Chapter 1

Introduction
1.1. The premise

Around the world breast cancer is a leading cause for death among women. Incidence of BC\(^1\) varies from region to region so as the mortality; which is dependent on various factors (Augustine P, Jose R, Peter A, 2014). Across the globe, standardized BC incidence rate is 43.3 per 100,000 female population and; 25.8 per 100,000 females is located figure in India (Ferlay J, Soerjomataram I, Ervik M, 2012; The Global Cancer Atlas – Asia, 2014; Bray F, Ren J-S, Masuyer E, 2008; Jemal A, Center MM, DeSantis C, 2010). Indian Council of Medical Research (2010) published that India has a mixed incidence pattern as in rural areas of India, breast cancer is second to cervical cancer but in the cities like Mumbai, Delhi, Trivandrum; breast cancer has crossed the number of cervical cancer incidence. Jayalekshmi P, Gangadharan P, Mani KS (2006) identified the BC incidence in Kerala state of India; as 30.5 per 100,000 female population in urban areas and 19.8 in rural areas. Sankaranarayanan R, Ramadas K, Thara S (2011) conducted a study on ‘Clinical Breast Examination as a Screening Method’ spotted that the BC incidence per 100,000 women was from 29.8 in the control group to 38.4 in the intervention group. A report of EY\(^2\) on ‘Call for Action: Expanding cancer care in India’ (2015) revealed that an increase of 20% is observed in the BC incidence from the last two decades.

\(^1\)BC is the abbreviation used for Breast Cancer throughout this study.

\(^2\)Earnest and Young India- An organisation works for building a better working world — with increased trust and confidence in business, sustainable growth, development of talent in all its forms, and greater collaboration.
As cancer has become one of the ten leading causes of death in India (National Cancer Control Programme), quality of life of the person with cancer is taken into consideration of health policies along with the medical care. Health related quality of life is now considered as important endpoint in cancer clinical trials. Women with BC often face stress that result in distress even after treatments. It has been shown that assessing quality of life in cancer patients can contribute to improved treatment and also; be prognostic as medical factors. Studies of QOL (Quality of Life) further indicate the directions needed for more efficient treatment of cancer patients. The issues related with illness and of hospitalization result in the serious impact on their Quality of Life.

Providing physical care and information, as well as psychosocial support become visible important aspects of quality care (Lowdermilk D &Germino B, 2009).\(^3\) It has also been suggested that seeking adequate supportive care services may be an adaptive coping strategy that could help moderate the psychosocial distress of women with breast cancer. Therefore, it is important to understand the broad range of supportive care needs (SCN) of women with breast cancer and the hindrances they face to seek help or to get it available for them, so that the care providers can develop appropriate interventions that could be targeted towards women who need help. Thus, optimized care could be provided, and efficient allocation of resources could be ensured.

The present study looks at the women with breast cancer; in order to understand their health related quality of life (HRQOL) and supportive care needs (SCN). It is framed in a

\(^3\)Lowdermilk D, Germino B. (2009) argued the importance of integration of psychological support as part of treatment of any cancer in their paper ‘Helping women and their families cope with the impact of gynaecological cancer. (p.653)
fashion; which appear as a descriptive understanding of the HRQOL and SCN of the women with BC through the eyes of a medical social work researcher, in order to look forward for a better holistic supportive care delivery during their breast cancer journey. The factors that are addressed in relation to HRQOL are physical, psychological, social, familial and spiritual well-being. The study also views to an extent; about the issues of women with cancer through gender lens. This research addresses the socio-cultural context of the area of the study- Kerala; which is prominent positioning in health indicators and development status as well as a state shows alarmingly increase in the prevalence of breast cancer. Supportive care needs associated with physical, psychological, social, spiritual, informational as well as health care delivery aspects are studied qualitatively. Also, this study considered the formulated ethics while conducting studies with persons who are undergoing life threatening illness; cancer. This chapter presents and establishes the major concepts- Clinical and social picture of Breast cancer on women’s life, HRQOL, SCN concerns of women with BC, the available support programmes in India and the scope of studying HRQOL and SCN of women with BC.

1.2. Clinical perspectives of Breast cancer

The malignancy or cancer of cells of the breast is known as breast cancer (American cancer Society), usually on the ducts (tubes carries milk) and lobules (glands where the milk is produced) (Moore and Yoder 2006; Rajendra, S., Rampaul, S E., Pinder, J.F 2006). Although breast cancer happens both in males and females, cancer among males are rare (Giordano, S. H., Cohen, D. S, Buzdar et al, 2004). Early diagnosis and treatment in BC usually leads to chances of cure and survival among women (Nair K. M.,
Sankaranarayanan, R., Nair, K. S. et al., 1993). Early diagnosis is most often related to the awareness and identification of the symptoms of breast cancer.

1.2.1. Causes of Breast Cancer

Understanding the risk factors in association with the incidence in particular region is the popular way of knowing the reasons. The approaches towards diagnosis and treatment of BC are based on the understanding of certain risk factors that related to the disease as the medical world is exactly not aware of its reasons. Various studies (Clemmesen 1979; Hughes and Courtney 1985; Bevers 2008) came up with a number of established risk factors for breast cancer. Having one or more risk factor does not always lead a woman to meet the criteria of breast cancer. Moreover the role that the risk factors play in causing BC can change over the time. Other variables as the nature of its influence and impact are not completely known yet.

The unalterable risk factors related to BC listed by Indian Cancer Society are- Gender, age, genetic risk factors, family history, personal history of breast cancer, dense breast tissue, certain benign tumours (not cancer) and noncancerous breast conditions such as Lobular carcinoma in situ\(^4\), menstrual periods and breast radiation early in life. Nulliparity\(^5\), use of certain contraceptive methods, pregnancy and childbirth in the late ages, administration of hormone therapy after menopause, not been breastfeeding and obesity are considered as risk factors of BC related to the life style choices world-wide (American cancer society). Higher rate of breast cancer incidents in Kerala is also understood in terms of the changing reproductive factors and life style choices and

\(^4\) In this condition, cells that look like cancer cells are in the milk-making glands (lobules), but do not grow through the wall of the lobules and cannot spread to other parts of the body.

\(^5\) Not having children
practices such as - early age of menarche, age at first delivery and breast feeding, nulliparity, avoidance of breast feeding, family history of breast cancer (Augustine P, Jose R, Peter A, 2014).

1.2.2. Symptoms

Often BC appears silently without showing any symptoms (Donegan 2002); however the most common symptom is a new swelling or lump. These lumps usually appear as painless, hard, and with irregular boundaries but among some women, these are tender, soft, and rounded and painful. Frequently observed symptoms of BC are:

- Enlargement of all or part of the breast or change in the size or shape of the breast
- Irritation or dimpling or puckering of breast skin
- Pain on the breast
- Pain on nipple or areola or inward turning of the nipple
- Redness, scaliness, or thickening of the nipple or breast skin
- A lump or thickening in or near the breast or in the underarm area

1.2.3. Screening, Detection and Diagnosis

Clinical breast examination: In which the health care professional examines the patient’s breast to detect the chance of breast cancer (Soyer, Ciceklioglu and Ceber 2007). Breast Self-Examination (BSE) and Physician Breast Examination (PBE) are widely encouraged methods for early diagnosis of BC (Nair, K. M., Sankaranarayanan, R., Nair, K.S. et al. 1993) as its recognition leads to further tests that are needed to diagnose the disease.
**Mammogram:** Is a kind of X-ray picture of tissues inside the breast used for diagnostic purpose for BC among women. Presence of BC is not always detected by mammogram, however, it shows chances of BC by revealing a breast lump before it is felt by touching.

**Breast ultrasound:** it is conducted by using an ultrasound device which sends out sound waves to sketch the body part by picking up the sound wave echoes; and create the picture with the help of a computer. A small, microphone-like instrument is placed on the breast skin after the application of gel in order to look at the screened areas on breast and under arm located by mammogram. It can detect a cyst or a solid mass (tumour). This is helpful because many cysts are not needed to be biopsied. In someone with a breast tumour, it is also used to look at the lymph nodes under the arm (National Cancer Institute 2003).

**Magnetic Resonance Imaging (MRI) of the breast:** Using magnets and radio waves (instead of x-rays) to produce very comprehensive, cross-sectional images of the breasts.

**Biopsy:** is the diagnostic test to look for cancer cells by examining the extracted breast tissue. A biopsy makes sure the presence of cancer in the cells (Bevers 2008). Fine-needle aspiration biopsy\(^6\), Core biopsy\(^7\), Skin biopsy, Lymph node biopsy and surgical biopsy are the types of biopsy administered for diagnosis (National Cancer Institute 2003).

**Lab examinations of breast tissue:** Hormone receptor tests\(^8\), HER2/neu test\(^9\) and the tests for gene patterns\(^10\) are the usual lab tests performed to detect as well as to decide treatment modes.

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\(^6\)Using a thin needle to remove cells or fluid from a breast lump and tested
\(^7\)A wide needle to remove a sample of breast tissue
\(^8\)The hormone receptor tests show that the presence of the receptors of the hormones estrogen, progesterone, or both which allows the breast tumors to grow.
Tests to find breast cancer metastasis\textsuperscript{11}: Chest x-ray, CT (computerized tomography), MRI (magnetic resonance imaging), Ultrasound, and PET scan (positron emission tomography)\textsuperscript{12} are used to understand the cancer spread.

\subsection*{1.2.4. Breast Cancer Staging}

Staging is the process of identifying the widespread of cancer by looking at the results of test and scans. Staging is significant and critical in cancer as this acts as the foundation on which the treatment decisions are made for breast cancer. “The stage is based on whether the cancer is invasive or non-invasive, the size of the tumors, how many lymph nodes are involved, and whether it has spread to other parts of the body” (American Cancer Society Booklet). TNM\textsuperscript{13} system is the most popular system used to describe the breast cancer stages. This system considers- a) the tumor size and its spread (T- tumor), b) whether the cancer has spread to lymph nodes (N- lymph nodes) and c) the spread to distant organs (M- metastasis). Numbers given after the letters- T, N, and M provide details about the patients’ cancer stages (cancerresearchuk.org) and on the basis of cancer stages, further treatments are decided.

\textsuperscript{9}To find out the presence of HER2/neu protein in the cancer cells and on the basis of this test results targeted therapy is considered as the treatment option.
\textsuperscript{10}To understand the pattern of a number of genes at the same time can help tell the chances of recurrence after the first treatment.
\textsuperscript{11}Is the spread of a cancer or other disease from one organ or part to another not directly connected with it.
\textsuperscript{12}A test using a form of sugar which contains a radioactive atom is put into a vein and travels throughout the body. A special camera is looking for the cancer cells which absorb high amounts of this sugar and there by doctors locate the cancer spread.
\textsuperscript{13}Tumour, Node, Metastasis
1.2.5. Treatment for Breast cancer

The major types of BC treatment are: Surgery, Radiation, Chemotherapy, Hormone therapy, Targeted therapy and Bone-directed therapy. The same patient may undergo one or more types of treatments concurrently or one after other (Miller 2008).

Surgery for Breast Cancer:

Surgery is the most common and most primitive treatment option for BC and this undergoes a number of modifications by its nature and procedure. Surgery of the breast is intended to remove the maximum cancerous cells possible, as well as; at times it is done to identify the cancer spread to the lymph nodes at underarm, to restore the shape of the breast after a mastectomy, or to relieve symptoms of advanced cancer (American Cancer Society Booklet).

Breast-conserving surgery (BCS): This is the surgical removal of only the infected part of the breast. Extend of the removal depends on the factors like- the size and place of the tumor and other significant clinical factors. Medically, this surgery is called as partial (or segmental) mastectomy, or often called as lumpectomy.

Mastectomy: is the surgical removal of the entire breast; often removes all the breast tissue or sometimes beside tissues as well. Mainly, simple (or total) mastectomy\textsuperscript{14} and modified radical mastectomy\textsuperscript{15} are the surgical way of treating BC.

Adjuvant therapy: Is the treatment and drugs used after, and in addition to surgery. Chemotherapy is also used prior or after the surgery. Presently for adjuvant breast cancer

\textsuperscript{14} Only the breast is removed (and not lymph nodes under the arm)
\textsuperscript{15} Is when a simple mastectomy is combined with an axillary lymph node dissection
treatment, three main groups of medications are used (Levenson and Jordan 2008) – a) Hormone Blocking Therapy b) Chemotherapy c) Monoclonal Antibodies.

**Hormone therapy for breast cancer:** in some breast cancers where the hormone receptor\(^{16}\) is positive, the growth of the cancer is aggravated by the female hormone; estrogen. In such cases, hormone therapy is used for blocking or subsiding the effects of estrogen and also to prevent the recurrence of BC and treating advanced BC (American Cancer Society Booklet). Medicines like-Tamoxifen, Toremifene, and Fulvestrant are administered to block the effect of estrogen in breast cells by stopping the tissues from making estrogen and induce an effect like menopause.

**Chemotherapy:** It is a process in which Cancer-killing drugs are administered among women with BC by injecting in veins or as pills; thereby it enters the blood stream and kills the cancer cells. It often destructs some normal cells, which may cause certain side effects. It is used for treating BC, (mainly used for stage II-IV BC), predominantly beneficial for the women whose estrogen receptor is negative (ER-). Usually these drugs are given in combinations and take a course of three to four months. In early-stage breast cancer, chemotherapy is used either before or after surgery; when chemo is given after the surgery to the women who do not show symptoms of cancer spread it is called adjuvant chemotherapy and chemo when given before the surgery for the curative purpose is neo-adjuvant chemotherapy.

**Radiation therapy (Radiotherapy):** It is a process in which high-energy rays (such as x-rays) are used to kill the cancer cells. Radiotherapy is advised to kill remaining cancer cells in the breast, chest wall, or underarm area after the surgery or, rarely at times, used

\(^{16}\) Cancers that have hormone receptors in the cells (are ER-positive or PR-positive)
before surgery to shrink the tumor. After breast-conserving surgery, often radiotherapy is used; also in general, it is given after any chemotherapy procedure. Another purpose of radiation therapy is treating cancer-spread to other areas, for instance to the bones or brain. Mainly in two ways radiation therapy is administered in patients-external beam radiotherapy\textsuperscript{17} and brachy therapy\textsuperscript{18} (internal radiotherapy). External beam radiotherapy is the most popular radiation therapy used for treating breast cancer. It is almost same as getting a regular x-ray but with more intense radiation.

1.3. Women and Breast Cancer

Women in India as of other countries are also influenced by the dominant notions and dynamic expectations of constructed gendered expectations; which vary as they grow in age, across cultures, regions, religions or even from houses to houses. The learned and inscribed efforts to meet the expectations of ‘being a woman’ is often distressing when translation of social ideals of performing the roles in family and society as well as sexually pleasing physical appearance is not met (Sanger, 2009). Medical world is also influenced to a far extend by differently constructed views of gender (Lorber, 1994) as the treatment for a woman’s disease is administered often not in direct consultation with her, or not sharing the information with her. Therefore, involvement or participation of women in the treatment of their own bodies is marginalized. When it concerns breast cancer, there is long history of silence of health professionals is recorded before 1940s.

Breast were not discussed publicly or in conferences so as the female health information was kept undisclosed as part of the power dynamics by authoritative male doctors and

\textsuperscript{17} The radiation is focused on the area being treated from a machine outside the body.

\textsuperscript{18} The radiation is given to the breast is to place radioactive seeds (pellets) into the breast tissue
uneducated female patients (Schulzke, 2011). A complete dependence on medical physicians’ or husbands’ decisions is observed among women for their health concerns. This dependence controls their access to the information and treatment choices as the male counterpart often denies the women getting information or renders complete guidance (Schulzke, 2011).

It is essential to look at women’s perceptions of their body and health issue like breast cancer when it is particularly concerned with their body identity, appearance and body image, sexuality and most of all their existence. The stressful nature of BC is potentially impacted by the real possibility of losing a body part (breast) which has been sexualized and glorified by many cultures; as it is influenced by its fatal nature (Keitel & Kopala 2000). The wish to have a ‘good physical appearance’ is challenged among sexually active women with BC due to mastectomy (Fobair, P., Stewart, S. L., Chang et al. 2006). Various studies argue that disturbed self-identities of women due to the treatment side effects is the real reason for the women with BC feel threat to their body image and appearance (Ucok 2005; Hall et al, 2002 ; Pelusi 2006). In the same line, the impact of BC on sexuality, body image, and intimate relationships is examined by studies by Henson (2002); Schover (1991). Martinez et al (2006) found the negative effects of BC on women’s sexuality, sexual response, sexual roles, and intimate relationships. “Breasts being a part of female identity, defining its aesthetic importance, the disease and surgery of the organ have its social ramifications since she is living in the society where woman body is objectified and aestheticised” (Devika 2004 cited in Vijayan, A, 2012). All these suggest that breast cancer affect women’s self, sexuality and identity in terms of the physical changes which persuades.
When cancer experience is not limited only to body, but different aspect of women in her socio-cultural context, breast cancer treatment in Kerala is mostly tend to put its focus on healing of the body. Therefore, a need for understanding the cancer experiences with its elevated threats to the loss of wholeness; and incorporating the knowledge experience of the context in the totality of care is in high demand.

1.4. Breast cancer and Health related Quality of Life

The impact of breast cancer on quality of life of women has been an important area of concern in research and practice (Ferrel et al. 1996, Ferrel et al. 1997, Ferrel et al. 1998, N Rustoen et al. 1999). Mixed kinds of observations and findings have come to the discourse such as- breast cancer patients have poorer QOL as compared to patients with other cancer diagnosis (Rustoen et al. 1999, Engel et al. 2003); in other hand QOL of patients with breast cancer is observed as moderately high when they survive over time (Rustoen et al. 1999, Sammarco 2001, Uzun et al. 2004). However, without much argument researchers and practitioners agreed on the fact that BC causes serious impact on various aspects of women’s life. The following sections explain the meanings, QOL carried over time.

Quality of life- Meanings and definitions carried overtime

HRQOL carries different meaning over time and at different contexts. Quality of life has been a concern from the times of Aristotle, thereafter different people looked at this concept with different meanings (A few meanings of QOL sum up in Box 1.1). Three approaches to QOL definitions have been suggested by Farquhar (1995) - a) global, b) component and c) focused definitions. Global definitions are focusing on general views
of QOL in terms of *ideas of satisfaction/dissatisfaction and happiness/unhappiness*. Identifying certain characteristics for evaluating QOL is the key concern of component definitions. Focused definitions referred to one or a small number of QOL components. QOL as a complex term referring to individual concerns of their physical, mental and social aspects of life is addressed by combination definitions (Farquhar 1995.)

Understanding QOL as a *dynamic and multidimensional construct* with specific unique characteristics was indeed a milestone in doing research in cancer care (Ferrans & Powers 1992). Even though several dimensions have been proposed to understand QOL in terms of various aspects, the concept of HRQOL narrowed down by excluding the aspects of QOL like cultural, political or societal attributes that are directly not related to health (Ferrans et al. (2005). This narrowed down concept of QOL; which is more focussed on the effect of illness and treatment on QOL domains sourced a lot of debates. Also, this definition has been theoretically problematized by researchers, in terms of its inclusion of debates on its conceptual and practical concerns (Farquhar 1995, Joyce et al. 2008, Rustoen et al. 1999, Carr et al. 2002).

Health related quality of life is defined as one person’s ability to perform expected roles and have psycho-social well-being in particular life situations related to health issues (Padilla, 2003). In line with this, in 1993 the World Health Organization Quality of Life Group (WHOQOL Group) defined QOL as “*an individual’s perception of his/her position in life in the context of the culture and value systems in which he/she lives and in relation to his/her goals, expectations, standards and concerns. It is a broad-ranging concept incorporating in a complex way the person’s physical health, psychological state, level of independence, social relationships, personal beliefs and relationship to*
“salient features of the environment.” Considering the breast cancer illness context, Ferrell, Hassey-Dow, and Grant (1995) suggested a theoretical quality of life framework for cancer survivors including physical, social, psychological, and spiritual well-being; which served as the foundation for this study.

**Box 1.1. Overview of a few meanings of QOL**

- QOL- Related to concept of happiness, life satisfaction, well-being started from Aristotle (332 BC)
- QOL- with wide range of meaning
- Subjective well-being (studies from 1960 onwards)
- ‘Output’ of physical and spiritual interactions (Liu, 1974)
- Extend of pleasure and satisfaction (Andrews, 1974)
- Affective response to one’s role situation and values (Andrews, 1976)
- A personal statement of positivity or negativity of attributes that characterize one’s life (Grant, 1980)
- QOL as Goodness of life (1979)
- QOL as good life (Lawton, 1983)
- Crepancy between desired actual circumstances (Krupinski, 1980)
- Degree to which a person accomplishes life goals’ (Chella and Cherin, 1987)
- as well-being and ill-being, QOL – importance of external factors, human needs (theories- objective and subjective theories)
- Globally, QOL as an outcome indicator has been to social as well as health, service programmes (DHSS, 1989)
- As HRQOL (Various studies referred in this study) - as a multi dimensional construct in health context.
1.5. Supportive care needs and Breast cancer

1.5.1. Need – Meanings pertaining to Supportive care in cancer

Concept of need over time carried different and variety of meanings at times nebulous; according to the context. Bradshaw (1972) argued the importance of redefinition of ‘need’ in concern of health sector incorporating a holistic view beyond medical care rather considering personal and family care needs to manage their lives. He also differentiated between ‘felt’ and ‘expressed needs’ as the earlier refers to wants, wishes and desires and the latter mentions the vocalised or communicated needs for a service (demand). The available literature concerns psycho-social aspects of both the types of needs mentioned above. When finding the meaning of supportive care needs, Seedhouse (1994) argued that, applicability of need is relevant; only when somebody expresses it when they experience difficulties; if not, the problems and concerns can simply exist. Many researches happened in the area of quality of life and patient satisfaction in cancer care listed the concerns of dissatisfaction but did not mention the types of requirements the patients have for their assistance (Foot & Sanson-Fisher, 1995; Miller et al., 2003). In the context of lack of reflection about the needs arising from a wide spectrum of cancer experience, Foot & Sanson-Fisher (1995) defined ‘need’ as the “demand of necessary, desirable and useful action or resource to attain optimal well-being.” When many definitions have taken ‘need’ at individual level, Seedhouse (1994) defined need in a larger group level as “the population’s ability to benefit from specific services”.

Although, meaning of ‘supportive care needs’ has been discussed in various dimensions for decades, most of the researchers agreed on the output of better service availability for
attending ‘felt’ and ‘expressed’ needs of people with cancer on care demand. When developing the Supportive Care framework, Fitch (1994) came up with a comprehensive meaning for supportive care needs including “patient’s physical, informational, emotional, psychological, social, spiritual, and practical needs during the pre-diagnostic, diagnostic, treatment and follow-up phases- which has become a foundation stone for several studies in the field.

1.5.2. SCNS and Women with Breast cancer

Understanding and putting the supportive care needs of women with BC under one umbrella is a convoluted task as the breast cancer experiences bring alterations and transformations; especially in one’s life in terms of needs and expectations. Although conversely this section cites the supportive care needs of person’s with breast cancer in general. The categorization of needs followed the domains from ‘Supportive care framework’ by Fitch (1994), as this gave a foundation to build upon the perceptive of domains (Table 1.1).

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19 ‘Supportive care’ is an umbrella term used to understand the support services that may be required by persons with cancer and their families considering five domains- physical, social, psychological, spiritual and information needs (Fitch, Supportive care framework). The same framework is used to understand the literature in the chapter 2, and the primary data in chapter 6; also explained in the section- theoretical frame work of chapter 3.
Table 1.1 Domains and examples of needs of person with cancer (Table replicated from Supportive care frame work with the permission of Margaret I Fitch)

<table>
<thead>
<tr>
<th>Definition of Need Categories</th>
<th>Specific Examples of Supportive Care Symptoms and Needs in Cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical</strong></td>
<td>• pain               • incontinence          • impotence</td>
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<tr>
<td>Needs for physical comfort and freedom from pain, optimum nutrition, ability to carry out one’s usual day-to-day functions (i.e., activities of daily living)</td>
<td>• weakness           • thirst              • changes in bowel habits</td>
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<td></td>
<td>• fatigue            • cough               • difficulties with diet/fluid intake</td>
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<tr>
<td></td>
<td>• anorexia           • shortness of breath • difficulties with sleeping</td>
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<td></td>
<td>• nausea             • spitting up blood  • weight changes</td>
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<tr>
<td></td>
<td>• vomiting           • loss of appetite  • menopause</td>
</tr>
<tr>
<td></td>
<td>• mobility           • hair loss          • difficulties swallowing/speaking</td>
</tr>
<tr>
<td></td>
<td>• lymphedema</td>
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<tr>
<td><strong>Informational</strong></td>
<td>• cancer treatment and side effects procedures/test results</td>
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<tr>
<td>Needs for information to reduce confusion, anxiety and fear; to inform the person’s or family’s decision-making; and to assist in skill acquisition</td>
<td>• communication with caregivers</td>
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<td></td>
<td>• how to handle or manage side effects</td>
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<td></td>
<td>• care processes</td>
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<td><strong>Emotional</strong></td>
<td>• fear               • guilt                • to talk with a peer</td>
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<tr>
<td>Needs for a sense of comfort, belonging, understanding and reassurance in times of stress and upset</td>
<td>• distress           • grief               • powerlessness</td>
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<td></td>
<td>• anxiety            • abandonment         • shame/self-blame</td>
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<td></td>
<td>• depression         • hopelessness         • isolation</td>
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<tr>
<td><strong>Psychological</strong></td>
<td>• changes in lifestyle</td>
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<tr>
<td>Needs related to the ability to cope with the illness experience and its consequences, including the need for optimal personal control and the need to experience positive self-esteem</td>
<td>• loss of personal control</td>
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<td></td>
<td>• sexual problems</td>
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<td>• diminished cognitive ability</td>
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<td></td>
<td>• loss</td>
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<td><strong>Social</strong></td>
<td>• changes in roles</td>
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<tr>
<td>Needs related to family relationships, community acceptance and involvement in relationships</td>
<td>• difficulty dealing with the responses of family members/children</td>
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<tr>
<td></td>
<td>• social relationships</td>
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<td></td>
<td>• interpersonal communication</td>
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<tr>
<td></td>
<td>• telling other people</td>
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<tr>
<td><strong>Spiritual</strong></td>
<td>• search for meaning</td>
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<td>Needs related to the meaning and purpose in life to practice religious beliefs</td>
<td>• examine personal values, priorities</td>
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<td>• existential despair</td>
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<td>• spiritual crisis/resolution</td>
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<td>• feelings of hopelessness</td>
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<td><strong>Practical</strong></td>
<td>• daily home help</td>
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<tr>
<td>Needs for direct assistance in order to accomplish a task or activity and thereby reduce the demands on the person (e.g., homemaking services, financial assistance)</td>
<td>• assistance in activities of daily living</td>
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<td></td>
<td>• shopping</td>
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<td>• transportation</td>
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<td></td>
<td>• child care</td>
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<td>• prostheses</td>
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<td></td>
<td>• travel to and from treatment appointments</td>
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<td>• menu planning/food preparation</td>
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1.5.3. Supportive care services for persons with cancer in Indian scenario

This section attempts to plot the available supportive care services for persons with cancer in India. Most of the State-run schemes and programmes for the cancer care are focussed on awareness, financial aid for the poor patients and the hospitals, registries, research and documentation. To an extend travel concession is also identified and addressed by the Government. This section discusses the state-run programmes and schemes for persons with cancer.

1.5.4. Central Government funded Government Schemes

National Cancer Control Programme- With the purpose of primary prevention, early detection, treatment and rehabilitation, National Cancer Control Programme was launched by India Government in 1975-76. Revisions were happened to cater the changing needs in terms of disease and programmes, the last documented revision happened in December, 2004. Addressing the cross wide geographic disproportion in the country with regard to the availability and accessibility of cancer care facilities was considered as primary focus of the revised programme. Identification of new Regional Cancer Centers (RCCs), Strengthening of existing RCCs, establishment of Oncology Wing in the Government Medical Colleges and hospitals and district Cancer Control Programmes were the major schemes planned under this programme. Provision of grant for decentralised NGOs was also included in the scheme.

Prime Minister's National Relief Fund (PMNRF)- The Prime Minister’s National Relief Fund (PMNRF) was established in January, 1948 with people’s contributions to
support migrated persons from Pakistan. Later, PMNRF rendered assistance to support the expenses for cancer treatment, heart surgeries, kidney transplantation etc.

**Ministry of Health & Family Welfare:** provides financial support for treatment for the poor patients at different hospitals in all over the country under the following two schemes:

a) **Health Minister’s Cancer Patient Fund (HMCPF) within the RashtriyaArogyaNidhi ("RAN")** - In 2009, under the RashtriyaArogyaNidhi (RAN) Scheme, "Health Minister's Cancer Patient Fund" (HMCPF) has been established. For the easier and speedy utilization, proposition for a revolving fund has come up with collaboration of RAN in the different Regional Cancer Centre(s) (RCCs) which are getting fund from Govt. of India’s Cancer Programme. Up to Rs.1,00,000/- (Rs.one lakhs only) of financial assistance would be given to the poor patients processed through the concerned channels.

b) **Health Minister's Discretionary Grants (HMDG)** - A maximum of Rs. 50,000/- is given from the Health Minister's Discretionary Grant as a part of the expenditure on Hospitalization/treatment for the poor indigent patients in Government Hospitals where free medical facilities are not available.

(3) **Central Government Health Scheme (CGHS)** - Retired Central Government employees and dependents are eligible to avail the services of this scheme. In June 2011, one private hospital in Hyderabad and 10 Private hospitals in Delhi have been included in the panel for better cancer treatment; exclusively for cancer surgery as per the rates of

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Tata Memorial Hospital. Adding to this, CGHS beneficiaries can avail cancer treatment at approved rates from any hospital, where cancer treatment is available.

(4) **Railway concession for cancer patient and one bystander**- Indian Railway has given total free travel for the cancer patients. 25% of the actual II class fare has to be paid by the bystander. Applicability of this concession is only for commuting between the nearest hometown station and the treating cancer hospital/cancer.

(5) **Air concession for cancer patients**- Air India is charging cancer patients, only 50% of the basic fare of the normal economy class. Applicability of this concession is only for the Indian resident citizens who are suffering from cancer and for the travel with the purpose of medical check-up/treatment.

To avail this facility, the passenger has to put up an application stating that he/she is travelling for the cancer treatment and with the certificate issued by cancer hospital or an institute.

(6) **Income Tax relief for cancer patient**- Income tax relaxation is available for the cancer patients in India

1.5.5. **State Government funded schemes**

**Chief Minister's relief fund**- Except Assam, Meghalaya and Nagaland, all the states of India has the Chief Minister’s relief fund which provides required assistance for the distressed people affected by the major natural calamities like flood, drought, fire accident etc. It also rendered financial assistance for the poor patients’ treatment of cancer, cardiac surgery, kidney transplant, liver and multi-organ failure etc. A filled
application form with supporting medical certificate taken within a period of six months has to be submitted to village Office/ Taluk Office/Collectorate.

**Government of Kerala- programmes and schemes**

**Cancer Suraksha** - On 1st November, 2008 the Government of Kerala launched the Cancer Suraksha Scheme for children suffering with cancer who are below the age of 18 years and belong to families that cannot afford the treatment. Regional Cancer Centre, Sree Avitam Thirunal (SAT) Hospital, Thiruvananthapuram, Government Medical College- Kottayam, Thrissur, Kozhikode, Co-operative Medical College, Pariyaram- Kannur, Malabar Cancer Centre, Thalassery-Kannur and Government General Hospital, Ernakulam are the nine hospitals empanelled in this scheme and this scheme is implemented by the Social Security Mission. At all these nine hospitals, counsellors are posted to assess the eligibility of the applicants for the free treatment and to provide counselling services to the patients.

**Sukrutham** - is the first of its kind in India launched by Government of Kerala on 1st November 2014 for free cancer treatment for patients at Government hospitals with an assumption that this scheme will benefit 47% of the population. As the first phase this free treatment is available at five medical colleges and three cancer specialty hospitals. Those patients who are holding BPL (Below Poverty Line) cards or covered under RSSY

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21 Means ‘security’
22 First state initiated programme in India for free cancer treatment (Malayalam word means ‘goodness’) - http://www.sukruthameancercare.in/
are eligible to avail the service of this scheme. This programme was taken by the Union Health Ministry for replicating across the country as part of the next five year plan\textsuperscript{23}.

Although this section has consolidated the available programmes and schemes for the cancer patients, no holistic care programme has been established by any state-run programmes. A few schemes by Government (Karunya lottery, insurance of RCC, ESI, and medical reimbursement) and private firms (Medi-claim policies) are also benefiting cancer patients of India. The studies on quality of life and existing need demands the state-run programmes go in the same direction incorporating the work of NGOs and voluntary groups. This collaboration can do at different phases when the patient is need of a holistic care. In this context, this study indented to locate the care spectrum for persons with cancer in order to identify the potential gaps and strategies in demand.

1.6. Supportive care in Breast cancer- Social Work concerns

Cancer impacts quality and quantity of life of the women with BC. The challenge and opportunity of Social Work profession is to address both the constituents with compassion and empathy in order to make the best possible professional service and care.

In west, social worker is an essential part of health care team; but a few hospitals in south and middle regions of India, include medical social worker in the team. The practices and services social work professional can do for cancer care is presented in this section. Social work professionals in cancer care can assure coordination of services inside and outside the hospital, counselling, group interventions, referrals and synchronisation of

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community and Government resources, including social support for the provision of better services for the persons with cancer. The purpose of oncology social work practice is to liaison between patients and the medical team in order to support and help the people to navigate the cancer and health care system. Although informed treatment choices are not very popular in India, the social work profession can help the people to understand the treatment choices and related issues considering their needs and challenges of living with breast cancer.

Extent of care and services by the professionally trained oncology social workers can ensure better care for the whole person than a pure clinical subject. Social work intervene various aspects of a person with cancer; considering the unique ways breast cancer affects them. The most noticeable challenge in cancer navigation is the accessibility and availability of the medical team for discussing the issues; in this context social worker acts as a bridge between the person with cancer and the medical team. For passing information, helping the people to manage their situations and to enable them for better coping; social worker can develop strategies and programmes on individual and group basis. Cancer diagnosis creates new roles and challenges to the existing social roles in a person’s life. Sexuality and body image concerns are reported as a challenging subject for the patients to talk on. Other issues like financial troubles, social support concerns, employment and career are certain things significantly impact ‘a person as a patient’ but less relevant for the medical team. In this context, social work profession is relevant in cancer support and care to help a person as a whole.
1.7. Chapter Summary

Breast cancer; rather than a disease affects the body but also which impacts various aspects of a women’s life such as- personal life, psychosocial well-being, femininity, sexuality, spirituality; family and finance. Therefore, the HRQOL and SCN of the women with BC becomes a larger frame to understand than being a patient in medical context. This chapter presented the ways BC impacts women clinically and socially; in addition to that the HRQOL concerns, common supportive care needs of the women with BC have been discussed.