

The Impact of a Supportive Group on the Satisfaction of Bladder Cancer Patients with their Health Service in West Bengal.

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ABSTRACT

Objectives: Urinary bladder lesions pose a significant health concern, as they rank among the top ten most prevalent cancers globally. Although there are no longer any studies on it, mental health during treatment may be just as important as physical health in the success of cancer patients. Cancer Support Groups are becoming a more formal source of information, experience and empowerment for patients with cancer. The aim of this study was to understand how support groups (SG) impact patients' satisfaction with their healthcare services.

Methods: This study was an observational study with a cross-sectional design. Purposive sampling was used with a sample size of 49 diagnosed bladder cancer patients. Research assistant divided the patients into two groups A = 25 (newly diagnosed patients with bladder cancer who participate in a support group program) and B = 24 (bladder cancer who did not participate in the program). All patients completed the baseline questionnaire (short form patient satisfaction questionnaire) administered by a trained clinical psychologist after completion of the program. Patients' follow up numbers were also noted from the cancer registry book to measure the impact of SG on health care service satisfaction. The impact of support group was defined based on the mean PSQ-18 score and the follow-up number over the period of this study.

Results: The demographic distribution of male patients (81.22%) within the age group of 51.23±1.78 years showed a higher proportion compared to female and other age groups. There was a significant difference in satisfaction score between these two groups (p=0.000). The demographic and clinical pathological factors of patients were not found to be significantly correlated with their satisfaction scores (p<0.005). According to the uro-oncology registry, patients who participated in a support group maintained a significantly higher rate of follow-up (p<0.000) compared to those in the control group.

Conclusion: Support groups have the potential to be established within Cancer layer residences with the aim of enhancing physical outcomes that can be observed in the quality of life experienced by patients.

Introduction

According to the GLOBOCAN 2020 database report, bladder cancer is the 17th most prevalent cancer in India. It seems that the 5-years prevalence is 3.57 per 100,000 people, which results in roughly 11000 deaths annually. The lowest rate is in Dibrugarh (1.1), whereas Delhi has the highest incidence rates (7.4) among men, followed by Thiruvananthapuram (4.9) and Kolkata (4.0). Delhi has the highest rate of females overall [4].

The difficult experience of dealing with cancer is unique to each patient [1]. Based on individual needs, patients seek psychological and emotional support at different phase of cancer survivorship. During the first few months of diagnosis, most of the patients are experiencing emotional distress. Patients are highly likely to continue to suffer from emotional and psychological distress due to side-effects and negative impacts on Quality of Life (QoL) [10]. Cancer patients and survivors may be able to form a cancer support groups with the intention of addressing patients' unmet psychological needs and providing peer-support where patients can exchange clinical information, share experiences and express emotions for the benefit of each other. Following studies, emotional cancer support enhances a patient's adaptation of the present situation. People having less emotional problems are those who successfully cope with life events and have plenty of family contacts and multiple supporting resources [2]. Following observational evidence, support groups reduce feelings of isolation, depression and anxiety, and enhance knowledge, coping and self-management among cancer patients and survivors. Moreover, the battle against cancer can be overwhelming, lonely, and emotionally taxing. It is not unusual for a cancer diagnosis to have a significant impact on both the patient's life and the lives of his entire family. As a result of the disease's frequent perception as a life-threatening condition, to observe significant psychological and emotional stress in cancer patients. Psychological distress

has been utilized as a sign of people's mental wellbeing frequently in public health [12].

Previous study had identified having contracts with patients with similar experiences as one of the major and special and opportunities for personal growth of cancerous patients. In other words, while the patients consider individuals with an experience of the trauma about the word "cancer" are considered as a reliable resource, they may find the ideas rendered by other resources as trivial and useless [1].

A crucial component of health care should be the social and psychological support provided to cancer patients and their families [6]. Cancer self-help groups (CSHG) may experience group dynamics that produce members who are so bonded and cohesive that they form a particular group culture [7,8]. The group model of disease and recovery in the case of breast CSHG is distinguished by an ideology that includes a positive, self-assured outlook on life [7]. Co-survivors of cancer are those whose partners have the disease and are therefore also affected by it. They participate in the activities and are seen as a support system for the patients in some groups [3]. There are limited studies about impact of support groups on patients' QOL. According to one study on The Effectiveness of Psychoeducational Support Groups for Women with Breast Cancer and Their Caregivers, family involvement ensures the best possible outcomes and that these groups are valuable not only on an individual level but also from a systems perspective [6].

The objective of this research was to gain insight into the influence of support groups (SG) on the level of satisfaction that diagnosed bladder cancer patients experience with their healthcare services. Furthermore, it is important to consider whether support groups provide the necessary motivation for individuals to consistently adhere to their follow-up appointments.

Methodology

The current investigation was a solitary observational and cross-sectional study carried out at a tertiary cancer hospital in Eastern India following approval from the institutional review board. Patients were selected for enrollment with the assistance of a skilled clinical research assistant (who is present during daily OPD hours). Between January 2023 and September 2023, 19 out of the 500 patients in the urology department were identified as survivors of bladder cancer. These individuals had completed their treatment six months prior and were currently receiving follow-up care in the uro-oncology department. In a span of 6 months, the clinical research assistant successfully identified a total of 52 patients who were newly diagnosed with bladder cancer. In the current investigation aimed at assessing the influence of support groups (SG) on the satisfaction levels of diagnosed bladder cancer patients with their healthcare services, the research assistant purposefully segregated the participants into two distinct groups. - i) recently diagnosed bladder cancer patients who 1st time attend the support group (Group A= 26) & ii) recently diagnosed bladder cancer patients but do not attend the support group (Group A= 26). Sample size was calculated based on power 80% and alpha 0.05 and few patients previously agreed to take part in study and refused later. Hence, we omitted those patients leading to sample size- Group-A=25 and Group-B=24. All patients were asked to complete the questionnaire: Short Form Patient Satisfaction Questionnaire (PSQ-18), after attending supportive group program. And those did not attain supportive group they had completed PSQ-18. After fulfilling eligibility criteria patients were enrolled and clinical psychologist had explained about importance of support group program. Psychologist messaged all the patients as reminder before one day of the supportive group program and no reply from the patients was translated to the number of drop-outs in the study. We also noted the cause for refusal to participate in the study. This

information helped to determine the acceptability of the support group program as well as document the major barriers to participation.

Inclusion criteria

Patients diagnosed with bladder cancer undergoing treatment at a Medica Super Specialty Hospital, Kolkata in the oncology department.

Patients are of the age ranging from 45-65 years old according to the frequency of patients being diagnosed with bladder cancer at the hospital.

Patients are all physically sound.

Follow up patients who are willing to share their experiences in the program.

Willing to participate

Exclusion criteria

Not suffering from any other life-threatening diseases.

Those were diagnosed with metastatic Bladder cancer

Supportive group intervention

Uro-oncology department had organized total monthly 6 programs within 6 months which was supervised by doctors, psychologist and coordinators. Participants included individuals who were recently diagnosed with non-metastatic bladder cancer, as well as those undergoing follow-up care as survivors of the disease. The primary objective was to unite recently diagnosed patients with ongoing care who share common cancer experiences under one roof. Along with, to offer psychological fortitude and assistance to the recently diagnosed patient prior to their upcoming standardized treatment. The patients in follow-up were contacted according to their follow-up date. While newly diagnosed individuals were regularly encouraged to attend the support groups each month. The support groups provided an opportunity for the recently diagnosed patient to discuss with those who have already undergone treatment, allowing them to ask questions about the standard care they will receive and their capacity to resume activities after treatment. For example, the

majority of patients and their family members often have similar inquiries that come to mind like: - they can use the same bathroom used by the patients. Moreover, patients have various doubts about the ostomy bag and they also have concerns regarding their sexual lives as the prostate gland is also removed during the bladder surgery. The program typically runs for approximately 50 to 60 minutes and is held on the initial Monday of every month. The program usually lasts for around 50 to 60 minutes and takes place on the first Monday of

each month. Once the session concludes, we gather insights about the session's outcome by administering a standardized validated questionnaire to the participants. By referring to the register book, we have noticed a significant increase in the number of follow-up patients, resulting in a commendable 0% mortality rate within a span of 6 months. It is worth mentioning that the register is diligently maintained for a duration of 6 months as well. (Table-1)

Table- 1 Supportive Program

Program and Subdivisions	Description
Presentation by doctors	Uro-oncology surgeons give a presentation in Ppt form that provides information about the aetiology, treatment and management of disease-related symptoms.
Discussion about mental health care by clinical psychologist.	Psychologist discusses about how to take care of the mental health and wellbeing after diagnosis and during the period of treatment. Emphasis is laid on how to involve the patients in daily life activities post treatment. Families of the patients are made aware of ways through which they can involve patients in daily life activities.
Sharing of experiences by follow up patients, undergoing standard care treatment.	Patients diagnosed with bladder cancer who are in follow up treatment share their experiences about their entire journey from diagnosis to treatment and the various problems faced by them. Newly diagnosed patients interact with follow up patients which clears various doubts that the newly diagnosed patients might have regarding the treatment and its outcomes.

Tools

Structured proforma

A structured proforma was developed to assess the socio-demographic including-age, gender, residential areas, relationship status, education and occupation. Clinicopathological details include- duration of biopsy, duration of investigation, duration of diagnosis, treatment duration of illness and surgery plan yes or no.

Patients Satisfaction Questionnaire-18 (PSQ-18)

The modified PSQ-18 scale used here yielded separate scores for each domain: General satisfaction (Items 3 and 17), Technical quality (Items 2, 4, 6, and 14), Interpersonal manner (Items 10 and 11), Communication (Items 1 and 13), Time spent with doctor (Items 12 and 15),

and Accessibility and convenience (items 8, 9, 16, and 18). All items were scored on an ordinal scale from one to five so that high scores reflect satisfaction with health care [5].

Statistical Analysis

SPSS program version 25 was used for compilation and analysis of data. Patients' age was calculated as the mean ± standard deviation and frequency of demographic factors like gender, areas of residence, relationship status, education and occupation were tabulated. Chi square was applied to tabulate the comparability according to the two cancer groups. Prevalence of patients' satisfaction was calculated as mean ± standard deviation and 't'- test was used to determine the significant difference between two groups. An ROC curve was used to show

the performance of attending supportive group and patients' follow-up following two parameters: - satisfied about health service yes or no vs. maintain follow-up yes or no

Results

Table 2 depicts the baseline demographic and clinical characteristics of the study participants. The majority of them belonged to middle-class socioeconomic status (1000 to 2000 Indian rupees per capita per month). Both the study groups were comparable at baseline.

Table-2 Prevalence of demographic and clinicopathological details among participants

Demographic details	Group- A (N=25)	Group-B (N=24)	p- value
Age	51.23±1.78	51.07±2.19	1.14
<i>Gender</i>			
Male	81.22%	81%	1.13
Female	18.78%	19%	
<i>Residence</i>			
Rural	65.4%	69.3%	1.07
Urban	34.06%	30.7%	
<i>Relationship status</i>			
Living with spouse	85%	88%	1.14
Living without spouse	15%	12%	
<i>Education</i>			
Illiterate	9%	7.5%	1.09
Primary Education	19%	20.1%	
Secondary Education	31%	29.1%	
Graduate	26%	33.2%	
Master	12%	9%	
More	3%	1.1%	
<i>Occupation</i>			
Working	39%	11.8%	1.13
Unemployed	15%	9%	
Business	28%	20.1%	
Student	3%	39%	
Retired	8%	13.2%	
Housewife	7%	6.9%	

In group-A, the mean age of participants was 55.33±1.05 years. 79% were male, 61% were residing in an urban area, 74% were living with their spouse and 31% received up to secondary education.

In the control group, the mean age of participants was 51.07±2.19 years. 81% were male, 46% were residing in an urban area, 73% were living with their spouse and 26% received secondary education, 49% were unemployed.

Table-3 Association between the scoring of patients' satisfaction score and selected demographic variables among all participants

Sociodemographic Details	Mean±SD	p- value
Age		
45-55	51.1±1.02	1.12
55-65	49.6±1.14	
>65	52.5±0.87	
Education		
Primary Level	54.7±1.10	1.34
Secondary Level	56.4±1.03	
Graduate Level	51.1±1.41	
Family Income		
<500	55.1±1.05	1.65
500-1000	51.3±1.10	
1000-2000	53.1±0.76	
>2000	50.5±1.05	
Marital Status		
Living with spouse	56.4±1.13	1.71
Living without spouse	57.2±1.02	
Family structure		
Joint	53.2±1.01	1.81
Nuclear	54.13±0.98	
Occupation		
Home maker	56.5±1.73	1.21
Engaged with type of work	55.2±1.21	

Table-3 Patient's demographic (age, residence, relationship status, education and occupation) did not significantly correlated with PSQ-18 score.

Table- 4 Prevalence of satisfaction score in two groups

Groups	PSQ-18 score	t- value	P= Value	95% confidence interval of the difference	
Group- A	57.23±1.81	4.13	0.000*	Lower	Upper
Group-B	81.45±1.7			1.46	4.98

Table-4 There was a statistically significant interaction in PSQ-18 score between two groups: P=<0.005.

Fig: 1 Study Design

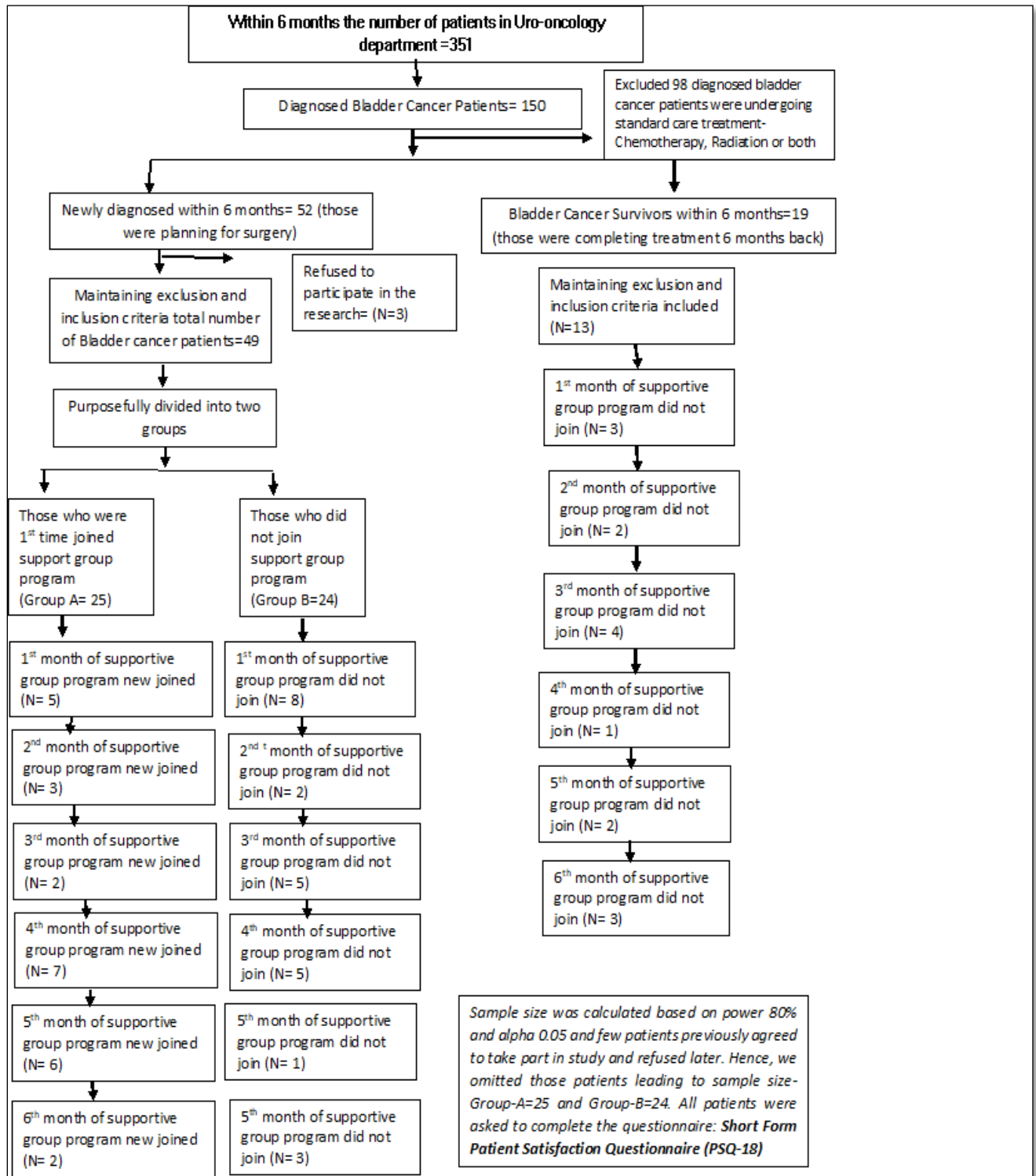


Figure- 2 ROC Curve

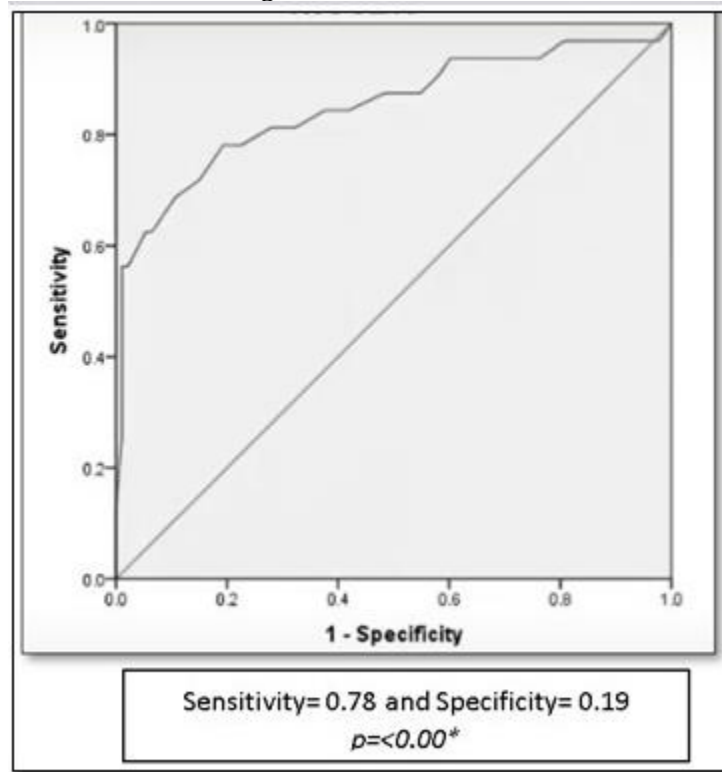


Figure-2 presents increased follow-up rate among bladder cancer patients during the period of research in a statistical report. ROC curve present overall follow-up patients and compared to those who attained in supportive group program and who did not. As statistical report, Sensitivity= 0.78 and Specificity= 0.19 $p=<0.00^*$.

Discussion

Emerging data has suggested that in standard care treatment, mental health may play as important a role in patient outcomes as physical health. Despite the fact that the majority of bladder cancer literature has been devoted to optimizing oncological outcomes and concentrates on physical prognostic criteria like nutritional and performance status [11]. According to our perspective, most of the patients in our hospital originate from rural regions. For them, factors such as the treatment process, medical expenses, and duration of treatment hold greater significance as they

impose a significant burden, impacting the psychological well-being of both the patients and their families. These individuals harbour numerous uncertainties regarding the prognosis and treatment of their ailments, yet they refrain from inquiring with doctors due to communication barriers. A supportive community serves as a platform where survivors can exchange their experiences, enabling patients to acquire knowledge about treatment and symptoms. In addition to doctors, patients can also direct their inquiries to this group.

In the present study following the descriptive statistical report, third stage of cancer patients are more compared to other stage. In our perspective, that might be due to the lack of awareness of the symptoms of bladder cancer among the general population. In India, there are lack of knowledge about bladder health may also be influenced by socio-cultural factors, such as religious beliefs and working conditions, as well as environmental factors, such as toilet access and clean water. Even, smoking and diet

also play a role in bladder health differences across countries and cultures. In the present study, satisfaction score did not have any impact on sociodemographic factors, education and residential areas. Our opinion, this is because discussion in the support group is done in colloquial language known to all and the concepts are explained in a simplified way by the doctors. Family members of the patients are also invited to these gatherings so that they can gain awareness about the aetiology and treatment of the disease and spread information about the same.

Patients who were involved in bladder cancer support groups reported a higher level of satisfaction with their understanding of the healthcare services protocol they received, in contrast to those who did not participate in the sessions. Based on the PSQ-18 domains, patients' communication skills refer to the interactive sessions conducted by survivors with newly diagnosed patients, which have a significant impact on patients' satisfaction scores. Based on the outcome, we can conclude that “supportive group program” is an “active support therapy” that encourages the patients to live a healthy lifestyle and to be able to make informed decisions about their standard of care treatment.

This was the part of the doctor's presentation that focuses on disease-related topics and provides emotional support from a trained clinical psychologist in the support group program. This helped to reduce the patient's fear of treatment. Because from our point of view, in India still now, receiving a cancer diagnosis brings about a greater sense of anguish than other illnesses, which frequently affects their psychological health and results in

a worse prognosis too. High levels of mental stress experienced over extended periods of time are the root cause of their long-term disease related treatment. Depression in these patients results in lower QOL, which has an impact on treatment outcomes. According to a few research, cancer mortality rates are higher when depressed [9]. Following this, clinical psychologist discussed how to involve themselves with their daily routine activities that was meant to lower the patient's anxiety level. In addition, their adequate understanding becomes the patient's incentive to improve their overall well-being while adhering to their prescribed follow-up.

Limitation

We observed few limitations while conducting the study: (1) the small number of participants (2) Limited number of literature reviews were available as we were not sure about supportive group protocol recruitment due to lack of availability in West Bengal for particularly Bladder Cancer Patients.

Conclusion

This research concludes that the support group has a significant impact that reflected on patient satisfaction scores and manifested through in number of follow-up bladder cancer patients during the period of research. Patients in the support group show a significant mean difference in the score of patients' satisfaction with health service between group A and group B. A cancer support group may be formed as part of cancer treatment during the phase of treatment protocol, with better health conditions.

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