Living with Breast Cancer and Experiencing Womanhood embedded within the context of ‘Self’ and ‘Disease’, in Islamabad Pakistan.

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Living with Breast Cancer and Experiencing Womanhood embedded within the context of ‘Self’ and ‘Disease’, in Islamabad Pakistan.

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Thesis to obtain the Master’s Degree in Medical Anthropology
About the title page

Titled as “Female Figure”, is a famous painting by Ustad\(^1\) Allah Bux (1895-1978). He is among the famous painters of Pakistan. He joined Master Abdullah at the age of five, who was the Mughal miniature artist, and at the ages of fourteen, Ustad Bux developed the skills to become a signboard painter. He then worked as the railway and theatrical painter for a couple of years. In 1914 he was employed at Bombay art studio and on his return to Lahore in 1919 he established himself as a commercial artist.

\(^1\) *Ustad* is a title given to respected people in honor of their work; it means the same as *Sir* in English language.
Dedication

I dedicate this thesis to my mother, Mrs. Rashida Saeed, who loved me, protected me and nourished my soul.

And to my beloved grand-parents, Mr. Muhammad Iqbal Chohan and Mrs. Zakia Begum, who saw a dream and waited until it came true.

And all the women who suffer from Breast Cancer: “All created things must pass, strive on, diligently” (Budha).

And to Prof. Dr. Stan Gielen, who supported me and understood me at his best.
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My grandparents who, despite their short term memory, never forgot to ask me about my research, thesis and writings and tried their best to make my life easier, with their never ending love, support and prayers,

Rest of my extended family,

Thanking all of you who made this possible is a very small thing to do but still thank you all for your help, support and guidance.
re: Edited painting of Ustad Allah Bux, “Female figure”
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Abstract
Breast cancer is the second leading cause of death among women in Pakistan (SKMCH). A large number of women in Pakistan are diagnosed with breast cancer at late metastatic stages (Khan et al., 2000), which is devastating for them and their families and makes the treatment more difficult. Cancer really is a silent killer and enroots itself deep inside its victims, though if found early it remains curable but in later metastatic stages, it is harder to treat and often is incurable. However, treatment generally improves the quality of life of the patient.

This study mainly focuses on the late diagnosis of breast cancer in women and their experiences with the disease and their bodies at the same time. In Pakistan, breasts are an issue of prestige and honor, as well as discussing about breasts makes them a taboo, holding immense importance in the culture and the lives of women. Therefore, I tried to seek into the lives of women and study their coping strategies towards their disease and their bodies.

This problem is approached through conducting an in depth study on the key concepts; body image and breast cancer, changed roles during the disease and treatment period, stigma and shame related to hair and breast loss, peer support and the socio-cultural practices that benefit or hinder the coping of women. In addition spirituality and religion are also analyzed as forming one of the major parts of coping mechanism.

The main findings of the study include that breasts hold importance in the Pakistani society. A woman’s dignity, pride, honor and prestige are related to her breasts and covering them and protecting them also enhances her family’s honor. Furthermore, women with breast cancer (who had to undergo mastectomy) are an acceptable figure among the society. However, women actually undergoing mastectomy feel it hard to accept and adapt to their new selves. Most of the studied women are satisfied with their body images before the disease and found it comfortable to adapt with their breasts during puberty, but learning to live without their breasts is painful, distressing and hard to accept. Women feel deprived and impaired though later they found methods to cope with their disease.

Religion and spirituality was the most common method used for coping with breast cancer. Women interviewed reported that reciting the verses from the Quran helped them think positively. Women also
used sharing of their feelings as a coping method, however, sharing was difficult at times due to the inability of ‘significant others’ to understand the pain and misery of these women. At this time traditional healers proved to be psychotherapists as well. They provided attention; care and concern to women that helped them come out of their distress.

Breast cancer has a great impact on the lives of women, physically as well as psychologically. Women fear the illness itself, its treatment, reoccurrence and then the greatest fear, death. Breast cancer in Pakistani society is misjudged to be the second name of death that induces a great depression in women once they learn about their disease. Secondly breast cancer is also misunderstood as contagious which results in a changed perception of disease among other society members. This also induces stigma among society. Felt stigma arising from hair and breast loss hindering the social activity of women, which negatively impacts their coping. This also brings a need for isolation which at times has positive results for women. However, most of the time isolation results in despair and more distress. Here again women use spiritual healing as a common strategy to overcome these feelings of emotional instability, despair, loneliness and distress.
**Prologue**

This research stems from the experience and the time I had spent with my mother accompanying her through the treatment for breast cancer. Unfortunately, she did not successfully recover from the disease; however, treatment has worked out for many other women who have survived from breast cancer. My research salutes all those women who were encouraged to undergo the tough treatment and aims to serve as an inspiration for those women who hesitate to do so.

While I was planning and scheduling my research, my mother was undergoing her treatment and before I started the research, she passed away. It was an unbearable loss for me that led to an empty space that will never be filled again. It was her idea that motivated me to conduct my research on breast cancer and the survival experiences of women. Every survivor had a lot to share and tell her experiences to other women going through the same troubling times. Although I did not record interviews with my mother formally, I have quoted her at many places as she saw the things and explained them to me in her own way. She kept a diary with contacts of other women undergoing the treatment at the same time and some notes explaining the slight track changes and combination of therapies for every individual patient. There were hundreds of entries in her diary from women all over Pakistan; however, due to time and resource limitations, I selected the research group from women in Islamabad only.

I had already decided to look for my informants through snowball technique. I had a few contacts and a good rapport with them and as discussing my research and its outcomes, they had agreed to talk to me. I contacted all those women but received mixed replies when I began the research process. Some had already expired as I prepared for my fieldwork while some were seriously ill and had been admitted to the hospital and the others refused to discuss their problems, their family had some reservations and they did not want to talk about them. During my stay, I often used to call them and ask about their health or pay visits along the way and every time they said, ‘this won’t change our minds’.

After recovering for a short while, I started the “hunt” for respondents again. Finally, I got in touch with my mother’s homeopathic oncologist who referred me to some women interested in discussing their problems related with their disease. This helped me finish my search for informants and start with the research. Out of the twenty-two respondents that I approached, ten women agreed to participate. I chose

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2 She was employed at a medical college as a senior lecturer and therefore had adequate knowledge and interest in the disease.
focused group discussions and interview techniques to draw my data from the field. The main concepts I used in this research were body image, the relation between the female body and the disease, changing roles and support in the society, socio-cultural factors affecting the disease perception among the society and stigma related to breast cancer. I tried restricting my fieldwork to the interactive side where the interaction with patients was of their choice and there were minimal influences on my part. By doing so, I gained their confidence, in my work and in me, and minimum stress was induced among the patients. The research duration was a limitation of the study, but for an exploratory study it was interesting to finish it in six weeks. It took me more time than expected to transcribe the interviews and analyze them due to my sensitivity to the topic.

I was conscious about the gravity of its sensitivity for women as well, and that is why I tried not to express my grief and sorrow to the women as much as possible. It was difficult to discuss their private lives and their self-satisfaction on their “new selves”. They said they felt like different persons now but most of them failed to explain in what way they were different from other people around them. Women were happy with their lives but losing a breast was surely devastating. Younger women were more interactive than the older women were. Younger women were also more amicable, amenable and confident when answering the questions. With an exception, elderly women were found more interested in speaking about treatment choices and the methods they used to cope, while younger women found it hard to discuss treatment choices and the pain they went through. I also found many similarities with previous findings discussed in literature coming from western cultures. Overall women had more discrete issues to discuss than I expected.
Figure: Islamabad
1. Introduction and Background

Cancer today is an emerging problem in economically developing countries. In the last two decades cancer has shown a striking increase in the incidence rate worldwide, partially due to improved diagnosis (Bhatti 2007:1) and an increasing proportion of old age people (Parkin 1994; Bhatti 2007:1).

It is clear that cancer will become an increasingly important challenge to health services of developing countries in the coming decades. Not only is the population increasing, it is also aging (P. Boffetta and D. M. Parkin 1994:81).

Cancer occurs due to the malfunctioning of body systems; medically it is the uncontrolled growth of cells that can happen at any site within the body. Like many other cancers, breast cancer is one such type of uncontrolled cell growth, targeted at women’s body parts that are sexually symbolized and noted as the dignity of a woman at the same time, particularly within Pakistani culture. Breast cancer has become a major health issue and therefore has led to concern worldwide (WHO 1998). However, recently an increase in the incidence rate in developing countries has grabbed international attention (Ahmed 2006: 2). Worldwide breast cancer is the most common cancer among women (WHO 1998). As Parkin (1994) argues, breast cancer mortality and incidence are increasing among young women, as was predicted in the 90s; “[t]he cancer incidence rate will increase ten folds in the coming years, worldwide” (Pisani 1992: 11).

It is the most common and dreaded malignancy in females. It is rare in women under 30, but occurs more frequently in later years. Men can also develop breast cancer but is uncommon. Amongst women, breast cancer leads all other cancers i.e. 28 percent and is the second leading cause of cancer death. It occurs for 19 percents of all new cases of female cancer. (Shaukat Khanum Memorial Cancer Hospital, (SKMCH) 2007).
Research and ongoing studies present a wide range of factors that cause breast cancer and how it is affecting the lives of people among the western populations; however, no study reports the experience of women undergoing the treatment from Pakistan, a factor that I have remedied through my research.

1.1. Breast Cancer in Pakistan

Among all the diseases affecting the Pakistani population, cancer is the second leading cause of death (Tovey 2007:652; Ministry of Health 2004). In Pakistan, out of every nine women, one surely will fall victim to breast cancer, out of every twenty-seven women suffering from breast cancer, one dies (Khan et al. 2007:1). Ahmed et al. (2006) argue that the burden of breast cancer in Pakistan is very high and more than half of all the cases reported are at later stages (Bhurgri et al 2006:126; Hussain et al. 1996; Ali et al. 2003) that result in higher cases of mortality. In 2008, approximately 80,000 cancer patients registered with Shaukat Khanum Memorial Cancer Hospital Lahore (SKMCH), one of the main hospitals specializing in cancer treatment (SKMCH 2008). Of all the cancers, breast cancer is most common among Pakistani women and it is the leading cause of death (SKMCH 2008). Each year 100,000 Pakistani people develop cancer out of which 7,000 to 10,000 new cases are present in Karachi only, the largest city and commercial capital of Pakistan. In Karachi 34.6 percent of all cancer cases among women are suffering from breast cancer (Ahmed 2006:2; Tovey 2007:654; Bhurgri 2006:127). The incidence rate in Karachi was 69.1 breast cancer patients reported among 100,000 women, at stage III and IV, averaged over 1998-2002 (Ahmed et al. 2006:2). By the end of 2008, the figures of breast cancer changed to 40,000 deaths per annum and 90,000 new cases countrywide (Daily Times report 2007). WHO estimated that within the coming years this estimate will be 150,000 new cases annually (Sethna 1999).

In 2007, an estimated 90,000 women reported suffering from breast cancer; half of these women reported were in Punjab province alone (Daily Times report 2007). Punjab is the second largest province
of Pakistan, with an estimated population of a hundred million people (World Gazetteer 2008). Only 10 percent of these women from Punjab seek treatment, the rest of them die untreated within five years of diagnosis (Daily Times 2007). The report also consists of an interesting observation by the controller of examinations, University of Health Sciences, Dr Junaid S. Khan, who stated, “...it was unfortunate that in Pakistan it was still considered a taboo for women to take care of their bodies…. women were afraid to talk about breast cancer” (Daily Times 2007).

In an article about breast cancer awareness of women in Pakistan on the regional level, Prof. Ruffina Soomro, a breast cancer surgeon and consultant, noted that 68 percent of all cases were present in urban areas, while only 32 percent were present in rural areas (Aligi 2009). This may be an attribute to the better care and diagnostic facilities in the cities though the rural population constitutes of two-third of the total population. In addition, urban women are more focused on their bodily health and image than rural women.

Khan et al. (2006) have contributed a lot in awareness campaigns for women at risk of breast cancer. Khan et al. (2006) present a commentary in cancer screening in Pakistan that claims, “[i]n Pakistan, a large proportion of cancers present at an advanced stage” 3 (Ahmed et al. 2006:2; Bhurgri et al. 2006:126). The epidemiology is difficult to describe due to an inadequate tumor registry system. Despite improved diagnostics, there is a delay in the diagnosis of breast cancer at early stages linked with inadequate screening programmes for breast cancer, a nationwide problem (Ahmed 2006:2).

1.2. Prolonged/ Late Diagnosis
Ahmed et al. (2006) argue that breast cancer risk factor management and awareness among women can affect the diagnosis process. Due to scarce understanding and awareness campaigns, previously the

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3 It is noted that among the total number of diagnosed patients with breast cancer annually, more than 50 percent of cases are premenopausal (Salem et al. 2007), though the risk of breast cancer increases after menopause, hence requiring an initiative for breast self-examination.
disease was not reported in time, and therefore a cure not possible. “The most pragmatic solution to early detection lies in breast cancer education of women” (Ahmed et al. 2006). However, to date women in Pakistani culture remain reluctant to get themselves diagnosed for breast cancer though the prognosis is far better than it was ten years ago. In 1995, the rate of survival after breast cancer treatment was 53 percent (Bhurgri et al. 2006:127) whereas in 2008 it is 85 percent after five years of treatment.

Various factors are involved in delayed cancer diagnosis; for example, Pakistan has a different risk factor profile than other countries, there is insufficient awareness about the symptoms of cancers in general, screening interventions are not enough to proceed and countless socio-cultural factors may prove to be a barrier for seeking help. With breast cancer, governmental programmes are actively trying to create consciousness of breast cancer through news, media and articles published often in newspapers. The government has introduced awareness of breast self-examinations and stimulated women to report lumps; however, women still do not do so. There is no study available on why Pakistani women are reluctant in reporting breast lumps when found, or why there is a delay in diagnosis. For this we need to conduct research among women suffering from breast cancer. Women experiencing breast cancer have a lot to tell. This study aims to explore the experience of women undergoing the illness trajectory and facing a long devastating situation.

1.3. Economic Situation
In Pakistan, in 1999 0.7 percent of the budget was spent on health and only 55 percent of the population had access to modern biomedical facilities (Malik et al. 2000). In 2006, 1 percent of the total Gross Domestic Product (GDP) was spent on health as reported by Tovey et al. There is an expected 56 percent increase in the health budget during the years 2009-2010 allowing everyone to have access to biomedicine (Daily Times, May 24, 2009). The low health budget greatly affects the type of treatment cancer patients receive. A low medical budget also links to late diagnosis and lesser diagnostic facilities.
Dr Samina Hashmi explained to the Daily Times (2008), that the government was spending a minute amount on health and “[i]t is impossible for these tiny allocations to create a healthier nation.”

Cancer treatment is expensive, each chemotherapy cycle costing between 60,000 to 500,000 Rupees (7500 USD to 6000 USD). Both diagnosis and complete prognosis are very costly in a country where almost 50 percent of the population is living on less than 2USD per day. SKMCH (a private charity hospital) supports patients who cannot afford the treatment. In the year 2008, they supported 70 percent of all patients financially (SKMCH 2008). It would be interesting to know how the lack of funding affects the type of treatment choice people have. The lack of funding for breast cancer treatment and awareness ultimately affects treatment choice and late diagnosis.

1.4. Cancer Centers and Treatment in Pakistan
Besides many general public hospitals, there are two specialized public cancer hospitals, the ‘Institute of Nuclear Medicine and Oncology’ (INMOL) and the ‘Nuclear medicine Oncology and Radiation Institute’ (NORI) while ‘Shaukat Khanum Memorial Cancer Hospital and Research Centre’ (SKMCH & RC) is the most renowned in the public and private sector. Inaugurated in December 1994, it serves as the specialized cancer hospital in Pakistan. The Agha Khan University Hospital established its cancer surveillance and registry centers in 2000. It covered a wide range of the Pakistani population through 64 centers in 2006 with an estimated increase rate of 10 centers annually (Bhurgri et al. 2006:125). In other hospitals, later specialized clinics were established for outpatients and were extended for inpatients as well. SKMCH treats a wide range of patients coming from all four provinces of Pakistan. However, out of a staff of 41 doctors, only eight specialized female doctors are working in different departments.

One presumption of delayed diagnosis can be the presence of these male oncologists verse female oncologists. Women may also avoid diagnosis due to the involvement of ‘touch and sight’ of a private part of their body. Breast lumps and cysts are quite common among women in Pakistan, ranging from
the age of 13 to 50+. Depending upon various factors, these women do not report their lumps or other symptoms. Once these women are diagnosed, problems start in treatment seeking and factors that affect the choice of treatment. Problems start one after the other.

First, the diagnosis takes plenty of thinking due to various reasons such as the woman’s body being subjected to the presence of male oncologists, husband or family’s will and exposure of private body parts. If diagnosed, treatment choice plays a role. Treatment highly affects the body image and general well-being of women and their families. Treatment is often uncomfortable, invasive and mainly involves having a mastectomy that leave women disfigured, hence, rupturing overall self-satisfaction. Women suffer physically and psychologically while being treated for the disease (Vilhauer 2008:256). Women face many difficulties once tracked with breast cancer which may prolong treatment recovery.

Treatment, itself, is not only hard physically but it is also psychologically painful (Helms 2008). Women undergo severe and violent therapies and suffer with different problems during and after the treatment. Part of the treatment is a surgical procedure called mastectomy, removing one or both breasts, something that cannot fully be replaced, however, breast reconstruction is a very popular surgical method to overcome the mastectomy disfigurement (Frierson 2006:77). The methods of mastectomy have improved greatly but they remain a challenge in acceptance and “living with it” experiences of women. Although with the help of reconstruction and prosthesis women find themselves in a better position to overcome the loss, it is not possible for all women to undergo plastic surgery depending on their financial situation and the will of male members in their family.

Nowadays there are also breast saving surgical procedures but during the research, I did not hear from any doctor or patient about these practices in Pakistan. Other methods are radiotherapy, chemotherapy and hormonal therapy, also called endocrine therapy, which are chemically violent and often invasive,
allowing biomedicine to be perceived as violent and iatrogenic (Bode 2008). One of the consequences of therapy may be feeling emotionally low and deprived. Some other conventional treatments of breast cancer involve traditional herbal medicine, spiritual healing and homeopathic medicines (Shaikh 2005:140; Tovey 2007:654). These conventional treatments are widely accepted and practiced among the Pakistani population (Malik et al. 2000:156). The physical and psychological distress that these women face may push them towards alternative treatment. Women and their families place a lot of effort on coping with their disease and their bodies.
2. **Focus of the Study**  
Initially the focus of my study was ‘coping’, how women coped with their illness, their bodies and their societal obligations. I was interested in exploring the perception and experience of women with their illness and their self. My mother’s illness inspired me to dig into the lives of breast cancer survivors. However, during the study many other important issues popped up and I decided to cover them as a part of the study. Other topics were as important and linked to coping, these include the late diagnosis and the taboos linked with the disease, stigma and shame related to breast cancer, men’s perception about the illness and financial matters affecting the treatment choice of people.

2.1. **Late Diagnosis/ Lack of Female Doctors**  
It is reported in the literature that Pakistani women are diagnosed in the later stages of breast cancer. I was interested in the delayed diagnosis of women due to my past experience and background knowledge about the culture and society. This knowledge allowed me to predict that there might be a link between late diagnosis and male doctors, which is intriguing and important since late diagnosis more often leads to death.

2.2. **Taboo**  
Socially women are well protected and breasts are confidential issue for both society and women. In Pakistani society a woman is often subjected to family prestige and honor. It is a taboo to discuss and talk about private problems openly in society especially for women. Therefore, female bodies and related problems such as breast cancer are not discussed. Due to these societal taboos and limitations, women suffer from many problems that are not disclosed until a point where women cannot hide them anymore. These societal taboos may be a reason that affect diagnosis, treatment or even seeing a doctor and thereby result in worse side effects.
I felt a need to study all these factors relating to women and breast cancer among the Pakistani population. The main aim of the study was to investigate how the meanings and perceptions of the female body affect the illness experience and treatment seeking behavior of women with breast cancer. I felt a need for this study that aims at exploring the experiences that women have of their body image and its impact on their illness, how women felt once diagnosed with breast cancer, in what ways women prepared themselves to cope with their illness and treatment experience and how they maintain their self-esteem.

2.3. **Objective**

To date there is no evident study on women’s experience with their body and its reflection on breast cancer in Pakistan. This study aims to analyze how women feel about themselves and the disease that is so closely associated with their “private” body parts. In addition, I elaborate on how men and women in general see and perceive the female body and how this perception has an effect on women suffering from breast cancer and their coping. The study also discusses the psychological stress of affected women, induced by the environment due to social-cultural practices.

2.4. **Questions**

The core question this research tries to answer is the socio-cultural understanding of the female body and its impact on the experience of breast cancer in Pakistan. I strive to give insight to the understanding of the female body and female image in Pakistani culture. In addition to the general perception of a woman in the society, how does the society view mastectomized\(^4\) women? How do women experience their disease, its diagnosis and its treatment? What factors affect treatment choice? How do women cope with the diagnosis and treatment? How do their families understand their illness? How do women cope during social gatherings, with visible stigma? In addition, how do women adjust to their identities and changed roles? This study focuses on women, their agency, and their resilience.

\(^4\) I use the term *mastectomized* for the patient’s post mastectomy status.
3. Concepts

3.1. Body Image, Female Bodies and Breast Cancer
Helman (2007:19) describes body image as distinctively formed in every individual mind partly due to cultural and social backgrounds. Building a body image of oneself is also dependent on the social and cultural practices of a region or a family. Thus, body image is the perception of one’s body, as one wants it to be or as one likes it to be and how one wants others to see it or how one believes that others may see it (Helman 2007:19). Body image constitutes multiple dimensions including physical appearance linked with psychological phenomenon. Body image is also “…..to perceive some parts of body as public, and others as private; … to view some bodily functions as socially acceptable and others as morally unclean” (Helman 2007:19).

Female bodies are noticed by the presence of breasts, breasts that are the dominant characteristic features of the female body; breasts shape the body image of women. Breasts being a body part symbolized as the dignity of a woman and as a sexual entity at the same time in Pakistan. As Dr Soucasaux (2004), a Brazilian gynecologist argues in his article, ‘Women’s experience of breast’, breast are the only sex organ, protruding in the space and therefore being a part of a woman’s external body image. However, breasts are also perceived as ‘public’ in western cultures, as shown in ‘A history of breasts’ by Yalom (1995), who wonders, ‘Who owns the breast?’. Dr Soucasaux also argues that it is dominant in patients that women get nervous and confused during the pelvic examinations while in breast examination, women are more relax. However, for Pakistani women, this may not be the case.

In Pakistan, women are as sensitive about their breasts as their intra-pelvic region (as observed through my research). Breasts may bring honor and shame to a woman at the same time. Having breasts means a
lot to women as this completes their womanhood, however, they are the most “private” body parts visible externally. Though visible externally, women in Pakistani culture try to cover their breasts with their dressing. This is culturally and religiously valued. Girls are socialized to protect their breasts from ‘evil eyes’ \(^5\) with the help of a veil or long shawl (chaddar\(^6\)).

\(^5\) A belief that the evil eyes of other people can create problems in the future life of girls.
\(^6\) A very long shawl that covers a woman from head to knees so that very little is visible.
Figure: Communication
A young Pakistani girl veiling her face as she poses for a photograph

A woman’s body in Pakistani society is more collective than individualistic and it is culturally a taboo to speak and discuss about the female body, in specific about breasts. In contrast with American society, bodies in Pakistan are similar to Fijian bodies (Becker 1995:46); they are embodied in the culture and society. Women largely see themselves through the eyes of their family and peers and consider it religiously a taboo to talk and care about their bodies. For a woman it is compulsory to cover her breasts in a way that no one can directly see them, it is a cultural and religious taboo to show off or discuss breasts and sex organs. Talking about one’s own body or seeing oneself is considered a great sin.

With the modernization of Islam and Pakistan (Kumar 2006; Raja 2007), the trend of body veiling is changing but still strictly practiced in rural settings where women cannot leave their homes without a chaddar in contrast to urban women (Raja 2006:57). Women in rural settings are considered social entities rather than individual mindful bodies, whereas in urban settings many women are now being independent and care about their bodies. Traditionally urban women also use a chaddar to cover themselves; however, the new trend in urban cities is leaving behind the traditional value of veiling and replacing it by a small scarf (Raja 2006). Young girls find themselves comfortable with scarves. The purpose of veiling is to protect the female body especially the breasts and the hips of a woman that serve as eye-catchers for men in the society. The scarf does not serve this purpose; it is considered a symbol of modernity. Despite the new trend, a large group of urban women still experience their bodies as collective and dependent, hence they wear a chaddar and protect their bodies.

Usually in Pakistan, young girls in their teens start to develop interest in fashion and various outfits that complement their figure. They become conscious and aware of their external images and try to improve them continuously. Girls shape their body image with the perception of breasts as an attraction criterion.
Elder women in Pakistan develop their ‘self and body image’ in accordance with their husbands. A woman sees herself as beautiful and attractive if she satisfies her husband. Women feel complimented about themselves when their husbands appreciate and value them. Many women facing infidelity and inadequate attention from their husbands develop negative self and body images resulting in serious health and psychosocial problems.

In modern times, however, the worst stress-induced threat to women is breast cancer, which may alter their bodies permanently. Breast cancer is a dual threat for women by being life threatening as well as impairing the body eternally, causes physical as well as prevalent psychological problems (Elema 2001). Helms (2008) discussed the body image issues among women with breast cancer and found that the concern of disfigurement was so intense that it could alter the treatment choice for breast cancer. Vilhauer (2007) presented a study of experiences among Caucasian women suffering from breast cancer and reported that the worry of stress as an effect of treatment made them more distressed about their illness. The knowledge that stress could progress their disease, made them terrified and they feared the related debilitation. I will explore this concept of stress and fear later on.

3.2. Changing Roles
A person medically listed as ill enters the sick role (Scambler 1990). A sick person is then allowed to deviate from normal social behavior. The normal role of an individual in the society changes to a sick role where the individual is not responsible for his condition and therefore is free from normal responsibilities (Scambler 1990). Culture gives meaning and labels the disease, whereas society embodies the disease into roles. The disease changes the social roles of breast cancer patients in the society. During the treatment, women suffer physically due to violent reactions to medication and are unable to continue their normal routine life (Vilhauer 2008:253). Another problem women come across during treatment is fatigue. Fatigue leaves the women no other choice than changing their role from a
normal person to a sick individual meaning that they are no longer able to take care of themselves or their families. They are not fit and cannot fulfill their mandatory household tasks anymore. This causes distress, depression and anxiety in women. Due to these circumstances women require other family members to look after them, thus caregivers and care-providers become care-acceptors and previously care-acceptors become care-providers.

In Pakistani culture, women are the backbone of a household. They form a network of the family. A mother takes care of her children, her husband and her in-laws. Similarly, the males are socialized to work outside the home and support the family financially. If something happens to the female, the whole family is disturbed as food and other necessities are the basics of a living. While if something happens to the male, the family is disturbed financially as money is the requirement to buy the basics of a living. Nevertheless, there are urban women, employed and supporting their family financially as well as committed to their household chores. Breast cancer and its treatment affect diversely the variant groups of sufferers. Women are distressed, because of changed roles and want to recover quickly; however, if delayed their self-esteem is affected.

3.3. Stigma and Shame
As soon as a person is labeled as ill, he or she enters the ‘sick role’. This ‘sick role’ changes the perception of ‘significant others’. People suffering from severe illness become obsessed and stubborn; it is part of the illness. However, patients soon perceive themselves as being isolated; therefore stigma also enters the boundary of social activity. Scambler (1990) defined two types of stigma. One is enacted stigma, the real marginalization that occurs on the basis of having an illness. The other is ‘felt stigma’ that consists of shame caused by having a certain illness on one hand and fear of ‘enacted stigma’ on the other hand. Felt stigma is found to be more influential and important for ill individuals. Even if enacted
social stigma may be absent, patients with a certain illness may undergo ‘felt stigma’. This may lead to hiding a shameful part of them and end as an inferiority complex (Wales Institute 2009).

In a study by Rosman (2003), she interviewed 34 people. Initially she wanted to study fatigue and the coping experience of patients during the treatment. However, she ended with answering another important issue related with cancer treatment, alopecia. She found that baldness discredited patients. When alopecia was visible to others, stigma was also visible. Patients used wigs to hide their hair loss and camouflage their baldness and shame. Hair loss was an inevitable side effect of chemotherapy that induced stigma. While in Pakistan, female patients use caps or head veiling to hide their baldness, lesser women use wigs to gain the same effect, in an attempt to hide their disease from others.

Studying other literature in Urdu I found that patients suffering from any illness self-presumed stigma. Some websites show that social stigma against cancer patients really exists (Curtin 2004). Patient forums adopted by some countries are trying to end social stigma related to cancer. However it still exists in many circumstances as Sinnex (1995) points out, stigma and isolation affect the treatment and recovery stage of an illness.

Until now, people with cancer were often forced to face their disease alone, isolated by society's fear and loathing of "the Big C." Family members sometimes cut ties with the cancer patient, or lob criticism. (Sinnex, 1995)

In men, one of the most common cancers is lung cancer where men feel stigmatized due to the relation of lung cancer with smoking (ACS News Center 2004), although even non-smoking men also suffer from lung cancer. People perceived others holding them to be responsible for developing the disease (ACS News Center 2004.).
In women, breast cancer is the most common and heavily stigmatized cancer in developing countries like Kenya (Neondo 2003), Egypt (BUSINESS WIRE 2009) and Pakistan. A patient from Kenya, Julia Akinyi Mulaha, was shocked and devastated when she learned about her breast cancer not only due to the disease but also due to attached stigma (Neondo 2003). At one account Mulaha says that she would have joined dying with hundreds of people who died because of the myths and lacking knowledge surrounding breast cancer making it synonymous to death (Neondo 2003).

Yet in Uganda, stigma happens due to insufficient acquaintance with breast cancer (Kabweyere 2009). Due to minimum knowledge, the disease is associated with sorcery, witchcraft and curses where women die within five years of breast cancer diagnosis. Breasts representing womanliness creates another stigmatizing belief; after mastectomy women are found to become less attractive and inadequate knowledge about prosthesis and breast reconstruction contributes to stigma against the womanliness of mastectomized women (Kabweyere 2009).

In addition, women think that breast examinations may create problems at their home and between their husbands as witnessed by a health specialist, Knaul, while a team trained rural Mexican women for breast examinations (Neergaard 2009). Women further thought that raising the problem with their husbands may result in financial crisis, thus breast cancer becomes the disease of poverty (Neergaard 2009). The article concludes the problem that breast cancer in developing countries is now striking younger women and stigma attached to breast cancer is equivalent to poverty (Neergaard 2009).

While I observed enacted stigma in Pakistan during my stay with my mother, people presumed breast cancer as a contagious disease. They refused to eat from the same plates or use the same glass\(^7\) as my

\(^7\) It is customary in Pakistani families to share the utensils among siblings or close friends; however, people are often afraid and reluctant to do so when somebody is diagnosed suddenly with a terrifying disease.
mother. I also observed that other cancer patients\(^8\) felt isolated and left out. Their families would go around and shop while patients would sit and wait at home. However, with the perception of breast cancer as being contagious for some people, it could induce stigma in the overall society as well. I felt that looking at ‘felt stigma’, which is more important at the individual level, would be interesting and informative since there is no data available on ‘felt stigma’ among breast cancer patients from Pakistan.

3.4. Socio-Cultural Factors and Peer Support
Other factors involved in diagnosis and treatment may perhaps also be considered such as socio-cultural and the socio-economic backgrounds of women (Azaiza 2008:35), gender relations, personal life and sexual relationships (Andersen 2007:3151; Ashing 2003:38; Azaiza 2008:36). Socio-economic conditions are crucial and affect the choice of treatment altogether with gender roles and power relations, as one of the characteristics of Pakistani society is male dominance. Males are highly influential in decision-making about almost everything starting from cleaning to sexual relationships. Treatment choice also largely depends on the male members of the family and their perception about the female body similar to other health related choices in Pakistan.

Partly, culture and religion also play a role in making a disease embodied in a society. Within the socio-cultural context of Pakistan, breast cancer links to women refraining from their obligations in the society such as breast feeding, giving birth to children and not obeying their husbands. In Pakistani society, sorcery and witchcraft is also associated with all types of cancer and breast cancer is linked to household problems such as infidelity and lack of attention from husband and problems with in-laws. Factors relating to socio-cultural issues affecting breast cancer and their influence on peer support have not been supported in literature related to Pakistan, creating a knowledge gap that my study has explored.

\(^8\) By other cancer patients, I mean patients with brain, blood, lung and cervical cancers. They were all living in the neighborhood and diagnosed prior to my mother.
Sometimes women are discriminated against due to socio-cultural factors and taboos. The possible ways that these women feel secure about themselves may be through their family’s support and care for them. Women feel themselves in dismay and disbelief about their disease and often do not know the meaning of this life threatening illness. However, women try to label the disease from their perspective and their experience making them better equipped to deal with the illness.
4. Methodology

4.1. Study Type and Design
This study was a qualitative study, exploring the experiences of Pakistani women living with breast cancer and the relation between their bodies, their ailment and its diagnosis and treatment in a Pakistani society. It was a small-scale study planned over a period of six weeks. This study was designed to require a sample group of women chosen by the snowball technique and convenience sampling. All women were followed for six weeks. It was also a retrospective study in that it explores the experiences of women about their bodies before and after the disease. What did it mean for them to live with breast cancer and the side effects of the treatment that mainly focused on mastectomy?

4.2. Study Location and Sample
Research was carried out in Islamabad, Pakistan. Since discussing breasts boldly is in itself audacious in Pakistan, Islamabad, an urban and modernizing city, was selected for the exploratory study. I approached 22 women for this research. All the women were contacted in their urban homes. Each woman was given a telephone call on her private number. After introducing myself as a post-graduate student at the University of Amsterdam, I explained to them the research and its objectives. After some questions about the research, women became excited and interested in the research and its objectives and agreed to participate. Women were assured about their privacy and confidentiality of the research. However, for various reasons at the end of the research only ten women were able to participate. For personal reasons one informant quit after two sessions and one requested that I do not include her data after the successful completion of the research.

Out of 22 respondents, ten women agreed to participate. The criterion of selection was simple, they were readily willing to participate in the research, they had confidence in me for masking them and their
personalities, they relied on me and had faith in research, and they formed a diverse group of informants. Another commonality among these women was they were all willing to support my research and help other women think about themselves in a positive way as these women did.

All the women had at least bachelors as a minimum education, one woman was a PhD student, one was a post PhD, six were homemakers, one was a professor at a college and the last one was an ex-school teacher. They ranged from 28 years of age to 62 years of age and had diverse thoughts regarding their illness that might be an influence of their age, culture, religion and family. At the age of 28 a Pakistani girl usually starts her own household while at the age of 62 a woman is often retired from her housekeeping life and has her daughter-in-law to take care of her. The wide age range made for a large variety of life styles and experiences between the informants.

The study also required a general societal perception about the female body and the relation of breasts to womanhood. For this reason, randomly five males and five females were engaged in two separate focus group discussions (FGD) to prove me with an idea about general perceptions of the female body in society. The criteria for selection were to make a diverse group of people, coming from different social and educational backgrounds. It was also a matter of concern that all people were willing to participate and nobody was forced to answer any question. For these reasons I contacted a few people I already knew and they told me about other people who may have been willing to participate as well. All the people I contact were interested in discussing the female body and breast cancer and hence participated in the FGDs.

4.3. Data Collection Techniques

4.3.1. Focus Group Discussion
The idea of carrying out a focus group discussion among a small group of randomly chosen men and women, came from the need to understand my findings in the context of the general perception held by
society members of the female body. The idea was to explore the daily lives of people in Pakistani society, and their view of female bodies around them and norms and customs attributed to female bodies. It was interesting to know the advance pre assigned roles for girls by the society and learn about how the socialization of girls takes place, adjusting them within the roles.

One focus group discussions included five males with different educational levels. The other FGD included five women with different educational and family backgrounds. Both discussions were held separately with unsuccessful results. The male group included two doctors, one PhD student, one laborer and one security guard. Among the five women were one PhD student, a student, an unmarried household girl, a housewife and one housekeeper.

I hired a male anthropology student for the male FGD. Culturally it was awkward for me to sit among five men and ask about the female body; therefore I decided to hire a man. After a short training and prepared with a questionnaire, I sent him to conduct the FGD, which I had pre arranged. At the same time, I conducted an FGD with the women in another room. Both FGDs were a failure, which I discuss later in the challenges. Due to the failure of the FGDs I decided to conduct individual interviews to grasp the idea of the female body and breast cancer as a threat to it.

4.3.2. In-Depth Unstructured Interviews
In-depth interviews allow for a detailed account of the problem and permit the informant to validate the information. Structured and semi structured interviews were used to document the experiences of people negotiating the therapeutic pluralism of cancer already studied in a Pakistani population by Tovey and colleagues (Tovey et al. 2007:653). Vilhauer (2008) studied the experiences of 14 Caucasian women suffering from breast cancer. He claims that, “[i]nterview data for example, can provide information that may not be revealed through psychometric tests” (Vilhauer 2008:250). In another study on stigma related to alopecia after breast cancer, by Rosman (2003:334), she claims that interviewing is the only
technique used to generate qualitative data to analyze the impact of fatigue on breast cancer patients. From the literature I found that interviewing was the best method I could use to draw and validate the data in such a short time. My sample size was also small thus I used interviewing technique as my main research method.

It was easier to discuss the topic list during the interview as the respondents found themselves in solitude and their family members were absent. They took some time to adjust to my presence but after one or two sessions they became comfortable in talking and discussing their feelings with me. Time and place was decided and appointments were made. The length of interviews varied due to multiple factors. On average the interviews lasted about one hour ranging from as short as fifteen minutes to as long as five hours. Direct data was extracted during the sessions and the sessions were tape recorded. On reaching home, I revised the recordings and transcribed them; this made it easier to formulate the topics to be covered in the next interview, however, sometimes I didn’t have sufficient time to transcribe the interviews and had to wait for another day.

Each woman was scheduled at least twice and a maximal of five times to be interviewed during the study as per her convenience and comfort. Sometimes the interviews were terminated early, later to be rescheduled due to unforeseen appointments of the women. Interviews were mainly conducted at the informant’s house ensuring minimal stress for the informant, but the location ultimately depended on their physical health and willingness; three interviews were conducted at other places. One interview was held in an office in the evening hours of a Saturday when few people were working late. One interview was held in a private office at a university, therefore entering personnel knew me as an ex-student. Women in their offices appeared more comfortable with interviews than women in their homes. Usually appointments were scheduled at odd hours when guests were not expected. However, if by chance someone came, they were told I was a researcher working on domestic hygiene, only the
significant others were told the exact purpose of my presence and were allowed to stay for a short time where I could also discuss a few things with them.

Interviews were open-ended to ensure maximal coverage of the experiences of women after the diagnosis and during the treatment of breast cancer. Sessions covered a topic list given in the annex on page 101. The sequences of the topics covered varied from woman to woman, depending on her experiences and intrusion of other topics brought in relation to previous answers. Interviews were conducted in total privacy to ensure a stress free response from the respondents. It also ensured the secrecy of the responses and helped in preserving the confidentiality of research. One exception occurred when the male members of the family were not ready to leave and wanted to share in the experiences of the woman. I conversed with the male members from that family also but did not include the responses from that woman as most of the answers were plain ‘yes’ and ‘no’. I clearly felt that the answers were influenced by the presence of the males. At another instances, I also talked with two other males who were interested in updating me with the latest treatment and financial issues. Each time I visited them, they asked me about my research and its outcome.

4.3.3. Informal Interviews
Informal conversations were effective among the informants, their families, their physicians and their on-spot guests or the significant others they introduced to me. These informal conversations recorded and transcribed proved to be the most valuable data source. The informal interviews were very informative about the perception of female bodies and the effect of breast cancer on these bodies. Informants were too sensitive and scared about the outcome of formal interviews so after conducting two formal interviews I decided to stick with the informal approach to cover the necessary details and data about the patients and their relatives. Using informal interviews allowed my informants to be relaxed and free of stress while answering the questions. Sometimes the tape recorder hindered the
comfort of the respondents and I switched it off. There were many sessions when women did not want a tape recorder and therefore they told me to switch it off. Sometime it was an issue of privacy but other times they were just not comfortable with it. I took notes of those interviews with their permission. Sometimes women wanted to discuss their personal problems, too personal to record or write. In these instances I just observed and made mental notes.

It was hard for men to speak about their perception of the female body with me. For individual interviews I did not hire a male to discuss issues with men like I did during the male FGD, therefore, initially many men found it difficult to discuss my interview topics with a female. After the initial two minutes, they relaxed with the questions, as I did not ask deep and protruding questions.

4.3.4. Participant Observation
Direct observation is also an important useful tool in anthropology that gives an opportunity to record the data directly from the environment in its original form (Vilhauer, 2008:250). During the course of research, it was possible for me to accompany two different informants on their chemotherapy and radiotherapy sessions, where I recorded some notes and ideas that were exchanged during the course of treatment and observed the interactions between informants, their families and the hospital staff.

I made general observations when I visited my respondents at their homes. The interaction between them and their families helped me gain insight into their daily lives and power relations within the society. Some of the families were quite happy of my visits and welcomed me while others were hesitant. Women in general were happy to discuss their personal issues with me. These observations helped in my analysis where I made conclusions based on the interaction of men and women, their guests and how they presented me to their guests. All these observations were found useful in data extraction.
4.3.5. Transcription and Analysis
Transcription consumed a lot of time. Some interviews were transcribed the same day while others stayed pending until I found adequate time to transcribe them. Transcription was one of my main challenges, because it was emotionally close to my experiences with my mother; this will be further discussed under challenges. It took me more than two months to completely finish the transcription of all interviews. After transcription, I coded my data and then sorted it into themes for thematic analysis. I used different fonts and text styles for each respondent to differentiate the data of one informant from the others. I also printed the transcriptions on colored papers to further enhance the difference. I used the cut, copy and paste technique to sort my data and arrange it into different themes. Once achieved, it became easier to interpret the data with the help of other reading material and similar case studies in western culture. I used interpretive and symbolic means to analyze my data. I also used studies coming from Pakistani culture to confirm my findings, and through my research I discovered that many findings contribute to these existing studies.

4.4. Ethical Consideration

4.4.1. Secrecy/ Anonymity
I informed all women about the research and they gave consent. I assured anonymity and promised them that their privacy would be maintained before and after the research. Anonymity of the women was the primary concern and was maintained throughout the research. The recordings and data obtained were destroyed after the analysis to maintain confidentiality, once the desired results were obtained and validated. In Pakistani society, secrecy is very important. Often neither the women nor the women’s partners disclose the illness status to the extended family, therefore, it is very important to maintain the anonymity of the informants for their benefit. For this reason, interviews were conducted in isolation from family and peers. Personal history and personal life questions were a part of the interview.
However, ethical boundaries of the questionnaire were pre-determined and were discussed with the patients prior to the interview.

I did not use any pseudonym for my respondents; however I did not differentiate between informants in this report. In this way I was able to keep them anonymous. The data is used as a collective body where different experiences are quoted without the names, pseudonyms or codes for any informant in order to protect their privacy.

4.4.2. Sensitive Topic
Breast and the associated illness, breast cancer, are very sensitive and bold topics in Pakistan. Women refrained from discussing their bodies and their experience during the illness initially. Later women would cry and tell their experience about themselves. Other times they would say they wanted to let it go by, but something obstructed them and they feared to lose the self-esteem that remained. Sometimes women became emotional about their loneliness and issues that bothered them after the onset of the disease, like their limited social activity and solitude. They were grateful to their families for supporting them however many times they said that their families could not understand them, as they desired.

4.4.3. Health of Informants
I strictly observed whether the health of the patient allowed her to sit and talk for long periods of time. Interviews were mainly informal and in parts depending upon the health and comfort of the patient. They were as short as fifteen minutes in length to a maximum of one half hour if the patient was not feeling up to the interview. Sometime I had appointments with the same respondent in continuity. Seeing a patient’s condition and weakness I would tell her politely that it was not possible for me to see her the next day. While two times the respondents cancelled their appointments due to fatigue and fever.
4.4.4. Questions: Culturally and Age Appropriate
I tried to refrain myself from asking questions which were not considered as “proper” in the society. One of my friends reviewed my topic list and the questions in order to evaluate their sensitivity level. He also rephrased personal questions in more polite and informal words and I told respondents to skip questions if they experienced any questions as disturbing. Women were included in the research if they voluntarily accepted and wished to participate in it. They were informed that there was no possible benefit to them from the research. However, at the end of the research they were asked if in any way they had benefited from the research and all of them had something positive to say in return.

4.5. Challenges
4.5.1. Finding Informants
I had my mother’s personal diary, where she kept contacts of some women undergoing the treatment along with her in the same hospital. Before going to the field, I selected some women from that diary based on their location in Islamabad. I contacted all those women and some of them agreed to participate in the research, while a large majority of them were confused about the outcome of the research and therefore did not want to participate. I discussed briefly the aims and objectives of the research with them, promising a detailed account on my arrival to Islamabad. However, out of the women willing to participate, three had expired; two were very seriously ill and hospitalized which meant that they could no longer participate. I paid regular visits to them during my stay to wish them health and make observations. Women still were eager to participate but they could not talk frequently and needed rest. Seeing their willingness and responses, I tried to jot their quotes in my daily diary, which I used throughout the research. Two other women did not agree to participate due to personal reasons not mentioned.

Finally, I contacted my mother’s oncologist for some help. Since I had limited time and finding respondents was one of the biggest challenges for me, snow ball technique made it easier. The
oncologist helped me find some respondents and these respondents helped me locate some other people they knew would be interested in talking to me. Out of the multiple people I contacted there were ten women interested in discussing their illness with me. In this way I was able to locate enough informants to complete the research.

It was presumed that selecting an urban capital as a location may make it easier to discuss breast cancer with women, a location where women were believed to be more open in their conversations and felt free to discuss their bodies. However later I found that this was only an assumption and the facts were different. Being a native, I had not realized that the Pakistani society is very traditional and conservative. Women fear expressing certain things related to their bodies and their private parts. There was a missing link between the women and their expressions; communicating about one’s self with somebody was difficult and nearly impossible. These factors further inhibited me in finding willing and open participants.

4.5.2. FGDs
Another challenge was the focus group discussions I planned for discussing the general perception of the female body in Pakistani society. It was difficult to conduct these FGDs and discuss issues related with femininity and breast cancer. I found both groups hesitant and unwilling to answer the questions. This showed a general perception of the female body as a matter of shame and honor\(^9\) at the same time, which is discussed later in my research findings. Though they were not related to or familiar with each other, the cultural barriers still restricted them when answering the questions promptly and directly. After insisting for a long time on the same question and its different aspects I could only get some answers.

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\(^9\) Breasts are perceived as a matter of honor for the whole family and in general society experiences breasts as a matter of dignity and pride, however if breasts are not taken care of, they are thought to bring shame to the family and in general to the society.
leaving the main questions behind. That made me quite upset. I thought that I was influencing my respondents more than getting their personal view.

I perceived from the discussions that it was a general taboo in the society to discuss bodies, especially the female body and breasts. Breasts being associated with ‘sex’ made it more difficult to discuss. It became sensitive and cold at the same time. As one of the ladies said,

You should be ashamed of what you are discussing.

After the second focus group discussion among women, which only lasted fifteen minutes, I decided to interview each respondent individually and ask their views on the related topics. This idea proved to be fruitful as individual interviews provided more information about the society, culture and their interface with religion. Though it was time consuming it was the best method for collecting data.

4.5.3. Influences: Males or Family
In general women were told about the sensitivity of the topic and hence they were forced to be alone during the interviews. Women did not agree immediately but once rapport was build they reluctantly agreed to discuss their problems privately. There were also women with whom I only had one or two sessions after which they said their male relatives would not allow them to talk to me. With one exception, women were always interviewed alone.

Culturally I felt they only spoke about things that were acceptable in the society but in later meetings when women felt relaxed with me, they corrected their previous answers. It was disturbing for them to speak boldly about their illness and for some women their men forced them to quit in the middle despite their own willingness to participate. They were reluctant to disclose their personal situations though I told them to skip personal questions if they felt uneasy. They were also uncertain about the results and
were afraid of being misunderstood. One man said that since there is no chance that they will benefit, they will not speak about anything.

As I later describe, the transcriptions that were done on the same day (for most of the women) were validated by women themselves. If any misunderstanding or misinterpretation (for feelings and other unclear words) was found, the women corrected me. For some interviews women also asked me to omit their answers and re-record for certain questions. This helped me interpret the influence of society and culture on the answers of women previously given in an acceptable notion.

I expected that the male relatives might like or dislike the research objectives and methodology. One should be open to their comments and critique. It was hard to make them agree on discussions and make clear the objectives of the research. One of the men said it was a taboo to discuss bodies and he would not let his wife commit a sin. I tried to explain to him that I was also from the same culture and I respected his feelings and I did not mean to mock his beliefs but my objectives were not related to them. After sometime I left the family unconvincing. At other instances some men allowed me to speak with their women once the objectives of the research were clear. At another situation, after hearing the objectives and significance of the research from me, the man allowed me to speak with his wife for only an hour and requested that I never show up again.

Yet at another place, the men from the family were interested in sitting with us, hearing how the woman felt, and sharing her feelings. I felt that data was often biased and influenced in one way or another by the men’s presence. Even if the woman forgot the influences of her society, most of the time her relative men were answering on her behalf. Even upon request, the men from that family did not leave the room. It was also fortunate that I had a chance to discuss the disease and the life with it with these men directly related to the respondent. However, the data coming from that informant is not validated by her in the
form of transcription. When I took the transcription to her home, I felt she had some other answers and was willing to discuss them but after a couple of minutes and two questions, one of the men entered the room and she was quiet again. The man read the transcription and said it was ok, whereas the transcription mainly included yes and no as the main answers. I felt that the woman was forced to say certain words as a reply which made the data biased. At other instances I felt that women were free and relaxed to answer and validate the data and therefore the influences from their family and my presence was minimized.

4.5.4. Health of Informants
I was very concerned about the health of my informants. The majority of the women participating in the research were at advanced stages of breast cancer and I was afraid to lose them\textsuperscript{10}. It was expected that during the time of the research i.e. six weeks, one or more patients could fall seriously ill and hence would not be able to contribute and continue with the research. Therefore I made a decision that if this happens in the first three weeks then the informant will be replaced by another woman, if found, but if it happens after the second half of the research then the informant would not be replaced. Instead, the findings and analysis produced from the available data would be useful.

4.5.5. Sensitive Topic
I found it challenging to initiate the discussion about female body perceptions. As previously mentioned it is a taboo in Pakistani society to think about and see a “body”. Talking and discussing about a female body can be more problematic and this goes especially for the breasts, which are the symbol of sexuality in modern times more so than femininity. Islam, which is the predominant religion in the country, also teaches about veiling and covering the body. Nevertheless, Pakistani culture is similar to Indian culture and most rituals and lifestyle reflect Indian cultural values. In that culture, women are compared to

\textsuperscript{10} I contacted the women in April, just before I was planning to start my research, and by the start of May, three informants had already expired and two were seriously ill. This made me concerned about the health of my informants.
Hindu goddesses in the light of religion, yet in everyday life they are treated as lonely subjects and their dependency on men is expected. Though Islam gives women freedom of choice and equal rights, the influence of the subcontinent culture on Pakistani society does not allow women to speak for themselves. This issue in specific made it harder for me to discuss the problems of women, especially when I was looking for an influence-free response. I felt influenced by the cultural and societal norms and therefore it was hard to ask directly about the body and breasts and I felt that many times I tactically influenced the conversation and steered them towards the topic I wanted to discuss. It was not that I was putting words into their mouth but I was just making them head towards the body and around the breasts.

Another challenge was the use of a tape-recorder. Women often found it as an obstacle between themselves and me as they wanted to discuss many issues which were not possible in the presence of a tape recorder. They said that they were uncomfortable and not used to it. Often on their request I would switch off my tape recorder and either take notes in my diary or make mental notes. Sometimes women wanted to talk more or less than others but each woman had something to tell about her own perceptions of the body and her own “self”, which was the main theme of this research. Many times women formulated incomplete sentences or they would use vague or symbolic language due to the sensitivity of the topic or may be due to the influence of the tape recorder. During the interviews I also wrote down their expressions in my journal, which helped me later in the transcription phase. While transcribing, I also wrote the expressions and sounds made by women while thinking on a topic or while crying due to sensitive issues.

4.5.6. Transcription and Analysis
Most interviews were transcribed the same day the interview was held, some were validated by the respondents to make sure everything was true and what they wanted to communicate. Sometimes
respondents corrected me for misunderstandings in the transcriptions. For some of the respondents this was not possible and the transcriptions were done later on my return to The Netherlands. For those respondents who provided their email address, I mailed their transcriptions and they were happy with them.

It took me a long time to transcribe the interviews due to my own health reasons and issues related to my mother. While I interviewed the women, I do not know how, but I focused on the research itself, maybe because I was able to see my family often. During the time I transcribed the interviews, it was hardest of all. I just could not stop myself from thinking about the pain and misery my mother had been through the previous twelve months and the same pain all these women have had during their course of illness. The only difference was that my mother passed away and these women successfully fought cancer.

4.5.7. Native Interviewer: Challenge or Benefit?
I imagined that “being a native among natives” (Zaman 2004:2026) may be interesting and challenging at the same time. Being an insider, I was aware of my society but the lens of medical anthropology showed me my unawareness about the people around me and therefore I re-viewed the Pakistani society from the lens of gender issues, power relations, body politics, coping with the disease and routine life, stigma and shame related to it, and women and their resilience. Being a native and speaking the same language, it was easier for me to integrate with the informants and build rapport in a short time. Women were willing to discuss issues other than their illness and that helped me to reflect on their lives before and after the disease, however, due to being an ‘insider’ I fail sometimes to provide an ‘emic’ view of the society. I misinterpreted and misunderstood the interviews and required the help of women to correct me where I was wrong. At other instances being a native I overlooked small points and had to go back and explain them later. Being an insider does not allow me to reveal everything that may be difficult for the reader to understand. At some places I fail to explain things for the reader as I take them for granted.
5. Research Findings
With the spread of breast cancer over the last two decades, and its commonness in Pakistan, people are becoming more responsive towards women and especially breast cancer patients. However, this mainly remains limited to urban areas. Like many other countries, breast cancer is the most common type of cancer affecting women in Pakistan; it is the second largest cause of death among women. However, to date experiences of women from Pakistan are not registered. How women discover and deal with the diagnosis followed by prognosis and its long term effects remain unknown in Pakistani society.

5.1. The Body
Over the past decades the body has captured the interest and concern of many anthropologists. In a study by Reischer and Koo (2004) on the body beautiful, they report that the body is continuously reshaped in culturally myriad ways. Bodies have been a continuous subject of change. They are prone to be beautiful and attractive. The appearance of body gives rise to the symbolic body hence the body is a symbol in the social world depicting one’s social standing. For instance, Reischer and Koo (2004) claim that, “one’s body is a physical reflection of one’s internal capacity for commitment and self control”. Therefore, the changing body type is one’s contribution and acceptance towards the culturally valued norms and rituals about the accepted levels of ideal body type.

Reischer and Koo (2004) further claim that, “We meet the world around us through our bodies. Therefore, bodies necessarily participate in the agency of selves.” They also claim that the attention towards the relationship with the body enables us to redefine the relation of body with imagination, intuition, perception and sensation (2004:308). The most discussed body type is the woman’s body, which can be found abundantly throughout literature.
5.1.1. Importance of Breasts in Pakistan
In most of the cultures in the world, the female breast connotes specifically to femininity, sexuality, motherhood, womanhood (Khan et al. 2000; Elema 2001) and in addition to it, honor, dignity, pride and prestige in Pakistan. Among my informants the notion of “being a female body” is largely linked to breasts and therefore healthy and round breasts are a trait of beauty, attractiveness and symbolic perfection of a woman. Men and women generally perceive a female body as attractive due to its eyes, hips and breasts. Remarkably, breasts and hips are considered the main attractive feature and beauty symbol rather than facial looks or other factors such as height. An hour-glass shaped body is appreciated more than other bodies with lesser demarcation between breasts, waist and hips. Obesity also hinders attractiveness and women who are heavy at their waistline, are considered less attractive. On the other hand, women who are too slim are also considered as less attractive by men. People said that the religion tells to opt for a mid-way so they appreciate bodies that are not too obese or too slim.

Women with a heavy bust line are considered to be “attractive”, “beautiful” and “perfect”, while those with a small cup size are not appreciated as much. In addition to the physical features and appearance, facial looks also played a part but only in the initial phase of a relationship. Most men explained that they want to have long-term relationship with women holding a heavy bust line. In a similar context women are also conscious about their appearance and though not discussed openly in the society, women are aware of this attractiveness criterion. They know that they attract men when they have a large bust line and are thinner around the waist. Women were generally conscious about their physique at younger age and found it hard to maintain their figure after having children. Women usually accepted themselves as they were after their mid-thirties with a few exceptions.

I asked all of the women about their body image and their perception of self; they were confident and happy about their bodies and satisfied with their selves. When asked about breasts and its meaning for a
woman, different responses were generated among my informants. All of them considered breasts as honor, dignity and the pride of a woman. Breasts are also considered as prestige for the family. The honor of a family is linked to the notion of the protection of breasts. It is thought that well protected breasts never invite other people in the society to look at them and therefore protect the family’s honor and pride.

Although breasts are a sensitive area for women, they are lustful for men at the same time. In Pakistani society men often pinch the breasts or hit the hips of woman in crowded places to express their lust and desire for them. Therefore, women in markets or crowded areas especially try to veil themselves, cover their faces to protect their body and above all, their breasts. All the women who experienced these pinches felt sad and ashamed about it and used bad words for such men. They also agree that it was somehow their own mistake.

Both men and women felt that breasts played an important role in defining womanhood however, seven people felt that the purpose of breasts is for breast-feeding, while the rest saw a cultural attribute for them. I felt that breast-feeding is culturally accepted and also religiously it is instructed, therefore it is easier for men and women to speak openly about breast feeding than breasts themselves. They felt it to be respectable and honorable and that it is necessary for the completion of motherhood thus completing the womanhood.

Women were more confident and felt strong if they had an “accepted” figure and were shy and shameful if their figure was not up to the “accepted” level. These accepted figures rose from the discussion of men with their wives and thereby are conveying to their daughters and so on. It was not the society and the family that hindered a female and her socialization but the female herself involved and deeply affected by the agreed societal level of femininity.
Women in general and those with breast cancer as well, were more comfortable talking about breasts than men. One of the women said that until she was fully developed she was ashamed of her tiny breasts. She felt that they hindered her socialization and she could no longer play with other children in the street. It was hard for her to grow old. She said that initially she was not ready to sacrifice her independence for her breasts. The shawl she used to cover her breasts hindered the interaction between her and children making her movements conscious and restricted. Soon she became used to having breasts and covering them in a way that they were no longer visible. However, she felt that covering the breasts might have made others more curious about them, since she was one of the firsts to enter puberty.

5.1.2. The Female Body and Breast Cancer

Within Pakistan there are many different views of the female body with or without breast cancer. Furthermore, breast cancer has various different meanings and understandings within the society. One of the informants of the FGDs said that,

Being a female is not defined with breasts but it (breasts) is attributed to femininity.

In reference to this person’s previous arguments the above quote meant that breasts defined femininity. By femininity, he meant beauty and attractiveness, and female meant his own wife. He said that for him his wife would remain as ‘her’ and she would remain as beautiful as before even if she had to go through her mastectomy.

Out of ten general people I talked to, only two had relatives and one had a close friend suffering from breast cancer. Five of the other people had an idea of breast cancer while two only vaguely knew about the disease. Everybody knew it was a potential deadly disease but did not personally see it as life threatening. ‘How it happens’ was an unanswered question for many; people had misconceptions of how breast cancer develops. Some people told that it was actually the malfunctioning of the cells within the
body and several treatments were possible to cure it. They were sure it finally goes away and never happens again, at least they never heard of anybody having it again.

Four of the people perceived a female body with breast cancer as normal. With the exception for the attractiveness criteria, everything is normal with that body after having a mastectomy and one can perform the daily chores, once fully recovered. They thought that the energy lost during the treatment can be recovered with the help of diet, other energizing things and family support. Once the lost health and energy is regained the body is able to cope with the daily routine and perform tasks that seem impossible at the beginning.

Two of them said that the image of being female ruptured with a thought of a mastectomy, though it could happen to anybody and one should fear it, but still it is difficult for them to think of a female as a female after mastectomy. The women after mastectomy lost attraction, thus they are not up to the accepted level anymore. This made people think that the loss of breast meant loss of womanhood. Three people thought that it is a permanent disability and it is difficult for them to consider that a female body anymore. One person was not sure about what is meant by female body with breast cancer. Nine people said that if this happened to one of their first relative she would remain as attractive and beautiful as before. It was not only the breast which defined her as a female and beautiful but the life they had spend with her made her beautiful.

5.1.3. Changing Body Image and Perceptions of ‘Self’
It was hard for women to discuss their bodies and their body image. They said it was something weird and strange for them and they had never thought about their bodies this way. It took women by surprise that I was interested in their body image and its impact on their illness. It was very difficult for them to express the concern about their body initially. It is part of the culture that such things are not spoken about so direct and in the first meeting. Being a native, I was aware of this factor and prepared for this
situation. I asked women different questions where they told about other things that meant their perceptions about ‘self’.

For example, I asked a woman if she takes care of her hair and she could not openly say she cared for herself but replied,

No, I never go to a beauty parlor or get involved in such activities. I go to a parlor for cutting otherwise I never go there. It is not our culture. I went for having my eyebrows done, that is all… it is a waste of time… I go for facials…. After every fifteen days I go for a facial…my skin is like this… you see…. People say I look fresh….

This woman was very conscious about herself but she did not want to express her care and love for her body. I had several discussions with her on similar topics and she never directly said that she loved herself but indirectly she always told that people appreciated her and this is how she knew she was loveable and attractive. She was confident and happy about herself because people appreciated her but later after her mastectomy she was unhappy and did not like herself anymore until her husband started telling her that she was still beautiful.

Most of the women were satisfied with their bodies before the illness; however the women said different things when asked if they cared about themselves and their bodies. One woman was interested in wearing different modern clothes and her idea of taking care was to wear bright colors of finely stitched cloth. She felt happy when clothes fit her and she looked nice to herself and her husband. She said that puberty made her feel like a princess. When her breasts started to grow, she was happy that she would now look like her mother and wear nice traditional clothes instead of frocks.\footnote{A long and loose outer garment, usually till the knees or even below them worn by women}

Six women were happy with their physique but they did not remember growing up as women. They said it was an old thing and they forgot it and I felt they did not want to discuss the topic. One of the women
said that growing up was not an issue, until another woman from the family made her realize. She told that the other woman was concerned about her breasts while she was playing with other children.

I was much precautious (of the social environment) and was not using a bra when my aunt said, “don’t jump! Your breasts move and it does not look nice”…. I was embarrassed and took a shawl the very moment… later I started wearing a training bra.

Two women expressed their dissatisfaction with their body image and their self-perception after the treatment. Prior to mastectomy, three women suffered from cervical problems resulting in a hysterectomy\(^\text{12}\). Two women felt that hysterectomy shattered their image as a woman and hence disturbed the femaleness or the womanliness. It was not visible from outside but on the inside these women were experiencing many hormonal changes and instead of being tolerant towards it they said, they felt ‘it’ (womanhood) going away. While they underwent the mastectomies, it made them think more negatively about themselves than other women who underwent only mastectomies, and they were afraid that their men would leave them. Mastectomy negatively impacted on women as the loss of breast was visible on the outside, as compared to hysterectomy which is hidden inside. Women tried to cover their body with the help of their dressing but often this made them uncomfortable and pessimistic about their lives.

Four women said that their body image was disturbed for a brief time but with the support of their family and predominantly their husbands, they healed their body images and recovered from the loss. Two women were not affected in anyway; they said that they had accepted themselves as they were before and after the disease. They said that the body image was an ongoing thought of any person that should shape itself with the changing images of oneself.

I am the way I am…. I never felt anything about it (mastectomy) seriously.

\(^{12}\) Hysterectomy is the condition where uterus is removed from the body.
Initially some women felt that breast cancer would make them less attractive and unacceptable to other people. They felt deprived and impaired. They did not want to look at their bodies. This made them look ugly to themselves and reminded them of what they had suffered. Breast cancer induced a sensitivity in women which was explained by their avoidance to look at their bodies and their extra concern about their dressing. One of the women said,

Even if I am cured this scar will always remind me that I once had cancer.

Figure: Scars
The photograph details said, “In one week it will have been three years since I had my bilateral mastectomy. I was 27 years old. What a birthday present! Although I feel this was the best decision I've ever made for myself, I have always been super self-conscious of the scars. Today I'm confronting my fear and shame associated with the scars. It is an affirmation of pain, courage and identity. This is now part of who I am”. Source: http://blogs.mirror.co.uk/sex-doctor/2009/08/hes-scared-by-my-cancer-scars.html.
After fourteen years of survival, a woman was never comfortable looking at her body, she felt that the scars came alive and made her vulnerable. The above quote is from another woman, young and undergoing the treatment who felt similar to the other women. Later I found that the scars impacted negatively on the women belonging to the younger age group while they had no effect on older women or they felt it too private to discuss.

This data shows that breast cancer is experienced and understood in multiple ways depending on each woman’s own experience and her level of acceptance. Women were found to discuss about their self-perception, some were found to express their concern while others denied talking about it. Particularly the scars contributed to an inevitable loss that was accepted by only a few women. Women of older age were found to accept their bodies and also reluctant to talk about them at the same time. Younger women were found more concerned and sensitive about their body image yet they discussed it freely. I analyzed that scars were a small part of the vicious circle of life that women could use as a carrier to express their grief and vulnerability towards breast cancer.

5.1.4. Male Perceptions of Breast Cancer
It was fortunate that I had a chance to discuss the disease and the life with it with several men directly related to the informants. Whether being a brother, father, husband or son they were all affected. Men said that they were equally as devastated as their women. It was hard for them to believe that they had breast cancer. For them it was a major concern to take their women to oncologists and get them treated. Men said that they were dependent on these women and they wanted them back, happy and healthy. One of the men said,

I consider it fortunate that we came to know about the cancer at its initial stage. What if we didn’t find it? I pray for her health and thank Allah for giving us the strength to fight back.

Another man said,
This woman has sacrificed her life for bringing up me and my children. She groomed me and developed me mentally. I can never repay her for this. But I know what she means to us. I can never think of losing her. I am so glad she is healthy again and back to normal.

Some men being directly affected by the illness of their women helped these women cope with their disease. For that time period, the men forgot everything except the illness and their wives or mothers. Women were happy about the fact that their men stood by their side throughout their illness.

Well it is my illness what brought us so near. My unexpressive husband suddenly became very expressive and emotional. I enjoy the benefits more now.

Every time I visited this one woman her husband would present me her files, he welcomed me with a bunch of reports and all her new scans and tests. He read all the reports to me, one by one, and asked me my experiences with similar reports. He paid all his attention towards his wife and during the time of interview, he sat in the corner of the room, far away but he could see us. He said that he wanted to be with his wife always. While at other instances, women complained that their men were more distracted and stayed away from them. Women getting the support of their family and especially their men were found to recover soon and had strong will power. While other women found it hard to go through the treatment and recovery phase alone. They were distressed and found life to be a meaningless thing.

I felt that the family support was largely linked to the perception of cancer by men. Men often perceived cancer as their enemy that would take their beloved ones away. However, with the passage of time they recovered from initial feelings and were determined to combat cancer at any cost. They were, like

13 He knew that my mother was also a breast cancer patient and that I have been by my mother through that time. His wife’s case was similar to my mother’s and she was a last stage patient so he always asked me if I had some tips for her health or the bad taste she got in her mouth.

14 His wife passed away this August.
women, concerned about mastectomy but later their aim was to have their women alive rather than losing a body part.

5.2. Confronting Breast Cancer and Initial Feelings
Breast cancer is one of the worst nightmares for many women worldwide. However, in Pakistan, the low level of knowledge on the disease is problematic in that the women do not know the causes of breast cancer and its effects on one’s life until they suffer from it (Bhatti 2007:57). They also do not know the ways they can avoid breast cancer. Breast cancer specifically hits the private body parts of women, which are most cared for and protected within the group of Pakistani urbanized women. These women equate their breasts with the honor of their families, their own dignity and their pride of having them.

Women found themselves in a difficult situation when first diagnosed with breast cancer and the first thought, seven out of eight women had was that they would die soon. One woman was positive that she had to live for her children and family. The first reaction to the initial diagnosis was dismay, shock and disbelief for women and their families. They had immense fear of death. However, when told about the treatment the most fearing thought was about losing a breast and hair, like Elema\(^\text{15}\) (2001:23) describes, but later survival became necessary at any cost. With time they found other ways to mask the loss of their breasts.

It was very difficult for all of my respondents to face the fact that their bodies had betrayed them, as they called it. Their bodies had something that was life threatening and very grave. It was a devastating thought. Women were frightened, in disbelief and completely in loss. It was difficult for them to admit that they were on the way to starting a long journey and the battle against cancer.

I could not believe that a mere spot of blood on my bra could make me a breast cancer patient….gosh!

\(^{15}\) Elema is an ex-AMMA researcher as well as a Breast Cancer survivor.
The thought of having breast cancer was simply unbelievable; I had just started with my life and this…no way I am going to accept it!

I had a hysterectomy a few years ago, and then suddenly I was diagnosed with breast cancer, I don’t know what was the reason and how it happened, it was so quick, all of a sudden my world was upside down, I was on hormonal replacements but I don’t know why breast cancer took me….

Just the diagnosis (of breast cancer), changed my life, it was this disease which ruined my life; it ruined everything, my relationship, my circle, my job, my mother, my liabilities, everything just finished. My family crashed!

I was shocked when my doctor said that I was a breast cancer patient from now onwards, it was so ridiculous. One day I am entering the clinic so normal and the next day my doctor says that I am a breast cancer patient and not only that but I am at stage three. I had nothing, no complaints at all and I was a patient….It was really very hard to believe!

Can you imagine what kind of a shock it was? It was so difficult to accept, a very difficult situation. I and my family were just not ready to accept it that I was suffering from breast cancer.

However, not all women were devastated and unwilling to accept their diagnosis. There were women who not only accepted it but also were ready to combat it.

“What is done is done. If this is it I have to fight against it”

Though I hadn’t thought that I could also have breast cancer, when I sat down to rethink upon it, I said why not? I am also as human as others are on earth and as much as a woman as others are. What was special in me to skip it? It is part of life; of course, I have to die of something. However, what I fear the most is the terrible pains I have heard about. I hope I can fight it.

Another woman said,

It was difficult for a couple of minutes but then I took it easy, I have to fight against it and there is no question then why should I depress and stress myself with the overwhelming thoughts. I have to fight against breast cancer and I have to live for my children.
After the initial disbelief some women remained stressed while others had a positive impact on their illness, finding the strength to battle the disease. However, all women, whether ready or not, now had to undergo the treatment which was another hard and difficult thing to decide.

5.3. Illness Trajectory: Complaints and the Onset of Disease

“Women report lumps more commonly than blood and pus, which are serious symptoms at the initial stages,” said one of the oncologists I interviewed. He said that women were aware of lumps as being benign\(^ {16} \) or malignant\(^ {17} \) but not blood and pus as symptoms of breast cancer, which I found to be true later in my research. Oozing blood and pus from the nipples, lumps and general soreness of the breasts were the serious complaints that forced my respondents to report them. Other complaints, before diagnosis, also included fatigue, dizziness and headaches followed by body aches and numbness. Women also reported weakness and exhaustion as a major problem after diagnosis. In later stages women reported bone pains and frequent stomach cramps. They were in dismay of what could happen if doctors diagnosed them with something serious.

Guess what I found…. the lump….. which every woman fears.

Respondents had delays in diagnosis but with three exceptions, the delay was only for one or two days. One woman found the lump and the next morning she was at a general hospital for her diagnosis. Another woman also found a lump and her husband took her immediately to a doctor. Another woman told her family about her lump and they discussed it with their family doctor. Two days later the treatment started.

On the other hand, one woman found blood on her bra every day, until a week passed. She told her husband every day that blood was oozing but she could not find any soreness or pimple. Her husband

\(^ {16} \) Lumps that do not turn into cancer are benign.
\(^ {17} \) Lumps that turn into cancers are cancerous or malignant.
kept on delaying it for another week until they told their daughter. Her son in law was a doctor and they forced her to do a mammogram and a biopsy. Another woman, after finding a lump, waited for her husband to return and debated during that time whether she should or should not go to a doctor. It was then, her husband returned from his field job and took her to the hospital. She felt confused and unconfident to seek the help from a doctor alone. She told that her husband decided everything related or unrelated to health issues for her in the past and therefore she was so used to her husband making decisions that she could no longer make decisions on her own.

One of the women also reported numbness as an initial symptom. While on treatment for numbness, doctors found that she suffered from breast cancer. She had a lump for the last twenty-two years, but her doctors said it was benign. However, she thought that her hysterectomy might have accelerated the malignancy process. She held it until other problems started and she was compelled to seek help.

From the data it is evident that the delay in diagnosis is mainly due to lack of disease awareness, dependency and other things that are more important than one’s self. Lack of symptom awareness is partially associated with lack of interest and the thought that it can never happen to one’s self. Dependency here means that women are dependent on their male partners for diagnosis and treatment. The woman who waited for her husband’s return was primarily due to her being accustomed to her husband making her decisions for her. This ties into power relations within the society.

Other important things for the women included their children and their children’s well-being. In the study by Ashing et al. (2003) they studied experiences of Asian American women where they found that the feeling of motherhood overwhelms the feeling of a woman therefore the main concern among the life of these women are their children. They prioritized their children over their health (2003:42). There was a woman who had the lump for the last 22 years, after initial follow-ups and finding it benign she
stopped following it up. After a few years she experienced other symptoms linked with breast cancer but she\(^{18}\) was afraid of her check up. The reason for this delayed diagnosis was not due to male oncologists or other factors but due to her children. She was the only financially supporting member of her home. Her husband was earning but did not use the money to pay the bills and education fee of their children. While she was on the job and her children were in the school, she thought that her illness may affect her children’s education and hinder their well-being. She struggled for another couple of years until her children were settled in their lives and the symptoms were completely exposed. Later she was diagnosed at the last stage, her desire to support her children ultimately prolonging her diagnosis.

5.3.1. **Approaching the Doctor and Clinical Encounters**

In the country culturally a distance maintained between the genders is appreciable. Women do not shake hands or hug their male fellows in the society despite familiarity with them. Shaking hands, hugs and kisses are only limited to their partners and husbands. Therefore, women prefer to seek help with female doctors rather than male doctors and vice versa. However, when it comes to oncology this is problematic since in Pakistan the best oncologists are males (SKMH). This also goes for best surgeons and anesthetists who are also males (SKMH&RC). Female doctors are generally married after the completion of their studies. Once married, they are dependent on their partners for further studies, which is not always possible. Therefore, this is one big reason for less female specialists in all fields. In Pakistan, doctors usually run their private practice in the evening hours which is again not possible for most female doctors without the consent of their husbands. It is largely believed among the society that doctors running private clinics are very devoted and dedicated in looking after the people. They are believed to be in the process of learning and more experienced than other doctors who do not practice privately.

\(^{18}\) She was familiar with the medical profession therefore she knew that her checkups and other tests might result in a breast cancer diagnosis.
All women explained that approaching the doctor was one of the most difficult things they had to do. Seven out of eight women had family and peers who wanted to get them diagnosed and treated with a female oncologist, which best suits with the Pakistani culture and is not specifically restricted by the religion either. However, not everyone was preoccupied with finding a female doctor; one woman and her husband did not think of male or female oncologists. Initially they were only looking for a cure and wanted to save the life of the woman.

Breast cancer diagnosis involving “touch” and “sight”, affect the woman physically as well as psychologically causing her stress (Helms 2008:313). Women feel isolated and stigmatized making it difficult for them to seek treatment. One woman told that initially male doctors wanted to feel her lump and that was uncomfortable for her. Although she managed initially during the diagnosis stage, later she refused to show herself or let the doctors feel her lump. She said that it made her stressed and she started having problems with her husband who felt comfortable with the doctors and their treatment.

Two of the women under study went to female oncologists while the other five went to different male oncologists. The course of diagnosis was almost the same however the treatment was different: an ultrasound followed by a mammogram and then either by a Fine Needle Aspiration (FNA) biopsy\textsuperscript{19} or a Tru-Cut biopsy\textsuperscript{20}. Diagnosis is in general a quick process that takes around a week. The result of ultrasound and mammogram are delivered on the same day while the biopsy results are presented within two to three days. In total within a week, a woman knows how her body is affected by the disease, unlike many other countries where it may take weeks of frustration before knowing the status of one’s

\textsuperscript{19} FNA is a simple procedure performed when a suspicious lump is found in the breast or lymph node area. This procedure is often invasive and involves passing a thin needle and collecting the sample from the lump or cyst. The sample is then analyzed by the pathology laboratory.

\textsuperscript{20} Tru-cut biopsy involves a needle with external cannula and an inner notched rod that cuts the tissue sample trapped within and is withdrawn.
body (Elema 2001:27). Once diagnosed all the women were immediately made to follow the treatment procedures as per instructed by their doctors and per the will of their family.

Women generally felt uncomfortable with male doctors; however, the treatment was satisfactory. Women undergoing treatment with female oncologists felt that it is harsh on their body and psychologically more painful. They compared their prescriptions with other women undergoing the treatment in the same hospital and found that they were given more drugs than women undergoing treatment with male oncologists. I found similarities with my mother’s prescriptions as well; she went to a female and a male oncologist simultaneously. Female oncologists are known to prescribe more drugs and injections when compared to male oncologists. Women told that the number of injections administered to them made them think about the pain instead of feeling it and letting it go by. Thinking of pain made them feel that their bodies were like strainers, allowing everything to pass through them. While women who approached male oncologists were satisfied and the number of injections was as minimal as possible.

The data shows that women initially had problems with male oncologists due to cultural and social boundaries between men and women. However women seeking help from male doctors found themselves in better situations than other women seeking help from female oncologists. It was hard for women at the beginning to show their bodies to male doctors but later they felt that they were satisfied with their treatment. For the women who saw female oncologists, it was also hard to show their bodies and they had to confront their dissatisfaction with their treatment as well.

5.3.2. Approaching Traditional Healers
A large group of traditional and spiritual healers believe that cancer occurs due to the malfunctioning of bodily systems, which is ‘actually’ due to certain acts that deviate from ‘normal’ womanly behavior. Women who are deemed as close to nature by giving birth and breast feeding are believed to be less
likely to develop breast cancer, while women who refrain from natural behavior are seen as more likely to acquire the disease. All women, with one exception\textsuperscript{21}, had children and breast fed them for at least six months, thus making them unlikely to develop breast cancer in the eyes of the traditional healers. Despite this contradiction, five women in total approached several traditional healers; four of them also saw biomedical doctors simultaneously, while one was solely treated with the help of a traditional healer. The reason for them being patients of traditional healers differed, but they did not disagree with the sayings of the traditional healers. Most women told me that they must have done something against the law of nature as their traditional healers told them; they agreed that it was their fate to live and die with breast cancer. In general women were more at ease with traditional and spiritual healers than with biomedical doctors.

Seeing a biomedical doctor had to do a lot with “touching”, particularly a private body part in this instance. Women told that they like seeing traditional healers because they don’t have anything to do with touching sensitive parts of the body. The women in the study explained that they were not comfortable in breast examinations with either male or female doctors. This is unlike the western culture as explained by Dr Soucasaux (2004) who says that women get nervous and confused during the pelvic examinations while in breast examination, women are more relax due to the acceptance of breast scans in western societies. Some of the patients expressed their dislike of the biomedical exams in the following ways:

\begin{quote}
He touched it (lump) and felt it was hard… and while he was feeling the ‘lump’ I was so… I can’t tell it in words…the feeling at that time was so creepy more than the cancer itself….it was something I really can’t tell ….no I can’t put it in words!
\end{quote}

\textsuperscript{21} She was unmarried and had no children; therefore she did not breast feed.
It was so embarrassing for me, my husband was standing by my side and the doctor asked me to lift my shirt and open my bra… I was as confused and embarrassed as never before!

For the first time I was helpless! I wanted to be healthy again but my doctor used to touch my breasts again and again… it was hurting a lot (psychologically) and I felt weak and sad.

For seven women only their husband had seen their breasts. The last was unmarried and had no relationship before; therefore, no one had seen her breasts before, making the diagnosis even more difficult for her. She went with her mother to the doctor. Her mother was very distressed after the checkup and felt more uncomfortable than the woman herself. Once diagnosed, she did not go to the biomedical doctor.

I went to a traditional healer and he asked me about my condition. He saw some of the reports and asked me to read what they said. I was so scared that he would also examine me but he did not! He gave me some herbs and other medicines like powder and told me how to use them… I feel a lot better now…. They were the revitalizing ones.

The data shows that all five women were satisfied with traditional treatment and feel that the alternate medicine would have been the only choice if they had made the treatment decision instead of their families. From the findings it is clear that women feel traditional medicine helped them recover fully and especially the diet treatment\(^{22}\) made them healthier and psychologically stable. Traditional and spiritual treatment is also largely believed to improve the quality of life. This happens when women are told to believe in themselves and Allah. Women told that this helped them strengthen their faith and this resulted in building a positive attitude towards themselves and their illness. Women felt strong and satisfied and were able to cope with their disease and body image. The data also shows that the satisfaction of women with traditional treatment helped to minimize their stress hence making it easier for them to accept and adjust to their disease.

\(^{22}\)Two women approached different traditional healers who told them to avoid some foods such as cow meat and change some of their food habits. This is called diet treatment and this helped them recover fast and made them healthy.
5.4. Treatment Choices and Decision Making

When I asked women without breast cancer (during the FGD) if in the future they suffered from breast cancer what they would do, all of the women readily said that they would report their lump or symptoms to their family doctors. However, after a short interval one of the women said that she would tell her husband and he would decide what to do. Other women also looked at her and felt uncomfortable. After some pause, three women said that they would also tell their husbands. One said she would tell her parents if it happens now and when she would be married, she would tell her husband and they would decide together what they would do. This was because of cultural and social pressure on women and the requirement of consent from their husbands. As in Pakistani culture women are dependent on men from A to Z of their lives. Men are dominant in making decisions on behalf of their women that are accepted by these women without any objection. However, the women suffering from breast cancer had different opinions about their treatment choice and decision making once they recovered from the disease.

As soon as the women were diagnosed with breast cancer, their family forced them to undergo treatment. It was not the women who chose the type of treatment for themselves but their family members and peers. In all the cases, it was a very sensitive issue for women that they did not choose the treatment for themselves. One of the women admitted to the hospital told me that she did not know the disease was breast cancer until the doctors operated on her. Generally medical related discussions took place between doctors and the patient’s family. During check-ups women would interact with their doctors, otherwise they were not present during discussions about their health.

In Pakistan, a male\textsuperscript{23} member has to accompany a woman on her treatment. He makes the schedules and appointments on her behalf and handles the financial matters. At large, the treatment for cancer is expensive in Pakistan and therefore the male has the responsibility to decide the type of treatment. It is

\textsuperscript{23} It is supposed to be the first relative such as father, brother, husband or son of the woman. However, in special cases some other relative can also accompany the woman.
also customary that the treatment is not discussed with the patient already suffering due to depression and anxiety induced by the disease. The data shows that men and women knew there were various treatments available for breast cancer that include biomedical, traditional herbal medicine, homeopathy and spiritual healing. However, seven women underwent biomedical treatment as the first choice and after sometime, four opted for other treatments themselves, later the other five also tried alternate treatments. The other woman was forced by her family to undergo the traditional herbal and spiritual treatment.

Some of the women thought that it would have been much better if they had chosen the type of treatment for themselves; after all they were the ones ‘who owned the breasts’ and were suffering from the disease, in contrast to Yalom (1997) who claims that breasts are owned by all the people related to them in one way or the other. The women felt that due to the devastating effects of the disease their families found them unfit to reach a definite decision due to the depression and anxiety they were experiencing. Despite the depression and anxiety, women felt that they would have made better decisions if allowed. They strongly opposed their families for making decisions.

It was so strange that my family took me away from my husband and my children, to treat me for breast cancer. I was not told what was going to happen or what would be the course of treatment. I was just treated!

Two other women expressed their feels by saying,

I wanted to keep my breast but my husband said it was necessary for me to have a mastectomy… Later they found that only a small part of it was infected and they could have done a lumpectomy instead. I cried for days over the inevitable loss… but nothing could bring it (breast) back!

Some things happen so quickly that you are not given a moment to think about them, later you think there is nothing except the agony and pain…. My treatment is a similar situation… it gives me nothing but pain though I thank everybody for my health and good life now.
Treatment decision was one of the hard choices made by other people for the women. This made them unhappy and dissatisfied with their present condition during the initial stages. Later in their lives, when the women felt that despite the life-threatening illness they survived the disease, they were happy. For a few women mastectomy still remained a reason for their dissatisfaction and frustration. Women told that they would choose their treatment themselves if reoccurrence happened to them, their greatest fear being reoccurrence.

The data showed that women were generally in distrust and disbelief about their treatment and though they agreed that mastectomy was the best option, they still found it hard to accept. Mastectomy was the main reason that made the acceptance delayed and caused much psychological stress on the women. This stress made most women dissatisfied with their body image hence inducing a break in their will power to recover fully. While for some other women problems started among the family which delayed their recovery. Treatment choice was felt to be an adequately important decision by the women who were dissatisfied with their treatment. However, some women were thankful to their families for making the right decision to save their lives and expressed their sorrow and grief that their families had to pass through those tension filled moments to save them.

5.5. Treatment
Once the treatment is decided women start it right away. The biomedical treatment has three main sequences: radiotherapy\(^{24}\) followed by a mastectomy\(^{25}\), chemotherapy\(^{26}\) and hormonal therapy\(^{27}\),

\(^{24}\) Radiotherapy for seven of my informants was for twenty two days, the other patient didn’t opt for radiotherapy.
\(^{25}\) Mastectomy or lumpectomy is a short duration operation where the complete or part of the breast is removed. All informants had mastectomies and one also had a lumpectomy prior to her mastectomy.
\(^{26}\) Each chemotherapy cycle is a seven day (short) or a twenty one day (long) cycle. It is recommended from four cycles to as many as eight cycles for one treatment. It can be repeated after treatment as well depending upon the malignancy. Chemotherapy resulted in the majority of the side effects reported in my study.
\(^{27}\) Hormonal therapy consists of some drugs such as Femara, Nolvadex and Tamoxifen, taken for five years depending upon the receptor test done on breast tissue. Breasts have estrogen and progesterone as hormones.
chemotherapy followed by mastectomy, radiotherapy and hormonal therapy and last chemotherapy, radiotherapy, mastectomy followed by hormonal therapy.

As previously mentioned, seven women followed biomedical treatment while four also followed traditional healing. They took care of themselves, had better diets and prevented certain taboos that are linked to breast cancer. The women feel that treatment itself has many side effects on the health as well as the psychology of women. Women weep when they are alone and feel that weeping releases their sorrow and sadness that is now part of them however, more weeping makes them depressed and the feeling of loneliness extreme.

It does not necessarily mean that I was depressed. I was only feeling a bit low. And as I cried I felt it was going away.

The best thing I could do to calm myself was to recite the verses from the Quran. It helped me release the frustration I kept inside for long.

After their completed treatment, three women also tried alternate medicine. Four women undergoing the treatment were already taking a combination of biomedicine, herbal, spiritual and homeopathy while one was completely dependent on traditional treatment except for mastectomy. All women were interested in exploring alternative medicine like explained in the article of Tovey et al. (2007: 653) who claim that the Pakistani cancer patient negotiates over the plurality of therapeutic choices available within the country. They found that patients in Pakistan perceive traditional medicine is for lower income groups and educational levels while biomedicine on the other hand is for higher economical and educational level groups. The trend from the last thirty years or so has changed from traditional medicine to modern medication. These cancer patients are now shifting back to traditional medication for diseases as serious as cancer, irrespective of their education or economic background. From my data, it is evident that
traditional as well as biomedical treatment.

Traditional treatment was more appreciated than biomedicine as women felt that spiritual healing made them relax and satisfied with themselves and herbal treatment improved their health and digestion, while biomedicine had adverse side effects that induced depression in them. From the patients’ comments I analyzed that biomedical treatment had its side effects on the health of the patients, many of the side effects manifesting in a visible form. However later these visible side effects turn into emotional distress and above all the feeling of loneliness was exacerbated. Initially treatment affects the social life and activity of women but later this becomes extreme as it is seen in three cases where one of the women received psychological counseling.

5.6. Recovery Phase: (Discovering “Who I am”?)

Sometimes, you know, I cry, and sometimes I scream. And I get really angry. And I get really upset, you know, into wallowing in self-pity sometimes. And I think that it’s all part of the healing. (Christina Applegate 2008).

Christina Applegate is one of the superstars who recently underwent a double mastectomy and the above quote is taken from one of her interviews where she tells about how she coped with her “new self”. Women in Pakistan had similar feelings as Applegate, crying, yelling, screaming, depression and anxiety were all part of recovery. For some women, weeping is a positive expression that helps to calm themselves and bring them to normal life while for other women weeping made them distressed. There was a period when they found it hard to overcome the fear of reoccurrence. Schmid-Buchi (2008: 2895) argues that women suffer from emotional distress and the fear of reoccurrence makes them bear depression, hopelessness and anxiety. Despite a lot of literature available on the successful survivors of

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28 Women always chose the treatment with the help of their first relative men. In other words, men helped and allowed them to make decisions about the alternate treatment.
breast cancer, it was hard for women to believe they could be cured and come out of it. All women felt mood fluctuations, psychological distress, depression, overwhelmed and a series of mixed emotions, in accordance with Andersen (2007), Helms (2008) and Vilhauer (2008).

Initially all women experienced bitter mouth, a side effect of chemotherapy, and some of them did things to recover the taste on their tongue. Some women used to drink a lot of water and frizzy drinks so that the bitterness is washed away. One woman used to eat small pieces of crisps that gave a mild salt taste. She was a hypertension patient as well and had to keenly observe that salt quantity does not affect the blood pressure however she felt nothing else helped her with the bitter taste in her mouth left as a result of chemotherapy. One of the woman tried sweet things that did not help her. She figured out that homeopathic medicines helped her improve the taste in her mouth and her appetite as well.

Alopecia also affected women. In different cultures, hair is affiliated with religion, gender, class, beauty, vitality, maturity, femininity, attractiveness (Rosman, 2004:334) and age as described by Freedman (in Helms et al. 2008:319). In Pakistani culture hair is also affiliated with beauty and attractiveness thereby loosing it affects women psychologically. Although doctors promised that their hair would grow soon, women felt despair and agony. All women were disheartened when their hair started to fall out. Some of them started veiling and using caps. After the alopecia was prominent some of them started veiling which made them upset. Two of the women told that they were not used to veiling or using a chaddar and because of alopecia their dressing changed hence changing their appearance altogether. While telling about the first time their hair started to fall, most women cried at their loss.

I was taking a shower…during the shampooing my hair started to come in my hands…tress by tress… they stacked on my hands and then slowly with the water they slipped to the floor. It dampened my spirit. I came out … cried… and cried… and cried until my husband came. He
encouraged me and reminded me that the doctors say the hair will come back. I don’t know if I was only crying due to the hair loss.

Later women were happy when their hair started to grow. One woman started to massage her head to form strong and shiny new hair. Five women did nothing but wait for the new hair to come. All women were happy with their new hair. One woman told that her new hairs were much better than the previous ones:

Suddenly I had curly hair, though totally white, I think as a side effect of chemotherapy… but I like them a lot. I never had curly hairs but they grew in curls and I am very happy now. They are now shoulder length and they never remind me of breast cancer.

Mastectomy may have had the strongest impacted on the women. All the women feel that mastectomy proved to be the turning point in their life. Half of the women said that it brought positive changes in their lives while the other half explained that mastectomy made them pessimistic and depressed. Breast scarring, left from the mastectomy, reminded all women of their disease and they feared looking at their scars. Bhatti (2007) and Ogden et al. (2008) also found that breast scars contributed to the low levels of self-esteem and attraction that post breast cancer patients experience. This low self-esteem resulted in the poorer body image of women. All the women feel that adjusting to these sudden changes in their life will take a lot of time as one of them said,

There are many challenges to face that can be difficult and adjusting to these will take time.

Another said that,

When choosing between two, the one with more benefits always wins.

This meant that in comparison with her breasts, her life was more important and the wish of her family to see her healthy and happy made their decision about her mastectomy.
Three women ordered their prosthesis immediately after their surgery while four did not use prosthesis; instead, they tucked cotton pads inside their bra. They feel that prosthesis was not their need but a luxury. They are comfortable tucking the cotton pads; they can wash and reuse them whenever desired. When asked, they replied that prosthesis and reconstruction are important in younger women. One of my respondents told that she had many problems with prosthesis and developed rashes and other irritation problems on her skin, which later forced her to have reconstruction. Two other women feared the post-operative effects and pain.

I suffered many problems with both surgeries (hysterectomy and mastectomy). I think that the first aggravated the symptoms of breast cancer finally making way for the second surgery and now I cannot think of undergoing a third surgery… just to aggravate something else… I think I am good like this.

Out of eight women in my study, only one had reconstruction. When asked she replied in accordance with the findings of Schover (1991), that she wanted to be complete again. Schover (1991:116) argued that women had reasons for reconstruction that included the desire to feel ‘whole’ again, eliminate the prosthesis and that women wanted to wear different dressing styles. In contrast with the literature, the patient told that she had young children and when they hugged her, she felt incapable to hug them back due to the fear of conveying her incompleteness to her children. All these factors forced her to undergo the reconstruction despite the disapproval of her husband.

I didn’t want my children to know that their mother had one breast. It was offensive.

The disapproval of her husband did not influence her decision to undergo reconstruction. She said it was hard to decide it alone but she did it.

My brother helped me make an appointment with the doctor and he stood by throughout the process. The second surgery had its side effects but I recovered soon.
Women also feel that their intimate lives were affected due to the disease but their partners helped them recover after the treatment. All the women agree that intercourse was something that made their relationship stronger, but due to their disease and its treatment they could no longer continue frequent intercourse. Their husbands understood them and supported them during this time, and once the women recovered they were able to start to enjoy their normal lives again.

As Andersen (2007: 3151) argues in her paper, a patient maintains intimate life despite the disruption of reoccurrence, although the frequency of intercourse is significantly low. Two of my informants suffered reoccurrences. Treatment helped one of them while the other was still undergoing the treatment during my fieldwork. One of these women maintained her intimate life and had satisfactory results while the other, undergoing the treatment was gloomier and the prognosis was unpromising for her. The fact that she already had a hysterectomy and then was diagnosed with recurrent breast cancer within five years, she lost her faith in life. She felt a loss of libido that increased her depression. She said though her husband understood the changes in her body and self, he was not comfortable with them and still wanted to have sex. At times, it was torturous and painful for her to make him understand her condition. She feels that loss of libido made her relationship weak.

From the data I conclude that all women experienced depression, anxiety, stress, weakness and loneliness as part of their recovery. However, some women maintained their will power and a hope to come back to life, health and happiness while other women could not come out of the depression and stress that was induced in them as a result of treatment. Women are forced to accept hard choices throughout their treatment made by their family and peers. Most women who found it difficult to accept that they had breast cancer also had difficulties in adjusting to the treatment and later adjusting to their new bodies and changed body image. One of the women did not respond to the treatment at all and thought that it was the end for her until she was later treated by another doctor and a traditional healer.
Other women who accepted their illness and were ready to combat it adjusted easily to the therapies and later they recovered earlier than other women.

5.7. Changing Roles

In Pakistani culture, women are the backbone of a household. They serve as the bridge between other members of the family. A mother can well negotiate and argue the wishes of her children with her husband as his wife. Moreover, a wife can well communicate her husband’s desires and wishes regarding the future of their children to them as a mother. A woman therefore acts as a bridge among other roles in society, being the centre herself. A woman acts as a focal point of the house as she manages the utility bills, food, laundry and all other small necessities of daily life. Unlike in western culture, children in Pakistan reside with their families even after their own marriage. Children in their teens are still considered dependents on their parents and largely on their mothers for the daily acts of life. In this culture the socialization of roles makes it clear that men work outside to earn money and women work inside the home to balance the life. However, in modern times, homemaking is also a part of a working women’s life. Women traditionally identified in their roles as, mothers, wives, sisters or daughters, and none other than that.

The group of women I chose for my study were quite diverse in age, some having just started their own families and others enjoying retirement. However, these eight women who were highly affected by their disease faced changing roles within their families. From care-providers, they changed into care-receivers and this is felt as greatly affecting the recovery process. Even though it was nice to lie down and be pampered by their children and other family, they discussed it as depressing and were full of disbelief in the end. The disbelief and depression are accompanying factors of breast cancer in these instances.
Hard times and tough decisions…. Really, a woman has to think more than of herself and her life. While I was lying there on the bed, my daughters would come and ask me to find their clothes and stuff for the party.

For me things were bizarre as my mother never accepted that I was ill and not the same anymore. I could not work for hours and hours now as I did before. I had to rest and quit working.

…lying down and doing nothing was not easy at all. The food was awful. I then realized that I was so used to doing the cooking myself that I could not bear any other tastes. That is how positions change when you are ill… not only ill but seriously ill.

My sisters came to our house for looking after my children and other stuff… but I was in an awkward position… my sister was young and beautiful and my husband was always flirting with her…that made me upset and agonized… after a few days I got up from the bed and never let anyone come back again… I did everything during and after the treatment… although it made me tired but it was worth it.

The data shows that women living in extended families find it easier to accept the changed role of being sick while women living in nuclear families have problems in accepting and then coping with their sick roles. The feelings of loneliness and insecurity are dominant in women living in nuclear families as it was observed in the field. Women were observed to be upset and distressed when somebody visited them to ask about their health, as women could no longer offer them tea or drinks and their men had to serve the guests. This enhanced a feeling of insecurity within them that their husbands would remarry. They felt loneliness when they found nobody in the house to discuss their problems or share their fears. The data shows that in most cases these feelings of loneliness and insecurity proved to strengthen the will power among the women to become cured while in other cases women lost hope and found it hard to cope with their disease.
5.8. **Stigma and Shame Related to Breast Cancer**

Women often feel ashamed of disclosing their status of breast cancer, they feel uncertain about the prognosis, and therefore reluctant to get it bio-medically diagnosed.

Women are dishonored and disgraced if somebody finds out that they have breast cancer, it sinks a woman into self pity and burial. How can you even imagine a woman surviving while people around her are drowning her into a well? It is a matter of great secrecy, if somebody comes to know about it other than the family members and close circle peers, it is a great shame.

The above quote is from one of the woman who feels that her cancer is linked to her breasts that have been long protected, cared and nourished by herself. She also feels that bringing her cancer to everybody’s notice will make her feel shameful and stigmatized due to the belief that breast cancer is also associated with the deviant behavior of women.

One woman said that she could not convey to her male colleagues that she was suffering from breast cancer and therefore she told them that she had lung cancer. Although lung cancer is common among men and associated with heavy smoking, this woman felt she could convey that she had cancer, just not breast cancer. She felt it was hard to say that she had breast cancer and the first thought that came to her mind was lung cancer. Later she also said that her colleagues knew she did not smoke while her husband was a heavy smoker and it is possible that she got lung cancer as a result of his smoking.

It was when one of the colleague’s wives, also suffering from breast cancer, asked me, why I was using Tamoxifen, and I told her as a hormonal therapy. She said, oh do they (doctors) give hormonal therapy for lung cancer? And I was drowned. It was so embarrassing.

For four women it was easy to communicate to other male colleagues. One woman was a housewife and thereby her husband was responsible for the communication with doctors and other male relatives therefore the shame of conveying her disease to others was rather less experienced by her. She told that it was easy for her to tell other women about her disease and she liked when they consoled and shared
her experiences however, the shame was not part of it. To some extent she felt stigmatized by other women but that experience was minimal.

Alopecia is another visible side effect of the treatment and it is found to be socially stigmatizing. It is visible shortly after the treatment starts. In a review by Rosman (2004), it is stated that hair loss is a traumatic experience that is some times more severe than the loss of breast (Freedman 1994; Borowall 2006). Another review by Helms (2008), states hair loss to be the loss of individuality, however in my research the reaction towards hair loss was not that extreme but it impacted on women’s social interactions, which ultimately affected their own self-esteem and the coping process. It was depressing for all women when they encountered alopecia as a side effect of their treatment. For one woman the loss of hair was visible in the initial chemotherapy sessions making her stressed and uncomfortable. Two other women in a similar situation started veiling (using scarf and chaddars) to cover their missing hair, a practice they did not partake in before breast cancer. This headed them towards distress and social isolation. While sitting between their family members they could not take off their scarf despite the hot summer (47ºC). One woman had to receive psychological counseling to get herself back to normal life and cope with the alopecia.

Although studies show that alopecia is socially stigmatized, my data shows that alopecia among these women also created ‘felt’ stigma. They were conscious about their appearance and dressing, which forced them to be isolated. This visible loss of hair is depressing and disturbing for most women. The love of women for their hair and the fact that hair is seen as an accessory to the beauty of a woman creates agony and depression when one looses their hair. This depression ultimately negatively affects how women cope, generally drawing out the process.
Alopecia was more problematic and discouraging for those women who did not use to veil and thus enhanced the feeling of incompleteness⁴⁹ within them. Women perceived themselves as less attractive and stigmatized due to this loss. They also felt that this visible hair loss hindered their social activity hence creating social stigma as well. Furthermore, the alopecia makes their sickness visible for others, allowing a once hidden problem to become public knowledge similar to the findings of Helms et al. (2003:320). This shows a desire for women to hide their disease from others and hence prevent the stigma attached to it.

Moreover, the insufficient knowledge about breast cancer and its disabilities shape the attitude of people towards breast cancer patients. Children are especially found to mock women who suffer alopecia limiting the social interactions of these women and enhancing the felt stigma. Veiling did not eliminate others questioning either and thus did not prevent felt stigma, resulting in difficulties with social activities and coping with the environment.

In a study by Rosman (2004) she interviewed women with hair loss, experiencing stigma and she claimed that the loss of hair can contribute to the loss of personality (2004:335) therefore alopecia can be experienced as a traumatic event in the series of treatment. Some women in my study reported hair as the symbol of health and vitality and loss of hair made it visible that they had some problem which is similar to Rosman (2004) where alopecia induced the awareness among women about their fatal illness. This awareness both positively and negatively affects the coping among women. Those women who experienced a positive impact resulted in earlier coping and those women who had a negative impact of this awareness resulted in isolation, that induced despair in them and hence coping became a long, difficult and sad process. For some women hair loss was a symbol that their bodies were reacting and responding towards the chemotherapy. This induced a positive feeling among them and helped them

⁴⁹ They had mastectomy prior to the chemotherapy hence their alopecia increased the sense of loss.
continue their routine lives. It was analyzed that seeing the illness as a positive process helped in better coping.

Four women also felt that being open about their cancer status might jeopardize relationships, as ‘breast cancer and its treatment’ were not comfortable topics to discuss openly. One woman initially was positive about herself and continued with her social life; however, she soon noticed that people began to isolate her cutlery and other utensils she used. They said it was a contagious disease and she should stay away. Her husband would no longer eat with her on the same plate and that drowned her in severe depression that lasted for months after a physically complete recovery. She later divorced her husband and is now happy.

Two women were more worried about getting better instead of what people thought and did, similar to a study by Bhatti (2007) who studied factors affecting the treatment of breast cancer among Pakistani women. Bhatti (2007) also found that some women were eager to recover and start their routine lives, rather than being stigmatized and distressed. This eagerness was due to their disturbed household and routine life, which was dependent on them.

The data shows that many women coped with their felt or social stigmas and shame in parallel ways. After the successful treatment women found ways to overcome their loss of breasts and therefore were able to minimize the felt stigma. Once the felt stigma was overcome by the women they did not worry about the social stigma. Most women asked for help from the spiritual healers and diverted their attention towards religion. They later told that they felt peace while reciting verses from the Quran and it helped them overcome the feelings of marginalization. Some women discussed issues with their relatives whom they trust and felt they were satisfied after that.
Women also tried other unique mechanisms. One of the women isolated herself from other peers and occasional visitors. She spent most of her time arranging old photo albums to occupy her time. Another woman tried sleeping. She told that she had been working for over thirty years and now she thinks it is time to rest. Yet another woman spent her time writing poems for her grandchildren. When the disease was diagnosed to her, the immediate thought and fear of dying struck her. Although her children were married, she did not have any grandchildren at the time. She thought of writing poems and conveying her love for her grandchildren to come. This kept her busy in her new activity for most of the time and also helped herself to overcome the felt stigma.

Almost all women tried diverting their attention in other fields of life and not thinking about the felt stigma. This showed that women overcame felt stigma by helping themselves divert their attention in other aspects of life. Women found themselves happier once they felt the stigma was gone. One woman told that the stigma was not gone but she felt that it never was present; she felt that she perceived strong stigma because of her illness, but it was not there. She told that it was just an illusion. Other women also agreed with this that stigma was strongly felt by them but they also said that social stigma against breast cancer was present at large among the society.

5.9. Socio-Cultural Factors and Peer Support
Family is found to play the main supportive role in the illness of a person in Pakistan. Women seek help within their families and try to keep themselves busy within the daily activities of their families (Ashing et al, 2003:42). They are also found to be dependent on their families for their diagnosis, treatment and recovery (Ashing et al. 2003:42). Once diagnosed, women worry about the financial issues though usually men are responsible for handling financial matters. Women are found to worry about the financial burden they place on their families and this helps them recover early so that the financial burden is removed.
Sometimes women feel they are isolated from their family and that contributes to their stress. The changed social role, wish to continue the previous life and a need for rest, clash and contribute to their depression. Women seek attention from their family members and feel sad if inadequate attention is provided. This lowers their self esteem and confidence. They suppress their problems to the extent that they can no longer bear them and the problem is visible to others.

Despite their bad health women are often found to do the usual household tasks such as cleaning, cooking and washing. Family members ignore that they are ill and think that maybe in this way they are recovering, whereas women do this to seek the attention of their family members and a will to continue their old role. A woman told that when nobody asked her to stop washing or cooking, she became tired and left everything where it was and went to bed.

After sometime my husband came home and my daughter told him that I left everything here. He was so angry at me and he scolded me for not completing what I had started. I cried a lot that day. He was not concerned with my health, nor was my family. They were only concerned with the left over work and things.

She was very depressed and later she felt that this poor support prolonged her recovery.

It is a fact that any woman suffering from breast cancer is certainly not the first and last one to do so. I believe that there may be ways to sensibly combat breast cancer, while doing it alone only prolongs the process, thus social support is vital for a successful recovery. Based on his experience as an oncologist, a man said that if the male members stand by their wives, the confidence of these women is highly promoted. Three men said that if peer support was maintained throughout the treatment and during the recovery phase, it is more likely that they would recover earlier.

Six women were satisfied with the support of their family and peers. Their husbands supported them morally as well as financially. However, one woman told that her children were too young to understand
her pain and her husband was not very expressive, which made her distressed and hurt. Her parents supported her financially as well as morally, but her husband was not part of this.

I now tell my husband, rather I complain that he left me in the dark times and he never expressed his care or love for me. Maybe if he had done so I would have recovered earlier.

When asked why her husband was not expressive, she said that he had been like this since she met him. She abstained from further comments and changed the topic. She told that though her children were young her elder son, who was around three years at that time, cared for her and asked her over and over again about her health and how was she feeling. He understood that she was ill but did not understand her illness. At that time he only knew that his mother was ill and he loved her.

Another woman developed many problems with her husband and in-laws that ended in conflicts. She felt pressured to fulfill household chores and despite her bad health, she was not treated with care. She was dependent on her savings and her parents’ financial support for the treatment. She was in disbelief that her husband would threaten to leave her and remarry ending the support and love of the person she depended on the most. She later ended the relationship in divorce.

It was my children who kept me alive, their love and support made me return otherwise I would have died long before the treatment. I loved my husband and especially because he was the father of my kids, I adored him. However, he did not leave me with other choices except to leave him. I did not want to spend the rest of my life in a thought that he did not support me in this painful time. You know it really shattered me… even more than the illness did.

From the data I conclude that breast cancer is a part of life’s larger sphere and sometime there are things that affect people more than breast cancer such as peer support and social understanding of the disease. However, all women feel that the disease made them better persons and they were more positive about life than before. Women told that they loved their bodies and cared for them, although they feared
reoccurrence but they had faith in their destiny. Women were mostly satisfied with peer support however at times they cried and told that despite the presence of their family they felt isolated and depressed. This is in accordance with Baider (2003) who studied psychological distress in women in different cultural settings. He showed that 20 to 38 percent of women were found to be psychologically distressed within the first year of breast cancer diagnosis. If this distress was not cured, it had negative effects on the quality of life of these women. My data showed that women getting adequate family and social support recovered earlier from this distress, and are psychologically healthy and satisfied with their environment.

5.10. Search for Meaning and the Cause of Breast Cancer

Thus far, medical science has no adequate explanation on how a given patient develops breast cancer while others do not. There are a number of hypotheses about certain chemicals in the environment and hormones in the body (Howard 1994) that trigger breast cancer. Many risk factors are also associated with breast cancer that include genetic inheritance, early menarche, late menopause, nutrition and dietary problems, life style, multiple pregnancies and miscarriages, long-term hormone use that includes contraceptive use in nulliparous women, age of last full-term pregnancy and stress (Bhurgri et al. 2006; Bhatti 2007; Smellie and Sacks 1994).

Apart from all other risk factors, women related stress with their cancer. They developed the opinion that they suffered from cancer due to a lack of will to cope with their personal situations. For example, women related stress with their divorce, infidelity of husbands, and lack of attention from husbands, late marriage, infertility, stress on behalf of daughters and excessive work from one’s boss. All women were of the opinion that their disease could not develop overnight, rather it took many years for it to develop, similar to how stress has manifested over many years. In these instances women felt that stress expressed itself as the disease.
One woman was divorced some years ago. Her husband was a heavy alcoholic and used to beat her and the children. The woman decided to support herself and get divorced from her husband. For years she worked hard to raise her children and groom them. She provided them with the best possible education. After continuous hard work, she was able to provide her children with a better living. When her children went abroad for higher studies, she stayed back in Pakistan and her husband began to ring her and ask for money. It was then that she felt a lump and went for its diagnosis. She underwent the treatment successfully for the first time. She gave her husband all of her left over savings. Within one year of treatment, she developed the cancer for a second time in the same place. This time she had no money. Her children did not come to see her or send money for her treatment. She was undergoing homeopathic treatment, and related a hard life and stress to her breast cancer.

Another woman was married in her early thirties. Generally, the age to get married in Pakistan is between 15 and 25 years. Younger girls find marriage partners easier. The woman felt stressed due to her growing age and developed fibroids in her uterus. During the first pregnancy, she was also operated on for the fibroids. As she was a working person, she received loads of work from the office. Many a times she had to stay at the office late to complete the work. Stressed all that time, she could not give adequate attention to her family and work. Although her husband understood many things, she developed problems at home and work. She related that stress and the burden of work that resulted, to traumatic events in her life including her breast cancer.

Other women related husband’s infidelity and lack of attention to their stress, which later resulted in breast cancer. One woman had lived quite a happy life, until she married off her daughter. Her daughter developed problems with her husband and was later diagnosed as a schizophrenic. As a mother, that woman could not bear the pain and grief of her daughter. She felt immense pain for her daughter that reflected as stress induced breast cancer.
Apart from associating breast cancer with stress, women found other ways to explain why they developed breast cancer. For example, one of them related her disease to the high fat and carbohydrate diet she had been consuming since her childhood. She said that she never thought that junk food could have contributed to her illness until she realized that she generally consumes a fatty and carbohydrate high diet, rather than a balanced diet.

Women who had a hysterectomy prior to the onset of breast cancer were in a view that the hysterectomy was related to their disease onset and made them prone to breast cancer. Another woman said that she had been taking contraceptive pills for a long time and she thinks that the use of hormonal drugs has made her susceptible to breast cancer. She told that using contraceptives was a need at that time which she spent with her husband abroad where abortions were illegal. To prevent any unwanted pregnancy she used contraceptives that greatly influenced her monthly menstrual cycles. This resulted in early menopause and further in a hysterectomy that aggravated other problems in her body resulting in breast cancer.

Only one of the women did not relate her stress to her disease, though she had lived a tough life, she did not link her problems with her health. She explained that she has a strong faith in religion and therefore she believes that her disease was her destiny. She said that everything has to occur as it is written in the book of fate. She strongly argues that despite her normal health and other factors related to breast cancer, she was suffering from the disease simply because she had to. She also believes that her strong faith had helped her recover earlier than other people she knew suffering from cancer.

The data shows that women had their own reasons for why they suffered from breast cancer. It was necessary for them to know ‘why’ they suffered from breast cancer while most women they knew were not suffering. Most women felt initial disbelief and agony but after confronting breast cancer they were
able to think back to situations or instances in their lives that may explain why they developed the
disease in the first place; they were able to provide themselves with a reason for their suffering.

While women discussed their problems and reasons with me, searching for the meaning of breast cancer
popped up repeatedly. Women relating their stress to their disease were found more indulged in denial
and had lesser acceptance towards their illness making their recovery difficult for them and their
families. While other women who related other issues with their disease such as diet, contraceptive use
and fate were found to recover fast. These women were satisfied with their treatment, recovery and their
new selves. They were optimistic about their future and the degree of reoccurrence fear was lesser than
that of other women. Two women who related stress to their disease and were more stressed after their
treatment, suffered reoccurrence shortly after they were cured. This made them vulnerable and
distressed. One of the women passed away this August. Stress appeared to be a great factor in causing
breast cancer, however, stress caused from diagnosis and treatment can give rise to other problems that
might negatively affect the treatment or hinder in the recovery. Searching for meaning within their
disease helped the women cope with the suffering they had encountered.

5.11. Coping
All the women in the study opted for different ways to cope with their illness. One of the most profound
and common way to cope was religion and spirituality. Women seek help from spiritual healers who tell
them various verses of the Quran to recite. Women told that they find peace and satisfaction in reciting
Quranic verses. These women offer regular prayers that help them gain conviction in themselves and
have faith in Allah. They ask for help from Allah and believe that He will cure them and in this they find
contentment.

They believe that the death has to come after life and it comes by Allah’s will, therefore they find
themselves relaxed and much stronger with no fear of death anymore. However other fears of disease
progression and reoccurrence still remain. In accordance with Ashing et al. (2003:42), religion has an important role in the lives of women. They believe that cure depends on Allah’s will and therefore the best thing they can do is to pray for the cure. When asked about the medication, all women agreed that the medication worked because Allah wanted it to, otherwise it would not have worked.

One of the women said that if breast cancer reoccurs, she would only depend on faith healing and would not go for any medication. She believes that shifa\textsuperscript{30} has to come from Allah and not from the medication. She also told that if breast cancer reoccurs she would make the decision herself. This shows the importance of religion and spirituality in the lives of Pakistani women. These women coped with their disease with the help of religion. Most of the women told that their belief became stronger and stronger with each passing day that Allah was by them and helped them throughout their illness (Ashing et al. 2003:46).

Women explained that while they were trying to cope with their illness, they turned into more positive persons. They had developed pessimism over time that changed into optimism while they recited the verses from the Quran. They also developed calmness in their nature.

Women are also found to be reluctant in discussing their personal problems and emotional distress with other people. They told that they sometimes discussed their problems with their close friends or some family member. Sometimes it was even difficult because they felt that the other person was not capable of understanding their situation and misery. They were also unhappy with their husbands at times due to lack of support and concern despite that they agreed that their husbands were always present. Women appreciated when they could talk with someone who had similar problems, even if the person may be a complete stranger. This is in contrast with the study done by Ashing et al. (2003) where they studied the

\textsuperscript{30} Shifa is an Arabic word for cure.
experiences of Asian American women and found that the culture hindered them to ask for help and discuss their emotional distress and other psychological problems with strangers. One of my respondents also had sessions with a psychological counselor which shows a changing trend that city people in Pakistan are accepting psychological help in a positive way, rather than considering it only limited for mentally ill people as in the study of Ashing et al (2003:42).

Besides the modernization of the country and people, within Pakistani society, psychological treatment is still considered odd. People still do not generally accept someone going to a psychological counselor for help. However, traditional and spiritual healers are also believed to be working on the same level as psychotherapists and are accepted among the society. Usually women suffering from chronic illnesses prefer going to traditional healers; along with the treatment traditional healers also listen to them and help them overcome their depression and anxiety in a culturally acceptable way.

From the data it is evident that women decide to seek help from traditional healers because of various reasons, one being the comfort and attention that results in early coping and early recovery. In addition, sharing their disease and other psychological stress proves to be a relief from the emotional distress they suffer.
6. Analysis and Discussion
The analysis done here is based on thematic analysis and further symbolic and interpretive traditions are used for the in-depth understanding of the experiences of women and the way they negotiate their individual identities and self-esteem among the Pakistani society. I realize that the sample size (n=8) is very small and thus proving to be a limitation that data cannot be generalized over all the women experiencing breast cancer in Pakistan. Despite the small sample size the women’s stories are still beneficial when answering how women cope with breast cancer. My main focus was the coping behavior that women used to protect their identities and self-esteem while dealing with the hardships that breast cancer brings. Further aims of the study were to investigate the experiences of women with breast cancer and its impact on their body image. How women coped with their illness and their changed body image was a main part of overcoming their disease. In addition to coping and body image I also explored the general perception of femininity among the society and how this perception impacts on breast cancer and coping behavior.

Coping here is defined as a multi stage process where women adjust to every change or mutation that happens in and around them. Disease not only affects a certain person but also impacts on his surroundings thereby coping with the disease allows the person not only to adjust to his surroundings but also the internal changes faced by him. Coping will recurrently pop up during the analysis and discussion which further has two other links, body image and social networking. Body image is greatly affected by the disease and a person’s significant others. It is shaped by the women’s perceptions of disease and its treatment. Treatment also alters body image and hence it forms an important part of coping. As body image is also influenced by others, it links to social networking where these networks are found to be important in one’s life to help overcome the disease, depression and relieve stress. However at many instances it is found to be difficult to maintain these social networks once a life
threatening disease is disclosed giving rise to the coping behavior with the environment that directly affects the suffering individual.

In addition, the ambivalence of women for themselves is a dominant theme that pops up in every other theme. Body image, social networking and coping with the disease are all related with the ambivalence of women and their agency that is depicted throughout the data. Some women thought they had lost themselves and while others didn’t, they renegotiated their identities and came up with new selves. For most of women living with breast cancer, accepting the existing ‘new self’, became the major difficulty which in turn affected their mental make up to continue as valuable and/or respected part of their family and the society as they were previously. The felt, unwanted place in their society and perceived end to their life put them in a state of ambivalence and vulnerability hence, creating difficulty to cope with the disease. The choice between their old perfect bodies and new damaged images made women more vulnerable and acceptance proved to be problematic for them.

6.1. Body Image and the Coping Process
In all societies the body has certain notions attached to it, such as in Pakistani society a woman’s body is appreciated when it is optimal in shape and size. Therefore body shape and size are subjected to a continuous change to fit in the culturally accepted notions, as also explained by Elema (2001:5). Moreover, within present day society a woman’s body is not only an agent for her social acceptance but also a commodity where it is used for different purposes. Thus a threat to a woman’s acceptance by the society is any disease that alters her body in an unchangeable way. Breast cancer is one such disease that permanently alters the woman’s body leaving her with an altered body.

Breast cancer related to breasts becomes much more than just a disease in Pakistan. As the data shows, breasts are not only a female body part but socially they are valued as honor, dignity, pride and the prestige of a woman and her family. Socially breasts are accepted as milking glands and therefore breast
feeding is not only accepted but can also be discussed openly in urban settings because it is something noble and not a taboo as breasts are when linked to sex or sexuality.

Breasts contribute to build the body image of women and play an important role in bringing the womanhood to its bloom. The data shows that the women under study agreed that their breasts were important for them in one way or another. In comparison with life before breast cancer, it was found that women were dissatisfied with their new selves for some time. Later coping with the new selves released them from the misery, anguish, depression and stress they had long endured. This depression and anxiety led them to a height of psychological pain that every woman experienced. After that height these women coped with their disease in varying ways and hence accepted themselves as they are now.

In similarity with other studies, I found that the treatment of breast cancer had a negative impact on women and their body image. As Helms et al. (2008) conclude from the study of Lichtenthal et al. (2005) the more importance that is given to the body image the more it becomes problematic in adjusting to breast cancer, its treatment and after effects. In accordance with Helms (2008), younger women were found more disturbed and emotionally unstable due to the loss of their body part(s). However, all women feel stigmatized as a result of their amputated bodies. Generally women want to seek alternative treatment and one that conserves their breast is wanted most.

As Vilhauer (2007) discusses the experiences of women with metastatic breast cancer, he claims that eventually everything is related to the distress. This distress comes from the concerns about body image, social acceptance, declined sexual activities and the stress of illness. In addition this stress comes from the various fears of death, disease progression, debilitation, reoccurrence and social insecurity as also seen in my respondents. Women are found worrying about what has not happened to them and the thought of what will happen does not leave them.
The negative impression of women’s bodies on them, similar to the findings of Ashing et al. (2003:50), is another factor contributing to the distress. Most women feel incomplete without their breasts but they cope with it with the help of prostheses, cotton pads and reconstruction. Younger women with children had more problems adjusting and accepting their new bodies while older women were found more relaxed and took their new bodies casually. This shows the importance of beautiful bodies in younger age groups and acceptance towards the bodies in older women.

Women in general found it difficult to face their naked bodies as seeing their bodies reminded them of their disease and the hardship they had faced similar to the report by Ashing et al. (2003:50). Women also found themselves less attractive and unacceptable for their partners, which contributed to their sadness, despair, frustration and loss in accordance with Ashing-Giwa et al. (2004:422). For the women under study, during their initial stage of treatment, ambivalence was dominant over the coping but later as they progressed with their treatment and recovery they changed as they perceived the disease impacted positively on them. This shows that recovery by itself is a positive process that made acceptance towards their new selves easier and led them towards coping, hence, ending their ambivalent state.

Veiling became a major part of their dressing that helped disguise their bodies and prevent stigma. Veiling is also related to the distress of women that shows their reluctance to face themselves naked. This also shows their helplessness and ambivalence as this creates pessimism and frustration among women, which is overcome by some women while other women continue facing distress, disgrace, disturbance and dissatisfaction with their new body image.

I found that breast cancer is generally linked to distress. Even when women had successful treatments they did not stop worrying about different aspects of life, death, family, finances, etcetera. This
continued frustration creates other problems for them that are related to health, family, work, finances etcetera. This continued frustration eventually leads to coping with the situation in most of the cases and making it easier for the women to adjust to their changing environment and identities. Sometimes women cannot cope with their situation and this leads to aggravation with their disease.

Breast cancer not only affects women physically and emotionally but also interrupts their personal lives, such that the disease impairs women for some time and does not allowing them to continue with their previous life. This fatigue and weakness overburdens them mentally with thoughts that they are permanently impaired and may never be able to continue their lives as they had before. This leads to frustration, dismay, agony and anxiety that are supported by pessimism about one’s life.

This pessimism is overcome by the strong social networks that these women possess. In Pakistani society it is customary to visit someone who is ill, this is called ayadat. Ayadat helps these women overcome the pessimist thoughts they build during the change of their roles. This networking also allows women to say something about their disease and sometimes disclose their feelings to significant others. This has a positive impact over the health of women and thus leads them to positively cope with their situations.

From the data it is known that alopecia hinders social networking due to the felt stigma experienced by women. Alopecia thereby negatively impacts on the psychology of women. It is evident from the data I collected and previous studies that alopecia affects the body image of women to a great extent. The impact of alopecia on women and their coping can be positive or negative therefore enhancing or discouraging the recovery process. Thus, alopecia affects body image, which often accelerates the

\[\text{Ayadat} \text{ means to visit someone who is ill accompanied by some fresh flowers, fruit or home-made recipes.}\]
feelings of stigma among women and influences social networking, eventually resulting in stress and effects on the coping process.

Having a mastectomy also impacts on how women deal with their disease in many ways. Generally dissatisfaction and unhappiness was seen among post mastectomized women. Despair and agony was dominant with an overwhelming feeling of loss. However, this feeling remains only for some time. Later the overwhelming feeling is overcome by the thought of having a life threatening illness similar to Vilhauer (2008) findings. The feeling of being better and alive among the women eliminates the feeling of loss altogether; however some women remain distressed over a long period of time, prolonging the coping process. Mastectomy also changes the body image of women overall and therefore adjusting to the new body image takes time. This adjustment is also aided by the social interactions where women get to know of other people who also developed breast cancer and have been cured through mastectomy. These discussions help them overcome the pain and frustration about their bodies hence resulting in coping with their disease.

Mastectomy also relates to the power relations with men among the society. As the decisions about the treatment are made by men, women feel themselves isolated and depressed. This isolation results in distress and therefore affects the treatment and coping process. Isolation also results from the limited social activity that these women experience. It is difficult to understand the feelings and emotion of mastectomized women altogether. However, limited social activity is also seen as part of coping where women find different ways to adjust with their new selves in isolation.

Mastectomy also leaves scars on the bodies which impact negatively and make it difficult for women to accept them. Generally scars were reported as a constant reminder of breast cancer for these women and made the recovery a difficult process. Bhatti (2007) and Ogden et al. (2008) found that breast scars
contribute to the low levels of self-esteem and attraction that post breast cancer patients experience. This low self-esteem results in the poorer body image of women similar to my findings where poorer body image severely impacts on coping, often prolonging the process. Coping with scars is seen as the most complex and intricate phenomenon.

Breast cancer diagnosis results in overwhelming physical and psychological transformations among women and their families. Analysis shows that the treatment mainly affects the body image of women by alopecia and mastectomy hence aggravating distress, disturbance and dissatisfaction among women. Breasts linked with womanhood induce the ambivalence among women suffering from breast cancer therefore affecting how they cope with the disease. Altered body image also impacts on social networks that in return affect coping.

6.2. Social Networks
While dealing with breast cancer, women experience a change in their social activity, social status and roles. This change in their social activity depicts their worry about the felt stigma, which result in stress. In a study by Vilhauer (2007), this declined social activity is due to declined daily activity, disease and medicalization of the life style of these women which is similar to my findings. In addition, women decrease their social activity intentionally because the more they see people the more people ask them about their condition, which reminds them of their disease, resulting in more stress. Moreover, inadequate support and lack of understanding by the majority of people around women affects their adjustments with their environment and daily routine tasks. This adds to stress and depression thus making it difficult for them to cope with their social activities.

Social interactions also involve the communications between men and women. These interactions between the genders impact on the perception of body image and a fear of being taken or symbolized as a deviant of the society. This fear results in shame and therefore a felt stigma is created hindering the
social interactions and affecting the coping process. In this study a factor that predominantly accelerated the distress among women was their interactions with males. Working women are reluctant to disclose their disease status to other male colleagues that demonstrates their fear and shame at the same time. This shame is a resultant of their changed body image, which affects these interactions. Shame and disgrace about the disease repeatedly follow these women and result in stigma and distress hence affecting the coping behavior.

Social networking also involves the gender issues and difficulties that come across during the treatment seeking phase. Women generally seem reluctant to seek help from male doctors and this remains true in cases of breast cancer. Seeking treatment with male doctors induces shame, stress and felt stigma among these women. This shame is related to the felt stigma and thereby results in stress that makes it more difficult for them to accept their illness or the relating causes. Women isolate themselves and become stubborn as a result that hinders their social interactions and at the same time helps them recover and adjust to their present situation.

Strong social networking results in earlier recovery therefore coping with the disease and the situation around them is quick. In this study social interaction is one of the main themes that link body image, coping, ambivalence and agency together. Body image is affected by treatment and in return it is positively or negatively accepted by women due to their social networks. These social networks help the women to cope with their disease or discourage them. Culturally, social networking is important and viral in Pakistani society. The restricted activity of women due to changed body image also hinders social interactions because of stigma. This stigma impacts negatively on women, inducing stress and depression among them and affecting their coping and recovery.
6.3.  Agency
Every action performed by any individual with a free choice is agency. From the data it is evident that women show agency at every phase of their treatment. As a result of the treatment women develop strong will power to survive their disease. This will power is due to their responsibilities for their family, work and their liabilities, making women determined to get cured and survive. This helps build their confidence and hence makes coping easier for them.

Will power and determination is partially also induced by social interactions where women come to know about other survivors or other women constantly remind them about their liabilities, which helps them come out of the despair and depression. Women also experience isolation or loneliness at time, which helps them think about their lives and people associated with them giving them a desire to overcome and cope with their disease.

Spirituality also plays its role in the lives of these women. It was seen that spirituality repeatedly popped up during the discussions about coping strategies. Spirituality helps maintain self-esteem and remove the anguish and depression attached with the disease and the after effects. It also helps women to build stronger faith and therefore minimized the worries and stress related to the disease. In these ways women find it easier not only to cope with the disease but also maintain their social network and build a positive and satisfactory body image.

However, the agency of women is also affected by the structure. The structure includes the society, religion, ethnicity and gender. Societal rules and gender issues sometimes negatively impact on the agency of women and hence the freedom of choice or attitude is overcome by the structure. Structure affects the agency and in turn affects coping making women suffer from grief, sorrow and additional stress. This distress again aggravates the disease and hence women feel themselves staying in the vicious circle of life with disease forever.
6.4. Future Lines
This was an exploratory study to give an overview of the experiences of urban women suffering from breast cancer in Pakistan. More studies on detailed insights of women and their experience with breast cancer would be useful to fully understand body image and how women deal with breast cancer in Pakistan. It would also be interesting to conduct a cross cultural study among various cities in Pakistan, particularly where culture changes from north to south within the country. From urban to rural areas women’s ideas and perception about the disease can be expected to vary, affecting how women perceive body image and cope with breast cancer.

To improve the situation of women in Pakistan I suggest that awareness about the disease and the related stigma needs to be addressed. The disease itself is often perceived as contagious and thereby stigma is induced among society members. In addition, disease symptoms and the side effects of treatment are not well known among society members, thus giving rise to a need to create social awareness about the disease and its affects. There is a need to develop a better understanding towards the disabilities that are followed by the treatment so that stigma and stress is minimized helping patients cope with their disease better and faster. I also suggest that women be given a role in decision making, which might provide confidence and satisfaction among the women helping them to cope better with the disease and leave a lasting satisfied impact over their body image and psychology.

Support groups may also help lower the levels of frustration and depression that are induced in women as a result of treatment and other related factors. Listening to stories from survivors may help build confidence, increase self-esteem and create awareness among women and their families. All women who are diagnosed with breast cancer immediately acquire fears about death, disease, treatment, reoccurrence, and etcetera. It would be interesting to study how support groups may affect recovery, coping strategies, and treatment seeking behavior of women.
6.5. **Final Conclusion**

Breast cancer affects women physically as well as psychologically devastating them. Feelings of stress and despair surround women and affect all aspects of their lives. This feeling of despair is composed by the fears of disease itself, treatment, illness, reoccurrence and the knowledge that is related to the disease. Once diagnosed a general ambiguity about the treatment plan is dominant that shows the inadequate knowledge about the disease among the society at large. Disease is also mistaken as contagious which alters the meaning of disease for others.

Treatment affects the body image of women by induced alopecia and mastectomy. Alopecia induces stigma among social interactions and thereby limits social activities and brings depression among women. This depression results in feelings of low self-esteem and delayed recovery. Mastectomy also supports these feelings of low self-esteem, lowered confidence levels and limited social activity with a negative body image. All together these factors influence the adjustments made by women and hence affect the coping behavior of these women. Mastectomy also makes the women conscious about their body image and diverts their thinking towards pessimism. This results in limited social activities and provokes a need for isolation. Isolation enhances the feelings of loneliness and dependency at the same time. Sometimes this isolation results in despair, distress and frustration while at other times isolation gives the time needed to heal and therefore the best strategy for coping with the disease and the environment.

The misinterpretation of breast cancer as a contagious disease shows inadequate knowledge among the society. People do not see breast cancer as a life threatening illness instead they retreat from the relations with these patients. These retractions negatively impact on breast cancer patients and thereby induce depression in them. This is also a factor that results in isolation.
Women most commonly overcome depression, despair, isolation, and stigma through spiritual healing, the main strategy used during the coping process. Practicing spirituality gives peace and satisfaction to women and reduces their despair and depression. At large it is believed that spiritual and faith healing helps improve the health as well as increase self-esteem and confidence levels. Spirituality is seen to positively impact on the psychology of women and therefore results in improved body image, social networks and coping. Spirituality improved the social networks of women by making the bonds strong between them and their families and peers.
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8. **Annex**

*For record*

Name (for personal reference only)

Age

Marital Status: married/ widowed/ single/ separated/ divorced/ other

Occupation before and after the onset of disease

Reproductive history

Onset of Menarche

Miscarriages/ Abortions

Number of children

Onset of Menopause

Length of treatment

Family history of breast cancer or any other cancer

**Topic list for interviewing patients:**

During the research, women will be asked about the following topics:

Body image consciousness about image

Being a woman and experiencing female body

Family history

Food habits

Life style

Own considerations
Complaints and the onset of disease

Hysterectomy (removal of uterus) followed by mastectomy (removal of breasts)

Treatment choices

Treatment and body image

Body image and disfigurement

Illness trajectory

Chemotherapy

Radiotherapy

Weight gain or loss

Alopecia hair loss

Excessive bleeding

Temper and hunger

Family and peer support

Post treatment life

Reflections of one’s body on breast cancer