

Original Article

Study of factors determining caregiver burden among primary caregivers of patients with intracranial tumors

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Abstract

Background: Caregivers of patients with intracranial tumors handle physical, cognitive, and behavioral impairments of patients. The purpose of this study was to assess the magnitude of burden experienced by primary caregivers of patients operated for intracranial tumors and evaluate factors influencing it.

Methods: Descriptive cross-sectional design was used to assess home-care burden experienced by primary caregivers of patients operated for intracranial tumors. Using purposive sampling, 70 patient-caregiver pairs were enrolled. Modified caregiver strain index (MCSI) was used to assess the caregiver burden. Mini mental status examination (MMSE), Katz index of independence in activities of daily living (ADL), and neuropsychiatric inventory questionnaire (NPI-Q) were used to assess the status of patients.

Results: Of 70 caregivers, 45 had mild, and 22 had moderate MCSI burden. A number of behavioral changes in NPI-Q had a significant correlation with MCSI burden ($P < 0.001$), whereas MMSE and Katz-ADL of patients did not show significant relation with caregiver burden. In NPI-Q, irritability, agitation, anxiety, depression, and sleep disturbances had a significant impact on MCSI. Among caregiver factors, unemployment, low per capita income, time spent, inability to meet household needs, quitting the job, and health problems had a significant impact on MCSI. In separate multivariate analyses, irritability component ($P = 0.004$) among behavioral changes of patients and caregivers' inability to meet household needs ($P < 0.001$) had a significant association with caregiver burden independent of other factors.

Conclusions: Behavioral changes in patients (especially irritability) and financial constraints had a significant independent impact on the burden experienced by primary caregivers of patients operated for intracranial tumors. Identifying and managing, these are essential for reducing caregiver burden.

Key Words: Caregiver burden, intracranial tumors, Katz activities of daily living, mini mental status examination, modified caregiver strain index, neuropsychiatric inventory questionnaire

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INTRODUCTION

Healthcare has seen burgeoning of research into the area of family caregiving during the past three decades, as it became evident that caregivers of patients with long-term illnesses go through physical and psychological challenges resulting in poor quality of life (QoL).^[14] The caregiver burden is the burden experienced by a caregiver while giving care to the sick at home, or the state resulting from necessary caring tasks, or restrictions that cause discomfort for the caregiver.^[35] Caregiving for patients with intracranial tumors has been noted to be a real challenge and threat to caregiver's health due to the cognitive changes, seizures, and neurological deficits in patients, and other social, psychological, and financial factors.^[2,6,18,24,26,28] Various researchers have reported caregiver burden among caregivers of patients with intracranial tumors due to physical and emotional stress such as insomnia, depression, social isolation, strain, anxiety, fatigue, and nervousness.^[2,14,17,20,24-26,28,29,34] Other than physical and psychological stress, caregivers of patients with intracranial tumors are at risk of social morbidity too.^[20]

However, the independent impact of various factors contributing to caregiver burden has not been studied using multivariate model. The aim of this study was to assess the caregiver burden experienced by the primary caregivers of patients operated for intracranial tumor and assess the independent impact of various factors influencing it.

MATERIALS AND METHODS

The study was conducted on patients and caregivers attending Department of Neurosurgery, Post Graduate Institute of Medical Education and Research, Chandigarh, a tertiary level healthcare and research institute in North India. All the adult primary caregivers who stay with the patient at home and involved in direct care of adult intracranial tumor patients were identified and invited for written consent. Caregivers with any communication disability were excluded. The study was explained to 78 caregivers who attended the Outpatient Department during the study period, but a sample of 70 patient-caregiver pairs were involved in this study. The subjects were explained regarding objectives and duration of the study. The subjects were ensured confidentiality of information provided by them. The main reason for not participating was a lack of time. Written permission for conducting the research study reported by caregivers was obtained from Institute Ethics Committee.

Instruments

Modified caregiver strain index (MCSI), a tool with a high internal reliability (0.9) which quickly identifies the caregiver strain,^[30] was used to measure the caregiver burden. It measures financial, physical, psychological,

social, and personal strain. It is a 13 items questionnaire with a maximum score of 26 and minimum of zero. The level of caregiver strain increases with MCSI score. Based on MCSI score, the burden was categorized as low (0–8), moderate (9–18), and high (19–26). The questionnaire was translated to Hindi with the help of experts. Content validity of the translated tool was obtained from experts in Hindi language. Content validity was also obtained after back-translating to English.

Neuropsychiatric behavioral changes in patients were assessed using neuropsychiatric inventory questionnaire (NPI-Q) which identifies 12 behavioral disturbances occurring in patients such as delusions, hallucinations, dysphoria, anxiety, agitation/aggression, euphoria, disinhibition, irritability, apathy, motor activity, sleep disturbance, and appetite disorder. Information about the behavior is obtained from the primary caregiver who is familiar with the patient's behavior. The interview was conducted in the absence of the patient to obtain an accurate report on patient behavior. NPI-Q is reported to have high reliability, sensitivity, and validity in cross cultural studies.^[9]

Mini mental status examination (MMSE) was used to assess the cognitive status of patients. It examines functions including registration, attention and calculation, recall, language, ability to follow simple commands, and orientation. It is a widely used cognitive test with high reliability, and validity of 0.70–0.90.^[13,31] Due to its short administration period and ease of use, it is useful for cognitive assessment at the bedside or during the follow-up visits. The score ranges from 0 to 30 and normal cognition is considered if the score is more than or equal to 25. The impairment is graded as mild (19–24), moderate (10–18), or severe (≤ 9).

Katz index of independence in activities of daily living (ADL) was used to assess the functional status and independence of patients. The Katz ADL index has good reliability and concurrent validity.^[32] This scale assesses the ability of the individual to perform six functions which include bathing, dressing, toileting, transferring, continence, and feeding. Clients are scored "yes" or "no" for independence in each of the six functions. The score of this scale ranges from 0 to 6. A higher score indicates better functional status. A score of 6 indicates full function, 4 indicates moderate impairment, and 2 or less indicates severe functional impairment.

Procedure of data collection

The caregivers were explained about the self-report MCSI and asked to give their honest option for each item in the questionnaire. Patient's cognitive status was assessed using MMSE and their functional status was assessed using Katz ADL. Behavioral changes of patients were reported by caregivers based on the items given in NPI-Q. A pilot study was done on 10 subjects to assess feasibility and applicability of the tools.

Data analysis

Continuous variables were considered nonparametric and reported as median with inter quartile range (IQR). Categorical data were reported as counts and proportions in each group. SPSS21 software (IBM Corp., New York, USA) was used for the statistical analyses. Univariate analyses of continuous variables across binary categories were compared using Mann–Whitney U-test, and across multiple categories using Kruskal–Wallis test. The bivariate relationships between two continuous variables were assessed using Spearman correlation coefficient. The significance level was kept at $P < 0.05$. Only those factors impacting MCSI in univariate analyses with $P < 0.20$ were considered for multivariate analysis. General linear model was used for multivariate analysis with the mandatory significance of model coefficient to be <0.05 for the validity of outcome prediction.

RESULTS

The profiles of patients and caregivers are depicted in Tables 1 and 2, respectively.

The mean age of patients was 40.2 (± 1.48) years with a male:female ratio of 1.2:1. Of the total 70 patients, most (44%) had tumors which were Grade 4. As per MMSE, 69% of the patients had various degrees of cognitive impairments. On behavioral assessment with NPI-Q, 63% of patients were noted to have irritability/liability, 51% anxiety, 46% agitation/aggression, 40% depression/dysphoria, 28% disturbed night time behavior, and 24% with change in appetite [Table 1]. Other behavioral changes seen in patients included apathy (18%), elation/euphoria and hallucination (12%), delusion (10%), and motor disturbances (4%). As per Katz ADL level of dependency, 47% of the patients were fully functional in meeting the ADL and 53% of them had moderate to severe functional impairments [Table 1].

The caregivers of patients were in the age ranging from 18 to 78 years with a mean of 37.3 (± 9.88) years [Table 2]. Most of them were males and only 52% of them were employed. The time spent by the caregivers in caring activities for their patients ranged from 2 to 18 h in a day with mean of 10.4 (± 3.86) h. It was also noted that 41% had spent more than 8 h in a day in caring for their patients. Only 31% of the caregivers reported being comfortable to meet their households needs along with spending money for the patient. When the majority of the caregivers reported themselves healthy, 23% were suffering from some illness.

Caregiver burden

As per MCSI self-reported data, all caregivers had some degree of burden. About 64% of the caregivers were found to have mild burden, 31% with moderate burden, and 5%

Table 1: General profile of patients

Variables	n (%)
Age (years)	
<18	10 (14.28)
18-40	31 (44.28)
>40	29 (41.42)
Gender	
Female	32 (46)
Male	38 (54)
Habitat	
Urban	28 (40)
Rural	42 (60)
Education	
Illiterate and primary	37 (53)
Elementary to senior secondary	28 (40)
Graduate and above	5 (7)
Marital status	
Married	56 (80)
Unmarried	14 (20)
Occupation	
Unemployed	36 (51)
Employed	26 (37)
Student	8 (12)
Duration of disease	
<6 months	40 (57)
>6 months	30 (43)
Tumor grade	
Grade 1	13 (19)
Grade 2	15 (21)
Grade 3	11 (16)
Grade 4	31 (44)
Presence of comorbid disease	13 (19)
Chemotherapy received	7 (10)
Radiotherapy received	29 (41)
Functional status	
Fully functional	33 (47)
Moderate impairment	16 (23)
Severe impairment	21 (30)
Cognitive status	
Normal	22 (31)
Impaired	48 (69)
Behavioral changes	
Irritability/liability	44 (63)
Anxiety	36 (51)
Agitation/aggression	32 (46)
Depression	28 (40)
Sleep disturbances	28 (26)

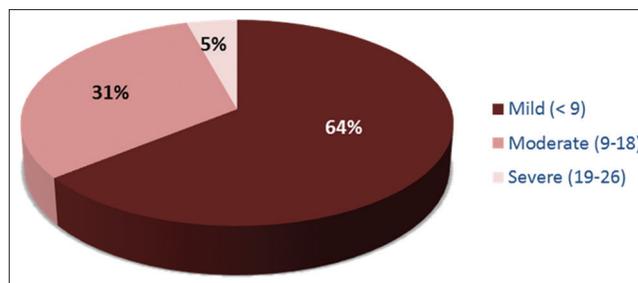
having severe burden [Figure 1]. The median MCSI score was 6 (IQR 1–13).

As shown in Table 3, 87% of caregivers had reported that caregiving contributed to financial strain, and 59% of them were upset due to the changes observed in patients

Table 2: General profile of the caregivers

Variables	n (%)
Age (years)	
18-40	39 (56)
>40	31 (44)
Gender	
Female	28 (40)
Male	42 (60)
Education	
Illiterate and primary	22 (31)
High school to senior secondary	34 (49)
Graduate and above	14 (20)
Relationship with patient	
Spouse	20 (29)
Parent	17 (24)
Sibling	9 (13)
Children	14 (20)
In laws	10 (14)
Marital status	
Married	60 (86)
Unmarried	10 (14)
Family type	
Nuclear	26 (37)
Joint	44 (62)
Occupation	
Unemployed	29 (41)
Employed	36 (52)
Student	5 (7)
Per capita income (Rs./month)	
<1000	30 (43)
>1000	40 (57)
Time spent on caring activities (h/day)	
<8	36 (59)
>8	34 (41)
Money spent on patient (Rs./month)	
<2000	39 (56)
2001-5000	12 (17)
5001-10,000	16 (23)
>10000	3 (4)
Meeting the household needs	
Comfortable	26 (37)
Enough to make ends meet	27 (39)
Not able to make ends meet	17 (24)
Self-health status	
Healthy	54 (77)
Unhealthy	16 (23)

during the disease process. Sleep disturbance was reported by 46% caregivers. While 53% of them felt that caregiving lead to physical strain, 50% of them felt that it was inconvenient, and 50% felt overwhelmed due to the caregiving experience. The majority of the caregivers also felt the behavioral changes in patients to be upsetting.

**Figure 1: Severity of caregiver burden among caregivers based on modified caregiver strain index**

Impact of patient related factors on caregiver burden

As shown in Table 4, caregiver burden had direct relation to the number of behavioral symptoms in patients, with a significant positive correlation between the number of symptoms in NPI-Q and MCSI ($\rho = 0.57$, $P < 0.001$). However, cognitive impairments and functional status of patients did not show significant correlation with caregiver burden. Other demographic and clinical parameters of patients also did not show significant association with caregiver burden.

The impact of neuropsychiatric behavioral changes of patients on caregiver burden is represented in Table 5. A higher caregiver burden score was associated with all the behavioral symptoms in patients. The burden (MCSI) was significantly higher among caregivers of patients with agitation (10.5 vs. 2, $P = 0.004$), depression (10.5 vs. 2.5, $P = 0.006$), anxiety (9 vs. 2, $P = 0.01$), irritability (9 vs. 1, $P < 0.001$), and insomnia (10.5 vs. 3, $P = 0.02$), as compared to others. However, among these, only irritability remained to have a significant impact on caregiver burden independent of other behavioral changes in multivariate analysis ($P = 0.004$).

Impact of caregiver related factors on caregiver burden

As shown in Table 6, caregiver burden was significantly higher among caregivers who were unemployed ($P = 0.03$), those who had low income ($P = 0.02$), those who were not able to make end needs comfortably ($P < 0.001$), those who spent <8 h in a day on caring activities ($P < 0.001$), those who had quit job to look after their patient ($P = 0.01$), and those who were themselves sick ($P = 0.004$). In multivariate analysis, only caregivers' perception of the inability to meet household needs ($P < 0.001$) had a significant association with caregiver burden independent of other factors [Table 6].

DISCUSSION

The functional, cognitive, and neuropsychological changes of patients with intracranial tumors make their primary caregivers exposed to a great burden^[3,8,10,33] and

Table 3: Burden reported by caregivers as per MCSI

Questions	n (%)		
	Always	Sometimes	Never
My sleep is disturbed	11 (16)	21 (30)	38 (54)
Caregiving is inconvenient	12 (17)	23 (33)	35 (50)
Caregiving is a physical strain	10 (14)	27 (39)	33 (47)
Caregiving is confining	11 (16)	18 (26)	41 (58)
There has been family adjustment	16 (23)	29 (41)	25 (36)
There have been changes in personal plan	19 (27)	31 (44)	20 (29)
There have been other demands on my time	5 (7)	29 (41)	36 (52)
There have been emotional adjustment	16 (23)	15 (21)	39 (56)
Some behavior is upsetting	17 (24)	29 (41)	24 (35)
It is upsetting to find the person I care for has changed so much from his/her former self	6 (9)	35 (50)	29 (41)
There has been work adjustment	17 (24)	21 (30)	32 (46)
Caregiving is the financial strain	29 (41)	32 (46)	9 (13)
I feel completely overwhelmed	12 (17)	23 (33)	35 (50)

MCSI: Modified caregiver strain index

Table 4: Correlation of cognitive status, neuropsychiatric symptoms, and functional status of patients with caregiver burden

Neurofunctional status	Caregiver burden (MCSI) Correlation coefficient (ρ)	P
Cognitive status of the patients (MMSE)	0.01	0.95
Neuropsychiatric symptoms (NPI-Q)	0.57	<0.001*
Functional status of the patients (Katz ADL)	-0.18	0.22

*P<0.05. MCSI: Modified caregiver strain index, MMSE: Mini mental status examination, NPI-Q: Neuropsychiatric inventory questionnaire, ADL: Activities of daily living

poor QoL.^[14,23] Nevertheless, the factors responsible have never been studied for their independent impact on the objectively assessed caregiver burden.

Most of the patients (68%) in our study had high grade glioma followed by meningioma, as per their reported prevalence.^[11,19] The majority of caregivers in the present study were spouses, parents, or children of the patients.^[16,29] We noted all the caregivers to have a certain level of burden. There have been reports of clinically significant impairment of QoL, caregiver burden, deep level of anxiety and depression,^[23,34] among caregivers due to their patients' cognitive-behavioral symptoms, physical disability, uncertainty of prognosis, and immediate family role changes.^[7,25,26]

Cognitive and functional impairments along with neuropsychological changes faced by patients of intracranial tumors are well evident. In the present study, 64% of patients were found to have cognitive impairments. We could not find any significant association of cognitive impairments with caregiver

burden while they have been reported to influence caregiver stress in other caregiving populations.^[24,28] The cognitive functioning of patients with high grade glioma has been reported not to have significant association with caregivers' mental health.^[4,27] The caregivers had reported feeling that their patients with cognitive impairment were different than before^[27,28] and expressed difficulty in understanding their behavior.^[34] We noted 40% of patients to be dependent in performing ADL such as bathing, dressing, toileting, transferring, and feeding. Similar to the most other studies, there was no significant association between patients' functional impairment and caregiver burden,^[15,27] while some have reported a weak association between patients' physical impairment and well-being of caregivers.^[24]

The neuropsychiatric symptoms of patients in our study had a significant impact on caregiver burden. About 82% of patients reported one or more behavioral changes in NPI. There was a significant positive correlation between the number of symptoms in NPI-Q and the caregiver burden. Caregivers experienced significantly more burden when the patient had behavioral changes such as agitation, depression, irritability, and disturbed night time behavior. These behavioral changes in patients probably demand more time and effort from the caregiver to fulfill even their basic needs. Patients who are irritable and agitated are difficult to be convinced to do any activities because of their rebellious nature.^[28] More time and energy have to be invested when patients with neuropsychiatric symptoms do not co-operate with caregivers during the care. Furthermore, patients who are anxious can become victims of distorted thinking and logical reasoning, making them more prone to depression and other symptoms leading further to diminished caregivers' mastery.^[29] Unlike functional and cognitive status, behavioral changes are more explicit. Patients may not be having the insight or awareness about these changes and may not be willing to accept them. It is difficult to quantify the magnitude of behavioral changes in these patients as they were reported by caregivers. Sleep disturbances in patients can make the caregivers' night also sleepless.^[22] Similar to earlier report,^[1] caregivers in the present study revealed that they had more demands on time while caring for their patients and often felt completely overwhelmed, lonely, and troubled with the upsetting behavior of patients. It becomes, therefore, vital to assess these behavioral changes in patients, so that appropriate interventions can be planned for patients and effective training can be provided to the caregivers to handle these changes.

The present study has highlighted the association between caregivers' socioeconomic profile and caregiver burden. The monthly expenditure for treatment related issues was considerably higher as compared to their monthly per capita income. It was noted that caregivers

Table 5: Impact of patients' neuropsychiatric changes on caregiver burden

Behavioral changes	MCSI score Median (IQR)	Univariate P	Multivariate P
Delusion			
Present	8 (6-11)	0.30	NA
Absent	6 (1-13)		
Hallucination			
Present	7 (1-14)	0.83	NA
Absent	6 (1.5-12)		
Agitation			
Present	10.5 (7-14)	0.004*	0.30
Absent	2 (1-8)		
Depression			
Present	10.5 (3-14)	0.006*	0.06
Absent	2.5 (1-8.5)		
Anxiety			
Present	9 (3-14)	0.01*	0.91
Absent	2 (1-8)		
Elation			
Present	7.5 (3-11)	0.46	NA
Absent	6 (1-13)		
Apathy			
Present	8 (2-16)	0.37	NA
Absent	6 (1-11)		
Irritability			
Present	9 (6-14)	<0.001*	0.004*
Absent	1 (1-3)		
Motor disturbances			
Present	9.5 (3-16)	0.42	NA
Absent	6 (1-12)		
Night time behavior			
Present	10.5 (8-14)	0.02*	0.29
Absent	3 (1-9)		
Loss of appetite			
Present	5 (1-12)	0.46	NA
Absent	6 (2-14)		

*P<0.05. IQR: Inter quartile range, NA: Not applicable, MCSI: Modified caregiver strain index

who were unemployed and those who had quit their job to look after their patients had reported significantly more burden. Unemployment adds to the financial and emotional burden of low income and makes it difficult for them to meet even their basic household needs. Caregivers with lower income and those who were not able to make their ends meet had significantly higher level of burden. Lower socioeconomic status has been reported to influence caregiver burden in many illnesses thereby impacting the outcome.^[12] As the caregivers in our study experienced more burden in financial and emotional domains, as compared to physical and social burden, there is a need for identifying various available

Table 6: Impact of caregiver factors on caregiver burden

Variables	MCSI score Median (IQR)	Univariate P	Multivariate P
Age (years)			
18-40	3 (1-9.5)	0.47	NA
>40	7.5 (2-14)		
Gender			
Female	9.5 (1-16)	0.18	0.26
Male	4.5 (1.5-10)		
Education			
Illiterate	5.5 (2-14)	0.42	NA
Senior secondary	6.5 (2-13)		
Graduate	3.5 (1-9)		
Marital status			
Married	6.5 (1.5-13)	0.65	NA
Unmarried	2.5 (1-11)		
Relationship with patient			
Spouse	7 (1-11)	0.26	NA
Parent	13 (3-14)		
Sibling	2 (2-7)		
Children	2.5 (1-10)		
In laws	4 (2-6)		
Type of family			
Nuclear	6 (1.5-9.5)	0.62	NA
Joint	5 (1-14)		
Occupation			
Unemployed	11 (7-14)	0.03*	0.83
Employed	3 (1-8)		
Student	2.5 (1.5-10)		
Monthly per capita income (Rs./month)			
<500	14 (9-16)	0.02*	0.42
501-1000	2 (1-10)		
1001-2000	4 (2.5-8.5)		
2001-3500	7 (2-11)		
3501-5000	4.5 (1-9)		
>5000	1 (1-4.5)		
Time spent on caring activities (h/day)			
<8	9.5 (7.5-14)	0.01*	0.16
>8	2 (1-6)		
Meeting the household needs			
Comfortable	1.5 (1-3)	<0.001*	<0.001*
Enough to make ends meet	9 (7-13)		
Not able to make ends meet	14 (11-16)		
Quitting job			
Yes	12 (8-14)	0.01*	0.13
No	3 (1-9.5)		
Self-health status			
Healthy	3 (1-9)	0.004*	0.36
Unhealthy	13 (9-14)		

*P<0.05. IQR: Inter quartile range, NA: Not applicable, MCSI: Modified caregiver strain index

financial supports,^[5] to alleviate their burden, especially in economically challenged communities.^[12]

A significantly higher burden score was reported by caregivers who could spend only short time in caregiving. This might be due to their employment or poor health status. Managing caregiving along with job and household activities would add to their stress. Caregivers who reported themselves unhealthy also had the higher burden. Higher burden score was found when the caregivers were parents of patients. Other demographic factors of the caregivers such as age, gender, education, marital status, and type of family were found to have no significant influence on the care burden in this study.

The significant independent impact of irritability ($P = 0.004$) of patients and financial constraints of caregivers ($P < 0.001$), with the caregiver burden noted in multivariate analyses, have never been reported previously. These highlights are a profound need for managing behavioral symptoms in patients and financial support for caregivers more effectively.

This evidence on caregiver burden suggests the importance of formal caregiver empowerment programs and support groups to improve the quality of caregiving as well as the life of the caregivers.^[7] Due to lack of professional support, caregivers often tend to seek informal support networks. Hence, it becomes essential to provide caregivers with home care advice at discharge and follow-up and to refer them to appropriate support groups. Hence, communication among the healthcare workers, patients, and caregivers is very important to facilitate the support from community, hospitals, or organizations.^[21,26] Involving patients in self-care to the best of their ability could also bring resilience to caregivers. Findings from the present study could be a base to develop cognitive-behavioral therapies for these patients and empowerment programs for their caregivers. It is also necessary to include caregivers' issues in the training program for healthcare providers.

Merits and limitations

Caregivers and patients were directly interviewed in our study with the help of appropriate standard tools while other reported studies had telephonic interviews. Furthermore, the cognitive status of patients was assessed directly rather than relying on caregivers' perception. We assessed independent impact of various factors using multivariate analysis while previous studies had relied on univariate analysis. The subjective elements experienced by primary caregivers such as spiritual perceptions and support from other family members were not feasible to be evaluated objectively in our study. We also did not study the tolerance threshold and personality of caregivers.

CONCLUSION

Within the caregiving dyad, the burden is related to characteristics of both the caregivers and patients. Behavioral changes in patients (especially irritability) and financial constraints had a significant independent impact on caregiver burden. Hence, managing behavioral changes of these patients and empowering their caregivers are essential in overall health delivery. With better management of patients' behavioral changes and providing social support to the caregivers, we could definitely bring some ray of hope.

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Conflicts of interest

There are no conflicts of interest.

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