

CHAPTER 6

Conclusion and Suggestions

"Imagination is more important than knowledge. Knowledge is limited. Imagination encircles the world."

- Albert Einstein (1879-1955)

Grounded theory is a respectful methodology in which the participants' views are sought, listened to and valued (Crooks 2008). The aim of this study is to understand the psychosocial experiences of women with breast cancer from diagnosis to two years post mastectomy. When the interviews and analysis begin, it becomes clear that the symptoms and diagnosis of breast cancer and the subsequent treatments have resulted in the phenomenon of perception of threat to self in women which necessitate coping through various strategies. Thus perception of threat to self and coping is emerged as the basic psychosocial experiences of women with breast cancer. I believe that the unique contribution of this study is the retrospective experience of young women with breast cancer at their reproductive age. The coping strategies are evolved throughout the cancer journey according to the demands created by the disease at different stages as well as the intervening conditions present both within the inter-personal and the intrapersonal environment of the survivors.

Enriching the existing knowledge about the impact of breast cancer on femininity as well as coping with cancer, the theory I propose sheds light on the phenomenon of amputated femininity of Indian breast cancer survivors, thus signifying the importance of contextualizing the socio-cultural influence on women's breast cancer experience. This new perspective will serve to increase understanding of the disease process among this population.

Implications for Intervention

Cancer has traditionally been conceptualized as an acute illness (Tritter and Calnan 2002), but when the acute nature of the illness ends in the hospital after cancer treatment is over, the chronicity begins in the form of consequences of diagnosis and treatment of cancer. The chronic nature of the disease, the treatment procedures, and the expenses involved is high. Further, it has an impact that is life threatening, disfiguring with sexual, emotional, and familial implications, and this calls for a multi-faceted approach to provide a comprehensive

psychosocial management of the disease. The in-depth analysis of the lived experience of the participants provides an evidence base for the researcher to develop this intervention package that aims at helping women with breast cancer. This intervention package can be used in a hospital setting to help women enhance their quality of life – the physical, mental and social well being, during and after treatment of cancer within their socio-cultural context.

Significance of social work intervention:

Every medical team consists of different groups of professionals, taking care of diverse needs of the patient. In the field of Oncology there are different groups involved in delivering health care. The team includes surgical, medical and radiation oncologists, nurses, physiotherapists and other para-medical professionals. Everyone has well defined areas to address. As per the study, a hospital gives importance mainly to the treatment and clinical aspects of the disease. The participants in this study report multifaceted problems, especially with respect to the psychosocial consequences of the diagnosis and treatment (such as mourning the loss of breast, femininity, concerns about changed appearance while in public, sexual changes and physical as well as sexual intimacy between partners, concerns as a mother, concerns about the social attention towards the disease and breast loss, economic consequences of the treatment and fear of recurrence) of women with breast cancer. But according to the participants, a professional is not available to address these issues.

In such a context, a person responsible for addressing the social and psychological ramifications of the disease is required at the hospital. A social worker with his/her knowledge regarding psychosocial aspects of the disease can help the patient in meeting the above mentioned concerns. The principles and values of social work profession, which emphasize individuality, non judgmental attitude, confidentiality, respecting the worth and dignity of the individual and acceptance will enable the social worker to understand the patient as a person with varied needs and concerns. Hence the role of a social worker in working on such issues is not only imperative but also helps to promote healing. Thus a team approach would be significant in dealing with the problems faced by women and family members, especially partners and children, in dealing with the consequences of the disease in their personal, interpersonal as well as social life.

Focus of intervention:

The focus of the intervention is not only the woman with breast cancer, but also her family and the community in which she lives. The researcher's work experience as well as the present study suggests that cancer care is often restricted to medical, surgical, and radiation Oncology and does not involve the physical (breast loss, sexual changes as well as the concerns of women about the appearance after treatment), psychological, social, rehabilitative and preventive aspects of the treatment. She is considered as a patient and not as a person with diverse and multiple roles, meaningful relationships, emotional concerns and needs, fears, doubts, dilemmas and misconceptions about the disease and treatment. A medical social worker can bridge this gap and ensure that comprehensive attention and intervention is provided to the patient and her social support system. So, this intervention package is aimed at the woman and her family in a hospital setting to ensure that, the social and psychological concerns of the patient are addressed, coping skills are enhanced, and also to empower the resilience and enduring capacity of the individuals and family members (significant others) in dealing with the demands created by the disease at various stages of its journey. The Medical Social Worker can also coordinate the hospital team to take initiatives at the community level to implement interventions focusing on women regarding primary, secondary and tertiary stage preventive measures of breast cancer.

Psychosocial assessment:

The experience of diagnosis and treatment is intertwined with significant psychological distress in the participants. The psychosocial concerns and needs of women vary with different stages of treatment. The analysis reveals that, in the absence of medical social workers, the psychological issues of the participants are not dealt adequately by the health care providers. Understanding the psychosocial needs of each individual is crucial in providing psychological support to ensure the effectiveness of medical care. A comprehensive psychosocial assessment of the patients in the socio-cultural context of Kerala, will provide relevant information about the patient; personal details (demographic details, occupation, education, personality related information, history of past and present illness, predisposing risk factors), family dynamics, spiritual beliefs and social support systems including personal as well as material and economic resources available to the cancer care.

The psychological factors such as patient's and family understanding of the disease and reactions to diagnosis, possible risk factors such as suicide or homicide, the meaning a woman attaches to her breast and thus her (and partner's) concerns about her appearance and sexuality need to be addressed in order to ensure adequate psychological care of the treatment. The woman's perception of the cultural aesthetic value of her breast is another area which needs to be assessed to ensure that supportive techniques are tailored to help woman combat the aftermath of breast loss. The spiritual orientation linked to their religion is a strong influencing factor in dealing with a life threatening disease like cancer. It is important to assess the spiritual/religious interpretation the woman and her family members have about the diagnosis, the coping strategies they undertake to deal with the distress of the disease, since spiritual coping can have both constructive as well as destructive consequences in cancer experience. A social worker can conduct a psychosocial assessment prior to the patient's consultation with the Oncologist.

Intervention:

Based on the psychosocial assessment, social worker can plan intervention strategies which would be reassessed at each stage of the treatment and prognosis to address the specific concerns and needs of participants. The intervention package includes the following:

Application of social work methods in Psycho-Oncology:

Different social work methods such as case work, group work community organization, social action and social work research can be applied to interventions in the field of Psycho-Oncology in a hospital setting.

Working with individuals - case work:

This method of social work is a direct one to one relationship where individuals are helped to cope more effectively with their psychosocial problems associated with diagnosis and treatment of breast cancer. The various psychological reactions of the research participants on hearing diagnosis are in the form of shock, denial, violent spell of anger, blankness, helplessness, lost feeling, feelings of 'why me', loneliness, and feeling ruined. This can be effectively addressed through guidance and counselling, leading to better treatment outcome, compliance, well being of the patient and family. A social worker can make use of case work method to assess the financial crisis, occupational readjustment of the patient and family

problems associated with disease to assist the patient in exploring and mobilizing resources from patient's own social support systems to ensure sustainable patient care.

Onco-education:

Participants report lack of resources to educate themselves in terms of their cancer specific concerns and needs during diagnosis and treatment. Information about various aspects of the disease (such as stage and prognosis) and treatment (the severity of side effects and its consequences in the physical as well as sexual domains of the individual) can be very beneficial to the patient and family. This can be provided in various ways; through interactive classes, poster exhibitions, printed materials such as brochures, audio-visual means, discussions and query sessions with experts. Patient education regarding breast reconstruction as well as ensuring health care providers attention to this unmet needs can be advocated by social worker. Making oneself aware about the disease and treatment is important to enable the individuals and significant others to accept the diagnosis and to remove the uncertainty one face in the treatment process. Family members and patients must also be involved in the decision making process of treatment.

Counselling:

The diagnosis shrouds individuals and significant others in a multitude of psychosocial issues associated with the disease. The individual counselling sessions using different therapeutic approaches such as Rationale Emotive Behaviour therapy (teaching the client to dispute the irrational beliefs, especially unfounded health beliefs about disease or treatment to substitute logical and rational beliefs in order to enable her continue treatment from the initial shocks of the diagnosis) as well as Cognitive –Behavioral therapy (helping the client to identify distorted thinking that causes emotional discomfort and behaviour such as interpreting diagnosis as punishment by God), Solution Focused Brief Therapy (for solving current psychosocial problems of diagnosis and treatment through the identification of resources from the client's own personal as well as social support systems) Neuro Linguistic Programming (NLP - by enabling the client to remodel her preconceived negative psychological construct about the disease or treatment). Religious beliefs or faith can also be used in order to provide the client hope for the best to undergo treatment in NLP and crisis management (to handle the acute emotional constraints during diagnosis and treatment phase) a short term helping process and supportive techniques such as allowing the patient to

ventilate the emotions and feelings, helping the woman to identify resources and prioritize her concerns and helping her accept breast loss and consequent physical changes.

Providing spiritual and religious support is another dimension of supportive therapy in cancer care. In the present study, the spiritual beliefs drawn from the participants' religion were found to have a strong influence on the coping process with the experience of breast cancer. Since spiritual coping can have both positive and negative outcomes, it is important that the social worker needs to assess the religious or spiritual interpretation and coping of woman with diagnosis, treatment and prognosis of the disease. In order to maintain and enhance hope and positive thinking, religious beliefs of the patients can be used. In the Indian context, people have strong spiritual orientation based on their religion. A social worker with the knowledge regarding the role of religion and spirituality in enhancing the personal coping skills of the patient can make use of the facilities such as halls for conducting prayer sessions particular to religion, with the help of principles and techniques of spiritually sensitive social work practice. Survivors of breast cancer can also be included in leading the session by citing how they could use religion and spirituality in seeking comfort to themselves during their journey with the disease.

Liaison:

By meeting patients and family members regularly, a social worker can act as link between patients, family members and treatment team. This facilitates a more open channel of communication between patient and medical team. Lack of personal attention from the doctor due to time constraints is a major issue reported by the participants during follow up. This is found to add to psychological distress since the participants believe that a quick physical examination by the doctor might leave their symptoms of recurrence unobserved during their follow up. Such kinds of dissatisfaction can be put forth or communicated to the health care team by a medical social worker who would help to alleviate psychological distress associated with medical care.

Resource Mobilization:

Armed with the strong belief that the community is an oasis of resources (Saleebey, 2002) the social worker makes an attempt to network with various sources of support within the community. S/he also encourages and empowers the patient to identify resources in the

community on their own. This can help them to meet the varied needs like finance, social support, accessing health care, and rehabilitation.

Rehabilitative Services:

Its purpose is to ensure that, the support provided by the medical team continues in the psychological and social milieu of the patient and her family. Rehabilitation of woman after the completion of the treatment enables her to function at a pre-cancer comfortable level. Follow up care and support is essential for ensuring this. The family members must also be oriented about the importance of rehabilitating the client as per her own convenience and comfort level (for example enabling the woman to use breast and hair prosthesis to continue her professional and social life or environmental modification such as helping the client to find another job or change the previous dressing style). It will provide psychological support while the client is back to the life after treatment.

Discharge Planning:

A social worker can assist in discharge planning process where necessary arrangements can be made to ensure sustainability of the supports provided by the medical as well as psychosocial dimensions of the treatment. Treatment compliance and regular follow ups can be promoted by a well chalked out discharge plan. A social worker, by building an effective rapport and strong therapeutic alliance with the participants, enables them to achieve it.

Table 6.1 gives the description of the strategies which can be used for individual care:

Table 6.1

Individual Intervention Strategies

Type of distress	Specific strategy to address the distress
Existential threat	Onco-education about the cause, nature and prognosis of the disease and treatment counselling the client with appropriate therapeutic techniques such as REBT, CBT, SFBT and NLP, providing religious or spiritual support and arranging experience sharing with breast cancer survivors.
Financial difficulties	Resource mobilization from the client's own social support systems, referrals to community resources and available health

	insurance policies and concessions for transportation.
Physical problems	Onco-education about the side effects of chemotherapy and surgery, referral to physician, physiotherapist, dietitian and Oncologist.
Emotional distress	Understand the meaning client attached to the breast and disease, sensitivity towards cultural aesthetic value of breast and stigma, listen to the specific physical concerns regarding change in physical appearance due to breast and hair loss, ensuring female staff during physical examination by a male Oncologist or physician, using therapeutic techniques to challenge negative mental constructs and cognitions about chemotherapy, cancer and physical changes and providing relaxation techniques such as yoga, meditation and prayers.
Sexual changes and psychological distress due to changed physical appearance	Onco-education about the side effects of chemotherapy, fertility issues, encouraging open communication about the sexual concerns of women, referral to sexologist (if needed), introducing woman to breast prosthesis or reconstruction facilities, combined and separate counselling sessions with partners, experience sharing with the survivors, conducting support groups and role plays.
<p>A Wellness Recovery Action Plan (WRAP) can be used for overall approach to treatment and progress towards recovery (Copeland 2004). WRAP is a self-management program whose goals are to help participants acquire new skills and information to better manage troubling symptoms, reduce personal risk factors, and achieve higher levels of health, wellness, and functioning. Participants identify internal and external resources for facilitating mental health recovery and promoting health. These resources are then utilized as "tools" to create an individualized plan for successful living. WRAP can be used for women to develop a personal Wellness Tool Box consisting of safe, free, or low-cost self-management strategies such as healthy diet, exercise, medication, self trials with breast and hair prosthesis, relaxation techniques such as yoga and meditation.</p>	

Working with Groups:

This method of social work develops relationships among patients through group activities. Support groups can be formed in the hospitals for patients at different stages of their treatment such as diagnosis, treatment and follow up. The study participants reported that sharing their concerns with others who had breast cancer helped them stabilize their own distress. The feeling that there are others in the same journey that one is not alone provides women comfort and solace. The group sessions can be conducted during the waiting time in the outpatient department which is often spent idly instead of being put to constructive use. Support groups of children of mothers with cancer, survivors group, family members group, especially husband (spouse groups), will reduce their anxiety and related emotional distress. The group sessions with people who share similar experience provide them a space to share their doubts, concerns and distress with others and share notes. Group therapies can also be conducted for mourning loss of breast, femininity, and changed physical appearance. Survivors can be used to address the concerns such as loss of breast, femininity, and changed physical appearance.

Needs and concerns of the family members of the patients can be addressed by conducting group sessions using survivors and their family members. This will help the partners and children of the women in identifying techniques used by survivors and their family members in dealing with the demands created by the disease and treatment at different stages. This may also help in creating a support network among the family members beyond the hospital premises. This network will help them in seeking support through home visits and phone calls.

Community Outreach Programmes:

Patient care should not be limited to the hospital premises but should extend to the larger community. Health care providers should reach out to the people in order to help them in early detection of the disease and thus ensure good prognosis and a better quality of life. Departments of Community Medicine in hospitals is essential to launch these kinds of initiatives where a multi-disciplinary team can work together for conducting medical camps, awareness programmes, and resource mobilization strategies. The department can mobilize women peer educators from Self Help Groups (SHGs), for example, 'Kudumbasree' units of each ward of the panchayath in different districts of Kerala, and they could provide awareness to women regarding Breast Self Examination (BSE), need for early detection and

treatment, in each household. Women peer educators are important since the site of the tumor is sensitive for a woman. The patient, family and community will respond positively due to the sense of community responsibility that the organization has shown. Early identification of symptoms, and need for participating in breast cancer screening programmes can be inculcated in women through such programmes.

Community sensitization programmes are of prime importance to reduce the social stigma, discrimination and disbeliefs about breast cancer prevailing in the society which prevent women from seeking early treatment. The hospital team can take initiative to observe 'breast cancer'- day/week/month/year to propagate the primary, secondary and tertiary level preventions targeting women in different domains such as house wives, IT professionals, teachers, health care providers, teenage students, middle aged and old aged women. The hospital can tie up with residence associations, religious institutions, local or national clubs, NGOs or professional unions at work place for targeting different groups of women. Regular publication in mass media about the disease, treatment and prognosis, experience sharing with survivors, and research update is another mode of community sensitization.

Preventive Services:

Preventive Oncology has special importance in Kerala, since there is high prevalence and alarming increase of breast cancer. Provided the disease is largely preventable, if adequate, appropriate and timely awareness, intervention and care are provided. All stages of prevention such as primary, secondary and tertiary level can be applicable extending its scope from awareness programmes to early intervention to breast loss prevention (if detected early, lumpectomy can be preferred over mastectomy and thus can prevent breast loss).

Research:

The psychological, social and financial needs and concerns of individuals and family members vary over time, which should be regularly researched and the findings can be used for designing interventions and also published for wider consumption and dissemination. Based on that, the hospital can modify their intervention strategies periodically to comprehend the current changes in the psycho-oncology field. Such studies can also be utilized as making the clinical practitioners understand and recognize the psychological and social needs of patients in receiving Oncology treatment. Experimental research can be conducted using the interventions that have been developed. This will throw light on the need

of addressing the psychosocial issues of the women and family. The effectiveness of the intervention will also be revealed through the studies. This will provide evidence base for the profession, which will result in acceptance of medical social worker as an integral part of the Oncology team in every hospital. Training of health professionals who will deliver psychosocial intervention is another target area for intervention.

Social action:

By involving the stake holders, efforts towards sensitization and collectivization can be made to highlight the social issues that survivors face, such as confronting social stigma attached to the disease and the feeling of aesthetic humiliation due to breast loss. Through such an action, it would be possible to act and reflect upon the actions and thus a methodology can be evolved gradually for addressing the social, psychological, familial and economical problems that are being countenanced by the survivors.

Policy implications:

Social work interventions need to be implemented as mandatory for Oncological care in Kerala since the psychosocial aspect of the treatment left untreated in their absence.

The revision of social work curriculum in Kerala, especially regarding the specialization of the profession, ‘medical and psychiatric social work’ is of urgent concern since the syllabus does not adequately address the disease, its treatment, rehabilitation and the role of social worker in the field of Oncology. Students who specialize in medical and psychiatric social work must also be sent to hospitals with Department of Oncology to provide themselves with the basic knowledge about the field.

Health care insurance should be broad enough to cover the expenses towards the treatment of breast cancer treatment since majority of the patients cannot afford the expensive treatments in private hospitals in Kerala.

The ethical principle of ensuring the dignity and worth of individuals throughout the treatment regimes is of great importance while addressing sensitive issue like breast cancer. Participants outline the influence of the gender of medical professionals in dealing with the disease of the woman’s sensitive organ. They are not psychologically comfortable consulting male doctors since the organ involved in the disease is the breast. This is a major factor which prevents women from seeking diagnosis at an early stage since they feel ashamed of

consulting male doctor for their health concern regarding their for breast. The experiences of feeling embarrassed and ashamed can be minimized with the presence of female staff during the physical examination of the breast by the physician. Such personal problems can be advocated by a social worker to ensure the presence of a female staff during physical examination. The clinicians (especially male) must be provided with adequate assistance in dealing with breast cancer to ensure dignity and avoid embarrassment to women in the male dominant Oncology field in Kerala. The right to know one's diagnosis is also an important ethical aspect of Oncological treatment that the health care providers need to be taken care of in their interaction with patients and family members. This also necessitates a healthy relationship between the doctor and the patient. During such a revelation of the diagnosis, the social worker must be definitely an essential member of the treatment team.

By considering all these, a transdisciplinary team approach is strongly recommended since the approach ensures the full participation of the family members starting from the point of diagnosis, decision making on treatment and the rehabilitation of woman after treatment. In a transdisciplinary team, the patient and her family members along with the professional health care team conduct comprehensive assessment and develop service plan based upon family priorities, needs and resources. The line of communication is regular and continuous due to periodical meetings of the team with the patient and her family members (Woodruff and Hanson 1987).

Centers on the lines of Voluntary Counseling and Testing (such as ICTC – Integrated Counseling and Testing Centers for HIV/AIDS) with women counselors can be set up in different districts to provide basic information about symptoms, risk factors and Breast Self Examination or Breast Examination by Physician, leading to diagnosis at an early stage. Woman who has a doubt or concern about symptoms can approach such counselors leading to early diagnosis and thus a better prognosis.

Palliative care units can also be initiated at each district which should ensure free delivery of medicines and palliative care.

Table 6.2 represents the above discussion in a nutshell:

Table 6.2

Stake Holders and Programmes of Intervention

Stake Holders	Programmes
Individuals	Work with individuals – Onco-education, counselling, resource mobilization and rehabilitative services.
Group	Work with groups – Support groups and Onco-education groups with women, children, family members, spouses and survivors, involving the family in decision making process of treatment, and resource mobilization
Community	Primary, secondary and tertiary prevention strategies, resource mobilization, palliative care units and referral services for clients.
Policy Level	Making Departments of Social Work, mandatory in hospitals with Department of Oncology, ensuring dignity of patient care, ensuring female staff in physical examination of patients, disclosing diagnosis to patients must be considered as an ethical responsibility of the health care providers, revision of social work curriculum to address the requirements of social worker in the field of psycho-Oncology.

Suggestions and Implications for Future Research:

- The propositions emerged from the study can be empirically tested through further studies using quantitative research approach.
- Experimental research can be conducted with the intervention package proposed in this study to assess the effectiveness of the same.

- The family members especially spouse and children are found to be undergoing the similar emotional ramifications of the disease and treatment along with survivors. Future research is needed to obtain deeper understanding about the experiences of children and partners of women with breast cancer.
- In this research, five Muslim women are selected through theoretical relevance and found that they perceive less distress in their experience of physical changes due to the dressing pattern of the community. Perhaps a larger sample of Muslim women would be able to throw more insight regarding the phenomenon among Muslim women.
- Since the subject matter of the study is highly subjective as well as culturally sensitive, the findings are limited to the socio-cultural context of the participants. But it serves to increase the understanding of the disease process among this population.
- The long term impact of breast cancer on women with regard to her psychosocial context is another area for future research.