Chapter 2

Review of Literature
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This chapter is an attempt to sum up the existing knowledge including theoretical as well as empirical contributions of various studies on the theme- women with breast cancer. It precisely talks about the discourse in breast cancer as a disease and as an illness experience with a focus on HRQOL and SCN on women. It is organised in a sequence where women with breast cancer is the central theme, breast cancer experience as the disease and illness experience are discussed under the first sub theme. Sequalae of breast cancer as symptoms and side effects are discussed under the second sub theme- women’s experience of breast cancer. Third subtheme discuses the theme- women as a cancer patient; brings light to the experiences and effects of women being a patient on her personal and social life. Fourth sub-theme is about HRQOL and breast cancer specifically on various domains, determinants including demographic factors, treatment related factors, psycho social factors, sexual functioning and well being, spirituality/religious beliefs and HRQOL & social support. Fifth subtheme presents the supportive care needs of women with BC; factors affecting SCNS, common areas of need-incorporating informational needs and health care system delivery needs. This chapter concludes with specifying potential gaps in understanding the women with breast cancer.

This chapter excluded studies related to pain and palliative care, alternative medicines and therapies as the present study is limited to hospitalisation of women with BC but it talks about the reasons of exclusion of certain themes from this review.
2.1. Breast cancer as disease and or illness

The terms ‘illness’ and ‘disease’ as synonyms are widely used and popular in clinical practice and general communication though, several medical anthropologists have categorically presented its analytical distinction (Cassell E J, 1978; Kleinmann, 1980). However, these two terms are not separate entities, but to some extent overlapping and explanatory concepts (Helmann G C, 1981). Breast cancer is a disease comparable in its explanations of clinical parameters for that cause, but the illness experiences varies across the globe as socio cultural variations. This portion discusses both the aspects.

2.2. Brief history of breast cancer- evolution of disease treatment

The word ‘cancer’ is credited to ‘father of medicine’, Hippocrates (460-370 BC) who was a Greek physician used the terms ‘carcinos’ and ‘carcinoma’ to explain non-ulcer forming and ulcer-forming tumors (The history of cancer, American Cancer Society). Later Celsus (28-50 BC), a Roman physician translated this into cancer and another Greek physician Galen (130-200 AD), used the term ‘oncos’ to describe tumors. This term is used to mention treatment branch as oncology and specialists as oncologists.

When specifically talking about breast cancer, it is considered as the most ancient cancer and most mentioned type of cancer in every period of the recorded history. From an

24 Disease is considered as a medical model term which talks with an assumption that health and illness universal in its form, content and progress, whereas illness is defined as the subjective response of a person to being ill. And it is influenced by various factors such as socio cultural background, socialization and personality traits. (Fox, 1968, Helmann C C, 1981)
25 Crab is the meaning of these words in Greek, used to refer this disease because of “the finger-like spreading projections from a cancer called to mind the shape of a crab”
26 Latin word of crab
27 Greek word for swelling
Egyptian physician- Edwin Smith surgical papyrus (3000-2500 BC) came the first
evidence of record about breast cancer with a description of eight cases of breast cancer
and ‘admitting that there was no treatment’(Akram M & Siddiqui S A, 2012). Evolution of treatment for breast cancer developed from very unprocessed modes as one
case in that had been treated by cauterization with a fire stick. There are found to have
many writings from India mentioning the treatment of breast cancer with surgical
excision, cauterization and arsenic compound from 2000 BC. Almost at the same period,
ZacutusLusitani (1575-1642) and Nicholas Tulp (1593-1674), from Holland, argued that
cancer was contagious based on their experiences with breast cancer in members of the
same household. They publicized the contagion theory in 1649 and 1652 and suggested
isolation of those cancer patients with the aim of prevention of the spread of cancer
(Shou-He Yan, 2013).Hippocrates in 460 BC considered breast cancer as humoral\textsuperscript{28} disease and in AD 131-203, Galen recognized breast cancer as excessive prevalence of
black bile or a particular humorin the body.

Eventually new treatment techniques were introduced and towards the end of 16\textsuperscript{th}
century, advanced practices initiated in surgery like removal of the pectoral muscle
along with the breast by Vesalius (1514-64) and removal of axillary nodes along with
the breast by Severinus (1580-1659). Later on came the lymph theory of origin by Descartes (1596-1650). Breast cancer is a local disease at its earliest stage, which
spreads to lymph nodes and then spreads to the circulation was an important theory
proposed by French surgeon Henry Le Dran in 1757 and he proposed that early
performed surgery might cure the disease. This theory was well accepted and in 1871,

\textsuperscript{28} Meaning of humoral is of, relating to, proceeding from, or involving a bodily humor (as a hormone)
(www.merriam-webster.com/dictionary/humora)
Henry Arnott restated the local origin of breast cancer and advocated the principle of curative surgery. Until the 19th and early 20th centuries surgery was very primitive with many complications and major advances in cancer surgery happened afterwards. Focus on prevention of breast cancer was another important discovery in 19th century by the invention of relationship of the ovaries to milk formation in the breasts by Thomas Beatson in 1874. Later he found that removal of ovaries often resulted in improvement for breast cancer patients and it became a foundation for the modern use of hormone therapy to treat or prevent breast cancer (The history of cancer, American Cancer Society).

Radiation started to be used for diagnosis and therapy in the early years of the 20th century, later it was discovered that it could lead to cancer as well. But during the last years of the 20th century, more precise and accuracy in radiation therapy was introduced because of the advances in radiation physics and computer technology (Olson & James. 2002). Other successful treatments like chemotherapy, hormone therapy and targeted therapies were integrated or used for breast cancer treatment in the due course of time (Hajdu SI, 2000).

In early 20th centuries, only a few small and localized cancers were considered to be curable, which were completely removable. In a while, radiation started using after surgery in order to control surgically unresolved small tumor growths. Finally, chemotherapy was added to destroy small tumor growths that could not be removed by surgery or radiotherapy. Adjuvant chemotherapy was also started, which was used to destroy the cancer cells in the body remaining after surgery. Slowly, medical scientists identified genes that can cause cancer, the ‘oncogenes’ and tumor suppressor genes.
Discovery of 2 genes, BRCA1 and BRCA2 in 1990s was a step forward to identify people who are at high risk of developing breast cancer (Hajdu SI, 2011). And many researches and advancements are happening in developing more successful treatment modes and its impacts have intensely reflected on the number of survivors of breast cancer across the world.

2.3. Woman as a breast cancer patient

Diversity in women’s breast cancer experiences, have studied by various researchers; considering their whole life experiences and role expectations. Veloshnee Govender and Loveday Penn-Kekana (2007) in their background paper for the women and gender equity knowledge network of the WHO commission on social determinants of health, argue that the gender of the patient is one of the most significant factor in over all treatment and care context which defines the quality of access and shaping the interaction between them and the care providers. Gender as a determinant of health is understood in literature; however this review recognizes that the dynamics of what is to be a woman changes over time and across the culture, which more over reflects on the illness experience.

The ways health issues are reflected by gender have been specifically studied by various scholars. Socially, women with an illness were moreover not accepted in certain instances like marriage, where married women even faced risk of divorce and unmarried women were completely not favoured to be considered for it. Economic burden and consequences of a disease is considered as a major issue of men in certain cultures (Johansson, Long et al. 2008). The themes- ‘woman being ill’ and their ‘navigation
through the illness and treatment’ are demanding an extra mile of understanding towards the visible breast cancer picture by facts and data. As an illness complicates many of the social roles; how the women perceives their lives when ‘being patient’ becomes another role for them- is an important concern towards further studies. Other important concerns - femininity concerns and sexuality are discussed in the later sessions.

2.4. Femininity, body image and sexuality concerns and breast cancer

The word ‘breast’ sounds synonymous to the female body opening a wide variety of cultural and historical narratives (Lammer, A.et al, 2007). From the time of first diagnosis of BC, the breasts become a point of discussion in public. Conversation on an organ becomes in public domain, which she must have kept very personal and feminine, follows all through her cancer journey or till the end of her life. Though the completion of this journey is affected by various external and social factors, moreover it depends upon the woman’s personal perception of her illness in relation to herself as well as the coping behaviors (Vijayan A, 2012). Eisenstein Z (2001) a political scientist, when sharing her own BC experience explained the femininity concerns as- the “breast speaks sexual desire, maternal feeding and mammies, and the objectification of females, reducing them to their bodies”. Young, Iris Marion (1990) in her essay, “Breasted Experience: The Look and the Feel,” explained the influence of the body organ- breast on women forming her values and roles as the women as breasted beings.

A multitude of feelings and psychological problems related to body image are involved in association with the breast cancer diagnosis. Auchincloss S S (1995) argued that a sense of loss of femininity and motherhood are being created in the women with cancer because of the disturbances in body image and identity. Decreased body image is

Oktay and Walter (1991) wrote about the challenges faced by woman with BC such as trouble in their identity as a female body, their sexual relationships, relationships in the family and society, and the performance of social roles. Vijayan A. (2012) describes that the impaired body image after mastectomy and chemotherapy generate severe disruption in their sexuality, as the perceived sexual interest is lost. She further added that the consequence of the altered body after BC treatments generates disturbances in their body image, physical beauty and appearance and therefore, their femininity. When it concerns to motherhood, Vijayan A (2012) explained that BC makes the journey of motherhood difficult, when continuing daily life with the illness experience, especially, at lactating phase. She also denoted, a right turn towards successful survivorship is possible when the woman is able to combine the support system and the inner strength to a positive perspective to fight against the illness. O’Mahoney and Carroll (1997) found that the BC influences the woman’s relationship with spouses in both positive and negative ways. Intimacy in terms of concerns and care is found as increasing, and communication of the feelings also reported a positive impact; whereas the effects of depression, sexuality and body image concerns affect the couple relationship negatively. They found that the quality of relationship among couple before the cancer becomes the most determining factor in the women’s adjustment to femininity concerns.
2.5. Sequelae of breast cancer

The understanding of breast cancer as a disease and development of its treatment has been altered by the advancement of medical world as well as the dynamics in the society. This section deals with studies dealt with the portrayal of noted effects and experiences of breast cancer disease in the woman’s life. The concerns related to different domains such as psychological, social, functional, sexual and spiritual- will be discussed in the later sessions; in relation with HRQOL and SCNS.

2.5.1. Symptoms and side effects

A women’s journey from the identification of symptom till treatment is influenced by her complex set of interactions with demographic, medical, psychological, behavioural and social factors (Bish A, Ramirez A, Burgess C, Hunter M; 2005). They identified awareness of symptoms as an important precursor to seek help for treatment and care. Andersen RS, Paarup B, Vedsted P, Bro F and Soendergaard J (2010) and many other studies reported that incorrect and poor knowledge of cancer symptoms lead to hindrance in help seeking, delayed diagnosis and treatment which would go ahead to poor prognosis and reduced chance for survival. A literature review on Women’s awareness of cancer symptoms done by Sandra C. Jones and Keryn Johnson (2012) shows a picture that how the symptoms are being understood by the women using the findings of the two ‘symptom recognition’ studies, conducted first in the UK with a sample of 1854 woman by Brunswick N, Wardle J and Jarvis MJ (2001) and the second in Netherlands with 1221 women by De Nooijer J, Lechner L and De Vries H (2002) –
“…thickening/lump (84.0 and 56.0%); change in a mole or wart (79.0 and 82.3%); bleeding/discharge (74.3 and 62.6%; described as ‘unusual’ bleeding or discharge in the Dutch study); change in bowel or bladder habits (73.7%; separated in the Dutch study into bowel [44.6%] and urinary [32.0%]); and persistent cough or hoarseness (53.8 and 55.0%). Less than half responded affirmatively to a sore that does not heal (47.3 and 39.0%) and indigestion or difficulty swallowing (37.7 and 42.4%). Recognition of symptoms only included in the Dutch study was 61.9% for unusual weight loss and 58.8% for new warts.”

Most commonly, breast lump, secretion from nipple or breast pain are the symptoms identified by the women. Various studies noted pain as the most commonly reported symptom of breast cancer (Ferrel BR, Grant M, Funk B, Otis-Green S & Garcia N (1997), Lehto-Järnstedt 2000, Rietman JS, Dijkstra PU, Debreczeni R, Geertzen HB, Robinson DPH & deVries J (2004), Avis NE, Crawford S & Manuel J (2005), Steegers MA, Wolters B, Evers AW, Strobbe L & Wilder-Smith OH (2008). Studies by Armer JM (2005), Shih Shih Y-CT, Xu Y, Cormier JN, Giordano S et al. (2009), Norman SA, Localio AR, Potashnik SL et al. (2009) reported that lymphedema as the initially noted symptom. Decreased mobility of shoulder and arm are other important symptoms noted by studied by Ferrel BR, Grant M, Funk B, Otis-Green S & Garcia N (1997) and Rietman JS, Dijkstra PU, Debreczeni R, Geertzen H B et al. (2004).

2.5.2. Side effects

Side effects of Surgery: Pain, swelling, bleeding, and infection are the common short time physical side effects as accompanied by any other surgery. Swelling in the arm/s or
chest (lymphedema), tightening of skin, stiffness and weakness of the arm and shoulder are the other physical side effects. Most of all these, the loss of breast is considered as the main side effect after BC surgery by the women (Vijayan, A, 2012).

**Side effects of hormone therapy**- General side effects of hormone therapy are same as in the symptoms of menopause like hot flashes, night sweats and vaginal discharge and dryness. Irregularity of menstrual periods, tightening bones, headache, fatigue, nausea, vomiting, vaginal dryness or itching, irritation of the skin around the vagina, and skin rash are a few other side effects observed (Shockney 2008). Cancer of the uterus and blood clots are rarely associated with the use of Tamoxifen.

**Side effects of chemotherapy**- Side effects of chemotherapy often depend up on the type of drug, the amount administered as well as the treatment length (American Cancer Society booklet). In addition to surgery, chemotherapy also causes serious impact on body in terms of physical issues and appearance (Fobair, P., Stewart, S. L., Chang et al. 2006). Hair loss, differences in appetite, nausea and vomiting, a higher risk of infection (from low white blood cell counts), abrupt medical menopause, easy bruising or bleeding (from low blood platelet counts) and fatigue are the reported short term side effects of chemotherapy (Wolf and Davison 2008; Vijayan, A, 2012). Possible long term side effects of chemotherapy are the menstrual changes and nerve damages caused by some drugs. The nerve damages occasionally causes indications such as “*pain, burning or tingling, sensitivity to cold or heat, or weakness mainly in the hands and feet*” (American Cancer Society booklet).
Side effects of radiotherapy- Side effects of radiotherapy are mainly depending up on the dose and type of radiation. Swelling and heaviness in the breast, skin changes over the treated area, redness to blistering and peeling, fatigue, hardening of the breast and skin changes are the short term side effects of radiotherapy. Some long-term side effects are also reported like long-term arm swelling (called lymphedema) due to the damage of some nerves to the arm (Vijayan, A, 2012; American Cancer Society booklet).

2.6. Health related Quality of life and breast cancer

2.6.1. Studying Health related Quality of life and breast cancer

The impact of BC on QOL is different not only between individuals, but also varies overtime within the individuals (Bowling 2003). Women who go through the illness are the appropriate assessors of their QOL as the given importance to the experiences vary in unique ways (Ferrans, 1996). Multidimensionality and subjectivity are the two major approaches to understand QOL in cancer (Fayers & Machin 2000). Although the purpose differ with assessing QOL using different disease- specific tools, all of them serve the aim of reflecting BC related issues and concerns on cancer patient’s well-being and thereby it becomes worth quantifying (Fayers & Machin 2000).

2.6.2. Factors associated with HRQOL in Breast Cancer patients

Several studies have come up discussing Health related Quality of life and breast cancer (Ferrel et al. 1996, Ferrel et al. 1997, Ferrel et al. 1998, Rustoen et al. 1999, Shimozuma et al. 1999). A tendency of comparatively poor QOL is observed in BC patients than persons with other cancers (Rustoen et al. 1999a, Engel et al. 2003), particularly in the domains of psychological, sexual (Rustoen et al. 1999) and emotional functioning.
Impact of cancer is reported as evident on the QOL domains (Rustoen et al. 2000). Changes in QOL related to the ongoing treatment, especially between the first and second year after breast cancer surgery has been studied by Engel et al. (2004). Likewise different factors are associated to breast cancer patient’s HRQOL in different ways.

2.6.3. Determinants of QOL in Women with BC

Socio-demographic variables and disease related variables as the determining factors of BC have been studied by many researchers. The aspect of age has also been studied in association with QOL, as older women with BC have higher QOL scores (Rustoen et al. 1999, Ganz et al. 2005. Greater QOL disturbances are observed in younger women (Wentzel et al. 1999, King et al. 2000, Sammarco 2001). Medical menopause, fertility concerns, concerns on disturbed body image and sexuality are certain physical issues in younger women causing poor QOL scores than of the older women (King et al. 2000, Engel et al. 2003, Ganz et al. 2003). In addition to that, career, job and financial security are also often associated with QOL of women with BC (Andrykowski et al. 2000, Sammarco 2001, Avis et al. 2005). Effects of BC experiences on younger women have been studied by different researchers in terms of their higher psychological disturbances, low social and emotional well-being (Engel et al. 2003, Wentzel et al. 1999). Marital status is studied as positive and negative in its effect on QOL as unmarried women is reported with low psychological well-being as well as married women with low sexual and functioning well-being (Broeckel et al. 2000). Uzun et al (2004) studied effect of employment status of Women with BC as the better QOL is found in the employed women than the unemployed women.
Treatment modalities are also studied as determinants of HRQOL of breast cancer patients. Radical mastectomy is the most reported treatment mode that disturbs QOL of women with BC as in relation to the sexuality and body image variables. Women who underwent breast conservation surgery are reported with better QOL scores than women who had lost their breast by mastectomy (King et al. 2000, Engel et al. 2004, Fobair et al. 2006). Arora et al. (2001) found that emotional well-being scores in women who underwent lumpectomy were significantly lower; and they argued it is because of the anxiety regarding the symptoms and the further possible complications.

Negative effects of adjuvant therapies on QOL has been studied by many researchers; especially its effect on psychological and sexual well-being as well as on body image (Arora et al., 2001, Watters et al. 2003). The effect of chemotherapy is widely studied as nausea, vomiting, hair loss and fatigue (Haas 2010). He also found that chemotherapy had a negative effect on the sexual functioning of the breast cancer patients. Watters et al. (2003) added the impact of chemotherapy on physical well-being, role functioning and total health status of the patients. Schover et al. 1989; McIlfatrick et al. 2007, Turgay et al. 2008 studied the chemotherapy impact on body image, psychosocial well-being scores.

Women’s inability to perform their expected roles in the family creates severe impact on the psychological and function scores of QOL (Watters et al. 2003). Physical and psychological impact of post chemotherapy patients were reported as- reduced physical activity, exhaustion, sleep disturbances, loss of interest in participating in social events or meeting people (Byar et al. 2006; Turgay et al. 2008). Swelling on shoulder and arms were found as the serious physical issue with persons undergoing chemotherapy and radiotherapy (Schultz et al. 2005) and therefore the lower QOL scores (Ridner, 2007).

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Physical QOL is observed as poor, in patients who undergo radiotherapy as the result of treatment side effects. Darkening of skin and nails and fatigue are certain side effects impacting the QOL of the patients (Whelan et al. 1997). Smets et al. (1998) found that the fatigue associated with radiotherapy is distressing and impacts patient’s emotional and physical well-being. Hormone therapy also causes higher levels of fatigue among women with BC thereby leading lower QOL (Haas, 2010). Women who belong to lower and middle income groups were found with lower psychological well-being scores because of the burden of treatment cost (Khan et al. 2012). Cancer recurrence is another important determinant of HRQOL which affects negatively on physical and psychological well-being of the patients (Helgeson & Tomich, 2005).

Studies by researchers like Auchincloss S S (1995), Cain E. N., Kohorn, E. I., Quinlan, D. M et al., (1983) and by Greimel E R & Freidl W (2000) mainstreamed the argument-breast cancer diagnosis and treatment not only affect a woman’s physical functioning but the social, psychological, sexual and reproductive functioning are also impacted by the illness experience, which later showed way to incorporation of these domains into consideration of care for the patients.

2.7. Breast cancer and Supportive care needs

Considering holistic approach of providing best care for the cancer patients; supportive needs of the patient and family have to be addressed in addition to the medical interventions (Miller, Pittman, & Strong, 2002). For decades, the term supportive care has been used in oncology referring care provided for the people with cancer. Whelan T. J., Mohide, E. A., Willan, A. R., et al. (1997) defined supportive cancer care as the activities related to help the cancer patients and families with their experience during
diagnosis, treatment, recovery, and palliation. Richardson, A., Medina, J., Brown, V. & Sitzia, J. (2007) came with a broader concept of addressing areas of supportive care needs which include physical, emotional, psychological, social, informational, financial, sexual, existential, spiritual, and cultural aspects. He explained this concept as “the quality of supportive care can be considered to be the extent to which needs are addressed and met considering the patient perspective.” As survivors are increasing in number, managing to live through is an important aspect to be taken care of at the time of interventions and service delivery. Different researchers talked about the importance of understanding the supportive care needs of the people with cancer and their families when outlining programmes for quality care (Hodgkinson, Butow, Hunt, Pendlebury, Hobbs, & Wain, 2007; Donabedian, 1990).

2.8. Factors affecting SCN of the women with cancer

Identifying the factors influence the recognition and communication of the SCN by the people in fact, will be comprehensive enough to address the individual differences and context (Butow et al., 2007; Rumsey & Harcourt, 1998). Review of several literatures are consolidated and presented thematically in the following sections.

2.8.1. Disease and treatment related factors

Sanson-Fisher R., Girgis, A., Boyes, A., Bonevski et al (2000) found in their large multi-centre study that type of cancer, ongoing treatment, time since the last treatment session, prognosis and emission status and the hospital from where they receive treatment were certain other factors that have direct impact on cancer patient’s needs. They also talked about the varying influence of all these factors according to the need domain. Extent of
the disease and treatment, side effects and functional stressors, healthcare accessibility are certain factors that influence SCN (Andersen, 1994).

**Cancer phases**- The article ‘*Seasons of survival*’ by Mullan F (1985) was a milestone study quoted by most of the studies then onwards, which reflected on his personal and professional cancer experience. This study gave a framework of three survival phases and over time supportive care studies have been captured the broad similarities and differences, of a person’s cancer journey. The three phases of psycho-social adjustment to cancer (survivorship) as- first phase, “*Acute survival*” starts from diagnosis and treatment through to the first year, second phase “*Extended survival*” counted from the beginning of the second year to approximately three years. From three years when the risk of recurrence reduces, referred as the third phase- “*permanent survival*”. In 2001, Clipp, Hollis and Cohen came with an addition of four psychosocial illness phases- 1) Crisis, 2) Early chronic, 3) Late chronic and 4) terminal phases of cancer.

Identification of needs during each of these phases is a complex process and which evolves over time and phases of the disease.

**Stages of cancer and treatment** - Cancer stages, the treatments they receive and the remission are certain factors inter-linked and which are closely associated with the needs they have during their cancer experiences. Diagnosis and hospital admission for treatment were identified as certain times of every cancer patient’s life associated with SCN (Sanson-Fisher R., Girgis, A., Boyes, A., Bonevski et al, 2000). Decades before in 1988, HoutsP. S., Yasko, J. M., Harvey et al mentioned the link between the phases of patients’ cancer journey- diagnosis, treatment and follow up with their SCN. Several other studies also ascertained the same argument very strongly that, diagnosis and the stage of disease

**Treatment decisions** - When understanding the literature of breast cancer treatment and care, a variety of models and practices can be observed across the world where treatment decisions are impacting various needs of the cancer patients especially women with breast cancer. Studies of Thibodeau J & MacRae J, 1997; Van Der Molen B, 2000 have talked about the complexity of feelings (fear, anxiety, shock and disbelief) associated with the reaction of women breast cancer patients towards diagnosis for the first time. In every phase of cancer journey, treatment decisions are directly or indirectly connected with various factors (Knobf, 2007) like- woman's participation in overall decision-making, persistence and styles of decision making, age, coping mechanisms, stage of cancer, adjuvant therapies, risk of recurrence, consideration of treatment alternatives, suggestions by people and personal choices. Mental and emotional state of the women and the family is mentioned as a challenge in taking decisions as they are often confused and worried about their lives.

Participation of women in their treatment decision has been differently perceived and practiced across the world. A report of a study conducted among 1012 women with breast cancer, 34% wanted doctors to take complete responsibility of the treatment decisions, 22% wanted to have the choice of their treatment and collaboration and consultation with doctors when taking decision had been opine by 44% of the respondents (Degner et al 1997).
Ganz PA (ed) (2007), Surbone A, Peccatori F (2006), Ganz PA, Desmond KA, Leedham B et al (2002) argued the priority of immediate treatment decision making with the consideration of psychological, emotional, and social factors, thinking from the doctor and care professionals perspective. The initial phases are crucial in terms of beginning of the medical and psychosocial issues of survivorship, and they talked about the consideration of all these issues in consultation with the patients.

A research on Ethical concerns in clinical trials in India: an investigation done by Centre for Studies in Ethics and Rights, India in the year 2009 says people’s participation in cancer clinical trials are often getting consent by suggesting a person who cannot afford the treatment to join a trial by offering free treatment. So in the context in particular, lack of awareness about the treatment choices and consideration of treatment cost or resources plays some part in the service availability, areas and the extend of patient participation in treatment choices have to be studied and understood further.

Comorbidity - The importance of considering comorbidity with a great attention when it comes to cancer care had been ascertained by various researchers. Calvo-Espinosa C, Ruiz De E, Gonzalez-Anguren C et al (2015) checked the usefulness of age-adjusted comorbidity index (ACCI) among people with advanced cancer and found that the patients with higher ACCI scores are associated with lower survival rates. They also

29 A narrative of an oncologist is given here on getting consent for participation- (taken from Ethical concerns in clinical trials in India: an investigation done by Centre for Studies in Ethics and Rights) ‘In India, patients may give consent very easily, leaving such decision to the doctor. Further, it is very easy to provide the patient with choices in such a way that trial participation seems to be easily acceptable. I can say, ‘These are the choices, and these are the limitations and strengths of each choice, and there is also an experimental drug which is being tried out and these are the possible risks and benefits of participating in a trial.’ Or I can say, ‘These are the choices, and this is what they cost, and there is an experimental drug which is being tried out and if you join the trial you will get free treatment.’ http://environmentportal.in/files/Ethical_concerns_in_clinical_trials_in_India_An_investigation.pdf

30 NCI dictionary of cancer terms defines comorbidity as “The condition of having two or more diseases at the same time”. (http://www.cancer.gov/publications/dictionaries/cancer-terms?cdrid=256556)
suggested the need of further research in the area of advanced cancer care in terms of the comorbidity concerns as it implicates certain important changes in the treatment and care scenario and also very little studies have happened.

Rosenbaum E H., listed comorbid diseases existing simultaneously with cancer are- Coronary artery disease (CAD), Cerebro-vascular disease (stroke), Chronic obstructive pulmonary disease (COPD), Diabetes, Heart disease and Hypertension, Osteoporosis and Overweight/Obesity. This disclosure of complexity call for supportive care programmes to have a notice on the needs associated with physical and psychological comorbid diseases.

2.8.2. Individual factors

Socio demographic factors- The factors which bring about individualistic view to the problem have been talked by different researchers. Age, gender, marital status, geographic location influences and brings diversity in terms of needs when a person is living with cancer (Sanson-Fisher R., Girgis, A., Boyes, A., Bonevski et al, 2000; Andersen, 1994). Studies from across the world talked about varied socio economic characteristics like- class, caste, community inter-relationships, religion, income; marital status, type of family which influence the nature and expense of SCN among women with BC.

Social and cultural factors

Social support is recognized as one of the key consideration in cancer care as other medical prognostic factors (Hewitt M, Herdman R & Holland J, 2004; Manne S., 2003). Social stressors, social networks and support care are reported as certain factors
influence SCN of cancer patients (Andersen, 1994). Difference in geographical location as rural and urban and associated social dynamics, norms, interactions and accessibility of professional support have been taken as influencing factors on SCN of cancer patients. Perceived social support is also seemed as an interesting area particularly which determines, the extend of need one person feels about his/ her situation and which would further push off to search for further support.

Cultural values and ethnic background are certain factors highlighted by Molassiotis, A., Chan, C. W. H., Yam et al. (2002). Patients’ perceptions about their body and illness as well as expectations of the health system have been studied as impacted by a wide range of personal, environmental and cultural factors. This is mainly depends upon the individual’s ability to articulate how she feels about the unmet needs.

The factors affecting the women with BC with regard to their SCN reviewed in these sections have been summarized in the figure 2.1
2.8.3. Psychological factors

Prior to physical and mental health status been studied by Andersen (1994) as a key consideration when assessing a cancer patient’s SCN. Rosenbaum E H mentioned about psychological comorbid diseases with cancer such as – Psychosocial stress, (Depression, anxiety, insomnia, cognitive deficiency) and Parkinson's disease in the list. The complexities of the treatment and care especially with breast cancer in terms of psychological comorbidity have been addressed by various studies (Ganz, PA, 2007; Knobf, MT, 2007; Aapro, M & Cull, 1999). Other psychological factors in particular,
personality traits of the patients and the patterns of coping impact patient’s demand for care (Molassiotis, A., Chan, C. W. H., Yam et al., 2002). They strongly recommended integration of the reproductive factors, sexual orientation, and existential factors in the studies regarding SCN among patients with breast cancer and other gynaecological cancers.

2.9. Chapter summary

This chapter reviewed the literature on women with breast cancer as the central theme; and discussed the historical perspective of breast cancer; BC as disease and illness experience; women as breast cancer patient and their health related quality of life and supportive care needs. This chapter also attempted to address and review various factors determines expression of their needs specifically in concern with their illness experience.

Potential gaps in research have identified by the review are:

- Majority of the available literature are on the topic- ‘women with BC’ have been studied by researchers from medical profession; which is observed as naturally tend to give prime focus on the biological body and later a few other elements. Although studies have come up from sociology, anthropology and psychology; were studied more over the complexity of the issues but not focused on immediate and practical help and support.

- Studies from social work discipline were addressing more on psycho-social and financial support for the patients; studies to address ‘the patient as a whole’ are yet to be brought out towards the discourse.
Though a few feminist perspective studies on breast cancer have come, generally majority of the studies are not looking at the gendered aspects of the issues but not considering its essentiality to recognize the complexity which makes in studying quality of life and supportive care needs.

Increasing breast cancer incidents in India, especially among women in Kerala and the continuing mainstreaming biomedical treatment and care; demand attention of studies towards the need of considering the patient as a person. Also, studies are needed; in order to understand their needs from patient perspectives.

Studying cancer as any chronic life threatening illness, with increasing possibility of cure and survivorship; where ‘living as a functioning female’ involves a lot of issues and demands in supportive interventions. In this context, studies focusing on intervention for better supportive care service delivery are needed.