RESEARCH COMMUNICATION

Coping Mechanisms Among Long-term Survivors of Breast and Cervical Cancers in Mumbai, India

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Abstract

Accumulated evidence indicates that the positive coping means a good quality of life, which will contribute significantly to improvement in the prognosis. In low resource settings, it is a challenge for medical teams and patient families to provide psychological and emotional support throughout the fight against the disease. This paper appraises coping mechanisms among the long-term survivors of breast and cervical cancers in Mumbai. Women surviving for at least five years were extracted from the Bombay cancer registry patient index for evaluation: a simple and locally developed instrument was used for In-depth Interviews (IDI's) at patient residences. A total of 80 survivors were interviewed but only findings for 52 subjects with complete information are presented in this paper. Parameters were studied in the order of personal, psychological, emotional, physical and spiritual well being of the patients. The analysis is mostly descriptive in its nature: qualitative analysis techniques (free listing and clustering) were adopted to present the data. Positive thinking, purpose in life, and strong family support played key roles in achieving completion of treatment then prolonging survival. An appropriative health seeking behaviour, good general medication, and emotional support from friends and family members were revealed to be very important factors for coping capably. An unmet need for knowledge of symptoms was identified, which suggests that appropriate messages should be generated to reach women in conventional families. Despite the small sample size, our findings broadly provide a base for large-scale future studies and suggest gaps to be filling in counselling interventions in Mumbai.

Key Words: Coping - quality of life - cancer survivors - developing countries - breast - cervix - cancer

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Background

In developed countries cancer detection programs, health education and awareness has helped the down staging of disease so that overall survival has been improved. However, in developing countries the same cancers are generally found at more advanced stages and are mostly handlde through aggressive treatments, which duly interferes with general health-related parameters and social life of the patients (Panday et al., 2000). Breast and cervical cancers contribute half of the female cancer burden in India, including Mumbai (Ferlay et al., 1998), where five-year relative survival rates are 55.1% for breast and 50.7% for cervical cancers (Snakaranarayanan et al., 1998). Assessment of stage wise survival divulge that 80%, 29% and 12% patients survived in Stage-I, Stage-II and Stage-III, respectively, for cervical cancers even 15 years after diagnosis (Yeole et al., 1999), which means that due to treatment a good proportion of patients survive for a long time in Mumbai and it is important to know how they cope in their life for effective management.

Accumulating evidence indicates that patient coping mechanisms of life have considerable relevance to improve the cancer prognosis in two ways: by selection of therapeutic regimen, selection of a hospital, or patient satisfaction with that selection and by affecting biological mechanisms that may affect risk of disease, response to treatment, and disease progression (Dow, 1993). The relation between behavioural choices, social and emotional factors is now recognized to influence women's risk of developing breast and cervical cancer, response to treatment, as well as contribute to quality of life among cancer survivors (Dow, 1996; Ferrell et al., 1995).

Given the complications of the interactions postulated,

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a very few studies have been attempted in India to determine the coping mechanism among advanced breast and cervical cancer patients (Panday et al., 2000; Pandey et al., 2002; Ramanakumar, 2000). But relatively little is known in the context of mumbai, where advanced curative facilities are accessible. Knowing the difficulties in developing local version of standard instruments due to lack of resources, qualitative research tools were employed to test the interactions of physical, psychological, social and spiritual well being with survivorship of cancer patients.

Methods

For this study Bombay cancer registry area with defined boundaries was selected (population 11.0 millions). A simple and locally developed questionnaire was used to obtain the information through structured In-depth Interviews (IDI's) at patient residences during December 1999 and early 2000. For this purpose, the patients diagnosed between 1982-97 were selected from the Bombay cancer registry address index, where the survival status was clearly marked as alive. A stratified random sample was drawn from the list based on age, social segment, and stage of cancer at diagnosis. A total of 80 interviews were conducted, some women hesitate to express opinion on sensitive issues, some women were less willingly shared information and some expressed impatient. After excluding the incomplete and unclear responses, 27 breast cancer patients, and 25 cervical cancer patients were selected for this analysis. The analysis is basically descriptive in nature (some of them were tabulated and rest were narrated in the results section).

Before the discussions, the patients were approached by the registry social worker to inform the purpose of the study, written or verbal consent (for illiterates) was obtained from the patients and also from the head of the household (culturally essential in India) before we approach the patient. Much of the information was collected through the in-depth interviews and most of the conversations were recorded (wherever possible) to make formal notes in due course.

These interviews consists of five major sections based on the literature review of coping mechanisms encompassing physical, psychological, social and spiritual well being, which evolved from over a decade of research on cancer survivors (Dow, 1993; Dow, 1996; Ferrell et al., 1995).

Personal information; Age, Religion, Education, Family situation, Employment, Income, Family Income, Migration history, other illness, cancer stage, treatment.

Physical well-being; general health status, strength, sleep and rest, Fatigue related complaints, Fertility, menstrual changes, Pain related complaints, appetite, nausea, constipation.

Psychological Well-being; Usefulness, happiness, attitude, memory, concentration, fear of recurrence, distress, treatment perception, appearance.

Social Well-being; Family distress, Roles in the family, society, sexuality, childbearing, Isolation at work, relations with friends and family, social support, advice, symptoms. Spiritual well-being; purpose, religious, daily way of life, hopefulness, uncertainty, positive, participation, change in spirituality

The data was analysed using 'free listing' and 'clustering' techniques with help of Anthropac software (Snkaranarayanan et al., 2003). Extra care has been taken to translate the local terms from Marathi/Hindi (local language) to English with help of an experienced professional.

Results

Of the 52 patients interviewed, age is reported between 34 to 72 years, all of them had been married except two. Religion wise, 42 Hindus, 6 Muslims, 2 Parsis and the two Christians constitute the study group. Many of them were treated with combination of surgery, radiotherapy or/and chemotherapy in various hospitals of Mumbai. The family income reported from rupees.1200 (30$) to 75, 000 (1600$) per month for the study group.

Table 1 presents best five top reported symptoms by the patients. In many cases, despite of the unusual symptoms; patients were delayed for long time to visit a doctor (up to 2 years). On average, each person reported 4.3 symptoms.

Among the breast cancer respondents, two-third of the women said that they have observed lymph in their breast and half of the women have experienced some pain in their breast. In case of cervical patients, pain in the vagina, white discharge and a kind of water leakage (No translation found, just as said) were common symptom.

Initial reaction is very important to determine the treatment seeking behaviour and further to influence the decision to fight against cancer. The best five terms of initial reaction was presented in Table 2. With some unusual symptoms, each and every patient initially visited their family doctor and was referred to a cancer specialist /clinical

Table. 1 Free Listing of Initial Symptoms Reported Before the Onset of Breast and Cervical Cancer

Rank	Breast Cancer Patients (27)			Cervical Cancer (25)		
	Symptom	Frequency	Resp %[1]	Symptom	Frequncy	Resp%
1	Lymph	17	63	Pain	11	44
2	Pain	14	52	White discharge	10	40
3	Oddness	8	30	Water leakage	10	40
4	Tumour	5	18	Problem in Urine	9	36
5	Some Spots	4	15	Node in Vagina	8	32

[1] Resp % = (Frequency/Number)*100 Resp%= Respective percentage

Table. 2 Free Listing of Initial Reaction After the Onset of Breast and Cervical Cancers

Rank	Breast Cancer Patients (27)			Cervical Cancer (25)		
	Initial reaction	Frequency	Resp %	Initial reaction	Frequncy	Resp%
1	Depressed	11	41	Darkened	12	48
2	Shocked	7	26	Collapsed	7	28
3	Fatal feeling	7	26	Shocked	5	20
4	Cried a lot	4	15	Worried	5	20
5	Doomed	3	11	Cried a lot	4	16

tests. After hearing about the disease, four of them got it reconfirmed with other pathology labs and seven of them have taken second opinion from other doctor. More than half of these women immediately met their relatives or friends in order to gather more information on cancers. Seven women had even purchased basic information books to read more about cancer. Two patients informed that 'cancer' has become the regular topic of discussion for all the family members and they used to listen success and failure stories of other patients.

Mostly, breast cancer patients were predominantly treated by surgery whereas cervical patients undergone radiation in Mumbai. Women recollected the associated physical side effects of treatment such as hair loss, fatigue, nausea and pain etc. It was reported that waiting for treatment is real pain since it depends on their economic ability and also on the choice of doctor they chosen for treatment (some body has to wait up to 3 months). The complications reported due to light (radiation) were tiresomeness, water discharge (some times with bad odour), over heat in the body, little nausea and lack of appetite. The side effects for chemotherapy were feeling of drained out, nausea, diarrhoea, and unbearable weakness. After treatment nine-in-ten managed their routine like going to the toilet, dressing themselves etc soon after the treatment. But the people who have undergone surgery reported difficulty to comb their hair. About three-fourth was completely given up heavy household duties like cooking, sweeping, washing for sometime after the treatment where as one-third left them permanently.

The most five personal problems reported by the study group were free listed in Table 3. Cancer is more than a health problem for Indian women; it creates a great annoyance in the family. Young and low socio-economic strata are at disadvantage as they bear more risk as they were thinking seriously about their children's education and bear a guilty that they were unable to perform their duties properly towards their family. Among cervical cancer patients, 8 women panicked about retreat of their relation with their spouses. Regarding other problems; housing was found as a real problem as most of them live in a single room with their in-laws (joint families). Due to congestion in the city only 12 per cent of them got a separate room for their privacy.

None of the women reported any change in their role even after occurrence of this disease. Friends and relatives remain visit them frequently. One-fifth of them doesn't disclosed about this disease even to close friends due to the fear and stigma in the society about their acceptance as active citizens. Some of them stopped outdoor activities like shopping because of fatigue ham jyada vajan uta nai saktha '(We were unable to lift heavy things)' and 'lovkar thakaila hothe (Soon I felt tired)' compared to those days before the inception. Most of the patients still actively participate in the community functions like marriages. When disclosed this disease to the neighbours and relatives they received support and courage, patients reported that their status in the society remain same.

Top emotional problems reported by the survivors are free listed in Table 4. Initially, all patients reported to be depressed but over the period of time many patients (two-third) started feeling better. Twelve patients told that they used to depress once a while, particularly when they were alone at home even after five years of their treatment. The common negative feelings were fear of remission, fear of death and hate, and anger whenever they had a simple disappointment. The frustration some time seen as jealousy too, six of the study group were suffering with inferiority complex and occasionally thinking of suicide, as they were burden to their family.

After onset of the disease, many of them want to spin to their native places (many of the Mumbai inhabitants are migrants from different parts of Maharastra and India) because it is wish of everybody in the community to die in their own village. One old woman reported that 'Currently, we live in a rented house, but if I die the landlords won't permit my dead body to enter into the house, how my son

Table 3. Free Listing of Personal Problems Reported by the Breast and Cervical Cancer Patients

Rank	Breast Cancer Patients (27)			Cervical Cancer (25)		
	Problem	Freq.	Resp %	Problem	Freq.	Resp%
1	Future of family	15	56	Future of Kids	17	68
2	Responsibilities not completed	14	52	Economic burden	11	44
3	More burden on family	7	26	Social negligence	10	40
4	Social negligence	4	15	Husband behaviour	8	32
5	Economic burden	4	15	Physical burden	5	20

Table 4. Free Listing of Emotional Problems Reported by the Breast and Cervical Cancer Patients

Rank	Breast Cancer Patients (27)			Cervical Cancer (25)		
	Problem	Freq.	Resp %	Problem	Freq.	Resp%
1	Fear of remission	16	59	Fear of Remission	17	63
2	Continued depression	13	48	Lack of confidence	14	56
3	Hate herself	7	26	Fear of Death	13	52
4	Frequent Upset	6	22	Rejection feeling	11	44
5	Irritation	4	15	Hate feeling	8	32
6	Jealous of others	3	11	Angry	7	28
7	Inferiority	3	11	Jealous of others	5	20
8	Rejection feeling	3	11	Often broke into tears	3	12
9	Thought of death	3	11	Inferiority complex	3	12
10	Tension	2	7	Depression	2	8

will perform my rituals? so it is better to go back to my village (her native place)'.

Table-5 reveals the spiritual well being of the cancer survivors. Some of the survivors attributed this disease with karma (an Indian philosophy of sin) and considered as a result of their own 'sin'. A good proportion of survivors started visiting temples more frequently than earlier. After cancer diagnosis, prayers and religious activities have become their regular activities. Three in four have visited some place of religious importance and four out of ten visited some pilgrimage in last one year. Four-fifth expressed a strong belief that only god will save them from this disease, as a woman said 'almighty will take the responsibility of saving me and I am confident about it'.

Some strongly believe that practicing "yoga" will save them as helps to strengthen their mental ability to fight with their negative thoughts. Four breast cancer patients have undergone even formal training, one patient who is a volunteer in a support organization working for cancer patients told, "classical Indian music may save a person from this sadden and I am the best example". Half breast and only three cervical cancer patients have reported that they listen to devotional music every day. "Reading philosophical books has helped me tremendously in giving courage and hope" as reported by a retired teacher. It also confirmed by another six patients that philosophical readings might play a vital role to improve quality of life. A patient reported, "positive talks from spiritually matured people gives happiness to their min, during that time I just forget about cancer".

Participatory observation involving in Bhajan (a rhythmic enchanting of Hinduism) by a famous singer (himself a cancer patient) organized by v-care voluntary organization revealed that this kind of programs would give great relief to the participants from the routine thinking. It is observed that cope is smooth among the patients with sound spirituality.

Discussion

Recent advances in diagnosis and treatment have lead to an improvement in cancer survival, so health professionals in Mumbai need to pay more attention on quality of life for these survivors (Ramanakumar, 2000) in the follow-up care more attention is required on physical well-being, pains aches and fatigue which were common complaints among the cancer survivors because they have received greater clinical attention only in the first few years of the diagnosis and draw less or no attention in due course.

The treatment delay (up to three months) clearly compress that there is need to increase hospital beds and cancer wards in the metro. Popular strategy home-based care may be cost-effective but congestion of house is the main problems (current population 12 millions) in Mumabi. So some of the new models like BHH (Bologa Hospital-at-Home) in our urban settings (Mohanti et al., 2001; Tanneberger and Pannuti, 1998) may be devised.

There is an unmet need for health information in Mumbai

Table 5. Free Listing of Religiosity Reported by the Breast and Cervical Cancer Patients

Rank	Breast Cancer Patients (27)			Cervical Cancer (25)		
	Spiritual indicators	Freq.	Resp %	Spiritual indicators	Freq.	Resp%
1	Belief in god	16	59	Belief in god	17	63
2	Belief in karma	13	48	Belief in karma	14	56
3	Increased temple visits	7	26	God is responsible	13	52
4	Increased religious activities	6	22	Increased temple Visits	11	44
5	Visiting religious place	4	15	Prayer regularly	8	32
6	Pilgrimage	3	11	Attended religious function	7	28
7	Yoga	3	11	Pilgrimage	5	29
8	God will save	3	11	Positive that god will save	3	12

Only maximum 8 indicators are mentioned in the answers.

since most of the patients ignored the initial symptoms for long time. It is clear in the discussions that they were not aware of symptoms and they never thought that those symptoms would turn as cancer. For breast cancer, low cost interventions like Breast Self Examination (BSE), Physical examination (PE) by health workers can also be integrated in the existing health care programs in India (Chandra et al., 1998; Mitra, 1995). For cervical cancer diagnosis, cost-effective interventions like visual inspection with acetic acid (VIA) and lugol's iodine (VILI) may be used in community level to detect cervical carcinoma (Snkaranarayanan et al., 2003). It clearly marks the need of strong awareness programs, at least for these two common cancers.

During this long journey, survivors underwent lot of pain, strain, anxiety, and fear. They always want to attain gusts of tenderness, love and affection from dear and near. Expressively, recalling distress associated with initial diagnosis, recollection of highly threatening life events and thought of remission were the worst emotional outcome. The survivors have developed positive feelings after interacting with support groups; their morale went high after conversation with survivors (arranged by care groups). More attempts were required to made available the information with success stories of cancer survivors with complete information, facilities, contact numbers and discussion forums. Frequent encounters with long time survivors will restore the confidence and hope to overcome the emotional difficulties. With increasing network connections in India, a web-based database also useful for the patients.

In a traditional family setting (only women were responsible for specific household duties), responsibility towards family and children, differences with spouses were seen as the worst outcome for young patients. It was also observed that the life is more difficult for poor women (mainly cervical cancer survivors); the younger women have shown relative deterioration to cope than elders. They failed to erect constant support and assurance from the family members and society. Hopefulness, having a purpose in life and positive thinking about recovery were the better outcomes. Feeling of improvement in the current condition, happiness and satisfaction have a great potential to balance this outcome. Counselling facilities should be extended not only to the patient but to entire family, particularly to the spouse and decision makers (in-laws some instances) of family, to educate them about cancer.

In low-income families, onset of cancer has seen as a very big financial set back. Generally the treatment options and delayed decision-making were attributable with income level of the family. Cancer treatment is a big burden to any family; women with low status were at disadvantage to seek their treatment if it is costly. In early 90's some Non-governmental organization started cancer insurance policies in collaboration with New India Assurance Company, during the policy period an individual is entitled for periodical checks and this scheme pay for the patient hospitalisation, treatment and follow-up (Anna, 2002). Many of the patients in the study group were not aware about such schemes; extra efforts were needed to make aware of such schemes to each and every body.

Yoga and meditation practices were showing excellent impact on the survivors as reported, 10 years and above survivors suggested that each and every patient should practice yoga to divert their mind from routine negative thoughts. From the reported experiences it is clear that participating in Bhajans (Chanting spiritual songs with rhythm), and attending devotional programs heals patients and gives positive hope.

This study tried to explain various questions augment at various levels of treatment, positive outcomes and role of cultural values to prolong life of cancer patients; on the same hand presents the hardships to deal the social and financial barriers in low-resource settings. But it has not totally captured the mechanism because of small sample size. There is a great need to check the hypothesis how patients were coping in life aspects through certain parameters at a larger scale to generalize our results. Yet, the evidences were sufficient to suggest the requirement of women's advocacy, social role and policy options. It clearly states the need for media attention, further research on quality of life, strong participation of non-governmental organizations and care groups to cope the disease among long-term survivors of cancer.

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References

Anna Peter (2002). Affordable insurance cover against cancer. The Hindu Business line. Saturday, Oct 05 edition.

Chandra PS, Chaturvedi SK, Channabasavanna SM, et al (1998). Psychologial well-being among cancer patients receiving radiotherapy-a prospective study. *Quality of Life Res*, **6**, 495-500.

Dow HK (1993). On the nature and meaning of locally recurrent breast cancer. Quality of Life: A Nursing Challenge 2, Meniscus Ltd., and PA. 65-70.

Dow HK (1996). An Evaluation of quality of life among the long time survivors of breast cancer. *Breast Cancer Research and Treatment*, **39**, 261-73.

Ferlay J, Parkin DM, Pisani P (1998). GLOBOCAN Cancer incidence and mortality worldwide. IARC cancer Base 3 on CD-ROM. Lyon, International Agency for Research on Cancer.

Ferrell BR, Dow KH, LeighS, Ly J, Gulasekaram P (1995). Quality of life in long-term cancer survivors, *Oncol Nurs Forum*, **6**, 915-22.

Mitra I (1995). Early detection of breast cancer in industrially developing countries. *Gan To Kagaku Ryoho*, **22 Suppl 3**, 320-5.

Mohanti BK, Bansal M, Gairola M, Sharma D (2001). Palliative care education and training during the residency: A survey among residents at a tertiary care hospital. *Natl Med J India*, **2**, 102-4.

Panday M, Singh SP,Behere PB, et al (2000). Quality of life in patients with early and advanced carcinoma of breast. *Eur J Surg Oncol*, **1**, 20-4.

Pandey M, Thomas BC, Ramdas K, Eremenco S, Nair MK (2002). Quality of life in breast cancer patients: validation of a FACT-B Malayalam version. *Qual of Life Res*, **11**, 87-90.

Ramanakumar AV (2000). An Epidemiological Study of Breast and Cervical Cancers in Greater Mumbai; India. PhD thesis of author. International Institute for Poulation Sciences, Deonar, Mumbai-72.

Snakaranarayanan R, Black RJ, Parkin DM (1998). Cancer survival in developing countries. IARC scientific publication No.145. Lyon: International Agency for Research on Cancer.

Snkaranarayanan R, Wesley R, Thara S, et al (2003). Test characteristics of visiual inspection with 4% acetic acid (VIA) and Lugol’s Iodine (VILI) in cervical cancer screening in Kerala, India. *Int J Cancer*, **3**, 404-8.

Tanneberger S, Pannuti F (1998). The Bologna Hospital-at Home: a model for cost-effective care of advanced cancer patients in developing countries. *Natl Med J India*, **5**, 231-5.

Yeole BB, Sankaranarayanan R, Jussawalla DJ (1999). Long-term survival from uterine cervical cancer in Mumbai, India. *Int J Cancer*, **78**, 394-5.