

# Assessment of Caregivers' Strain during Radiation Therapy of Head-and-Neck Cancer Patients: An Institutional Report using Modified Caregivers' Strain Index Scale

Kazi S. Manir, Sourav Ghosh<sup>1</sup>

Department of Radiation Oncology, Medica Cancer Hospital, Siliguri, <sup>1</sup>Department of Medical Oncology, Apollo Gleneagles Hospital, Kolkata, West Bengal, India

## Abstract

**Aims:** Very little works have been reported on the issues of burden perceived by the caregivers of head-and-neck cancer (HNC) patients. Job of the caregiver is complex, and it limits their social, psychological, and economical well-being. Our study aims at assessing caregivers' strain during radiation therapy (RT) of HNC patients using the Modified Caregivers' Strain Index (MCSI) Scale. **Materials and Methods:** In this single-institutional cross-sectional study, we interviewed caregivers of HNC patients undergoing curative RT. Along with MCSI, a 13-point questionnaire, which was self-administered in local languages; we collected baseline data of patients and their caregivers. Scores were evaluated. For each question, score varies 0–2. Higher the Median Hazard Score (H Score), more was the level of the strain. **Results:** We interviewed 24 participants. Response rate was 100%. About 45.8% of patients were in Stage III. The median age of caregivers was 40 years; 58.3% were male, 79.2% were employed, and 58.3% were belonging to the upper-lower class. Nearly 66.6% were spouse of the patients and 70.8% belong to joint family. In MCSI score analysis, H Score was 22 (range 14) with a minimum score of 14 and maximum score of 26. The most common score was 20. About 65.1% of participants responded Score 2 in all aspects of strain indices. Travel time had a significant positive association with total H Scores (Pearson's  $r = 0.663$ ,  $P < 0.05$ ). **Conclusion:** Majority of the caregivers was suffering from severe physical, personal, emotional, and social/financial strain. This issue must be addressed in holistic cancer care.

**Keywords:** Caregiver, head-and-neck cancer, strain

## INTRODUCTION

Head-and-neck cancer (HNC) is a major health problem in India with 77,000 new cases being diagnosed every year,<sup>[1]</sup> accounting for 3% of all neoplasms. There are enormous challenges associated with it due to the disease itself, and intense and prolonged treatment that demands efficacious and persistent caregiving. Nightingale *et al.* in their work showed different challenges in formal caregivers and family members of HNC patients face in day-to-day life that impedes their social, personal, and psychological health.<sup>[2]</sup> Despite best efforts by health-care professionals, a lot of patients end up in palliative care suffering from increased pain and anxiety as majority of patients in Southeast Asia present as Stages III and IV.<sup>[3]</sup> Bond *et al.* demonstrated that facial disfigurement, speech, swallowing dysfunction, poor feeding, pain, and depression are the different problems that make the task of the informal caregiver difficult in such patients.<sup>[4]</sup>

Certainly, little have been focused on the issues of the caregivers' burden of HNC patients.

Although there have been quite a few published literature addressing the caregiver strain using different scales (caregiver strain inventory and caregiver reaction assessment) in the Western world, data from India are lacking to a large extent to plan a proper follow-up and intervention to reduce the burden of caregivers.<sup>[5]</sup>

With this background, we decided to study on this topic to see the status of caregivers of patients of head-and-neck

**Address for correspondence:** Dr. Kazi S. Manir,  
Department of Radiation Oncology, Medica Cancer Hospital,  
Siliguri - 734 434, West Bengal, India.  
E-mail: kazi.dr@gmail.com

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malignancies attending our clinic using Modified Caregiver's Strain Index (MCSI).

MCSI is a 13-item questionnaire tool that is easy to use, self-administered, and broadly encompasses physical, personal, emotional, and social/financial health of the caregivers.<sup>[6]</sup> Caregiver's Strain Index, originally developed in 1983, has been updated and MCSI showed a little more internal consistency (Cronbach's alpha=0.90). The advantage being it included equivocal responses perceived by the caregivers.<sup>[7]</sup> The validity of this tool has been tested in multiple studies to assess the strain of the informal caregivers both in oncology and chronic medical conditions such as stroke and dementia patients.<sup>[8]</sup>

## MATERIALS AND METHODS

Between September 2015 and April 2016, a cross-sectional survey was carried out among informal caregivers of 27 HNC patients who are undergoing radical and curative radiation therapy (RT) at our institute using convenience sampling. Caregiver in our study was defined as the person who principally took care of the patient and accompanied him to our center with whom we interacted as doctors. Informed consent was obtained, and the study was approved by the Institutional Ethical Committee. Out of 27 caregivers, 1 was not ready to give consent and 2 others were lost to follow-up after giving consent. It was a single-time, single-institutional study having a sample size of 24 caregivers. Each of the participants was given the MCSI questionnaire explained in their own language (Hindi/Bengali/English). While most of them ticked the options after self-understanding, for some options were read aloud and explained after which they could comfortably answer. Along with MCSI questionnaire, we also collected baseline data of the patients (age, sex, and Eastern Cooperative Oncology Group Performance Status), stage of the disease (American Joint Committee of Cancer staging, 7<sup>th</sup> edition), and location of residence (rural/urban) and caregivers (age, sex, socioeconomic status, employment status [employed/unemployed], relation with the patient, and family status [joint/nuclear]). For socioeconomic status, we used modified Kuppaswamy's Socioeconomic Scale update 2015.<sup>[9]</sup>

This process was carried out in a single room, besides outpatient department where there was no interference. We interviewed the caregivers on the 5<sup>th</sup> week of their patients' RT. At the end of survey, each participant was told about their score out of maximum 26.<sup>[10]</sup> For each question, if the answer was yes 2 points given, for sometimes answer was 1 and for no zero mark awarded. Higher the score more was the level of strain, though there was no definite cutoff. In cases, where the caregivers were found to be suffering from depression, they were referred for psychological counseling.

## RESULTS

We interviewed 24 caregivers and analyzed the results. Response rate was 100%. All of the 24 caregivers answered all topics of the questionnaire.

### Baseline characteristics of patient and respective caregivers

Baseline parameters of the patient and his/her caregivers are detailed in Tables 1 and 2.

### Travel time and mode

We stratified travel time (residence to RT unit) into three groups. About 33.3% (8) of patients reside <2 h distance and 58.3% (14) and 8.3% (2) of patients reside 2–5 h and >5 h distance, respectively. About 70.8% (17) of patients availed public transport and 29.2% (7) had availed private transport.

**Table 1: Baseline parameters of patients (n=24)**

Parameters	Number (Percentage)
Patient details	
Median age (years) (range)	47.5 (43)
Sex, n (%)	
Male	13 (54.2)
Female	11 (45.8)
ECOG performance status, n (%)	
0	5 (20.7)
1	11 (45.7)
2	7 (29.1)
3	3 (4.2)
Location, n (%)	
Rural	13 (54.2)
Urban	11 (45.8)
Stage, n (%)	
I	3 (12.5)
II	7 (29.2)
III	11 (45.8)
IV	3 (12.5)

ECOG: Eastern Cooperative Oncology Group

**Table 2: Baseline parameters of the caregivers (n=24)**

Parameters	Value
Median age (years) (range)	40 (40)
Sex, n (%)	
Male	14 (58.3)
Female	10 (41.7)
Economic condition*, n (%)	
Lower class	1 (4.2)
Lower-middle class	9 (37.5)
Upper-lower class	14 (58.3)
Employment status, n (%)	
Employed	19 (79.2)
Not employed	5 (20.8)
Relation with patient, n (%)	
Husband	8 (33.3)
Wife	8 (33.3)
Son	3 (12.5)
Daughter	2 (8.3)
Relative	3 (12.5)
Family status, n (%)	
Nuclear	7 (29.2)
Joint	17 (70.8)

\*Kuppaswamy's Socioeconomic Scale update 2015

### Modified Caregiver's Strain Index score

MCSI score distribution (question wise) is detailed in Table 3. On average, 65.1% of participants responded "Yes-on Regular Basis" (Score 2) in all aspects of strain indices, 33.3% of participants responded as "Yes-sometimes" (Score 1) in all indices, and 1.6% of participants responded as "No" (Score 0) in all indices. Median Hazard Score (H Score) was 22 (range 14) with a minimum score of 14 and maximum score of 26. The most common score was 20.

### Correlation between scores and baseline parameters

We tried to find correlation between different parameters and H Score and question-wise subscore also. We used Pearson's Correlation coefficient, Spearman's correlation coefficient, and nonparametric tests to analyze the association between different parameters (continuous and categorical variables) and scores. Majority of the parameters do not have correlation which is statistically significant. Only travel time has a significant positive association with total H Scores (Pearson's  $r = 0.663$ ,  $P < 0.05$ ).

## DISCUSSION

Ours was a cross-sectional descriptive study with an aim to assess the burden of caregivers of patients of HNC in a tertiary oncology clinic. It showed that males of fifth decade of life are the most common hit (median age was 47.5 years and male: female ratio = 1.18) by the disease with majority presenting

as Stage III disease (45.8%), which was roughly in tune with the patient profile data of other Indian and overseas literature.

As discussed above caregiving in any cancer is a unique job that is often overlooked in therapeutic arena with a negative impact of personal/social/financial life of caregiver. In an Indian study by Sivakumar,<sup>[11]</sup> majority of the caregivers were females (75%) which is in contrast to our studies where majority were male caregivers (58.3%) though the most common age group of caregivers in both the studies was third-to-fourth decades (the median age was 40 years in our study).

Ross *et al.*<sup>[12]</sup> and Geriani *et al.*<sup>[13]</sup> in their study demonstrated that spouse turned out to be the most common caregiver for chronically ill/terminal cancer patient, which was compatible with the results of our study where majority of the primary caregivers were spouse of the patient.

Nayak *et al.*<sup>[14]</sup> conducted a study on 768 caregivers of cancer patients from South India, and 85.1% of the study population had financial problems for caregiving and 70.3% could not continue their functional daily activities. In our study, 95.8% of the caregivers had financial difficulties and majority (91.7%) had to do work adjustment during their patients' treatment.

In another Indian study, Varma *et al.*<sup>[15]</sup> reported that 91% of the caregivers of cancer patients were employed but had an annual income of <40,000 Indian rupees. In our study, 79.2% of the caregivers were breadwinners for their family, and majority

**Table 3: Modified Caregivers' Strain Index Score distribution (Stratified question wise)**

n	Question	Response rate %			Median score
		Yes=2 On a regular basis	Yes=1 Some times	No=0	
1	My sleep is disturbed (For example, the person I care for is in and out of bed or wanders around at night)	66.7	29.2	4.2	2
2	Caregiving is inconvenient (For example, helping takes so much time or it's a long drive over to help)	70.8	25	4.2	2
3	Caregiving is a physical strain (For example, lifting in or out of a chair; effort or concentration is required)	58.3	41.7	0	2
4	Caregiving is confining (For example, helping restricts free time or I cannot go visiting)	37.5	62.5	0	1
5	There have been family adjustments (For example, helping has disrupted my routine; there is no privacy)	58.3	41.7	0	2
6	There have been changes in personal plans (For example, I had to turn down a job; I could not go on vacation)	66.7	33.3	0	2
7	There have been other demands on my time (For example, other family members need me)	66.7	33.3	0	2
8	There have been emotional adjustments (For example, severe arguments about caregiving)	58.3	33.4	8.3	2
9	Some behavior is upsetting (For example, incontinence; the person cared for has trouble remembering things; or the person I care for accuses people of taking things)	45.8	54.2	0	1
10	It is upsetting to find the person I care for has changed so much from his/her former self (For example, he/she is a different person than he/she used to be)	54.2	41.6	4.2	2
11	There have been work adjustments (For example, I have to take time off for caregiving duties)	91.7	8.3	0	2
12	Caregiving is a financial strain	95.8	4.2	0	2
13	I feel completely overwhelmed (For example, I worry about the person I care for; I have concerns about how I will manage)	75	25	0	2

of them belonged to upper-lower class (58.3%) according to economic scale. A significant number of caregivers had to play dual roles and had drop in their educational activities and social disruptions to look after their patients as evidenced in literature.<sup>[16]</sup>

Maheswari and Mahal in their study showed that belonging to a rural area and distance from the treatment centers are important variables that affect the family burden.<sup>[17]</sup> Similarly, in our study also, the duration of travel time was on the only stressor found to be statistically significant. It ascribed to a significant number of patients belonging to rural belt and availing public transport during busy office hours.

Although there is a paucity of worldwide as well as Indian data on this ill-explored topic, our attempt to find the shortfalls in our patients and their family just could provide a small glimpse as limited by small sample size, single institutional, based on a specific subsite and lack of interventional or active support. We understand and suggest similar studies on larger population to validate this utmost issue.

## CONCLUSION

In this single-institutional cross-sectional study, we tried to estimate the different aspects of strain of caregivers of the HNC patients undergoing curative RT. Majority of the caregivers was suffering from severe physical, personal, emotional, and social/financial strain as evident by the score responses. Distance from home to hospital is also a pivotal factor here. This unaddressed issue is very crucial for holistic cancer care, especially in low resourceful country such as India, where paucity of cancer care facilities and poor socioeconomic conditions of majority of patients also make the task of the caregiver more challenging.

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### Conflicts of interest

There are no conflicts of interest.

## REFERENCES

1. Tuljapurkar V, Dhar H, Mishra A, Chakraborti S, Chaturvedi P, Pai PS. The Indian scenario of head and neck oncology – Challenging the dogmas. *South Asian J Cancer* 2016;5:105-10.
2. Nightingale CL, Curbow BA, Wingard JR, Pereira DB, Carnaby GD. Burden, quality of life, and social support in caregivers of patients undergoing radiotherapy for head and neck cancer: A pilot study. *Chronic Illn* 2016;12:236-45.
3. Lal P, Verma M, Kumar G, Shrivastava R, Kumar S. Initial experience of head and neck cancer patients treated in an oncologist led palliative cancer care clinic at a tertiary cancer care center in Uttar Pradesh: Is the initiative of a full-fledged palliative care for cancer patients justified. *Indian J Palliat Care* 2016;22:477-84.
4. Bond SM, Schumacher K, Sherrod A, Dietrich MS, Wells N, Lindau RH 3<sup>rd</sup>, et al. Development of the head and neck cancer caregiving task inventory. *Eur J Oncol Nurs* 2016;24:29-38.
5. Badr H, Gupta V, Sikora A, Posner M. Psychological distress in patients and caregivers over the course of radiotherapy for head and neck cancer. *Oral Oncol* 2014;50:1005-11.
6. Omega LL. Helping those who help others: The modified caregiver strain index. *Am J Nurs* 2008;108:62-9.
7. Thornton M, Travis SS. Analysis of the reliability of the modified caregiver strain index. *J Gerontol B Psychol Sci Soc Sci* 2003;58:S127-32.
8. Ain QU, Dar NZ, Ahmad A, Munzar S, Yousafzai AW. Caregiver stress in stroke survivor: Data from a tertiary care hospital – A cross sectional survey. *BMC Psychol* 2014;2:49.
9. Available from: [https://www.researchgate.net/profile/Jugal\\_Kishore/publication/312894228\\_Kuppuswamy%27s\\_Socioeconomic\\_Scale.Update\\_for\\_July\\_2015/links/5889d27145851570120361fc/Kuppuswamy-Socioeconomic-Scale-Update-for-July-2015.pdf](https://www.researchgate.net/profile/Jugal_Kishore/publication/312894228_Kuppuswamy%27s_Socioeconomic_Scale.Update_for_July_2015/links/5889d27145851570120361fc/Kuppuswamy-Socioeconomic-Scale-Update-for-July-2015.pdf). [Last accessed on 2018 Jul 23].
10. Chiluba BC, Moyo G. Caring for a cerebral palsy child: A caregivers perspective at the university teaching hospital, Zambia. *BMC Res Notes* 2017;10:724.
11. Sivakumar C. Role change as breadwinner in cancer caregiving. *Indian J Cancer* 2017;54:467-9.
12. Ross S, Mosher CE, Ronis-Tobin V, Hermele S, Ostroff JS. Psychosocial adjustment of family caregivers of head and neck cancer survivors. *Support Care Cancer* 2010;18:171-8.
13. Geriani D, Savithry KS, Shivakumar S, Kanchan T. Burden of care on caregivers of schizophrenia patients: A correlation to personality and coping. *J Clin Diagn Res* 2015;9:VC01-4.
14. Nayak MG, George A, Vidyasagar MS. Perceived barriers to symptoms management among family caregivers of cancer patients. *Indian J Palliat Care* 2018;24:202-6.
15. Varma LS, Jahagirdar S, Anjum MS, Reddy PP, Pratap K, Reddy VS. Perceived levels of supportive care needs of the patients with oral cancer in a metropolitan city in South India – A cross-sectional questionnaire-based study. *J Indian Assoc Public Health Dent* 2017;15:78-83.
16. Murthy RS. Caregiving and caregivers: Challenges and opportunities in India. *Indian J Soc Psychiatry* 2016;32:10-8.
17. Maheswari PS, Mahal RK. Perceived social support and burden among family caregivers of cancer patients. *Int J Health Sci Res* 2016;6:304-14.