

**Informal Caregivers' Psychological Distress and Coping Style during Cancer Care****Arnab Bhattacharjee<sup>1</sup>, Ananya Mondal<sup>2\*</sup>, Mandira Chakraborty<sup>3</sup>, Tanima Chatterjee<sup>4</sup>, Swarup Poria<sup>5</sup>, Pritha Mukhopadhyay<sup>6</sup>**<sup>1</sup>Department of Radiotherapy, R.G. Kar Medical College and Hospital, Kolkata, India,<sup>2,3,4,6</sup>Department of Psychology, University of Calcutta, Kolkata, India,<sup>5</sup>Department of Applied mathematics, University of Calcutta, Kolkata, India.**\*Corresponding Author:**

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**Abstract:** Caregiving is a complex task that may affect physical as well as mental health. Without proper supervision and skills, caregiving may become burden for some for the healthcare systems. The current paper made an attempt to uncover the respective roles of different cancers and stages variation of cancers on the mental health of the caregivers in terms of psychological distress (burden and burnout) and the coping strategies (to deal with their distress). In this study, primary informal caregivers of cancer patients were selected. Burden assessment schedule, burn out inventory and Coping checklist II had been selected to assess their psychological distress and coping styles. Comparison among the groups of caregivers reveal that in terms of burden and burnout there are significant variations among caregivers of stage wise different cancers. In case of coping strategies caregivers show significant stage wise difference on emotion focused coping strategies (distraction positive, acceptance, and denial) and problem focused coping strategies. Our findings may be helpful to improve the public health policy about family caregivers.**Keywords:** Informal cancer caregiver, psychological distress, coping style.

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**INTRODUCTION**

Cancer being a terminal illness brings about considerable needs and problems to patients as well as caregivers throughout the trajectory. [1]. With time it has been understood that comprehensive care for cancer patients includes providing attention to the psychosocial needs of their informal caregivers [2, 3]. Now-a-days researches on physical and psychological health of caregivers of cancer patients is an emerging public health issue. Most of researches [4, 5, 6, 7] examining the emotional and physical impact of caregiving on cancer caregivers. However, there is a paucity of research examining the roles of different cancers and stages variation of cancers on psychological distress and coping styles in unpaid informal caregivers of women cancer patients. The present study is a humble attempt to throw light on this uncovered area.

According to WHO (2012), three most common cancers in Indian women are breast cancer, cervical cancer and colorectal cancer. Breast cancer comprises of 27 % of all cancers in Indian women while cervical cancer comprises of 22.9 % and colorectal cancer 5.1 %. Side by side, if we go through the mortality rate of different cancers in Indian women, it again shows Breast cancer being the predominant cancer (mortality rate 21.5 %) followed by cervical

cancer (mortality rate 20.7%) and colorectal cancer (mortality rate 6.4 %) . Regarding 5 years prevalence rate Breast cancer possessing the maximum prevalence rate (35.3 %) followed by cervical cancer (27.4 %), ovarian cancer (4.9 %) and colorectal cancer (3.3 %) [8]. so, it is quite obvious that breast, cervical and colorectal cancer are the predominant types of cancers in Indian women. We also have observed similar pattern in the female cancer patients of Kolkata based population. So, in our study we decided to consider caregivers of these three types of cancer patients of West Bengal.

Many patients with advanced cancer, and their families, have a preference of home care instead of long-term hospitalization which results in a trend towards early discharge of hospitalized cancer patients to their private homes [9, 10]. As a consequence, it becomes responsibility of the patients' closest to take more of their care [11]. At home the primary caregivers are those who spent substantial amount of time regularly in caring for the patients providing physical and emotional support. They could be the patient's spouse, partner or closest relatives, but significant others can also take care of that role and function.

Being diagnosed with cancer by itself is

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recognized as a significant stressor and the intricacies and difficulties of cancer treatment are additionally dreadful. When family members faced these challenges, most of them have a tendency to view the caregiving role as a liability. Because, for cancer patients informal caregiving is a vital part of managing patients and providing care which results extensive burden for the caregiver [12].

Growing researches has supported the fact that cancer distresses not only the patients but also their caregivers. Patients diagnosed with breast cancer, cervical cancer and colorectal cancer fail to exert adequate control over their daily livings. It then becomes the responsibilities of their caregivers to ensure their physical and psychological wellbeing and needless to say this is not an easy task. Thus, care giving can exert a heavy toll on those who provide care [13,14].

Apart from stress and burden being common hallmarks of care giving, previous research findings reported the prevalence of anxiety and depression in informal caregivers [15, 16, 17]. Majority of the literatures' have reported that caregivers' experiences psychological and emotional distress [18, 19]; physical illness [18, 20,21]; disruption of social and sexual relationships[22]. These manifold dimensions of distress results from an incongruity between care demands and the accessibility of resources to deal with those. Caregivers' individualistic reactions to these multiple dimensions of demands are often ascribed as "burden". The increased responsibility knowing the fact of "no cure can be expected" (as often happens in late-stage cancer) often may lead to negative consequences on caregivers' mental health. [23, 24]. Even caregivers' observation of the patient's suffering also contributes to their depression and burden [25].

Research has shown that unmet needs, dissatisfaction with care, getting no help when need and imbalance between care demands and resources, may lead to burnout. An exhaustive state of physical, emotional, and mental health which goes along with a detrimental change in caring attitude is termed as caregivers' burnout. Burn out is also characterized by reduced feelings of personal accomplishment [26] and may experience fatigue, stress, anxiety, and depression [27].

Caregivers can learn effective coping strategies to take care of their psychological distress without being persistent until they reach the exhaustive state. They need to be self-aware and recognize their own constraints to acquire effective coping skills. Coping strategies include attempt to preserve mental and physical health by moderate or buffer the effects of stressors on physical and emotional wellbeing [28]. Caregivers coping strategies are related to caregivers' burden and burnout even though the strength of this

relationship is not clear [29, 30]. However, many researcher, found that lesser the burden healthier will be the coping strategies such as problem-focused coping strategies[40-41].

According to Mehrotra, family caregivers have received very little attention in the published literature from India[31]. Most of research on psychological distress of family caregiver has been conducted in the Western countries and did not adequately cover population from other culture. Therefore, in this study, we aimed to describe psychological distress and coping strategies of informal caregivers of West Bengal. Keeping all these in mind, the present study is an attempt to uncover the respective roles of different cancers and stages variation of cancers on the mental health of the care givers in terms of psychological distress (burden and burnout) and the coping strategies they used to deal with their distress. In case we are able to find out their level of distress and coping strategies, that knowledge will impart great significance in the therapeutic interventions and counseling for caregivers.

## OBJECTIVES

The specific objectives were:

1. Whether there is any stage wise difference among the caregivers of cancer patients (stage II, III, IV) in terms of psychological distress (burden and burn out) and coping strategies.
2. Whether there is any difference among the caregivers of different cancer patients (breast cancer, cervical cancer, and colorectal cancer) in terms of psychological distress (burden and burn out) and coping strategies.
3. Whether different types of cancer and stages of cancer, both combinely exert any effect on caregivers' psychological distress and coping strategies.

## MATERIAL AND METHODS

### Participants:

In this study, the sample consisted of caregivers of cancer patients {patients had been diagnosed by the different hospitals of Kolkata}, who had the primary responsibility of caring of the patient. He/she might be family member, close relatives, friend etc.

In this study, informal caregivers of cancer patients with breast cancer, colorectal cancer and cervical cancer (stage II, III, IV) were selected. Non probability snowball sampling technique had been used.

### Selection criteria:

#### Inclusion Criteria

1. Informal caregivers of cancer patients with breast cancer, colorectal cancer and cervical cancer.
2. The caregivers who spent substantial amount of time regularly in caring for the patients.

3. The caregivers who are willing to participate in the study and had given written consent for participation in this study.
4. The caregivers aged between 20-65 years were included.
5. The caregivers those who could easily understand English and /or Bengali languages were included in the study.

**Exclusion Criteria**

None of the subjects had chosen for the study those who had any clinical evidences of psychiatric or other major physical illness.

**Ethical Considerations:**

Informed written consent had been collected from each of the informal primary cancer caregivers. The purpose of the research was explained to the caregivers and was assured of confidentiality and of their right to withdraw from the study at any stage.

**Tools:**

**An information schedule:**

It is prepared for the purpose of collecting personal information. The information collected from the caregivers are as follows: Name, Age, Sex, Relationship with the patient, Patient diagnosed with breast cancer, colorectal cancer or cervical cancer, Stage of patients’ diagnosed cancer, Length of caregiving, Whether have you any psychiatric or major physical illness.

**Burden assessment schedule:**

This instrument was developed by Thara et al., [32]. It was designed to measure the subjective and objective burden of caregivers of chronic mental ill (e.g.: schizophrenia) persons. Since there is no item specification for schizophrenic patients’ caregiver or that of any other mental illness and cancer is also considered as chronic illness, this instrument has been used to assess the burden of cancer patients’ caregivers.

This instrument is comprised of 40 items and rated on 3 point scale (1= not at all, 2= to some extent,

3= very much so). The higher the score on this scale greater will be the burden level of the caregiver.

**Burn out inventory:**

The burnout inventory [33] used in the present study ( to assess the extent of burnout in the caregivers of the patient) has been adapted from the Freudenberger burn out scale [34]. This inventory is not meant to replace clinical assessment but to help one assess how one is doing. If one’s score is high he/she may need to seek help.

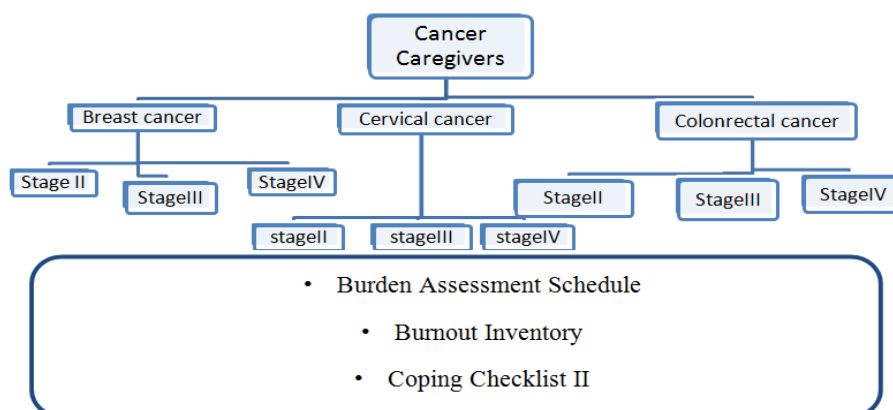
It assesses the level of burn out of the individual on the basis of how one has felt during the last three months. The inventory comprise of 15 items and rated on a 6point (0 to 5, 0 = no change and 5 = most change) scale. The inventory is computer scored.

**Coping checklist II:**

This scale was developed by Rao, Subbakrishna and Prabhu [35]. The checklist cover behavior pertaining to three domains for coping, i.e. emotion focused problem solving and social support. The checklist was developed keeping in mind the Indian socio-cultural set up. This scale is comprehensive as well as user friendly.

The scale is comprised of 70 items describing a broad range of behavioral, cognitive and emotional responses that may be used to handle stress. The items were scored dichotomously on “yes or no” response, suggesting the presence or absence of a particular coping behavior. The more the number of “yes” response to items, the greater the coping repertoire. The score on each of the subscales: Problem Focused, Emotion Focused (Distraction Positive, Distraction Negative, Acceptance/Redefinition, Religion Or Faith, Denial/Blame) And Social Support; was considered to determine the extent to which the care givers rely on each of the coping behavior.

**DESIGN OF THE RESEARCH**



**Procedure:**

Participants were described about the purpose and steps of the study, written consent were taken from them after proper explanation. 45 primary caregivers were selected using non probability snowball sampling technique. Among 45 primary caregivers; 15 caregivers were of breast cancer patients (5 caregivers in each of the stages II, III and IV), 15 caregivers were of cervical cancer patients (5 caregivers in each of the stages II, III and IV) and the rest were of colorectal patients (5 caregivers in each of the stages II, III and IV). Participants were given the test materials.

Burden assessment schedule and burn out inventory were selected to assess psychological distress of the caregivers. Coping checklist II had been selected to assess how they deal with their psychological distress. The ease of administration and scoring of the tests and its reliability and validity, make it appear that the tests are satisfactory one. The participants were instructed and made to understand the test materials; properly in English as well as in Bengali.

Factorial design has been used to compare the groups of caregivers in terms of psychological distress and coping strategies. After the data collection, based on the scoring procedure and norms of the test, scoring, statistical analysis and interpretation have been done. Complete confidentiality had been assured and was maintained.

Comparison among the groups of caregivers in terms of psychological distress and coping strategies were done. Subsequently for analysis, 0.05 and 0.01 level of significance is to be fixed as critical level.

**STATISTICAL ANALYSIS & RESULTS**

To determining significant difference among groups univariate two-way analysis of variance was done. For further investigation Post-hoc analysis has been done. Mean and standard deviation for all the data were computed. The results of comparison among the groups of caregivers in terms of psychological distress and coping strategies are presented in Table 1, Table 2 and Table 3.

**Table 1: Skewness and kurtosis measures of the dependent variable distribution (psychological distress and coping strategies) for each category of independent variables (caregivers of different types of cancer patients and of cancer patients with stage II, III, IV) are as follows.**

	Breast Cancer		Cervical Cancer		Colorectal Cancer	
	Skewness Standard error (.580)	Kurtosis Standard error (1.121)	Skewness Standard error (.580)	Kurtosis Standard error (1.121)	Skewness Standard error (.580)	Kurtosis Standard error (1.121)
Burnout	.278	.326	-.118	-.443	-.420	.110
Burden	.747	-.841	.671	-1.161	.445	-1.013
Distraction positive	-.931	-.155	-.127	-1.032	-.078	-.714
Distraction negative	.128	-1.348	.274	-1.499	-.227	-.970
Acceptance	-.100	-1.070	.412	-.010	-.080	-1.102
Religious	.113	-.484	.276	-.646	.341	-.330
Denial	-.168	-.033	-.282	-.917	-.276	-.646
Social support	.000	-1.615	.601	-1.494	.000	-1.615
Problem focused	-.587	-.723	-.127	-.988	.117	-1.026

	Stage II		Stage III		Stage IV	
	Skewness Standard error (.580)	Kurtosis Standard error (1.121)	Skewness Standard error (.580)	Kurtosis Standard error (1.121)	Skewness Standard error (.580)	Kurtosis Standard error (1.121)
Burnout	.098	-1.293	.322	-.340	.461	-.354
Burden	.616	.109	.606	.474	.160	-.784
Distraction positive	-.498	-.334	-.461	-.354	.355	-.783
Distraction negative	.128	-1.348	.000	-1.615	.000	-1.077
Acceptance	.128	-1.348	-.062	-.810	-.101	-.676
Religious	-.128	-1.348	.256	-1.131	.113	-.484
Denial	-.168	-.033	-.282	-.917	-.276	-.646
Social support	.555	-1.132	.000	-1.974	.000	-1.615
Problem focused	-.587	-.723	-.127	-.988	.117	-1.026

From the above table of skewness and kurtosis measures, it was found that the dependent variable distribution for each category of independent variables

is approximately normal; so parametric test has been done.

**Table 2: Mean and Standard deviation of the groups on psychological distress and coping strategies.**

	Breast cancer		Cervical cancer		Colorectal cancer	
	Mean	Standard deviation	Mean	Standard deviation	Mean	Standard deviation
Burnout	42.0667	1.33452	42.2000	1.14642	42.9333	1.38701
Burden	45.4000	5.81623	46.4000	6.23126	47.8000	3.91335
Distraction positive	11.0667	1.62422	10.9333	1.22280	10.5333	1.40746
Distraction negative	4.9333	.79881	4.8667	.83381	5.1333	.74322
Acceptance	6.5333	1.06010	6.6667	1.11270	6.6667	1.04654
Religious	5.4667	.91548	5.3333	.97590	5.4000	.91026
Denial	5.6667	.81650	5.7333	1.03280	5.6667	.97590
Social support	5.0000	.84515	4.7333	.88372	5.0000	.84515
Problem focused	7.6000	1.88225	7.4667	1.55226	7.6000	1.54919

	Stage II		Stage III		Stage IV	
	Mean	Standard deviation	Mean	Standard deviation	Mean	Standard deviation
Burnout	41.6667	1.34519	42.6000	1.18322	42.9333	1.16292
Burden	41.8667	2.26358	44.6000	2.44365	53.1333	2.44560
Distraction positive	11.7333	.96115	11.0667	1.16292	9.7333	1.33452
Distraction negative	4.9333	.79881	5.0000	.84515	5.0000	.75593
Acceptance	5.9333	.79881	6.6000	.98561	7.3333	.89974
Religious	5.0667	.79881	5.6667	.97590	5.4667	.91548
Denial	6.2667	.70373	5.8000	.77460	5.0000	.84515
Social support	4.7333	.79881	5.0000	.92582	5.0000	.84515
Problem focused	9.1333	.74322	7.6000	1.05560	5.9333	1.09978

**Table 3: The results of Univariate Two-way Analysis of Variance, effect size(Partial Eta Squared) and Post hoc analyses, for each dependent variable distribution (psychological distress and coping strategies) in terms of independent variables (that is, caregivers of different types of cancer patients and of cancer patients with stage II, III, IV) are as follows: Psychological distress (Burnout and Burden):**

VARIABLES	BURNOUT	BURDEN
	F Ratio (Partial Eta Squared)	F Ratio (Partial Eta Squared)
STAGES variation	4.217* [.190]	133.983** [.882]
CANCER variation	2.130 [.106]	5.638** [.239]
INTERACTION EFFECT [stage variation*cancer variation]	.348 [.037]	3.638* [.288]

\* p < 0.05 \*\* p < 0.01

Coping strategies:

VARIABLES	DISTRAC- TION POSITIVE  F Ratio (Partial Eta Squared)	DISTRAC- TION NEGATIVE  F Ratio (Partial Eta Squared)	ACCEP- TENCE  F Ratio (Partial Eta Squared)	RELIGI- OUS  F Ratio (Partial Eta Squared)	DENIAL  F Ratio (Partial Eta Squared)	PROBLEM FOCUSED  F Ratio (Partial Eta Squared)	SOCIA- L SUPPO- RT  F Ratio (Partial Eta Squared)
STAGES variation	12.727** [.414]	.032 [.002]	8.487** [.320]	1.595 [.081]	9.390** [.343]	36.400** [.669]	.444 [.024]
CANCER variation	.945 [.050]	.413 [.022]	.103 [.006]	.076 [.004]	.034 [.002]	.084 [.005]	.444 [.024]
INTERACTIO N EFFECT	2.145 [.192]	.413 [.044]	.718 [.074]	.646 [.067]	.644 [.067]	.495 [.052]	.444 [.047]

\* p < 0.05 \*\* p < 0.01

Post-hoc analysis:

Dependent variable	Difference	Mean difference
Burnout	Stage IV - stage II	1.2667*
Burden	Stage IV – Stage II	11.2667**
	Stage III – Stage II	2.7333**
	Stage IV – Stage III	8.5333**
Burden	Colorectal cancer- breast cancer.	2.4000**
Distraction Positive	Stage IV – Stage II	-2.000**
	Stage IV – Stage III	-1.333**
Acceptance	Stage IV – Stage II	1.4000**
Denial	Stage IV – Stage II	-1.2667**
	Stage IV – Stage III	-8.000*
Problem focused	Stage IV – Stage II	-3.2000**
	Stage III – Stage II	-1.5333**
	Stage IV – Stage III	-1.6667**

\* p < 0.05 \*\* p < 0.01

**DISCUSSION**

The present study utilized an univariate two way analysis of variance in order to assess stage wise (stage II, III, IV) difference and difference among the caregivers of different cancer patients (breast cancer, cervical cancer, colorectal cancer), in terms of psychological distress (burden and burn out) and coping strategies. Our findings reveal that in terms of burden (with large effect size, i.e. 0.88) and burnout (with small effect size, i.e. 0.19) there are significant stage wise variations among caregivers of different cancer patients.

According to previous literatures incongruity between caregivers' demands and their availability of resources to deal with those demands may lead to psychological distress. Many care givers have to devote his/her self to perform multifarious responsibilities of the patients. As stated by the role strain theory, greater the number of roles, greater will be the demand that can be burdensome[36]. Caregivers' psychological distress is also determined by the caregiving length, prognosis of patients, stage of illness etc.

Post hoc analysis suggests that caregivers of patients with stage II (41.8667), III (44.6000) and IV (53.1333) differ significantly in terms of burden. Whereas, caregivers with stage IV (42.9333) patients feel more burnout than stage II (41.6667) patients. The psychological distress reaches its peak when the disease progresses to the incurable phase. In the context of the dying process, on stage IV, the caregiver have to come across a new set of challenges in dealing with increasing functional constraints, increasing dependence of the patient, without the expectation of any good outcome from the patient[37, 38]. According to Tang, Li, &Chen, 2008, the anticipated loss, persistent psychological distress and physical demands of caregiving affect significantly the quality of life of terminally ill patients' family caregivers [14]. As the treatment gets lengthened, the resources of caregivers to meet the demands become severely strained; it might cause more burden as well as burnout among them [23, 24, 25].

The findings also reveal that the caregivers of different cancer patients differ significantly (with small

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effect size, i.e. 0.23) on burden assessment schedule. As well as Interaction effect of stage wise difference and cancer variation on caregivers' psychological distress and coping strategies has been assessed. The result indicates that interaction effect is significant on burden assessment schedule (with small effect size, i.e. .288). The post hoc analysis indicates that caregivers with colorectal cancer feel more burden than caregivers with breast cancer. Most of the caregivers find difficulty to provide care to clients of colostomy with optimum quality.

Several studies showed that many patients need to undergo surgeries which come with unwelcome side effects. These side effects exert taxes not only on the patients but also on the caregivers. Beach, 1993, in his study found caregivers' burden increases with chronic condition like colostomy of colorectal cancer patients and also noted that prolonged physical and emotional work of caregiving for years can increase perceived senses of burden [39].

In case of coping strategies caregivers show significant stage wise difference on emotion focused coping strategies (distraction positive, acceptance, denial) with moderate effect size (i.e. 0.41, 0.32, 0.34), and problem focused coping strategies with large effect size (i.e. 0.66). post hoc analysis suggests that Caregivers of patients with stage II patients show more distraction positive, denial and problem focused coping strategies than stage IV, whereas, caregivers with stage IV patients show more acceptance as coping strategy than stage II to deal with their psychological distress. In case of stage III patients' caregivers show moderate level of emotion focused and problem focused coping strategies.

Earlier findings claim that caregivers' emotion focused coping styles characterized by distancing, escape-avoidance, resignation acceptance, and self-blame is consistently related to increased level of psychological distress. However, resources such as social support and active coping styles that promote self-efficacy are significantly linked to lower burden and distress [40, 41].

The above literatures go in line with the present findings. Since caregivers of stage IV cancer patients feel more psychological distress they showed more acceptance as coping strategy. This may be because the caregivers accept the crude reality of their dying relative. Whereas stage II shows more denial may be because they did not accept the fact that their loved ones are diagnosed with the terminal disease. They try hard for their loved ones' better health and that's why might use more problem focused coping strategies and distraction positive emotion focused strategy to take care of their own stress.

### **Limitations**

The present study is not without limitations. This study was conducted on a small scale sample. Only primary informal caregivers are selected for the study. Caregivers are heterogeneous as a group in terms of age, gender. The stage of the cancer patients were taken as per the last follow up prescription. The study however did not cast light on the role of other subject relevant variables, such as, personality, gender variation, caregivers' locus of control etc. in future study these variables may be studied independently.

### **Implication:**

Though this research needs some more control measures for more generalizability, it has also certain implications. The diagnosis of cancer has enormous physical, emotional, and practical impact on the lives of cancer patients' family, as well as on the patients themselves.

Caregiving as a rising area of research is important for policy-making, professional training and practice in our society. To improve the public health policy about family caregivers, we need a better understanding of the caregivers and the caregiving effects over caregivers' mental health. These findings, taken together, have important implications for policy making as well as for the development of future interventions and research. There should be facilities to relieve the caregivers from care-giving burden and stress.

### **CONCLUSION**

The findings of the present study show that psychological distress of the caregivers of cancer patients is found to be highest during stage IV of the disease hence they acquire emotion focused coping strategies to deal with their distress. Further the result shows that caregivers of patients with colorectal cancer have higher level of psychological distress than caregivers of breast cancer and cervical cancer patients.

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