Chapter 7

Conclusion
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Although Kerala is a much celebrated state because of its high position in health indexes; better treatment availability and quality of services; the alarming increase in the prevalence of breast cancer cases in the state is still a major health issue to be tackled. In addition to attending the increasing number, a strategic shift from the biomedical practices of treatment to a person cantered approach need to be extended. Based on the field experiences of the researcher in the breast cancer care, it makes sense to add an important note before concluding this study. Naming for identification of a person changes as a ‘patient’, ‘customer’ from the time when he/she enter a hospital in particular among communication between the treatment professions and the administrative people. Often, they are called as ‘their bed number’, ‘Ca-breast’, ‘Ca-case’ and so on for the alleged practical internal communication. Even though these communications peripherally seem not be so dangerous, which indirectly identifies a person just as a clinical subject or a customer who pays for the services where the person’s name, gender and other contextual details becomes less important or even unidentified. The perspective- ‘patient as a person’ and ‘patient in the environment’ put forwarded by Mary Richmond, a pioneer social worker (1861-1928) is still valid and essential to be incorporated in the treatment and care for the women with BC. When addressing a person with an illness; cancer requires much more ‘person centered approach’ for their support or their care.
This chapter summarises the major findings of this study, suggestions, limitations and perspectives for further research. It also proposed a hospital based supportive care model to the cancer specialty hospitals of Kerala.

**MAJOR FINDINGS**

**7.1. SOCIODEMOGRAPHIC AND CASE PROFILE**

- Majority, 28.3.8% of the respondents belong to the age group 50-59 years, which is considered as usual menopausal age group among females in India. It is seen that the age groups 40-49 years as well as 60-69 years is also have 25% and 21.7% of number of respondents respectively.

- An important trend observed in this data is that women who are under 40 years of age is almost 19.2%, which remind the alarming nature of BC incidence happens at early ages and which demands extra emphasis on the preventive actions such as high risk management, awareness, early detection and treatment.

- 44.2% of the respondents belong to the religion Hindu, 41.7% are Christian and the rest of 14.2% belong to Muslim.

- Majority, 52.5% of the respondents belong to middle income group and 34.2% belong to low income group and only 13.3% belong to high income group.

- Majority, 62.5% of the respondents have an education up to plus two or pre degree (34.2% high school level and 28.3% plus two level). Only 3.3% are illiterate among the total respondents. All of the respondents who are not formally educated and illiterate belong to the older age group.

- Only 26 out of 120 women with BC are able to do the previous job or activities in which, 20 of them were doing only home making, two of them
were Government employees, two were self employed another two were not doing any work as such.

✓ Majority of the women are (78.3%) are married, out of four unmarried women three were nuns, rest of the 22 women were without husband.

✓ 75.8% of the women had children and the rest twenty nine women (24.2%) did not give birth to a child. Nulliparity as a risk factor of breast cancer has been told by several studies and which is very much evident from this study data as well, though this study was not indented to look on risk factors. However, this information calls for much study as which is much higher than the said averages.

7.2. CASE PROFILE (DISEASE RELATED FACTORS)

✓ The results (11.67% of the women with BC) of this study confirms to a similar reported proportion (15%) of breast cancer family history in Kerala.

✓ 70% of the 120 women with BC identify a lump as the first symptom of breast cancer. Pain in their breast, discoloration, numbness or hardness in breast and discharge from nipple are the other significant symptoms observed initially by the women.

✓ 52.5% of the respondents reported that they had hesitation to consult doctor initially due to issues such has shyness, fear about the diagnosis, certain family issues.

✓ 25% of the women reported that they have other illness. Diabetes, blood pressure, head ache are the most reported health issues. Heart disease and skin disease is also reported. 3 women reported that they had hysterectomy.

✓ Ongoing treatment of the women at the time of interview: 66% of them were receiving chemotherapy treatment, 24% of them were under radiation
therapy. 7% of the women were met just after their surgery. 3% of women were taking hormone therapy.

✓ Fear of BC recurrence: 15.8% of the women expressed that they have strong fear that this disease will attack again even if the treatments going on is over. 41.7% do not know about probability of recurrence but they have fear. 25.8% told that it is not a concern 11.7% said they do not have fear thinking of recurrence. Six women were at the recurrent phase at the time of interview.

✓ Activities of daily living: 43% reported that they have severe impairment that is they need assistance for certain activities but can do things which is not requisite of much physical exertion for example able to take food by self but not able to dress or bathe independently. 13% of the women said they requires full assistance for doing any activities.

✓ Mobility: Among 120, 14.2% of the women were able to move independently out of the house without any assistance. 10.8% of the respondents were completely bed bound and 45% were house bound due to the physical difficulties related to the illness.

Findings from the qualitative elements used to understand the case profile

✓ Among the 30 women except six who participated in the in-depth interviews suspected that the observed symptoms could be related to breast cancer. Although, taking the next step towards treatment is influenced by various factors the rising exposure to information about symptoms directly (Popular health care magazines, women’s magazines, classes, doctor’s talks on TV, health awareness classes and seminars) or indirectly (informal talks, listening to cases etc) create awareness in most of the women in Kerala.
Paradoxically, it is observed as the time from observation of initial symptom to get specialized treatment is delayed by various reasons and which is reported by the women themselves that it worsened the cancer in their body. Only 6 women with BC out 30 women participated in the in-depth interview, consulted surgeon or oncologist in the same week itself. Three women approached specialized hospital after six months of observing the symptoms.

Knowledge about the illness, fear of worsening of symptoms, encouragement or pressure from the family and the usual way of dealing a health issue were the factors influenced the women with BC who accessed cancer specialized treatment within the two weeks after observing the symptoms.

A trend is observed that gender operates the women relating their symptoms to the possible reality (breast cancer diagnosis) - accepting it and get treated were got stuck for a while. Misinterpretations and incomplete knowledge of symptoms and avoidance of health care by thinking for instance, ‘why to trouble others if it is not disturbing the immediate daily activities’ is another generally observed trend among women with BC especially who crossed 50 years.

The symptoms other than lump or nipple discharge are not generally registered as a symptom of BC and the construction of breast cancer with middle age or above is also came into view as the reason for ignoring the symptoms. In addition to that, all the women used their own mechanisms to disapprove initially and to deal with the doubt- ‘this symptom could be of breast cancer.

The women with BC prefer to discuss with a female member of the family or friends if not with husband, also prefer to consult to a female treatment professional in the beginning. Construction of breast as a ‘sexual’ or ‘private’
organ is the general view and changes can be observed when the treatment of the illness proceeds with. Postpone the treatment unless the health issue obstructs the daily activities by its symptoms is most commonly observed among woman with breast cancer.

✔ Patterns of Pathway towards specialised cancer treatment: Only 9 women consulted surgeon then oncologist (Pattern- 4) initially when they observed the symptoms. 5 women opted alternative medicine in the beginning for treatment initially among this 2 opted Ayurveda and 3 opted Homeopathy. 6 women told that after chemotherapy they went for homeopathic treatment and which helped them to feel better and improve immunity.

✔ The themes related to the Reasons or huddles in order to delay in proceeding with treatment initially has been viewed as overlapping and inter-related in its complex roots of individual’s very own context are briefed below-

- “It can be waited” (postpone) or “After it...” (Priority): Several women reported that they schedule their health issue not prime in the priority list unless it would not hinder daily activities.

- “Why to take it as a tension?” (Avoidance): Before knowing the diagnosis; women tend to avoid the symptoms because of its nature of not disturbing in the initial stages or lack of awareness about the symptoms. Avoidance of dealing the health issue as negligence of own health, and prioritising other things to do in family or career is observed as the contributory factors.

- “How to proceed with...?” (Ignorance and confusion): Lack of proper awareness about the symptoms and treatment as well as women
considering an issue on her breast as very private to discuss with were noted as the cause of women delaying breast cancer diagnosis.

- “Whom to say…?” (Seeking support): Comfortably sharing their anxieties about symptoms in terms of seeking and receiving help from preferably somebody from the same gender was another reported constraint.

- “How can we afford?” (Financial worries): A trend observed among women that a few women delayed the diagnosis by not communicating their symptoms thinking the cost for the treatment.

- “They will operate it” (body image & sexuality issues): Considering mastectomy as the preliminary picture of breast cancer and sexual concerns while living without breast as a reason for delayed diagnosis reported by a few women. A woman told her feeling of guilt in talking about sexual concerns while discussing a critical illness. Fear of losing attention and love is also reported as the reason for suspending diagnosis and treatment.

- Nevertheless, the women with BC go through difficult physical and psychological phase after confirming their diagnosis, a thirst to know about their illness, treatment and prognosis is observed among most of the women.

- Women were reported informal sources, awareness programmes, discussion with treatment professionals as the major sources of information regarding their illness.

- Raising influence of health magazines, health awareness programmes as part of audio-visual media, Government and people initiatives have increased the awareness among women about the illness. Quite a few women with BC
reported health magazines as well as health awareness classes helped them to recognize their symptoms and lead them to a doctor and with the treatment.

7.3. HEALTH RELATED QUALITY OF LIFE

✓ In this study, majority of the respondents (76.47%), who have low PWB scores, belonging to the occupation category have changed the nature of job because of the illness and majority of the high score category (50%) are able to do the previous job.

✓ Among, disease profile variables, treatment related variables- treatment received and ongoing treatment is associated with PWB subscale score of the respondents. Majority of the respondents were undergoing chemotherapy at the time of the interview. Among the low score categories 76.5% within the PWB scores were undergoing chemotherapy.

✓ In this study, 60.8% of the respondents belong to medium SWB category (10-18), 23.3% have high score range (19-28) and 15.8% belong to Low score range (0-9).

✓ Cross tabs performed on SWB scores with each SDCF variables showed that current occupation status, marital status and treatment ongoing were related to SWB.

✓ All who are unemployed due to illness and treatment belong to low SWB score category and middle SWB score category. 45% of the respondents changed the nature of job; among that 33.33% belong to high SWB score category. Among 25.8% of the total participants were not able to do any work for a long time, 32.25% were into low SWB score category and 58.6% in medium SWB score range. No participant who lost job due to illness and
treatment showed high SWB scores that also shows the importance of occupational status in association with better SWB for women with BC.

✓ Comparatively high and medium scores among majority of the married respondents show that the presence of spouse associate to better SWB scores. No respondents without partner, irrespective of their marital status as widow, unmarried or separated showed high SWB scores.

✓ 26.02% of the respondents undergoing chemotherapy had high SWB score range. The rest 73.98% having low and medium scores showed the association of SWB with chemotherapy.

✓ 57.5% of the respondents belong to medium FWB category (10-18), 36.7% have high score range (19-28) and 5.8% belong to Low score range (0-9).

✓ Occupational status and ongoing treatment is found as associated to functional well-being of the women with BC. Majority (65.38 % within higher score category) of women who have high FWB score category are able to do the previous job. Women who are not able to do any work for a long time and changed the nature of the job reported with lower FWB scores.

✓ Woman who receive hormone therapy have higher FWB scores than women who receive radiation therapy, chemotherapy and surgery.

✓ 64.2% of the respondents belong to medium EWB category (9-16), 23.3% have high score range (17-24) and 15.8% belong to Low score range (0-8). Age, current occupational status and marital status, ongoing treatment and fear of recurrence have been found associated with EWB scores.

✓ Women belong to younger age categories showed comparatively low scores than women of the middle age. Older women also showed lower EWB scores.
than the middle aged women. Majority of the woman below 40 years had lower EWB scores than of woman in the range of 40-60 years.

- Higher EWB scores were shown by the women who changed the nature of their previous job. Women who were not able to work for a long time; as well as those who were able to do the previous job also reported higher EWB scores as compared to women who are on leave or lost their job due to illness and treatment.

- Marital status was another factor which was found to be associated with higher EWB scores. Married respondents showed higher EWB scores than all the other categories. Absence of spouse is associated to EWB in women with BC.

- Ongoing treatment and comorbid illness were the two factors found relevant in connection with emotional well-being of the respondents. Majority of the respondents from each treatment group belong to the medium EWB score range. 17.5% of the total respondents who are undergoing chemotherapy and 7.5% of the participants who were undergoing radiotherapy have shown high EWB scores.

- Among the high EWB score categories, majority 85.29 % (within total participants in high score category) did not have any comorbid illness. Most of the respondents who do not have any other illness have shown better (medium and high) EWB scores.

- 77.5% of the respondents belong to medium SpWB category (17-32), 22.5% have high score range (33-48) and 15.8% belong to Low score range (0-16).

- Ongoing treatment is found to be associated with spiritual well-being of the respondents. Among the high score category, 22.58% (within the total women
undergoing radiotherapy) have shown the highest SpWB scores as compared to other treatment modes.

### 7.3.b. Domains of well-being and HRQOL of the Women with BC

- **Physical wellbeing:** This study found that physical wellbeing has strong positive association with functional well-being, total outcome index and the total quality of life of the women with BC.

- **Social well-being:** A strong positive association is found with emotional well-being (r=.739) and the overall HRQOL (FACT-G; r=.699 and FACT-B; r=.607) of the women with BC. Breast cancer concerns and total outcome index is positively correlated with social well-being of the respondents.

- The significant association between social well-being and emotional well-being of the respondents indicates the importance of social support in order to have better emotional well-being among women with BC.

- **Emotional well-being:** Emotional well-being scores of the respondents have shown a significant positive correlation with SWB and the total scores; FACT-G (.788) and FACT-B (.729). PWB (r=.354), FWB (r=.432), BCS (r=.504) and TOI (r=.473) showed a moderate correlation.

- **Functional well-being:** Result show strong positive correlation between FWB and the subscales- PWB (r=.792) and BCS (r=.812) as well as with the total scores TOI (r=.925), FACT-G (r=.818) and FACT-B (r=.857).

- It is evident from the results that functional well-being is significantly associated with physical aspects and breast cancer specific concerns of well-being.

- **Spiritual well-being:** No significant statistical correlation was found between spiritual well-being scores and quality of life scores. Most of the participants
were in an ambiguous emotional state to relate their spiritual concerns with quality of life.

✓ **Breast cancer concerns:** A strong positive correlation between BCS and the subscales - PWB (r=.764) and FWB (r=.812) as well as the total scores; TOI (r=.944), FACT- G (r=.789) and FACT- B (r=.902) have observed in this study.

✓ EWB (r=.504) and with SWB (r=.332) showed a moderate positive correlation with BCS scores of the respondents.

✓ Breast cancer specific concerns of well-being are observed as very significantly associated with all the subscale scores except SpWB.

✓ **Total Outcome Index:** TOI scores of the respondents have shown a strong positive correlation - BCS (r =0.944), FWB (r = 0.925) and PWB (r = 0.908).

✓ The subscales – EWB (r = 0.473) SWB (r = 0.300) are moderately positively correlated to TOI score of the respondents.

✓ Results show that the total outcome is mainly determined by the physical, functional and disease specific aspects of the women with BC; however emotional and social aspects are associated positively to the total outcome index.

✓ **FACT-G (General):** Strong positive correlations are found between FACT G and- BCS (r= 0.789), FWB (r= 0.818), EWB (r= 0.788), SWB (r= 0.699) and PWB (r= 0.789). Correlation coefficient between FACTG and TOI (r= 0.859) and FACT- B (r=.977) proves the existence of a significant correlation between the total HRQOL scores.

✓ **FACT-B (Breast cancer specific):** Strong positive correlations are observed with FACT B as- with the total scores; FACT-G (r= 0.977) and TOI (r =
0.932) the subscale scores - BCS (r= .902), FWB (r = 0.875), EWB (r = 0.729), PWB (r = .802) and SWB (r= 0.607). Result of this study did not show significant correlation between FACTB and sub scale score SpWB.

Therefore, this study says all of these domains of well-being except spiritual well-being is impacting overall HRQOL of the women with BC.

7.4. SUPPORTIVE CARE NEEDS

Key issues and concerns of women with BC associated to various types of their SCN

7.4.1. SCN and physical concerns

✓ Needs related to management of disease related physical issues and treatment side effects are one of the most reported need for managing the symptoms and treatment side effects of BC.

✓ Women who underwent mastectomy reported the need of physical assistance to help them in managing the pain and communicating and ensuring the care when are on bed. The pain they feel is also associated with anticipation of death, adapting to an illness other than the physical pain experienced in any surgery.

✓ Availability of family caregiver is complicated by certain other needs of the family in concern with the treatment of the women with breast cancer especially the financial and employment needs.

✓ Factors like family dynamics, absence of care giver availability, physical weakness are complicating the need for assistance in women with BC.

✓ Most reported physical needs were related to chemotherapy.
The information from the other patients and their experience of coping were reported as really helpful for better coping.

A few women with BC is observed as preferring much comfortable or informal ways of collecting information related to coping with treatment side effects and verifying that with the treatment professionals.

Participation in treatment decision is observed as following what doctors are saying or believed as saying yes is the right way of participation. A few women preferred to experiment with other treatment methods like Homeopathy or Ayurveda for managing the side effects.

Women were relaying 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 it not completely addressed.

Limited or restricted physical activity and disability because of surgery was a great issue for women with BC.

Reaching and knowing about the care providers whether it is hospital, or other people like NGOs or voluntary organisations was a challenged reported by women with BC.

Although the kind of assistance patients need is available in the hospital but lack of staff and increased number of patients requesting the same service became an important hurdle in getting assistance at the time of need.

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. High expenses for the transportation as they hire because of the physical weakness becomes another issue for them.
✓ Lack of free/concession in the expense of travel not available with mostly using public transport system- buses but limited to trains where as several women reported that train is not the easy mode of transportation from their places.

✓ In certain areas, lack of geographical coverage of expansion of the services of palliative care clinics was an issue in getting support; and in such places, availability of caregiver to take them to the clinics are situated were another issue.

✓ In concern with communicating the physical needs, the patient is reported as not accessible to the details of the illness as the family conceals the information as part of their concern. When it comes to a critical illness, it is observed that women also accept the decision of husband though she wants know and communicate directly; but this becomes a hindrance for her to know more about her illness, communicate her physical issues and find more support in this regard. Doctors’ lack of time to discuss with patients is also reported as a challenge in communicating the needs.

✓ physical issues related to the space is also shared by the women with BC as they spend more time as- the issues of monotony, being in bed, restricted mobility outside the houses were certain things causes the physical exertion. Lack of awareness about the physical issues related to long term stay on bed is another reported issue by the women.

7.4.2. SCN and Psychological concerns

✓ It is observed that the reasons for anxiety and fear vary among women with BC over different phases of the treatment and the stages of the disease.
Fear and anxiety were the major issues of women who were undergoing chemotherapy. Though most of the women talked about their anxiety about illness related issues, thinking about family without them and financial sources for the treatment were observed as their worries more than their illness and existence.

In different ways, women shared their adjustment to the illness, not in a defined process of coping but 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’.

Narratives of women with BC in the perspective of metastasis showed that their major concerns were less hopeful future of cure and the future of their family.

Concerns about altered body by mastectomy were as the most stressful experience shared by several women with BC.

A few women with BC reported that the actions they took in order to readjust to have self esteem were causing more distress.

Women shared their 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 be playing 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’.
7.4.3. SCN and Social concerns

✓ Gendered family roles were a disturbing factor reported by women with BC like male counterparts are doing cooking, washing, taking care of children and so on.

✓ Financial contributions to the family, being in brother’s home, dependency are certain reported issues. 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. Emotional trouble associated with physical and financial dependency on maternal home is also found as distressing.

✓ Beliefs that functioning or being productive is one of the essentiality of existence by a few women with BC.

✓ All the interviewed women with BC expressed their concern of coping with cancer cure or their existence; in relation with the future of their family.

✓ Dealing with the conversations on illness is reported as the most challenging social experience of women with BC. Insensitive comments, conversations about illness and treatment were shared as 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.

✓ Financial need is observed as a constraint and a base factor on which other concerns and needs were built upon. Wage loss and indirect cost is also mentioned as financial concerns they face. Cost of investigations, treatment, indirect costs, wage loss of the family were the reported cost related to their 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 they are ineligible for concessions and other support as per the required documents; but facing 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.

7.4.4. SCN and Spiritual concerns

Most of the participants expressed their belief in destiny, fate and God’s will; in relation to their diagnosis. 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.

A few women with BC reported that they believe Karma (result of their work) is the reason for their illness. 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 belong to Islam referred will of God as ‘Al Qadar’ (Allaah has decreed everything happens).

‘Fulfillment of dharma’ is observed as using by the women with BC 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 by a few women with BC as a spiritual way of coping with the distress related to the illness.

Increased faith and religious activities, meditation as a help to feel good about life and prayer as the only solution were certain spiritual ways of coping shared by the women with BC.

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 faith in God, angry on God’s decision is also accounted by the respondents.

Concerns about death and afterlife, diversity of religious teachings and practices were observed as certain areas of challenges in order address the spiritual concerns of women with BC.

The thoughts about the rest of the time and death is shared by one women with BC as improved her way of looking at life and increased her threshold to do better things in the remaining time as- thinking good and doing good.

7.4.5. Informational support needs

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.

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.

7.4.6. Health care system delivery needs

Partaking in care, decision making and information availability – one of the commonly reported issues were related to the direct communication from the treatment professional’s part. 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.

Adequacy of information (diagnosis, treatment and Investigations)- lack of clarity about the needed information is also another area of concern of women with BC. Departmentalisation 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.

Opportunity to have discussion with treatment professionals (ask questions) was another issue related to information gathering in the hospital. Lack of time
of the treatment professionals to discuss with the patients is one challenge shared by the women.

✓ Women from certain regions like Idukki, Wyanad, and some other places reported their issues in accessibility of care and support as the limited nearby treatment facilities. Long journeys, weakness, expenses for treatment were added problems to that.

✓ Support for transportation to and fro hospital was a major concern of a few women with BC.

✓ Provision of equipments (prosthesis), aids and appliances as 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. Especially continually changing the team of treatment professionals often reported as the repetition of the experience become stressful for patients.

✓ Need for a hospital based system for co-ordination with service programmes and referrals to the voluntary organisations or NGOs is one of the most reported needs by women with BC.

Keeping all these findings of this study especially on supportive care needs in mind, a model for Hospital based Supportive care system is proposed and explained in the later section.
7.5. Suggestions

Proposition of a Hospital Based Supportive Care Programme Model

The journey of the researcher through the experiences and expression of needs of the women with BC which are unmet or without optimum support or without finest coordination, drove towards a supportive care model which would be addressing Kerala’s socio-cultural as well as health care delivery context. Findings of this study suggested the needs of the women with BC to be addressed. This model stirs towards coordination of all the available services for addressing the unmet needs and also gives indications for Social work profession to intervene.

Overview of the model

Figure 7.1 explains an outline of the model for hospital based supportive care programme. It has three major elements described as follows-

1. Departments of the cancer specialty hospitals- These are the treatment based departments such as- radiation oncology, surgical oncology, breast cancer clinics (OPD) etc; already established and functioning in almost all of the cancer specialty hospitals in Kerala.

2. Supportive care coordinating team- A team of social work professionals are needed to network with different support systems existing inside and outside the hospital. This team can have an advisory committee constituting expert multi-disciplinary professionals and representatives from the state and NGOs who work for the better support delivery for cancer affected persons. The supportive care team is designed as a part of the Social Work department of the hospitals. A Medical Social work Department is needed to be established in all the cancer specialty hospitals as a mandate for better service and support.
3. **Support Service Pool**- Different support services are functioning in relation with cancer care hospitals. However, the identified need for coordination of all the available support services and the understanding of unmet needs leads the researcher to use the term- ‘support service pool’. ‘Support service pool’ is the consolidated picture of all the support services available inside and outside the hospital and make it available for the people with cancer. Seven consecutive elements are included in this concept.

i) **Treatment teams**- including all the multi-disciplinary treatment professionals of the various departments inside the hospital.

ii) **Hospital authority**- the decision makers / board of the hospital.

iii) **Psychological care wing**- a psychological care wing should be established in order to provide psychological supportive care more than individual counselling. A multi disciplinary psychological care team has to be organized in the cancer specialty hospitals.

iv) **Social support wing**- The medical social work department and public relation department of the hospital can constitute this wing.

v) **Orison suit**- This is a space defined to address spiritual concerns of the persons with cancer. Considering the diversity of religious beliefs and its association with spiritual concerns; this place can include various provisions and programmes.

vi) **Information outlet**- this wing is designed to address the information needs of the persons with cancer, directly or by networking with other wings and support bank.
Figure 7.1 Outline of the model of hospital based supportive care programme.
vii) **Support bank:** the term support bank is used to describe the consolidation of all the support services available from hospital, Government, NGOs and voluntary organisations. This unit is designed with a purpose to function in collaboration with the supportive coordinating team; for the provision of necessary services by networking with various stakeholders at the time of need.

Inspired by the findings of this study and discussion with treatment professionals, model coordinating programmes for addressing various needs of the women with BC is proposed below-

1. **A model of Physical supportive care coordination plan**

Figure 7.2 explains a model for coordinating the physical supportive care needs of the women with BC. As the diagram says, a woman with BC can approach supportive care coordinating team directly or by the reference from treatment departments or information outlets; and communicate their needs. After assessing the needs and provision of services, the coordination team can help them either by providing direct support or by referring to appropriate service wings.

Apart from networking with the other wings; programmes like- survivor’s talks, provision of information -leaflets/videos, training the volunteers in collaboration with colleges and voluntary organisations, group therapies, specifically designed Exercises and game based activities can be included in the physical supportive care coordination programme. Volunteers for Physical assistance, provisions for food/ stay, transportation help for the needy, help in getting financial assistance from Government and other sources, provision of prosthesis are certain things to be included from the support service pool.
Figure 7.2. Physical supportive care coordination plan
2. **A model of Psychological Supportive care coordination plan**

Figure 7.3 explains a model for coordinating the psychological supportive care needs of the women with BC. As the diagram depicts and also mentioned in the previous section, women with BC can approach supportive care coordinating team directly or by the reference from treatment departments or information outlets; and communicate their psychological needs. After assessing the needs, the coordination team can help them either by providing direct support or by referring to the psychological wing.

The psychological wing can provide services including- information -leaflets/videos, individual and family counselling, survivor’s talks, group therapies, interventions based on needs and game based activities etc. Volunteers can be trained in order to address certain psychological issues related to social support. In coordination with spiritual care; meditation, Yoga, music therapy, spiritual counselling can be arranged according to the demands of the persons with cancer. Informal visits of treatment professionals, programmes focused on sharing and caring like professionals-patient care cells groups for hospitalized women with cancer, survival care group can be included in this programme.

3. **A model of Social supportive care coordination plan**

When women with BC approach the supportive care coordinating team directly or by reference, this coordination plan can be activated. Supportive care coordinating team is designed to act as a bridge between the needy and the services. Figure 7.4 describes the proposed model for action plan concerning social support.
Psychological supportive care coordination plan

- **Service bank**
  - Volunteers for cultural programmes
  - Referrals to the psychological support groups
  - Financial support
  - Government programmes
  - Provision of prosthesis, wigs

- **Information - leaflets/videos**
  - Training the volunteers
  - Individual/family counselling
  - Survivor’s talks
  - Group therapies, interventions based on needs
  - Specifically designed exercises and game-based activities

- **Coordination of spiritual care**
  - Meditation
  - Yoga
  - Music therapy

- **Multi-disciplinary treatment team/at different departments**
  - Including psycho social care professionals

- **Informal visits of treatment professionals**
  - Sharing programmes like professionals-patient care cells or survival care groups
  - Follow up care

- **Supportive care coordinating team**

- **With psychological supportive care needs**

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**Figure 7.3 Psychological supportive care coordination plan**
Figure 7.4. Social supportive care coordination plan

Social supportive care coordination plan

- Information outlet
- Supportive care coordinating team
- Multidisciplinary treatment team at different departments

- Service bank
- Social sensitization for cancer care
- Media partnership programmes
- Financial support programmes

- Social support groups
- Corporate partnership in cancer care

- Community partnership/volunteers programme

- Survivor groups
- Link with in hospital care - psychological, spiritual and information wings
Requirements and expected challenges for the implementation of the model

✓ Finance for the implementation of the action plan.
✓ Excessive training for the professionals, volunteers and stakeholders.
✓ Sensitising the professionals in order to have a strategic shift from bio-medical care to holistic care.
✓ Establishment of the necessary elements for the implementation.

Other Suggestions

✓ Apart from the information outlet, a self-run computer system can be launched in the hospitals for providing necessary information and info booklets can also be published.
✓ Oncology Social work should be a part of social work curriculum and necessary steps should be initiated towards establishment of medical social work departments by the social work educational institutions.
✓ Holistic care propositions are necessary to be made towards the draft of National Cancer Policy.

7.6. Limitations of this study

Translating the extremely sensitive emotions of women with BC towards the objectives of the research was the utmost difficult task and limitation of this study. As this study was focused on hospitalization phase, other phases that women go through such as- at home, work place, follow up period and later cancer stages are not included in understanding the HRQOL and SCN. Views of various stakeholders in supportive care were not possible to be included; is another limitation apart from the challenges faced at the time of data collection.

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7.7. Implications for future research

✓ Experimental research can be conducted in order to check the effectiveness after implementing the proposed supportive care model.

✓ As family members of cancer patients are considered as the second order patients; future studies are needed to understand the ramifications on them as well as their needs for support.

✓ Though, nine nuns were met at the course of this study, this study did not focus on them. A few studies have come across the world but not in India; were studying breast cancer prevalence among nuns; especially in Canada, where breast cancer was called as Nun’s disease from 14th century. In this context, further studies are needed to investigate the causes in terms of risk factors- whether as an organised group of unmarried women or any other factors are involved.