

Home Care of Tracheostomized Chronically Critically Ill Patients: A Study of Caregivers' Burden and Comparison with the Burden of Palliative Care Patients in India

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ABSTRACT

Introduction: Chronically critically ill (CCI) patients often have high costs of care and poor outcomes. Disease management programs offering home care may reduce costs but need buy-in from informal caregivers. An understanding of caregiver burden in this population is lacking. We aimed to study the caregiver burden, its change over time, and factors affecting it, in post-ICU tracheostomized patients. We compared the caregiver burden among CCI carers to that of palliative caregivers.

Materials and methods: Informal caregivers of thirty chronically critically ill tracheostomized patients (CGcci) were administered the Caregivers Burden Scale (CBS) tool at discharge, 2 and 4 weeks after discharge. A one-point assessment of burden was made in 30 caregivers of patients enrolled in Pain and Palliative care clinic (CGpc). Linear mixed models for repeated measures were used to analyze score of CGcci over time and compared to the burden in physical, psychologic, economic, time, and social domains between groups.

Results: All 60 caregivers were young (33–35 years), predominantly male, and children of the patients. Both CGcci and CGpc had moderate burden score of 60.5 (14.7) vs 61.5 (13), respectively. Physical burden (11.5 vs 8) was greater in CGcci ($p = 0.001$) compared to psychologic domain (10 vs 12.5) in CGpc ($p = 0.01$). Burden score over all domains in CGcci decreased rapidly from 67.5 (8) to 55 (16.5) ($p = 0.001$) in the first month after discharge.

Conclusion: Burden of care among caregivers of tracheostomized chronically critically ill patients is comparable to those of palliative caregivers and reduces significantly with time.

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Keywords: Caregiver burden, Chronically ill, Critically ill, Palliative, Rehabilitation, Tracheostomy.

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HIGHLIGHTS

Burden in the caregivers of chronically critically ill in India is lacking. In this study, the burden and the affecting factors were studied among the caregivers of tracheostomized patients who were discharged from ICU for homecare. The burden score was moderate, and the physical burden domain was greater in the caregivers of chronically critically ill.

BACKGROUND

Involvement of family caregivers becomes essential in the care of the chronically critically ill (CCI) patients who undergo an extended recovery, first after discharge from the intensive care unit (ICU) and thereafter, the hospital.¹ Prolonged hospital stay has consequences of increased cost, infection, and utilization of manpower. Healthcare systems in low/middle-income countries (LMIC), traditionally, are ill equipped to respond to the increased burden and challenge of care of the chronically ill patient, increasing the physical as well as psycho-socio-economic burden on unskilled family members.^{2,3}

Patients having neurological or laryngeal disease may need temporary or permanent tracheostomy long after their period of critical illness. Burden is greater when the patients have been discharged home with tracheostomies *in situ*.⁴ Patients having neurological or laryngeal disease may need temporary or

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permanent tracheostomy long after their period of critical illness. The higher the caregiver burden, the higher their level of anxiety and depression, and lower the health-related quality of life. Up to 18–47% of caregivers face depression.⁵ There is a greater chance of patient abuse by depressed, burdened caregivers.⁶

A recent meta-analysis of worldwide literature has found consistently high anxiety that correlates to burden among informal carers of dependent patients.⁷ Of the 74 studies included, care recipients included dementia (24 studies), older people (11 studies), cancer (12 studies), and stroke (eight studies). There was very little information from CCI patients or from LMICs.

Therefore, the primary objective of this study was to analyze the caregivers' burden for tracheostomized patients discharged home after ICU care as part of a larger project. We aimed to explore the change over time and factors associated with the burden of caregiving. Since palliative care (PC) is an important component of care for CCI,⁸ we compared the burden of caregiver of chronically critically ill caregiver (CGcci) with that of caregivers of patients in palliative care (CGpc).

MATERIALS AND METHODS

This study was undertaken vide the AIIMS ICU Rehabilitation (AIR) project that aims to develop a complex healthcare intervention to engage, empower and enable home care and rehabilitation of tracheostomized CCI patients. The caregivers of recruited patients receive equipment and hands-on training in all aspects of patient care. They can contact the AIR team for consultation and telephonic follow-up as a part of the project.

The project was approved by the Institute Ethics Committee (IEC) of AIIMS Bhubaneswar (Grant number: T/EMF/Anaesth/20/53) and registered prospectively in CTRI CTRI/2020/11/029443 [Registered on: 27/11/2020]. All the participants were explained about the study and written informed consent taken from them.

Study Site

AIIMS Bhubaneswar is a 900-bedded tertiary care teaching center having 56 non-COVID and 61 COVID adult ICU beds. The ICUs are managed by different departments, with most patients in this study being recruited from the central ICU (14 bedded, surgical, and medical), neurology and respiratory ICU (7 beds), neurosurgery ICU (7 beds), and emergency room (16 beds). The center runs twice-weekly outpatient services for "Pain and Palliative Care" and caters to patients from backgrounds of oncology, oncosurgery, and radiotherapy.

Inclusion and Exclusion Criteria

Adult (age >18 years) caregivers of adult tracheostomized CCI patients consenting to be a part of the AIR project and consenting caregivers of patients joining the PC services were included in the study. The patients had to be hemodynamically stable, on minimal respiratory support and dependent on the caregiver for at least one basic daily activity. Otherwise active, physically independent patients tracheostomized for laryngotracheal-tracheal disease or staged oncology or reconstructive surgery were excluded.

Data Collection

Demographic data such as age, gender, relation with patient, occupation and educational status were collected for all caregivers. Data for length of stay of the patient in the hospital and change in quality of life (QOL) as measured by EuroQOL 5D 3L version from

premorbid period to after discharge were collected. We used the questionnaire of Caregivers Burden Scale-Indian Population (CBS-IP) for assessing the burden for all care givers.⁹ The CBS-IP has physical, economical, time, social, and psychological domains. Each domain consists of four-point Likert scales (1–4): higher points correlate with higher burden. The burden is graded as absent or little (0–25), mild (26–50), moderate (51–75), and severe (76–100). The CBS-IP has been validated in chronically ill Odia-Indian population, but the Odia version was not available from the developers who permitted its use and translation. It was validated linguistically in Odia by doing forward and backward translation from English, by the Brislin's technique.¹⁰

Assessment of burden for caregivers of tracheostomized chronically critically ill patients was performed prospectively at three time points. The first interview was face to face just prior to discharge from the hospital/ICU, and the second and third interviews were done either telephonically or face to face at 2 and 4 weeks of discharge, respectively. The interviews for the caregivers of the palliative patients were single cross-sectional event, done face to face at the outpatient clinic. A trained psychologist collected the data. A short introduction based on an interview guide was followed by the collection of demographic details and administration of the CBS tool.

Sample Size and Statistical Analyses

A sample size of 60 (30 caregivers in each group) was taken based on the previous study.⁹ We used IBM-SPSS (version 25) for statistical calculations. For nonparametric paired data Wilcoxon signed-rank test and for nonparametric unpaired data Mann-Whitney *U* test were used. Linear mixed effects models were created for repeated measures of care burden over time, for within participant data analysis. A multivariate regression model was run to assess factors affecting burden among all 60 caregivers after correcting for baseline parameters. The *p*-value <0.05 was taken as statistical significance.

RESULTS

Demographics of Caregivers

All caregivers in our cohort were informal (family member or relative of the patient). Mean age was 33 years in the CGcci group and 35 years in CGpc group (Table 1). Majority of the caregivers were male (80% in CGcci group and 66.6% in CGpc group). The marital status, level of education, dwelling area, type of family, and occupation were similar between groups (Table 1).

Patient Details

Majority (80%) of the tracheostomized patients in CGcci group had neurological illness (stroke, head injury, or brain tumors) with an ICU stay of 14 (\pm 7) days and hospital stay of 24 (\pm 5) days prior to discharge. All patients were fully dependent on caregivers for mobility and self-care. Six patients were oxygen dependent and two needed ventilation support. All patients had to be fed via the nasogastric tubes and needed routine bed care and tracheostomy care.

In CGpc group, majority had malignancy of head and neck, lung, and gastrointestinal tract (Table 1). The QOL of this group of patients was not assessed formally as a majority were bed ridden, 10 patients had tracheostomy and were on nasogastric feeds.

Care-burden and factors affecting it: Comparing change of burden with time, in CGcci group on the day of discharge and follow-up at 2 and 4 weeks, there was a significant decrease in median total

Table 1: Demographic characteristics of the caregivers

	CGcci (n = 30)	CGpc (n = 30)	p value
Gender			
Male	21	20	0.468
Female	9	10	
Mean age in years (IQR)	33.5 (10)	35 (15)	0.573
Median days of caregiving (IQR)	42.0 (0)	288 (700)	<0.001
Marital status			
Married	21	19	0.7
Unmarried	9	11	
Education level			
Undergraduate	19	18	0.95
Graduate and above	11	12	
Dwelling area			
Rural	25	19	0.1
Urban	5	11	
Family			
Joint	22	18	0.43
Nuclear	8	12	
Occupation			
Employed	8	9	0.98
Unemployed	8	5	
Business	7	6	
Student	3	4	
Housewife	4	6	
Relation with the patient			
Children	14	10	
Siblings	3	5	
Parents	1	1	
Spouse	4	7	
In-laws	3	3	
Others	5	4	
Diagnosis of the cared patient			
Head injury	8	0	
Stroke	10	0	
Brain tumors	6	0	
Poisoning	1	0	
Metabolic disease	2	0	
Peptic perforation	1	0	
Pulmonary disease	2	0	
Head and neck cancer	0	7	
Lung cancer	0	7	
Breast cancer	0	4	
GI cancer	0	7	
Cervical cancer	0	3	
Skeletal cancer	0	2	

CBS score (67.5 IQR 8 vs 60.5 IQR 14.75, $p < 0.001$). The time, social, and psychological domain of the CBS score were significantly decreased after 2 weeks ($p < 0.05$) (Fig. 1). The decrease in burden, continued to be significant in the following weeks, especially in the domain of economic burden (Table 2). The linear mixed effects models for CGcci demonstrated a significant reductive effect of

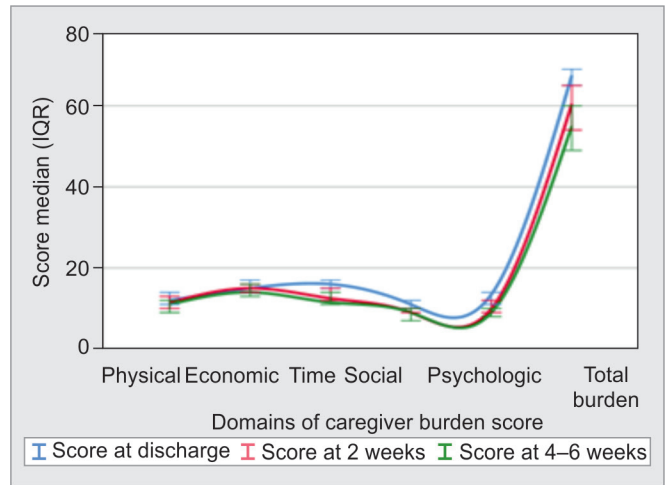


Fig. 1: Change in caregiver burden over time

time over care-burden scores across all domains ($p < 0.001$). In the multivariate regression analyses, female caregivers reported greater total burden scores than men ($p = 0.04$). The physical burden domain was greater among females ($p = 0.02$), and the economic burden was more in caregivers from a nuclear family ($p = 0.02$) in the CGcci.

Comparison of burden between CCI and PC: Total CBS score was similar in the CGcci and CGpc groups ($p > 0.05$) (Table 3). The physical burden was significantly more in CGcci group ($p = 0.001$), while psychological burden was greater in CGpc group ($p = 0.01$). While as majority of the caregivers reported moderate care-burden in both tracheostomized (73.3%) and palliative care patients (70%), “severe” burden was less among the CGcci (Table 4).

DISCUSSION

In what we believe to be the first study of its kind from an LMIC, the caregiver burden among the tracheostomized CCI patients in our cohort was moderate to start with and decreased significantly in the first month after discharge from the hospital. While the overall burden was similar among caregivers of both groups, the physical burden was more in CGcci compared to the psychological domain which was greater in CGpc.

Demographics of caregivers: The caregivers of both the groups in our cohort were young (33.5–35 years), predominantly male family members, and similar to Indian caregivers (36 years) of people living with HIV/AIDS (PLWHA).^{10,11} In contrast, caregivers from studies originating in developed countries have been older (>60 years) with a female predominance.^{12–14} The relationship of the caregiver to the patient has varied across studies, while mostly offspring in our cohort, others have reported spouses of (male) patients of oral cancer and elderly patients undergoing surgery.^{14,15}

Total care-burden: The median burden score was 60.5 for tracheostomized and 61.5 for palliative patient caregivers among our patients. This is not unlike the burden among caregivers of oral cancer patients (57.1; IQR 44.62–75.0)¹⁵ and those caring for bedridden patients.¹⁶ The burden reported in an Indian study, among the caregivers of PLWHA (37.8%), appears much less.¹⁶ The impairment of physical functioning of the care receiver is associated

Table 2: Change of burden over time among the caregivers of chronically ill tracheostomy patients

CBS domain	Median (IQR) at discharge	Median (IQR) at 15 days of discharge	Median (IQR) at 30 days of discharge	p value (At discharge vs 15 days)	p value (At 15 days vs 30 days)	p value (At discharge days vs 30 days)
Physical	12 (4)	11.5 (4)	11 (3.25)	0.08	0.03	0.03
Economical	15 (4)	15 (3)	14 (4.25)	0.34	0.02	0.02
Time	16 (3)	12.5 (5)	11.5 (5.25)	0.001	0.01	0.01
Social	11 (3)	9 (4)	9 (4)	0.04	0.03	0.02
Psychological	13.5 (5)	10 (5)	9 (4)	0.002	0.001	0.001
Total score	67.5 (8)	60.5 (14.75)	55 (16.5)	0.001	0.003	0.003

Table 3: Difference in burden of care domains among chronic critically ill and palliative care patients

CBS domain	CGcci		Z value	p value
	Median (IQR)	Median (IQR)		
Physical	11.5 (4)	8 (4)	-3.36	0.001
Economical	15 (3)	15 (2)	-0.5	0.95
Time	12.5 (5)	14 (4)	-1.16	0.24
Social	9 (4)	10.5 (4)	-1.42	0.15
Psychological	10 (5)	12.5 (5)	-2.63	0.01
Total score	60.5 (14.75)	61.5 (13)	-0.51	0.6

Table 4: Difference in severity of burden among caregivers

Severity of burden	CGcci % (n)		CGpc % (n)
	At discharge	After 2 weeks	
Little or no burden	0	0	0
Mild burden	3.3% (1)	23.3% (7)	23.3% (7)
Moderate burden	86.6% (26)	73.3% (22)	70% (21)
Severe burden	10% (3)	3.3% (1)	6.6% (2)

with higher burden to the caregiver¹⁶ and may explain the higher burden in our cohort, compared to PLWHA caregivers.

Change of burden over time: Burden of care was reported maximum at discharge and reduced with time in our cohort. This was similar to that reported among the caregivers of patients of major abdominal surgery.¹⁶ Although there was a steady decrease in burden after discharge, it is interesting to note that the decrease was more significant in the latter period, after second week in all domains except that of time spent in caregiving (and therefore available for self-care). We hypothesize that as the caregivers return home from the hospital, time available for self-care increases, causing a sharp fall in burden score in the time domain in the first quarter. The initial denial and self-doubt in the ability to care for their loved one, manifesting as psychological burden also decreased with time as patients improved over time, or stayed status quo.

Factors affecting care of burden: Studies have found caregiver burden to be less in the presence of positive family support¹⁷ and better economic status.¹⁸ This was also seen in our study, where caregiver burden in nuclear families was reported to be significantly greater, especially in terms of economic burden. Although not explicitly examined, the earning member of the family being afflicted, or

inability of caregiver to pursue daily bread earning was often the reason cited in our cohort. The female gender has associated with more CBS score in our study although a previous study in palliative caregivers had reported less burden in female caregivers.¹⁹

STRENGTH AND LIMITATION OF THE STUDY

We have used the CBS-IP scale, which is an objective tool and previously validated in our population. All interviews were carried out by a trained psychologist and included at least one face-to-face meeting. The patients were tracheostomized and bedridden, requiring considerable care such as nasogastric feeding, suctioning, and bed care. The limitations of our study were the small sample size and few patients on home ventilation. We have not studied the association of burden with a change in patients' clinical status over time. However, the status may not have changed dramatically as demonstrated by the marginal improvement in quality-of-life scores of the CCI patients over the 4 weeks after discharge.

IMPLICATIONS OF THE STUDY

Additional support is required for caregivers for CCI patients, especially in the physical domain. Female caregivers may face greater distress. The significant fall in burden scores over time may guide disease management programs in this cohort. Future studies may attempt to develop a framework to identify factors that impact on caregiver burden. More studies on caregiver burden in males and for ventilated patients should be explored. There is a need for greater programs for home rehabilitation and care of the CCI patients, along the lines of palliative care, especially in LMICs.^{20,21} Understanding the key stakeholder issues as in our study is important to avoid the pitfalls faced in developed countries, improving patient outcomes, and unloading the stretched healthcare resources.²²

CONCLUSION

The burden score was moderate among the caregivers of both tracheostomized and palliative care patients. The physical burden domain was greater in the caregivers of tracheostomized patients, and psychological burden domain was more in the palliative patients.

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