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Original Article

Psychosocial implications of Hair loss following Chemotherapy Intervening with completion of Adjuvant Therapy for Breast Cancer

Authors
Chandan Roy Choudhury[1], Anis Bandopadhyay[2], Priyanka Mandal[3]
[1,3]Dept of General Surgery, [2]Department of Radiotherapy Medical College and Hospital 88 College Street Kolkata – 700073, India

Abstract

Context: *Hair loss has been the most feared side effect of chemotherapy for women and it may be more distressing than the loss of her breast.[2]Depression, shame and loss of confidence[2] and anxiety[4] also have been associated with alopecia in women with breast cancer, and as many as 8% may be at risk of refusing chemotherapy because of this fear.*

Aims: *To assess the patient's awareness regarding the side effects of chemotherapy and surgery for breast cancer , perception of study subjects regarding chemotherapy induced hair loss as a psychosocial burden and to measure the relative burden of depression and anxiety*

Settings and Design: *The study was an observational, descriptive and institution based cross sectional study. A predesigned, pretested and semi-structured schedule along with HADS was used for interviewing the consenting breast cancer patients who had already received at least one cycle of chemotherapy.*

Results: *Majority of the respondents are more concerned about the chemotherapy related side effects than the consequences of surgery. About 88.9% of the patients had inhibition of sexual activities while almost half of the study population felt the need to hide their cancer to avoid being stigmatized. 36.6% had thought about discontinuing treatment due to chemotherapy induced hair loss while majority (77.8%) felt the need to address chemotherapy induced hair loss and considered cosmetic grooming and counseling as a treatment option.*

Conclusions: *Sudden diagnosis of breast cancer in a female patient is a traumatic experience and may lead to depression. However the effect of the treatment like removal of the breast or hair loss and other side effects of chemotherapy may have an influence over the recovery from breast cancer and further research is required to understand the severity of the situation.*

Introduction

In India, 144,937 women were newly diagnosed with breast cancer and 70,218 died due to the same in the year 2012.[1] Hair is of great social significance. For time immemorial healthy hair has been a criterion for choosing a mate; an indication of youth, good health and is a symbol of femininity and an integral part of a person's identity.

The number of breast cancer survivors has increased significantly in recent years owing to the advances in early detection and treatment. The treatment for breast cancer includes- surgical management, radiotherapy, chemotherapy and hormone replacement therapy. Major consequences or side effects of the course of treatment includes - incisional hernia, scar, asymmetry after reconstruction (due to surgery);

lymphoedema of the arm, radiation necrosis (due to radiation); hair loss, vomiting and nausea, leucopenia (due to chemotherapy) ; and these can be major stressors in a patient with breast cancer who is undergoing treatment for the disease.[2] Therefore, addressing the impact of breast cancer and its treatment and related side effects on long-term outcomes is an important issue and must be addressed.[3]

Review of literature

It is seen that hair loss has been the most feared side effect of chemotherapy for about 56% of women and for some women hair loss may be more distressing than the loss of her breast.[2] Depression[4], shame and loss of confidence[2] ,lowered self-esteem, negative body image and anxiety[4] also have been associated with alopecia in women with for breast cancer, and as many as 8% may be at risk of refusing chemotherapy because of this fear.[2,5] Studies have shown that chemotherapy induced hair loss is considered to be most burdensome[6] and distressing[7] factor for female breast cancer patients keeping in mind the social stigma associated with women with short hair or being bald. In a study conducted at an oncology centre in South India on 294 newly admitted cancer patients revealed that 46% of patients reported non-awareness of diagnosis and majority belonging to this group refused treatment for psychological distress. (8) A study on breast cancer patients from Australia highlighted the psychosocial concerns of these patients which included coping with side effects, dealing with the change in their concept of self, the need to manage others' changed beliefs and emotions, the associated stress and issues with survival and growth(9). Study by Benjamin B, Ziginskas D et al shows encouraging results that reducing alopecia due to chemotherapy has the potential to increase CMF treatment compliance, enhance patient self-esteem, and improve overall quality of life during this stressful period.(10) Harcourt, D., & Frith, H. also explored breast cancer patients' experiences of chemotherapy treatment, mainly assessing the appearance related changes, focusing on : anxiety associated with the perception that chemotherapy will render them identifiable as a 'person-with-cancer'; and problematic interactions with others. (11) 221 female breast cancer patients were included into the study and assessed at the time of diagnosis, 6 months and 12 month thereafter using Hospital Anxiety and Depression Scale (HADS) and distress thermometer. Findings suggested that anxiety is a more significant psychological state that leads to the feeling of distress in breast cancer as compared with depression. Levels of anxiety at diagnosis in this study justified screening for anxiety, early identification and therapy for maintaining the psychological well-being of breast cancer patients[12] A meta-synthesis conducted by Bertero et al highlighted that the nurses who were aware of the problems faced by breast cancer patients were better able to link those women with resources to help them adapt to living with breast cancer;(13) while another study showed that telephone-delivered psychosocial interventions were effective for decreasing symptoms of depression and anxiety to improve psychological quality of life in both the breast cancer patients and their partners.(14) Till date, understanding the influence of chemotherapy induced hair loss on deterring the patient from completing the adjuvant therapy in breast cancer patients along with the associated depression and anxiety has not been widely explored in India.

Objectives

1. To assess the patient's awareness regarding the side effects of chemotherapy and surgery for breast cancer including reconstructive procedures
2. To evaluate the perception of study subjects regarding chemotherapy induced hair loss as a psychosocial burden and its impact on future treatment options.
3. To measure the relative burden of depression and anxiety among the study subjects using HADS (Hospital Anxiety and Depression scale).

Subjects and Methods

Type of study – observational, descriptive and institution based study**.**

Study design- Cross sectional**.**

Place of study- OPD of General Surgery and Radiotherapy department, MCH, Kolkata.

Study population- pre-menopausal, peri-menopausal and post-menopausal patients with breast cancer, attending OPD of radiotherapy department at MCH, Kolkata.

Inclusion criteria- The participants were chosen according to the following criteria-

1. Consenting patients of breast cancer.
2. Patients who were undergoing chemotherapy with at least cycle of completed chemotherapy for breast cancer were chosen.
3. Patients of age more than 18 years were included in the study.

Exclusion criteria-

1. The patients who did not receive any chemotherapy for breast cancer (neither NACT nor adjuvant)
2. Vulnerable population (like critically ill patients, immune-compromised and pregnant patients)
3. Patients older than 65 years of age
4. Patients with pre-existing depression, anxiety or other psychiatric diseases
5. Patients with pre-existing alopecia of any kind were excluded

Sample size- 45

The study was conducted over a period of 6 months but the sample size has been small due to non-compliant and non-consenting patients. Some patients had an emotional breakdown in between the interview, thus interview couldn't be completed. A total of only 45 patients responded positively to all our questions out of a total patient of 78 selected by inclusion criteria and patients were recruited via convenient sampling.

Research Design

This study utilized an observational, descriptive research method using a prepared interview guide (Appendix A). Questions used were directed at eliciting responses from a number of women who had been diagnosed with breast cancer and had received at least one cycle of chemotherapy which may have resulted in hair loss or appearance-related issues. The interviews were recorded in writing. The data was analyzed identifying major themes common to all participants. These interview questions were intended to assess their awareness regarding side effects of the treatment and how these changes may have affected their self-esteem, social functioning and to measure the relative burden of depression and anxiety in these patients and if it interfered with their willingness to continue the treatment.

Study Tools

A predesigned, pretested and semi-structured schedule which had some questions set by the researcher was used. HADS was used for quantifying depression and anxiety among the study subjects. HADS is a 14 item questionnaire consisting of two subscales: anxiety and depression. Each item is rated on a four-point scale, giving maximum scores of 21 for each anxiety and depression. Scores of 11 or more on either subscale are considered to be a significant 'case' of psychological morbidity, while scores of8-10 represent 'borderline' and 0-7 'normal'.

Data Collection

After relevant ethical approval and permissions pretesting of schedule was done and the data was collected by interviewing consenting study subjects who met the inclusion criteria with the help of a predesigned, pretested and semi-structured schedule and HADS. Ultimately 45 study subjects were interviewed. The anonymity of all of the participants was protected in presentation of the findings.

Data Analysis

The statistical analysis was done using SPSS version 19 software. The basic analysis was done by frequency and percentages for categorical data and mean standard deviation for continuous data. Appropriate statistical associations were made by using Chi square tests. Results have been displayed with the help of simple cross tables and

figures wherever suitable.

Results

A total of 45 female breast cancer patients were studied ranging from 28 years to 64 years, most of them belonged to the age group of 41-50 years with mean age as 43.56 years and S.D. was 8.99. Majority of the respondents were married (84.4%) and only 22.2% of the respondents had educational qualification of secondary examination passed and above. Eight (3 were unmarried and 5 married women didn't have any children) out of 45 (17.7%) patients had no children. 73.3% of our study subjects were Hindu while 26.7% were Muslims. There was almost equal distribution of the respondents with respect to area of residence, though it was slightly skewed towards the rural area (55.6%). 70% of previously working study subjects discontinued their occupation following cancer diagnosis. Family history of cancer was found in 26.7% of the total study population. It was seen that in most of the respondents, breast cancer was diagnosed with in 6 months to 1year from the day of interview though the range from time since breast cancer diagnosis was 1-48 months. Mean duration of time since breast cancer diagnosis was 10.89 months, while standard deviation was 10.24.There was almost equitable distribution among the breast cancer patients undergoing NACT (48.9%) and those undergoing adjuvant chemotherapy (51.1%). Table-1 shows the socio-demographic characteristics of the study population.

About 28.9% and 17.8% of the study population were unaware of the side effects of surgery and chemotherapy respectively. The surgical side effect of asymmetry of breast was known by many (87.5%) though their knowledge regarding incisional hernia following reconstruction after TRAM flap was the poorest (12.5%) [Fig-1]. Awareness regarding hair loss as a side effect of chemotherapy was maximum (94.6%) followed by nausea and vomiting (89.2%) and diarrhea (83.8%), while cardiac complications was least known (13.5%). [Fig-2] According to the study subjects the most severe side effect of chemotherapy was hair loss (56.8%) followed by fatigue (27%) and nausea and vomiting (16.2%). Majority of the respondents are more concerned about the chemotherapy (71.1%) related side effects than the consequences of surgery**.**

About 91.1% of the respondents had experienced appearance related changes i.e. hair loss due to chemotherapy when they were interviewed and there was an equitable distribution of respondents with respect to preparedness to accept chemotherapy induced hair loss(48.9% were prepared to accept chemotherapy induced hair loss). Majority (64.4%) claimed that their self esteem had decreased since diagnosis of breast cancer, while 17.8% reported increased self esteem

Fig : 1

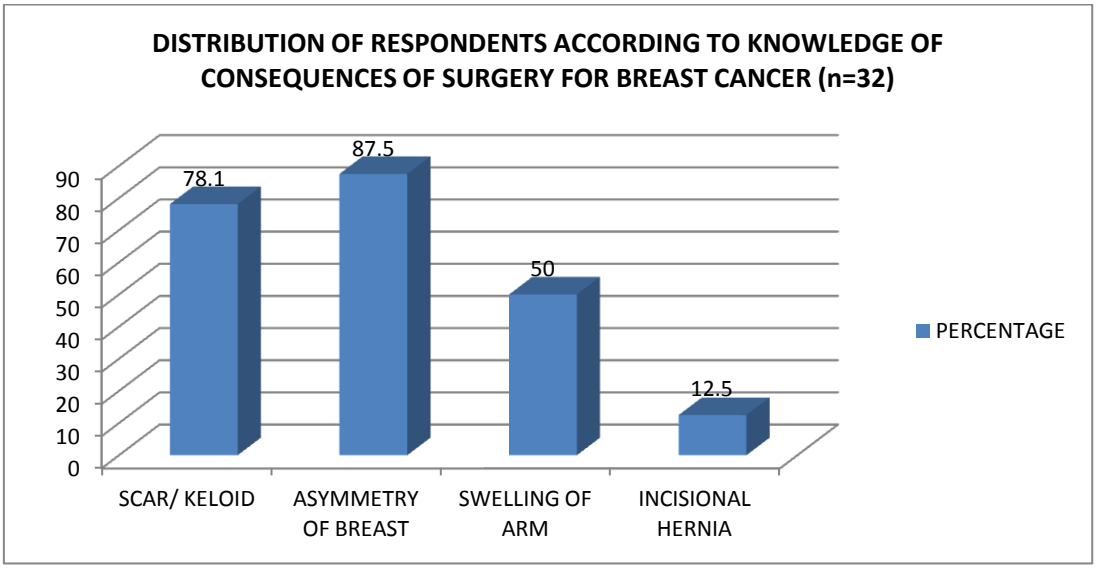
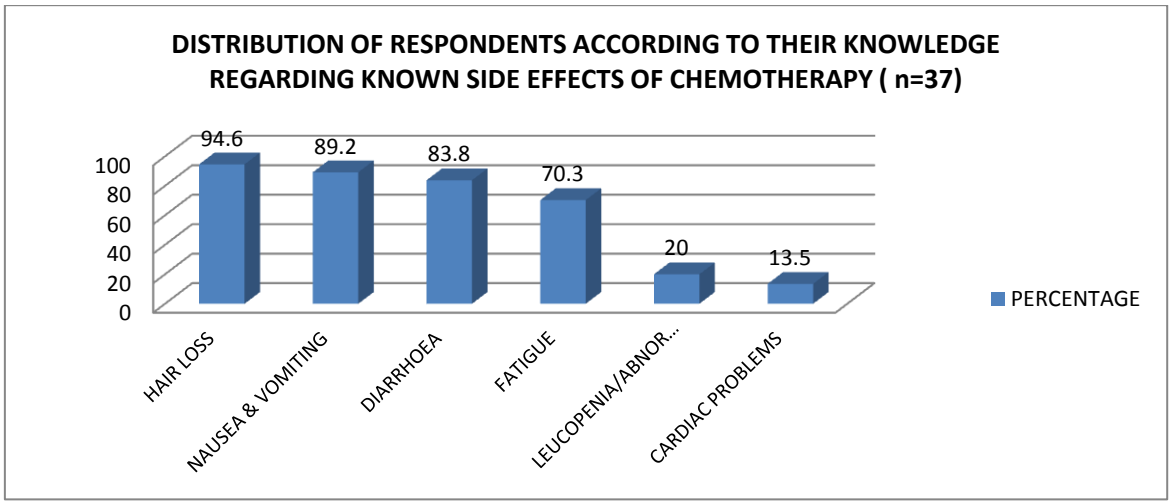


Fig : 2



Out of 45 study subjects, currently married females who were within the reproductive age group (up to 45 years) were considered for evaluating inhibition of sexual activities and among them 88.9% reported inhibition of sexual activities post-cancer diagnosis which may have been influenced by chemotherapy induced hair loss. It was seen that 40% of the study population felt the need to hide their cancer to avoid being stigmatized.

As shown in Table-1, majority of the respondents felt there was no change in perception of their partner though it is observed that about 45% of the respondents felt a change in the perception of friends followed by the surrounding general public unknown to the patient(25%). Out of 45 patients 41 experienced chemotherapy induced hair loss and 77.8% patients felt the need to address it and considered cosmetic grooming and counseling as a treatment option. 60% of them preferred group approach over one to one approach technique for counseling, while a striking percentage of 36.6% had thought about discontinuing treatment due to chemotherapy induced hair loss.

Almost equitable distribution of respondents was seen according to normal, borderline and abnormal status of anxiety and depression among the study subjects while about 22.2% had both depression and anxiety when screened for depression and anxiety using HADS. Total of 16 patients had abnormal depression score according to HADS. (Table -2)

Table -1: Distribution of the study population according to different aspects of perceived stigma following diagnosis of breast cancer

		Frequency	Percentage
1.	Felt partner perceived differently **(n=38)**	1	2.6
2.	Felt other family perceived differently (n=45)	6	13.3
3.	Felt friends perceived differently (n=45)	9	45.0
4.	Felt co- workers perceived differently **(n=20)**	5	25.0
5.	Felt perceived differently in public place (n=45)	17	37.8
6.	Ever felt the need to hide cancer to avoid being stigmatized (n=45)	18	40.0
7.	Withdrawal from normal social activities due to chemotherapy induced hair loss (n=45)	28	62.2
8.	Inhibition of sexual activities **(n=27)****	24	88.9

**8.Inhibition of sexual activities (n=27): Out of 45 study subjects, currently married females who were within the reproductive age group (upto 45 years) were considered

Table-2: Distribution of the study population according to their overall psychological status: (n=45)

Psychological Status	Normal Frequency (%)	Borderline Frequency (%)	Abnormal Frequency (%)	Total Frequency (%)
Depression	14(31.1)	15(33.3)	16(35.6%)	45(100.0)
Anxiety	11 (24.4)	18(40.0)	16(35.6)	45(100.0)

The correlation between depression and age (p value is 0.895), religion (p value = 0.851), type of chemotherapy (p value = 0.175) and preparedness for hair loss (p value = 0.256) was statistically insignificant. It is seen in our study that among the married respondents, 42.1% had abnormal depression score according to HADS, while widows and single patients had normal score (p value -0.032) and thus statistically significant. Among those who had family history of cancer 8.3% had abnormal depression. score while 45.5% had depression without any family history of cancer (p value=0.021) and was statistically significant.

Neoadjuvant chemotherapy patients had more abnormal depression scores in comparison to those receiving adjuvant therapies. Abnormal depression scores were seen higher among those who weren't prepared for the hair loss than those who were prepared. When anxiety scores were correlated with age, marital status, family history of cancer, preparedness for hair loss and type of chemotherapy and religion, the results were statistically insignificant. Though it is seen that abnormal anxiety scores were more common with study subjects aged more than 50 years, followed by 31-40 yr and 41-50 yr age group. Only 25.0% of the study population within 30 years of age had abnormal anxiety scores. Among married respondents 39.5% had abnormal anxiety scores followed by 14.3% in the study population of widows and patients who were single.

Among patients with no family history of cancer, 39.4% had abnormal anxiety scores where as those who had family history of cancer it was only 25%. It is seen from our study that anxiety is more common among patients undergoing NACT (40.9%) than those undergoing adjuvant chemotherapy (30.4%). Study subjects who were not prepared for hair loss due to chemotherapy 43.5% had abnormal depression scores, while among those who were prepared it was only 27.3%.

Discussion

This study was conducted among 45 breast cancer patients ranging from the age of 28 years to 64 years, with maximum belonging to the age group of 41-50 years. There was almost equal distribution of the respondents with respect to area of residence, though it was slightly skewed towards the rural area which may be governed by the fact that the study was conducted in a government tertiary care hospital. There was almost equitable distribution among the breast cancer patients undergoing NACT and that undergoing adjuvant chemotherapy. A considerable part of our study population, 28.8% and 17.8% were unaware of the side effects of surgery and chemotherapy respectively probably because only 22.2% of the respondents had educational qualification level of secondary and above and since majority came from rural areas. Data from a study in South India suggests that about 46% of their study population were unaware of their cancer diagnosis itself. Majority of the respondents are more concerned about the chemotherapy related side effects than the consequences of surgery and maximum response to most severe side effect of chemotherapy was for hair loss followed by fatigue and then nausea and vomiting in our study. Though over time there has been an enormous development in the healthcare sector giving rise to newer drugs every year, these have lead to a significant decrease in the intensity of the side effects of chemotherapy. For example In the past two decades, we have seen the ranking of nausea has considerably decreased over time though hair loss has remained in a higher rank over the course of time. [15,16]

Hair loss has been associated with decreased self esteem in our study as well as in other studies too, it is also considered as a visible reminder of the disease[17]. 70% of previously working study subjects discontinued their occupation following cancer diagnosis in our study and hair loss may be having an influence on willingness to continue working or creating apprehension about returning to work as documented in previous studies[18]. Majority of our study population claimed that their self-esteem had decreased since diagnosis of breast cancer, while some said their self-esteem has increased. The change in the perception of the sense of self and self-esteem and the decrease in sensuality and sexuality has also been felt to be related to hair loss [19] and inhibition of sexual activities was reported in our study also.

It was seen in our study that almost half of the study population felt the need to hide their cancer to avoid being stigmatized. Majority felt the need to address chemotherapy induced hair loss and considered cosmetic grooming and counselling as a treatment option. Imparting education, involving support groups, and implying self-care strategies have also been suggested as important components of any management approach in these cases.[3]

It is reported that patients who fear chemotherapy induced hair loss may sometimes select regimens with less favourable outcomes or may refuse treatment[3]. A striking percentage of 36.6% had thought about discontinuing treatment due to chemotherapy induced hair loss among our study subjects, however the percentage is comparatively less, i.e. only 8% in the West[2]. About 77.8% felt the need to address chemotherapy induced hair loss and considered cosmetic grooming and counseling as a treatment option in our study and 60% of them preferred group approach over one to one approach technique for counseling. other studies have suggested that health care providers should use an individualized approach with a focus placed on the actual moment of hair loss while treating patients suffering from chemotherapy induced hair loss.[3]

In our study about 35.6% of the study population had abnormal anxiety and depression scores each according to HADS, while 22.2% had abnormal scores for both anxiety and depression. in a similar study conducted by Srivastava et al. showed the prevalence of anxiety and depression as 37.0% and 28.0% respectively when studied among 200 breast cancer patients.[20]It is seen in our study that the total study population who were married, 42.1% had abnormal depression score according to HADS, while widows and single patients had normal score and was statistically significant. Married women reported to have more depressed because of their constant worry about their family's well-being, being well aware of excessive financial burden that comes with this disease and the uncertainty of the future, this association has been seen in other studies too.[20] Among our study subjects less than half of NACT patients had depression while only some patients undergoing adjuvant chemotherapy had depression, this could be due to the fact that by the time a patient is being subjected to adjuvant therapy, she has already come to terms with most of the side effects of surgery and chemotherapy due to the period of time between surgery and initiation of chemotherapy.

It is seen that near majority of the respondents who were not prepared for hair loss had abnormal status of depression according to HADS, whereas among those who were prepared 27.3% had abnormal status of depression, showing that being prepared for hair loss can reduce the psychiatric morbidity of the patient. Lastly this study shows that depression is prevalent among the younger population (<30 years) , married women and those undergoing NACT, where as anxiety is more common in those more than 50 years of age, single/ widowed, those without any family history of cancer and those undergoing adjuvant therapy.

Limitations

The selected study sample was undergoing either surgery, radiotherapy, chemotherapy, or a combination of treatments. Since it was not a

homogenous sample undergoing the same mode of treatment, the influence of a particular treatment modality on depression was not assessed. Tumor staging was not done for the study sample; hence, the effect of cancer stage on depression was not assessed. Those patients with depression would benefit from pharmacotherapy and psychotherapy which was beyond the scope of this study. The pattern and severity of hair loss was not assessed.We suggest that for future studies prospective study type should be preferred for long term observation.

Conclusion

Sudden diagnosis of breast cancer in a female patient is a traumatic experience and may amount to depression. However the effect of the treatment like removal of the breast or hair loss and other side effects of chemotherapy produces more depression in the minds of the patient which might have an impact on recovery of breast cancer. Our study was aimed to find the impact of the treatment on the psych of the patient of which depression and anxiety is the main component and we tried to evaluate the awareness of the related side effects of surgery and chemotherapy and to assess the psychosocial burden of chemotherapy induced hair loss and its impact on future treatment options.

We found that hair loss due to chemotherapy not only lead to depression and anxiety but also inhibition of sexual activities, social withdrawal and felt they were perceived differently among peers, co-workers and in general public and led to discontinuation of their occupation. Hair loss was the most dreaded side effect of chemotherapy and 33.6% of the study population thought of discontinuing chemotherapy due to the same and this issue must be addressed properly before instituting chemotherapy otherwise it might lead to treatment discontinuity and reduced compliance. Further research on the side effects of the treatment is necessary not only to assess a detailed psychosocial impact but also to assess the long term prognosis and recurrence due to depression and anxiety.

Acknowledgement: To the nurses and paramedics for their support and to the patient relatives for their help to conduct the interview

Confidentiality: The participants were made aware that the information they share will be utilized for research purpose only. And any document such as consent forms, or any other document that could be used to identify them is strictly confidential and their identity will not be disclosed, not even during the presentation of the findings.

Informed consent: Consent forms (Appendix B) were made following all of the necessary guidelines to conduct this study. The consent forms were read and signed by the research participant after they were screened and agreed to voluntarily participate in the research study

Ethical Clearance- the study was conducted only after the required Institutional Ethical Committee approval at Medical College Kolkata.

Conflict of interest: none.

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