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Fear of Cancer Recurrence and Coping among Breast Cancer Survivors among Indian Females: A Longitudinal Study

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Abstract

Introduction Breast cancer survivors (BCSs) may experience a cascade of negative reactions during the entire treatment process. Post-treatment, the most common challenge among all fears is cancer recurrence. The fear brings many forms of psychological morbidity during follow-up. However, coping throughout and beyond cancer helps survivors hold a strong pillar of support as part of backup.

Objective This study aims to assess the interplay of the fear of cancer recurrence (FCR) and how it impacts the distress and relation of coping with recurrence.

Materials and Methods A longitudinal study was conducted in a tertiary care center in North India: T1 (January 2021–April 2021) and T2 (May 2023–September 2023). A total of 700 BCSs were approached initially, and after 2 years, they were again screened using the purposive sampling technique. Statistical Package for Social Sciences (SPSS) 23 was used to analyze the data.

Results The patients' mean age (standard deviation [SD]) was 48.14 (8.53) years. The mean (SD) FCR score was 15.26 (4.45). There was an inverse association between the FCR score and the coping score. The higher the age, the lesser the FCR score and the better religious coping.

Conclusion Psychological FCR is a detachable part of patients' worry once a person is diagnosed with any threatening illness. The coping mechanism should be strengthened by providing psychosocial interventions, family therapy, and other individual-centered therapies.

Keywords
- breast cancer survivor
- fear of cancer recurrence
- coping
- psychological distress
- depression
- women
- India

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Introduction

Fear of cancer recurrence (FCR) among breast cancer survivors (BCSs) is a significant and often enduring psychological challenge that profoundly impacts their quality of life. This phenomenon encompasses a broad spectrum of emotional responses, ranging from mild anxiety to debilitating distress. Understanding the predictors, magnitude, and coping strategies associated with fear of recurrence is vital for enhancing this unique population's well-being and long-term survivorship. This study embarks on an exploration of these facets to shed light on the complex landscape of FCR among BCSs.

Fear of recurrence has garnered increasing attention within the oncology community due to its pervasive influence on survivors' psychological and emotional well-being. As breast cancer (BC) is one of the most common malignancies affecting women, its survivors represent a substantial proportion of the cancer survivor population. For these individuals, the specter of cancer recurrence looms as an ever-present concern, casting a shadow over their lives long after treatment has ended.[1]

This study's primary objective is to find the predictors that contribute to the magnitude of fear of recurrence. Various factors, such as demographic characteristics, disease-related variables, and psychosocial factors, have been identified as potential contributors. For instance, age, time since diagnosis, and treatment type are among the predictors that may influence the intensity of fear of recurrence.[1]

Furthermore, BCSs' coping strategies to manage their fear of recurrence will be scrutinized in this study. These strategies can profoundly impact survivors' overall well-being and quality of life. Gaining insight into these strategies, which may encompass emotional regulation, information-seeking, and social support utilization, will provide a more comprehensive understanding of how individuals navigate the ongoing psychological challenges associated with BC survivorship.

This research endeavors to contribute to a deeper understanding of FCR among BCSs by examining its magnitude, coping strategies, and intricate relations with different demographic and clinical variables. By doing so, we hope to provide first-of-its-kind findings per our literature search till September 2023; no Indian data are available in this area. This can inform the development of tailored support and interventions for this resilient and unique population, ultimately enhancing their overall well-being and survivorship.

Materials and Methods

We conducted a longitudinal study: T1 (January 2021–April 2021) and T2 (May 2023–September 2023). We have approached (matching the study population) 700 BCSs for the study who have taken treatment from our institution between January 2016 and June 2020. We conducted detailed review of the patients' medical records to verify their BC diagnosis, the timing of diagnosis, the treatment methods utilized, and the cancer stage. The study sample in T1 was 165 and in the follow-up study (T2) the study sample was 142, which were meticulously selected following specific criteria for inclusion and exclusion. Patients were actively recruited using a purposive sampling technique during their follow-up appointments, while some individuals were contacted via telephone for participation. We clearly explained the study's objectives in the participants' native language.

In phase 1, we have included women aged between 18 and 60 years who had been diagnosed with and treated for BC and had completed their active treatment regimen, encompassing surgery, chemotherapy, and radiotherapy, for a minimum of 3 months, and patients with metastatic cancer, cancer recurrence, or those currently undergoing treatment for any psychiatric comorbidities were excluded from the study. During follow-up, the inclusion criteria were those who participated in previous study and willing to participate while patients having any severe ailment, and metastasis and recurrent cancer were excluded. To safeguard the anonymity of participants, no names or other personally identifying information were included in the questionnaires or the database.

Measure

A semi-structured proforma was used to examine patients' socio-demographic and clinical characteristics. Psychological distress was assessed using the Depression, Anxiety, and Stress Scales-21 (DASS-21), the FCR Scale, and Brief COPE. All of the tools were administered by the interviewer (mental health professional). Patients confirmed positive for any psychiatric illness were sent to the Department of Psychiatry for further evaluation.

Fear of Cancer Recurrence

The fear of cancer recurrence inventory (FCRC) SF was developed for assessing fear of recuurence among cancer patients.[1] The FCRI-SF measures FCR through a 9-item Likert scale, where each item assesses a distinct aspect of FCR. The response options range from 0 (not at all or never) to 4 (a great deal or all the time), capturing the intensity and frequency of fears related to cancer recurrence. Summing the items yields a total score for each subscale as well as the total scale. A higher score reflects higher levels of FCR.

Depression, Anxiety, and Stress Scale

The DASS-21 is a self-report questionnaire that assesses three dimensions of negative emotional states: depression, anxiety, and stress.[2] Each dimension is measured by seven items, each of which is computed on a 4-point Likert scale ranging from 0 ("did not apply to me at all") to 3 ("applied to me very much, or most of the time"). Scores of at least 10 for depression (DASS-D), 8 for anxiety (DASS-A), and 15 for stress (DASS-S) indicate clinically significant distress for each subscale. We utilized the Hindi version of the tool.[3]

Brief COPE

The "Brief COPE" is a widely used and well-established psychological assessment tool designed to measure how individuals cope with stress and challenging life events. It was developed by *Carver, Scheier, and Weintraub in 1989* and has since become a

valuable instrument in psychology and health research. The Brief COPE assesses people's coping strategies when faced with stressors, providing insights into their adaptive or maladaptive responses.[4] The Brief COPE comprises 28 items divided into 14 subscales, each reflecting different coping strategies. These subscales cover a mix of adaptive and maladaptive coping methods, ensuring a comprehensive assessment of how individuals handle stress. Examples of these subscales include:

- Adaptive strategies:
  - Active coping.
  - Planning.
  - Positive reframing.
  - Acceptance.
  - Humor.
  - Use of emotional support.
  - Use of instrumental support.
- Maladaptive strategies:
  - Denial.
  - Substance use.
  - Behavioral disengagement.
  - Self-blame.

Statistical Analysis

Statistical analysis was performed using SPSS-23 software. The statistical tests were used after checking the data for normal distribution.

Ethical Approval

The procedures followed were according to the ethical norms of the responsible "*Committee on human experimentation and with the Helsinki Declaration of 1964, as revised in 2013*." The Institutional Ethics Committee "King George's Medical University Lucknow, Uttar Pradesh, India" approved the study (*Ref code: 104th ECM IIA/P14*). Data were collected once. Patients provided informed consent.

Results

Socio-demographic and Clinical Details of the Study Sample

During phase 1 (T1), the mean age of patients was 48.14 (8.53) years. Homemakers comprised 158 (95.8%) of the study's patients, and 56 were illiterate (30.8%). Among the BCSs, 163 (98.8%) were married, 142 (78.9%) were of the Hindu religion, 129 (78.2%) were living in joint families, 115 (69.7%) were from urban or semi-urban backgrounds, and their monthly family income ranged from 5,000 to 10,000 INR 119 (72.1%).

Treatment was completed in a mean (standard deviation [SD]) of 13.05 (10.54) months, with a median of 12 months from 4 to 64 months. In the subjects, family history was negative for cancer—159 (96.4%). Most patients received a diagnosis of cancer at stage three—89 (53.94%). More than half of the women, 72 (43.6%), were in premenopausal status. The majority, 152 (92.10), of the patients expressed "fear of recurrence of BC." There was little variation in phase two (T2); an almost similar trend was observed (►**Table 1**).

Prevalence of Distress

The prevalence of DAS (*depression, anxiety, and stress*) in our study was 29.11, 33.5, and 25.25%, respectively. The majority of the patients were mildly ill (►**Table 1**). In phase 2, patients still had depression but comparatively at less frequency; the majority had mild scores (24.20, 23.5, and 26.25%).

Coping

The most commonly used coping strategy was acceptance, followed by religion and positive reframing, and the least used was humor (►**Fig. 1**). One of most used maladaptive strategies was self-blame, and the least used was substance use (►**Fig. 2**). The mean (SD) coping score was 13 (8.2). The mean subdomain score of various coping strategies is given in ►**Fig. 2**. Coping was inversely associated with FCR and it is found to be inversely correlated with anxiety, depression, and stress.

Discussion

Demographic and Clinical Variable

The mean age of the participants was 43.25 (8.53) years. The mean (SD) of "*duration of the completion of treatment*" in this study group was T1: 13.64 (10.45) and T2: 28 (10.46) months. The mean age of the participants was increased as we conducted this study after 2 years. Another factor is the higher incidence of BC in this age group.[1] The demographics of our study are similar to other studies conducted in this area. This tertiary care center provides free-of-cost care and serves people from low socio-economic backgrounds and rural backgrounds, making the population sample not only limited to one area but an entire region, making the findings' implications more generalizable. Most patients were treated for third stage of malignancy—(54.04%) (T1) while 85 (59.85%) in T2. Lack of awareness, poor financial status, and lack of resources in nearby treatment facilities can be the plausible reasons for the majority of the patients in third stage of malignancy.[5,6]

FCR, Coping, and Distress

Most patients expressed a "fear of recurrence" in both time T1 and T2. The finding itself is significant with respect to percentage of patients having FCR, which shows that survivors have many underlying concerns, resulting in psychological disturbances and decreased quality of life. Evidence suggests FCR as one of the most frequent unmet supportive care needs among BC patients. The study suggested that FCR will be present among all patients irrespective of its high and low percentage, which can go as high as 40 to 60%.[7–9]

Since the initial assessment, there have been no significant changes in the FCR level, as indicated by a meta-analysis conducted by Luigjes-Huizer et al in 2022. The findings suggest a consistent score over time, with no discernible variations or significant differences observed since the completion of cancer treatment. This lack of change could be attributed to repetitive testing and inadequate coping mechanisms, resulting in heightened fear. Furthermore, patients may experience psychological distress when anticipating

Table 1 Socio-demographic and clinical details of the study sample of Time 1 and Time 2 (follow-up)

Variable	Categories	T1 frequency and percentage ($n = 165$)	T2 frequency and percentage ($n = 142$)
Age (in years)	Mean	42	48.14 (8.53)
Occupation	Nonworking (homemaker)	158 (95.8%)	135 (95.07%)
	Working	7 (4.2%)	7 (4.9%)
Education	Not literate	53 (32.1)	50 (35.21)
	Primary	15 (9.1)	14 (9.8)
	High school	40 (24.2%)	34 (23.94%)
	Intermediate	15 (9.1)	16 (11.26)
	Graduation and above	42 (25.5)	30 (21.12)
Marital status	Married	163 (98.8%)	139 (98.8%)
	Single/widowed/ divorced/separated	2 (1.2%)	2 (1.2%)
Religion	Hindu	129 (78.2%)	121 (85.21%)
	Muslim	36 (21.8%)	21 (14.78%)
Family monthly income (Rs)	Up to 2,500	13 (7.9%)	12 (8.4%)
	2,501–5,000	9 (5.5)	8 (5.63)
	5,001–10,000	119 (72.1%)	105 (73.94%)
	Above 10,000	24 (14.5)	17 (11.97%)
Type of family	Nuclear	50 (30.3%)	41 (28.87%)
	Joint	115 (69.7%)	101 (71.12%)
Domicile	Rural	57 (34.4%)	44 (30.98%)
	Urban	108 (65.5%)	98 (69.01%)
Family history of BC	Yes	6 (3.6%)	5 (3.52)
	No	159 (96.4%)	137 (96.47%)
Stage of cancer	Stage 1	5 (3.03%)	5 (3.52%)
	Stage 2	71 (43.03%)	62 (43.66%)
	Stage 3	89 (53.94%)	85 (59.85%)
Time of completion of treatment (months)	Mean (SD); **T1**: 13.64 (10.45); **T2**: 28 (10.46)		
Menopausal status	Premenopausal	93 (56.4%)	62 (43.66%)
	Postmenopausal	72 (43.6%)	80 (56.33%)
Fear of recurrence	Yes	152 (92.10%)	132 (92.95%)
	No	13 (7.9)	10 (7.04)

Abbreviations: BC, breast cancer. SD, standard deviation.

test results, contributing to a sustained level of fear that may not diminish, especially when health care professionals also cannot provide unrealistic assurances. Our study also suggested a correlation between distress scores and fear of recurrence, which might be due to a high fear of recurrence that leads to distress among patients; hence, it can be indicated that although distress decreases over a period of time, factors like FCR can be responsible for its maintenance. Age was associated negatively, which is similar to multiple kinds of literature as young people have more depression; hence, they tend to worry more about the future, directly or indirectly contributing to the FCR.[7,9–13]

Our findings suggest that more or almost equal growth in the adaptive coping subdomain occurs among survivors. The ability to cope with stressful situations tends to develop confidence in oneself.[14] A possible explanation is the high score in the domain of *acceptance.* The reason for a higher mean score in this domain can be associated with acceptance of illness as it starts or comes in many ways and warning to patients. First, the general symptoms bring the patient to the doctor. Second, all the assessment and diagnostic tests performed by the hospital make patients aware that something is wrong with them. Third, delivery of the diagnosis/ breaking bad news and planning of the treatment. Although

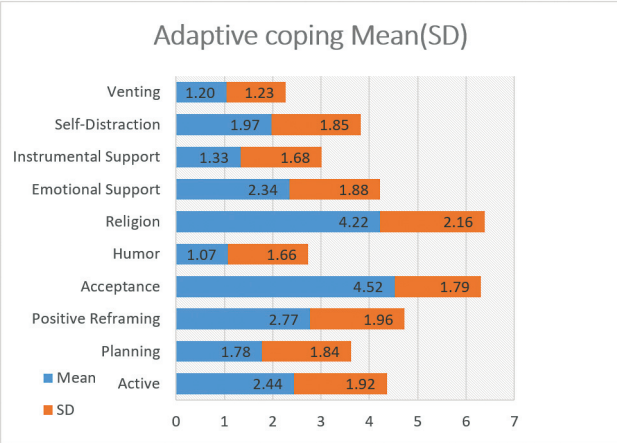

Fig. 1 Depicting mean (SD) of adaptive coping strategies. SD, standard deviation.

treatment comes in the form of shocks, the process, if seen backward, has an entire process of acceptance, making patients cope with the illness easily, at least by accepting and doing whatever possible to reduce its further growth and cure.[15,16]

When individuals fall ill, they often turn to prayer or embrace a path of spirituality. In many cases, people find solace in religious beliefs, especially among cancer patients, where such beliefs contribute positively to coping with adversity. Previous literature has indicated that individuals may perceive illness as a divine test or a consequence of their past life's karma, leading them to turn to belief in a higher power as a final solution to their problems.[13,15–18]

Contrary to this, some individuals may experience a loss of trust in the face of illness.[19,20] The limited growth reported in these areas in past research studies may be attributed to demographic variations and cultural values, especially within the Indian subcontinent. In this region, spiritual beliefs and family support form integral parts of the value system, fostering a more positive trajectory in dealing with challenges.[16]

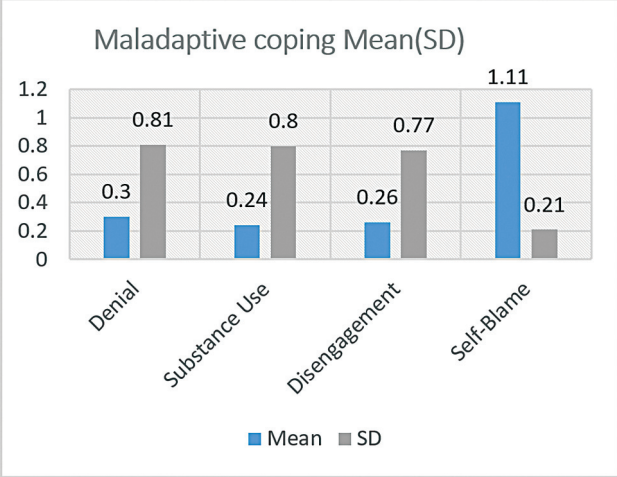

Fig. 2 Depicting mean (SD) of maladaptive coping strategies. SD, standard deviation.

Coping was not correlated with age, suggesting a lack of relationship between age and coping, which is similar to other data. However, some findings contradict our current findings, where results differ in the relationship between age and coping, revealing that the older generation has better and more mature coping mechanisms.[16] Since most of the women in our study belong to rural demography, most have no employment, and coping might differ completely among urban women with active jobs and challenges to meeting financial expenditures and loss of job or work adjustment.

Clinical Implications

The clinical implications of this study can guide clinicians in tailoring psychosocial support for patients by identifying specific coping strategies that survivors employ, allowing for personalized interventions that address individual needs. Assessing the impact of fear of recurrence on functional impairment informs intervention planning, allowing for collaborative efforts to address specific areas of life affected by fear, such as family, work, and relationships. Moreover, recognizing time since diagnosis as a variable of fear informs long-term survivorship planning, emphasizing the need for ongoing support beyond the active treatment phase. Additionally, understanding the correlation between the severity of fear and psychological distress enables clinicians to stratify patients based on their risk for emotional challenges, leading to more targeted monitoring and mental health support for those at higher risk. The study underscores the need for proactive mental health screening, early identification of high-risk individuals, and support. Furthermore, the study emphasizes on explaining the research purpose. The use of tools in the local language underscores the significance of cultural sensitivity in patient communication, ensuring effective understanding and engagement in psychosocial care. Overall, the clinical implications derived from such research contribute to enhanced, patient-centered care, promoting improved quality of life and well-being for BCS.

Limitations

Since the study was conducted in a single facility with outpatients, using a small sample was one of the limiting factors for generalizing the results. Also, some treatment variables like chemotherapy, hormonal therapy, radiation therapy, may impact treatment, may impact the outcome of distress, impact the FCR, and distress might be the result of poor coping. Further longitudinal research should be focused on results predicting the protective factor for FCR and strengthening coping mechanisms. Future studies should also consider including women from urban backgrounds and employed women, which might provide a different understanding of this issue. To our knowledge, no data on

this topic are available among Indian patients, which makes these results very relevant for future studies.

Conclusion

In conclusion, recognizing the intricate interplay among FCR, coping strategies, distress levels, and clinical variables is imperative for a comprehensive understanding of the patient experience. The dynamic relationships between these factors may act as a complex web, each influencing and potentially serving as a protective mechanism for the others. A nuanced understanding of this nexus is crucial for health care professionals as it allows for a holistic approach to patient care. This knowledge fosters a more empathetic and patient-centered care model and underscores the importance of a multidisciplinary approach in addressing the diverse dimensions of the cancer survivor experience.

Data Availability Statement

Author elects to not share data.

Patient's Consent

Informed consent was obtained from the patient before participating in the study.

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None.

Conflict of Interest

None declared.

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Note: Affiliation 1 has been updated after the eFirst publication.

