Quality-of-life: A study on patients of carcinoma breast and its pitfalls in Indian society

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Abstract

Background Traditionally outcomes of treatment have been limited to survival. However, the disease and its treatment may have an impact on Quality-of- Life (QoL). The major concerns for patients of carcinoma breast involved are survival, appearance and a fear of recurrence. In Indian society we may need a separate and modified approach to assess QoL.

Aims & objective The aim of this study was to assess the QoL of patients of carcinoma breast and to ascertaining pitfalls for suitable correction in future studies on Indian patients.

Materials & methods 250 diagnosed patients of carcinoma breast were studied by a questionnaire on physical and psychological parameters. The results were assessed for applicability to our clientele.

Results We found that majority of patients enjoy a good and non-capacitating QoL. Factors that may contribute to poorer health perceptions and QoL include experiencing a menopausal transition as part of therapy, and feeling more

vulnerable after cancer. Overall QoL was better in the older and illiterate patients. Patients with no co morbidity and early stage disease fared better against patients with co morbidities and advanced stage of malignancy.

The parameters used in QoL studies in west may not be directly applicable to Indian patients but it does give us a start. We need to adapt to these parameters and draw our conclusion. But there are many methodological challenges inherent in working with our population. Researchers interested in studying our clientele's QoL need to be cognizant of certain issues to ensure high quality results.

Keywords Breast cancer · Quality of life · Treatment of breast cancer · survival in breast cancer

Introduction

The effects of disease and its treatment in patients have traditionally been assessed by studying clinical outcomes such as crude or overall survival, disease specific or corrected survival, disease-free survival, recurrence-free survival and length of hospital stay [1–4]. However, the disease and its treatment may have an impact not only on survival (quantity-of-life) but also on well being of the individual QoL.

World Health Organization Quality-of-Life Group (1996) has defined QoL as “An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social

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relationships and their relationships to salient features of the environment” [5].

Patients of carcinoma breast mainly involves women of age group of 20 years and beyond. The amount of compromise involved and stress-related to her outlook to life carries an enormous amount of change in her attitude towards life. The major concerns involved are survival, appearance and a fear of recurrence.

The female breast is seen as an important symbol of both womanhood and sexuality [6]. Many women regard their breasts as a major part of their potential to attract or retain a partner, and surgery is perceived as having a major impact on a woman's feelings of attractiveness and sexual desirability [6]. Breast cancer and its treatment can change the way a woman thinks and feels about her whole body, her femininity, her self-esteem and the way she behaves. The treatment of breast cancer with chemotherapy or hormonal therapy may also affect self-image, fertility and libido. Loss of hair and early menopause may constitute a serious threat to a woman's image of herself [6]. Along with these concerns regarding attractiveness and sexuality, women may fear that their partners will leave them or that their couple relationship may deteriorate.

In Indian society we may need a separate and modified approach to assess QoL as our clientele belongs to different level of education, income and demography.

Aims and objective

The aim of this study was to assess the QoL of patients of carcinoma breast and to ascertain pitfalls and make suitable correction for future studies on Indian patients.

Materials and methods

Two hundred and fifty diagnosed patients of carcinoma breast undergoing treatment and under regular follow up at our centre were included in the study. Forty-six patients were enrolled on diagnosis, 83 patients on completion of treatment and 121 patients were undergoing treatment on enrollment.

A detailed history was taken taking into account name, age, place of residence, occupation, education, symptom of presentation, co-morbid conditions, any previous surgery/chemotherapy, radiotherapy and case summary recorded.

Patients were evaluated by a four part questionnaire pertaining to physical in capacitance and psychological distress at various stages of treatment and follow up to study the effect of the disease on QoL. Part I and II of the questionnaire dealt with physical in capacitance. Salient features of part I was difficulty in walking, climbing stairs, standing, household activities, nausea and feeling of illness or tiredness and part II pertained to ambulation, activity,

evidence of disease and degree of self-care. Part III and IV of the questionnaire dealt with emotional and psychological impairment by using parameters like dependency, invalid, restriction on chores and problems with chores, feelings, sadness and inner tension.

At the end of the study period the answers were compiled as per scores and analysed to assess the QoL the patient has during the course of diagnosis, treatment and follow up. Statistical analysis was done using the software Epi 6 [7]. (A database and statistics software for public health professionals.) A p value of < 0.05 was considered significant. It was also considered necessary to reassess our results for its general applicability to our clientele.

Results

1. **Demography profile:** In the study group 51% patients belonged to the age group of 40–55 years followed by the age group of 55–70 years at 26%. Twenty-nine patients were in age group of 25–40 and 27 patients were over 70 years. The mean age was 48.2 years (range 26–92 years). All 250 patients were married. One hundred and fifty-three patients were in postmenopausal group and 97 patients were premenopausal. Only one patient was nulliparous and rest of the patients had 2 to 3 children. All patients in our study belonged to the families with annual income above Rs. 60,000.
2. **Education status:** Forty-two percent of patients were illiterate and 26 patients were graduates. Eighty-two percent of patients were housewives rest of patients were working and majority among them were in the teaching profession.
3. **Stage of disease:** Maximum patients in our study group had presented with locally advanced stage of disease (132) while early breast cancer was seen in 86 patients and 32 patients presented with metastatic disease.
4. **Co-morbid disease:** Co-morbid disease refers to the presence of concomitant disease (in addition to breast cancer) that may affect the diagnosis, treatment, prognosis and QoL for the patient [8]. Eleven percent of patients had more than one disease and NIDDM was commonest. Other diseases were hypertension, low back ache, osteoarthritis, psychiatric disorders, tuberculosis, hypothyroidism and bronchial asthma.
5. **Treatment stage:** Forty-six patients were assessed at the time of initial diagnosis (19.4%), 121 patients were assessed for their QoL during treatment while 83 patients were assessed during follow up.
6. **QoL results:** QoL results seen as per group of patients:
 - a. Good QoL: 43%
 - b. Excellent QoL: 12.8%
 - c. Moderately compromised QoL: 30.6%
 - d. Severely compromised QoL: 8%
 - e. Poor QoL: 5.6%

To nullify various confounding factors the result was assessed under subheads like age, education, co-morbidity, stage of disease, stage of treatment and radiotherapy.

- **Age:** There was no significant difference in physical aspect of QoL for age group < 55 years (157 patients) and > 55 years (93 patients) with p value being 0.74 and 0.49, respectively. The elder age group reported better QoL on emotional and psychological front, p value being 0.01 and 0.02, respectively.
- **Education:** The illiterate group (105 patients) reported better QoL in all walks of life. p value being 0.002, 0.002, 0.00 and 0.00 in the four parts of questionnaire.
- **Co-morbidity:** Presence of co-morbid conditions did not adversely impact QoL in the physical domain as p value was 0.53 and 0.23 but they definitely reported a decline in emotional domain where p value was 0.02 in both parts.
- **Treatment stage:** Patients undergoing active treatment scored poorly on physical aspect of QoL p value 0.00. On evaluating for emotional aspects, patients on follow up and initial presentation group scored poorly, p value being 0.00.
- **Stage of disease:** Patients who had presented with metastasis (32 patients) had poor QoL (all four parts) as compared to the patients presenting with early (86 patients) and locally advanced (132 patients) stage of breast cancer. p value being 0.00 for all.
- **QoL in relation to radiotherapy:** Patients who had never received radiotherapy (144 patients) fared well for physical domain of QoL as against 106 patients who underwent radiation therapy, p value being 0.00 for both parts. This difference was lost on psychological front with p value at 0.59 and 0.41.

Discussion

There have been recent improvements in management of carcinoma breast, with very high proportions of women surviving past 5 years [9]. With these gains, it is increasingly important to study the psychosocial impact of breast cancer and its treatment. A key issue in this context is the patient's QoL. In previous breast cancer studies, QoL served primarily as a means of evaluating somatic treatment concepts, for instance, when comparing different operative techniques – breast conservation versus mastectomy [10–12], or different chemotherapeutic and radiotherapeutic regimens [13]. These studies, in which QoL assessment was an “add on” to the clinical protocol, were primarily concerned with the short-term effects of the therapies employed. There are only a few studies of breast cancer survivors dealing with the long-term adaptation beyond the first year of diagnosis.

We found that majority of patients enjoy a good and non-capacitating QoL. (55% were in the bracket of good and excellent QoL) There are studies with similar results and most of them have concluded that overall QoL in women who survive breast cancer is good [14–19]. Factors that may contribute to poorer health perceptions and QoL include experiencing a menopausal transition as part of therapy, and feeling more vulnerable after cancer [14].

Overall QoL was better in the older population as compared to the younger group. The findings in older women are slightly difficult to interpret, as certain domains of QoL may be more salient to older women than other groups of breast cancer patients. For instance, older women ambulation and mobility impairments may make the difference between independent livings and assisted living [16, 20]. Likewise, mild fatigue may have a multiplicative effect in impairing activities of daily living in a frail older woman, while only being bothersome to a younger woman. Patients with breast cancer frequently complain of problems with their memory and concentration. Such reports are known colloquially as “chemobrain” or “chemofog”. Empirical evidence is accumulating that cognitive problems are associated with use of surgery and chemotherapy [21]. For example, Cimprich [22] examined attention and reported decrements in attention-related tasks in older, but not in younger breast cancer patients. Tamoxifen has also been found to negatively affect cognition in a sample of women aged 57–75 [23].

Patients who were illiterate enjoyed a better QoL as compared to their educated counterparts. No studies were found however, taking this aspect into consideration. In a study, education was found to be a significant predictor of overall QoL in univariate analysis, (as against the finding in our study) however this significance was lost in the multivariate analysis [24–26]. Maximum illiterates in the study group were in the age group of more than 50 years, it would be appropriate to say that elderly and lesser-educated group had a better QoL [15] as such populations are less demanding and have a minimal expectation from life.

Patients with no co-morbidity fared better as compared to the group of patients with presence of co-morbidities. Consideration of co-morbidity data is essential for future outcomes research among older women. Exclusion of older women with multiple co-morbidities from clinical trials may result in less representative samples of breast cancer patients and interfere with improving understanding of the impact that such conditions have on QoL. Presence of co-morbid conditions may also limit discussion of treatment options [17] or complicate delivery of treatment such as chemotherapy [18, 27, 28]. Specialised tools and methodologies may need to be developed and applied to research with older female populations to fully capture non-cancer influences on outcomes. Examples could include the multiple informants approach when working with cognitively

impaired women [29] or the comprehensive prognostic index [30] which is created by combining indices of co-morbidities that impact breast cancer survival with age and cancer stage.

Patients who had completed their treatment had better QoL on physical domain; however they scored poorly on emotional and psychological scale. A similar finding was seen in patients who were assessed on diagnosis. Patients undergoing treatment had a compromised overall QoL and their physical capabilities were restricted leading to poorer scores. Related studies have shown similar findings and it has been reported that with the exception of axillary dissection, the processes of care, and not the therapy itself, seem to be the most important determinants of long-term QoL in patients of carcinoma breast [14]. One study quotes that; most women who survive breast cancer enjoy a high QoL well over 5 years after diagnosis [31]. But systemic adjuvant treatment can lower long-term QoL, especially in the area of physical health [31–36]. Specifically, women who had chemotherapy or tamoxifen were less able than before to do vigorous physical activity [23] and also reported greater sexual discomfort [37]. The patients who had not received the radiotherapy (144 patients) had a better QoL especially in physical domain. The remaining 106 patients who received radiation scored poorly on physical aspect of QoL but were psychologically as comfortable as the non-radiation group.

The QoL significantly varied as per the stage, with early breast cancer patients faring well in physical as well as psychological aspect. The patients in stage IV had a poor QoL. This can be due to the fact that the presenting populations are either aware or well counseled that the treatment offered will be with the intent of cure for early and locally advanced stage disease. A stage IV disease is usually offered either palliative treatment or best supportive care.

At this stage, we need to highlight that all QoL parameters were picked up from questionnaire used in western society. Though all efforts were made to include the parameters relevant to our set up, but it still appears lacking at various aspects. Firstly, in our country lifestyle varies with variation in social status of patients, rural or urban, education, occupation, nuclear or joint family and the list is endless. In west a sample of patients will not have such disparity, making a uniform assessment possible. Secondly, the stage of disease which is a significant predictor of QoL remains an important confounding factor. In the advanced western nations diagnosis of breast cancer has undergone a dramatic evolution since the mid-1980s and 50–75% of all breast cancer is detected by self-examination. Subsequent to better imaging, there has been a shift toward the diagnosis of clinically occult and non-palpable lesions. Thus, such people are likely to have a better QoL against our population where majority present as Locally Advanced Breast Cancer (LABC). Thirdly, understanding of the disease in our society

may affect the outcome directly or indirectly. Survivors continue to experience the uncertainties of the illness. Many will have to come to terms with having a progressive illness and an impending death. Death and recurrence remain a major common factor in both side of the globe. But other concerning factors are appearance, matrimonial relations, sexual functions and continuing with job. These factors may or may not have equal importance in our set up but will definitely affect the outcome if we do not segregate our samples accordingly. Last of pitfalls is that culturally, Indian parents are substantially involved in their offspring's personal and social development, education, and more importantly their marriage, as majority of the marriages are arranged. Such marriages are stressful particularly for the parents of girls. Adding the taboo of a parent with cancer affords even greater psychological pressure and financial burden on a family with unmarried children. The diagnosis of cancer in a family also has its social stigma, which may influence the marriage prospects of children [24].

Conclusion

Women with breast cancer represent the largest population of cancer survivors. Although breast cancer patients may not show obvious signs of disease, they do appear to suffer from restrictions in their QoL, possibly indicating problems with long-term adaptation.

Mainly surgical interventions aim to restore the patient to a normal state of health and to achieve an effective cure. Sometimes a procedure will confer only partial improvement to the patient, and achieving a cure may not be an option. Where the benefits derived from a procedure can be counted in the same units as the risk pertaining to it (e.g. survival) a direct comparison can be made, but where they are in different units, another approach to treatment must be adopted. Even where there is the possibility of increased survival from a procedure, the QoL of the patient during that survival must be taken into account.

The parameters used in QoL studies in west may not be directly applicable to us but it does give us a start. We need to adapt to these parameters and draw our conclusion before we design our own questionnaire and validate it.

Thus, there are many methodological challenges inherent in working with our population. Researchers interested in studying our clientele's QoL need to be cognizant of these special issues to ensure high quality results. Further research is necessary to ensure that we are using the proper approaches to obtain valid information and to improve the quality of care for our clientele.

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