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Evaluation of cancer related fatigue (CRF) in women with gynecological malignancies: a subjective report of psychosocial issues in patients receiving chemotherapy for malignant ovarian tumors in India

Abstract

Background: Cancer Related Fatigue (CRF) is one of the most disabling and distressing symptoms affecting physical and emotional wellbeing of patients diagnosed with cancer or receiving its treatment. This poses a detrimental impact on Quality of Life (QOL) of majority of the patients. Although its assessment and identification has been enormously acknowledged in oncology care, however it is being seldom addressed or reported in majority of the Indian patients.

Objective: The current study explores the prevalence of Cancer related fatigue among Indian ovarian cancer patients receiving chemotherapy.

Material and Methods: Using Multidimensional Assessment of fatigue inventory (MAF inventory), fatigue and its severity was assessed and an in-depth semi structured interview schedule was constructed to explore psychosocial concerns of the patients. Statistical analysis was done using SPSS 21.

Results: Eighty-nine women with confirmed ovarian malignancies were included, and 38% of them were in fourth decade of life, followed by 28% and 20% in fifth and sixth decades respectively. Almost 41% of women had not even received their primary education and most (83%) came from middle social economic families. Nearly half of them were aware of their diagnosis but only 13% had awareness of the prognosis.

Conclusion: Majority of Indian women with malignant ovarian cancer experience fatigue, during their chemotherapy. Elderly women experience it more than younger counterparts. Also associated with it are many psychosocial concerns that are of significant relevance, while they receive chemotherapy. Future research should explore more physical and psychological parameters associated with fatigue so that appropriate psychological therapies and intervention are designed to address this clinically significant issue. Also irrespective of their awareness of their disease diagnosis and prognosis, patients should be counseled for expected fatigue so that they cope up well it, which can lead to their better Quality of Life.

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Introduction

Cancer Related Fatigue (CRF) is the most common symptoms affecting people with cancer and for some, this is most distressing. At its worst, cancer-related fatigue is a draining, ongoing exhaustion that limits one's ability to enjoy life and do activities.[1] It is also one of the disabling phenomenon that can have profound impact on the Quality of life (QOL) of the patients diagnosed with cancer or receiving its treatment,[2,3] This can be affected by many factors, both intrinsic to the patient and extrinsic, such as therapeutic interventions.[3,4] CRF due to treatment is reported in 14% to 96% of patients undergoing cancer treatment[5–11] and in 19% to 82% of patients post-treatment. [3,4] For example, a study reported that up to 90% of patients treated with radiation and up to 80% of those treated with chemotherapy experience significant fatigue.[4] CRF may continue for months and even can last for years following completion of treatment in approximately one third of the patients with cancer.[5] Several studies have also reported significantly worse fatigue in cancer survivors compared with non-cancer populations.[3] One of the study for example, revealed that seventy-six percent of patients experience fatigue at least a few days each month during their most recent chemotherapy; 30% experience it on a daily basis, 91% of those who experience fatigue report that it prevented a "normal" life, and 88% indicate that fatigue caused an alteration in their daily routine and made it more difficult to participate in social activities and perform typical cognitive tasks.[5] Evidences suggest that severe fatigue is more prevalent in patients receiving chemotherapy 58/59 (98.30%), and concurrent chemo-radiation (33/42 (78.57%)) as compared to radiotherapy alone (Moderate-9/20 (45%) and Severe-9/20 (45%)).[2] Chronic CRF has been reported to be also associated with multiple psychosocial problems, somatic complaints, and poor quality of life, and is also associated with considerable psychological distress and can impose a significant financial burden by limiting a patient's ability to work.[8]

Numerous recommendations for fatigue management have also been suggested by various studies that focus on identifying factors contributing to fatigue.[8–11] Hence, there is a great deal of improvement in managing CRF among cancer patients, like implementing pharmacological and non-pharmacological interventions, which may consist of psycho stimulants and placebos. These combinations of interventions have showed a promising out come in managing CRF.[12–14] A study by Marrow et al. 2005 suggests individualized treatment for CRF which included use of hematopoietics, antidepressants,

corticosteroids, and psycho stimulants.[15] Another such study by Mustian et al.,[16] 2007 suggests interventions like exercise, psychosocial support, stress management, energy conservation, nutritional therapy, sleep therapy, and restorative therapy for the effective management of CRF [16]. A similar study on the effectiveness of behaviorally oriented intervention reported a significant improvement in physical functioning and indicated a trend towards improved CRF.[17]

On the one hand abundant guidelines and interventions are stated in the West for identifying and managing CRF.[8,12–14,16,17] CRF has also been accepted as a diagnosis in the International Classification of Diseases, Tenth Revision, for which appropriate interventions are provided to address it,[18] however in India CRF still remains under-reported, under recognized and under treated.[9]

Materials and methods

This was an exploratory study, for which a purposive random sampling technique was adopted. All the patients with histopathologically proven ovarian malignancies receiving chemotherapy were included. Patients were enrolled in the study only when they have been thoroughly counseled about the study and its importance. After receiving their signed informed consent, or in some cases from their immediate caregivers (family members), patient's detailed demographics were recorded. The assessment of the level and extend fatigue was taken using the 16-item Multidimensional Assessment of Fatigue (MAF) scale, that measures fatigue according to four dimensions: degree and severity, distress that it causes, timing of fatigue (over the past week when it occurred and any changes), and its impact on various activities of daily living (household chores, cooking, bathing, dressing, working, socializing, sexual activities, leisure and recreation, shopping, walking and exercising).

To calculate Global Fatigue index (GFI), item 15 is to be converted to a 0-10 scale by multiplying each score by 2.5 and then the sum of items 1, 2 and 3 is to be calculated, an average score of item 4-14 and newly scored item 15 is obtained. Scores are not assigned to items 4-14 if the respondent gave a response of" do not do any activity for the reasons other than fatigue." If a respondent selects "no fatigue" on item 1, assign a zero to items 2 -16. Item 16 is not included in GFI. Interpretation of scores: A higher score indicates more severe fatigue, fatigue distress, or impact on activities of daily living. For this study scores were categorized as "no fatigue, mild fatigue, moderate fatigue and severe or extreme fatigue", according to the scores obtained, which were documented, following the norms and protocol of the scale.

Patients enrolled in the study must have received at least the first cycle of their chemotherapy for confirmed and documented ovarian malignancies for both curative and palliative intend, at Rajiv Gandhi Cancer Hospital and Research center, New Delhi India. Data was collected from August 2015 to February 14 2016. For fulfilling the inclusion criteria for the study, patients must be fully oriented, with age not more than 70years. The patients receiving concurrent chemo-radiation were excluded in order to focus only on chemotherapy related fatigue, for which the current study was designed. Patients were also excluded if they were receiving intensive care in ICUs; had been admitted for supportive care for post chemo morbidity or admitted in emergency; had active infection; had dual malignancies, one of which is malignant ovarian tumor; had a history of illicit drug use or alcohol abuse; had a mental incapacitation or emotional or psychiatric disorder and had metastasis of unknown origin (MUO) or concurrent medical conditions. These variables were controlled in order to avoid them to confound with the results of the study or pose unwarranted risk in administering the tool or conduct the interview.

Using a 10-item semi-structured questionnaire, which was developed by the researcher, the psychosocial concerns during the chemotherapy were also assessed in the study. This questionnaire was developed to address various psychosocial concerns that go alongside the treatment, and have a significant impact to overall quality of life of the patients. This questionnaire comprised of items based on concerns like: subjective fears of patients related to treatment, knowledge of diagnosis and prognosis, level of interactions with the treating oncologist, satisfaction with communication with treating team, awareness of treatment related side effects, and logistic issues during chemotherapy. The semi-structured questionnaire was used only after establishing its content validity. To conduct this in-depth interview for the study, it took 8 to 10minutes for the researcher to complete it. After taking the in-depth semi-structured interview, patients' responses were recorded and transcribed. The themes for psychosocial concerns of the patients that emerged from the interview were categorized and coded.

For this study, the professional and ethical code was followed and if the patients showed emotional outburst or displayed any psychological or behavioral crisis during the assessment or interview, it was made sure that the process would be stopped. For such situations, patient was given psychological and emotional counseling support or psycho therapy and assessment and interview were-conducted only if the patient is in optimum psychological well being and has given permission for same. Assessment and interview was conducted by qualified researcher, who was a professional "psycho-oncologist" with a vast experience in the field of oncology.

The responses received for the fatigue scale was marked for each patient and the responses received for the questionnaire were recorded and transcribed and further manually typed. Once the data from all the respondents were collected, the description of options, opinions, feeling, behavior, thoughts, comments suggestions etc. were identified, categorized and coded accordingly. Descriptive statistics (Mean, Frequencies distribution, Tabulation, Charts, Pie diagrams and Percentages), t-test was employed to find the difference of demographics of the patients. Correlation and multivariate analysis were also employed to find the relationships between various variables using SPSS 21.

Results

A total of 89 female patients were enrolled for the current study, pre-stratified by diagnosis and modality of the treatment, which was chemotherapy. For the study all 89 patients completed the study (response rate 100%). Descriptive analysis of frequency of the demographic characteristics revealed that the age range of the participants was 23-74years, and of all, almost 65% (58/89) were in fifth decade of their life at the time of assessment, followed by 21 (23.3%) of patients in seventh decade; 4(4.5%) in their third decade and an equal percentage of women were in the fourth decade of their life. The men age of the participants was 54.6.

Details of demographic characteristics along with their frequencies are presented in (Table 1). Frequency analysis of the level of education revealed that almost half of the women in the study 44(49%) had not received even their primary education, 17(19%) of them had received their primary education and an equal number of women had received their secondary education. Of all the women who participated in the study, 9/89 (10%) had earned abachelor's degree in their education.

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Majority 84(94.5%) participants belonged to middle socio-economic status families and all were married.

The descriptive analysis of knowledge of diagnosis about the disease for all the participants revealed that nearly half of them (47%) were aware of their disease diagnosis and almost the same numbers of patients were unaware of it. Results also revealed that almost five percent of them were neither fully aware of their diagnosis nor unaware of it; however they had an vague idea about their malignancy and were only partially aware of their actual diagnosis. For the awareness about the prognosis of their disease, analysis of the patient data revealed that majority (67%) of the women were completely unaware their disease prognosis and only 13% of them were fully aware of their disease prognosis. Rest of them had only partial awareness of it. A detailed summery of the results about the understanding and awareness of disease diagnosis and prognosis are presented in Table 2.

Table 1 Demographic characteristics of patients as seen in the study

Characteristic	**(n=89)**
Age Decade wise	**(%)**
3rd Decade	4(4.5%)
4th Decade	4 (4.5%)
5th Decade	14(15.5%)
6th Decade	44(49.5%)
7th Decade	21(23.5%)
8th Decade	2 (2.2%)
Education	**(%)**
Illiterate	44 (49%)
Primary education	17 (19%)
Secondary education	17 (19%)
Bachelors	9 (10%)
Socio-economic Status	
Lower	5(5.5%)
Middle	84 (94.5%)

Table 2 Patients level of awareness about their diagnosis and prognosis of the disease

Knowledge of Diagnosis	**(%)**
Yes	47%
No	48%
Partially aware	5%
Knowledge of Prognosis	**(%)**
Yes	13%
No	67%
Partially aware	3%

Analysis of the date for fatigue was done using frequency distribution and the results revealed clinically significant fatigue in 77 (86.5%) of all the patients who participated in the study. Of them 36(40.5%) had moderate level of fatigue requiring clinical intervention for it and 41(38%) had extreme level of fatigue, needful of immediate clinical intervention. Correlation analysis of the data showed a statically strong linear correlation of fatigue with the age of the women, $t= (89) = 0.21$, $p < .05$, with more aged women having higher fatigue score (Table 3).

Frequency analysis of psychosocial concerns, that emerged out of the themes from the interview schedule of the patients showed nearly half them 40/89 (45%) had apprehension of chemotherapy related side effects as the top most concerns, followed by fear of pain in during chemotherapy in almost one-fourth (26%) of them. Concerns and worry about loss of appetite during chemotherapy was reported by 9% of the patients, followed by a combination of many concerns/ miscellaneous (5.5%), generalized anxiety about chemotherapy by (4.5%) and guilt, hopelessness and lack of confidence among (4.5%), concerns about finances and logistics by (3%) and concerns about unfulfilled responsibilities by one percent of all patients. Figure 1 Gives a detailed over view of the psychosocial concurs as found in the participants who participated in the study.

Table 3 Overall Percentage of Patients level of Cancer Related Fatigue (CRF)

Fatigue	**(%)**
No fatigue	4 (3.7%)
Mild Fatigue	8(7.5%)
Moderate Fatigue	36(5%)
Extreme fatigue	41 (38.3)

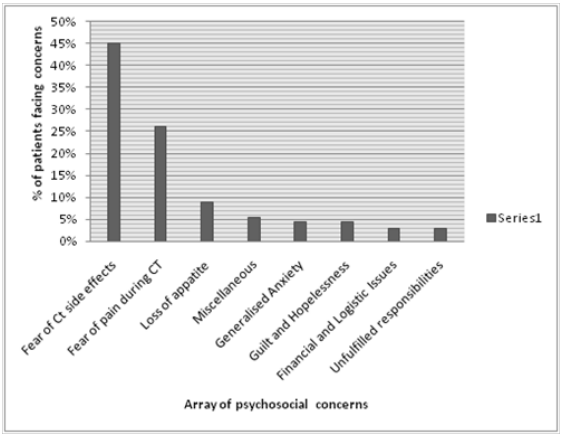

Figure 1 Most common psychosocial concerns reported by the patients while receiving chemotherapy for ovarian cancers.

Discussion

Little is known about the level and extends of the Cancer Related Fatigue (CRF) among Indian cancer patients receiving anti cancer therapy. However, this is one of the significant challenges faced by majority of the patients receiving cancer treatment. A review study on meta-analysis on published articles on fatigue revealed that most of the Chemotherapy patients experience cancer related fatigue. It also revealed that fatigue is experienced even after months of completion of chemotherapy.[5] One of the Indian studies goes in parallel with such findings, that explored the prevalence of rate of fatigue in cancer patient receiving various anti cancer therapies, and its impact on QOL, found that Severity of fatigue was more after chemotherapy and concurrent chemo-radiation therapy while impact on QOL was more after the radiotherapy.[7] Such finding suggest that the prevalence rate of CRF is found more in patients receiving chemotherapy for cancer which may potentially have a challenging threat to the Quality of Life of these patients, even long after the treatment is completed.

Most of the Western studies exploring the impact of chronic fatigue on different parameters of QOL have also found various psychological factors associated with it. A multi-centric comparison study conducted on examining the prevalence of chronic CRF in Norwegian testicular cancer survivors compared to chronic general fatigue (GF) in the Norwegian general population, and associations between a variety of relevant variables found that chronic CRF was

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far more common among testicular cancer survivors than chronic general fatigue in the general population and is associated with poor QOL and multiple psychological and somatic health problems.[7]

In our analysis, what was interesting was the fact that wefound althoughhalf of the patients were not aware of their diagnosis, however they were receiving chemotherapy in a tertiary care cancer hospital and most of them where un aware of their prognosis as well. In our country, not revealing the diagnosis or not breaking the bad news of cancer diagnosis to the patient is a common practice in oncology fraternity. Diagnosis and treatment plans are discussed with the family members and there is a great deal of medical collusion among the oncology specialist.[22,23] Still, most of the studies have emphasized on the fact that there are immense information needs among majority cancer patients regarding their disease diagnosis and treatment plan, along with the prognosis. An Indian study exploring the need of knowing the cancer diagnosis among Indian population revealed that most of them have a strong need of knowing if there disease was cancer and nearly 92% had a strong need of knowing the treatment outcome. Age, education and type of cancer strongly affected the information preferences in them.[18]

Another interesting finding of our study also revealed that majority of the patients has clinically significant fatigue due to chemotherapy. Moderate level of fatigue was found in 40.5% of all the patients who participated in the study requiring its clinical attention and 38% had severe fatigue requiring immediate clinical interventions. Results of our study also revealed a significant linear correlation of fatigue with age of the women, with more fatigue seen with increased age. Other demographic parameters like socio-economic status, education level and knowledge of diagnosis and prognosis of the disease had no association with the level of fatigue in over all patients.

A significant finding of our study also revealed an array of psychosocial concerns that are faced by the patients along with the CRF during the chemotherapy treatment, which pose a significant challenge to many parameters of QOL. It was found that nearly half of the patients have apprehension of Chemotherapy related side effects, followed by nearly one-fourth patients having anticipated fear of pain due to chemotherapy, loss of appetite by 9%. Combination of many concerns, generalized anxiety, guilt and hopelessness were found in nearly 5% of overall patients. This goes in agreement with many studies that have been reported CRF and its implications on different parameters of psychological wellbeing.[6–12,18]

Current study has tried to provide an understanding on the prevalence and trend of CRF that is not addressed robustly during the course of treatment. This study has also explored significant psychological issues that are faced by Indian patients while receiving treatment for cancer. Assessment and management of CRF should be implemented in cancer care and individualized and multi modality approach for its treatment may be adopted, including pharmacological and non pharmacological therapies to relieve symptoms and improve QOL. This may help in achieving optimum treatment outcomes.

Implications

Current study explores a general scenario of prevalence of cancer related fatigue among Indian cancer patients. Fatigue, which is one of the significant disease and treatment related outcome, should be assessed on regular basis in oncology setting. Education programs for treating team, patients and caregivers may be developed to access and report Cancer related fatigue. Also a combination of pharmacological and psychological interventions may be incorporated in general line of cancer treatment for these patients, which will aim in reducing fatigue and improving overall QOL, that may ultimately lead to better satisfaction with treatment and reduced cancer related burden among these families, their caregivers and also the treating team.

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Conflicts of interest

Authors declare there are no conflicts of interest.

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