Social Support System in Cancer Care: Understanding Dynamics of Women Patients

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***Abstract*—** The bio-medical model of treatment of cancer provides the importance of varied process of chemotherapy, radiation or surgery dominantly. In current world where massive importance is given to the HPV clinical trials for the women breast cancer, this paper attempts to look into the different social systems for the women cancer patients. As part of bio-psychosocial model these systems are important and critical in treatment. The participants in this are individuals under follow-up or over treatment; survived for at least 5 years. A retrospective understanding and analysis was done of the social systems available for the women based on the positive experiences shared during the unstructured interviews. The social systems ranged from immediate family to doctors, every system having unique, distinct yet interplaying roles to contribute to the quality of life of the women cancer patients.

***Index Terms* —** Cancer, Care, Social, Support, System, Women

I. INTRODUCTION

Cancer is a term for diseases specifically characterized by abnormal cells divide without control and are able to invade other tissues [1]. This makes the health condition of having cancer fatal and thus requires early diagnosis. Cancer cells affect near and distant cells through the blood and lymph systems. It is complicated as it is not a single disease but a range of disease. There are more than 100 types [1].

Both sexes, male and female are susceptible of having cancer at any time of the life-span. In Canada, the Annual Canadian Institute Report 2012 reveals gender divide especially smoking related cancer statistics [2]. Coming to India, the Public Health projects have made an attempt to understand the gender differences in context of cancer in India. In 2006, the 'Cancer Incidence and Mortality in Greater Mumbai: Mumbai Cancer Registry' [3] identified 11033 new cases of cancer in a year 2004-05 of which 5350 were males and females being 5683 in number. This reflects the increased cancer morbidity among the women in Greater Mumbai. This generalized to the whole country with the existing distribution of female cancer patients as 51.5%. However, women are prone to certain cancer than cancer in general. The reason for this may vary from biological physique to social liabilities. The three most common cancers among women according to 'Centre for Disease Control and Prevention' are breast cancer (121.9), lung cancer (54.5) and colorectal cancer (38.7) [4]. In India, analogies as well as empirical descriptions identify women being largely diagnosed of breast, uterus, cervical and ovarian cancer. In all sites except breast and genital organs, high occurrences noted among men [3]. Thus looking at the other way around, women patients are seen in breast and genital units. In females, breast cancer is ranked first in incidence followed by cervix, ovary, lung and leukemia [3]. These medical complications are not merely a condition of disease but also result in incapacity of physical performance leading to psycho-social impairment.

The treatment, the disease of cancer through bio-medical approach, is only chemotherapy, radiation, X-ray or cobalt therapy with high density electron therapy and also surgery in extreme condition; a combination of all these may also treatment intervention. The patients after the treatment requires ample follow-up and after care by environmental systems. The bio-medical model for treatment negates to counter the psycho-social concerns of the patients.

Psycho-social concerns of women cancer patients

Individuals suffering from serious illness and disability often experience high levels of anxiety, depression, anger and hopelessness. Sarason and Sarason [5] were of the opinion that even in minor health illness temporary negative feelings does come.

Similarly, in cancer patients, the 'tumor' is the overt physically visible illness but the socio-emotional issues also begin with the day of diagnosis. The diagnosis is a big blow that the family along with the family receives; this sudden announcement of the having cancer in itself results in familial and individual tension. The patient tends to develop the fear of being typified as 'non-entity' in the entire social fabric [6]. Suddenly, the Quality of Life (QoL) gets highly compromised [7].

Health conditions and care get double marginalized by the social hierarchical status of gender. Women have a hidden oppression gender factor creating psycho-social problems, the major being premature menopause, pregnancy related issues, lack of interest and body image [8]. As a woman, she is expected to perform certain reproductive responsibility towards the future generation but her sexual complication contradicts with this responsibility. This can develop sense of worthlessness. Adding to the sense of worthlessness is the inability to contribute productive work. Among women aged 24-64 years who tend to be sole care-takers of the house and the family and in many cases significant contributors to family income, this mortality burden of not producing and increased medical costs poses heavy economic burden on the families. A person becomes barren

(economically and reproductively) for the family. In fact in India, the years of life lost (YLL) due to cervical cancer in India is 936.6, highest in world. The complications are not restricted to having cancer but also during treatment and living life with cancer.

The treatment procedure of cancer also creates tension among the patients considering the fact that they are in a constant fear of the unknown [9]. The panic towards the unknown extends to consequences, side-effects and future as a social being. This cumulated with the reactions of people during the diagnosis and treatment. Moreover heavy medical cost of treatment impoverishing the individuals [10] leads to psycho-emotional blockade in the process of recovery.

II. Research Concern

The bio-medical model considers cancer as 'abnormal growth of cells' and thus the treatment being medical and hospital based. Many clinical trials throughout the world revolve with the aim of proving HPV vaccine for treating cancer. The medical fraternity to the rare condition recognizes or mostly fails to recognize the factors outside hospital affecting the process of overcoming cancer; either treatment, living along or follow-up.

However Engels through the bio-psychosocial model conceptualizes influence of three basic components through systems. A system is a dynamic entity with constituents that continuously interrelate [11]. Associations among functions (physical, emotional, cognitive and social roles), symptoms (fatigue, nausea/ vomiting, pain) and supportive care needs (physical, psychological, patient care and support, health system and information, sexual) are interrelated and influence each other. [9]. In Mila Gustavassan - Lilius's work [7], the researcher has spoken about support systems as a construct that has been widely acknowledged to be important in adjustment to somatic illness and to predict better Health Related Quality of Life (HRQL).

Similarly, social systems around cancer patients could help in enhanced quality of life. Patients could develop their support systems- partner, peers or family. Under this paper an attempt has been made in identifying support systems established or created among female cancer patients in context of Indian society wherein cancer is still a socio-cultural taboo.

III. Methodology

The study was administered as a part of the social work field practicum at an organization called 'Indian Cancer Society: Parel'. But it is to be considered that no response or any part the process of research has been influenced by the organization.

The method of priori of qualitative methodology was applied in choosing the population of the research study. All the women working the organization were informed about the research. The women who voluntarily came in and agreed upon being participants were registered under this research. 32 women cancer patients participated in the understanding and identifying social systems. They have had cancer of different parts specifically breast, uterus and ovary. They had survived cancer; they could be divided in two categories: over-treatment or follow-up, surviving cancer for the minimum of 5 years. It is a retrospective case study design wherein the researcher through interviews and oral history looks into the historical and contemporary roles of social systems in their lifes.

The life experiences of the participants describing the social systems have been analyzed on the parameters of 'Quality of Life (QOL)'. The QOL indicates the effectiveness of social support system. It is a multidimensional construct that encompasses perceptions related to physical condition, psychological state, social status and other factors [12], [13]. Herein on the subjective content of the interviews, the QOL has been categorized into five heads: perception on general health, perception on cancer, attitude towards self, attitude towards self and mental health.

As part of methodology, a varied range of secondary literature has been referred and analyzed for developing and understanding linkages between social systems in Indian Context.

IV. Results

Identifying support systems

The study with the interview of 27 women and oral histories of 5 elder women surviving cancer put forward the opinions and narratives of self-claimed women cancer survivors. The responses of the participants varied in terms of identifying social systems. But significant contributing social systems with specific yet common roles were mentioned and thus listed in the study.

Out of 32 respondents, 25 of them lived at homes and 7 lived in 'Residential Centers for Cancer Patients' in the city. Out of the 25 women living at home, 18 were married and others never married. Adding to this never married number, the respondents from the residential homes never married either. But in these 'residential homes', it is mandatory for a relative to accompany the patients. The residential home with co-patients and relative over a period of time becomes a close-knit community of support. The caretaker who is the relative or any member of the family becomes the immediate support system for the patient to look forward to. However it is recorded that these patients being women, the family puts in an unproductive (economically) member of the family like an uneducated sister. On the contrary there also has been instances where attendants act as caretakers as for the domicile to explore scope of jobs in the city. No matter under all circumstances, the caretakers' relation with the client determines the progress of general health cancer in specific.

"My brother lives with me in GBA (name abbreviated for confidentiality). He is one of the few members in the house who has been with me since diagnosis. Though he never comes for follow-up or even my workplace, but the fact that I have dinner with him together makes me happy" expresses the relief of having a support system in an emotionally-laden interview of a young lady of 33-year old.

On the contrary to this lady, the women living in residential homes were mostly looked after by other female

member from the family who is also unmarried. The 7 participants living in residential homes were high praises to their caretakers as they had taken the risk of being with them against the complaints from other family members. As mentioned earlier no earning member would agree to be with the women patients.

The women living in houses with families could be categorized into: a. single women living with their parents b. married women living in their maternal houses and c. married women living with their spouses and siblings. This categorization has been done on the responses of the participants in identifying immediate environment being support system. Thus the primary support system for women living in families varies from their own parents to spouses. The system with which the woman patient had the most supportive relationship, she ended up being with that system as the immediate surroundings. Living with supportive families with positive interaction and clear communications has shown to be associated with low levels of stress-coping behavior, good psychological health, active adaptive to acute and chronic illness and high levels of adherence to treatment (Wambodt & Wambodt 2000). Thus it could under-consideration that the women living in these familial categories exhibited good responses to treatment process and follow-up because of their comfortable family system; be it with parents or spouse and children. "I did not have any problem of vomiting though I had 8 chemo as part of the treatment. I believe neither my parents nor my friends left me alone. My mother was sad and used to cry, but my friend was there to give me strength and my family too. Marrying was not an option for me, never will I but still I do not feel lonely" articulated a 45 year old cervical cancer survivor who identified peer circles in addition to family as an important part of social system.

Of 18 married cancer survivors, 11 lived with their husbands and the rest with maternal families. Living together or separated creates a difference in treatment adherence could not be analyzed; it was considered to be a sensitive issue to be discussed.

Dominantly the responses identified the 'workplace' as a social system. It being a rehab centre provides cancer patients especially women to have a common platform to discuss concerns on cancer, self, family and other. In cases of lack of familial support, the center support is of utmost important and thus can be considered as a secondary relationship. All 32 women identify this as a crucial support system through the co-patients as well as the medical social workers.

A unique but critical support system identified it the medical/ paramedical staff involved in the treatment or follow-up process. 5 out of 32 recognize the doctor-patient relationship. Motivation from the doctors and the nurses can become the ultimate complex binding of professionalism and principle of individualization enabling the patient to adhere to the treatment and follow-up.

Effects on Quality of Life (QOL)

The effectiveness of the support system has been classified into five dimensions of individual growth and development.

B.1 Perception on General Health

The interaction with the immediate support system as mentioned in the above section, determines the general health conditions of the individual. Accompanying the patient or fixing an appointment with the doctor influence the process of compliance among cancer patient in maintaining their general health graph. The respondents varied on aspects of identifying specific people persuading their health related quality of life. One of the respondents spoke of co-workers from the rehab- centre visiting her while she was suffering from fever; this made her feel good and significant. On similar line "being with my mother, parents have helped me maintain scheduled life and not just listen to orders. I can eat, drink and take no tensions to go to the doctor" says a participant who never married due to her breast cancer, who considers herself to be fit credits to her family.

B.2 Perception about Cancer

Cancer in the time of diagnosis was a sudden shock to all the participants; this was a common reaction for all. The participants spoke of the interactions with medical social workers and doctors reducing the burden of emotions and fear. Also the social worker's intervention on subsidized treatment or sponsored treatment lessens the self-guilt of financial pain on the family.

Perception on cancer, however as described by the participants was larger affected by the shared experiences of the co-patients in rehab-centre and residential homes. "I always used to wonder why me and why cancer; I must have done some sin to be punished and thus need to die. But I met at least five women cancer patients a day surviving cancer in the rehab-centre. They lived more months and years …7-8 years; I could never believe before. But now I know I too can" a breast cancer survivor survived for 8 years now spots out the distinct role of co-patients (co-workers) in recovery process.

B.3 Attitude towards self

Sense of worthlessness and concerns about body image are of prime importance during the treatment that was spoken by all 32 participants. The earnings from the rehab centre directly implied into economic contribution and thus being productive. The engagement, interaction and the facilities of scholarships and sponsorship of continuing education or for children as well as for treatment helped in overcoming the situation of self-burdening on the family. "I earned. I am here so I get scholarship for my children; I have breakfast, three meals and milk. What else do I want: I am contributing and self-sustaining. My husband abandoned me anyways. NO changes in my body but he still he did." explains a woman living with her sister with her children.

The response also expresses the partner support towards physical concerns. She related physical changes to her abandonment. In spite of none, she was left. The sense of sexual infertility and physically deformed exists high among individuals being separated. For 17 women mentioned that the acceptance of themselves by their partners, peers or family members would

help them lead the same life as before cancer; a life full of self-confidence.

B.4 Attitude of others

"My in-laws were of the opinion that I carried cancer germs in ovary from my maternal house. Do not know how much it is true but signs of their rejections, facial expressions and acts hurt me. Gradually my husband started talk to them about my condition and convinced mother-in-law to go to doctor with me. I was surprised she agreed and many a times later she repeated this" a female did experience in attitude of other family members with the support of immediate social system.

Support systems work in such a manner that they could influence each other. However all the women are of the opinion; the process of acceptance and positive attitude towards them by others is slow and sometimes miraculous. Mostly primary caregivers and attendants have a hope of recovery for the patients.

B.5 Mental Health

Out of 32 participants, 26 responded that having a peer or a partner to share gave them a sense of mental peace. The peer or the partner could vary from an old friend, co-patient or co-worker or even counselors/ social workers. It develops a peer importance defining social roles and status. All support systems indirectly affected the mental well-being; components of stress, tension and conflict are shaped by participants' social life at place of residence (home or residential homes), workplace (rehab centre), hospital and larger community.

"I wanted to end my life but I joined the rehab to re-visit myself. I started earning every day. That is when I realized I can do something. It brought me some sense of liberation, responsibility and worthiness" a 38 year old married suffering from severe depression leading to suicidal tendency a year back.

V. Discussion

A cancer diagnosis often results in a reassessment of life that does not correspond directly with health status [14]. The life shakes to the extent to distorted relationships, defining newer economic, social and individual communication patterns. In this hassle of tumbled relationships, existing social systems are key and defining factor to determine the course of action of the patients with reference to cancer treatment and care. The result has prominently reflecting social systems helping in influencing and developing the positive attitude of patients maintain life style and structure.

Durkheim [15] in his analysis advocates; suicide rates were higher among individuals who were less socially integrated than among those who had many social ties. Drawing lines on similar grounds, social relationships for women cancer patients have developed them to develop spaces for self as individual and social being establishing an optimistic understanding.

The qualitative description of the participants identifies definite dominant social systems acting as active support mechanism and system for the patients.

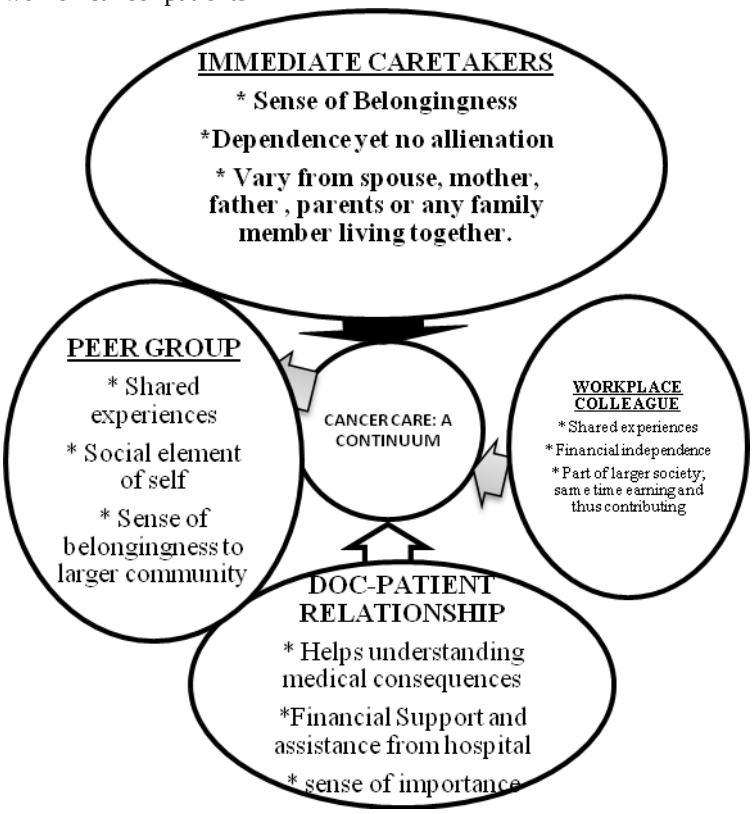
1. Immediate Caretakers: Family member, parents or spouse

2. Doctor-patient relationship: Principle Doctor Investigator, associate doctors or nurses

3. Peer Group: Co-patients or friends

4. Workplace colleague: co-workers who have survived/ with cancer

Diagram 1: Social systems with significant roles for the women cancer patients



The definite roles and influences on the woman cancer patient have been explained in the diagram above. The different social systems interplay and also contribute uniquely to the conditions of life; these support the well-being of the individual cancer patient enhancing the Quality of Life (QOL). The relationship of living with husband, family or a person is related to a positive reflection on oneself. It cuts across the feeling of worthlessness but also institutes women cancer patients as companions or members of the household. Women, who were divorced, separated or never married reported higher levels of fatigue [14]. In this study women married or not, but sharing a household space with any person, husband, siblings, parents ascertain the sense of belongingness. This results in health mental health and also lesser fatigue. The inherent anthropological understanding that 'man is social' is retained making these women part of the society. Under such conditions of acceptance, there not scope for the feeling of rejection from social functioning to affect adherence in cancer treatment or follow-up. In fact it is significantly expressed that the family members or co-workers accompanying the patients during chemo-therapy diminishes the mental-emotional side-effects of

the therapy; less fatigue, pain and nausea is witnessed among these women.

Starting from diagnosis, the major fundamental system associated is medical professional. They are the doctors, investigating and visiting doctors, nurses and ward boys, medical social workers, chemotherapist and in many case the physiotherapist. The patient-doctor relationship as the respondents usually uses for the whole set of professional in hospital setting, determines long term continuity towards treatment. The style of interaction, time spent on sessions and visits, tone of speech is critical in the relationship in creating and sustaining the rapport with the patient. Adherence to treatment has also been influenced by the co-workers and the professionals at the rehabilitation center. The colleagues accompany each other on scheduled chemo and radiation dates. The professionals, the medical social workers makes periodic visits to the place of treatment and also follows-up with patients. It is critical as researchers to recognize and realize the importance of rehab centre as a created and established social system by the women cancer patients. In generic workplace, the people at workplace are compassionate and helpful but in many ways hostile [16]. In the rehab center specifically for cancer patients, the co-workers and the professionals are extremely encouraging and empathetic.

The circles of social support system thus provide a prospect for identity building, befriending and helping self and others. Working in a rehab is a scope for facilitating self an emotional exchange among similar individuals with the sense of self- appraisal of being productive.

There are 11 women living with partners. Though under-discussed specifically in living with partners, it is reflected in regularity and activeness in the centre. Mila Gustavasson-Lilius et. al. [7] concluded female cancer patients who receive high appraisal of partner support display more optimistic appraisals. In this study overt establishments associated with these two variables could not be visible as the 11 married living with their husbands refused to speak in details about the familial conditions. But individuals have mentioned "their husbands being cooperative" in terms of accompanying them to treatment or other social visits or even general check-up. Also the study has not been able to indicate a direct correlation between partner systems and sense of being a woman among women cancer patients. But abandonment creates a sense of risk and impaired body image among women which can point towards the negative impact of partner systems when negated.

VI. CONCLUSION

With reference to the positive experiences from the social systems, it can be derived that along with medical hospital based intervention in treatment and follow-up, the care and support of the social systems can accelerate the process of healing of women cancer patients. The family, parents, or partner system, each patient develop and live with a unique social system of their own. The most fundamental system being the immediate system in the nearest proximity; nevertheless every social system has definite yet complex roles interplaying within and across systems in the environment of society. The process of cancer treatment definitely contributes to the mental and spiritual well-being in Quality of Life of the individuals. Women being more vulnerable with social hierarchy, the social systems acceptance and understanding create a motivational impulse to live/fight, thus survive cancer.

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