaction as psychological support. Hence, it seems that the void of emotional need among patients was filled to a certain extent by the psycho-social care givers through their interaction.

Theme 5: The psycho-social care givers in cancer hospital can play a positive role in improving the strained familial relationships of cancer patients due to this illness.

There are various studies that show that cancer affects the familial relationships and puts family members of the patient also in distress, especially patient's spouse. According to a study, although

majority of spouses (70 percent to 80 percent) appear to adapt to the stress of cancer without exhibiting clinically significant levels of psychological distress, it is estimated that a significant minority of spouses, (20 percent to 30 percent), suffer from mood disturbance and psychological impairment (Blanchard, Feb, 1997).

Hence, this study attempted to find if the psycho-social care givers had interacted with family members of patients and whether that made any positive impact on the patient and the caregivers. The researcher came across a patient who revealed that her son and daughter in law started behaving differently with her when she was detected with cancer. They feared that they'll also contract the disease being in the same house. However, when their misconceptions were cleared by good and convincing interaction by the psycho-social care giver, they realized their folly and now the patient admits that they have changed their behavior towards her. One of the psycho-social care giver narrated an incident about a patient who was extremely depressed and about to leave the treatment due to ill-treatment by her husband and family members. After a long session of counselling with her husband, the psycho-social care giver convinced him about the need to treat his wife properly and take good care of her. The counselling helped and the patient continued her treatment and received a good family support then onwards.

This shows not only that psycho-social care givers can play a positive role in improving familial relationships of patients but also the need of such interactions between the counselors and caregivers as strained familial relationships further adds to the emotional distress of the already devastated patients.

Theme 6: Despite the fact that Sanjeevani psycho-social care givers do not provide any financial help, in majority of the conditions the help provided by them in other aspects was instrumental, more so at psychological level.

The abysmally low population coverage of health insurance in India and a poorly managed public health sector puts a heavy burden of out-of-pocket spending on households affected by cancer. A study shows that the annual additional expenditure (per member) incurred on inpatient care by cancer-affected households is equivalent to 36 percent to 44 percent of annual household expenditures of the families in similar size and status that are not affected by cancer (Mahal, Karan, Fan, & Engelgau, Aug, 2013). It shows that financial help is one of the important aspects where cancer patients, especially from lower economic class, require help. Such help is provided by many state governments to their respective residents. For example, in Maharashtra, such help is provided under the 'Rajiv Gandhi Jeevandayi Aarogya Yojana' scheme. Such state government schemes have proved beneficial for many patients in the lower economic strata. From the quantitative data, it was found that around 78.7 percent patients (N=122) mentioned that they availed existing central or state government schemes to meet the expenses of the treatment (as per Table 19 in the Annexure).

However, Sanjeevani as an organization does not provide such financial help. Even then, the psycho-social care givers were found to play an important role in facilitating such help for the patients. The psycho-social care givers provided information about the state government schemes and helped them avail it by directing them through the entire procedure. In cases, where patients were not eligible for such government schemes, the psycho-social care givers proactively guided the patients by connecting them to appropriate sources from where they could get financial help. This sort of help provided by the Sanjeevani staff was not a part of their roles and responsibilities. They were found to go out of their way to help the patients get financial support which was commendable. This in no way reduces the impact made by them at the psychological level of patients. Patients admitted that they felt more positive and strong after talking to the psycho-social care givers. The patients strongly suggested the need of such psycho-social care givers to give strength to patients so that they won't give up on their treatment. They also said that patients' mind is diverted because of the psycho-social care giver's dialogue with them. This throws the light on importance of counselors in the hospital and emphasizes that the state government should also provide psycho-social care to patients along with the financial help.

Theme 7: The psycho-social care givers reported of being unable to provide psychological support to each and every patient owing to time and space constraint.

As discussed in the previous theme, the Sanjeevani psycho-social care givers were able to provide information on diet, exercises, government schemes etc. to almost every patient that they had interaction with. However, they were not able to build rapport and relationship with each of those patients so as to make a greater psychological impact on them. Various reasons as to why psycho-social care givers were unable to provide psychological support to each and every patient has been elaborately discussed as part of challenges faced by the psycho-social care givers in section 3.7 in this report.

To summarize, analysis of the data reveals that cancer patients who are helped by Sanjeevani staff tend to remember their psycho-social care givers more than the organization which calls for certain measures on the part of the organization to increase their visibility. It was found that the psycho-social care givers are able to help almost every patient with regards to handholding and provision of information about diet, nutrition, exercises and government schemes; however due to time and space constraints, they are not able to provide psychological support to each patient they meet. Despite this finding, it was found that cancer patients perceived this help to fulfil their emotional needs in a sense that they did not feel lonely and bogged down by all the procedures and painful treatment in the hospitals. The psycho-social care givers were also able to change the perspective of the patient towards cancer and their life when they could interact more and build rapport with them. Even though, the psycho-social care givers did not provide financial help as expected by the

patients, they were undoubtedly able to play a positive role in patient's mental and emotional fight against cancer.

3.6.2 Perspective of doctors towards the interventions made by Sanjeevani

It was crucial to understand the perception of oncologists regarding the role of Sanjeevani and the impact of interventions made by it. In this context, the following section discusses doctor's perception about type of help provided by Sanjeevani psycho-social care givers and to what extent they are able to provide satisfactory services to the cancer patients. It also covers the opinion of these medical experts about the oncology certificate course initiated in collaboration with the Tata Institute of Social Sciences, Mumbai.

3.6.2.1 Perception about type of help provided by Sanjeevani psycho-social care givers

According to majority of the doctors the kind of help provided by Sanjeevani psycho-social care givers consists more of providing general guidance and information to patients and their relatives. Couple of doctors from Mumbai did highlight the psycho-social role performed by the Sanjeevani angels. A doctor from Ahmedabad mentioned about chemo counselling sessions carried out by them and guidance provided to avail government schemes, whereas an oncologist from Mumbai cited the role of the wellness center and its activities in rehabilitating the cancer patients. One of the doctors from Ahmedabad seemed to be not precisely aware about the type of help provided by Sanjeevani, however she admitted that Sanjeevani is doing something good. In a nutshell, the oncologists perceive Sanjeevani psycho-social care givers as mere facilitators and there is clear lack of recognition of psycho-social support provided by them among doctors. This also indicates that there may be lack of information and understanding amongst doctors about activities carried out by Sanjeevani. Concerted efforts need to be made to orient the medical experts about the role played by Sanjeevani staff and to reduce the communication gap between doctors and Sanjeevani angels.

On inquiring whether doctors tend to send every patient or only specific patients to the Sanjeevani angels, the doctors mentioned that not all patients are directed towards them but only those whom they feel are in need of counselling. These include those who have been newly diagnosed with cancer and who now have planned for treatment or terminally ill patients or specific cases who have some problems. The doctors agreed that presence of Sanjeevani psycho-social care givers has facilitated better and meaningful interaction between patients and doctors. In fact one of the doctors from Bikaner even mentioned that the addition of the psycho-social care giver in the last few months have definitely made a positive change to the way they dealt with their patients. The doctor added that the psycho-social care giver spends quality time with every new patient and provides them the appropriate details.

According to the doctor, the counselor is also trying to contact the defaults and they are in the process of reducing those defaulters.

By and large, the medical experts agreed that there should be more NGOs like Sanjeevani. Moreover, one of the doctors from Ahmedabad mentioned that there should be a joint venture between government and NGOs like Sanjeevani who can work collectively for welfare of patients. The other doctor from Ahmedabad agreed that there is a need of more NGOs like Sanjeevani, however she emphasized that the intervention should be in consultation with the hospital administration and under strict guidance/monitoring of oncologists/hospital staff. It is thus essential to make efforts to bring more clarity to the role of Sanjeevani staff and also enhance the communication with hospital authorities and involve them to strengthen the interventions made by Sanjeevani.

3.6.2.2 Opinion about Oncology course organized by Sanjeevani and TISS, Mumbai

The medical experts were asked about their opinion regarding the oncology certificate course initiated by Sanjeevani in collaboration with TISS and to what extent it is beneficial in building the capacity of the psycho-social care givers to provide better services. All the doctors unanimously approved this course. According to them a course like this is essential to orient the to-be psycho-social care givers. An oncologist remarked *“It is a power packed course!”* while another oncologist opined that it is a very basic course and a lot can be modified in it to make it more effective. It was also highly recommended that the module on psycho-social care along with some technical orientation should be included in the syllabus of TISS oncology course.

The doctors also emphasised on selecting appropriate candidates for this course. They stressed on choosing candidates who have the attitude to help and contribute to the society. Another doctor mentioned that currently many students enrolled for this course are cancer survivors and they come up with huge baggage of their own past experiences, and at times fail to see the bigger picture. Thus according to him/her this might act as a hindrance in providing quality psycho-social counselling to patients. The doctors also suggested that there has to be more emphasis on the techniques and methods of psycho-social counselling. Proper technical orientation

“It is a power packed course!”

Opinion of a leading oncologist about Oncology course organized by Sanjeevani and TISS, Mumbai

about cancer should be given and more focus could also be provided on aspects where they actually have the potential to help such as psycho-social counselling, helping the patients with logistics and accommodation, general hand holding and most importantly listening to them rather than guiding patients about diet and nutritionists which is not their domain. The doctor also suggested to include home visits to patient's home as part of the training so that they gain more practical knowledge as well.

3.6.3 Perspective of psycho-social care givers regarding the interventions made by Sanjeevani

In line with the objectives of the study, it was imperative to understand the opinions of the psycho-social care givers who have been working for Sanjeevani to achieve its vision and mission. Hence, the study attempts to assess the perceptions of the psycho-social care givers with regards to their roles and responsibilities, the impact that they have been able to achieve, their expectations and suggestions given by them. In this context, the following section discusses the perspective of the psycho-social care givers regarding the interventions made by Sanjeevani.

3.6.3.1 Services provided by the Sanjeevani psycho-social care givers

The Sanjeevani psycho-social care givers were asked about the type of services provided by them to the cancer patients. In response it became clear that they portray a diverse role as far as helping the cancer patients is concerned right from **directing the patients to appropriate sections of the hospital** for various tests and treatments to **rehabilitation and counseling their caretakers** to keep the patients positive and motivated.

When asked about services provided by Sanjeevani as a part of telephonic interviews, patients reported diverse areas where they had been supported by the care givers (refer Table 15 in the Annexure). Almost over three fourth patients (77 percent) reported that Sanjeevani staff helped them in understanding about hospital services and navigating through hospital while 65 percent of them were helped in counseling about chemo therapy, its side effects and diet to be followed. Of the total patients, 45 percent reported of receiving help with regards to getting information about government schemes for financial help. It was also observed that psycho-social care givers helped 44 percent patients to encourage them to continue taking treatment. About 31 percent patients said that psycho-social care givers helped them in coping up with their fear and anxiety. Even with presence of other

Even with presence of other NGOs in the hospital, almost 84 percent (N=250) patients have reported of availing help only from Sanjeevani angels and not from any of the other NGOs.

NGOs in the hospital, almost 84 percent patients have reported of availing help only from Sanjeevani angels and not from any of the other NGOs.

A similar set of support areas emerged from the interaction with the patients on a personal level through the in-depth interviews and FGDs. The psycho-social care givers provide guidance related to the **diet and exercise and its importance** in the process of improving the immunity for faster recovery. They also provide information about an appropriate diet plan especially with regards to homemade food, how to maintain **personal hygiene**, benefits of drinking more water and **guidance about schedule of intake of medicines**, such as which medicine is to be taken when and its frequency. The psycho-social care givers also **facilitate the radiation and chemotherapy cycles** and explain about ways to deal with the side effects of these treatments.

One of the key roles the psycho-social care givers play is to **advise them about** the available **government financial schemes**. They also facilitate the procedures like filling up forms and compliance of necessary documents to apply for the financial schemes. Certain NGOs provide the services of accommodation at subsidized rates along with other services for the cancer patients and their families. Sanjeevani psycho-social care givers **help the patients by directing them to these appropriate NGOs providing accommodation facilities**. The psycho-social care givers also facilitate small financial help from the OPD staff in case the patients do not have any cash money to initiate the process of treatment. Furthermore, psycho-social care givers from Ahmedabad also reported of having facilitated the travel tickets for the outstation patients and the accompanying family members.

As a part of experience sharing of the staff, one of the psycho-social care givers also narrated her experience of developing a strong relationship with the patients. Just being with the patient and giving an empathetic ear is something the cancer patients are looking forward to during their visit to the hospital for treatment. As rightly pointed out by the psycho-social care giver, the patients need to visit the hospital many times for the treatment and so developing a bonding with him/her becomes extremely crucial so that they share their psycho-social problems and needs with the Sanjeevani staff. In case of personal queries, which patients find awkward discussing with the young practicing doctors, they usually open up with her (preferably in a separate room if available). Counselling the patient as well as the partner in case of sexual problems is also reported to have undertaken by this psycho-social care giver. Another psycho-social care givers also reported of providing elaborate counseling related to personal hygiene particularly in case of gynecological cancers. The patients feel free to discuss such issues and get the queries sorted out by the Sanjeevani staff more so if the consulting doctor is a male.

The patients also need to be consoled through a longer duration counseling in case she/he breaks down and feels traumatic to face the situation of cancer detection. In such cases the psycho-social care givers are seen to **reduce their anxiety and trauma and motivate** them enough to accept

the fact that they are now suffering from a chronic illness and need to undergo its proper medical treatment.

Eight out of 12 psycho-social care givers reported of having completed the oncology certificate course organized by TISS while others mentioned that they would be undergoing it in due course of time. When inquired about the efficacy of the course, one of the psycho-social care givers positively asserted that the course helped her a lot. She learnt a lot of things in totally unexplored areas like psychology, science, diet etc. She also added that she learnt how to do the care giving to the cancer patients in a more professional way. Another psycho-social care giver opined that the course served as a concrete foundation to serving as a counselor. Yet another psycho-social care giver mentioned that the course helped him with in depth knowledge about human body, yoga and nutrition. *“There is lot of difference between previous interaction and current. Current interaction is far better”* he added. The course also resulted in improving the confidence level of the psycho-social care givers as reported by all of them. It also helped the psycho-social care givers improve their English language which they were happy about.

3.6.3.2 Psycho-social care givers’ commitment towards Sanjeevani as an organization

The psycho-social care givers were asked, how long they have been associated with Sanjeevani. The period ranged from recently joined to as long as three years of service with Sanjeevani. Furthermore, they also shared details about their previous job i.e. before joining Sanjeevani as a psycho-social care giver. One of them reported of having left the job as a dentist to join this service. Another two psycho-social care givers mentioned that they were associated with some NGO prior to this job. One of the psycho-social care givers was a data entry operator. Two of them were teachers for nine and five years respectively and yet another three were serving in a bank, a private firm and in sales and marketing industry with nine years of experience respectively. The varied professions mentioned by the psycho-social care givers strongly support the fact that in spite of being in good jobs with lucrative pay packages, the present group of psycho-social care givers found it more worthy to leave the jobs and join this philanthropic profession of serving the cancer patients through the Sanjeevani.

When they were asked the reasons to take up a psycho-social care giver’s job, one of them said *“I felt people here are needy, illiterate, they do not know anything, and do not know about chemo therapy as well. So then I thought I should work here full day so that I can help the patients properly.”* Another psycho-social care giver was

“There is lot of difference between my interaction before and after attending the course. Current interacting is far better”

Opinion of Sanjeevani psychosocial caregiver about Oncology course organized by Sanjeevani and TISS, Mumbai

fulfilling her mother's dream who was a cancer patient to help ignorant and depressed patients. It was because of the strong willpower, that her mother survived for ten long years after doctor had lost all hope. That made the psycho-social care giver realize the importance of enhancing the willpower of patients by giving them courage and hope to face this disease. Another psycho-social care giver accepted this profession as he realized the dearth of counselors to provide psycho-social support to cancer patients. Yet another staff shared her experience, when her father was detected with cancer and there was no one to help. This made her give a serious thought of providing services to the cancer patients which were not available to her father. One of the psycho-social care giver tried to confront and in the process relieve the pain of losing her two children one after the other by joining Sanjeevani and helping the cancer patients with care and love. Another Sanjeevani angel was awed with the rising incidences of cancer in North India which inspired him to join this organization, working for the betterment of the cancer patients.

When questioned about the chances of shifting to a better job opportunity, all of them in unison asserted that none of them is interested to leave this job for a better one. They all were happy and totally satisfied with their present roles as Sanjeevani "angels". "Unless Sanjeevani throws me out, I am not going to leave" was the reply by one of the senior psycho-social care givers. A couple of psycho-social care givers admitted that they have been getting better job opportunities, but they were clear that they would not quit.

This clearly brings out the fact that majority of the Sanjeevani psycho-social care givers are committed and content with their work. They are true to their profession as well as to the organization. The psycho-social care givers deputed by Sanjeevani across their nine centers were undoubtedly putting their best efforts in providing timely psycho-social services to the cancer patients.

3.6.3.3 Impact of the psycho-social services on the cancer patients as perceived by the Sanjeevani staff.

All the psycho-social care givers affirmed that the patients are nervous and utterly confused when they come to the hospital for the first time. They have lot of problems and are especially worried about lack of sufficient finances to undergo uninterrupted treatment. They also stressed the fact that 99 percent patients are depressed and need motivation particularly because they strongly believe that cancer is a terminal disease.

Majority of the Sanjeevani psycho-social care givers are committed and content with their work. "Unless Sanjeevani throws me out, I am not going to leave" admitted one of the senior psycho-social care givers.

The psycho-social care givers unanimously reported that the patients feel happy and comfortable talking to them. During interaction, one of the psycho-social care givers said *“Whoever comes to me for advice leaves with a happy and smiling face.* The very fact that the patients come looking for the Sanjeevani staff during their next visit speaks volume about the influence of services provided by the psycho-social care givers. The patients are also seen to diligently follow the advice rendered by the psycho-social care givers and feel satisfied with the outcome. That in turn enhances their trust and brings them emotionally closer to the psycho-social care givers. The Sanjeevani care givers also reported of getting calls from the patients even after their treatment is over. They continue to get their queries sorted out by keeping in touch with the Sanjeevani staff even months later. Even when the patients leave, they show they care and the psycho-social care givers become a part of their extended family as remarked by a few Sanjeevani angels.

“Whoever comes to me for advice leaves with a happy and smiling face.

....Sanjeevani psychosocial caregiver

One of the psycho-social care giver shared his experience of having boosted the morale of an 80 year old lady suffering from cancer. He said she felt much better when he told her that there is a lot to Life Beyond Cancer. He also mentioned that she now has complete trust in him and is taking the treatment with a happy state of mind.

The role of the counselor becomes especially crucial when the patients are given a strong indication by the doctors that they would not survive for long. In such situations the patients desperately look out for an emotional support and tend to depend completely on the counselors’ words of hope and motivation. The absence of the Sanjeevani staff from the hospital premises disturbs the patients and they miss the smiling faces of the psycho-social care givers and their consoling words as reported by most of the psycho-social care givers.

“Just the touch and merely being there for them is what helps, moral support is important.”

.....Sanjeevani psychosocial caregiver

One of the psycho-social care givers narrated her experience of having spoken to a patient from Odisha on request. The psycho-social care giver reported of having sat next to her during her radiation in the hospital when she was in tremendous pain. She said *“Just the touch and merely being there for them is what helps, moral support is important.”* They both didn’t know each other’s language but the mere voice of the counselor on phone made the patient feel happy and relaxed when she was back to her hometown. Another psycho-social care giver narrated her experience with a lady cancer patient who had breast cancer but had eventually developed metastatic tumors (mets) all over the body. She was a positive and a strong lady who despite not getting support from her daughter-in-law survived the cancer for many years simply because of the affection she had towards the psycho-social care giver. The patient use to travel just to meet the psycho-social care giver

and also had written letters to her. She also use to discuss her family problems with the psycho-social care giver. She use to admit that *"I come to you so that I can breathe!"* She had metastatic tumors even in her lungs. She was in terrible state. But in spite of that she used to come to meet the psycho-social care giver at least once or twice a month. This meeting used to give the patient strength and boost her up to stay alive for the entire month as reported by the patient. Another psycho-social care giver shared an incident about a patient from Punjab who was terribly upset and not responding to medicines because of the ill treatment by her own son and daughter-in-law. The patient and her husband use to eat out, stay in hospital entire day and go back home only at night. The psycho-social care giver made her open up and share her problems thus making her comfortable. She also called her son and daughter-in-law and counseled them as a result of which everything was sorted out and the patient was happy. An experience with a patient who had stopped coming for follow up treatment as she was highly depressed was shared by a psycho-social care giver. Her husband had deserted her and no medical treatment was benefiting her directly taking a toll on her recovery from cancer. The psycho-social care giver advised her to take good care of herself and undergo regular treatment without which there were more chances that she would lose her husband. With persistent counseling the patient was convinced and started coming up regularly for the follow up treatment.

Overall, the patients were found to be satisfied and happy after interacting with the Sanjeevani psycho-social care givers. They were also found to gather more courage not only to accept the fact that they were suffering from a terminal illness but also face the painful treatment with smile on their faces due to the presence of psycho-social care givers at the treatment locations. The patients were found to emotionally depend more on the psycho-social care givers than their immediate caregivers and family members. Thus the psycho-social impact of the services provided by the psycho-social care givers was considerably high.

3.6.3.4 Concerns voiced by the Sanjeevani psycho-social care givers

The researcher also thought it to be imperative to understand the hardships and difficulties faced by Sanjeevani staff while providing their much needed services to the cancer patients. The study brought out the fact that the psycho-social care givers are not given a clear idea of their roles and responsibilities when they join. Most of them start their work intuitively by helping the cancer patients in whatever way they can like reducing their fear, anxiety, giving them idea about treatment protocols, guiding them in the hospitals for various tests etc. All those who have completed the TISS oncology certificate course have some idea about what is expected from them as psycho-social care givers. Others however, work with senior psycho-social care givers and get hands on training primarily through observation.

All the psycho-social care givers who have undergone the oncology certificate course organized by TISS were satisfied with it and recommended it for the newcomers. They also admitted that the

course is improving gradually. However, they all stated that the course should be looked upon only as a basic requirement. Something advanced is needed to build the capacity of the psycho-social care givers further. So an upgraded version of the course is needed. All the psycho-social care givers unanimously voiced the need for regular capacity building workshops or orientation programs to keep themselves abridged with latest developments in their field.

The psycho-social care givers' another concern revolves around reporting of patients whom they help in order to maintain data records. The psycho-social care givers fill up a draft format for their own reference and convenience which during late evenings after getting done with their routine tasks is transferred onto the booklet provided by Sanjeevani. The details about the services provided to the patients is also sent to the Sanjeevani management staff by WhatsApp on daily basis. The selection criteria to include the patient in the report was largely identical for all psycho-social care givers. Majority of them reported only those patients to whom they cater to for considerable time. On an average the psycho-social care givers were found to cater to 10 to 15 patients in a day. However, all of them commonly mentioned that though they report this complete figure on WhatsApp to the management staff, they include details of only selected 8-10 patient in their report format in hard copy. This is primarily because of two reasons. Firstly, it becomes practically difficult and time consuming to write about all the patients to whom they have provided service. Furthermore, most of the psycho-social care givers pointed out that patients tend to come on repeated visits to the hospital for treatment. In such cases, they intentionally avoid reporting the patient again to prevent duplication of records. Also some patients tend to come and ask the same information every time they come for their chemotherapy cycle for clarity which is also not reported by the psycho-social care givers. Secondly, they tend to help patients in many small ways depending on the need and requirement of the patient. It is only with a few that these psycho-social care givers actually spend their considerable time with providing psycho-social support in literal sense. One of the psycho-social care givers also mentioned of providing services to 10 to 15 patients in a day providing them information about diet, nutrition and psychological counselling including telephonic counselling to the patients if required. Another psycho-social care giver reported of helping the patient with small things like directing towards the right place for tests, helping them locate the agencies which help the patients financially etc. She reported to have selected the criteria of at least 15 minute interaction with the patient to report it as given the service. This as she said is satisfying to either parties. In one case, the psycho-social care giver also mentioned about group counseling in the waiting area which is reported by her on daily basis at the end of the report. The benefit of this type of counseling is the presence of family members and caretakers with the patients who also get sensitized along with the actual patients.

The psycho-social care givers were found to introduce themselves as Sanjeevani staff to the patients' right at the beginning of their interaction or whenever the patients got comfortable with them. However, one psycho-social care giver clearly revealed that he avoids giving his introduction at the beginning as the patients then are unlikely to trust and open up with him. They

tend to trust the hospital staff more than any NGOs. This particularly happens with those coming from remote rural areas. So he honestly said that once he gets to build a rapport with them and they start trusting him, only then he reveals his true identity as a Sanjeevani staff. Another psycho-social care giver shared a similar concern saying patients find it hard to remember or recollect the name “Sanjeevani” as it is difficult. This happens predominantly in Tata hospital with nearly 20 odd NGOs working there in parallel. The psycho-social care giver from Ahmedabad happily added that it becomes easy for the patients to approach the psycho-social care givers because of the Sanjeevani banners which are displayed in the common sitting areas.

3.7 CHALLENGES FACED BY PSYCHO-SOCIAL CARE GIVERS OF SANJEEVANI

The psycho-social care givers were found to provide tireless and ceaseless services to the cancer patients’. Interacting with the patients and their family members, helping them cope up with the trauma, empathizing with them, motivating them to continue the treatment for a speedy recovery is emotionally an extremely exhausting process. Consequently it is very likely that the psycho-social care givers themselves pass through bouts of depression and phases of low self-morale.

An attempt was made through this study to understand the challenges and the hardships they face in dealing with cancer patients’ on a daily basis. Majority of the psycho-social care givers reported of having passed through depression at their individual level due to constant interaction with cancer patients. There is a tendency of counselors to get emotionally attached to the patients especially in cases of long term treatment. So in case the patients’ health gets deteriorated, it sometimes takes a toll predominantly on the mental health of the counselors. They tend to feel low for a few days but then manage to collect themselves and get back to counseling the patients again. They also experience depression owing to their own cancer in spite of having overcome it completely. Being with the cancer patients throughout the day takes them down the memory lane of their own struggle with the life-threatening illness.

When questioned ‘What is it that you find the most challenging while counseling the patients?’ varied responses were obtained. Making the patients smile is the one of the most challenging tasks as patients tend to lose the smile on their faces the moment they come to know about cancer. The psycho-social care givers then takes help of their pleasant past memories when they were leading a normal healthy life and motivate them to maintain a happy disposition by convincing them that having a positive attitude and a smiling face in itself is the most effective medicine for this

“It is very important that they express the negative emotions and cry profusely. I personally face this challenge. Unless they open up they are not able to clearly understand what they want.”

.....Sanjeevani
psychosocial
caregiver

disease. Another psycho-social care giver stated that making the patients express their piled up emotions openly and freely is the most challenging task. He said *“It is very important that they express the negative emotions and cry profusely. I personally face this challenge. Unless they open up they are not able to clearly understand what they want.”* When asked about how he deals with this challenge, the psycho-social care giver replied that when discussion about their past life and close family members starts, the patients begin to break down and slowly start sharing everything with the psycho-social care giver. This sharing is what makes the patients feel light and emotionally attached to the psycho-social care giver.

Another challenge expressed by the psycho-social care givers was reaching out and helping the patients coming especially from an extremely poor background. Helping them get financial support to avoid meeting the cost of treatment by selling land, property and jewelry remains a big challenge to this psycho-social care giver. Another psycho-social care giver stated that providing emotional support to those patients who belong to outside states and have absolutely no family support is a herculean task. They usually are unaccompanied and mentally disturbed to a large extent and so handling them is the biggest challenge.

The psycho-social care givers also asserted that dealing with relapse patients is a big challenge as they no more trust the doctors and the counselors. They argue saying they were being told that cancer would be completely cured and so usually get into the denial mode which is highly deterrent factor to their continuation of treatment. One of the psycho-social care givers shared her views on what she thinks as the biggest challenge. According to her the major challenge is building trust in the patients who think now since they have come to Tata, they are soon going to bid goodbye (Tata) to life. *“I have actually heard patients say this. Making them aware of Sanjeevani’s tag line of Life Beyond Cancer and building hope in them about such a life is a big challenge.”*

Another psycho-social care giver opined that dealing with the caretakers of palliative cancer patients and counseling them is a far bigger challenge. Disclosing the reality to them and preparing them to accept the hard fact of facing death is extremely difficult. However, in such situations counseling the patient is less arduous than counseling the caretakers. It becomes extremely difficult to console the caregivers and prepare them for the loss of their near and dear ones. One of the psycho-social care givers also expressed the difficulty of dealing with gynecological issues with patients like explaining to them about vaginal exercises and its importance etc.

Thus as psycho-social care givers, the Sanjeevani staff faces lot of challenges while dealing with the cancer patients on a routine basis. Their roles are highly emotionally demanding and mentally depleting. There is a good chance of such work conditions affecting the health of the psycho-social care givers, especially of those counselors who are cancer victors. They may suffer from relapse. Hence, periodical counselling of the psycho-social care givers was strongly suggested by the team.

It will not only help them cope up with such emotionally demanding work but also improve their efficacy as psycho-social care givers.

3.8 SUGGESTIONS BY CANCER PATIENTS, ONCOLOGISTS AND SANJEEVANI PSYCHO-SOCIAL CARE GIVERS

This section describes the suggestions given by patients for the welfare of the cancer patients in the country and elaborates upon the suggestions given by oncologists and psycho-social care givers which are addressed separately to both - the government agencies as well as the Sanjeevani organization in the following subsections.

3.8.1 Suggestions from Cancer patients

Society needs to change its attitude and behavior towards cancer patients. People should think of cancer as an illness that can happen to anyone, it is not contagious and more importantly that it can be cured. Many researched patients think that if the government can start a campaign through media for generating awareness about cancer on the similar lines of TB, it would greatly help in busting myths and misconceptions about cancer. Patients expect the government to build this faith among masses that cancer is normal for which examples of celebrities who came out victorious can be used such as that of Yuvraj Singh, Manisha Koirala, Sharad Pawar etc. Posters should be put up in all public health facilities right from grass root level Primary Health Centers and Community Health Centers to super-specialty hospitals. Another patient reported of having witnessed a group of girls standing at the juncture of bustling street of Mumbai making public aware about misconceptions about cancer through their interesting skits. Such street plays need to be replicated on a large scale across every rural and urban areas.

Interaction with patients brought out clear and strong expectations from the government. The cancer patients have requested the government to undertake research studies that focus on investigating the root causes of cancer. Some of them also suggested further that such research studies need to be conducted to discover vaccines that would prevent the incidence of this horrifying chronic illness. One of the patients mentioned that the government should validate alternative treatments such as oxy therapy, specific food treatment etc. which can act as replacements for painful chemo and radiation therapies. The patients also suggested that therapies such as naturopathy, meditation, yoga which are provided by Sanjeevani would be of great help to patients. A recent study on cancer patients showed that Pranayama could influence in reducing the cancer related fatigue and increasing the level of non-enzymatic antioxidants (Jyothi, 2013). The patients suggested that such therapies should be made available in cancer hospitals itself.

Majority of the patients also suggested that a toll free helpline for cancer patients would be useful, especially for those hailing from remote rural areas. One of the patients however told that such

helpline can help only few cancer patients as it would not be as good as meeting a counselor or a doctor in person. Another patient suggested an alternative to toll free helpline of using modern day technology. He suggested that groups or forums on WhatsApp, Facebook, Twitter and similar social platforms could help where patients can talk to counselors. One of the benefits of such technology oriented interactions would be that important conversations with the counselors can remain saved with patients which can be referred at any later date they want. Also, it will resolve the issue of helpline often being busy which could create anxiety and trouble patients even further.

3.8.2 Suggestions by Oncologists

The medical experts voiced certain suggestions based on their expertise and experience in the field of oncology to address the issues of cancer patients. Several suggestions were put forth for various stake holders such as the government, hospital authorities and NGOs like Sanjeevani which are discussed in this section.

3.8.2.1 Suggestions to the Government

If people's welfare at mass level is concerned, it can be operationalized only by the government interventions. The role of government is crucial for addressing the prevailing challenges in public health care and achieving health equity. As discussed in the earlier section, according to the oncology experts, provision of psycho-social care to cancer patients and their families is crucial to enable them to confront the traumatic illness and undergo the complete treatment well for faster recovery. However the doctors emphasized that the recognition of the vital need for psycho-social counselling to cancer patients and their caregivers needs to happen not only at the level of health care professionals but government as well.

There are a certain suggestions provided by the doctors to the government to ensure provision of psycho-social counselling to cancer patients as discussed below:

a) Need and effective ways in increasing understanding and creating public awareness about cancer amongst masses

There are a lot of myths and misconceptions prevalent amongst masses and cancer patients and their families pertaining to cancer as discussed earlier. All the doctors highlighted the need to increase public awareness and understanding about cancer amongst the patients and society at large. Moreover, the doctors highlighted the alarming fact that in our country majority of the cancer patients are diagnosed only at the advanced stage. This calls on for a dire need of attention in the area to create awareness amongst masses about preventive measures and early warning signs of cancer. An oncologist from Mumbai remarked that a lot of people still feel cancer is incurable. In our country, cancer gets diagnosed in advanced stages for about three quarters of the cancer patients. Thus the public perception that cancer means death, is more or less correct but that hold

true only for the advanced stage cancers. If detected early, cancer can be cured. This awareness needs to be generated among masses, he emphasized. The doctor also remarked that *“The people who have cancer need support. They don’t need sympathy, they need empathy. Most cancer patients hate when people show sympathy.”*

On inquiring about ways to create awareness amongst masses, various ways have been suggested by the doctors as below:

i) Screening at Regular interval:

Regular screening program for early diagnosis of diseases is lacking in the health system set up of India. It is a general belief that if a person is not showing any symptoms, she/he are perfectly fit and need not go for screening like bronchoscopy or so. However, in developed countries, they have screening programs at regular intervals irrespective of the health status of the citizen. That is why malignancies like bronchial or abdominal/visceral which are usually picked up at very advanced stages, are diagnosed at an early stage. Thus awareness to carry out screening at regular intervals is imperative. The doctors emphasised that screening has to be part of the routine check-up for everyone, including children.

ii) Sensitize school/ college students:

It was suggested that cancer awareness focusing on prevention and early symptoms should be incorporated in the education module to sensitize the younger generation. Aspects pertaining to control of disease such as, educating students about ill effects of tobacco, and how it can lead to cancer should be highlighted. The students should be made conscious about having overall fitness and a healthy lifestyle.

iii) Awareness at PHCs:

It is imperative to have a program of cancer care awareness and prevention as an integral part of the health system. According to a doctor from Ahmedabad, holding a camp or making an awareness program or celebration of few days will not help, the awareness paradigm needs to be integrated right in the system. The doctors mentioned that there is a need to initiate cancer awareness right at the grass root level through the primary health centers where people visit for their routine ailments like cold and cough. People should be alarmed about what is to be done if the symptoms worsen. If they have to undergo health check-up, it also should include a few tests regarding cancer diagnosis.

iv) Role of mass media

The oncologists also suggested the use of mass media in cancer awareness in higher proportions. According to the doctors, movies and serials, social media like Facebook and WhatsApp etc. have a tremendous hold over societies. One of the doctors, while highlighting role of mass media in promoting negative stereotypes pertaining to cancer said that if we read novels written in early 20th

century by Sharad Chandra, the famous Bengali guru, most of his heroes use to die of TB. It was once upon a time a taboo. Now heroes die of cancer in novels and in movies, which is not correct. On emphasising the need to normalise cancer he remarked, *“The moment you start talking about cancer, they say poor fellow got cancer. I think I can’t remember any movie where the hero was a cancer survivor where he said that I had cancer 8 years back and the focus is not about his cancer or that he survived cancer but it’s just one of the things he’s had in his life. I think we need to normalise cancer which has not happened yet. We need some stories where cancer has been normalized and that cancer is just one of the things which has happened to that person in the past.”*

Another doctor, while elucidating positive role of mass media in cancer awareness commented *“I think print and mass media have a large role to play. The average size of a breast tumor in 1991 amongst women with breast cancer operated at our hospital was 5.5cm, now currently the average size is around 2.6cm. Now that has happened without systematic screening. The average size of a tumor has reduced because now the patients approach the health care system earlier than they use to 25 years ago. And that is solely the result of awareness. This 2.7cm or 2.5cm decline in the average size of a tumor will have an enormous and indescribable impact on the outcome of the disease. That means the fraction of those who will be cured will be much, much, much more.”*

b) Health Awareness coupled with good quality health infrastructure

There have been noteworthy improvements in health indicators of the country past few decades. However a huge disparity in the availability of healthcare resources continue to exist in India. The doctors strongly suggested that awareness in the general population is absolutely vital but along with awareness, there should be provision of adequate health care infrastructure in the cancer hospitals. With high awareness levels, if the quality of health care infrastructure is poor, then awareness in its own right will not work. Hence, the unanimous opinion from the medical experts was that awareness coupled with the good health care infrastructure that is designed to take on the diseased individuals is imperative.

c) Provision of counselling centers and counselors in hospital settings

Provision of counselling centers in hospitals was voiced as the fundamental requirement to address psycho-social counselling needs of cancer patients by the oncologists. They emphasized that there should be provision of allocating space for counselling, allocating funds for human resources and developing yards sticks to measure the effectiveness of psycho-social counselling. The doctors also emphasized that government should employ counselors and the provision of psycho-social care to cancer patients and their family members should be made

“We need some stories where cancer has been normalized and that cancer is just one of the things which has happened to that person in the past.”

.....A Leading
Oncologist

mandatory for all hospitals. With the number of patients increasing sharply, there should be sufficient number of counselors to brief patients about the nature of the treatment they need to undergo and help them cope up with the side effects. Creating awareness on the mode of treatment is as significant as generating awareness about the disease.

d) Helpline for cancer patients

All the doctors agreed that there should be a dedicated helpline for cancer patients in all the states. A helpline would be definitely useful since the patients have many questions and cannot rush every now and then to the hospitals or approach the doctors all the time. Talking with someone can certainly help reduce their anxiety and stress. Since hospitals cannot cater to psycho-social and information needs of each and every cancer patients due to logical, administrative and time constraints, a dedicated toll free helpline can surely be helpful. However, some of the doctors were skeptical about its implementation and emphasized on the recruitment of appropriate staff for the task of counselling via helpline. An oncologists from Mumbai commented that *“if someone who is a good listener and a sweet talker, someone who can just put them at little ease and soothe their afraid nerves, it would help. But that is a special skill, not all have that knack particularly comforting on the phone without knowing that person. It’s either the quality of the voice, the tone of the voice, the words they use is such that which would make the patients feel at ease. If there are people like that and they have suggestions and guidance for general problems and issues about cancer, it will be of use.”*

It was also suggested that a helpline should provide factual information to cancer patients like providing information about cancer hospitals, type of treatment available in the nearby vicinity of the patient’s location or details about the treatments available in the country. A website linked with telephone as a source of information pertaining to cancer treatment would also help.

The medical expert from Mumbai emphasized the apprehensions that cancer patients go through during and after the treatment like *“Will my cancer come back? When will it come back? And if it will come back will it be cured? How long will I live? These are certain things which no one answers”* Thus the counselor should be adept to address such specific queries along with the general guidance. Some of the doctors even suggested that one to one counselling interaction would be more effective for cancer counselling as compared to a telephonic encounter. Thus a follow up telephonic counselling maybe useful once you have already had a face to face interview.

e) Ban on the availability of Carcinogenic Substance

Studies indicate that there is a definitive link between the use of tobacco products and the development of cancer (How Cigarette Smoke Causes Cancer: Study Points To New Treatments, Safer Tobacco, March 2008).

The need to ban availability of tobacco which is one of the leading cause of cancer and cancer deaths across the globe was emphasized by the oncologists. Moreover, the people whose livelihood is associated with tobacco industry should be provided with some alternative livelihood options to support their families. It was also suggested to have De-addiction centers in every PHC and CHC to rehabilitate the persons with addiction issues.

3.8.2.2 Suggestions for Hospitals/Doctors

The lack of recognition about significance of psycho-social care amongst medical professionals as of the major barriers in delivery of psycho-social care to cancer patients was brought out by majority of the medical experts. One of the doctor from Mumbai said *“Only when medical professionals recognize that this is a very vital component of the care that they deliver to their patients, will everyone make efforts to incorporate it. It starts at a very basic level when we have our DM course, we have a syllabus that we teach our students undergoing training in oncology. So psychological care and social aspects of medicine are only peripheral discussions if at all, so we all have to acknowledge the importance of this.”*

The oncologists while highlighting the significance of psycho-social care emphasized that although aspects of psycho-social care are present in the syllabus of medical oncology course, it needs to be given due importance and not ignored as one of the peripheral thing. The doctors suggested that aspects of psycho-social counselling should also be integrally incorporated in to the teaching curriculum. The students also need to be taught the art of communication and that will be vitally useful for the next generation of doctors. Studies have highlighted that good communication skill in a doctor improves overall satisfaction and patient’s compliance. The doctor recommended inclusion of formal training in communication skills in medical curriculum and training of practicing doctors which is significant in the delivery of high-quality health care.

It was also suggested that there should be a system like triaging in hospital settings to systematize the functioning. *“A system of easy triage in the sense, ‘who needs what’, a simple brief interaction and referral, who needs to be referred to a pain clinic, a counselor-a psychological counselor, which patient needs what kind of thing, so based on their requirements one should be able to immediately triage.”*, remarked an oncologist from Mumbai.

The doctors also suggested that the students need to imbibe some appreciation of humanities during the course. *“You see we doctors cannot have tunneled vision.*

“Psychological care and social aspects of medicine are only peripheral discussions if at all, so we all have to acknowledge the importance of this.”

.....A Leading
Oncologist

Doctors do not know anything about music and drama. They have no interest in literature. Some of the older time doctors were connoisseur of literature, jazz and I think that improves you as a human being. It also goes into making of a better doctor and a better health care professional.” he added.

3.8.2.3 Suggestions for Sanjeevani

The doctors were requested to put forth their suggestions and expectations which they feel need to be addressed by Sanjeevani as an organization working for the welfare of cancer patients in order to make its interventions more effective and fruitful.

a) Need of counsellors with specific knowledge and specialization in domain

The medical experts stressed the need of counsellors to be technically oriented about cancer and its treatment. Just as there are doctors with specialization, there must be counselors also taking care of those specialized domains. *“When a patient approaches a counselor and says - I am very scared that I will die very soon and there will be nobody to look after my daughter. Then the counselor has to first understand what the outcome of that patient is likely to be, how that treatment will impact that outcome and is it really true that the patient is likely going to die very soon or is it the case that the patient actually has a probability of a good outcome but is scared. So to be able to understand that, they need to do some domain specialization. Some of them should take on 3 or 4 types of cancer –pediatric cancer, gynecological cancer, head and neck or lung cancer and then try to educate themselves about the disease. Because it is no good saying that don’t worry things will be alright, nothing will happen. The patient will know that this person is just speaking from the top of their heads. Counselling needs specific knowledge to be able to pull up the counselling well.”* commented a leading oncologist from Mumbai.

It was also recorded that despite the availability of counselors, patients always want to talk to doctors, the reason being the medical experts are able to provide them with specific technical information. General guidance, as remarked by an oncologist, can be even provided by giving a pamphlet. *“The counselors should know what they are talking, the patients desire specific information. It is no good saying that you should be happy, you should not let anxiety overtake you, all of that is useless. You have to provide specific information to patients and then they should also know that if somebody says that I am very anxious that I have such beautiful long hair and I will lose those hair they should know what to expect in terms of their hair coming back. What is the timeline by which a person should expect, they*

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*.....A Leading
Oncologist*

should also know that there are other ways in which they configure a wig out the patient's own hair or whatever else they can suggest but they should know. Only then in the true sense they can take the responsibility of the doctor. Doctors have to deal with many other things. So sometimes they are even better than doctors. But they have to specialize, they have to have the technical knowhow of the disease in which they wish to counsel.

They emphasized on building expertise in specific domains so that the counselors are well read and can address some technical issues of the patients with confidence and adequate clarity. The doctors are of the opinion that it is important for the counselors to understand details about the treatment and its side effects and explain it properly to the patients. This will certainly be beneficial for reducing the load on medical experts and in turn make patients more happy and satisfied with the counselors. One of the doctor further suggested that even if the counselors do not understand the technical medical terminologies, they can write out the queries of the patients and convey them to the doctors. The counselors should act like the mediators between the doctors and the patients. Wrong information given to patients can create a negative impact and so the counselors can actually make or break the patients.

It was suggested that counselors should be able to meet the information needs of patients as doctors are unable to provide adequate time to address their queries. According to the medical experts, there are variety of pamphlets and booklets provided by many NGOs, however there is no good evidence that the information provided has factual base. Thus the role of the counselor becomes imperative.

b) Training the counselors

The doctors suggested the need to train/upgrade the counselors at regular intervals. The medical experts emphasized on providing adequate and regular training in psycho-social counselling to the counselors. Communication skills of counselors also need to be enhanced as mentioned by some of the doctors. Communication with patients as well communication with hospital authorities need to be focus. “Sanjeevani should have a good coordination with the administrator, the treating doctor and amongst their volunteers. That is required” said an oncologist from Ahmedabad.

c) Increase awareness about counselling amongst other health care professionals

It was suggested that Sanjeevani management should interact with health care professionals and also increase awareness about the need for counselling both

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Medical expert

psycho-social and other counselling among the health care providers. Sanjeevani can organize seminars, group discussions, panel discussions on counselors and counselling, involving doctors and nurses and other individuals to enhance the awareness levels of the health care professionals.

d) Composition of the team

According to the doctors Sanjeevani can also build some sort of a hierarchical structure. Support from the nurses can be fetched who can then oversee a group of five or six counselors. Nurses are already medically trained. So few nurses can act as the nodal person and can provide support to the counselors along with monitoring their activities.

e) Support Groups

The doctors also suggested to facilitate support groups of cancer patients as it could be one of the best way to counsel the patients as they can relate to one another and empathize with each other. Interacting in groups with others passing through the same struggle and pain helps relieve the stress and anxiety to a large extent. The medical experts further mentioned that it is convenient for patients to visit hospitals as compared to any other place and they are more comfortable in the hospital premises. Thus, support groups could be facilitated in hospital settings on days when hospitals are less crowded, for instance on Saturdays in Tata Memorial Mumbai.

f) Scale Up

According to the oncologists, there is a need for Sanjeevani to scale up their interventions as it is able to reach a fewer number of patients currently.

g) Appointing Survivors as counselors

One of the key features of Sanjeevani organisation is deputing the cancer survivors as psycho-social care givers for better results. The doctors, however had differing views on appointing cancer victors as counselors. One of the medical experts felt that it will be more effective to have cancer survivors as counselors as they can empathise with what the patients are going through and it was suggested that family members of cancer patients as well can be tapped as counselors, as even they have experienced the trauma and struggle. On the contrary, another doctor opined that it is not a necessity to have counselors as cancer survivors. He emphasised that it is important that the counselors do not apply their own experiences and thought processes while interacting with patients as it may not be applicable to everyone as each person has a different treatment and experience of the same. The psychological barriers which they might carry because of their own past experiences may act as a hindrance to provide quality counselling to patients. Instead, those interested and inclined towards social work should be given preference to counsel the cancer patients.

3.8.3 Expectations of the Sanjeevani psycho-social care givers

The psycho-social care givers reported of meeting the Sanjeevani management staff once a year on an average. When asked about the opportunities to voice any issues during such meetings, one of the psycho-social care givers mentioned that these meetings have a pre-planned agenda and are usually in a workshop mode with limited scope for open discussions. When asked directly about the expectations they have from Sanjeevani management, quite a few of them openly shared their views. A couple of psycho-social care givers opined that management support is lacking and decision making is slow. Moreover there should be a yearly plan for the management as well as the counselors to follow. Presently the events are planned and executed at individual levels. There needs to be clear instructions from the management related to the available funds etc. to execute such plans. The psycho-social care givers reported rather unhappily of having to spend from their pockets and are not sure whether it would be reimbursed. The need to have some petty cash from Sanjeevani to help the underserved patients with minor expenses like bus fare etc. which presently they are spending from their own pockets was one of the suggestions from the staff. They also suggested the need to be more organized.

One of the psycho-social care givers also said *“We need to get something in return of our sincere efforts. We all work hard because we are emotionally attached to our work. We go out of the way to help patients. But the returns are not much. Nothing is much added to our resume. Other NGO staff make fun of us. I land up doing a lot of stupid work but I don’t think it is adding any value to me.”* This point was well supported by other psycho-social care givers as well. Another psycho-social care giver added *“If we get proper support, we will feel further motivated to do more and better work.”* The psycho-social care givers also expressed their disappointment on not receiving an official appointment letter in spite of having completed over one year of service with Sanjeevani.

The point of view regarding getting underpaid by Sanjeevani was supported unanimously by all the psycho-social care givers. Sanjeevani also needs to be more professional in its approach was the suggestion made by a few psycho-social care givers. All of them agreed to the idea of having some hierarchical organizational structure, a definite administrative structure like coordinator, senior and junior psycho-social care givers etc. This would enable a systematic approach and proper distribution of work load reducing the individual load. Juniors need to respect the seniors and learn from their experience. Another suggestion from a psycho-social care giver was that a proper document with clear roles and responsibilities and timings to be adhered to must be handed over to the newly joined Sanjeevani angel as an official appointment letter. *“These are basic things. This is what we lack.”* She said. The psycho-social care givers want Sanjeevani to respect their roles, understand their problems and attempt to resolve them.

3.8.4 Suggestions by the Sanjeevani psycho-social care givers

Towards the end of the interaction with the psycho-social care givers, they were requested to suggest changes they feel need to be done by Sanjeevani in order to make its interventions more effective and beneficial. When the psycho-social care givers were asked their ideas to improve visibility of Sanjeevani among patients, majority of them opined that patients are more likely to remember Sanjeevani if they are provided with monetary help. Support in terms of providing money or food and accommodation would help them remember the NGO strongly. *“Patients are looking for monetary help although whatever we do is also important”* commented a psycho-social care giver.” *Some of the patients even walk away when they realize that we don’t provide monetary help.”* Another psycho-social care giver was of the opinion that Sanjeevani can help the patients with diagnostic tests. She said *“All the tests like 2D echo, CT scan etc. are available at Tata at subsidized rates. But it takes over a month to avail these services due to long queues. They can’t get these tests done from outside as they are too expensive. They simply cannot afford them. I have seen a few NGOs intervening in this area. If Sanjeevani also can support for such diagnostic tests, it will be good.”* Another psycho-social care giver expressed a strong support to this suggestion. She added that such tests can at least be made available for extremely poor patients to begin with.

One of the psycho-social care givers however gave very practical suggestions to improve the visibility of Sanjeevani among masses. She insisted on having a printed manual giving all the information about Sanjeevani. She said *“My view is different. We need to give a brochure containing all the information. This is missing. Even the doctors don’t have any printed information about us. Paperwork is important to prove our authenticity. Despite being uneducated, patients look out for some printed information. So a good quality brochure with latest updated information is necessary particularly in large hospitals like Tata. The counselors should also be given some brochures with a view of training us and updating our knowledge as to what and how to counsel. A booklet will also do. But a brochure or booklet in local language is needed to improve visibility and for convincing the authenticity.”* She was also of the strong opinion that with increasing cancer patients, it is not feasible to provide financial help to all. On the contrary, it is important to sensitize the patients and their caregivers about the various government schemes and facilitate the procedure for them. They are illiterate and fearful of this process.

The psycho-social care givers were asked whether a dedicated toll free helpline initiated by the government for the cancer patients to resolve their doubts and queries will benefit them. Majority of the psycho-social care givers supported the idea as not all patients can come to the hospital all the time. *“A single telephone line all over India may help. Many people are not able to come back from remote villages after chemo and have a lot of queries. Everyone has a phone today. They can at least call and ask. It will certainly help at least to sort out minor queries.”* opined a psycho-social care giver. It was also suggested to use this helpline to generate awareness about cancer among masses. The helpline can also be effectively deputed to educate the caregivers about the

do's and don'ts and preventive care of cancer. It would enable the patients to follow the instructions particularly when they don't trust their family members' advice. Another psycho-social care giver suggested that such a helpline can be used to provide information about the contact person across various hospitals to facilitate and speed up patients' treatment. However, a couple of psycho-social care givers did not welcome the idea of a toll free helpline. *"Counseling at personal level is far more effective". "The patients are already very weak. They also do not have patience to sit and wait till the call gets connected. So in my personal opinion I do not think this will work."* were some of the opinions expressed by these psycho-social care givers.





CHAPTER 4

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

4.1 Introduction

4.2 Summary, Inferences and Suggestions

4.3 Recommendations

CHAPTER IV

SUMMARY, CONCLUSIONS & RECOMMENDATIONS

4.1 INTRODUCTION

This chapter provides the reader with the summary and inferences of the study along with the recommendations that emerge directly from the findings. The recommendations have been posed independently to the government agencies and Sanjeevani organization. In the context of the objectives of the research study, comprehensive data was collected from 250 cancer patients and survivors through telephonic interviews all over the country and through one to one interaction through FGDs and IDIs predominantly at Tata Memorial hospital and ACTREC Mumbai and GCRI, Ahmadabad. Interaction with the oncologists from Mumbai and Ahmedabad and the Sanjeevani psycho-social care givers working with Sanjeevani across nine centers in India brought out interesting viewpoints regarding the importance of psycho-social care and support for cancer patients and the challenges involved in integrating it into health system. The following section portrays the perception of these stakeholders with regards to the need of psycho-social care for cancer patients in India and the impact of the interventions made by Sanjeevani in this direction followed by the challenges faced by the Sanjeevani psycho-social care givers while rendering services to the cancer patients.

4.2 SUMMARY, INFERENCES AND SUGGESTIONS

This section is further divided into two broad sub-sections-first sub-section deals with the key findings with regards to significance of psycho-social support and perception of cancer patients, medical experts and psycho-social care givers about the need of psycho-social care among cancer patients in India while the second sub-section talks about the impact of the interventions made by Sanjeevani organization to help provide psycho-social support to cancer patients and survivors. The third section summarizes the challenges faced by the Sanjeevani psycho-social care givers in delivering their roles and responsibilities towards improving the life of cancer patients.

4.2.1 Need of psycho-social care

This section summarizes the perception of patients, oncologists and the Sanjeevani psycho-social care givers with regards to the need of psycho-social care for cancer patients in India.

a) Perspective of cancer patients

Cancer affects a person not only at the physical level but much more at the mental and emotional level. Majority of the cancer patients turn to proper medical treatment once cancer is detected but are largely ill-equipped to deal and cope up with this traumatic disease at the psychological level. The interaction with the researched cancer patients strongly brought out the need of psycho-social support in their fight against cancer. They all firmly expressed that it is important to provide emotional and psychological support to cancer patients through counseling and handholding as it can help reduce their fears and anxieties, help them to instill back confidence about their survival and to change their outlook towards this seemingly fatal disease. The patients agreed that if their mind is positive, strong and at peace, the medical treatment will be effective. On the contrary if they are fearful and distressed, the treatment will not have the desired medical impact.

The patients also recognized that counseling by a third (unknown) person is always far more effective than the suggestions and advice by the near and dear ones. It was also observed during the study that the response given by doctors particularly in the initial period of the treatment influences patient's mental state of being either positively or negatively. Whenever doctors talked positively with the patients, the patients reported of being less fearful about the disease whereas when doctors could not give proper information to the patients due to lack of time or were unresponsive towards patients, it has marked negative impact on the patient. However, it may not be possible for doctors to give more time to patients given the highly disproportionate ratio of oncologists and cancer patients in India. Hence, the need of psycho-social care givers working within cancer hospitals to help the cancer patients was brought forth even more strongly.

Though majority of the researched cancer patients were fortunate to have received support from their families, they still reported to have suffered from many psychological issues such as stress due to emotional over-dependency of family members, fear of relapse, uncertainties about future and so on. It becomes difficult for patients to share such anxieties with their family members with a fear that it would distress them further. Hence, patients find it necessary to share their anxieties and doubts more freely and receive emotional and psychological support from someone other than their family members. Moreover, a life threatening disease like cancer affects family members and caretakers of cancer patients equally. Once someone in the family gets detected with cancer, the entire household tends to feel lost, confused and worried. Hence, patients perceived that counseling sessions are vital for family members as well to sensitize them about the importance of their role in patient's treatment and speedy recovery. As remarked by a patient '*When you get good support from the family, you feel like a winner*' which calls for effective counselling to the family members along with the patients.

The need of counseling for family members was strengthened by an insight that emerged through patients' responses which clearly showed that strong familial support and care is one of the major

factors that tends to persuade patients to continue their treatment. Patients tend to feel more positive and hopeful if they receive emotional support from their immediate family members. It also emerged through the data that counseling to family members about cancer, its treatment and its side effects, and how to handle the patients at psychological and emotional level can help cancer patients deal with this illness more positively. This insight reinforces that many family members also need to be counseled so that they provide hope, strength and emotional support to patients on a regular basis to enable them cope with cancer in a far better way.

There were some patients who shared their experiences about misconceptions related to cancer in the society such as cancer is contagious, or it is a terminal illness that has no cure and so on. However, it was found that such misconceptions among other people had no negative bearing on the patients' emotional state of being. On the contrary, they were more worried about psychological issues such as fear of relapse, not being able to be there for family members like before, not being able to become a mother, feeling lonely at home and so on. Furthermore, it was interesting to find that though many patients had not experienced any instances of discrimination against them due to cancer, they still regarded counseling very important alongside their medical treatment more so in larger perspective of the society.

b) Perspective of medical experts (Oncologists)

According to the doctors, psycho-social problems such as psychological stress, hampering of interpersonal relationships, stress due to physical changes, stigmatization and discrimination, lack of information about the disease and treatment are the major critical problems faced by cancer patients. Some of the prominent aspects where they need support to cope up with cancer are provision of proper and adequate information about disease and treatment, psycho-social support and rehabilitation and logistical assistance. The discussion with doctors revealed that cancer patients are more prone to psycho-social stress and it is imperative to address them for their better recovery and coping behaviour.

The psychological impact of cancer on patients has been an important but relatively neglected aspect for health professionals involved in the treatment process. All the doctors interviewed in this study have unanimously emphasized the need and significance of psychosocial support for cancer patients and their families. They have also expressed a strong need of integrating psycho-social care in the cancer care hospitals along with the regular medical line of treatment. The doctors were of the opinion that provision of psycho-social care will help in reducing treatment default, alleviate anxiety and promote faster recovery thereby improving quality of life of the patients. If aspects of psycho-social care are handled by para professionals which would be their field of expertise, it will also be helpful for the medical practitioners, as they will be able to give more priority, time and focus on their precise medical treatment.

The oncologists have also openly recognized the need to encourage Para Professionals and psycho-social care givers like Sanjeevani to support not only the cancer patients but also to improve the interaction between doctors and patients. Higher influx of patients coupled with inadequate time and interaction with the doctors emerged as one of the important reasons for the need of para professionals like Sanjeevani too cater to psycho-social needs of the patients. The need of a multidisciplinary approach to cancer treatment and significance of paraprofessionals who operate under the guidance of oncologists was also emphasized.

A cancer diagnosis is a highly traumatic and shocking event not only for the person diagnosed with but also for his or her family members and caregivers. Some studies report that a cancer diagnosis actually has a greater impact on family members than patients. Family members of cancer patients are more susceptible to depression, probably due to adverse change in socioeconomic status (Lim, Kim, & Lee, 2013). Majority of the doctors in this study emphasized the need to counsel immediate family members and care givers of cancer patients and also sensitize them about psycho-social support needed by the cancer patients. This will enable them to handle the patient with more care, affection and ensure positive atmosphere at home to help reduce the stress and fear.

Lack of recognition of significance of psycho-social care amongst medical professionals, logistical impediments such as lack of space and privacy in hospitals, lack of trained counselors are the major barriers in delivery of psycho-social care in hospital settings as mentioned by these medical experts.

c) Perspectives of Sanjeevani psycho-social care givers

All the psycho-social care givers unanimously admitted that there is a strong need of psycho-social support for cancer patients based on their experiences while working as Sanjeevani angels. They clearly reported of having witnessed the emotions of relief and gratitude on patients' faces after interacting with them. It also emerged strongly that presence of psycho-social care givers make a marked difference to the extent to which the cancer patients respond to the medical treatment.

The Sanjeevani also emphasized that the interaction of cancer patients with medical doctors has a great influence on patients. Thus, it is imperative that the doctors need to be sensitive enough to understand patients' emotional needs and talk with them empathetically at least for few minutes as the patients look up to the doctors as 'life savers'. Some of the Sanjeevani angels however, believed that it is not possible for doctors to do that with every patient given the huge load of cancer patients they need to cater to on a daily basis. Consequently, with limited time and interaction with the available oncologists, the patients looked forward to the support, strength and solace in the psycho-social care givers with whom they sort out the queries, anxieties and fears in their mind.

However it is extremely important that the Sanjeevani angels work in close coordination with the medical experts. It will also be beneficial if the doctors build the capacity of the counselors whenever possible in terms of orientation about medical terms involved in the treatment, associated side effects and other issues so as to improve the services rendered to the patients by the psycho-social caregivers in terms of technical knowledge. Most of the psycho-social care givers seemed to share cordial and supportive relationship with the doctors in the hospital where they work. The medical experts were also satisfied about the contribution of Sanjeevani angels towards enhancing the wellbeing of cancer patients. In fact in most of the centers, the oncologists were found to depend greatly on the support rendered by the Sanjeevani angels. This in turn was found to motivate the staff further to put in more efforts towards providing quality support to the cancer patients.

Thus, it was evident that psycho-social caregivers must be made available in all cancer hospitals not just to cater to the emotional and other needs of cancer patients but to make the job of oncologists easier by enabling them focus well on their expertise.

4.2.2 About the interventions of Sanjeevani...Life Beyond Cancer

This sub-section pertains to the findings about adequacy and impact of the Sanjeevani organization on the lives of the cancer patients as perceived by the patients, doctors and psycho-social care givers. It also describes opinions and perceptions of the oncologist about the interventions of Sanjeevani in helping the cancer patients. The challenges faced by the Sanjeevani angels while imparting services to the cancer patients and their caregivers have been discussed in the subsequent sub-section.

a) Perspective of cancer patients

The researched patients seemed to remember the Sanjeevani angels more than the name of the organization because of their good rapport with the counselors and the crucial psychological support they received from them. Many patients admitted that the psycho-social care givers approached them proactively to provide help which suggests the highly sincere and committed attitude of the Sanjeevani staff.

During the interaction with the cancer patients, they were asked about their opinions regarding services provided by the Sanjeevani psycho-social care givers and to what extent they found these beneficial. The patients and their caregivers asserted that they received more information about diet and food habits from the counselors than other aspects of cancer during their interaction. Relatively few patients reported of receiving support at the psycho-social level such as counseling for reducing patients' stress, fear or anxiety, motivating to continue the treatment, sensitizing the caregivers about cancer, its side effects and handling the patients positively and so on. The patients,

however, perceived this information about diet to be important as it is not provided by their doctor or other hospital staff in such detail. The patients also expressed concern about lack of awareness among cancer patients regarding dietary habits which makes the role of counselor very important for them. Such information has undoubtedly helped the cancer patients to ensure good diet and follow the do's and don'ts in it; however, keeping the main aim of the organization in view, there is a need on part of the Sanjeevani angels to prioritize their roles and devote more time on providing psycho-social care to the cancer patients than mere information based support.

There was an interesting insight that came forth while analyzing the services provided by the psycho-social care givers and the impact they had on the patients. As mentioned before, even if the help provided by the Sanjeevani angels was more of a nature of information provision, the patients seemed to perceive this help from the psychological point of view. The act of psycho-social care givers of approaching patients to help them in any way possible without them asking for it was in itself highly emotionally fulfilling for the patients. It made them feel that there is someone whom they can trust and depend on for all their problems and related struggle during their visits in the hospital.

In situations where psycho-social care givers provided emotional support to patients in addition to provision of information, patients reported of having a marked change towards their overall attitude towards the traumatic and stressful illness. Many patients reported of having got motivated by the psycho-social care givers and expressed gratitude for instilling a sense of hope and faith in them that cancer is curable. This was found to reduce their fear substantially. The patients, who always looked tensed, worried or cried most of the times fearing the uncertainties of life, reported of having started smiling and feeling less stressful after their interactions with the psycho-social care givers. This highlights the significance and influence of psycho-social care provided by Sanjeevani angels to cancer patients. It was also found that more the time spent by the psycho-social care givers in building rapport and relationship with the cancer patients, higher was the psychological impact of this interaction on cancer patients.

The analysis of the data also revealed that the psycho-social care givers in cancer hospital tends to play a positive role in improving the strained familial relationships of cancer patients due to this illness. For instance, it was found that in one of the cases, the patient's son and daughter in law started behaving differently with her when she was detected with cancer thinking it is contagious. However, the psycho-social care giver was able to convince them of the misconceptions about the cancer after which they changed their behavior towards the patient. This again highlights the need of counseling not only the patients but also their family members and caretakers as perceived by the cancer patients.

The long and arduous treatment of the cancer puts the patients under tremendous financial burden which has been reinforced by the patients under the study as well. However, Sanjeevani

organization does not provide any financial support to the patients. Even then, the psycho-social care givers played an important role by providing information about the state government schemes and helped patients avail it by directing them through the entire procedure. In cases, where patients were not eligible for such government schemes, the psycho-social care givers proactively guided the patients by connecting them to appropriate sources from where they could get financial help. Hence, the help provided by the Sanjeevani psycho-social care givers in other aspects as well was perceived as instrumental by the patients, more so at psychological level. However, the psycho-social care givers were not in a position to provide psychological support to each and every patient, main reason being limited number of psycho-social care givers available to cater to consistently increasing number of patients putting pressure on them. Lack of space and privacy within the hospitals were other constraints shared by the patients for not being able to interact longer with the psycho-social care givers.

b) Perspective of medical experts (Oncologists)

An attempt was made to understand the opinion of the doctors from Mumbai and Ahmedabad about the services provided by Sanjeevani. Majority of the oncologists emphasized on the need of having more NGOs like Sanjeevani to facilitate the provision of psycho-social counseling in cancer hospitals.

However, while interacting with the doctors it was apparent that the oncologists were not well aware regarding the precise role of Sanjeevani angels. They had limited information about the roles and responsibilities fulfilled by them. Consequently, the doctors listed down a certain set of suggestions for Sanjeevani to improve their services. According to them, providing in-depth technical knowledge and training about psycho-social counseling and cancer treatment to the counselors was extremely important to equip them to provide evidence based information to the patients. This would result in reducing the ignorance based anxiety among cancer patients and also help in easing out the pressure on the doctors. Enhancing communication skills of counselors was also emphasized by the doctors for improved counseling and its impact. A few doctors also stressed on maintaining better coordination with hospital authorities and reducing the communication gap between them for enhanced functioning of either party. The need to increase awareness about the significance and need of psycho-social counseling amongst other health care professionals was also pointed out by the oncologists. A few doctors also suggested that support groups in hospital settings can be formed and facilitated to supplement the roles and responsibilities of the Sanjeevani psycho-social care givers and to reduce their burden. It was also highlighted during the discussion that there is a need to integrate psycho-social care module in the teaching curriculum for medical professionals.

Furthermore, according to the doctors, the role of government interventions is significant to operationalize provision of psycho-social counseling in cancer hospitals. The government needs

to ensure provisions of logistics for counseling centers and appoint counselors through trusts like Sanjeevani. The doctors also highlighted the need of health awareness coupled with good quality health infrastructure. A dedicated helpline for cancer patients also emerged as one of the probable ways to address information needs of the patients and also provide psycho-social counselling. The lack of recognition about significance of psycho-social care amongst medical professionals was highlighted as one of the major barriers in delivery of such services to cancer patients.

As per WHO, more than 30 percent of cancer cases could be prevented by modifying lifestyle or avoiding key risk factors. About one third of cancer cases could be reduced if cases are treated and detected at an early stage (World Health Organisation, n.d.). The doctors in this study emphasized that there is an alarming need to increase public awareness and understanding amongst masses about preventive measures and early warning signs of cancer. They also suggested some of the effective ways in increasing public awareness about cancer such as sensitizing students in schools and colleges, making people understand the importance of regular screening, creating awareness at PHCs, appropriate use of mass media to create awareness as well as challenging prevalent stereotypes pertaining to cancer. It was also emphasized to ban availability of carcinogenic substances such as tobacco which is one of the leading causes for cancer worldwide.

c) Perspective of Sanjeevani psycho-social care givers

The Sanjeevani angels portray a diverse role in helping the cancer patients' right from directing them to appropriate sections of the hospital for various tests and treatments to rehabilitation and counseling their caretakers to keep the patients positive and motivated. They provide guidance related to the diet and exercise and its importance in the process of improving the immunity of the cancer patients for faster recovery. They also facilitate the radiation and chemotherapy cycles and explain about ways to deal with the side effects of these treatments. One of the key roles the psycho-social care givers play is to advise them about the available government financial schemes and facilitate the procedures like filling up forms and compliance of necessary documents to apply for the financial schemes. Majority of the Sanjeevani psycho-social care givers are committed and satisfied with their work of motivating and supporting the cancer patients in their fight with cancer.

All the psycho-social care givers unanimously affirmed that the patients feel happy and comfortable after talking to them. They mentioned that it is common for patients to get nervous, confused and fearful once they enter the hospital premises. They feel depressed particularly because they believe that cancer is a terminal disease. Post interaction with the Sanjeevani angels, a marked change in the patient's behavior and in their emotional state is visible. As a consequence, the patients come looking for the Sanjeevani staff during their next visits. This in itself speaks volume about the influence of services provided by the psycho-social care givers. The patients are also seen to diligently follow the advice rendered by the angels and feel satisfied with the outcome. That in turn enhances their trust and brings them emotionally closer to the psycho-social care givers to the extent that the angels become a part of their extended family. As a consequence, continuation of treatment which otherwise is a challenge becomes far easier for the patients. The

angels also emphasized the fact that their responsibility to give a patient ear and build hope and strength for the patients and caregivers greatly increases due to unavailability of medical experts for the same.

The role of the counselor becomes especially crucial when the patients are clearly told by the oncologists that they would not survive for long. In such situations the patients desperately look out for emotional support and tend to depend completely on the counselors' positive words of hope and motivation. The patients reported of being emotionally more dependent on the Sanjeevani angels than their immediate caregivers and family members. The absence of the Sanjeevani angels from the hospital premises disturbs the patients and they miss the smiling faces of these angels and their consoling words as reported by all the patients as well as psycho-social care givers.

Hence, according to the Sanjeevani angels, psycho-social services provided by them form an important part of the treatment process for the patients and have proved beneficial not only in changing their attitude towards this traumatic and lethal illness but have also proved crucial in continuation of the treatment leading to speedy recovery of the patients. Thus the psycho-social impact of the services provided by the Sanjeevani angels was considerably high.

4.2.3 Challenges faced by Sanjeevani psycho-social care givers

Understanding the challenges encountered by the Sanjeevani angels formed an essential aspect of the interaction with them during the study. It has thrown light on the emotionally demanding work profile of the psycho-social care givers as they are constantly exposed and emotionally engaged in handling fears, stress and anxieties of cancer patients and in motivating them to change their outlook towards cancer. With regards to their personal level challenges, it was revealed by most of the Sanjeevani angels that emotional attachment with the patients affects them to a large extent. This pushes them into temporary phases of depression particularly while dealing with terminal cases. Some of the Sanjeevani angels are cancer victors themselves. This helps them empathize with other cancer patients in a far better way. Understanding their mental frame and relating with their fear of uncertainty comes naturally to the cancer victors. However, it has its own disadvantage. While dealing with other patients, they tend to relive the time when they were undergoing the trauma and treatment.

Major challenge reported by the psycho-social care givers was the difficult task of making patients forget all their stress and worries and bring a smile on their face. Though by now, the Sanjeevani angels have devised several ways to achieve this based on their experience, they are constantly required to keep finding new ways to make the patients feel positive and hopeful. It becomes even more arduous in relapse cases of cancer patients. Such patients find it difficult to trust anyone including doctors and the psycho-social care givers. In case of palliative cancer patients, the most challenging task becomes consoling the family members and caretakers and bringing them to the

point of acceptance of loss of their dear one. It becomes even more difficult for them in cases of palliative cancer patients. In such situations counseling the patient is less arduous than counseling the caretakers. Most of the patients come from extremely poor background and all their emotional distress spans from the financial constraints particularly if they belong to rural villages. Knowing this, it is challenging for the psycho-social care givers to help patient cope up with their stress without providing actual financial support to them.

Thus, it is evident that the role of the Sanjeevani angels is emotionally demanding and living up to the expectations of patients, caregivers, medical experts and the Sanjeevani management proves to be quite a strenuous task for them. Clearly, the psycho-social care givers also undergo a turbulence of emotions almost every day while providing emotional and psychological support to cancer patients. Hence, it was suggested by few of the Sanjeevani angels that there should be periodic counseling sessions for the staff to equip them handle their own stress more effectively leading to improved work efficiency towards their role.

4.3 RECOMMENDATIONS

Based on the analysis of the data collected, this report puts forth certain relevant and independent recommendations for the government agencies as well as for Sanjeevani as an organization. It is highly advisable to implement these recommendations in their true spirit for the welfare of the cancer patients and their caregivers in this country to enable and empower them to face and emerge as true cancer victors.

4.3.1 Recommendations to the Government agencies

1. The state government should entrust the responsibility of spreading awareness about cancer, and to reduce the myths and misconceptions about it with the local self-government bodies. They should be given directives to increase the community participation in best possible way for spreading such awareness. Print and electronic media should be efficiently put to use for spreading adequate awareness about cancer among public. The medium of TV advertisements, smart phones could also be utilized for the same. Street plays and skits are another effective medium which can be utilized to reach out to remote pockets of the community.
2. Awareness about cancer should be incorporated in the generic academic curriculum and students in schools and colleges should be sensitized about the same.
3. The state as well as central government should make budgetary provisions to set up cancer screening center at every district hospital that would offer early check up to everyone in the district at nominal charges. Awareness should be spread, especially among girls and women, about such facility and they should be encouraged to utilize it since late detection of cancer due to ignorance is one of the prime causes of cancer among women.

4. Every state government should make budgetary provisions in order to set up a state cancer hospital with all the required, affordable and state of art facilities for cancer patients to minimize the difficulties faced by cancer patients and to minimize their influx to select cancer hospitals in the country.
5. There should be adequate number of counselors/psycho-social care givers appointed in every government or government aided hospital that caters to cancer patients to provide psycho-social support to cancer patients along with the regular medical line of treatment. The private hospitals should be given directives to appoint counselors/psycho-social care givers for the same purpose. These should also be trained to counsel the family members and caregivers of patients as and when necessary.
6. Psycho-social care module should be given due recognition in teaching curriculum for medical professionals and adequate provisions need to be made to operationalize it such as having specific sessions, discussions, workshops and so on.
7. There should be a provision of orientation and counseling sessions for practicing doctors in both government and private cancer hospitals in order to sensitize them about the need of psycho-social support to cancer patients and about their role and its influence on patients' emotional and psychological state.
8. All cancer hospitals should be given directives to prepare clear guidelines for cancer patients for easy and hassle-free access to the entire hospital and about the entire course of the treatment.
9. With sharp rise in the incidence of cancer, government should now increase the budgetary allocation for providing monetary support to the patients particularly in case of those below poverty line.
10. The schemes devised by respective state governments to financially help poor cancer patients should be made applicable in case of relapse of cancer as well.
11. There should be dedicated toll free helpline for cancer patients in every state. This can be primarily used to generate awareness among masses. It can also help sorting out minor health related queries, in understanding various side effects of cancer treatment along with the do's and don'ts and preventive care of cancer and clearing up myths associated with it. The helpline will also be instrumental to connect patients to appropriate health care institutes to facilitate and speed up their treatment and provide information about government schemes devised for them.
12. The state cancer hospitals should provide accommodation facilities at subsidized rate for patients who are in dire need of it based on their physical and economic conditions. Such stay facilities should have separate toilets for each family and which should be maintained hygienically.
13. In the interest of public health, the government should ban tobacco and other carcinogenic substances that are linked with cancer genesis. Provisions need to be made to rehabilitate the people involved in tobacco trade.

14. Appropriate and adequate regulatory mechanism should be in place to prevent any adverse side effects of artificially injected or produced fruits and vegetables, especially on patients. Food Safety and Standards Authority of India (FSSAI) should be adequately equipped to contain malpractices of artificially injecting banned chemicals in fruits and vegetables.
15. The state governments should provide incentives to farmers to adopt organic farming and other sustainable agricultural practices to improve the quality of food grains, fruits and vegetables. This will help people in increasing their immunity against diseases like cancer in the long run.
16. There are various studies which show the positive influence of yoga and Pranayama (breathing exercises) on cancer patients. The government should spread awareness about the importance of yoga for cancer patients among masses. Furthermore, appropriate personnel should be appointed to conduct regular yoga and pranayama sessions for cancer patients within each cancer hospital.

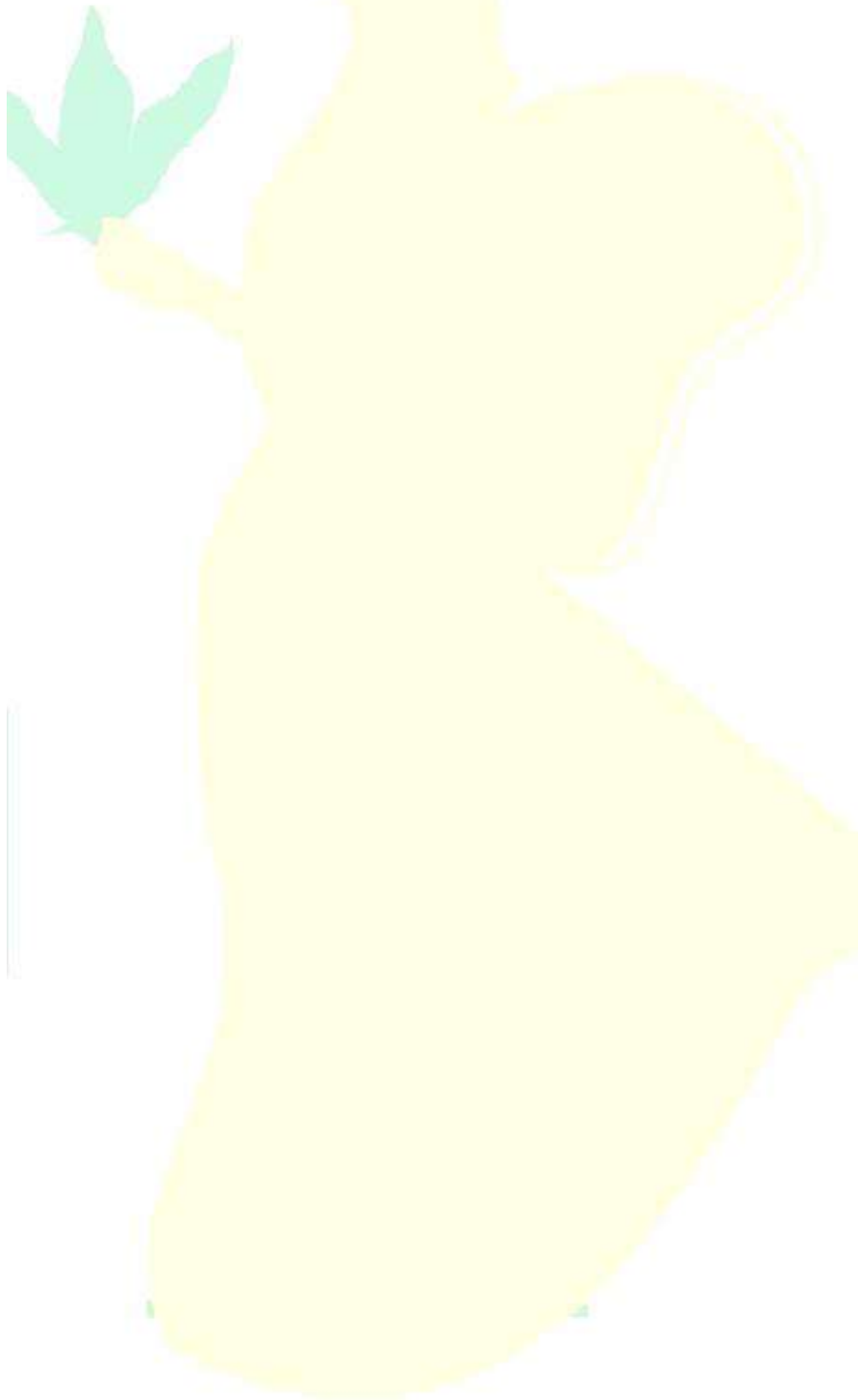
4.3.2 Recommendations to Sanjeevani...Life Beyond Cancer

1. The organization should develop a definite organizational structure specifying clear roles and responsibilities of each employee working for the organization. It would help in bringing uniformity with respect to understanding each one's role and hence uniformity in the output as well.
2. The psycho-social care givers should be given clear guidelines about their key roles and responsibilities in hospitals. In line with the goals of the organization, more focus should be laid on providing emotional and psycho-social support to cancer patients than provision of information and handholding.
3. It is of vital importance to appoint a supervisor in the organization with appropriate skills to guide all the psycho-social care givers on regular basis. The duly appointed supervisor should not only assess the performance of the psycho-social care givers vis-à-vis their roles and responsibilities but also address their needs and problems. This would make a positive impact on the outcomes of the program.
4. Every newly appointed psycho-social care giver (may or may not be a cancer victor) must complete the oncology certificate training course organized by TISS, Mumbai which serves as an induction program. However, for senior level staff (those completing two years or more), regular capacity building opportunities should be made available in order to keep themselves abreast with latest developments in their field.
5. The organization should maintain follow-up sessions with patients requiring psycho-social support even after their regular visits to hospitals. In order to achieve this, personnel with appropriate qualifications should be appointed at respective centers to make regular home visits. The expenses incurred for such visits should be borne by the organization.
6. In the context of psycho-social counseling, different skills are required on part of counselors to deal with cancer patients at different stages of their diagnosis. The psycho-social care givers need to develop specialization in a certain domains and enhance their skills in assessment and

management of psycho-social issues. Hence, Sanjeevani angels should be provided adequate and scientific training pertaining to psycho-social counseling. Furthermore, it is also recommended that they should also be provided with some technical knowledge about cancer and its treatment.

7. The Sanjeevani angels should be trained to enhance their communication skills to facilitate better interactions with patients as well as hospital authorities.
8. It is also recommended that apart from the cancer survivors, personnel with no prior association with the disease may also be involved to enhance service delivery.
9. It is commendable that group counseling sessions are undertaken at one of the centers of the organizations. Such group counseling sessions should be increased and conducted at all other centers as they tend to have greater positive impact on patients.
10. The organization should develop a course for family members of cancer patients in order to help them manage their stress and anxieties and to balance the family homeostasis. It would also help family members to look after the patient more effectively after their psychological needs are addressed.
11. The organization should engage itself in communities in which their centers are set up especially for spreading awareness about cancer, its treatment and myths and misconception associated with it.
12. Periodic counselling sessions must be arranged for the psycho-social care givers to help them manage stress and help relieve their emotions and anxiety piled up due to constant interaction with cancer patients.
13. Efforts need to be made to orient the medical experts about the role played by Sanjeevani and to reduce the communication gap between doctors and Sanjeevani angels.
14. There is a strong need to improve visibility of the organization in cancer hospitals. A printed manual, pamphlet or brochure containing detailed information about Sanjeevani and its services should be made available in local languages if possible at all centers to help the patients and caregivers. Patients can also be given small badges (to be pinned on their sleeves) which would not only help psycho-social care givers to identify and cater to their patients easily but also enable the patients recognize (remember) the organization during and after the treatment is over.
15. With passing time, Sanjeevani may think about providing financial support to deserving cancer patients (particularly those belonging to states outside Maharashtra) in terms of support for ration, medicines and accommodation along with psycho-social support.
16. Reporting mechanism can be made online through tablets. Easy to use reporting software may be designed and adopted to maintain data on a daily basis. This will avoid duplication, ensure completeness of data thereby enhancing the data quality and leave the psycho-social care givers with more time for psycho-social interaction with the cancer patients.
17. The organization should arrange quarterly meetings with the Sanjeevani angels with more of open discussions than pre-planned agenda to understand and resolve their queries and problems.

18. All the Sanjeevani psycho-social care givers work proactively and are enthusiastic, committed and efficient. Hence their salary structure needs to be at par with the other NGOs. Better remuneration will serve as a motivating factor towards their higher degree of involvement and consequently performance.





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ANNEXURE

1

Annexure

I. Quantitative Survey Results -Tables

Table 1: Name of Center

Name of Center	Frequency	Percent
Tata Memorial Hospital, Mumbai	165	66.0
GCRI, Ahmedabad	31	12.4
SMS Hospital, Jaipur	26	10.4
Sevagram at Wardha	18	7.2
RST Cancer Hospital, Nagpur	8	3.2
Acharya Tulsi hospital Bikaner	1	0.4
Chittranjan Hospital Kolkata	1	0.4
Total	250	100.0

Table 2: Age of Respondents

	N	Minimum	Maximum	Mean	Std. Deviation
Age Of Respondents	250	17	72	44.78	13.206

Table 3: Sex of Respondents

Gender	Frequency	Percent
Male	39	15.6
Female	211	84.4
Total	250	100.0

Table 4: Type of Cancer

Cancer type	Frequency	Percent
Blood Cancer	11	4.6
Breast Cancer	93	38.6
Germ Cell Cancer	6	2.5
Gynecological Cancer	71	29.5
Lung Cancer	6	2.5
Mouth Cancer	7	2.9
Other type of Cancer	49	20.3
Stomach Cancer	13	5.4
Total	241	--

Multiple Response: Percentage and totals are based on respondents

Table 5 : Household Size of Respondents

N	Valid	245
	Non response	5
Mean		5.44
Std. Deviation		3.439

Table 6: Earning Members in the family

No.of earning members	Frequency	Percent
0	6	2.4
1	126	50.4
2	82	32.8
3	19	7.6
4	7	2.8
6	3	1.2
11	1	0.4
16	1	0.4
Sub Total	245	98.0
Non response	5	2.0
Total	250	100.0

Table 7: Households having cancer patient as the earning member of family

Response	Frequency	Percent
Yes	62	24.8
No	184	73.6
Non Response	4	1.6
Total	250	100.0

Table 8 (a): Likely Problems faced by cancer patients as perceived by the patient

Problems	Frequency	Percent
Financial Problems	76	34.2
Physical Problems	179	80.6
Psychological Problems	59	26.6
Social Problems	57	25.7
Total	222	--

Multiple Response: Percentage and totals are based on respondents

Table 8 (b): Likely Problems faced by cancer patients as perceived by the patient

Problems	Frequency	Percent
Psychological Problems		
Anger/Frustration / Guilt feeling / Pain / Agony	25	11.3
Irritability/Mood swings/ Suicidal thoughts or behavior	8	3.6
Excessive Stress / Depression Distress	25	11.3
Loss of self-esteem / confidence	9	4.1
Social Issues		
Discrimination / Stigmatization	17	7.7
Education Hampered	11	5.0
Difficulties in Marriage	2	0.9
Other problems at societal level	4	1.8
Physical Problems		
Change in appearance (hair loss/ eyebrow loss etc.)	78	35.1
Pain due to chemo / Radiotherapy and other treatment	50	22.5
Vomiting and Uneasiness	45	20.3
Excessive Fatigue and Tiredness	52	23.4
Loss of Appetite	17	7.7
Loss of freedom of movement at home/work place	27	12.2
Other Physical Problems	12	5.4
Financial Problems		
Fund crisis to undertake treatment	27	12.2
Unemployment / Loss of Job	42	18.9
Traveling and Accommodation during treatment	21	9.5
Total	222	--

Multiple Response: Percentage and totals are based on respondents

Table 9: Support areas needed to cope up with cancer

Support areas	Frequency	Percent
Emotional Support and Counselling	190	77.2
Financial Assistance	164	66.7
Spiritual coping mechanisms (Yoga , meditation)	143	58.1
Counselling to family members and care givers	134	54.5
Therapeutic treatments (Reflexology, Naturopathy etc.)	120	48.8
Help in sorting out social issues Help in sorting out social issues like misconceptions about cancer, social abuse, stigmatization, discrimination etc.	93	37.8
Help with nutrition and diet related queries	92	37.4

Support areas	Frequency	Percent
Employment opportunities	48	19.5
Any other	11	4.5
Total	246	--

Multiple Response: Percentage and totals are based on respondents

Table 10: Awareness about Sanjeevani organization amongst beneficiaries

Response	Frequency	Percent
Yes	77	30.8
No	173	69.2
Total	250	100.0

Table 11: Awareness about Sanjeevani psycho-social care givers amongst beneficiaries

Response	Frequency	Percent
Yes	85	34.0
No	60	24.0
Maybe	105	42.0
Total	250	100.0

Table 12: Patients Directed towards Sanjeevani Counselor by

Personnel	Frequency	Percent
Doctors in Hospital	48	26.5
Nursing Staff of Hospital	35	19.3
Staff Approached themselves for help	113	62.4
Any Other	20	11.0
Total	216	--

Multiple Response: Percentage and totals are based on respondents

Table 13: Time spent by the counselor with the patient (in minutes)

Time spent	Frequency	Percent
2	7	2.8
4	1	0.4
5	18	7.2
8	1	0.4
10	63	25.2
15	32	12.8
20	8	3.2
30	9	3.6
35	1	0.4
45	1	0.4
60	2	0.8
90	1	0.4
120	1	0.4
Sub Total	145	58.0
Non Response	45	18.0
Not applicable	60	24.0
Total	250	100.0

Table 14: Time spent by the counselor with the patient (in minutes)

N	Valid	145
	Non response + Not applicable	105
Mean / Std. Deviation		14.25/14.160

Table 15: Nature of Help Received from Staff

Nature of Help	Frequency	Percent
Help understand about/Navigate through hospital services	147	77.4
Explain about Government schemes for getting financial help	86	45.3
Encourage and help to continue the treatment	84	44.2
Help cope up with trauma/anxiety	59	31.1
Help in dealing with personal relationships	28	14.7
Help understanding the role and importance of wellness clinic activities	43	22.6
Chemo Counselling	123	64.7
Any other help received from staff	4	2.1
Total	574	--

Multiple Response: Percentage and totals are based on respondents

Table 16: Attitudinal behavioral change in patient after interacting with staff

Response	Frequency	Percent
Yes	141	74.2
No	49	25.78
Total	190	100.0

*Not applicable 60***Table 17: Help expected from staff by patients in any other area/aspect**

Response	Frequency	Percent
Yes	46	18.4
No	188	75.2
Non Response	16	6.4
Total	250	100.0

Table 18: Awareness about financial help provided by government schemes

Response	Frequency	Percent
Yes	122	48.8
No	127	51.2
Total	250	100.0

Table 19: Availed financial support by accessing existing government schemes

Response	Frequency	Percent
Yes	96	78.7
No	26	21.3
Total	250	100.0

*Not applicable 127***Table 20: Help taken from representatives of other NGOs in the hospital apart from Sanjeevani**

Response	Frequency	Percent
Yes	40	16.0
No	210	84
Total	250	100.0

Table 21 a: Earning status Vs Emotional Support and Counselling

Earning status of the respondent			Emotional Support and Counselling		Total
			Yes	No	
Are you an earning member of the family?	Yes	Count	39	23	62
		% within Emotional Support and Counselling	20.5%	38.3%	24.8%
	No	Count	148	36	184
		% within Emotional Support and Counselling	77.9%	60.0%	73.6%
	No Response	Count	3	1	4
		% within Emotional Support and Counselling	1.6%	1.7%	1.6%
Total		Count	190	60	250
		% within Emotional Support and Counselling	100.0%	100.0%	100.0 %

Table 21 b : Earning status Vs Emotional Support and Counselling - Chi-Square Test

Statistic	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	7.817 ^a	2	.020
Likelihood Ratio	7.359	2	.025
Linear-by-Linear Association	.004	1	.949
Number of Valid Cases	250		

II. Data Collection tools

Impact assessment study of Sanjeevani...Life Beyond Cancer, Mumbai College of Social Work, Nirmala Niketan, Mumbai

A. Telephonic Interview Schedule used for Cancer Patients

1. Name of the Patient: _____
2. Place of origin: _____
3. Centre : _____
4. Age (in completed years): _____
5. Gender : M / F / Other
6. Household size: _____
7. Number of earning members in the family : _____
8. Are you an earning member of the family? : Yes / No
9. Type of Cancer : _____
10. When was the cancer detected clinically? (Year) : _____
11. When you came to know about having cancer, how did your family members/friends react to it? Did cancer affect your personal relationships in any way? If yes Please elaborate

12. What other problems did you face when your cancer got detected?

13. Can you share with us some areas where you feel you need support to cope up with this disease?
 - ☐ Emotional Support and Counselling
 - ☐ Counselling to family members and care givers
 - ☐ Help in sorting out social issues like misconceptions about cancer, social abuse, stigmatization, discrimination etc.
 - ☐ Help with nutrition and diet related queries
 - ☐ Financial Assistance
 - ☐ Spiritual coping mechanisms (Yoga, meditation)
 - ☐ Therapeutic treatments (Reflexology, Naturopathy etc)
 - ☐ Employment opportunities
 - ☐ Any other
14. Have you, anytime during your visit to hospital, heard about Sanjeevani trust or NGO? Yes/No
15. Do you remember name of staff other than doctor that helped you in the hospital during your treatment? Yes / No **If NO skip to 21**
- 15.1 If yes, can you please provide their name? : _____
16. Who directed you to the staff who helped you in hospital? (Multiple response)
 - ☐ Doctors in hospital
 - ☐ Nursing staff of hospital
 - ☐ Staff approached themselves for help
 - ☐ Any Other

17. How much time did the staff/counselor spend with you?.....mins

18. What sort of help did you receive from the staff?

- ☐ Help understand about/Navigate through hospital services
- ☐ Explain about Government schemes for getting financial help
- ☐ Encourage and help to continue the treatment
- ☐ Help cope up with trauma/anxiety
- ☐ Help in dealing with personal relationships
- ☐ Help understanding the role and importance of wellness clinic activities
- ☐ Any other

19. Do you think there was any *attitudinal and behavioral change* in you after interacting with the staff?
Yes/ No

20. Do you feel the staff should have helped you in any other area/aspect? Yes/No

20.1. If yes, can you please elaborate in what way?

21. Did you know about the financial help provided by government through its various schemes? Yes/No

If No skip to 23

22. Did you avail any kind of such financial support by availing existing central and state government schemes? : Yes / No **If NO Skip to 23**

22.1 If yes, how much of your total expenditure was covered through it?

23. Did you take help from representatives of other NGO's in the hospital apart from Sanjeevani? : Yes / No

23.1. If yes, what was the nature of such help?

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Impact assessment study of Sanjeevani...Life Beyond Cancer, Mumbai

by

College of Social Work, Nirmala Niketan, Mumbai

B. Guidelines for the In-depth Interview with Cancer Patients

Namaste. With your permission, can we talk to you for some time? We would like to know your views on psycho-social care and experiences about Sanjeevani angels and suggest ways to improve so that cancer patients in future can get better services from them. Be assured that this information would be kept strictly confidential and will solely be used for research purpose. Your name will not be disclosed under any circumstances. So please feel free to voice your concerns and opinions to help identify the gaps for improvement. Shall we begin? (Please take signature on informed consent before the interview)

- Name of patient :
- Gender:
- Age:
- Center:
- Place of origin:
- Contact details:
- Educational Qualifications:
- Household size:
- Number of earning members in the family:
- Are you an earning member of the family? If yes, would you like to tell us your income?
- Type of Cancer :
- When was the cancer detected clinically? Have you been a patient of relapse?
- Have you ever left your treatment incomplete? If yes, what were the reasons? What made you return back to the treatment? What was the role of counselors in getting you back to treatment?
- When you came to know about having cancer, how did you react to it? What was the reaction of your family members/friends/neighbors? Did cancer affect your personal relationships in any way? If yes Please elaborate
- What other problems did you face when your cancer got detected? Which according to you are the most critical problems faced by you and your families? Can you please list atleast two major problems?
- Have you, anytime during your visit to hospital, heard about Sanjeevani trust or NGO?
- Do you remember name of staff other than doctor that helped you in the hospital during your treatment? If yes, can you please provide their name? How much time did the staff/counselor spend with you? Was this time sufficient in your opinion?
- Who directed you to the staff who helped you in hospital? (Multiple response-Do not read out options. probe if required)

Doctors in hospital/Nursing staff of hospital /Staff approached themselves for help/ Any Other

- What sort of help did you receive from the staff? In what way did they help you? (Do not read out options, Probe if necessary)
 - Navigate through/Help understand about the hospital services
 - Explain about Government schemes for getting financial help
 - Encourage and help to continue the treatment
 - Help cope up with trauma/anxiety/ irritation/isolation
 - Help in dealing with personal relationships
 - Help understanding the role and importance of wellness clinic activities
 - Diet and Nutrition counselling
 - Any other
- Do you think there was any *attitudinal and behavioral change* in you after interacting with the staff?
 - Reduced anxiety and trauma
 - Improved confidence to face the situation
 - Better idea about the disease, its treatment and side effects
 - More positive outlook regarding to face the disease
- For a disease like cancer, along with the regular line of medical treatment, do you think psycho social services is important for cancer patients? Should it be included in cancer care? Would you benefit from it? If Yes, in what way? If No, why? Please elaborate.
- Do you feel there is a need to increase public awareness and understanding about this disease? If yes, what would be the effective way to do it?
- In your opinion, in what way should government help/support the increasing incidences of cancer in the country? What should be government's role in making life easy for cancer patients?
- Do you feel presence of Sanjeevani psycho-social care givers have facilitated better and more meaningful inter action between you and the doctors? If yes, how?
- Should there be more NGOs like Sanjeevani? What more do you expect from such NGOs?
- Do you feel the Sanjeevani staff should have helped you in any other area/aspect? If yes, can you please elaborate in what way?
- Did you know about the financial help provided by government through its various schemes?
- Did you avail any kind of such financial support by availing existing central and state government schemes? If yes, how much of your total expenditure was covered through it?
- Did you take help from representatives of other NGO's in the hospital apart from Sanjeevani? If yes, what was the nature of such help?
- Can you share with us some areas where you feel you need support to cope up with this disease?
 - Emotional Support and Counselling
 - Coping with side effects (both at physical and mental level)
 - Counselling to family members and care givers
 - Help in sorting out social issues like misconceptions about cancer, social abuse, stigmatization, discrimination etc.
 - Help with travel and accommodation
 - Help with nutrition and diet related queries
 - Financial Assistance
 - Spiritual coping mechanisms (Yoga, meditation)
 - Therapeutic treatments (Reflexology, Naturopathy etc.)

- Employment opportunities
 - Any other
- Should there be a dedicated toll free cancer helpline (like in WB) through which people/patients can telephonically get information and advice on causes, detection, diagnosis and treatment of cancer with more emphasis on psycho-social counselling? Please elaborate as to how it will help

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C- Guidelines for the In-depth Interview with Doctors/Medical experts

Hello. We wish to interact with you to understand your perspectives regarding need and provision of psycho-social care to cancer patients and the interventions made by Sanjeevani...Life Beyond Cancer in this sphere. Please feel free to voice your opinions and share your feedback in this regard. Be assured that this information would be kept strictly confidential and will solely be used for research purpose. Shall we begin? (Please take signature on informed consent before the interview)

- Name:
- Qualifications with specialization:
- Affiliation /Hospital/Expertise:
- Experience in the field of Oncology (in years):
- On an average, how many patients do you cater to on daily basis? How much time do you get to spend with one patient?
- In your opinion, is there a dearth of oncologists in the country keeping in view the rapidly increasing incidence rate? If yes, should para professionals like Sanjeevani angels be encouraged to support the interaction between doctors and patients?
- According to you, how much is the proportion of patients leaving the treatment halfway/incomplete? What are the probable reasons for leaving the treatment halfway?
- What is the proportion of patients with a relapse?
- Which according to you are the most critical problems faced by the Cancer patients and their families? Can you please list major problems in each case? (Do not read out options, Probe if necessary)
 - Financial
 - Social- stigmatization, discrimination, strain on personal relationships etc
 - Psychological-anxiety, trauma, depression, self-image etc.
 - Physical - Changes due to chemo and radio therapy, excessive fatigue etc.
- Primarily, what areas do you feel the patients need support to cope up with this disease? And why? Please elaborate (Do not read out options, Probe if necessary)
 - Emotional Support and Counselling
 - Coping with side effects (both at physical and mental level)
 - Counselling to family members and care givers
 - Help in sorting out social issues like misconceptions about cancer, social abuse, stigmatization, discrimination etc.
 - Help with travel and accommodation
 - Help with nutrition and diet related queries
 - Financial Assistance
 - Spiritual coping mechanisms (Yoga, meditation)
 - Therapeutic treatments (Reflexology, Naturopathy etc.)
 - Employment opportunities
 - Any other
- For a disease like cancer, along with the regular line of medical treatment, do you think psycho social services are also crucial for cancer patients? Do you feel psycho-social support to be an

integral part of quality cancer care at hospitals? How do you think would patients benefit from it? Please elaborate.

- Due to abysmally low doctor patient ratio in most of the government hospitals, how according to you can the need of psycho-social care among cancer patients be addressed? In other words, every individual is different with unique sets of problems. In what way can we ensure that the individual psycho-social needs of patients are met? What is your opinion/perspective about this?
- How many NGOs work in your hospital to help cancer patients? Can you please tell us more about them and their work?
- Have you heard about Sanjeevani...Life Beyond Cancer? If yes, when and how did you come to know about it?
- Do you direct each and every patient to Sanjeevani psycho-social care givers or is it only specific cases? Please tell us more about it.
- What sort of help do you think is being provided by the staff of Sanjeevani? (Do not read out options, Probe if necessary)
 - Navigate through/Help understand about the hospital services
 - Explain the Government schemes for getting financial help
 - Encourage and help to continue the treatment
 - Help cope up with trauma/anxiety/ irritation/isolation
 - Help in dealing with personal relationships
 - Help understanding the role and importance of wellness clinic activities
 - Diet and Nutrition counselling
 - Any other
- What more would you expect them to do?
- Do you think patients and care givers also need to be sensitized about psycho social care and its effects in coping up with cancer? If yes, in what way?
- What according to you are the existing barriers to the delivery of such services to the cancer patients at hospital level?
- Do cancer patients still face stigmatization/ discriminatory behavior of family members/relatives and community once they come to know about it? Do their personal relations get affected because of this dreadful disease? Can you please share your experiences on this?
- Do you feel there is a need to increase public awareness and understanding about this disease? If yes, can you suggest some effective ways to do it?
- In your opinion, what should be government's role in providing effective psycho-social cancer care for patients? Do you believe there is a need to develop innovative models (eg.PPP) to provide better medical and psycho social services to the cancer patients? Please elaborate.
- What is your opinion about the services provided by Sanjeevani? Do you feel presence of Sanjeevani psycho-social care givers have facilitated better and more meaningful interaction between the patients and doctors? If yes, in what way? Are there any areas where you feel there is a scope of improvement?
- What are the challenges faced by the Sanjeevani psycho-social care givers in addressing the psycho social needs of the patients?

- What is your opinion about the oncology certificate course conducted by TISS? In order to better equip the counselors, should there be a separate course/module on psycho-social care in the oncology course? If yes, why?
- Should there be more NGOs like Sanjeevani? What more do you expect from such NGOs?
- Should there be a dedicated toll free cancer helpline (like in WB) through which people can telephonically get information and advice on causes, detection, diagnosis and treatment of cancer with more emphasis on psycho-social counselling? Please elaborate as to how it will help the patients and the caregivers.

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D- Guidelines for the In-depth Interview with Sanjeevani psycho-social care givers

Namaste. You have been working as a Sanjeevani Angel and helping cancer patients a lot. We wish to talk to you in this regard and understand your views on psycho-social care and the problems and challenges faced by you as a Sanjeevani angel. Be assured that this information would be kept strictly confidential and will solely be used for research purpose. Your name will not be disclosed under any circumstances. So please feel free to voice your concerns and opinions to help identify the gaps for improvement. Shall we begin? (Please take signature on informed consent before the interview)

- Name of psycho-social care giver:
- Gender:
- Age:
- Center:
- Place of origin:
- Contact details:
- Educational Qualifications:
- Number of years working as Sanjeevani angel:
- Type of work prior to joining Sanjeevani (if working) :
- Are you a cancer survivor? If yes, what type of cancer did you suffer from?
- How did you come to know about Sanjeevani? How did you get associated with Sanjeevani?
- According to you, what are your roles and responsibilities as Sanjeevani Angels? Have they been clearly told to you by Sanjeevani?
- What sort of training have you received from Sanjeevani with respect to your job roles and responsibilities?
- Have you completed the oncology certificate course by TISS? If yes, how did you find the course? In what way did it help you?
- From your day today experiences, which type of cancer do you think is getting more common? What may be the reasons?
- Do you feel you are equipped enough to deal with patients suffering from any type of cancer?
- How many patients on an average do you cater to in a day?
- In what way do you help cancer patients in your hospital? Is it in line with your defined roles and responsibilities or do you land up doing certain things outside it also?
- How important is the role of Sanjeevani angels for cancer care?
- Being a cancer survivor yourself, how do you think it helps dealing with cancer patients?
- What do you understand by psycho-social care/services? How different are they from medical treatment?
- What according to you is the importance of psycho-social services for cancer patients? Along with the medical line of treatment, do you feel there should be psycho-social counselling for cancer patients? Will it benefit them? In what way?
- Do you know any other NGO which provides such services to cancer patients?
- How much time do you spend with one cancer patient? Do you think it is sufficient from patient's point of view?

- What is patient's reaction/ feedback when you provide help/support? Are they satisfied? Do they expect anything more? If yes, what?
- Do you think or have you come across cases where there are still misconceptions/stigmatization/discrimination/abuse related to cancer?
- What difficulties/challenges do you face while dealing with cancer patients? How do you cope up with them? Please elaborate (mental/physical/language barrier/social challenges)
- How is your relationship with the doctors? What expectations do you have from doctors? Do you feel doctors/oncologists should also help cancer patients with some sort of psycho-social counseling?
- How much do you feel the doctors depend on Sanjeevani angels for support?
- According to you, what should be done to improve the visibility and awareness about Sanjeevani among cancer patients?
- What are the areas where cancer patients should be given counselling?
 - Emotional Support and Counselling
 - Coping with side effects (both at physical and mental level)
 - Counselling to family members and care givers
 - Help in sorting out social issues like misconceptions about cancer, social abuse, stigmatization, discrimination etc.
 - Help with travel and accommodation
 - Help with nutrition and diet related queries
 - Financial Assistance
 - Spiritual coping mechanisms (Yoga, meditation)
 - Therapeutic treatments (Reflexology, Naturopathy etc.)
 - Employment opportunities
 - Any other
- Are all these covered in the oncology certificate course? If No, do you feel they should be covered?
- Are you satisfied doing your job? If given a better opportunity would you like to do a better job instead of being a Sanjeevani angel?
- How do you try to improve upon your skills to provide better services? Do you need additional training /orientation?
- What is reporting mechanism of your daily activities to Sanjeevani? Are you satisfied with it or should they be any different?
- How frequently do you meet authorities of your parent organization? If you have any issues/grievances, how do you communicate them? How are they tackled or addressed by Sanjeevani?
- Should there be a dedicated toll free cancer helpline (like in WB) through which people/patients can telephonically get information and advice on causes, detection, diagnosis and treatment of cancer with more emphasis on psycho-social counselling? Please elaborate as to how it will help

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E- Guidelines for FGD with Cancer Patients

Hello everybody. We will be asking you a few questions related to Sanjeevani trust and your experiences with Counselors and doctors. Please answer them very honestly and openly. Be assured that this information would be kept strictly confidential and will solely be used for research purpose. Your name will not be disclosed under any circumstances. So please feel free to voice your concerns and opinions to help us identify the gaps for improvement. Shall we begin? Let us start with your introduction-

- Name :
- Age:
- Gender:
- Place of origin:
- Center of treatment:
- No. of members in the family
- No. of earning members in the family
- Type of cancer
- When it was detected clinically (year)
- When you came to know about having cancer, how did you react to it? What was the reaction of your family members/friends/neighbors/relatives and society as a whole? Did cancer affect your personal relationships in any way? If yes Please elaborate
- What other problems did you face when your cancer got detected? Which according to you are the most critical problems faced by you and your families? Can you please list at least two major problems which you thought were most difficult to handle?
- Have you, anytime during your visit to hospital, heard about Sanjeevani trust or NGO? If yes, do you remember name of staff that helped you in the hospital during your treatment?
- How much time did the staff/counselor spend with you? Was this time sufficient in your opinion?
- Who directed you to the staff who helped you in hospital? (Multiple response-Do not read out options. probe if required)
 - a. Doctors in hospital
 - b. Nursing staff of hospital
 - c. Staff approached themselves for help
 - d. Any Other
- Have you ever left your treatment incomplete? If yes, what were the reasons? What made you return back to the treatment? Was it because of the counselor's motivation that you resumed your treatment? What exactly was the role of counselors in getting you back to treatment?
- What sort of help did you receive from the staff? In what way did they help you? (Do not read out options, Probe if necessary)
 - a. Navigate through/Help understand about the hospital services
 - b. Explain about Government schemes for getting financial help
 - c. Encourage and help to continue the treatment
 - d. Help cope up with trauma/anxiety/ irritation/isolation
 - e. Help in dealing with personal relationships

- f. Help understanding the role and importance of wellness clinic activities
 - g. Diet and Nutrition counselling
 - h. Any other
- Do you think the time given to you was sufficient? Do you feel the Sanjeevani staff should have helped you in any other area/aspect? What are your expectations from counselor?
- Do you think there was any *attitudinal and behavioral change* in you after interacting with the staff? Did this interaction make your journey easier? If yes, how?
- Do you know about Sanjeevani Wellness center? Have you visited the wellness center? What activities did you attend in that center?
- In your opinion, is the current support from government enough? If not, what kind of support should be required from government, organization or any other source for cancer patients?
- Do you feel there is a need to increase public awareness and understanding about this disease? If yes, what would be the effective way to do it?
- Do you feel presence of Sanjeevani psycho-social care givers have facilitated better and more meaningful inter action between you and the doctors? Should there be more NGOs like Sanjeevani? What more do you expect from such NGOs?
- Did you know about the financial help provided by government through its various schemes? Did you avail any kind of such financial support by availing existing central and state government schemes? If yes, how much of your total expenditure was covered through it?
- Did you take help from representatives of other NGO's in the hospital apart from Sanjeevani? If yes, what was the nature of such help?
- Can you share with us some areas where you feel you need support to cope up with this disease? (Do not read out options. Probe if necessary)
 - a. Emotional Support and Counselling
 - b. Coping with side effects (both at physical and mental level)
 - c. Counselling to family members and care givers
 - d. Help in sorting out social issues like misconceptions about cancer, social abuse, stigmatization, discrimination etc.
 - e. Help with travel and accommodation
 - f. Help with nutrition and diet related queries
 - g. Financial Assistance
 - h. Spiritual coping mechanisms (Yoga, meditation)
 - i. Therapeutic treatments (Reflexology, Naturopathy etc.)
 - j. Employment opportunities
 - k. Any other
- Should there be a dedicated toll free cancer helpline (like in WB) through which people/patients can telephonically get information and advice on causes, detection, diagnosis and treatment of cancer with more emphasis on psycho-social counselling? Please elaborate as to how it will help?

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F- Guidelines for FGD with Sanjeevani psycho-social care givers

Hello everybody. We will be asking you a few questions -

- related to your experiences with cancer patients,
- about your perspectives of the need of psycho-social services for such patients
- Work done by Sanjeevani trust in this area and
- Challenges you face while providing services to cancer patients.

Please answer them very honestly and openly. Be assured that this information would be kept strictly confidential and will solely be used for research purpose. Your name will not be disclosed under any circumstances. So please feel free to voice your concerns and opinions to help us identify the gaps for improvement. Shall we begin? Let us begin with your introduction. Please tell us your name and center.

- How long have you been working for Sanjeevani?
- Type of work prior to joining Sanjeevani (if working)
- How did you come to know about Sanjeevani? What made you take up this job as Sanjeevani angels?
- Are you a cancer survivor? If yes, what type of cancer did you suffer from? If not, what is your connect with cancer?
- According to you, what are your roles and responsibilities as Sanjeevani Angels? Have they been clearly told to you by Sanjeevani?
- What sort of training have you received from Sanjeevani in light with your job roles and responsibilities?
- Have you completed the oncology certificate course by TISS? If yes, how did you find the course? In what way did it help you? If No, why haven't you not done it yet?
- How many patients on an average do you cater to in a day? How many do you report? Why the gap?
- Do you ensure that you introduce yourself and Sanjeevani to every patient? If yes How? If No, why?
- What sort of help do you provide the cancer patients? In what way exactly do you help cancer patients in your hospital?
- How much time do you spend with one cancer patient? Do you think it is sufficient from patient's point of view? Do you feel the need to have more helping hands to help you serve better?
- Do you think or have you come across cases where there are still misconceptions/stigmatization/discrimination/abuse related to cancer?
- What is patient's reaction/ feedback when you provide help/support? Are they satisfied? Do they expect anything more? If yes, what?
- What kind of schemes government or any other organization providing for cancer patients
- Being a cancer survivor yourself, how do you think it helps dealing with cancer patients?
- What difficulties/challenges do you face while dealing with cancer patients? How do you cope up with them? Please elaborate (mental/physical/language barrier/social challenges)
- How is your relationship with the doctors? What expectations do you have from doctors? Do you feel doctors/oncologists should also help cancer patients with some sort of psycho-social counseling?

- How much do you feel the doctors depend on Sanjeevani angels for support?
- What do you understand by psycho-social care/services? How different are they from medical treatment?
- What according to you is the importance of psycho-social services for cancer patients?
- How important is the role of Sanjeevani angels for cancer care? Along with the medical line of treatment, do you feel there should be psycho-social counselling for cancer patients? Will it benefit them? In what way?
- What are the areas where cancer patients need help and should be given counselling?
 - Emotional Support and Counselling
 - Coping with side effects (both at physical and mental level)
 - Counselling to family members and care givers
 - Help in sorting out social issues like misconceptions about cancer, social abuse, stigmatization, discrimination etc.
 - Help with travel and accommodation
 - Help with nutrition and diet related queries
 - Financial Assistance
 - Spiritual coping mechanisms (Yoga, meditation)
 - Therapeutic treatments (Reflexology, Naturopathy etc.)
 - Employment opportunities
 - Any other
- Are all these covered in the oncology certificate course? If No, do you feel it should be covered?
- Do you know any other NGO which provides such services to cancer patients?
- According to you, what should be done to improve the visibility and awareness about Sanjeevani among cancer patients?
- Are you satisfied doing your job? If given a better opportunity would you like to do a better job instead of being a Sanjeevani angel?
- How do you try to improve upon your skills to provide better services? Do you need additional training /orientation?
- What is reporting mechanism of your daily activities to Sanjeevani? Are you satisfied with it or should they be any different?
- How frequently is the meeting with your parent organization conducted? If you have any issues, how do you flag them and how are they tackled or addressed by Sanjeevani?
- Can you share some areas where you need support from organization or hospital where you work ?
- Can you please share one or two unique/ memorable experiences with patients and doctors while working in this field?
- In your opinion, should there be a dedicated toll free cancer helpline (like in WB) through which people can telephonically get information and advice on causes, detection, diagnosis and treatment of cancer with more emphasis on psycho-social counselling? Please elaborate as to how it will help the patients and the caregivers.
- Anything else you would like to share with us.

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III. Informed Consent forms

Impact assessment study of Sanjeevani...Life Beyond Cancer, Mumbai

College of Social Work, Nirmala Niketan, Mumbai

Informed Consent form for Sanjeevani psycho-social care givers

Namaste. You have been working as a Sanjeevani Angel past few years and helping cancer patients a lot. We wish to talk to you in this regard and understand your views on psycho-social care and the problems and challenges faced by you as a Sanjeevani angel.

This research will involve your participation as a respondent and our discussion will take about one and a half hour.

You are being invited to take part in this research because we feel that your experience as a Sanjeevani angel has been instrumental in helping alleviate the sufferings of cancer patients and that can contribute to improving the services further.

If you do not wish to answer any of the questions during the interview, you may say so and the interviewer will move on to the next question.

Be assured that this information would be kept strictly confidential and will solely be used for research purpose. Your name will not be disclosed under any circumstances. So please feel free to voice your concerns and opinions to help identify the gaps for improvement.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Name of the respondent:

Signature of the respondent:

Place:

Date:

Name of Interviewer:

Signature:

Impact assessment study of Sanjeevani...Life Beyond Cancer, Mumbai
College of Social Work, Nirmala Niketan, Mumbai

Informed Consent form for cancer patients

Namaste. We would like to know your views on psycho-social care and experiences about Sanjeevani angels and suggest ways to improve so that cancer patients in future can get better services from them. This research will involve your participation as a respondent and our discussion will take about one and a half hour.

You are being invited to take part in this research because we feel that your experience can help alleviate the sufferings of other cancer patients and it can contribute to improving the services provided to cancer patients further.

If you do not wish to answer any of the questions during the interview, you may say so and the interviewer will move on to the next question.

Be assured that this information would be kept strictly confidential and will solely be used for research purpose. Your name will not be disclosed under any circumstances. So please feel free to voice your concerns and opinions to help identify the gaps for improvement.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Name of the respondent:

Signature of the respondent:

Place:

Date:

Name of Interviewer:

Signature:

Impact assessment study of Sanjeevani...Life Beyond Cancer, Mumbai
College of Social Work, Nirmala Niketan, Mumbai

Informed Consent form for doctors/oncologists

Hello. We wish to interact with you to understand your perspectives regarding need and provision of psycho-social care to cancer patients and the interventions made by Sanjeevani...Life Beyond Cancer in this sphere. We would like to know your views on psycho-social care and experiences about Sanjeevani angels and suggest ways to improve so that cancer patients in future can get better services from them.

This research will involve your participation as a respondent and our discussion will take about one and a half hour.

You are being invited to take part in this research because we feel that your experience can help alleviate the sufferings of cancer patients and can contribute to improving the services provided to cancer patients further.

If you do not wish to answer any of the questions during the interview, you may say so and the interviewer will move on to the next question.

Be assured that this information would be kept strictly confidential and will solely be used for research purpose. Your name will not be disclosed under any circumstances. So please feel free to voice your concerns and opinions to help identify the gaps for improvement.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Name of the respondent:

Signature of the respondent:

Place:

Date:

Name of Interviewer:

Signature:

Impact assessment study of Sanjeevani...Life Beyond Cancer, Mumbai
College of Social Work, Nirmala Niketan, Mumbai

Informed Consent form for cancer patients in FGD

Namaste. We wish to talk to you about the problems and challenges faced by you as cancer survivors, your experiences with Sanjeevani trust and understand your views on need of psycho-social care.

You are being invited to take part in this research because we feel that your experience can contribute to improving the services provided to cancer patients further.

This research will involve your participation as a respondent in a group and our discussion will take about two hours.

If you do not wish to answer any of the questions during the interview, you may say so and the interviewer will move on to the next question. Be assured that this information would be kept strictly confidential and will solely be used for research purpose. Your name will not be disclosed under any circumstances. So please feel free to voice your concerns and opinions to help identify the gaps for improvement.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Sr.No	Name of respondent	No. assigned for FGD	Signature
1			
2			
3			
4			
5			
6			
7			
8			
9			
10			
11			
12			

Name of Interviewer(s): 1.

2.



Oil on Canvas by Ruby Ahluwalia



**Sanjeevani...Life Beyond Cancer,
Mumbai**



**Research Unit
College of Social Work
Nirmala Niketan, Mumbai**



Research Unit
College of Social Work,
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