CHAPTER TWO

Review of Literature

“Not everything that can be counted counts, and not everything that counts can be counted”.

- Albert Einstein (1879-1955)

2.1 Introduction to Chapter

This chapter is an endeavor to summarize the current knowledge including the empirical findings as well as theoretical and methodological contributions of various researches on women with breast cancer. Looking back at the previously done studies the researcher tries to summarize the findings, ideas and gaps of the existing information which underpin the knowledge base of the field of Psycho-Oncology. The terms Psycho-Oncology refers to the diverse psychological, social, behavioral and psychiatric issues related to cancer prevention, cancer illness and treatment and cancer survivorship (Breitbart and Chochinov 1998). The research in the field of Psycho-Oncology examines the host of psycho-social factors that are likely to have a bearing on overall health and well being of the cancer patients and their care givers at various points in the illness-trajectory (Mehrotra 2008).

A concise description of the arguments and ideas of other research in the field is given on the following themes of the breast cancer experience of women.

1. Psycho-social experiences
   a) Awareness and Education

2. Body image and sexuality

3. Pregnancy and motherhood and

4. Marital and Family relationship
A conclusion is given towards the end of the chapter focusing on the need of further study to fill in gaps in the presented literature. The graphical illustration serves as a quick overview of the same.

Breast cancer is the leading cause of cancer death among women around the world. In India it shows mix incidence pattern with breast cancer being second to cancer of the cervix in rural areas (Parkin et al. 1997) however, in metropolitan cities like Mumbai, New Delhi and Trivandrum, the incidence of breast cancer has crossed that of cervix. According to The International Agency for Research on Cancer, which is part of the World Health Organization, there were approximately 79,000 women per year affected by breast cancer in India in 2001 and over 80,000 women in 2002, and over 85,000 women in 2007.7

2.2 Psychosocial Aspect of Breast Cancer:

According to Pandey et al (2005) the diagnosis of breast cancer and its subsequent treatment has a significant impact on the woman's physical functioning, mental health and her well-being, and thereby causes substantial disruption to quality of life (QOL). This study aims at identifying the determinants of QOL of Indian women with breast cancer treated with curative intent, on a cross-sectional cohort of patients interviewed at a single cancer care centre. The study sample consisted of 504 breast cancer patients (age ranged between 20-80 years) who were undergoing or have undergone curative treatment at Regional Cancer Centre, Trivandrum. The tool was administered either at the beginning of the treatment or at follow-up after the treatment. The earlier validated local language version of the Functional Assessment of Cancer Therapy-Breast, Version 4 (FACT-B) was used. FACT-B is a 36 item self administered scale containing 4 general subscales i.e. physical, social/family well being, functional and emotional well being, the fifth subscale contain 9 items and is specific for breast cancer. Factors like patient education, spousal support and employment status and financial stability had been found to influence QOL in the breast cancer patient. Women having unmarried children, nodal and/or metastatic disease, and those currently undergoing active treatment showed significantly poorer QOL scores in the univariate analysis. The diagnosis of a cancer in the family also had its social stigma, which may influence the marriage prospects of the children. The number of unmarried children was found to significantly affect emotional well-being of the participants. The authors were of the opinion

that the goals of planning a psychosocial intervention in the Indian breast cancer context would be to support the patient's ability to cope with the stress of treatment, helping them to tolerate short term loss for long-term gain, and to assist in symptom management. However, owing to increased patient burden, in-depth psychological intervention to each patient may not be feasible, and some sort of mechanism to cater to psychosocial problems need to be identified.

The study of Pandey et al. 2005 reveals determinants of quality of life of Indian women with breast cancer treated with curative intent. They recommend the preparation of a psychosocial intervention package to enhance the coping skills of Indian women to face the stress of treatment. This can be supported by a detailed age specific (young, middle and old age) context based study among women with breast cancer. The authors claim that due to increased patient burden in India, in-depth psychological or psychosocial intervention to each patient is not feasible. This is in contrast with the study conducted by Khan et al. (2010) which suggests the implementation of a detailed intervention package inclusive of psychosocial aspects of the treatment specific to Indian context on larger breast cancer patients.

Yet another study by Pandey et al. (2006) talked about the factors responsible for distress in cancer patients, who were undergoing curative treatment in India. This study was carried out to measure distress and contributory factors in 103 cancer patients undergoing treatment for cancer. The patients were interviewed using the Distress Inventory for Cancer (DI-C) which contained positively and negatively toned items. The data on social, demographic, clinical, treatment, and follow-up details was collected from case records. Patients with lower income, those who were single /widowed, or divorced, those living between 150 and 350 km (3–6 h commuting distance) from the cancer centre, presence of pain and patients with advanced tumors at presentation showed higher distress.

Park and Hwang (2009) investigated the predictors of depression and coping and the correlation between depression and use of coping among breast cancer patients in Korea. Of 1,250 eligible breast cancer patients attending Yonsei University, Severance Hospital, 1,160 completed their surveys. Depression and coping were assessed using the Beck Depression Inventory and Korean Cancer Coping Questionnaire. Socio-demographic characteristics were included in the survey and medical factors were compiled by reviewing each patient’s
medical chart. Education, economic status, the level of daily activities, menopause and the type of surgery significantly predicted depression. Age, education, economic status, time since surgery, the level of daily activities, and menopause were significant in the coping process.

Social norms commanding a widespread silence around breast cancer in rural African American communities have made it difficult for survivors to express their quality-of-life (QOL) concerns. Lopez et al. (2005) described how they blended the photovoice method (providing participants with cameras so they can record, discuss, and relate the realities of their lives) with grounded theory techniques to assist 13 African American breast cancer survivors from rural eastern North Carolina. Photo voice method was a unique data collection method used in this study which involves placing cameras in the hands of the participants so that they can record, discuss and relate to others in the community, the realities of their lives through their own eyes. Each participant had to take the required number of photos in one photo assignment and then come for a discussion on how they explain each snap in relation to the social stigma associated with their cancer. The framework that emerged reveals that three social forces (racism, stigma regarding cancer, and cultural expectations of African American women) drive four QOL concerns (seeking safe sources of support, adjusting to the role of cancer survivor, feeling comfortable about the future, and serving as role models) and that survivors addressed these concerns by relying on spiritual faith and devising strategies to maintain social standing.

A comparison of the above two studies shows the advantage of conducting studies from the perspective of the researched. Application of standardized questionnaire in the first study (Park and Hwang, 2009) could cover 1160 participants. But the psychological experience of breast cancer (such as body image and sexuality) has been left unaddressed without explaining how they contribute to the coping process of breast cancer experience. That study is not conducted to elicit the lived experiences and the perspectives of Korean women. It does not address the social and cultural factors that play a crucial role in the coping process of breast cancer. The second study used interpretivist approach to explain the subjective experience of women. Such studies can produce rich descriptions of the lived experience of a phenomenon. But, research with a positivist paradigm with its preference for standardized tests and questionnaires hardly consider the individual woman’s voice. In such a paradigm, the participants are forced to limit their experience with the provided options or alternatives.
as answers. Research with subjective interpretation of the experience of breast cancer in the social context of women is rare in India. So context specific studies through the eyes of women need encouragement to acknowledge as well as understand the lived experience of women with breast cancer.

Roff et al. (2009) highlighted the importance of providing spiritual support among breast cancer patients during diagnosis and treatment. The aim of the study was to learn about African American breast cancer survivors’ experiences with those who provided them with spiritual support and how they assessed this support. It dealt with how the participants interpreted their own religious belief and the prayers and support of others as way of psychological support to deal with the hardships of diagnosis and treatment. The study used a phenomenological approach to identify and articulate the lived experiences of African American breast cancer survivors in receiving spiritual support (the knowledge of possible sources of prayer for their disease, ex. priest). Eighteen women were interviewed in private locations, typically their own homes, for 2 to 4 hours. The awareness of the presence that there were others to pray for them provided the participants great relief. The participants reported receiving spiritual support (getting prayers and support) in dealing with their breast cancer experiences from four primary sources: God, people associated with religious communities, family members and friends, and health care personnel. The spiritual support they received from their health care providers had a significant meaning in their cancer experience.

All participants of the above study are Christians. In a country like India, where there is a diversity of religious beliefs, the meaning of religious and spiritual beliefs of the patients and that of their significant others in breast cancer experience is not adequately explored. The influence of one’s spiritual belief in receiving medical tests and accepting diagnosis and treatment needs further exploration. The proposed research hopes to fill this gap by investigating the influence of spiritual beliefs in a woman (in her socio-cultural context) in dealing with diagnosis and treatment.

Guided by grounded theory methodology, Sarenmalm et al. (2009) explored the main concerns of women with recurrent breast cancer, and how they dealt with their situations in Sweden. Data was collected from 40 in-depth interviews with 20 women diagnosed with recurrent breast cancer. Participants ranged in age between 55 and 81 years. The interviews
consisted of a series of open-ended questions designed to explore the experience of difficulties, challenges, and strategies. The core category, making sense of living under the shadow of death, encompassed three subcategories: (a) confronting, involving shifting expectations and shifting awareness; (b) struggling/easing distress, entailing losing/fearing, letting go/being reassured; and (c) transcending, involving re-evaluating, re-patterning relationships, and creating wellness. The breast cancer and its treatment generated body image impairment after mastectomy, and participants also experienced additional sexual disruption with total loss of sexual interest. Participants also appraised themselves as having lost their femininity, their physical appearance, and their attractiveness.

This grounded theory study is focused on older participants in their experience of cancer recurrence. The participants are not in their reproductive stage and participants might have undergone natural menopause before the recurrence or medical menopause after the first treatment of cancer. Their body image and sexuality experience prior to recurrence must have also been studied to evaluate the changes that happen exclusively due to recurrence.

Another study, (Ching, Martinson and Wong 2009) in the outpatient departments and surgical wards of two hospitals in Hong Kong explored how Chinese women cope with breast cancer, identified the contextual factors, and described their influence on the women’s coping at the beginning of the cancer experience. Based on grounded theory, sampling was done on the basis of theoretical relevance. Divergence in the sample was maintained by using variables such as age, marital status, educational level, employment status, personality, predominance in use of cognitive or behavioral strategies and actual support from family members. During the interviews, the women were asked to share their experiences since the time the cancer was diagnosed. In-depth interviews were conducted with 24 women. The interviews lasted for an average of 1.5 hours. Of the 24 informants, 15 were between the ages of 40 and 59, 4 were between the ages of 60 and 79 years, and 5 were between the ages of 20 and 39 years. Seventeen were married, 4 were single, and 3 were divorced or widowed. “Reframing” was the core category of the early adjustment process of breast cancer so as to accept diagnosis. After recovering from the initial shock reaction, they needed to reconstruct a frame that could accommodate the diagnosis and the impact of breast cancer enabling them to understand, predict, and continue to live and function in the new situation. Orienting self to reality, estimating the impact of breast cancer, and assessing the ability to cope were the three courses of action in the women’s appraisal. These findings highlighted the significance of
focusing on coping and realizing the role of the self in creating a subjective positive interpretation, which subsequently enhanced acceptance of the disease even during the onset of cancer.

The above narrated study in China is part of a larger study on how Chinese women cope with breast cancer. The role of self in the subjective experience of the diagnosis is highlighted in the study. Similar studies need to be conducted to understand the lived experience of women with breast cancer from the perspective of women in Indian social context.

Coward and Khan 2005 conducted a phenomenological qualitative study to describe the experience of self transcendence in women newly diagnosed with breast cancer in United States of America. Fourteen women were assigned from a larger project for in-depth interviews and each woman was interviewed three times over an 8-month period. Audio taped transcripts were analyzed using Colaizzi’s\(^8\) phenomenological techniques. Loss of a personal perception of good health and fear of dying from cancer forced women to reach both inside and outside of themselves for support and information. Bonding with other women with breast cancer led to further expansion of self-boundaries that brought comfort, a desire to modify life priorities, and enhanced appreciation of supportive others and of life itself.

The above mentioned phenomenological study explained how women make meaning of their diagnosis and treatment of breast cancer by enabling themselves to seek psychosocial support in dealing with their diagnosis. This study discusses about the context specific psychosocial requirements and support women make use of to cope with the demands of breast cancer diagnosis along with the professional medical treatment. There is dearth of knowledge on the subjective psychosocial concerns and needs of women with breast cancer in their diagnosis and treatment phase in Indian context. This highlights the need to undertake further research to understand context specific (socially as well as culturally specific) psychosocial concerns and demands that influence the coping process of women with breast cancer. Acknowledging

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\(^8\) The techniques include the following steps; Read all three of each participant’s interview transcripts several times, highlight phrases or sentences that directly pertain to the investigated phenomenon, try to spell out the meaning of each significant phrase or sentence, aggregate the “formulated” meanings into themes that are common to all transcripts, validate that the themes are accounted for in the original transcripts and that there are no additional themes, integrate the themes into an exhaustive description of the phenomenon, identify the fundamental structure of the phenomenon, return to the study participants to support that the results are in keeping with their experiences and that no aspects of their experiences have been omitted.
the contextualized experience of psychosocial concerns of the treatment is essential for the development of the intervention package which will address the context specific psychosocial concerns and needs of women with breast cancer.

Rosedale (2009) found that women experience ‘survivor loneliness’ following breast cancer treatment. She conducted a qualitative phenomenological study with 13 women who had completed one to eighteen years of breast cancer treatment. The researcher conducted open ended interviews which lasted more than one hour and the participants were encouraged to share written and artistic expressions that shed light on their experience. Women brought journal entries, photographs, poetry, and stories they had written. They described how they felt alone in the awareness of mortality and were invalidated in the experience of ongoing symptom burden, a changed sense of identity and connection, and an altered threshold for distress that pervaded their long-term experiences. Some women were found to be more vulnerable to heightened psychological distress. Loneliness was found to be a vital dimension in the overall experience of breast cancer survivorship.

The study participants are cancer survivors for at least one year to eighteen years. The author is of the opinion that future research using a grounded theory approach should be used to outline the phases and challenges of breast cancer survivorship. Such studies focusing on the experiences of breast cancer survivorship could capture the live picture and hear their voices, might provide additional knowledge beyond the acute diagnosis and treatment phase. My proposed study contains retrospective analysis of the breast cancer experience from diagnosis to two years post mastectomy that hopes to uncover the survivorship experiences of the participants.

Ramanakumar, Balakrishna and Ramarao (2005) conducted a qualitative study in Mumbai, India among both cervical and breast cancer patients. With the help of qualitative research tools the interactions of physical, psychological, social and spiritual well being with survivorship of cancer patients were studied. For this purpose, the patients diagnosed between 1982-1997, were selected from the Bombay Cancer Registry address index, where the survival status was clearly marked as alive. A stratified random sample was drawn from the list based on age, social segment, and stage of cancer at diagnosis. In-depth interviews were conducted with 27 breast cancer patients aged between 34 to 72 years at their homes. The five major sections covered through interview are 1) personal information; age, religion,
education, family situation, employment, income, family income, migration history, other illness, cancer stage, treatment; 2) physical well-being; general health status, strength, sleep and rest, fatigue related complaints, fertility, menstrual changes, pain related complaints, appetite, nausea, constipation; 3) psychological well-being; usefulness, happiness, attitude, memory, concentration, fear of recurrence, distress, treatment perception, appearance; 4) social well-being; family distress, roles in the family, society, sexuality, childbearing, isolation at work, relations with friends and family, social support, advice, symptoms and 5) spiritual well-being; purpose, religious, daily way of life, hopefulness, uncertainty, positive, participation, change in spirituality. Positive thinking, purpose in life, and strong family support played key roles in achieving completion of treatment then prolonging survival. Timely health seeking behaviour, good general medication, and emotional support from friends and family members were revealed to be very important factors for coping capably. Spirituality also played a vital role in the coping mechanism of participants. Participants reported to have less knowledge about breast cancer symptoms in this study which was not properly dealt by the health care providers and it emphasizes the need for awareness programmes as part of the clinical treatment among women.

The study uses qualitative analysis techniques (free-listing and clustering of data). This study includes participants who are aged between 34 to 72 years of age which is not a homogeneous group in terms of reproductive as well as sexual characteristics. It reveals the coping mechanisms employed by the long term survivors of breast cancer in Mumbai. The authors acknowledged the scarcity of Indian literature on the coping mechanisms of breast cancer and survivorship. The scarcity of published data on breast cancer experience is a gap in the field of Psycho-Oncology that needs to be filled. The psycho-social experience of breast cancer from the perspective of women in Kerala is hardly captured by other frameworks such as quality of life after breast cancer treatment (see for example Pandey et al. 2005). It needs an urgent investigation which enhances the knowledge base of field of Psycho-Oncology since it will unearth the social and cultural specific experiences of distress and coping associated with diagnosis of breast cancer and treatment.

2.2.1 Awareness and education

Young women who undergo chemotherapy for breast cancer face serious consequences to their reproductive health. Duffy, Alen and Clarke (2005), conducted a study with a total of
166 premenopausal women aged less than 50 years. One hundred forty-four patients were premenopausal at the time of diagnosis of breast cancer, and were included in the menopause analysis. One hundred seven women were aged 45 years or younger, and were included in the analysis examining fertility counseling. Participants completed the baseline telephone interview on average 3.7 weeks (standard deviation, 2.3) after receiving their first chemotherapy treatment. All participants were asked to complete several cancer-related scales for the main study including the Cancer Rehabilitation Evaluation System (CARES) for quality of life, the Mental Health Inventory (MHI-5) for emotional distress, and the Impact of Events Scale (IES) for post-traumatic stress disorder symptoms. Many women failed to recall discussions regarding the reproductive health impact of chemotherapy. Demographic, psychological, and disease-related variables were related to recalling such discussions. It necessitated the importance of explaining the impact of chemotherapy on fertility, sexuality and body image aspect of younger women prior to the starting of treatment.

This study examines the reproductive health counselling young women receive before undergoing chemotherapy for breast cancer. Further investigation can explain the subjective benefits of medical education provided to patients by the medical team as part of the breast cancer treatment. Uncovering the subjective experience of the effectiveness of receiving Onco education about breast cancer on the side effects of chemotherapy such as infertility, changes in body image and sexuality will provide knowledge on how it help the women prepare psychologically to cope with the distress.

The use of chemotherapy and endocrine therapies in the treatment of pre-menopausal women carried with it reproductive and gynecological implications which younger women may find both unpleasant and discordant with plans for childbearing (Thewes et al. 2003). They conducted a study aimed to investigate the information needs related to menopause and fertility of younger women with a diagnosis of early breast cancer. A retrospective qualitative methodology was chosen. Twenty-four women aged between 26 and 45 years at diagnosis participated in focus group interviews and telephone interviews. Many women thought that the information they had received in the past about fertility and menopausal symptoms was either insufficient or unavailable. Some women felt that, while information on fertility and menopause issues had not been paramount at the time of diagnosis, it became increasingly important after diagnosis. Many women believed that information about fertility should be given prior to or during decision-making regarding treatment, and that information related to
the management of menopausal symptoms should be delivered during or after treatment when menopausal symptoms begin.

The above mentioned study signifies the importance of awareness and education on the impact of treatment on reproductive and gynecologic aspect of younger breast cancer women at different stages of their cancer experience. The sexual aspect of the treatment is the least discussed topic between patients and doctors in India, considering it a taboo topic (Bharath and Parikh 2010). So it is important to know how women perceive the support provided by the medical professionals in resolving the fertility, sexuality and body image discrepancies of the treatment.

Yet another study (Awasthil, Mishra and Shahi 2006) examined illness beliefs and health seeking behaviour of educated, uneducated, rural and urban Indian women suffering from the cancer of cervix. A control group (of non–patients) was also studied. The findings revealed that individual and psychosocial causes were more strongly represented in the belief system of patients than environmental or supernatural causes. Patients often hold a variety of beliefs about supernatural causes, consequences, control and outcomes of the disease, such as the disease is the decision by God, punishment from God. The perceived consequence of illness was negatively correlated with the degree of social support available to patients. Patients characterized by a high level of social support strongly believed that their disease was under the control of either “self” or “doctor”. They resorted more to “approach–coping” strategy, experienced lesser pain and severity of illness, and expressed greater hope for a disease free life than patients characterized by low social support.

The above study signifies the importance of social support and relationship between psychosocial illness beliefs (subjective interpretation of causes, consequences, control and outcomes of the disease) and health seeking behaviour of cervical cancer patients. Such studies are essential with breast cancer survivors to understand the subjective interpretation of their social support and illness beliefs in health seeking behaviour in the trajectory of cancer.

A study at the Regional Cancer Centre, Trivandrum, Kerala, India, (Nair et al. 1993) analyzed 449 patients with breast cancer registered during the year 1983-1984, to assess the overall survival as related to menstrual, reproductive, clinical, and treatment related factors. Survival analysis was done by the Kaplan-Meier Product Limit method. The survival curves
were compared by the log-rank test. A forward stepwise procedure with the Cox Proportional Hazards Regression Analysis was performed to identify factors influencing survival. Two-thirds of patients with an advanced stage of disease on presentation seemed to account for the poor overall survival. Early detection of breast cancer by breast self-examination and physician breast examination should be encouraged in developing countries to improve treatment results in breast cancer. The poor overall survival at 5 years reflected delay in diagnosis, advanced stages of disease at presentation, and, probably, inadequate facilities for early diagnosis and treatment. Survival analysis had shown clearly that those with earlier-stage disease had better survival rates. Therefore increased awareness among women, by means of health education, and professional updates for physicians appear to be feasible methods for controlling breast cancer in developing countries such as India. This might prompt women to examine their breasts periodically while bathing and encourage general practitioners to perform PBE (physician examination of the breast) on women at high risk.

It emphasized the significance of making the Indian women aware about the importance of practicing breast self-examination and physician examination of the breast to detect breast cancer at the early stage in order to achieve good survival rates. It does not address other issues related to breast cancer survival such as the physical characteristics, age of diagnosis, psychosocial aspect of treatment, influence of social stigma on diagnosis and treatment and economic background of the participants.

Similar to the above study, Somadatta and Baridalyne 2008 conducted a study on the awareness of breast cancer in women in a resettlement colony in Delhi, India. This community based cross-sectional study interviewed 333 women with a semi-structured interview schedule. This addressed various topics on awareness of breast cancer such as early warning signs, risk factors, early detection measures and their source of information. Modified Kuppuswamy’s Socio-Economic Status Scale was used for assessing the socio-economic background. Data analysis was conducted with Statistical Package of Social Sciences, version 11. Forty six percent of the participants were illiterate. Eighty eight percent of the women were aware about cancer as a disease. Only 185 women were aware of breast cancer, among them 51% knew about at least one symptom of breast cancer. Fifty three percentage of the participants were aware that breast cancer can be detected early and only 35% mentioned about risk factors of breast cancer. Television was the most common medium through which women heard about breast cancer. Awareness was increased with educational
status and it was statistically significant. Thus it was found that the awareness about breast cancer was low in the community and there was need for awareness generation programmes to educate women about breast cancer. But till now there is no established national screening programme on breast cancer for the country. Because of the cultural taboo associated with the disease, breast cancer was not freely discussed in Indian families and thus providing education on breast cancer is an urgent need in India.

Almost half of the participants (46%) in study are illiterate, and hence education seems to have a crucial role in the awareness of breast cancer in this study. It is found that the awareness about breast cancer is low in the community and there is need for awareness generation programmes. The authors are of the opinion that women find it difficult to talk freely about their symptoms or doubts even with family members and this might lead to worsening of symptoms and late stage diagnosis.

Another study (Basu et al. 2006) identified the immediate social and cultural barriers that prevented women from attending cervical screening facilities. Women non-compliant to a community-based cervical screening program were identified. From them 500 were randomly selected for interview using a structured questionnaire that was designed on the basis of feedback received from several focused group discussions. The questionnaire listed 24 possible reasons for non-compliance. The women were asked to select the most pertinent reason(s) for her non-attendance or to reveal if they had any reason other than the listed ones. A total of 469 non-compliant women were interviewed. They had a significantly lower literacy rate compared to the compliant women. Nearly half of the interviewed women responded that they themselves opted to stay away from the program. Most common reasons cited for non-attendance in this group were reluctance to go for medical test in the absence of any symptoms and apprehension to have a test that detects cancer. Second major group of responders comprised of women who were willing, yet could not attend due to various hurdles. Most common hurdles were inability to leave household chores, pre-occupation with family problems and lack of approval from husbands.

The success of community based intervention or screening programme aimed at women depends to a great extent on women’s perception and social barriers that influence their participation. Understanding the subjective perception and the influence of social factors preventing women’s participation needs further investigation to design such programmes.
A comparison of the results and discussions of the above three studies with another study (The Regional Cancer Centre 2005) would help explain significance of considering the psycho-social factors that can influence the stage of diagnosis of women in Kerala. The Regional Cancer Centre, Trivandrum, launched its community-level randomized trial for breast cancer, a project supported by the International Agency for Research on Cancer, which involved screening 1,20,000 women and then following them up for seven years. Women in the age group of 30 to 70 years in 13 panchayats in Chirayinkeezh block in the district have been part of the trial, which involved an intervention package, including awareness creation, early screening and diagnosis and treatment in the early stages for better outcome. While mammography is the standard tool for detecting breast cancer, it is too expensive an option for community-level screening. Hence the project focused on teaching women to do breast self-examination to identify any small lumps or nodes. Health workers thus visited women at their homes with a small prosthesis to teach them to feel for lumps. The screening programme could pick up about five per cent of women who had early cancer. But only about 48 per cent of those women who were screened and referred for further tests and treatment came to the centre for diagnosis and treatment.

Even though awareness of the better prognosis associated with early diagnosis and treatment of breast cancer has been going up in the community, the number of patients coming for treatment in the early stages continues to be low. Many women were fearful about undergoing confirmatory diagnostic tests, some have little support from their spouses and for many others, the difficulty in accessing treatment – distance to the hospital, and other family commitments delayed the treatment. Further, women tend to least prioritize their health concerns. Breast being a private part with a sexual connotation, there was reluctance on part of the women to seek help till it reached a point of desperation. The oppressive structure of patriarchy could also be seen as operating in this situation, where not only do men and male spouse ignored the health of the woman, but women themselves further reinforced it.

A scrutiny of the basic health indicators in Kerala\(^9\) reveals that the state has high life expectancy levels as being indicative of the ‘high health standards’ of its population. The state has the highest literacy rate in India. Despite being aware of breast cancer symptoms

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\(^9\) Cited from: http://www.kerala.gov.in/dept_health/healthstatus.htm, Retrieved from the official website of Kerala government, on 12-10-10
and access to high health standards the number of women opting treatment at the early stage continued to be low in the state. The reasons behind this contradiction require additional study from the perspective of women to explore the unseen psycho-social and cultural factors preventing them from early stage diagnosis (The Regional Cancer Centre 2005).

On the whole the findings of the above four studies indicate that it is important to consider the psychosocial and cultural factors of participants within a social context, while designing and implementing programmes in community level. This necessitates an urgent need to understand the socio-cultural as well as psychological determinants of people in a particular social context that determines their support seeking behaviour for cancer treatment. For sensitive issues such as breast cancer, research from the perspective of the lived experience of women can produce rich data on the psychosocial determinants that have influenced their experience with breast cancer. Intervention programmes can then be designed with target on such indigenous determinants.

Purakkal, Pullassery and Ravindran (2004) conducted a survey research at the Calicut Medical College, India, to estimate what proportion of patients attending radiotherapy services were aware of their diagnosis. The study participants were asked the following three questions, 1. Are you aware of the nature of your diagnosis; 2. If yes, what was your source of information, and 3. Did your doctor discuss the diagnosis with you? A total of 100 participants including 55 women and 45 men participated in the survey. Among them 62% were aware about their diagnosis, 45% of the patients had been told their diagnosis by their doctors. 55% of men and 27% of women stated that the doctor had discussed diagnosis with them. The rest of the participants learned from their family members, from other sources and some had guessed their diagnosis. The authors were of the opinion that further studies need to be conducted to understand the way diagnosis was revealed and the impact of diagnosis on the patients.

Awareness of nature of the illness and expected outcome can affect the prevalence of psychiatric morbidity (Alexander, Dinesh and Vidyasagar 1993). Sixty participants from the two Oncology units of Kasturba Medical College, Manipal participated in the research to obtain a valid estimate of the prevalence of psychiatric disorders among cancer patients in India. Patients’ awareness of the diagnosis of cancer and their perception of the nature of the treatment given (curative or palliative) were determined after detailed questioning by a
clinical psychologist who was blind to the psychiatric diagnosis. Each patient’s psychiatric status was evaluated in a detailed psychiatric interview by an experienced psychiatrist. Forty percent of the sample had a diagnosis of psychiatric disorder, based on the Diagnostic and Statistical Manual for Mental Disorders (3rd edition, revised). Adjustment disorders comprised most of the psychiatric diagnoses. Major depression was seen in 8 (13%) patients. One third of the patients were estimated to be unaware of the diagnosis of cancer, and 82% of patients perceived the treatment given as curative. Psychiatric morbidity was significantly less common in patients who did not know they had cancer, and in those who considered treatment as curative. The authors were of the opinion that there is need for further studies on the relationship between psychiatric morbidity and factors such as nature, type and stage of cancer, duration of illness, disabilities, and coping strategies. The social stigma attached to the disease cancer may also have psychological consequences such as experiencing the labeling of the disease by the person.

In a prospective study (Gautam and Nijhawan 1987), 100 cancer patients and their relatives were separately interviewed using a structured interview to examine whether the diagnosis of cancer should be communicated to patients and relatives; the reasons for doing so or not, the emotional reactions of patients and families; any change in the attitude of relatives; behaviour of patients and patient's expectation, diagnosis, the course of their illness. The majority of patients, who knew their diagnosis (71%), wanted to be told the truth. The majority of relatives wanted to know the truth themselves (81%) without informing the patients (77%). Patients did show immediate emotional reactions like anxiety and dejection; however they appeared to accept the diagnosis. Findings suggested that in an Indian setting, the attitude of family members was more positive and supportive.

Commencing from the detection of the first symptom, the most feminine and personal organ – the breasts, become social in terms of the consequences of diagnosis and treatment, and is discussed in the public domain. The psychosocial interaction of the organ follows her through her survival even after the completion of treatment. The successful accomplishment of this journey is influenced by various factors such as age, marital status, education, awareness about symptoms, self awareness, spirituality, stage of diagnosis, psychological support from partner, friends and family members, feelings of loneliness, health beliefs, economic background, medical support, social stigma attached to breast cancer, experience sharing with similar women and one’s own coping capacity and perception on health seeking behaviour.
2.3 Body Image and Sexuality:

Body image and sexual functioning are elements of human behavior that depend upon one’s vitality, physical functioning, role and social functioning (Mock 1993). The way in which one experiences her body is highly subjective, and is a product of her perceptions, thoughts, and feelings about body size, competence and function (Cohen, Kahn and Steeves 1998; White 2000).

Khan et al. (2010) studied psychosocial disorders in women undergoing postoperative radiation and chemotherapy for breast cancer in India. The study was conducted in a reputed hospital in Delhi aimed at evaluating the behavioral and psychosocial impacts before and after treatment of women with breast cancer. A total of 97 women with breast cancer (aged between 21 to 70 years) who matched for age and economic status were divided into two groups, group A (66) and group B (31) on the basis of treatment modalities offered to the patients. Interventions include patient education as IEC – Information, Education and Communication systems such as brochures, pictorial charts, leaflets, audiovisual aids and intervention counselling techniques. Anxiety (90 items Comprehensive Anxiety Scale), stress (Personal Stress Inventory with 35 questions) and depression (Beck’s Depression Inventory) were measured before and after treatment. Most of the patients reported severe anxiety. Breast disfigurement and sexuality were found to be least important (though 51.6% of the participants were pre-menopausal women), but psychological and social support appears to significantly influence the treatment outcome and rehabilitation of cancer patients in India. Sexual maladjustment was not a problem among the participants. Majority of the participants expressed their desire for breast reconstruction and prosthesis use and prefer to wear saree, the Indian traditional dress. The main factors responsible for the delayed adjustment were due to non-acceptance by the patient’s husband and family. The emotional distress seems to subside with time as they resumed normal activities quickly. Economic burden of the treatment added to the psychological stress. But the intervention counselling does not show any improvement in psychosocial morbidity.

The authors are of the opinion that absence of sexual malignancy among participants in the above study is a sharp contrast to that in the Western countries. Some important factors that might have influenced the sexuality aspect of the participants in the study will be described here. Though 51.6% of the participants were premenopausal women, 45 out of 97 participants
in this study were single (unmarried =10, divorced=19 and widowed=16) and the remaining 52 were married. Experience of sexuality and sexual problems of married and unmarried women is different which needs to be studied separately in terms of breast cancer experience. Also the experience of young women who are in their reproductive age cannot be compared with older post menopause women. The findings have another contradiction on the body image aspect of the treatment. The authors pointed out that breast disfigurement and sexuality were found to be least important among the participants. At the same time majority of the participants express their desire for breast reconstruction and prosthesis use. Since the intervention package is found ineffective, women might have utilized their own coping skills in their psychosocial context that would have then influenced the improvement of morbidity. This requires additional in-depth understanding of the unseen psychosocial factors in their coping process. Contradictions pointed out by the authors require further study with married pre-menopausal women with breast cancer in the Indian context.

The European Organization for Research and Treatment of Cancer (EORTC) module QLQ-C30 and the breast cancer specific module BR-23 had been validated in the Indian context to validate the quality of life of breast cancer patients by Parmar et al. (2005). QOL was assessed in relation to surgery, adjuvant chemo therapy, hormone therapy and radiation therapy in 299 Indian women with operable breast cancer at the Breast Unit of Tata Memorial Hospital, Mumbai. QLQ-C30 module was used to assess physical health, emotional, cognitive and social functioning, and the BR-23 module to assess breast cancer treatment related symptoms. EORTC module QLQ C 30 is a 30 item questionnaire composed of five multi item functional subscale; physical health, role function, emotional function, cognitive function and social function; three multi-item symptom sub-scales measuring fatigue, pain and emesis, a global health sub-scale and six items to assess the financial impact and general symptoms. The BR-23 module evaluated the treatment related symptoms of breast cancer. It incorporated three functional sub-scales (Body image, future perspectives and sexuality) and four symptom sub-scales (arm symptom, breast symptoms, hair loss and side effects) of systemic therapy. The translations of the scales were done in three Indian languages—Gujarati, Marathi and Hindi. The study was conducted at three phases. First stage was after surgery, second during adjuvant chemotherapy and the final at the completion of chemotherapy. Of these, 299 women (who completed the questionnaire at first visit), 274 (91.6%) completed the questionnaire on visit 2 and 239 (80%) on visit 3. One hundred and ninety-three women (64.5%) completed all the three visits. The mean age of the women was
44.2 years (range 24–72 years); 67% of women were premenopausal and 33% postmenopausal. This study showed no difference in any aspect of overall QOL between breast conservation therapy (BCT) and modified radical mastectomy (MRM) except body image, which was significantly better after BCT and breast symptoms which worsened during and after radiotherapy in the BCT group. The differences, however, disappeared by visit 3 (average 9 months after surgery) indicating a late coping capability and adjustment with self-image in women after MRM. There was no difference in the score of sexuality among the participants in these two groups.

The above mentioned study in India finds that there is no difference in the quality of life of mastectomized women when compared with those who have undergone breast conservation. The absence of changes in the sexuality of women of both groups contradicts the findings of the Western culture. Though there is a higher scoring on the body image of the BCT group over MRM, the study fails to explain the body image experiences of both these women, their subjective experience of body image after treatment. The questions in the interview schedule do not capture the perspectives of Indian women on their body image experience in their social context. As mentioned in the introduction chapter the experience of body image is highly subjective and hence the experience of women in this regard requires a subjective explanation in the words of those who experience it. Since social and cultural context has a significant influence on body image experience, the perspective of Indian mastectomized women must be studied from their perspective. The analysis of the below mentioned studies also support the need for research on subjective experience of breast cancer.

Younger women with age less than 35 years, diagnosed with non-metastatic breast cancer at the Department of Medical Oncology, Cancer Institute Chennai were studied by Dubashi et al. (2010). The study explored the Quality of Life (QOL) issues of young women with breast cancer who have undergone either mastectomy or breast conservation surgery during the years 1995 to 2005. 51 women with age less than or equal to 35 years with treatable non-metastatic stage I, II and III and those who had completed a minimum of 18 months follow up were included in the study. Socio-demographic variables included age at diagnosis, marital status, educational level, and employment status. Medical variables included cancer stage, type of surgery, hormonal status, menopausal function and child birth after diagnosis. QOL issues were studied during the follow up of the patients by using EORTC QOL C 30 and BR 23. In addition to the validated items of the scales, a few other issues related to fear
of recurrence and partner response, sexual dysfunction and menopausal symptoms were also measured. Premature menopause was seen in 29 cases. Sexual functioning and sexual enjoyment were significantly better in mastectomy group when compared to breast conservation group. Fear of recurrence was higher in mastectomy group. Breast conservation did not improve the body image scoring in this study. Younger breast cancer survivors may be in need of interventions that significantly target these issues such as non-systemic products, to alleviate vaginal dryness and also programmes to help women deal with body image concerns.

Though the above studies are conducted with Indian breast cancer patients, there is contradiction in the result of body image and sexuality aspect of the treatment. Breast conservation in the first study results in better body image scoring but the second study found no difference in body image score of women with mastectomy and breast conservation surgery. This can be investigated further by examining the subjective experience of body image and sexuality. Study on age specific breast cancer experience of sexuality within the social context is necessary.

Sheppard, Appl and Ely (2008) conducted qualitative inquiry in Australia using in-depth interviews to explore the spouse’s perceptions of body image and sexuality in relation to breast cancer, and the implications, these hold for the relationship. This research illuminated the fact that breast cancer had significant implications, for the patient and her spouse with regard to body image, sexuality and their relationship. Women found it exceedingly difficult to come to terms with the breast scar, and may wrongly perceive their partners to be repulsed and disturbed by changes in their body. Despite being an important aspect of the breast cancer experience, sexuality and body image are the topics that were not often discussed by healthcare professionals, with the patient or her partner.

The above study points out the difference in the body image and sexuality experiences of women before and after breast cancer treatment. Women experience sexual dysfunction and body image disturbance after the treatment. This result contradicts the body image and sexuality experiences of women in Indian studies (Parmar et al. 2005; Dubashi et al. 2010; Khan et al. 2010). This contradiction needs further context specific investigation. Also, Bharath and Parikh (2010) in the guest editorial of Indian Journal of Cancer commented that ‘Indian women with breast cancer, quality of sexual life and sexual satisfaction are almost
never discussed by the Oncologist and patients, considering it as “taboo” topics”. The influence of treatment on the sexual life of Indian women needs further exploration since the area is not adequately investigated by other studies from woman’s perspective. Such an exploration may also lead to the identification of the type of support women need to cope with their sexual changes in breast cancer survivorship.

Khubalkar and Khubalkar 1999 carried out a study with an objective to explore various psychological reactions of mastectomized Indian women to understand dynamics underlying non-utilization or under-utilization of prosthesis/reconstruction facility. A sample of 90 women was drawn and tested for neuroticism, (tendency to experience negative emotional state) body-self-image and physio-psychological complaints. The total sample comprised of three groups that included 30 mastectomized women (group 1); 30 non-mastectomized women operated for various other problems (group 2); and 30 non-mastectomized healthy women (group 3). They were tested with psychological tools viz., NSQ (Neuroticism Submissiveness Questionnaire), BSIQ (Body Sensation Interpretation Questionnaire), and SRQN (Self Regulation Questionnaire for Neuroticism). The obtained data were analyzed for one way ANOVAR (Analysis of Variance with Repeated Measures) design. Both the groups of mastectomized women and non-mastectomized operated for other problems showed poorer body-self-image than the non-mastectomized healthy women, but no significant difference was seen between mastectomized and non-mastectomized women operated for other problems. Similar picture emerged for SRQN scores i.e., neuroticism measured in terms of psycho-physical/physio-psychological complaints. With respect to NSQ scores, mastectomized women were found to score higher on submissiveness scale than the other two groups. Women in general did not show awareness about prosthesis or reconstruction facility. Results were interpreted in the light of psycho-social conceptualization of a "woman" in Indian psyche. The data seems to project a need for cognitive intervention in the treatment of the disease.

Mehrotra (2008) in her article “Psycho-Oncology Research in India: Current Status and Future Directions”, mentioned the above stated study to point out the contradiction of its results with the result of another study. De Souza & De Souza (1979), reported that 83% of the Indian women who underwent mastectomy would have preferred more information prior to their surgery. 94% of the women wanted a good prosthesis as soon as possible after mastectomy. Only 4% of the women clearly and consistently desired reconstructive surgery.
Opposing these results the above study indicated that mastectomized women were high on submissiveness than women operated for other problems and that they had low awareness about prosthesis/ reconstructive facilities. The differences between the results of these studies need exploration to fill the gap in data.

As per the findings of Fobair et al. (2006), difficulties related to sexuality and sexual functioning were common and occurred soon after surgical and adjuvant treatment. Addressing these problems was essential to improve the quality of life of young women with breast cancer. The purpose of this study was to determine the frequency of body image and sexual problems during the initial months after treatment among women diagnosed with breast cancer at age 50 years or younger. A multi-ethnic population-based sample of 549 women (Asian, Latina and Euro-American) aged 22–50 years who were married or in a stable unmarried relationship were interviewed within seven months of diagnosis. Half of the 546 women experienced two or more body image problems some of the time (33%), or at least one problem much of the time (17%). Among sexually active women, greater body image problems were associated with mastectomy and possible reconstruction, hair loss from chemotherapy, concern with weight gain or loss, poorer mental health, lower self-esteem, and partner's difficulty in understanding one's feelings. Among the 360 sexually active women, half (52%) reported having difficulties in two or more areas of sexual functioning (24%), or a definite or serious problem in at least one area (28%). Greater sexual problems were associated with vaginal dryness, poorer mental health, being married, partner's difficulty in understanding one's feelings, and increasing body image problems, and there were significant ethnic differences in reported severity. The authors attributed the lower prevalence of sexual activity of Asian women to the cultural differences between Asian and Euro-Americans values regarding the women’s relationship with her partner and her role within the family. Cultural factors appeared to be involved in the sexual and body image problems experienced and reported by both Asian and Latina women. Both cultures do not appreciate discussing sexual issues considering it as immodest. The authors were of the opinion that research is needed on the relationship of religion, ethnicity, and culture to sexual activity and problems of body image, and sexual functioning after breast cancer treatment.

Margolis, Goodman and Rubin (1990), conducted a study with 32 patients who had undergone lumpectomy with radiation and 22 patients who had undergone mastectomy to understand the psychological impact of these treatments on women in Philadelphia. All
participants had completed a minimum of one year after treatment. Two treatment groups were similar with respect to chemotherapy, educational level, marital status, socio-economic status and employment status. Patients who had had a mastectomy felt less attractive, less sexually desirable, and more ashamed of their breasts. They also experienced less enjoyment in their sexual relationships than they had before treatment. The mastectomy patients reported that if they had to choose again, they would want a lumpectomy to avoid disfigurement. Half of them regretted having chosen mastectomy.

The result of this study contradicts with that of a similar Indian study by Dubashi et al. (2010). Both these studies were conducted among breast cancer survivors following at least one year after treatment by comparing mastectomy and breast conservation treatment. As per Dubashi et al., (2010), sexual functioning and sexual enjoyment were significantly better in mastectomy group and breast conservation did not improve body image score. This strongly contradicts the findings of Margolis, Goodman and Rubin (1990) as women with mastectomy felt less attractive, less sexually desirable, less enjoyment in their sexual relationships and more ashamed of their breasts than women with breast conservation. The gap in the form of contradiction of findings can be filled up through additional research concentrating on the socio-cultural factors of sexuality and body image of Indian women.

To explore changes in physical and psychosocial function before and after breast cancer by age at diagnosis, Kroenke et al. (2004) conducted a study in United States of America. Functional status was measured using the Medical Outcomes Study Short Form 36 (SF-36). Mean change in health-related quality of life (HRQoL) scores was computed across categories representing the combination of incident breast cancer (yes or no) and age at diagnosis. The study population consisted of 122,969 women aged between 29-71 years. They were categorized under three groups such as young women (aged less than 40 years), middle aged women (41-64 years of age), and old aged women (65 and more). Young women fare worse than middle-aged or elderly women in both physical and psychosocial dimensions after breast cancer diagnosis. Larger declines in young women for physical role function and pain were not due to the severe disease state or aggressive treatment, but due to factors such as social networks, marital status, and education, family roles and expectations, ability to provide care for their children and their career. Psychosocial adjustment of young women was also worse in this study when compared to other two groups. Possible age-related reasons for greater emotional problems among younger women include greater fear of death,
greater issues with return to work, concerns about the impact on their families, and lost opportunities for childbearing. According to this study, young women at their reproductive age (pre-menopausal) represented a distinct experience in breast cancer when compared to older breast cancer patients.

The experience of body image and sexuality is highly subjective and the interpretation of the influence of breast loss on this experience needs a personal explanation of the lived experience of women. The familial and social aspect of a woman’s life has profound influence on her body image and younger women tend to experience more problems due to breast loss. Though many researchers have looked at various dimensions of women’s body image and sexuality, Indian studies too represent contradictory results. The gap needs to be filled up through further research.

2.4 Pregnancy and Motherhood:

Gestational or pregnancy-associated breast cancer is defined as breast cancer that is diagnosed during pregnancy or in the first postpartum year, or any time during lactation (Stuebe and Schwarz 2009). It is a relatively rare clinical situation that may present many difficult medical and psychosocial problems since diagnosis is commonly delayed, largely related to breast changes which normally occur during pregnancy (Gallenberg and Loprinzy 1989).

According to Moore and Foster, (2000), a diagnosis of breast cancer during pregnancy or the postpartum period is an unfortunate occurrence. Hormonal factors appear to play an important role early on in the development of breast cancer; however, pregnancy itself does not clearly influence the outcome of an established breast cancer. Diagnosis can be challenging in a pregnant woman and delays in diagnosis are common. Treatment decisions must take into consideration not only toxicity to the mother, but short- and long-term consequences for the fetus as well. Other special considerations with pregnancy-associated breast cancer include the timing of delivery, the potential for nursing, and concerns for future fertility. In general, management of pregnancy associated breast cancer follows the same principles as in non-pregnant patients of similar age. With thoughtful application of available therapies, the outcomes can be optimized for both the mother and her child.
Nugent and O’Connell (1985), reported that previous studies had found a poor prognosis for breast cancer occurring during pregnancy due to the intense hormonal stimulation produced due to the pregnancy. Their study of 176 patients revealed that pregnancy did not seem to directly affect the prognosis of breast cancer. Rather, poor survival was related to the patients’ youth (<40 years old) and to the large number of estrogen receptor-negative tumors. Of the pregnant patients, 71% had estrogen receptor-negative tumors, implying hormonal insensitivity. Terminating the pregnancy on this basis did not seem warranted. Subsequent pregnancies in young patients did not seem to affect survival adversely. Future pregnancy in patients with stage I tumors can be considered after two years. Survival was so poor in patients with stage II or III tumors that subsequent pregnancies should be discouraged for socio-ethical reasons.

Gorman et al. (2009) conducted a qualitative investigation of breast cancer survivor’s experience with breast feeding. Eleven women were studied using in-depth interviews. The main themes identified were: 1) **Cautiously hopeful** about their ability to breast feed, 2) **Exhausting to rely on one breast** due to mastectomy, 3) Motivated despite challenges. It means that the thought about the nutritional aspect of the baby and bonding with the mother, women motivated to feed their child though had modest supply of milk. 4) Support and lack of support from social systems and medical team, and 5) Encouraging to others. Women tried to encourage other survivors not to let breast cancer interfere with their desire to breast feed. Their decision to breast feed their child emerged from two main reasons. One is the benefit to their own health, probably reducing their risk of breast cancer recurrence, and the benefits of breast milk for their child’s health. Difficulties related to having only one lactating breast, including reduced milk supply, physical pain and exhaustion, posed significant obstacles for this group of breast cancer survivors. They reported that spousal support provided them with significant emotional support in handling difficulties.

If a woman is having chemotherapy treatment, she will be advised by the doctor not to breast feed her child since treatment drugs are likely to be present in her breast milk (Berry et al. 1999). The experience of women who are not able to breast feed their children due to breast cancer treatment provide another area of study. Women who have already undergone mastectomy before childbirth will have double psychological concerns of fertility issues as well as breast feeding in the near future. This also needs to be addressed through studies.
The experience of breast cancer in mothers of dependent children and the strategies these women use to handle their illness in relation to the children was studied by Billhult and Segesten (2003). Ten women with non-recurrent breast cancer were interviewed using phenomenology as a theoretical framework. The findings revealed that the women needed to balance themselves from being needed and perhaps not accessible, balancing between demands, a will to be strong and allowing herself to be sick, and balancing between telling the truth and protecting the children from the truth. The women had strategies to help them in this struggle. To carry on as usual and continue everyday life became very important to them. To do this they had to combine their own strength with support from others and try to turn things into a positive perspective. The essential meaning of living with breast cancer and having dependent children implied using the strength of motherhood to balance conflicting forces and thereby continuing everyday life.

Zahlis and Lewis (1999) conducted a retrospective qualitative enquiry into the perception of mothers. The school-age child's experience with their mother's breast cancer was analyzed from the perspective of mothers. Semi structured interviews were conducted with twenty six mothers who had one or more children (N = 36) aged 8 to 12 years when they were diagnosed with early stage breast cancer. Inductive data analysis techniques were employed to analyze the content of data. Mothers identified times during their diagnosis and treatment as the most difficult time for their children; behaviors they observed indicated that the child was manifesting difficulties in behaviour, having a difficult time and factors that prevented them from helping the child during those difficult times. The physical tiredness as part of the treatment prevented them from providing help to their children in their academic as well as day to day responsibilities. Mothers found it difficult to help the behavioral changes of their children that they exhibit towards the diagnosis and side effects of the treatment. Authors claim that the data provided a partial basis for developing materials, programs, and services designed to minimize the children's distress and to enhance the effectiveness of parenting when a mother has early stage breast cancer.

In-depth analysis of the experience of such mothers will help to identify strategies and services as a part of psychological intervention to women in similar situation.
2.5 Marital and Family Relationship:

Northhouse (1984) reported the result of a study based on review of literature. During the initial phase of cancer, family members felt excluded from care, had difficulty communicating with staff and experience considerable emotional tension. In the adaptation phase family members had problems with lifestyle changes, meeting the needs of well family members and living with uncertainty. In the terminal phase family members experienced role strain, communication problems on the subject of death and feelings of loss. Intervention strategies that have been used to assist family members to cope with the cancer experience are also reviewed. As per the study, the strongest predictor of the impact of the cancer experience appears to be the quality of the relationship women enjoyed with their partners before diagnosis and treatment. Breast cancer and its treatment affect not only the patient, but also her intimate partner and their relationship, including their communication, sexual relationship, and role identities. Both positive and negative effects of the experience have been identified.

Woman’s perception on the support from the partner in breast cancer experience requires special attention to understand how the relationship influenced a woman’s adaptive or mal-adaptive coping with diagnosis, treatment, breast loss, and changes in sexuality. The proposed study aims to explore how women perceive the support from their partners in their cancer trajectory.

Another study based on review of articles which examined the impact of breast cancer and its treatment on patient’s marital relationship was published by O’Mahoney and Carroll (1997). The study reports that breast cancer and its treatment affect not only the patient, but also her intimate partner and their relationship, including their communication, sexual relationship, and role identities. Both positive (physical closeness and increased communication) and negative effects (increased symptoms of depression, anxiety, and psychosomatic complaints) of the experience have been identified. Predictors of marital adjustment following breast cancer are also reviewed, including demographic factors, illness factors, and characteristics of the couple. Quality of premorbid relationship is a major influencing factor. Those in good relationships appear often to experience improvements in the relationship, especially in areas of closeness and communication.
Ptacek, Ptacek and Dodge (1994) in their cross-sectional study of 36 breast cancer patients and their husbands provided information about how each recalled coping with stress during a course of radiation therapy. Both spouses also were asked to report on one another’s coping efforts and to provide information about their own current psychological adjustment and marital satisfaction. The results indicated that wives engaged in more extensive and varied coping efforts than their husbands did and that the coping strategies which husbands and wives used were largely independent.

The experience of a wife being a cancer patient and her perception of her husband’s support in the context of breast loss requires attention. This study is aimed to understand her perception of this support during the phases of diagnosis, treatment and survivorship in cancer treatment. The impact of breast cancer on the family relationship is rarely addressed in Indian context. As pointed out by Mehrotra (2008), this was surprising that since the family forms the backbone of support in Indian culture, there existed a scarcity of research in this field. The subjective interpretation of the support received from the family members especially from partners and children, provided the lived experience of women in the context of Indian families.

2.7 Conclusion

From the above findings of different research, it is clear that breast cancer is not only a medical disease of the biological body of a woman, but also psychological as well as social. She is not alone in the experience; rather she is surrounded by her family, the primary social institution. Her breast cancer experience is profoundly shaped by the culture of the society in which she lives. More studies are needed to uncover the entire span of cancer trajectory starting from the symptom stage, engaging in screening, diagnosis, active treatment, remission, survivorship, recurrence and beyond. Such studies also need to focus in-depth on the role of psychological and social factors that impact the well being of individuals during the cancer trajectory.

Based on the studies reviewed in this chapter, the following gaps in the literature are identified.
Context specific studies need to be conducted in Kerala, India:

- There is sharp contradiction among the findings of Indian and Western research as well as research from India itself.
- Despite having high health and educational standards, women in Kerala represent poor health seeking behaviour regarding breast cancer leading to late diagnosis and a poor prognosis. A study from the perspective of women may address the psycho-social and cultural factors behind this contradiction.
- Many studies recommend the importance of providing psycho-social interventions to address the problems faced by women. Only through context specific studies culturally sensitive intervention package can be developed which address the unique areas where Indian women with breast cancer require support.
- Context specific studies are essential to determine the psychosocial factors that prevent women from participating in community screening or intervention programmes. Successful community programmes can be designed on the basis of such study.

2.8 The lived Experience of Breast loss from the Perspective of Women is Rarely Addressed in India:

- Social and cultural determinants on body image and sexuality needs to be studied to understand the experience of breast loss in Indian context.
- In-depth analysis of younger women with breast cancer who are in their reproductive age is another area which lacks information in Indian context.
- There is a dearth of literature on the pregnant women’s experience of breast cancer diagnosis in Indian context.
- Breast cancer and breast feeding experience is rarely addressed in Indian women.
- Field based grounded theory study which is based on field reality needs to be conducted rather than studies imposed by theories that fail to capture the lived experiences and hear the voices of women in their socio-cultural context.

The graphical representation of the above findings as the gaps in the existing literature is illustrated below:
Rationale for Conducting Research

Figure 2.1

Importance of Lived experience from the perspective of women

- Social and cultural determinants of body image and sexuality
- Experience of younger women with breast cancer in reproductive age
- Importance of Grounded theory with field reality

Rationale for a context specific study in India.

- Contradiction in Indian and Western literature
- Contradiction among Indian literature
- Importance of culturally specific Intervention package

Need for further study