A Medical Anthropological Study

Of

Illness Experience of Cancer Patients, Hyderabad, Telangana, India

A Thesis Submitted

In Partial Fulfilment of the Requirement

For the Degree of

MASTER OF PHILOSOPHY

By

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भारतीय प्रौद्योगिकी संस्थान हैदराबाद
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To the

DEPARTMENT OF LIBERAL ARTS
INDIAN INSTITUTE OF TECHNOLOGY HYDERABAD

APRIL – 2015

Dedicated to

My parents and friends

Indian Institute of Technology Hyderabad
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April 8, 2015

TO WHOM IT MAY CONCERN

This is to certify that Ms. Kanaka Himabindu Pottumuthu, Roll no. LA13M1004, a bonafide M.Phil. student in the Department of Liberal Arts, Indian Institute of Technology Hyderabad has submitted her M.Phil. dissertation on April 8, 2015 as partial fulfillment of the requirements for the M.Phil. degree. The title of her/his thesis is "A Medical Anthropological Study of Illness experience of Cancer Patients in Hyderabad, Telanagana, India". The viva-voce examination is awaited for successfully completing all the requirements for the degree of Master of Philosophy (M.Phil.).

To the best of my knowledge, her/his character and conduct during his/her period of stay at this institute was good.

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DECLARATION

, **Kanaka Himabindu Pottumuthu,** hereby declare that this thesis epresents my ideas in my own words and where others' ideas or words ave been included; I have adequately cited and referenced the original ources. I also declare that I have adhered to all principles of academic onesty and integrity and have not misinterpreted, plagiarized, fabricated r falsified any idea/data/fact/source in my submission. I understand that ny violation of the above will result in disciplinary action by the Institute nd can also evoke penal action from the sources that have not been roperly cited or from whom proper permission has not been taken when eeded.

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ABSTRACT

Cancer has now become a widely discussed and feared disease among the public in India. This study is a qualitative approach in order to understand the ways in which ordinary people, called ‘laymen’ by medical practitioners, understand and experience cancer. Based on in-depth interviews and observations among fifty informants drawn from the middle class and wealthy backgrounds at a private hospital in Hyderabad city. The study takes medical anthropology’s approach to disease and illness by examining cancer patients’ ‘illness narratives’ (Kleinman 1989). This study focuses on tracing the journey of the patients through their explanations for various issues related to cancer. The ‘illness narratives’ highlight the trauma that cancer patients undergo, particularly in the questions they ask about their own individual ‘selves’, and their social obligations. One should give space for the patients to express how they experience the impact of the disease and subsequent treatments such as chemotherapy on their body and changes in their food habits caused due to intake of medicines. These subjective insights can substantially contribute to improving the kind of care cancer patients receive, from family and the medical professionals. This research will also discuss issues of (lack of) compliance with medication and treatment, and access to alternative medical systems. An anthropological study of this nature can also complement research on cancer in fields like genetics. A discipline like medical anthropology, which deals with both biological and social aspects of the medical settings, is well suited to study diseases like cancer from multiple perspectives in hospital settings.

SYNOPSIS

The increased numbers of deaths because of chronic diseases are posing an alarming necessity to research in understanding various factors about those illnesses. Cancer being one of such horrifying diseases which makes the patient undergo physical and psychological trauma, it becomes imperative to study the “illness experience” through the patient’s perspective. The fieldwork was carried out in a private hospital, which is a corporate hospital located in Hyderabad. The sample considered in this research includes 50 patients in total and includes both male and female patients. The primary objective of the study is to understand the illness experience of the patients.

The introduction explains about cancer and the various causes of the disease. The statistics regarding the disease from different sources substantiates the importance of the study. Objectives of the study which provoked the research to continue further and the significance of the study, in general, have been explained. The chosen field area and the methodology employed for the study are described in detail.

Chapter one would discuss the impact of cancer treatment on patients’ selfhood and the analysis about their questioning ‘self’ has been portrayed in a sensitive manner. It is important to understand the patients’ perspective after the amputation of the private body parts, which define their sexuality in the cases of both men and women patients. A total of eight case studies related to selfhood of the patients who have been encountered during the study are discussed in this particular chapter.

Chapter two describes the importance of family role during the period of the treatment from the perspectives of the patients and caregivers. The importance of helping-hand is extremely

needed and persuaded by the patient during such a traumatic treatment of cancer. The patient during such a period, not only expects the physical help but also the psychological support. Eight case studies have been taken into consideration for this topic and the diverse explanations given by the family, or the caregivers have been narrated in this chapter.

Chapter three discusses the treatment process, and the difficulties being faced by the patients during their treatment. The patients move from one hospital to another hospital in search of better treatment. The chapter delves with the different constraints (social and economic) along with the delay in diagnosis and misdiagnosis faced by the patients in the cancer treatment. The delay in diagnosis and misdiagnosis leads to many complications for the patients which result in making the patients regretting about their past deeds.

Chapter four discusses the mixed opinions about alternative medicines and their role in the patients search for better treatment. Eight cases among the fifty samples have reported the use of alternative medicines and same has been discussed in this chapter. The opinions consist of both positive and negative feedback about the use of alternative medicines from the patients.

Concluding chapter presents the summary of the thesis and also throw insights about the future research in hospital settings for both the policy makers and the practitioners. The limitations of the present study and scope of the future research are also discussed in the conclusion part of the dissertation.

CHAPTER I

INTRODUCTION

According to a WHO report of 2005, chronic diseases are projected to account for 53% of deaths in India. The total projected deaths in India, in 2005 were 10,362,000 of which 5,466,000 deaths are due to chronic diseases. Cancers figure among the leading causes of death worldwide, accounting for 8.2 million deaths in 2012 by WHO report (Fact Sheets, Cancer, WHO website, 2012). 8% of total deaths in India in 2005 occurred due to cancer, which is considered to be a prevalent number and these numbers are increasing tremendously every day (Impact of Chronic Disease in India, WHO, 2005).

Cancer is a general term for a large group of diseases that can affect any part of the body. Other terms used are malignant tumours and neoplasm. One defining feature of cancer is the rapid growth of abnormal cells that grow beyond their usual boundaries, and these can spread across other organs also. The process is referred to as metastasis, and these are the primary causes of death from cancer. Cancer arises from one single cell. The transformation is a multi-stage process, and the progression occurs from pre-cancerous to malignant tumours. These changes are the result of interaction between a person’s genetic factors and also because of few external factors such as,

- Physical carcinogens, such as ultraviolet and ionizing radiation;
- Chemical carcinogens, such as asbestos, components of tobacco smoke, aflatoxin (a food contamination) and arsenic (a drinking water contaminant); and

- Biological carcinogens, such as infections from certain viruses, bacteria, and parasites.

These classifications were given by WHO through its cancer research agency, International Agency for Research on Cancer (IARC) on cancer-causing agents. Another important factor is aging which is linked with the cellular repairing mechanism. The increase in age would lead to the less effectiveness to fight with the abnormal cells decreases.

Review of Literature

Cancer figures among the leading reasons for death worldwide, accounting for 8.2 million deaths in 2012 by WHO report (Fact Sheets, Cancer, WHO website, 2012). According to a WHO report of 2005, chronic diseases are projected to account for 53% of deaths in India. The total projected deaths in India, in 2005 were 10,362,000 of which 5,466,000 deaths are due to chronic diseases. Report suggests 8% of total deaths in India in 2005 occur due to cancer, which is considered to be a prevalent number and these numbers are skyrocketing every day (Impact of Chronic Disease in India, WHO, 2005). The articles and books which reviewed focus on the ethnographic work done in hospital settings and among cancer patients' in Hyderabad. The research method is incorporated in the study carried out in the hospital settings. 'Participant Observation' means staying in the selected field area and staying with the people. Despite staying with the people, you have to make them comfortable so that the researcher can observe the details of the field area and the selected topic. There are several ethnographic studies conducted among patients in various areas such as sociology (Alex Broom and Assa Doron, 2011) and anthropology (Jessica L. Gregg, 2003). This study has also looked at topics such as illness experience which is popularly known as five stages of illness by Suchman, quality of life as mentioned by Fayers and Machin (2009:4).

Medical anthropology came into existence the aftermath effective of World War II and due to the increased emphasis of health and well being of the Third World people. (Singer and Erickson, 2011). Foster and Anderson (1978:1) defines medical anthropology as "...the cross-cultural study of medical systems and ... the bioecological and sociocultural factors that influence the incidence of health and disease now and throughout human history" (Singer and Erickson, 2011:3).

My fieldwork concentrates on topics like illness experience, patient's perspective on quality of life, importance of caregivers and their perspectives on the patients. The study attempts to trace their journey from diagnosis to the current situation. The study also throws light on "hospital ethnography" (Debbi Long, et.al. 2008).

"Illness Narratives" of the Patients'

Susan Sontag says, "conventions of treating cancer as no mere disease but a demonic enemy make cancer not just a lethal disease but a shameful one." (Sontag, 1978:59) As the treatment of cancer leaves a person with fatigue, hair loss, excess gain or loss of weight, and in some cases, permanent loss of body parts and the personal experience needs to be understood. In supporting this argument, Arthur Kleinman (1988), discusses the concept of 'illness narratives' in his book. Thus, the concept of "illness narratives" provides the base for this research. The study focuses on the narratives of patients about the journey of treatment. Information has been collected on information on issues like the time of diagnosis, impediments to timely diagnosis or treatment, process of the treatment plan and other complexities faced during the treatment. The study engages with the important facets of patients' expectations with regard to caregivers and also the caregivers' view concerning patients'.

Role of Caregivers and Doctors

The space of fieldwork, i.e., the hospital provides an opportunity to talk with caregivers as well. Since it is a corporate hospital, caregivers are expected to be with the patient and take care of them. The emphasis on caregivers is immense because in diseases like cancer, where long-term treatment plan is the norm and caregivers support is instrumental. The initial constraint came up in the form of disclosure of information. Such a constraint is highly debatable in a space where the research is conducted. Most of the caregivers were from educated and middle-class background. They can easily understand the diagnosis which is written in the reports and also with the help of "Google Knowledge"[1] available on the internet with the advancement of technology.

Disclosing a disease to the patient and the society are two issues which should be considered in this scenario. In the case of the patient, it is important according to the doctors and paramedical staff as further treatment cannot continue without explaining the side-effects. Almost all the interviewees in the study know about their condition expect few who were just admitted for their treatment. Soon after the disclosure the

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[1] Phrase mentioned by the researcher.

question,“Why me?” comes up “because of countless metaphoric flourishes that have made cancer synonymous with evil, having cancer has been experienced by many as shameful, therefore something to conceal, and also unjust, a betrayal by one’s body” (Susan Sontag, 1978:110). Sontag in her work explains about the stereotypes of the national character about diseases like cancer, AIDS, etc. It takes time for the patients and also for the caregivers to understand the nature of the illness but meanwhile the use of illness as a metaphor in the everyday setting would be a painful experience. The patient is treated as untouchable, and fear of the disease would exist among the caregivers that they might also get affected. For the patient, the denial and reconfirmation about the illness would exist initially. However, after accepting the fact that they are suffering from cancer, disclosure to the peer group or relatives is another major issue because of the opinions and misconceptions which already prevail in the mindset of people. Audre Lorde (1980) mentions in her book about the avoidance by family, friends and peer group after being labeled as a cancer patient or survivor. Few of these points emerge in this research. Susan Sontag states, “Thus, a surprisingly large number of people with cancer find themselves being shunned by relatives and friends and are the object of practices of decontamination by members of their household, as if cancer, like TB, were infectious” (Susan Sontag, 1978: 2). The patients and their family are stigmatised in the case of chronic disease as the imagination about the illness dominates the necessity for inquiry in the initial stages. Misdiagnosis and delay in diagnosis are primary reasons for patients to move from one hospital to another. These reasons are discussed by Julie Livingston (2012) and the work also indicates about the lack of equipment in the public sector hospitals.

Even though the patients had not mentioned in their words, another issue which appears as a bottom line in all the case studies is that about the authority of decision making in crucial times. It is generally doctor and caregivers who decide about an individual or patient. Tancredi and Barsky (1974: 856) discusses that there are three steps would be occurring during the decision making in health care, "i.e., there is a diffusion of decision making by virtue of technology, a relinquishment of the power of the decision maker from his traditional authority, and the object of the decision is becoming the major factor in decisions regarding the development and the use of technology." With regard to amputation of body parts during critical situations, it is the family or caregiver, who takes the responsibility of decision making. Even with regard to discussion of health status and regular checkups, the decision making lies with the family.

Questioning 'Self' and Trauma of Losing Organs

A significant part of the research deals with patient experience. It is important to understand that irrespective of the effort taken by doctors and caregivers, it is the patient who bears the pain and trauma associated with the disease. This aspect of cancer is discussed in detail by scholars such as David Hufford (1990) and David Perusek (2012) where the illness experience of a patient is drawn from qualitative interviews. David Perusek's (2012) article is a narrative of his experiences about his brother Ted. The work presents detailed narratives based on the experiences of his brother suffering from cancer. Audre Lorde (1980) talk about the "pain of loss" of few organs which define sexuality. In this context, particular questions can arise such as, what defines the sexuality of a person (either male or female)? Is it the organs or personality? Is it that a person's sexuality is questioned when his/her defining sexual organs are removed? In such a case, who has the authority to decide? Is it the family or the individual?

Contrasting the 'self' before and after the treatment is another topic, that is widely discussed. Audre Lorde (1980:55) says, "… In the process of losing a breast I had become a whole person". One can infer from this statement the reality of life in the process. "…Self-scrutiny and an evaluation of our lives, while painful, can be rewarding and strengthening journeys toward a deeper self" (Audre Lorde, 1980:58).

As mentioned by Mulemi (2008), non-compliance of patients with respect to caregivers or the doctors plays a significant role because the sheer ignorance and also lack of understanding between the triad of "doctor-patient-caregiver" may lead to some drastic decisions such as, not continuing the treatment. According to the dictionary definition, 'care' means "a provision of welfare and protection" (Oxford English Dictionary, South Asian Edition, 2008). The definition of 'care' should be understood clearly because the expectations from the patient are entirely different from that of a caregiver and doctor. Annemarie Mol (2002) in her book about explains the contrast between logic of care and logic of choice. Parson's (1951) concept of 'sick role' should be noted, in particular. 'Sick role' comprises four elements, and it is called functionalism. Parson mentions in a footnote about physician/physiologist L.J.Henderson, "Physician and patient as a social system" [Henderson, 1935]. He also discusses how there has been paradigm shift since twenty years about choice and especially the selection of the patient. In a medical setting where the hierarchy lies with the doctor, there would be a 'force' first and ‘choice’ next, and this is of not much use according to Annemarie Mol (2002:50). Albert (1990) talks about culture of caregiving as an idea of dependency and obligation. However, in this research I observed that many informants perceive that caregiving as a responsibility. The parent-child relation by Albert combines dependency and obligation as in his research, but any study shows that a couple sees responsibility and affection for caregiving.

Hospital Ethnography

Hospital ethnography is another significant topic which influences this study, the idea of which is taken from Debbi Long, et.al. (2008). The various hierarchies and roles in the hospital where the field investigation is conducted will be mentioned in detail. The roles and responsibilities define the working principle of a hospital which was portrayed by Julie Livingston (2012) in her hospital ethnography in an African Cancer-Ward. The experience through her book is instrumental for any person working in a hospital setting. Patients also talk about the ambiance of the hospital and also how the hospital staff takes care of them. Livingston also explains about the emotional bonding which happens between the patients and the staff, which would make the patients comfortable and reduce the complexity of the hierarchy. In addition, Livingston (2012) argues that the work pressure faced by the hospital staff is more where the doctor and patient ratio is higher. As it is difficult for the doctor, who is an individual to give time to understand the problem of patients completely. Quality of the food in the hospital is another point which is emphasized by patients as food is considered imperative for recovery. Audre Lorde (1980:11) explains, “It is such an effort to find decent food in this place, not to just give up and eat the old poison." In order to gather information on such experiences from a stranger (patient), Gitte Wind's (2008) concept of "negotiated interactive observation" which was proposed by her as a more appropriate way to conduct fieldwork in hospital setting is useful.

Role of Alternative Medicines

Apart from the above-mentioned information on the journey of cancer, the patients and caregivers frequently talk about alternative medicines and traditional medicines. Ethnomedicine is an area of anthropology that enquires into the notions of health and illness across different societies. Gradually the focus flows into traditional medicine and biomedicine also. According to Quinlan (2011), "Medicine- like language, music, and politics- is a subset of culture which is situated locally." The term 'ethnomedicine' is used in different connotations in different cultures. However, the charismatic effect which is expected from an ethnomedicine practitioner is also expected from biomedicine practitioners in a country like India.

The belief system and '*hastha vaasi*' which we call in Telugu plays a fundamental role even in today's generation. Two things are important in any healing, *Dawa* and *Duwa* while treating anyone. The *Dawa* is the medicine, and the *Duwa* is the healing effect. Absence of any one will not attain popularity and belief in any healing system. Even a specialized biomedicine specialist cannot popularize practice if he does not talk properly. However, the charisma is something which is, above all, the credentials in any form of medicine. It gives authority to the healer/doctor. As said by Amma in Amma's healing room, the pen and paper gives the authority to speak, and that is very much important for a healer/doctor (Fluckeiger, 2006). Narasimhan (2013) explain about the charismatic effect as *kairaaci* (equivalent to *hastha vaasi* in Telugu) among Tamilians. My study does not exactly explain about the divine hand of the doctor but in one case study the patient explains her feeling that for her doctor is equivalent to god. Narasimhan (2013:168) mentions that “A “doctor” needs to become a “healer”.” Adler (1999) in her article on complementary and alternative medicine mentions about the misconception that Complementary and Alternative Medicine (CAM) is being used among the folk cultures rather than the mainstream population. I too encountered this idea while doing this research which is mentioned in further chapters.

Ayurveda, as mentioned by Bode (2012), is generally/mostly used as secondary treatment after biomedicine fails. Trawick (1991) in her narrative study writes about the ayurvedic practitioner called Mahadeva in Kerala. At some point in the article, while he was explaining about the vegetarian and non-vegetarian diet, he says that they are soft and hard respectively but he also claims that people’s hearts also would be like their food. While talking about the diseases, he says that people, who tend to leave their ‘*Jati*’ rules, get such diseases. The typical Brahmanical notion is clearly portrayed. Another widely prevalent view about Ayurveda is that it does not comprise treatment or medicine for one particular problem like allopathy; rather it provides body rejuvenating process or therapy. This was confirmed during conversations with doctors in Ayurvedic hospital, Hyderabad.

The article published by Alex Broom and Assa Doron (2011) on the rise of cancer in urban India is very similar to the research findings from the study which is a combination of theoretical and methodological inferences are drawn from the work of the scholars mentioned above to develop the study. The research work of Jessica L. Gregg (2003) among Brazilian women who feel that breast cancer and cervical cancer is only caused if a woman is involved with multiple partners is countered in this research work. The ideal values in the Brazilian community are similar to India, but the practice of having multiple partners for sexual relations did not come up is my study.

Finally I want to say that Groddeck's equation "Cancer = Death" (Susan Sontag, 1978:20) is not accepted by people and that is the reason why they want to fight for themselves and their family. The strong desire to live a happy life with their beloved ones is very evident. The caregivers also feel the same way in a majority of cases. There are some peculiar about the uninterested caregivers cases which I would be explain later in the thesis which convey.

Objectives of the Study

The study is carried out by keeping the following objectives in the backdrop.

The study intends to understand the narratives about impact of treatment on patient' selfhood, as the selfhood is being very individualistic and the treatment has an impact on the change of perception of the patients especially, when the cancer treatment demands amputation of body parts. The perceptions of selfhood become more complex especially when it involves the amputation of private parts of the patient.

In the process of treatment, it is not only the patients who suffer pain and go through the traumatic situation but also the caregivers or family members go through the pain and agony. This study also tries to understand and collect the response about the role of caregivers or family during the treatment process.

As the doctors have put it, each and every individual case is unique in its own form. The doctors need to adopt a method for treating the patients, as every patient's body respond differently to a different method of treatment. Hence, this study tries to explore and understand the narratives involving the difficulties faced during the treatment process by the patients.

The patients who are battling the chronic disease such as cancer do not depend only on single way of medication, they tend to explore and make use of another medication process such as Naturopathy, Ayurveda, and Homeopathy along with allopathic. So, this study tries to understand the role of alternative medicines from the patients' perspective.

Significance of the Study

Cancer, as a chronic disease not only has the impact on the body organs where the cells are affected, but it also deals with the psychological aspect of the patient or their caregiver or their family. Generally, the cancer as a disease is given a color of extremely dangerous and death-dealing disease one will get. The moment any person is diagnosed and informed about the cancer, their psychic behaviour gets affected and which will take a plenty of time to accept the fact that they are diagnosed with cancer and make themselves ready for the treatment. Thus, understanding the narratives of illness behaviour among the cancer patients, which are emphasized in this study, play a crucial role in understanding the other stereotypes attached to the disease and its treatment. The narratives not only portray the visible side effects of the treatment but also the psychological side of the story is emphasized.

Context of the Study

The region selected for the fieldwork is Hyderabad, which is one of the metropolitan cities located in Telangana State, India. The fieldwork was carried out in a private hospitals, a unit of Hyderabad Institute of Oncology located in Banjara Hills, Hyderabad. The reason for choosing this field site is that the in-flow of patients is quite high. As the time is one of the limiting factors, high number of in-patients would be of extreme help to carry out the research for a short period. Acquiring permission to conduct the research in such type of setups is difficult without knowing the people inside the hospital. As the research might be suspected or not being a comfort factor for the hospital administration. Hence, the research sought help to acquire permission from the established network.

Tools, Techniques and Method of Data Collection

In the recent years, qualitative research had developed into a broad and sometimes almost confusing field of study. In the words of Uwe Flick, Ernst von Kardorff and Ines Steinke (2004:3), “Qualitative research also claims to study ‘from the inside out’, that is, from the participants point of view”.

Ethnography is one of the major approaches being followed in social science research and mainly in anthropology. Paul Atkinson and Martyn Hammersley (1995) explain that it is not necessary to use ‘ethnography’ in the standard fashion, but its meaning may vary according to the context. There can be considerable overlaps with ‘qualitative inquiry’, ‘fieldwork’, ‘interpretative method’, and ‘case study’ also. The origins of the term ‘ethnography’ lie in the nineteenth century in Western anthropology where it means a descriptive account of a community or culture, usually located outside the West.

H. Russell Bernard (2006) in his book on research methodology in anthrpology gives a clear explanation of ‘direct and indirect observation’ and ‘participant observation’ but since it is a hospital setting and the researcher is not related to medical profession, observation had been done and interviews has been recorded with the consent of the patients.

The concept of interviews covers a lot of ground. For this particular research, I have used semi-structured interview as a technique to collect the data. In the words of H. Russell Bernard (2006:210), “Semi-structured or in-depth interviewing is a scheduled activity. A semi-structured interview is open-ended but follows a general script and covers a list of topics”. Patients were interviewed on the basis of semi-structured interview schedule. The interviews were based on the set of questions which were prepared on the hypothesis is developed after visiting multiple hospitals for the pilot study. The data collected was purely qualitative in the form of informal interviews. The quantitative data such as demographic information will be extracted from the transcription of the interviews. A sample of 50 was taken but of which 40 would be considered as the actual sample for analysis. Most of the interviews were conducted after initial rapport building which made researcher and the informant comfortable.

Case studies have a special role in conveying something about the research clearly and precisely. There are some interesting case studies which are analyzed and presented in the thesis. The cases emphasize the importance of money, familial support, philosophy of life, the trauma of the treatment, etc. which will be substantiated through the study in this dissertation.

Ever since Malinowski (1922) had set ‘doing ethnography’ as the standard for anthropology and the common understanding of participant observation in ethnography, researchers take part in the day to day activities of the people and observe them. Participation gives the ethnographer, a two-sided approach as an insider – that is participation and also as an outsider – the observer of the host community.

David Hufford (1990) mentions that “ordinary people tend to be underestimated and… their knowledge tends to be discredited by authorities.” Basic problems like weight loss and hard substance being felt are reported by many patients in the pre-diagnosis stage. Another issue is that patient experience with the hospital (doctor’s and staff) has to be given preference, not just treatment. Since the fieldwork space is in a private corporate hospital, it is important to talk about patient’s rapport with the hospital. The staff necessarily need not mean the nurse or doctor but people like medical counselors who are also investigated in this fieldwork. A number of patients and caregivers feel the necessity of counselors and psychologists during treatment time. Such an aspect is rarely found in many articles, the reason being the increased importance and awareness about psychology in the recent past.

This study supports Albert (1990) and Annemarie Mol's (2002) findings by emphasizing not just care but 'good care'. Betty Risteen Hasselkus (1992) in her article mentions about caregiver as "interpreter". In order to make a patient comfortable, it is important to use caregiver as interpreter because he/she acts as a catalyst between the researcher and the respondent. The communication mode of caregiver as facilitator, intermediary and direct source would make him/her very important part of the research because some personal questions cannot be directly asked to the patient but explaining to the caregiver can be comparatively easy. So, using some probes according to the situation would be giving a hint to the interpreter and he/she can make them recollect the situations which happened in the past.

In order to do an 'interactive observation' and 'hospital ethnography', it is essential to maintain a good relationship with the staff of a particular hospital rather than just getting permission. To be more specific, conducting fieldwork in a private hospital is not that easy as most of the patients and the caregivers would be educated and conscious about the questions asked. So, it is important to give justifications to the questions which they have in mind. Why am I there? Since how long I have been there? Did I have permission to do research? If so from whom do I have permission? What is the sole purpose of recording? What is the motive of my research? Why I am still not married? What am I studying? What caste do I belong to? Questions about my family background and many more have to be answered, both by patients and also to the people associated with patients and hospital staff.

The excitement about recording their interviews is like a two-edged knife where the researcher experiences supportive people and some who were not supportive. Some expressed their discontent about the recording as they are not comfortable. Some others asked to replay the recording to hear their voice. These experiences will be shared in depth further in chapters.

The Process of Fieldwork

The inspiration for this research started since the school days because my sister is a qualified Radiation Safety Officer and works in a cancer hospital. She would tell many things related to cancer whenever she gets a special case. However, there is always some gap present between doctor-patient, patient caregivers, and many more aspects.

Initially, the aim was to get permission from three hospitals offering cancer treatment to different medical systems within in Hyderabad. With the motive of studying Socio-Cultural response to Cancer treatment in Allopathy and alternative therapies.

Last December Nature Cure (Which is located near S. R. Nagar in Hyderabad) hospital was approached in order to seek permission for carrying out the fieldwork as a part of the initial plan of this study. But the permission was denied on the premise that they do not take or treat any cancer patients and especially any patients with malignant metastasis. In spite of explaining the nature and objectives of the study the hospital administration denied the permission hence, the study was not possible in that hospital.

After being denied the permission in the above hospital, the research was narrowed down to conduct only in two places instead of three as planned in the initial stage of this research. Ayurvedic College, which is attached to the hospital in Erragadda, Hyderabad, was approached in order to seek permission for the study. The Assistant Research Officer in the hospital showed patience to understand the research objectives and the nature of the study and suggested to approach Superintendent of the hospital. The superintendent of the hospital was approached on December 2013, the Government Research Officer and Superintendent of the hospital was very kind and suggested lot of inputs for the research and asked to get a Memorandum of Understanding from IIT-H for further proceedings. And he also asked to submit a report as soon as possible about the research to consider giving permission for the study. Further meetings with the superintendent had revealed that, he is having an idea of collaborating with a private hospital and provides Ayurvedic treatment to patients and also briefed about the importance of Ayurveda, in the long run. On the fourth meeting with the superintendent, he suggested to post an advertisement in newspapers saying that 'I am a research scholar from IIT, who wish to collect data from patients for two days in a week under the guidance of couple of doctors in their hospital'. Along with this advertisement, he also asked to add an advertisement stating that doctor consultation for Ayurvedic medication for cancer can be done during this period. The complexities and obfuscatory intentions of the hospital administration made to exclude the Ayurvedic College also from the focus of the study.

A third attempt was made to get permission from the Unani Research Centre located in Erragadda, Hyderabad in December, 2013. The Head of the Institute suggested going to Unani hospital located in Charminar, Hyderabad. The referred Unani Hospital was also approached and had a meeting with superintendent of the Unani hospital, though in the initial stages the response was positive, the superintendent of Unani Hospital, Charminar asked to meet the principal of Unani Tibbi College. The Principal after enquiring about the research objectives and nature of the study politely discouraged saying it is quite hard to do research on cancer-related issues in the Unani hospital, as the patient visit is very rare, and the treatment is also not possible for chronic diseases such as cancer. So the initial plan to compare Ayurvedic, Unani and allopathic medications regarding cancer treatment could not materialize.

Fortunately, the permission was acquired from a private hospital, Jubilee Hills, Hyderabad. The research had to be restricted to narratives related to patients who approach Allopathic type of medication. The permission was given only after a long process of meetings and the chief medical officer on December 2013 has agreed to grant permission to carry out the study. The study was conducted after consulting the Head of the medical counselling and also took help to finish this research under her purview.

Men	22
Women	28

Table 1.1: The sample details for the study

The sample size considered for this research is a homogenous group with regard to class, religion, disease pattern and financial situation. Below are the tables which indicate the diversity.

Type of payment	Number of patients
Cash	10
Private insurance	9
Central or state government employees (either patient or spouse or children)	27
Cash and credit	4

Table 1.2: Represents the type of payment pattern followed by the patients.

Mostly the patients who approach Private hospital are the ones who have insurance. As the above table depicts, central and state government employees are mostly observed because expenses are completely covered for central government employees and partially covered for the state government employees. The high expenditure makes the treatment affordable only for the rich and for the families of the government employees. The other private insurances cover the medical expenses only for some treatments.

Type of cancer	Number of male patients
Rectum	5
Prostate	3
Oesophagus/larynx	2
Sarcoma	4
Stomach	2
Anus	1
Pancreas	2
Colon	2
NHL	1

Table 1.3: Shows the types of cancer encountered among the male patients in the sample.

Type of cancer	Number of female patients
Breast	14
Ovary	2
Ovary and liver	2
Sarcoma	1
Lung	2
Thyroid	1
NHL	4

Table 1.4: Shows the types of cancer encountered among the female patients in the sample.

As random sampling is done for the study, the sample consists of homogenous sample of all cancers among men and women. The above two tables depict the varied variety of cancers by which patients are being affected. If we specifically observe the sample, rectum cancer is most prevalent according to the sample and breast cancer remains the frequently occurred cancer among women. The results cannot be compared with that of the national samples because certain factors affect the results. Only one hospital has been taken into consideration and random sampling may be the major reasons.

Religion	Number of patients
Hindu	47
Muslim	1
Christian	2

Table 1.5: Shows the religious composition of the patients.

The above sample shows the religious composition in the selected sample. Religion has been looked from a broader perspective in this study and aspects like caste and class had been remained as a limitation in the present study because it is a private hospital where any of the public projects like aarogja sri, etc., are not being implemented. So, the emphasis on caste and class are not considered by the hospital authorities to be diplomatic.

Gunjan is one of the medical counsellors in this hospital, who had served as a key informant to re-confirm the data. During the initial days of my fieldwork, Gunjan allowed me to accompany her in daily rounds in the wards and this made the patients get acquainted with me to an extent. The sense of security has been created among them and after 10 days, I had actually started my work.

Gunjan is a cancer survivor and that passion to serve patients with counselling is extremely present in her that is also one of the reasons for me to quickly get acquainted with her. She used to share her experiences with me and explained me the ways to build rapport with the patients. She also used to warn me while going near some patients, who has got infections and precautions used to be given by her. With regard to some patients, she used to instruct them about my research and request them to give information. Patient identification was one more challenge for me during the study because not everyone would be an active informant and in many cases they would be passive respondent, just giving their basic details.

Hospital Setting

The research place as mentioned above is located in Jubliee Hills, Hyderabad. The entrance of the hospital will lead you to reception desk and towards left of the reception desk, patient waiting space and way to other departments. In the cellar of the hospital, radiation department is situated. In the ground floor, PET-CT, Medical counselling room, Canteen and doctor cabins are located. The first floor has triple sharing a/c rooms and day care centre rooms on one side; and general a/c rooms (male and female wards) and MIC unit on another side. The second floor consists of double sharing a/c rooms. The third floor consists of operation theatres and the fourth floor has single sharing a/c rooms.

Type of room	No. Of rooms	No. Of beds
General ward (Male and female)	2	28
Day care	1	14
MICU	1	9
Triple sharing	6	18
Double sharing		
Single sharing		
Paediatric		
General ward (small)		
Operation Theatre		

Table 1.6: The count of number of beds in the hospital.

The ambience of the hospital is always maintained by using light colours everywhere and plants are kept in corners in order to make the place have a pleasant look. The hierarchy among the staff can be noticed by their dress code. The staff at the billing counters, reception, security people and cleaners have their dress code to distinguish with the technical staff and doctors.

Limitations of the Study

As the research is conducted in the partial fulfilment of the M.Phil. Degree, a short period of fieldwork is only possible. The fieldwork was carried out between May to July, 2014. Hence, limited time period of fieldwork allowed to restrict the research to practically possible objectives as mentioned above. The fieldwork in the urban setup, especially when the research is supposed to be carried out in the private hospitals such as the one selected for this particular research has proved difficulty in acquiring permission. The process of acquiring permission was difficult, and the patients' inflow is also very low in the above-mentioned cancer treatment centres. Limited time constraint is also another reason which made the research preferred to be conducted in the private hospital as the in-flow of the patients is high than the above two hospitals which were not chosen for this study. After finally being deciding upon the hospital, the paediatric cases and children are excluded from the study because the emotional levels attached to such patients require more time to conduct the research and the child patients are not the focus of this study. Hence, this study has excluded paediatric and child patients. This study also has the limitations in understanding the narratives taking into consideration of social factor such as caste because the patients or the informants were not comfort to reveal their caste which is an important factor to understand the narratives. The chosen sample of patients is of a homogenous group because the setting consists no distinguishing by class. Another limitation for the study is that doctor's perspective has not been considered in a formal interview but frequent inputs had been taken into consideration from medical counsellors, doctors and paramedical staff. The key informant of the study is Gunjan, who is a medical counsellor in the hospital. The researcher had accompanied Gunjan in everyday rounds in the wards.

Chapterization

The present study has been divided into six chapters where:

The Introduction discusses the statistics of cancer across the world in general had been mentioned to support the importance of the study. It also explains the objectives and significance of the study. The field area had been explained and the tools and techniques followed during the fieldwork are elaborated.

Chapter I discusses the impact of cancer treatment on patients selfhood and the analysis about their questioning 'self' had been portrayed in a sensitive manner. It is important to understand the patients' perspective after the amputation of private body parts which define their sexuality in the case of both men and women.

Chapter II discusses the importance of family role in the opinion of patients and even the caregivers. The importance of helping a hand is extremely needed and persuaded by the patient during such a traumatic treatment of cancer. The patient during such a period, not only expects the physical help but also the psychological support.

Chapter III discusses the treatment process, and the difficulties being faced during their treatment. The patients move from one hospital to another hospital in search of better treatment. The major problems being the delay in diagnosis, misdiagnosis, social and financial constraints make the disease grow worse.

Chapter IV would be about the contradicting opinions about alternative medicines and their role in both positive and negative ways in their life.

The conclusion finally discusses the summary of the thesis and through insights about the future research in hospital settings for both the policy makers and the practitioners. The limitations of the present study and thoughts about future research by the researcher will also be explained.

Finally, to make a note from the researcher side, to confide the identity of the informants, pseudonyms have been given and their occupations were not clearly mentioned. This helps to keep the informants anonymous.

CHAPTER II

IMPACT OF CANCER TREATMENT ON PATIENT SELFHOOD

Selfhood is something which has been perceived by one’s ‘self’, which has been again considered as abnormal when compared to the normality. Patients’ understanding of selfhood plays a key role in cancer treatment because the treatment often involves amputation of private parts such as breasts (in the case of breast cancer) and testicles (in the case of prostate cancer). The following narratives explain the notions of selfhood of the patients and its impact on cancer treatment.

The Sense of Emptiness

> “You feel a gap or missing after surgically your body parts have been amputated. You feel as if you have lost something. You can overcome after some days, but it will take time to cope with the fact. We can get implantation done, but you have to be mentally prepared for it and be positive to accept the change”.

Aamani is thirty-seven year old woman, married and mother to a daughter of three years. She was detected with breast cancer and was advised to go for mastectomy for both breasts at the same time. Her family thought of concealing her diagnosis, but she was firm to accept the fact about her diagnosis. Initial diagnosis was done by a needle biopsy, and then they rushed her to Hyderabad to get better treatment. Aamani’s family thought that this hospital can be a better place as recommended by the office staff of her husband. All the respective diagnostic tests were conducted and in the hospital, it was decided to give eight cycles of chemotherapy to her for reducing the size of the tumour. Then, mastectomy was done for both the breasts. She was undergoing the seventh chemotherapy after the surgery at the time of the interview. When she was asked whether she had any pain or complications, she responded by saying the above-quoted words about the feeling of emptiness, '*Kaali pan*' (Hindi: *kaali*-empty, *pan*-feel) to explain her loss of body part after surgery. Breasts are considered to be defining the identity of a woman. When that is lost, the informant felt that her femininity will be questioned. Since this informant is in her thirties, she is worried about the attention from her husband. Her perception of her husband's perspective may or may not be accurate. But since the interview was also conducted with her husband Vignesh, we can understand that he is of both psychological and physical support to her from his response to Aamani' medical condition. According to Aamani, Vignesh played a significant role to counsel her during her treatment for coping with the pain. She continues to say that, "If you had come 4 months before, I would not have spoken with you." as it was very depressing for her to accept that she had cancer. She conveyed during the interview that, it took some time for her to cope with the situation and the fact that she does not have breasts anymore. But the support from her husband and family was extremely helpful. While talking about her husband, she says that he never gave a notion that he deserted her. Surgery was followed by chemotherapy which was more painful according to the informant and a gap of one month from chemotherapy had given her strength and allowed to cope with the medical situation she has been facing.

In the same manner, there are many women who say that it is quite difficult to deal with the loss of breasts says Gunjan (medical counsellor). She had narrated her experiences with patients who hold her how the in-laws had left them at their natal home as they can no longer be considered as real women. So the question arises as to how the society, in general, is defining women. But contrary to the examples given by the counsellor, the interviews with patients and their caregivers revealed that the patients never had a problem with their in-laws or husbands. On the contrary, it is the patient who feels the loss as these are “private” parts of the body and also considered to be the defining feature of a woman. Accepting the fact of losing something has to be very fast as the decision has to be taken quickly to ensure quality treatment in a chronic disease like cancer. There would be situations where the doctors would plan for lumpectomy but while the surgery is ongoing, they would decide to do a mastectomy. According to the doctor’s, they do not wish to hide the truth but there would be situations where the necessity of avoiding future complications is essential.

Acceptance of Conscience

> “There was a doctor named Shastri in Guntur. He told me that by doing an operation, he will remove my testicles. I was unable to accept the fact that I will be losing my testicles as my conscience did not agree with what the doctor has suggested”.

Just like how women felt that losing breasts due to cancer is not normal, even this informant man, felt that way. The sense of masculinity lies in having testicles and it does not matter whether that person can produce sperms or not but the pride of having them is expressed by the informant. Male patients who have a problem with their reproductive organs like testicles, often hesitated to complete some sentences which has to end with the word testicles and which related to the narrations of the prostate cancer. For instance, if they have to say that testicles were removed after surgery, they will say “They had done surgery and then my…. were removed.” The pause at that point in time between the conversations indicates testicles, but they do not use it several times. They feel shy to use the name of reproductive organs several times. The same case was observed while talking to women as well. Even though, they do not complete sentences, but the message is conveyed appropriately to the other person. Ganesh is a seventy-six years old man, who was suffering from prostate cancer and was admitted for treatment. While he was narrating his journey to the hospital since the time of diagnosis, he explained that his prostate was slightly expanded, due to which he had a constipation problem. He went for diagnostic tests in Guntur assuming that it was some urinary infection as he had a burning sensation on the verge of anus. The doctor in Guntur communicated to Ganesh that his testicles had to be removed by carrying out a surgery, which he could not accept. He was undergoing a lot of pain and trouble but finally decided to go for surgery. He told the doctor to make necessary arrangements but meanwhile his son had consulted doctors in U.S.A, Canada, Rai Vellore, Professors from S.R.M College of Madras and also an expert on urology in Madhura Meenakshi College. Doctors had informed that going for surgery at this age is a waste, so it is better to continue with medication. Doctors told that an injection once in three months or six months and appropriate medication would be enough. So, the doctor in Guntur had given Ganesh an injection which is a three-month course at a time. After taking that injection, it seems that Ganesh used to feel irritated and restless. Like, if you are talking with him, he felt “why should I talk to you?” He felt that it was better not to talk with anyone. Even if relatives come home, he never felt like speaking. He felt, Sleep deprivation, some fear while having bath, eating food and even had a fear to go out. So, the effect of injection lasted for three months, and he suffered the whole time. After suffering a lot, he decided not to take the injection again and had try for alternative therapies. But that made the disease adverse. He went to Nagpur for naturopathy treatment[2] after that his prostate gland counts varied between 0-14 and had become stagnant at 14. But the burning sensation and the constipation problem remained the same. When Ganesh's son consulted doctors in Hyderabad, they suggested not to go for treatments such as Naturopathy, at this age and advised to get him admitted to the hospital for treatment. The alternative therapies opted by Ganesh will be discussed in brief in the fourth chapter of this thesis. During the study, Ganesh was undergoing bones strengthening treatment, which is an intravenous liquid given to strengthen bones. While continuing his narrations, Ganesh also said that he was also taking Homeopathy medicine to get rid of constipation problem.

Envisaging Future Social Obligations in Mind

"Everyone will see there (breast) right!"

Mani is a thirty-eight year old woman and is suffering from breast cancer. Mani is a housewife, and her husband was a constable in a police station. Mani identified swelling in her breast and went to consult the doctor. The doctor identified that it is cancer and referred for three chemotherapy sessions with a gap of three weeks for each chemotherapy session. Doctors had suggested that the patient has to undergo surgery after the chemotherapy session. During the study, Mani was undergoing fourth chemotherapy session after her surgery. While reporting about her symptoms, she told that she will have fever and body pains. Her husband was present during the interview

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[2] The details of the treatment would be further explained in chapter IV.

with her. He was supporting her as a caregiver and asked a lot of questions regarding breast reconstruction and side effects of undergoing breast reconstruction. Mani says that it is common that while talking to a woman, anyone (either male or female) would look at breasts and sense the abnormality, if any. The informant accepted the fact that any abnormality would result in gaining attention, and this made her enquire about breast reconstruction. She further adds that unless and until the reconstruction is not like removing a body part or some artificial insertion, it is fine for her to undergo such reconstruction. While continuing with the discussion, they (Mani and her husband) say that as they have two girl children, it is important to avoid unnecessary questions in the future during their marriage. During the study, conversations with patients and their families revealed that the stigma associated with the family of the cancer patient or cancer survivor has led to avoiding of marriage alliances from such families. It also became clear how cancer is perceived by common public as a genetically transmitted disease. Being parents of a girl child, Mani and her husband may have to answer questions about the disease and also about the absence of an important and striking bodily part like the breast when the situation comes to arranging a marriage alliance for their girl child. This is one social factor that women patients are worried about.

A woman’s femininity is weighed by the externally visible body parts like breasts and whether she can give birth to a child or not. But until anyone knows a woman personally, he/she cannot comment on a woman’s reproductive status. The only parts which can be observed are breasts. Any abnormality can be observed with regard to breasts which would be subjected to a lot of questions and suspicions. Mani tried to explain the social stigma attached to having an abnormal body part and its social consequences. She also opines that the best possible solution to avoid such questions from strangers and also avoid any future consequences in arranging the marriage for their progeny is to go for breast reconstruction.

Health Ailments Related to Private Parts and the Sense of Shame

“I feel uncomfortable to reveal that I have piles complaint.”

Karthikeya is a sixty-seven year old man, a graduate from IIT Madras and a retired bank employee. The problem with regard to private parts decreases the chances of being able to share the details even with the family members. The informant said that the symptoms were similar to piles, so he followed some advertisements on television. The advertisements on television would convince the viewer about the symptoms and offer saying that the possible solution would be the product offered. The adverse effect of not being treated by a practitioner with expertise was told by the informant. During the diagnosis, the junior doctor had examined (“poked” as told by the informant) Karthikeya at the same spot where he had a problem. One point to be noted is that all the patients who had acquaintance with the medical terminology despite being literate or illiterate are comfortable in explaining their problem.

The general notion that male patients may not be comfortable with the interviewer if it is a female was contradicted during the study because the male informants are quite comfortable in sharing their experiences. That is the time when the patients emphasized that professionals like counsellors can be good icebreakers in conveying the deadly news of cancer. Also, after the patient comes to know about his/her problem, timely counselling sessions were requested in order to motivate and convince them about the treatment. Convincing during treatment is very important because of the heavy dosage of the medicines; patients would not be ready to continue the treatment if they are not aware of the adverse effects of the medicines. Such issues should be dealt with a lot of sensitivity.

The increased awareness of patients about various science related disciplines would help in ample utilization of their subject related services such as, counselling by psychologists, etc,. Informants repeatedly emphasized the need for someone to listen to them. They just need someone to hear rather than being judgmental. This does not mean that the person who is listening is going to reduce their pain or suggest how to get better treatment but just the fact that they can share their experiences seems to relieve them from the pain they are going through. Caregivers or the close associate within or outside the family can really make a difference during the period of treatment. The neurological functioning would be obstructed by chemotherapy and patients suffer from severe irritation when they are undergoing the process of radiation. Many informants have reported that they used to feel irritated by each and every small sound when they are under the process of treatment. Many informants reported how they became allergic to food smell and used to vomit countless times. The intake of food also affects the body as immunity can only be developed by proper food according to the doctors.

Relief after Follow-ups

> “If we come for a checkup once after that we can feel relaxed for the next six months. We may or may not have the problems with our health if we have any issues we can

> go through the treatment, if not we be rest assured and feel
> relaxed”.

Lalitha is a forty-six year old woman, who is an employee at coca-cola and a cancer survivor. She was detected with cancer in her right breast and has finished her treatment. Remembering times of her diagnosis and treatment, she says that she sensed something rough and abnormal in 2009 and consulted doctor. Soon after detecting, surgery had been performed, followed by six chemotherapy sessions. Since it was not third or fourth stage of cancer, she was lucky enough to get cured. Lalitha is now on follow ups and says that she would be slightly tensed during tests, and that would last till the reports arrive. Then she feels that she can relax and live her life happily for another six months, until her next check-up. She also feels that follow-ups are important to detect if there is any recurrence at an early stage, but most of the people have a misconception that the corporate hospitals suggest them to come for check-ups just for the sake of charging money, even after the treatment is over. During the time of this study, she was undergoing some intensive tests as she was suffering from back pain since few days. Lalitha says that after getting cured with cancer treatment, any slight problem is taken seriously. People who have access to good facilities would normally say that it is good to undergo intensive medical tests and those who cannot afford say that all this is done just for the sake of acquiring money by the corporate hospitals. Some hospitals are commercial and suggest the patients to undergo irrelevant tests which make people think that follow-ups are not that important. In a disease such as cancer, even doctors could not help when the cells multiply at a faster pace. Therefore regular follow-ups are advisable and should be carried out without any negligence. Lalitha said it is a chance to live for another six months in peace. The most difficult part concerning cancer is that the treatment once given cannot be assured that the disease will not recur again. Any time in life, the disease can recur and once it is recurred it will affect some other body part and the patient will not have any other choice than to go for treatment again. Lalitha expressed her joy and sense of pleasure only because she has confidence in the doctors, and she is coming for the timely check-ups and following the doctor's advice without fail.

Lalitha believes that once a person is diagnosed with cancer, there is nothing called cure; it is just a process of extending the period of one's life. Even the paramedical staff and counsellor Gunjan said me the same.

The Financial Burden

> "I have undergone eight chemotherapy sessions which cost eight lakhs. Each chemotherapy had cost one lakh…. In order to mobilize the money, we had to sell two acres of land".

Mahesh is a forty-nine years old man and was suffering from Non-Hodgkin's Lymphoma and cancer in testicles. Initially when Mahesh was admitted to the hospital the doctor has told that removing one testicle will be enough but later as the second testicle was also affected with cancer the doctors decided to remove the second one as well. Mahesh and his family showed discontent with his initial diagnosis in the other hospital where the doctors suggested removing both the testicles but the doctors over here had made decision to remove just one testicle. Mahesh and his family reports that now he had to take surgery twice, and it was quite traumatic. It is not just that it was difficult for Mahesh to cope physically but also the expense occurred for the second-time surgery was also something which they were not ready for. The economic status of the family has made them sell their property and for a person who is a farmer, sustaining on the land he cultivates, it is painful to sell the land for any purpose. He also continues to narrate how one is helpless in these situations. He emphasised the high expenditure and also said in a sarcastic tone that this being a private hospital, such expenditure was expected. The patients will be depressed about their weight, diet and change in appearance. They want to lead a normal life as soon as possible. Doctors would prefer them to eat food rather than to take medicines, but the patients feel that their taste buds are dead. After such a treatment where the neurological system gets affected, it is quite difficult to follow normal intake of food. Some patients complained that they have nausea because of food. In such a situation, the contrasting opinions of the doctors and the patients regarding the food and medicines are never negotiable. Patients and caregivers say that even food has to be consumed as medicine for better cure.

Mahesh, like Karthikeya, was also hesitant to utter the word ‘testicles’. The common point to be noticed in both the cases is that whether or not the larger society questions them, the person himself feels bad about losing vital parts and the doubts revolving around his selfhood.

Being Distanced from the Family Members

> “I want my mom back as same as the past; I do not like the way you are now.”

Sandhya is a forty-four year old woman who is also a bank employee and is admitted to hospital for cancer being detected in the left breast. She had gone for annual health check-up and was informed that she was detected with cancer. Sandhya has undergone surgery and consecutively was suggested to go for chemotherapy, radiation, and hormone therapy. During the period of this study, she is undergoing ninth chemotherapy. She tells that because of this cancer treatment there will be total weakness, and a person tends to get irritated for every tiny sound. While continuing her narrations, Sandhya told that her parents would be there to support and even her son who is very young is also struggling because of her situation. Her eyes welled up when I enquired about her health and familial support she received during the process of her treatment. It is difficult for her to explain to her son about her disease and at the same time to get accepted by him as he is very young to understand the pain she is going through. The physical changes and also the mental status of the patient make the family members see a gap between the patient and the family, especially when the family members such as sons/daughters who are young cannot understand and show discontent because their mother is not the same as she used to be.

The misconceptions about the disease that it is infectious or gets spread would make the patient think a lot and keep a distance with the family and of course even by the family, when they have children, the sense of insecurity that cancer is a contagious disease leaves a physical distance. To be in specific, the disease would grow internally in many cases but when the treatment is going on, the side effects of chemotherapy and radiation have to be dealt with. In such situation, keeping physical distance from others is advised but in that same situation, the patients expect a soothing touch from their family members. Sandhya also expresses that her son hurts her with his words saying that, she is not the same person (mother), whom he wants to be with (change was observed by her son after amputation).

Contrasting Notion of Selfhood Regarding Transfusion of Blood

> “I do not know whose blood they had transfused into me.
> Now I feel that I have others’ blood in my body.”

Mary is a thirty-eight year old woman, who is working as a government employee. Mary got married at an early age and had a girl child. Her husband believes in Hindu religion whereas Mary is a converted Christian and gets involved in missionary activities. According to Mary, they give mutual respect to each other’s beliefs. Mutual understanding about their religious beliefs and not enforcing each other with their beliefs has been a major reason for lead their happy lives.

Mary has been detected with ovarian cancer in 2014 and had undergone a surgery. While she was recollecting her treatment experiences, she told that she had a lot of complications before and after surgery. Her haemoglobin counts were around 6.5 and then the doctors had suggested injecting four packs of blood by which haemoglobin reached 15. Mary was initially reluctant to get the blood transfusion but later agreed to it according to the suggestion of the doctor. The inherent feeling that someone else’s blood is flowing in her body is unacceptable situation for her. The perception of ‘my blood’ and ‘someone else blood’ is strong in the informant’ mind. Mary also says in between that no one is sure whose blood is being injected and what kind of habits the donor has. Mary is an educated and working woman who has the ability to distinguish between right and wrong but she gets worried that her ‘self’ is occupied by someone else’, a fact difficult for her to digest.

Conclusion

The above cases and narratives given by the patients, explains the notion of ‘self’ by both genders. The physical difference in appearance is questioned by others and also by the patients themselves. The emotional factors which are very important for the patients seems to be not a bothering factor for the doctors, as the doctors are more concerned about preventing the cancer doing damage to the patients’ health. The doctors will go to any extent to do their jobs like performing the amputation (if in need be) to ensure the cancer does not spread. These narratives also suggest that the stigma attached to determining and defining characters of a man and woman were questioned when the amputation was carried out. The patients not only worried about their treatment but also about their children’s marriage in the future.

Through narratives, the patients get a chance to explain the struggle which is going on in their mind regarding several issues. Sometimes, it need not necessarily be the patients but also the caregivers, who equally struggle because of the treatment and as they are also in the stage to learn how to be supportive for the patient to cope with the medication situation which they are facing.

Throughout the study, the patients consider being hospitalized for a disease like cancer is hard to digest, as they never had a medical history of getting detected with a mild disease (which is not considered as chronic). Often patients say that, they are more worried about the attention they get either from the medical staff or the caregivers, because the medical staff considers them as just another patient, and caregivers are also coping with the situation. Moreover, the caregivers have to run around to the hospital to make sure the patient gets enough attention and treatment. Often caregivers take turns in order to attend to a patient and to give their best attention. In case, if any patient feels that the adequate attention has not been given to them, they generally tend to associate this less attention from the caregivers as the result of amputation carried out as a process of treatment and they go to the extent of questioning their selfhood. The patients feel insecure about the loss of body parts. Loss of organs or body parts is not just the reason for a feeling of loss in self but as can be seen in the case of Mary, something like a blood transfusion can also go to the extent of making the person question what is her ‘self’ and what is not. The impact of selfhood on cancer treatment or *vice versa,* and the result of cancer treatment on questioning the selfhood is an important factor to understand.

CHAPTER III

ROLE OF FAMILY IN THE OPINION OF PATIENTS AND EVEN THE CAREGIVERS

Family broadly includes many people. However, in the context of caregiving, the close relations of parents, spouse and children play a key role. The crucial decision-making lies with these close relatives in the course of medical treatment. The treatment makes the patient physically and mentally weak. Personal assistance is needed to motivate the patient and monitor the symptoms regularly. The role of family and caregiving becomes instrumental in the course of medical treatment. There are possibilities of differences between the expectations of the patients and caregivers. The complexities that arise because of these differences, the role of caregivers and the enriched narratives are presented in the chapter.

From Patient's Perspective

> "For me, my wife and son are the only supporters. My son could not even go to school properly this whole one year. Since this one year, they are my only support."

Chakri is a forty-six year old male working in the real-estate business. Chakri witnessed blood during defecation and approached a doctor. The doctor suggested that perhaps it is piles[3]. After taking medication, the flow of blood did not reduce but rather increased. When Chakri reported the intensity of the problem, the doctor advised him to go to

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[3] Piles: Hemorrhoids are vascular structures in the anal canal. In their normal state, they are cushions that help with stool control. They become pathological or piles, when swollen or inflamed.

Tirupati.[4] A doctor in Tirupati advised Chakri to undergo sigmoidoscopy[5], in which Chakri was diagnosed with cancer. The sample of the rectum was sent for biopsy after the opinion of the doctor to proceed further with the surgery. Chakri's family decided to admit him in Vellore for further treatment. However, the delay in the medical reports resulted in the decision to join in this private hospital in Hyderabad (after watching some advertisement on television).

After getting admitted in this hospital, the initial treatment plan was to give radiation and chemotherapy simultaneously. Then, doctors suggested Chakri to rest for one month and prepare for surgery after critical examinations. After surgery, chemotherapy sessions started again, and Chakri underwent six chemotherapy sessions. When Chakri consulted about the status of treatment, doctors advised him to go for further medical examinations. The reports stated that his disease did not respond to the six chemotherapy sessions done after surgery, following which doctors changed the course of the treatment (combination of different medical treatments). With the revised combination, Chakri underwent four chemotherapy sessions. At the time of interview, Chakri was waiting for the tests advised by doctors. Chakri faced different side effects with each and every session of the treatment. After the change in chemotherapy session, he suffered from mouth ulcers and loss of taste. But according to him, the revised chemotherapy reduced the side-effects (like constipation issues) and resulted in a better appetite.

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[4] Tirupati: A town in Andhra Pradesh, India.

[5] Sigmoidoscopy: it is a procedure used to see inside the sigmoid colon and rectum.

While talking about the role of his family in the treatment, Chakri seems to be euphoric and proud. His wife is a school teacher, and they have two children. Since Chakri has to consult doctors and get admitted, they left their daughter in their hometown and their son continued to be with him. In spite of being only a matriculate, Chakri’s son took interest in learning about the medical proceedings and discussing his condition with the doctors. Chakri’s son actively participated in the decision making during the treatment plan. Chakri regrets the challenges faced by his son in the course of the treatment. His son scored lower marks in school examination. However, Chakri consoles himself by feeling proud of the crucial role played by his son throughout his treatment. Chakri’s wife is a working woman who balances the household responsibilities and professional commitments effectively. He proudly acknowledges the caregiving role of his wife and son during the painful phases of the treatment. They provided unconditional care without losing patience in spite of harsh remarks made by Chakri out of pain and trauma.

Chakri indicates the importance of the role of understanding family members in dealing with the challenges of an intense cancer treatment. The kindness and strength of the caregivers are crucial for continued motivation to fight the pain. Chakri believes that his son’s support for him at such a young age will help him in dealing with challenges in the future.

Loneliness and Lack of Assistance

> "…no one was there with me and that loneliness gave me a thought that you should not send all your children out. At least one should be with you for assistance. That depression made me think like that."

Khan is a sixty-seven year old retired bank employee, who is suffering from prostate cancer. He was diagnosed in October, 2013. The initial symptoms included frequent urination which increased gradually. Over the period of time, the informant continued to suffer from sensation of urination, but the urine droplets reduced. The disturbance in sleep cycle due to the sensation of frequent urination troubled him. As the symptom continued, Khan visited a nearby corporate hospital out of concern. The doctors suggested diagnostic tests and biopsy. Khan was detected with a problem in the prostate gland.

During the course of the treatment, Khan tried homeopathy and also browsed on the internet regarding some remedies in Ayurveda. But finally, nothing turned out to give a positive result. Khan approached a urologist in another nursing home. Doctor A in that hospital observed the medical reports and informed him about expansion in the prostate gland. The increase in sugar level followed this. One doctor advised him to go for surgery only after reducing sugar levels. Then, Khan consulted another doctor near his home and undertook treatment to reduce sugar levels within ten days. He then approached the doctor he had consulted earlier to continue with the surgery. The doctor advised him to undertake a biopsy, which confirmed the cells to be cancerous. Khan was shattered as all his children are settled abroad, he stayed with his wife. Khan's wife suffered from arthritis which restricted her movement. Khan realized the need for a constant caregiver.

The lack of family support made him struggle psychologically during the course of the treatment.

Khan took help of his close friend and colleague during the surgery but for post-surgery treatment he called his distant relative to help him in traveling to the hospital. After surgery, he was advised to take twenty-six days of radiation and five doses of calcium treatment because of weakness in bones. Later it was increased to twelve doses as weakness in hip bones started. The lack of family support increased Khan's worries. Khan said, "During the treatment, the realization occurred that sending all the children abroad can be problematic in the painful phases". He regrets the decision of sending his children to foreign countries. Khan was financially secure yet missed the familial support in such a critical time. Khan acknowledges the support from the medical counsellor, Gunjan in this hospital. He says, "A patient becomes jubilant when medical counsellor reports the person to be healthy."

Similar to the previous case study, Khan also concurs on the need for caregiving and the role of family for effectiveness of treatment. He considers that the touch of the family members or beloved ones, and the acknowledgment of improved health make the patient confident.

Even though an individual spends lakhs of rupees on the medical treatment, a soothing word, and a caring hand is what patient craves for in this situation. Along with, "*Dawa*[6] and *Dua*[7]", medicine and counselling are equally important. An individual need

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[6] Dawa: Medicine given by the preacher in Islam.

[7] Dua: An act of supplication (a form of prayer) in Islam.

not be a psychological counsellor but an assurance that ‘nothing would happen’ is imperative, even if, that patient is in a critical state. This hospital where the research is conducted takes regular sessions on the role of caregivers by emphasizing on the responsibilities of the caregiver (like, diet plan). During the researcher’s stay in the hospital, this session had been attended and the effective participation by the caregivers is observed.

Day to Day Support from Family Members

> “If I start for my duty at 5 AM also she will cook and make
> food ready for me.”

Bhadra is a fifty-seven year old government employee suffering from stomach cancer. Bhadra found stool to be black in color for about ten days which proved to be the initial symptom. He went for further diagnostic tests. The ultrasound reported that everything is normal, but endoscopy resulted in identifying stomach cancer. Then, further biopsy confirmed stomach cancer. Bhadra underwent two chemotherapy sessions before the surgery. Post-surgery, he underwent four chemotherapy sessions. Bhadra was cured in 2002. But the cancer recurred though not in the same place. Doctors suggested six more chemotherapies after which the cancer was cured. Again in 2014, Bhadra was detected with cancer in the stomach in another area and underwent six chemotherapies but the metastasis did not respond to the chemotherapies so the medicine was changed. At the time of this interview, he was on the improved chemotherapy medication of four cycles. Now, the improved drug is effective because constipation has reduced, which is considered as a sign of cure according to him.

Bhadra feels that intensity of chemotherapy results in common side-effects. He thinks that it would be better if patients get involved in their day to day work in order divert their mind from the pain. Bhadra found it difficult to take food in the first week after chemotherapy. Bhadra acknowledges the role of his wife as caregiver in the treatment. He agrees that his body does not support work like before but still he manages to work. He also says that it is important to restrict outside food strictly to be healthy. Bhadra says that he ceases to consume street food and when there is no option he prefers food from the office canteen. Even if he has to start at 5 AM in the morning, his wife manages to make food and give it to him. Except his mother, everyone in his family was informed about the problem. Bhadra does not want his mother (eighty-six years old) to know about his condition.

Family Friends Becoming the Core Family

> "Everyone thinks that both of them are my sons and there is
> one more boy who is very close to me like my son."

Manjula is a fifty-three year old breast cancer patient working as a school teacher in a private school. Once Manjula found a lump in her breast which she neglected and after two months, it started to hurt so she consulted a doctor, and it was diagnosed to be breast cancer. Chemotherapy sessions were given pre-surgery and then after the reduction of tumor size, surgery was performed. At the time of this interview, post-surgery chemotherapy sessions were going on for her. Manjula's husband passed away. Her daughter is married and stays in another state of India. Her son works in a multi-national company in the city. Manjula stays with her son Vishal and in the whole discussion, she never mentioned anything about her family other than Vishal's friends. Two friends of

Vishal are the only ones who help them. She says that everyone in the hospital thinks that she has got three sons.

In Manjula's opinion, it is not always true that family is the only bond which would be beside us during our difficult times. Friends are also part of the family. Manjula says that Vishal's friends cook and get home-made food for her whenever she is hospitalized. The researcher encountered with the genuiness of the discussion as both Vishal and his friend were skeptical of the questions asked in the interview. They interrupted Manjula during the interview and since, the research time was of short time duration, another session of interview was not conducted. The medical counsellor suggested that the difficulty in finding a partner for a son of a cancer survivor resulted in the skepticism. The case exposes the social stigma associated with cancer.

From Caregiver's Perspective

> "But if I had to stay totally here with my mother, just because I am a housewife, it would be very difficult for me and my family, who are dependent on me."

Appamma is a seventy-six year old lady, who was totally bedridden at the time of interview. The informant was assisted by her daughter during the treatment. The case study is based on the interview with the medical counsellor, Gunjan. Appamma went to her daughter Sujatha's house to stay for few days. During her stay, she noticed a lump and informed to Sujatha, who took her to the doctor. After diagnostic tests, it was identified as breast cancer and Sujatha informed her other sisters and brothers.

All the children gave excuses for looking after her. The son excused himself on the premise of health concerns and commitments of their partners. And, eventually the responsibility of caregiving fell on Sujatha. Sujatha remarked sadly, “My brother blames me for my mother’s the condition. According to him, my mother was healthy until she came to my place”.

Sujatha, on whom responsibilities were entrusted also looked for ways to avoid caregiving. Eventually, the siblings decided to contribute the share of Rs.15, 000 per month for the treatment of Appamma in a nearby hospital. The financial burden was mostly taken care of by a sister who was an employee in a public sector firm, under the central government insurance scheme. Sujatha concludes that she has been entrusted with this responsibility since she is a housewife. She complains of back pain and developing allergies in the hospital environment.

The elder sister of Sujatha, who accompanied her to the hospital was reluctant to engage in the conversation. Sujatha talked about the inhibitions of sharing information with outsiders. Sujatha says, “If the other siblings get health problems, their children are in the position to support them whereas her children are not yet independent and self-sufficient”. Appamma’s health situation is thus a bone of contention among her children.

Loss of Patience because of Treatment

> “Sometimes she will be asking “how many more chemotherapies?” And I say two or three more, and she says “Ok” with a sigh.”

Sita is a seventy-one-year-old lady, and her husband Ram is a retired army man. The interview was done by Ram as Sita was unable to speak due to weakness. In 2008, Sita observed a lump in her breast at the time of her daughter's marriage. Doctor advised chemotherapy, but the marriage of her daughter, delayed the treatment. Ram opines that they decided to face the consequences of the delay in treatment as the marriage was more crucial. Post-wedding, Sita undertook the surgery and following chemotherapy sessions and radiation treatment for about four to five months. In the periods 2008 to 2013, Sita was on regular check-up. In 2014, Sita suffered from weakness and consulted a cardiologist. The doctor could not identify an abnormality in her health. In June 2014, the hoarseness of the voice was followed by reduction in the volume. The vocal cord eventually got paralyzed, and she was unable to speak. During these complications, Sita resided at her daughter' place in Baroda. Sita consulted a cardiologist nearby, who suggested CT scan. Cancer spread everywhere in the body, blood, spleen, etc. So, they were anxious and returned to Hyderabad. After consulting the doctor in Hyderabad, Sita underwent 15 to 16 chemotherapy cycles.

Ram and Sita have three daughters, and all are married. During the painful stages of the treatment, Ram took the role of caregiver and provided all the needed help to Sita in the hospital. Ram maintains the records systematically with notifications of chemotherapy sessions and the medicines required in the treatment. After undertaking many chemotherapy sessions, Sita was restless and frustrated. Ram as a responsible caregiver continues to provide support. Ram is retired from a public sector and the financial condition is adequate to deal with the medical treatment.

Occupational Problems Faced due to Long-term Treatment Plan

> “We have to attend to our duties as well. If not who will pay salaries? Because of her treatment, even I have to leave my job. She has a leave for medical problems for 6 months from the government but still long term leave is difficult. For a treatment like this it takes years to the treatment plan for which leaves would not be sufficient. The higher officials are considering a lot of things with a good heart.”

Mridula is a forty-two year old head constable, and her husband Sailesh is a government school teacher. Mridula identified her problem in 2012 and after mammography, it was confirmed that she had breast cancer. For reconfirmation, she underwent a biopsy, as suggested by the doctor in their hometown. The doctor advised Mridula to consult this hospital, and he also briefed the patients’ health condition to the chief doctor in the hospital. Doctor advised surgery followed by chemotherapy and radiation. Mridula underwent diagnostic tests after one month of surgery. Recurrence of cancer in the lungs was identified. The treatment was continuing at the time of interview.

Mridula complained of side effects such as motions, weakness, tastelessness for tongue and other multiple complexities post chemotherapy sessions. Sailesh as a concerned caregiver discussed with the doctors in the nearby hospital about the recurring side effects. In spite of the medical suggestions given by the doctor the side effects did not subside. Sailesh consulted the doctors in this hospital; he was counseled to adjust to the mood swings in Mridula as a result of the chemotherapy sessions. Eventually, after two chemotherapy sessions, Mridula got adjusted to the complexities of treatment. Sailesh continues to motivate Mridula after the painful chemotherapy sessions, which helped the informant to cope with the course of the treatment.

During the interview, Mridula said that she notified the respective police department about her health condition so that she will be spared from night duty and more responsibilities.

Sailesh says that complications during intense chemotherapy sessions are common. However, the role of the caregiver is crucial to motivate the patient. By maintaining systematic records and periodic discussions about the progress of the patient with the medical staff, the caregiver can play an instrumental role in the treatment. Sailesh faced a lot of constraints during the process of treatment in the form of personal commitments. The children being young often neglect their education, and this acts as another challenge for the caregiver and the patient. Balancing the complexities of the treatment along with the personal constraints poses to be the biggest challenge to the caregiver.

Acquiring Convincing Skills

> “Actually we have to support them according to their version. They want to take the treatment and also think whether we can have some easy procedure for the treatment. They will not say ‘no’ because they want to live, have attachments, see children, but medication would be difficult for patient. So we being caregivers have to go according to their thought process. Actually we would generally be strong and emphasize strictly on medicine having a fear that they would deny treatment.”

Aamani is a thirty-seven year old housewife, and her husband, Vignesh is a police officer as already mentioned in Chapter I. Vignesh also indicates similar issues as referred by Sailesh in the earlier case. However, one interesting point to be drawn is the fact that in spite of the patient’s willingness to live, they get discouraged during the course of treatment. The chemotherapy medicine is intense, and it is given through intravenous. In the process of eliminating bad cells, it also kills good cells and hence, the immune system becomes weak. So, no individual is willing to live over the period of pain and trauma. It is the responsibility of the caregiver to motivate the patients to understand the essence of life. According to Vignesh, even though patients are aware of these aspects. The consolation “we are there for you”, can motivate them during the pain. It is obvious that any person would lose temper at times. Vignesh opines, “the kind of love and affection which exists towards the patient also makes the caregiver to be harsh at times, but it is imperative to converse politely. Politeness is hard to come as time is a constraint in this treatment.” The emphasis of quick decision-making given the time constraint is made clear by Vignesh. There are situations where doctors come in the process of the surgery and ask to make decisions in few minutes also. The caregiver should be in a position to make decisions given the considerations at that particular time.

While narrating about the emotional bond that prevails between the patient and caregiver, Vignesh mentions about the bond between the husband and wife. Vignesh feels, “Kindness towards the patient during the treatment is crucial. In this regard, the male companion considers caregiving as a responsibility, whereas female companion are more emotional while giving care”. Vignesh continued, “Women continue to care in spite of any challenges in the course of the treatment. Men cease to care over the course of the treatment in many cases”. Vignesh is critical of such aspect and believes a man and a woman should contribute equally towards the responsibilities in the course of life. According to him, the bonding is easily broken in today’s world, wherein people are hesitant to face such hurdles. Vignesh philosophically narrates, “A human is a collection of desires. In a garland, the thread is the life, and the flowers are desires. Flowers can perish, but the thread remains forever”.

Vignesh narrates the importance of understanding the woman waiting for the man at the home giving utmost care to him. In the similar sense, a woman should recognize the efforts put in by a man for giving her the care. These efforts strengthen the relationship, and that works as an important healer during the painful phases of life. He again philosophically exclaims, “there is a difference between eating the food and enjoying the essence of it. By enjoying the taste of the food, one eats more than for just the sake of eating”. He says any hurdles and challenges in the life should be countered with a positive frame of mind.

During the interview, it was evident that Vignesh provided utmost care to Aamani. In the period of counseling, Vignesh followed the advice of medical professionals and incorporated them in the caregiving to the patient. The detailed understanding of the treatment and the complexities of the patient in the painful phases along with help from medical counselors is vital for caregiving.

In the analysis of the above-mentioned eight cases, it can be observed that an understanding and supporting family makes a considerable difference to the caregiving. The effective caregiving is instrumental for the treatment of the patient. The caregiving blend with emotional kindness and medical knowledge of the treatment can be more effective. The absence of family makes no difference in treatment but effects on positive thinking of patient. The patient should be frequently motivated for better results. Even though, extended treatment plan make the patients and caregivers impatient, since the disease is highly unpredictable, it is important to keep up the spirit.

CHAPTER IV

THE TREATMENT PROCESS AND THE DIFFICULTIES FACED DURING THE PATIENTS JOURNEY FOR TREATMENT

The ‘illness narratives’ highlight the trauma that cancer patients undergo, particularly in the questions they ask about their ‘selves’, and the socio-economic problems they face during the treatment process. The subjective insights discussed in this chapter substantially contribute to the notions of ‘care’ cancer patients receive, from family and the medical professionals. This chapter discusses issues of (or lack of) compliance with medication and treatment the patients look for and receive. The treatment is case-specific from individual to individual, which increases the complexity of the treatment. There is a need to incorporate the patient’s condition and the seriousness of the particular type cancer while analyzing the narratives. Based on the conditions, the treatment is structured and initiated. This stage proves to be a major challenge to the patient as well as the professionals. Apart from the medical aspect, superstitious beliefs also play a fundamental role in understanding the narratives and explaining the experiences of the patients. Such notions are, however, a clearly discouraged by the medical professionals.

The treatment is also affected because of several social, occupational and economic constraints. For instance, the impending marriage of a grown-up daughter at home can act as a social constraint delaying the treatment. Medical treatments are delayed due to the inability of receiving permission in the workplace of the patient and caregivers. Other impediments in the form of infrastructural constraints faced by patients from rural areas also prevail. The poor development of medical infrastructure in rural areas delays the treatment and follow-ups. Most importantly, the high expense involved in the cancer treatment can act as a crucial barrier to the treatment. The wait for assurance from the insurance company and delay in the arrangement of money acts as impediment in the treatment. In few cases, patients discontinue the treatment without financial assistance.

The chapter intends to highlight the narratives which clearly point out the various impediments as mentioned above. The narratives offer interesting insights further to understand the notions of 'care' and the challenges faced by the patients.

Misguidance and Its Consequences in Delayed Diagnosis

> “I go home and come back, but this time I stayed back, and this counts had been drastically down to about 900. Earlier I used to be at home and after falling (platelets), I used to come. It is difficult, so I used to feel very weak. I told the doctor that I wanted to stay here.”

Indumathi is a sixty-six year old woman, is working in a private firm. She stays with her husband in the railway quarters. She takes the help from the maid when she visits the hospital, but not from the family members. Even during the study, it was observed that she was rarely accompanied by her family members during hospital visits. Swollen leg was one of the initial symptoms observed and experienced by the patient. The swelling of legs continued for two months, after which, she was referred to this hospital by a doctor in the Railway Hospital. After ruling out the possibility of surgery, the doctors at this private hospital directed the patient to undergo chemotherapy. Chemotherapy was the only medical treatment left for the patient. During the initial period of the treatment, the swelling in legs restricted the patient from reporting to work. After the treatment, the patient managed herself efficiently.

Prior to this swelling of legs, Indumathi suffered from psoriasis[8]. Indumathi took treatment using homeopathy medicine. The homeopathy doctor, she consulted, advised her to continue the treatment. The idea was the decline in the intensity of the infection as it descends from the head to the toe during the course of treatment. She was convinced that as the infection reaches the toe, there is a complete cure for *psoriasis*.

The pain continued, and it became almost unbearable. And at this stage, the homeopathy doctor advised Indumathi to refer to allopathic practitioner for further medical help. The informant visited the Railway Hospital, from where, she was directed to this private hospital. In January 2014, Indumathi was admitted to this hospital. During the time of field investigation, she was in the sixth month of chemotherapy treatment.

The informant shares her experience of falling rate of RBC, WBC and blood platelets following each chemotherapy session. During the initial phases, the informant struggled to walk owing to weakness. At the time of interview, she was walking. Indumathi gladly shares the appreciation received from the doctors for her speedy responsiveness to the treatment. She had other side effects like nausea, dizziness, and weakness. Indumathi is touched by the empathy shown by the doctors in the hospital. She feels that the reason could be her getting the treatment without any family help.

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[8] Psoriasis: is a common, chronic, relapsing/remitting, immune-mediated systemic disease characterized by skin lesions including red, scaly patches, papules, and plaques, which usually itch.

The importance of family support for is necessary for patients to cope with the treatment especially when they are dealing with chronic diseases such as cancer[9]. The informant shows utmost respect for the doctors. During the course of the interview, Indumathi considers the doctor as a manifestation of Sai Baba[10], who has come to relieve her from the pain.

Indumathi delayed the diagnosis owing to the slackness involved in the treatment by homeopathy practitioner. The delay in treatment was intertwined with other medical complications like HBsAg[11] positive. The informant is glad that her belief in god also provides her with the strength to deal with the complications of the treatment. She is reluctant to take help from family members as she is unwilling to get accompanied them to the hospital. She prefers seeking help from the maid. Indumathi says that she does not like to bother her family members by calling them to hospital.

Indumathi hides the reality of her health complications from her relatives and peer group. She narrates, “No one from the family is aware of the disease as they will feel sad and will approach me with sympathy”. She argues that the sympathetic approach from the people is one thing which is unbearable for her. Indumathi hides her whereabouts by stating reasons such as being out of station for work.

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[9] Importance of familial support and the narrations which show, how it helps the patients to cope with the treatment has been discussed in the chapter II

[10] Sai Baba is believed to be a prophet, who preached equality between Hindu and Muslim religions. And he is considered and revered as god till date by people, who belong to the different religions.

[11] HBSag: HBSag is the surface antigen of the hepatitis B virus. It indicates current hepatitis B infection.

One such interesting insight that can be perceived is that, patients tend to ignore the symptoms in the beginning and show extreme negligence in undertaking appropriate medical treatment. Though, in this particular case Indumathi was misled by the homeopathy doctor. General notions and popular beliefs act as an important social impediment which delays the course of treatment.

It is thus necessary not to turn a blind eye towards any constant, worrisome symptoms as they can often be the alarm for the chronic diseases like cancer. Another interesting inference that can be drawn from this case is the necessity to understand the disinterest shown by the informant towards sympathetic approach by family. The reluctance of informing the family about the disease also unravels the possible social stigma associated with the disease.

Negligence of Symptoms

> “The fault is ours too; we failed to come here in advance. Back there in our place there was only one doctor available, and the decision-making becomes a problem because of that. The surgery lasted for five hours. The surgery resulted in twenty-three stitches which were extended to the pelvic bone. In the span of one to one and half years, the surgery was done four times and among the four surgeries, once the surgery was done on the same place again”.

Saraswathi is a fifty-eight year old government employee, and her husband took voluntary retirement from government services, as a driver. Pricking sensation in the stomach was one of the first symptoms faced by the informant. Though, the informant initially assumed that to be an outcome of dehydration, but eventually observed the recurrence of pain on one particular side of the stomach. She consulted the gynaecologist and was informed of the cyst. The medical help based on doctor advice resulted in temporary relief for the informant. However, over the course of time, the pain recurred.

Saraswathi approached a surgeon for addressing the recurring pain. The surgeon assumed it to be the outcome of psychological stress regarding the pain and suggested her not to worry. The advice of the surgeon acted as an impediment to getting the appropriate medical help. The informant regrets the decision of not verifying the reason for pain from other medical professionals. The informant at that point of time was convinced by the suggestion of the surgeon.

The pain became unbearable and in the third stage; Saraswathi approached a homeopathy doctor in Ananthapur as other symptoms like dizziness; nausea and loss of weight also developed. During this course of homeopathy treatment, the informant recollects further loss of weight and dropping of stomach to an abnormal shape. One day, the informant recognized a lump near the breast along with pain in the stomach.

The informant reported to an allopathy doctor regarding the symptoms but in vain. Saraswathi decided to take homeopathy medicines along with the allopathic medicines. In this course of time, the gynaecologist identified some protrusion in the body of the informant. The protrusion when pushed went inside revealing an alarming symptom along with drastic weight loss. The scan reports at that point of time indicated the possibility of cancerous mass. The mass was removed after an extensive surgery. The informant recollects that the mass was removed along with five centimetres of the large intestine (as the mass was stuck to the large intestine). After the surgery, nine chemotherapy sessions were given and then the scan reports were normal. However, in a few days the informant experienced similar symptoms, and the diagnostics revealed the possibility of CA 125[12]. The doctor explained the reason for reoccurrence of the tumor as delayed diagnosis, and they advised her to go for chemotherapy session again. Saraswathi saw some advertisements about the chief doctor in the hospital and also heard from friends about the treatment facilities before coming to this hospital. According to the medical oncologist, the cancer cells spread to ceretonium and chemotherapy was inevitable. Saraswathi adds, “People opine that it is a silent killer and is accompanied in the case of ovarian cancer. But it was fortunate that it came outside in the case of mine”.

Saraswathi has told many people about her disease, but some ask her, “Why do you want to say to everyone about your problem?” She thinks that her case can be an example for others to understand and take quick steps when it comes to treatment for such chronic diseases as cancer. After counselling with a close person, she gained strength to face the complexities associated with the disease.

Her husband was a government employee but took voluntary retirement because of medical reasons. Saraswathi does not have children, and her husband helps her in the course of treatment. The informant also adds that her younger sister who is married extends support during the course of treatment. She also narrates, “Living in a village taught us to face challenges. The sight of many people suffering makes us recognise the better position we are in to face such chronic diseases”. Since, she works as a supervisor in public health centres, she understands her medical situation clearly. She strives to fight with the disease to lead a peaceful life.

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[12] Cancer antigens 125

Her husband thinks that people publicize incidents of failure rather than narratives of successful patients. In this regard, the informant and her husband believe the narratives of successful stories can motivate patients to fight cancer and cope with the medical complexities.

A Case Study for End of Life

> "….once in 15 days I have to undergo chemotherapy. They gave a four months gap for the treatment after making me go through 6-8 months of chemotherapy. After giving gap, it has grown and now once in every 15 days I have to take chemotherapy. Mine is 4th stage, so it is not possible to go for surgery. If it is 1st or 2nd stage, then they might have suggested me to go for surgery. Now using medicines is the only way for me. There will be six types of medicines it seems. Now they are giving me 2nd type of chemotherapy. Each chemotherapy session runs for 48 hours."

Ayyappa is a sixty year old man, who worked as a contractor. The initial symptom the informant experienced is stomach pain, and when he consulted doctor concerning his stomach pain, the doctor predicted the possibility of the ulcer. Six months later, through the CT report, the informant was diagnosed with cancer. After taking various opinions, he decided to approach this private hospital for treatment. The patient knew his condition and accepted the fact. Now, he is in stage IV of cancer of the pancreas. Other than chemotherapy there is no option of treatment left. He further explains the treatment and the six types of chemotherapies. He is undertaking the second type of chemotherapy, and each session lasts for forty-eight hours. The chemotherapy cycles will lead to increase in the sugar levels, and this causes problem in following proper diet. They cannot eat according to their wish because there are chances of fluctuations in sugar levels.

Ayyappa tried homeopathy for the curing of ulcer, but it was not effective. The allopathic doctor suggested him to approach Ayurvedic method. He started using Ayurveda, and continues along with allopathic treatment. Ayyappa is satisfied with the Ayurveda medicines as he feels that at this stage, it provides strength to cope with the treatment. He says that it is easy for him to drive back home after chemotherapy.

Ayyappa is in a stage where rather than prolonging his life nothing else is possible. It is important to accept the seriousness of the stage and move further. It was clear from his words that Ayyappa knows his condition and he accepted the fact by understanding it.

In normal cases, doctors do not suggest other types of medication. In Ayyapa's case, it is important to make him live by using one or another option. One of the Ayurvedic doctors at Government Ayurvedic hospital said that, the Ayurveda method of treatment does not target the action therapy; rather it strengthens the whole body. It is possible that strengthening of the body helped Ayyappa to cope with chemotherapy.

Complications during Treatment and Lack of Family Support

> "Though we are educated, we tend to ignore the symptoms of cancer. After initial symptoms were neglected but later I have experienced a lump in the armpit; apparently the lump was in the advanced stage. Then I rushed to NIMS hospital for treatment. However, the doctors in the hospital have said that "Madam, you are too late." I met Dr. Surya Narayan, a known doctor, and he said that he will try his best but could not assure me of complete recovery. I proceeded further with the relevant tests and sadly during all this my son was in Canada."

Subba Lakshmi is a sixty year old, retired professor, who was suffering from breast cancer. She observed a lump of a stagnant size and assumed it to be a benign lump. She delayed the diagnosis as there were few responsibilities with regard to her son. She is a wodow single women living with her only. Subba Lakshmi says that being aware of health and diseases cannot be equated with being educated. People who are also educated tend to forget and ignore many health problems. In the same way, she also turned a blind eye towards the earlier symptoms. Then, her disease went to the next stage where she discovered another lump in her armpit, which made her rush to the hospital. The doctors at that hospital told her that she was too late. She tried with another doctor who said that he will treat her but was not given assurance of complete recovery. Subba Lakshmi did not inform her son as he was out of the country for his training, and the news might disturb him. The medical consultations were undertaken by her alone, and someone suggested her to go for the second opinion. The second consultation gave her a 50% chance of hope. Then one of her relatives brought Subba Lakshmi to this private hospital for confirmation, and the doctors advised immediate treatment. She was content with the hope given and joined for the treatment, but the diagnostic tests were not sufficient, so the doctors sent her for further examinations. The metastases spread into lungs, and the disease grew at a faster pace. She underwent two surgeries, number of chemotherapy sessions and radiation sessions. After that, she thought she got cured completely. However, three years later, there was a recurrence. During the course of the interview, she was undergoing radiation treatment.

Since Subba Lakshmi never had any of her family members present with her during treatment, she gets emotionally attached to hospital staff like Gunjan. She discusses with Gunjan about her son’s wedding proposals and many personal issues as. During the chemotherapy sessions, she faced lot of troubles. The first four chemotherapies were taken entirely by her but after that, each chemotherapy session was split into three and was given once in a week. After one month of radiation was given to her, right side breast was removed entirely through surgery and the second surgery (hematoma) was done under the armpit which was a complicated procedure. She also reported that there was a lot of blood loss but miraculously got cured by itself. She says that even the doctors were content with her because of the positive attitude. The doctors were surprised as all the tests were clear, but they already suspected chances of recurrence after five years or so. However, due to family pressures, the recurrence was identified within three years. At the time of this study, she was taking radiation treatment. During the interview, when questioned about the emotional support from her son, she declined to answer and hinted that her son mostly stayed outside the country. She adds, “Doctors appreciated me for the strength displayed which helped me to fight and live.”

A Case Study of ‘Recurrence of Cancer’

> “In the initial phase they had given me four chemotherapy sessions and that time I did not have the problem of hair fall. I think I was young, I was able to bear it during that time. Twenty-five days the radiation was also given, but now I experience the chemotherapy different”

Bhavani is a fifty-four years old housewife. She suffered from cervical cancer in 2003 and undertook treatment, and was cured. In January 2014, Bhavani complained of severe headache and constant pain in the hand. In the nearby railway hospital, doctors prescribed calcium medicines and tablets for subsiding the headache. Bhavani and her family assumed the pain to be a result of migraine. After the cancer treatment in 2003, Bhavani ensured to remain healthy by continuing to walk and exercise every day. The weakness post the recent headache continued. Bhavani frequented her visits to the nearby railway hospital. At one such instance, a doctor from a corporate hospital visited that hospital and confirmed the possibility of cancer after analyzing the diagnostic reports. The diagnostics revealed the presence of bubbles in her lungs and confirmed it to be the lung cancer. After consultations from different networks, the family decided to take Bhavani to this private hospital for the further treatment.

The diagnostics revealed the possibility of weakening of bones. A treatment to address that continued along with the cancer treatment. The side-effects of the treatment resulted in hair fall, constipation and constant itching (primarily because of radiation). Bhavani claims that during the previous radiation session for cervical cancer, the symptoms mentioned above did not occur. The reason for this could have been the result of growing age as in 2003, she was relatively younger and was able to bear the effects.

Delay in diagnosis was the crucial reason for the recurrence in the case of Bhavani. According to her, a repeated diagnosis periodically (once in six months) is imperative for cancer survivors. The skipping of such sessions associated with the delay in diagnosing cancer resulted in recurrence. Many times, the patients and the caregivers tend to overlook owing to lesser inclination to be careful after a successful treatment. They tend to blame the physicians if prescribed for tests periodically assuming it to be a part of ‘corporate money-making’ strategy.

Chronic Recurrence of Cancer and It's Narrations

Another interesting case study is that of a woman who underwent major surgeries three times. Cancer recurred twice and she underwent the radiations and chemotherapies. The woman without losing hope continues to take the treatment further. At the time of field investigation, the woman was not in a comfortable position for recording an interview. Thus, the case study is presented, in brief.

Kutty is a fifty-five years old housewife, diagnosed with ovarian and liver cancer. In the year 2012, she had frequent urination, which she initially thought to be a common urinary infection. She used homeopathy treatment to address the infection. The consultant doctor observed a lump while testing for urinary infection. Doctor suggested consulting a physician as the lump can be a symptom of cancer. After the completion of further formalities in detection and confirmation of cancer, a major surgery was undertaken. The surgery lasted for eight hours and the ovary, uterus and some parts of the digestive system were removed. A small lesion left in the liver was expected to reduce in the course of further chemotherapy sessions. In the process, Kutty underwent six cycles of chemotherapy and was exposed to all possible side effects. After a gap of fifteen months, the lesion recurred in the liver and in order to remove the lesion, instead of chemotherapy, the doctors suggested stereotactic radiosurgery. Despite the high expense associated with radiosurgery, Kutty agreed. The lesion was removed after the surgery.

Post-surgery, Kutty and her husband relocated to Mumbai from Hyderabad. After six months, diagnostics revealed the presence of another lesion. Another surgery was undertaken for the removal of the lesion in the liver. She mentioned that the emotional attachment with this hospital for more than a year made her request the chief doctor (who is the surgeon in another hospital) to perform the surgery in this same hospital. While recollecting the experience of ICU, Kutty says, “the closed atmosphere and the people who were getting treated for cancer, made me sicker.” The strength to fight the disease prevailed yet the pain suffered by the rest in that environment depressed her. She was engulfed by the feeling of isolation in that closed atmosphere. The desire to shift to the normal ward was rejected by the doctor as intensive care and attention were necessary at that juncture of treatment. Many chemotherapy sessions followed and at the time of interview the sessions were over. To ensure a comfortable radiation session, Kutty, and her husband ensured to reach the hospital by 5 AM starting as early as 4.30, from the home, in the morning. In total, she was given twenty-seven chemotherapies and two cycles of radiation. At such a stage, finding a vein also became difficult. The peripheral neuropathy problem further accelerated the difficulty. The peripheral neuropathy problem gives the sensation of stepping on a ball, and can result in the collapse of balance as a result of it.

During the interview, Kutty recollected one such incident involving her mother-in-law who was also in a similar condition. After helping her mother-in-law and taking efforts during the illness, Kutty wondered when will the mother-in-law die? The efforts to take care of mother-in-law in such a situation was not possible for Kutty. In such phases of illness it is challenging to deal with it yet one cannot abstain from the responsibilities. She believes in accepting the situation as given by god, but according to her, managing responsibilities and completing the household tasks should continue despite being sick. Kutty and her husband will continue to manage responsibilities on their shoulders until they can. Kutty strongly believes problems and hurdles are part of survival, and it is necessary to face the challenges i life. She believes in applying a similar approach to deal with her conditions.

Through these case studies, it is evident that the delayed diagnosis and misdiagnosis because of several factors is a major problem. The delayed diagnosis has lead to the problems of side effects and recurrence of the cancer in many patients. Taking for granted, the awareness of this chronic disease, is another major challenging factor one should address. The social constraints being reason for the delayed diagnosis or starting the treatment late has made the situation of the patients worse than they would have if the diagnosis and the treatment would have started early. In several cases, it has also been observed that the patients were guided by popular notions. The belief is other medical systems has lead some patients to suffer more. Often the medical professionals who depend on diagnostic tests, which are not adequate enough to reveal cancer, have misguided the patients. However, as seen in the case of the Ayyappa, where the future was bleak, the doctor felt it best to make use of method possible to keep prolonging his life span, such as Ayurveda. This has in fact helped the patient to cope with the challenges posed chemotherapy.

As explained in the introduction of this chapter, if the narrations are taken into consideration it might help the situation of patients to get better treatment. Though the socio- economic and occupational constraints determine the process of treatment, the patients should be educative enough to give priority for treatment and diagnosis rather than subjugating for these constraints.

CHAPTER V

ALTERNATIVE MEDICINES AND THEIR ROLE IN CANCER TREATMENT

The patients who are suffering from any disease tend to opt for multiple methods of treatment. As each and every disease and the body is case specific, the body responds differently to each kind of medication. Those who find it comfortable with a particular medication prefer to continue with that system of treatment.

Sujatha and Abraham (2012) discuss the multiple treatment procedures followed in India. The significance and the intensity of the existence of medical pluralism in our country is highlighted as both ISM (Indigenous Systems of Medicine) and CAM (Complementary and Alternative Medicine) deal with the indigenous systems of medicine in India. This research found that patients had encounter ayurveda, homeopathy and naturopathy along with the allopathic medications. The informants narrated how and why they opted for alternative medicines. Some case studies detailed in this chapter show that patients were using two or three different methods at the same time and some other instances one at a time.

Margret Trawick (1991) explains that Ayurveda is one of the healing systems which are extensively practiced in South Asia. The knowledge of Ayurveda was encrypted in Sanskritic texts two thousand years ago. The etymological meaning of Ayurveda is “that which has been seen to be true about long life” (Trawick 1991:121). As a part of the study, to understand the ues alternative medicines, some ayurvedic practitioners were interviewed. It is revealed in the interview that ayurveda does not have target action therapy; rather it rejuvenates the whole body. Ayurveda makes the entire health system to fight against the health ailments, hence, this process is time-consuming, and the patients are expected to show forbearance during the treatment procedure. The Ayurvedic treatment procedure does not have a diagnostic method to find out the disease of the patients. The medical practitioner suggests medicines based on the symptoms expressed by the patients. Only a few people approach Ayurveda as people seek instant relief from the pain, and this method of treatment does not promise that.

Gasparin J (2005) describes homeopathy as a curative method in medicine which began almost 200 years ago in Germany. It was practiced and spread across the world by Samuel Hahnemann. The process explains that a substance which causes certain symptoms in a healthy person can also cure an ailing person who has similar symptoms. The theory may sound vague but treatment is distinct from the rest. Homeopathy does not include surgical methods and in terms of vaccine, it is different from other medical systems. The treatment procedure in homeopathy has relations with ancient healing traditions but it has its uniqueness, which is not related to any other medicine systems.

In the present study, such cases were encountered but the responses varied from patient to patient. Some patients opined that approaching alternative medicines along with allopathy had an impact in battling their disease, whereas others disagreed that there was any notion of getting benefit from alternative medical treatments. A total of 8 out of 50 have narrated their experiences concerning alternative medicines.

Opting *Gomutram* and Homeopathy for the Prostate Cancer

Ganesh, as mentioned in chapter II, narrated his experiences of trying alternative medicine. As an alternative medicine, the informant visited Nagpur[13], the medical practitioner there, suggested him to consume the urine of a cow. The urine of a cow is considered sacred, and it is deemed to contain medicinal power to reduce prostate cancer. The informant followed the advice and started using the '*Gomutram*', a pill and some medicine mixed with *ghee* for seven months. The informant also added that, this helped him in battling the prostate cancer. As during the treatment, his prostate count which was 19 had come down to zero after using this alternative medicine for seven months. However, the count again rose to 8, 11 and 14 and later, stagnated at 14. However, in the due course of time, the informant also complained of the burning sensation and constipation problem. So, his son consulted doctors in this hospital, and they advised him not to visit Nagpur for alternative medicine during this course of time and at that age. Thus, the doctors advised the patient' son to get the patient for consultation.

The informant narrates that while undergoing the Allopathy treatment he also opted for another alternative medication called Homeopathy at the Batra's[14] suggestion. He has requested the homeopathy medical practitioner to give medicines which helps him to ease the constipation problem and also to reduce the burning sensation during urination. The informant did not experience any relief after a week of medication. He

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[13] Nagpur: is the second capital and third largest city of the Indian state of Maharashtra.

[14] Batra's: is a homeopathy hospital in Hyderabad.

stated that the medication was ineffective and discontinued the homeopathy way of treatment for his health ailments.

Home Remedies for the Prostate Cancer

Khan, as mentioned in Chapter III, tried different home remedies along with the allopathic treatment for his prostate cancer. The informant narrates how he made use of internet to find what can be done to ease and make allopathic treatment effective. He came to know that using *amla* as a mixture with turmeric and honey in ½: 1:2 ratios will lead to a better result and experiment the same. The informant also came to know about a fruit, which is called as 'soursop.' The particular fruit is not available in India and Khan requested his daughter to send this fruit from Dubai, where his daughter resides. He also procured this fruit once from a dry fruit seller in the old city, Hyderabad. He said that that 'soursop' fruit costs about Rs. 650-700 per fruit. The outer layer of the fruit has to be removed; the fruit has to be cut into 30 equal parts and stored in the deep freezer. That fruit has to be consumed twice a day, an hour before a meal. He also told that the content of that fruit is available in the form of a powder as 'vita plus' which he had got it through his brother from Saudi Arabia. Khan had also tried to get Asparagus (a vegetable) which is suitable for cancer cure as informed by someone to the informant. His son orders asparagus in an American online website. His daughter sends 'soursop' fruits which would be available in sealed form. Khan says that the home remedies mentioned above have helped him, and he also feels that using the home remedies is the reason he can sustain the allopathic treatment.

Herbal Medicines and Home Remedies

In Sita’s case (Chapter III), her husband Ram narrates how they opted for alternative medicines such as herbal medicine (which they came to know through the television advertisement) for 2-3 months. The medical practitioner advised following the treatment through herbal medicine for 6-8 months. However, the chemotherapy treatment also started, and the informant and caregiver felt that using both might lead to adverse effects, and they decided to stop using the herbal medicine. The informant also narrated how they had come across another television advertisement which says about a fruit called ‘Ramphal’ the television advertisement has propagated saying ‘cancer cure’ with ‘Ramphal.' Sita tried ‘Ramphal’ and says that it helped her to cope with the disease.

Homeopathy and Allopathy

Bhadra, as mentioned in Chapter III, narrates how he opted for Homeopathy after being referred by someone. He had started using the Homoeopathy along with the allopathy; others also informed him that by using homeopathy the recurrence of cancer will be stopped. Hence, he started using the homeopathy and ended up spending 70-80 thousand rupees on the homeopathy medication. However, that homeopathy treatment was in vain; as cancer recurred in the patient. While recollecting his experiences about the homeopathy, the informant has also told that twice a day he used to spend one and half hours to take this homeopathy medication. The Homeopathy doctor gave four liquids to be consumed with a gap of 5-10 minutes and also ten types of pills which has to be taken with a gap of 5 minutes for each tablet. The Homeopathy doctor suggested the informant to maintain a gap of 15-20 minutes in case of using allopathic medicines to avoid any side effects. Bhadra narrated about using the combination of homeopathy medicines along with the allopathic medicines to his Allopathy consultant. However, the doctor did not discourage him from using the homeopathy and, in fact, said it is good to give a try though he believes that using both would not be effective.

Alternative Medicine Delayed Diagnosis and Adverse Effects

Indumathi, as mentioned in chapter III, narrates, about using homeopathy medicines for psoriasis. Apparently the cancer was misunderstood as psoriasis by the homeopathy doctor, and he started the medication. Despite using the homeopathy medicines the pain continued, and the doctor advised her that, the disease is cured eventually as it passes from the top to toe. The informant was convinced by the doctor's logic of getting relieved from the leg pain. However, after waiting for a long period, when the leg pain was unbearable, and the informant was unable to walk, later she decided to give a try with the allopathic medication. Her consultation with allopathic doctor had revealed that she has cancer, and she started taking chemotherapy sessions.

Misdiagnosis and Alternative Medicines

Saraswathi, as mentioned earlier in chapter IV, has approached general physician when she had health ailments. The general physician had chided away her illness feeling after going through her reports saying 'the reports says she is perfectly fine, and the health problems she expresses are just psychological feeling.' However, the unsatisfied informant decided to opt for the homeopathy medication. Since, homeopathy practice does not have diagnostic tests, the doctor asked her symptoms and gave medication accordingly. The homeopathy treatment was not effective in relieving her from the pain so she decided to consult another allopathic doctor and which resulted in the diagnosis of cancer for the informant.

Eating Habits, Illness Behaviour and Allopathy

Dinesh is a forty-four years old government employee who has piles complaint, initially opted for Ayurvedic medicines and used the medicines for about four months but the treatment proved to be futile. Moreover, the informant also felt that he was becoming weak day by day and losing weight steadily. Later he consulted an allopathic practitioner and was diagnosed with cancer. The informant narrated how someone told him that the brinjal might have adverse effects on his health as it possesses the allergic elements; the informant stopped eating the brinjal. However, the allopathic doctors suggested him that the allergic factors affect only those who are proven to be allergic to the brinjal, and thus, he can consume brinjal if he wishes to.

Support of Alternative Medication to the Allopathic Treatment

Ayyappa as mentioned in chapter IV, the informant is a stage IV pancreatic cancer patient. His situation is critical and hopeless, after understanding his condition; the allopathic consultant suggested him to try Ayurvedic medication along with the chemotherapy sessions. Following the advice of the doctor, the patient started using Ayurvedic medication. The informant opines that he can cope with chemotherapy sessions just because of these Ayurvedic medicines; he also added these two medications did not have any side effects and proven to be healthy. He continued saying that he is managing his personal work and even driving (which was not the case earlier) just because of Ayurvedic medication which stands as a support for the allopathic treatment.

Conclusion

The study portrays the emotional experiences of the patients' and caregivers on various aspects like questioning individual ‘self,' roles and responsibilities, role of alternative medication and treatment difficulties. From this study, it is clear that we need to understand and give space to voice the challenges and feelings of both the patients and caregivers. The findings of this study may contribute to understanding the illness narratives overlooked by the hospital staff. It might help the medical staff to understand and mend their methods while dealing with the patients' treatment process. Chronic diseases such as cancer need to be addressed without any further delay.

The cost involved in the treatment process is becoming a serious barrier for patients and their families to go ahead with the treatment. At private hospitals such as one where this current study was carried out, the process of providing better health care results in costing the patients an extraordinary amount. Currently, cancer treatment is considered as affordable only for the economically privileged class. In order to address the economic constraints faced by the larger sections of the society while dealing with cancer, more public treatment centers should be established. Government should encourage the research in the field of cancer treatments to work out a viable treatment policy for all the groups of people.

The government should come up with guidelines for public and private sector employees, allowing them to claim medical leave in case of diagnosed with chronic disease such as cancer. Treatment often involves extended sessions of chemotherapy and other treatment procedures such as surgery, radiation, and regular follow-ups in order to avoid the recurrence of the disease in the patients. The employer and the government should stand by the employee who has been diagnosed with cancer, at such a crucial time.

Chronic disease such as cancer, are often viewed with stereotypes. These stereotypes are fed in due to incomplete information about the illness. Patients suffer social isolation due to misconceptions about cancer (being a communicable disease) being nurtured in the mindset of the society. These perceptions result in constraining the patients' ability to cope with the treatment. It contributes to the adverse psychological effects. Patients therefore look out for alternative medicines. Such constraints can delay further treatment.

In this regard, state-sponsored advertisements and active media campaign can raise awareness regarding the illness and wither away the general misconceptions about the disease. Currently, many media groups and non-governmental organizations are at the forefront in spreading awareness by roping in celebrities for popularity and mass appeal. The attempt has been partly successful in creating awareness about the disease among the public.

The stereotypes associated with the illness is also making the patients think about their children's marriage aspects. The social problems faced by the patients who underwent amputation of parts are expressed in feelings about being judged after the surgery (like breast cancer patients). The social stigma associated with the disease explains the need for educating and redefining the notion of ‘sexuality’ and crushing the stereotypes associated with it. By doing so, patients can be more comfortable during the treatment, and this can increase the effectiveness of the treatment. The case studies substantiate the skepticism faced by the patients while undergoing surgical removal of the private parts.

The future research in this particular topic allows to extend the study to understand the narrations from different social and religious background, as they are one of the many determining factors to shape the narrations of the patients. Research should be extended to hospitals run by the government in order to make the hospital ethnography rich and also to collect the narratives which might be determined by the different economic backgrounds. There is also a need to understand the perceptions and narrations of the paramedical staff and nursing staff in hospitals because they observe the patients more than the doctors. Their narrations might throw some light in understanding the problems involved in the treatment process and in the psychological trauma the patients go through.

CHAPTER VI

CONCLUSION

This study portrays the emotional experiences of cancer patients and caregivers on various aspects, like questioning individual ‘self,' roles and responsibilities, role of alternative medication and treatment difficulties. From the study, it is evident that there is a great and urgent need to understand and give space to voice the opinions of patients and caregivers. The findings of this study based on examining people’s illness narratives, overlooked by the hospital staff, could help them to understand and modify their methods while dealing with the patients’ treatment process. The chronic diseases such as cancer need to be addressed from a social science perspective, in India, without any further delay.

The cost involved in the treatment process is becoming a barrier for the patients or their families to go ahead with the treatment. The private hospital such as one where this current study was carried out, the process of providing better health care results in costing the patients an expensive amount. Currently, the cancer treatment is considered as affordable only for the economically privileged class. In order to address the economic constraints faced by the larger sections of the society while dealing with cancer, more public treatment centers should be established. Government should encourage the research in the field of cancer treatments to work out a viable treatment policy for all the economic classes of people.

The government should come up with the guidelines for the public and private sector employees, benefiting them to claim their medical leave in case of diagnosed with chronic disease such as cancer. The cancer treatment often involves extended sessions of chemotherapy and other treatment procedures such as surgery, radiation, and regular follow-ups in order to avoid the recurrence of the disease in the patients. The employer and the government should stand by the employee who has been diagnosed with the cancer, as their hard labor has contributed to the growth of the venture involved. It is a typical gesture any patient will expect in reciprocity.

The chronic disease such as cancer, are often viewed with stereotypes. These stereotypes are fed in due to the incomplete information about the illness. Patients suffer social isolation due to the misconceptions about cancer (being a communicable disease) being nurtured in the mindset of the society. These perceptions result in constraining the patients' ability to cope with the treatment. It rather contributes to the adverse psychological effects and they look out for alternative medicines. Such constraints can delay the treatment.

In this regard, the government sponsored advertisements and campaign along with active media programs can raise the awareness regarding the illness and wither away the general misconceptions about the disease. Currently, many media groups and non-governmental organizations are taking a forefront in spreading awareness by roping in celebrities for more popularity and mass appeal. The attempt has been partly successful in creating awareness about the disease among the public.

The stereotypes associated with the illness are also making the patients think about their future generations' marriage aspects. The social problems faced by the patients who underwent amputation of the private parts expressed their feelings about being judged after the surgery (like breast cancer patients). The social stigma associated with the disease explains the need for educating and redefining the notion of 'sexuality' and crushing the stereotypes associated with it. By doing so, patients are more comfortable during the treatment, and this can increase the effectiveness of the treatment. The case studies substantiate the skepticism faced by the patients while undergoing amputation of the private parts.

The limitations of the present study as mentioned earlier in the introduction chapter are the short duration of the study is one major drawback for the sample size and also constraining the research with one hospital. The practical possibilities of the data collection are kept in mind, and the research questions are framed accordingly. The main reason to consider the particular field site is that of the high inflow of in-patients when compared to other hospitals which have not been considered for the study. The primary objective of choosing "illness narratives" is that it will give the opportunity for the patient to talk more about open-ended questions. As from the researcher point of view, extending this study further, in the long run, would be much easier.

The future research in this particular topic allows extending the study to understand the narrations from different social and religious background, as they are one of the many determining factors to shape the narrations of the patients. The future research should be extended to hospitals run by the government in order to make the hospital ethnography rich and also to collect the narratives which might be determined by the different economic background. The future research may also be extended to understand the perceptions and narrations of the paramedical staff and nursing staff in hospitals because they observe the patients more than the doctors. Their narrations might throw some light in understanding the problems involved either in the treatment process or in the psychological trauma the patients go through.

Appendix

Interview Schedule

- **General sociological data**

1. Name:
2. Sex:
3. Age:
4. Code name:
5. Address:
6. Date:
7. Time:
8. Place of interview:
9. Also present:
10. Marital status:
11. Religion:
12. Educational background:
13. Occupation:

- **Related to Disease**

1. What is the purpose of your stay in hospital?
2. Since how long are you suffering with this problem?
3. How did you feel when the problem was first diagnosed?
4. What steps have been taken to cross check the problem which got detected?
5. Was the diagnosis same when you went for the second opinion?

6. Who all were involved in decision making for further treatment?
7. What kind of problems did you face during this process of undertaking treatment (emotional, social, familial, financial, etc.)?
8. What sort of support did you get from the hospital and doctors?
9. Did you ever feel that the doctors or the hospital can be much more supportive? If so, in what way?
10. Was doctor or hospital involved in decision making of your treatment?

- **Dietary Patterns**

1. What kind of dietary restrictions have been given by the doctors?
2. Did you feel that following such dietary restrictions are useful?
3. Did you follow any other alternative medicine systems like Ayurveda, Unani, Siddha, etc. before or after the treatment?
4. Did you personally follow any kind of home remedies suggested by family, friends or T.V programs?
5. Did you personally feel that some foods did not suit while taking the treatment and stopped eating those foods?
6. What is your experience related to food while the treatment is going on?
7. Do you feel that the suggestions given by the dietitian are useful?
8. Do you watch any programs in T.V on diet and try to follow?
9. Do you think that those programs are useful to you or your family?

Bibliography

1. Mol, Annemarie. *The logic of Care: Health and the problem of patient choice.* Routledge: Taylor and Francis group, 2011.

2. Arthur Kleinman. *The Illness Narratives: suffering, healing, and the human condition*. USA: Basic Books, 1988.

3. Audre Lorde. *The Cancer Journals*. Aunt lute books, 1980.

4. Benson A. Mulemi, “Patients’ perspectives on hospitalization: Experiences from cancer ward in Kenya”, Anthropology and Medicine, 15:2 (2008): 117-131. Accessed May 14, 2012. doi: 10.1080/13648470802122032
5. Bernard H. Russell, *Research Methods in Anthropology: Qualitative and Quantitative approaches*. UK: AltaMira Press, 2006.
6. Betty Risteen Hasselkus, “The family Care giver as Interpreter in the Geriatric Medical Interview”, Medical Anthropology Quarterly, 6:3 (1992): 288-304.
7. Cecilia Van Hollen, “*Birth on the threshold: childbirth and modernity in south India*”. University of California Press, 2003.
8. David Perusek, “Cancer, Culture and Individual Experience: Public Discourse and Personal Affliction”, ETHOS 40:4 (2012): 476-506. ISSN 1548-1352. doi: 10.1111/j.1548-1352.2012.01271
9. Debbi Long, Cynthia Hunter and Sjaak van der Geest, “When the field is a ward or a clinic: Hospital ethnography”, Anthropology and Medicine, 15:2 (2008): 71-78. doi: 10.1080/13648470802121844

10. Gitte Wind, “Negotiated interactive observation: Doing fieldwork in hospital settings”, Anthropology and Medicine, 15:2 (2008): 79-89. doi: 10.1080/13648470802127098
11. Haripriya Narasimhan, *Multiple Voices and Stories:Narratives of Health and Illness,* ed. Arima Mishra and Suhita Chopra Chatterjee (New Delhi: Orient Blackswan 2013).
12. Hufford, David J. *Folklore and Medicine. In Putting Folklore to Use.* Michael O. Jones, ed. Pp. 117-135. Lexingto: University Press of Kentucky, 1990.
13. Jessica L. Gregg, “An Unanticipated Source of Hope: Stigma and Cervical Cancer in Brazil”. ISSN 0745-5194. Medical anthropology quarterly by American Anthropological Association. Vol.25, issue 1 (2011): 70-84.
14. Jessica L. Gregg. *Virtually Virgins. Sexual Strategies and Cervical Cancer in Recife.* Stanford University Press, 2003.
15. Joyce Burkhalter Flueckiger. *In Amma’s Healing Room: Gender and Vernacular Islam in South India*. Hyderabad: Orient Longman Private Limited, 2006.
16. Julie Livingston. *Improvising Medicine. An African Oncology ward in an Emerging Cancer Epidemic*. Duke University Press, 2012.
17. Margaret Trawick, “An Ayurvedic theory of Cancer, Medical Anthropology”: Cross-cultural Studies in Health and Illness, 13 (1991):1-2, 121-136, doi: 10.1080/01459740.1991.9966044
18. Martyn Hammersley and Paul Atkinson. *Ethnography: Principles in practice*. Taylor and Francis e-library, 2007.

19. Merrill Singer, “Down Cancer Alley: The lived experience of health and environmental suffering in Louisiana’s chemical corridor”. Medical anthropology quarterly by American Anthropological Association. ISSN 1548-1387. Vol. 25, issue 2 (2011): 141-163.
20. Paul Atkinson and Martyn Hammersly. *Ethnography: Principles in practice*. Third edition. London and New York: Routledge. Taylor and Francis Group, 2007.
21. Shelly R. Adler, “Complementary and alternative medicine use among women with breast cancer”. Medical anthropology quarterly by American Anthropological Association. ISSN 13(2) (1999):214-222.
22. Steven M. Albert, “Care Giving as a Cultural System: Conceptions of Filial Obligation and Parental Dependency in Urban America”. American Anthropologist, volume 92 (1990).
23. Susan Sered and Ephiraim Tabory, “You are a Number, Not a Human Being”: Israeli Brest Cancer Petients’ Experiences with the Medical Establishment. Medical anthropology quarterly by American Anthropological Association. ISSN 13:2 (1999):223-252.
24. Susan Sontag. *Illness as Metaphor and AIDS and its metaphors*. Penguin Books. Modern classics, 1983.
25. Tancredi Laurence R., and Barsky Arthur J., “Technology and Health Care Decision Making: Conceptualizing the Process for the Societal Informed Consent”. Medical Care, Vol . 12, No. 10 (Oct, 1974). doi: 218.248.6.153

26. Uwe Flick, Ernst von Kardoff and Ines Steinke. *A companion to Qualitative Research*. Sage Publications, 2004.
27. V.Sujatha and Leena Abraham (ed.) *Medical Pluralism in Contemporary India*. New Delhi: Orient Black Swan Private Limited, 2012.
28. "WHO fact sheets, copyright: 2015

- http://www.who.int/chp/chronic_disease_report/media/india.pdf?ua=1
- http://www.who.int/mediacentre/factsheets/fs297/en/

CHAPTER I

INTRODUCTION

According to a WHO report of 2005, chronic diseases are projected to account for 53% of deaths in India. The total projected deaths in India, in 2005 were 10,362,000 of which 5,466,000 deaths are due to chronic diseases. Cancers figure among the leading causes of death worldwide, accounting for 8.2 million deaths in 2012 by WHO report (Fact Sheets, Cancer, WHO website, 2012). 8% of total deaths in India in 2005 occurred due to cancer, which is considered to be a prevalent number and these numbers are increasing tremendously every day (Impact of Chronic Disease in India, WHO, 2005).

Cancer is a general term for a large group of diseases that can affect any part of the body. Other terms used are malignant tumours and neoplasm. One defining feature of cancer is the rapid growth of abnormal cells that grow beyond their usual boundaries, and these can spread across other organs also. The process is referred to as metastasis, and these are the primary causes of death from cancer. Cancer arises from one single cell. The transformation is a multi-stage process, and the progression occurs from pre-cancerous to malignant tumours. These changes are the result of interaction between a person’s genetic factors and also because of few external factors such as,

- Physical carcinogens, such as ultraviolet and ionizing radiation;
- Chemical carcinogens, such as asbestos, components of tobacco smoke, aflatoxin (a food contamination) and arsenic (a drinking water contaminant); and

- Biological carcinogens, such as infections from certain viruses, bacteria, and parasites.

These classifications were given by WHO through its cancer research agency, International Agency for Research on Cancer (IARC) on cancer-causing agents. Another important factor is aging which is linked with the cellular repairing mechanism. The increase in age would lead to the less effectiveness to fight with the abnormal cells decreases.

Review of Literature

Cancer figures among the leading reasons for death worldwide, accounting for 8.2 million deaths in 2012 by WHO report (Fact Sheets, Cancer, WHO website, 2012). According to a WHO report of 2005, chronic diseases are projected to account for 53% of deaths in India. The total projected deaths in India, in 2005 were 10,362,000 of which 5,466,000 deaths are due to chronic diseases. Report suggests 8% of total deaths in India in 2005 occur due to cancer, which is considered to be a prevalent number and these numbers are skyrocketing every day (Impact of Chronic Disease in India, WHO, 2005). The articles and books which reviewed focus on the ethnographic work done in hospital settings and among cancer patients' in Hyderabad. The research method is incorporated in the study carried out in the hospital settings. 'Participant Observation' means staying in the selected field area and staying with the people. Despite staying with the people, you have to make them comfortable so that the researcher can observe the details of the field area and the selected topic. There are several ethnographic studies conducted among patients in various areas such as sociology (Alex Broom and Assa Doron, 2011) and anthropology (Jessica L. Gregg, 2003). This study has also looked at topics such as illness experience which is popularly known as five stages of illness by Suchman, quality of life as mentioned by Fayers and Machin (2009:4).

Medical anthropology came into existence the aftermath effective of World War II and due to the increased emphasis of health and well being of the Third World people. (Singer and Erickson, 2011). Foster and Anderson (1978:1) defines medical anthropology as "...the cross-cultural study of medical systems and ... the bioecological and sociocultural factors that influence the incidence of health and disease now and throughout human history" (Singer and Erickson, 2011:3).

My fieldwork concentrates on topics like illness experience, patient's perspective on quality of life, importance of caregivers and their perspectives on the patients. The study attempts to trace their journey from diagnosis to the current situation. The study also throws light on "hospital ethnography" (Debbi Long, et.al. 2008).

"Illness Narratives" of the Patients'

Susan Sontag says, "conventions of treating cancer as no mere disease but a demonic enemy make cancer not just a lethal disease but a shameful one." (Sontag, 1978:59) As the treatment of cancer leaves a person with fatigue, hair loss, excess gain or loss of weight, and in some cases, permanent loss of body parts and the personal experience needs to be understood. In supporting this argument, Arthur Kleinman (1988), discusses the concept of 'illness narratives' in his book. Thus, the concept of "illness narratives" provides the base for this research. The study focuses on the narratives of patients about the journey of treatment. Information has been collected on information on issues like the time of diagnosis, impediments to timely diagnosis or treatment, process of the treatment plan and other complexities faced during the treatment. The study engages with the important facets of patients' expectations with regard to caregivers and also the caregivers' view concerning patients'.

Role of Caregivers and Doctors

The space of fieldwork, i.e., the hospital provides an opportunity to talk with caregivers as well. Since it is a corporate hospital, caregivers are expected to be with the patient and take care of them. The emphasis on caregivers is immense because in diseases like cancer, where long-term treatment plan is the norm and caregivers support is instrumental. The initial constraint came up in the form of disclosure of information. Such a constraint is highly debatable in a space where the research is conducted. Most of the caregivers were from educated and middle-class background. They can easily understand the diagnosis which is written in the reports and also with the help of "Google Knowledge"[1] available on the internet with the advancement of technology.

Disclosing a disease to the patient and the society are two issues which should be considered in this scenario. In the case of the patient, it is important according to the doctors and paramedical staff as further treatment cannot continue without explaining the side-effects. Almost all the interviewees in the study know about their condition expect few who were just admitted for their treatment. Soon after the disclosure the

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[1] Phrase mentioned by the researcher.

question,“Why me?” comes up “because of countless metaphoric flourishes that have made cancer synonymous with evil, having cancer has been experienced by many as shameful, therefore something to conceal, and also unjust, a betrayal by one’s body” (Susan Sontag, 1978:110). Sontag in her work explains about the stereotypes of the national character about diseases like cancer, AIDS, etc. It takes time for the patients and also for the caregivers to understand the nature of the illness but meanwhile the use of illness as a metaphor in the everyday setting would be a painful experience. The patient is treated as untouchable, and fear of the disease would exist among the caregivers that they might also get affected. For the patient, the denial and reconfirmation about the illness would exist initially. However, after accepting the fact that they are suffering from cancer, disclosure to the peer group or relatives is another major issue because of the opinions and misconceptions which already prevail in the mindset of people. Audre Lorde (1980) mentions in her book about the avoidance by family, friends and peer group after being labeled as a cancer patient or survivor. Few of these points emerge in this research. Susan Sontag states, “Thus, a surprisingly large number of people with cancer find themselves being shunned by relatives and friends and are the object of practices of decontamination by members of their household, as if cancer, like TB, were infectious” (Susan Sontag, 1978: 2). The patients and their family are stigmatised in the case of chronic disease as the imagination about the illness dominates the necessity for inquiry in the initial stages. Misdiagnosis and delay in diagnosis are primary reasons for patients to move from one hospital to another. These reasons are discussed by Julie Livingston (2012) and the work also indicates about the lack of equipment in the public sector hospitals.

Even though the patients had not mentioned in their words, another issue which appears as a bottom line in all the case studies is that about the authority of decision making in crucial times. It is generally doctor and caregivers who decide about an individual or patient. Tancredi and Barsky (1974: 856) discusses that there are three steps would be occurring during the decision making in health care, "i.e., there is a diffusion of decision making by virtue of technology, a relinquishment of the power of the decision maker from his traditional authority, and the object of the decision is becoming the major factor in decisions regarding the development and the use of technology." With regard to amputation of body parts during critical situations, it is the family or caregiver, who takes the responsibility of decision making. Even with regard to discussion of health status and regular checkups, the decision making lies with the family.

Questioning 'Self' and Trauma of Losing Organs

A significant part of the research deals with patient experience. It is important to understand that irrespective of the effort taken by doctors and caregivers, it is the patient who bears the pain and trauma associated with the disease. This aspect of cancer is discussed in detail by scholars such as David Hufford (1990) and David Perusek (2012) where the illness experience of a patient is drawn from qualitative interviews. David Perusek's (2012) article is a narrative of his experiences about his brother Ted. The work presents detailed narratives based on the experiences of his brother suffering from cancer. Audre Lorde (1980) talk about the "pain of loss" of few organs which define sexuality. In this context, particular questions can arise such as, what defines the sexuality of a person (either male or female)? Is it the organs or personality? Is it that a person’s sexuality is questioned when his/her defining sexual organs are removed? In such a case, who has the authority to decide? Is it the family or the individual?

Contrasting the ‘self’ before and after the treatment is another topic, that is widely discussed. Audre Lorde (1980:55) says, “… In the process of losing a breast I had become a whole person”. One can infer from this statement the reality of life in the process. “…Self-scrutiny and an evaluation of our lives, while painful, can be rewarding and strengthening journeys toward a deeper self” (Audre Lorde, 1980:58).

As mentioned by Mulemi (2008), non-compliance of patients with respect to caregivers or the doctors plays a significant role because the sheer ignorance and also lack of understanding between the triad of “doctor-patient-caregiver” may lead to some drastic decisions such as, not continuing the treatment. According to the dictionary definition, ‘care’ means “a provision of welfare and protection” (Oxford English Dictionary, South Asian Edition, 2008). The definition of ‘care’ should be understood clearly because the expectations from the patient are entirely different from that of a caregiver and doctor. Annemarie Mol (2002) in her book about explains the contrast between logic of care and logic of choice. Parson’s (1951) concept of ‘sick role’ should be noted, in particular. ‘Sick role’ comprises four elements, and it is called functionalism. Parson mentions in a footnote about physician/physiologist L.J.Henderson, “Physician and patient as a social system” [Henderson, 1935]. He also discusses how there has been paradigm shift since twenty years about choice and especially the selection of the patient. In a medical setting where the hierarchy lies with the doctor, there would be a ‘force’ first and ‘choice’ next, and this is of not much use according to Annemarie Mol (2002:50). Albert (1990) talks about culture of caregiving as an idea of dependency and obligation. However, in this research I observed that many informants perceive that caregiving as a responsibility. The parent-child relation by Albert combines dependency and obligation as in his research, but any study shows that a couple sees responsibility and affection for caregiving.

Hospital Ethnography

Hospital ethnography is another significant topic which influences this study, the idea of which is taken from Debbi Long, et.al. (2008). The various hierarchies and roles in the hospital where the field investigation is conducted will be mentioned in detail. The roles and responsibilities define the working principle of a hospital which was portrayed by Julie Livingston (2012) in her hospital ethnography in an African Cancer-Ward. The experience through her book is instrumental for any person working in a hospital setting. Patients also talk about the ambiance of the hospital and also how the hospital staff takes care of them. Livingston also explains about the emotional bonding which happens between the patients and the staff, which would make the patients comfortable and reduce the complexity of the hierarchy. In addition, Livingston (2012) argues that the work pressure faced by the hospital staff is more where the doctor and patient ratio is higher. As it is difficult for the doctor, who is an individual to give time to understand the problem of patients completely. Quality of the food in the hospital is another point which is emphasized by patients as food is considered imperative for recovery. Audre Lorde (1980:11) explains, “It is such an effort to find decent food in this place, not to just give up and eat the old poison.” In order to gather information on such experiences from a stranger (patient), Gitte Wind’s (2008) concept of “negotiated interactive observation” which was proposed by her as a more appropriate way to conduct fieldwork in hospital setting is useful.

Role of Alternative Medicines

Apart from the above-mentioned information on the journey of cancer, the patients and caregivers frequently talk about alternative medicines and traditional medicines. Ethnomedicine is an area of anthropology that enquires into the notions of health and illness across different societies. Gradually the focus flows into traditional medicine and biomedicine also. According to Quinlan (2011), “Medicine- like language, music, and politics- is a subset of culture which is situated locally.” The term ‘ethnomedicine’ is used in different connotations in different cultures. However, the charismatic effect which is expected from an ethnomedicine practitioner is also expected from biomedicine practitioners in a country like India.

The belief system and ‘*hastha vaasi*’ which we call in Telugu plays a fundamental role even in today’s generation. Two things are important in any healing, *Dawa* and *Duwa* while treating anyone. The *Dawa* is the medicine, and the *Duwa* is the healing effect. Absence of any one will not attain popularity and belief in any healing system. Even a specialized biomedicine specialist cannot popularize practice if he does not talk properly. However, the charisma is something which is, above all, the credentials in any form of medicine. It gives authority to the healer/doctor. As said by Amma in Amma’s healing room, the pen and paper gives the authority to speak, and that is very much important for a healer/doctor (Fluckeiger, 2006). Narasimhan (2013) explain about the charismatic effect as *kairaaci* (equivalent to *hastha vaasi* in Telugu) among Tamilians. My study does not exactly explain about the divine hand of the doctor but in one case study the patient explains her feeling that for her doctor is equivalent to god. Narasimhan (2013:168) mentions that "A "doctor" needs to become a "healer"." Adler (1999) in her article on complementary and alternative medicine mentions about the misconception that Complementary and Alternative Medicine (CAM) is being used among the folk cultures rather than the mainstream population. I too encountered this idea while doing this research which is mentioned in further chapters.

Ayurveda, as mentioned by Bode (2012), is generally/mostly used as secondary treatment after biomedicine fails. Trawick (1991) in her narrative study writes about the ayurvedic practitioner called Mahadeva in Kerala. At some point in the article, while he was explaining about the vegetarian and non-vegetarian diet, he says that they are soft and hard respectively but he also claims that people's hearts also would be like their food. While talking about the diseases, he says that people, who tend to leave their '*Jati*' rules, get such diseases. The typical Brahmanical notion is clearly portrayed. Another widely prevalent view about Ayurveda is that it does not comprise treatment or medicine for one particular problem like allopathy; rather it provides body rejuvenating process or therapy. This was confirmed during conversations with doctors in Ayurvedic hospital, Hyderabad.

The article published by Alex Broom and Assa Doron (2011) on the rise of cancer in urban India is very similar to the research findings from the study which is a combination of theoretical and methodological inferences are drawn from the work of the scholars mentioned above to develop the study. The research work of Jessica L. Gregg (2003) among Brazilian women who feel that breast cancer and cervical cancer is only caused if a woman is involved with multiple partners is countered in this research work. The ideal values in the Brazilian community are similar to India, but the practice of having multiple partners for sexual relations did not come up is my study.

Finally I want to say that Groddeck's equation "Cancer = Death" (Susan Sontag, 1978:20) is not accepted by people and that is the reason why they want to fight for themselves and their family. The strong desire to live a happy life with their beloved ones is very evident. The caregivers also feel the same way in a majority of cases. There are some peculiar about the uninterested caregivers cases which I would be explain later in the thesis which convey.

Objectives of the Study

The study is carried out by keeping the following objectives in the backdrop.

The study intends to understand the narratives about impact of treatment on patient' selfhood, as the selfhood is being very individualistic and the treatment has an impact on the change of perception of the patients especially, when the cancer treatment demands amputation of body parts. The perceptions of selfhood become more complex especially when it involves the amputation of private parts of the patient.

In the process of treatment, it is not only the patients who suffer pain and go through the traumatic situation but also the caregivers or family members go through the pain and agony. This study also tries to understand and collect the response about the role of caregivers or family during the treatment process.

As the doctors have put it, each and every individual case is unique in its own form. The doctors need to adopt a method for treating the patients, as every patient’s body respond differently to a different method of treatment. Hence, this study tries to explore and understand the narratives involving the difficulties faced during the treatment process by the patients.

The patients who are battling the chronic disease such as cancer do not depend only on single way of medication, they tend to explore and make use of another medication process such as Naturopathy, Ayurveda, and Homeopathy along with allopathic. So, this study tries to understand the role of alternative medicines from the patients’ perspective.

Significance of the Study

Cancer, as a chronic disease not only has the impact on the body organs where the cells are affected, but it also deals with the psychological aspect of the patient or their caregiver or their family. Generally, the cancer as a disease is given a color of extremely dangerous and death-dealing disease one will get. The moment any person is diagnosed and informed about the cancer, their psychic behaviour gets affected and which will take a plenty of time to accept the fact that they are diagnosed with cancer and make themselves ready for the treatment. Thus, understanding the narratives of illness behaviour among the cancer patients, which are emphasized in this study, play a crucial role in understanding the other stereotypes attached to the disease and its treatment. The narratives not only portray the visible side effects of the treatment but also the psychological side of the story is emphasized.

Context of the Study

The region selected for the fieldwork is Hyderabad, which is one of the metropolitan cities located in Telangana State, India. The fieldwork was carried out in a private hospitals, a unit of Hyderabad Institute of Oncology located in Banjara Hills, Hyderabad. The reason for choosing this field site is that the in-flow of patients is quite high. As the time is one of the limiting factors, high number of in-patients would be of extreme help to carry out the research for a short period. Acquiring permission to conduct the research in such type of setups is difficult without knowing the people inside the hospital. As the research might be suspected or not being a comfort factor for the hospital administration. Hence, the research sought help to acquire permission from the established network.

Tools, Techniques and Method of Data Collection

In the recent years, qualitative research had developed into a broad and sometimes almost confusing field of study. In the words of Uwe Flick, Ernst von Kardorff and Ines Steinke (2004:3), “Qualitative research also claims to study ‘from the inside out’, that is, from the participants point of view”.

Ethnography is one of the major approaches being followed in social science research and mainly in anthropology. Paul Atkinson and Martyn Hammersley (1995) explain that it is not necessary to use ‘ethnography’ in the standard fashion, but its meaning may vary according to the context. There can be considerable overlaps with ‘qualitative inquiry’, ‘fieldwork’, ‘interpretative method’, and ‘case study’ also. The origins of the term ‘ethnography’ lie in the nineteenth century in Western anthropology where it means a descriptive account of a community or culture, usually located outside the West.

H. Russell Bernard (2006) in his book on research methodology in anthrpology gives a clear explanation of ‘direct and indirect observation’ and ‘participant observation’ but since it is a hospital setting and the researcher is not related to medical profession, observation had been done and interviews has been recorded with the consent of the patients.

The concept of interviews covers a lot of ground. For this particular research, I have used semi-structured interview as a technique to collect the data. In the words of H. Russell Bernard (2006:210), “Semi-structured or in-depth interviewing is a scheduled activity. A semi-structured interview is open-ended but follows a general script and covers a list of topics”. Patients were interviewed on the basis of semi-structured interview schedule. The interviews were based on the set of questions which were prepared on the hypothesis is developed after visiting multiple hospitals for the pilot study. The data collected was purely qualitative in the form of informal interviews. The quantitative data such as demographic information will be extracted from the transcription of the interviews. A sample of 50 was taken but of which 40 would be considered as the actual sample for analysis. Most of the interviews were conducted after initial rapport building which made researcher and the informant comfortable.

Case studies have a special role in conveying something about the research clearly and precisely. There are some interesting case studies which are analyzed and presented in the thesis. The cases emphasize the importance of money, familial support, philosophy of life, the trauma of the treatment, etc. which will be substantiated through the study in this dissertation.

Ever since Malinowski (1922) had set 'doing ethnography' as the standard for anthropology and the common understanding of participant observation in ethnography, researchers take part in the day to day activities of the people and observe them. Participation gives the ethnographer, a two-sided approach as an insider – that is participation and also as an outsider – the observer of the host community.

David Hufford (1990) mentions that "ordinary people tend to be underestimated and… their knowledge tends to be discredited by authorities." Basic problems like weight loss and hard substance being felt are reported by many patients in the pre-diagnosis stage. Another issue is that patient experience with the hospital (doctor's and staff) has to be given preference, not just treatment. Since the fieldwork space is in a private corporate hospital, it is important to talk about patient's rapport with the hospital. The staff necessarily need not mean the nurse or doctor but people like medical counselors who are also investigated in this fieldwork. A number of patients and caregivers feel the necessity of counselors and psychologists during treatment time. Such an aspect is rarely found in many articles, the reason being the increased importance and awareness about psychology in the recent past.

This study supports Albert (1990) and Annemarie Mol's (2002) findings by emphasizing not just care but 'good care'. Betty Risteen Hasselkus (1992) in her article mentions about caregiver as "interpreter". In order to make a patient comfortable, it is important to use caregiver as interpreter because he/she acts as a catalyst between the researcher and the respondent. The communication mode of caregiver as facilitator, intermediary and direct source would make him/her very important part of the research because some personal questions cannot be directly asked to the patient but explaining to the caregiver can be comparatively easy. So, using some probes according to the situation would be giving a hint to the interpreter and he/she can make them recollect the situations which happened in the past.

In order to do an 'interactive observation' and 'hospital ethnography', it is essential to maintain a good relationship with the staff of a particular hospital rather than just getting permission. To be more specific, conducting fieldwork in a private hospital is not that easy as most of the patients and the caregivers would be educated and conscious about the questions asked. So, it is important to give justifications to the questions which they have in mind. Why am I there? Since how long I have been there? Did I have permission to do research? If so from whom do I have permission? What is the sole purpose of recording? What is the motive of my research? Why I am still not married? What am I studying? What caste do I belong to? Questions about my family background and many more have to be answered, both by patients and also to the people associated with patients and hospital staff.

The excitement about recording their interviews is like a two-edged knife where the researcher experiences supportive people and some who were not supportive. Some expressed their discontent about the recording as they are not comfortable. Some others asked to replay the recording to hear their voice. These experiences will be shared in depth further in chapters.

The Process of Fieldwork

The inspiration for this research started since the school days because my sister is a qualified Radiation Safety Officer and works in a cancer hospital. She would tell many things related to cancer whenever she gets a special case. However, there is always some gap present between doctor-patient, patient caregivers, and many more aspects.

Initially, the aim was to get permission from three hospitals offering cancer treatment to different medical systems within in Hyderabad. With the motive of studying Socio-Cultural response to Cancer treatment in Allopathy and alternative therapies.

Last December Nature Cure (Which is located near S. R. Nagar in Hyderabad) hospital was approached in order to seek permission for carrying out the fieldwork as a part of the initial plan of this study. But the permission was denied on the premise that they do not take or treat any cancer patients and especially any patients with malignant metastasis. In spite of explaining the nature and objectives of the study the hospital administration denied the permission hence, the study was not possible in that hospital.

After being denied the permission in the above hospital, the research was narrowed down to conduct only in two places instead of three as planned in the initial stage of this research. Ayurvedic College, which is attached to the hospital in Erragadda, Hyderabad, was approached in order to seek permission for the study. The Assistant Research Officer in the hospital showed patience to understand the research objectives and the nature of the study and suggested to approach Superintendent of the hospital. The superintendent of the hospital was approached on December 2013, the Government Research Officer and Superintendent of the hospital was very kind and suggested lot of inputs for the research and asked to get a Memorandum of Understanding from IIT-H for further proceedings. And he also asked to submit a report as soon as possible about the research to consider giving permission for the study. Further meetings with the superintendent had revealed that, he is having an idea of collaborating with a private hospital and provides Ayurvedic treatment to patients and also briefed about the importance of Ayurveda, in the long run. On the fourth meeting with the superintendent, he suggested to post an advertisement in newspapers saying that ‘I am a research scholar from IIT, who wish to collect data from patients for two days in a week under the guidance of couple of doctors in their hospital’. Along with this advertisement, he also asked to add an advertisement stating that doctor consultation for Ayurvedic medication for cancer can be done during this period. The complexities and obfuscatory intentions of the hospital administration made to exclude the Ayurvedic College also from the focus of the study.

A third attempt was made to get permission from the Unani Research Centre located in Erragadda, Hyderabad in December, 2013. The Head of the Institute suggested going to Unani hospital located in Charminar, Hyderabad. The referred Unani Hospital was also approached and had a meeting with superintendent of the Unani hospital, though in the initial stages the response was positive, the superintendent of Unani Hospital, Charminar asked to meet the principal of Unani Tibbi College. The Principal after enquiring about the research objectives and nature of the study politely discouraged saying it is quite hard to do research on cancer-related issues in the Unani hospital, as the patient visit is very rare, and the treatment is also not possible for chronic diseases such as cancer. So the initial plan to compare Ayurvedic, Unani and allopathic medications regarding cancer treatment could not materialize.

Fortunately, the permission was acquired from a private hospital, Jubilee Hills, Hyderabad. The research had to be restricted to narratives related to patients who approach Allopathic type of medication. The permission was given only after a long process of meetings and the chief medical officer on December 2013 has agreed to grant permission to carry out the study. The study was conducted after consulting the Head of the medical counselling and also took help to finish this research under her purview.

Men	22
Women	28

Table 1.1: The sample details for the study

The sample size considered for this research is a homogenous group with regard to class, religion, disease pattern and financial situation. Below are the tables which indicate the diversity.

Type of payment	Number of patients
Cash	10
Private insurance	9
Central or state government employees (either patient or spouse or children)	27
Cash and credit	4

Table 1.2: Represents the type of payment pattern followed by the patients.

Mostly the patients who approach Private hospital are the ones who have insurance. As the above table depicts, central and state government employees are mostly observed because expenses are completely covered for central government employees and partially covered for the state government employees. The high expenditure makes the treatment affordable only for the rich and for the families of the government employees. The other private insurances cover the medical expenses only for some treatments.

Type of cancer	Number of male patients
Rectum	5
Prostate	3
Oesophagus/larynx	2
Sarcoma	4
Stomach	2
Anus	1
Pancreas	2
Colon	2
NHL	1

Table 1.3: Shows the types of cancer encountered among the male patients in the sample.

Type of cancer	Number of female patients
Breast	14
Ovary	2
Ovary and liver	2
Sarcoma	1
Lung	2
Thyroid	1
NHL	4

Table 1.4: Shows the types of cancer encountered among the female patients in the sample.

As random sampling is done for the study, the sample consists of homogenous sample of all cancers among men and women. The above two tables depict the varied variety of cancers by which patients are being affected. If we specifically observe the sample, rectum cancer is most prevalent according to the sample and breast cancer remains the frequently occurred cancer among women. The results cannot be compared with that of the national samples because certain factors affect the results. Only one hospital has been taken into consideration and random sampling may be the major reasons.

Religion	Number of patients
Hindu	47
Muslim	1
Christian	2

Table 1.5: Shows the religious composition of the patients.

The above sample shows the religious composition in the selected sample. Religion has been looked from a broader perspective in this study and aspects like caste and class had been remained as a limitation in the present study because it is a private hospital where any of the public projects like aarogja sri, etc., are not being implemented. So, the emphasis on caste and class are not considered by the hospital authorities to be diplomatic.

Gunjan is one of the medical counsellors in this hospital, who had served as a key informant to re-confirm the data. During the initial days of my fieldwork, Gunjan allowed me to accompany her in daily rounds in the wards and this made the patients get acquainted with me to an extent. The sense of security has been created among them and after 10 days, I had actually started my work.

Gunjan is a cancer survivor and that passion to serve patients with counselling is extremely present in her that is also one of the reasons for me to quickly get acquainted with her. She used to share her experiences with me and explained me the ways to build rapport with the patients. She also used to warn me while going near some patients, who has got infections and precautions used to be given by her. With regard to some patients, she used to instruct them about my research and request them to give information. Patient identification was one more challenge for me during the study because not everyone would be an active informant and in many cases they would be passive respondent, just giving their basic details.

Hospital Setting

The research place as mentioned above is located in Jubliee Hills, Hyderabad. The entrance of the hospital will lead you to reception desk and towards left of the reception desk, patient waiting space and way to other departments. In the cellar of the hospital, radiation department is situated. In the ground floor, PET-CT, Medical counselling room, Canteen and doctor cabins are located. The first floor has triple sharing a/c rooms and day care centre rooms on one side; and general a/c rooms (male and female wards) and MIC unit on another side. The second floor consists of double sharing a/c rooms. The third floor consists of operation theatres and the fourth floor has single sharing a/c rooms.

Type of room	No. Of rooms	No. Of beds
General ward (Male and female)	2	28
Day care	1	14
MICU	1	9
Triple sharing	6	18
Double sharing		
Single sharing		
Paediatric		
General ward (small)		
Operation Theatre		

Table 1.6: The count of number of beds in the hospital.

The ambience of the hospital is always maintained by using light colours everywhere and plants are kept in corners in order to make the place have a pleasant look. The hierarchy among the staff can be noticed by their dress code. The staff at the billing counters, reception, security people and cleaners have their dress code to distinguish with the technical staff and doctors.

Limitations of the Study

As the research is conducted in the partial fulfilment of the M.Phil. Degree, a short period of fieldwork is only possible. The fieldwork was carried out between May to July, 2014. Hence, limited time period of fieldwork allowed to restrict the research to practically possible objectives as mentioned above. The fieldwork in the urban setup, especially when the research is supposed to be carried out in the private hospitals such as the one selected for this particular research has proved difficulty in acquiring permission. The process of acquiring permission was difficult, and the patients' inflow is also very low in the above-mentioned cancer treatment centres. Limited time constraint is also another reason which made the research preferred to be conducted in the private hospital as the in-flow of the patients is high than the above two hospitals which were not chosen for this study. After finally being deciding upon the hospital, the paediatric cases and children are excluded from the study because the emotional levels attached to such patients require more time to conduct the research and the child patients are not the focus of this study. Hence, this study has excluded paediatric and child patients. This study also has the limitations in understanding the narratives taking into consideration of social factor such as caste because the patients or the informants were not comfort to reveal their caste which is an important factor to understand the narratives. The chosen sample of patients is of a homogenous group because the setting consists no distinguishing by class. Another limitation for the study is that doctor's perspective has not been considered in a formal interview but frequent inputs had been taken into consideration from medical counsellors, doctors and paramedical staff. The key informant of the study is Gunjan, who is a medical counsellor in the hospital. The researcher had accompanied Gunjan in everyday rounds in the wards.

Chapterization

The present study has been divided into six chapters where:

The Introduction discusses the statistics of cancer across the world in general had been mentioned to support the importance of the study. It also explains the objectives and significance of the study. The field area had been explained and the tools and techniques followed during the fieldwork are elaborated.

Chapter I discusses the impact of cancer treatment on patients selfhood and the analysis about their questioning ‘self’ had been portrayed in a sensitive manner. It is important to understand the patients’ perspective after the amputation of private body parts which define their sexuality in the case of both men and women.

Chapter II discusses the importance of family role in the opinion of patients and even the caregivers. The importance of helping a hand is extremely needed and persuaded by the patient during such a traumatic treatment of cancer. The patient during such a period, not only expects the physical help but also the psychological support.

Chapter III discusses the treatment process, and the difficulties being faced during their treatment. The patients move from one hospital to another hospital in search of better treatment. The major problems being the delay in diagnosis, misdiagnosis, social and financial constraints make the disease grow worse.

Chapter IV would be about the contradicting opinions about alternative medicines and their role in both positive and negative ways in their life.

The conclusion finally discusses the summary of the thesis and through insights about the future research in hospital settings for both the policy makers and the practitioners. The limitations of the present study and thoughts about future research by the researcher will also be explained.

Finally, to make a note from the researcher side, to confide the identity of the informants, pseudonyms have been given and their occupations were not clearly mentioned. This helps to keep the informants anonymous.

CHAPTER II

IMPACT OF CANCER TREATMENT ON PATIENT SELFHOOD

Selfhood is something which has been perceived by one’s ‘self’, which has been again considered as abnormal when compared to the normality. Patients’ understanding of selfhood plays a key role in cancer treatment because the treatment often involves amputation of private parts such as breasts (in the case of breast cancer) and testicles (in the case of prostate cancer). The following narratives explain the notions of selfhood of the patients and its impact on cancer treatment.

The Sense of Emptiness

> “You feel a gap or missing after surgically your body parts have been amputated. You feel as if you have lost something. You can overcome after some days, but it will take time to cope with the fact. We can get implantation done, but you have to be mentally prepared for it and be positive to accept the change”.

Aamani is thirty-seven year old woman, married and mother to a daughter of three years. She was detected with breast cancer and was advised to go for mastectomy for both breasts at the same time. Her family thought of concealing her diagnosis, but she was firm to accept the fact about her diagnosis. Initial diagnosis was done by a needle biopsy, and then they rushed her to Hyderabad to get better treatment. Aamani’s family thought that this hospital can be a better place as recommended by the office staff of her husband. All the respective diagnostic tests were conducted and in the hospital, it was decided to give eight cycles of chemotherapy to her for reducing the size of the tumour. Then, mastectomy was done for both the breasts. She was undergoing the seventh chemotherapy after the surgery at the time of the interview. When she was asked whether she had any pain or complications, she responded by saying the above-quoted words about the feeling of emptiness, '*Kaali pan*' (Hindi: *kaali*-empty, *pan*-feel) to explain her loss of body part after surgery. Breasts are considered to be defining the identity of a woman. When that is lost, the informant felt that her femininity will be questioned. Since this informant is in her thirties, she is worried about the attention from her husband. Her perception of her husband's perspective may or may not be accurate. But since the interview was also conducted with her husband Vignesh, we can understand that he is of both psychological and physical support to her from his response to Aamani' medical condition. According to Aamani, Vignesh played a significant role to counsel her during her treatment for coping with the pain. She continues to say that, "If you had come 4 months before, I would not have spoken with you." as it was very depressing for her to accept that she had cancer. She conveyed during the interview that, it took some time for her to cope with the situation and the fact that she does not have breasts anymore. But the support from her husband and family was extremely helpful. While talking about her husband, she says that he never gave a notion that he deserted her. Surgery was followed by chemotherapy which was more painful according to the informant and a gap of one month from chemotherapy had given her strength and allowed to cope with the medical situation she has been facing.

In the same manner, there are many women who say that it is quite difficult to deal with the loss of breasts says Gunjan (medical counsellor). She had narrated her experiences with patients who hold her how the in-laws had left them at their natal home as they can no longer be considered as real women. So the question arises as to how the society, in general, is defining women. But contrary to the examples given by the counsellor, the interviews with patients and their caregivers revealed that the patients never had a problem with their in-laws or husbands. On the contrary, it is the patient who feels the loss as these are "private" parts of the body and also considered to be the defining feature of a woman. Accepting the fact of losing something has to be very fast as the decision has to be taken quickly to ensure quality treatment in a chronic disease like cancer. There would be situations where the doctors would plan for lumpectomy but while the surgery is ongoing, they would decide to do a mastectomy. According to the doctor's, they do not wish to hide the truth but there would be situations where the necessity of avoiding future complications is essential.

Acceptance of Conscience

> "There was a doctor named Shastri in Guntur. He told me that by doing an operation, he will remove my testicles. I was unable to accept the fact that I will be losing my testicles as my conscience did not agree with what the doctor has suggested".

Just like how women felt that losing breasts due to cancer is not normal, even this informant man, felt that way. The sense of masculinity lies in having testicles and it does not matter whether that person can produce sperms or not but the pride of having them is expressed by the informant. Male patients who have a problem with their reproductive organs like testicles, often hesitated to complete some sentences which has to end with the word testicles and which related to the narrations of the prostate cancer. For instance, if they have to say that testicles were removed after surgery, they will say "They had done surgery and then my…. were removed." The pause at that point in time between the conversations indicates testicles, but they do not use it several times. They feel shy to use the name of reproductive organs several times. The same case was observed while talking to women as well. Even though, they do not complete sentences, but the message is conveyed appropriately to the other person. Ganesh is a seventy-six years old man, who was suffering from prostate cancer and was admitted for treatment. While he was narrating his journey to the hospital since the time of diagnosis, he explained that his prostate was slightly expanded, due to which he had a constipation problem. He went for diagnostic tests in Guntur assuming that it was some urinary infection as he had a burning sensation on the verge of anus. The doctor in Guntur communicated to Ganesh that his testicles had to be removed by carrying out a surgery, which he could not accept. He was undergoing a lot of pain and trouble but finally decided to go for surgery. He told the doctor to make necessary arrangements but meanwhile his son had consulted doctors in U.S.A, Canada, Rai Vellore, Professors from S.R.M College of Madras and also an expert on urology in Madhura Meenakshi College. Doctors had informed that going for surgery at this age is a waste, so it is better to continue with medication. Doctors told that an injection once in three months or six months and appropriate medication would be enough. So, the doctor in Guntur had given Ganesh an injection which is a three-month course at a time. After taking that injection, it seems that Ganesh used to feel irritated and restless. Like, if you are talking with him, he felt “why should I talk to you?” He felt that it was better not to talk with anyone. Even if relatives come home, he never felt like speaking. He felt, Sleep deprivation, some fear while having bath, eating food and even had a fear to go out. So, the effect of injection lasted for three months, and he suffered the whole time. After suffering a lot, he decided not to take the injection again and had try for alternative therapies. But that made the disease adverse. He went to Nagpur for naturopathy treatment[2] after that his prostate gland counts varied between 0-14 and had become stagnant at 14. But the burning sensation and the constipation problem remained the same. When Ganesh's son consulted doctors in Hyderabad, they suggested not to go for treatments such as Naturopathy, at this age and advised to get him admitted to the hospital for treatment. The alternative therapies opted by Ganesh will be discussed in brief in the fourth chapter of this thesis. During the study, Ganesh was undergoing bones strengthening treatment, which is an intravenous liquid given to strengthen bones. While continuing his narrations, Ganesh also said that he was also taking Homeopathy medicine to get rid of constipation problem.

Envisaging Future Social Obligations in Mind

> "Everyone will see there (breast) right!"

Mani is a thirty-eight year old woman and is suffering from breast cancer. Mani is a housewife, and her husband was a constable in a police station. Mani identified swelling in her breast and went to consult the doctor. The doctor identified that it is cancer and referred for three chemotherapy sessions with a gap of three weeks for each chemotherapy session. Doctors had suggested that the patient has to undergo surgery after the chemotherapy session. During the study, Mani was undergoing fourth chemotherapy session after her surgery. While reporting about her symptoms, she told that she will have fever and body pains. Her husband was present during the interview

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[2] The details of the treatment would be further explained in chapter IV.

with her. He was supporting her as a caregiver and asked a lot of questions regarding breast reconstruction and side effects of undergoing breast reconstruction. Mani says that it is common that while talking to a woman, anyone (either male or female) would look at breasts and sense the abnormality, if any. The informant accepted the fact that any abnormality would result in gaining attention, and this made her enquire about breast reconstruction. She further adds that unless and until the reconstruction is not like removing a body part or some artificial insertion, it is fine for her to undergo such reconstruction. While continuing with the discussion, they (Mani and her husband) say that as they have two girl children, it is important to avoid unnecessary questions in the future during their marriage. During the study, conversations with patients and their families revealed that the stigma associated with the family of the cancer patient or cancer survivor has led to avoiding of marriage alliances from such families. It also became clear how cancer is perceived by common public as a genetically transmitted disease. Being parents of a girl child, Mani and her husband may have to answer questions about the disease and also about the absence of an important and striking bodily part like the breast when the situation comes to arranging a marriage alliance for their girl child. This is one social factor that women patients are worried about.

A woman’s femininity is weighed by the externally visible body parts like breasts and whether she can give birth to a child or not. But until anyone knows a woman personally, he/she cannot comment on a woman’s reproductive status. The only parts which can be observed are breasts. Any abnormality can be observed with regard to breasts which would be subjected to a lot of questions and suspicions. Mani tried to explain the social stigma attached to having an abnormal body part and its social consequences. She also opines that the best possible solution to avoid such questions from strangers and also avoid any future consequences in arranging the marriage for their progeny is to go for breast reconstruction.

Health Ailments Related to Private Parts and the Sense of Shame

"I feel uncomfortable to reveal that I have piles complaint."

Karthikeya is a sixty-seven year old man, a graduate from IIT Madras and a retired bank employee. The problem with regard to private parts decreases the chances of being able to share the details even with the family members. The informant said that the symptoms were similar to piles, so he followed some advertisements on television. The advertisements on television would convince the viewer about the symptoms and offer saying that the possible solution would be the product offered. The adverse effect of not being treated by a practitioner with expertise was told by the informant. During the diagnosis, the junior doctor had examined ("poked" as told by the informant) Karthikeya at the same spot where he had a problem. One point to be noted is that all the patients who had acquaintance with the medical terminology despite being literate or illiterate are comfortable in explaining their problem.

The general notion that male patients may not be comfortable with the interviewer if it is a female was contradicted during the study because the male informants are quite comfortable in sharing their experiences. That is the time when the patients emphasized that professionals like counsellors can be good icebreakers in conveying the deadly news of cancer. Also, after the patient comes to know about his/her problem, timely counselling sessions were requested in order to motivate and convince them about the treatment. Convincing during treatment is very important because of the heavy dosage of the medicines; patients would not be ready to continue the treatment if they are not aware of the adverse effects of the medicines. Such issues should be dealt with a lot of sensitivity.

The increased awareness of patients about various science related disciplines would help in ample utilization of their subject related services such as, counselling by psychologists, etc,. Informants repeatedly emphasized the need for someone to listen to them. They just need someone to hear rather than being judgmental. This does not mean that the person who is listening is going to reduce their pain or suggest how to get better treatment but just the fact that they can share their experiences seems to relieve them from the pain they are going through. Caregivers or the close associate within or outside the family can really make a difference during the period of treatment. The neurological functioning would be obstructed by chemotherapy and patients suffer from severe irritation when they are undergoing the process of radiation. Many informants have reported that they used to feel irritated by each and every small sound when they are under the process of treatment. Many informants reported how they became allergic to food smell and used to vomit countless times. The intake of food also affects the body as immunity can only be developed by proper food according to the doctors.

Relief after Follow-ups

> “If we come for a checkup once after that we can feel relaxed for the next six months. We may or may not have the problems with our health if we have any issues we can

> go through the treatment, if not we be rest assured and feel
> relaxed”.

Lalitha is a forty-six year old woman, who is an employee at coca-cola and a cancer survivor. She was detected with cancer in her right breast and has finished her treatment. Remembering times of her diagnosis and treatment, she says that she sensed something rough and abnormal in 2009 and consulted doctor. Soon after detecting, surgery had been performed, followed by six chemotherapy sessions. Since it was not third or fourth stage of cancer, she was lucky enough to get cured. Lalitha is now on follow ups and says that she would be slightly tensed during tests, and that would last till the reports arrive. Then she feels that she can relax and live her life happily for another six months, until her next check-up. She also feels that follow-ups are important to detect if there is any recurrence at an early stage, but most of the people have a misconception that the corporate hospitals suggest them to come for check-ups just for the sake of charging money, even after the treatment is over. During the time of this study, she was undergoing some intensive tests as she was suffering from back pain since few days. Lalitha says that after getting cured with cancer treatment, any slight problem is taken seriously. People who have access to good facilities would normally say that it is good to undergo intensive medical tests and those who cannot afford say that all this is done just for the sake of acquiring money by the corporate hospitals. Some hospitals are commercial and suggest the patients to undergo irrelevant tests which make people think that follow-ups are not that important. In a disease such as cancer, even doctors could not help when the cells multiply at a faster pace. Therefore regular follow-ups are advisable and should be carried out without any negligence. Lalitha said it is a chance to live for another six months in peace. The most difficult part concerning cancer is that the treatment once given cannot be assured that the disease will not recur again. Any time in life, the disease can recur and once it is recurred it will affect some other body part and the patient will not have any other choice than to go for treatment again. Lalitha expressed her joy and sense of pleasure only because she has confidence in the doctors, and she is coming for the timely check-ups and following the doctor's advice without fail.

Lalitha believes that once a person is diagnosed with cancer, there is nothing called cure; it is just a process of extending the period of one's life. Even the paramedical staff and counsellor Gunjan said me the same.

The Financial Burden

> "I have undergone eight chemotherapy sessions which cost eight lakhs. Each chemotherapy had cost one lakh…. In order to mobilize the money, we had to sell two acres of land".

Mahesh is a forty-nine years old man and was suffering from Non-Hodgkin's Lymphoma and cancer in testicles. Initially when Mahesh was admitted to the hospital the doctor has told that removing one testicle will be enough but later as the second testicle was also affected with cancer the doctors decided to remove the second one as well. Mahesh and his family showed discontent with his initial diagnosis in the other hospital where the doctors suggested removing both the testicles but the doctors over here had made decision to remove just one testicle. Mahesh and his family reports that now he had to take surgery twice, and it was quite traumatic. It is not just that it was difficult for Mahesh to cope physically but also the expense occurred for the second-time surgery was also something which they were not ready for. The economic status of the family has made them sell their property and for a person who is a farmer, sustaining on the land he cultivates, it is painful to sell the land for any purpose. He also continues to narrate how one is helpless in these situations. He emphasised the high expenditure and also said in a sarcastic tone that this being a private hospital, such expenditure was expected. The patients will be depressed about their weight, diet and change in appearance. They want to lead a normal life as soon as possible. Doctors would prefer them to eat food rather than to take medicines, but the patients feel that their taste buds are dead. After such a treatment where the neurological system gets affected, it is quite difficult to follow normal intake of food. Some patients complained that they have nausea because of food. In such a situation, the contrasting opinions of the doctors and the patients regarding the food and medicines are never negotiable. Patients and caregivers say that even food has to be consumed as medicine for better cure.

Mahesh, like Karthikeya, was also hesitant to utter the word ‘testicles’. The common point to be noticed in both the cases is that whether or not the larger society questions them, the person himself feels bad about losing vital parts and the doubts revolving around his selfhood.

Being Distanced from the Family Members

> “I want my mom back as same as the past; I do not like the way you are now.”

Sandhya is a forty-four year old woman who is also a bank employee and is admitted to hospital for cancer being detected in the left breast. She had gone for annual health check-up and was informed that she was detected with cancer. Sandhya has undergone surgery and consecutively was suggested to go for chemotherapy, radiation, and hormone therapy. During the period of this study, she is undergoing ninth chemotherapy. She tells that because of this cancer treatment there will be total weakness, and a person tends to get irritated for every tiny sound. While continuing her narrations, Sandhya told that her parents would be there to support and even her son who is very young is also struggling because of her situation. Her eyes welled up when I enquired about her health and familial support she received during the process of her treatment. It is difficult for her to explain to her son about her disease and at the same time to get accepted by him as he is very young to understand the pain she is going through. The physical changes and also the mental status of the patient make the family members see a gap between the patient and the family, especially when the family members such as sons/daughters who are young cannot understand and show discontent because their mother is not the same as she used to be.

The misconceptions about the disease that it is infectious or gets spread would make the patient think a lot and keep a distance with the family and of course even by the family, when they have children, the sense of insecurity that cancer is a contagious disease leaves a physical distance. To be in specific, the disease would grow internally in many cases but when the treatment is going on, the side effects of chemotherapy and radiation have to be dealt with. In such situation, keeping physical distance from others is advised but in that same situation, the patients expect a soothing touch from their family members. Sandhya also expresses that her son hurts her with his words saying that, she is not the same person (mother), whom he wants to be with (change was observed by her son after amputation).

Contrasting Notion of Selfhood Regarding Transfusion of Blood

> "I do not know whose blood they had transfused into me.
> Now I feel that I have others' blood in my body."

Mary is a thirty-eight year old woman, who is working as a government employee. Mary got married at an early age and had a girl child. Her husband believes in Hindu religion whereas Mary is a converted Christian and gets involved in missionary activities. According to Mary, they give mutual respect to each other's beliefs. Mutual understanding about their religious beliefs and not enforcing each other with their beliefs has been a major reason for lead their happy lives.

Mary has been detected with ovarian cancer in 2014 and had undergone a surgery. While she was recollecting her treatment experiences, she told that she had a lot of complications before and after surgery. Her haemoglobin counts were around 6.5 and then the doctors had suggested injecting four packs of blood by which haemoglobin reached 15. Mary was initially reluctant to get the blood transfusion but later agreed to it according to the suggestion of the doctor. The inherent feeling that someone else's blood is flowing in her body is unacceptable situation for her. The perception of 'my blood' and 'someone else blood' is strong in the informant' mind. Mary also says in between that no one is sure whose blood is being injected and what kind of habits the donor has. Mary is an educated and working woman who has the ability to distinguish between right and wrong but she gets worried that her ‘self’ is occupied by someone else’, a fact difficult for her to digest.

Conclusion

The above cases and narratives given by the patients, explains the notion of ‘self’ by both genders. The physical difference in appearance is questioned by others and also by the patients themselves. The emotional factors which are very important for the patients seems to be not a bothering factor for the doctors, as the doctors are more concerned about preventing the cancer doing damage to the patients’ health. The doctors will go to any extent to do their jobs like performing the amputation (if in need be) to ensure the cancer does not spread. These narratives also suggest that the stigma attached to determining and defining characters of a man and woman were questioned when the amputation was carried out. The patients not only worried about their treatment but also about their children’s marriage in the future.

Through narratives, the patients get a chance to explain the struggle which is going on in their mind regarding several issues. Sometimes, it need not necessarily be the patients but also the caregivers, who equally struggle because of the treatment and as they are also in the stage to learn how to be supportive for the patient to cope with the medication situation which they are facing.

Throughout the study, the patients consider being hospitalized for a disease like cancer is hard to digest, as they never had a medical history of getting detected with a mild disease (which is not considered as chronic). Often patients say that, they are more worried about the attention they get either from the medical staff or the caregivers, because the medical staff considers them as just another patient, and caregivers are also coping with the situation. Moreover, the caregivers have to run around to the hospital to make sure the patient gets enough attention and treatment. Often caregivers take turns in order to attend to a patient and to give their best attention. In case, if any patient feels that the adequate attention has not been given to them, they generally tend to associate this less attention from the caregivers as the result of amputation carried out as a process of treatment and they go to the extent of questioning their selfhood. The patients feel insecure about the loss of body parts. Loss of organs or body parts is not just the reason for a feeling of loss in self but as can be seen in the case of Mary, something like a blood transfusion can also go to the extent of making the person question what is her 'self' and what is not. The impact of selfhood on cancer treatment or *vice versa,* and the result of cancer treatment on questioning the selfhood is an important factor to understand.

CHAPTER III

ROLE OF FAMILY IN THE OPINION OF PATIENTS AND EVEN THE CAREGIVERS

Family broadly includes many people. However, in the context of caregiving, the close relations of parents, spouse and children play a key role. The crucial decision-making lies with these close relatives in the course of medical treatment. The treatment makes the patient physically and mentally weak. Personal assistance is needed to motivate the patient and monitor the symptoms regularly. The role of family and caregiving becomes instrumental in the course of medical treatment. There are possibilities of differences between the expectations of the patients and caregivers. The complexities that arise because of these differences, the role of caregivers and the enriched narratives are presented in the chapter.

From Patient's Perspective

> "For me, my wife and son are the only supporters. My son could not even go to school properly this whole one year. Since this one year, they are my only support."

Chakri is a forty-six year old male working in the real-estate business. Chakri witnessed blood during defecation and approached a doctor. The doctor suggested that perhaps it is piles[3]. After taking medication, the flow of blood did not reduce but rather increased. When Chakri reported the intensity of the problem, the doctor advised him to go to

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[3] Piles: Hemorrhoids are vascular structures in the anal canal. In their normal state, they are cushions that help with stool control. They become pathological or piles, when swollen or inflamed.

Tirupati.[4] A doctor in Tirupati advised Chakri to undergo sigmoidoscopy[5], in which Chakri was diagnosed with cancer. The sample of the rectum was sent for biopsy after the opinion of the doctor to proceed further with the surgery. Chakri's family decided to admit him in Vellore for further treatment. However, the delay in the medical reports resulted in the decision to join in this private hospital in Hyderabad (after watching some advertisement on television).

After getting admitted in this hospital, the initial treatment plan was to give radiation and chemotherapy simultaneously. Then, doctors suggested Chakri to rest for one month and prepare for surgery after critical examinations. After surgery, chemotherapy sessions started again, and Chakri underwent six chemotherapy sessions. When Chakri consulted about the status of treatment, doctors advised him to go for further medical examinations. The reports stated that his disease did not respond to the six chemotherapy sessions done after surgery, following which doctors changed the course of the treatment (combination of different medical treatments). With the revised combination, Chakri underwent four chemotherapy sessions. At the time of interview, Chakri was waiting for the tests advised by doctors. Chakri faced different side effects with each and every session of the treatment. After the change in chemotherapy session, he suffered from mouth ulcers and loss of taste. But according to him, the revised chemotherapy reduced the side-effects (like constipation issues) and resulted in a better appetite.

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[4] Tirupati: A town in Andhra Pradesh, India.

[5] Sigmoidoscopy: it is a procedure used to see inside the sigmoid colon and rectum.

While talking about the role of his family in the treatment, Chakri seems to be euphoric and proud. His wife is a school teacher, and they have two children. Since Chakri has to consult doctors and get admitted, they left their daughter in their hometown and their son continued to be with him. In spite of being only a matriculate, Chakri's son took interest in learning about the medical proceedings and discussing his condition with the doctors. Chakri's son actively participated in the decision making during the treatment plan. Chakri regrets the challenges faced by his son in the course of the treatment. His son scored lower marks in school examination. However, Chakri consoles himself by feeling proud of the crucial role played by his son throughout his treatment. Chakri's wife is a working woman who balances the household responsibilities and professional commitments effectively. He proudly acknowledges the caregiving role of his wife and son during the painful phases of the treatment. They provided unconditional care without losing patience in spite of harsh remarks made by Chakri out of pain and trauma.

Chakri indicates the importance of the role of understanding family members in dealing with the challenges of an intense cancer treatment. The kindness and strength of the caregivers are crucial for continued motivation to fight the pain. Chakri believes that his son's support for him at such a young age will help him in dealing with challenges in the future.

Loneliness and Lack of Assistance

> "…no one was there with me and that loneliness gave me a thought that you should not send all your children out. At least one should be with you for assistance. That depression made me think like that."

Khan is a sixty-seven year old retired bank employee, who is suffering from prostate cancer. He was diagnosed in October, 2013. The initial symptoms included frequent urination which increased gradually. Over the period of time, the informant continued to suffer from sensation of urination, but the urine droplets reduced. The disturbance in sleep cycle due to the sensation of frequent urination troubled him. As the symptom continued, Khan visited a nearby corporate hospital out of concern. The doctors suggested diagnostic tests and biopsy. Khan was detected with a problem in the prostate gland.

During the course of the treatment, Khan tried homeopathy and also browsed on the internet regarding some remedies in Ayurveda. But finally, nothing turned out to give a positive result. Khan approached a urologist in another nursing home. Doctor A in that hospital observed the medical reports and informed him about expansion in the prostate gland. The increase in sugar level followed this. One doctor advised him to go for surgery only after reducing sugar levels. Then, Khan consulted another doctor near his home and undertook treatment to reduce sugar levels within ten days. He then approached the doctor he had consulted earlier to continue with the surgery. The doctor advised him to undertake a biopsy, which confirmed the cells to be cancerous. Khan was shattered as all his children are settled abroad, he stayed with his wife. Khan's wife suffered from arthritis which restricted her movement. Khan realized the need for a constant caregiver.

The lack of family support made him struggle psychologically during the course of the treatment.

Khan took help of his close friend and colleague during the surgery but for post-surgery treatment he called his distant relative to help him in traveling to the hospital. After surgery, he was advised to take twenty-six days of radiation and five doses of calcium treatment because of weakness in bones. Later it was increased to twelve doses as weakness in hip bones started. The lack of family support increased Khan's worries. Khan said, "During the treatment, the realization occurred that sending all the children abroad can be problematic in the painful phases". He regrets the decision of sending his children to foreign countries. Khan was financially secure yet missed the familial support in such a critical time. Khan acknowledges the support from the medical counsellor, Gunjan in this hospital. He says, "A patient becomes jubilant when medical counsellor reports the person to be healthy."

Similar to the previous case study, Khan also concurs on the need for caregiving and the role of family for effectiveness of treatment. He considers that the touch of the family members or beloved ones, and the acknowledgment of improved health make the patient confident.

Even though an individual spends lakhs of rupees on the medical treatment, a soothing word, and a caring hand is what patient craves for in this situation. Along with, "*Dawa*[6] and *Dua*[7]", medicine and counselling are equally important. An individual need

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[6] Dawa: Medicine given by the preacher in Islam.

[7] Dua: An act of supplication (a form of prayer) in Islam.

not be a psychological counsellor but an assurance that ‘nothing would happen’ is imperative, even if, that patient is in a critical state. This hospital where the research is conducted takes regular sessions on the role of caregivers by emphasizing on the responsibilities of the caregiver (like, diet plan). During the researcher’s stay in the hospital, this session had been attended and the effective participation by the caregivers is observed.

Day to Day Support from Family Members

> “If I start for my duty at 5 AM also she will cook and make
> food ready for me.”

Bhadra is a fifty-seven year old government employee suffering from stomach cancer. Bhadra found stool to be black in color for about ten days which proved to be the initial symptom. He went for further diagnostic tests. The ultrasound reported that everything is normal, but endoscopy resulted in identifying stomach cancer. Then, further biopsy confirmed stomach cancer. Bhadra underwent two chemotherapy sessions before the surgery. Post-surgery, he underwent four chemotherapy sessions. Bhadra was cured in 2002. But the cancer recurred though not in the same place. Doctors suggested six more chemotherapies after which the cancer was cured. Again in 2014, Bhadra was detected with cancer in the stomach in another area and underwent six chemotherapies but the metastasis did not respond to the chemotherapies so the medicine was changed. At the time of this interview, he was on the improved chemotherapy medication of four cycles. Now, the improved drug is effective because constipation has reduced, which is considered as a sign of cure according to him.

Bhadra feels that intensity of chemotherapy results in common side-effects. He thinks that it would be better if patients get involved in their day to day work in order divert their mind from the pain. Bhadra found it difficult to take food in the first week after chemotherapy. Bhadra acknowledges the role of his wife as caregiver in the treatment. He agrees that his body does not support work like before but still he manages to work. He also says that it is important to restrict outside food strictly to be healthy. Bhadra says that he ceases to consume street food and when there is no option he prefers food from the office canteen. Even if he has to start at 5 AM in the morning, his wife manages to make food and give it to him. Except his mother, everyone in his family was informed about the problem. Bhadra does not want his mother (eighty-six years old) to know about his condition.

Family Friends Becoming the Core Family

> “Everyone thinks that both of them are my sons and there is
> one more boy who is very close to me like my son.”

Manjula is a fifty-three year old breast cancer patient working as a school teacher in a private school. Once Manjula found a lump in her breast which she neglected and after two months, it started to hurt so she consulted a doctor, and it was diagnosed to be breast cancer. Chemotherapy sessions were given pre-surgery and then after the reduction of tumor size, surgery was performed. At the time of this interview, post-surgery chemotherapy sessions were going on for her. Manjula’s husband passed away. Her daughter is married and stays in another state of India. Her son works in a multi-national company in the city. Manjula stays with her son Vishal and in the whole discussion, she never mentioned anything about her family other than Vishal’s friends. Two friends of

Vishal are the only ones who help them. She says that everyone in the hospital thinks that she has got three sons.

In Manjula's opinion, it is not always true that family is the only bond which would be beside us during our difficult times. Friends are also part of the family. Manjula says that Vishal's friends cook and get home-made food for her whenever she is hospitalized. The researcher encountered with the genuiness of the discussion as both Vishal and his friend were skeptical of the questions asked in the interview. They interrupted Manjula during the interview and since, the research time was of short time duration, another session of interview was not conducted. The medical counsellor suggested that the difficulty in finding a partner for a son of a cancer survivor resulted in the skepticism. The case exposes the social stigma associated with cancer.

From Caregiver's Perspective

> "But if I had to stay totally here with my mother, just because I am a housewife, it would be very difficult for me and my family, who are dependent on me."

Appamma is a seventy-six year old lady, who was totally bedridden at the time of interview. The informant was assisted by her daughter during the treatment. The case study is based on the interview with the medical counsellor, Gunjan. Appamma went to her daughter Sujatha's house to stay for few days. During her stay, she noticed a lump and informed to Sujatha, who took her to the doctor. After diagnostic tests, it was identified as breast cancer and Sujatha informed her other sisters and brothers.

All the children gave excuses for looking after her. The son excused himself on the premise of health concerns and commitments of their partners. And, eventually the responsibility of caregiving fell on Sujatha. Sujatha remarked sadly, “My brother blames me for my mother’s the condition. According to him, my mother was healthy until she came to my place”.

Sujatha, on whom responsibilities were entrusted also looked for ways to avoid caregiving. Eventually, the siblings decided to contribute the share of Rs.15, 000 per month for the treatment of Appamma in a nearby hospital. The financial burden was mostly taken care of by a sister who was an employee in a public sector firm, under the central government insurance scheme. Sujatha concludes that she has been entrusted with this responsibility since she is a housewife. She complains of back pain and developing allergies in the hospital environment.

The elder sister of Sujatha, who accompanied her to the hospital was reluctant to engage in the conversation. Sujatha talked about the inhibitions of sharing information with outsiders. Sujatha says, “If the other siblings get health problems, their children are in the position to support them whereas her children are not yet independent and self-sufficient”. Appamma’s health situation is thus a bone of contention among her children.

Loss of Patience because of Treatment

> “Sometimes she will be asking “how many more chemotherapies?” And I say two or three more, and she says “Ok” with a sigh.”

Sita is a seventy-one-year-old lady, and her husband Ram is a retired army man. The interview was done by Ram as Sita was unable to speak due to weakness. In 2008, Sita observed a lump in her breast at the time of her daughter's marriage. Doctor advised chemotherapy, but the marriage of her daughter, delayed the treatment. Ram opines that they decided to face the consequences of the delay in treatment as the marriage was more crucial. Post-wedding, Sita undertook the surgery and following chemotherapy sessions and radiation treatment for about four to five months. In the periods 2008 to 2013, Sita was on regular check-up. In 2014, Sita suffered from weakness and consulted a cardiologist. The doctor could not identify an abnormality in her health. In June 2014, the hoarseness of the voice was followed by reduction in the volume. The vocal cord eventually got paralyzed, and she was unable to speak. During these complications, Sita resided at her daughter' place in Baroda. Sita consulted a cardiologist nearby, who suggested CT scan. Cancer spread everywhere in the body, blood, spleen, etc. So, they were anxious and returned to Hyderabad. After consulting the doctor in Hyderabad, Sita underwent 15 to 16 chemotherapy cycles.

Ram and Sita have three daughters, and all are married. During the painful stages of the treatment, Ram took the role of caregiver and provided all the needed help to Sita in the hospital. Ram maintains the records systematically with notifications of chemotherapy sessions and the medicines required in the treatment. After undertaking many chemotherapy sessions, Sita was restless and frustrated. Ram as a responsible caregiver continues to provide support. Ram is retired from a public sector and the financial condition is adequate to deal with the medical treatment.

Occupational Problems Faced due to Long-term Treatment Plan

> "We have to attend to our duties as well. If not who will pay salaries? Because of her treatment, even I have to leave my job. She has a leave for medical problems for 6 months from the government but still long term leave is difficult. For a treatment like this it takes years to the treatment plan for which leaves would not be sufficient. The higher officials are considering a lot of things with a good heart."

Mridula is a forty-two year old head constable, and her husband Sailesh is a government school teacher. Mridula identified her problem in 2012 and after mammography, it was confirmed that she had breast cancer. For reconfirmation, she underwent a biopsy, as suggested by the doctor in their hometown. The doctor advised Mridula to consult this hospital, and he also briefed the patients' health condition to the chief doctor in the hospital. Doctor advised surgery followed by chemotherapy and radiation. Mridula underwent diagnostic tests after one month of surgery. Recurrence of cancer in the lungs was identified. The treatment was continuing at the time of interview.

Mridula complained of side effects such as motions, weakness, tastelessness for tongue and other multiple complexities post chemotherapy sessions. Sailesh as a concerned caregiver discussed with the doctors in the nearby hospital about the recurring side effects. In spite of the medical suggestions given by the doctor the side effects did not subside. Sailesh consulted the doctors in this hospital; he was counseled to adjust to the mood swings in Mridula as a result of the chemotherapy sessions. Eventually, after two chemotherapy sessions, Mridula got adjusted to the complexities of treatment. Sailesh continues to motivate Mridula after the painful chemotherapy sessions, which helped the informant to cope with the course of the treatment.

During the interview, Mridula said that she notified the respective police department about her health condition so that she will be spared from night duty and more responsibilities.

Sailesh says that complications during intense chemotherapy sessions are common. However, the role of the caregiver is crucial to motivate the patient. By maintaining systematic records and periodic discussions about the progress of the patient with the medical staff, the caregiver can play an instrumental role in the treatment. Sailesh faced a lot of constraints during the process of treatment in the form of personal commitments. The children being young often neglect their education, and this acts as another challenge for the caregiver and the patient. Balancing the complexities of the treatment along with the personal constraints poses to be the biggest challenge to the caregiver.

Acquiring Convincing Skills

> “Actually we have to support them according to their version. They want to take the treatment and also think whether we can have some easy procedure for the treatment. They will not say ‘no’ because they want to live, have attachments, see children, but medication would be difficult for patient. So we being caregivers have to go according to their thought process. Actually we would generally be strong and emphasize strictly on medicine having a fear that they would deny treatment.”

Aamani is a thirty-seven year old housewife, and her husband, Vignesh is a police officer as already mentioned in Chapter I. Vignesh also indicates similar issues as referred by Sailesh in the earlier case. However, one interesting point to be drawn is the fact that in spite of the patient’s willingness to live, they get discouraged during the course of treatment. The chemotherapy medicine is intense, and it is given through intravenous. In the process of eliminating bad cells, it also kills good cells and hence, the immune system becomes weak. So, no individual is willing to live over the period of pain and trauma. It is the responsibility of the caregiver to motivate the patients to understand the essence of life. According to Vignesh, even though patients are aware of these aspects. The consolation “we are there for you”, can motivate them during the pain. It is obvious that any person would lose temper at times. Vignesh opines, “the kind of love and affection which exists towards the patient also makes the caregiver to be harsh at times, but it is imperative to converse politely. Politeness is hard to come as time is a constraint in this treatment.” The emphasis of quick decision-making given the time constraint is made clear by Vignesh. There are situations where doctors come in the process of the surgery and ask to make decisions in few minutes also. The caregiver should be in a position to make decisions given the considerations at that particular time.

While narrating about the emotional bond that prevails between the patient and caregiver, Vignesh mentions about the bond between the husband and wife. Vignesh feels, “Kindness towards the patient during the treatment is crucial. In this regard, the male companion considers caregiving as a responsibility, whereas female companion are more emotional while giving care”. Vignesh continued, “Women continue to care in spite of any challenges in the course of the treatment. Men cease to care over the course of the treatment in many cases”. Vignesh is critical of such aspect and believes a man and a woman should contribute equally towards the responsibilities in the course of life. According to him, the bonding is easily broken in today’s world, wherein people are hesitant to face such hurdles. Vignesh philosophically narrates, “A human is a collection of desires. In a garland, the thread is the life, and the flowers are desires. Flowers can perish, but the thread remains forever”.

Vignesh narrates the importance of understanding the woman waiting for the man at the home giving utmost care to him. In the similar sense, a woman should recognize the efforts put in by a man for giving her the care. These efforts strengthen the relationship, and that works as an important healer during the painful phases of life. He again philosophically exclaims, “there is a difference between eating the food and enjoying the essence of it. By enjoying the taste of the food, one eats more than for just the sake of eating”. He says any hurdles and challenges in the life should be countered with a positive frame of mind.

During the interview, it was evident that Vignesh provided utmost care to Aamani. In the period of counseling, Vignesh followed the advice of medical professionals and incorporated them in the caregiving to the patient. The detailed understanding of the treatment and the complexities of the patient in the painful phases along with help from medical counselors is vital for caregiving.

In the analysis of the above-mentioned eight cases, it can be observed that an understanding and supporting family makes a considerable difference to the caregiving. The effective caregiving is instrumental for the treatment of the patient. The caregiving blend with emotional kindness and medical knowledge of the treatment can be more effective. The absence of family makes no difference in treatment but effects on positive thinking of patient. The patient should be frequently motivated for better results. Even though, extended treatment plan make the patients and caregivers impatient, since the disease is highly unpredictable, it is important to keep up the spirit.

CHAPTER IV

THE TREATMENT PROCESS AND THE DIFFICULTIES FACED DURING THE PATIENTS JOURNEY FOR TREATMENT

The ‘illness narratives’ highlight the trauma that cancer patients undergo, particularly in the questions they ask about their ‘selves’, and the socio-economic problems they face during the treatment process. The subjective insights discussed in this chapter substantially contribute to the notions of ‘care’ cancer patients receive, from family and the medical professionals. This chapter discusses issues of (or lack of) compliance with medication and treatment the patients look for and receive. The treatment is case-specific from individual to individual, which increases the complexity of the treatment. There is a need to incorporate the patient’s condition and the seriousness of the particular type cancer while analyzing the narratives. Based on the conditions, the treatment is structured and initiated. This stage proves to be a major challenge to the patient as well as the professionals. Apart from the medical aspect, superstitious beliefs also play a fundamental role in understanding the narratives and explaining the experiences of the patients. Such notions are, however, a clearly discouraged by the medical professionals.

The treatment is also affected because of several social, occupational and economic constraints. For instance, the impending marriage of a grown-up daughter at home can act as a social constraint delaying the treatment. Medical treatments are delayed due to the inability of receiving permission in the workplace of the patient and caregivers. Other impediments in the form of infrastructural constraints faced by patients from rural areas also prevail. The poor development of medical infrastructure in rural areas delays the treatment and follow-ups. Most importantly, the high expense involved in the cancer treatment can act as a crucial barrier to the treatment. The wait for assurance from the insurance company and delay in the arrangement of money acts as impediment in the treatment. In few cases, patients discontinue the treatment without financial assistance.

The chapter intends to highlight the narratives which clearly point out the various impediments as mentioned above. The narratives offer interesting insights further to understand the notions of 'care' and the challenges faced by the patients.

Misguidance and Its Consequences in Delayed Diagnosis

> “I go home and come back, but this time I stayed back, and this counts had been drastically down to about 900. Earlier I used to be at home and after falling (platelets), I used to come. It is difficult, so I used to feel very weak. I told the doctor that I wanted to stay here.”

Indumathi is a sixty-six year old woman, is working in a private firm. She stays with her husband in the railway quarters. She takes the help from the maid when she visits the hospital, but not from the family members. Even during the study, it was observed that she was rarely accompanied by her family members during hospital visits. Swollen leg was one of the initial symptoms observed and experienced by the patient. The swelling of legs continued for two months, after which, she was referred to this hospital by a doctor in the Railway Hospital. After ruling out the possibility of surgery, the doctors at this private hospital directed the patient to undergo chemotherapy. Chemotherapy was the only medical treatment left for the patient. During the initial period of the treatment, the swelling in legs restricted the patient from reporting to work. After the treatment, the patient managed herself efficiently.

Prior to this swelling of legs, Indumathi suffered from psoriasis[8]. Indumathi took treatment using homeopathy medicine. The homeopathy doctor, she consulted, advised her to continue the treatment. The idea was the decline in the intensity of the infection as it descends from the head to the toe during the course of treatment. She was convinced that as the infection reaches the toe, there is a complete cure for *psoriasis*.

The pain continued, and it became almost unbearable. And at this stage, the homeopathy doctor advised Indumathi to refer to allopathic practitioner for further medical help. The informant visited the Railway Hospital, from where, she was directed to this private hospital. In January 2014, Indumathi was admitted to this hospital. During the time of field investigation, she was in the sixth month of chemotherapy treatment.

The informant shares her experience of falling rate of RBC, WBC and blood platelets following each chemotherapy session. During the initial phases, the informant struggled to walk owing to weakness. At the time of interview, she was walking. Indumathi gladly shares the appreciation received from the doctors for her speedy responsiveness to the treatment. She had other side effects like nausea, dizziness, and weakness. Indumathi is touched by the empathy shown by the doctors in the hospital. She feels that the reason could be her getting the treatment without any family help.

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[8] Psoriasis: is a common, chronic, relapsing/remitting, immune-mediated systemic disease characterized by skin lesions including red, scaly patches, papules, and plaques, which usually itch.

The importance of family support for is necessary for patients to cope with the treatment especially when they are dealing with chronic diseases such as cancer[9]. The informant shows utmost respect for the doctors. During the course of the interview, Indumathi considers the doctor as a manifestation of Sai Baba[10], who has come to relieve her from the pain.

Indumathi delayed the diagnosis owing to the slackness involved in the treatment by homeopathy practitioner. The delay in treatment was intertwined with other medical complications like HBsAg[11] positive. The informant is glad that her belief in god also provides her with the strength to deal with the complications of the treatment. She is reluctant to take help from family members as she is unwilling to get accompanied them to the hospital. She prefers seeking help from the maid. Indumathi says that she does not like to bother her family members by calling them to hospital.

Indumathi hides the reality of her health complications from her relatives and peer group. She narrates, "No one from the family is aware of the disease as they will feel sad and will approach me with sympathy". She argues that the sympathetic approach from the people is one thing which is unbearable for her. Indumathi hides her whereabouts by stating reasons such as being out of station for work.

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[9] Importance of familial support and the narrations which show, how it helps the patients to cope with the treatment has been discussed in the chapter II

[10] Sai Baba is believed to be a prophet, who preached equality between Hindu and Muslim religions. And he is considered and revered as god till date by people, who belong to the different religions.

[11] HBSag: HBSag is the surface antigen of the hepatitis B virus. It indicates current hepatitis B infection.

One such interesting insight that can be perceived is that, patients tend to ignore the symptoms in the beginning and show extreme negligence in undertaking appropriate medical treatment. Though, in this particular case Indumathi was misled by the homeopathy doctor. General notions and popular beliefs act as an important social impediment which delays the course of treatment.

It is thus necessary not to turn a blind eye towards any constant, worrisome symptoms as they can often be the alarm for the chronic diseases like cancer. Another interesting inference that can be drawn from this case is the necessity to understand the disinterest shown by the informant towards sympathetic approach by family. The reluctance of informing the family about the disease also unravels the possible social stigma associated with the disease.

Negligence of Symptoms

> “The fault is ours too; we failed to come here in advance. Back there in our place there was only one doctor available, and the decision-making becomes a problem because of that. The surgery lasted for five hours. The surgery resulted in twenty-three stitches which were extended to the pelvic bone. In the span of one to one and half years, the surgery was done four times and among the four surgeries, once the surgery was done on the same place again”.

Saraswathi is a fifty-eight year old government employee, and her husband took voluntary retirement from government services, as a driver. Pricking sensation in the stomach was one of the first symptoms faced by the informant. Though, the informant initially assumed that to be an outcome of dehydration, but eventually observed the recurrence of pain on one particular side of the stomach. She consulted the gynaecologist and was informed of the cyst. The medical help based on doctor advice resulted in temporary relief for the informant. However, over the course of time, the pain recurred.

Saraswathi approached a surgeon for addressing the recurring pain. The surgeon assumed it to be the outcome of psychological stress regarding the pain and suggested her not to worry. The advice of the surgeon acted as an impediment to getting the appropriate medical help. The informant regrets the decision of not verifying the reason for pain from other medical professionals. The informant at that point of time was convinced by the suggestion of the surgeon.

The pain became unbearable and in the third stage; Saraswathi approached a homeopathy doctor in Ananthapur as other symptoms like dizziness; nausea and loss of weight also developed. During this course of homeopathy treatment, the informant recollects further loss of weight and dropping of stomach to an abnormal shape. One day, the informant recognized a lump near the breast along with pain in the stomach.

The informant reported to an allopathy doctor regarding the symptoms but in vain. Saraswathi decided to take homeopathy medicines along with the allopathic medicines. In this course of time, the gynaecologist identified some protrusion in the body of the informant. The protrusion when pushed went inside revealing an alarming symptom along with drastic weight loss. The scan reports at that point of time indicated the possibility of cancerous mass. The mass was removed after an extensive surgery. The informant recollects that the mass was removed along with five centimetres of the large intestine (as the mass was stuck to the large intestine). After the surgery, nine chemotherapy sessions were given and then the scan reports were normal. However, in a few days the informant experienced similar symptoms, and the diagnostics revealed the possibility of CA 125[12]. The doctor explained the reason for reoccurrence of the tumor as delayed diagnosis, and they advised her to go for chemotherapy session again. Saraswathi saw some advertisements about the chief doctor in the hospital and also heard from friends about the treatment facilities before coming to this hospital. According to the medical oncologist, the cancer cells spread to ceretonium and chemotherapy was inevitable. Saraswathi adds, “People opine that it is a silent killer and is accompanied in the case of ovarian cancer. But it was fortunate that it came outside in the case of mine”.

Saraswathi has told many people about her disease, but some ask her, “Why do you want to say to everyone about your problem?” She thinks that her case can be an example for others to understand and take quick steps when it comes to treatment for such chronic diseases as cancer. After counselling with a close person, she gained strength to face the complexities associated with the disease.

Her husband was a government employee but took voluntary retirement because of medical reasons. Saraswathi does not have children, and her husband helps her in the course of treatment. The informant also adds that her younger sister who is married extends support during the course of treatment. She also narrates, “Living in a village taught us to face challenges. The sight of many people suffering makes us recognise the better position we are in to face such chronic diseases”. Since, she works as a supervisor in public health centres, she understands her medical situation clearly. She strives to fight with the disease to lead a peaceful life.

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[12] Cancer antigens 125

Her husband thinks that people publicize incidents of failure rather than narratives of successful patients. In this regard, the informant and her husband believe the narratives of successful stories can motivate patients to fight cancer and cope with the medical complexities.

A Case Study for End of Life

> "….once in 15 days I have to undergo chemotherapy. They gave a four months gap for the treatment after making me go through 6-8 months of chemotherapy. After giving gap, it has grown and now once in every 15 days I have to take chemotherapy. Mine is 4th stage, so it is not possible to go for surgery. If it is 1st or 2nd stage, then they might have suggested me to go for surgery. Now using medicines is the only way for me. There will be six types of medicines it seems. Now they are giving me 2nd type of chemotherapy. Each chemotherapy session runs for 48 hours."

Ayyappa is a sixty year old man, who worked as a contractor. The initial symptom the informant experienced is stomach pain, and when he consulted doctor concerning his stomach pain, the doctor predicted the possibility of the ulcer. Six months later, through the CT report, the informant was diagnosed with cancer. After taking various opinions, he decided to approach this private hospital for treatment. The patient knew his condition and accepted the fact. Now, he is in stage IV of cancer of the pancreas. Other than chemotherapy there is no option of treatment left. He further explains the treatment and the six types of chemotherapies. He is undertaking the second type of chemotherapy, and each session lasts for forty-eight hours. The chemotherapy cycles will lead to increase in the sugar levels, and this causes problem in following proper diet. They cannot eat according to their wish because there are chances of fluctuations in sugar levels.

Ayyappa tried homeopathy for the curing of ulcer, but it was not effective. The allopathic doctor suggested him to approach Ayurvedic method. He started using Ayurveda, and continues along with allopathic treatment. Ayyappa is satisfied with the Ayurveda medicines as he feels that at this stage, it provides strength to cope with the treatment. He says that it is easy for him to drive back home after chemotherapy.

Ayyappa is in a stage where rather than prolonging his life nothing else is possible. It is important to accept the seriousness of the stage and move further. It was clear from his words that Ayyappa knows his condition and he accepted the fact by understanding it.

In normal cases, doctors do not suggest other types of medication. In Ayyapa's case, it is important to make him live by using one or another option. One of the Ayurvedic doctors at Government Ayurvedic hospital said that, the Ayurveda method of treatment does not target the action therapy; rather it strengthens the whole body. It is possible that strengthening of the body helped Ayyappa to cope with chemotherapy.

Complications during Treatment and Lack of Family Support

> "Though we are educated, we tend to ignore the symptoms of cancer. After initial symptoms were neglected but later I have experienced a lump in the armpit; apparently the lump was in the advanced stage. Then I rushed to NIMS hospital for treatment. However, the doctors in the hospital have said that "Madam, you are too late." I met Dr. Surya Narayan, a known doctor, and he said that he will try his best but could not assure me of complete recovery. I proceeded further with the relevant tests and sadly during all this my son was in Canada."

Subba Lakshmi is a sixty year old, retired professor, who was suffering from breast cancer. She observed a lump of a stagnant size and assumed it to be a benign lump. She delayed the diagnosis as there were few responsibilities with regard to her son. She is a wodow single women living with her only. Subba Lakshmi says that being aware of health and diseases cannot be equated with being educated. People who are also educated tend to forget and ignore many health problems. In the same way, she also turned a blind eye towards the earlier symptoms. Then, her disease went to the next stage where she discovered another lump in her armpit, which made her rush to the hospital. The doctors at that hospital told her that she was too late. She tried with another doctor who said that he will treat her but was not given assurance of complete recovery. Subba Lakshmi did not inform her son as he was out of the country for his training, and the news might disturb him. The medical consultations were undertaken by her alone, and someone suggested her to go for the second opinion. The second consultation gave her a 50% chance of hope. Then one of her relatives brought Subba Lakshmi to this private hospital for confirmation, and the doctors advised immediate treatment. She was content with the hope given and joined for the treatment, but the diagnostic tests were not sufficient, so the doctors sent her for further examinations. The metastases spread into lungs, and the disease grew at a faster pace. She underwent two surgeries, number of chemotherapy sessions and radiation sessions. After that, she thought she got cured completely. However, three years later, there was a recurrence. During the course of the interview, she was undergoing radiation treatment.

Since Subba Lakshmi never had any of her family members present with her during treatment, she gets emotionally attached to hospital staff like Gunjan. She discusses with Gunjan about her son's wedding proposals and many personal issues as. During the chemotherapy sessions, she faced lot of troubles. The first four chemotherapies were taken entirely by her but after that, each chemotherapy session was split into three and was given once in a week. After one month of radiation was given to her, right side breast was removed entirely through surgery and the second surgery (hematoma) was done under the armpit which was a complicated procedure. She also reported that there was a lot of blood loss but miraculously got cured by itself. She says that even the doctors were content with her because of the positive attitude. The doctors were surprised as all the tests were clear, but they already suspected chances of recurrence after five years or so. However, due to family pressures, the recurrence was identified within three years. At the time of this study, she was taking radiation treatment. During the interview, when questioned about the emotional support from her son, she declined to answer and hinted that her son mostly stayed outside the country. She adds, "Doctors appreciated me for the strength displayed which helped me to fight and live."

A Case Study of 'Recurrence of Cancer'

> "In the initial phase they had given me four chemotherapy sessions and that time I did not have the problem of hair fall. I think I was young, I was able to bear it during that time. Twenty-five days the radiation was also given, but now I experience the chemotherapy different"

Bhavani is a fifty-four years old housewife. She suffered from cervical cancer in 2003 and undertook treatment, and was cured. In January 2014, Bhavani complained of severe headache and constant pain in the hand. In the nearby railway hospital, doctors prescribed calcium medicines and tablets for subsiding the headache. Bhavani and her family assumed the pain to be a result of migraine. After the cancer treatment in 2003, Bhavani ensured to remain healthy by continuing to walk and exercise every day. The weakness post the recent headache continued. Bhavani frequented her visits to the nearby railway hospital. At one such instance, a doctor from a corporate hospital visited that hospital and confirmed the possibility of cancer after analyzing the diagnostic reports. The diagnostics revealed the presence of bubbles in her lungs and confirmed it to be the lung cancer. After consultations from different networks, the family decided to take Bhavani to this private hospital for the further treatment.

The diagnostics revealed the possibility of weakening of bones. A treatment to address that continued along with the cancer treatment. The side-effects of the treatment resulted in hair fall, constipation and constant itching (primarily because of radiation). Bhavani claims that during the previous radiation session for cervical cancer, the symptoms mentioned above did not occur. The reason for this could have been the result of growing age as in 2003, she was relatively younger and was able to bear the effects.

Delay in diagnosis was the crucial reason for the recurrence in the case of Bhavani. According to her, a repeated diagnosis periodically (once in six months) is imperative for cancer survivors. The skipping of such sessions associated with the delay in diagnosing cancer resulted in recurrence. Many times, the patients and the caregivers tend to overlook owing to lesser inclination to be careful after a successful treatment. They tend to blame the physicians if prescribed for tests periodically assuming it to be a part of ‘corporate money-making’ strategy.

Chronic Recurrence of Cancer and It's Narrations

Another interesting case study is that of a woman who underwent major surgeries three times. Cancer recurred twice and she underwent the radiations and chemotherapies. The woman without losing hope continues to take the treatment further. At the time of field investigation, the woman was not in a comfortable position for recording an interview. Thus, the case study is presented, in brief.

Kutty is a fifty-five years old housewife, diagnosed with ovarian and liver cancer. In the year 2012, she had frequent urination, which she initially thought to be a common urinary infection. She used homeopathy treatment to address the infection. The consultant doctor observed a lump while testing for urinary infection. Doctor suggested consulting a physician as the lump can be a symptom of cancer. After the completion of further formalities in detection and confirmation of cancer, a major surgery was undertaken. The surgery lasted for eight hours and the ovary, uterus and some parts of the digestive system were removed. A small lesion left in the liver was expected to reduce in the course of further chemotherapy sessions. In the process, Kutty underwent six cycles of chemotherapy and was exposed to all possible side effects. After a gap of fifteen months, the lesion recurred in the liver and in order to remove the lesion, instead of chemotherapy, the doctors suggested stereotactic radiosurgery. Despite the high expense associated with radiosurgery, Kutty agreed. The lesion was removed after the surgery.

Post-surgery, Kutty and her husband relocated to Mumbai from Hyderabad. After six months, diagnostics revealed the presence of another lesion. Another surgery was undertaken for the removal of the lesion in the liver. She mentioned that the emotional attachment with this hospital for more than a year made her request the chief doctor (who is the surgeon in another hospital) to perform the surgery in this same hospital. While recollecting the experience of ICU, Kutty says, “the closed atmosphere and the people who were getting treated for cancer, made me sicker.” The strength to fight the disease prevailed yet the pain suffered by the rest in that environment depressed her. She was engulfed by the feeling of isolation in that closed atmosphere. The desire to shift to the normal ward was rejected by the doctor as intensive care and attention were necessary at that juncture of treatment. Many chemotherapy sessions followed and at the time of interview the sessions were over. To ensure a comfortable radiation session, Kutty, and her husband ensured to reach the hospital by 5 AM starting as early as 4.30, from the home, in the morning. In total, she was given twenty-seven chemotherapies and two cycles of radiation. At such a stage, finding a vein also became difficult. The peripheral neuropathy problem further accelerated the difficulty. The peripheral neuropathy problem gives the sensation of stepping on a ball, and can result in the collapse of balance as a result of it.

During the interview, Kutty recollected one such incident involving her mother-in-law who was also in a similar condition. After helping her mother-in-law and taking efforts during the illness, Kutty wondered when will the mother-in-law die? The efforts to take care of mother-in-law in such a situation was not possible for Kutty. In such phases of illness it is challenging to deal with it yet one cannot abstain from the responsibilities. She believes in accepting the situation as given by god, but according to her, managing responsibilities and completing the household tasks should continue despite being sick. Kutty and her husband will continue to manage responsibilities on their shoulders until they can. Kutty strongly believes problems and hurdles are part of survival, and it is necessary to face the challenges i life. She believes in applying a similar approach to deal with her conditions.

Through these case studies, it is evident that the delayed diagnosis and misdiagnosis because of several factors is a major problem. The delayed diagnosis has lead to the problems of side effects and recurrence of the cancer in many patients. Taking for granted, the awareness of this chronic disease, is another major challenging factor one should address. The social constraints being reason for the delayed diagnosis or starting the treatment late has made the situation of the patients worse than they would have if the diagnosis and the treatment would have started early. In several cases, it has also been observed that the patients were guided by popular notions. The belief is other medical systems has lead some patients to suffer more. Often the medical professionals who depend on diagnostic tests, which are not adequate enough to reveal cancer, have misguided the patients. However, as seen in the case of the Ayyappa, where the future was bleak, the doctor felt it best to make use of method possible to keep prolonging his life span, such as Ayurveda. This has in fact helped the patient to cope with the challenges posed chemotherapy.

As explained in the introduction of this chapter, if the narrations are taken into consideration it might help the situation of patients to get better treatment. Though the socio- economic and occupational constraints determine the process of treatment, the patients should be educative enough to give priority for treatment and diagnosis rather than subjugating for these constraints.

CHAPTER V

ALTERNATIVE MEDICINES AND THEIR ROLE IN CANCER TREATMENT

The patients who are suffering from any disease tend to opt for multiple methods of treatment. As each and every disease and the body is case specific, the body responds differently to each kind of medication. Those who find it comfortable with a particular medication prefer to continue with that system of treatment.

Sujatha and Abraham (2012) discuss the multiple treatment procedures followed in India. The significance and the intensity of the existence of medical pluralism in our country is highlighted as both ISM (Indigenous Systems of Medicine) and CAM (Complementary and Alternative Medicine) deal with the indigenous systems of medicine in India. This research found that patients had encounter ayurveda, homeopathy and naturopathy along with the allopathic medications. The informants narrated how and why they opted for alternative medicines. Some case studies detailed in this chapter show that patients were using two or three different methods at the same time and some other instances one at a time.

Margret Trawick (1991) explains that Ayurveda is one of the healing systems which are extensively practiced in South Asia. The knowledge of Ayurveda was encrypted in Sanskritic texts two thousand years ago. The etymological meaning of Ayurveda is “that which has been seen to be true about long life” (Trawick 1991:121). As a part of the study, to understand the ues alternative medicines, some ayurvedic practitioners were interviewed. It is revealed in the interview that ayurveda does not have target action therapy; rather it rejuvenates the whole body. Ayurveda makes the entire health system to fight against the health ailments, hence, this process is time-consuming, and the patients are expected to show forbearance during the treatment procedure. The Ayurvedic treatment procedure does not have a diagnostic method to find out the disease of the patients. The medical practitioner suggests medicines based on the symptoms expressed by the patients. Only a few people approach Ayurveda as people seek instant relief from the pain, and this method of treatment does not promise that.

Gasparin J (2005) describes homeopathy as a curative method in medicine which began almost 200 years ago in Germany. It was practiced and spread across the world by Samuel Hahnemann. The process explains that a substance which causes certain symptoms in a healthy person can also cure an ailing person who has similar symptoms. The theory may sound vague but treatment is distinct from the rest. Homeopathy does not include surgical methods and in terms of vaccine, it is different from other medical systems. The treatment procedure in homeopathy has relations with ancient healing traditions but it has its uniqueness, which is not related to any other medicine systems.

In the present study, such cases were encountered but the responses varied from patient to patient. Some patients opined that approaching alternative medicines along with allopathy had an impact in battling their disease, whereas others disagreed that there was any notion of getting benefit from alternative medical treatments. A total of 8 out of 50 have narrated their experiences concerning alternative medicines.

Opting *Gomutram* and Homeopathy for the Prostate Cancer

Ganesh, as mentioned in chapter II, narrated his experiences of trying alternative medicine. As an alternative medicine, the informant visited Nagpur[13], the medical practitioner there, suggested him to consume the urine of a cow. The urine of a cow is considered sacred, and it is deemed to contain medicinal power to reduce prostate cancer. The informant followed the advice and started using the '*Gomutram*', a pill and some medicine mixed with *ghee* for seven months. The informant also added that, this helped him in battling the prostate cancer. As during the treatment, his prostate count which was 19 had come down to zero after using this alternative medicine for seven months. However, the count again rose to 8, 11 and 14 and later, stagnated at 14. However, in the due course of time, the informant also complained of the burning sensation and constipation problem. So, his son consulted doctors in this hospital, and they advised him not to visit Nagpur for alternative medicine during this course of time and at that age. Thus, the doctors advised the patient' son to get the patient for consultation.

The informant narrates that while undergoing the Allopathy treatment he also opted for another alternative medication called Homeopathy at the Batra's[14] suggestion. He has requested the homeopathy medical practitioner to give medicines which helps him to ease the constipation problem and also to reduce the burning sensation during urination. The informant did not experience any relief after a week of medication. He

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[13] Nagpur: is the second capital and third largest city of the Indian state of Maharashtra.

[14] Batra's: is a homeopathy hospital in Hyderabad.

stated that the medication was ineffective and discontinued the homeopathy way of treatment for his health ailments.

Home Remedies for the Prostate Cancer

Khan, as mentioned in Chapter III, tried different home remedies along with the allopathic treatment for his prostate cancer. The informant narrates how he made use of internet to find what can be done to ease and make allopathic treatment effective. He came to know that using *amla* as a mixture with turmeric and honey in ½: 1:2 ratios will lead to a better result and experiment the same. The informant also came to know about a fruit, which is called as ‘soursop.' The particular fruit is not available in India and Khan requested his daughter to send this fruit from Dubai, where his daughter resides. He also procured this fruit once from a dry fruit seller in the old city, Hyderabad. He said that that ‘soursop’ fruit costs about Rs. 650-700 per fruit. The outer layer of the fruit has to be removed; the fruit has to be cut into 30 equal parts and stored in the deep freezer. That fruit has to be consumed twice a day, an hour before a meal. He also told that the content of that fruit is available in the form of a powder as ‘vita plus’ which he had got it through his brother from Saudi Arabia. Khan had also tried to get Asparagus (a vegetable) which is suitable for cancer cure as informed by someone to the informant. His son orders asparagus in an American online website. His daughter sends ‘soursop’ fruits which would be available in sealed form. Khan says that the home remedies mentioned above have helped him, and he also feels that using the home remedies is the reason he can sustain the allopathic treatment.

Herbal Medicines and Home Remedies

In Sita’s case (Chapter III), her husband Ram narrates how they opted for alternative medicines such as herbal medicine (which they came to know through the television advertisement) for 2-3 months. The medical practitioner advised following the treatment through herbal medicine for 6-8 months. However, the chemotherapy treatment also started, and the informant and caregiver felt that using both might lead to adverse effects, and they decided to stop using the herbal medicine. The informant also narrated how they had come across another television advertisement which says about a fruit called ‘Ramphal’ the television advertisement has propagated saying ‘cancer cure’ with ‘Ramphal.' Sita tried ‘Ramphal’ and says that it helped her to cope with the disease.

Homeopathy and Allopathy

Bhadra, as mentioned in Chapter III, narrates how he opted for Homeopathy after being referred by someone. He had started using the Homoeopathy along with the allopathy; others also informed him that by using homeopathy the recurrence of cancer will be stopped. Hence, he started using the homeopathy and ended up spending 70-80 thousand rupees on the homeopathy medication. However, that homeopathy treatment was in vain; as cancer recurred in the patient. While recollecting his experiences about the homeopathy, the informant has also told that twice a day he used to spend one and half hours to take this homeopathy medication. The Homeopathy doctor gave four liquids to be consumed with a gap of 5-10 minutes and also ten types of pills which has to be taken with a gap of 5 minutes for each tablet. The Homeopathy doctor suggested the informant to maintain a gap of 15-20 minutes in case of using allopathic medicines to avoid any side effects. Bhadra narrated about using the combination of homeopathy medicines along with the allopathic medicines to his Allopathy consultant. However, the doctor did not discourage him from using the homeopathy and, in fact, said it is good to give a try though he believes that using both would not be effective.

Alternative Medicine Delayed Diagnosis and Adverse Effects

Indumathi, as mentioned in chapter III, narrates, about using homeopathy medicines for psoriasis. Apparently the cancer was misunderstood as psoriasis by the homeopathy doctor, and he started the medication. Despite using the homeopathy medicines the pain continued, and the doctor advised her that, the disease is cured eventually as it passes from the top to toe. The informant was convinced by the doctor's logic of getting relieved from the leg pain. However, after waiting for a long period, when the leg pain was unbearable, and the informant was unable to walk, later she decided to give a try with the allopathic medication. Her consultation with allopathic doctor had revealed that she has cancer, and she started taking chemotherapy sessions.

Misdiagnosis and Alternative Medicines

Saraswathi, as mentioned earlier in chapter IV, has approached general physician when she had health ailments. The general physician had chided away her illness feeling after going through her reports saying 'the reports says she is perfectly fine, and the health problems she expresses are just psychological feeling.' However, the unsatisfied informant decided to opt for the homeopathy medication. Since, homeopathy practice does not have diagnostic tests, the doctor asked her symptoms and gave medication accordingly. The homeopathy treatment was not effective in relieving her from the pain so she decided to consult another allopathic doctor and which resulted in the diagnosis of cancer for the informant.

Eating Habits, Illness Behaviour and Allopathy

Dinesh is a forty-four years old government employee who has piles complaint, initially opted for Ayurvedic medicines and used the medicines for about four months but the treatment proved to be futile. Moreover, the informant also felt that he was becoming weak day by day and losing weight steadily. Later he consulted an allopathic practitioner and was diagnosed with cancer. The informant narrated how someone told him that the brinjal might have adverse effects on his health as it possesses the allergic elements; the informant stopped eating the brinjal. However, the allopathic doctors suggested him that the allergic factors affect only those who are proven to be allergic to the brinjal, and thus, he can consume brinjal if he wishes to.

Support of Alternative Medication to the Allopathic Treatment

Ayyappa as mentioned in chapter IV, the informant is a stage IV pancreatic cancer patient. His situation is critical and hopeless, after understanding his condition; the allopathic consultant suggested him to try Ayurvedic medication along with the chemotherapy sessions. Following the advice of the doctor, the patient started using Ayurvedic medication. The informant opines that he can cope with chemotherapy sessions just because of these Ayurvedic medicines; he also added these two medications did not have any side effects and proven to be healthy. He continued saying that he is managing his personal work and even driving (which was not the case earlier) just because of Ayurvedic medication which stands as a support for the allopathic treatment.

Conclusion

The study portrays the emotional experiences of the patients' and caregivers on various aspects like questioning individual 'self,' roles and responsibilities, role of alternative medication and treatment difficulties. From this study, it is clear that we need to understand and give space to voice the challenges and feelings of both the patients and caregivers. The findings of this study may contribute to understanding the illness narratives overlooked by the hospital staff. It might help the medical staff to understand and mend their methods while dealing with the patients' treatment process. Chronic diseases such as cancer need to be addressed without any further delay.

The cost involved in the treatment process is becoming a serious barrier for patients and their families to go ahead with the treatment. At private hospitals such as one where this current study was carried out, the process of providing better health care results in costing the patients an extraordinary amount. Currently, cancer treatment is considered as affordable only for the economically privileged class. In order to address the economic constraints faced by the larger sections of the society while dealing with cancer, more public treatment centers should be established. Government should encourage the research in the field of cancer treatments to work out a viable treatment policy for all the groups of people.

The government should come up with guidelines for public and private sector employees, allowing them to claim medical leave in case of diagnosed with chronic disease such as cancer. Treatment often involves extended sessions of chemotherapy and other treatment procedures such as surgery, radiation, and regular follow-ups in order to avoid the recurrence of the disease in the patients. The employer and the government should stand by the employee who has been diagnosed with cancer, at such a crucial time.

Chronic disease such as cancer, are often viewed with stereotypes. These stereotypes are fed in due to incomplete information about the illness. Patients suffer social isolation due to misconceptions about cancer (being a communicable disease) being nurtured in the mindset of the society. These perceptions result in constraining the patients' ability to cope with the treatment. It contributes to the adverse psychological effects. Patients therefore look out for alternative medicines. Such constraints can delay further treatment.

In this regard, state-sponsored advertisements and active media campaign can raise awareness regarding the illness and wither away the general misconceptions about the disease. Currently, many media groups and non-governmental organizations are at the forefront in spreading awareness by roping in celebrities for popularity and mass appeal. The attempt has been partly successful in creating awareness about the disease among the public.

The stereotypes associated with the illness is also making the patients think about their children's marriage aspects. The social problems faced by the patients who underwent amputation of parts are expressed in feelings about being judged after the surgery (like breast cancer patients). The social stigma associated with the disease explains the need for educating and redefining the notion of ‘sexuality’ and crushing the stereotypes associated with it. By doing so, patients can be more comfortable during the treatment, and this can increase the effectiveness of the treatment. The case studies substantiate the skepticism faced by the patients while undergoing surgical removal of the private parts.

The future research in this particular topic allows to extend the study to understand the narrations from different social and religious background, as they are one of the many determining factors to shape the narrations of the patients. Research should be extended to hospitals run by the government in order to make the hospital ethnography rich and also to collect the narratives which might be determined by the different economic backgrounds. There is also a need to understand the perceptions and narrations of the paramedical staff and nursing staff in hospitals because they observe the patients more than the doctors. Their narrations might throw some light in understanding the problems involved in the treatment process and in the psychological trauma the patients go through.

CHAPTER VI

CONCLUSION

This study portrays the emotional experiences of cancer patients and caregivers on various aspects, like questioning individual ‘self,' roles and responsibilities, role of alternative medication and treatment difficulties. From the study, it is evident that there is a great and urgent need to understand and give space to voice the opinions of patients and caregivers. The findings of this study based on examining people’s illness narratives, overlooked by the hospital staff, could help them to understand and modify their methods while dealing with the patients’ treatment process. The chronic diseases such as cancer need to be addressed from a social science perspective, in India, without any further delay.

The cost involved in the treatment process is becoming a barrier for the patients or their families to go ahead with the treatment. The private hospital such as one where this current study was carried out, the process of providing better health care results in costing the patients an expensive amount. Currently, the cancer treatment is considered as affordable only for the economically privileged class. In order to address the economic constraints faced by the larger sections of the society while dealing with cancer, more public treatment centers should be established. Government should encourage the research in the field of cancer treatments to work out a viable treatment policy for all the economic classes of people.

The government should come up with the guidelines for the public and private sector employees, benefiting them to claim their medical leave in case of diagnosed with chronic disease such as cancer. The cancer treatment often involves extended sessions of chemotherapy and other treatment procedures such as surgery, radiation, and regular follow-ups in order to avoid the recurrence of the disease in the patients. The employer and the government should stand by the employee who has been diagnosed with the cancer, as their hard labor has contributed to the growth of the venture involved. It is a typical gesture any patient will expect in reciprocity.

The chronic disease such as cancer, are often viewed with stereotypes. These stereotypes are fed in due to the incomplete information about the illness. Patients suffer social isolation due to the misconceptions about cancer (being a communicable disease) being nurtured in the mindset of the society. These perceptions result in constraining the patients' ability to cope with the treatment. It rather contributes to the adverse psychological effects and they look out for alternative medicines. Such constraints can delay the treatment.

In this regard, the government sponsored advertisements and campaign along with active media programs can raise the awareness regarding the illness and wither away the general misconceptions about the disease. Currently, many media groups and non-governmental organizations are taking a forefront in spreading awareness by roping in celebrities for more popularity and mass appeal. The attempt has been partly successful in creating awareness about the disease among the public.

The stereotypes associated with the illness are also making the patients think about their future generations' marriage aspects. The social problems faced by the patients who underwent amputation of the private parts expressed their feelings about being judged after the surgery (like breast cancer patients). The social stigma associated with the disease explains the need for educating and redefining the notion of 'sexuality' and crushing the stereotypes associated with it. By doing so, patients are more comfortable during the treatment, and this can increase the effectiveness of the treatment. The case studies substantiate the skepticism faced by the patients while undergoing amputation of the private parts.

The limitations of the present study as mentioned earlier in the introduction chapter are the short duration of the study is one major drawback for the sample size and also constraining the research with one hospital. The practical possibilities of the data collection are kept in mind, and the research questions are framed accordingly. The main reason to consider the particular field site is that of the high inflow of in-patients when compared to other hospitals which have not been considered for the study. The primary objective of choosing "illness narratives" is that it will give the opportunity for the patient to talk more about open-ended questions. As from the researcher point of view, extending this study further, in the long run, would be much easier.

The future research in this particular topic allows extending the study to understand the narrations from different social and religious background, as they are one of the many determining factors to shape the narrations of the patients. The future research should be extended to hospitals run by the government in order to make the hospital ethnography rich and also to collect the narratives which might be determined by the different economic background. The future research may also be extended to understand the perceptions and narrations of the paramedical staff and nursing staff in hospitals because they observe the patients more than the doctors. Their narrations might throw some light in understanding the problems involved either in the treatment process or in the psychological trauma the patients go through.

Appendix

Interview Schedule

- **General sociological data**

1. Name:
2. Sex:
3. Age:
4. Code name:
5. Address:
6. Date:
7. Time:
8. Place of interview:
9. Also present:
10. Marital status:
11. Religion:
12. Educational background:
13. Occupation:

- **Related to Disease**

1. What is the purpose of your stay in hospital?
2. Since how long are you suffering with this problem?
3. How did you feel when the problem was first diagnosed?
4. What steps have been taken to cross check the problem which got detected?
5. Was the diagnosis same when you went for the second opinion?

6. Who all were involved in decision making for further treatment?
7. What kind of problems did you face during this process of undertaking treatment (emotional, social, familial, financial, etc.)?
8. What sort of support did you get from the hospital and doctors?
9. Did you ever feel that the doctors or the hospital can be much more supportive? If so, in what way?
10. Was doctor or hospital involved in decision making of your treatment?

- **Dietary Patterns**

1. What kind of dietary restrictions have been given by the doctors?
2. Did you feel that following such dietary restrictions are useful?
3. Did you follow any other alternative medicine systems like Ayurveda, Unani, Siddha, etc. before or after the treatment?
4. Did you personally follow any kind of home remedies suggested by family, friends or T.V programs?
5. Did you personally feel that some foods did not suit while taking the treatment and stopped eating those foods?
6. What is your experience related to food while the treatment is going on?
7. Do you feel that the suggestions given by the dietitian are useful?
8. Do you watch any programs in T.V on diet and try to follow?
9. Do you think that those programs are useful to you or your family?

Bibliography

1. Mol, Annemarie. *The logic of Care: Health and the problem of patient choice.* Routledge: Taylor and Francis group, 2011.

2. Arthur Kleinman. *The Illness Narratives: suffering, healing, and the human condition*. USA: Basic Books, 1988.

3. Audre Lorde. *The Cancer Journals*. Aunt lute books, 1980.

4. Benson A. Mulemi, "Patients' perspectives on hospitalization: Experiences from cancer ward in Kenya", Anthropology and Medicine, 15:2 (2008): 117-131. Accessed May 14, 2012. doi: 10.1080/13648470802122032
5. Bernard H. Russell, *Research Methods in Anthropology: Qualitative and Quantitative approaches*. UK: AltaMira Press, 2006.
6. Betty Risteen Hasselkus, "The family Care giver as Interpreter in the Geriatric Medical Interview", Medical Anthropology Quarterly, 6:3 (1992): 288-304.
7. Cecilia Van Hollen, "*Birth on the threshold: childbirth and modernity in south India*". University of California Press, 2003.
8. David Perusek, "Cancer, Culture and Individual Experience: Public Discourse and Personal Affliction", ETHOS 40:4 (2012): 476-506. ISSN 1548-1352. doi: 10.1111/j.1548-1352.2012.01271
9. Debbi Long, Cynthia Hunter and Sjaak van der Geest, "When the field is a ward or a clinic: Hospital ethnography", Anthropology and Medicine, 15:2 (2008): 71-78. doi: 10.1080/13648470802121844

10. Gitte Wind, “Negotiated interactive observation: Doing fieldwork in hospital settings”, Anthropology and Medicine, 15:2 (2008): 79-89. doi: 10.1080/13648470802127098
11. Haripriya Narasimhan, *Multiple Voices and Stories:Narratives of Health and Illness,* ed. Arima Mishra and Suhita Chopra Chatterjee (New Delhi: Orient Blackswan 2013).
12. Hufford, David J. *Folklore and Medicine. In Putting Folklore to Use.* Michael O. Jones, ed. Pp. 117-135. Lexingto: University Press of Kentucky, 1990.
13. Jessica L. Gregg, “An Unanticipated Source of Hope: Stigma and Cervical Cancer in Brazil”. ISSN 0745-5194. Medical anthropology quarterly by American Anthropological Association. Vol.25, issue 1 (2011): 70-84.
14. Jessica L. Gregg. *Virtually Virgins. Sexual Strategies and Cervical Cancer in Recife.* Stanford University Press, 2003.
15. Joyce Burkhalter Flueckiger. *In Amma’s Healing Room: Gender and Vernacular Islam in South India*. Hyderabad: Orient Longman Private Limited, 2006.
16. Julie Livingston. *Improvising Medicine. An African Oncology ward in an Emerging Cancer Epidemic*. Duke University Press, 2012.
17. Margaret Trawick, “An Ayurvedic theory of Cancer, Medical Anthropology”: Cross-cultural Studies in Health and Illness, 13 (1991):1-2, 121-136, doi: 10.1080/01459740.1991.9966044
18. Martyn Hammersley and Paul Atkinson. *Ethnography: Principles in practice*. Taylor and Francis e-library, 2007.

19. Merrill Singer, “Down Cancer Alley: The lived experience of health and environmental suffering in Louisiana’s chemical corridor”. Medical anthropology quarterly by American Anthropological Association. ISSN 1548-1387. Vol. 25, issue 2 (2011): 141-163.
20. Paul Atkinson and Martyn Hammersly. *Ethnography: Principles in practice*. Third edition. London and New York: Routledge. Taylor and Francis Group, 2007.
21. Shelly R. Adler, “Complementary and alternative medicine use among women with breast cancer”. Medical anthropology quarterly by American Anthropological Association. ISSN 13(2) (1999):214-222.
22. Steven M. Albert, “Care Giving as a Cultural System: Conceptions of Filial Obligation and Parental Dependency in Urban America”. American Anthropologist, volume 92 (1990).
23. Susan Sered and Ephiraim Tabory, “You are a Number, Not a Human Being”: Israeli Brest Cancer Petients’ Experiences with the Medical Establishment. Medical anthropology quarterly by American Anthropological Association. ISSN 13:2 (1999):223-252.
24. Susan Sontag. *Illness as Metaphor and AIDS and its metaphors*. Penguin Books. Modern classics, 1983.
25. Tancredi Laurence R., and Barsky Arthur J., “Technology and Health Care Decision Making: Conceptualizing the Process for the Societal Informed Consent”. Medical Care, Vol . 12, No. 10 (Oct, 1974). doi: 218.248.6.153

26. Uwe Flick, Ernst von Kardoff and Ines Steinke. *A companion to Qualitative Research*. Sage Publications, 2004.

27. V.Sujatha and Leena Abraham (ed.) *Medical Pluralism in Contemporary India*. New Delhi: Orient Black Swan Private Limited, 2012.

28. "WHO fact sheets, copyright: 2015

- http://www.who.int/chp/chronic_disease_report/media/india.pdf?ua=1
- http://www.who.int/mediacentre/factsheets/fs297/en/