Lived Experiences of Women with Breast Cancer and Their Care Givers: An Anthropological Perspective

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Thesis submitted to the Department of Anthropology, Quaid-i-Azam University Islamabad, in partial fulfillment of the degree of Philosophical Doctor in Anthropology.

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QUAID-I-AZAM UNIVERSITY, ISLAMABAD
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This is to certify that the research work presented in this thesis, entitled **"Lived Experiences of Women with Breast Cancer and Their Care Givers: An Anthropological Perspective"** was conducted by **Ms. Atiya Bibi,** under the supervision of Dr. Rao Nadeem Alam, Assistant Professor Department of Anthropology, Quaid-i-Azam University, Islamabad.

No part of this thesis has been submitted anywhere else for any other degree. This thesis is submitted to the Department of Anthropology, Quaid-i-Azam University, Islamabad, in the partial fulfillment of the requirements for the degree of Doctor of Philosophy in the Field of Anthropology, Department of Anthropology, Quaid-i-Azam University, Islamabad.

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I dedicate my thesis to my beloved PARENTS.

ABSTRACT

This research is ethnographic in nature and provides a “holistic” perspective on the lived experiences of the women with breast cancer and their care givers. This qualitative study made an attempt to explore the answers of some key questions that, what types of the enduring mechanisms are used by the breast cancer sufferers and their care givers to cope with this illness? What are the major obstacles in treatment seeking process? How significant is the role of care givers? The role of caregivers remained the focus of this study with references to the financial and social changes occurring in the life of breast cancer patient, hence the account of inter-subjectivities of patients and caregivers is provided to shed light on the trajectory of illness and its social influences. The trajectory is phasic in nature where diagnosis, chemotherapy, radiations, surgery and medications are chronological phases, each phase have a different kind of expectation from caregiver. Faith and belief of patients is also an integral and highlighted part of this study that provides reflections on praxis. Belief is at play in reactions and responses to the illness; multiple treatment venues including traditional healers and magico-religious practices are the playground for interplay of belief and illness. Moreover, this research provides insights about socio-cultural or socio-psychological significance and of the alternative treatment, like folk and faith healing.

What are the common responses of the breast cancer sufferers to the hospital treatment? What type of body image a breast cancer sufferer imagines about herself with the impacts of social, cultural, religious and environmental factors and how the care givers influence on the breaking of negative body image in the mind of breast cancer sufferer about herself? These questions are answered in this study.

In addition to this, this study attempted to understand the belief, knowledge, attitude, practices and body image of breast cancer women. It also observed the transformation of roles and identities of breast cancer women in maintaining social relationships. Major attention was given to describe the roles and behavior of the primary, secondary and tertiary care givers (i.e. family members, nursing staff and domestic servants) during the treatment seeking process of the breast cancer women. Hope and struggle are the primary focus when it comes to comprehend the experiential narrative of breast cancer patients and their caregivers, details about health seeking practices and a continuous struggle is reflected in this study. Finally, to collect the folk narratives on the alternative treatments, particularly spiritual treatment, availed by the breast cancer women was also one of the major objectives. This

research was multi-locale ethnography, therefore, the hospitals of Lahore, Islamabad and Rawalpindi and the families of the selected patients at their homes to observe the domestic life of the patients and their primary caregivers were frequently visited. Majority of the selected patients or interlocutors were from Attock, Rawalpindi, Lahore, Islamabad and Chakwal.

The study used interpretative phenomenological analysis (IPA) and thematic inductive analysis to explore the observed data and narratives to seek deeper insights. Although the body of literature on the social, physical and psychological health of women with breast cancer is increasing, only a few researches have concentrated on the lived experiences of women with breast cancer and their care-networks. Informal and semi-structured interviews and group discussions were conducted with the patients of breast cancer and their care givers. Transcriptions of the interviews were analysed using interpretative phenomenological analysis. Discovered themes bring forth the significance of relationships and resources. The study explored the belief, knowledge, attitude, practices and body image of breast cancer women. The study explored roles and behaviors of the care givers during the treatment seeking the process of the women with breast cancer and its outcomes on treatment seeking the process. This study revealed the obstacles in the way of hope and struggle for treatment among women with breast cancer and their care givers and its outcomes on treatment seeking process. The study collected the folk narratives on the alternative treatments, particularly spiritual treatment, availed by the women with breast cancer.

The present study revealed that the increase of a discourse on patients' care and care-givers is an intriguing area of research in the social sciences. In the previous researches, little attention was given to framing relationships between patients and their care givers. Therefore, this study addresses the gap of 'seeing' the experience in 'holistic' perspective. In addition, a dynamic relationship of reciprocity was observed during the fieldwork between the care takers and care givers. It identifies the difference between religious and spiritual treatments and documents the prevalent local ritual and spiritual healing methods. The present research establishes that the care givers, particularly family members as primary care givers play an important role in making breast cancer patients strong, talking about stress in family and renegotiating the roles of relationships within the family. Secondary care givers include nursing staff of the hospitals and clinics. Tertiary care givers include domestic servants. The present research also focuses on medical, folk and faith healers, who also have crucial medico-cultural role. This study brings forth the answers to the questions that how interpretations and explanations of sickness and health are perceived, shaped and reviewed in the light of psychological, social and cultural dynamics. The present research revealed that the lack of awareness and late diagnosis are major reasons of bad outcomes of breast cancer. The study provided suggestions in the furtherance of improving outcomes of this illness, and early detection is very critical. Countries with weak health mechanism and limited resources, where most of the women are detected in the late stages of their breast cancer, should put great attention on early detection schemes based on awareness of early manifestation and referral to detection and cure. Shame, shyness, and stigmatization about 'breast' in the cultural frame is significant aspect that creates hindrance for promotion of awareness, accessibility to diagnostic and treatment facilities and bringing forth the issue in routine vernacular among families.

Using the phenomenological approach, illness experiences of breast cancer women and the roles of their care givers were studied. To understand the roles of care givers, family members as primary carers, nurses as secondary and paid servants as tertiary were classified into three units of observation. The beliefs, knowledge, attitudes and practices were extracted from interactive instances, narratives, and dialogues or verbatim of breast cancer women and their care givers regarding breast cancer. Analysis used the apprehensions and motivations about the body image, spiritual healing, faith in divinity, obstacles and struggle in the treatment seeking process. Folk narratives on the alternative treatments were collected particularly spiritual treatment, availed by the breast cancer women. All the collected interactive instances, narratives, dialogues or verbatim were units of analysis.

In the findings of part one, major themes were: beliefs and knowledge about breast cancer, a collective experience, spirituality, concerns of body image, loss of control, and healthcare experiences. Second part deals with the role of care givers within the framework of the treatment of the breast cancer women. Third part deals with the exploration of diverse socio-economic statuses of the breast cancer women and their care givers and its upshots on treatment seeking process. 13 out of 27 breast cancer women, and their family members, were greatly impacted by the financial burden due to the expensive treatment. Fourth part deals with the folk narratives of the breast cancer women and their care givers regarding treatments of spiritual, homeopathic and bio-medical.

Spiritual, ritual, bio-medical treatments and support of care givers are enduring mechanisms to cope with the illness. Social and economic conditions create obstacles in the way of hope and struggle for treatment. Care givers play key role in whole illness phase. Faith and beliefs of the women and their care givers provide reflections on praxis that regulates the multiple treatment venues including traditional and magico-religious practices. This study also found that social, cultural, religious and environmental factors put negative effects on woman with breast cancer to imagine her body image a negatively.

This study calls for attention to study of the exchange relationship between a sufferer and her caregivers. Anthropological observation is implied as an attempt to bring forth a ‘holistic perspective’. Through this research a trajectory of feelings, reflections, reactions and effects associated to breast cancer experiences are comprehended among the sufferers and their care-givers. A study is required influencing outer and inner factors which incite negative and positive body image in the minds of breast cancer sufferers.

Cross-disciplinary discussions and conversations are possible and necessary to attain effective medicine, humane healing, and ethical science to bring an atmosphere equal for the rich and the poor patients. By observing the ways, this research has explored that how faith, folk and spiritual healings are interrelated and how the non-materials become very real for the people in sense of practicing spiritual healing. Furthermore, several ancient, spiritual and folk healing practices of the people of remote areas of Pakistan have been documented for the future researches in this account. There is need to think of plausible coping mechanisms for dealing with aggression and pessimism among the breast cancer sufferers, for example services of psycho-therapists should be provided to the breast cancer sufferers and their care givers. This research is the passage to many new inquiries that will open up the phenomenological details for better understanding and management of breast cancer patients and their care-network.

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CHAPTER 1
INTRODUCTION

The history of breast cancer is traced back to ancient Egypt, where the first case was recorded in 1600 BC. At that time, the reasons of this illness were not recognized well. Although, the ancient Greeks accepted that improper humors of body are the causes of breast cancer, many reasons of this illness were suggested in the 17th and 18th centuries (Brechon, 2012). In earlier times the treatments of breast cancer were not aimed at curing the illness but suggesting short reliefs. The Egyptian Edwin Smith Papyrus viewed this illness saying, "there is no treatment" (Brechon, 2012). Modern treatments of breast cancer started in the 19th century. In 1882, William Halsted started radical mastectomy in the United States which lasted until the 20th century. In 1895, first low-dose X-rays were invented by Wilhelm Rontgen in Germany. It was called mammograms for the diagnosis of breast cancer. Later on many developments in the medical field paved the way for treating and reducing the risks of breast cancer (Chun, 2017).

Breast cancer is a disease which is influenced by hormones, and is one of the most prevalent types of cancer all over the world. Each year, it appears one of the leading causes of death worldwide affecting 2.1 million women. According to an estimation, in the world in 2018, 627,000 women died of the breast cancer. It is nearly 15 % of all cancer deaths among women. It is considered as the most frequent and malevolent disease of women causing female mortality in the world (WHO, 2018). The cancer of breast is the most feared cancer among women due to its frequency, and socio-psychological impact. In developed and in developing countries, the rates of breast cancer are swelling day by day. Observing the age standardized rate per 100,000 among developed countries, Belgium has top rate of breast cancer with 113.2, Luxembourg has 109.3, Netherlands, 105.9, France, 99.1, the UK 93.6, and the US has 84.9 (WCRF, 2018).

Among the developing countries such as India, the rates of breast cancer increase every year. In India, breast cancer is diagnosed among 100, 000 women every year, and it was predicted that it will rise to 131 000 by 2020 (Oncol, 2009). In Singapore, the rates increased from 1968 to 1972, with 20.2 per 100,000 per year and from 2006 to 2010 with 60.7 per 100,000 per year. Over last 10 years, the rates of breast cancer in China and India have increased up to

30% (Bhatia, Gen Re, & Asia, 2016). Its prevalence is rising in the developing countries because of the increased exposure to carcinogenic foods and lifestyle. However with some prevention, risk reductions have been achieved, but these efforts have failed in low- and middle-income states, where this illness is diagnosed in the last or late stages (WHO, 2017). Breast cancer is omnipresent across all economic statuses, social classes or cultures. Pakistan is on the 58th position of the world ranking where breast cancer is widely diagnosed (WHO, 2010). In Pakistan, one in nine women is a breast cancer sufferer (Sohail & Alam, 2007).

The present research identified and focused upon the major themes such as the belief, knowledge, attitude, practices and body image of breast cancer women regarding their lived experiences of the illness. It made attempts to find out and analyze the impact of behaviors of the care givers such family members, nurses and domestic servants etc. on the process of the treatment and illness experiences of the women. Further, it tried to observe the roles and identities of breast cancer women in maintaining social relationships. It tried to observe the attitude of the practitioners towards the patients of varying financial statuses. The current study made attempts to observe and note down the prevalent alternative patterns of treatments particularly spiritual treatment and traditional healing practices. The cultural praxis to deal with the chronic illnesses is explored for its hermeneutics in social arena.

Among the Asian countries, Pakistan has the top rates of breast cancer (Menhas & Umer 2015). Since the inception of the hospital *Shaukat Khanum Memorial Cancer Hospital and Research Centre* (SKMCH&RC) in December 1994, the breast cancer has appeared continuously to be reported increasingly and being cured over the years (Banning, 2009). Due to early diagnosis and treatment, the survival rates of patients are better in the developed countries. Routine mammography, screening programs and awareness campaigns are not commonly available in the underdeveloped countries. Awareness of breast cancer among female population is considered primary workable solution. In the social and economic setup of the developing countries, it is the most feasible way to promote the idea that early detection of this disease is the best way for survival.

Through this research, an attempt has been made to understand the knowledge, attitudes, conceptions and practices of the Pakistani population towards breast cancer. Gender discrimination at homes works as a barrier, which negatively affects the treatment seeking. Chronic illness of breast cancer has a great social impact on the roles and identities of patients, and their families. Patients playing an ascribed sick role has many privileges. Her family members or primary carers pay many obligations to get successful survival and to diminish the fears of death.

1.1 Initiation into Research

It was my second semester of PhD course work that a course titled *Folklore Theory and Techniques* was taught to us by Dr. Sadia Abid. Fulfilling the partial needs of this course, I worked on an assignment, *Folk knowledge and practices of health*. I did field work for two months in rural areas of the Northern Punjab of Pakistan. The beliefs and practices of interlocutors regarding their faith, folk and ritual healings, fascinated me to understand the rural philosophy of health. After the submission of assignment, in a weekly meeting with my Supervisor, Dr. Rao Nadeem Alam, regarding the topic of PhD research, I shared with him my interest in researching folk beliefs, knowledge and practices of health. I told him about the role of family members in attaining treatment of this chronic illness and how much they suffer from psychological, social and financial issues because of this illness of their family member. I also shared the information about the rituals performed by the family members of the breast cancer. After a long discussion, Dr. Rao Nadeem suggested me to work on breast cancer patients as their rates are also increasing among women, and anthropological knowledge is needed to understand how the sufferers of breast cancer of different statuses cope with this illness with less available facilities. He suggested me, to make initial visits of the breast cancer hospitals and home settings of breast cancer patients and their care-givers to see whether they will share their lived experiences with me or not.

Before the proper data collection, I met with the breast cancer patients and their care givers in NORI (Nuclear Medicine, Oncology and Radiotherapy Institute), CMH (Combined Military Hospital) Rawalpindi, and Shoukat Khanum Memorial Hospital, Lahore.

Table 1. Hospitals where breast cancer women were approached

Sr.#	Names of hospitals	Registered women of breast cancer from 2016-18
1	NORI (Nuclear Medicine, Oncology and Radiotherapy Institute)	2400
2	CMH (Combined Military Hospital)	1942
3	Shoukat Khanum Memorial Hospital, Lahore	2520

(Source: Hospitals' administration)

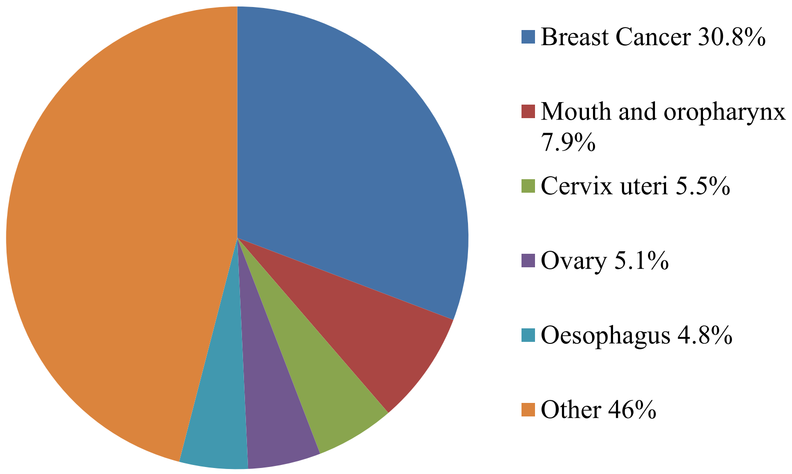
The table above shows the number of registered women with breast cancer from 2016 to 2018. Most of them came from the nearby districts of Rawalpindi, Lahore, Chakwal, Attock and Mianwali. I visited NORI (Nuclear Medicine, Oncology and Radiotherapy Institute), and met anonymously with a male oncologist sitting in OPD (Outdoor Patients Department). He welcomed but did not allow me to get in touch with patients and care givers sitting in the waiting area. He advised me to get permission first from the administration of the institute and then get in contact with the patients and their care givers. In my first visit to CMH (Combined Military Hospital), I met with a second stage breast cancer patient and her daughter who was her primary care-giver. The daughter of the patient gave me her address and allowed me to visit them at home. I reported my first success to my supervisor and then started work on my research proposal.

Under the topic of this research, attempts were made to cover anthropological perspective of a disease which is quite prevalent and putting grueling impacts on the attitude, responsibilities, identity and family life of the patient. This illness puts stressful impacts on the psychological and psychosocial aspects of life of the breast cancer sufferer and her family members. This qualitative study explored the experiences and coping mechanisms practiced by the Pakistani breast cancer sufferers in relation to its effects on their mental, physical health, family and religious issues.

Experiences of the breast cancer sufferers and their care givers were studied in a range of feelings, and their social relationships throughout the long sickness trajectory. The role of family members as care givers, friends, neighbors, colleagues, relatives as support groups and bio-medical, and faith and folk healers as practitioners were studied with their impacts and importance in the life of breast cancer sufferers. Prevailing spiritual, faith and folk healings as alternative bio-medical treatments among rural breast cancer patients and their carer givers were documented to understand the rural perspective of illness and health.

In countries with limited resources of diagnosis and treatments, majority of the patients appear with advanced stage of breast cancer that leads to poor outcome. Limited number of screening and diagnostic centers and absence of routine mammography are the major causes of the severity of the condition. Attempts have been made in the developing countries by some leading organizations to create Breast Self-Examination (BSE) and awareness campaigns for the purpose of early breast cancer detection. Basically *cancer* is the name of improper growth of cells in any part of the body. These cells in the body change their shapes. Generally a hard lump appears in the body and it stops or hampers the functioning of a particular part of the body. Breast cancer is a fatal disease that affects thousands of lives every year around the world. Cancer mortality profile of Pakistan has been shown below.

Figure 1. Cancer mortality profile of Pakistan



(Source: Cancer mortality profile of Pakistan (WHO, Cancer Country Profiles, 2014))

The chart shows that breast cancer is one of the major types of cancer among the women of Pakistan causing high mortality. Annually, the total number of deaths due to the all types of cancers are 52,500 (WHO.2014). In Pakistan, life expectancy among females is 66/67 years (WHO, 2016).

Pakistan spends its 2.6% of its total GDP on health sector (WHO, Cancer Country Profiles, 2014). During 2015-16, total expenditure was increased by 13 per cent over 2014-15 and during 2016-17, the health expenditure remained at Rs 145.97 billion (The Nation, 2019).

Currently government of Pakistan providing “ Sahet Insaf Card” to around 6 million families of province Punjab who are living below international poverty line of US$ 2 per day (Ministry of National Health Services Resolution and Coordination, 2019).

However diagnosing and screening facilities of breast cancer are limited. In Pakistan, breast cancer patients approach to clinics and hospitals at the late stages of their illness. Lack of awareness, low socio-economic statuses, social cultural barriers, and priority towards traditional healings are major reasons for this late presentation.

1.2 Statement of the Problem

Breast cancer is one of the most commonly reported types of cancer in the cancer hospitals of Pakistan. Contemporary literature about scientific reasoning is abundant; however, social and cultural aspects of the disease are under reported in the academic literature. It is equally important to study the lived experiences of breast cancer patients throughout the trajectory of their illness; this study attempts to fill this gap. For the provision of suitable treatment in the available resources, it is crucial to have established information regarding the psychosocial, religious and cultural context of breast cancer patients. This qualitative study was intended to explore the answers of some key questions such as: what types of the enduring mechanisms are used by the breast cancer sufferers and their care givers to cope with this illness? What are the major obstacles in treatment seeking process?

The role of caregivers remained the focus of this study with references to the financial and social changes occurring in the life of breast cancer patient. Hence, the account of inter-subjectivities of patients and caregivers is provided to shed light on the trajectory of illness and its social influences. The trajectory is phasic in nature where diagnosis, chemotherapy, radiations, surgery and medications are chronological phases, and different kinds of care-givers play an active role. Faith and belief of patients are also an integral part of this study that provides reflections on praxis that regulates the multiple treatment venues including traditional healers and magico-religious practices. Present study explores how much the alternative treatments, like folk and faith healings are effective in illness? What are the common responses of the breast cancer sufferers to the hospital treatment? What type of body image does a breast cancer sufferer imagine about herself with the impacts of social, cultural, religious and environmental factors? In a whole the problem of this study is to understand common experiences of breast cancer women and their care-givers about a phenomenon of illness.

This research was multi-locale ethnography; major visits were in the hospitals of Lahore, Islamabad and Rawalpindi, and the families of the selected patients were visited at their homes to observe the domestic life of the patients and their primary care-givers. Majority of the selected patients were from Attock, Rawalpindi, Islamabad and Chakwal.

1.3. Objectives of the Study

Keeping in view the magnitude and scope of the research topic, research objectives were very carefully framed to guide the research.

- To understand the belief, knowledge, attitude, practices, and body image of breast cancer women.
- To observe the transformation of roles and identities of breast cancer women in maintaining social relationships.
- To describe the roles and behaviors of the care-givers (family members, nursing staff and domestic servants, etc.) during the treatment seeking process of the women with breast cancer.
- To observe the obstacles in the way of hope and struggle for treatment among women with breast cancer and their care-givers and its outcomes on the treatment seeking process.
- To collect the folk narratives on the alternative treatments particularly spiritual treatment, availed by the breast cancer women.

1.4. Operationalization of key concepts

To understand the social, cultural processes of illness, cure, seeking of health care and the relationship of care seekers and care-givers, it is very important to operationalize the key concepts.

1.4.1. The concept of health: Health is a condition of complete bodily, mental, and social well-being (WHO, 1948). However, the concept of health is different in different cultures. The meanings and standards of health are not only geographically and culturally different but also change over times according to the prevailing socio-economic and cultural arrangements (Seymour-Smith, 1986).

In the present study, the idea of health among the breast cancer women and their care-givers has been found with its unique nature. For example, there are different meanings of health among patients of short illnesses and chronic illnesses. The concept of complete health includes short illnesses of temperature, flue, indigestion and diarrhea with the idea that these short illnesses will recharge body with the excretion of bad substances. Biting of Hoverfly, Bee and Hornet are considered good for health. A person with chronic illness is considered unhealthy.

1.4.2. Breast cancer sufferer's sick role: the term sick role is introduced by Talcot Parson (1951). According to his observation, a patient has four privileges and obligations.
Privilege: Not held responsible for having fallen sick.
Privilege: Given respite from customary work or involvements
Demand: Psychologically must want to get well.
Demand: Should seek care and cooperate with providers (Parsons, 1951).
In the field work of this research, it was found the breast cancer patient had many privileges and demands. After diagnosis, a breast cancer patient suffers from a psychological stress. She is freed from all kinds of responsibilities, particularly manual work. Even she becomes a responsibility of her family members. With the provisions of all services by her family members, she is expected to respect their wishes, to seek complete treatment and cooperate with them. Attention and care from the whole family make her sick role stronger. Many times emotions of sympathy of neighbours, friends, and colleagues and relatives turn into stigma which make her sick role unbearable for her and put her into psychological distress. Her sick role makes her think about opportunity cost that many possible gains were possible if she was not engaged in illness.

1.4.3. A carer or caregiver: Both terms are synonymously used. A patient has a strong connectivity with his or her social network. For effective healing, it is important to address the social dimensions of a patient's life (Mehl-Madrona, 2005). Generally any person having health impairment might use services of care-givers to make his/her life easier. The services of care-givers are usually used to meet impairments related to a disease, disability, old age or a mental disorder. A carer or care-giver is a paid or an unpaid person who assists another individual in his or her daily activities. In the current research, all those family members, who are looking after their breast cancer sufferer, are relatives, and are primary care-givers because of their great impact and importance in the life of the breast cancer patient. All the nursing staff of hospitals and clinics, and hired servants, who are serving their breast cancer patients, were categorized as secondary and tertiary care-givers.

In the present research, the roles of family members of the breast cancer have been seen very active during the whole treatment seeking process. In all the twenty seven approached breast cancer cases, it was observed that patients wanted survival for their loved ones. Many primary care-givers (loved ones/ family members) were observed taking care of their breast cancer sufferer, with the purpose, to keep the future of their family intact. These primary care-givers were observed, managing medications and working as a spokesperson to doctors and nurses. In addition, they were noticed, helping to bath, to dress up, when their breast cancer sufferer was physically and mentally frail. All 54 care-givers were found active in giving services to their breast cancer sufferer. The domestic servants of breast cancer sufferers were seen, taking care of kids of the breast cancer patient, preparing meals, paying bills and all daily chores that they were not able to do alone. Male and female nurses nursing staff were observed very active during their working hours in the hospitals and clinics.

1.4.4 Psychological distress: Psychological distress is frequently reported by the breast cancer sufferers and their family members; however, there is a little social support and normal attitude available to them. As cited in the work of Dockery (2014), studies report that in the world, 10 to 20% of women with breast cancer meet criteria for anxiety disorders (Bloch & Clarke, 2002; Burgess *et al.*, 2005; Dausch, *et al.*, 2004; Love, Kissane,). Psychological distress among the breast cancer patients and their care-givers is of multifaceted nature. Their socio-economic statuses have great impact on the process of their treatment seeking. Breast cancer patients have been seen in great psychological distress because of their body image with their perception that they have impaired features of body, particularly bald head, dull and pale skin and damaged breasts.

Distress of upper class patients is different from that of the middle, lower middle and lower class. Patients of upper-class have been found devoid of financial problems and receive treatment from private hospitals. They have been found in distress because of the social stigma of this illness. Leaving social gatherings and adapting a new sick role has put them in great psychological distress. Patients of middle class have been found in making new priorities of life. Patients of lower middle class were found getting loans, doing extra work, and approaching welfare organizations for financial helps. Three out of total twenty seven breast cancer women were found approaching Bait-ul-Maal Pakistan (بیت المال پاکستان) for the payment of tests in private hospitals as those tests were not available in the government hospitals. Moreover, patients from lower class have not been found getting regular hospital treatment because of the financial problems.

Psychological distress has also been found among the family members or primary care-givers of the breast cancer women. This distress is particularly due to the additional duties, which they found because of chronic illness and prolong treatment of their loved one. The nature of their role is ascriptive. Adaptability and consistency in the long period of taking care of their loved one becomes a reason of their psychological distress. While giving priority to the treatment of a sick person of their family, they have been found curtailing their domestic expenses, selling extra properties and spending past savings.

1.5. What sets this research apart from other researches?

Being a student of *anthropology,* I do believe that anthropological research and analysis is exclusive neither for anthropologists, nor for the classroom students of anthropology. It matters elsewhere. Whether it is breast cancer, physical disability, psychiatric disease, addiction of the drugs, injury or disability of any kind, health treatments discriminations for genders or disparities, genetic diseases, morbidity or short life expectancy, a medical anthropology researcher talks about the issues of major and minor importance for common persons in the world over. A comprehensive work is needed with the help of social work volunteers, medical professionals, patient advocates, and health NGOs for breast cancer on the societal and physical issues of the breast cancer sufferers of Pakistan. This study calls for attention to study exchange relationship between a sufferer and her caregivers. It investigates the social forces which materialize the care for a care-giver.

The lens used in this research was anthropological observation that consequently attempts to bring forth a ‘holistic perspective’. The field of medical anthropology pays attention to diseases of greater importance that is rarely understood by the field of biomedicine alone. A part of work has focused on how the breast cancer alters the public, social and domestic identities of the sufferers. Through this research, a trajectory of feelings with breast cancer experiences was seen among the sufferers and their care-givers. This study has introduced with the influencing outer and inner factors which incite negative and positive body image in the minds of breast cancer sufferers.

Political economy of health is a significantly under-researched area in the Pakistani context. In attempt to address the discrimination between the rich and the poor breast cancer patients by the practitioners and their assistants such as nursing and administrative staffs, this work has presented a clear divide between the medical need and the social barriers. This work is in the spirit that cross-disciplinary discussions and conversations are possible and necessary to attain effective medicine, humane healing, and ethical science to bring an atmosphere equal for the rich and the poor patients.

By observing the ways, this research has explored that how faith, folk and spiritual healings are interrelated and how the non-materials become very real for the people in sense of practicing spiritual healing. Furthermore, several ancient, spiritual and folk healing practices of the people of remote areas of Pakistan have been documented for the future researches in this account. With the anthropological perspective this study has its limitations as it was carried out on a segment of the population such as visiting hospitals and outreach centers of a specific healthcare system. It has also focused on domestic setting to observe the relationships between breast cancer sufferers and their primary care-givers. This qualitative research has offered an opportunity to oncologists, nurses, and other health care professionals to enhance their understanding regarding the need of open communication of illness with the sufferers and their care-givers. It, further, offers them to think of plausible coping mechanisms for dealing with aggression and pessimism among the breast cancer sufferers.

1.6. Ethical Concerns of Research

After the topic formation, I prepared a research proposal under the direct mentorship of my supervisor, Dr. Rao Nadeem Alam. The topic was approved by the ASBR (Advanced Studies Board of Research) of the university. Following an organized scheme of the department, named: pre-data collection seminar, I presented my research proposal before the senior, junior faculty members, and students of the department. I got a formal letter from the department, which entailed my connection with the university, purpose of my research and a request to all the hospitals, clinics and research centers of Rawalpindi, Islamabad and Lahore, treating breast cancer, to cooperate with me in the collection of data. While entering in discussion with the breast cancer patients and their primary care-givers, I got their consent by telling the purpose of my research. Before the interaction with the breast cancer patients during their chemotherapy, I got an informed consent of the concerned doctor. I approached only those breast cancer patients and their care-givers at their domestic settings, and they showed their trust in me, allowing me to meet them at their homes. Respecting the privacy of the patients and their care-givers, I used pseudonyms in writing the thesis. I also got the informed consent from bio-medical practitioners, folk and faith healers while visiting with the breast cancer patients and their care-givers.

1.7. Limitationsn

Following the ethnographic approach, the research was planned to start from cancer hospitals, particularly the breast cancer hospitals, with the purpose to observe the patients and healers' relationship and to get interaction with these patients and their care-givers to get lived experiences of their illness. One of the selected hospitals of Islamabad was affiliated with Atomic Energy Commission. Before giving permission of the data collection, the administration of the hospital asked me to submit a formal application, dully attested by the head of my department of the university and my degree supervisor, a certificate from local police station of the area of my residence and a certificate from local body administration of my residence. This procedure put me in delays for three weeks. The selected other two cancer hospitals in Rawalpindi and Islamabad were situated with distance of one hour drive. The selected cancer hospital in Lahore was at the distance of five hours' drive. For data collection in the hospital of Lahore and its breast cancer patients, I stayed for five months in Lahore.

Among all the approached breast cancer patients, three were not able to bear the fees of tests suggested by the doctors of the government hospitals to get results from the laboratories in private clinics and one was not able to get complete treatment including the suggested tests. I was embarrassed that I was not able to help them financially, but I took their applications to some non-governmental charity organizations and Pakistan Social Welfare Department (Bait-ul-Maal). There, they faced long delays; this was again embarrassing for me, but luckily they got financial assistance.

To get views of different kinds of respondents, method of Focus Group Discussions was used. During the research it was always very difficult to arrange these meetings, so all FGDs were conducted in parts. For example one part was conducted at home and second part at hospital to get participation of physicians and nurses.

It was also difficult to make male family members or male primary care givers to talk and tell me about the condition of their loved ones and tell the situation they are facing during the treatment seeking period. So, some of the male primary care givers were not ready to talk and sit in FGDs.

During long discussions with breast cancer affected women and their care givers, it was found that many times they mix the mental stress with physical side effects of breast cancer and its treatment.

Linguistic barrier was another challenge while collecting data of ritual healings for breast cancer. Most of the names and meanings of rituals were not easily understandable. So, educated informant was always required to get meanings of those health rituals to record the local information with meanings.

Religious beliefs of health were widely seen among respondents which were source of motivation for them and this information was recorded during the research. This thing was a challenge for me to differentiate between their belief and their indifference behaviour regarding health and illness. As many women got late diagnosis and later on advance stages put everything on Allah that this illness is because of divine wish.

The cases who participated in research were from different classes of society such as lower, middle and high. So, there was large information gathered from respondents of each class. It took my full concentration and sufficient time to all respondents to understand their economic issues.

Participants gave positive views of behaviour of health care professionals in hospitals. But at home their views were somehow different. It can be their fear that their views can affect the behaviour of these professionals.

One limitation was length of time since treatment was started of each case. Respondents were dealing this illness with different timings. Some of women with breast cancer were of varied ages, as some had adult children and some had kids.

During the research sensitivity of the topic was a big challenge. Great importance was paid on making of questionnaires with the aim that no one get hurt with words of the questions. Despite many limitations, it is important that current study will help further qualitative researches in the field.

1.8. Positionality and Addressing Subjectivity

In ethnographic research, where rapport building works great in establishing positive interaction with the respondents, there always remain elements of emotionality and subjectivity. Interacting with the breast cancer patients and their care-givers, and making them share with me their lived experiences needed building of cordial ties with them. Being a daughter and daughter in-law of an ex-army officer, I got concession to interact with the breast cancer patients and their care-givers in Combined Military Hospital.

I was a native researcher, had information about the culture, language and religion of the respondents but I had no information about the, psycho-social and economic issues of breast cancer patients except that it is a chronic illness which comes at a later age. Being a female observing the illness experiences of female patients and their care-givers, I built a quality of relationship between me and my respondents. To address my subjectivity, I always prepared an interview guide before a conversation with patients and their care-givers and followed a scheme of data collection. However, I also got long accounts of the breast cancer patients, as it was ethically not possible to ask them questions written on my personal diary.

It was a part of research to observe the interaction of breast cancer patients and their care-givers with the folk and faith healers and to record the practices of rituals performed by them. The rituals they performed were for different purposes, such as for killing the impact of black and envious eye, and for removing the effects of bad spirits. Many rituals were used to bring good effects on the body of the sufferer. It was first time in my life that I observed the performances by the primary care-givers, and ritual performances and making of amulets by the faith healers. In the scorching heat of summers, traveling with respondents to visit faith healers appeared very difficult. One of the breast cancer patients and their care-givers visited a faith healer at a distance of two hours by a mini public bus, but I did not show my fatigue to sustain good relationship.

This also happened in the research that a woman was diagnosed with breast cancer, but her husband was not ready to take her to hospital. I interacted with her on her test days in the hospital and after that, she never came to hospital. I approached her at her home. I controlled myself and did not interfere in their domestic matters. I made many visits of her home and also went with her to a faith healer. I am not sure, but probably the thoughts of her husbands changed with many of my visits that avoiding treatment will incur death to her wife. After some times, her husband was ready for radio-therapy but not for mastectomy surgery.

The performances of rituals by the faith healers and the patients with their primary care-givers were related to contagious magic. However, they used to believe these as knowledge of their elders and religious saints. Before the research, I was naïve to these health rituals. Once, I applied a ritual of removing negative impact of bad eye at my home. This ritual was used to practice by the interlocutors for both short and long illnesses. I colored an egg yellow, moved it around my body, clock wise for seven times and put it on the heated pan and covered it with lid. After some time, a blast of egg switched on the fire alarm. I did not practice this ritual any more.

1.9 Overview of the chapters

Chapter 2 starts with the framework of multiple approaches and anthropological perspectives. It discusses the body as manifest, body shame, and body image near a woman with breast cancer. It incorporates the literature related to the distress among primary carers of breast cancer women and its outcomes on the treatment. It, further, gives debates on the aspects of hope and struggle, ritual, faith and spirituality as coping strategies. It gives a detailed overview of cancer and its negative metaphors. It debates the aspects of family support, mental health, quality of life of the breast cancer sufferers and their care-givers. It also includes literature related to the revisiting of interpersonal relationships after breast cancer diagnosis. It overviews women's health, access and availability of health facilities.

Chapter 3 incorporates a combination of mixed qualitative methods to get the in-depth information regarding the lived experiences of women with breast cancer and their care-givers. It discusses positioning of the researcher within the research. Looking at the sensitivity of the issue of the part of female body, the research techniques were applied after building rapport with the care-givers of the breast cancer women. With the help of different methods of *participant observation, convenience sampling, group discussions, cases, informal and semi-structured interviews, and photography*, information was gathered in the whole research process.

Chapter 4 introduces the country, province and the targeted districts of the breast cancer sufferers. The aim of studying these four districts, i.e., Rawalpindi, Attock, Chakwal and Mianwali was that most of the studied breast cancer sufferers were from these districts. Looking at the tradition of *Purdah* (veil) observed by women of all these districts, this chapter explains tradition of veil. It explains possible factors that are responsible for cancer among the Pakistani women

Chapter 5 provides field findings and their analysis. It presents themes generated from the data. It presents key and verbatim accounts of women with breast cancer and their care-givers. It classifies the data and its analysis into four parts. The first part deals with beliefs and knowledge about breast cancer, a collective experience, spirituality, concerns of body image, loss of control, and healthcare experiences. The second part deals with the role of care-givers within the framework of the treatment of the breast cancer women. The third part deals with the exploration of diverse socio-economic statuses of the care-givers and its outcomes on the treatment seeking process of their breast cancer loved ones. The last part deals with the folk narratives of the breast cancer women and their care-givers regarding the treatments of spiritual, homeopathic and bio-medical.

Chapter 6 discusses major findings and themes of study. It discusses about opportunities and structures for diagnosis, stress after diagnosis, lack of screening facilities, adaptation patterns to post-diagnosis life, fear and threats as perceived to accompany breast cancer, religious and spiritual beliefs among breast cancer women and attitude towards the hospital treatment. It also discusses physical features of higher and significant concerns. It discusses care-givers as support groups. It also discusses the perceptions of breast cancer patients regarding their appearance. It covers discussions of many themes within the light of already carried out researches.

This chapter concludes with the anthropological perspective which is a holistic perspective. This perspective provides lenses to see human behavior focusing religious, social, psychological and economic aspects. It gives findings of all five objectives of the study. It concludes with the distinct information of body image concerns and "*Gherat*" a place of dignity of women with breast cancer.

CHAPTER 2

LITERATURE REVIEW

Many decades ago, Eric Wolf (1964) emphasizes that the field of anthropology has always had one foot in the sciences and one foot in the field of humanities. According to Wolf (1964), “Anthropology is both the most scientific of the humanities and the most humanistic of the sciences”. Another perspective of anthropology is its interpretive-humanistic perspective which gives a deep insight into the fine points or specifics of a particular human culture (Wolf, 1964, p.1). In already carried out researches, it was noted that the researchers of anthropology have been involved in the search for unique cotemporary cultures. They observed and interpreted multitude of diverse human beliefs, values and behaviors.

As a field of study, Anthropology is splendidly suitable to acquaint students with a universal or global perspective. By discovering the range and levels of human diversity in all the subfields of anthropology, it assists students to get knowledge about human condition across the world. The focus of anthropological perspective is usually critical thinking, assessment of contesting hypothesis and skillfulness to generalize from peculiar data (Scupin, 2012). According to Peacock (1986), there are broadly two elements of theoretical perspectives: one is the study of human behavior (being free from cultural influence), and another is holistic view (Peacock, 1986). The present study of lived experiences of women with breast cancer and their care-givers is much inclined towards holistic perspective of anthropology.

In every culture, there exist an integral body of beliefs, knowledge, and practices around the life experiences of health and illnesses (Scotch, 1963, p. 30) (Scotch, 1963). Although illness and cure are studied often within the biological sciences, there are many facts such as whether an individual gets sick at all, what illness he acquires and what type of cures he receives, depend widely on social factors. To understand diverse human behaviors and social structure, ethnographic lens could help understand conceptuality (Scotch, 1963, p. 30). The present research aimed to explore the prevalent beliefs, knowledge and practices of breast cancer women and their care-givers in Pakistan.

The terms, “anthropology of illness", "anthropology of health" and, “anthropology of medicine” have been synonymously used in Anthropological literature. These terms come under the field of "medical anthropology". It is translated from a Dutch term "*medische anthropologie*" of the 19th century, which was used by a few authors during the 1940s, signifying theoretical and philosophical understanding of concepts of illness, disease, cure and health (Entralgo, 1968). Development of medical anthropology can be traced in the four major streams of anthropological enquiry: the work of early physical anthropologists in evolution of man and his adaptation, ethnographic research in primitive medicine, researches in psychiatric issues in the school of culture and personality, and interest of anthropology in international health (Foster & Anderson, 1978; Levinson & Ember, 1996). The present study is related to the field of medical anthropology.

Using the lenses of anthropology and medical science, Parson (1951), Scotch (1963), Susan (1978), McElroy (1990), Comelles (2000), Gibbon (2006), Francine and Serge (2007), Anne Harrington (2008), Good, Byron, Michael, Sarah, & Mary-Jo DelVecchio Good, Eds. (2010), Mukherjee (2011), Leze (2014), Ismael and Oriol (2019) and many others gave deeper understanding regarding illness, sick role, health, folk medical beliefs and practices. Some of them worked particularly on breast cancer with different contexts of culture and systems of public health. According to the constitution of World Health Organization, "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being" (Lock & Nguyen, 2010, p. 3).

The current qualitative study debates some key questions, such as, what are the enduring mechanisms adopted by the breast cancer women and their family members to cope with the breast cancer? What are the major effects of breast cancer on the psychological, physical health, social and economic spheres of life? How much crucial is the role of family members and professional care-givers in the treatment seeking process of breast cancer? In addition to these questions, documenting the lived experiences of the breast cancer sufferers and choosing between rituals, spiritual and biomedical treatments by these sufferers were also the goals of the research.

2.1 Framework of multiple approaches and anthropological perspectives of illness

To address the above questions, "biocultural" model is supportive to make clear the multi-layered situations in which illness of breast cancer impacts women and their families. McElroy (1990) proposed "biocultural" model in which cultural information is collected and combined with environmental and biological data (McElroy, 1990, p. 243-265). Theoretical framework of the current research presents a fusion of structural-functional and cultural approaches. "Sick role" is a strong application of structural-functional theory which is widely used in Medical Anthropology. Talcot Parson (1951) was the proponent of this term. He theorized an element of the social structure that is sick role. The concept of sick role in medical anthropology is a very strong utilization of the structural-functional theory (Parsons, 1951, p. 289). ‘By institutional definition of the sick role, the sick person is helpless and therefore is in need of help’ (Parsons, 1951, p. 296). Parson (1951) postulated social structure of sick role in the United States of America after observing the demeanor of the sickness by its people. He advocated a kind of structural functional analysis in which interacting units make the structure of social system which supports in the growth and continuity of that system (Britannica, 2019). The breast cancer patients of the rural areas of Pakistan were found performing the same role.

Figure 2: Sick role defined by Parson (1951)

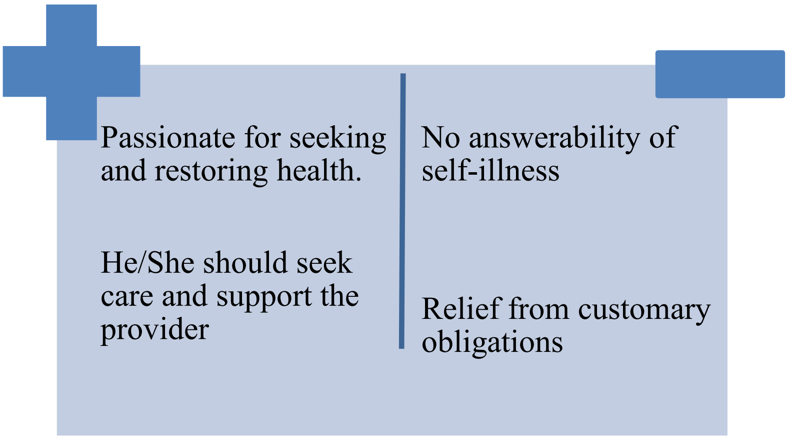


Figure 2: (Source: Parson's (1951) sick role)

He found that the position of a patient demonstrates four privileges, roles or obligations. Privilege: No answerability of self-illness. Privilege: relief from customary obligations. Demand: passionate for seeking and restoring health. Demand: should seek care and support the provider (Parsons, 1951, p. 294).

From the structural functional point of view, the sick role of an individual increases burden on family and society, particularly in the work area. There are fewer expectations from an ill person because of her legitimate sick role reduces stress in society. Privileges and demands create conducive environment for sick person to recover and re-enter in society which ultimately creates social equilibrium (Anderson, 1996, p. 132-133). Hospitals and doctors play a great role in regulizing a mechanism for handling problems of personality and its adjustment. A family of the patient plays the same function of regulizing mechanism. Both institutes of hospital and family perform the same role in some conditions. Readjustment and compromises at social level are required to regain the equilbrium (Parson & Fox, 1952).

The theoritical framework of this study presents a blend of cultural and material approaches. Dressler (2001) illustrates that being anthropologists studying health, we lurch in a place where it makes us understand the ways of cultual and structural construction interchange as this interchange leaves impacts on individuals (Dressler, 2008, p. 457). In medical anthropology, the framework of cultural and material approaches open doors of criticism on the interchange of culture, biology and their effects on human body. This framework is applicable in placing patterns of illnesses with social environments, historical contexts, and in the understanding of social structures that increase social disparity and burdens of illnesses (Leatherman, 1998; Oths, 1999; Leatherman, 2005).

Physical surroundings, social networks, social cultural belief system and historally constructed gender and power relationships are considered parts of social environement (Barnett, Anderson, Blosnich, & Halverso, 2005; Barnett & Casper, 2001). In social environment, culturally defined beliefs work to assist understanding of people regarding illness from prevention to cure (Dressler & Oths, 1997). Social environement assists in shaping the distribution of disease and health across human populace.

Dressler's and Leatherman's blend of cultural and structural approaches, and holistic approach of McElroy and Townsend develop a framework of biocultural approach which positions social phenomena, consisting health and disease with a large socio-historical, economic and political frameworks. This framework allows for concurrent assessment of the effects and results of forces of macro and micro level on the condition of the physical wellbeing of individual and population (Dressler, 2008; Leatherman, 2005; McElroy & Jezewski, 2000; McElroy & Townsend, 2004). These approaches give comprehensive understanding of diverse relationship between culture, disease, and risks of disease in given physical environments. Biocultural framework is helpful to understand illness and health issues of the women of Pakistan. Particularly in understanding the illness of breast cancer of females, where aspects of culture and structure interact constantly and diversely.

Farmer (1959) found that there are new challenges given by chronic illness such as AIDS to anthropology, and some of them are theoretical. These challenges are faced by ethnographers who want to study, understand and explain new phenomena. They face challenges regarding their contribution into the preventive efforts. He presents a processual approach as a need to study illness representations. In this approach, one is an observer of the arrival of a disorder previously anonymous to the observer's host community. Before the advent of new illness, there exist no knowledge about this new illness, and then a period of knowledge comes. With time and exposure to the new situation, the agreement and disagreement regarding the nature of the illness develops a cultural model to be understood and shared by the given community. In illness studies, medical anthropologists have been found researching the degree to which existing model is shared (Farmer, 1959).

Global interdependence has become an undisputable fact in the present world. As the developed industrial countries expanded, the world shrank and communication among different societies whether ther are close by or far off got frequent. Golomb (1985) in his research among Thai people found that globalization having its positive and negative effects has greatly affected the ecological and environmental balance of the planet. It has also affected the wellbeing and health of animal species and plants, predominantly human species. Although due to the globalization, advanced medical treatments are available in the whole world yet people follow all kinds of healing processes including traditional and religious treatments. Though Western-based scientific forms of medicine may be available, many Thais still rely on traditional practitioners. He observed that despite being educated and rich, *Thai* people adhere to traditional and religious treatments. He gave name of therapeutic pluralism to this belief and explained that people do not depend on only one therapeutic system. He observed that people rely on multi- therapies such as magic, rituals and advanced scientific medications and therapeutics (Golomb, 1985).

MAYS (Medical Anthropology of Young Scholars) 6th annual conference which held on 11-12 June 2015 in Amsterdam focused on emotions and feelings which are generally ignored by the researchers. Conference stressed, as once Reis (1998) stated, emotions are not an unnecessary 'fungus' that should be cleansed from research (Reis, 1998). Moreover, once implied by Claude Levi-Strauss (1966), anthropology works against the dichotomy between concepts of emotions and rationality. Emotions as research topic, methodology was discussed by the visitors of the conference. In addition, relationship of emotions with anthropology and its presence in the works of Levi- Strauss (1988) were also discussed. The present research also addressed the emotions of breast cancer sufferers and their family members as they were found emotionally disturbed by the physical, social and economic consequences of this illness.

Ellison narrates In *Yaya's Story*, how *Stoller* weaves the insights he gained from illness with those he attained from long-term ethnographic research to meditate on the human condition.

Well-being is elusive. How do we find it in ourselves and understand what it means to others? The way that we understand illness, how we experience it and tell about it, reflects our social framework. Furthermore, illness, like ethnographic fieldwork, may provide a conduit to create an existential connection that relies on 'what you have in your heart' (as citaed in Ellison, 2014).

Peter and Melvin (1991) in their work found that it is beneficial to see breast cancer patients and caregivers from evolutionary perspective by reason of its historical or classic scope. Genus Homo first appeared nearly two million years ago. The first accepted anatomically modern humans (Homo sapiens) appeared as prevalent about 40,000 years ago. Among the ancient cultural patterns, hunting and gathering were exclusive one and this initial lifestyle is rare with exception of some groups which have been a field of empirical anthropological study as "Culture in an anthropological science, entails learned patterns of behavior and belief characteristics of a particular society" (Petter & Melvin, 1991).

The anthropological research is creating and spreading global awareness. It is producing an acknowledgement for traditions and cultures other than our own. According to Scupin (2012, p. 2-3), "Anthropology promotes a cross-cultural perspective that allows us to see ourselves as part of one human family in the midst of tremendous diversity". The study of anthropology trains its students to inquire into a field which sheds light on both the humanities and the science. Among its major perspectives, the important one is its accurate scientific methods and research models which examine the role of social institutions in a society, social relationships, behavior and human evolution (Scupin, 2012, p. 2-3).

2.2 The body as manifest field

In the present research, the idea of body and its image has greatly been found**.** The idea of body in relevance to the health and sickness is well elaborated by the anthropologists. Hughes and Lock (1987) draw our attention towards the concept of "three bodies". First is Individual body: it is phenomenological impression of the lived actions of the body-self (Hughes & Lock, 1987, pp. 6-41). Despite having different individual bodies all the human beings share some common intuitive sense of body-self (Mauss, 1985 [1938]). Nonetheless, the composing elements of the body are mind, soul, self, psyche and their connections to each other and situations in which body experiences health and sickness. The second is the *social body* which represents body as a symbol to think about culture, society and nature as Douglas (1970) gave the same idea. This discussion follows the path of symbolic, social and structuralist anthropologists, who represented continuous exchange of contexts between the social and natural world. In health, body gives a model of organic collectivity or wholeness, and in sickness, body gives a model of social clash and disharmony. A society in both health and sickness gives a model for discerning and knowing the body. The third analysis of body is *body politic*. It refers to administer, coordinate and regulate the body in sexuality, reproduction, work, illness and any other form of human difference. Body is an “aesthetic” expression of social patterns and cultural categories (Desjarlais, 1992, p. 101).

2.2.1 Body Shame

Being the members of traditional society, women in the research were found greatly concerned about the aspect of body shame. Very often women feel shame to discuss their body issue with male health provider and particularly to give him a physical examination (Auerbach, 1982). Breast cancer women face a dilemma in which they think what to share with others and what not. This is also a management of uncertainty or social process which helps a patient to manage her social relationships (Tone, Rikke, & Mette, 2016).

The women, who have breast cancer cases in their family history, they believe their breasts to be ‘treacherous parts of body’ or ‘time bombs’. Different perceptions bring about different understanding about self (Robertson, 2000). In the recent research, it was noticed that women hide their illness of breast cancer from colleagues, neighbors and from friends, too. They feel shame to tell about the illness of their breast which they consider an important part of female body. Scott *et al*., (2005) address this behavior as an embodied risk. William (2006) used the concept of ‘bring the body in’ to understand the lives of those who are at risk. Kavanagh and Broom (1998) viewed that environmental and lifestyle risks have always been in focus of social scientists, but they missed embodied risk of a third type which people experience in illness. In this risk, women perceive their body as a source of danger.

2.2.2 Body image of a breast cancer woman

During the research, the aspect of body image was greatly shared by the women with breast cancer. The body image presents positive and negative perceptions of one’s physical appearance. Negative perceptions lead towards disruption in body image which causes mental discomfort with one’s self (Astrid, et al., 2013; Stokes & Frederick-Recascino, 2003). Combination of treatments such as raditation and chemotherapy cause discolouration of skin and neurological changes (Lundstedt, Gustafsson, Steineck, & et al., 2011). Body is a major theme when one studies homo-sapiens. Body is a contextualized product of historical, evolutionary and contemporary social differences resulting from endless interactions among people, their environment and the economic, political and social milieu in which they spend life (Lock & Nguyen, 2010). Symbolically breast is seen as feminine identity, motherhood and fertility (Pikler, Winterowd & Arthur, 2003). During the process of her treatment, a breast cancer woman thinks greatly about her body image and about her sexuality (Kinamore, 2008; Pelusi , 2006). Surgical treatments damage her self-image by damaging her natural beauty and affiliation with family (Anllo, 2000; Hanson Frost, *et al.,* 2000; Harmer, 2006). The loss of weight and hair, infertility, anxiety, less sexual desire and fatigue are major side effects which not only disturb her mind and body but also her social life (Shapiro, *et al*., 2001). Several breast cancer patients report menopausal indications, insomnia, weakness and disturbed normal memory (Bender, Ergun, Rosenzweig, Cohen, & Sereika, 2005). Great concerns of body image have been seen among the survivors of breast cancer. Among many concerns, major ones are related to lack of femininity, impaired appearance and sexual unattractiveness (Cohen, Kahn, & Steeves, 1998; Ganz, Greendale, Petersen, Kahn & Bower, 2003; Helms, O'Hea & Corso, 2008; Hopwood, 1993; White, 2000).

Many researches emphasized the need to find out that whether different surgical treatments bring different body image issues or not (Goldberg, Scott, Davidson, Murray, & Stallard, 1992; Schover, Yetman, Tuason, Meisler, & Esselstyn, 1995). It was found that in different types of surgical treatments, the issues of body image have not been found the same. There are differences in concerns regarding outer appearance with different treatments (Goldberg, 1992; Schover, 1995). In many researches, it was found that[1]mastectomy treated breast cancer patient faced more concerns of body image than the patient who receives [2]lumpectomy treatment (Avis, Crawford & Manuel, 2004; Ganz, Rowland, Desmond, Meyerowitz & Wyatt, 1998; Rowland, Desmond, Meyerowitz, Belin, Wyatt & Ganz, 2000). For instance, mastectomy treated patients told more about the alterations in their body image, decreases libido and feelings of sexually unattractiveness then the lumpectomy treated patients (Ganz, Rowland, Desmond, Meyerowitz & Wyatt, 1998).

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[1] Mastectomy refers to a treatment in which a breast cancer patient goes through a total removal of her breast. It is called mastectomy.

[2] Lumpectomy refers to a treatment in which a breast cancer patient goes through a breast-conserving surgery (lumpectomy). It is followed by radiation.

The negative body image of breast cancer patients can be dangerous to their whole quality of life and can increase and perpetuate their psychological stress even after their survival (Alfano & Rowland, 2006; NICE, 2004). After the treatment, the living of a survived breast cancer patient due to her depressions regarding body has been seen very terrible (Deshields, Tibbs, Fan & Taylor, 2006; Ganz, Kwan, Stanton, Krupnick & Rowland, 2004). Mental stress and anxious feelings related to the body image and standard of living have been identified to be the two mainly reported psychological issues experienced by the breast cancer patients (Burgess, *et al.,* 2008; Deshields, Tibbs, Fan & Tylor, 2006; Knobf, Fennie, Avila, Woodward, Thomp & Diepietro, 2006; Reich, Lesur & Perdrizet-Chevallier, 2008; Shapiro, *et al*., 2001; Thewes, Butow, Girgis & Pendlebury, 2004).

Mostly distress related to the body image has been reported in their post-treatment life. Especially in her first hundred days after treatment, she faces great emotional and mental dissatisfaction. She starts to reflect on her whole breast cancer experience. She tries to accept and understand her new assimilation and recognition as a breast cancer survivor (Knobf, 2007). Women during treatment feel themselves strong strugglers doing something great to get rid of this illness. Many times their emotions become self-center focusing all the time on their body image and about disturbed relationships because of their illness (Cowley, Heyman, Stanton, & Milner, 2000). Post-treatment time also becomes stressful when they follow regular check-ups. Fear of recurrence of illness, uncertainty of life, feelings of worry and many other feelings of loneliness, alienation, disaffection and antipathy are likely to reappear (Boyle, 2006; Knobf, 2007). The women who get late treatment suffer from many horrible side effects; they report the loss of hair and weight many times in different treatments of this illness, gain of weight, weakness in body, and other health issues (Boyle, 2006; Knobf, 2007).

2.2.3 Expressions of body and illness among South Asian women

Cohen Lawrence (1999) researched in Chennai in India among the people who sold their kidneys. The answer of the most women was common. “That’s where he hits me; there, when I do not have any more money”. The scar of operation of the removal of one kidney has two meanings for a woman: the first one is the effort that she helped her husband in his difficult times, and the second is a symbol of bad economic condition when she sold her body part for the family (Cohen, 1999, p. 135-165).

Margaret Lock (2015) found a kind of adaptation. In the process of this adaptation, a body is considered consolidated with environmental forces from the start of life to its living duration. She believes that development in epigenetics led us to the particulars of how events or happenings in life and ecological exposure incorporate, becoming the results of our illnesses and health (Lock, 2015, p. 151-177). Indians have been found pill conscious. It can be a tradition of their medical imperialism. Among the poor population, the tradition to follow the traditional remedies in pre- and post-diagnosis period is a substitute for western treatments and medicines (Greenhalgh, 1987, p. 307-318).

Because of cultural beliefs, the patriarchal family system and the communication barriers in the examination of a body part, the females of South Asia avoid screening tests (Bottorff, Johnson, Bhagat, Grewal, Balneaves *et al,* 1998; Scanlon & Wood, 2005; Watts, Merrel, Murphy, & Williams, 2004). Traditionally through their brought up, they are educated to sacrifice their life, time and efforts for their family. They give priority to the needs of their family ignoring their own health. In the South Asian societies, women's dignity and praise are attached with their sacrifices (Day, 1994). They avoid exposing and discussing their body part to any healer especially to a male practitioner. Even they deliberately avoid self-examination with fingers considering it inappropriate (Bottorff, Johnson, Bhagat, Grewal, Balneaves, *et al*, 1998; Lende & Lachiondo, 2009).

In South Asia, women suffering from breast cancer or survived from this illness have similar experiences. For example, the Pakistani breast cancer sufferers have same concerns which the women of other areas of South Asia have, too (Banning, Hafeez, Faisal & Hassan, 2009). Like white women, Asian women after the diagnosis of their illness remain concerned about the restoration of their health to fulfill their duties again. They report their concerns related to the body appearance, affected sexual health, fear of recurrence, financial burden on family, stress related to the future of children, etc. (Ashing-Giwa, Padilla, & Tejero, 2004). Apart from avoiding screening tests and check-ups, the South Asian women have additional challenges like lack of awareness, communication barriers especially to the remote rural women, traditional beliefs of hiding body features, gender specific duties and paying family obligations (Ashing-Giwa, Padilla & Tejero, 2004).

The South Asian women, due to social and cultural reasons, do not discuss their body even in the perspective of their illness. A story telling is a successful method in which they share their experience of breast cancer (Howard, Bottorff, Balneaves & Grewal, 2007). The story telling is one of successful and common methods in gaining in-depth information from the

South Asian women (Bottorff, Johnson, Bhagat, Grewal, Balneaves *et al.*, 1998). Like the South Asian breast cancer sufferers, the African American breast cancer survivors have been seen concerned about their body image, too. The loss of hair, damaged breast, their impaired skin, varying emotional, financial and social support from the family members, friends and health professionals are a source of great stress for them. These sufferers were found developing awareness and information among their peer groups regarding this illness and to make people aware of the damages of late diagnosis (Wilmoth & Sanders, 2001).

Wilmoth and Sanders (2001) state that during research among the South Asian women, four storylines emerged, such as "dealing with just another health problem'' (decreasing the illness by expressing her ability to defeat it), "getting through a family crisis" (the shock and anxiety suffered by the family members and their full emotional and financial support), "never-ending fear and suffering" (disbelief in the diagnosis and the trauma of the disease), and "a lesson from God" (a trial from God or beliefs of destiny, karma and faith in increase of prayer for the successful treatment.

For these cultural reasons, majority of the sufferers hide their illness. In such traditional societies, they are expected to avoid discussing illness regarding their body parts such as breast cancer. They hide in order to avoid the queries and thoughts of the people asking, "Is the breast cancer a genetic or endemic disease? The negative assumptions attached with cancer harm decisions for the future life of their children especially in search of marriage proposals (Bottorff, Johnson, Bhagat, Grewal, Balneaves & *et al.*, 1998; Guidry, Matthews & Copeland, 2003). Despite having or going through any illness, they expect to carry out their normal domestic duties. Within brought up, they are taught to give preference to the needs of family (Grewal, Bottorff & Hilton, 2005).

In the Pakistani traditional society, woman is considered dignity and respect ([3]*Gherat*) of the family. In her breast cancer experience, cultural beliefs, attitudes and traditions play an important role. She is expected to preserve the dignity of the family and hide the things which are considered dishonored in the society. Religious practices particularly in the South Asian societies are considered a source of inner peace, bravery and strength (Gurm, Stephen, MacKenzie, Doll & Barroetavena, 2008; Banning, Hafeez, Faisal & Hassan, 2009). Religious beliefs and practices do not always give positive outcomes for an ill person. Many times

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[3] *Gherat:* a local term refers to the dignity and respect. In a traditional society, it is generally used for the woman. The woman is considered a part of dignity and respect for the family, community or tribe.

feelings of anger and anxiety regarding the belief that their illness is a punishment from God, give negative results in the kind of high blood pressure, indigestion of food, depression, helplessness and hopelessness (Levine, Yoo, Aviv, Ewing & Au, 2007; Shaw, Joseph & Linley, 2005).

2.3 Distress among primary care-givers of breast cancer patients and its outcomes on treatment

This aspect has widely been seen in the present research. A cancer patient is never a lone sufferer of his or her illness, but people surrounding her or him also suffer from this illness in many ways. The cancer sufferer's social surroundings are shaped by the regular practices which aim to manage the illness and its treatment (Pérez, 2015, p. 1-2). Macmillan's Cancer Support reports that informal care-givers have been seen providing more hours of care per week to their cancer patients. Such attention and care normally provide multiple tasks from practical works to emotional support. Many psycho-social researches in oncology have revealed the repercussions of the illness of cancer and its care in the unit of family. These researches focused on the impacts of the experiences of this illness on the physical and psychological health of the members of family. These researches open ways for the anthropology of care to explore the dynamics, cognitive, practical and emotional features of care in the daily context of the people suffering from cancer (Pérez, 2015, p. 1-2).

Negative myths, analogy and suppositions give mental distress to the patient and her care-givers which lead towards severe anxiety and pessimism during the illness (Sontag, 2014). The anxious feelings from diagnosis to the post-treatment check-ups not only impinge the patients, but also disturb their families. Its diagnosis perturbs the net of the whole family (Rolland, 2005). In a long treatment, a patient always needs attention of the primary care-givers. In this relation, her family members play a very important role. Open communication related to the new changes in the body supports in the acceptance of the illness for the patient and caregivers, and finally decrease the stress related to the impaired features of the body (Oktay, Bellin, Scarvalon, Appling & Helzlsouer, 2011).

Several patients explain their story with anger, anxiety, distress and frustration, and these feelings are central to understand the social and cultural status of care seekers and care-givers (Jain, 2013, p. 235). To understand inequalities in the care and treatment of cancer is an anthropological objective (Lee, 2014, p. 255-268). Cancer should not be seen just an illness or disease, but a constructive aspect of economic and social life. In the health sector, “people’s accounts” work as “fabric of alternative social theorizing” (Petryna & Adriana, 2013, p. 3).

Continuous emotional support of the care-givers puts positive effects from diagnosis to the treatment process. In the treatment process of breast cancer patients, their primary carers also need emotional and psychological support (Hewitt, 2002). The whole process of struggle from diagnosis to its treatment is called cancer survivorship (National Coalition for Cancer Survivorship, 2007). After the diagnosis, breast cancer patients and their family members cope with the required medical and emotional needs (Cappiello, Cunningham, Knobf & Erdos, 2007; Hudson, 2005). The bio-medical practitioners and researchers of breast cancer have sufficient understanding regarding the distress of the patients and their care-givers. However, the literature on their emotional and psychological needs is very limited which only discuss the standard of life faced by the breast cancer patients and their primary care-givers (Vacek, Winstead-Fry, Secker-Walker, Hooper & Plante, 2005).

Mccubbin and Patterson (1983) state that a family can cope with stress successfully if it adapts the illness of its family member. In adaptation of illness, there are some beneficial strategies the family of breast cancer should follow. Firstly, it should adapt new coping behavior to accept the illness of the beloved one. Here it is important to interpret the illness. Secondly, it should accept the treatment process with the hope to restore health. The patient and her care-givers must understand the need of the essential treatments such as chemo, radio therapies and surgery. Thirdly, it should understand the new situation with giving it new meanings. Communication between patient and her care-giver works as a major supporter in the treatment process. The theory demands three steps or adaptations from the primary care-givers of the breast cancer patient to release the fatigue in the patient and in the family (Mccubbin & Patterson, 1983).

2.4 Hope and struggle

Hope is a goal or outcome one desires; willpower or motivating determination that is gained only after overcoming barriers’ way power, or the ability to find and act on effective method of attaining goals” (Synder & Donelson, 1991, p. 285-305). Ribera and Muela state that during fieldwork one of the care-givers of a breast cancer patient viewed hope saying, “The entire struggle, to get timely tests, check-ups, and treatments are hope to achieve survival. The social theorists gave an idea of “logic of actions” (Ribera & Muela , 2003, pp. 87-103). They added that during the fieldwork, hope and struggle were largely seen as logic of action among the health seekers and their care-givers in the treatment process. Efforts are made to "cool down" the illness by many healing practices (Ribera & Muela , 2003, p. 87-103).

Gap has been found between the beliefs of the patient and knowledge of the doctor (Colin, 2005, p. 91-103). This gap hampers the hope and struggle for the health seeking process of the patient and his or her care-givers. Lay concepts support in understanding how, why and when the sufferer of an illness presents his or her problem (Fitzpatrick, 1984). A little communication and different expectations between the medical practitioner and his or her patients leads towards ineffective clinical care. This gap brings less effective results and more medico-legal and health seeker management problems. Labeling, evaluating and arranging of sickness by the family members of a patient are very useful in understanding their struggle for survival (Kleinman, 1978, p. 85-93).

Families of the patients struggle and search ways of treatments, and this can be found in their verbatim (Topley, 1981, p. 332-334). During my fieldwork, communicating with the family members of breast cancer patients and listening to the lived experiences of patients particularly their feelings, optimism and struggle for treatment, a great need of sufficient health care has been found. The practitioners of the breast cancer believe that the survived patients are living longer with hope and struggle. They allow themselves to understand the basic need of their lives and that is hope. Practitioners acknowledge the positive and negative impacts on the condition of cancer. For a breast cancer patient, her survivorship has been admitted a positive phase in her cancer experience (Grunfeld, Coyle & Whelan, 2004; Hewitt, 2002;). It is one of the major progresses that two million women are breast cancer survivors in the United States (National Cancer Institute, 2006).

2.5 Ritual, faith, and spirituality as coping strategies

In the present research, respondents were found performing certain rituals for the eradication of illness. They were also found possesing and using certain beliefs to cope with illness psychologically. These rituals and belifs were a part of their culture. Maliknowski's Functionalism (1922) and Radcliff-Brown's (1933) Structural Functionalism illustrated cultural interconnections, beliefs and practices strengthning culture as a whole. Several health rituals are performed to kill the negative effects of evil eye, envious enemy and the influences of devil. This concept of symbolic causation can be taken a little bit similar to the Evans-Pritchard's (1937) narrations that how Azande associated death with fallen granary finally to witchcraft (Evans-Pritchard, 1937). The same findings were established in an Egyptian village, where the causes of blindness were apparent such as excessive weeping, dirt and untreated eye disease. However, most of the people believed that evil eye is a major cause of blindness (Sandra, 2010, p. 251). Blyth's (2012) work among Paiute can be illustrated here as a health related example. He found that beliefs about sorcery is appeared as a cause of illness. So, the fear of sorcery shapes illness behavior, which ultimately contributes to group endurance and survival (Anderson, 1996, p. 132).

The meanings of *rituals* were illustrated by many authors, such as Leach (1954) states that *rituals* are like actions, which are performed continuiously in community. Traditions of a community involve many rituals (Bell, 1997). Rituals are the product of a man's expereinces (Douglas, 1960). In the 19th century, the term *rituals* appeared to evaluate the experiences of man (Bell, 2009). In some researches, many respondents answered that for locally identified "illness", they utilize biomedical resources, but traditional medicine is widely preferred (Makemba, et al., 1996; Molyneux, Mungala-Odera, Harpham, & Snow, 1999; Tarimo, Lwihula, Minjas & Bygbjerg, 2000; Winch, *et al*., 1996).

Spirituality and religion are reciprocally used in health-related studies; however, efforts have been made to differentiate between the both (Baldacchino & Draper , 2001; McGrath, 2004). Religion can be defined as 'an organized system of beliefs, practices, rituals, and symbols", and spirituality can be defined as 'one's transcendent tie to some other types of higher power' (Thoresen, 1998). Coping with the help of religious beliefs give them psychological comfort. Religious coping includes: attending worship places like shrines, temples and mosques, praying, reciting religious scripts and hymns, and visiting religious healers like priests, saints and religious scholars.

Spirituality is also referred to the religious context through beliefs and practices, and experimental context through inner peace, understanding meaning of life and searching contentment. It has been found that many people consider themselves spiritual but not religious. They turn to spirituality without using reference of God. Their spiritual feelings work as an influential and vital source of coping. Through antiquity, it has been seen that Church remained an important part of the lives of Black people providing them education, companionship, place of worship, and spiritual guidance in all aspects of life (Bourjolly, 1998; Lincoln, 1990; Phillips, 1999).

2.6 Narratives of illness

Narratives of illness allow the researcher to understand questions of risk and real perspectives of cancer disease (Frank, 2010; Good, 1994). Narratives of illness in anthropology open individual subjectivities and adversity (Kleinman, 1989; Mattingly, 2000). Furthermore, narratives of illness help researchers to understand the reality and build social world (Mattingly, 1998).

On the basis of many narratives, new subjectivities (Foucault, 1978) and meanings are searched (Povinelli, 2010). During the last 30 years, personal narratives of cancer increased, comprising anthropologists and many other academics (DiGiacomo, 1987; Frank, 1991; Jain, 2013; Lorde, 1980; Stacey, 1997; Stoller, 2005). These pesonal narratives of cancer provide in-depth insights into the complete detail of the writer's experience of cancer, and the making of new subjectivities.

In many cultures rituals, faith, and spirituality are used as coping strategies. For example, all cultures have their narratives to answer their question that "why" these sufferings and illnesses happen to be. There are some major ideas which not only give the answer of question "Why", but also work as an alternative treatment. Anne Harrington (2008) proposed these ideas such as power of suggestion, the body that speaks the power of positive thinking broken by modern life, healing ties, and eastward journeys. The first gives the meaning of treating illness by using powerful figures with rituals and customs. The second idea gives power and makes the intentions of the patient strong to suffer all the severity of the illness. This idea also refers to the good results of firm faith. The third idea gives reason of our frequent illness that is modern life style. The fourth idea tells the immense importance of social support in illness and treatment. The last idea introduces the wisdom of Eastern part of the world: China, India and Japan to get treatment for contemporary decayed lives (Harrington, 2008).

2.7 Illness as deviance

Illness can be regarded both as a deviant social role and as a psychological disturbance. Intimate and cherished psycho-dynamic relationship has been found between the doctor and the patient. As illness is taken as a kind of deviant behavior, it is subjected to a classic sociological analysis of deviance. It encompasses withdrawal from normal responsibilities and regular activities. Illness is liberation from pressures and responsibilities of ordinary life. It is a strategic expression of deviance: firstly, culture puts great burden of activities on average individual and secondly, it is connected with the standard consequences of childhood dependency (Talcott, 1952, p. 31).

2.8 Concordance and compliance: Bio-medical, folk and faith healers

For the restoration of the sense of uniformity with a prescribed treatment, three kinds of concepts can be used to describe the attitude of the patients. These three concepts are compliance, adherence and concordance. The order of the concepts presents an order of the evolution of healer-sufferer equality (Leibing, 2010, p. 146). A change from compliance to adherence presents an increasing consciousness of power relations in healer and sufferer interactions and distrust in health institutions like biomedicine. However, the term 'adherence' progresses to move the 'residue of stigma and culpability' (Greene, 2004, p. 327–43) much relevant to 'compliance' (Trostle, 2000, p. 37-55). Adherence is moderately an inert impression of the consciousness of a moral plight, rather than an idea based upon a practice (Leibing, 2010, p. 146).

'Concordance' -- a new British concept -- intended to change the relationship of healer and health seeker in which the healer is powerful to force the patient to participate in the choices of treatment (Stevenson, 2004, p. 184–93 ; Stevenson & Scambler, 2005, p. 5-22). This term also refers to the formation of an accord that respects the desires and beliefs of the patients. Karnieli-Miller & Eisikovits (2009) named this shared decision-making and mutual understanding as 'the illusory power to decide'.

Constant support from healers provides them potential to carry on their normal living with normal sensibility (Knobf, 2007). Health care professionals play an important role in providing breast cancer patients with special support to make them get complete treatment and ultimately to restart the normal living (Maher & Fenlon, 2010). Professionals of all types like oncologists, psychologists, faith and folk healers have the same role in motivating the patient to get complete treatment with the hope of survivorship. Understanding the psychological, social and physical aspects of the patients can assist the healer to adapt suitable and appropriate type of treatment. The complete knowledge about the patient can support the practitioner to establish applicable care, assistance, guidance and interventions which can build up a perfect quality of life (NICE, 2004). The heath care provider can be a biased professional in his or her perceptions about patients and their problems (Musoke, Boynton, Butler & Musoke, 2015).

In his “explanatory model”, Kleinman (1989) assists in understanding that the patient and healer encounters are of sensual and temporary nature. As in the first step, people perceive the symptoms of their illness. On the second step, they try to understand the sense of symptoms. On the third step, they seek available medical help, and on the fourth step their doctor gives a diagnosis in which they get prescription of the treatment type. All steps are ignored what proceeds before the illness and clinical encounter (as cited in Ecks, 2014).

2.9 Revisiting interpersonal relationships after breast cancer diagnosis

A plenty of literature was found on the negative psychosocial effects of the breast cancer patients, but they missed one positive outcome that is the element of struggle. Generally old age patients of chronic illnesses seem stubborn and even become challenges for their nurses and health professionals (Brodaty, Draper, & Low, 2003). Fears of death, uncertainty of life and fears of leaving the loved ones incite the patient to struggle for survival. This struggle brings positive results such as understanding her life in a positive way (Andrykowski, Brady, & Hunt, 1993). In many researches, relevant to this area have found that women after getting treatment and survival have different views about life. By having different exposure to life as compared to other women, they praise life and prove stronger interpersonal ties (Collins, Taylor, & Skokan, 1990; Wyatt, Kurtz, & Liken, 1993).

During interviewing, it has been found that within five years of their illness from diagnosis to the treatment phases, cancer sufferers reported satisfactory and positive changes in their interpersonal relationships. They reported their positive perspective about themselves and about their life (Collins, Taylor, & Skokan, 1990; Wyatt, Kurtz, & Liken, 1993). During the research on the psychosocial aspects of the breast cancer patients, majority of the sufferers reported the emergence of minimum one satisfactory and positive outcome from experience of their breast cancer. These satisfactory and positive outcomes include contentment with new happenings of life, personal growth, praise for life and increase of spirituality (Sears, Stanton & Danoff-Burg, 2003). In the present research, it was found that it is a cultural rather personal choice to seek positivity; disease is as an opportunity to renogiatiate, and prioritize one’s relationships.

2.10 Women’s health, access and availability of health facilities

In the search of holistic perspective of breast cancer, this literature also reviews and examines general literature and knowledge on women’s health, and access and availability of health facilities. It also makes an attempt to elaborate major factors and reasons which prevent them to avail themselves of breast cancer detection and treatments. Majority of the women population suffer from poverty of health opportunities as compared to men in the same society. They suffer in terms of income, health facilities and education (Singh & Kapoor, 2009). During the present research, it was found that patients of breast cancer in Pakistan face severe social and financial challenges.

Women need trust and permission from the male head of the family to visit medical centers for check-ups and treatments (Kisttana, 2009; Milller & Arachu, 2004; Payne, 2006). Apart from illiteracy, deprivation and dependency on male family members, ethnic, religious and gender discrimination are the major factors in the access to health facilities (Ravindran, 1995). Poor female patients have limited access to medical centers which cause delay of diagnosis and treatment. Poverty badly affects female patients' health and their access to medical centers. As a result, this situation leads towards the last stage and hence death (Karen & Janes, 2009).

A woman's health including her mental, physical and social condition problems is affected by the social norms, values and attitudes prevailing in the society and family (International Monetary Fund, 2006). Socially and culturally constructed constraints make access of women to the health centers difficult. Disparate gender relations impact upon the choices of men and women in relation to seeking health and even employment. This leads to more discrimination on the basis of race, class and age. Gender perspective is important in analyzing prevailing customs, traditions and power relations (Lee & Callin, 2005).

A disparate approach and distribution of resources including medical services is apparent in the world in which clear gender discrimination and inequality are a reality. Unqualified, illiterate and poor debtors facing economic constraints stay behind in access to good health facilities and females centered health services. Inequality, lack of autonomy at household level, little decision power and no authority over material resources of the family make them very weak to move outside for seeking health treatment. Seclusion practices in a patriarchal family reinforce their dependency on males of the family. This leads to the self-denial of the women and their minimum access to the medical services. In addition, distance from the health service and low income are major factors among the rural patients in seeking health and treatment (Jejeenhoy, 2005). The place of residence is an important factor for a sick woman. Urban areas are equipped with modern health facilities than rural areas, where facilities are not available (Abosse, Woldie & Ololo, 2010).

In the developing countries, women face several challenges. These challenges include illiteracy, lack of awareness, dependency on male family members and many other socio-cultural and socio-economic factors (The World Bank, 2004). Culture and traditions of the given family or society influence the women's limited access to the medical centers and healers. Inherent disparity and discrimination affect the diagnosing and healing process (Alan, Julia, Guoxia, Terry, Cheng, Claud & et al., 2001).

Very often villages have distances and are isolated from one another. The people of rural areas have medical facilities at wide distances. Another hurdle is traveling; unavailability of transport and rough routes make their urge weak to seek treatment (Perry & Gesler, 2000). Organizational hurdles like sitting in waiting rooms for long times and waiting for tests and tests reports; limited number of nurses and specialists also disturb their access to the medical care services (Allman, Blumhagen & Brown, 1992). In the developing countries, overwhelming social and economic pressures encourage women to turn towards cheap traditional medical practices (Taylor & Dower, 1997). In traditional societies, women are expected to obey their social and gender roles. Being dependent on their male family members, they cannot afford the expenditures of their costly treatment. Food and education are usually considered more important than health seeking (Yoder, 1989).

A number of hurdles are there that affect women's health and their approach to health facilities. These hurdles consist of social and economic factors. Women's illness and poverty have direct relationship with each other. Illness is because of poverty and due to poverty illness cannot be cured. Environmental, demographic, economic, and socio-cultural, life style and hygienic factors are major contributors in women's access to health centers in the Pakistani society. In rural areas, unavailability of transport, lack of trained nurses and doctors, financial hurdles, attitudes and arrogant behavior of health facilitators are key reasons in lesser access to health centers and dependency on local healers (United Nation, 2004).

In many cases, despite the health center is geographically near, women avoid visiting that center for the preservation of their privacy. In this process, their disease transforms into chronic. Time taken to make decision in order to seek treatment may worsen the condition of the patient (Boeteng, 2006). Women's lack of interest in politics and economic sectors of the state make them unable to protect their health from disease and timely treatments. Social and economic hurdles are their major reasons (Wang, 2011).

Generally, the access to the health care center is affected by three major factors. The first is the characteristics of the population seeking health care. The second is the structure of the health center and the third is the behavior of health professional and health service providers (Alan, Julia, Guoxia, Terry, Cheng, Claud & et al., 2001). Majority of the health care centers do not have trained female staff, and this is a major reason for not visiting health care centers. In many societies, illiteracy, low level of low or high caste, and financial hurdles of women restrict them to visit and avail themselves of health care services. The absence of male family member also restricts them to visit health center (Skolnik, 2008). Mobility restrictions of females also work as barriers in the health seeking process. Lack of decision power of women is also a hurdle (White, 2005). Poverty is a big reason of women's lesser interest in seeking health. Traditional background, differences of patients and healers cause communication problem and consequently disease cannot be judged at time (Vera Lasch, Ute Sonntong, & Scnneider, 2010). Less than a decade ago, the biggest problem in global health seemed to be the lack of resources available to combat the multiple scourges ravaging the world's poor and sick. Heath of women is inevitably linked to their marginal status in society. They need economic resources to avail themselves of health facility (Garrett, 2007).

Studies of physical activities of women are important as their physical activities are different from men (Laura & Rutherfode, 2008). Socio-economic factors restrict women to approach health services. In many traditional societies, women work in an unorganized way and are poorly paid. In many health facilities, lack of female medical professionals is a gender discrimination which works as a barrier to the utilization of health care facility (Laura & Rutherfode, 2008). Health care statistics present discrimination against women globally (Isabel, Nancy , & Sara , 2001). Social scientists and feminists criticize biomedical model and socially constructed restrictions on women (Annas, Grodin, Gruskin & Mann, 1999). Traditional forces make women admit that their natural place is home. Their duties include child rearing and nursing elders of the family (Annas, Grodin, Gruskin & Mann, 1999).

The health of female population represents the health condition of the general population. Geographic, socio-cultural, economic and gender distances reflect the condition of the women's health of the given population. They have limited access and power over resources. The most important step in addressing the issue of gender disparity is stopping physical, financial and cultural pressures (Vera Lasch, Ute Sonntong, & Scnneider, 2010).

In some cultures, social-economic status, norms and traditions restrict women to discuss their physical problem with male health professionals. Absence or lack of female health professionals is a serious factor of women’s fewer visits to health care centers for check-ups, and treatments. Utilization of health facilities is highly affected by the charge of services, distance to health care center, cultural beliefs, level of literacy and health center’s inadequacies like out of stock medicines (Musoke, Boynton, Butler & Musoke, 2015). Providing income employments to the women can reduce their poverty and develop their living (Krogh, Nikolaj, Wendt, & Elkjaer, 2009).

2.11 Language of sickness: Analogies and metaphors ‘of’ and ‘for’ cancer/ illness

Aristotle narrates that metaphor is “giving something name that belongs to something else” (Aristotle, 1996). Metaphors rebuild intricate problems and assist to give meanings (Periyakoil, 2008). Susan believes that metaphors of illness and particularly for cancer create fear and stigma (Sontag, 1978). Researchers such as Reisfield and Wilson (2004) believe that metaphors of and for cancer are beneficial for the sufferers and their healers. For instance, the metaphor of “journey of life” provides patience and encourages setting of goals and progress. After diagnosis of breast cancer, a woman may feel herself a fighter. She may feel like “under attack”. She may conceptualize that she has to fight to survive for herself and for her family and will not give up (Mclean, 2014). She feels her illness of cancer as an “enemy”; her physician is playing the role of “commander”; she is fighting like a “combatant”; her care-givers are her “allies”, and the treatment she is receiving is “weaponry” with which she is fighting with the enemy of cancer (Mclean, 2014).

“Illness is a night side of life, a more onerous citizenship. Everyone who is born holds dual citizenship in the kingdom of well and in the kingdom of sick” (Sontag, 1978, p.). Everyone wants good health, but each one has to suffer spells of sickness. The stigma of its presence is more stressful than its diagnosis which leads a patient towards death. It is still a mystic black box and a mysterious entity, and still there are needs of extensive work on its happening and treatments (Sontag, 1978). Social stigma attached with this illness has always been seen. In early 1950s, Fanny Rosenow, a breast cancer survivor and an advocate of cancer requested New York Times for the purpose to post an advertisement for a helper group for the breast cancer patients. She received a strange response from the editor of the newspaper. With the expressions of reluctance, he replied her that he cannot publish word “breast” or “cancer”, she should use the word “chest wall disease in place of breast cancer” (Mukherjee, 2011). This illness is one of the major diseases of the modern time, and its metaphors are also modern.

This disease comes without specific symptoms as it comes without knocking the door. Cancer and tuberculosis both illnesses are of the same nature as both are abdominal, hideous and abhorrent to all (Sontag, 1978). This illness appeared for the first time in the period of Hippocrates around 400 BC in the medical literature. The word “crab” is derived from Greek word “Karkinos”, and the another Greek word “Onkos”, is used to describe “Tumor” which means “hardship and burden”. This illness is taken as a successful invader on the body features (Mukherjee, 2011). The doctors of nineteenth century linked this illness to civilization. They believe that this illness is caused by surge and turns off the modern life. Modern life style has increased pathological growth in the physique.

The people in traditional society rely on comparisons and metaphors of different types of medicines. Ayurvedic medicines are assumed to “balance” bodily harmone. Homeopathic treatments are taken as provokers of “vital force”. Bio-medical medicines work as “magic bullets” in treating a specific disease with determined drug elements (Ecks, 2014). Descriptive behavior of doctors increases when market competition and medical pluralism increase. Drug effects boost critical questions of post-colonial modernity, moral materiality, individual autonomy and connection between matters and mind (Ecks, 2014).

2.11.1 Cancer and its negative metaphors

Metaphor is the most real way of regarding a disease. In literature among several illnesses, Tuberculosis and Cancer have widely been used with distasteful and cumbersome metaphors. The continuous research will bring effective treatments. Karl Menniger writes in *The Vital Balance* that the illness of cancer will kill those patients who will be unable to bear its malignancy. He further viewed that most of the people will take their treatment against cancer as treatment against illness and many people will be demoralized knowing the fact of their illness (as cited in Sontag, 1978).

A major idea which is relevant to the negative way of thinking and expressing accounts about physical illness is “*broken by modern life”*. Alvin Toffler, in his idea of Future shock in 1970 says that a future shock is something in which we induce something new in individuals in very short time. The idea broken by modern life gives the same meanings (as cited in Harrington, 2008).

There is a great need of its conception among the common people. This illness should be de-mythicized. In Italy and France usually the doctor communicates with the patient’s relative when he or she is diagnosed cancer. According to the general opinion of the people, cancer is regarded as a scandal. News of this illness can jeopardize one's marital life, selection or promotion in job. Cancer is widely taken as a synonym for death. In Oxford English Dictionary, the word cancer has meanings of anything that agonize, frets, deteriorates and corrupts slowly and mysteriously. According to Thomas Paynell, cancer is a saddened thing which eats parts of the body (as cited in Sontag, 1978).

Throughout history, people made a personal sense of sufferings of illnesses on the basis of their experiences. Different cultures have their own interpretations on stockpile of moral, social and religious stories to answer the questions of the people that "why" they got ill. Traditionally some illnesses are linked with personal sin, bad deeds or a divine message from God to make correction in one's life style. This type of thinking about disease can be called as "mental illness". There is another way of thinking, i.e., telling stories about physical illness. This illness is claimed to be very close to science. Apart from traditional and physical illnesses, mind also matters. Rising questions in the minds of people regarding their illnesses like, why me?, why now?, and what next?, have meanings (Harrington, 2008).

The illness of cancer is believed as de-sexualizing. In this illness, the normal tissues of body turn hard. Among the oldest definitions of the cancer, this is widely accepted that cancer is an illness of growing abnormal cells, ultimately devastating growth that is measured with continuous speed. It is considered as demonic pregnancy. In this illness, the sufferer is attacked by alien cells which get double, and finally cause blockage of dis-functioning of body parts. Generally this illness is considered an illness of middle class. For a breast cancer patient, there is always a fight inside the body. Groddeck gave an equation that cancer is equal to death (as cited in Sontag, 1978).

Anxious feelings are considered a major reason among the causes of cancer disease. Many times repression of fierce feelings is imagined to cause cancer. Wilhelm Reich believes that cancer follows emotional resignation, a bio-energetic declining and losing of hope (as cited in Sontag, 1978). In the twentieth century, Tuberculosis was thought to be gruesome as the cancer is considered now. Sufferers of TB were considered as romantic personalities. The idea of sickness was attached with the ideas of "interest" and "romance" (Sontag, 1978). Schlegel in his remarkable essay, "On the study of Greek Poetry 1795", gives the idea of perfect heath by attaching "The interesting" with idea of modernity and romantic poetry (as cited in Sontag, 1978).

There are several metaphors which are attached with the cancer around the world. Novalis viewed in his works from 1799 to 1800 that sickness belongs to the idea of "individualizing".

Sadness is also attached with this illness which is considered a symbol of sensitivity and sensibility. This fatal disease is considered a test of noble character. Among Greeks, the fatal illness is considered as gratuitous or breach of divine law from ancestors. Many times, it is taken as a metaphor for the product of will. Kant in his work on Anthropology in 1798 makes metaphoric use of cancer. He believes that passion or cancer for real practical reasons is incurable (Sontag, 1978).

A common myth about cancer is the perception that the sufferer is responsible for his or her illness. Cancer is believed to be proposed as a situation of sadness and grief. Majority of the cancer patients report being stressed, anxious and disgruntled with their lives. They have depressed feelings of losing lovers, public identity, close friends, spouse or parents. It was believed that the sufferers of cancer got their illness because of hyperactivity and hypersensitivity. Golden found that melancholic women have more chances to get breast cancer than the sanguine women. During the spread of Plague in England in the sixteenth and seventeenth centuries, historian Keith Thomas found a widely believed concept that the happy people will not get plague and if they get it, they will be cured with their will power (as cited in Sontag, 1978).

Many times, it is believed that illness is interpreted as psychological event and people are motivated to get illness as unconsciously they want to have some illness, and they are again encouraged that they can treat themselves with their will power. Many times, it is believed that an ill person himself creates his illness. Many notions are attached with the treatment of cancer such as, “crusade against cancer”, “fight against cancer”, “cancer is a killer disease”, and people who have cancer in any part of their body are “cancer victims” (Sontag, 1978).

In the twentieth century, the metaphors that exhibit cancer give negative meaning such as abnormal growth, reluctance to consume or spend, and repression of energy etc. Cancer treatment in the twentieth century was believed worse than the disease. There were some military metaphors for cancer and its treatment such as metaphor of “areal warfare” was used for radiotherapy and the sufferers are “bombarded” with toxic radiations. Chemotherapy was used as “chemical warfare”, by using chemical as poison. Fight against cancer was also named as “colonial war” (Sontag, 1978).

Cancer was also used as a metaphor for brutal energy, and this energy constitute to work against the natural order of body. Many times it is understood as a disease of industrial world. It is also believed that the world without cancer is a fantasy. From environmental point of view, people started using cancer as metaphor for bad weather and environment, such as “environmental pollution is an epidemic or plague of cancer”. Cancer as a whole illness was also used as metaphor for corruption and injustice in society. Many times civil disorder was also perceived as a cancer. Foresight near Machiavelli, reason for Hobbes, tolerance for Shaftesbury, all these ideas can stop fatal disorder; these ideas were conceived on medical analogy. For all philosophers, the society was presumed to be in a normal healthy condition; its diseases means its disorders are manageable (Sontag, 1978).

2.11.2 Positivity and health seeking attitude

At times health seeking behavior is beyond financial affordability. Strategies are needed to involve all sources in making health seeking attitudes (White, 2005). In December 1998, on Sunday, The New York published an article of a famous medical cancer specialist Dr. Robert Buckman, who writes that, if the hope works in the cure of ailment than it was the most effective and powerful anti-cancer element the world had ever recognized (as cited in Harrington, 2008). After treatment mental relief shows their natural response that they feel their illness of breast cancer has been handled with complete treatment (Boyle, 2006; Knobf, 2007). In the traditions of Christian religion, Jesus of Gospel conveys to those who follow him, “your belief has cured you”. In second half of the nineteenth century, there were two groups with two beliefs regarding power of positive thinking. One group of scientists and doctors has great practical interest in power of positive thinking. In the modern world, they believe in the role of mental power but do not believe in supernatural or spiritual explanations of healing. Other group of scientists and doctors do not make clear distinctions between power of thinking of human mind and the spiritual or supernatural power (Harrington, 2008).

There is a famous idea, “The Body that Speaks”; that is attached with the way of thinking and expressing stories about physical illness. This idea is also taken as a self-conversation of a patient such as, “you know I cannot deliberate my feelings, I internalize, and I developed a tumor”. Idea of body that speaks has two ways in new medical narratives. The first is to express childhood emotions and fantasies that were forbidden in childhood. The second is the recovery of old buried memories of real events. Another major idea related to the way of thinking and expressing accounts about physical illness is, “the power of positive thinking” (Harrington, 2008).

Norman Vincent Peale (1898-1993) published his views about the power of positive thinking. He considers this thought very effective, “believe in yourself and have firm faith in your capability” (as cited in Harrington, 2008). Norman Vincent Peale (1898-1993) believes that it is the need of hour to do some practical things to cope with the problem of stress of modern society with positivity just like a pilot who never flies his plane on the same engine power. He changes with the requirement of smooth and safe flight. Stress is the worst enemy of the modern time. It is human's silent enemy. Pre-mature aging is one of major obvious results of modern stress (as cited in Harrington, 2008). Another idea related to the positive way of thinking is "Healing Ties". Dr. Gordon believes that loneliness is a danger for health which loses the sense of living together or living in the community and having intimacy with family (as cited in Harrington, 2008).

Pharmaceutical industry has multibillion dollars trade. Bill Moyers wrote "Healing and Mind" in 1993, focusing public's attention on their new mix and match idea of mind body healing (as cited in Harrington, 2008). New mix and match idea of healing includes ancient healing mechanisms, meditation, stress cutback, placebo healing and various other perspectives. Many scientists made efforts to knit together the gained experiences, making a relationship of diverse nature of medical, biological and cultural methods of treatments (Harrington, 2008).

2.12 Beliefs, knowledge, attitudes and practices regarding breast cancer

In ancient Greek philosophy, the word and idea of belief has two concepts, i.e., pistis and doxa. The concept pistis means "faith, conviction, confidence and trust", while the doxa refers to "opinion, sentiment, notion and assessment". Jonathan Leicester gave a comprehensive definition of belief, "it has the goals and purposes of guiding action in place of expressing and revealing truth" (Bastardi, Uhlmann, & Ross, 2011). Generally the word "belief" is used by philosophers to specific attitudes related to the correct or false concepts and ideas. Eric Schwitzgebel defines the term belief in the Stanford Encyclopedia of Philosophy saying, "It is an important aspect of mundane life" (as citef in Leicester, 2015).

According to Socrates, the term knowledge is referred to the "justified true belief". His definition of *knowledge* was many times challenged and interrogated by the sophists of their time (Gettier, 1963). Generally an attitude is a product of appraisal and judgment of any object which is expressed positively and negatively. In social sciences, the term *attitude* is widely used in declaring the liking and disliking of a place, individual, thing or an event. An individual can possess numerous attitudes towards person, place, object or event (Allport, 1935; Wood, 2000).

Generally, the knowledge of people regarding their understanding of illness, explaining the illness and healing is called health beliefs. Health beliefs among indigenous population remained the focus of many researches. The Western and industrial societies are quite developed in fields of diagnosis, tests and treating microorganisms such as virus and bacteria of acute nature. They believe that illness of breast cancer is a natural phenomenon which can be treated scientifically. People in traditional and unindustrialized societies believe in the supernatural reasons behind the breast cancer. They advocate and endorse faith healing and folk healing for treating breast cancer. They believe that western medicines have acute side effects which increase cancer (Dockery, 2014).

Health beliefs are found embedded in cultural beliefs. Rural people take female body as a symbol of shame and dignity. Because of these beliefs, they talk less about the severity of lumps in and around the breast which leads towards the sever stages of breast cancer (Bottorff & et al., 1998; Scanlon & Wood, 2005; Watts, Merrel, Murphey & Williams, 2004). Due to the cultural and religious reasons, rural women try to hide disease of their body part (Dockery, 2014). In South Asia, it is part of the local culture that women are brought up in such a way that they give priority to the needs of their family and ignore their personal health. They give priority to the honor and dignity of their family in the place of giving importance to their health. Ultimately, this negligence leads towards late detection and severity of illness (Day, 1994). Being members of traditional society, they avoid getting check-ups and treatment particularly from the male practitioners and many times they avoid self-examination considering it inappropriate (Bottorff & *et al*, 1998; Lende & Lanchiondo, 2009).

It is also a part of beliefs that the whole family makes decision in taking major steps regarding the type of treatment for breast cancer (Bottorff & *et al*, 1998; Bailey, Erwin & Berlin, 2000; Sadler, Dhanjal, Shah, Shah, Ko & C., *et al*, 2001). Modern practices of screening, check-ups, treatment and care are largely affected by factors of cultural beliefs. People shape their health beliefs with the help of their values and attitudes. For a clinician, it is highly desirable to be aware of cultural differences and try to provide health service putting attention to the cultural issues (Kleinman & Benson, 2006). Health care professionals and family members can play a vital role in making the breast cancer patient get all available and culturally suitable treatments. Educating family members on the consequences of late screening can change the cultural belief of hiding illness of breast and may create an eagerness to involve in the behavior of screening of breast (Scanlon & Wood, 2005).

2.13 Cancer and Psycho-social Impacts

An individual survived from the chronic illness of breast cancer is generally defined as "living with or beyond cancer" (Macmillan Cancer Support, 2008). This illness with its psychological impacts has been diagnosed as the second common cause of death among females after lungs cancer in the United Kingdom (Cancer Research UK, 2011). Psychosocial impacts of breast cancer on the lives of the patients have been widely discussed in the available literature. Psycho-social issues such as anxiety, social stigma especially in a traditional society, depression, damaged self-esteem, disrupted family and relationships, fear of future and death are mostly identified among breast cancer patients (Fobair, Stewart, Chang, D' Onofrio, Banks, & Bloom, 2006; Harmer, 2006; Hegel, *et al.,* 2006; Schnipper, 2001; Spencer, Lehman, Wynings, Arena & Carver, 1999). Despite timely treatment, the fear of recurrence of the cancer causes depression and anxiety among breast cancer patients (Ferrans, 1994). The terms of anxiety and depression are widely used by surgeons and physicians. Generally one thinks of anxiety and depression as feelings that anyone can experience through life. Depression and anxiety are expressions of the experiences of sadness, crying spells, fatigue, poor memory and hopelessness (Anderson, 1996, p. 245).

For a person, the diagnosis of cancer can be one of the most depressive medical diagnoses (Weisman & Worden, 1976). All steps like screening, diagnosis and examination of the type of the breast cancer brings out pessimistic feelings and distress in patient (Andersen, Kiecolt-Glaser, Glaser & Raymond, 1994).

There is a complexity of concepts when we consider a hypothetical relation between breast cancer and depression.

Several questions might be raised:

- Is depression a risk factor for breast cancer?
- Is depression a prognostic factor for breast cancer mortality?
- Is there a correlation between depression and disease severity (breast cancer advanced stage)?
- Is depression a protective factor for breast cancer?
- Is breast cancer a risk factor for depression?
- What is the impact of depression on the quality of life among breast cancer patients? (Perdrizet-Chevallie, Reich & Lesur, 2007).

Decisions regarding approving or disapproving the treatment options such as chemo, radio, surgery and other medications increase the feelings of anxiety, confusion, fear of death, and distress (Knobf, 2007; Reich, Lesur & Perdrizet-Chevallier, 2008). The level of anxiety depends upon severity of illness, treatment and medication. Illness of breast cancer is stressful for woman of any age, but young patients of breast cancer have been found more stressful than older women (Avis, Crawford & Manuel, 2004; Baucom, Porter, Kirby, Gremore, Keefe & Demore, 2006; Kroenke, Rosner, Chen, Kawachi, Colditz & Holmes, 2004). Women of older age undergoing malignant or tumor breast cancer have also been seen in great stress during examination and treatment (Ganz, Greendale, Petersen, Kahn & Bower, 2003).

After the completion of therapy treatments like chemotherapy and radiotherapy, breast cancer patients widely report about the lack of sleep, weakness, loss of memory, problems of concentration, increase of weight, and indications of menopause (Bender, Ergun, Rosenzweig, Cohen, & Sereika, 2005). From diagnosis to the side effects, all put severe mental shocks on women with increase of anxiety, fatigue and depression. Breast cancer survivors have been seen very concerned with their self-image, outer appearance, sexual unattractiveness, damaged self-integrity and strength of mind (Cohen, Kahn, & Steeves, 1998; Ganz P. A., Greendale, Peterson, Kahn & Bower, 2003; Helms, O' Hea, & Corso, 2008; Hopwood, 1993; White, 2000).

Earlier works on cancer in the field of anthropology focused on risks, causes and domestic and medical relationships created by the illness. Contemporary anthropological endeavors have expanded the attention to this illness as a “total social fact” (Jain, 2013). Through the sufferings like stigma, stress and inequality, cancer-driven relationships have been developed subjectively real (McMullin, 2016). Many anthropologists focused on the causes of cancer (Balshem, 1993; Chavez, Hubbell, McMullin, Martinez, & Mishra, 1995; Csordas, 1989; Hunt, 1998; Manderson, Markovic, & Quinn, 2005; Weiner, 1993). Sontag’s (1978) and Patterson’s (1987) detailed classic works on cancer gave multiple narratives that present a discourse of cancer and its stigma. Cancer develops mental stress indicated by rhetoric like, “dread disease”, “big C”, “cruel disease, “and “silent death” (Patterson, 1987; Sontag, 1978). The painful long treatment and fear of death create mental stress and dreadful feelings (Chavez, Hubbell, McMullin, Martinez, & Mishra, 1995; Gordon, 1990; Gordon, 1990b). Because of its many negative impacts on the life of the sufferer, cancer is considered as a dreadful illness (Macdonald, 2015; Trawick, 1991; Weiner, 1999).

Diagnosis and treatment cause emotional distress even this distress continues after survivorship (Epping-Jordan, Compas & Osowieki, 1999; Golden-Kreutz & Anderson, 2003;

Maunsell, Brisson, & Deschenes, 1992). During and after cancer treatment, depressive symptoms are largely reported (Golden-Kreutz & Anderson, 2003; Van't Spiker, Trijsburg, & Duivenvoorde, 1997). Among patients of all types of cancer, the breast cancer patients have third highest rate of depression in America (McDaniel, Hepworth, & Doherty, 1997).

Cancer survivors report distress if they get some major psychological concerns and they have been seen as they cope with these psychological concerns (Stanton, Danoff-Burg, & Huggins, 2002). In many researches, the stress has been seen as a life event, even the assumption of stress was seen requiring an individual to make some adjustment (Maunsell, Brisson, Mondor, Verreault & Deschenes, 2001; Golden-Kreutz, 2003). Quite often, it has been seen that women experience psychological stress doing complex decision-making. They feel threats to their body, and their ties with their loved one. Most of the survivors feel anxiety with the doubts that their cancer will return, particularly when they feel unknown symptoms on their bodies (Allen, Savadatti, & Levy, 2009; Thewes, Butow, Girgis, & Pendlebury, 2004).

Different studies indicate that stress and anxiety are dominant among the patients, their spouses, and care-givers (Boyer, et al., 2002; Grunfeld, 2004; Hasson-Ohayon, Goldzweig, Braun & Glinsky 2010). Most of the breast cancer patients meet criteria of anxiety and stress disorder (Burgess, Cornelius, Love, Graham, Richards, & Ramirez, 2005; Dausch, et al., 2004; Love, Kissane, Bloch & Clarke, 2002). During the period of recovery, fear of recurrence was largely reported as a psychological concern among breast patients (Cappiello, Cunningham, Knobf, & Erdos, 2007). Further, the breast cancer patients also experience the issues of body image, pain and fatigue for months and years (Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998; Leventhal & Shearer, 1989; Thewes, Butow, Girgis, & Pendlebury, 2004).

Based upon the current literature, it has been found that survivors of breast cancer suffer from psychological distress and many of them successfully cope with this stress. So, it can be assumed that ending treatment is not milestone for survivors and care-givers as there are always chances of emergence of distress among patients. Findings propose that the fear of recurrence is very common and is widely reported by the survivors. It has been found that 89% of 200 breast cancer successful survivors report fears of recurrence (Polinksy, 1994). After treatment of their breast cancer, they report about their greatest concern of recurrence (Fredette, 1995). Some survivors experience fear and distress, while others show acute resiliency (Allen, Savadatti, & Levy, 2009).

2.14 Family support and communication

Sidney Cobb an epidemiologist in 1976 views in his work, “Community as a Social Support”, that social support is an active agent (As cited in Harrington, 2008). Possessing information that one is beloved to others, esteemed, and associated with a network of common obligations, reduce mental stress and anxious feeling of loneliness. “Psychology Today” published an article, “Heart and soul” in which it conveyed a message that love is an efficient medicine (As cited in Harrington, 2008).

The diagnosis of cancer is taken as “blessing in disguise” by some people (Coreil, Wilke & Pintado, 2004). Dyer (2015) noticed among many families in Puerto Rico that they take cancer as a second trial of life or “second chance” (Dyer, 2015). Detailed ethnographic work presents the concerns of social relationships and importance of local community (Mathews, 2008; Burke, Villero, & Guerra, 2012). Macdonald (2015) illustrates that in illness of cancer psychiatric issues are not taken as serious as they should be. He further reports that many patients diagnosed with cancer found better support at home (Macdonald, 2015). People suffered from cancer or having their loved ones being suffering from cancer take their role as a volunteer service to others (McMullin, 2016). Experience of breast cancer from diagnosis to the survivorship provides an opportunity to see the effects of the long passage on the breast cancer survivor and her close relatives. Little work has been done on the aspects of struggle of the survivor in her fight against uncertainty of this illness, and how she manages this progression phase towards surviving a family group (Lederberg, 1998; Oktay, Bellin, Scarvalon, Appling, & Helzlsouer, 2011; Sherman & Simonton, 2001).

There is a persistent need of families to have information regarding the illnesses to discuss them among family members and primary care-givers (Rolland, 2005). Most of the people come in contact with illnesses about which they do not have understanding. Because of this limited information and understanding, suitable clinical intervention, national public health policies and family education to help these families are lacking (Rolland, 2005). Families need to have continuous “on-going” communication among patients and care-givers. A detailed communication in the whole family dealing with the experience of survivorship is important for smooth communication among members of the family (Corbett, 2010). Therapy is beneficial for the spouses and dear ones of the patients during illness of their family members (Hasson-Ohayon, Goldzweig, Braun, & Galinksy, 2010). Discussing the experiences of cancer with thought, ideas, emotions and sharing are beneficial in coping well (Mallinger, Griggs & Shields, 2006).

It was found that sharing experience of breast cancer with close ones and others can benefit psychologically and physically. Females who share their narratives about their breast cancer experience increase in their appreciation and support for living and readiness to move forward (Allen, Savadatti, & Levy, 2009). Women who share their narratives accept their illness of cancer as a phase of their lives without any worry of possible recurrence. Emotional and practical help from spouses, parents, siblings, children, extended family members, colleagues and friends is supportive for the survivor of the cancer patient (Thewes, Butow, Girgis & Pendlebury, 2004). Families need to have knowledge about illness and coming of new changes in emotions and body of their sufferer family member. Several researchers found that the patients who have emotional support from their dear ones have minimum levels of stress and anxiety (Edwards & Clarke, 2004).

Quite often families have to make adjustments of their lifestyles and have to correspond with one another about the need of psychological support by talking openly about the experiences of illness. The lack of psychological support can discourage the survivor and her care-givers which can lead towards uncertainty and anxiety of recurrence. Social support and effective coping strategies can increase hope that can effectively advocate healthy survivorship (Stanton, Danoff-Burg, & Huggins, 2002). Positive thinking and neglecting negative people who give discouraging views also play an important role in coping behavior (Henderson, Gore, Davis & Condon, 2003). Therapeutic interventions bring positive changes in the well-being of patients and her family members. There is a dire need of supportive programs for the spouses, concerning open communications about the illness of breast cancer and possible problems after the treatment (Shields & Rousseau, 2004).

2.15 Quality of Life of breast cancer patients and their care givers

The quality of life specifies comprehensive mental and social being, her performance of social roles, her emotional condition, her sensibility of well-being, and her ties with others (Levine, 1987). Over time, the quality of life changes because of phases of illness, age of the patient, and because of her good and bad experiences (Bloom, Stewart, Johnston & Bank, 1995). Concerns for quality of life differ in young and old patients. Expectations and aspirations of young patients are quite different because of their different decisions of life. For example, their expectations have different meanings concerning their bodily health and daily functioning (Bloom, Stewart, Johnston, & Bank, 1995). Old age breast cancer survivors have good scores on the assessment of quality life than the scores of young survivors (Ganz, Coscarelli, Fred, Kahn, Polinksy, & Peterson, 1996; Sarna, 1993).

Overall quality of life for survivors of all ages is multi-dimensional and can be according to the adjustments to education, family, physical, mental health, work, environment, marriage, and close relatives (Bloom, Stewart, Johnston, & Bank, 1995). Each survivor has different experience in each domain because of different systems that play different roles in her daily life. Some survivors and their care-givers manage possible recurrence and satisfactory quality of life very well (Rowland & Baker, 2005). The quality of life of a breast cancer patient after completion of her treatment has been found poor and awful (Deshields, Tibbs, Fan, & Tylor, 2006; Ganz, Kwan, Stanton, Krupnick, & Rowland, 2004). Flexibility with the quality of life concerns differently to different survivors and to their family members. This flexibility or resiliency can make positive adjustments in the attainment of a healthy living and physical health for the whole family (Rolland, 2005).

2.16 Women dealing with their experiences of breast cancer

Accounts and narratives of cancer patients are considered an important aspect of the illness in folk culture and anthropology (McMullin, 2016). Cultural background of a patient shapes her experience of breast cancer; this also develops counter strategies and mechanisms to deal with the experience. There are similarities and differences in countering strategies between black minority and ethnic and white breast cancer survivors (Bourjolly & Harischman 2001; Culver, Arena, Antoni & Carver 2002; Reynolds, Hurley, Torres, Jackson & Boyd 2000). A qualitative research in African American breast cancer women found that spiritual activities and their beliefs regarding God and support of family members, friends and other care-givers play a vital role in coping behavior of women (Henderson, Gore, Davis & Condon, 2003).

Spiritual relationship of breast cancer patients with their God supported them throughout their cancer experience (Lackey, Gates & Brown, 2001). Some comparative studies also introduced differences in coping behaviors of different ethnicities. The Asian and ethnic minority people have much interest in religious beliefs and spirituality (Ashing-Giwa, Padillo & Tajero, 2004; Bourjolly, 1998; Bourjolly & Harischman 2001; Culver, Arena, Wimberly, Antoni & Carver, 2004; Koffman, Morgan, Edmond, Speck & Higginson, 2008; Moadel, Morgan, Fatone, Grenman & Carter, 1999; Reynolds, 2000).

Social support has been commonly found in black ethnic minority and white women. African American breast cancer patients rely more on spiritual beliefs, while white women during their experience of breast cancer rely on their husbands (Bourjolly & Hirschman, 2001). Black Caribbean women are more influenced by religious beliefs and spirituality during their breast cancer experiences than white breast cancer women (Koffman, Morgan, Edmonds, Speck, & Higginson, 2008). Spiritual beliefs supported breast cancer patients in making them accept their illness and enabled them to get emotional and practical support from their religious institutions. Both acceptance and support help breast cancer patients during their illness experience as counter strategies (Koffman, Morgan, Edmonds, Speck, & Higginson, 2008).

People, who hold strong religious beliefs and affiliations, perceive their God, the only healer who can support, guide and grant strength for the person to bear the illnesses like breast cancer (Culver, Arena, Antoni & Carver 2002; Lackey, Gates & Brown,2001). Black breast cancer survivors trust God as a way of support more than their family members and friends (Henderson, Gore, Davis, & Condon, 2003). The people of South Asia have strong beliefs in religion and spiritualism which help them in dealing with many stresses. Generally their beliefs are based on fatalism or *Karma* (good or bad deed's reflection on one's life) (Bottorff, Grewal, Balneaves, Naidu, Johnson, & et al., 2007; Gurm, Stephen, MacKenzie, Doll, Barroetavena & et al, 2008; Howard, Bottorff, Balneaves, & Grewal, 2007). They believe that God is in their illness that will control their ailment and will protect them from miseries.

Their strong hold in religious beliefs make them passive as sufferers of illnesses accept diagnosis of severe disease and cope with struggle in positive manners. They accept illness as will of God, and believe that consequences of illness will be according to the will of God. With this thought, they deny to receive treatment (Gurm, Stephen, MacKenzie, Doll, Barroetavena, & et al, 2008). The Black and South Asian women have great religious and spiritual tendencies. They practice spiritual practices in their time of need particularly during illness to achieve relaxation, reduce anxiety, inner strength and fears of recurrence (Banning, Hafeez, Faisal, & Hassan, 2009; Gurm, Stephen, MacKenzie, Doll, Barroetavena, & et al, 2008). Although religion and spirituality both may not always appear as positive coping mechanisms yet both are highly appreciated among the communities of South Asia. Many times they have emotions of hopelessness and negative impacts on mental and physical well-being (Levine, Yoo, Aviv, Ewing, & Au, 2007; Shaw, Joseph & Linley, 2005).

In many researches, quantitative inquiry was used to research cancer and its impacts on family members of the sufferers (Jacobsen, et al., 2005; Jacobsen & Jim, 2008; Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001). There is a need to hear the multiple voices to understand different experiences in different families. Views of participants explain meanings and the basis of the breast cancer experiences of the family (Moustakas, 1994). There is also difference between the experience of an individual and her whole family. Illness is frequent to all members of family, but each individual perceives the experience in a different way (Corbett, 2010; Pelusi, 2006). It is important to get deep understanding of the lived experiences of the breast cancer patients to get uniqueness of their experiences. Each individual has unique voice or opinion; however, there are many common aspects in the illness accounts of survivors and their family members (Corbett, 2010).

Ability to search meanings in the experiences of breast cancer patients can help married people and their families to have knowledge to cope better with the chronic illness (Kissane, Maj, & Sartorius, 2011). This knowledge not only will contribute to the literature on the area of breast cancer patients' diverse experiences, but also will bring new techniques in the field of therapists and health policy makers. During long struggle, the breast cancer women deal with challenging moments in their lives with shuffling relationships with their friends and family members (Corbett, 2010; Katz, 2003).

CHAPTER 3

RESEARCH METHODOLOGY

3.1 Choosing appropriate research methodology

Generally the design of a qualitative study appears during the research. Many aspects contribute in making the study a good qualitative endeavor such as exhaustive data collection, thorough analysis, relativity, appropriate qualitative approach, convincing account, positioning of a researcher particularly reflection of his culture, contextualized history and personal experience.

In order to address the meanings of a concept or phenomena of several individuals, phenomenological study is the most appropriate approach. By using this approach, the researcher focuses on qualitative inquiry and research design illustrating what all interlocutors have in common during the experience of the phenomenon (e.g., sorrow is universally experienced) (Creswell, 2007, p. 58). The major purpose of phenomenological approach is to condense individual experience with a phenomenon to an illustration of the universal essence (“grasp of the very nature of the thing” (Van, 1990, p. 177)). It was appropriate for the current study to opt phenomenology as it was multi-sited and was not ethnography. This approach is popular in social and health sciences e.g. in psychology and nursing (Borgatta & Borgatta, 1992; Finlay, 2011; Giorgi, 1985; Nieswiadomy, 1993; Oiler, 1986; Polkinghorne, 1989; Smith, Flowers, & Larkin, 2013; Swingewood, 1991).

In the present study, the human experience was the phenomenon of breast cancer. The data was collected from those persons who experienced this phenomenon and developed a composite description of the essence of the experience of all the participants. This description comprises “what” they experienced and “how” they experienced it. In order to get fresh perspective in my qualitative inquiry and research design, I focused on the experiences of participants in which “everything is perceived freshly, as it for the first time” (Moustakas, 1994, p. 34). As a whole, it was an interpretative process, where I wrote description of the phenomenon and kept a strong relation to the title of inquiry.

To identify the whole phenomenon, it consisted of knowing the belief, knowledge, attitude and practices of breast cancer women regarding their illness, the role of the care-givers in the whole treatment seeking process, the attitudes of the practitioners towards the women’s of low and high financial status, the alternative patterns of treatments particularly folk treatment availed by these women themselves, and the transformation of identities of these women in maintaining social relationships. The data was reduced to significant statements and quotations. These statements and quotations were transformed into short themes. Following all this, two kinds of descriptions -- textural and structural were developed. Textural description included 'What' the participants experienced and structural description consisted of 'How' they experienced, which means the illustrations of their condition, or situation they went through. Then both descriptions were combined to convey a complete spirit of their experience. This approach attracted me because it has systematic steps in the analysis process of data, and it also gives techniques to assemble the textual and structural descriptions.

3.2 Positioning of a researcher within the research

The time before entering into the process of the interaction with breast cancer women and their care-givers was very challenging for me because I was neither a therapist, a health personal, a policy maker, nor a teacher. I had fears in my position that being a student going to inquire and disturb the individuals to share with me their heart rendering experiences although for research purposes. Phenomenology approach was appropriate to my goals of research, but I was using it for the first time to get the fresh and detailed illness experiences. By using this approach, I had to affirm its philosophical assumptions that the collected experiences should be taken from conscious ones who have experienced the phenomenon.

The time span of research was 13 months and during this period being a native anthropologist in a traditional society I was at advantageous position to get information from the sufferers about their illness, where the illness related to organ of the female body is not publically discussed. As the Ohnuki-Tierney (1984) narrates "native anthropologists are in a far more advantageous position in understanding the emotive dimensions of the behavior such as psychological dimensions of behavior are hard for outsiders to understand…. knowledge of daily routines that are exceedingly difficult for outsiders to….native anthropologist have easy access to not only the intellectual dimension but also to the emotive and the sensory dimensions of these behaviors" (Ohnuki-Tierney, "Native" Anthropologists, 1984). Being the member of the same society, I was scared from the missing or negligence towards the key information. In the struggle to cope with this throughout the data collection process, I avoided interference into the views and acts of the patients and their care-givers.

I tried to make my position strong by maintaining cordial relationships with each breast cancer woman and her care-givers. I spent time with them to make them comfortable and share what they feel, believe and assume. During the fieldwork, the second stage breast cancer patient *Rukhsana* (pseudonym) was initially not comfortable in my presence then my friendship with her younger daughter and accompanying them to hospitals, folk and faith healers made her comfortable with me.

3.2.1 Dichotomy of insider and outsider in positioning of the researcher during research

Several qualitative researchers described their position in research as insider or outsider which has influenced them in recruitment, collection of the data and analysis phase in the process of their research (Bhopal, 2001; Bonner & Tolhurst, 2002; Dwyer & Buckle, 2009; Etherington, 2004; Gunaratnam, 2003). The researchers who are familiar with the research community and share the similar or same characteristics, such as gender, sexuality, age, language, religion, ethnic identity and experiential base are insiders (Asselin, 2003). An outside researcher is one who is different to the community under research and unfamiliar to the characteristics of the research area (Louis & Bartunek, 1992).

During the research process, I felt myself both as an insider and outsider. As a Pakistani born and having knowledge about the characteristics of the community, it was easy to find them and understand their beliefs, knowledge and attitudes towards breast cancer. Nevertheless, at the same time, my role was also as an outsider because of having no direct or indirect experience of breast cancer. For example, during the fieldwork, when I was traveling with *Kinza* (pseudonym) daughter of *Rukhsana* a second stage breast cancer patient, who was going to the pharmaceutical store of the hospital, where treatment of her mother was under process for last seven months, here my role was as an insider. We were traveling on a local bus; the driver of the bus was listening to local music in a loud voice. It stopped at many stops, where the rush of passengers and noise of hawkers was understandable to me, but when she was telling the changed behavior of her mother because of illness and treatment's side effects, my role was as an outsider. All that information related to the breast cancer was new and different to me.

Although during the process of research, being a member of the same society, nothing was new for me yet all these were not a guarantee for my access to the breast cancer women who were ready to share their lived experiences. During the research process, quite often it happened like that, I got the reference of a breast cancer woman who knows me through one of her neighbour and when I approached her, she refused to show her a breast cancer patient and told that "yes, *I got a little lump and doctors mis-diagnosed and told that it is breast* *cancer but later in detailed examination it appeared that It was not a cancer*". In this kind of situation, I let her skip the interview. Such a situation disclosed that insider position can work as a barrier in the data collection process.

3.3 Participants

Total 27 women came forward to share their living and lived experiences of breast cancer. Fifty four care-givers including the breast cancer women's close family members, nursing staff and domestic servants participated in group discussions. They shared their views and also answered most of the questions. Eight care-givers declined to participate in group discussions due to their other family commitments, but they gave interviews in their spare time. The participants had different mother tongues including Pothohaari, Siraiki, Pushto, Hindko and Punjabi, but all could speak and understand their national language, i.e., Urdu. Nine participants wanted to give interview in their own mother tongue, and they were encouraged to continue. These interviews were recorded and interpreted soon after their completion, and often during the interviews their family members and fellows interpreted them in Urdu. All the data was side by side interpreted for themes in English. Out of twenty seven breast cancer women, eighteen were from urban and nine were from rural areas. The mentioned eighteen women were from the main cities -- Islamabad, Rawalpindi, Lahore, Mianwali, Attock and Chakwal, while the other nine women were from the far off places of these cities.

Table 2. Local languages spoken by the breast cancer women and interpretation in Urdu by their care-givers

Language	Number of breast cancer women sharing their illness and experience in their local languages	Interpreters
Punjabi	3	1. Daughter and sister 2. daughter, daughter in-law and son 3. Neighbor, daughter in-law, and husband
Siraiki	2	1. Daughter in-law, daughter and husband 2. Sister and domestic servant
Pothohari	1	1. Two daughters in-law and one daughter
Pushto	3	1. Son and domestic servant 2. Sister in-law and daughter of father's brother 3. Daughter and daughter in-law

(Source: Field findings)

Table 2 above shows the number of respondents sharing their illness and experiences in local languages. It also shows their close relatives as interpreters. Three women shared their experience in Punjabi. Two shared in Saraiki. One shared in Pothohaari and three shared in Pushto. Although except Pushto all other local languages were understandable to me yet I preferred to get help of the surrounding care-givers of breast cancer women because I heard these languages spoken by many local people, but I never spoke these languages frequently. They helped interpret all information into Urdu which was further described and interpreted in English.

3.3.1 Approaching participants

During the research process, the initial step was approaching participants. To visit hospitals with the aim to approach the breast cancer patients was first thought, and it was practiced but it proved not so fruitful. Patients and their primary care-givers sitting in the waiting areas of the hospitals were waiting for their turn to get check-ups and treatment. Seeming anxious and stressed, they were reluctant to give time and discuss their breast cancer experiences. Doctors and staff were also not in condition to give me time. Most of the women declined to share their experience because of the shortage of time and their focus was to get tests, check-ups and treatment and medicines. Many refused with anxiety of going through medical experience.

To approach the respondents to achieve detailed information using anthropological methods was not less than a challenge. Sharing and discussion with my friends, class mates, neighbors and relatives regarding breast cancer led me towards approaching breast cancer patients. At the initial stage of data collection process, I got access to four breast cancer patients through the references of my friends, neighbors and class fellows. While spending time with these breast cancer patients and their care-givers in hospitals and at folk and religious healer's places, I got access to other breast cancer patients and their care-givers. Apart from initial breast cancer participants in research, on duty doctors also worked as a support group in introducing other cases in the research process. In the data collection process, old age women were seen more willing to share their breast cancer experience than the young breast cancer women. Initial meetings and telephonic conversations with these women and their care-givers assisted in making familiar ties with them, which later on resulted in their sharing of breast cancer experiences.

3.4 Methodology, Techniques and Tools

Research was done with the help of conventional anthropological methods, techniques and tools. Phenomenological approach was used because the lived experiences were the focus of this study.

3.4.1 Participant Observation

Using method of participant observation in fourteen out of total twenty seven breast cancer cases, I came to know about the views, beliefs and acts of the breast cancer women and their care-givers about breast cancer. This was the only method with the help of which I noticed the impacts of this illness on them and their social life, their depression regarding long painful treatment, drastic side effects in body, expenditure of money and adopting different types of treatments, and how they hate the English medicine because of its side effects in body like loss of hair and fresh skin, but getting it because it was famous treatment in the time and many survived by using it. It was also observed that how the care-givers played their role for the survival of their loved ones. The roles of professional health care-giver or nurses and paid care-giver like servants were also observed.

For example, in a case a female nurse was informing an illiterate breast cancer woman about the procedure of treatment. She organized her treatment file and informed her to bring this file whenever she visits the hospital. Practices of traditional and spiritual healing by the care-givers were also observed when they were used to visit shrines of saints. Wearing amulets, drinking holy water and their offerings at shrines gave their information that they have belief in spiritualism for the health seeking purpose. Their health ritual activities showed that they are religious and cultural from health perspective, too. For example, it was observed in the case of a breast cancer woman that an egg was colored yellow presenting it an illness, moving that egg around the body of the breast cancer woman and placing it on hot pan until it was broken. The intention of this ritual was to attain removal of breast cancer as the egg was broken.

Method of participant observation was the key to get complete understanding about the performance of traditional practices and to understand their importance in healing psychological distress, body image concerns and firm beliefs in controlling the illness particularly in breast cancer. To become familiar with the clinical setting of doctors, traditional, religious healers and the circumstances that may influence interactions with patients and colleagues, I followed one particular health professional for one day at a time. Using the same method of participant observation, doctors, nurses and the staff of the hospitals were also observed during the interaction with the breast cancer women and their care-givers. Acquaintance with doctors and nurses of the hospital proved more helpful in observing the interaction of care-giver, treatment givers and treatment seekers. This allowed me to gain detailed information on the required aspects of treatment process and practice. It gave me the opportunity to talk and discuss my observations with different kinds of health professionals involved in the process, i.e. medical, homeopathic and religious healers. I noticed their classification of days and times of treatments, how they classified their work and communicated with patients and their care-givers.

3.4.2 Sampling: convenience sampling

The breast cancer women living in Pakistan were the sample of the study. In recruitment strategy, convenience sampling technique was adopted. It is a non-probability sampling technique, where the sample is chosen from those people who are easy to access. In the start of the research, it was difficult to find the breast cancer women in a sufficient number to ask them about their illness experience. In hospitals, it was also not possible to take a sufficient time of the patient and their care-givers, asking them to share their experience, and they were not in a comfortable situation to give me detailed interviews. So, the only option I had in finding breast cancer women was to ask some of the women who were ready to share their illness experience with me. They gave me contacts of other breast cancer women, and their care-givers whom they know by having understanding with them in getting the same treatment in the same hospitals. Some of cases I got through the references of doctors working in the breast cancer departments and clinics, and friends and neighbors. The research was conducted from March 2016 to April 2017. In this long journey of fourteen months, I contacted forty eight breast cancer women, out which only twenty seven agreed to share their illness experience with me.

This technique is also called availability sampling as there is no criterion in it for selecting participants except that respondents are available and ready to participate (Saunders, Lewis, & Thornhill, 2012). This technique maximized the recruitment of breast cancer women and their care-givers. It was also planned to recruit the participants through hospitals and investigate them at their home settings. The purpose for this was to achieve a reflective understanding of the lived experiences of their cancer of breast. Nursing staff and practitioners were enquired about their working places such as hospitals and clinics.

In the whole, in the research process the data collection was based upon my access to the nearest and available breast cancer women and their care-givers who were willing to participate in the research. This sampling technique was not only helpful in getting information from available breast cancer women and their care-givers, but also proved fruitful in the conduction of group discussions, and semi-structured interviews were also conducted with the available medical practitioners and folk and religious healers.

Table 3. Type and number of participants in the research

Type of Participants	Number of Participants		Total number of Participants
Breast cancer women	27	18 Urban	91
		9 Rural	
Care-givers	54	31 family members	
		14 Nurses	
		9 domestic servants	
Faith healers	6		
Medical specialists/ Oncologists	4		

(Source: Field findings)

Considering the limitations of a traditional society where a female does not discuss her body part except to her practitioners, this technique helped me in getting trust and information from the willing breast cancer women and their care-givers. During the fourteen months of data collection period, I remained successful in accessing twenty seven breast cancer women who were ready to share their lived experiences. Among twenty seven women, fourteen were studied as proper cases and thirteen were interviewed using informal and semi-structured interviewing technique. I got fifty four willing care-givers of the breast cancer women who participated and shared their experiences regarding the provision of their care to their breast cancer loved ones. All these care-givers were chosen by using the same type of convenience sampling considering their availability and willingness to participate in the research. Six faith healers and four medical specialists were interviewed and were invited to participate in group discussions looking at their availability and willingness of participation in the research. The total sample was ninety one.

3.4.3 Group Discussions

During the whole process of research, total twelve group discussions were conducted. Out of the total twenty seven breast cancer women, twelve women were greatly involved in the other kinds of treatments such as folk and faith healings. All the twelve group discussions were taken one by one when each breast cancer women was taken as a proper case. These group discussions were conducted at homes of the patients, at the work places of the medical practitioners such as in hospitals and in clinics, and at the sitting places (*bethak* or *Hujra*) of the folk and religious healers.

During discussions, a great role of nurses, oncologists, faith and folk healers in the views of the breast cancer women and their care-givers gave an idea to conduct the second sessions of these group discussions at the healing places with these family members and the health care professionals such as nurses and practitioners. Only five breast cancer cases showed their complete consent to conduct a second session with them at their healing places. Group discussions with these were conducted in two sessions such as first session was conducted at the home of the breast cancer woman and care-giver, and the second session was conducted at the healing places like hospitals and sitting places of religious and folk healers. The first sessions of group discussions included family members as primary carers and domestic servants as tertiary care-givers. The second sessions were comprised of some of the family members, domestic servants, oncologists, folk and faith healers particularly nurses as secondary care-givers.

It was an advantage to cross check the views and observe the roles of the care-givers at the hospitals, clinics, and other healing places of faith and folk healers after observing discussions at homes. Another benefit of two sessions' group discussion at two different places was the extra information received by the people working in healing places such as oncologists, nurses, faith and folk healers. In all group discussions, the total fifty four participants participated. These participants were selected on their availability according to the convenient sampling technique. These were family members, friends, neighbors, medical practitioners, folk and religious healers and nurses. All the group discussions were quite helpful in gaining complete information about the local beliefs and values about the illness of cancer. My gender made their participation and cooperation smooth and possible. Among many benefits of this technique to me, one was the collection of huge information at one place. Sharing of knowledge and information during interaction of the participants was also beneficial for them and their breast cancer loved one.

3.4.3.1 Crux of the Group Discussions

The most beneficial crux of the group discussions was the statements and quotations which resulted very useful in making themes. Participants took interest and described many issues which were not assumed before using this method. For example, they gave views on financial hurdles saying, it is a major reason of advanced stage of breast cancer and people try to get treatment from the traditional healer. They discussed the horrible side effects of bio-medical medicine and treatments. They also discussed the slow effects of homeopathic treatment and risks of life. Majority of them had firm belief in bio-medical medicine but complained about its expensiveness. Majority of the participants talked about the soothing effects of faith healing and some asked for the need of psychotherapies in hospitals for breast cancer women and their close family members as well.

Table 4 mentioned below shows the group discussions conducted with the family members, practitioners and health care professionals and practitioners of women with breast cancer. It also shows the places and time periods of discussions.

Table 4. Group discussions with the health care professionals, practitioners and family members of the breast cancer women

Sr.No	Number of participants	Relation with breast cancer woman	Place of discussion 1st at home and 2nd at hospitals/faith healers' places	Total time of 1st session of discussion	Total time of second session of discussion
1	5	Elder Daughter, younger daughter, husband's sister, female oncologist, female nurse	At home and at hospital	2 hours and 5 minutes	46 minutes
2	6	Mother, father, two sisters, sister in-law, faith healer	At home and the sitting place ([4]*Bethak/ Hujra*) of a [5]faith healer	1 hour and 10 minutes	1 hour and 31 minutes
3	5	Mother, two sisters, Aunt, faith healer	At home and the clinic of a homeopathic practitioner	1 hour and 35 minutes	50 minutes
4	7	Husband, daughter, one sister, sister in-law, younger sister in-law, two cousins	At home	2 hours and 10 minutes	-
5	6	Eldest sister, Second eldest sister, a female and a male oncologist , two female nurses	At home and at hospital	45 minutes	1 hour and 5 minutes
6	5	Two daughter, sister in-law, a friend, maid	At home	1 hour and 20 minutes	-
7	4	Daughter, daughter in-law, cousin, neighbor	At home	2 hours and 6 minutes	-
8	5	Daughter, daughter in-law, female oncologist , male nurse, female nurse	At home and at the hospital	1 hour and 15 minutes	45 minutes
9	4	Daughter, husband, two sisters in-laws	At home	45 minutes	-
10	5	Son, daughter, daughter in-law, two friends,	At home	1 hour and 38 minutes	-
11	4	Son, daughter in-law, daughter, maid	At home	50 minutes	-
12	5	Mother, sister, sister in-law, two friend	At home	1 hour and 15 minutes	-

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[4] A place attached with the home of faith healer, where visitors come to meet him and get treatment.

[5] Quite often during the research, it was seen that a religious healer gives medicines with some holy practices. He advises the primary care-givers of the patient to give *Sadka* (charity in kind of money or meat) to poor or put some money into the charity box of a mosque in return of this treatment.

3.4.4 Cases

During the research process, fourteen breast cancer women with their care-givers were studied as detailed cases. With the help of *participant observation,* this method enabled me to get comprehensive information from the breast cancer women and their care-givers about their beliefs and knowledge regarding their illness of breast cancer. During the research, I found that it is one of the most beneficial methods for data collection. I spent much time in arranging and making the participation of all participants possible, while in this method I focused on the patients and their care-giver by spending more and more time with them and getting familiarized by going to the healing places with them and observing the attitude of the practitioners with the low and high status breast cancer women. This method assisted me in my entire fieldwork. Studying fourteen cases gave in-depth information about the social and behavioral conditions of the breast cancer women and their care-givers. For example in case of *Shamim* (pseudonym), I came to know about the detailed information of her life and stress. Because of her breast cancer, she had no more cooperation from her husband; her parents were annoyed with her, she had bad financial condition and because of this illness she was not able to look after her kids. The case of *Shamim* like other cases gave in-depth information about the cultural beliefs and values, gender roles and duties, behavioral and social conditions. It also helped me to find out the financial and social support is very important to help fight against the chronic illness.

Table 5 mentioned below displays the demographic features of all twenty seven breast cancer women who participated in the research. Table 6 shows the demographic features of all 31 primary care-givers or family members of breast cancer women. Table 7 shows the demographic features of all fourteen secondary care-givers or nurses of the breast cancer women. Table 8 demonstrates the demographic features of all nine tertiary care-givers or domestic servants of breast cancer women.

Table 5. Demographic features of all 27 breast cancer women who participated in the research

Sr.#	Pseudonyms	Age	Rural/Urban	Marital status	Children	Age at diagnosis	Education	Employment status	Availing type of Bio-medical treatment	Overall preferred type of treatment
1.	Rukhsana	52	U	W	2	51	Edu	E	C,R	F,B
2.	Shamim	39	R	M	3	39	Un-E	Un	C,R	F,HO
3.	Shazia	34	R	S	-	32	Edu	Un	C,R,L	F, B
4.	Komal	22	U	S	-	22	Un-E	S	C	F, B
5.	Misbah	40	U	M	3	40	Un-E	U	C	F,B
6.	Masooma	43	R	M	4	42	Un-E	Un	C,R,L	F, HO
7.	Nazia	61	U	M	2	59	Edu	E	M,IR	F,B
8.	Samina	45	U	M	5	45	Un-E	Un	C,R	F,B
9.	Fazeelat	62	U	W	7	61	Un-E	R	C,R,M	F,B
10.	Noreen	49	R	M	3	47	Edu	Un	C,R,L,H	F,HO
11.	Adila	45	R	M	5	46	Un-E	E	C,R	F,B
12.	Ferzanda	55	R	M	4	53	Edu	Un	C,R,L	F, HO
13.	Suriya	62	U	W	4	60	Un-E	R	C,R,M	F, B
14.	Rehmat	60	U	W	6	58	Edu	Un	C,L,A	F, B,HO
15.	Sumera	40	R	M	4	39	Edu	Un	C	F,B

	Pseudonyms	Age	Rural/Urban	Marital status	Children	Age at diagnosis	Education	Employment status	Availing type of Bio-medical treatment	Overall preferred type of treatment
16.	Alia	57	U	M	6	56	Edu	E	C,R,L	F,B
17.	Noor	38	R	M	3	37	Edu	Un	C,R	F,HO,B
18.	Ghanza	62	U	M	5	60	Edu	R	C,R,L,H	F, B
19.	Almas	46	R	M	4	45	Un-E	Un	C	F, B
20.	Laila	53	U	M	3	52	Edu	Un	C,R	F,B
21.	Maryam	41	U	D	2	39	Edu	Un	C,R,L	F, HO
22.	Warda	57	U	M	5	56	Un-E	Un	M,IR	F,B
23.	Hareem	35	U	S	-	33	E	Un	C,R,L	F,B
24.	Isma	61	U	W	7	60	Un-E	Un	C,R,M	F,B,HO
25.	Rakhshanda	56	U	M	3	55	Edu	Un	C,R,L	F,HO
26.	Adeeba	32	U	S	-	31	E	E	C,R,H	F,B
27.	Zubaida	62	U	W	6	61	Edu	R	C,R,L	F, B

Living: R=Rural; U=Urban. Marital status: M=Married; S=Single, W=Widow, D=Divorced, SP= Separated. Education: Edu=educated; Un-E= Uneducated

Employment status: S= Student; E=Employed; Un=Unemployed; R=Retired, O= other

Treatment: M = Mastectomy; IR = Immediate Reconstruction; L = Lumpectomy; C = Chemotherapy; R = Radiotherapy; H = Herceptin; T = Tamoxifen; A = Arimidex; F=Faith healing; HO= Homeopathic treatment; B=Bio-medical treatment; O = Other

Table 6: Demographic features of 31 primary care-givers/family members

Sr.No	Pseudonyms	Age (years)	Gender	Rural/Urban	Relationship with breast cancer woman	Employment status	Monthly income of home (Pak.Rs.)	Daily Time spent with breast cancer woman(in hours)
1.	Kinza	22	F	U	D	S+U	53,000	11
2.	Shamsa	29	F	U	D	U	12,000	15
3.	Sidra	34	F	R	D-in-law	U	45,000	1
4.	Anum	18	F	R	D	S+U	40,000	12
5.	Arshad	49	M	U	H	E	35,000	07
6.	Tariq	43	M	R	H	E	45,000	09
7.	Saleema	55	F	U	M	U	13,000	15
8.	Khalid	43	M	R	H	E	23,000	5
9.	Sultan	51	M	U	F	E	35,000	8
10.	Nazira	48	F	U	M	U	10,000	8
11.	Minahil	28	F	R	D-in-law	U	25,000	4
12.	Haseeb	51	M	R	H	E	30,000	7
13.	Rashida	55	F	R	M-in-law	U	26,000	3
14.	Naveed	39	M	U	SO	E	22,000	4
15.	Sughra	43	F	U	D	E	70,000	6
16.	Sadique	54	M	R	B	E	52,000	2
17.	Iqbal	48	M	U	H	E	48,000	9
18.	Nasir	41	M	R	H	E	35,000	6

Sr.NO	Pseudonyms	Age (years)	Gender	Rural/Urban	Relationship with breast cancer woman	Employment status	Monthly income of home (Pak.Rs.)	Daily Time spent with breast cancer woman(in hours)
19.	Maria	30	F	U	D	U	50,000	10
20.	Rani	29	F	U	D	U	18,000	12
21.	Areesha	31	F	R	D	U	35,000	8
22.	Subaita	41	F	U	D- in-law	U	52,000	7
23.	Arooj	61	F	U	M	E	32,000	9
24.	Faiq	48	M	R	H	E	40,000	7
25.	Raheem	56	M	U	H	E	60,000	10
26.	Amir	52	M	U	H	E	56,000	7
27.	Faiz	49	M	U	H	E	70,000	5
28.	Shakra	56	F	R	M	U	25,000	9
29.	Aleesha	25	F	U	D-in-law	U	56,000	5
30.	Latafat	34	F	U	D	E	70,000	6
31.	Najma	24	F	R	D	U	55,000	8

Gender: M=Male, F=Female. Living: U=Urban, R=Rural.

Relationship with breast cancer woman: M=Mother, D=Daughter, S=Sister, H=Husband, F=Father, B=Brother, SO=Son, D-in-law=Daughter in-law, M-in-law=Mother in-law

Employment status: E=Employed, U=Unemployed, S=Student, UN=Unspecified

Table 7: Demographic features of 14 secondary care givers/Nurses

Pseudonyms	Age	Gender	Nursing qualification	Working in hospital/clinic since (in years)	Working in Oncology department since (in years)	Type of Job: Government/Private	Daily working hours in oncology department	Monthly Income
Iqra	24	F	4 years	2	1 year, 6 months	P	9	30,000
Hania	27	F	4 years	5	3	P	9	35,000
Mahnoor	41	F	2 years	3	2	G	7	42,000
Hameed	28	M	2 years	5	3 years, 4 months	G	7	46,000
Madiha	30	F	4 years	6	4	G	8	42,000
Rukhma	46	F	2 years	3	2	P	8	35,000
Shanzay	25	F	4 years	1	7 months	P	9	20,000
Fareeha	41	F	2 years	12	5	G	7	25,000
Noor Khan	32	M	4 years	4	2 years and 3 months	G	8	35,000
Shagufta	43	F	2 years	16	8	G	8	45,000
Firoz	26	M	4 years	3	2	G	9	25,000
Mahrukh	29	F	2 years	4	3	G	8	30,000
Mishal	23	F	4 years	2	2	P	9	18,000
Ali	31	M	2 years	4	3 years and 5 months	P	7	30,000

Gender: M=Male, F=Female

Type of Job: Government/Private: G=Government sector hospital, P= Private sector hospital/clinic

Nursing qualification: BS Nursing 4 years, Bsc Nursing 2 years.

Table 8: Demographic features of nine Tertiary care givers/ domestic servants

Pseudonyms	Age	Gender	Rural/Urban	Time since working for BC patient (in years)	Daily time spent with BC patient (in hours)	Daily services	Monthly payment for services in Pakistani Rupees
Mehreen	42	F	U	8	3	WC,WD,D,C	8,000
Aneela	38	F	R	3	4	WC,WD	4,000
Nafeesa	41	F	U	1	07	WD,C,G	7,500
Shabana	39	F	U	1.5	09	WC,WD,C,G	13,000
Akhter	48	F	U	3	4	WC,WD,G	5,000
Nazish	42	F	U	2	07	WC,WD,D,G,C	8,000
Nargis	54	F	R	1	05	WD,D,C	9,000
Saeed	45	M	U	4	1.5	C,D,G	4,000
Asif	28	M	R	2	2	G,C,WD	4,000

Gender: M=Male, F=Female
Living: U=Urban, R=Rural
Daily services: WC=washing clothes, WD=washing dishes, D=dusting and cleaning, C=cooking food, G=grocery

3.4.5 Informal and Semi-structured Interviews

The quality of open-endedness of both types of interviews paved the way for the researcher to get answers of many more questions asked for “the responses received from the informant, or interviewee” as well as the “observation” (Moore, 1998). During the data collection process, a combination of informal and semi-structured interviews was used along with the interview guide which provides “a set of clear instructions” (Russell, 2006, p. 212). Thirteen out of twenty seven breast cancer women and all fifty four caregivers, six faith healers and four medical practitioners were interviewed with the help of this technique.

During the Informal-Interviews, initial information regarding awareness of breast cancer, the provision of treatments and its access to them was achieved. The interview guide was comprising multiple queries from diagnosis to the survival, from their knowledge and awareness of breast cancer to the beliefs on the multiple treatments, from cultural beliefs and values related to this illness to hope and pessimism, from impaired features to the fear of death and loss of close relations and from beliefs in God to the struggle to get complete treatment. Both techniques supported to develop rapport with the interlocutors and get in-depth information. For example during interviewing the health professionals, they were asked to elaborate their work as health care providers, and how they classify their work, and their intercommunication with patients, particularly with breast cancer women. Moreover, during the long chemotherapy sessions, the family members were asked to share their experiences of the clinical encounter with the doctors, nursing and the administrative staff of the hospitals.

With the help of available literature, semi-structured interview guides were developed (appendices, 1, 2, 3). As it was difficult to get details from women about their terrible health issue, it was important to ensure them the flexibility to share their lived experiences. They were probed during the discussion for further details. The available literature helped in formulating and arranging the questions in their appropriate logical manner. keeping in view the exploratory and explanatory nature of study, broad topics were made in semi-structured interviews to let the women discuss and share their lived and living experiences (i.e. emotions and thoughts, they felt at the time of diagnosis, during the process of arranging money for treatment, in approaching the healthcare centers/hospitals/clinics, during the treatment, during the interaction with relatives / friends / neighbors / colleagues, the impact of their illness on their families, their body image concerns and plans for life after survival). Interview guides were reviewed by the supervisor and two other professors in the department. Their suggestions were followed and changes were made accordingly. They suggested probing techniques to add and rephrase some key questions were taken into consideration.

3.4.6 Photography

Photography of shrines and hospitals was not prohibited. I took photographs of the shrines which are perceived to be attached with the treatment of lumps and tumors. I took photographs of interesting performances of some healing practices with the consent of the patients, their family members, faith and folk healers. In fact, these photographs were taken with great care particularly after the informed consent of the performers of the rituals. I did not take photographs of patients and their care-givers, particularly their family members. Apart from ethical reasons, my purpose of not taking photographs of patients and their care-givers was building their trust and confidence in me. This way, they shared their lived experiences with me.

3.5 Initiating the research

Ethical approval was acquired from Advanced Studies and Research Board at the Quaid-i-Azam University, Islamabad, Pakistan.

The male and female nurses participated in interviews after getting permission from the heads of their nursing staff. They also helped in introducing me to the breast cancer women and their family members. Only those women and their care-givers were contacted for participation who gave consent and were comfortable in sharing the details of their lived and living experiences. These potential participants were further contacted at their home settings after their consent.

All nurses, breast cancer women, their family members and domestic servants preferred to be interviewed in Urdu. However, in some cases and in some aspects they shared their experiences by speaking in their mother tongue. Before conducting the interview, the participant was given a sheet regarding the aim of this inquiry. Except four cases, all other women and their care givers desired to listen to me instead of reading from the information sheet. In addition to the information sheet, they were orally informed about the purpose of the study to which they answered without any delay. As Breen (2007) in his work states that if the research groups are willing to voice their experiences, they will share.

Breen's view was found true when all participants were ready to share their information verbally, but many of them showed resistance in signing the consent form. May be they were afraid regarding the breach of their privacy of their health issue in public. To ensure their privacy and comfort, I never again asked them to sign the consent form and told them their real names will not be used in the research manuscript. Baskets of fruit juices were taken to the homes of all participants on the day of their interview as a token of respect for their great cooperation. On the completion of the interview, they were thanked for giving their valuable time and sharing their experiences.

3.6 Recruitment strategy

Most breast cancer women and their care-givers were initially inquired at hospitals. After achieving their consent, I got addresses of their residential places from them and approached them there. Most care-givers of these women were their close family members and were ready to describe their lived experiences as care-givers. The breast cancer women between the ages of 45 and above were very expressive in describing their experiences, and their care-givers were also very expressive. Other women younger than 45 were not much expressive, but their care-givers were very expressive. By running a fund raising campaign for three needy patients and awareness campaign for students in a local university, they helped me to get more contacts of the breast cancer women and their care-givers.

Figure 3. Fund raising and awareness campaign during research

Note: Fund raising for three needy patients and an awareness campaign regarding breast cancer for students and teachers in a female university, Islamabad.

Women and their care-givers were interviewed until I got a sense of getting plenty of data. The criteria of the participation of breast cancer women were over the age of 18, most women who participated were above the age of 40; however, three were found in the ages between 34 to 39. One woman was found with the age of 22. The criterion of inclusion for the care-giver was not specified as one of the breast cancer women was having a daughter, who was her only care-giver and she was 16 years old. Another woman was having three kids; her eldest son was her only carer at home and he was 12 years old. Because of the initial problems in recruitment, no upper limit was established. The women diagnosed within their last 6 months and are in the treatment process were focused to get their fresh reflection on their present experience. Here, it was very important to understand the needs of these women and their care-givers, while they were experiencing treatment and pain of cancer. Hence, the personal consent was always desired and the respondents were always requested and thanked for sharing their living and lived experiences.

3.7 Knowledge Sharing in Rapport Building

I was familiar with the culture of the women with breast cancer women, but I had very basic information about their beliefs and knowledge regarding their illness of breast cancer. Before the research, I never heard that they believe, *"the woman who has breast cancer is completely on risks and the most pitiable among them*" (from accounts of four breast cancer women). Before the research I never heard that they believe, *"illness of cancer as stamp of death"* (from accounts of a woman with breast cancer). During the research, I came to know the reasons of their negative perceptions related to the breast cancer. I found that a native researcher's knowledge about his/her research community increases as he/she starts to research the phenomenon. The knowledge of languages and accents of the interlocutors helped me to understand their ideas and views regarding breast cancer. Majority of the local languages spoken by the interlocutors were varying dialects. Among the major spoken languages by the interlocutors were Urdu, Punjabi, Siraiki, Pashto, Pothohaari and Hindko. Urdu is the national language and widely spoken by the urban population of Pakistan. All the reported spoken languages except Pashto were easily understandable to me. With the Pashto speaking interlocutors, I used Urdu language which was easy for them and me to communicate.

I gave importance to their views to get more details. This perspective helped me in gaining detailed information about the people's beliefs in the treatment of traditional and faith healing. My prior information of the culture of the breast cancer women was helpful for me, but I tried not to overlook or misinterpret the responses of the interlocutors and remained careful not to give importance of my point of view over them. Having unfamiliarity with the experience of breast cancer, my position in the fieldwork was of an outside researcher. I had no information how the breast cancer patients live with their illness. It is a need of the researcher to develop and establish trust with the interlocutors in order to make them relaxed and share their experiences with him/her (Keval, 2009). Keval's view appeared true during the fieldwork; I spent time with the breast cancer women and with their care-givers and finally was able to make familiar ties with them, and they were ready to share with me their experiences of the illness.

In some condition for male researchers, it becomes difficult to research females (Egharevba, 2001). Being a female, I was at great advantage to get detailed information as the Pakistani women do not like to share the issues related to their body part with a male with the exception of some religious and folk healers. They describe their illness to the religious and folk healers, but do not show the affected organ. All the interlocutors whom I studied informed that they do no show their breast to their religious and folk healers though some healers, too do not want to see for cultural and religious reasons. On description of the illness by the breast cancer woman and/ or her care-giver, the healer prescribes the treatment. In the Pakistani society, women are not expected to interact with men freely. They are not expected to discuss their body issues with men except those who are her close relatives called [6]*Mehram* or male doctors. Le Gallais' (2003) view was helpful in the fieldwork that the researcher should have an open mind to unexpected responses of the interlocutors during the research and should never assume that the interlocutor will behave in the same manner as the other behaved.

3.8 Units of observation and units of analysis

Using the phenomenological approach, the illness experiences of breast cancer women and the roles of their care-givers were studied. To understand the roles of care-givers, family members as primary carers, nurses as secondary and paid servants as tertiary carers were classified into three units of observation.

Interactive instances, narratives, dialogues or verbatim were extracted from the beliefs, knowledge, attitudes and practices of breast cancer women and their care-givers regarding breast cancer. Interactive instances and verbatim were deduced from the body image concerns and transformation of the roles and identities of breast cancer women in maintaining the social relationships. These were extracted from the dynamics of class and diverse socio-economic status of the breast cancer women in alternative healing practices. Folk narratives on the alternative treatments were collected predominantly spiritual treatment, availed by the breast cancer women themselves. All the collected interactive instances, narratives, dialogues or verbatim were the units of analysis.

3.9 Data Analysis

Interviews, proceedings of group discussions, and information obtained from the cases studied, were transcribed verbatim. Soon after obtaining the information from participants, it was translated into English with an attention to the meaning and context. The data was in five languages, i.e., Urdu, Punjabi, Hindko, Pushto and Pothohaari which were soon translated

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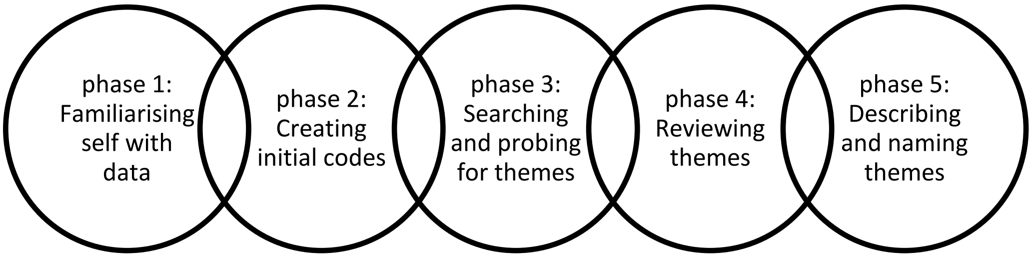
[6] *Mehram* is a religious belief which is largely followed by the natives. In Islam, *Mehrams* are called those men who have blood relationships with women such as their Fathers, brothers, sons, son's sons, daughter's son, brother's sons, sister's sons and have close affine relationships like husband and father of husband. Further in Islam, *Mehram* is also that person with whom a Muslim woman cannot marry.

into English transcripts. The people in community who were fluent in their local language and in their national language, i.e. Urdu helped in elaborating the contexts and meanings, making it vivid for the researcher's understanding.

Inductive thematic analysis (Braun & Clarke, 2006) and *interpretative phenomenological analysis* (IPA) (Smith & Osborn, 2003) were used for the analysis of dataset. The method of thematic analysis was used for "identifying, analyzing and reporting patterns (themes) within data" (Braun & Clarke, 2006, p. 79). The purpose of this analysis was to carry out a comprehensive and detailed analysis of the data, identify and categorize themes that have reflections and traces of the living experiences of women. In addition, the previous researches on women's illness experiences made women's health issues significant more than before. Keeping this idea in mind, this research adopted thematic analysis with supplemented contextualized epistemology. It was tried to make the sense of illness experiences of women within their private sphere and broader cultural setting. The analysis was also established at semantic level, whereby the condensed themes reflected the apparent meanings of the data. It was described, summarized and then interpreted with broader meanings and implications, which are supported by the researches already carried out. Patton states the similar model in his book (1990). At the first place, themes were extracted, which were differently coded. Leading these themes Interpretative Phenomenological Analysis was done. As Interpretative Phenomenological Analysis (IPA) demands complete understanding of the way the people understand their situation, reality and world around them (Smith & Osborn, 2003), this type of analysis was very close to the nature of data.

By using the bottom up approach, themes were drawn or written with the data. Braun and Clarke's (2006) guide was consulted step by step to carry out the analysis of the data. All transcriptions were read attentively and for several times, and notes were made. In fact, this phase of analysis helped familiarize me with the gathered data. In the process of reading the data, stimulating, remarkable and unique aspects were noted. Largely this process was done by the researcher herself. After the phase of reading, and re-reading of the data, initial codes were generated. This process was time consuming, but it has ensured that nothing had been missed out. Figure 4 below shows the phases of data analysis.

Figure 4. Analysis of findings



Note: Phases of the analysis of findings

After generating a list of codes, the codes were grouped into potential themes. A map of codes, themes and sub-themes was drawn. Themes were reviewed to see their accuracy and filtered to remove the repetition. Each transcript was again reviewed at this stage for additional coding if anything was missed in early coding and removing the repetition. Finally, all themes and sub-themes were again reviewed to make sure whether they described a clear story and caught the depth and breadth of the gathered data or not. In this stage, they were labeled in such a way to identify each theme.

For validation and precision of the interpretations (Mays & Pope, 1995), the findings were verified by two qualitative researchers who were experienced in thematic analysis. From the entire data that was randomly selected, a transcripts and its copy was given to both researchers. Both produced the same themes which validated the other efforts made for coding and producing themes. All transcripts were shown to both the researchers, and they agreed on the interpretation and the production of themes.

CHAPTER 4
LOCALE

4.1 Pakistan

A country is located in South Asia with 32,205,111 households and total population of 207.774,520. She consists of 10, 64, 49,000 males and 10, 13, 14,000 females with the average annual growth rate of 2.40 (Population Census, 2017). It is spread over 881,913 square kilometers (340,509 square miles), sharing the border in its East by India, West by Afghanistan, Southwest by Iran, China by Northeast and has 1,046-kilometre coastline along the Arabian Sea. The land that constitutes Pakistan is acknowledged a cradle of civilization (Feuerstein, Kak & Frawley, 1995; Mohiuddin, 2006; Wright, 2010). "The Indus civilization is one of three civilizations in the 'Ancient East' that along with Mesopotamia and Pharonic Egypt, was a cradle of early civilization in the Old World. Mesopotamia and Egypt were longer lived, but coexisted with the Indus civilization during its florescence between 2600 to 1900 B.C.E. The Indus was the most expansive, extending from today's northeast Afghanistan to Pakistan and India" (Wright, 2010).

It was the home of many ancient cultures, together with the [7]Mehrgarh of the Neolithic, Indus Valley Civilization of Bronze Age and later this territory was ruled by many people of different cultures and faiths, including Hindus, Indo-Greeks, the followers of Islam, Turko-Mongols, Afghans and Sikhs. The territory was invaded and ruled by several dynasties including the Persian, the Alexander III of Macedon, the Indian Mauryan, the Arabs, the Delhi Sultanate, the Mongols, the Afghans, the Sikhs, and the British. Country has seven administrative units that consists of Azad Jammu & Kashmir (autonomous territory), Gilgit-Baltistan(autonomous territory), Islamabad Capital Territory (federal capital territory), Balochistan (province), Khyber Pakhtunkhwa (province), Punjab (province) and Sindh (province). All these ethnic groups have their own local languages, but all accept Urdu as integrative device in the country. Despite the absence of their official recognition, these

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[7] An earliest settlement was populated from circa 6500 BCE covers area of 495-acre (2.00 km). A team led by Jean-François Jarrige, and Catherine Jarrige, French archaeologist excavated from 1974 to 1986 and again from 1997 to 2000 (Sharif & Thapar, 1999).

indigenous languages have tradition of literacy since 18th century; their books have been read by the people of South Asia (Tariq, 2001). The indigenous languages of Pakistan are Punjabi, Sindhi, Siraiki, Balochi, Pashto, Kashmiri, Brushaski, Marwari, Shina, Balti, Brahui, Hindko, Wakhi, Haryanvi, Kalasha, Dhatki, Dogri and Paharri (Eberhard, Gary, & Charles, 2019).

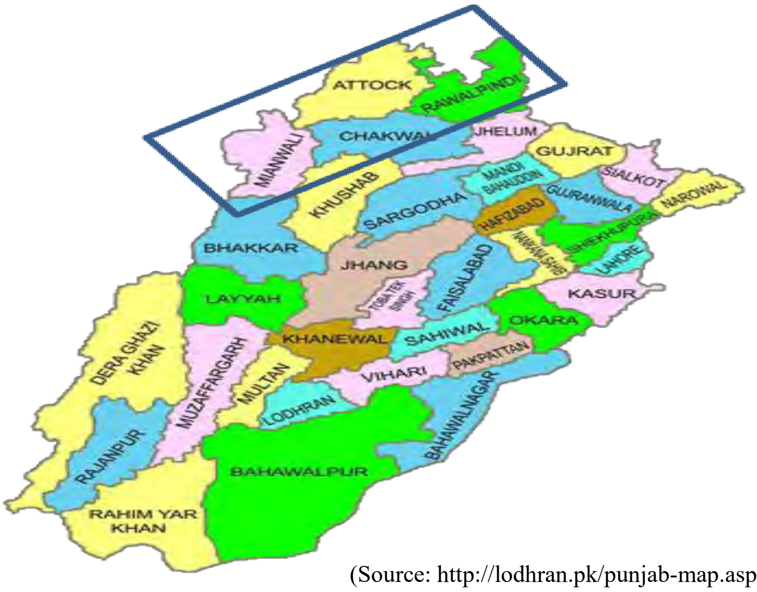
Figure 5. Map of Pakistan

(Source: https://www.nationsonline.org/oneworld/map/pakistan_map.htm)

4.2 Province Punjab

The Punjab province is famous for its five rivers, i.e., Indus (Sindh), Ravi, Sutlej, Chinab and Jehlum. Its provincial capital is Lahore, a historic, cultural, economic and metropolitan center of the country. This city is also famous for its base of fashion and cinema industry. Since ancient times, Punjab is inhabited. The Indus Valley Civilization in 2600 BCE was discovered at Harappa (Linda , Larry, Phillip, & Dahia, 2005). The number of households in the province of Punjab are 17,103,835 with total population of 110,012,442 and growth rate of 2.13%. The Punjab forms 52.94% of the total population of the country (Population Census, 2017).

Figure 6. Map of four districts of Pakistan



(Source: http://lodhran.pk/punjab-map.aspx)

The majority of breast cancer patients, who participated in the study, were from the areas highlighted with the help of a rectangle in the map of the Punjab. The highlighted areas are four districts including Rawalpindi, Attock, Mianwali and Chakwal. Majority of the breast cancer patients whom I met in hospitals or got contacts to meet them at their home settings for data collection were from these districts. These areas are not so far from the capital city, Islamabad. For example, the district Rawalpindi is adjacent to the capital and both cities are considered sister cities. The distance between district Mianwali and Islamabad is 257.0 km, between Attock and Islamabad is 93.7 km, and between Chakwal and Islamabad is 174.0 km.

4.3 District Rawalpindi is adjacent to the capital, i.e., Islamabad that is spread over 5285 sq. kms. Its population is 2,098,231 (Population Census, 2017). According to the census report of

1998, 51.20% population consists of males and 48.80% of females. The urban population of the district is 53.16% and the rural population is 46.84 %. Average household size of the district is 6.2 % (Population Census, 2017). Quite often both the cities, Rawalpindi and Islamabad, are called twin-cities. It is situated at the Pothohar Plateau, area renowned for the existence of a community of Buddhists. Rawalpindi is also neighboring town of Taxila, which is accepted as a World Heritage Site. Since the independence of Pakistan from the sub-continent, this city became home of the Pakistan Army headquarters. The total housing units of the city are 521507 among which 88.73 % are paved and 90.98 % have facility of electricity; 41.29 % have piped water, and 52.89 % have the facility of Gas for cooking (Population Census, 2017). The city has major hospitals of all kinds of illnesses. The breast cancer patients from the nearby districts of the province come here for treatment.

4.4 District Attock is spread over 6857sq. kms in Pothohar Plateau of the Punjab. According to the census, the district has population of 1,274,935, and consists of 636338 (49.91% males) and 638597(50.08% females) (Population Census, 2017). In the district Attock, urban population is 21.26%, and rural is 78.74%. Average household size is 6.2. The total housing units are 206678 and paved ones are 76.76%, 69.67% and have electricity; 27.00% have the facility of piped water and 17.41 % have the facility of Gas for cooking. The annual growth from 1981 to 98 was 2.23% (Population Census, 2017). Among widely spoken languages, Hindko, Pashto and Urdu are noticeable. The hills of Kala Chitta in the region of Pothwar come under the area of district Attock. The land of the district is a combination of plains, hills and dynamic climate with diverse floral and faunal richness. The people have rich folk traditions and rural culture; further, the people have distinct weddings, birth, death rituals and belief systems.

4.5 District Mianwali is spread over 5840sq.kms. According to the census of 1998, the district phas 1056620 people (Population Census, 2017). The population consists of 50.19 % males and 49.81% females. The urban population of the district is 20.82% and the rural population is 79.18 % with the average household size of 7.1 %. The total housing units of the district are 148837 and 64.65% consist of paved housing units. 65.44 % have the facility of electricity; 23.24% have piped water facility and 3.88% have the facility of Gas for cooking (Population Census, 2017). The area of district Mianwali is an extension of the Kohistan-e-Namak and Pothohar plateau. On the northern side of the district, there is Thal Desert. The Indus River passes through the whole district. It has extreme climate with hot and long summers and cold, dry, dusty winters. Among local languages, Punjabi, Saraiki and Pashto are widely spoken here. However, the population of Mianwali speaks and understands their national language, i.e., Urdu. The people of Mianwali district are traditional and have diverse religious and spiritual beliefs for birth, marriage, death and life. They have strong belief in traditional and faith healing.

4.6 District chakwal is located in Pothohar Plateau, north side of the province Punjab. It covers the area of 6524 sq. kms. According to the census, the district has population of 1083725 (Population Census, 2017). The population consists of 47.82% males and 52.18 % females. 12.15% of the whole population lives in urban areas, and 87.85% lives in rural areas with the average household size of 5.7. The district has total 187076 housing units and 32.57% are paved ones, and 47.95 have the facility of electricity, whereas 7.89 have piped water and 0.99 % have the facility of Gas for cooking (Population Census, 2017). Chakwal is famous for its oranges, crops of barley, sugarcane and wheat. Among the spoken languages in the district are Punjabi, Dhani and Awankari and their dialects. Pashto and Urdu are also spoken. The people of Chakwal strongly follow their social beliefs and values. Although they have accepted the hospital treatment, also known as western treatment yet they have strong belief in faith and spiritual healing.

4.7 Women observing Veil (Purdah)

Aurat is an Urdu word which means woman. It was originated from Arabic word Awra or Aurah. It is a noun that comes from the verb “Awira” which means “something too shameful to look at” (Goto, 2004). The word Awira also means “private parts” (Zeno, 1996). Aurah or Aurat has two meanings in the Dictionary of Islam: one is modesty or shame, second is the portion of body that must be concealed (Hughes, 1995). Jain explains many types which are used synonymously to the Purdah in South Asia. These are Ghunghat (a veil dragged over face), chunri or chadri (a cloak, mantle) odhni (a head cover or scarf that is used to cover face) (Jain, 2008). Marker explains that in Pakistan, Purdah has its solid expression in dress, and has different forms to cover women’s body. She describes “Burga”, (generally translated as Burqa), as a cloth attached to skull cap, and covers the head and face of a wearer; it has a netted section that lets the eyes see outer things. It also covers the whole body from head to food. The Chadar “an ankle- length cloak or shawl” covers the wearer’s complete body. The wearer can let the face and eyes exposed. The Dupata, a “two-meter-square scarf” is wrapped round the shoulder and breasts, it usually covers the head (Marker, 1989).

4.7.1 What is Veil or Purdah?

The veil is a type of dressing that involves the covering of body including hair. In fact, it is a piece of fabric draped as a head and upper or full body covering that functions as an item of dress. Despite using as an item of clothing, it has two-fold meaning. Veils are used to cover the body and at the same time draw attention to apparent aspect of the wearer (Daly, 2005). Purdah, a local connotation of veil, is a system which secludes women in South Asia. It brings forth two theoretical agendas concerning Purdah. Purdah as women's seclusion and men's honor (Mandelbaum, 1988), and Purdah as isolated and separated worlds and shelter (Papanek, 1973). Mandelbaum sees purdah with the idea of honour and shame, and Papanek sees it as a division of labour between sexes. Ring (2006) identifies it in a more comprehensive way saying, "Purdah is a social-cultural institute" that draws men's space from women's space. According to her, "it is a system of veiling and seclusion of women in zenana, or space of women" (Ring, 2006).

4.7.2 How purdah is observed in all four districts

Women in all four districts are considered dignity (*Gherat*) of the family. With little exception, women in these areas observe veil (*Purdah*). In Rawalpindi, women widely use *Abayas,* a long loose dress to cover their bodies while moving outside. In Attock, women commonly wear a long cloak covering the whole body, while moving outside. In Mianwali, with *Abayas, a* long cloak or shuttle-cork and burka are widely used for covering body for moving outside. In Chakwal, all kinds of veils mentioned above are used to wear. Breasts are one of the most tangible parts of women's body and purdah in all forms is observed by all women. According to my respondents, the purpose of Purdah is to hide the noticeable parts of body. There was a consensus among women that the covering of face and head with body is very important before going in public areas. Near them face and head are the core of beauty and uncovering of these parts can damage the moral order of the society. Women were seen the observers of Purdah covering their body from head to toe leaving hands and feet uncovered.

4.7.2.1 Burqa a Purdah-Dress

Women are widely seen in Burqa, a kind of purdah dress. Technically, this dress can be divided into three parts -- a flat-cut cloth, a tailored cloth and a wrapped up cloth (Andrewes, 2005). The flat-cut cloth consists of no shape or lines; the wearer ties it over the face. The tailored cloth is a loose stitched gown which hangs over the body. The headscarf covers hair and neck and also supports the flat-cut cloth which is tied over it.

4.7.2.2 *Chadar* (Ankle-length Shawl)

It covers the whole body. Though the wearer can let face and eyes exposed. The women of Rawalpindi and Attock districts were noticed observing this kind of Purdah. Purdah Chadar consists of two and half meter length. They wrap it around the body covering face, head, shoulders, breast, waist and legs. Marker (1989) described it as, “an ankle-length shawl”.

Figure 7. *Chadar* (Ankle-length Shawl) worn by women

(Source: Field data)

4.7.2.3 Shuttle-cork

This kind of Purdah was widely seen among women of Mianwali District. A big cloth is stitched with many curves and all curves are attached with a cap. That cap is also made of the same cloth. In cap, a netted section is made for eyes to see. This purdah looks like the shape of a shuttle cork. It covers the complete body from head to toe.

Figures 8,9. Shuttle-cork veil observed by a Pashtun women

(Source: Field data)

4.7.2.4 Abaya

This kind of Purdah consists of two parts; these are long gown or body cover, and a head scarf or Dupata. Women were seen wearing in all four districts. Some of the wearers of this kind of purdah told that they wear Abaya in black color to show that their body is ugly and unattractive. Some explained that they prefer to wear Abaya in black color to make their body invisible. They also explained that this kind of purdah is very easy to carry than the other kinds of Purdahs. It consists of only two pieces, one to wear and other to wrap. It has less cuts and curves which make them comfortable particularly with their breasts and waist issues.

Figures 10,11. Abaya, a kind of a veil observed by a daughter/care-giver of a woman

(Source: Field data)

4.8 Possible factors those are responsible for cancer among Pakistani women

Over the period of 8 years, only at Shaukat Khanum Memorial Hospital, Lahore, 3,338 women were diagnosed with breast cancer (Badar, Moid, Waheed, Zaidi, Naqvi & Younus, 2006). According to the recent figures in Pakistan, both young and middle-aged women were affected by the breast cancer, and there is a possibility of women getting affected as young as 20 years. The etiology of this illness is very complex as various indicative causes involve in its occurrence such as food, genetics, chemicals and ecological factors. It has been assessed that in Pakistan the germ line mutations in the BRCA1 and BRCA2 genes causes 5% of breast cancer (Rashid, Zaidi, Torres, & *et al.*, 2006). Among the Pakistani families with several breast cancer cases, it was found that the occurrence of BRCA1 or BRCA2 mutations was 42.8% and 11.9% for single cases (Rashid, Zaidi, Torres & *et al.*, 2006). So, the Pakistani women who have either of these harmful mutations suffer a life time danger of occurrence of early breast cancer.

Pakistan is one of the developing countries of Asia, and its most population is living in rural areas. Although there are Basic Health Units in rural areas yet there is no infrastructure for screening of several diseases such as cancer, hepatitis and tuberculosis. The lack of screening centres in front of large population is also one of the major reasons where women visit at a very advanced stage of breast cancer, which puts negative effect on prognosis (Menhas & Umer, 2015). Most of the women cannot afford Mammogram screening program. Awareness programs are not held on national level, giving awareness to women with simplest technique of Breast Self-examination (BSE). A less number of trained practitioners and nurses at health centers is another major reason of the un-awareness of women, learning the breast self-examination techniques (Menhas & Umer, 2015).

Illiteracy is one of biggest reasons of breast cancer because most of the women have no understanding and awareness regarding personal hygienic conditions. Unable to access a medical facility due to the gender discrimination is another major reason of breast cancer among the Pakistani women when delays in getting permission from the male or female heads of the families adverse their health condition. Half of the population consists of women and is also a marginalized sector of the society. Socio-economic conditions are also one of the major reasons of poor health of women in Pakistan (Menhas & Umer, 2015; Sohail & Alam, 2007). Breast cancer is also an inherited disease which has possibilities of transmission from mother to daughter. The Pakistani women are suffering from some other types of cancers, too such as cervical, ovarian and uterine cancers (Badar, Moid, Waheed, Zaidi, Naqvi & Younus, 2005).

CHAPTER 5
DATA ANALYSIS

5.1 Introduction

In this chapter, the primary research findings have been illustrated. The research findings were developed using analytical processes, described in the previous chapter. Using the anthropological lens, this chapter presents unique lived experiences of breast cancer women and their care-givers. I begin this chapter by discovering the lived experiences of these people including their belief, knowledge, attitude, practices, body image concerns, transformation of roles and identities, roles and behaviors of the car- givers (family members, nursing staff, social networks and domestic servants) in the health seeking process. The obstacles in the way of hope and struggle for treatment, and the folk narratives on the alternative treatments, particularly spiritual treatment, availed by the breast cancer women are also elaborated.

Among traditional methods, techniques and tools of *anthropology*, participant observation, rapport building, informal, semi-structured interviews, interview schedule, convenience sampling, group discussions and cases were used during the data collection process. All these methods proved helpful in making the care-givers and their breast cancer loved ones share their lived experiences. The collected data was transcribed verbatim. It was in five languages, i.e., Urdu, Punjabi, Hindko, Pushto and Pothohaari. Taking into consideration the meaning and context carefully and without delays, it was translated into English. Interactive instances, narratives, dialogues or verbatim were drawn from the knowledge, beliefs, attitudes and practices of care-givers and their breast cancer loved ones regarding the breast cancer.

Thematic Inductive Analysis and *Interpretative Phenomenological Analysis* (IPA) were used to understand the way the women with breast cancer and their care-givers understand their reality, condition and world around them. *Thematic Inductive Analysis* is used to identify, analyze and report themes within the data (Braun & Clarke, 2006). Smith, Flowers and Larkin (2013 p. 110) define it as, “IPA narrative represents a dialogue between participant and researcher and that is reflected in the interweaving of analytic commentary and raw extracts”. In this chapter, I share the living experiences of the participants in ways that can help understand their lives. As IPA is a mutual approach to research, I engrossed myself in the accounts of the participants by asking questions to make clear and correctly reflect the living experiences of breast cancer women and their care-givers.

5.2 Field findings and presentation of themes

Each theme is explained below as a heading. Sub-themes are italicized and described in detail as sub-headings. Participant observation was used to observe the contexts of the lived experiences, and communication between patients and their carers. Lived experiences of care-givers and their breast cancer loved ones were probed and enquired through conversation. To refer to the respondents in this text, pseudonyms have been used. In the research, the respondents were of three types, such as breast cancer women, their care-givers and treatment professionals, but the focus of the current research was care-givers.

Findings and analysis are classified into three parts. The first part deals with beliefs, knowledge, attitudes and practices of breast cancer women and their care-givers. The second part deals with the role of care-givers (family members, nursing staff and domestic servants etc.) within the framework of the treatment of the breast cancer women. The third part deals with the exploration of the dynamics of class and diverse socio-economic status of the care-givers and their breast cancer loved ones. This part also deals with the folk narratives in different treatments, particularly spiritual, homeopathic and bio-medical treatment availed by the breast cancer women themselves. Demographic features of all women with breast cancer and their care-givers have been mentioned in Chapter three, tables 5 and 6 respectively.

Part 1: In this part, major themes were: beliefs and knowledge about breast cancer, a collective experience, spirituality, concerns of body image, loss of control, and healthcare experiences. Italicized sub-headings are subthemes that appeared in the data. Verbatim is provided to substantiate the context and understanding. It is important to note that all the recruited breast cancer women and their care-givers were descriptive in sharing their experiences, but they were quite often unable to describe their emotional aspects. Therefore, it required an extensive probing to make the care-givers and breast cancer women open up and express their feelings. The answer of every question was containing a description which let me ask them more questions. This can be seen in the examples below.

Extract 1:

The researcher: In what ways, do you feel changes in your life? Can you please tell me about your illness and changes you feel?

Rukhsana: Um, I feel like I am a completely changed person. This illness has not only made me bald headed and wrinkled my skin but has also changed my mind.

The researcher: What changes do you feel have happened in your mind, can you please share with me?

Rukhsana: My mother never had this illness, but I got it. I never had much knowledge about it. Its diagnosis was like a blast in my life. I lost my money through its treatment. I lost my beauty and confidence of life. My daughter looks after me. I stop her from spending money on my treatment which I saved for her marriage. We live in the rural area, and it is expensive to approach and get medical treatment, but we are going and we assume that this is a trial from Allah and one day He will give us success in our struggle.

The researcher: What kind of trial are you facing?

Rukhsana: Illness is nothing, but a trial from Allah. He wants to test our faith in Him. My daughter is optimistic and struggling to get treatment, and we would be successful in this trial from Allah.

The researcher: What types of changes do you feel have occurred in your body, and who is responsible for that?

Rukhsana: Medicines of cancer have changed my body and mind. The side effects of medicines are more horrible than cancer itself. The Western medicines have burnt my stomach. I feel pain in my teeth and limbs. I cannot even the digest normal food.

Extract 2:

The researcher: Did you ever hear about breast cancer or anything related to this illness before?

Shamim: I heard about cancer of women but never had information that it brings many problems.

The researcher: After the diagnosis of breast cancer, what kind of major problems do you feel for yourself and for your family?

Shamim: After the initial diagnosis, a lady doctor at a local hospital suggested me to get some tests. I was not having enough money to get tests. The hospital was 4 hours away from my home and except me, there was no other carer of my kids. My husband runs a corner shop and that is our only source of income. Before the diagnosis of breast cancer, I was a seamstress.

The researcher: What are your beliefs regarding your illness?

Shamim: I do not think that it is an illness. It is a kind of punishment from Allah. I married without the consent of my parents and Allah has punished me through this illness, but I am fighting hoping that I will survive.

The researcher: What are the factors which motivated you to receive treatment?

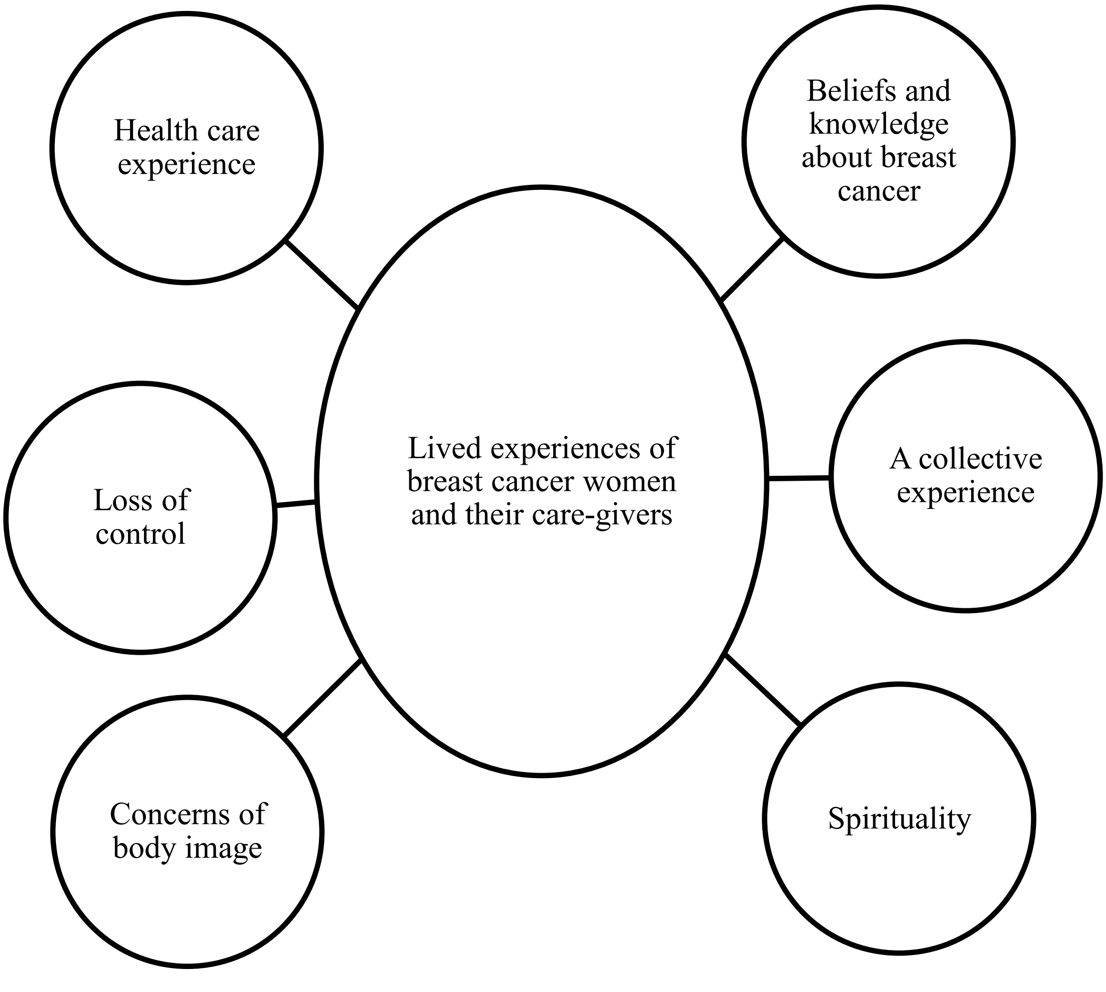
Shamim: I was hopeless, but my friends motivated me to get treatment for kids and husband. Although I am financially poor yet I am trying hard to get treatment. I want to live for my family. My all three kids are school going; they need me.

The researcher: How did you have your tests if you were not financially strong to get tests and treatment?

Shamim: I approached two big government hospitals of the city. There were delays and staff of the hospitals suggested me to go to the private clinics or hospitals for initial tests. One of my customers and friends guided me to apply for free tests and treatment as a needy patient. This process took four months, but at last my tests and treatment started as a needy patient.

In both extracts, descriptive nature of the women allowed considerable probing. They were encouraged to open up and share what they feel. All this helped understand the true meanings of their beliefs. For example, apparently punishment and test seems the same, but there is difference in connotations of both the beliefs. Punishment is for a sinner or criminal, whereas test is for a pious person. This proved helpful in assuming that how they construct their self-image. The woman in the first extract has a positive self-image as she takes her illness as a test from her God, while the woman in the second extract has a negative self-image as she feels punished by God for her bad action in her past life.

Figure 12. illustration of six themes



5.2.1.1 Beliefs and knowledge about cancer

Taking everything into account, the lived experiences of the breast cancer women were very stressful. There was not much difference in beliefs and knowledge regarding the breast cancer among rural and urban women. However, the way they managed the breast cancer was different. Diagnosis and making sense of breast cancer was the most challenging time for every patient and her family members. All the women recognized that there is no available information regarding the breast cancer in their local languages, but as they know their national language, i.e., Urdu, its understanding is not difficult for them. Generally cancer is perceived as a fatal disease in their society. Their perception leads towards certain cognitive schemata. They think every kind of cancer is fatal. It is termed as "Sartaan / سرطان" and its diagnosis is considered a message of death. Culturally, they had very little awareness of it, taking it a matter of shame to discuss an illness related to the breast of female body. Due to the cultural taboo, they never talked openly about it. Majority of the women acknowledged that doctors in hospitals guide them and their care-givers about the new types of treatments and advise them to spread the information among more people.

5.2.1.1.1 First response without realization of breast cancer

For most women, it was first time they had come to know about breast cancer. It was very bewildering for them that a tumor or lump can be linked with a chronic illness and negligence can be fatal. Further information like prolonged and expensive treatment was found to be greatly appalling for them all. This situation left them and their family members in a baffled and confused state. An aged and two middle-aged women stated that:

> *"I heard about cancer but never heard about breast cancer. Even my whole family was unaware about it".* (An informal interview with case number 3: *Shazia*, aged 34)

Similar initial reactions about the lumps were found in practice.

> *"A lump below my left armpit was hurting for many weeks. Because of this lump, moving the shoulder was painful, so I massaged it with a balm (ointment),*

> *ignored it and avoided to go to the hospital for the check-up".* (An informal interview with case number 2: *Shamim*, aged 39)

> *"I found it here (pointing her right armpit) but when it increased in size I bandaged it with the idea that it will get removed".* (An informal interview with case number 1: *Rukhsana*, aged 52)

> *"I never thought it would cause great damages in her life. I took her to a local shrine when her lump got worse.* (An informal interview with the care-giver, case number 13: Mother of a breast cancer woman, aged 55)

Less open talk about the body part was attached with the local taboos which consequently appeared in ignorance towards an illness of a part of female body. Majority of the women shared that with the idea of shame; they kept their illness hidden from friends, colleagues and neighbors. Keeping it to them only made them isolated and quiet. Later on, when they visited hospitals and clinics, they found other women going through the similar situation. In the hospital, they came into contact with patients of different types of cancer. This made them expressive and they talked and shared their cancer experience with the people surrounding them.

> *Before going to the hospital, I felt myself alone suffering from this illness. I saw many patients in the waiting area of the oncology department of hospital. I was shocked to see when a mother of a young girl told that her daughter is suffering from breast cancer. During my visits to the hospitals, I saw that many of the patients come for their regular check-ups and treatments from far-off places of the country. A Pashtun woman told me that her husband was not ready for this check-up and treatment; she came with her sister and father. Stories of other women were more painful than my story. For the first time, I felt that I can share my experience with them because only they can understand what I feel.* (An informal interview with case number 11: *Adila*, aged 45)

> *"I shared my experience with a Siraiki woman who was also suffering from it. She also shared her experience with me. She told me that with medical treatment, she is also getting faith healing and she advised me also to get faith healing, too.* (A semi-structured interview with *Rakhshanda,* aged 55)

This is a reality that many women were not educated. Fourteen out of twenty seven total breast cancer women had never gone school and never got any formal training in reading and writing. They felt hesitation from doctors to ask questions about their illness. For doctors, it was also difficult to tell them in easy words. They felt beneficial sharing their experiences with one another to get more information about this illness and about further treatment, their side-effects and total cost. All women were aware about their national language, i.e., Urdu and felt easier to communicate with one another.

> *It is not easy to communicate and get answers from doctors of all those questions you have in your mind as doctors usually hide possible side effects of their treatments from us and do not make us mentally prepared facing them. However, when you share with the person who is suffering from a similar disease, you do not feel yourself alone in suffering.* (An informal interview with case number 10: *Noreen*, aged 49)

> *A sister of Misbah told me what kind of side effects of chemotherapies can be on my mother. She told me the herbal remedies for decreasing effects of this treatment. We exchanged our mobile numbers to stay in touch with one another.* (An informal interview with care-giver: a daughter of breast cancer woman aged 22)

They were comfortable in sharing information with the patient and their care-givers suffering in the same conditions. Their interaction in hospitals and clinics was a source of knowledge sharing among them the treatment process of their illness. They were not using the names of medical treatments like the word “radiations”; they were using the local word “Shuaaen” that meant radiations. They had no basic understanding of treatment but were able to describe the procedures of treatment that they experienced. *Shazia* shared her initial experience that the suggested treatment gave her information about her illness and its treatment.

> *There were two lymph nodes (she raised her arm and points to her right armpit). Doctors took out a small matter from these and tested it. Both lymph nodes had lump, so doctors suggested me the treatment of chemotherapy.* (An informal interview with case number 3: *Shazia*, aged 34)

5.2.1.1.2 What and Why me?

Unexpected diagnosis of cancer and limited information about this disease put women in a perplexing condition that why they got it. In this self-blaming and self-cursing condition, they look for many explanations. Many women also attributed their cancer to anxiety. For instance, Komal thinks that why she had cancer as none of her elders in the family had cancer? She believes that her illness is due to her stress which she took during her studies.

> *I was surprised to know about the reasons and factors of it. Elder women of my paternal and maternal families never had this disease. This can be the result of my depression which I took during my stay in hostel. I felt home sickness there and stress related to my studies.* (An informal interview with case number 4: Komal, aged 22)

Misbah thinks that she had breastfed her kids, and did not know why she developed breast cancer.

> *Before my diagnosis, I used to believe that tumors appear in and around the breast and shoulders when a woman does not breastfeed her kids. But I am caught by it despite I breastfed all my kids.* (An informal interview with case number 5: *Misbah*, aged 40)

Shamim thinks that she had never eaten fast food and breastfed her kids, then why she caught this disease.

> *Once in a Morning Show of a TV channel, I heard that eating too much fast food is one of the major reasons of breast cancer, but since my childhood I barely eat it more than five times.* (An informal interview with case number 2: *Shamim*, aged 39)

All of the women were not sure about the reasons of their cancer which are usually claimed by the oncologists. A fatalistic attitude was observed when they rejected all the reasons they heard in hospitals, whereby they related diagnosis with religious beliefs. Many believed their diagnosis as the will of Allah. They were relating it with their examination taken by Allah. In a dialogue with Masooma given below, she accepted her illness as a part of her destiny.

> *"This pain was a part of my destiny; I have to endure it".* (An informal interview with case number 6: *Masooma,* aged, 43)

Many were claiming a very good time after death as they believed that they had suffered a great deal in this world. *Nazia* blames herself for her condition and finds it a chance to ask for forgiveness for her misdeeds.

> *It is the result of our misdeeds what we did in our past life. It is not punishment from Allah, but a chance to ask for forgiveness from Him to get a protected resurrection in the eternal life after death.* (An informal interview with case number 7: *Nazia*, aged 61)

Sufferings during treatment also let them blame themselves for their illness. For instance, *Shazia* shared that people waiting in the waiting areas of the hospitals let her think bad that why she is chosen for this illness.

> *During long waits for treatments, I used to feel extremely bad that why Allah chose me for it, and why me?.* (An informal interview with case number 2: *Shamim*, aged, 39)

Sad feelings of blaming herself and destiny emerge also with bearing the bad side-effects of treatments. These effects are: insomnia, indigestion of food and diarrhea. Such feelings were seen going along with the whole treatment and its side-effects. For instance, *Kinza* (pseudonym) shared that her mother blamed herself when she saw dark patches on her skin, and was unable to digest food and was suffering from insomnia.

> *You know! With pinky skin she was very beautiful. In beauty, I do not look like her; she was very beautiful. The diagnosis of breast cancer was very disturbing for my Mum; she was very upset and remained upset until the end of her chemotherapies. She was unable to eat food and digest it; she could not take a relaxed sleep. Moreover, she did not tell her colleagues about her illness and pretended that she was suffering from the disturbance of stomach. She used to*

> *cover her head with a doubled scarf.* (An Informal interview with care-giver: the daughter of a breast cancer woman, aged 22)

5.2.1.1.3 Body shame: a barrier to talk about breast cancer

Women explained that they are not culturally expected to talk about illness related to the breasts of female body. Besides wearing dress, they cover their upper part of body with a cloak. Many women and their care-givers shared their views and beliefs regarding body shame and barriers in talking about breast cancer.

> *"Never talked before about breast as it is a body shame"* (An informal interview with case number 6: *Masooma*, aged 43)

> *She felt shame for a long time after its diagnosis as, you know, it is perceived a disease of modern women who do not breastfeed their kids and of those women who eat junk and fast food and did not live a simple life.* (An informal interview with care-giver, case number 3: a daughter in-law of a breast cancer woman, aged 34)

Komal feels it shameful to share her condition with her friends.

> *It is not fever or diarrhea that one can tell others; it is a matter of breasts of female body. I do not share it with my friends even.* (An informal interview with case number 4: *Komal*, aged 22)

Rukhsana believes that the news of her illness is shameful and can create problems in the search of marriage proposals of her daughter.

> *I did not tell my colleagues in school (where I teach). I cover my chest with a double cloth and tell them that I have ulcer in my stomach. That's why I do not feel good and remain tired all the time. If I discuss with them, they will ask so many questions, which will give me more stress. The news of my breast cancer can stop people who want marriage proposal of my daughter for their son.* (an informal interview with case number 1: *Rukhsana*, aged 52)

Shazia shared that it was very embarrassing for her to face members of her family particularly male members.

> *I was feeling shy from the male members of my family. After the diagnosis, I was very embarrassed thinking what wrong I did to myself that I have this illness. My mother told them the common reasons that doctors told about.* (an informal interview with case number 3: *Shazia,* aged 34)

Many women and their care-givers shared that the feelings of shyness reduced among them over time. Sharing of their experiences resulted in their family members being more open to discuss about this disease and issues related to it and let them be willing more than before to learn about this disease. *Fazeelat* shared her experience saying that:

> *I kept my cancer in secret until the chemotherapy started. After that there was hope that bad cells will have been killed and I will survive. I was able to discuss it in birth, marriage and death gatherings of my social circle. People talked with me about it, and I told them about its possible reasons, treatments, side effects and survival.* (An informal interview with case number 9: *Fazeelat,* aged 62)

Samina shared that people surrounding her have more information than before regarding this illness.

> *When people surrounding me heard about the diagnosis of my cancer, they felt that it is a death message for me. They thought that it is like TB (tuberculosis), and will spread to the people who come into contact with me. But now they know that is not a contagious disease.* (An informal interview with case number 8: *Samina*, aged 45)

Noreen shared that after her treatment, she arranged awareness campaign in her college hoping to break the taboo about a female organ for health purpose.

> *A screening team of the hospital came to my college, where I teach. I saw the doctor; she checked and diagnosed a lump. She recommended me to see a doctor in the general hospital of the city for further tests. To break the element of shyness in talking about an affected female body organ, I arranged awareness*

> *campaign in college. We called two oncologists from the hospitals as speakers of the event; we talked about it and spread information pamphlets about it.* (An informal interview with case number 10: *Noreen*, aged 49)

5.2.1.2 A collective experience

It was evident from the shared stories of the women that their illness affected the lives of many other people. These people were their family members, whose role was very significant from the time of diagnosis to the stage of post-treatment check-ups.

5.2.1.2.1 All the members of family are affected by it!

All the women shared that the time of diagnosis was very critical for their family members as they heard about diagnosis; they were shocked, worried, distressed and sad. Misbah shared that the news of her illness was very painful for her mother.

> *"When I was diagnosed with the breast cancer, my mother started crying. She never heard about it but heard that a cancer is a deadly disease.* (An informal interview with case number 5: *Misbah*, aged 40)

Adila told that his husband was indirectly suffering from the side-effects of her illness.

> *It was very disturbing for my husband; diagnosis and then long treatment and painful side effects such as in-digestion of food, insomnia and stress, all were adding to his stress. He was unable to decide what next step should be taken to save my life. He was worried about our children, and it caused disturbance in their normal lives.* (An informal interview with case number 11: *Adila,* aged 45)

From the accounts of the women, it was evident that the illness penetrated in their whole family. The close family members were their primary carers. Among all major effects such as anxiety was most apparent. All the women shared that their illness disturbed them, and they have lost their normal family life as all members were playing their parts for the survival of their loved one. *Rukhsana* shared her concerns regarding her expensive treatment and the possible needs of her daughter in future.

> *I saved money for my daughter's higher education and for her wedding. After the diagnosis and required information regarding the cost of treatment, I was not willing to have treatment, but my daughter was not ready to neglect it. Now I am*

> *getting chemotherapy treatment, and it is expensive. For me, it is a matter of tension. What will she do in future if she needs money for business or wedding?* (An informal interview with case number 1: *Rukhsana,* aged 52)

A daughter shared her sad feelings for her mother.

> *After the death of father, she is our lone supporter. With this illness, she is searching suitable matches for me and my brother. We feel sorrow for her that she is living a painful life.* (An informal interview with care-giver of a breast cancer woman: aged, 29)

Ferzanda shared that she wants her daughter to get married soon before the spread of the news of her illness. She is afraid that the responses of people regarding her illness can disturb the marriage life of her daughter.

> *With this illness, I cannot trust the recovery of my health. I want to see her (daughter) married. People can ask questions on my health issue and possibly about the health of my daughter. Nevertheless, she is reluctant and wants that I should restore my health first. I want to get successful treatment and be a survivor only for my daughter. This physical illness has placed me in a psychological stress.* (An informal interview with case number 12: *Ferzanda*, aged 55)

The women, who were playing major roles in their families, their experiences of cancer were intensified. It was difficult for them to focus solely on the treatment of their illness. For example, *Rukhsana, Shamim, Fazeelat* and *Misbah* were worried about their children. These women tried to avoid their illness, thinking it will add miseries to their families. Rukhsana was a widow, and being a single carer of her daughter, was worried about the completion of her daughter's bachelor degree and for her wedding. *Shamim* was worried, for she had three kids, who were in ages from 3 to 7 years to care for. *Fazeelat* was a widow and was worried about a suitable match for the marriage of her daughter and son. For her, it was her first and foremost religious and moral obligation to get her children married in her life. *Misbah* was worried for her husband, who was facing problems in taking care of children alone. For these women, their illness was secondary. They were concerned more about other issues than their illness. They were not focusing on the recovery, but trying to help their family members even with their illness. This can be observed in the following lines.

> *"I have to fulfil my duty to see my children settled down in their lives.* She emphasized, saying *I want to see my daughter and son get married".* (An informal interview with case number 9: *Fazeelat,* aged 62)

> *I cannot live in my home. If I live there, my husband will have a burden of caring me. He does a job, looks after the children and handles chores of home. I am living in my mother's home; she look after me. He takes many days off from office for me and children. I am worried about his job as the company will fire him if he gets more days off.* (An informal interview with case number 5: *Misbah* aged 40)

5.2.1.2.2 Support of family members and desire to survive for them

All women described that the support of their family members was very significant in helping them endure the experience of cancer. Particularly the members of immediate family like husband and children of a woman and if she is unmarried, then her mother, father, brother and sister, were seen playing a vital role in helping her get through her experience of cancer. They were contributing their practical help such as shopping, cooking food, cleaning home, washing clothes, taking them to hospital, during treatment waiting for long hours in the waiting areas of hospitals. Due to surgeries, many women were unable to do many other tasks such as taking bath and brushing hair. All this made women focus on recovery without taking other worries and responsibilities. For example, Adela's husband and Rukhsana's daughter were very supportive from practical and emotional perspectives, and they decided to fight against their illness, trying to achieve survival for their loved ones.

> *"They are supportive and I am fighting for them* (An informal interview with case number 10: *Noreen*, aged 49)

> *I was very much scared about my treatment. Without the help of my husband, I was unable to get timely check-ups and treatment. In his absence, it was impossible for me to live and fight against cancer. Without his healthcare*

> *support, I had a little chance of survival as I was not hopeful mentally that I will beat cancer.* (An informal interview with case number 11: *Adila*, aged 45)

> *My daughters want me to see cured but I know that I will not survive as my husband died because of a cancer. My daughters want me to survive. They are hopeful regarding my survival. I am getting my treatment from a private hospital and want survival only for my daughters.* (An informal interview with case number 1: *Rukhsana,* aged 52)

Majority of the women talked about the members of their immediate families, but some also described the support of other people such as friends and neighbors. The women, who were open about their illness, got moral and social support from their friends, colleagues, neighbors and distant relatives. Therefore, it was important for those women living at some distance from their relatives, or were not having many family members to get support from others. For example, *Shamim* was not having much support of her husband. Her parents were also not ready to help her as she got married without their consent. So, she got help from her neighbor and friend, *Mehreen* (a pseudonym). She took her to hospital for screening tests and then helped her in collecting funds for her treatment.

> *For many months, I was feeling pain under my left armpit. I did not think it serious and neglected to go to the hospital for check-up. I continued moisturizing it with a cold cream and mustard oil. Soon this lump became more painful during my working hours. I discussed this situation with one of my neighbors and friends, Mehreen. She suggested me to go for a check-up in the hospital. I went to a nearby government hospital. In the OPD (outdoor patients department), a lady doctor on duty examined my condition and referred me to go to a cancer hospital for a screening test. In tests, my breast cancer was diagnosed, and it was on the second stage. I informed my husband about my illness. After getting information regarding the cost of the treatment, he suggested me to get herbal and faith healing. Lumps will burst automatically and cancer will be cured. His non-cooperative attitude on my illness was very depressing for me. I believe that his indifferent attitude regarding my illness is a punishment for me from Allah (God) because I married him against the consent of my parents and siblings. I did not receive good wishes from them for a prosperous future. This is a punishment that*

> *I am suffering from this illness with a fear of death. I waited for a month and illness became unbearable. I was unable to perform my daily activities. My friend collected 10,000 rupees from her job place and I got initial tests and check-ups. She collected 30,000 more for my treatment, but this amount was not sufficient for the complete treatment. She guided me and I applied in the hospital for free treatment. This process took a long time and my illness aggravated to a horrible extent. My friend helped me to fight against the illness and get treatment in any situation. Her social and moral support helped me in the struggle for regaining health.* (an informal interview with case number 2: *Shamim*, aged 39)

The women who were open about their illness with others described that they got moral and practical support from the people surrounding them. For them, these people were like their family members who helped them to fight against the cancer. The women, who were not having many number of immediate family members, shared their illness with their neighbors, friends and colleagues and received the possible support.

5.2.1.2.3 Company of a close and confident member of family

Twenty five out of twenty seven women shared that they feel problem in communicating with doctors. They viewed that they like the company of a close and confident member of family to go along them at the appointment days in hospitals and work as a translator of their feelings. They described the reasons of their desire to be with their close and confident family member in hospital.

Adila, a rural breast cancer woman, shared that her husband is very close to her, understands her feelings and is involved in the decision making process of her treatment.

> *My husband accompanies me in the hospital visits. I never think to visit alone; I did not feel comfortable in communicating with doctors. He understands my feelings, communicates with the doctors and decides what feels best for me. After diagnosis, he did not tell me directly that I am an affectee of breast cancer. He made me accept this illness telling that there is a bad tumor, and it should be taken out, so that it may not damage other parts of the body. You know, in the hospital it feels like you are not a normal healthy person. In this kind of distressed mental condition, I cannot understand the details about check-ups, tests, treatments and medicines. He understands all these things easily, and I*

> *would say yes, I have trust in him.* (An informal interview with case number 11: *Adila,* aged 45)

Rakhsanda, an urban breast cancer woman, shared that her daughter always accompanies her when she visits hospitals for the treatment.

> *I never went alone to the hospital; my daughter gets off from her school, where she is doing job as a primary teacher. She accompanies me in hospital appointments. She gets medicines and receipts of the check-ups and tests.* (A semi-structured interview with *Rakhshanda*, aged 56)

Suriya shared that after the death of her husband, she is close to her son who looks after her.

> *My daughter in-law does not pay much attention to me in hospital, instead she remains busy in mobile. She missed the results of my last test in hospital. So, I prefer to go with my son who gives full attention to the details given by the doctors. He gets off from his office to accompany me in the hospital.* (An informal interview with case number 13: *Suriya*, aged 62*)*

Rehmat shared that she feels herself satisfied depending on her daughter particularly in the hospital.

> *I do not know where labs and pharmaceutical stores in the hospitals are. I depend on her as she is educated and knows all this. She is very close to me as well; I feel comfortable with her in my hospital visits. She communicates with doctors and the staff of the hospital very well.* (An informal interview with case number 14: *Rehmat,* aged 60)

The nursing staff also feels satisfied in communicating with the family members instead of telling the treatment schedule, tests dates, appropriate diet, and the scheme of medicines directly to the patient. Shagufta told that nursing staff of her oncology department talks in detail regarding the illness with the family member of breast cancer patients.

> (She is telling this going towards her work desk) *We talk with patients but do not advise them.* (Speaking with arranging files on the table). *Definitely with a bad health, they are not in a position to understand the treatment schedule, test dates, diet pattern and the schedules of medicines. We always ask the patient to come with a family member, and we talk with that family member regarding the*

> *condition of illness and the treatment procedure.* (A semi-structured Interview with a nurse, case number 10: *Shagufta*, aged 43)

5.2.1.3 Spirituality

The focus of this theme is mixed spiritual attitudes that have inclined the experiences of women. These themes helped them in accepting their illness, i.e., cancer.

5.2.1.3.1 Spiritual attitudes

All the twenty seven women described their spiritual attitudes in one form or another. They discussed how these attitudes have played a vital role in helping them to accept and to deal with their cancer. Twenty three women shared that they visited holy shrines of local saints who were famous for being more close to Allah than others and with the perception that Allah hears their requests.

Samina shared that after her diagnosis, her faith in Allah got stronger than before. This faith helps her to be close to her God and be strong in the time of sickness.

> *I believe that Allah will help me in getting through this by making me closer to Him. Before the diagnosis, I was close to Allah like many other people, but after the diagnosis I got closer to Him. My faith in Allah got stronger after the diagnosis. I recite the Holy Quran more than before, call names of Allah again and again for having good effects of mind and body, and chant religious hymns. Thanks to Allah that I am a Muslim, and I have the power of faith which helps me to be strong in this time of sickness.* (An informal interview with case number 8: *Samina*, aged 45)

Rakhshanda shared that how her visits to a shrine help her feel peaceful, calm and patient.

> *Thursday of every week, I visit the shrine of Peer Hazir Shah. As you know, the shrine remains opened for all poor, rich, pious and sinful. People enter the shrine by taking their shoes off and after ablution. Birds chirp on the tomb of the shrine. The peaceful and holy environment of shrine gives me peace of mind, patience, control of emotions, understanding of the inner-self and less negative feelings of stress and anxiety. I distribute food among the visitors there; it gives me satisfaction and mental healing, and I feel that cancer has broken my body, but it*

> *cannot break my mind.* (A semi-structured Interview with case *Rakhshanda,* aged 56)

Out of twenty seven women, one was found blaming Allah for her current condition, but this attitude was found for a little time. During conversation, she shared how she recites the Holy Quran and sings Hymns and gives money in charity to cope with her illness with her strong faith in Allah.

> *What I share with you, you know, I don't know, why Allah chose me. I was okay, doing my domestic duties efficiently. Sometimes, I have very negative feelings towards my Allah, but all this happens for a very short time as it is a matter between me and my Allah….I think this condition is due to my weak faith in Him. I know success is in patience, and hopelessness is a sin in our belief. He says to ask Him for everything what you need, and He listens. I recite the Holy Quran and sing Him Hymns; paying visits to the shrines of His saints, and helping the needy people with money are good deeds. On the whole, I try to accept and deal with my cancer, having a strong faith in Allah.* (An informal interview with case number 6: *Masooma*, aged 43)

Figure 13. A procession at a shrine

(Note: Field findings)

Figure 14. Carrying offerings towards a shrine

Note: field findings

The spiritual attitudes of these women have helped them to control their emotions and grief regarding their illness. Their faith and engagements in religious activities gave them mental and bodily relaxation.

Zubaida, a 62 year old woman with breast cancer visited a local shrine called *Saiyen Hazir Shah,* located in Attok. The descendent of the shrine gave her three different amulets. The one was for wearing aound her neck for safety from the severity of the illness; the second amulet was for burning with the intention that illness is getting burnt soon, and the third amulet was for burying which symbolizes to bury the illness.

Figure 15. Amulet for wearing around neck

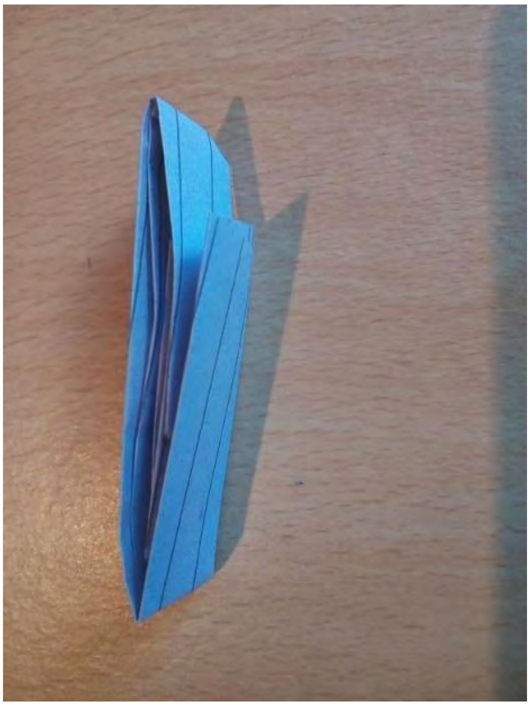
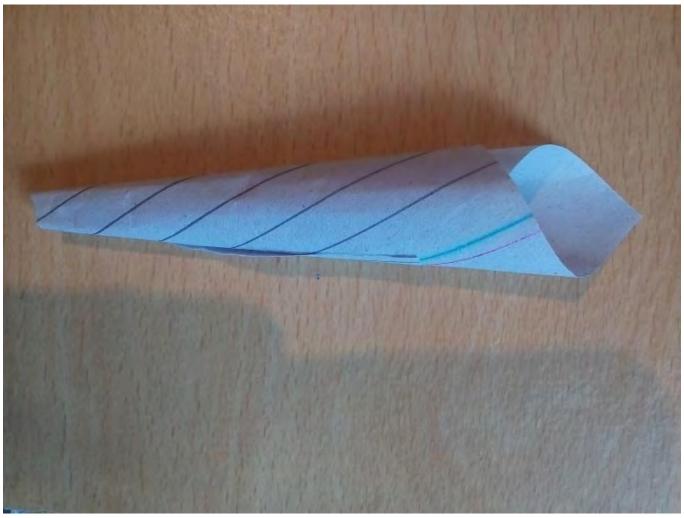


Figure 16. Amulet for burning

Note: The amulet was classified into nine pieces; each piece to be burnt in consecutive nine days

Figure 17. Amulet for burying



Source: This amulet to be filled with salt before being buried under soil and water. This action symbolized that illness will vanish soon as the salt dissolves in water.

During the research, spiritual healing techniques were observed many times attached with religious healing practices. The concomitant adherence to biomedicine and spiritual healing practices is a significant finding because it reflects concomitant trust and mistrust on biomedicine. The seekers of biomedicine treatment with spiritual healings believe that these healings give them psychological comfort, release their stress, and decrease their pain without giving side effects.

Misbah, a 40 years old woman with breast cancer, was seeking biomedicine treatment and using spiritual treatment concomitantly. She believed that biomedicine treatment will restore her health soon, but it will have side effects on her mind and body. She also added that spiritual healings will provide her psychological comfort and satisfaction.

Misbah shared that:

> *Radiations and medicines have largely disturbed my mind and sleep. By visiting the shrine of Maira Shareef, I feel mental comfort and satisfaction.*

Figure 18. *Maira Shareef* shrine

Figure 19. Descendant of the saint was giving soil of shrine in a cloth

Figure 20. Faith-healer and woman with breast cancer with her care-giver

Note: Faith-healer brushing the patient's body to symbolically brush away the illness and negativity from the body of the visiting patient

The shrine of *Maira Shareef* was famous for its spiritual healing effects. *Misbah* visited this shrine many times with her mother. A ritual of restoring health was performed by this healer, and it was also observed. He asked *Misbah* to sit on the ground. He moved the brush of shrine on her body. He finished this ritual in seven minutes and gave her a pinch of salt to add it into the salt of her kitchen and also gave soil (collected from the shrine courtyard) in a piece of cloth to take it to her home. She was instructed to keep that handkerchief containing soil mud from the shrine in her home for blessings (Local word: *barakah*). According to his description, the brush of shrine will remove illness from her body. The salt will heal by adding it in her food and by putting salt in house, she will be blessed.

The spiritual healer performed the ritual of healing in such a way that he said to *Misbah* to sit in front of him. He took a brush which was used for healing practice and moved it slowly on the body of *Misbah*. He recited some words silently and kept on moving the brush on her body. He took seven minutes in this process and picked a pinch of salt from a stone pot and gave it to her mother advising her to add it in the salt of her kitchen. He advised *Misbah* to give some money in charity to any Mosque after the completion of this ritual.

The visit for healing and cure is an evidence of affection or reverence towards any particular saint. Shrines are spaces of affection, bonding, faith and miracles for the followers of the saint. These are cheap, accessible and affordable alternatives in seeking health if one observes the shrine as a space to address the illness of the adherents. That healer had the knowledge of culture of local people, had simple living, so people had trust in him that he had no need of money rather he was serving the people of Allah.

The daughter and a friend of *Ruksana* took her to a religious healer at his shrine. Rukhsana is a 52 year old woman with breast cancer. The ritual of healing is a structured process and is scheduled for first Wednesday of every lunar month. The Islamic calendar is a lunar calendar; therefore, the months are actually Islamic months in this context. It is usually customary to visit the shrine for seven times. The spiritual healing is a systematic and integrated set of practices that include intentionality, faith, practices, sacrifices or offerings, amulets, recitation, and schedules to follow. The ultimate goal of spiritual healing is a complete recovery and perfect health. Therefore, a temporary relief from pain is one milestone often described by the believers of effectiveness of spiritual healing during conversations. There are significant symbolic meanings associated with Wednesday and number seven. The first Wednesday of the lunar month was the day when saint was born, so this day of each lunar month is celebrated by the followers of the saint. They believe that the saint hears their problems on this day and ask Allah for their help. A visit for seven times is connected with the seven rounds of *Khana Kaba* (the house of Allah). Muslims visit *Makkah* and make seven rounds of *Khana Kaba* and finish their 1 *Umra* or visit to the home of Allah.

Sumera, a 40 years old breast cancer patient with her sister-in-law was also found performing a folk ritual activity. For them, this ritual performance will lessen the illness steadily and will restore the health. The ritual involves carrying water in a strainer/sieve and walking ten steps at midnight. She and her sister-in-law filled the strainer with water from a bucket and tried to take water in it to a marked destination of ten steps. They ran to take water in the strainer to that marked place successfully which was not easy because of the holes in strainer. The time of its performance was mid-night when majority of the people should be in deep slumber.

Figure 21. Strainer used by *Sumera* in her ritual and ten step walk for healing

Figure 22. Sumera with her sister in-law carrying out the healing task

On asking about this performance, the sister-in-law of *Sumera* explained the ritual that*"the strainer is the illness and water is life. We try to take our life and health to a destination without losing water by the strainer which is a symbolic of disease".*

For *Sumera* and her sister-in-law, this spiritual activity in their village is of great value for chronic illnesses of all kinds. The symbolism attached to props and the performance in any ritual is significant for the practitioners of that ritual. These rituals are pathways of satisfaction and relaxation even if they fail to achieve the intended goals per se.

5.2.1.3.2 Fatalistic attitude

The internalized fatalistic attitude was commonly found among all women. This attitude was found disturbing their psychological strength to cope with their illness.

Maryam shared that her fatalistic attitude has increased depression and demotivation in her to understand cancer and deal with it positively.

> *You know! With this illness, there is no betterment in me and my family; even things got worse. It is what He wishes for me; there is definitely something good hidden behind my illness of cancer. He can grow horns on our heads even. He controls everything.* (A semi-structured interview with *Maryam*, aged 41)

Two out of twenty seven women were found in an attitude of self-pity and self-blaming. Suriya blames herself for her illness.

> *Suffering from this illness made me depressed and I ask Him that why, why and why me. This is may be the result of my unwise acts in my past life. Allah is annoyed with me and showing His anger to me through this illness. I recite, "O Allah forgive me (She used an Arabic word: Astaghfirullah), for all my acts which I did in my entire life consciously and unconsciously.* (An informal interview with case number 13: *Suriya,* aged 62)

Komal was found in an attitude of self-pity during her all conversations. In an afternoon getting back home from the hospital, I and Komal were in the car and waiting for her father who went across the road to purchase her medicines from D. Watson (name of a store) pharmaceutical store.

> *You know, this weakened there will be a farewell party in our department. I got this update on WhatsApp group of my class fellows. They were discussing dances*

> *and dresses for the party. I don't know why I am different from them and got this illness. May be Allah wants me to be closer to Him as I feel that when I cry; He listens to me; He wants me to be different from many other people.* (An informal interview with case number 4: *Komal*, aged 22)

5.2.1.3.3 Punishment from Allah

Four out of twenty seven women were found questioning themselves during long conversations with them. One common question they were asking about their actions was, "Something wrong was done by me, that I am punished by Him (Allah)". They believed that their misdeeds in their past life are the reasons of their current condition. Their belief was strengthened by the people who, on visiting them, imply that they definitely have done misdeeds and deserves this condition.

Rukhsana shared that her God wants to save her from severe punishments of the Day of Judgment and gave this illness as a punishment for her bad acts.

> *"I might have done wrong things consciously or unconsciously; this is all the result of my doings, but He (Allah) still loves me and wants to save me from the dire punishment of the Day of Judgment and punishment here signifies send me in heaven as a clean and sinless body".* (An informal interview with case number 1: *Rukhsana*, aged 52)

Misbah shared that her illness is because of her indifferent attitude towards the worship of God.

> *I believe that my cancer is the result of my ignorance from His (Allah) worship (Local word: Ebadat) and he wants me to remember Him all the time and ask for His mercy.* (An informal interview with case number 5: *Misbah*, 40)

Suriya told that her illness is a kind of a charity of body (she told this by touching her right hand on her left arm with a facial expression of biting the lower lip with front teeth showing patience and sorrow). By using the example of the patience of the Prophet Hazarat [8]Ayub

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[8] Prophet Hazrat Ayub (PBUH) suffered from skin dgisease. Loathsome sores covered his body. Sores were filled with worms. If any worm fell down,he used to pick up that and put in sore with praising Allah that he created them. People surrounding him blamed his misdeeds for his bad health condition. During his adverse condition, he prayed to Allah. Allah soon removed that adversity. This story is written in Surah 21: verse No 84 of the Holy Quran.

(Peace Be Upon Him), she told about her thankfulness to Allah who gave her illness to purify her soul.

> *It is a charity of body, He (Allah) is purifying my body from sins what I earned in my past life. Our prophets taught us patience. I am thankful to Allah for His kindness to me that He wants to purify my soul.* (An informal interview with case number 13: *Suriya*, aged 62)

Fazeelat shared that she and her neighbors believe that bad acts bring bad happenings in life.

> *Any act we do here has its good or bad repercussions in this world. I, umm... my neighbors and relatives also believe in it and happening of an illness is also the result of our unwise acts which we do in our lives.* (an informal interview with case number 9: *Fazeelat*, aged 62)

A belief that the members of the women's community would often speak of themselves internalized *karma*. A few women spoke of how they believed that their cancer was a consequence of having done something bad in their present or previous part of life and felt they had to go through this journey as a way of repentance for their past mistakes.

5.2.1.4 Concerns of body image

The theme of 'body image concerns' shed light on the impact that different treatments like chemotherapy, radiotherapy, surgery, medications and other related treatments had on body image of women. All twenty seven women were anxious about the loss of hair. Among all twenty seven women, nineteen were greatly concerned about their breasts and twenty one were anxious about their skin. Table 9 below shows body features that are of great concern for women with breast cancer and their coping strategies.

Table 9. Body features of great concern for women with breast cancer

Sr.No	**Pseudonyms**	**Stage of cancer**	**Care-givers**	**Treatment in Process**	**Impaired features**	**Features of great concern**	**Thoughts with impaired features**	**Coping strategy**
1.	Rukhsana	Second	Daughter	C,R	Loss of hair, patched/ pale skin	Hair and skin	Depression, Loss of control, isolation	Faith healing, use of scarves, wearing loose shirts, practicing rituals
2.	Shamim	Second	None	C,R	Loss of hair, pale skin	Hair and skin	Depression, Loss of control	Faith healing, use of scarves, wearing loose shirts, practicing rituals
3.	Shazia	Second	Mother + Sister	C,R,L	Loss of hair, pale skin, damaged breasts	Hair, skin and breasts	Depression, self-pitying, isolation	Faith healing, Make-up, use of scarves, wearing loose shirts, practicing rituals
4.	Komal	First	Mother + sisters	C	Loss of hair, pale skin	Hair, skin	Depression	Faith healing, use of scarves, wearing loose shirts, practicing rituals
5.	Misbah	Second	Mother + Husband	C,R,L	Loss of hair, pale skin, damaged breasts	Hair, skin and breasts	Depression, Loss of control, isolation	Faith healing, use of scarves, wearing loose shirts, practicing rituals
6.	Masooma	Third	Husband	C,R,L	Loss of hair, pale skin, damaged breasts	Hair, skin and breasts	Depression, Loss of control, isolation	Faith healing, use of scarves, wearing loose shirts

7.	Nazia	Third	Daughter	M,IR	Loss of hair, damaged breasts	Hair and breast	Depression, Loss of control, isolation	Faith healing, use of scarves, wearing loose shirts
8.	Samina	Second	Daughter + husband	C,R	Loss of hair, pale skin	Hair and skin	Depression, Loss of control	Faith healing, use of scarves, wearing loose shirts
9.	Fazeelat	Second	Daughter	C,R,M	Loss of hair, pale skin, Loss of breasts	Hair, skin and breasts	Depression, Loss of control, isolation	Faith healing, use of scarves, wearing loose shirts
10.	Noreen	Third	Husband	C,R,L,H	Loss of hair, pale skin, damaged breasts	Hair, skin and breasts	Depression, Loss of control	Faith healing, use of scarves, wearing loose shirts
11.	Adila	Second	Sister	C,R	Loss of hair, pale skin	Hair and skin	Depression, Loss of control, self-pitying	Faith healing, make-up, use of scarves, wearing loose shirts
12.	Ferzanda	Third	Daughter	C,R,L	Loss of hair, pale skin, damaged breasts	Hair and breasts	Depression, Loss of control, isolation	Faith healing, use of scarves, wearing loose shirts
13.	Suriya	Third	Daughter+ Daughter in-law	C,R,M	Loss of hair, pale skin, loss of breasts	Hair and breasts	Depression, Loss of control	Faith healing, use of scarves, wearing loose shirts
14.	Rehmat	Third	Daughter+ Daughter in-law	C,L,A	Loss of hair, pale skin, damaged breasts	Hair and breasts	Depression, Loss of control	Faith healing, use of scarves, wearing loose shirts

15.	Sumera	Second	Husband+ Mother	C	Loss of hair, pale skin, damaged breasts	Hair, skin and breasts	Depression, Loss of control, self-pitying, isolation	Faith healing, use of scarves, wearing loose shirts
16.	Alia	Third	Daughter	C,R,L	Loss of hair, pale skin, damaged breasts	Hair, skin and breasts	Depression, Loss of control, isolation	Faith healing, use of scarves, wearing loose shirts
17.	Noor	First	Mother	C,R	Loss of hair, pale skin	Hair and skin	Depression, Loss of control	Faith healing, make-up, use of scarves, wearing loose shirts
18.	Ghanza	Second	Daughter	C,R,L,H	Loss of hair, pale skin, damaged breasts	Hair, skin and breasts	Depression, Loss of control, isolation	Faith healing, use of scarves, wearing loose shirts
19.	Almas	Second	Mother+Sister+Husband	C	Loss of hair, pale skin	Hair and skin	Depression, Loss of control, isolation	Faith healing, use of scarves, wearing loose shirts
20.	Laila	Second	Daughter+ Maid	C,R	Loss of hair, pale skin	Hair, skin and breasts	Depression, Loss of control, isolation	Use of scarves, make-up
21.	Maryam	First	Mother+Maid	C,R,L	Loss of hair, pale skin, damaged breasts	Hair, skin and breasts	Depression, Loss of control, self-pitying	Faith healing, use of scarves, wearing loose shirts
22.	Warda	Third	Maid	M,IR	Loss of hair, pale skin, damaged breasts	Hair, skin and breasts	Depression, Loss of control, isolation	Faith healing, use of scarves, wearing loose shirts
23.	Hareem	Second	Mother	C,R,L	Loss of hair, pale skin, damaged breasts	Hair, skin and breasts	Depression, Loss of control	Faith healing, make-up, use of scarves, wearing

								loose shirts
24.	Isma	Second	Daughter+ Maid	C,R,M	Loss of hair, pale skin, Loss of breasts	Hair	Depression, Loss of control	Faith healing, use of scarves, wearing loose shirts
25.	Rakhshanda	Third	Daughter	C,R,L	Loss of hair, pale skin, damaged breasts	Hair	Depression, Loss of control, isolation	Faith healing, use of scarves
26.	Adeeba	Second	Mother	C,R,H	Loss of hair, pale skin, damaged breasts	Hair, skin and breasts	Depression, Loss of control, isolation, self-pitying	Faith healing, make-up, use of scarves, wearing loose shirts
27.	Zubaida	Third	Daughter	C,R,L	Loss of hair, pale skin, damaged breasts	Hair, skin and breasts	Depression, Loss of control, isolation	Faith healing, use of scarves, wearing loose shirts

Treatment: M = Mastectomy; IR = Immediate Reconstruction; L = Lumpectomy; C = Chemotherapy; R = Radiotherapy; H = Herceptin; T = Tamoxifen; A = Arimidex; O = Other.

5.2.1.4.1 Changed look

Most of the women shared about their changed look due to loss of hair, wrinkled, dull and pale skin, dark circles and removal of breasts. They spoke about the results of using medicines such as insomnia, indigestion of food, diarrhea and hot flashes. The women, who underwent surgeries such as lumpectomy and mastectomy, spoke about the change of body into an incomplete and abnormal one. Those who underwent radiations discussed about the upsetting impact of losing their normal body, tightening of skin, and becoming pale and dull. Hormonal therapy resulted in further impacts like gaining of weight and pain in limbs. They described their feelings of anxiety, depression, shame, loss of control and self-esteem. Many times they tended to make comparisons of how they used to look now and how they used to look before the cancer. This thought reduced their confidence and affected their personality. All single women among research interlocutors reported their concerns for getting married (one woman faced cancellation of her wedding, two got their engagements broken).

Misbah shared her concerns related to her changed appearance.

> *Don't you see the color of my hands, the wrinkles on it? These were not before cancer; I was a fair and glowing woman. Cancer has made me ugly.* (An informal interview with case number 5: *Misbah*, aged 40)

Rukhsana told me how she hides her impaired featured from her colleagues using different techniques. Later she told that she hides it to complete her job period and get pension later on. Another reason was to search for a suitable proposal for her daughter as she was scared that if she tells others, people will not think to marry her because of her mother's breast cancer.

> *In school, to hide my cancer from my colleagues I cover my head with a doubled scarf. When they ask about my continuous weakness and bad health, I tell them that I have developed an ulcer in my stomach and due to that I feel week and lethargic. I can't publicize it to get sympathies, and lose my job without pension. I told you,... I have to search for a suitable boy for my daughter to marry her.* (An informal interview with case number 1: *Rukhsana*, aged 52)

Rehmat shared that she feels incomplete with the absence of her one side breast. She also shared when she feels embarrassment and shame.

> *Umm feeling with absence of one complete breast is like feeling incomplete, umm specially when facing a person if she asks about health and I tell that, umm, I went through a surgery and lost my breast; umm I feel embarrassment and ashamed".* (An informal interview with case number 14: *Rehmat*, aged 60)

Adeeba, a single woman shared that how her changed appearance resulted in the cancellation of her marriage.

> *You know, my dresses were stitched and ready at the shop of a tailor; the list of guests was ready and wedding cards were distributed. Well, it's third year I have been weeping and remembering the entire situation. When my father and the brother of father (Local kin term: Chacha) informed the family of boy about the diagnosis of my cancer. They rang my eldest brother and said sorry for marriage. They said, "we need a beautiful girl, and with cancer how she can remain beautiful". First, they postponed marriage for 6 months and later cancelled it completely. Although it was the first stage of cancer, but it was impossible for them to accept me with cancer and a changed look.* (A semi-structured interview with *Adeeba*, aged 32)

Hareem shared how a time long engagement was broken due to her changed looks.

> *It was a long engagement since my childhood. Marriage was getting late due to my treatment. In a family function, my cousin with whom I was engaged (Kin term: Mangetar) saw me. I needed his moral assistance. He told his family that he does not want to marry me because of my dark patched skin. They (the family of boy) broke engagement and he (boy) married one of my other cousins.* (A semi-structured interview with *Hareem,* aged 35)

Shazia shared that how his fiancé broke their engagement because of her weak body.

> *In village, you know! people rarely break engagements (Kin-term: Mangni). It needs a plenty of reasons to break it. Apart from the diagnosis from a big hospital of the city; weak body and dull skin made my cousin break engagement with me. Like my family, his family also works in fields and he and his family needed a healthy woman to assist them instead of a sick woman.* (An informal interview with case number 3: Shazia, aged 34)

All twenty seven women shared that they were conscious about their changed look. Because of the feelings of embarrassment and shame, they avoided looking themselves into the mirror. A woman reported that after her diagnosis, she left social gatherings for six months. Another woman reported that after her mastectomy, she left the birthday and wedding gatherings. Their feelings of anxiety and self-consciousness increased when people associated their body with abnormal and dysfunctional one. One woman spoke that she left joining all gatherings for one and half year because she was very uneasy to face others.

Ferzanda shared that after her surgeries, she attended a social gathering in which she felt embarrassment.

> *My all surgeries were over. In a social gathering, I was feeling highly embarrassed even among my friends and relatives. Radiations have tightened the skin of my whole body. Um, I was worried how abnormal I am looking before women who are perfect with their feminine body.* (An informal interview with case number 12: *Ferzanda*, aged 55)

Rakhshanda shared that how a woman in a gathering stared at her and asked her about breasts.

> *In a religious gathering a woman, who didn't know about my mastectomy, stared at my face and body and then asked me pointing, one is bigger and why there is a lope in another side? I smiled and avoided her. One of my neighbors told her all about my cancer from diagnosis to the surgeries. Um, this time I was very embarrassed to hear about my body from a woman telling another woman.* (A semi-structured interview with *Rakhshanda* aged 43)

Although changes in bodily appearance brought severe impacts on them yet some of the women prepared themselves for the possible outcomes or side-effects of the treatments. They managed their side effects by using appropriate information about maintaining outer look. For example, they started covering head, shaving head before the hair fall, eating less-spicy food and fresh juices to avoid the indigestion of food, and using the cloth to fill the lopsidedness of the breast.

> *I feel myself normal as I feel before this. Um.., my daughter helped me handling all this. It is not harmless and it gives peace to the mind that nothing very bad*

> *happened in looks. It has not wasted leg or arm, the breast can be covered intelligently and easily.* (an informal interview with case number 7: *Nazia*, aged 61)

Out of twenty seven, one women shared that she left kissing her children and meeting people with the idea that the radiations which she received as a treatment can harm them.

> *After radiations, I left letting my children close to me particularly for kissing and hugging; I don't want my radiations to get into them. I avoid meeting people for the same concern.* (A semi-structured interview with *Almas*, aged 46)

5.2.1.4.2 Dressing and sartorial issues

All the women reported their concern of clothing that with cancer they have very limited choice to wear. They were unable to wear fit, silky, sleeveless, embroidered, fit and low neck dresses. Most of them were used to wear traditional dresses by covering up chest and shoulders. From their cultural and religious perspective, they were not used to wear short dresses. All women were seen wearing local cultural Shalwar and Kameez -- a baggy pair of trousers with a long tunic. Most of them were seen wearing this dress in cotton stuff as recommended by their doctors.

> *The embroidered dress was appropriate for that function as all had worn the same, but I was unable to wear an embroidered silky dress. I wear cotton Shalwar and Kameez; it looked very odd to many people and particularly to the people who had no knowledge about my cancer, and they came to know it by knowing the reason of my wearing cotton dress.* (An informal interview with *Samina* aged, 45)

> *It is very uncomfortable to wear a long shirt; it is very disturbing when I used to take a side in bed. I wanted to wear loose trousers or short skirts in place of baggy trousers, but I was unable to wear those because many people used to come to see me and it will look nasty, umm… it was not appropriate religiously and culturally to wear those dresses.* (An informal interview with case number 14: *Rehmat* aged, 62)

The comments of both women with cancer have great concerns of dresses particularly when they go through surgeries and side effects of medication.

5.2.1.4.3 Inner Vs Outer

Women above the age of 47 were not greatly concerned about their outer condition or appearance. They were anxious more about the inner of body. For them, pale, wrinkled skin and bald head are temporary. Most of the women who underwent mastectomy focused on their inner treatment, survival, and permanent diminishing of the recurrence of their cancer. Most of the old aged women were not concerned about their outer condition. For them, diminishing of cancer was most important than dull appearance.

> *I want real healing and that is the elimination of cancer from inside of the body. If the health comes back, the good appearance will automatically return.* (A semi-structured interview with *Alia*, aged 57)

The color and wrinkles over it cause great depression; it is very disturbing for me to see myself into the mirror. My health deteriorates because of my outer looks, for me it is very disturbing. Nobody knows much about cancer here in our village; my appearance tells them the story that I am not Ok, umm…inner… As my fiancée broke engagement just for the reason that I do not look beautiful as I was earlier. (A semi-structured interview with *Hareem*, aged 35)

The young women were observed more concerned about their appearance as they reported that their outer condition tells them mental stress which consequently has adverse effect on their inner health, too.

5.2.1.4.4 Feminine concerns

The loss of self-confidence because of new changes in the body was reported by all women. They explained that the things which define them as a female were badly affected by the medications, radiations and surgeries. They reported that the new changes such as menopause, the loss of hair and breasts were badly affected, and they feel like incomplete women.

> *When I look at my body into the mirror, I feel myself that I am no more a woman.*
> (A semi-structured interview with *Sumera*, aged 40)

Elderly women who underwent mastectomy reported that they did not feel the removal of a breast is a loss of their femininity. Twenty one out of twenty seven women reported that it is the people around them who make them think about the loss of femininity. One female nurse sharing her experiences in the hospital with breast cancer women and their care-givers viewed that the attitude of an intimate partner matters a lot in making her feel that after this illness whether she lost her femininity or not.

> *If the family members, particularly husbands do not think much about the appearances of their wives, the women also ignore these changes. Equally, if men feel that their women are no more attractive, their women would believe that they are less like women.* (A semi-structured interview with a female nurse*: Fareeha*, aged 41)

5.2.1.4.5 Feelings of shame in front of male healthcare professionals

All women showed their concerns regarding male healthcare professionals. They were uncomfortable in getting check-ups and treatments from male nurses. It was embarrassing for them to expose their body in front of male health care professionals. They had knowledge that this embarrassment keeps many women avoiding check-ups and treatments, and consequently it causes the adversity of illness. This thought made many women face this embarrassment with a positive mindset that their timely efforts for survival will be successful.

Hareem, an un-married breast cancer woman shared that she felt discomfort in exposing body for radiotherapy.

Quite frequently, there were men in radiotherapy, and it was very difficult to expose body; in fact, it was death before a long painful treatment. My mother used to advise me to close eyes before nurses and practitioners. (A semi-structured interview with *Hareem*, aged 35)

Rukhsana shared that it is unacceptable for her to visit a male practitioner alone.

> *It was completely unacceptable for me to get check-up of breasts alone. It was also allowed by them to accompany with a close male or female member of family during check-up by male practitioners.* (An informal interview with case number 1: *Rukhsana*, aged 52)

Noreen said that her husband was not ready for her treatment until there are female practitioners in any hospital.

> *My husband made decision of my treatment only when he came to know that in Combined Military Hospital two female oncologists with their female staff deal with the breast cancer patients.* (An informal interview with case number 10: *Noreen*, aged 49)

Samina shared that once she missed her appointment with the doctor when her all family members were busy and were not available to go with her to the hospital.

> *Once my family was busy somewhere and it was not possible for my family members to accompany me. I missed my appointment in the hospital which was with a male practitioner. I waited for their availability first then I visited the doctor in another appointment. I don't remember that ever I visited the male practitioner alone; it seems immoral to me.* (An informal interview with case number 8: *Samina*, aged 45)

Knowing the fact that people prefer the female practitioners, many private hospitals hired the female practitioners and nursing staff in their departments dealing with the breast cancer patients.

Sadaf, an oncologist shared that how she and her colleagues conduct campaigns in different universities of the capital.

> *We annually conduct awareness campaigns in universities and colleges of Islamabad to give them awareness that our hospitals have all facilities with female practitioners and nursing staff to provide comfort to patients at all levels.* (A semi-structured interview with oncologist working in a semi-government hospital: *Sadaf)*

Noor maintained that she always got an appointment of a female practitioner for her gender concerns.

> *For check-ups, you have to expose your breast, so I always got appointments of Lady doctor Swera (a pseudonym), you know.., before a same gender, it is less annoying.* (A semi-structured interview with *Noor*, aged 38)

It is cultural and religious issue to get treatment from females only. For this reason, the decision making by the women and their families for treatment was very important as in many hospitals there were male practitioners and staff, or this staff was working with female practitioners. The affected women and their families always tried to get appointments of female practitioners.

Rizwana (a pseudonym), a senior oncologist and the head of department of Oncology in a semi-government hospital shared that for cultural issues she and her hospital staff never take male practitioners with them during awareness campaigns.

> *When we arrange campaigns for awareness of breast cancer in different institutes, we never allowed a male practitioner to be a speaker in awareness seminar. In some cases, we allow only one male speaker to talk on general health issues and taking steps for getting treatment. We do this only for cultural reasons as people get annoyed when they hear the issue of female body by a male whether he is a practitioner or one of the donors of the hospital. (A* semi-structured interview with the Head of department of Oncology in a semi-government hospital, *Rizwana)*

5.2.1.5 Loss of control

All women reported that they felt a loss of control at the time of diagnosis of their cancer. It was a critical time for them and their family members because they had to accept and understand it.

5.2.1.5.1 Illness beyond comprehension

Twenty five women and their family members as care-givers viewed that the causes they heard and read after their diagnosis were never been the part of their life. They never did smoking in their entire life, never had any breast cancer patient in elder women of their families and have breastfed their kids, then why it has attacked their bodies. Its diagnosis caused a great confusion, upheaval and frustration in them and in their families. Twenty three women described that they were living a healthy life and the news of diagnosis was very confusing for them. Women found the practitioners and the staff of hospitals a major source to get answers of their questions and to get information for avoiding its recurrence.

Rakhshanda said that she breastfed all her kids and never did drinking or smoking, so the diagnosis of breast cancer is shocking for her.

> *I am living in a rural area of the capital. I breastfed all my children and never had drinking, smoking in my whole life and never had any case of breast cancer among the elders of my family. I was surprised to hear its diagnosis in me; I had knowledge about this and its causes, but I never had that kind of life style, so why this kind of thing.* (A semi-structured interview with *Rakhshanda*, aged 43)

Twenty five out of total twenty seven women believed in the diagnosis of this illness, considering it a will of Allah. Three women considered it a punishment for their specific sin or wrong doing. Twenty one women considered it an unjust divine punishment.

Shamim maintained that her illness is the result of her disobedience to her parents and siblings. She believes that it is a punishment from Allah.

> *Four years ago, I married against the will of my parents and siblings. For this act, they got angry with me and left me alone to live life with the husband of my choice. I believe my illness is the result of this disobedience to my parents and siblings.* (An informal interview with case number 2: *Shamim*, aged 39)

Rehmat believes that this illness is a part of her destiny. She explains her view that death looks for a reason or source, and diagnosis of this illness will give reason to my death.

> *It is nothing, you know, but a part of destiny… Death needs a source or reason, and this would be a source or reason of my death.*
>
> An informal interview with case number 14: *Rehmat,* aged 60

Ferzanda told that she asks a question to herself that she never went against norms of her culture, then why she is caught by this illness.

> *I followed a religious life and never went against the norms of my culture as well like drinking and smoking, so why me, why me?* (An informal interview with case number 12: *Ferzanda*, aged 55)

Shazia complains that because of this illness she faced breakage of her engagement. She adds that, she does not know the reason of her illness.

> *My fiancée has broken the engagement,… Many times I think, "Does he know the reason of my cancer", as I don't know. I want to understand it that why it*

> *attacked me and why it caused turmoil in my life?* (An informal interview with case number 3: *Shazia*, aged 34)

5.2.1.5.2 Controlling illness

In the belief systems, fate refers to an idea that " whatever will be, will be" (Singh, 2019).
In the fatalistic attitude, a person believes that things will turn out badly. With this fatalistic attitude, many women seemed complaining about Allah, but they try to accept His will and fate for them. They accepted it with the view that there is something good for them in it.
For example, one woman spoke that Allah never puts burden on a person that he cannot bear. Another woman spoke that it is a trial from Allah, and it is her strength that Allah has chosen her for examination. He wants to see the patience in her and with patience she will be successful in this trial. With medical treatment, all women were found receiving faith healing by visiting shrines and their saints to get peace of mind and patience to control their mental stress and anxiety.

> *I believe in Allah, and you know, He never puts burden on His people which they cannot bear...After the start of my treatment, I started visiting the shrine of Sayen Hazir Shah. I got amulets to wear and burn and bury the ashes of burnt amulets in the wet mud. With and after practicing these acts, I felt that I am getting peace of mind and can control myself.*[9] (An informal interview with case number 11: *Adila*, aged 45)

> *I am chosen for the examination, and it is a trial. I recited some of the selected verses of the Holy Quran; it put me in meditation which helped me to have patience (Local word: Saber صبر) to bear the side effects of the treatment. I gave extra attention to my religious beliefs and thought to change my mind from stress to the fears of the Day of Judgment. To get control over mind was difficult with multiple new changes in inner and outer body, but I coped with all that with the*

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[9] *Adila* and her primary carer shared that the shrine of *Sayen Hazir Shah* is famous for healing of chronic illnesses. They got amulets from the descendant of the shrine. Here amulets gave some key symbolic meanings. These amulets were in the shape of writing with black ink on two pieces of white paper. The idea of white and black was telling about a contrast between good and bad, and, clear and mysterious. One amulet was to wear around neck and another was to burn in evening. Adila shared that her step of wearing amulet gave her a sense of protection from all evils which want to kill her. Burning of another amulet gave her psychological power that her plans of her enemy is going to be wasted soon. Burying ashes in mud was an idea that soon she will get relief and will regain life.

> *intention that I have to survive for my children and for success. I would have to control my mind and behavior.* (An informal interview with case number 1: *Rukhasana*, aged 52)

5.2.1.6 Experience of healthcare

This theme summarizes the women's healthcare experiences, and explains their lived experiences.

5.2.1.6.1 Contented with healthcare

The majority of the women were contented with the care that they received. They described breast cancer nurses as compassionate, caring and helpful. Physicians and nurses described them the treatment process and its side effects. The support of nurses was invaluable in providing them information regarding treatment and giving emotional support by introducing them with survived and under treatment patients. Many women explained that nurses listened to their concerns and worked as counselors. Two women described how their nurses made home visits and provided them services at their homes. The women who underwent surgeries spoke very high about the care and the support of the breast cancer nurses.

> *After the diagnosis of breast cancer, I stopped normal interaction with people. It was very difficult time for me to accept the illness before making it public. The breast care nurse supported me in accepting and making my mind to discuss this illness with friends and neighbors. So, it was not only a physical support, rather a psychological help, too.* (An informal interview with case number 5: *Misbah*, aged 40)

Majority of the women mentioned that their nurses guided them how to dress up and to apply make-up, and wear wigs to present themselves in a good way, and feel good without feeling shyness from people because of their changed appearance.

> *Despite there are booklets in the oncology department to advise the breast cancer women and their family members about how to dress up with an easy dress, the nurses advised them orally, too. The booklets were in English, and nurses know*

> *that many women can't read English.* (A semi-structured interview with *Maryam*, aged 41)

All women did not have the same healthcare experience. There were many women who seemed dissatisfied with the care of the nurses. They explained that their nurses were not always concentrating and supportive. They were not well explained regarding their treatment process and its side effects. Some viewed that nurses did some time-restricted duties for pays only, and they lacked empathy. For these women, their breast cancer experience appeared very challenging. These women had to be very proactive in achieving emotional support and treatment guidelines.

5.2.1.6.2 Long travel and transportation expenses

Accessibility to hospital was found a major issue for rural women as all big hospitals were in cities. The travel expenses were another issue for them. The referral system of advising patients and their care-givers to go to other hospitals for tests and check-ups was also found to be a source of fatigue for them.

All rural women showed their concerns related to the long travel they faced in approaching hospitals. Many middle and lower middle class women also explained their troubles that how they arranged money for transportation. *Shazia* shared that how her family managed travel expenses by selling their cow and its calf.

> *Because of bad health condition, it was not possible to travel in village buses. With hand to mouth income, it was difficult to hire a van or car; we sold out our cow and her calf for meeting travel expenses of regular visits to hospital.* (An informal interview with case number 3: *Shazia*, aged 34)

Rukhsana shared that long traveling disturbed her psychologically and especially during her visits to hospitals for chemotherapy.

> *Often I felt nausea during car traveling of four hours. The driver was my neighbour living in my home with his family on rent; he was very supportive. Although he always opted for motorway in approaching the city instead of general road yet I felt this traveling very disturbing psychologically during my treatment process. Particularly after chemotherapies, it was very painful to travel.* (An informal interview with case number 1: *Rukhsana*, aged 52)

Long traveling with bad physical health was a major factor of worsening of the illness of some women. Some described that they travelled in village buses, which was economical for them, but it put them in great fatigue as they had to follow bus timing. Rush and noise of passengers made them exhausted, and it was difficult to understand the process of treatment and get treatment with a comfortable mind.

5.2.1.6.3 The Need for a family member to accompany

The majority of women described their emotional need of a family member to accompany them to hospital. Some of them spoke that with disturbed health they were unable to explain their condition before the doctor, and accompanied family members who communicated with them. Some explained that they see the doctor with one or two family members, and they communicated with the doctor as a part of their moral duty in taking care.

Rakhshanda told about the sacrifice of her daughter that how she gets days off from her office and accompanies her to hospital.

> *My daughter takes days off from her job and accompanies me to hospital. She missed her some very important tasks because in those days I was going through chemotherapy.* (A semi-structured interview with *Rakhshanda*, aged 55)

Misbah shared the way that how her mother and husband accompanied and helped her in hospital.

> *I don't remember that during my breast cancer treatment I ever had visited hospital without a family member. My mother or husband accompanied me in my every visit to hospital. They took care of me in the waiting areas; they paid fee in accounts office, collected medicine from pharmacy of the hospital. During my chemotherapy, they accompanied me and right after chemo when I needed juice or water, they always provided me.* (An informal interview with case number 5: *Misbah*, aged 40)

5.2.1.6.4 Gender of healthcare professionals

The majority of the women explained their cultural reasons regarding receiving care only from the female nurses. For many, it was impossible to expose themselves before a male nurse. Many got permission of treatment from male heads or female heads of their families only with a condition that they will get treatment from female doctors and nurses. The religious mind-set was another big reason to get services only from female nurses and doctors.

Rehmat shared that how she felt shame when a male practitioner did her screening test. She also blames herself for cultural and religious reasons that why she went to a clinic where there was no female practitioner.

> *I got my screening test from a male practitioner; at that time, I felt as I died before my survival or death. I will not be saved from the punishment of Allah. I felt uneasiness mentally, and still I feel embarrassment that why I went in that clinic for screening where there was no female practitioner.* (An informal interview with case number 14: *Rehmat*, aged 60)

Noreen maintained that her mother accompanied her throughout the radiotherapy session as there were only men in room.

> *During the radiotherapy, there were men, and I felt hesitation. My mother accompanied me all the time during the therapy. I knew that it was impossible for me to get radiotherapy in the absence of my mother, even my husband would never have allowed me to get treatment (this idea has a local word: Ghairat غیرت)*[10]. (An informal interview with case number 10: *Noreen*, aged 49)

Shazia found to be thanking Allah for the availability of female practitioners in the hospital of her treatment.

> *Thankful to Allah that in Combined Military Hospital Rawalpindi, there were female staff and I had not to take my top off in the presence of male nurses and doctors.* (An informal interview with case number 3: *Shazia*, aged 34)

Many women explained that they prefer to get treatment from women; however, they show the reports of their tests to male practitioners for consultation. Two women described that their husbands were not ready for giving them permission for surgeries with the idea that many times male practitioners lead the surgeries and in all surgeries male practitioners also participate.

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[10] *Ghairat:* It is referred to praise, respect, pride and honor attached to the woman. It also gives meanings of possession; for example, a woman is considered the possession of her husband, father and brother.

Shamim asserted that her husband did not allow her for surgery until he was ensured that there will be only female practitioners and nurses during the surgery.

> *Doctors recommended lumpectomy, my husband was not allowing me. It took five months to decide only after when my doctor (lady oncologist) assured him that there will be no male practitioner and nurse during my surgery.* (An informal interview with case number 2: *Shamim*, aged 39)

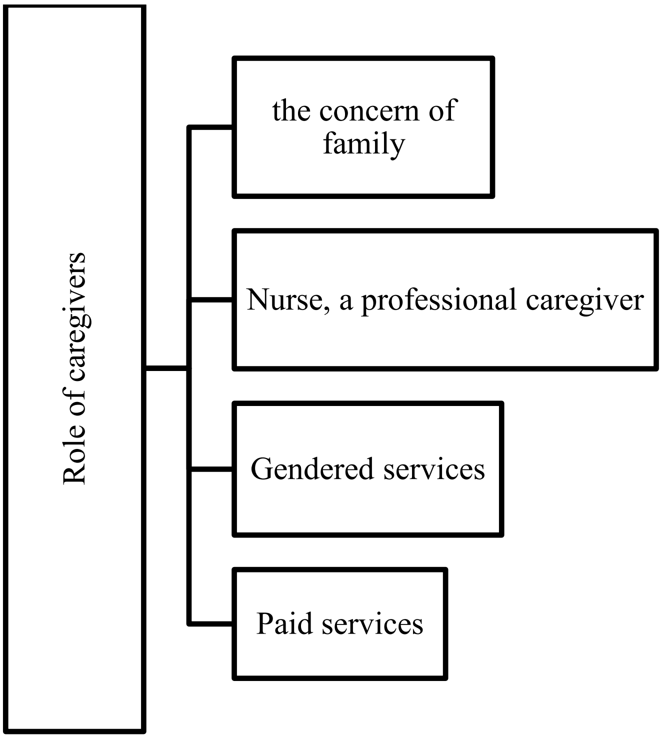
Table 10. Summary of themes and sub-themes in the data collected from the breast cancer women and their care-givers

Belief and knowledge about breast cancer	**A collective experience**	**Spirituality**
• *'I never had heard about the breast cancer'* • *'What and why me?'* • *'Never talked before about breast as it is a body shame'*	• *'They all are affected by it'* • *'They were supportive and I am fighting for them'* • *'She understands me and would go along with me everywhere'*	• *'Spiritual attitudes'* • *'Fatalistic attitude'* • *'Punishment from Allah'*
Concerns of Body image	**Loss of control**	**Experience of healthcare**
• *'A changed look'* • *'A sartorial issues'* • *'Inner Vs Outer'* • *'Feminine concerns'* • *'Body feels shame in front of male healthcare professionals'*	• *'Its happening is not understandable'* • *'How am I controlling it?'*	• *'Contented with healthcare'* • *'Long traveling and transportation expenses'* • *'Need of a family member to accompany'* • *'Male and female healthcare professionals'*

Note: Themes and sub-themes were deduced from the research findings.

Part 2: The second part deals with the role of care-givers within the framework of the treatment of the breast cancer women. During the research process, the role of care-givers was seen very important in the living experiences of these women. To handle the gathered information carefully, care-givers were classified into three categories: family members were classified as primary; nursing staff were secondary, and servants were tertiary caregivers. Thematic examination of the role of care-givers revealed four main themes with sub-themes developing within each. These themes were: the concern of family, nurse, a professional caregiver, gendered services, and paid services. These themes cover the lived experiences of breast cancer women and the ways the caregivers provide services. After the diagnosis of breast cancer, physical condition and the behavior of surrounding people let these women observe transformation of their roles and identities in maintaining social relationships. Figure 6 shows the themes found in the transformation of roles and identities in maintaining social relationships of women. The italicized sub-headings display sub-themes with transcriptions. The original responses of respondents are used to validate the deduced themes. In the place of real names, pseudonyms of the participants are used in the text.

Figure 23. Diagram illuminating the four themes



5.2.2.1 The concern of family

Majority of the family members shared that the diagnosis of breast cancer in their loved one was very shocking and distressing for them. For many, its occurrence was life altering for the whole family. Majority of them expressed the feelings of devastation, fear, anxiety, stress, confusion and anger. Many of them felt that their loved one can no more fulfill cultural expectations like upholding house wife duties. Twenty five out of thirty one primary care-givers expressed that the treatment cost is a type of burden on the family.

5.2.2.1.2 Affecting family members

All the participants' care-givers viewed that the breast cancer of their loved one has affected the life of all family members. The diagnosis was shocking for them predominantly for husband and children; it was hard to accept the diagnosis of cancer of their wife and mother respectively and see her going through the process.

Kinza said that how she faced the time of diagnosis of her mother's illness.

> *I was busy in mid-exams of my semester when my mother was diagnosed with it. I skipped my remaining two papers, I was emotionally shocked. She is the only parent I have. I was worried that I will lose her, too; my father died of cancer. I saw his worst health condition and was thinking that my mother will face the same. I was feeling like broken in heart and mind. (An* informal interview with a care-giver, case number 1: the daughter of a breast cancer woman: *Kinza*, aged 22)

Husbands of three affected women explained that their instant response at diagnosis was anxiety for the wellbeing of their children. Two expressed that their children left schools and started doing crazy things like roaming in markets most of the time. Five husbands explained that they are unable to look after their children as their wives used to do.

Tariq is the head of his nuclear family. He shared his concerns and losses he faced after the illness of his wife.

> *We were a complete family: I, my wife, two sons and one daughter. Children were going to school according to the normal routine. My wife was diagnosed with it; the routine of home and school of children continued for seven months only. They left going to school; I was unable to get retirement from the bank (job place) because it was the only source of income. I would say one thing as a whole -- the death of father is a financial loss, and the death of mother is a family loss. (An*

> informal interview with care-giver number 6: Husband of a breast cancer woman: Tariq, aged 43)

5.2.2.1.3 Staying strong only for her survival

It was observed that the diagnosis of breast cancer of a family member let her require treatment in priority position than the needs of other family members. Care-givers were found lessening their expenses only for the timely treatment and survival of their family member. They were observed spending most of their time at home to give her a psychological support. All thirty one primary care-givers viewed that the news of diagnosis was very disturbing for them mentally, but they are strong only for achieving the survival of their affected family member. To keep the situation of home normal, they portray themselves optimistic, and do not remind them that they are suffering from cancer. By avoiding talk related to cancer, they were found portraying themselves optimistic, keeping their affected family member optimistic. Three of the care-givers were found keeping their affected family member busy in different activities to ensure her that they will fight against it and will succeed.

Resuming normal duties proved useful for women, but some of the women found it very hard to accomplish their previous domestic roles and duties. The daughter of a breast cancer woman explained that she kept her mother busy in daily routine works without pressurizing her to do these tasks only to assure her that she is a beneficial part of the family.

> *My mother is a school teacher; she did not share her illness with any of her colleagues. She tries to present herself a normal person before them and tells about stomach indigestion – a reason of her bad health. She has a day off on Sunday and she feels quite negative at home, whereas in school she remains busy with children and colleagues. She did not leave school and I too did not advise her to leave school because of her illness. (An* informal interview with the care-giver number 2: the daughter of *Rukhsana*, aged 29)

The mother of *Shazia* told how she made her daughter strong by showing herself a strong person.

> *To accept and to share it with others that my daughter is caught by the breast cancer is something very sad and mentally very troubling. Internally I was broken, but I presented myself stronger to tell her that I am with her, and will not let her die. I talked to her in different ways that she will survive because she is not*

> *alone. We are with her. (An* informal interview with the care-giver number 13: the mother of *Shazia*, aged 55)

5.2.2.1.4 Serving the affected family member as a moral and religious duty

Two sons and eleven daughters as primary care-givers expressed that they are serving their mothers as their religious obligation from God. For six husbands, it was a moral duty to look after their wives in their sickness. For five mothers, it was a trial from Allah to see their daughters in sick conditions and find it their obligation to look after them. Two brothers were found getting loan for the treatment of their sister as a religious duty. Two daughter in-laws were found looking after their mother in-laws as their moral duties. Twenty eight out of all thirty one primary care-givers explained about the expensive treatment and how they got loans for the treatment of their sick family member.

Naveed maintained that he got a loan from his office for the treatment of his mother. He believes that his service for his mother is his prime obligation. He further added that his heaven is under the feet of his mother and his service to her will be a source of attaining happiness of Allah.

> *I got a loan for her treatment. It is my prime duty to serve my mother. I have my heaven under her feet. Allah will be happy if I serve my mother. (An* informal interview with the care-giver number 14: the son of a breast cancer woman, *Naveed*, aged 39)

Faiz believes that it is his goal of life to serve his mother. He wants to make his Allah happy by serving his mother. In the book of Allah, i.e., the Quran which was revealed on the last prophet, Muhammad (Peace Be upon Him) Allah advised the people to serve their old age parents.

> *I feel satisfied by serving my mother. Allah will be happy for my service that I am rendering to her. She is my heaven on earth (Local word: Jannat). In the Quran, He ordered His people to serve their parents.* (An informal interview with the care-giver number 27: the son of a breast cancer woman, *Faiz,* aged 49)

Kinza said that she is serving her mother as a moral and religious duty because her mother always supported her.

> *At young age of 14, I saw the death of my father… After that my mother is the only person in the world, looking after me. She never married again, and made efforts for my bright future. Now she needs me; I will serve her for my whole life; this is my moral and religious responsibility. (An* informal interview with the care-giver 1: the daughter of a breast cancer woman, *Kinza*,aged 22)

The daughter in-law of *Ferzanda* shares that she understands the reason of her mother-in-law's furious behavior and serves her as a moral duty.

> *She is very hot tempered. I passionately listen to her furious feelings; it is natural as she is suffering from a very painful illness. I wash her and feed her with spoon, and do everything only as a moral duty.* (An informal interview with the care-giver number 30: the daughter in-law of *Ferzenda*, aged 34)

The daughter in-law of *Nazia* told me about a tradition, where the wife of son is expected to serve the sick mother of her husband. She is serving her as a moral duty but more to save her marriage.

> *I look after her as a moral duty, but it is also a truth that I am doing this for saving my marriage because his son expects me to look after her.* (An informal interview with care giver number 11: the daughter in-law of Nazia, aged 28)

The husband of *Masooma* shared that it is his religious obligation to look after his wife. For this obligation, he sold out his two cows and also got loans to get her treatment.

> *A member of family is just like an organ of body and if he/she gets sick, other parts also get disturbed. I sold out my two cows to get timely tests and treatments. But later I was not in position to manage dues of radiotherapies and routine check-ups. I got loans from the head of village. I did this because it was a religious obligation to look after her.* (An informal interview with the care-giver number 8: the Husband of Masooma, aged 43)
>
> *Noor's* brother shared that it is a religious responsibility to look after relatives and neighbors.
>
> *My religion preaches that there are great rights of relatives and neighbours on a person such as keeping always good relations (local words:صلحہ رحمی Silah Rehmi) with relatives. I am serving her following the orders of my Allah. (An* informal interview with the care-giver number 16: *Noor's brother*, aged 54)

During interaction with care-givers, it was observed that the care they provide their sick relative is not a kind of burden on them, but they think it their moral and religious obligation. By describing the feelings of moral and religious duty, they also expressed their grief of expensive treatment and limited resources. They maintained that their limited resources are a major hurdle in the health seeking process.

5.2.2.1.5 Nurse, a professional caregiver

Nurses, as healthcare professional, were defined as very compassionate, caring and supportive. Majority of the women and their family members were satisfied with the attitude and support of the nurses. Some of the women and their family members expressed that how nurses explained them about the breast cancer and the steps and procedures of treatment.

5.2.2.1.6 Different attitude of the nurses of private and government hospitals

Many women described different attitudes of private and government hospitals. Majority of the women were satisfied with the attitude of the nurses of private hospitals. On asking the nurses about the nature of their job, they expressed their reservations.

A nurse working in a government hospital stated that the rush of patients and care-givers make them furious particularly in Open Patient Days of check-up.

> *I am working here for last six years. Yes, it is my permanent job. We work according to our schedule prepared by the head nurse and hospital administration. We face great number of patients from morning till afternoon. In the OPD (outdoor patient day) rush -- you know…umm…makes us sometimes very upset and furious, but we get relaxed after the end of OPD. (A* semi-structured interview with a nurse working in the government hospital aged 30)
> The demographic features of nurses have been mentioned in Chapter 3, Table 7.

A nurse stated that the rush of patients and their care-givers exhaust her mind. She guides them to come with only one care-giver and other should stay in the waiting areas. She further stated that she and her doctor can handle and communicate with the patient.

> *The rush of patients and their family members exhausts mind. I tell them to come with only one care-giver, and others should wait in the waiting areas, but they make rush in the check-up room. We can handle a patient and ask her what she*

> *feels.* (A semi-structured interview with a nurse working in the government hospital, aged 43)

A nurse expressed that despite feeling tiredness by handling many patients daily, she feels happy to serve them finding it her religious duty.

> *Yes, it is my permanent job. I handle many patients daily; I get tired, but I feel happy to serve them. I feel it a religious obligation, too.* (A semi-structured interview with the nurse working in the government hospital, aged 43)

A nurse shared that she is sad because of no promotions in her six year service.

> *I am permanent here; I am here for last six years, but there is no promotion. This makes me sad all the time.* (A semi-structured interview with the nurse working in the government hospital, aged 46)

Figure 24. A nurse in her duty hours in the oncology department of a government hospital

A nurse shared that her pay is not enough to meet all the needs of her family which makes her sad.

> *It was a contract job; this year, I got permanent, but pay is not enough to meet all the needs of my family. I am a single parent; I have to look after my family alone. I serve here working eight hours daily, but my pay makes me unhappy.* (A semi-structured interview with the nurse working in the government hospital, aged 41)

A nurse said that how patients try to give bribe to nurses, but they refuse to receive.

> *Patients and their family members try to give us money for our support, but we reject because of the strict rules of hospital. Quite often they need urgent appointments and ask us to receive money and give their required timings of check-ups. A note is written in all nursing staff offices of the hospital that it will take serious steps against those nurses who will take bribe of any kind from patients and their relatives. Local words:* کسی بھی طرح کی شے نرس لینے والی کے خلاف کاروائی کی جائے گی (Translation: If anyone (from nurses) receives money or gift of any kind from patients and their attendants, the hospital will take a strict notice against him/her.) (An informal interview with a nurse working in a private hospital, age 27)

It was observed that nurses in their daily routine handle many patients at different stages of their illness. Eighty to ninety percent include new and old regular patients who come daily in the oncology department of a government hospital of the capital. The responses of nurses showed that the permanent nature of job makes them a bit inefficient to control their personal issues and handle a great number of patients in the hospital. They were fulfilling their duty hours, but their attitude was not friendly as the patients expect to receive guidance and support from them. Many women and their family members praised private and semi-private hospital nurses. On asking these nurses about the nature of their job, they responded that the administration of the nursing staff always keeps an eye on them and any complain against them leads towards firing from job. They also viewed that they get lessons to be helpful and supportive to all patients in training workshops.

A nurse stated that she is doing a job in a private hospital and the continuity of her job depends upon her performance.

> *“The continuity of my job depends upon my performance at work”. (A* semi-structured interview with a nurse working in a private hospital, aged 24)

A nurse shared that patients request the nursing staff to deal with her alone because of her good behaviour.

> *In my absence, many people ask other nursing staff about me, and want to be dealt with by me only.* (A semi-structured interview with a nurse working in a private hospital, aged 27)

> A nurse working in a private hospital said that the repute of a hospital depends greatly upon the attitude of its nursing staff.
>
> *“The repute of this hospital is based upon the attitude which we have with all the patients. We are trained to be supportive with patients”.* (a nurse working in a private hospital, aged 46)

A nurse working in Military Hospital stated that she and other nurses are extra paid for extra duty hours. She added that they are told to deal with patients in a good manner.

> *I get extra pay for extra working hours; I have health facility, too. You know, then the administration demands from us to work and deal with patients sympathetically.* (A semi-structured interview with a nurse working in Military Hospital, aged 26)

Another nurse stated that women dislike the presence of male nurses to be around them.

> *I have my duties in the oncology department; I assist in the technical issues like noting down blood pressure, checking pulse rate and arranging patients’ turns and appointments with doctors. I know women do not like the presence of a male nurse.* (A semi-structured interview with a male nurse working in Military Hospital, aged 31)

5.2.2.2 Gendered services

Majority of the women expressed that they always preferred those hospitals and clinics for treatment which have female practitioners and nurses. They know that their late treatment will cause serious problem for them, but they avoid male practitioners and nurses.

5.2.2.2.1 Being naked before *Na-Mehram*[11] is a sin, a taboo

All women viewed that it is shameful and embarrassing to expose their breasts before males even for health perspective. Two women expressed that husbands did not allow them for lumpectomy and mastectomy surgeries because they knew that male surgeons perform these surgeries.

Suriya shared her religious belief regarding bath and dressing of a dead body of a Muslim woman. She adds that a dead body is covered by eight pieces of cloths when she meets with her creator. If she goes naked before a *Na-Mehram* with whom intimate relation is not allowed, Allah dislikes that woman.

> *See, When a Muslim woman dies, she is bathed and dressed with eight pieces of cloths (Local word: Kafan*[12]*). There is a meeting of Allah and His creature. He demands women to cover themselves. Further, if a woman goes naked before a Na-Mehram person, she will be punished by Allah.* (An informal interview with case number 13: *Suriya* aged 62)

Samina shared that her husband was not ready for her surgery until he was assured by my doctor that there will be no male surgeon and nurse during surgery.

> *I was diagnosed with breast cancer and we started getting treatment. When doctors recommended for lumpectomy, my husband forbade me to get this treatment. He searched for and contacted folk healers. We did not avail ourselves of this treatment until my sister talked with the doctor and she herself explained to my husband that observing your concerns there will not be any male surgeon and nurse during surgery.* (An informal interview with case number 8: *Samina* aged 45)

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[11] A *Mehram* is a person with whom a woman's sexual intercourse is illegal. There is not allowed except with her husband. A Mehram is also a person for whom veil of woman is not compulsory. Mehrams include parents, children, siblings, and sibling's children and children's children. Na-Mehram is a person whom a woman can marry but cannot travel alone with him. (Sahih Al-Bukhari) (Abdul & Muhammad , 2007).

[12] *Kafan* includes pieces of cloths in which the dead body is wrapped and buried.

5.2.2.2.2 Being naked before *Na-Mehram* a taboo, diminishes dignity of femininity and family

All women expressed that being naked before an unknown person is like diminishing dignity of femininity and family. They viewed that they feel shame and disgraced by exposing body to unknown person.

Warda said that during her radiotherapy in the presence of male practitioners she felt discomfort.

> *During radiotherapy, there were two male practitioners and one female nurse. Despite in the presence of one female, I was feeling ashamed and embarrassment even all that was for my health.* (A semi-structured interview with *Warda*, aged 57)

Noreen stated that she prefers female practitioners despite a male doctor is a nice person.

> *I discussed my reports with Dr. Faisal. He is very nice and a professional person, but never went to his OPD for check-up. I always got check-ups by Dr. Azra. Once she went to the US for a month. I got my check-ups from a young doctor but still did not prefer to have check-ups by a male doctor.* (An informal interview with case number 10: *Noreen*, aged 49)

Isma shared that she does not receive charity from any one and cannot get married with whom intimate relation is considered a taboo because of a religious status of her family.

I am from a Syed family (inherited from the family of the last prophet of Islam, Hazrat Muhammad Peace Be upon Him). We never receive charity (Local word: Sadka)[13] *from any one. We get married in the same Syed family. We, you know, women of this family cannot expose our body before a Na-Mehram person.* (A semi-structured interview with *Isma*: aged 61)

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[13] *Sadka* is a charity given to needy people of the society.

5.2.2.2.3 Suicide is easy than being exposed and treated by a *Na-Mehram*

Two women expressed that for them suicide is easy than being exposed before a *Na-Mehram* person. They preferred those hospitals which have the facility of female practitioners. Even those hospitals were private and relatively expensive. They rejected those hospitals where treatment was carried out by male practitioners and was not so expensive.

Warda shared her experience of check-ups by a male practitioner.

> *It was not a touch -- you know -- it was a death pain. I died that moment; I was demoralized internally… I left hope and struggle… for achieving survival. It was not a touch -- it was a death pain…* (A semi-structured interviewed with *Warda*, aged 48)

Isma talked about her preference for seeking treatment from female practitioners only.

> *If my family members were to offer me to choose between death or survival in the case of check-ups by male practitioners, I would accept death. I sold out my two Marla plot and got treatment from a private hospital…I got treatment from female practitioners.* (A semi-structured interviewed with *Isma*, aged 53)

From religious and cultural perspectives, these women were not in favour of receiving treatment provided by male practitioners. This behavior is one of major reasons of avoiding initial tests and screenings which cause delays and lead towards the advanced stages of breast cancer.

5.2.2.3 Paid services

Some of the servants, who were working in homes of the breast cancer women, were also interviewed.

5.2.2.3.1 Preferences to hire maids

Among all nine tertiary care-givers or hired servants, seven were females. All these seven maids were looking after the breast cancer women, their kids, and their home duties. The demographic features of maids have been mentioned in chapter 3, Table 8.

Mehreen talked about her daily duties which she performs at home of her *Baji.*

> *Washing dishes, cleaning home and massaging the body of Baji* ([14] باجی) *are included in my daily duties.* (A semi-structured interviewed with maid, *Mehreen* aged 42)

Nazish talked about the escalation of her routine work because of the illness of her *Baji*.

> *Before the illness of Baji, I used to come only for dish washing but now as Baji cannot do other chores of her home also, so I come in the morning around 7 o'clock and do all the tasks, including washing, cleaning, grocery, and cooking. I go in the evening at 5 o'clock when the husband of Baji comes from the office.* (A semi-structured interview with a maid *Nazish*, aged 42)

Aneela shared her routine works and also told the reason of *Baji's* inability to work.

> *I come for two tasks, dish washing and washing clothes… because her cancer does not allow her to do these.* (An informal interview with maid *Aneela,* aged 38)

Nafeesa said that her *Baji* is suffering from such an illness of cancer in which she cannot do demanding chores particularly visiting markets for grocery.

> *She is suffering from an illness in which she cannot do heavy chores, such as going to the market for grocery…she hired me for washing dishes, cleaning of home and doing grocery.* (A semi-structured interviewed with maid *Nafeesa*, aged 41)

Shabana stated that the husband of *Baji* hired her for their domestic tasks.

> *Baji was unable to handle the chores of home; her husband hired me for helping her in getting shower, washing dishes, clothes, cooking, grocery and supervising the cleaning of home by a sweeper.* (a semi-structured interviewed with the maid *Shabana,* aged 39)

Akhtar told that the Mother in-law (Local word: *Saas* ساس) of her Baji hired her for domestic tasks.

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[14] *Baji* (باجی); a term usually used for elder sister, often used contextually by the servants for the adult woman of the household.

> *Mother in-law of Baji hired me for 5000 monthly. Baji is a breast cancer patient. Both of them cannot do daily chores of home. I do washing clothes, dishes and grocery.* (A semi-structured interviewed with the maid *Akhtar*, aged 48)

Majority of the women who have hired maids were living in a nuclear family set-up, where they were unable to fulfill their duties alone. Some of them viewed that they have cut short their other expenses like purchasing seasonal dresses and new items for home, and hired maids for assistance in domestic chores.

Samina shared that she has a nuclear family system. After her illness, she was unable to fulfill her home duties, so she hired a maid.

> *My husband, our three kids and I are living together in our home. After my illness, I am unable to do my domestic chores as I was used to doing before it. So I hired Nafeesa for domestic chores.* (An informal interview with case number 8: *Samina* aged 45)

The women, who were unable to fulfill their duties of home after the illness, were getting help of hired servants in tasks particularly of washing dishes, clothes, cleaning, dusting, grocery and cooking.

> *With this illness, I feel fatigued all the time, and I can't stand for cooking, washing, cleaning. I hired Sakeena (maid) for these tasks.* (An informal interview with case number 5:*Misbah*, aged 40)

Ghanza shared that because of the side-effects of medicines, she cannot eat spicy food. So, she hired a maid to cook un-spicy food for her.

> *By using heavy doses of medicines, I feel burning inside and I cannot consume spicy food. I hired Faiza to cook un-spicy food for me as directed by the doctor.* **(A** semi-structured interviewed with *Ghanza*, aged 62)

5.2.2.3.2 Specific tasks for male servants

Some of the women have hired male servants, but their services were limited to the grocery, cooking and cleaning.

Saeed is unaware about the illness of the wife of his master. He shared that he was hired particularly for outdoor duties like grocery and two tasks including dusting and cooking.

> *I was hired by the Master (Local term: Sahib)صاحب(). I do grocery, dusting, and cooking. Bhabi (بھابھی)*[15] *is unable to do these tasks for some health reasons.* (A semi-structured interviewed with the male servant *Saeed*, aged 45)

Asif also does not know about the illness of the wife of his master. He shared that he visits home of the master daily for three tasks.

> *I come in the morning and do grocery, cooking and washing dishes. I give two hours to these chores daily. Baji cannot work. I am paid by Baji for these chores.* (A semi-structured interviewed with the male servant *Asif*, aged 42)

Women who hired male servants viewed they never asked their servants for massaging, showering and their personal looking after. However, their support in domestic chores was very beneficial in the lives of these women.

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[15] *Bhabi (بھابھی)*a term usually used for the wife of brother.

Table 11. Summary of themes and sub-themes in the data collected from the tertiary caregivers or hired servants

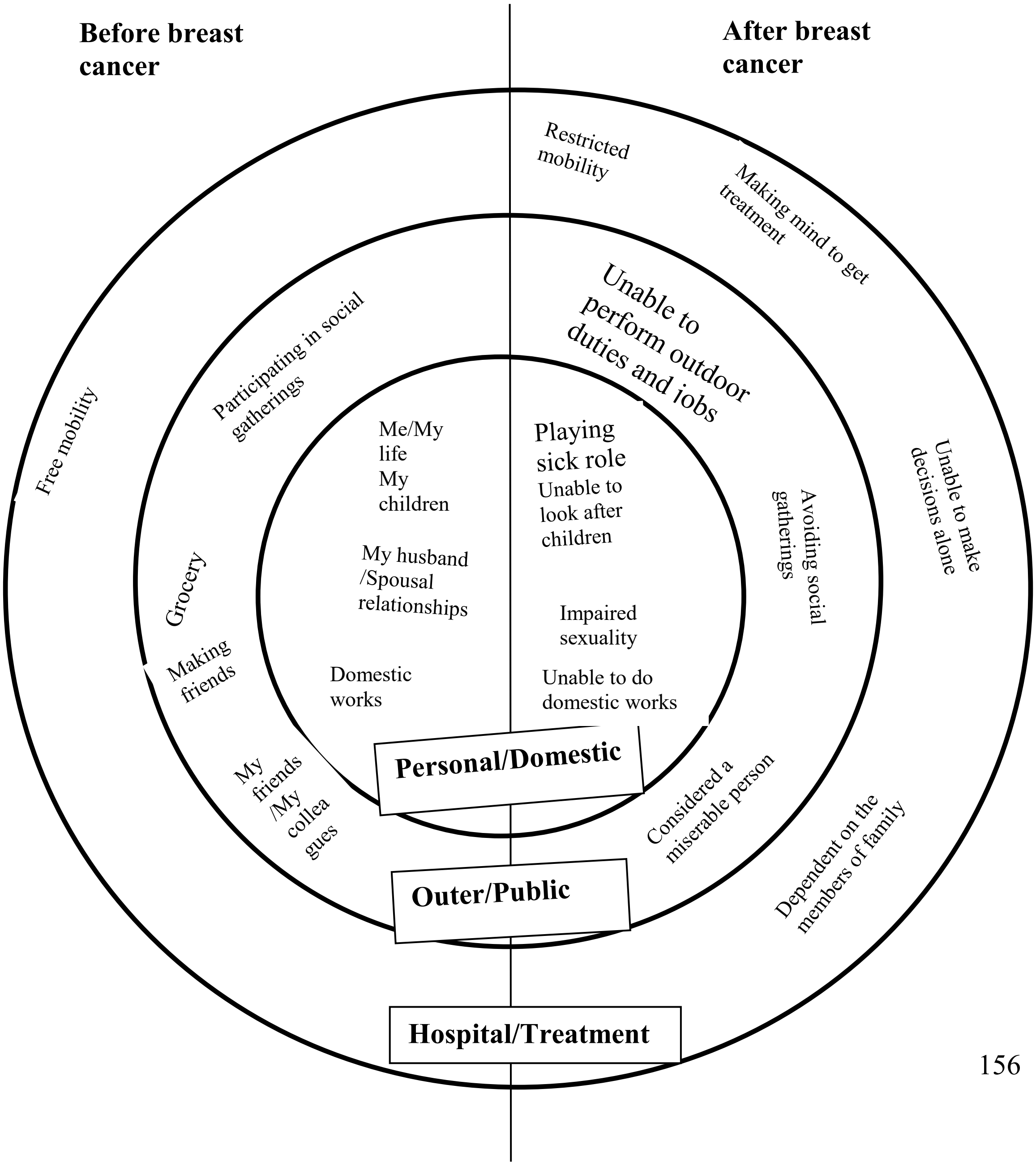
Themes and sub-themes	Indicators/expressions	Challenges
1. *Concern of family*	The diagnosis of breast cancer in their loved one is very shocking and distressing for them.	The treatment cost is a burden on the family
Affecting family members	Hard to accept diagnosis reports	Lives of all family members may get affected
Staying strong only for her survival	Treatment at priority position	Diagnosis is disturbing psychologically
Serving loved one as a moral and religious duty	A trial from Allah and obligation to look after the sick member of family	Expensive treatment and taking loans
2.Nurse,a professional caregiver	Women and their family members were satisfied with the attitude and support of the nurses	Nurses of different attitudes
Attitude of the nurses of private and government hospitals is different	Majority of the women were satisfied with the attitude of the nurses of private hospitals	Nurses of government hospitals were not as helpful as those of private hospitals
3. Gendered services	Preference to those hospitals and clinics for treatment which have female practitioners and nurses	*Na-Mehrum,* a Taboo
Being naked before a *Na-Mehram* is a sin	It is shameful and embarrassing to expose breasts before a male even for health perspective	Cultural and religious concerns
Being naked before a Na-Mehram diminishes dignity of femininity and family	Feelings of shame to expose body before an unknown person	Feelings of discomfort
Suicide is easy than being exposed and treated by a *Na-Mehram*	Suicide is easier than being exposed before a *Na-Mehram* person	Choosing expensive hospitals for gender concerns
4. Paid services	Hiring of maids and servants	Cut short of other expenses and hired maids
Preferences to hire maids	Looking after of kids and doing home tasks	Unable to fulfill home tasks in a nuclear family set up
Specific tasks for male servants	Services limited to the grocery, cooking and cleaning	They were asked for massaging and help in showering.

Note: Themes and sub-themes were deduces from data analysis.

5.2.2.4 Transformation of roles and identities of breast cancer patients in maintaining social relationships

Themes under this heading identify how the women expressed transformation of their roles and identities in maintaining social relationships. These themes have been classified as personal or domestic spheres, outer or public spheres, and hospital or treatment spheres. With the classification of themes, the diagram given below has been demarcated under two headings of ‘before’ and ‘after’ the breast cancer. The changed roles and duties have been mentioned under the heading of ‘after breast cancer’.

Figure25. Diagram illustrating themes of transformations of roles and identities of the breast cancer women in maintaining social relationships



During the research, all twenty seven women stated that before the diagnosis of their breast cancer, they used to fulfill their personal and domestic roles of self-care, patterning mothers, grocery and cooking, and spousal relationships. After the diagnosis, they are playing a sick role which included their being unable to look after their own selves, children, unable for domestic chores like grocery and cooking, and impaired sexuality. All women told that their outer and public roles of participating in social gatherings, visiting markets and making friends were changed and they started avoiding social gatherings, and presenting a picture of a miserable person. Some of the women expressed that before their diagnosis they were confident to visit hospitals for treatment, but after the diagnosis they needed encouragement of their care-givers like family members and nurses in making mind to get treatment. They said their role has changed and are unable to decide alone about their treatment and have become quite dependent on other family members ever than before.

The elaborations of themes discussed below show how transformations of their roles help maintain social relationships.

5.2.2.4.1 Playing a sick role

Majority of the women expressed that how they are playing a role of being sick among the healthy family members. This role and identity has maintained a kind of social relationship in which all the family members of breast cancer women understand that her role is not her fault, and she deserves their sympathies.

Shamim asserted the manifest expressions of care which she is receiving from her mother and husband.

> *I left my job; my mother takes care of my children. Rahim (husband) runs a shop from early morning to evening. He works all seven days of week except the day of my check-up in the hospital. He wants to collect money to meet the requirements of my treatment.* (An informal interview with case number 2: *Shamim*, aged 39)

Rakhshanda shared that after her illness she was unable to do work as she was a needlewoman before her illness. She added that her family members are more hard working than before with the aim to get my survival with the help of proposed treatment.

> *All members of family give me great attention, which I never got before my illness. I feel myself changed; they have sympathetic feelings for me. I was a needlewoman (Local word: Darzan) and with this illness, I became unable to work anymore. My family members are now more hardworking than before; they want to have successful treatment. I feel my family is more united (Local word: Mutahid) than before.* (A semi-structured interview with *Rakhshanda*, aged 55)

5.2.2.4.2 Dependent on other members of family

Majority of the women viewed that this illness and its long and expensive treatment made them dependent on other members of their families. Many told that they cannot cook their food, wash clothes, and bring medicines from the market. Their dependency on others has maintained that they deserve attention of other members of family, too.

Komal said that her sister cooks a separate kind of food for her.

> *With Augmentin (name of a medicine), I cannot eat that food which my family eats; I feel burning in stomach. My sister cooks vegetable and chicken broth for me; she does this as a part of her love for me.* (An informal interview with case number 4: *Komal*, aged 22)

Shazia maintained that her mother givse her shower, help her in wearing clothes and comb her.

> *My mother gives me a shower, I cannot clean my body. She helps me in wearing shirt and combing hair.* (An informal interview with case number 3: *Shazia*, aged 34)

Rukhsana stated that she is completely dependent on her daughter. She gets her appointments, communicates with her doctors, and receives medicines from the pharmaceutical store.

> *You know, there always remain rush in the hospital, and it is not easy to get medicine from the pharmacy of the hospital. My daughter gets an appointment; she helps me in telling what I feel and all about the changes in my body. She tells them all the side effects of medicines which she observes in me. It is because of my daughter that I am alive and getting treatment.* (An informal interview with case number 1: *Rukhsana*, aged 52)

5.2.2.4.3 Free from fulfilling domestic and outdoor duties

Majority of the women stated that being a sick member of family, they are not restricted to perform the duties which they used to do before their illness. With this identity, most women feel themselves free from domestic and outdoor responsibilities, and their family members understand this reality without complaining.

Adeeba stated that after her diagnosis, she was never asked to perform the task of cleaning home which was assigned to her before her illness.

> *Cleaning home was my duty among the distributed chores of home for me and my two sisters. After diagnosis, I left this and I was not asked by any member of my family that why she is not cleaning even when I was feeling better.* (A semi-structured interview with *Adeeba* aged 32)

Misbah shared that after her illness, she is not asked to look after children.

> *Now I am never asked to dress up my school going children, cook food for them, and give them pick and drop as I was doing all these duties before my illness. My mother in-law performs all these duties with the help of my husband; they do not complain me for this.* (An informal interview with case number 5: *Misbah*, aged 40)

Fazeelat said that after her illness, she left her duty of attending and representing her family in social gatherings.

> *I am restricted by my faith healer to attend any marriage ceremony and go for condolence to the family of any diseased person. I am the eldest member of my family. Before my illness, I used to represent my family in marriage and death ceremonies of the people who are close to my family. Now I am not fulfilling this responsibility, and my family understands this.* (An informal interview with case number 9: *Fazeelat*, aged 62)

5.2.2.4.4 Unable to make any decision alone

Majority of the women expressed that after the diagnosis, they are perceived by their family members as unable to make any decision alone. Many stated that decision regarding their treatment was also not taken by them independently. This identity has made their position weak in family.

Ferzanda told that her social and economic dependency on family members has put her in a weak position, and she is perceived as unfit to take a decision alone.

> *My stress due to sickness in family puts me in a condition that they consider me unable to take a good decision alone. My complete dependency on them has put me in a weak condition that I accept all their decisions even about my health. They take me mentally unfit to decide about important matters of family.* (An informal interview with case number 12: *Ferzanda*, aged 55)

Shamim shared that she was waiting for the decision of her husband for her surgery as she was not able to decide alone for cultural reasons and females do not decide key matters of family in our society.

> *My husband decided to get all kinds of treatment except lumpectomy and mastectomy. Doctors were worried; the cancer was about to go behind the breast. I was stressed… I told them and talked with my husband if he allows me for this treatment.* (An informal interview with case number 2: *Shamim,* aged 39)

5.2.2.4.5 Making mind to get treatment

Some of the women were very determined not to let this illness take over their life and were making efforts to be optimistic regarding their survival. With this thinking many women tried to maintain their social relationships strong, giving the idea that she wants survival for them only.

Masooma perceives her children a natural power that made her fight against the illness and survive for them.

> *Children, umm! You know a natural power, made me fight against this illness and get survival to educate them; get them married, and live for them.* (An informal interview with case number 6: *Masooma*, aged 43)

Suriya believes that life is a gift from Allah and it should be lived with efforts despite sufferings.

> *Although side effects of treatment are horrible yet I do believe that life is a gift… You can't imagine for how many times I visit washroom when I have loose motions, but I want survival and want to live a life, given by my Allah and want to support my family as they desire to see me with a healthy person.* (An Informal interview with case number 13: *Suriya*, aged 62)

Fazeelat shared that she is a lone carer of her children, and she must get treatment and survival.

> *Diagnosis made me upset but I know (*she seems so upset here*,)… although they are grown up yet I feel that there is no one carer of my children except me. I have to get my children settled in their lives. I would have to get regular treatment to survive for my children.* (An informal interview with case number 9: *Fazeelat*, aged 45)

5.2.2.4.6 A Miserable person

Views shared by many women displayed that the identity of a miserable person has made them mentally stressed. Many viewed that this identity has made many people sympathetic towards them. Some women shared that their self-respect has widely been damaged by this identity. It has maintained a unique social relationship. Although being a miserable person, they feel stressed and get moral support from all people around them.

Nazia shared that she needed a mental comfort which was disturbed after the side effects of chemotherapy. One of her neighbors took her to a shrine where she received amulet from a saint. She added that that amulet gave positive effects to her mind.

> *After chemotherapy, I was feeling many changes in my body, particularly the color of skin and the losing of hair. I needed a peace of mind. A woman living in my neighbor took me at the shrine of a saint. The descendant of the saint gave me an amulet that has really put positive effects in my mind.* (An informal interview with case number 7: *Nazia*, aged 61)

Shazia shared that the people of her village gave sympathies to her and her relatives. She explained how a boy of her village always got her appointments from the hospital as she and her family live in a remote village and people are not much educated to get appointment on phone.

> *The people of my village have sympathetic feelings for me. They helped my brother and uncle in collecting money for my treatment. A boy of my village does a job in city; he is not our relative, but he always gets appointment for me. He takes a leave from his job and guides my family in the hospital. It seems to me that I am miserable, but I praise all these people who are helping me.* (An informal interview with case number 3: *Shazia*, aged 34)

Shamim shared that how a doctor helped her husband, convincing him for her surgery. She added that she was miserable at that time, and is thankful to that doctor who helped her beyond her hospital duties.

> *Dr. Azra contacted and influenced my husband that surgery is very important for my survival. She understood my miserable condition and wanted to persuade my husband of the immanent problems if surgery is not performed. I was miserable and thankful to that doctor for her support beyond her hospital duties.* (An informal interview with case number 2: *Shamim*, aged 39)

Transformation of the roles and identities of women have maintained and strengthened their social relationships.

Table 12. Summary of themes and sub-themes of transformation of roles and identities in maintaining social relationships

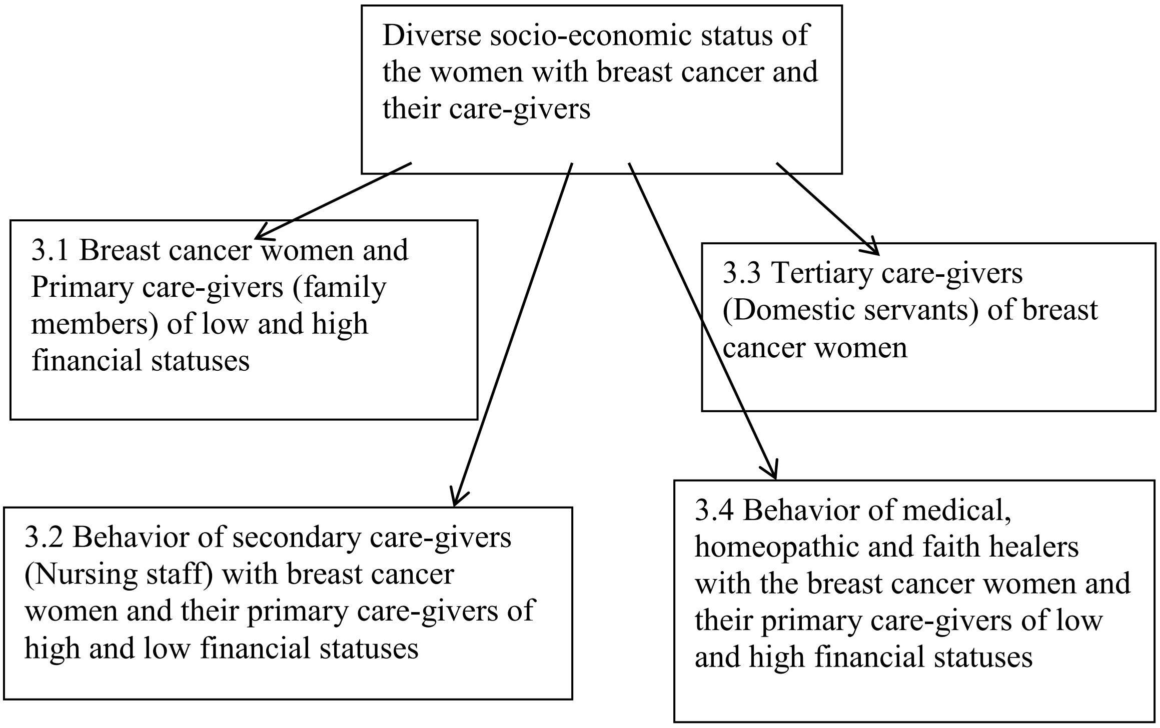
Transformation of roles and identities of breast cancer patients
A sick member of family Dependent on other members Not restricted from fulfilling domestic and outdoor duties Unable to make any decision alone Making mind to get treatment A miserable person

Themes and sub-themes were deduces from the data analysis

Part 3: The third part deals with the exploration of diverse socio-economic statuses of the women with breast cancer and their care-givers. It focuses upon the behavior of primary care-givers with breast cancer women. It also focuses upon the behavior of the secondary and tertiary care givers with the breast cancer women of low and high financial statuses. It also deals with the behavior of bio-medical, homeopathic and faith healers' with these women and their family members. Moreover it also focuses upon the outcomes of their behaviors on the treatment seeking process of their breast cancer woman.

Thirteen out of twenty seven breast cancer women with their family members were greatly impacted by the financial burden due to the expensive treatment. The shortage of money for treatment, and the loss of job were major financial challenges. Irregular treatment due to the shortage of money let the behavior of the medical and homeopathic healers uncooperative.

Figure 26. Diagram illustrating four themes



5.2.3.1 Breast cancer women and their care givers of low and high financial status

Breast cancer women and their family members as primary care givers were found in different problems chiefly in financial problems during the treatment seeking process. Their financial statuses were measured by their source of income, amount of monthly or annual income, possession of home, and vehicle for their transportation.

5.2.3.1.1 Breast cancer women and family members as primary care-givers of low financial statuses

All of the low financial status women and their family members as primary care-givers were found depressed due to the expensive treatment. They were seen managing the cost of the treatment through different ways such as doing extra jobs, taking loans and getting helps of their relatives. *Naveed* talks about his financial troubles during the treatment seeking process of his mother.

> *I got loans for the treatment of my mother. Now I do extra work to meet the needs of travel and treatment. (A* semi-structured interview with the care-giver: the son of a breast cancer woman. *Naveed*: aged 39)

Nasir says how he faced his major troubles and the burden of extra responsibilities during the illness of his wife.

> *I asked my relatives for financial support as after the diagnosis of it, I left my job. My wife left giving attention to home and children. My children and I saw a very horrible time when we stopped doing grocery, purchasing clothes, and asking for Sadka/Khairat (charity).* (An informal interview with the care-giver: husband of a breast cancer woman. *Nasir*: aged 41)

Shamsa told that how she faced many problems.

> *Before its diagnosis, we were living in a house on rent. Later, we left home and got shifted in the home of my father's brother…we saved money to get timely check-ups. You know - it is not easy to meet the cost of treatment. It was my father's brother's house, but it was difficult to cook separate food for mother and give her shower.* (An informal interview with the care-giver: the daughter of a breast cancer woman. *Shamsa*: aged 29)

Noreen shares that her husband is doing extra work to meet the needs of her treatment.

> *I am very anxious and want a survival because my husband pays the treatment cost by doing extra jobs.* (An informal interview with case number 10: *Noreen*, aged 47)

Shamim told that the expensive treatment of her illness has made her family members poorer than before.

> *This illness has made us poorer. The cost of transport and check-ups are fine, but the treatment and medicines are very expensive. (An* informal interview with case number 2: *Shamim*, aged 39)

Some of the women with low income were found getting treatment from different hospitals and clinics. For example, they got test, check-ups and treatments, particularly radiotherapies from different hospitals. *Masooma* shared that she approached different hospitals from screening to regular check-ups after radiations.

> *I waited for 42 days, but I got screening tests from government hospital as these tests were expensive in private hospitals. After tests, I went to a private hospital for treatment. There was delay in the treatment of government hospital. When I was recommended for radiotherapies, I went in an institute of radiations which treats patients on the basis of charity. After radiations, I got regular check-ups from a private hospital. (An* informal interview with case number 6: *Masooma,* aged 43)

Kinza told that she took her mother to two different hospitals for treatment.

> *I got chemotherapies of my mother from a national institute of radiations as it was very expensive in a private hospital. We are getting treatment from the semi-private hospital.* (A semi-structured interview with the care-giver: the daughter of a breast cancer woman. *Kinza*: aged 22)

Iqbal shared that he is thankful to an oncologist who guided her to approach a clinic for inexpensive screening tests.

> *I am thankful to Dr. Azra; she advised me to get initial tests from a particular clinic as tests in this hospital were expensive.* (An informal interview with the care-giver: the husband of a breast cancer woman. *Iqbal:* aged 48)

All of the low income women and their family members were seen getting faith healing besides the hospital treatment. For them, their illness can be removed taking the spiritual and faith healing. *Rehmat* viewed that faith healing has a great effect on body.

> *Illness can be healed with the help of a faith and spiritual healer (Local words: Peer fakeer soro). (An* informal interview with case number 14: *Rehmat,* aged 60)

Minahil viewed that faith healing is cheap and affordable for them.

> *Faith and spiritual healing is available in our village, and it is free as well. Approaching the hospital takes money and time for travel and treatment.* (A semi-structured interview with the care-giver: the daughter in-law of a breast cancer woman. *Minahil*: aged 28)

> *Rashida* shared that she has firm belief in faith healing.
> *"Hakeem bra ya yakeen (translation: Faith is greater than healer)".* (An informal interview with the care-giver: the mother in-law of a breast cancer woman*. Rashida:* aged 55)

5.2.3.1.2 Breast cancer women and their family members of high financial status

Woman and their care-givers of high financial status were found avoiding rush days of hospitals. They were selective in choosing the particular practitioner. They were not having trust in doctors sitting in government hospitals. They shared that those doctors waste time, requiring patients to wait for long, and they do not display a serious behavior towards patients. *Misbah* shared that she likes the polite and sensible attitude of Dr. Sadaf and wants treatment from her only.

> *"I will get check-up and treatment only from Dr. Sadaf. I like her empathetic behavior".* (An informal interview with case number 5: *Misbah,* aged 40)

Sughra told that she never goes to the hospital without proper appointment.

> *"I do not take my mother to the hospital without appointment".* (An informal interview with care giver: Daughter of a breast cancer woman, *Sughra:* aged 43)

Haseeb shared that he does not bring her wife in very busy days of hospital.

> *"Monday and Thursday are OPD (Out Door Patients day); we come on special appointment in other days of week".* (An informal interview with care giver: Husband of a breast cancer woman. *Haseeb*: aged 51)

Sadique viewed that private hospitals give more attention to patients than that of government hospitals.

> *" There are long waits in government hospitals and doctors do not pay much attention".* (An informal interview with the care-giver: the brother of a breast cancer woman. *Sadique*: aged 54)

5.2.3.2 Behavior of secondary care-givers (Nursing staff) with breast cancer women and their primary care-givers of high and low financial status

Nurses, being professional carers of the breast cancer women, were classified into secondary care-givers. The following excerpts clarify the nature of their dealings with women and their care-givers.

Fareeha, a senior nurse, is dealing with the daughter of a breast cancer woman who came in Combined Military Hospital for her regular check-up. I accompanied them on the day of their check-up. The nurse does not know that her dealing is being watched and noticed. She guided the girl and also promised to give her quick entry as she missed to read recommendations of the doctor to come with the results of a test.

> *Your mother is 6th in the queue of patients, and wait for your turn in the sitting area.* (*Fareeha* saw the file), *Look! In the last check-up, you were asked to come with LIPID profile. Please go downstairs, there is a laboratory and get your mother's test, and come with the results of test. I will not delay your mother's check-up; first bring the test results.* (A semi-structured interview with the female Nurse: Fareeha, aged 41)

Nurse *Iqra* suggested a patient to get check-up from the doctor whom she saw in her last check-up. It was a good suggestion as the doctor had knowledge of the patient's history.

> *If you got your last check-up from Dr. Nazia, You should wait for her, and get check-up from her only as she knows your history. It is a surgery day, but she will come in clinic in the break.* (A semi-structured interview with the female Nurse: *Iqra*, aged 24)

Madiha and *Mahnoor* work in the government hospital. They were observed in dealing with the breast cancer women in the ward of Oncology department of a government hospital. Their attitude was found different from those nurses who were found working in private and semi-private hospitals. Usually low financial status patients come in government hospitals. The nature of permanent job and low financial status of patients can be the reasons of their indifferent behaviour.

> *"Please don't ask me for anything now; my shift of work is finished. I will see you tomorrow only in my working hours".* (An informal interview with the female nurse: *Madiha*, aged 30)
>
> *Doctor will come in the round check-up only. We have Flagyl for controlling loose motions; there is no other treatment other than this. You can move to any other hospital if you don't feel better here.* (An informal interview with the female Nurse: *Mahnoor,* aged 41)

5.2.3.3 Tertiary care givers/Domestic servants of breast cancer women

The behaviours of domestic servants were observed at home settings of breast cancer women. They were found doing several duties at home. Majority of the women who were getting their services were from good financially. Out of twenty seven breast cancer cases, seven were found getting services of female servants and only two cases were seen having male servants.

Aneela, Nafeesa, and *Nazish* shared their activities which they perform at the homes of sick women. Only Aneela knows that her owner is suffering from breast cancer. *Nafeesa* and *Nazish* had no information regarding this illness. They assume that their owners are suffering from deadly and painful diseases.

> *Baji (Lady Owner) hired me 3 years ago. I daily spend 4 hours here. I come from a nearest village. As Baji get her bandages of breast changed daily, I wash her*

> *dresses. Washing dishes and clothes of the whole family are my duties.* (A semi-structured interview with maid: *Aneela*, aged 38)
>
> *One year ago I was hired to do all household chores; a daughter of the owner of house is suffering from an illness of breast. She remains worried about her daughter's illness. Washing dishes, clothes and grocery are my responsibilities. I spend seven hours here and monthly they pay me 7,500 rupees.* (A semi-structured interview with maid: *Nafeesa,* aged 41)
>
> *Baji is suffering from a painful disease. She hired me two years ago. Washing clothes, dishes, cleaning home, grocery and cooking are my daily duties which I perform here during the day.* (A Semi-structured interview with maid: *Nazish*, aged 42)

During the fieldwork, only two breast cancer cases were found attaining the services of male servants. In the first case, it was a nuclear family. The wife was suffering from breast cancer, the husband was doing a double shift, and three children were in the ages of from 7 to 12 years. The wife was unable to do dusting, grocery and cooking. Her husband hired a male servant to work more actively than a woman. Saeed shared his activities which he performs daily. He assumes that his lady owner is suffering from a disease and had no information that the disease is breast cancer.

> *I was hired by the husband of Baji as she is suffering from a disease and is unable to do these chores. I do dusting, grocery and cooking. Baji does not ask me for washing clothes. She hired a woman for washing her clothes.* (A semi-structured interview with the male servant: *Saeed*, aged 45)

In the second case, the servant was provided by the husband's firm. Serving the officer was his job duty for which the firm was paying him monthly. He was doing all activities except washing clothes of his officer's wife. He feels that the wife of his officer is not well, but had no information that she is suffering from breast cancer.

> *I was hired by the company of my officer and paid by the company. Grocery, cooking, washing clothes and dishes are my duties to perform daily. I am not allowed to wash the clothes of his wife. For this task, a woman comes daily. Most*

> *of the time, she looks sick; I finish my work and go back.* (A semi-structured interview with male servant: *Asif,* aged 28)

5.2.3.4 Behavior of medical, homeopathic and faith healers with low and high financial status breast cancer women and their care-givers

Behaviors of the medical, homeopathic and faith healers were observed at their work places such as at hospitals, clinics and sitting places. I visited these places with women and their family members, and kept my status hidden as the researcher from them. The purpose of doing this was to observe their original behaviour; otherwise, they could have changed their behaviour. Behaviors of practitioners were measured through their communication with the women and their care-givers. The behaviors of all three kinds of practitioners are mentioned below.

5.2.3.4 .1 Behavior of medical practitioners

Women and their care-givers shared the behaviors of medical practitioners to them. Many breast cancer women and their care-givers viewed that behaviors of practitioners matters a great deal to them; it can make their mind for complete treatment or leave the illness unattended.

Kinza, the daughter of a breast cancer woman shared that the behavior of one of the practitioners was very motivating for her. She got treatment of her mother from a private hospital.

> *Dr. Sadaf motivated me by telling the experience of her personal life. She told me that I was a lone carer of my mother. She was in the advanced stage, but my dedication to get regular and complete treatment gave me success as my mother survived.* (A semi-structured interview with care-giver: the daughter of a breast cancer woman, *Kinza* aged 22)

Rehmat, a breast cancer woman shared that how a medical practitioner encouraged her to start getting treatment when she was very depressed after the diagnosis. She got treatment from a private hospital.

> *She talks very politely; I was encouraged by Dr.Uzma. Mentally I was feeling that this diagnosis is the end of life. I was not ready to get my treatment started very soon after the diagnosis, but she made me take steps soon and do not waste time.* (An informal interview with case number 14: *Rehmat* aged 60)

Just before the check-up, a female oncologist was talking with the daughter of Rukhsana, an advanced stage breast cancer woman. She owned her patient and paid her attention to her patient warmly.

> *"Now she is not your person, she is ours".* (A semi-structured interview with the female oncologist working for last 7 years in a semi-government hospital)

A male oncologist was communicating with the son of a breast cancer woman. He guided how to get free treatment in the hospital.

> *"Go to the foundation section of hospital and ask for 'Needy Patients Free Checkup Form' for free treatment".* (A semi-structured interview with male oncologist working for 3 years in the private hospital)

A female oncologist was seen asking the woman about the payment of check-up at the accounts desk. She did not check her and guided her to come through a proper way by submitting check-up fee.

> *I cannot check you, first pay the payments of check-up fee at the accounts desk.* (A semi-structured interview with female oncologist working for last 9 years in a private clinic)

A female oncologist was found refusing check-up of a woman and told her husband that bring new form.

"This is your previous visits' form of visiting the hospital, go and get today's entry form". (A semi-structured interview with a female oncologist working for the last 4 years in a government hospital)

It was found that the behaviors of the oncologists were influenced by their places of work. Due to rush in the government hospitals, they were not focused as other oncologists were observed in private clinics and hospitals dealing with the women and their care-givers who came with the appointments. Practitioners working in private and semi-private hospitals were found focused towards their patients. Giving expensive treatments can also be a reason of their focused behavior.

5.2.3.4 .2 Behavior of homeopathic practitioners

Majority of the women shared that they were impressed by the confident attitude of the homeopathic practitioners towards their illness. Behaviors of two homeopathic practitioners were observed during their dealings with the women and their care-givers. Both homeopathic practitioners were male.

A homeopathic practitioner forbad a woman from entering his office, asking to wait outside.

> *"Wait I am with my regular patients".* (The first homeopathic healer sitting in his private clinic)

Alia was seen sitting in the waiting area of the clinic. She showed her trust in the treatment of this practitioner when she was asked to share her initial experience with this practitioner.

> *"It is my second visit to this clinic. He just checks pulse and tells the entire inner condition of the body and about the affected place".* (A semi-structured interview with *Alia* aged 57)

A homeopathic practitioner ordered his attendant to tell the family members or primary care-givers of the women that only one family member can stay with the woman in the check-up room.

> *"In the check-up room, only one carer of a patient can come with his or her patient"* (The second homeopathic healer in his private clinic dealing with a patient)

This homeopathic healer also advised the woman and her care-giver that they should have complete trust in him and never go for screening. He assured them that treatment will take time and be regular in check-ups.

> *"Cure (Local word: Shifa) is from Allah; I will give the treatment only. I will advise you that do not go for any screening during this treatment and never miss the date of your check-up". (The* second homeopathic healer in his private clinic dealing with a breast cancer woman)

5.2.3.4 .3 Behavior of faith healers

All twenty seven breast cancer women were seeking faith healings besides other types of healing such as medical and homeopathic. They and their care-givers viewed that faith healers helped them to accept their illness positively. This positivity possessed remembering Allah (Local word: *Ziker*) in pain, keeping patience and endurance, making efforts to seek treatment for serving others and understanding life as a gift of Allah.

Noreen viewed that she visited the faith healer of her village every Friday during her illness and how faith healing made her attitude strong.

> *After Friday prayer (Juma ki namaz), he sits in his drawing room (Baythak). I regularly visited him, and never missed any Friday (Juma) during my illness. He made me keep firm belief in Allah; life is given by Him and we will return towards Him. His teachings made me psychologically strong that not only I accepted my illness, but also took it as examination that Allah wants to make me strong.* (an informal interview with case number 10: Noreen aged 45)

Masooma shared that the faith healer of her village made her accept illness with a positive mind.

> *Qaazi sahib is a very pious person of our village. After the diagnosis of this cancer, I was mentally very disturbed. He taught me that pessimism is a sin in our religion* (Local words*: Na-umeedi gunah hay*). *Life is short and one day we will have to be accountable to Allah, so accept the pain with patience and have strong belief in Him.* (An informal interview with case number 6: *Masooma* aged 43)

The descendant of a saint maintained that faith makes mind positive and it can heal any kind of illness.

> *Faith is greater than the healer (Local words: Hakeem bra ya yakeen), and it can heal any kind of illness. The soul of Baba Ji asks Allah for help on behalf of the people who pay their homage to his shrine. People come here with tears and get back with smiles.* (A semi-structured interview with the descendant of a saint: *Shah Shabeer*)

Peer sahib of a shrine said that in his whole life he experienced this fact that when people come to the shrine and pray for cure, they get cured and they pay here offerings after their cure.

> *"Illness can be healed with the help of a faith and spiritual healer (Local words: Peer fakeer soro)".* (Semi-structured interview with the descendant of the saint Saaen Hazar Shah)

Minahil stated that as compared to the hospital and homeopathic treatment, faith healing is free and available at all times.

> *"Faith and spiritual healing is available in our village, and it is free as well. While for approaching hospital, it takes money and time for traveling and treatment".* (A semi-structured interview with the care-giver, *Minahil*: the daughter in-law of a breast cancer woman, aged 28)

Rehmat shares her respect for faith healers. She appreciates they are not supposed to wait for long at the sitting places of these healers.

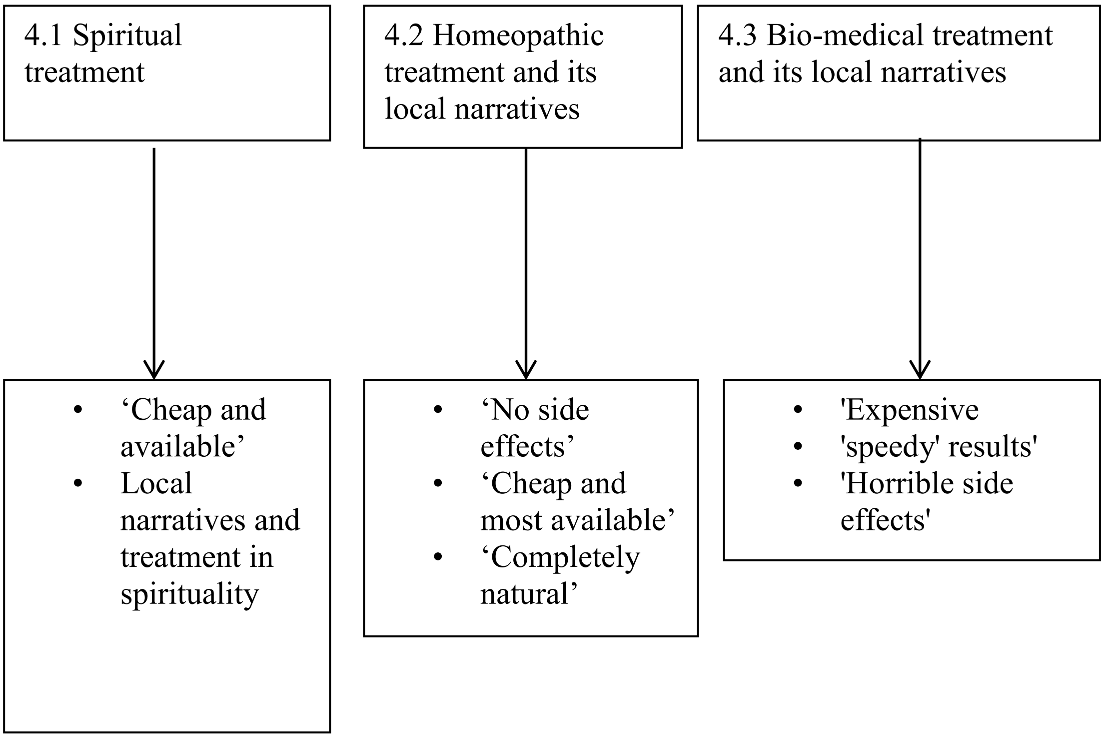
> *I like and have respect for their various services such as convincing towards positivity and having firm belief in Allah that He can do anything what He feels better for humans. But, a good thing in this type is short wait and less fatigue. They read the holy verses which give a peace of mind.* (An informal interview with *Rehmat,* aged 60)

All women were satisfied with the behaviors of faith healers. Patience, peace of mind, control of emotions, understanding of self, and avoiding negative thoughts were the major aids they got from these healers. Their belief in faith healings showed their traditional and religious gestures.

Part 4: Folk narratives verbatim, particularly of spiritual, homeopathic and bio-medical treatment availed by the breast cancer cases

This part deals with the folk narratives of the breast cancer women and their care-givers regarding spiritual, homeopathic and bio-medical treatment.

Figure 27. Diagram illustrating the themes of the narratives on spiritual, homeopathic and bio-medical treatment



5.2.4.1 Spiritual treatment

This theme brings forth diverse advantages of spiritual behaviors of women and their care-givers that helped them in fighting against their cancer.

5.2.4.1.1 Cheap and most available

All twenty seven breast cancer women stated that faith treatment is cheap and easily available. Family members of these twenty seven women shared that their society has great influence of religious figures particularly the Imams of Mosques, Peers and descendants of shrines. In addition, they are asked for spiritual treatment if you have bad health.

Arshad shared his experience with a spiritual healer who was the Imam of a mosque. He shared that he found him always there in Mosque.

> *Imam Sahib recited the holy Quran and gave blows of breathe (Local words: Dums). We visit the Mosque (Local word: Masjid) for seven times. After every namaz, he was available in the mosque. It was very easy to get this spiritual treatment. Imam Sahib was always there in the mosque and was found busy with people who come for religious solutions for their problems.* (A semi-structured

> interview with a care-giver, the husband of a breast cancer woman: *Arshad*, aged 49)

Anum said that except spiritual treatment all kinds of other treatments were expensive.

> *The only treatment which was free was the spiritual treatment. Junior Peer sahib who was a descendant of the peer of the shrine was happy to see us in his shrine. He encouraged my mother to get her hospital treatment without any kind of irregularity. He advised us to visit the shrine on every Friday evening and do charity among the needy people.* (An informal interview with the care-giver, the daughter of a breast cancer woman: *Anum*, aged 18)

Nazira shared that she took her daughter to a spiritual healer many times. They used to welcome people and refused all kinds of gifts which increased her trust in them.
Shah ji (a descendant of the family of the last prophet of Islam, Hazrat Muhammad Peace Be Upon Him) gives spiritual treatment that is free of cost. We visited his home many times and had faith in his spirituality. He never accepts any kind of gift and money for his treatment. He always welcomes people who come for the spiritual treatment (Local words: Dum and Drood). (An informal interview with the care-giver, the mother of a breast cancer woman: Nazira, aged 48)

5.2.4.1.2 Local narratives and treatment in spirituality

All the women and their family members narrated about spiritual treatment. The narratives they told display their firm belief in this kind of treatment. Their common spiritual narratives are being mentioned here.

Saleema shared a narrative that meant the illness attacks in short time but takes much time to heal up, but visits to shrines will help heal the body.

> *"Penri lakhin r chukni tilen tilen,perr mezar pay hazri asar dekhae ge. (Translation: Illness comes soon and has drastic impacts on the body, but it takes time to vanish)".* (An informal interview with the care-giver, the mother of a breast cancer woman: *Saleema*, aged 55)

Nasir, the husband of a breast cancer woman and Masooma, another breast cancer woman, both stated that they are making efforts to be successful in getting survival because hopelessness is a sin according to their religious beliefs.

> *"Na-umeedi gunah hay (Translation: Pessimism is a sin. We are trying to get survival and are hopeful)".* (A semi-structured interview with the care-giver, the husband of a breast cancer woman: *Nasir*, aged 41)

Rashida viewed that one should go for spiritual treatment as it has many positive impacts on the body and mind.

> *"Follow a saint and get treatment; it gives remedy to body and mind (Local words: Peer faker soro)".* (A semi-structured interview with care giver/Mother in-law of a breast cancer woman: *Rashida*, aged 55)

Nazira maintained that the illness of her daughter is due to the spell of envious or black eye of an enemy who was unhappy to see her daughter happy. She visited a religious figure to break this spell.

> *There is no reason of her illness except the spell of an envious eye or black eye of the enemy. I went to the shrine of Peer Sahib and he has broken the spell of envious eye. (Local words: Hasid ki nazer lagi hay ya kisi dushmen ki nazar lag gai hay. Peer sahib say Nazer ka torr kerwaya hay).* (An informal interview with the care-giver, the mother of a breast cancer woman: *Nazira*, aged 48)

Shamsa shared that the illness of her mother is only because of a black magic of the enemy who wants to kill her and destroy her family. Her father arranged a religious gathering at home and fed the poor people.

> *Maa is suffering from the black magic of enemy (Local words: Kala jadu kia kisi dushman nay). He definitely wants to destroy her family by killing her. The father conducted a religious event (Local words: Melaad), distributed food among the poor to break the spell of black magic.* (A semi-structured interview with the care-giver, the daughter of a breast cancer woman: *Shamsa*, aged 29)

Shazia was getting faith healing from the descendant named *Shah Shabeer* of a local shrine. The close and distant relatives of *Shazia* paid an offering *Gharroli* to the shrine of the elders of *Shah Shabeer* for the sake of her health. All the close and distant relatives of *Shazia* gathered in her home, renovated a water pitcher, and a cart with original and artificial flowers. They cooked salty and sweet rice for the distribution at the shrine. A procession of these well-wishers went to the shrine, prayed for her health and distributed food among the people.

Figure 28. A spiritual activity of *Gharolli*

Note: This spiritual activity of Gharolli is performed by the close and distant relatives of *Shazia* for the good wishes of her health.

> *Shah Shabeer told my family to come to the shrine of his elders and pray for her successful treatment which is going in the hospital of Lahore city. This procession gave me and my family members a satisfaction that all are praying; Allah will listen to their prayers and will bless me with speedy recovery.* (An informal interview with case number 3: Breast cancer woman: *Shazia*, aged 34)

5.2.4.2 Homeopathic treatment and its local narratives

Two out of twenty women were seeking complete homeopathic treatment. Six women were seeking this treatment with their bio-medical treatment. All eight women viewed that in this chronic illness, this treatment takes time in bringing positive results. Some of the common local narratives regarding this kind of treatment are mentioned here.

Nazia shared that anti-biotic of bio-medical treatment disturbed her stomach while homeopathic treatment has put no side-effects in her body.

> *In medical treatment, I was taking anti-biotic; they damaged my stomach badly. The day I started these homeopathic medicines, I felt betterment in stomach. The pain of breast is there as it takes time to bring good results in severe illness. These medicines have* ***no side effects*** *in body and mind.* (An informal interview with case number 7: *Nazia*, aged 61)

Sultan shared that this treatment is available in their town and is not expensive. For bio-medical treatment, they travel for four hours.

> *This treatment is easily available in our town and is* ***not much expensive,*** *while for bio-medical treatment we travel to Lahore which is 4 hours away from our town.* (A semi-structured interview with the care-giver, a Father of a breast cancer woman: *Sultan,* aged 51)

Ferzanda shared that this medicine has not brought side effects as the bio-medical medicines brought in her body. She told that homeopathic medicines are made by natural things like vegetables and fruits, while bio-medical medicines are made by chemicals.

> *This treatment has no mixture of chemicals. It is completely* ***made of natural items****. For example, it is made of the seeds of vegetables and fruits which have powers to bring positive results without damaging other parts of body.* (An informal interview with case number 12: *Ferzanda* aged 55)

5.2.4.3 Bio-medical treatment and its local narratives

Twenty five out of twenty seven women were seeking bio-medical treatment. Although their views regarding the side effects of this treatment were not positive, they were seeking this for the reason of its speedy results in killing infections and healing the body. Some of the common local narratives of this treatment are mentioned here.

5.2.4.3.1 Expensive

All women stated that bio-medical treatment is expensive. The women, who were from rural back ground, complained about the access to hospitals. They viewed that all the process and stages in this treatment such as initial tests, check-ups, medicines, radio-therapies, surgeries and post-treatment regular check-ups are expensive.

Rehmat shared that although her sons were in good financial condition yet the treatment was expensive and they got loans and sold home for her treatment.

> *My sons are bearing the expenses of my treatment. They are gold smiths, but still they took loans and sold one home for my treatment. This illness has badly affected my sons financially.* (an informal interview with case number 14: *Rehmat*, aged 60)

Shazia talked about her financial condition and problems that she and her family faced from the time of diagnosis to the regular check-ups and treatment.

> *During the harvesting season of wheat crop, I was busy in cutting wheat crop with my other family members and I felt pain under my armpit. On the appearance of lumps, my mother took me to a shrine of village. My mother and I used to perform some rituals at the shrine such as offering pieces of sweet loaves to the birds of shrine, lighting lamp with oil and taking a stone of the shrine home with a promise to bring it back after applying it on painful place of the body. Despite my continuous visits to the shrine, I was not getting cured, my pain was increasing day by day. My mother was very much anxious about my health. She took me to a nearest health centre of the village. A lady doctor examined me and recommended my mother to take me to a big hospital of the city, Mianwali. My mother told the doctor about our financial condition and requested her to give me medicines instead of referring to the big hospital of the city. The doctor encouraged my mother and advised her to get my screening tests because it is dangerous for my life if neglected. My mother took me to the civil hospital of the city, where it was diagnosed that I am suffering from the second stage of breast cancer. They referred me to NORI (Nuclear Medicine, Oncology and Radiotherapy Institute), an institute famous for its cancer tests, treatments and especially for its radiological facilities. The cost of treatment was quite high which was not easy to pay. After initial tests we applied in Bait-ul-Maal -- a*

> *Social Welfare and Women Development Department for financial assistance). After a long process of verification, Social Welfare and Women Development Department paid four hundred thousand rupees to the hospital for my treatment.* (an informal interview with case number 3: *Shazia*, aged 34)

5.2.4.3.2 Speedy results

All twenty seven women stated that bio-medical treatment has speedy effects on the body. Bio-medicines bring speedy but positive and negative results.

Rukhsana told her experience that medicines have very speedy results as she takes a pain killer which kills the pain for a short time.

> *"The pain killer removes pain, but it gives a short time relief only. After some hours, it again starts and irritates me".* (An informal interview with case number 1: *Rukhsana*, aged 52)

Misbah shared that speedy results of medicines have disturbed her stomach. Tablets of stomach relief let her feel hunger and eat.

> *Tablets for relief in stomach remove stomach burns and I can eat food which I do not like to eat. The medicines have speedy results and have disturbed my tastes and hunger.* (An informal interview with case number 5: *Misbah*, aged 40)

Rehmat stated that due to the speedy results of medicine, she feel disturbance in sleep.

> *" Augmentin (a medicine) has disturbed my sleep; I take it twice a day".* (An informal interview with case number 14: *Rehmat*, aged 60)

Suriya shared that speedy results of chemotherapies have altered her appearance.

> *"Due to the quick outcomes of chemotherapies, my skin has dark patches, and I lost my hair, too".* (An informal interview with case number 13: *Suriya*, aged 62)

5.2.4.3.3 Horrible side effects

Twenty five out of twenty seven women who were taking bio-medical treatment talked about the side effects of this treatment. These women related bio-medicines with the western medicines. Some common narratives regarding the side effects of bio-medical treatment are mentioned here.

Masooma called bio-medicines as western medicines and says that these medicines have disturbed her stomach. She feels disturbance in the digestion of food.

Western medicine have burnt my stomach (Local words: Angrezi dwaion nay mera maida jalla dia hay). (An informal interview with case number 6: *Masooma,* aged 43

Shamim also calls this treatment western treatment and says that her patched skin is the result of severe side effects of this treatment.

Western medicine has burnt color of my skin. It has created dark patches on my whole body. (An informal interview with case number 2: *Shamim*, aged 39)

Suriya lying in her bed in the women ward of a general hospital stated that this treatment gives survival, but it disturbs body inwardly.

Western medicines give survival with speedy effects in body, but in fact, these medicines eat body inwardly (jism ko kha jati han under say). (An informal interview with case number 13: *Suriya*, aged 62)

Noreen told about her illness experience that the bad thing in this kind of treatment is horrible side effects in the body.

The worst thing I feel in this treatment is speedy side effects in body which alter the outer condition of body. (An informal interview with case number 10: *Noreen*, aged 49)

Rukhsana shared that bio-medical treatment has disturbed her physically and mentally. She told that diarrhea, indigestion and insomnia are major side effects of this treatment.

Injections with heavy doses of medicines have disturbed me physically. Diarrhea, indigestion of food and insomnia have fatigued my body. They have affected me mentally, too. I don't want to stay at home alone; I like the company of my family members. (An informal interview with case number 1: *Rukhsana*, aged 52)

CHAPTER 6

DISCUSSION AND CONCLUSION

Data was analyzed from the lenses of *inductive thematic analysis* (Braun & Clarke, 2006) and *interpretative phenomenological analysis* (IPA) (Smith & Osborn, 2003). This belongs to the first objective of the study to understand the diverse and in-depth beliefs, knowledge, attitudes, practices and body image among breast cancer women and their primary care-givers. Interactive instances and narratives, dialogues or verbatim of the breast cancer women and their care-givers showed their beliefs, knowledge, attitudes, practices and body image concerns. Culture was seen having a great role in the management of illness. Mallinger, Griggs and Shields (2006) indicated in their research that beliefs, thoughts, ideas and emotions can be important elements in fighting against the breast cancer. In addition, Allen, Savadatti and Levy (2009) in their research showed that how positive beliefs, attitudes, and knowledge among women increased their appreciation for living to move forward.

6.1 No worry before diagnosis

During the research, it was widely seen that the people suffering from the breast cancer do not take their illness seriously until its complete diagnosis and confirmation. One of its major reasons is very common symptoms of this illness that people do not take them seriously. They take their fever, appearance of lumps and vomiting normal as in many other illnesses they face. Wilmoth and Sanders (2001) described that the South Asian women ignore their illness with the idea that “illness is never-ending fear and suffering”. They do not believe in diagnosis and the trauma of disease. Ashing-Giwa, Padilla and Tejero (2004) in their research found that the South Asian women avoid screening tests and check-ups. They added that these women have additional challenges like lack of awareness and communication barriers. Pale and dull skin before the diagnosis of breast cancer was not seen a part of great concern and distress. Although, after diagnosis body image was seen as a great concern because of the severity of illness and its effects on the body appearance.

On diagnosis of this illness, women and their family members get worried and start getting treatment after the consensus of family members. Hewitt (2002) described that continuous emotional support of the family members has positive effects from diagnosis to the entire treatment process. The family consensus was widely seen among all twenty seven women.

Karnieli-Miller and Eisikovits (2009) named this shared decision-making and mutual understanding as ‘the illusory power to decide’. This consensus was also important for psychological and financial support for treatment seeking. Twenty six out of total twenty seven breast cancer women despite from different religious sects moved towards local and distant shrines and saints to get cured with their care-givers. They perceived their illness as punishment from Allah, effects of evil eye, black magic and stress of work or depression. Wilmoth and Sanders (2001) described that the South Asian women take their illness as “a lesson from God’’ (a trial from God or belief in destiny, karma, faith, and prayed for successful treatment).

In all twenty seven cases, the realization of the diagnosis of breast cancer happened suddenly. Avoiding annual screening, taking time by the family members to make decision in seek treatment for their loved one and arranging money for the treatment were major reasons that lead to the advanced stage of their illness or worsening of health. Apart from arranging money and making decision for treatment, care, access to the hospital, required financial support and cooperation of the whole family are the social dimensions of the whole treatment process. The effects of illness of breast cancer is not limited to the patient only, but it extends to the whole family. Perez (2015) discussed that a cancer patient is never a lone sufferer of his or her illness, but people surrounding her or him also suffer from this illness in many ways. In the present research, a case of a second stage breast cancer woman, *Sumera,* left going to school and her sons remained no more serious in their studies because of the diagnosis of her illness. Her husband got days off from office to take *Sumera* to the hospital for check-up and treatment. Things were not much worse during her pain and disturbance, but after diagnosis her whole family got affected.

They seek alternative spiritual healing by visiting shrines and by offering gifts (Local word: “*Niaz”*), lighting oil lamps, offering food to poor, offering fabric to cover the grave of the saint and performing other similar rituals as part of health seeking practices. Janes (2006) explains that ritual healing is a part of culture. The frequency and expense on offerings is reciprocal to affordability and the level of pain the patient is going through. These ritualistic healing practices cause delay in the formal diagnosis of breast cancer.

6.2 Opportunities/Structures for Diagnosis

Opportunities include health insurance or illness expenses covered by the employer, social security, employment in urban setting and access to the hospitals. Structures include hospitals and clinics. Vacek, Winstead-Fry, Secker-Walker, Hooper and Plante (2005) described that bio-medical practitioners and researchers of breast cancer have sufficient understanding regarding the distress of the patient and their care-givers. Due to the updated beliefs, knowledge, attitudes and practices about the modern treatment, women from the urban areas approach the hospital with lesser delay. The fact is that when they visit city hospitals for check-ups the medical professionals suggest them screening tests of breast cancer, so their illness is diagnosed at the early stage. Their residences in cities and information regarding the available services of the hospitals help them in approaching hospitals relatively quicker than the rural women. Many times in the whole family, one member has family health insurance which supports the whole family in getting expensive treatment free of cost. Women and their family members focus on treatment and let the side effects of the medicines and surgeries handle later. They were observed worrying about their body image before other people.

This situation is opposite in the cases of breast cancer women of the rural areas. Existing indigenous knowledge or cultural categories of illness symptoms in cognition work as a barrier in the diagnosis of breast cancer. Seven out of all nine rural breast cancer women shared that they assumed the appearance of lumps in the chest and shoulder area as normal tumors which automatically get removed with the help of local health practices such as using continuous bandages of onion. The existing referral system helped them to approach big hospitals of the city for treatment. On visiting the BHU (Basic Health Unit) of the village, two women were referred to the Tehsil hospital of the city for a detailed examination. Four women were referred to the general hospital of the city from the Tehsil hospital. Three women were referred to the general hospital of the city from the district hospital. For example, in the case of *Shazia,* a 34 year old breast cancer woman, it was seen that she saw traditional healers and made visits of faith healers to get physical and psychological comfort. On the severity of the illness, she visited the nearby Basic Health Unit and was advised to go for screening tests from a big hospital of the city.

The sufferer is taken to the city hospital after a consensus of the whole family. When she is diagnosed with breast cancer and was suggested by medical practitioners to start getting treatment without more delays, she and her family members think and made consensus to get hospital treatment, traditional or faith treatment. The decision to approach the city hospital is not made by the breast cancer woman alone, or by her spouse. Milller and Arachu (2004) found that women need trust and permission from the male head of the family to visit medical centers for check-ups and treatments. In the present research, Masooma a 43 years old rural breast cancer woman shared that after her diagnosis, the decision of her treatment was taken by her mother, husband, brother of husband and her two brothers.

> *It was not my individual decision to get hospital treatment. Mother, Husband, husband's brother and my two brothers decided to collect the money to treat me from the hospital. They are the elders of my family and decide about every important matter.*

Sharing of illness was observed among these women. The oral tradition to express grief or misery was also observed among the rural families. Family members discuss the illness with others to get moral and practical sympathies in the form of approaching cheap treatment places and successful healers. The women of the village and surrounding villages come to see the sufferer and show their love in the shape of good wishes for the breast cancer's health. Many women who are close to the breast cancer sufferer look at the affected part, too. The males come to meet the male members of the breast cancer woman's family and give good wishes for her health. The family members of the breast cancer woman show their grief by telling the whole story from the start of pain to the diagnosis of the illness including the comments of doctors. The story of traveling and meeting of expenditures in approaching hospitals and diagnosis are also told. They also discuss the total treatment cost and the cost of every visit and check-up in hospital. They discuss the cost of treatment to get social prestige that they are spending on the health of their family member. A unity among people was seen in the breast cancer cases of rural areas.

People working in cities support people of their villages who come for treatment. All the nine rural cases out of total twenty seven breast cancer women were found taking help from the relatives who were working in the cities. As observed in the case of *Shazia,* a rural breast cancer woman of District *Mianwali* and diagnosed with the second stage breast cancer, a boy of her village who was working in the office of oversees department as a clerk supported her and her family in gaining complete information about the treatment process. *Shazia* and her family members were novice to the routes in the city. The boy of their village used to pick them from the city bus stop and take them to the hospital. Being too simple, *Shazia* and her family members were unable to get tests; the boy of their village helped them in getting tests from the cancer hospital. Because of lack of awareness about the severity of the illness and the available treatments in the hospitals, *Shazia* and her family approached the hospital at later stage of the illness. Lack of awareness regarding the illnesses and the available facilities in the hospitals caused late diagnosis and made it hard for the patient.

Women of rural areas were also found worried about body image, but they preferred to get the treatment first and handle body issues later.

6.3 Stress after diagnosis

All twenty seven breast cancer women and their primary care-givers shared their stress regarding the illness. Their belief that cancer is a fatalistic illness is very stressful. Lack of knowledge regarding the available treatments is another cause of stress. Their preferences towards traditional and faith healings and later on aggravations of illness increase stress. They feel stress regarding body image. Thinking about patched, dull and wrinkled skin due to coming chemotherapies and surgeries make them stressful. The coming changes in appearance disturb their emotions, too. They were stressed about the side effects of the hospital treatment. Sharing and hiding of illness was also observed a part of stress after diagnosis. Rolland (2005) explains in his work that the anxious feelings from diagnosis to the post-treatment check-ups not only impinge on the patients but also disturb their families. He adds that diagnosis perturbs the net of the whole family. Jain (2013) explains that anger, anxiety, distress and frustration are central to understand the situation of care seekers and care-givers.

During the research, it was found that through different ways these women and their care-givers were stressing themselves out. Twenty six out of all twenty seven breast cancer women and their primary care-givers were observed having firm belief in the spiritual healing with hospital treatment. They feel their stress released when they get the sympathetic words and support from others. They believe that by sharing they receive moral and psychological support. They practice religious activities which give comfort to their minds, and it ultimately results in making their mind in getting complete treatment. Those breast cancer women and their care-givers who did not participate in the research were observed hiding the illness and found not willing to share their illness with others. They believe that their sharing will cause increase of their mental stress and lack of moral and psychological support.

Thirteen out of twenty seven were found optimistic regarding their survival by making future plans; for example in case of *Shazia*, it was seen that she wanted to be cured though her fiancé refused to marry her because of her illness. She is optimistic and wants survival to become a teacher in a primary school of the village. In case of *Misbah,* it was observed that she was having high chances of survival, but she was pessimistic during her treatment. She was depressed because of the negative views of her in-laws related to her illness. She was not sure about her survival. For making her optimistic and releasing her depression, her mother took her to a saint at a shrine for faith healing.

6.4 Lack of screening facilities

To understand the beliefs, knowledge, attitudes and practices among breast cancer women regarding their illness, it was very important to understand the facilities available to them and their approach concerning accessibility and affordability to those facilities. It was found that most of the breast cancer women got their screening tests on the recommendations of their doctors. They did not have screening tests on their own wish or tried to have knowledge about the good functioning of their body part. Despite having facility in the big hospitals of their cities, women avoid screening tests because of the fear of diagnosis of cancer and the cost of tests. Absence of screening facilities or alternative cheap tests in the basic health centers of the small and largely populated towns is a big reason of the ignorant behavior of the people. All twenty seven women shared that they were feeling hesitation in initial check-ups of the breast due to the factor of body shame and the idea of nudity before a practitioner. They also shared that before the diagnosis due to the inter-gender and intra-gender communication barrier, they were unaware of the availability and unavailability of treatments. Maher and Fenlon (2010) found that health care professionals play an important role in providing breast cancer patients in supporting them to get complete treatment and ultimately to restart a normal life.

Knob (2007) also explained that constant support from healers provides patients of breast cancer a potential to carry on their normal living with normal sensibility. Skolnik (2008) described that in many societies illiteracy, low or high caste and financial hurdles restrict women to visit and avail themselves of the health care services. The absence of a male family member also restricts them to visit health center. Mobility restrictions of females also work as a barrier in the health seeking process. According to The World Bank (2005), lack of decision power of women is also a hurdle in the way of seeking treatment.

6.5 Adaptation patterns to post-diagnosis life

Brodaty, Draper and Low (2003) found that generally old age patients after the diagnosis of chronic illness seem stubborn and even become a challenge for their nurses and health professionals. However, Andrykowski, Brady and Hunt (1993) found that the fear of death, uncertainty of life and the fear of leaving loved ones incite the patient to struggle for survival.

They added that this struggle brings positive results like in understanding life in a positive way.

In the present research, one thing was widely noticed that breast cancer women and their care-givers leave or change their routine activities after the diagnosis of their cancer. *Komal,* a first stage breast cancer woman, was a student in a university. After the diagnosis of her cancer, she ceased her studies and stayed at home. *Shamim* a second stage breast cancer woman, was a seamstress and after her diagnosis she quit working. Many close family members of breast cancer sufferers were also seen leaving or ignoring their jobs to give more time to the patient or to complement their responsibilities. In case of *Rakhshanda,* her daughter was a school teacher and was also her only primary care-giver at home. Because of the illness of *Rakhshanda,* her daughter's job was getting affected. She had to get days off from school if she would have to take her mother to hospital for the regular check-ups and treatments. In the case of *Rukhsana,* a second stage breast cancer patient, her elder daughter was married and younger daughter was her only primary care-giver at home, she was also studying in the university and on the days of her check-ups and treatments, she had to get a leave from her university. During her mid-exams, she was having the date of surgery of her mother, she requested her teacher and gave exams before the scheduled date, and this way she accompanied her mother in the hospital. Her mother was forcing her to give her exams on the scheduled dates by delaying the surgery. However, she did not ask the doctor to change the date of surgery and surgery took place on the recommended date of the doctor's prescription.

6.6 Fear and threats as perceived to accompany breast cancer

Susan (1978) explains that metaphors of illness and particularly for cancer create fear and stigma. Earlier research works in Niger should be studied to understand the doubts of life and uncertainty with cancer (McMullin, 2016, p. 259). During the research, fear of death was found very common among breast cancer women. The idea of breast cancer (Local word: *Sartan*) gave them fear and threat. With this idea of fear, they were found relating their illness to the will of *Allah*. All twenty seven breast cancer women and their family members relate their illness with evil eye, bad luck or punishment of Allah. These women and their care-givers relate their illness with the trial from Allah. Twenty six women out of twenty seven were religious and had spiritual beliefs. During the research, it was found that ten out of twenty seven women after diagnosis of lump in breast visited shrines and approached traditional or faith healer. They approached the medical treatment after getting treatment of these healers. Quite often, it was observed that due to the fear and threat of losing life, they were availing themselves of both kind of treatments. They were seen availing chemotherapies with drinking holy water given by saint, wearing amulet around neck, burning of amulets in the evening daily, and performing specific spiritual practices for healing.

6.7 Religious and spiritual beliefs among breast cancer women

According to Banning, Hafeez, Faisal & Hassan (2009), religious beliefs and practices provide inner peace, bravery and strength in the South Asian societies. However, these beliefs and practices do not always give positive outcomes for an ill person. For example, Levine, Yoo, Aviv, Ewing and Au (2007) and Shaw, Joseph and Linley (2005) in their researches found that feelings of anger, anxiety and beliefs like "illness is a punishment from God", give negative results in the form of high blood pressure, indigestion of food, depression, helplessness and hopelessness.

All respondents of this research were the followers of Islam. Only one respondent declared herself [16]*Wahabi*, whereas rest of the respondents associated with [17]Ahl-e-sunnat Brelvi (Hanafi) sect. She visited the shrine and gave offerings in a different way according to the teachings of her sect. Twenty six women were found to be the followers of *Brelvi* and *Hanafi* sects. These women were frequently found visiting and giving offerings at the shrines of saints. Shrine veneration is an important part of the socio-religious life of these people of the research locale. One of the breast cancer patients answered the question about the significance of the hope while going through a lengthy, expensive and painful treatment that "*in our religion pessimism is a sin*". During the research, women were found seeking religious healings by visiting shrines of religious saints, giving charity, and reciting health seeking verses of the Holy Quran. Philanthropy is a part and parcel of the spiritual experience, while manifesting one's veneration for any saint or shrine. The recitation of text from the scripture is another aspect of this religious and spiritual experience.

Maintenance of the threshold and separation of the diseased from the realm of health was observed in Mianwali. This belief was known as "*Rakh*" (meaning: safety particularly from the visitors). A bunch of *Neem* branches (local name of tree genus Azadirachtaa) was

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[16] Wahabi is named after Muhammad ibn Abd al-Wahab (1703-1792), a preacher and activist of eighteenth-century. He emphasized the principle of oneness of Allah and condemned venerations of saints and visiting of shrines (Commins, 2009).

[17] Ahl-e-Sunnat Brelvi and Hanafi is a movement derived from the town of Bareilly in the north India. Ahmed Raza Khan was its founder. Key principals of this movement are personal devotion to Allah, and last prophet Muhammad, combination of Sharia with Sufi practices such as respects of saints and visiting shrines (Kenneth, 1989).

hanging on the door of the breast cancer woman's room to restrict the entrance of outsiders. This hanging bunch was a symbolic barrier for the visitors other than affine and blood relatives. This was a kind of segregation of care-givers and ill woman from visitors in the situation of illness. Creating isolation through symbolic barriers helps regulate relationships and space during the time of suffering without harming relations. However, the care-givers were allowed to meet visitors away from the place where the patient is confined. This practice helps in multiple ways; it keeps the patient away from any responsibility towards the visitor; it helps her to be away from any negative comments or situation. Further, it helps safeguard the shame; it helps the care-givers to communicate without creating rupture in relations, and above all it allows the patient to have control over her space. Visiting spiritual personalities and receiving amulets for wearing around the neck, some amulets for burning and some for burying were the activities largely seen among women with breast cancer and their care-givers. Amulets are perceived as an effective tool to cope with the illness. They perceive illness as a result of sorcery and jealousy of relatives or enemies alike. Here an example of Paiute can be illustrated. Blyth (2012) found that among Paiutes sorcery appears as a cause of illness.

6.8 The attitude towards hospital treatment

One of the respondents was vocal about the shift from homeopathic treatment to biomedical treatment skeptically, and it was prevalent among her relatives.

> *Masooma,* a breast cancer woman says,
>
> *Our elders had never chosen a hospital for treatment; they always preferred wise suggestions of experienced Hakeems (a wise physician). Over time, we saw progresses of hospitals in the form of successful treatments. Now we approach hospitals and bio-medical doctors feeling any problem in body. Although we trust in the bio-medical treatment yet have doubts about the medical treatment.. They have many side effects though it cures in short time.*

This statement may be rendered to multiple factors including the transformation in education and knowledge over generation and the growth of new hospitals in the vicinity. Three decades ago, the number of hospitals was less than today in the locale. The frequency of diagnosis of cancer increased over time. In the last few decades, advancement of diagnostic technology transformed drastically. Shaukat Khanum Memorial Hospital was one of the leading hospitals that changed the awareness about cancer. The fame of the cricketer, Imran Khan had the celebrity catch, raising awareness about cancer. The trust in biomedicine is subject to cultural nurture, where indigenous healing practices are praised and appreciated for being not harmful or without any side effects. The cognitive image of biomedicine among respondents was within the schemata of side effects accompanied with relief from illness culminating into another health issue. The referral system was very poor, and that was one of the many reasons to avoid hospitalization. Thus, skeptic appreciation of hospitalization and the use of modern biomedicine is prevalent among caregivers and the breast cancer patients in the locale; this could be changed if a more subjective approach using cultural relative logic and rhetoric is used for raising awareness.

The cost of the treatment including traveling, hospitalization and medicine expenses is quite burdensome in the absence of health insurance and other safety nets in the locale. There is plausibility that this unaffordability is translated into mistrust towards hospitalization and the use of biomedicine. Unable to bear the expenses of the hospital treatments was one major reason of their adoption of faith and homeopathic healings which were cheap and affordable to them. The rural breast cancer women were seen getting all the available treatments such as faith, homeopathic and medical treatments. Except one, all twenty six women with breast cancer admitted that they used faith healing in some form after the diagnosis. For some of them, biomedicine treatment and spiritual healing methods were concomitant realities. Garret (2007) explains that less than a decade ago, the biggest problem in global health seemed to be the lack of resources available to combat the multiple scourges ravaging the world’s poor and sick.

6.9 Self-image or body image of breast cancer women

Body image was found a great cause of concern among breast cancer women. Body and self will be used synonymous or interchangeably in this text. The perceptions regarding self or body image were influenced by their social environment, and consequently it had significant impact on their efforts to recover and survive. Thoughts about changes in the body such as loss of hair, pale and dull skin, and a damaged breast, were observed putting the breast cancer sufferer in great distress and leading to discouragement or pessimism. Among many sufferers, it was observed that the impaired features were affecting their perception about their control over self and body that culminated into expressions of distress and anger. Comparing their impaired features with healthy features of others was a source of great psychological stress for them. Comparison is habitual cultural feature among the interlocutors of this research, and this is usually expressed in the contextual terms of friendliness that includes the social status and prestige; hence, it was a great cause of feeling deprived of many social privileges that are otherwise available to a healthy body. Lende and Lachiondo (2009) write that females avoid exposing and discussing their body part to any healer especially to a male practitioner. Even they deliberately avoid self-examination with fingers considering it inappropriate. Scanlon and Wood (2005) explain that because of cultural beliefs, patriarchal family system and communication barriers in the examination of a body part, females of the South Asia avoid screening tests.

6.9.1 Physical Features with Higher and Significant Concerns

Some of the features were of great concern for women with breast cancer. All twenty seven women were anxious about the loss of hair. Among all twenty seven women, twenty one were anxious about their pale skin and 19 were greatly concerned about their damaged breast. Wilmoth and Sanders (2001) described that woman with breast cancer faces stress regarding the loss of hair, a damaged breast and impaired skin, varying in emotional, financial and social support from family members, friends and health professionals. They added that these women were found developing awareness and information among their peer groups regarding their illness and the damages of late diagnosis.

6.9.1.1 Loss of hair

All women stated their anxiety regarding the loss of hair; they generally faced this after the phase of radiations. This was found a major reason of dissatisfaction among them because hair has great importance in the cultural and religious life of the Pakistani women. For example, *Rukhsana,* a second stage breast cancer woman shared her anxiety regarding the loss of hair in the following words,

> *After chemotherapy, I faced drastic loss of hair. It was a difficult time to see myself bald-headed into the mirror. You know! We never see bald headed women in society because hair is considered one of the main beauties of a woman. I told you that I did job in school as a senior teacher. To sit among colleagues in the staffroom with this bald head was psychologically a great depression. I started covering my head with a cap inside the scarf to make it a normal look. I used to cover it at home as well because it was difficult to live like that.* (An informal interview with case number 1: *Rukhsana*, aged 52)

The views of *Suriya* informed about religious importance of hair for a Muslim woman.

I am worried! With the bald head, I will be buried and angels will not welcome me as they welcome a pious Muslim woman. You know! When a Muslim woman dies, her hair is laid on both sides of her shoulder. Her hair is believed to be a part of her corpse. (An informal interview with case number 13: *Suriya* aged 62)

All twenty seven women were found covering their head with scarf or cap. Two of the interlocutors were using cap under scarf to make sure that they have hair inside the scarf without being visible. Apart from covering outside, they were found covering head in their homes, too. It also seemed difficult for them to face their family members with bald head. Three women shared that they take bath with great care that after bath their family members may not see their complete head. This shame adds to the burden of disease, making their social and domestic life a challenge for them.

Close family members as primary care-givers were seen very concerned in managing anxiety related to the loss of hair among their loved ones due to cancer. Among forty one out of fifty four care-givers, it was observed that they talked about their depression regarding the loss of hair of their loved ones. Forty six maintained that bald head of a male or female is considered a symbol of bad health in their society. Seeing bald head, they were observed concerned about the survival of their loved one. One care-giver who was the husband brought a wig for his wife to lessen his and her wife's anxiety. Five of the care-givers shared that they got many scarfs for their ill mothers to cover their head.

6.9.1.2 Damaged breast

Nineteen out of twenty seven breast cancer women were anxious regarding their damaged breast. Elderly women were not found as much worried as the women below the age of 50. The age of these nineteen women ranged from 22 to 49 years; hence, majority of the interlocutors was concerned about the outlook of their breasts. All twenty seven women were found facing partial or complete damage of breasts going through different phases of radiations, lumpectomy and mastectomy. Two women shared that they used clothing to hide the lopsidedness of their missed breast. Twenty four women stated that they used to wear loose shirts and covered their breast with cloaks to hide the lopsidedness. In the Pakistani society, the breast of a female body is considered a cause of body shame. It is part of their culture to hide it with shirt and cloak called *Dupata* or *Chadar*. Eight elderly women were not anxious regarding the appearance of their body without a breast as they were already in the habit of using cloaks. Other women were also observed wearing loose shirts and cloaks but with the idea of saving their beauty and marital life. Two women shared their fiancées refused to get married with them due to cancer and damaged breast which is a part of femininity.

Rakhshanda expressed that how a woman in a gathering stared at her and asked about her breast.

> *In a religious gathering, a woman, who didn't know about my mastectomy, stared at my face and body and then asked me, "the one is bigger and why there is a loop in another side"? I smiled and avoided her. One of my neighbors told her all about my cancer from diagnosis to the surgeries. Um, this time, I was very embarrassed to hear about my body from a woman telling another woman.* (A semi-structured interview with *Rakhshanda,* aged 43)

Primary relatives as care-givers of these women were also seen helping them in coping with this issue. All daughters, who were looking after their mothers, were found helping their mothers in covering breasts. Seven care-givers who were also husbands shared that they made their wives accept major changes in body, for example, a damaged or loss of breast. Five daughters were found making their mothers accept the loss of breast as survival is important than the loss of a body part.

6.9.1.3 Pale skin

Twenty one out of twenty seven women were greatly concerned about their pale skin. The age of these women ranged from 22 to 52 years. Two women were students and three women were doing jobs; they were very anxious about their patched, wrinkled, dull and pale skin. For them, changes in their skins appeared after radiotherapies and heavy doses of medicines. One woman, who was an undergraduate student in a university, got her semester ceased because of the dull and pale look of her face. One woman got retirement from work after her radiotherapies as its effects were coming on her face in form of patches and wrinkles. Fiancées of two women refused to marry them because of their damaged body and pale look. *Hareem* stated the situation she faced due to her pale look.

> *The color and wrinkles caused great depression; it is very disturbing for me to see myself in the mirror. My health deteriorates because of my outlook, for me it is very disturbing. Nobody knows much about cancer here in our village; my appearance tells them the story that I am not okay, umm…inner, my fiancée broke*

> *engagement just for the reason that I do not look beautiful as I was earlier.* (A semi-structured interview with *Hareem*, aged 35)

It was observed that elderly women were not as much concerned about their pale skin as the younger ones were. They were more focused on the healing of their body from inside in place of focusing on changes on skin. *Ghanza* shared that she was concerned about the healing of cancer inside the body and good appearance will return with good health.

> *I want real healing and that is the elimination of cancer from inside of the body. If the health comes back, the good appearance will automatically return.* (A semi-structured interview with *Ghanza*, aged 62)

Two women were found making plans to get dermatological treatment after their cancer treatment. Thirty six out of fifty four care-givers were found anxious about the pale skin of their loved ones. They were observed insisting their loved ones to take fruit juices to have a fresh look of the skin. Three daughters were found getting skin serums for their mothers. Twenty five out of twenty seven women believed that western medicines and treatments have brought changes in their skin. Two husbands were seen getting appointments of homeopathic doctors. For them, the medicines of homeopathic doctors have no side effects on skin. Therefore, this consequence of pale skin might create a distance among many women to opt biomedical treatment for breast cancer. It may lead many women to fall in dilemma and have crises.

This discomfort of mind was found as an internal mechanism of the breast cancer sufferers. Dull and pale skin, extensive loss of hair and weight, and a damaged breast were found causes of their great concerns. All of the breast cancer sufferers were observed in great stress because of impaired skin and loss of hair. Five out of 27 breast cancer women were not found anxious about the breast. The reason of less stress regarding a damaged breast was found that they hide their breast by wearing loose shirt and quite often they covered the torso of the body with a cloak. That’s why most women had plans for skin and hair treatment, but no plans for breast surgery after the cancer treatment. The sufferers who had plans for breast surgery were only those who were feeling insecurity in their marital relationship. Only two relatively rich young married breast cancer sufferers had plans for breast cancer surgery for the safety of their marital relationship. Most of the breast cancer sufferers were seen anxious for the loss of their hair more than their dull and wrinkled skin.

6.9.2 Perceptions of breast cancer patients regarding their appearance

There are two famous measures to assess the perceptions of breast cancer patients regarding their appearance: *body image scale* (Hopwood, Fletcher, Lee, & Al Ghazal, 2001) and the *body image after breast cancer questionnaire* (Baxter, 1998). In current qualitative study, *interview guide* was used when perception regarding appearance triggered psychological issues. Theory of Mind (Gweon & Saxe, 2013) was followed in the preparation of *interview guide* to study women's mental states such as knowledge, beliefs, emotions, etc. feelings to oneself, and interaction to others. Asking them about their sad feelings and dull look, they shared what they feel in the front of mirror and while watching other women on television and magazines. They assume their image in the eyes of the visitors and relatives and a subjective hermeneutics is created by the patient. That leads her to make her self-image by herself.

The views of close and distant relatives were observed regarding the illness of a breast cancer sufferer who made her perception negative about herself. Over-sympathetic feelings also give psychological stress to the sufferers. For example in the case of *Rukhsana* 52 years old, a woman with second stage breast cancer, it was found that sympathy of one of her distant relatives had *Rukhsana* and her daughter in great stress when someone said, "*a cancer patient does not survive*". The daughter of *Rukhsana* viewed that after hearing this, "*mother starting looking at her body features with great distress and started thinking about her death".* The views and acts of people surrounding the breast cancer sufferer have great impact on their psychology and even change their life plans. For example, *Shazia* and *Hareem,* who are young and unmarried breast cancer women, their fiancées broke the engagements and chose other life partners by rejecting them because of their breast cancer. This incident changed their perception about their appearance that no one will marry them. Both had plans to work and support their families instead of thinking about getting married. Both blame their appearance as the reason of their broken engagements.

Negative perceptions and the change of goals due to this illness were largely observed in the research. For example in the case of *Komal* a 22 years old, a first stage breast cancer woman, the same situation was observed. She ceased her semester and left the university because she was unable to face her friends with this illness in the university and in her hostel. She was unable to give attention to her studies. Her attendance in the class and her results were not satisfactory as she used to have in the past. She had negative perception regarding her appearance and hence ceased her semester. The same thing was found in the cases of *Hira* and *Misbah*; both had negative perceptions about their appearance and blamed their appearance the major reason of their bad marital relationships. Researches of Astrid, et al. (2013) and Stokes & Frederick-Recascino (2003) also showed that negative perceptions lead towards disruption in body image which causes mental discomfort with one's self.

Guidry, Matthews and Copeland (2003) write that majority of the sufferers hide their illness for many cultural reasons. They added that they are expected to avoid discussing illness regarding their body parts like breast cancer in traditional societies. They hide in order to avoid the queries and thoughts of the people such as, is the breast cancer a genetic or endemic disease?

In the research process, it was found that most breast cancer women left joining social gatherings because they feel themselves uncomfortable among many people who ask the same questions. People expressed their sympathies with them. They orchestrate themselves in different settings like what they are meant for society versus an individual. All twenty seven women shared that they feel anxiety when they see healthy people in social gatherings. This negative perception regarding their appearance not only disturbs their social life but also affects them psychologically. They feel themselves responsible for all bad happenings in their lives. For example in the case of *Fazeelat,* a second stage breast cancer patient, it was found that she was worried about her appearance and was searching suitable matches for her unmarried daughter and son. She used to cover her bald head with double scarf while meeting people.

6.9.3 Factors in the construction of positive or negative perception of body image among breast cancer women

Susan (1978) believes that metaphors of illness and specially for cancer create negative perception. Mukherjee (2011) inscribes that the illness of cancer is a successful invader on the body features. In the present study, the feelings of the breast cancer sufferers about their physical self were observed to understand their body image for themselves. This image was seen constructed by their social, cultural and religious environment. Beyond the outer factors, the inner factor was also observed in the construction of this body image. For example during the research, *Rukhsanaa* and *Shamim,* both second stage breast cancer patients were facing loss of hair and weight, dull skin and a damaged breast due to chemo and radiotherapies. Both were found with negative perceptions about their appearances. The made comparisons of their present with past days of good health and beautiful appearance quite often, and it made them anxious and full of depression. Their family members were found anxious because of their depression for bodily appearance. Their family members commonly reported that indigestion of food, loose motion, lack of sleep, weakness of eye-sight due to extensive weeping, loss of patience and aggressive attitude were the consequences of their negative thinking about the bodily appearance.

Making comparisons of their impaired body features with the healthy features of others perverted their normal mind to abnormality. For example, *Rukhsana*'s daughter viewed that:

> *My mother makes comparisons of her appearance with the healthy appearance of her colleagues in the school, where she teaches. She wears doubled head scarf to hide her bald head from them. Frequently by touching the wrinkled skin of her hands, she remembers her old days of beautiful appearance. With all these thoughts, she does not act normally. She becomes aggressive when I give her food or leave for university. She screams loudly and breaks anything that is placed on the side table of her bed. She wants me to get married and leave her because she is no more beautiful to live with.*

Negatives thoughts with the feelings of agony make them feel depressed and they suffer from inferiority complexes which ultimately destruct their whole personality. Close and distant relatives, colleagues, neighbors and social media such as digital and print were found playing the role of external factors.

In shaping the body image of the breast cancer women, religion was also found one of major outer influencing factors. Thoughts of punishment from *Allah* in the form of this illness affected them greatly. A fear of death adds more anxiety to their life. For example, *Shamim* a 39 years old and a second staged breast cancer woman with low financial status, was found blaming her past deeds as the reasons of her present afflictions. She married against the will of her parents and siblings, and she believes that her illness is a punishment from *Allah*. In another case, *Misbah* a 39 years old second staged breast cancer patient was found believing, "my *ugly appearance because of this illness is a trial from Allah. He wants to see my patience in this disease and in its bad impacts".*

During the research process, it was widely observed that religion is a strong influencing factor in shaping the body image. In the case of *Suriya* a 65 years old third staged breast cancer woman, it was observed that she attached her illness and its impacts with the religion. She was not found scared of death but was much concerned about the appearance of her body from a religious perspective, too. She viewed about her body image and its importance in the religion saying:

> *A "Momin" (a pious) woman dies in good appearance. I feel that it is "karra imitehaan" (a hard examination) from Allah. I am scared that I will die with my*

> *bald head and women of the village will gossip that she was not a good woman that's why Allah gave her death in an ugly appearance. In our religion when a woman dies, her hair is placed on both sides of her shoulders with the idea that good angel will come and will write her good deeds. In the case of bald head, good angel will not come and this will cause transfer of my soul to hell.*

According to the International Monetary Fund (2006), problems of woman's health including her mental, physical and social condition is affected by the social norms, values and attitudes prevailing in society and family.

6.9.4 Efforts of Breast cancer women in making positive body image

According to The World Bank (2005), strategies are needed to involve all sources in making health seeking attitudes. During the research, it was widely seen that the breast cancer sufferers were making efforts for achieving positive body image. In this effort, they were observed looking for all available forms of treatments. For example, *Misbah* a 39 years old second staged breast cancer patient was visiting the holy places to get positivity of mind and body. *Fazeelat,* a 62 years old second staged breast cancer woman was wearing scarf over bald head to hide her illness from many people. *Komal* and *Saira,* both young and early staged breast cancer women, were having plans of dermatological treatments after their cancer treatment. Young and early staged breast cancer patients were seen more optimistic than old age and later staged sufferers about the results of their efforts for the restoration of good appearance.

Many breast cancer sufferers and their care-givers believe that their ugly appearance is the result of hospital treatment such as horrible therapies and heavy doses of medicines. With this thought, they approach spiritual and folk healers which they believe have no side effects. Many sufferers were found getting both kinds of treatments -- medical and herbal (as a part of spiritual healing). They believe that faith healing gives them mental strength and power to fight against the illness. Positive impacts of faith healings were reported by the research population. Most of the breast cancer sufferers were found desiring to restore positive body look and image for the restoration and strengthening of their marital ties. For example in the cases of *Misbah* and *Hira,* who are young second staged breast cancer sufferers, want dermatological treatment in order to strengthen their marital relationships. *Fazeelat, Shamim* and *Rukhsana* want to get treatment and survival for the sake of their children. It was mostly observed that the sufferers seek treatment not only for themselves but also for their close relatives.

6.9.5 Body image among breast cancer women and requirements of society

Tone, Rikke and Mette (2016) found that women with breast cancer face dilemma regarding sharing their illness with people in society. They added that these women hide their illness to manage social relationships. Kinamore (2008) and Pelusi (2006) also find that women think great about their body image and requirements of society. In the current research, it was found that breast cancer sufferers form their body image according to the requirements of society. They feel depressed and anxious because people around them do not take them normal members of society. They leave joining social gatherings and crowds not only because of their physical sickness but also because of their mental disturbance. Many of their inner thoughts are the results of outer social and cultural influences. For instance, the selection of a healer for the treatment is decided by the social and cultural principles.

Women were found focusing on getting treatment from female practitioners. In traditional society, such social and cultural issues have great importance they do not go towards a male healer that even for health purposes. The same is the case that women approach a female gynecologist in place of a male gynecologist. People feel scared that if their social circle came to know that the treatment of female parts of body was received from some male practitioners. They are given strange comments regarding the breakage of local traditions. However in the absence of female practitioners, the treatment from male practitioners is considered acceptable. Commonly it was observed that the breast cancer sufferers and their family members try to seek female healer instead of a male healer. They were comfortable in seeking treatment from faith healers instead of bio-medical practitioners. They feel comfortable instead of faith healers where people of other illnesses also used to visit them, whereas in the oncology and radiology departments, they had to face oncologists and the patients of cancer only. To faith healers, they were allowed to accompany with relatives while during bio-medical treatment they were not allowed to have relatives all time. The faith healers were not touching body with hand which was comfortable for the patient and her relatives, while bio-medical practitioners were using hand which was not comfortable for them. The faith healer was not looking at the impaired part, while bio-medical practitioners used to remove the cloth which was uncomfortable for them and their relatives. Auerbach (1982) also found that very often women feel shame to discuss their body issue with male health provider and particularly to give him physical examination. In the present study, these issues of breast cancer women including space, familiarity with space, absence or presence of relative in the confined space, direct or indirect touch, and body shame (removing of cloths), etc. were discussed according to the requirements of society.

6.9.6 Breast cancer sufferers and their family members following the requirements of society

Cappiello, Cunningham, Knobf and Erdos (2007) found that after the diagnosis, breast cancer patients and their family members cope with the required medical and emotional needs. In the present research, most breast cancer sufferers were found anxious about the damaged breast, skin and hair. Many of them were found planning dermatological treatments after their cancer treatment. Their planning and care for the appearance after the treatment is the result of requirements of society. For example in the cases of *Hareem* and *Saira,* this fact was observed that due to their breast cancer their engagements got broken. *Saira's* mother viewed," *Saira was in severe depression and anxiety when she heard that her engagement has been broken because of her disease. After that she started relating her impaired body image with her failure to meet the requirements of the society".* They have up-to-date knowledge about the requirement of their society through digital and print media such as television, magazines and papers. Most breast cancer sufferers were found reluctant looking themselves into the mirror or in reflecting surfaces. Moreover, they left joining social gatherings.

Most women following the requirements of society get dermatological treatment or make plans of getting hair and facial treatments after their cancer treatments. Young married and unmarried breast cancer sufferers and their care-givers were found anxious about the damaged breast. For example in unmarried breast cancer cases of *Komal, Saira* and *Hareem,* it was found that the damaged breast is a point of big concern for their family members and for them from the point of view of their marriage. Negative body image works as a source of anxiety and depression. Self is pushed back and social compulsions are preferred. Social compulsions of getting married takes preference to the idea of personal health as an individual. Society is significant than self. For example in the case of a 62 years old second staged breast cancer patient *Fazeelat,* it was found that she was hiding her illness to find suitable marriage partners for her unmarried children. She was asked many questions regarding her illness such as, *"Did you get this illness from any infection? Or "Is it your family disease"?.* She was hiding her illness fearing that her children would not get suitable partners if she tells about her illness. Among twenty seven breast cancer women none was found making plans for the breast restoration surgery after their treatment. This is just because women cover their upper part of the body with a cloak and the breast part remains covered all the time in the Pakistani society. They prefer their hair and skin treatment to get back their old look.

6.9.7 Role of surrounding people in shaping positive or negative body image in the mind of a breast cancer woman

Astrid (2013) says that body image presents positive and negative perceptions of one's physical appearance. He adds that negative perceptions lead towards disruption in body image which causes mental discomfort with one's self. Oktay, Bellin, Scarvalon, Appling and Helzlsouer (2011) found that primary care-givers have great role in shaping positive or negative body image in the mind of a breast cancer woman. They added that open communication related to the new changes in the body supports in accepting the illness for the patient and caregivers, and finally decrease the stress related to the impaired features of the body. In the whole process of current study, this fact was widely observed that close relatives of the breast cancer sufferers who were categorized as primary care-givers including parents, siblings, spouse, and kids have great role in the construction of their body image.

Nursing staff as secondary care-givers and other people including friends, neighbors, distant relatives, colleagues and practitioners also have a strong role in the construction of this image. For example in the case of *Misbah,* a 39 years old, second staged breast cancer woman was found anxious because of the views of her in-laws about her illness. Her doctors were hopeful about her survival but she was depressed because of the negative views of her in-laws. She was depressed saying, "*My in-laws believe that I will not survive because it is a chronic disease and no one survives".* She was feeling scared of the idea of death and losing her husband and kids.

In the Pakistani rural areas, most people move from their homes to nearby urban centers or distant metropolitan cities. Although they move for education, job and for other purposes yet they do not leave permanently the place of their forefathers. Many live at their places for generations. Majority of them live in joint and extended family units. Living in one town for number of years, they have knowledge about the old and new dwellers and their socio-economic and health conditions. Among the rural people, information sharing regarding the health is considered a moral duty. For example, if they come to know that an individual of their village has been caught by a chronic illness, the villagers will go to meet the sufferer and his/her family members. The sufferer and his/her family members do not hide illness because the whole population of the village is considered a large family unit. The rich people give financial support to the affectees and the members of village who work in the city, support in searching, approaching and facilitating in getting tests, check-ups and treatments in hospitals.

This situation was observed in all 11 rural breast cancer women. For example, in the rural case of *Shazia* a 34 years old, second staged breast cancer patient, it was observed that she was from a poor farmer family. On diagnosis of her illness, the rich people of her village provided her support financially to carry out tests and get treatment. A boy, who was working in the city, was not a relative of *Shazia,* but he supported *Shazia* and her family members in the city hospital and helped them in getting tests and check-ups in the hospital. He applied to the Social Welfare and Department of Women Development for financial grant on the behalf of *Shazia.* Among rural breast cancer women, it was found that they do not hide their illness the way the urban patients do. Experienced and sane people of the village recommend them to the helpful healing places. Irrespective of the caste, color and status, people visit their homes and give them good wishes regarding health.

6.9.8 Influence of faith and belief system in making positive or negative body image among breast cancer women

Gurm, Stephen, MacKenzie, Doll and Barroetavena (2008), and Banning, Hafeez, Faisal and Hassan (2009) found that in the South Asian societies religious beliefs and practices are considered a source of inner peace, bravery and strength. However, these beliefs and practices do not always give positive outcomes for an ill person. Levine, Yoo, Aviv, Ewing and Au (2007) found that many times feelings of anger and anxiety regarding the belief that their illness is a punishment from God, give negative results in the form of of high blood pressure, indigestion of food, depression regarding body image, helplessness and hopelessness.

Further, people were found strong believers of the religion, Islam. They possessed many local narratives of health, sickness and treatment related to their belief system. Some of them are described here which were very commonly used by the researched population, such as: "*Bemari Allah ki tarf say aik aazmaish hay"* (Translation: disease is a trial from Allah). Some of the women with breast cancer had belief that their illness is kind of a trial from their God. "*Na umeedi gunah hay"* (Translation: pessimism is a sin). This belief was commonly seen among many women and their care givers. This belief was kind of source of hope for them that they have to be optimist in any kind of bad situation during treatment seeking process. "*Hakeem bra ya yakeen, so yakeen hakeem say bra hay"* (Translation: faith is bigger than healer). This belief was also seen prevalent among many women that they have faith in God and their faith will do it, will save them which their healer cannot. "*Allah bejnay wala, Allah jaalnay wala*"(Translation: Allah is the sender of disease and he is a lone saver). This belief was giving them patience that God gave them this illness with his own wish and he will remove it. "*Kamyaabi koshush ma hay"* (Translation: success is in struggle).This belief was a source hope for them that success is in struggle. "*Barron ki nafermani ki sza such na pana hay"* (Translation: disease is a punishment for disobeying elders of the family). This belief was a regret regarding disobedience with elders that they got this illness due to their disobedience. "*Baap mray to mali nuksan, maa mray to khandani nuksan"* (Translation: if father dies, it is a financial loss; if mother dies, it is a family loss). A husband of a breast cancer woman shared his belief that death of father is a financial loss while mother's death cause loss of whole family. "*Banday nay pichay bnda, bnday na haal manda*" (Translation: suffering comes because she was chased by enemy or ill-wisher). This believe shared by two women with breast cancer. They shared that their illness is because of their enemies. *"Peni ik wari, chukni tele tele"*(Translation: disease comes suddenly but its treatment takes time). This belief was found among two women that illness comes with speed but takes time to go. This belief was also a source of patience for them.

All these local narratives were observed with their powerful impacts in making positive body image among breast cancer women. With these narratives, many had beliefs that their suffering is for a short period as it is a trial from Allah who wants to see their strength and make them powerful. One important aspect in these local narratives was observed that this local knowledge was also influenced by their religion, giving equal message to the people of high and low financial status. In cases of low financial status, such as *Shamim, Shazia* and *Hira*, it was observed that in initial stages they were unable to get hospital treatment because of their inability to go to the big hospital for many social and economic reasons, they got faith healing in the form of amulets, having verses of the Holy Quran inscribed on them. Faith and local belief system impact the body image positively. Colin (2005) explains that a gap has been found between the beliefs of patients and their knowledge. This gap hampers hope and struggle for the health seeking process of the patient and his or her care-givers.

6.9 Transformation of roles and identities of breast cancer women in maintaining social relationships

Many years ago, Parsons (1951) enlightened that a person after illness demonstrates four roles. He has no accountability of self-illness; secondly, he gets relief from customary obligations. Thirdly, he is passionate for seeking the restoration of health. Fourthly, he should seek care and support the provider. Transformation of their roles helps them to maintain social relationships. Apart from the transformed identities, some efforts of these women help them to maintain their social relationships. In the present study, it was found that many breast cancer women strive hard to sustain their professional and public identities by hiding their illness to maintain social relationships. For them, disclosing their illness of cancer will damage their position in the society and will become unable to fulfill their life tasks. For example, in the case of *Fazeelat,* 62 years old second staged breast cancer woman was hiding her illness of breast cancer. She was in search of suitable matches for her unmarried daughter and son. She was scared that if people come to know that she has cancer, nobody will accept her daughter as a wife. According to her, "*with double covered head, I meet with people*". Her daughter and son were also supporting her in hiding her illness and treatment. They were sure that their mother will survive, so disclosing this illness will create many misconceptions which can affect them to find suitable life partners.

Another woman *Rukhsana* 52 years old and second staged breast cancer patient was a senior teacher in a local government high school for girls. She kept her illness hidden from her colleagues in the school, from neighbors and relatives to maintain her public identity. On asking the reason, she replied:

> I *have two daughters: one is married and another is unmarried. I am receiving treatment from a hospital and I want survival only for my daughter. If I disclosed my illness, all the people including my colleagues, relatives and neighbours will think that I am nearing death. Their thoughts and comments will discourage me to survive. I am unable to pay my duty well as a teacher as I used to do. My colleagues ask me reasons, but I avert them saying that I have stomach issue. One of my best friends knows about my illness. I told her because I visit a faith healer with her.*

Some of the breast cancer women have been found unsuccessful in maintaining social relationships. It was observed that like many other women they also discuss their illness with the wise people of the family and start getting treatment from the expert doctors and reputed hospitals. Feelings of sympathies are attached with them but their public and professional identities do not remain the same as were before their illness. For example in the case of *Shazia,* it was seen that she left helping her family members in the fields after the diagnosis of her breast cancer. Her fiancé refused to get married with her assuming that she is unable to help in the fields and in chores at home. Her social identity remained just of a cancer patient (*Sartaan ki Mariza).*

6.10 Efforts of breast cancer women to save their Self-esteem and to sustain social relationships

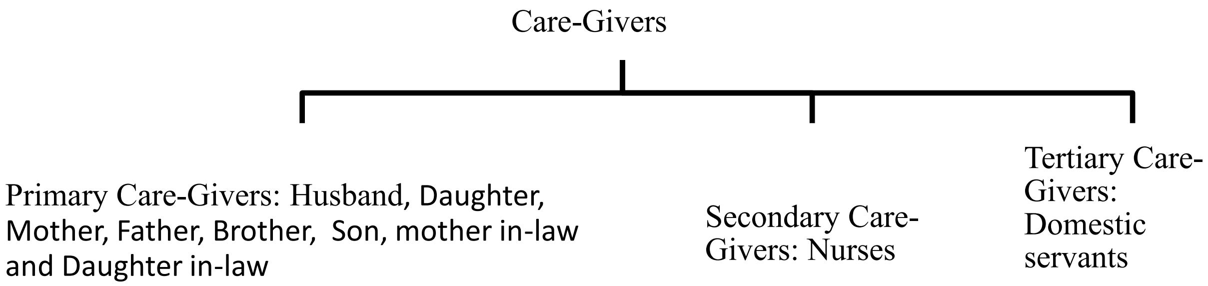
Day (1994) found that women's dignity and praise is attached with her sacrifices in the South Asian women. He added that they give priority to the needs of their family ignoring their own health. This fact was widely observed among breast cancer women of this study. Impairment of body features such as skin, hair and breast was found a big damage to their self-esteem. Although they were found unable to maintain their social roles as wives, mothers and workers, etc. yet they were making efforts to save their self-esteem by hiding their illness from strangers, avoiding guests who come home, and avoiding social gatherings. With these efforts, they try to get psychological relaxation and get their treatment first and then again become an active member of the society. Many women were seen covering heads with two scarves aiming to hide their bald head. A bald head with pale and wrinkled skin, and damaged breast were causes of great concern for them. The conversations in which women with breast cancer and their care-givers talk about their dull appearance and it increases their stress.

Many women were seen having intension for dermatological treatment and surgical treatment for their impaired features after the cancer treatment. Many women were seen making different plans to compensate their damaged self-esteem because of bodily features with their efforts to be again successful members of society. They were making plans of getting more education, doing work, and supporting their families. For example in the case of *Shazia,* it was seen that her fiancé refused to get married with her because of her breast cancer and her family was suffering financial crisis because of the cost her treatment. She was having plans to serve as a teacher in the local school and to support her family.

6.11 Care-givers as Support Groups

Anne (2008) writes that epidemiologist, Sidney Cobb gave an idea of social support. "Social Support: information that one is loved, esteemed, and belongs to a network of mutual obligation" (Harrington, 2008, p. 84). In relation to the illness of a person, care-givers as support groups provide social support. The present study found that care-givers provide social support. To make the data gathering convenient during the research process, care-givers or the agents of support were classified into three categories -- primary, secondary and tertiary. This is apropos to the third objective of the study to observe and analyze the impacts of behaviours of the care-givers on the treatment of women with breast cancer. The primary category consisted of family members of the woman with breast cancer such as husbands, parents, siblings and children. The secondary care-givers included health care professionals for example nurses. The tertiary care-givers included domestic servants who were paid for their services.

Figure 29. Diagram illustrating the classification of care-givers



UNESCO defines family as a “unit of kinship” that helps its members to be strong enough to achieve something in life. Further, it classifies the family setup into five kinds in which joint and nuclear is the main family setups in Pakistan (Bilal, Tariq, Aleem, Shabbir, & Parveen, 2013; Sharma 2003). In the present research, gender specific roles have been widely seen in the unit of kinship. Many times their genders reflected their socially constructed behaviours and roles. These roles are considered appropriate for males and females in their society. For example: males earn the money, handle the outdoor tasks of the home and females run the houses with husband’s money, make savings and give full time to their children and home chores. Before wedding, a female is considered completely dependent upon her father and brother and after wedding on her husband. Over the time, increase of responsibilities, access to resources and decrease of social limitations let many women work and earn money by adopting different professions such as seamstress in government and private sectors, doctors in hospitals, teachers in schools, colleges and universities, nurses in hospitals and clinics, domestic servants or maids, and labourer in different manufacturing industries. Their earning is considered a contribution to the husband’s earning. However, the social and cultural construction of roles depicts females dependent on the income of the male members of family. This fact leads towards other key aspects regarding the position of a woman in the family. Although she often stays at home in taking care of children and in doing home chores, she is considered a prime carer of the home. The roles of male and female make their unit of kinship strong enough to face the challenges of life particularly in the situation of bad health or financial crisis. Their roles work as a social support for each other. Anne and John Cassel (2008) said that social support reduces stress.

6.11.1 Primary care-givers

Primary care-givers were family members of women with breast cancer. They were categorized at the top because these were prime carers, helpers, motivators, supporters and providers of treatments. Pérez, (2015) says that Macmillan Cancer Support reports informal care-givers who have been seen providing more hours of care per week to their cancer patients. He added that this care includes multiple tasks from practical works to emotional support. In the present study, one out of total 31 primary care-givers, ten were husbands, nine were daughters, five were daughter in-laws, four were mothers, one was a father, one was a son and one was a brother. They were seen playing great role in looking after their loved one suffering from breast cancer. They were observed serving their loved ones with breast cancer at homes and in hospitals.

6.11.1.1 Husband as care-giver

Out of 27 women with breast cancer, ten were looked after by their husbands only. These husbands were seen giving 5 to 9 hours daily to their wives with breast cancer. They were seen accompanying them to hospitals and holy places. All were seen doing grocery for home and getting medicines for their wives. Four were found cooking food for their wife, children and themselves. The effects of their wives' illness were seen penetrating in their thoughts: for example, *Tariq* the husband of a woman with breast cancer shared:

> *You know! We were a complete family: my wife, two sons, one daughter and I. Children were going to school according to the normal routine. My wife was diagnosed with it; the routine of home and school continued for seven months only. They left going to school; I was unable to get retirement from the bank (job place) because it was the only source of income. I would say one thing as a whole, death of father is a financial loss, and death of mother is a family loss.*
> Caregiver: the husband of a breast cancer woman: Tariq, aged 43

Ten husbands, the participants of the study, as primary care-givers were found in stress related to the bad health of their wives; they had to get treatment and look after the children. Adila shared that the diagnosis, treatment and side effects of treatments were stressful for her husband.

> *It was very disturbing for my husband; the diagnosis then long treatment and painful side-effects such as un-digestion of food, insomnia and stress were adding to his stress. He was unable to decide what next step should be taken to save my life. He was worried about our children, and it caused disturbance in their normal lives.* A breast cancer woman: Adila, aged 45

These husbands were seen playing the role of a motivator during the illness of their wives with breast cancer. Their efforts of getting appointments of doctors, approaching faith healers and searching for unavailable medicines from different pharmaceutical stores were giving a sense of optimism and struggle for survival to their wives. This support was seen giving them courage to forget uncertainty and fear of death and fight against the illness. Noreen stated that how her husband was doing extra jobs to pay for the cost of her treatment.

> *"I am very anxious and want to get survival because my husband pays for the cost of my treatment by doing extra jobs".* A breast cancer woman: Noreen, aged 47

All ten husbands were seen making efforts to meet the financial needs of their wives during the treatment seeking process. One of them left the job to look after his wife and children. One of them sold out his animals for the treatment which were the only source of his income. During an interview, he stated that how he gave attention to the treatment of his wife as a religious obligation.

> *The member of family is just like an organ of the body and if it gets sick, the other parts also get disturbed. I sold out my two cows to get timely tests and treatments of my wife. But later I was not in a position to manage the dues of radiotherapies and routine check-ups. I got loans from the head of village. I did this because it was a religious obligation to look after her.* The husband of Masooma, aged 43

Apart from them, one husband was not a direct care-giver, but he was found doing work the whole week. He was collecting money to fulfill the cost of treatment of his wife. Shamim shared that how much her husband is working hard to meet the expenses.

> *I left job; my mother takes care of my children. Rahim (husband) runs the shop from the early morning till evening. He works all seven days of week except the day of my check-up in the hospital. He wants to collect money to meet the needs of my treatment.* A breast cancer woman: *Shamim*, aged 39

6.11.1.2 Daughters as care-givers

Among all 31 primary care-givers, nine were daughters of the women with breast cancer. They played an important role in the health seeking process. They were seen giving time from 6 to 15 hours daily to their mothers. During this time, they were found giving them bath, helping in wearing clothes, cooking food for them, accompanying them to hospitals and getting medicines for them. One daughter was found interacting with the care-givers of other women in the oncology department to get information and knowledge regarding the treatment process of breast cancer. One daughter got the dates of her final exams of graduation changed in the university to give more time to her mother in the hospital. Un-married daughters were found giving more time to their mothers than the married ones. All nine daughters were found accompanying their mothers to clinics and hospitals. Three daughters were found taking their mother to faith healers to seek psychological comfort for them. Two were found doing job to meet the cost of treatment. Shamsa shared that how much she faced problems in looking after her mother.

> *Before its diagnosis, we were living in a house on rent. Later we left home and got shifted in home of my father's brother…we saved money to get timely check-ups. You know- it is not easy to meet the cost of treatment. It was father's brother's house, but it was difficult to cook separate food for mother and give her shower.* Care-giver: the daughter of a breast cancer woman. Shamsa: aged 29

Among daughters, the intensity of belief in spirituality was found the same as it was seen among their mothers. All were accompanying their mothers to faith healers and shrines. Apart from looking their mother, one daughter, aged 18 was seen taking care of the younger siblings.

6.11.1.3 Mothers as care-givers

Out of 31 care-givers, four mothers were seen looking after their daughters suffering from the breast cancer. They were seen spending eight to fifteen hours with their daughters. They were found giving bath, changing bandages of breast, helping them in wearing clothes, accompanying them to hospitals and shrines. All four were seen very active in communicating the illness of their daughters to care-givers of other women with breast cancer to get more knowledge and information regarding the treatment processes. Three were found using simple words in communication; for example, they used the word "*Shuaaen* (radiation)" in talking about the side effects of the radiations.

Adila maintained that she was sad before her interaction with other people suffering from the same illness, but later on she felt better as she met and shared her experience with them.

> *Before going to the hospital, I felt myself alone suffering from this illness. I saw many patients in the waiting area of the oncology department. I was shocked to see when the mother of a young girl told that her daughter is suffering from breast cancer…Stories of other women were more painful than mine. For the first time, I felt that I can share my experience with them because only they can understand what I feel.* A breast cancer woman: Adila, aged 45

Meeting and interacting with people and going through the same suffering made them expressive to discuss about their illness which is usually not discussed because of feminine concerns. All four mothers were found performing rituals to regain health of their daughter. The mother of *Komal* was found performing a ritual by measuring the body of *Komal* with a thread and tying it with two clapped nails into soil and finally burying this thread under soil with the intention that illness of her daughter's body will relinquish soon.

6.11.1.4 Father, Brother, Son, mother in-law and daughter in-law as care-givers

One father, one brother, one son, one mother in-law and four daughters in-law were found as care-givers. Father, brother and son were found spending from 2 to 8 hours daily and accompanying them to hospitals and visiting faith healers. Their active role was seen in fulfilling the financial needs. Although they were not seen active in other tasks such as in giving bath, changing clothes and changing bandages of breast yet they were giving them confidence and hope by giving financial assistance for treatment. *Naveed,* the son of a woman with breast cancer expressed that how he collected money for the treatment of his mother.

> *"I got loan for the treatment of my mother. Now I do extra work to meet the needs of travel and treatment".* Care-giver: the son of a breast cancer woman. *Naveed*: aged 39

One mother in-law was found taking care of her daughter in-law. She was found spending three hours daily with her. In these hours, she was found giving medicine, and accompanying her in the hospital and shrines.

Four daughters in-law were found as care-givers to their mother in-law. They were found spending 4 to 11 hours. They were seen helping their mother in-law in giving bath, helping in wearing clothes, giving medicines, cooking food, changing bandages and accompanying them to hospitals and shrines. Two daughters in-law shared that they are caring their mother in-law to keep their husbands happy. The other two were looking after as a moral duty since she is a sick member of their family.

6.11.2 Secondary Care-Givers: Nurses

The secondary care-givers include health care professionals such as nurses. Colin (2005) states that a gap has been found between the beliefs of patients and the knowledge of doctors or care providers. This gap hampers hope and struggle for the health seeking process of the patient and his or her care-givers. In the present study, social support of nurses was found very affective in making the mind of women with breast cancer and their care-givers to get complete treatment. Their role was seen very important in spreading optimism or pessimism among women with breast cancer and their family members. Fourteen nurses of the oncology departments of different private and government hospitals participated in the present study in which ten were females and four were males. All these nurses were qualified in Nursing. They were working in different shifts, i.e., morning and evening in their hospitals. Six nurses worked in private and 8 in government hospitals. They were doing their duties from 7 to 9 hours daily.

All women stated that they feel themselves uncomfortable in the front of male nurses. *Hareem* stated that how she managed her discomfort during her radiotherapy in the presence of a male nurse and doctors.

> *Quite often there were men in radiotherapy, and it was very difficult to expose body. In fact, it was a kind of death rather than a long painful treatment. My mother used to advise me to close eyes before nurses and practitioners.* A breast cancer woman: *Hareem*, aged 35

All four male nurses who participated in this study were found giving appointments, arranging files of the patients and getting necessary kits of operations from pharmaceutical stores of the hospitals. They were not seen inside the clinic during the check-up of woman with breast cancer. Female nurses were seen doing bandages of the breast of these women. They were observed telling the women and their care-givers about the processes of treatment.

6.11.2.1 Health Care Professionals/Nurses with Breast Cancer Women in Private and Government Hospitals

Maher and Fenlon (2010) state that health care professionals play an important role in providing breast cancer patients special support, making them get complete treatment and ultimately restart the normal life. In hospitals, the support of the nursing staff is as important as the practitioners. Eight women, who were getting treatment from private or semi-private hospitals, were satisfied with the nursing and administrative staff of the hospitals. One major reason behind the good behavior of the administrative and nursing staff of the private hospital is the status of the patients. Rich patients usually come here for treatment and pay high cost for the treatment. So, the hospital staffs tries to support and cooperate with the patients to widen the fame of their hospital. The second reason of the good behavior of the administrative and nursing staff of the semi-private and private hospital is the provision of gendered services. These hospitals provide female nurses in the oncology department to make women comfortable. The third reason behind the well behavior of the administrative and nursing staff can be the non-permanent status of their jobs which always scares them that if they misbehave with a patient or her/his family member, he/she will be fired from the job. So they remain obedient to the laws of hospital. They give guidance regarding medicine, pharmaceutical store of the hospital, and payment of bills. They provide facilities of neat and clean environment, TV, Air conditioners, neat washrooms and cafes. *Misbah, a, 39* years old woman with breast cancer was receiving her treatment from a private hospital of the city. On asking about the administrative and nursing staff of the hospital, she viewed:

> *The administrative staffs is very cooperative; when my husband needs reports of my tests and treatment with the purpose to show them in his office to get leaves for my look after, they completely cooperate and give prints of my reports to him. Nursing staff is also very much cooperative. Two nurses all the time remain vigilant on the counter desk and visit the patients after short breaks.*

Nineteen out of 27 women with breast cancer and their care-givers were not found happy with the nursing and administrative staff of the government hospitals. These women and their care-givers reported against the careless behavior of the administrative and nursing staff of these hospitals. One reason of their careless behavior is the permanent status of their jobs. With this status of job, they feel less scared thinking they will not be fired from their jobs.
The second reason is a great number of patients who come daily and dealing with them is quite a difficult task. Moreover, the practitioners too do check-up of a great number of patients daily, but they are never rude with the patients. The third reason is the low financial status of the patients that the staff members do not treat them with good manners. During the research, it was observed that they do not discuss the health issue with the patients or with their family members and work silently without answering the questions of the patients and their care-givers. Noor, a 38 years old woman with breast cancer viewed about the nurses of the hospital where she was getting treatment saying:

> *They come to check the blood pressure, temperature and sugar and if we or our any family member ask them any information or need guidance, they condemn and behave rudely. A very little number of the staff members behaves well.*

The fourth reason behind their rude behavior is the negligence of the heads of the staff that they do not pay attention on the social behavior of their staff with the patients. During the research, it was frequently seen that the patients remain quite on the bad behavior of the staff because of the fear that if they complain, treatment of their loved one will be delayed intentionally by the staff members. *Suriya* a 62 years old woman with breast cancer shared the rude behaviour of the nurses.

> *Nurses of my ward are very rude. I cannot complain, Umm- You know, I will stay here for more weeks, and they will not care for my treatment.*

Positive and negative attitudes of the nurses put great impacts on the patient to decide whether she wants to complete her treatment or not. Nineteen women and their care-givers also shared that in government hospitals the administrative and nursing staffs both behave rudely not only with them but also with other patients. According to *Sajida,* a 52 years old woman with breast cancer:

> *I saw that their rude behavior is not limited to me and the patients of my ward only but with the patients of other illnesses, too.. I can discuss any issue related to my physical and mental health with the doctors, but I cannot discuss with the nurse because she does not behave well. If I ask her about my treatment period or any other question related to the health, she replies rudely, and says ask the doctor when she comes.*

6.11.3 Tertiary care-givers: Paid servants

The tertiary care-givers include domestic servants who were paid for their services. Total nine paid servants participated in this study. Seven were females and two were males. They were paying their services from three to fifteen hours daily for which they were paid accordingly. Eight out of nine servants were working in the nuclear families where wife was unable to perform the tasks of home. Their services included washing clothes, washing dishes, dusting and cleaning home, cooking food and grocery. Although male servants were never asked for washing clothes with the idea that he should not see the stained shirt of the lady owner. These stains were of the bandages of breast. During the conversation with male servants, it was found that they knew about the sickness of their lady owner but they did not know that this was the breast cancer. Five out of seven female servants had knowledge about the breast cancer of their lady owner. Six women with breast cancer shared that they hired maids and cut their other expenses short such as getting new dresses and home utensils.

6.12 Religious and Traditional Health Beliefs as Support Groups: Optimism and Struggle

Anne Harrington (2008) states that rituals, faith, and spirituality are used as coping strategies in many cultures. According to the National Coalition for Cancer Survivorship (2007), the whole process of struggle from diagnosis to its treatment is called cancer survivorship.

Prevailing religious and traditional health beliefs of the women with breast cancer and their care-givers were found as major support groups for their optimism and struggle. They were seen relating their illness, pain, hope, struggle, survival and all the bad happenings of the illness to their religion. They were seen having strong beliefs in their religion and its teachings regarding patience in illness. Their religious and traditional health beliefs were a source of optimism and struggle for treatment and survival. For example, the mother of *Shazia* (an unmarried woman with breast cancer) shared a religious belief saying:

Verbatim: "Bemari Allah ki tarf say Imtehaan hay, aur Shazia poora utray ge imtehan ma".

Translation: "Illness is an exam from Allah, and *Shazia* hopefully will pass this exam".

The mother of Shazia believes there is no reason for her illness except it is an exam which is taken by Allah.

Masooma, a woman with breast cancer shared that after the diagnosis of cancer, she was very upset mentally. A religious scholar of her village taught her that pessimism is a sin in her religion, and she should believe in Him with strong belief.

> *Qaazi sahib (a religious scholar) is a very pious person of our village. After the diagnosis of this cancer, I was mentally very much disturbed. He taught me that pessimism is a sin in our religion* (Local words*: Na-umeedi gunah hay*). *Life is short and one day we will have to be accountable to Allah, so accept hardships with patience and with more strong belief in him.* An informal interview with case number 6: Masooma aged 43

Other similar health beliefs were, "Life is in the hands of Allah", "health is in the hands of Allah", "It is a trial from Allah", "It is an examination of one's contentment", and "one should pray for health and should struggle by using his blessings like money". Their religious and traditional health beliefs also include seeking faith healings by wearing amulets, taking processions towards shrines, performing rituals, sacrificing animals and giving offerings (*Charhavay*) at shrines.

6.13 Obstacles in the way of hope and struggle for treatment and its outcomes in the treatment seeking process

These findings are apt to the fourth objective of the study, i.e., to observe the obstacles in the way of hope and struggle for treatment faced by the women with breast cancer and their care-givers and its outcomes on the treatment seeking process. Twenty five out of total twenty seven women and their primary care-givers were found facing common types of troubles in seeking treatment which were affecting their support group elements such as efforts, hope and struggle for survival.

Milller and Arachu (2004) state that women need trust and permission from the male head of the family to visit medical centers for check-ups and treatments which cause delay in treatment. Ravindran (1995) also writes that dependency on male members of family is a big obstacle in the access to health facility. Karen and Janes (2009) state that poverty is a big obstacle which causes delay in diagnosis and treatment. Major obstacles in the way of hope and struggle for treatment found in present study are discussed below.

6.13.2 Financial troubles -- an obstacle in the way of hope for treatment

According to the resources of different hospitals, normal expenditures of the treatment of breast cancer of a woman require 18, 00000 PKR (11,623.68 USD). Twenty one care-givers' monthly income was from 10,000 PKR (64.58 USD) to 50,000 PKR (322.88 USD). Ten care-givers' monthly income was from 52,000 PKR (335.80 USD) to 70,000 PKR (452.03USD). Five women were living with their families in the rented houses. All twenty seven women with their care-givers were from middle, lower middle and lower class of the society. The cost of treatment was a great trouble in the way of hope and struggle of survival for women and their care-givers. Delayed tests and treatments let them move towards private hospitals. The cost of tests and treatments in the private sector disturbs their living conditions.

For example, in the case of *Rehmat, a* 60 year old woman with breast cancer, it was seen that her both sons were Goldsmiths. Their business got affected by the treatment cost. She shared that:

> S*he got treatment from military hospital. Treatment was satisfactory but business of her sons suffered a lot because of the cost of treatment. On weekly basis, I needed 75,000 (483.98 US Dollar) for check-up and medications*.

Seven women got tests from different hospitals for satisfaction which caused financial trouble in the treatment seeking process. Two women got their radiotherapies from expensive institutes becoming financial burden for them. For example, in the case of *Rukhsana,* a woman of 52 year old with second staged breast cancer, was a government teacher and a lone bread winner of her family. Her daughter was studying in a university. According to her daughter, "*she and her mother needed 55000 rupees (355.34 USD) for a single visit for chemotherapy, and it includes medicines, check-ups fee and transport expenditures for approaching the hospital. These expenses are so heavy that I am thinking to leave my university education*".

Expenses to approach the hospital was seen another trouble in the way of hope and struggle for treatment. In order to avoid these expenses, two women with their care-givers preferred faith healing which resulted in the worsening of cancer later on. Four care-givers were from a lower class of society; they sold out their properties to get timely medical treatment without wasting time. As in the case of *Masooma,* it was seen that her husband sold out her two cows for timely tests and treatments. Financial obstacles in the way of hope and struggle for treatment take the patient and her family members in psychological distress.

6.13.2 Distress for the loss of identity and hope for treatment

During the research, it was observed that new changes in the life of breast cancer women due to illness disturbed their public identity and hope for treatment. Identity as a sick and ill member of society gives them feelings of inability. In additions, these feelings of inability to perform activities at home and the outside put them in distress and give them feelings of a useless member of the family and society. Their feelings of distress regarding their inability to do normal tasks were seen damaging their hope for treatment and survival. For example in the case of *Komal,* a 22 year old woman with first staged breast cancer, it was observed that she was an undergraduate student in a university of the capital, but she ceased her education when her cancer was diagnosed. During the research, she was found depressed, feeling that her friends and class fellows will become her seniors and she will miss them when she sits with other girls in the class. In the case of *Shazia*, the same thing was noticed when she left working with her family members in the fields. Her family members were also suffering from financial problems for her treatment. The identity of *Shazia* as a supporter of family turned into a burdensome member of the family, and it made her depressed. All twenty seven breast cancer women were found struggling to regain their public identity as a useful member of their families.

6.13.3 Effects of pessimistic thoughts and words on treatment

Among all twenty seven women with breast cancer, their pessimistic attitude can be seen in the use of words when they talk about their illness. Many pessimistic phrases reflected their mental stress. These negative narratives and phrases were not only used by the breast cancer women, but also by the people who come to see them. For example in the case of *Rukhsana,* a 52 year old woman with second staged breast cancer, it was observed that her sister in-law came to see her and maintained, "*now she will not survive, because cancer does not let its affectees live*". *Rukhsana* became very pessimistic on hearing this and started stopping her daughter from spending money on her treatment which she had collected for her study and wedding.

It was observed that during treatment, the use of optimistic thoughts and words give courage and satisfaction to the women and their primary care-givers. It was also seen that pessimistic thoughts and words not only discouraged the sufferers but also their care-givers.

Furthermore, pessimistic words badly affected the mental status of the breast cancer sufferers and their care-givers. For example in the case of *Adila,* a 45 year old woman with breast cancer, during an interview with her family members, her husband expressed that *'if a father dies, it is a financial loss, and if mother dies, it is a family loss*'. He explained that how the whole life of his family was completely disturbed because of his wife's illness. Their sons were no more serious in their school education. His job was getting disturbed and their daughter left going to school because of taking care of her mother. Due to the stressed situation, he was completely hopeless about the survival of her wife. *Adila* was also pessimistic about her survival due to such words; however, her doctors were optimistic about her survival and advised her family to keep her happy and optimistic about her survival.

In addition, in the case of *Samina,* a 35 year old' first staged breast cancer woman and mother of two kids, it was found that her doctors were hopeful regarding her survival. Her close family members especially her mother and husband were giving her great care. They were also hopeful for her survival, but she was having pessimistic views about her survival. According to her mother, "*she is a pessimist because of the negative views of her in-laws about her illness and she believes that she will not survive and her husband will remarry another woman".* She further says that, "*her cancer is on first stage and doctors are hopeful for her survival but she is pessimistic and talks about her death*". Her doctors, husband and mother are completely hopeful about her survival. During spending time with *Samina*, she further stated that, "*I am on death bed and my husband should not waste money on my treatment*". The use of pessimistic words and thoughts showed her stress.

6.13.4 Absence of care-givers in the struggle for treatment

During the research, it was found that the absence of the primary, secondary and tertiary care-givers can have great negative effects on the treatment and survival chances of women with breast cancer. In the present study, it was found that family members as primary care-givers encourage their loved one to get treatment. Nurses as secondary care-givers look after in hospitals. Paid servants as tertiary care-givers look after at home in a condition when the patient cannot take care of herself and members of her family. Other such practitioners, friends, colleagues, neighbours and distant relatives are also important who encourage patients to hope for survival but their services are not as important as of primary, secondary and tertiary care-givers. The absence of care-givers can create problems in the treatment seeking process. Musoke, Boynton, Butler and Musoke (2015) state that a health care provider can be biased professional in his or her perceptions about patients and their problems which also disturb the treatment seeking efforts.

In the present study, all nine rural and five urban women out of total twenty seven were living in extended family system. Their struggle for treatment looked like a common goal for all members of the family. It was observed that the close or distant relatives of the rural women who were working in cities were also helping their village people who came to the cities for treatments. Their knowledge about the available type of treatment of the hospitals and doctors was seen encouraging to the women with breast cancer and their family members. All nine rural and 5 urban women were living in extended families. Living in extended family system was seen helpful for them in receiving treatment and in getting complete care from their family members.

Shamim, a 39 years old woman with breast cancer was living alone with two sons and one daughter and was suffering a great deal. The absence of care-givers was making her devoid of seeking timely check-ups, tests and treatment. Another urban case of *Rukhsana* a 52 year old woman with second staged breast cancer was also suffering from the absence of primary care-givers. She was having two daughters, one was married and another was studying in a local university. Her daughter was feeling burdensome because of her mother's illness as she alone had to do chores of home, her study, and taking mother to the hospital. *Maryam, a 41* year old divorced woman with second staged breast cancer was a mother of two kids and was a lone carer of her family. She was living alone and there was no adult for her care. She was receiving treatment from a hospital of capital, but she was suffering from burdens of many tasks in the absence of her primary care-givers as she was having no parents and siblings and in-laws.

6.14 Psychologically Internalized beliefs of Optimism and Struggle and Reasons of these Beliefs behind the Scene

In the present study, some of the beliefs of the participants were found so imbedded in their minds that they attracted my attention. Harrington (2008) also stated beliefs like: "Power of suggestion", "the body that speaks the power of positive thinking", "broken by modern life", "healing ties", and "eastward journeys" in his study. By using different beliefs, the respondents of the present study were endorsing positive attitude towards the attainment of treatment and rejection of worsening the illness. For example, a care-giver daughter viewed during a conversation :

> *"Ker heela banray wasila (Translation: one should struggle, the sources of help will automatically appear)".*

Through this internalized belief the respondent emphasizes the struggle with a hope for survival. The beliefs of optimism and struggle were their religious and traditional beliefs. With these beliefs, nine women and their care-givers gave importance to approaching the treatment without focusing on quality of treatment. They got faith and folk treatment first and got late diagnosis of breast cancer in the hospital. Low cost of the faith and folk treatment and high cost of hospital treatment can be its reason. The second reason can be this that faith and folk treatments are easily accessible than hospitals of the cities. So their beliefs were attached with economic aspects, too. The third reason of their health beliefs of optimism and struggle for treatment can be their trust in these ideas which they got from their elders. The fourth reason for these beliefs can be an effort to release depression of illness. Faith healers provide peace of mind as in the case of *Shamim*, it was observed that she was not financially strong to get treatment from private cancer hospitals. While getting delayed treatment from a government hospital, she was also getting faith and folk treatment from a faith healer who was famous for his faith and folk healing. Getting treatment from faith and folk healer was giving her mental comfort and courage to get available treatments. For example in the case of *Shamim,* she was seeking faith healing to get mental relaxation and patience.

> *I was in great depression before getting treatment from Peer Allaud Din; his treatment is not giving me positive results in my illness of breast cancer but giving me mental relaxation and patience.*

The fifth reason of these beliefs can be their firm belief in death that no one has eternal living in this world and everyone has to leave by one reason or another. *Shah Shabeer,* a local faith healer shared his concept of struggle and death that one should struggle for healthy life but he should accept one thing that death is a fact. He explains that like everything has its start and end, so does the man, too.

> *Death is obvious and one should always get ready for it. One should struggle for a healthy living but should not be scared of death. Everything has a start and end. Death is a fact, and no one can evade it. One should make efforts to get remedy from illnesses but not from death.*

During the research, more or less the same views regarding death were found among the women with breast cancer and their care-givers. Their firm belief in death can be one reason of their health beliefs of struggle and optimism. Beliefs of virtue and sin were also seen with their health beliefs. For example, a local narration of the people was very commonly found, i.e., *"hopelessness is a sin (naa-omeedi gunah hay)"*. Psychological internalized beliefs of faith, hope, struggle, patience, no fear from death, and many other beliefs gave a holistic view of non-materials which were very real for the participants. All these beliefs helped in understanding spirituality and sensory experiences of breast cancer sufferers and their care-givers in the long process of treatment.

6.15 Practitioners with Breast Cancer Women of Low and High Financial Status

Knobf (2007) states that constant support from healers provide potential to carry on their normal living with normal sensibility. Practitioners of breast cancer include medical oncologists, radiation oncologists, surgical oncologists and care-managers or caseworkers. A case-manager or caseworker usually arranges appointments with surgeons, medical oncologists and radiation oncologists and saves the extra trips of the breast cancer woman to the hospital. The breast cancer women and their care-givers who participated in the study, have the same experiences from private and government practitioners but have different experiences from administrative and nursing staff members of the private and government hospitals. All 27 breast cancer women were getting treatments from the hospitals of Islamabad, Rawalpindi and Lahore. Most of the women with breast cancer were found visiting different private and government hospitals for screening tests at initial stages. This initial stage of treatment gives different experiences to the patients of high and low financial status.

Stevenson (2004), and Stevenson and Scambler (2005) proposed a term "concordance". This term refers to the formation of an accord that respects the desires and beliefs of the patients.

Breast cancer women were found satisfied with the behaviours of the surgeons, medical oncologists, radiation oncologists and nurses. They were found praising their health care professionals. Good behavior of the medical practitioners made them feel satisfied and they supported them to understand and regulate their illness positively. The behaviour of a young medical oncologist Dr. *Sadaf* (pseudonym) can be quoted here in describing the impact of a medical practitioner's behavior on motivating and encouraging the patient and her care-giver to get complete treatment. *Rukhsana,* a 52 year old second staged breast cancer patient came to hospital with her daughter for her scheduled chemotherapy. *Rukhsana* was in a bad stress because of the side effects of last chemotherapy. She was looking tired and weak suffering from indigestion of food and loose motion for last some days. Her daughter was also stressed to get another chemo despite the bad effects of last chemotherapy. Dr. *Sadaf* welcomed them and without wasting time started her chemo. She shared her mother's experience of breast cancer with *Rukhsana* and her daughter that how her mother survived even at third stage of her illness and how she supported and encouraged her mother to get complete treatment. She told them that she alone handled home duties and taking care of younger siblings with her medical studies. Cooperative and understanding behavior of Dr. *Sadaf* made *Rukhsana* and her daughter feel comfortable. further, she told them how she managed her mother's hospital visits with her university education. The attitude of Dr. *Sadaf* with *Rukhsana* and her stressed daughter was like a psychologist. During and after the conversation of Dr.*Sadaf*, they were looking relaxed and were not as much stressed as they were looking before this conversation.

After the chemotherapies and during the surgery dates of *Rukhsana,* her daughter viewed that,

> *All the medical practitioners were cooperative with us though we do not have a high financial status. My mother is a teacher in a local government high school, and she is a lone breadwinner of our two members of family. I am a student and do not have any job. The cost of treatment is heavy but affordable to us.*

The reason of the well behavior of the practitioners can be the private status of the hospital. The hospital where *Rukhsana* is getting treatment is a military hospital; it is free for military personals and their families but very costly for the civilians. *Rukhsana* was a civilian case in this hospital. On each chemo, she spent 55,000 PKR *(355.34 USD)* including transport cost, check-up, tests, chemotherapy and medicines.

Women with low financial status were found facing problems of timely treatment in all hospitals. During the initial stage of illness, screening tests are needed and many women were found getting screening tests from different government and private hospitals. Screening cost make them aware about the treatment expenses. Twenty two of them get treatment from different hospitals like they get check-ups and chemotherapies from one hospital and for radiotherapies they move to another hospital or institute of radiology. *Shamim,* a 39 year old woman with second staged breast cancer was unable to get treatment from a private hospital because of her weak financial conditions. After the recommendation of early diagnosis by her local hospital, she went to a radiology institute of the city for screening tests. She was diagnosed with a second staged cancer of breast. She gave application in foundation section of a semi-government institute of radiology for her free treatment which was accepted and partially free treatment was given to her. She approached the government hospital; they referred her to the same institute of radiology for required tests, which were not possible because of her inability to afford the cost of the tests. The institute processed her application so late that her cancer became very severe. After delays of three months her treatment got started on the basis of those tests. According to the *Shamim*:

> *The behavior of the medical practitioners in the radiology institute was supportive, but the administration was not supportive. They were not polite with me and with my friend who went with me. Long waits in the institutes deteriorated my condition and quite often made me reluctant to get treatment. I started getting faith healing by visiting a shrine and the descendant of the saint of this shrine.*

During the research, it was found that for smooth and successful treatment only practitioners' behaviour is not important but the attitude of the staff and administration of the hospital is also very important. *Shazia,* a 34 years old woman with a low financial status faced the same issues which were faced by *Shamim*. She belonged to a poor farmer family and was unable to bear the cost of the tests, check-ups and treatments. On the information given by doctors, her family gave application to the social welfare organization of the country called *Bait-ul-Mall Department of Social Welfare and Women Development.* This organization gave payments to the radiology institute and to the hospital where she was getting treatment. She and her family were satisfied with the conduct of the medical practitioners but were annoyed with the conduct of the administrative staff that put them in long waits and delays.

6.16 Faith Healers' Behaviour with Low and High Financial Status Breast Cancer Women

During the research, six faith healers were found giving faith healings to women with breast cancer. Five were male and one was female. These healers were famous for treating various kinds of body and mental illnesses. Pseudonyms of all faith healers have been used in the study. These healers were from rural background and had great number of followers from their villages and outside the villages. These faith healers were commonly known with the local names of *Peer Sahab, Baba Ji, Shah Ji, Qaazi Sahab* and *Hakeem Sahab.* These names have significance and respect. Their behavior with low and high financial status breast cancer women and their care givers was equal.

These six healers were having no standard fee for their healing practices. In all cases, it was found that the amount of fee was set and given by the visitor or patient according to his or her own wish and affordability.

One reason of their free treatment was their fame in the area as a religious and spiritual healer. For example in the case of *Komal,* a 22 year old woman with breast cancer patient, it was found that *Peer Saif-ur-Rehman* was a religious scholar and was providing faith healing to *Komal* free of cost. It was a wide hall made of mud walls and roof which was the sitting place of *Peer Saif Ur Rehman*. *Komal* and her mother and I sat in the female's waiting room which was attached to that wide hall. Including *Komal,* 13 women were waiting for their turns. Among those women, *Komal* was the only woman with breast cancer. On each turn, three patients were allowed to come in the room. However, it was also allowed to come alone if one wants to come separately and discuss her issue in segregation. It was observed that he was giving 30 to 35 minutes to each person.

He maintained that he got knowledge from his experiences and from his elders. According to *Peer Saif Ur Rehman,*

> *People ask for fee; I suggest them to contribute in the construction of the mosque or give it to a needy person… Several people come and tell their financial, mental, familial and social troubles and get a solution with future perspective. I learnt from my experiences and my elders. I do not believe that I have some power, whereas it is blessing of Allah who gave me knowledge to solve the sufferings of His people.*

The second reason of their cheap treatment was the type of the visitors who come in great numbers. During the research, it was found that most of poor people approach this faith healer because of their unaffordability to get treatment from the hospitals. The rich people also approach these healers along with the attainment of medical treatment to get cure soon. For example in the case of *Misbah,* a 39 year old woman with breast cancer, It was found that she was getting treatment from a private hospital and was also getting faith healing from a faith healer known as *Morra Shareef.* The third reason of their cheap treatment is the safety of their inheritance as a descendant of saint. Local people respect and follow them. For the preservation of this respect, they give equal and cheap treatment to the patients of low and high financial statuses. People believe that these treatments do not have side effects, while medical treatments have horrible side effects which initiate other illnesses, too.

Twenty six out of 27 women and their care-givers were found getting faith healing along with medical treatment. Two out of six faith healers were also found giving some herbs to grind and eat to kill the cancer. All six were found giving written versus of the Holy Quran to wear as an amulet around the neck, to burn and bury inside the soil. All six faith healers also were found giving amulets for the whole family of the sufferer to get better results in the mind and body of the sufferer. Faith healers also recommend performing specific traditional activities to bring health and remove illness from the body of the sufferer. For example in the case of *Bibi Shah Jahan,* a female faith healer, it was observed that she was treating women and children by reciting verses of the Holy Quran and performing spiritual activities. During the conversation about the faith and spiritual practices, she told:

If a woman with breast cancer comes for treatment, I give her religious and spiritual treatment. The whole treatment consists of seven [18]Dums (visits). In her each visit, I recite the holy verses and Duas (prayers) of the prophets and saints for the treatment of chronic illness. Then with the help of a grass stick, I do spiritual treatment. I dip this stick into water and move it on the affected part of body. I repeat this action seven times in her each visit. I never accept fee and charges. I advise them to give 1kg meat to a poor family or purchase one head of a slaughtered black goat from the market and throw it in an unpopulated area. I usually suggest them to put beans to the birds. In these practices, the illness gets removed from the body.

Like *Bibi Shah Jahan* other five faith healers were also observed practising spiritual healings with faith healings. The spiritual healings were in the form of making amulets of papers for wearing around the neck, mixing it in drinking water, burying it under the earth and burning it taking great care of time and place. For example in the case of *Baba Saif Ur Rehman,* a religious healer recited verses of the Holy Quran for the recovery of *Komal* and was observed healing other case in the same way. He elaborated his practice:

> *In the first step, I listen to the issue of the person. In this step, I use my knowledge which is given by Allah and tell them the condition they are going through. I tell them about the figures and factors that are creating problems. In this step, the visitor accepts or rejects what I tell them. Quite often the visitors accept what I foretell them about their present condition. In the second step, the sufferer or his companion tells me about the remaining issue. In the third step I recite Ayats (verses of the Holy Quran) and blow on the affected person. In the fourth step, I write my knowledge in pieces of paper and make Taveez (amulets). I give one paper for wearing around the neck and another for burning daily in the evening. Last piece of paper I give them after making it a cone to fill it with salt and bury under the soil. I also foretell them about the most possible happenings but also*

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[18] *Dum or Dums* refers to the visits of patients to the religious healer. In this visit, the religious healer recites verses of the Holy Quran. He uses his or her knowledge learned from his/her elders or from his/her experiences. He reads *Duas (*prayers) of different prophets and finally blows on the face and body of the patient.

> *tell them that my knowledge is nothing, it is Allah who gives knowledge. I am telling you but it can be false as Allah knows the truth. The people from many distant places come for the solutions of their troubles. I also break Jadu Toona (spell of magic) and Bandish (hurdles). The patients of chronic diseases come for faith healing and I give them treatment in the form of amulets to wear and burn. I also suggest them some Ayats (verses of the Holy Quran) to recite all the time.*

6.17 Spiritual and Ritual Healings

Lackey, Gates and Brown (2001) state that spiritual relationship of breast cancer patients with their God supported them throughout their cancer experience. The Asian and ethnic minority people have been found much interested in religious beliefs and spirituality (Ashing-Giwa, padillo,Tejero, 2004; Bourjolly, 1998; Bourjolly, Hisrschman, 2001; Culver, Arena, Wimberly, Antoni, Carver, 2004; Koffman, Morgan, Edward, Speck, Higginson, 2008; Moadel, Morgan, Fatone, Grennan, Carter; Reynolds, Hurley, 2000). This was apropos to the last objective of the study to observe the alternative patterns of treatments particularly spiritual treatment availed by the women with breast cancer and their care-givers. They were seeking spiritual and ritual healing side by side availing themselves of the biomedical treatment. All their religious practices were spiritual, but all spiritual practices were not religious as some of the practices were learned through experience. It was also observed that the spiritual practices were not only practiced by the religious scholars but practiced by common people, too. For example, *Bibi Shah Jahan,* a faith healer was also famous for her spiritual healing practices for the illnesses of women and children. She belonged to *Syed* caste which is considered connected with the last prophet of Islam (the descendants of grandsons of the last prophet of Islam, Prophet Muhammad PBUH). If a woman comes with tumor, she treats with religious and spiritual methods both. She learned spiritual knowledge from her husband who was considered a religious scholar of the village. She does not differentiate between her ritual healing from her spiritual healing and believes that both are one method of healing "*Rohani Elaaj (spiritual healing) / Mazhabi Elaaj (religious healing)* because it is given by Allah.

> *If a woman with breast cancer or a tumor comes for treatment, I suggest her to come seven times and get a proper session of each visit. Her each visit includes my recitation of verses of the Holy Quraan which I blow on the face of the sufferer and is called Dum. Then with the help of a one foot grass stick, I do another treatment* (shah Jahan considers this spiritual treatment which is a part of

> the whole religious treatment). *I dip this stick into "Zam Zam" (water from the well of Makah) and move it on the affected place of the body (that is breast). I repeat this action seven times in each visit. I never accept fee and charges. I advise them to give 1kg meat to a poor family or purchase one head of a slaughtered black goat from the market and throw it in an unpopulated area or graveyard and get out of that place without turning back and looking that what happened to that head. Frequently, I suggest them to put beans to the birds. In these practices, the illness gets removed from the body.*

She described the themes of this spiritual and ritual activity. Number 7 is important because all Muslims make seven rounds around the "*Khana Kaba*" (the Holy place of Allah) and finish their *"Umra*" (visit to Home of Allah). Recitation of the verses of the holy book, Quran brings blessings from Allah. The use of holy water of Makah brings kindness of Allah which heals the illness. To give meat to a poor family works as showering of Allah's kindness. The black colour is considered the colour of agony. Goat is considered a beloved animal of prophets of Allah. Animals and birds of unpopulated area will eat the head of goat which will again bring kindness of Allah. By giving head to graveyard or unpopulated place, the body of the sick will stay alive.

Five out of six healers were found practicing spiritual healing practices and recommending their visitors to perform the prescribed spiritual healing practices. For example in the case of *Shah Shabeer* (pseudonym) a spiritual healer, it was observed that he practiced spirituality and also recommends his followers to practice the same.

> *I suggest them to take salt in quantity that is according to the size of your lump and put it under the filled earthen water pitcher. I recommend them to practice this in the early morning before the sun rises. This traditional healing puts great effect on healing as the sault dissolves in water, the cancer will disappear, too.*

During the research, many spiritual and ritual practices were performed by the women with breast cancer and their care-givers. In the performance of these spiritual and ritual practices, the presence of the sufferer was considered important. Among the rural population, these practices were largely seen and they perform these practices irrespective of their caste and color. They believe that they had spiritual and traditional healing for each kind of illness but because of the medical treatment these practices are disappearing slowly and steadily. Now they practice some spiritual activities for healing chronic illnesses. It was observed that many performers of these spiritual and ritual activities believe that there are always some evil actors behind the illnesses. They also believe that by performing these activities, the evil actors can be wiped out. A respondent who was a mother of a breast cancer woman viewed while practicing a spiritual activity:

> *Shaitani asar khatm kernay kay leay amal kia jata hay wrna wo peecha nahi chorrta. (Translation: Some specific activities are important to be practiced to annihilate the devil's influence on the sufferer).*

It was also noticed that all the spiritual and ritual activities were full time practices. For example in the case of *Rukhsana,* it was noticed that a folk healer practices a full time spiritual performance taking ten minutes. He did ablution and sat in front of *Rukhsana* on the ground. He drew five straight lines with a piece of coal and placed a stick in between lines. He closed his eyes and recited verses of the Holy Quran. After this step, he picked up the stick in his left hand and started slapping on these lines. While slapping on the lines, he kept his right hand on the forehead of *Rukhsana.* The spiritual healer elaborated the meanings of the steps of the activity saying that he did ablution to make himself clean as cleanliness is a very basic thing in Islam. The act of drawing five lines with coal were giving meanings of the spread of evil on the five sides of the sufferer such as, inside, left side, right side, upside and downside. Placing of the stick in between lines was signifying the start of fighting with the five spread evils. He closed his eyes to give more concentration on reciting the Holy Quran's verses. Picking up of stick with the left hand means to fight with the illness which always remains on the negative side. The black color of black coal was signifying the evil spirit or witch. The act of slapping on the black lines with the stick and placing of right hand on the forehead of *Rukhsana* entails detaching of illness from her body.

Komal is a 22 year old girl and a first staged breast cancer patient. Her mother practiced a ritual. Her mother believed in the activity she learned from her elders to perform for wiping out of a chronic illness. She clapped two nails of the same size in the ground when there is half sun shine and half shadow. She took a thread role; she did measurement of *komal*'s hight with the thread and tied it to clapped nails. After these steps, she took that thread from nails and buried it in the ground. This whole practice was consisted of ten minutes. She told the meanings of this activity that clapping nails in the ground gave meanings of tying illness. The half sun shine and half shadow signified healthy life and sick life respectively. The Measuring body with thread entailed measuring all bad effects of illness from top to bottome of her body. Then burrying of that thread meant the burying of illness in the ground forever.

The idea of evil eye was largely seen during the whole research process. Twenty six out of twenty seven women with breast cancer were found believing that they got ill because of an evil eye of an envious person. *Misbah,* a 39 year old woman with breast cancer was found repeating that she got sick because of some evil eye. Her mother practiced a ritual which was not only interesting but also had psychologically positive results on *Misbah.* Her mother told that she learned this activity from her elders. The performance followed these actions. She took an egg and coloured it yellow. Among the natives, the yellow colour was considered a color of illness. She moved the egg clockwise around *Misbah* for seven times and placed that egg on a hot pan and covered it with a lid. After some times, we heard the sound of blast. This blast was perceived as the removal of *Misbah*'s illness. This practice took twenty minutes.

The mother of *Misbah* elaborated that the meaning of a colored egg was tumor or illness and moving it clockwise around *Misbah* meant collecting illness of her whole body in this egg. Number seven is an odd number which is considered more good than an even number in Islam. Placing it on the hot pan over the fire gave meanings of destroying it. The blast of an egg signified the destruction of illness.

Misbah stated that:

> *I saw the practice of this ritual since my childhood. The people of my family and I go to hospital for treatment but also practice this activity. This stops the effects of the evil eye or envious one.*

Misbah and her family take this activity as remedies from the effects of evil eye which brings sever illness.

The ritual activities were largely seen among the rural women with breast cancer and their care-givers. In the case of *Shazia,* a 34 year old woman with breast cancer, a ritual activity was observed. Every morning, her mother placed a piece of hard salt that was the size of *Shazia*'s tumor beneath water pitcher. She believed that by performing this practice, tumor will disappear as salt dissolves in water. She told meanings of this activity that a piece of salt gives meaning of tumor and the selection of salt in place of any other thing implies that as salt dissolves, her illness will disappear. It was believed that by performing this practice daily, her tumor will get decrease and finally will get disappear.

Among all rural and urban women with breast cancer, a common ritual regarding the removal of effects of evil eye was widely seen. This ritual was called *"Dhooni" (smoke).* In the case of *Suriya,* it was found that her *Bahu* (daughter in-law) used to perform it in the evening by burning a fire in an iron pot. After adding a herb, *Guggul (English name of the herb:*

Commiphora wightii) in fire, its smoke will reach all the corners of home. With this practice, the family of *Suriya* believed that the bad elements and influences (Local word: *Asar*) will be removed. Her daughter in-law elaborated the meanings of this activity that they consider evening time as the time of coming of evil spirits in homes. The herb *Guggul* is used widely for the magic purposes to confront with evil spirits. She added *Guggul* in the fire and it changes the fire in smoke. Taking the smoke by moving that pot to all corners of home implied the killing of evil eye and evil spirits with the smoke. During the study, it was noticed that timing and acts of performing spiritual activities were related to the desired effects of the activity. Placing hard pinch of salt under water pitcher in the morning, also known as practicing ritual of *Dhooni* in the evening and many other rituals were observed with the importance of timing.

Another very common practice of removing the effects of evil eye was widely seen among the women with breast cancer and their care-givers and it was called "*Nazr otarna*". In the case of *Rakhshandan,* her daughter performed this act. She took one pinch of sugar and moved this pinch of sugar in clockwise direction around her mother's body. With this procedure, she recited four *surahs "Chaar Kul" verses* of the Holy Quran. Then she dropped sugar on a hot pan. For one minute, there was fire on the pan and then there was smoke which remained for two minutes. *Rakhshanda* and her daughter believed that the influence of evil eye "*Asar aur Nazar* "has been removed by reciting the holy verses and by firing the evil eye. Her daughter told the meaning of this act that they believe, reciting *"Chaar Kul"* of the Holy Quran work well in breaking of the magic, spell or the effects of evil eye of the envious or enemy. Fire and smoke give meanings of the presence of the evil eye's effects or evil spirit. This act reduces their fear regarding the effects of evil eye.

6.18 Patterns of faith and spiritual healing

During the research, faith healing was found among all women and their care-givers. Faith healing was performed by the famous religious figures. These healers were renowned and had names such as *Peer Sahab, Baba ji, Qaazi Sahab, Saaen Ji* or *Shah Ji.* Some of the faith healings were performed by the sufferers and some were performed by the religious healers. For example, *Shah Shabeer* (pseudonym), a 55 year old faith healer is from *Syed* family *(*the descendants of grandsons of Islamic prophet Muhammad PBUH*).* He gives faith healing to a woman with breast cancer. According to him*:*

> *I give faith healing following three steps. I recite verses of the Holy Quran and then think by keeping my eyes close. In this step, I go into my spiritual world and*

> *understand the causes and reasons of her illness (he used the words, "ma Hisaab ligata hun"). Second, I write versus and words of the Holy Quran with a black ink and a pen made of thick grass. One amulet I give to wear around the neck. Another amulet I give to put in her water jug with the advice that she will drink only that water. Last amulet I give to dip it in water in a bowl and after mixing it in that water, sprinkle it in all corners of home. I advise them to have strong belief in Allah and soon they will get rid of tumor or malignant cancer.*

Faith healing was practiced by all women of high and low economic statuses. For example, *Misbah,* a 39 year old woman with breast cancer was receiving treatment from a private hospital. With medical treatment, she was getting faith healing, too. Her mother was regularly taking her to the descendant of a saint who was famous for his faith healing to the patients of chronic illnesses. According to the descendant of the Saint, *Mairra Shareef:*

> *In faith healing, I give amulets to wear, give salt to add it in the salt of kitchen. I also give soil to keep it in home and holy water from the well of the shrine to drink. I recommend the sufferers to make regular visits of the shrines until they are completely well.*

During the research, a strong belief in faith healing was found among the people. In some cases, a crowd of health seekers was found at the meeting places of the descendants of the saints. For example in the case of faith healer, *Baba Saif Ur Rehman* (pseudonym), a great rush of health seekers was seen. He was famous for his power of breaking black magic and telling the sources of suffering. According to him:

> *For last thirty years I have been treating people. I never joined any institute for the learning of faith and folk healing. Allah inserted faith healing in me. I learned folk healing from my experience. Allah gave me knowledge for treating the patients of minor and major illnesses. People come from far off places for getting treatment from me.*

He shared that he never learned or got knowledge from anyone and believes that he got all knowledge by his own experiences and by the blessings Allah. Further, he explains the method of his faith healing:

> I *recite verses of the Holy Quran and blow them on the affected person. Then I write my knowledge on pieces of paper and make amulets (Taveez). I give one paper for wearing around the neck, another for burning daily in the evening and*

> *last piece of paper I give them after making a cone. I advise them to fill this cone with salt and burry it under the soil.*

On asking about the results of his faith healing, he elaborated that his faith healing is very effective and people experience the good results. That's why there remains a huge rush of the faith healing seekers. In all patterns of faith healing, it was commonly found that the healers use verses of the Holy Quraan and make amulets because the health seeker population is mostly Muslims. Charity in kind of cash and goods were also seen part of faith healing. For example, *Bibi Shah Jahan* suggests that her health seekers purchase one kilo gram meat and give it to a poor family or get the head of a slaughtered black goat and throw it in an unpopulated place. These kinds of suggestions are not part of religion but the religious healers recommend these to their health seekers. The faith healers believe that these suggestions are part of faith healings because there is great connection of mind and body. The illness will be detached from the body by throwing the head of a slaughtered black goat in an unpopulated place or graveyard and getting out of that area without looking back. This practice also symbolizes that the sufferer will not go to the graveyard with this illness. This practice implies the restoration of health. The practice of giving meat or head to a poor family to eat signifies charity and making poor family happy eat meat symbolizes the reduction of suffering.

6.19 Narratives about the Results of the *Tib-e-Nabwi* (treatment with methods of last prophet Peace Be Upon Him).

Two faith healers were seen attaching faith healing with *Tib-e-Nabwi* . They were seen giving herbs to their followers to grind them and use with food. They named their healing *"Tib-e-Nabwi"* (treatment with the methods of last prophet Peace Be Upon Him). Four out of twenty seven women were seen following this kind of treatment with their bio-medical treatment.

Rakhshanda, a 55 year old woman with breast cancer was seen getting faith healing and *Tib-e-Nabwi* treatment from the descendant of saint *Saaen Hazar Shah.* She was depressed because of the side effects of her medical treatment. The daughter of Rakhshanda shared that she heard from her neighbor that the descendant of saint *Saaen Hazar Shah* is famous for his *Tib-e-Nabwi* treatment. After hearing the sick condition of *Rakhshanda* from her daughter, the descendant of saint *Saaen Hazar Shah* started his healing practice.

> *He closed his eyes, recited some selected Quranic verses for 6 minutes and blew them on Rakhshanda. He picked up dried turmeric of little amount from one of his table drawers and gave it to Hina (the daughter of Rakhshanda) by advising her*

> *to crush it on a stone and save it in an air tight jar. Take one spoon of this grind turmeric and cook it in ghee or oil and add one glass of milk in it. Give it to her to drink before sleep. He added, "Inshallah (if Allah/God wishes), she will be fine very soon.*

During the research, it was observed that people accept a religious healer as an illness healer, too. For example in the case of *Shah Shabeer* (pseudonym), a religious and folk healer, it was found that he was a religious healer but at the same time he was a folk healer, tpp. According to him:

> *When a woman with breast cancer comes for healing, I recommend her to avoid eating meat, going in social gatherings especially in funeral ceremonies, going to graveyards, wearing black and green color, wearing jewelry especially made of gold, and eating excessive beans. With these recommendations, I give them Tib-e-Nabwi treatment such as, take an onion after cutting it in pieces; fry it in a pan with adding one spoon of oil until it gets brown. Then make it cold and put it on the lump and tie the place with a piece of cloth. Practice it daily and soon you will see that onion will extract the bad blood and lump will disappear within thirty to forty days. Another very beneficial way of releasing pain which I recommend my followers is, to put hot wheat in a cloth and apply it on the affected place. This act will release the pain and will give comfort.*

By following faith, spiritual and ritual healings, the respondents of the study showed their trust spiritual practices. They possess certain religious and local narratives regarding the idea of illness and treatment. Such as "*Bemari Allah ki tarf say azmaesh hay*" (any kind of illness is a trial from God), "*na umeedi gunah hay*" (pessimism is a sin), *"Hakeem bra ya yakeen, so yakeen hakeem say bra hay*" (faith is bigger than the healer), "*Allah bejnay wala, Allah jaalnay wala" (*God is the sender of disease and he is a lone saver), "*kamyaabi koshush ma hay)*" (success is in struggle), "*barron ki nafermani ki sza such na pana hay*", (disease is a punishment of disobeying the elders of family), " *baap mray to mali nuksan, maa mray to khandani nuksan*" " if father dies, it is a financial loss; if mother dies, it is a family loss, "*Banday nay pichay bnda, bnday na haal manda*" (suffering comes because of her chased by enemy or ill-wisher) "*peni ik wari, chukni tele tele*" (disease comes suddenly but its treatment takes time). These local narratives give the idea of struggle and hope for survival which ultimately create positive body image among the sufferers of both high and low financial status. The women who were getting homeopathy treatment believe that it is harmless and does not have side effects *"Garm Taseer"* on the organs of the body.

CONCLUSION

With the help of holistic perspective this qualitative study explored the lived experiences of women with breast cancer and their care-givers. It found answers of the research questions Spiritual, ritual, bio-medical treatments and the support of care-givers are enduring mechanisms to cope with the illness. Social and economic conditions create obstacles in the way of hope and struggle for treatment. Care-givers play a key role in the entire health seeking process. Faith and beliefs of the women and their care-givers provide reflections on the praxis that regulates the multiple treatment venues including traditional and magico-religious practices. This study also found that social, cultural, religious and environmental factors have negative effects on women with breast cancer such as having negative body image. The study found that breast cancer women and their family members have common experiences with health care professionals and practitioners. The present research revealed that the lack of awareness and late diagnosis are major reasons of bad outcomes of breast cancer. The study provides suggestions in the furtherance of improving outcomes of this illness, and early detection is very critical. Countries like Pakistan with weak health mechanism and limited resources, where most of the women are detected in the late stages of their breast cancer, should put great attention on early detection schemes based on awareness of early manifestation and referral to detection and cure.

In relation to several theories, there are several perspectives of *anthropology* which give different lenses to observe a human behavior. By emphasizing "holism", a key characteristic or perspective of the subject, *anthropology*, one can focus on the human behavior of the participants by using ethnographic method, focusing culture, emic and etic approaches, studying cultural symbols, and focusing on pro-people paradigm. In other words, anthropological perspective of a phenomenon is critical thinking, appraisal of contesting hypothesis, and competence to generalize from distinct information of a happening or situation. The present research aimed to understand the lived experiences of women with breast cancer and their care-givers from the anthropological perspective.

Many social scientists worked on the illness of breast cancer. Sontag and Anne Harrington made remarkable contributions in giving anthropological perspective of the illnesses, i.e., cancer. Sontag (1978) maintains that "Illness as metaphore" is, "The concept of disease that is never innocent". Anne Harrington gave a diverse perspective that there is deep connection between a disease and feelings. She believes that all the cultures have their local narratives regarding the reasons of their illnesses. Proposing the reasons of illness, she also suggests ways of treating the illness. She writes, “You know I can’t express emotions. I internalize; I grow a tumor” (Harrington, 2008, p. 67). In accordance with the social sciences, *anthropology* as a discipline has great emphasis on researching biological and cultural diversities. Anthropologists make attempts to compare and recognize the social behavior of one group to the social behavior of a larger group. These comparisons are intended to make the basic principles clear that are equal to common human behavior. Anthropology is the only field which has the characteristics to focus on non-western and tribal people.

At present, breast cancer is one of the major causes of women mortality in developing countries. A breast cancer sufferer and her family members face multi-dimensional effects of this illness from post diagnosis period to the survival stage. The role of care-givers for breast cancer sufferers in the treatment process is as crucial as the treatment itself. People have strong belief in spiritual and ritual healings. Most of the Pakistani families live in joint family and nuclear family system (Bilal, Tariq, Aleem, Shabbir, & Parveen, 2013). Present study found that in case of a chronic illness of one member, the whole family shows unity as a part of social norm in approaching and receiving treatment. Normally, the females are dependents on the male members of the family. All decisions such as selection of treatment and the healer are made by the male members of family. However in case of absence of male members in the family, the sufferer herself makes the decision. Because of the great influence of male members of the family in selection and decision making for the treatment, they are positioned as primary care-givers.

Following specific aims and objectives, the present research has used qualitative methods to explore and increase the understanding regarding illness and health beliefs of the women with breast cancer and their care-givers. Many women with breast cancer ignore timely diagnosis because of many social and cultural reasons such as lack of awareness regarding the severity of this illness, hiding illness from all others to maintain their public identity, avoiding check-up from male practitioners, having complete dependency on male members of the family and financial problems, and the absence or lack of screening facilities in small cities.

The symptoms of breast cancer are usually so common that people cannot understand the real illness. On appearing lumps, women move towards spiritual and traditional healers which cause late diagnosis and severity of their illness. Faith healers, who are mostly the descendants of saints of the shrines, diagnose that evil eye, black magic or pressure of responsibilities are the causes of illness and give treatments in the form of amulets with certain attached practices. Limited income makes them approach faith and folk healers only.

For them, spiritual healing is not only cheap but also a treatment without side effects unlike medical treatment. Many women with breast cancer take the appearance of tumor normal which causes delay in the diagnosis. Another belief regarding the illness among women with breast cancer is concealing of the female body parts. After the diagnosis of cancer, elders of the family make decision regarding the selection of treatment. This decision is usually made by the male heads of the family. In decision making, it is decided to get the entire treatment or to skip some of its steps. For example, some families avoid surgery of breast and get only chemo and radiotherapy.

Impaired body features give a great set back to the self-esteem of breast cancer sufferer. Loss of hair, sudden change in weight, wrinkled and faded skin, pain and disturbance of mind, and the damage of femininity in the form of losing breast not only damage their self-esteem but also hamper their normal social position as a wife, mother, and worker etc. Affected self-esteem stops her joining the social gatherings. Feelings and thoughts of the women with breast cancer showed their concern related to the body image or physical self. Concerns related to the body features greatly disturb hope and struggle which ultimately create negative body image in their minds about themselves. They lose confidence and stop to struggle for their survival. Impaired features and requirements of society make them stressful. Loss of hair, skin and breast give her feeling of ugliness. Feelings of the loss of beauty affect their control over senses. They make comparisons with the normal features of other people giving them psychological distress. Many factors are involved in the construction of their body image such as social, cultural, religious and environmental. The thought that a male always needs a normal and beautiful girl make the unmarried breast cancer woman distressed with negative body image in her mind about herself. The agonic feelings of housewives, who are breast cancer sufferers, cannot do inside and outside tasks of home making them depressed with their negative body image about themselves. Many young married breast cancer sufferers have negative body image about them and feel scared of their relationship with their husbands. Many create negative body image with the feelings that they are no more important in decision making in family issues. They possess different beliefs such as: they are punished by Allah; they are under the trial of Allah and they will be forgiven by Allah on the Day of Judgment as they have suffered badly in this world. Elderly women with breast cancer believe that after death with this bald head and pale skin, there will be no brightness on their face and the angel of good deeds will not come in their graves.

Besides the outer factors, some internal factors were also observed active in the construction of negative or positive body image among breast cancer sufferers. Many breast cancer sufferers create their negative body image by themselves because they keep thinking about their faded appearance and malfunctioning of the body parts. They keep making comparisons of impaired body parts with the normal body parts of others which make them create negative body image in their minds. Family members of a breast cancer sufferer also seem depressed because of the negative body image of the sufferer about herself. Negative thinking about herself leads her towards indigestion of food, lack of sleep, loose motions, weakness of eye sight due to extensive weeping, loss of patience and quarrelsome attitude. Negative image with depressed feelings makes her feel ashamed and puts her in inferiority complex which demolishes her personality as a whole.

This is in accordance with the second objective of the study, where the breast cancer women transform their roles and identities to maintain their social relationships. Women with breast cancer feel that disclosing of their illness will harm their social and professional position in the society and make their tasks of life unfulfilled. In an effort to hide their illness of breast cancer, they were seen using cap and head scarf to hide the bald head; further, they use make-up to hide the wrinkled and pale skin and padding of cloths in the place of breast to hide the damaged shape of their breast. With medical treatment, they also get faith and spiritual healing. They pretend to have a minor illness to save their jobs and self-esteem in workplace among colleagues and distant friends. They were found hiding it from their distant relatives and neighbours with intentions that their views will hamper their efforts for survival and the fulfillment of their tasks in lives.

This is apropos to the third objective of the study to describe the roles and behaviors of the care-givers during the treatment seeking process of the women with breast cancer. The care-givers of the women with breast cancer were classified into primary, secondary and tertiary care-givers. Family members were categorized as primary care -givers. Health care professionals or nurses were classified as secondary care-givers. Paid servants were classified as tertiary care-givers. Among primary care-givers, close relatives of the women with breast cancer such as mothers, daughters and husbands were seen more active in helping during the treatment seeking process. Family members provide social and psychological support to women to cope with her illness. It was noticed that illness is not attached with the sufferer alone but is attached with the whole family. Illness is considered as a bad time or a time of trial from Allah for the whole family. Elements of unity and sympathy were seen between women and her care-givers. Social support from the secondary care-givers such as health care professionals or nurses was also seen with its great positive and negative effects during the treatment seeking process. Their support was seen in the provision of information regarding the treatment process. Their role was important in making breast cancer women and their care-givers optimistic to receive complete treatment for survival. After observing the services of family members and nurses, the paid servants who were categorized as tertiary care-givers, were found serving these women and their family members carefully.

The fourth objective of the research was to find out the obstacles in the way of hope and struggle for treatment among women with breast cancer and their care- givers and its outcomes on the treatment seeking process. The social and economic conditions create hurdles in their access to the treatment. They feel shy to go for check-up to hospitals and deal with it through spiritual healing by visiting shrines and saints. The unavailability of screening facilities in town and small cities is also a hurdle in access to treatment. According to the doctors' estimations, a breast cancer sufferer needed 1.8 million Pakistani rupees (11,615.57 United States Dollars) for medical treatment from a private hospital, and it includes diagnosis to the post treatment check-ups. Moreover, it is not easy to pay it for a lower and middle lower class family. In government hospitals, medical treatment is free but initial tests are required from good private hospitals and are quite expensive. The unavailability of medicines in the government hospitals makes the primary care-givers approach private pharmaceutical stores. So, the treatment of breast cancer becomes a challenge for the whole family especially for the adult male members of the family. The absence of care-givers also works as an obstacle in the way to seek regular treatment. Pessimistic thoughts and views of people around these women and their care-givers also work as an obstacle in the treatment seeking process and hope for survival. Many women and their care-givers preferred female practitioners in hospitals. In the absence of female practitioners, they avoid seeking treatment which causes the worsening of their cancer. In a traditional society like Pakistan, females are considered a responsibility of the male adult members of the family. Although they support their family in form of household services and some cases as an earning hand, too yet adult males are considered the only bread winners of family. Being the responsibility of male adult members of family, they achieve a place of dignity in the family which is called *"Gherat"*. In case of diagnose of a chronic illness like breast cancer, the whole family especially adult male members of the family suffer from financial hurdles. The social, psychological and financial support of adult male members of the family is very essential in the struggle for survival.

Encouraging attitude of the practitioners, nurses and the family members of the breast cancer sufferer incredibly work in the remedy of her physical and mental illness. In the same way, their discouraging and pessimistic attitudes not only dissatisfy the sufferer but also damage her struggle for survival. Pessimistic thoughts not only damage the normal mental condition of the sufferer, but also has negative effects on the hope and struggle of family members. The illness of a breast cancer sufferer penetrates in her entire family and disturbs the normal living of all members of the family. Medical, folk and faith healers play a significant role in making her optimistic in getting complete treatment and survival. Practitioners frequently give hope even to the patients of the fourth stage saying, "*they are just helpers, Allah is the only giver of health*" and survival is possible. Optimistic and pessimistic words have great effects on the psychological and physical conditions of the breast cancer sufferer.

It was found that medical practitioners of private and government hospitals deal equally with the patients of low and high financial status. Patients also admire their equal behavior, but they feel discrimination and adamant attitude of the nurses of the government hospitals. However, they admire the administrative and nursing staff of the private hospitals for their good attitude. Breast cancer sufferers move in different government and private hospitals for tests, therapies and surgeries, so they have a comprehensive experience of the medical practitioners, and other staff members of the hospitals. Among the major reasons of the harsh behavior of nursing staff of government hospitals can be their dealings with a large number of patients on daily basis. Another reason can be the permanent status of their jobs and lack of direct observation from the heads of hospitals unlike the heads of private hospitals. For a successful treatment, the attitude of hospital staff is as important as of the healers. The good conduct of nursing staff makes the patient of a chronic illness and her family members get complete treatment. Many breast cancer women and their care-givers were not found happy with the nurses of government hospitals.

This is apposite to the last objective of the study, i.e., to collect folk narratives on alternative treatments, particularly spiritual treatment, availed by the breast cancer women themselves. Faith healers play a role of religious and spiritual healer. Among all 27 breast cancer women and their care-givers, majority was found seeking faith healing along with medical treatment. The faith healing included visiting shrines, making offerings on the shrines in form of cooked food, wearing amulets and reciting verses of the Holy Quran. They treat people with religious methods in form of [19]*Dums* (reciting specific verses of the Holy Quran for treatment) as well as giving amulets for wearing or tying on a part of body such as the shoulder or around the neck and waist. They recommend some spiritual activities to wipe out the effects of the evil

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[19] *Dum or Dums* refers to the visits of patients to the religious healer. In this visit, the religious healer recites holy verses of the Quaran, uses his or her knowledge learned from the elders or through experiences and *Duas (*prayers) of different prophets and finally blowing them on the face of the patient.

on health. These spiritual activities are performed by the sufferer herself or by her close family members. All the spiritual healers show their connection with religion making the beliefs of health seekers strong in this type of treatment. Seekers of spiritual healing have some specific thoughts such as, "Nazer *ka lag jana* or *Nazraran Jana* (caught by an evil eye or the eye of an envious), "*Saya hona"*, (under the effects of an evil spirit), "*Kam ni maari*" (a sufferer of workloads or heavy works in life) and "*Miskeen*" (a harmless and poor individual suffering from illness). Spiritual or faith healers are famous among people of all kinds of statuses. For them, faith and spiritual healing is more than just a mind healing and psychotherapy. The importance of these healing practices is considered as important as the medical treatment.

People do not approach psychotherapists; this need is fulfilled by their faith healers. Followers of the spiritual and ritual healers believe that they will get recovery in health by visiting specific shrines and descendants of the saints. They believe that amulets around neck will save them from the shadow of devil powers. They follow all the practices attached with the amulets given by the descendants of the saint believing that these practices will remove satanic influences from their mind and body. Many religious optimistic beliefs are psychologically internalized in people. This process of internalization of optimistic attitude towards the illness is done as a part of socialization from childhood to old age. In minor and major illnesses, the suffering is attached with religious ideas. Some very commonly found ideas are, "*Bemari Allah ki tarf say aazmaish hay"(*illness is a trial from Allah), "*Bemari say gunah jharrtay han" (*illness is a source of forgiveness of bad deeds) and , "*Peer bra ya Yakeen*" (faith is greater than the healer), *"Naa Omeedi gunah hay" (*pessimism is a sin). Such beliefs are strongly internalized in the minds of the people though they approach hospitals for bio-medical treatment, too. Some other important ideas which make the breast cancer sufferer strong and fearless are related to death. These ideas are attached with the religious belief, such as "*Moat barhak hay*" (death is an obvious fact), "*Moat zindagi ki hifazat kerti hay" (*death safeguards life), "*Moat zindagi ki amaanat hay*" (death is a faithful guard of life). People have strong beliefs in these local health narratives which are not mentioned in religion but attached with the sayings and good deeds of the local and distant saints. One major reason of people's trust in faith healings is its cheapness and its availability in all times and places. Faith healing with its attached practices like wearing of amulets and reciting verses of the Holy Quran give comfort to the mind of breast cancer sufferer, and they feel themselves capable of going through chemo and radiotherapies.

Because of the attached fame and dignity of the shrine, the descendants of saints behave in good manners with the visitors of all types of financial statuses. Their followers believe that the faith healers have no monetary purposes as the doctors have in their hospitals. Faith healers do not have check-up and treatment fee. Their followers believe that they are serving humanity for the pleasure of Allah instead of monetary purposes. For this reason, many people avoid medical treatment and prefer spiritual and ritual healings. They also believe that there are no side effects of these treatments. As Sontag writes about this illness, *"The fight is all inside one's own body*" (Sontag, 1978, p. 15). Faith healers give one very common view that, *"we are treating people for the sake of Allah to keep Him happy and not for collecting money*". This thought strengthens the trust of people in faith healers. Side effects of medical treatments such as indigestion of food, loose motion, lethargic body, fever and dull, pale skin and high cost of these treatments make the breast cancer sufferers suspicious about their survival.

Located in South Asia, Pakistan has total population of 207.774,520. Population consists of 106,449,322 males, 101,314,780 females and 10,418 transgender (Census, 2017; Gallup, 2019). The average monthly income of each household is 35,662 (RS.) and the average monthly expenditure of each household in medical care is 2134 (RS.) (Gallup, 2019, p. 5). According to thw estimation of The World Health Organization, Pakistan used 2.6 per cent on health of its total Gross domestic product in 2014 (WHO, 2017). Further, in the fiscal year of 17-18, it used 1.12 per cent of its total GDP. For the fiscal year of 2017-18, Pakistan's allocated health budget on health and nutrition was 12, 944 Million RS and for 2018-19; it was 13, 897 Million RS**.** (Gallup, 2019)**.** According to the Bureau of Statistics and National Health Accounts Pakistan 2015-16, health investment has been improved in health care professionals and facilities. By 2017, Public sector hospitals increased to 1, 211, including Basic Health Units (BHUs) 5,508, Rural Health Centers (RHCs) 676 and dispensaries 5,697 (Gallup, 2019).

The rates of breast cancer sufferers are increasing in developing countries. In Pakistan, out of 30.8 per cent of annual total deaths, 52,500 females die due to breast cancer (WHO, Cancer Country Profiles, 2014). According to some estimation, the percentage of middle class is growing in Pakistan. It is 40 million people that belong to this class (Indrawati, 2015). For a large population of 207.774,520, seeking medical treatment has become difficult. Although the treatment of breast cancer and other illnesses in government hospitals is free yet the cost of availing themselves of this treatment is quite burdensome. Despite availing themselves of free check-ups in government hospitals, transportation cost for approaching the hospitals, initial tests from private clinics, and purchasing of medicines from private stores due to their unavailability in government hospitals, all these add to the financial hurdles for people and they are unable to get proper and timely treatment. Many breast cancer sufferers move towards semi-government hospitals. Many get treatment in parts from different hospitals like check-ups from Military Hospital, and chemotherapy and radiotherapy from a government institute of Radiology. They change their hospitals according to their experiences with practitioners, nursing and administrative staff, too.

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Appendices

Appendix 1:

Semi-Structured Interview Guide with Breast Cancer Women

I Atiya Bibi student of PhD in Department of Anthropology at Quaid-i-Azam University Islamabad conducting a research on the topic: Lived Experiences of Women with Breast Cancer and Their Care Givers: An Anthropological Perspective. The research is a degree requirement. Kindly note that all the personal information will be kept confidential and will only be used for the purpose of the research. Your views are very respectable for me and it is also affirmed that there are no right or wrong answers, therefore I request you to answer to every point what you feel or believe genuinely. Participation in this research as a respondent is completely voluntary. You have right to take break or quit any time during interview. Thank you for your time and cooperation. I will not take any photograph nor will make any video. Your views will be used for academic and research purposes.
Any question if you have in your mind? Should we start now?

Can you please give me your demographic information? If **"yes"** then!

1. Name ___(your real name will not be mentioned in the research)
2. Age ___________________________
3. Qualification ________________________
4. Marital status __________________
5. No of family members___________________
6. Treatment Hospital/clinic/center where you are getting treatment____
7. Stage of cancer____
8. Your average no of visits in a month_____________________
9. Duration of each visit at hospital ____________________
10. Treatment hours_________________________
11. Wait hours___________________________
12. Monthly expenditure on treatment and hospital visits________________
13. Monthly income__________________
14. Independent Yes No

<u>Knowledge of breast cancer before Diagnosis and experience of Diagnosis</u>

How did you discover that you have breast cancer?

Did you went for screening or you discovered it by yourself?

Before your diagnosis you had information about this illness?

After the first diagnosis did you went for another screening for cross check?

At the time of its diagnosis at which stage it was?

Had you any information about its stages at the time of diagnosis?

How were you told that you have this breast cancer?

How were you feeling when you was assured that you have this illness?

How much time you took to decide for the treatment?

What were initial thoughts related to the attainment of treatment?

Were you independent in making decision regarding selection of treatment?

Did your family members decided type and location of treatment for you?

<u>Experience during treatment</u>

Are you satisfied with treatment?

How do you feel effects of treatments?

Did you choose the same treatment which your doctor prescribed you?

Were you given options of treatments?

Did your doctor discussed with you surgical treatment?

Did you take time in deciding for a treatment?

Did your doctors treated with you according to your financial status?

Did you think religious and folk healing is better than hospital treatment, If yes, then you did left hospital treatment?

How much awareness regarding this illness is important for all?

Have you felt changes in body features of your body?

Are you informed about the progress during the treatment?

Which type of physical changes you felt in your body?

Which type of thoughts you feel with breast cancer experience?

Did you experienced change in relationships because of this illness?

Did you felt that this illness has disturbed your public identity, if yes then how?

Have you left doing the activities which you used to perform before this illness?

What type of reaction you find in your family members, friends and distant relatives?

Has your illness affected your ties with family friends, if yes, then how?

Has your illness damaged your relationship with your spouse, if yes, then how?

Do you feel that you need more love and attention after having this illness?

How does you feel yourself as strong or weak, having this illness?

Have your spouse concerns for your appearance?

What does you feel about your appearance?

How did you think and feel about appearance of your body?

Do you feel difference in appearance of your body since diagnosis of breast cancer?

Are your impaired features having concerns for you?

Do you think you have to cope with challenges of breast cancer or you feel that you cannot do anything with this illness?

How you will manage alone if you have to cope with all the results of illness?

Do you find anything difficult?

Do you feel need of support group?

Do you have some suggestions for a new diagnosed breast cancer patient or even healthy women regarding this illness?

Are you interested in worldly affairs during this illness?

Do you find that after this disease still you have power in your opinion in opposition to the most of the people?

Do you give normal time to your social circle?

How do you see yourself having breast cancer?

Appendix 2:

Semi-structured Interview Guide with Medical practitioners

I Atiya Bibi student of PhD in Department of Anthropology at Quaid-i-Azam University Islamabad conducting a research on the topic: Lived Experiences of Women with Breast Cancer and Their Care Givers: An Anthropological Perspective. The research is a degree requirement. Kindly note that your views will be used for only study and research purposes so I would request you to answer what you believe genuinely. Your participation in the research as a respondent is highly valuable and is completely voluntary. You are completely free to take break or quit during interview. I am obliged for your interest and participation in my research. I am again repeating that your views will be used for research purposes not for any investigation against you.

Any question if you have in your mind? Should we start now?

Can you please give me your demographic information? If **"yes"** then!

1. Name ___(your real name will not be mentioned in the research)
2. Gender ___________________________
3. Age ____________________________
4. Qualification _________________________
5. Treatment Hospital/clinic/center where you are serving_________________________
6. Your specialization in any specific field____________________________
7. Your total working days in a month______________________
8. Your timing of work at hospital _____________________
9. Treatment hours__________________________
10. Your sitting days in Outdoor patient department in a week ___________
11. Your days of surgery in a week ___________
12. Monthly expenditure on treatment and hospital visits________________
13. Number of patients daily you check________________________
14. For how long you are working here_______________________

Knowledge of breast cancer before diagnosis among patients and informing them diagnosis of this illness

At which stage most of the patients come for diagnosis?

What do think what common reasons of late diagnosis are?

Do you consult with the patient after diagnosis of her breast cancer?

Do you use encouraging words for receiving complete treatment or left on the thoughts and choice of the patients and her family members?

Do you recommend the diagnosis breast cancer patients for screening tests in other hospitals for cross check?

Do you put options before the patients to choose the type of treatment or follow what you think better for the patient?

Does the patient understand when you discuss with her the needs for the treatment like timely check-ups and treatments?

Do the patients prefer lady practitioners and hesitate from male practitioners?

Experience during treatment process

Do all the diagnosed breast cancer patients take treatment or some leave without taking completer treatment.

What kind of reasons could be behind leaving incomplete treatment?

Do you give other medicines to cope with the side effects of treatment?

Which is the most reported treatment the patients suffer from its severe side effects?

Which are the major side effects of the treatments on the mind or thinking of the patient?

Which are the major side effects which affect body parts of the patient?

How much the chemotherapy takes a normal time?

Do you refer the patients towards psychotherapists?

Do you feel that primary care givers or family members of the patients need family psychotherapists?

Do you give importance to the patients who come with some references or you treat on the normal turn.

Do the patients show hot temper and behave badly with you?

Do the family members of the patients sometimes behave badly with you?

How do you handle the patients of hot temper to make them get complete treatment?

Do the survived patients follow post-treatment check-ups or left considering that they are cured?

How you make the patients and their care givers to get treatment and bear the side effects for successful cure?

Which kind of financial status mostly patients come?

Do they ask for financial support, if yes then do you have any foundation for the needy patients?

How you feel the mental condition of the patient?

Do you forbid them from taking herbal, folk and religious treatment?

Do you feel that your behavior put effects on the treatment of the patient?

Appendix 3:

Interview Guide: Body Image of the Breast Cancer women

This interview guide is for research and study purposes.
Date ____________________________________ Name ____________________
1) Sex: Male Female
2) Age: ________________
3) Weight: ________________ Height: _______________
4) Marital Status: Tick one option Single Separated/Divorced
Married Widowed
5) Stage of Breast cancer: Tick one option
First Second Third Fourth Survived
5) Current Employment Tick one option Unemployed Long-term sick leave
Employed or Self-employed Retired Student (Full-time)

6) Features Causing Concern: Description of the feature(s) of body which has been affected by the breast cancer disease and which you dislike or would like to improve.
Please tick the option if she wants dermatological procedure for the feature either now or in the future.

1st Feature:
Loss of hair due to chemotherapies, being bald-headed feels me ugly. Procedure sought
Now Future Not desire any procedure

2nd Feature:
Pale and dull skin of face, black dots/patches, scars on face and whole body, wrinkled skin of hands arms. Procedure sought
Now Future Not desire any procedure

3rd Feature
Damage of breast because of surgery. Procedure sought
Now Future Not desire any procedure

Estimation of the percentage of concern allocated to each feature
Tick one option from each disturbed feature

Loss of hair	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
Pale and dull skin	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
Damage of Breast	0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%

The time you spend thinking these 'feature(s)' in a day
7) On an average day, how many minutes or hour(s) do you currently spend thinking about your feature(s)? Please add up all the time that your features are at the forefront of your mind.
______ minutes or _________ hour(s) a day_______All the time
Please read the next set of questions below carefully and circle the number which best describes the way that you feel about your feature(s). Please read the labels carefully to ensure you are circling the number that reflects how you feel because some of the answers are worded in a reverse order.

8) How often do you deliberately check your feature(s)? Not accidentally catch sight of it. Please include looking at your feature in a mirror or other reflective surfaces like a shop window or looking at it directly or feeling it with your fingers.

Please tick an option

About 40 times   About 20 times   About 10 times   About 5 times
a day   a day   a day   a day

9) How much do you feel because of breast cancer and its treatment your feature(s) are currently ugly, unattractive or ‘not right’?

Very   Markedly   Moderately   Slightly
unattractive   unattractive   unattractive   unattractive

10) How much does your feature(s) currently cause you a lot of distress?

Not at all   Slightly   Moderately   Markedly   Extremely
distressing   distressing   distressing   distressing   distressing

11) How often does your feature(s) currently lead you to avoid daily situations or activities?

Avoid about   Avoid about   Avoid about   Never avoid
three quarters of the time   half of the time   a quarter of the time

If so, what do you avoid?

____

____

7

12) How much does your feature(s) currently preoccupy you? That is, you think about it a lot and it is hard to stop thinking about it?

Slightly   Moderately   Very   Not at all
Extremely preoccupied   preoccupied   preoccupied   preoccupied

If you rated you preoccupation with your feature(s) as 4 or above, for how long has it preoccupied you?” Months ________ or Years ____________

13) If you have a partner, how much does your feature(s) currently have an effect on your relationship with an existing partner?

Slightly   Moderately   Markedly   Not at all
Extremely

14) How much does your feature(s) currently have an effect on an existing or potential sexual relationship? (e.g. enjoyment of sex, frequency of sexual activity)

Slightly   Moderately   Markedly   Not at all
Extremely

15) How much does your feature(s) currently interfere with your ability to work or study, or your role as a homemaker? (Please rate this even if you are not working or studying: I am interested in your ability to work or study.)

Slightly   Moderately   Markedly   Very severely   Not at all
I can’t work   If so, how?

____

____

16) How much does your feature(s) currently interfere with your social life?

Slightly Moderately Markedly Very severely Not at all
If so, how?

17) How much do you feel your appearance is the most important aspect of who you are?
Slightly Moderately Mostly Totally Not at all

18) How noticeable do you feel your feature is to other people (if you do not camouflage yourself e.g. with clothes, padding and/or makeup) and the feature has not been pointed out to them)?

Slightly noticeable	Moderately noticeable	Markedly noticeable	Very noticeable	Not at all
(to a stranger less than a foot away)	(to a stranger about 3 feet way)	(to a stranger about 6 feet away)	(to a stranger passing in street)	

19) How does your feature compare to others of the same age, sex, and ethnic group?
a) Everyone has the same feature or degree of abnormality
b) Many people have the same feature or degree of abnormality
c) Some people have the same feature or degree of abnormality
d) Few people have the same feature or degree of abnormality
e) No one has the same feature or degree of abnormality

20) What do you avoid because of the way you feel about your feature(s)? Please read the situations below and in the second column rate the degree to which you currently avoid each of these situations on the following scale:

0	1	2	3	4
Never avoid	Occasionally avoid	Often avoid	Frequently avoid	Always avoid

I avoid going to a party or social gathering because of my disturbed features because of breast cancer	
I would avoid exercising in a gym or playing a sport because of my disturbed features	
I avoid being physically close to someone because of my disturbed features	
I avoid making love or intimacy because of my disturbed features (or only under certain conditions e.g. lights off or wearing your make up).	
I avoid certain types of clothes because of my disturbed features (please specify)	
I avoid certain types of lighting because of my disturbed features (please specify)	
I avoid looking at pictures in magazines or on television because of my disturbed features	
I avoid having a photo or video taken by someone else because of my disturbed features	
I avoid looking at old photographs because of my disturbed features. (Please	

specify if you have destroyed them)	
I avoid looking at my features in mirrors or reflective surfaces	

OTHERS (please specify)

____

21) Please read the list of activities below that you might do because of the way you feel about your disturbed feature(s) and in the second column rate the degree to which you currently avoid each of these situations on the following scale:

Behaviour Frequency

0	1	2	3	4
Never avoid	Occasionally avoid	Often avoid	Frequently avoid	Always avoid

I check my disturbed feature(s) in mirrors	
I use a particular light to check my disturbed feature(s) in a mirror (please specify)	
I check my disturbed feature(s) in other reflective surfaces (e.g. cutlery, windows, CDs) (Please specify)	
I check my disturbed feature(s) directly by looking at it without a mirror	
I check my disturbed feature(s) by taking photographs of myself	
I check my disturbed feature(s) by feeling it with my finger(s)	
I compare my disturbed feature(s) to others in magazines or on television and film I compare my disturbed feature(s) to other people I meet	
I compare my disturbed feature(s) with old pictures of my self	
I wear something to distract attention from my disturbed feature (e.g. jewellery, a tattoo) (Please specify)	
I change my posture to avoid my disturbed feature being seen at a certain angle. (Please specify)	
I hide my disturbed feature(s) with something (e.g. my hand, hat, scarf, baggy clothing, artificial hair) (Please specify)	
14 I use padding in my clothes to camouflage or increase the size of my disturbed feature. (specifically breast)	
I ask others to confirm the existence of my defect in my features	
I seek reassurance about whether my disturbed feature has got worse	
I seek reassurance about whether my disturbed feature is camouflaged (for example by make up)	
I keep changing my clothes before I go out I get my partner or family member to “help” me in camouflaging or checking my appearance. (Please specify)	
I keep measuring my all body feature(s)	
I use medication to promote breast growth	
I use medication to promote hair growth on my head	
I clean my skin more than most people	
I wear more make up than most people to hide my pale, dull and wrinkled skin of face.	
I use cover up stick for spots or blemishes	
I use facial peel, scrubs or saunas for my skin	
I bleach my skin	

Glossary

Gherat	A local term refers to the dignity and respect. In a traditional society it is generally used for the woman. Woman is considered part of dignity and respect for the family, community or tribe.
Mastectomy	A treatment in which a breast cancer patient goes through a total removal of her breast.
Lumpectomy	A treatment in which a breast cancer patient goes through a breast-conserving surgery (lumpectomy). It is followed by radiation.
Mehram	It is a religious belief which is largely followed by the natives. In Islam, *Mehrams* are called those men who have blood relationships with women such as their Fathers, brothers, sons, son's sons, daughter's son, brother's sons, sister's sons and have close affine relationships like husband and father of husband. Further in Islam *Mehram* is also that person with whom a Muslim woman cannot marry like father, brother, son, brother's son and sister's son.
bethak	Sitting places of the folk and religious healers where people come for healing.
Hujra	Sitting places of the faith or religious healers where people come for healing
Perda	veil
Shifa	It is a local term which is derived from Arabic and Persian language. It means restoration of health with the blessings of God.
Allah	In Pakistani society people use word in place of God, they believe that word God does not fulfil meanings of word Allah. As translation of God in National language Urdu is *Khuda*, it means a guardian. While word Allah has wide meanings but ninety are largely accepted in the religion Islam, like creator, provider, healer and well-wisher etc.
Shirk	Belief that there is more than one God in the world, and placing other

	Gods with one God.
Kufer	It mean denial to God’s decisions
Maghreb	Evening time
Maghreb ki Nemaz	Evening prayer offered by the Muslims
Hakeem	Local Physician
Na *omeedi*	Pessimism
gunah hay	sin
penri	(illness comes sudden
manray manry,	In great volume
chukni	vanishes
telin telin	slowly
Meethay	sweet
Chawal	rice
Halwa	names of a local sweets dish
Inshallah	*if Allah/God wishes*
Manat	Promised charity which is offered after the completion of the task, it is generally given in kind of sweet food like pudding and sweet colorful rice dish. It is distributed on the shrine where it is promised and affiliated with the acceptance of *dua* (prayer).
Yakeen	believe
Azamaesh	trial
Bemari	Disease
*Bhab*i	Brother’s wife, husband’s sister
Sada	simple

zindagi	life
guzaro	Live or spend
Ahadith	Actions of Holy Prophet (Peace Be Upon Him)
Karam	blessings
Darbaar	Shrine
Susraal	In-laws, family of husband, parents, brother and sisters and their children
maali	*financial*
madad	*support*
Elaaj	Treatment
Nazr lag gae	Evil eye or envious eye
dushman	Enemy
Tashkhees	Diagnosis
kismet	destiny
Taveez	amulets
Ayats	Verses of Holy Quran
Jadu toona	*magic*
Bandish	hurdles
Mureedains	followers
Duaa	good wishes
Dum or Dums	It refers to the visits of patients to the religious healer. In this visit religious healer uses his or her knowledge and recites holy verses of Quaran and *Duas (*prayers) of different prophets and finally blows on the face of the patient.

Shaitaan	devil
Asar	Effect or influence
Google	an herb laser
raza	Happiness
Peer Sahab, Kazzi sahib, Baba Ji, and *Shah ji*,	Local names of faith healers

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No. CE/2020- 1667

Dated: 06-07-2020

Subject: **Ph.D. thesis evaluation report**

Enclosed please find copy of Ph.D. thesis evaluation report (1st repo received through e-mail from **Dr. James W. Green,** Foreign Evaluator in respect **Ms. Atiya Bibi,** Ph.D. Scholar, Department of Anthropology for your informatio perusal.

The Supervisor is requested to share the comments of the external examir / evaluator with the scholar.

Controller of Examinations

Through the Incharge
Department of Anthropology

Recieved
8/07/20

Kindly share it
with concerned Sup
and the Studen

Dr. Rao Nadeem Alam
(Supervisor of the scholar)

UNIVERSITY OF WASHINGTON

DEPARTMENT OF ANTHROPOLOGY

28/06/2020

Syed Muhammad Aqil Gillani
Controller of Examinations
Quaid-I-Azam University
Islamabad 45320, Pakistaan

I write concerning the Ph.D. thesis of Ms. Ativa Bibi entitled *Lived Experiences of Women with Breast Cancer and their Care Givers: an Anthropological Perspective.* The thesis is an excellent one and for a number of reasons.

Conceptually, the author takes an interesting and useful approach: not just the patient's stories but also their relations with family, community, and caregivers. Equally important, attention is given to folk beliefs concerning illness and rituals both in and beyond the clinic. Ms. Bibi well demonstrates the power of an ethnographic approach to this important medical issue. "Thematic Inductive Practice" guides her research. Given the sensitive location of the illness in the body, the subject is rarely discussed by patients or families as this is seen as shameful. Thus seeking treatment is often delayed. Discussions with medical staff are difficult and often carried out by the husband. Said one, "A family member is just like an organ of the body and if he/she gets sick, other parts get disturbed" (p. 143). In fact, most clinical visits are family visits with the patient saying little. Discussions of breast cancer were especially difficult when working with male nurses and are often delayed or even avoided.

Both the family and even other community members jointly make the decision to seek treatment, especially with women living in rural areas. Describing how this happens is one of the strengths of this thesis. That information would be crucial to care providers, especially those who want to promote early disease detection and treatment for those in rural areas. The author has done a real service here in describing local oral traditions toward disease identification and treatment. The medical interview guide (Appendix 2) should be especially useful for that.

3/07/20

I am impressed by the richness of Ms. Bibi's thesis and the frequency with which she reports her interviewees concerns. She is obviously a good interviewer and ethnographer and her work is an important contribution to planning better health care for women. Her thesis is very good and she has earned her Ph.D.

James W. Green

James W. Green
Senior Lecturer

3/07/20

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QUAID-I-AZAM UNIVERSITY
(Examination Section)

No. CE/2021-1046 Dated: 01-07-2021

Subject: **Ph.D. thesis evaluation report**

Enclosed please find copy of Ph.D. thesis evaluation report (2^{nd} report) received through e-mail from **Dr. Vijayan K Pillai,** Foreign Evaluator in respect of **Ms. Atiya Bibi,** Ph.D. Scholar, Department of Anthropology for your information / perusal.

The supervisor of the scholar is requested to share the comments of the external examiners / evaluators with the scholar and send her report as supervisor to the undersigned through the Incharge, Department of Anthropology for placing the case before the Advanced Studies & Research Board for consideration.

Controller of Examinations

Through the Incharge
Department of Anthropology

for Supervisor and Student

Dr. Rao Nadeem Alam
(Supervisor of the scholar)

05/07/21

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University

Controller of Examinations <exams@qau.edu.pk>

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i, **Vijayan K** <pillai@uta.edu>
ontroller of Examinations <exams@qau.edu.pk>

Thu, Jul 1, 2021 at 3:19 PM

s Atiya Bibi

),
ed Muhammad Aqil Gillani)
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1/7/2021

ear Prof. Gilani:

ease find the eval of Ms Atiya Bibi attached to this email. Thank you.

ith best wishes,
d/-

ijayan K Pillai, MSW.,Ph.d., Dip. in Plg., FRSPH, FACE
rofessor
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Proforma for PhD thesis Evaluation by Foreign Examiner (S)

Name of Candidate: **Ms. Atiya Bibi**
Department: Department of Anthropology
Faculty: Faculty of Social Sciences

Title of PhD Thesis: ***"Lived Experiences of Women with Breast Cancer and Their Care Givers: An Anthropological Perspective."***

In the context of my accompanying thesis evaluation report, I recommended following for consideration in Advanced Studies & Research Board (AS & RB) of the University:

S. No.		Please tick (√) one
1.	**Acceptable/Pass:** Thesis (as it is) meets the required international standards for award of PhD Degree.	
2.	**Acceptable/Pass (with minor changes)** Thesis (with minor corrections as given in the attached list) meets the required international standards for award of PhD degree after minor revisions.	Yes x
3.	**Acceptable with major changes** The candidate may be directed to incorporate the major changes suggested in the accompanying evaluation report. The thesis may be resubmitted for re-evaluation by a local committee, constituted by AS & RB before the viva-voce examination is conducted.	
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1/7/21

	awarding M.Phil degree to the candidate after conducting local oral examination.	

Address of the Examiner

Signature of the Examiner.

Vijayan K Pillai, MSW.,Ph.d., Dip. in Plg., FRSPH, FACE
Professor
Editor, Social Development Issues (2010-2020)
Faculty Affiliate, Women and Gender Studies
School of Social Work
University of Texas at Arlington
211 South Cooper Street
Arlington, Tx 76019
Ph.:817 272 5353
EMail: Pillai@uta.edu

1 July 2021

Minor suggestions

1. First I want to congratulate this candidate for having written an excellent dissertation. The candidate throughout shows her mastery over the theories and methodologies used to explore several aspects of the subject matter. The skill with she has used the two (method and theory) to inform each other is simply admirable.
2. I have supervised 28 dissertations and served on at least dissertation committees during my career as at teacher at the university. I can only remember about four dissertations which just brought me joy reading . This dissertation is one of them. Please convey my congratulations to this candidate. She has a very bright career ahead of her.
3. Having said what I did, I have minor suggestion. I would like her add, a couple of paragraphs on what she feels are the limitations of this study.

1/7/21