Chapter 6

Supportive care needs of women with breast cancer
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Backdrop to the chapter

This chapter is an attempt to understand supportive care needs of women with BC who are under treatment in any cancer specialty hospitals of Kerala. The meaning of SCN in this study has already discussed in the chapter 3, however it focuses on various kinds of needs (physical, psychological, social and spiritual) after breast cancer diagnosis and during treatment (phases of the patient’s journey through illness trajectory) in order to encompass the issues they encounter (survivorship from, through and over the illness, palliation, managing their lives and the treatment) (see figure 6.1).

Figure 6.1 Elements of Supportive Care in Cancer Care

This chapter is framed in a fashion which gives a picture on two research questions that arise on the SCN of women with BC-
1. What are the key issues and concerns of women with BC associated to various types of their SCN?

2. How the women with BC do/did view the availability of existing supportive care provisions in terms of information needs and health care system delivery and their expectations regarding better supportive care availability?

With an objective to address the questions mentioned above, this chapter attempts to look at the in-depth interviews with thirty women with BC. To get the quantitative picture of certain issues, questions were asked to the 120 women with BC, and integrated to the categories of need which fits in. In addition to that, the data collected from treatment professionals have been analyzed and incorporated to certain themes where it adds information, comments and suggestions.

This analysis chapter is divided into three parts. Sections 6.1 to 6.5 discuss about key issues and concerns of women with BC as well as SCN associated to various types of their well-being and functioning, particularly issues related to physical, psychological, social and spiritual functioning respectively. Section 6.5 describes the major informational needs during the phases of the illness trajectory of women with BC, especially the course of disease such as needs related to diagnosis, tests and examinations, treatment, follow up and services. The views of women with BC on the availability of existing supportive care provisions are discussed in the final section 6.6. It also gives an account of the expectations of women with BC in order to avail better supportive care; and informational needs are also described here. The process of analysis is presented in the diagram 6.2. As an additional note before proceed, all the names of the participants are changed as symbols like W1, W2…, W30 to keep

55 Who participated in this study, and the profile of them have discussed in the chapter 3.
their anonymity in this research report, also their profile have been discussed in chapter three

Figure.6.2. Analysis process

Part 1-Key issues and concerns of women with BC associated to various types of their SCN
6.1. Physical functioning and well being- Issues and concerns

- Physical assistance

Figure 6.3. Types of needs for physical assistance at different areas of physical functioning (Out of a total number 120)

The most reported needs regarding complete physical assistance were; at the hospital (98 women with BC), for the management of side effects (87 women with BC) and; at home (67 women with BC). All the 120 women with BC reported that they need professional assistance for the management of their treatment side effects. (See diagram 6.1)

Needs related to management of disease related physical issues and treatment side effects

This section discuss the needs related to physical issues women with BC faces in their daily functioning especially to manage or to cope with the illness and the treatment related difficulties.

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Reported physical issues related to the disease symptoms and treatment side effects

Pain on the breast is reported as a symptom by many women with BC. W7, of 32 year old young mother who diagnosed breast cancer just after stopping breast feeding her child told that-

“\textit{I was feeling pain on my left breast when I stopped breast feeding my son. I thought it is because I just stopped the feeding. So I did not go to doctor for this but took a pacha marunnu (natural medicine) to dry up the milk. But after six months only I went to doctor. By the time the pain was severe...}”

Pain of the breast and shoulders are a few of the symptoms ignored and considered as the symptoms of some other disease. Pain is reported by most of the women interviewed especially the women who underwent surgery, chemotherapy and radiation. Going through mastectomy as a painful experience- not only the pain of surgically removing a body part but also the long term physical impact it causes like swelling on arms, difficulty in moving and lose of balance in the body and so on. However, pain is an important issue they faced during mastectomy for which they need support from family as well as professionals.

W1, explained pain related to mastectomy: \textit{When I looked at it (breast), draining tubes were there. I felt pain on the operated portion. I wanted to see that. Next day when they (doctor and nurses) came for dressing I saw the deep wound and the scar at the place of my breast. It was paining so badly. I wanted to shout and cry but I was alone in the ward amidst of unknown people. It was the post surgical ward. I wanted somebody to make me numb”}

Similarly, W13 also expressed the need of somebody to comfort her when she was sharing her experience of pain related to amputated breast,
“I was so scared to go for the surgery. I knew that to look at it would be difficult. Pain was unbearable when they were cleaning and when it (wound) was getting dried as well. I was looking for somebody to massage my hands it was paining so bad but bystanders were not allowed inside. I thought ohh! Should I be alive now on?”

Women who underwent mastectomy reported the need of a caregiver from the family to be with them to help them in managing the pain and communicating and ensuring the care when they are on bed. Apart from the physical pain experienced in any surgery, it is important to see the pain that they go through which is associated with anticipation of death, adapting to an illness which is perceived as a critical illness which needs chronic treatment, loss of their perceived identity of feminine body and so on.

Nausea and vomiting, constipation, appetite related issues, fatigue, breathlessness are the other reported physical issues by many women with BC.

W24 shared the experience of unmanageable treatment side effects as: “It was unbearable, the side effects of chemotherapy... I had severe sense of nausea all the time. I was asked to stay back in the hospital itself because of dehydration and vomiting. It was tough thinking about it. I could not eat anything. My mouth was full of sores. I wished to just stop the treatment and better stay home.”

**Supportive care needs associated to physical issues related to the disease symptoms and treatment side effects**

Most of the women interviewed also reported different kinds of supportive care needs related to management of disease symptoms and treatment side effects following the
trend showed in the diagram 6.1. Need of supportive care for symptom management are presented as themes with narrations below-

**I need somebody to be with me always (Physical assistance)** - From the time they heard cancer diagnosis, twenty three women told that they needed somebody’s presence all the time for some kind of physical need they had.

“My husband told me that he needs to go for work. I know our financial state was not good. We did not have anyone to come home to take care of me. He took several leaves but what to do... I was scared. I cried a lot... I felt very much difficulty even to go toilet.” -(W28)

Financial issues, employment need of the family caregiver especially of spouse put together the complexity of availability of caregiver all the time for the physical assistance.

W11, not legally but separated from her husband said:

“I knew he (husband) did not have interest to take care of me. He asked me to go my brother’s house. Brother is interested to look after me because he knows I don’t have anyone else. But there are others... they have other things to do. Of course they give food and medicines. But they cannot help me with everything I need. Yesterday, I fell down... I was so weak. Nobody was around.”

Factors like family dynamics, absence of care giver availability, physical weakness add to the felt supportive care needs of the patients.

The narrative of W29 explains the complexity of chemotherapy she felt and the kinds of physical support needs she had during that time:

“It was my first chemotherapy; I could not bear the side effects of chemotherapy. I was looking around for somebody to talk to me or comfort me
but everybody was busy around. I started vomiting from the first course itself. My hair started falling just after that. It was terrible. I was completely on the bed. All the chemotherapies were terror for me. I could not take any food because of sour mouth. All the time I was looking for somebody... at times to communicate my concerns with the doctor or nurses, at times keeping the bucket near me when I vomit, at times just to console me or pray for me. Most of the times, I wanted someone just to sit near me...”

It is difficult to differentiate the type of needs, however when physical supportive care needs from the narratives of the women are located; we understand that their physical weakness call for dependency for the things they cannot perform by themselves but which cannot be avoided as well. For instance, getting a bucket when they vomit, assistance to sit and walk, access and communicating with treatment professionals so on.

**Medical assistance, Information about management of side effects and attention from treatment professionals**

Although it is sure that the medical assistance is assured as all of the participants were interviewed at the hospital, several women shared about the adequacy of assistance they receive, time of availability of assistance and the need for better care.

W11 explained her experience of asking help: “I was crying all the day, I did not know what I should do to get out of the horrible irritation, numbness I had felt at the time of chemo. With that I started vomiting. I asked doctor, he said ‘I said you before that these are a part of the treatment’ Nurses were taking care of several patients. Whenever I ask for something she (nurse) says I will come now and goes. Hours we need to wait for getting attention. In fact, I
don’t know whether they can do something to suppress this. I hope...for sure something to help out”

Most of the reported needs in connection with medical assistance for management of side effects were related to chemotherapy. Management or support to suppress the uneasiness during chemotherapy was again and again came as an unmet need.

W2, A widow of 57 years: “Though doctor was explaining the side effects of treatment (chemotherapy), I could not understand many things. When I had gone through it, I was trying to explain it is more than tolerable... But somehow I learned that they are doing their best by giving medicines. And all were busy. When I said to a nurse about vomiting sensation I had all the time, she said ‘ammachi, (addressing elderly woman) it is because of medicine, everyone will have this... (Vomiting)”

Narratives show that explanations, generalizations or information about possible side effects of treatment was not helpful after an extent of tolerance. Information related to management of treatment effects, certain symptoms were discussed by participants as they need support.

W26 remembered her concerns after the treatment, who was in the recurrent phase at the time of interview: “He (doctor)said my chemos are over. Now on you come for check-ups. I and husband were really worried about the chance of getting it again. But they were quiet sure saying everything is okay. We had discussed everything even our private (sexual) concerns with the counsellor. But it was not that helpful for us. Don’t know what is written on my head (fate) is like this... I know, ladies who were admitted with me during previous times used to share how did they have gone through... and managed. Those
things helped me a lot that time. You must know that how important such things (information) are for us.”

14 women with BC reported that the information from the other patients and their experience of coping helped them cope better. Another thing noted was many women preferred much comfortable or informal ways of collecting information related to coping with treatment side effects and verifying that with the treatment professionals. Other few women (9) especially educated ones reported that they would like to follow what doctors are saying. But a few (3) among them reported that they wanted to experiment with other treatment methods like Homeopathy or Ayurveda for managing the side effects. All of the respondents mentioned that they relies various sources such as treatment professionals, experience of others, opinion of spouse for better management of symptoms and side effects; but often troubled because the need for information is not completely addressed.

**SCN related to Physical functioning**

This section deals with the supportive care needs related to physical functioning specifically physical issues related to mobility, self-care activities, activities of daily living, limited or restricted physical activities and disability (see table 6.1). Out of thirty interviewed women with BC in which 16 women were at chemotherapy treatment, 9 were undergoing radiation, and the rest five were interviewed just after their surgery. So the importance of viewing the experience of any physical issue had been considered their treatment context also, during analysis of their narratives.

**Mobility**

Physical issues related to mobility are one of the major issues reported by 22 women with BC. Mobility is described to the respondents as the limitation of free movement on the bed, around the bed, in and around home or hospital, or at work place. Other
issues specific to breast cancer such as arm mobility, upper body mobility etc are dealt in later section limited physical activity.

W30, 39 years explained the difficulty of being physically dependent:

“I used to do everything for my children...shopping, cooking and all. Initially I tried doing my best for keeping my children happy. Now this pain and weakness does not allow me to do all those things. Being on this bed and looking for help from someone for my needs is terrible for me.”

Several women identified that the availability of people to help or to take care is the biggest crisis they feel at the time of long term hospitalization. Employment, looking after their children, meeting other family needs are certain issues related to the availability of family caregiver reported by several women with BC for chronic nature of the treatment and care.

W9, a 38 years old business woman explained how she felt the need of people’s availability during hospital and at work:

“Now I am managing everything so well- my home and business. At some points, I also thought I will not be able to do anything. Then I decided, No, till the moment I am not completely on bed, I will have to do everything. I got two people to do whatever I need to do physically to manage home and business and I guided them. Till now that strategy works for me. But I always think about the people who cannot afford to hire someone to help. I talked to Sheeba ma’am (who is running an NGO for cancer patients) and doctors about this. I think people’s availability is the great crisis after money. So some
volunteership could be thought of... at least in the hospitals...to help the patients, may be in connection with NGOs or colleges...”

W21 explained the need of better infrastructure and sitting arrangements in OPD:

“I was waiting near OPD. He had to go to take appointment for next session. I felt like I would fall... There was a huge rush and hence it was difficult anyone who can help. Luckily, I did not fall down because bystanders of other patient’s had held me from falling. I always think of telling or writing to the hospital administration about inadequate sitting or resting arrangements in the OPD. This is not enough. A lot of patients are coming... weak people like us.”

Self care activities

Self care activities are another area of need as been told by the women with BC.

W19: “I had very tough time with my chemotherapy. First session of chemo, I started vomiting. After that I had severe body pain. I was not able to sleep. After three chemos they performed the surgery. Both these treatments made my entire life so tough. I was not able to eat or do anything... I needed someone to help me all the time.”

W4 explained that the fatigue after radiation therapy made her completely dependent:

“I was so tired of the light (radiation). Extremely tired... u cannot even imagine. I became so dark like this. I don’t even think I would be able to sit on this bed by myself. I was doing everything by myself before this. Now I need to depend for everything.”

Outpatient department
Limited or restricted physical activity and Disability

Surgical removal of breasts and other treatment procedures often restrict the physical activities of women with BC. The areas and SCN related to restricted physical activity or disability reported by the participants are explicated below. The impact of surgery and radiation had appeared to be significantly affected on arms of the women with BC as swelling or difficulty in moving.

W7: “You must know how important our hands are… it is swollen and I am stuck, so cannot do anything.”

W26: “They asked me to do certain exercises after surgery. I was not able to move my hand. I tried but it was so painful. It is almost 3 months now. I have serious difficulty to move my hand or hold something with this hand. If I try I have stretching pain on my shoulder and armpit. Then the whole body will ache.”

Pain on the shoulder is another issue reported by many women with BC as the above mentioned narrative.

Accessibility of care, help and support

Reaching the care providers whether it is hospital, or other people like NGOs or voluntary organisations, is one of the major SCN most of the women were telling. Different issues which need to be addressed in relation with accessibility of care is described in this session.

Proximity of help/assistance at home and hospital

Waiting to get immediate assistance is another important issue pointed by the women with BC. Most of them considered that hospital is the place, where they found much difficulty in getting assistance at the point of need.
W26: “Attenders are there in the hospital to transfer us from one department to other. But the time, we have to wait for them is too much. It is not their problem I think. Number of patients coming here every day is more than they can manage. So I think they need to consider hiring more people for such assistance.”

The above narrative shows us that the kind of assistance patients need is available in the hospital but lack of staff or increased number of patients on request of the same service becomes a hurdle in getting assistance at the time of need.

Transport to and from hospital

W12, a widow of 57 years shared her difficulty in reaching hospital:

“Earlier I used to come with my nephew. But we had to take rooms every time we come for chemotherapy. Then somebody who came for the treatment said about this place (organisations provide free accommodation and food for the patients). Around 70 kilo meters distant is my home. We have to come here for better treatment.”

As cancer specialty hospitals are less in number and on an average one per 5 or 6 districts, the distance and transport to the hospital were a reported problem by the women with BC. A number of women shared their difficulty in commuting as they are physically exhausted by the treatment and hiring a car became essential and expensive for each visits.

W28: “…she said that in train there is concession for us. But we don’t have train to our place. Coming by bus is expensive and tiring. Even though I think
it is better if they (Government) give travel concession in KSRTC\textsuperscript{57} as well.

When radiation started I was extremely tired so every time we come by car. Everything is expensive... although the treatment cost is exempted, yet there are a lot of expenses I cannot afford.”

Here, W28 is asking the attention of Government in getting free/concession in the expense of travel not only in the trains but in other public transport system- buses.

**Link with pain and palliative care clinics**

Support and services by the pain and palliative care clinics in Kerala has gained attention in the global level as well especially with their work with participation of people (neighbourhood networks, palliative care clinics and community participation). Here, certain issues in accessing the support from pain and palliative care clinics pointed out by the women are been discussed.

W2: “I heard about it. But don’t know whom to approach... and what they will do for me.”

W28: “My son in law said over his aunty’s place certain palliative people are coming home, enquiring about people like us and helping with different needs. Here (the place she stay) when we enquired it was not available and so we need to go to the Govt. hospital. They don’t have people working here. Going to hospital again for this, he (son) needs to be available... and he cannot go for job. So I am not going anywhere.”

W17 nurse in private hospital: whoever I met over this period of treatment I asked them to be in touch with the nearest palliative care clinics. But many asked that it is when there is no hope in treatment right? I tried to explain. I

\textsuperscript{57} Kerala state road transport corporation buses
know I, myself have difficulty in accessing the clinic. The hospital I worked before the work was excellent. It is good if people are connected”

Lack of awareness about the clinics and the services, lack of geographical coverage of expansion of the clinics in all the areas, availability of caregiver to take them were certain issues reported by the women with BC.

Issues in communicating physical supportive needs

W5, a retired teacher: “They (family) hid from me thinking that I may not withstand it... but when doctor insisted them they said your treatments are starting. I feel that the more I want to know about my illness....the more they are hiding it from me. My husband becomes arrogant and shouts at me when I ask. I know it is because of love. That is why I don’t know how I should get support for the problems I have...”

Husband is the communicator for an educated woman like W5 when it comes to a critical illness; family members believe that the patient should not know the details of the illness as part of their concerns. It is observed that the patient accepts the decision of her husband, though she wants to know and communicate directly with the medical professionals but the attitude of her family towards her becomes a hindrance for her to know more about her illness communicate her physical issues and find more support in this regard.

W25 shared her confusion with the available information and worries regarding doctors’ lack of time to discuss with patients and her need for better listening from treatment professionals-

“I started googling and read whatever report I get. Many things are confusing. And nobody has the time to explain us what is happening. In
awareness classes they say that we should be aware and communicating. But when we try to communicate they will say it is unnecessary anxieties and misinterpretations. Must be... we care and are anxious... of course this is our life and we have concerns... and they are busy with the unknown things in our body. At times I doubt... do they understand everything before we complete saying... may be out of experience. But many times... they treat some general categories of symptoms and some categories of medical reports...and I am left with the things to be cared but, what I feel about my body without even communicated...”

W14, a woman of 72 years of age shared her confusion with symptoms and old age issues as a hurdle in proper communication:

“I don’t know many times when I say my problems (physical) they tell me- it is because of my age... and if I do not say then they (doctors and nurses) ask why I don’t say... I don’t know what to be said and what to be ignored. In this age they should allow me to die peacefully. I told my son”

Related to the Space where the woman is admitted/ spend most of her time

W15: “Of course they (family) concern if I go out. But this (care) is something I am in bondage.”

W28: “I was not aware of these types of wound (bed sore) could happen to me.”

W11: “There is nothing to engage us... for sure we will feel more tired and exhausted.”
Several women accounted their physical issues related to the space they spend more
time as the monotony, being in bed, and restricted mobility outside the houses were
causing physical exertion. Lack of awareness about the physical issues related to long
term stay on bed is another reported issue; certain kinds of physical activities were
preferred by the women who were admitted in the hospital for a long time.

6.3. SCN - Psychological concerns
This session is focused on the psychological SCN specifically. The first session
presented in order to give an account of the themes related to psychological issues
concerns after their breast cancer diagnosis and the second session will be discussing
the specific kinds of support reported by the women with BC.

Deal with Anxiety
Anxiety and ambiguity among breast cancer patients is reported by various studies. It
is understood and discussed at the global platform by multidisciplinary care
disciplines as well. Particularly, this session portrays the thoughts and concerns that
make the women with BC anxious about their lives. The reasons for anxiety and fear
vary over different phases of the treatment and the stages of the disease.

W3 told that her anxiety and doubt turned true when the two doctors she
consulted did not take her doubt seriously: “I consulted two doctors
before... when I noticed this numbness but nobody had the doubt that it will be
cancerous. But somewhere down I had this tension that happened to be true.”

W14 shared here issues were fear and anxiety related to chemotherapy: Before
my first chemotherapy doctor explained me everything. But I had strong fear
so, I asked doctors that please could you avoid doing this on me...”
W6 conveyed her anxiety and sadness thinking about her daughters’ future: “I know that I will die very soon. That is not my problem. But my daughters... nobody is married. How will they survive after my death... they are going for jobs and finding money for my treatment”

W1, a woman belonging to the middle income category shared her worries about sources for her treatment: “We don’t get any concessions or any support. Only thing we have is a house and that too my father in law had taken a loan against it. I don’t know how I can get treated further.”

Anxiety and fear is closely associated with persons with breast cancer as it is reminding them the lack of their control over the current treatment and associated uncertainty over the prognosis (Takahashi T., Hondo, M., Nishimura et al., 2008). Most of the patients, cancer diagnosis comes as a threat to their lives. Many at times it is observed as the anxiety after cancer diagnosis as in abnormal ways affect the patients coping and adjustment to the treatment. As mentioned in the above narratives, a variety of incidents a cancer patient as a person feels and experiences- (related to the diagnosis, personal life, treatment, outcomes, death or life- uncertainty, responsibilities etc.) affect their psychological well-being (Sheard T, Maguire P,1999; Sherbourne CD, Wells KB, Judd LL, 1996).

**Adjustment to illness and treatment**

Cancer diagnosis and treatment is perceived as a threat to normal life expectations and often this illness journey inscribe prolonged existential crisis\(^58\). So adjustment and coping to the treatment becomes an important area of consideration of psychological support.

\(^58\)Certain moments at which an individual’s meaning, purpose and value has been questioned by him/her, Richard K. James, *Crisis intervention strategies*
W20 shared her emotional distress associated with diagnosis –

“I observed he (husband) was so sad and tensed after meeting the doctor. I kept on asking. He did not say anything. He was telling and preparing me that we need to face whatever happens in our lives, with lot of courage and then he said yes! It is cancer… I felt like I was breaking into pieces. And any day after that has not been the same for me.

Different sections of this study reveal different ways women with BC adjust to their illness, not in a defined process of coping by their own very ways. It was observed that very rare respondents seek professional psychological help to cope with their illness but instead the trend was to discuss with doctors to know more about coping and trusting their spiritual beliefs in order to ‘feel fine’.

**Psychological issues related to recurrence**, **metastasis** and prognosis

Breast cancer recurrence with obvious complexities, are most likely to be causing significant distress among patients; also most of the times which comes with progression or metastasis.

W15, 38 year old woman explained her emotional trauma associated with BC recurrence: ‘doctor was explaining the same diagnosis again, and it is stage III then I lost all hope in the treatment. Again! Going through the treatment

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59Cancer recurrence is defined by American Cancer Society as- “the return of cancer after treatment and after a period of time during which the cancer cannot be detected. (The length of time is not clearly defined.) The same cancer may come back where it first started or somewhere else in the body”.-

60“Metastatic cancer is a cancer that has spread from the part of the body where it started (the primary site) to other parts of the body”-American Cancer Society
seemed so difficult for me. I told my husband that now I don’t need the
treatment. He was crying…and said let’s try fighting again. But I already had
lost all the hope… now it’s only for him I am here”

Living those experiences again was the major issue for four interviewed women with
recurrent breast cancer. The women (not in recurrent phase); were under treatment;
said that they are scared of thinking about recurrence.

W28 explained it by a Malayalam saying-

“aana koduthalum aasa kodukkaruth” (means- it is better you give elephant
than giving unrealistic hope- by saying this she was intending to express her
worry about the recurrence- ‘giving hopes of cure by treatments and asking
about recurrence’)

Metastasis is another issue where most of the women participants were understood by
the word “spread” and they considered then onwards their illness is critical. Only 2
women with metastasis have been included in the study considering the health and
emotional factors. One woman had metastatic lung cancer and another had lung and
brain cancer that were willing to talk about their emotional troubles.

W13: “Yes, I know it is complex now. I understand...Now I have stopped thinking
about myself, my cure, my life... Instead I think about the world without me. I
asked my husband about taking care of my children. His life after me and so
on... I feel worried and I often complain God. I know healing is something
unsure. So I ask for peace...peaceful death”

W24: I have difficulty to connect things and speak. I never thought it will spread
everywhere, now what is left with me... nothing”

The recurrent breast cancer is seemingly more distressing than the initial breast
cancer. Physical, functional and emotional well-being is found to be impacted by
recurrence in women and their family members (Northouse et al., 2002). When concerns recurrent BC, the focus changes to the patient’s balance to manage everyday illness, surviving, healing and preparing for death (Lewis & Deal, 1995). The narratives of women with recurrent BC show their adjustment and perception of recurrent diagnosis experience means adjusting to a forecast of restricted and uncertain future than they hoped before.

Metastatic breast cancer is more often associated with hopelessness and depression as the appearance of metastases limits the potential for cure. The nature of their disease changes to an incurable and a progressive disease depending on the location and extend of metastasis. However, incidences of survival for decades have been recorded. Most of the patients anticipate death when they hear metastasis. Many patients view the rest of their life as dying, a very few view it as living with cancer (Benner & Wrubel, 1989). When we consider the narratives of women with BC in this perspective, their major concerns become future and family.

**Femininity and lost breast/s, Body image (living with altered body, hairless head...)** Sexuality (how is it a concern after cancer diagnosis?) - Body image and sexuality concerns of women with BC

Altered feminine body due to breast cancer treatment has been an interesting concern when psycho social issues started incorporated among breast cancer studies. Radical mastectomy, chemotherapy and radiotherapy side effects- bald head, darkening of skin and nails, rashes, scars, weight loss, tired look all these were reported body image concerns of women with BC. Mastectomy creates serious impact on sexuality (preferences, activity, satisfaction of women with BC and their spouses). Prominence of hair and breasts are historically considered as distinguishing physical elements of female body and essentialities of feminine beauty (Lerner 2002; Carswell and Stafford 2009).
W29 in her III stage of cancer shared her concern about breast:

“They were dressing up the wound. I saw my body with a wound instead of my breast. I felt so sad. I am told that there is a spread on my skin and lungs. I know this is a serious illness and surviving is luck. But it is really sad for me that I lost my breast... you may think that what is losing breast in front of death... but I feel sad whenever I see myself on mirror”

A study by Vijayan A. also mentioned the women in advanced stage of cancer were also concerned and sad about their lost breast. Chemotherapy induces changes in women physically and sexually as in- the distress they feel in their body parts which defines them feminine is reported as distressing by the women with BC.

W11 shared her emotional issues with loss of hair:

“The change was so sudden. I started crying. I had good hair. A few hairs left on my head when I touched. I could not imagine my face like that. It was so tough for me to see myself on mirror and to face people.”

Mastectomy- the surgical removal of breasts created impact on their perception about body; femininity and sexuality have been reported by women with BC.

W8, an unmarried woman of 26 years viewed her mastectomy as the end of her femininity and sexuality:

“You know, what will be my future? I feel like committing suicide. I, a beautician see myself as so ugly. How can I get married? Even if I am cured who will marry a girl like this. And after hearing about cancer and surgery... nobody... I know, I am not beautiful anymore for anyone. When I look forward I don’t see anything.”

W16, a married woman, teacher by profession explained how mastectomy affected her body image and sexuality:
“I used to enjoy my body by looking its structure in this age as well. We had a good sexual life. Now I am so distressed by losing my breasts. How important it is to feel like a woman and to feel like to be loved and curdled. I feel like everybody is looking at my chest and sympathizing. If anybody hearing breast cancer would look at your chest. I feel disgusting, I know, we both would not be interested in our sexuality anymore.”

Surgical removal of breast impact body image and sexuality of cancer patients in terms of distress and poor adjustment has been studied by many researchers (Cash TF, 1990). As mentioned in the experience of W16, the concerns of her body is not always individual bound but these are certain translated reactions more than clinical phenomena such as concerns about societal perceptions about her body, intrusive thoughts, thoughts about incomplete body without breast, unhappiness related to the altered body and so on. The psychological effects including self consciousness, timidity, weakness, inferiority and fear of unattractiveness and undesirability is significantly associated with breast cancer in woman (Young I M, 1990). Also they experience other changes such as medical menopause, hormonal changes, vaginal dryness, infertility concerns and loss of sexual desire and satisfaction which are impacting sexual well-being of the people when it concerns the survival.

Self esteem (worth living?)

Concerns of the woman for using internal and external resources to feel good and adjust to bodily and psychosocial changes because of the illness, breast cancer is discussed in this section.

W2: “the relatives (women) wanted to see my chest to check how it looks like (after mastectomy). What if I ask them the same?... Thereafter I started feeling everyone would be looking at me like this. Otherwise also I suffered a lot in
my life. Now I feel like what I am living for? I don’t feel like meeting people at all.”

W29: “I used bra which has pads and wigs. But I felt very bad when I started meeting people as of all of them know that these are fittings (prosthesis). I felt like throwing all those. But somehow I did not have the courage to do that; at least unknown people would not look at me with sympathy.”

Women with BC undergo a wide range of treatments during their hospital phase and which produces side effects as well. Multi factorial impacts of breast cancer on body; like- partial or complete loss of breast/s, lymphoedema, hair loss, weight reduction, darkening of skin, nails and fingers, hot flashes, medical menopause and sometimes progression related neurophysiologic changes bring negative effect on perception regarding their lives (Vadivelu N, Schreck M, Lopez M et al, 2008; Swenson K, Nissen M, Ceronsky C, Swenson L, et al, 2002; Crane-Okada R, Wascher R, Elashoff D, 2005; Andersen B, Johnson J., 1994). W2 was sharing about the people responses to her altered body created psychological distress where W29 was disturbed with the actions she took in order to readjust to live in with self-esteem. Particularly, these factors are not within individual’s control; therefore further attempts to adjust and restore the changes often causes prolonged feelings of regret, confusions about worth-living and psychological distress (Tacon A, 2011; Sheehan J, Sherman K, Lam T, Boyages J, 2007). Other women who were sharing their issues regarding lack of hope in cure, difficulty in accepting their own altered body, issues in dealing with expectations of people around and the roles they used to play before the diagnosis, the feeling of worthlessness because of the dependency the disease caused in their lives
were certain concerns which make them ‘feeling not good’ or not ‘feeling worth-living’.

### Box 6.1. Summary of psychological concerns of women with BC

<table>
<thead>
<tr>
<th>Concern</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deal with Anxiety - disease, treatment and the concerns of life.</td>
</tr>
<tr>
<td>Fear of recurrence, metastasis, prognosis and death</td>
</tr>
<tr>
<td>Sadness and depression</td>
</tr>
<tr>
<td>Adjustment to illness and treatment</td>
</tr>
<tr>
<td>Coping with the changed life</td>
</tr>
<tr>
<td>Sexuality (how is it a concern after cancer diagnosis?)</td>
</tr>
<tr>
<td>Body image (living with altered body, hairless head…)</td>
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<tr>
<td>Femininity and lost breast/s</td>
</tr>
<tr>
<td>Self esteem (worth living?)</td>
</tr>
<tr>
<td>Acceptance of recurrence and metastasis</td>
</tr>
<tr>
<td>Post traumatic concerns, survivorship</td>
</tr>
</tbody>
</table>

### 6.4. SCN – Social concerns

Breast cancer diagnosis most often seemed as threat against the normal flow of life which causes whirls of decisions, treatments, challenges one need to face further. Rather than biomedical picture, breast cancer impacts a person’s life in a more complex way when considering her whole-being - as an individual and social being.

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61 The terms used by women with BC participated in the interviews referring self esteem.
This section discusses different concerns of women with breast cancer in terms of social side of the whole picture.

**Family relationships, coping with functioning of roles with changed physical status**

Keeping in mind the factors affecting the expression of SCN have been discussed in the chapter II, the experiences of the women with BC related to the expected roles; and these roles, varies from person to person and across the cultures and families.

W13: “He (husband) did not do any work at all home before knowing about my illness. Now he does everything. Taking care of me and children… I feel sad. But what should we do otherwise? Recently my family (maiden family) took me to my home. I am not at all feeling peace thinking about them (husband and children). Perhaps, now they don’t have to take care of me that is comparatively easy.”

Metastatic BC made W13 hopeless about her physical condition even after then she is concerned about husband doing all the things that she used to do before and thinks that at least taking care her health should not be a burden upon them.

W11: “I am staying with my brother and family since my husband left me. It is really difficult for me. It is better dying than being dependant. Earlier I used to earn and contribute to the expense. Now I am completely dependent on them”

Financial contributions to the family, being in brother’s home, dependency are certain things that trouble W11. Most of the woman considering returning to their own home or sibling’s home after marriage or marriage break ups is not desirable as the
construction of ‘being dependent’ on them. Her emotional trouble also associated with her physical and financial dependency on her brother and his family.

W7: “I worried a lot... you know, without doing anything for anyone or even for me, what kind of a life is this? Even then I hope this phase will change... so I will be able to go back to my life and support my family.”

W7 also believes in functioning or being productive is one of the essentiality of existence. However she hoped that a change back to her functionality and support her family. All respondents concern coping with cancer cure or existence in relation with their family. This may be explicating the primary concern of an individual’s need related to love, belongingness, and acceptance (Maslow, 1943). In addition to dependency, Adjustment issues, damaged relationships, marital problems were also noted concerns with family. De Cosse & Cennerazzo (1997); Rait and Lederberg, (1989) also pointed out major issues in terms of family of cancer patients as they have been considered as the second order patients and the social adjustment, impaired bond within family, marital problems, and restricted social activities are certain identified problems of breast cancer patients.

**Deal with the conversations on illness**

Conversations about disease related things and life after breast cancer diagnosis have been reported as traumatic by the women with BC.

W7, a woman of 32 years shared her experience with visitors: “They (visitors) were asking me- ‘ohh.. Did they cut it off? Both??’ (Breasts). She (one relative) wanted to see the scar (after surgery). U know, she wanted to see that. I wanted to cry and shout at her... but could not. My mother in law said to
show. I felt bashing her. Then I showed...(Crying)... They came with some money for my treatment.”

W29: “I told her (sister) please tell them not to visit me. It was her daughter’s marriage and they live next to my house... She (niece) is my own daughter but... I did not go. She told them my immunity will be impacted. I did not want to meet anyone. I was ‘motta thala’ (head with no hair) and they all will think.

‘ayyo kashtam lle’ (feel sad about her in sympathetic way)

Insensitive comments, conversations about illness and treatment have been reported by the women with BC as one of the most traumatic and troubled area after their social life. Telling stories connected, suggesting alternative treatments were often accounted as useful by a few women but most of them found it very difficult. Experience of W7 showed that she was compelled to show her bared chest to the relatives as her obedience to mother in law’s instruction and the financial help made her submissive. Gender and financial need often identified as the factors negatively impact the women with BC in all aspects. Although at times as W29, the women with BC would want to be in social and family events, the emotional turmoil they go through in addition to undesirable conversations often leads to avoidance of social gatherings and thereby related emotional issues.

Managing Finance

Nair K. S, Raj S., Tiwari V. K et al (2013) in their paper on cost of cancer treatment in India mentioned that only for radiotherapy for course of 4-8 weeks, around USD 1350-2600 is charged by one corporate hospital group in India. Government hospitals offer less charge for the treatment but the other cost of supportive medicines and indirect costs (conveyance, accommodation, food etc.) have to be taken by the patient.
and family. Throughout the data collection and analysis, financial need is observed as a constraint and a base factor on which other concerns and needs were built upon.

W22 shared that she postponed her visit to hospital because of the financial trouble:

“I postponed coming to hospital because I knew my family could not afford the treatment. My entire family was running for arranging money for my treatment but it was so difficult. Then church where I used to go for work gave some money and a few good people. Otherwise I would have died at home.”

W7 shared her concerns about the expenses to treat as well as the financial impacts because of the employment loss of the caregiver:

“First thing came to my mind when I heard about my diagnosis was the treatment cost. I thought Oh God! Why did I know about this? How many people know about their disease at their last stage... It would have been better for me. Then we enquired about what could be done to source us. People from palliative care and other kind people helped. Of course it was helpful, but many times worries about money for the next day were the hurdle. Husband was the only working person and he is accompanying me here so how can he earn? A lot of issues- people often help us for the treatment but needs are more that. You know, if my husband is not working then everything would be stuck- children are studying, food and other expenses...”

W1 expressed her financial concerns as she does not belong to BPL category:

“He (father in law) has taken loan over our (W1) house. That is the only asset we have. We cannot sell it off also. Some case is there over this property. Because of this property we belong to middle income but we are totally broke. We are not eligible for any help or concession because we don’t have the BPL card. To cut short people like us are in real trouble.”
As W22 a few more women said their worries regarding treatment cost delayed their treatment and family and relatives were in search of sourcing for the treatment. Wage loss and indirect cost is also mentioned as financial concerns they face (reported by 4 women with BC). Cost of investigations, treatment, indirect costs, opportunity costs (wage loss of the family) were the reported cost against cancer treatment. Most of the respondents said their family savings, borrowings, sales of assets (gold and other assets), medical reimbursements, and other schemes of Government were the source they met the treatment cost. The difficulty of middle income group is also noted as their ineligibility for concessions and other support as per documentation but they face serious difficulty in meeting the expense of the treatment. Provision of free services becomes difficult because of lack of BPL cards or ineligibility as per the categorization of the hospitals Nair K. S, Raj S., Tiwari V. K et al (2013). Also, the facility of socio economic assessment for the free/subsidized treatment done by social workers is available only in a few tertiary hospitals.

**Perceived social support**

Social support is often very subjective or depends on the perception of the person about the extent of help or resources s/he receives in order to manage cope and adjust to the difficulty. Experiences and expectations of women with BC in this dimension is explained in the later sessions 6.6 and 6.7 as discussing the informational needs and health care system delivery needs.
Box 6.2. Summary of social concerns in relation to SCN

- Coping with functioning of roles with changed physical status
- Family relationships
- Deal with the conversations on illness, treatment and life after diagnosis
- Facing and being in social gatherings
- Responses of relatives and friends of the exhausting experience of living with breast cancer
- Managing the finance
- Perceived social support

6.5. Supportive care needs- Spiritual concerns

Considering Indian context, collaborating spirituality in health care seemed like challenging as the existence of wide variety of beliefs and practices to meet the spiritual needs of a person. As anything challenges the existence of oneself, breast cancer experience also viewed in terms of spiritual concerns.

Reasoning in spiritual terms

This section discusses the spiritual interpretations of women with BC regarding their breast cancer experiences. Fate, destiny or will of God and result of Karma were the reported interpretation or explanation of reasons for their breast cancer.
**Fate**\(^{62}\) and destiny or will of God- as reason and facilitation

Most of the participants expressed their belief in destiny, fate and God’ will in relation with their diagnosis; nevertheless the affinity towards fatalism does not always imply vulnerability and was not at chances of one’s capability to change perceived destiny through human activity (Florez, Aguirre, A., Viladrich, A et al., 2009; Obeidat R., Lally, R., & Dickerson, 2011)

W19 expressed her belief that her cancer is her fate:

“All through these phases I was thinking that this is fate. No one could deal with that or change that.”

W26: “This is written on my head. When I checked my horoscope also they said after 45 years the time is not favourable for me. I didn’t think that the bad time will affect me like this disease. Death would have been better than this.”

W16: “Yes I believe in destiny. It must have been written in my destiny that I should have gone through this. And I console myself that if it is in my destiny then I will be alive. Otherwise I would be dying because of this.”

Cancer is more often associated with fatalistic beliefs as this is a predetermined and inevitable condition as everybody needs some reason to die so be it cancer (Chavez LR, Hubbell FA, Mishra SI, et al., 2005) and apparently this pessimistic outlook serves as obstructor in their betterment and cure.

W18 viewed her illness happened because of God’s will:

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\(^{62}\)Although different definitions are there, fate refers to the universal trend to believe that life events are predetermined or programmed by outer forces such as God/planets and that nothing can change its course
“I am sure there is a purpose. It is God’s decision who are we to ask why? I must have done something what God does not desire... or else what it could be. So I am praying for forgiveness.”

Studies (Clark-Tasker, 1993), in certain communities especially in African Americans regarding health also suggested the same line of belief that the reason of sickness may be a failure to obey God’s will. Majority of these perceptions are closely related to the religious upbringing and understanding they have. Also observed in the respondent women with BC that these beliefs act as consolation as finding reason will initiate some remedy actions like prayer, offers and so on.

Result of ‘Karma’ - ‘Karma- phala’ as a cause and consolation

Karma- is believed by Hinduism that the principle rules a person’s life which is based on the actions and (by some philosophers) even thoughts of one’s previous births. Karma is viewed as encompassed in each one’s soul and not an imposed punitive force or God, but is rather an “exercise of the moral law in the universe” (Bowker J, 1970)

W10: “There is nothing that could be saved from the result of our karma. But I don’t remember anything that I have done intentionally to cause some trouble for others then why this is happening to me. Must be of karma of my previous births, apart from that I don’t find anything which can cause this to me”

W16 shared that she started offerings to temples to get saved from the result of Karma:

“I made several offering to get rid of my ‘karma-phala’ (result of the work) to palani and thirupati and all... anyways my hair will be gone very soon. I thought before that I will offer it before bhagavan (God)”
A number of women with BC reported that they believe Karma is the reason for their illness. As in Indian and certain South Asian countries, people have strong belief in Karma as the reason for their cancer diagnosis, and because of this belief they find consolation and strength to cope (Gurma B K, Stephen J, MacKenzie G et al, 2008). And a few rejected the idea of Karma by saying the observed nature of affected people.

W20: “Yea people do believe that all things happened to me because of karma. But I don’t see this like that...Many good people are being affected and suffered by this disease.”

Personal accommodation of such beliefs reflected both interpersonal and intrapersonal processes, especially among people with cancer vary from person to person. Where Hindus called it as Karma, women belonging to Islam referred this as will of God as ‘Al Qadar’\(^{63}\). The notion of “fulfillment of dharma”\(^{64}\), often used by the patients as observed by the narrative of W16 such as – offering something to do for the religious places, or poor, pilgrimage, specific worships, keeping fast and pray as the means to negotiate and to cope with experience of the illness (Pandey, M., Latha, P.T., Mathew, A 2003)

**Coping and spirituality**

Recently, spirituality and religion based coping strategies have become an important area of interest among cancer research. This section attempts to understand coping experience of women with BC in terms of spiritual concerns.

**Increased faith and religious activities, Meditation as a help to feel good about life and Prayer as the only solution**

\(^{63}\)“Qadar means that Allaah has decreed everything that happens in the universe according to His prior knowledge and the dictates of His wisdom”.

\(^{64}\)Dharma is the duty to family and the group, and represents an obligation as well as protection
Hussain and Cochrane (2003) stated that in India and South Asia, spirituality/religion is the most prevalent coping strategy adopted by the cancer patients. Ashing-Giwa, K.T., Padilla, G., Tejero J, et al, (2004) also documented and incorporated spirituality as an important component of wellbeing among breast cancer patients as well as the use of prayer and trust in God regardless of their religious or cultural background is observed as better coping (Reynolds D, 2006).

W26: “I went to bhrahmakumari rajayoga with my friend. It helped me to calm down my mind. Yes, initially it was tough... But now I feel good.”

Yoga and meditation is also considered as a spiritual way of coping with the distress related to the illness, cancer.

W21, have Christian beliefs: “Of course I believe in God. If He allowed this to happen then He will get me out of this. My prayer will not go in vain.”

W16: “Prayer is the only hope I see when I look forward. See all these people are talking about cure and absolute care. But what we see around is cancer, cancer everywhere. I don’t think no one else can save or enable us to go through this suffering.”

W20: “I want to live... yes they say I won’t be dying. May be, nobody is assured of the fact that this treatment will be effective... Ohh Yes... Then I don’t understand why they are rejecting God as he or she alone can sustain us in these hurdles.”

Belief in God’s control over everything and predetermination by God’s mighty power are certain common things irrespective of its basic notable philosophic difference

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65 A yoga center
among women with BC regardless of their religious beliefs. Hussain and Cochrane, 2003; Pandey M, 2004 argued that these beliefs influence them in both the ways-inactive and submissive stand- submissive to control of God (God’s will), secondly a vigorous coping by praying for cure (help to deal with disease). In this context, the spiritual concerns evidently seek consideration and collaboration with holistic betterment and quality of care for the persons with cancer.

Conflicted or challenged belief system as loss of faith in God, angry on God’s decision is also accounted by the respondents.

W27: “I just don’t want to talk about. They (Gods) are not doing justice... I didn’t lead a wrong life. Still... I just don’t want to talk about it”

W8: “Why should I believe God? When I am suffering like this... I stopped going to temples or praying. I did not do any wrong intentionally to harm anyone”

W7: “There are hundreds of bad people enjoy their lives. Why am I into this and suffering like hell. I am born and brought up like I used to attend every mass. But there is nothing to be done. It is just a belief”

The narratives of women were expressing anger at God as Elizabeth Kubler Ross (1969, 2005) discussed "Why me?" as feeling that more deserving people are enjoying life.
Box 6.3. Summary of spiritual concerns and SCN

- Reasoning in spiritual terms-Fate and destiny or will of God
- Result of ‘Karma’
- Coping and spirituality - Increased faith and religious activities, Meditation as a help to feel good about life
- Prayer as the only solution
- Challenged spirituality- Conflicted or challenged belief system (Loss of faith in God, Angry on God’s decision)
- Concerns about death and afterlife
- Confusion and doubt
- Diversity of religious teachings and practices
- The rest of the time and death-Increased threshold to do better things in the survival period

6.5. Informational support needs

The observed informational support needs of the women with BC were related to illness and treatment, procedures and treatment decisions, adequacy and efficiency of the information system of the hospitals, need of professional help in sharing information, services and schemes of government, NGOs and other voluntary organizations. Information regarding their prognosis, management of side effects, sexuality and body image, financial aid, Schemes and insurances were the most expressed needs of the patients whereas breast cancer communication trends in India shows the awareness campaigns are mostly prevention and treatment related in nature as well as charity and fund raising programmes are proficient in the scene.
The need for information is substantial when women with BC encounter their disease and also related to the decisions they often come across their cancer journey (Loiselle, Lamert, & Cooke, 2006). Information about choices and options regarding their treatment and care are important consideration irrespective of the fact the patients are participating in the treatment decisions (Mills & Sullivan, 1999).

Key concerns related information

Related to illness and treatment

“I did not know that this mark could be cancer” (W10) – Although, awareness creation is the primary focus of all cancer prevention and care; the narratives of women with BC expressed their need to be informed about their symptoms.

W12: “The women on the next bed told me that I may get concession for treatment. I asked many staff in the ward. All were telling go there approach them and all. It has to be written somewhere”

“Whom can I approach”- is the most reported informational need. Majority of women had the opinion that written information about the services has to be published or circulated for the patients. Concerns about the recurrence of cancer were other information they were rigorously searching for. All the respondents reported that availability of readily understandable information materials are one of their greatest needs. Other shared informational needs were in terms of treatment decisions, adequacy and efficiency of the information system of the hospitals and need of professional help in sharing information, services and schemes of government, NGOs and other voluntary organizations. Information regarding their prognosis, management of side effects, sexuality and body image, financial aid, Schemes and insurances were the most expressed needs of the patients whereas breast cancer
communication trends in India shows the awareness campaigns are mostly prevention and treatment related in nature as well as charity and fund raising programmes are proficient in the scene.

**Box 6.4. Summary of Informational needs**

- Related to illness and treatment
- Related to and treatment decisions
- Competence and quality of the information system of the hospitals
- Need of professional help in sharing information, services and schemes of government, NGOs and other voluntary organizations.

**Health care system support needs**

The support needs related to the health care system from the narratives of the women with BC have coded, categorized and presented as table with illustrative comments in this section.
Table 6.1. Health care support needs of women with BC

<table>
<thead>
<tr>
<th>THEMES</th>
<th>Illustrative quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partaking in care, decision making and</td>
<td>“They did not tell me but asked for my husband to talk to them. I wanted to know about my illness.” - (W3)</td>
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<tr>
<td>information availability</td>
<td>My family was so arrogant; and said you don’t need to know more. They said we are there. When the doctor comes we will ask and tell you. May be out of concern they are saying so. But then how would I know what is happening with me.” - (W5)</td>
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<td></td>
<td>I definitely feel that they should directly tell me the things. But who have time here? If they are saying they say plain and simple… and it hurts. But if they don’t take time how would I know about it. Of course, the family will be concealing many things and we cannot blame them. But yea, they explained me about the treatment procedures and side effects. But the need to know more is higher than they explain…” - (W25)</td>
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<td></td>
<td>I feel this is perfect! They are doing their best I know. Rest is up to God. If they include us also (in decision making) what we can ask them. I don’t know. I trust them because they know better” - (W27)</td>
</tr>
</tbody>
</table>
| Adequacy of information (diagnosis, treatment and) | “Yes, they explained me everything. And I was so
<table>
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<tr>
<th>Investigations</th>
<th>disturbed. I did not know what to ask.” - (W15)</th>
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<td></td>
<td>“I wanted to know the treatment cost, and the subsidy and all. We had difficulty in finding a person to help within the hospital” - (W21)</td>
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<td></td>
<td>“I have heard about the tests before itself. But I want to know more, which happens at different stages and different times. I know it is not easy to find somebody for my help all the time” - (W18)</td>
</tr>
<tr>
<td></td>
<td>“It (information availability) was very much section-wise. All know what concerns their department. But we are not here to know things department-wise… Right? So I definitely feel some system should be here more than this ‘may I know’ section directing towards departments.” - (W24)</td>
</tr>
<tr>
<td>Opportunity to have discussion with treatment professionals (ask questions)</td>
<td>“During my second visit, I wanted to ask many questions to doctor, but he was so busy. And I could not meet any social worker as you say… is there somebody that we can ask all these things?” - (W26)</td>
</tr>
<tr>
<td></td>
<td>“The staffs are always busy, the people are more. So even if they ask us do you want to know more? They expect a ‘No’” - (W4)</td>
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</tbody>
</table>
| Accessibility of care and support | “We don’t have a treatment facility in our district (Idukki). People from our place go to Kottayam medical college; a journey of 5-6 hours, it is really difficult. I
| Support for transportation | “Every chemo we came by car (taxi). It was difficult to afford it but people from nearby club sponsored it.”- (W15)  
- Coming from our place (Palakkad) to this hospital is also taking a lot of trouble. Waiting for my nephew to take me here or depending on someone for accompanying me, that too males are needed, I am so week”- (W25) |
| Provision of home care | “I asked here, will people from palliative care clinics come home, but it is not in our place.”- (W28) |
| Provision of equipment, aids and appliances as free of cost or at subsidized rate | “Here, sisters (nuns) are making bra for people like us. But when I was there (RCC) there is no such things”- (W18)  
- “I asked my husband to buy me a wig. It was so costly. And my in-laws scolded him as they already spent a lot of money for my treatment. I found going out as the most difficult thing. I have heard that people donate hair for the patients but I did not know how to get it for me”- (W20) |
| Continuity and availability of Healthcare professional | “Every time when we come here we don’t get to see the same doctors. So we ask the sisters (nurses) this particular doctor’s time. But the juniors change every
DISCUSSION AND SUMMARY

‗Supportive care needs‘ is called by researchers and practitioners as an ‗umbrella‘ term addressing various needs of a person experiences in his/her cancer journey (Fitch M (2000). As the word ‗umbrella term‘ denotes this is an attempt to put various aspects of needs such as - physical, psychological, social, spiritual and informational needs of a woman with breast cancer(Sanson-Fisher R, Girgis A et al, 2000). It is critical to study the supportive care needs which are essential to help the persons with cancer to achieve optimum well-being and to ensure the best health care service delivery (Minstrell M, Winzenberg T, Rankin N et al, 2008). The supportive care needs changes over time and among individuals. This chapter analysed the narratives of the women with BC thematically; in order to understand their needs for optimum care and support when they are under treatment in cancer specialty hospitals of Kerala. The suggested aspects of literature review– women as a cancer patient in concerns of femininity, sexuality and body image associated with breast cancer as well as the
social roles and expectations gives the study context. In addition to that, the State of Kerala of India, showed remarkable ways in its health indices and health care programme implementations as comparable to the developed countries of the world, gives the regional and cultural context for this study. It is relevant to look at Kerala nevertheless the promising health indices; the increase of breast cancer incidences is alarming in the state. It adds relevance as the only state in India that has an active palliative care policy in action; the state and the society is sensitized to an extent on supportive care needs of persons with cancer no matter this study did not look at palliative care aspects. Identified supportive care needs of the women with BC are discussed below.

SCN- Physical concerns

Needs related to management of disease related physical issues and treatment side effects: Issues related to caregiver availability was a major one reported by the women as their long stay in hospital created issues in the family caregiver's job and earning. Women who underwent mastectomy reported the need of a family caregiver to assist them in managing the pain and communicating and ensuring the care when they are on bed. The pain they feel is often seemed associated with anticipation of death and adapting to an illness. Factors like family dynamics, absence of care giver availability, physical weakness, employment, looking after their children, meeting other family needs were the other issues in caregiver availability. Though it is difficult to separate the types of needs from their physical weakness; dependency on others for necessary things of daily life is reported as most distressing by the women with BC. Several women shared their concern about the adequacy of medical assistance during
hospital stay although which is available but not adequate. Most of the assistance needs were related to chemotherapy.

**Communicating and coping with physical issues:** Other patient’s experience of coping is reported as helped the women with BC to adapt to the issues better. Several women preferred much comfortable or informal ways of collecting information related to coping with treatment side effects and verifying that with the treatment professionals. Most of the women trust treatment professionals for coping information. A few women wanted to experiment with other treatment methods like Homeopathy or Ayurveda for managing the side effects. All of the respondents mentioned that they relied various sources like treatment professionals, experience of others, opinion of spouse for better management of symptoms and side effects but often troubled because the need for is not completely addressed.

**Physical issues related to mobility and transportation:** Limited or restricted physical activity and disability, reaching the care providers whether it is hospital, or other people like NGOs or voluntary organisations were the reported physical issues related to mobility. Lack of staff or increased number of patients on request of the same service became a hurdle for the patients in getting assistance at the time of need in the hospital. As cancer specialty hospitals are less in number and on an average one per 5 or 6 districts, the distance and transport to the hospital were a reported problem by the women with BC. A number of women shared their difficulty in commuting as they are physically exhausted by the treatment and hiring a car became essential and expensive for each visits. The women suggested that the free/ concession in the expense of travel not only in the trains but in other public transport system- buses will help to solve this issue to an extent.
Link with palliative care clinics/ home based care: Lack of awareness about the clinics and the services, lack of geographical coverage of expansion of the clinics in all the areas, availability of caregiver to take them were certain issues reported by the women with BC.

Communicating physical need: For most of the women, husband or male family members are the direct communicators of the illness and issues with the treatment team. The women often want to know the details of the illness but when it comes to a critical illness; family members’ concern that the patient should not know the details of the illness. So the indirect and partial information about their illness becomes a hindrance for them to know more or to communicate their physical issues and find more support in this regard. Treatment professional’s busy schedule is another reported issue for the women to discuss their issues and clarify their doubts.

Physical issues related to the space they spend more time: Monotony, being in bed, restricted mobility outside the houses were causing the physical exertion in women with BC. Lack of awareness about the physical issues related to long term stay on bed is another reported issue.

SCN- Psychological concerns

Fear and anxiety: The reasons for anxiety and fear vary over different phases of the treatment and the stages of the disease. For most of the women, shared fears were related to chemotherapy. Concerns about family’s future, children’ future, and worries about financial sources for treatment were the other reasons for their stress. It is observed that women with BC in Kerala cope to their issues in their very own ways rather than seeking a defined process of coping with the help of professionals; unless they approach the women. It was observed that very rare respondents seek
professional psychological help to cope with their illness but instead the trend was to
discuss with doctors to know more about coping and trusting their spiritual beliefs in
order to ‘feel fine’.

Breast cancer recurrence and metastasis cause severe distress among patients. The
recurrent breast cancer is seemingly more distressing than the initial breast cancer
(Northouse et al., 2002) and keeping balance in every day illness, survival and
preparation for death becomes the stressors (Lewis & Deal, 1995). When metastasis is
known, the rest of their life is viewed as dying experience by most of the patients
rather than living experience with cancer (Benner & Wrubel, 1989).

**Body image and sexuality concerns:** Radical mastectomy, chemotherapy and
radiotherapy side effects- bald head, darkening of skin and nails, rashes, scars, weight
loss, tired look all these were reported body image concerns of women with BC.
Mastectomy creates serious impact on sexuality (preferences, activity, satisfaction of
women with BC and their spouses). Chemotherapy induces changes in women
physically and sexually as causing distress in their body parts which defines them
feminine is reported as distressing by the women with BC.

For many women, the concerns of her body is not always individual bound but these
are certain translated reactions more than clinical phenomena such as concerns about
societal perceptions about her body, intrusive thoughts, thoughts about incomplete
body without breast, unhappiness related to the altered body and so on. Breast cancer
causes psychological effects in women including self consciousness, timidity,
weakness, inferiority and fear of unattractiveness and undesirability is significantly
associated with in woman (Young I M, 1990). Multi factorial impacts of breast cancer
on body; like- partial or complete loss of breast/s, lymphoedema, hair loss, weight
reduction, darkening of skin, nails and fingers, hot flashes, medical menopause and sometimes progression related neurophysiologic changes bring negative effect on perception regarding their lives. The responses of people to their altered body; and at times the actions they take in order to readjust to have self esteem is also a cause of psychological distress among women with BC. Issues regarding lack of hope about cure, difficulty in accepting their own altered body, issues in dealing with expectations of people around and the roles they used to play before the diagnosis, the feeling of worthlessness because of the dependency the disease caused in their lives were certain concerns which make them ‘feeling not good’ or not ‘feeling worth-living.

**SCN - SOCIAL CONCERNS**

Rather than biomedical picture, breast cancer impacts a person’s life in a more complex way when considering her totality as an individual and social being. The role expectations of the women with BC vary from person to person and across the cultures and families. Metastatic cancer often makes women hopeless about her physical condition; but at that time also roles in the family become an important area of concern. Most of the woman considering returning to their own home or sibling’s home after marriage or marriage break ups is not desirable as the construction of ‘being dependent’ on them. All respondents concern coping with cancer cure or existence in relation with family.

Insensitive comments, conversations about illness and treatment have been reported by the women with BC as one of the most traumatic and troubled area of their social life. Telling stories connected, suggesting alternative treatments were often accounted as useful by a few women but most of them found it very difficult. Financial need is observed as a constraint and a base factor on which other concerns and needs were
built upon. Income loss, indirect expenses, prices of lab tests and treatment were the reported financial expenses/ needs cancer treatment. Most of the respondents said their family savings, borrowings, sales of assets (gold and other assets), medical reimbursements, and other schemes of Government were the source they met the treatment cost. The difficulty of middle income group is also noted as their ineligibility for concessions and other support as per documentation but they face serious difficulty in meeting the expense of the treatment. Provision of free services becomes difficult because of lack of BPL cards or ineligibility as per the categorization of the hospitals.

**SCN- SPIRITUAL CONCERNS**

Most of the women with BC, expressed their belief in destiny, fate and will of God in relation with the reasoning their cancer diagnosis. The reason of sickness is perceived and a failure to obey God’s will. Majority of these perceptions are closely related to the religious upbringing and understanding they have. Also observed in the respondent women with BC that these beliefs act as consolation as finding reason will initiate some remedy actions like prayer, offers and so on (Belief in Karma as the reason for their cancer diagnosis, and because of this belief they find consolation and strength to cope). Where Hindus called it as Karma, women belong to Islam referred will of God as ‘Al Qadar’. The notion of ‘‘fulfillment of dharma’’ often used by the patients such as – offering something to do for the religious places, or poor, pilgrimage, specific worships, keeping fast and pray as the means to negotiate and to cope with experience of the illness. Yoga and meditation is also considered as a spiritual way of coping with the distress related to the illness. Hussain and Cochrane (2003) stated that in India and South Asia, spirituality/ religion as the most prevalent coping strategy adopted by the cancer patients. Beliefs in God’s control over
everything and predetermination by God’s mighty power are certain common things irrespective of its basic notable philosophic difference among women with BC regardless of their religious beliefs. Conflicted or challenged belief system as loss of faith in God, angry on God’s decision is also accounted by the respondents.

**Informational support needs**

Information about their symptoms, recurrence of cancer, treatment decisions, and the services was the most reported information need. Availability of readily understandable information materials is the solution suggested by many women with BC. Adequacy and efficiency of the information system of the hospitals and need of professional help in sharing information, services and schemes of government, NGOs and other voluntary organizations are certain areas to be addressed to provide better care for the patients. Information regarding their prognosis, management of side effects, sexuality and body image, financial aid, Schemes and insurances were the most expressed needs of the patients; whereas breast cancer communication trends in India shows the awareness campaigns are mostly prevention and treatment related in nature as well as charity and fund raising programmes are the focus.

**Health care system delivery needs**

Direct communication from the treatment professional’s side is one of the needs by a few women with BC. For treatment decisions, most of the women trust the doctors completely. Only part they do is choosing the same doctor by taking the appointment on his/her consultation day; or if they are not satisfied then changing the hospital for their treatment is the observed options they consider as decisions; rather than having a discussion for treatment choices practices in the West. Lack of clarity about the needed information is also another area of concern of women with BC.
Departmentalization of services and lack of coordination of all these services under one team or person or system is another important issue reported by the women.

**Figure 6.4 Summary of supportive care needs of women with BC**
Lack of time for the discussion of treatment is one challenge shared by the women. Long journeys, weakness, expenses for treatment were the problems in accessibility of care and support as there are limited nearby treatment facilities in some regions. Provision of equipment (prosthesis), aids and appliances free of cost or at subsidized rate such as wigs, padded bras, wheel chair, commode etc was another reported need for help. Continuity and availability of Healthcare professional (who are aware of previous history and illness experience) were considered as a challenge by the women with BC. Need for a hospital based system for co-ordination with service programmes and referrals to the voluntary organisations or NGOs are also found essential for better service delivery.

**Chapter Summary**

This chapter identified and consolidated various types of supportive care needs of women with BC. Keeping major findings from this chapter, a hospital based supportive care model is proposed and presented along with guidelines for implementation in the next chapter (VII).