Original Research Article

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A comparative study on the health status of caregivers between intensive and non-intensive care unit patients in a tertiary care hospital of urban Bengaluru

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ABSTRACT

Background: Caregivers providing care to hospitalized family members are potentially at risk for declining physical and psychological health. To assess and compare physical and psychological burden of caregivers of Intensive care unit and non-Intensive care unit (non-ICU) patients.

Methods: A descriptive, hospital-based, cross-sectional study was conducted among 256 caregivers (127 Intensive care unit and 129 non-ICU patients) in a tertiary care hospital in urban Bengaluru for 6 months (July-December, 2019). A modified Hospital anxiety and depression scale (HADS) and Perceived stress scale was used to assess the anxiety and stress burden among the caregivers, respectively.

Results: Out of 256 caregivers, 196 (76.56%) experienced some form of physical burden, 112 (57.14%) belonged to ICU group and 84 (42.86%) non-ICU group (Z=2, p=0.045). Anxiety problem was observed in 54.29% caregivers, and was found statistically significant in caregivers of ICU (62.59%) patients than non-ICU (37.41%) patients (Z=2.969, p=0.002). Similarly, the burden of stress was observed in 203 (79.29%) caregivers, predominantly in ICU group (54.19%) compared to non-ICU (45.81%) group.

Conclusions: Three-fourth of the caregivers had one or the other physical symptoms and nearly half of them had stress and anxiety irrespective of ICU or non-ICU admission. The financial burden was more among the ICU caregivers and the longer duration of stay had affected the health of the caregivers.

Keywords: Caregivers, Health status, Intensive care unit, Patients

INTRODUCTION

Caregiver's burden, a multidimensional toll exacted on care providers, can be defined as the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning. 1.2 caregivers care of hospitalized patient is an important aspect of any health system. 3 In many low- and middle-income countries, formal systems of long-term hospital care are poorly developed and have

a strong negative impact on the physical, emotional and economic status of caregivers family.⁴

In India, there has been a steady increase in the annual hospitalisation rate from 16.6 to 37.0 per 1000 population between 1995-1996 to 2014 and a mammoth brunt of care of the patient is mostly borne by the caregivers viz. family, friends or relatives.⁵ Emotional or psychological health is more disturbed in family members or caregivers of the hospitalized patients.⁶ The suffering of caring for a family

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member may differ depending on the disease severity and time that has passed since the diagnosis, with the burden of some diseases being felt by every member of the family. Another important aspect is the financial cost on care of the hospitalized patient, usually leading to stress, worry and face greater problems with social functioning and relationships. In India, the middle class and lower income families face the brunt as majority clear the dues by out of pocket expenses often having to mortgage their properties.

One of the issues least focused in any hospitalization of patients are the role of the caregivers in the nursing of the patients. They play an equally vital role in the recovery of patient. Very little information is available on the burden of the caregivers in India. It is generally assumed that Intensive care unit (ICU) patients' caregivers are more susceptible compared to non-ICU patients in view of the critical nature of care.

Comparatively less is known about the emotional/psychological, physical and financial demands and responsibilities that are placed on the attender of the patient during his/her hospital stay. Thus, the objectives of the study are to describe the socio-demographic profile of the caregivers of ICU and non-ICU patients in a tertiary care hospital in urban Bengaluru and to assess and compare the physical and psychological burden among the caregivers of ICU and non-ICU patients.

METHODS

A descriptive, hospital-based, cross-sectional study was conducted among 256 caregivers of ICU and non-ICU patients in a tertiary care hospital in urban Bengaluru for a duration of 6 months from July to December, 2019.

Sample size and data collection

The prevalence of burden on family caregivers of cancer patients as mentioned by Lukhmana et al was 43.5%. Assuming a confidence interval of 95%, α =0.05, precision of 10% and a design effect of 2, sample size of 197 was calculated. A 30% non-response rate was added to it and final sample size of 256 was achieved. The study enrolled 127 caregivers of ICU patients and 129 of non-ICU patients who satisfied the inclusion and exclusion criteria. All subjects who were 18 years and above at the time of interview and were available throughout the hospital stay of the patient were included in the study, while those not willing to give consent were excluded. The study was done on only those caregivers of patients who were admitted in the hospital and excluded day care and OPD patients.

A pretested, semi-structured questionnaire having detailed information on socio demographic profile and health status was used for the collection of data by interview method. A modified Hospital anxiety and depression scale (HADS) was used to assess the anxiety burden among the caregivers. ¹⁰ The questionnaire had 5 items reflecting anxiety and each item had been answered by the patient on

a four points (0-3) response category so the possible scores ranged from 0 to 15 for anxiety. On analysis of scores, a score of 0 to 5 was regarded as being in the normal range, a score of 6-7 was considered as borderline and score of 8-15 indicated abnormal or the presence of the anxiety state.

A modified perceived stress scale was used to assess the stress burden among the caregivers.¹¹ The scale had 5 items with score from 0-4 for each item, thus total score ranged from 0-20. Responses included as never (0), almost never (1), sometimes (2), fairly often (3) and very often (4). A score of 1-7 was considered as low stress, 8-13 as moderate stress and 14-20 as high stress.

Ethical issues

The study was approved by Institutional Ethical Committee and does not involve any intervention. Written informed consent was taken from the caregivers before enrolment in the study and their confidentiality was maintained at all times.

Statistical analysis

The data collected in the study was entered in MS Excel and analysed using IBM-SPSS statistics software package version 21.0. The normality of the data was checked using Shapiro-Wilk test in SPSS 21.0, since it was not normally distributed, non-parametric tests were used for statistical analysis. The results were expressed as median, interquartile range, frequency and percentages.

The physical, psychological and financial burden was compared across groups by Chi-square test. The anxiety and stress score were compared within the group using Wilcoxon Sign test and across groups using Mann Whitney U test. The association between the caregivers' demographic characteristics and anxiety, stress scores was evaluated by univariate and multivariate analysis. For all statistical tests, a p value <0.05 was considered statistically significant.

RESULTS

This study included a total of 256 caregivers of a private medical college tertiary care hospital, among whom 127 were ICU patients' caregivers and 129 of non-ICU patients.

Characteristics of the caregivers

The socio-demographic variables of both the groups are described in Table 1. The median age of the caregivers was 37 (28-50) years ranging from 15 to 72 years; maximum of them being females (72.26%). Majority of them were immediate family members viz. 59 (29.04%) spouse, 58 (22.66%) children, 54 (21.09%) parents followed by 58 (22.66%) relatives and only 2 (0.78%) siblings. 145 out of 256 caregivers belonged to upper lower socio-economic class and 179 (69.92%) resided in urban area. Only 24

(09.37%) of all caregivers had health insurance of either government and private. The median duration of stay in the hospital was 3 (2-6) days with minimum being 2 hours and maximum being 47 days. The hospital stay duration varied significantly between caregivers of ICU and non-ICU group (χ^2 =9.036, p=0.0026), and more than 7 days stay was mostly observed non-ICU group 52 (64.19%) compared to 81 (31.64%) in ICU group (Z=2.556, p=0.010).

Caregiver burden

Out of 256 caregivers, 196 (76.56%) experienced some form of physical burden, 112 (57.14%) belonged to ICU group and 84 (42.86%) non-ICU group (Z=2, p=0.045). Psychological problems like anxiety were observed in 139 (54.29%) caregivers, 87 (62.59%) were from ICU and 52 (37.41%) from non-ICU group (Z=2.969, p=0.002) and stress was observed in 203 (79.29%) caregivers, predominantly in 110 (54.19%) ICU group compared to 93 (45.81%) non-ICU caregivers (Z=1.193, p=0.23).

The common physical symptoms observed was in 100 (39.06%) headache, 77 (30.08%) leg cramps, 68 (28.56%) heaviness in the head and 43 (16.79%) chest pain/heartburn respectively. The other symptoms were palpitation, bloating, post prandial acidic regurgitation and gastrointestinal symptoms as shown in Table 2.

There was no significant difference in the physical burden seen across of caregivers of both groups. There was significant difference between the non-ICU and ICU caregivers in the practice of personal hygiene (χ^2 =4.827; p=0.027) and oral hygiene (χ^2 =10.210; p=0.001). The psychological symptoms observed are described in Table 3.

The anxiety score (Z=-4.986, p<0.001) was higher among ICU caregivers (mean rank=151.68) as compared to non-ICU (mean rank=105.68). Similarly, the stress score (Z=-4.395, p<0.001) was higher among ICU (mean rank=148.94) as compared to non-ICU (mean rank=108.38) caregivers. Both abnormal anxiety score

 $(\chi^2=20.51; p=0.00003)$ and high stress score $(\chi^2=11.87; p=0.002)$ was considerably greater in ICU caregivers. On comparison, the anxiety and stress score within the group was not significant. Only 14 (11.02%) ICU caregivers and 10 (07.75%) non-ICU caregivers had health insurance (Z=9.075; p \leq 0.001).

Overall, median expenditure was Rs. 30,000 (Rs.10,000-8,0000), ranging from as low as Rs. 1,000 to maximum Rs. 8,49,000 among 256 caregivers. 164 (64.06%) of total caregivers had an expenditure of less than Rs. 50,000, followed by 59 (23.05%) who spent Rs. 50,000 to 1 lakh and 33 (12.89%) had more than Rs. 1 lakh for medical expenses. A significant greater financial burden was observed in caregivers of ICU patients (χ^2 =31.167, p value \leq 0.001).

Factors affecting anxiety and stress score

The univariate analysis of the anxiety score and caregiver demographic characteristics was significantly associated with the caregiver's medical expenses (OR=0.147, p=0.019), loss of sleep (OR=-0.296, p≤0.001), loss of appetite (OR=0.185, p=0.002) and not associated with the caregiver's age, gender, religion, residence, socioeconomic status, type of family and duration of hospitalization). Whereas, the caregiver's stress score was associated with place of residence (OR=-0.154, p=0.01) and time since admission (days) (OR=-0.161, p=0.006) along with medical expenses (OR=-2.102, p=0.037), loss of sleep (OR=-3.762, p≤0.001) and loss of appetite (OR=-3.064, p=0.002) (Table 4).

Multivariate analysis revealed that caregiver burden's anxiety score was independently related with their medical expenses (OR=0.132, p=0.03), loss of sleep (OR=-0.324, p \leq 0.001) and loss of appetite (OR=0.188, p=0.001); on the other hand, their stress score was independently associated with time since admission (OR=-0.192, p=0.002), loss of sleep (OR=0.265, p \leq 0.001) and loss of appetite (OR=0.184, p=0.002).

Table 1: Distribution of the study subjects according to socio-demographic profile.

Parameters		ICU (n=	:127)	Non- IC	U (n=129)	X ² , P value
		N	%	N	%	A,1 value
	<18	1	0.78	-	-	
Age (years)	18-59	112	88.19	116	91.33	1.092, 0.57
	≥60	14	11.02	13	10.24	
Gender	Male	40	31.49	31	24.03	1.779, 0.18
Gender	Female	87	68.50	98	75.97	1.779, 0.18
	Hindu	95	74.80	104	80.62	
Religion	Muslim	31	24.41	25	19.37	2.034, 0.36
	Christian	1	0.78	-	-	
Residence	Rural	42	33.07	35	27.13	1.07.0.200
Residence	Urban	85	66.93	94	72.87	1.07, 0.300
Type of family	Joint	53	41.7	62	48.06	1.026.0.200
	Nuclear	74	58.27	67	51.94	1.036, 0.309
Health insurance	Yes	14		10		0.8436; 0.35

Continued.

Parameters		ICU (n=	127)	Non- ICU	U (n=129)	X ² , P value
		N	%	N	%	A,1 value
	No	112		119		
Socioeconomic status	Lower	8	6.30	15	11.62	
	Lower middle	24	18.90	21	165.28	
	Upper	3	2.36	2	1.55	5.981, 0.201
	Upper lower	78	61.2	67	51.94	
	Upper middle	14	11.02	24	18.60	
Time since admission (days)	<7 days	98		77		0.026.0.0026
	≥7 days	29		52		9.036, 0.0026

Note: *Figures in parentheses indicates percentages; #p value<0.05=significant.

Table 2: Description of common physical symptoms in the caregivers.

Donomotore	ICU (n=127)			U (n=129)
Parameters	N	%	N	%
Headache	51	40.16	49	37.98
Leg cramps	42	33.07	35	27.13
Heaviness in the head	37	29.13	31	24.03
Chest pain/heartburn	21	16.54	22	17.05
Palpitation	21	16.54	11	8.53
Bloating	16	12.60	10	7.75
Post prandial acidic regurgitation	10	7.87	10	7.75
Forgetfulness	24	18.90	22	17.05
Others	43	33.86	56	43.41

Note: *Multiple responses, **Figures in parentheses indicates percentages; #No significant difference observed. Others: excessive sweating, pain abdomen, constipation, loose stools, nausea, vomiting, fainting, cough.

Table 3: Comparison of the psychological health status of caregivers between ICU and non-ICU patients.

Parameters		ICU (n=127)		Non- ICU (n=129)		V ² n volue	
		N	%	N	%	\mathbf{X}^2 , p value	
Disturbed sleep	6 to 8	24	18.90	51	39.53		
Disturbed sleep	Less than 6	95	74.80	68	52.17	21.955; <0.001	
(hours)	More than 8	8	6.30	10	7.75		
	Decreased	66	51.97	51	39.53		
Disturbed appetite	Increased	2	1.57	2	1.55	4.048; 0.132	
Disturbed appetite	Normal	59	46.46	76	58.19	4.046, 0.132	
	No	41	32.28	26	20.16		
Feel left alone	Yes	40	31.50	37	28.68	0.241; 0.624	
reel left alone	No	87	68.50	92	71.32	0.241, 0.024	
	Most of time	75	59.06	50	38.76		
Feel tensed up	Occasionally	36	28.34	51	39.53	10.84; 0.004	
	No	16	12.60	28	21.71		

^{*}Figures in parentheses indicates percentages; #p value<0.05=significant.

Table 4: Association between factors and anxiety score of caregivers of ICU and non- ICU patients (univariate analysis).

Domomotono	Anxiety score				Stress score		
Parameters	OR	t	P value	OR	t	P value	
Age (years)	-0.030	-0.514	0.607	-0.010	-0.176	0.860	
Gender	0.044	0.717	0.474	0.085	1.399	0.163	
Religion	0.096	1.626	0.105	-0.113	-1.935	0.054	
Residence	0.066	1.109	0.269	-0.154	-2.613	0.010	
Socio-economic status	0.026	0.413	0.680	-0.049	-0.779	0.437	
Type of family	-0.028	-0.501	0.617	0.055	0.990	0.323	
Time since admission (days)	-0.041	-0.697	0.487	-0.161	-2.768	0.006	

Continued.

Donomertons	Anxiety	score		Stress score		
Parameters	OR	t	P value	OR	t	P value
Expenses (Rs.)	0.147	2.357	0.019	-0.130	-2.102	0.037

DISCUSSION

The health of the caregiver will greatly enhance the doctor patient relationship which of late has taken a course to the worst. The caregivers go through a great deal of physical pain, psychological distress and financial burden in the care of their loved ones. There is hardly any literature available in India looking at these determinants of health. In the present study, the physical, psychological and economic burden on the caregivers of the hospitalized patients in the care of ICU and non-ICU patients was assessed and the factors associated was analysed. Most of the caregivers, in both groups, were adults, urban, elderly, majority being females and were spouse/parents/children of the patients contrary in a study by Xiao et al had observed that majority were elderly (69.28±7.19 years), males and 84% were spouses of the patients. 12 However, these demographic characteristics did not aggravate the burden of the caregivers in another study by Li et al.¹³

A variety of physical symptoms were reported by the caregivers which was almost similar in both ICU and non-ICU patients. Identically, studies on caregivers of hospitalized persons had reported that long-term caregiving can adversely affect caregivers' physical health. Impaired sleep and fatigue are other prevalent health risks in family caregivers. There was significant drop in the practice of personal and oral hygiene due to the stay in hospital.

In current study, borderline and abnormal anxiety was noted in both groups, higher in ICU group similar to a study by Zahrani et al had shown high rates of depression (72.8%), anxiety (76.5%) and stress (61.5%) among caregivers of chronic illness including 17% ICU admission. The duration of stay and caregivers physical, anxiety and stress scores were significantly associated indicating longer the stay, greater was the chances of being affected. Caregivers' stress levels were less common among patients with short-term hospital stay (<7 days) than long-term hospital stay, in concurrence to present study. 16 On the contrary, longer duration of care was associated with psychological symptoms observed more among caregivers of children with phenylketonuria by Gharaei et al and half of the participants had mild to severe levels of depression, anxiety and stress scores respectively.17,18

In the present study, most of the caregivers had enormous medical expenses including indirect expenditure, had to support family and experienced significant life pressures in concurrence to a study where economic resources had exceeded in 78.7% in a study done by Lkhoyaali et al, 56% had to take credits, 18.7% sold their goods and 70.7% requested help from benefactors. ¹⁹ Other studies showed

that caregivers had higher mean score of financial problems due to reduced income and increased cost due to medical needs. ^{20,21}

In country such as India, the accessibility and availability to health care services is dependent on the financial status of the individual. The government has introduced health insurance schemes and is moving towards universal health coverage; however, the mass is yet to utilize the benefits. The individual with health insurance is better off than those paying out of pocket expenses and those seeking care in public hospital are in safety net, but as they come from low income families, they are worried about the loss of income due to their presence in the hospital. Focus on health of caregivers is need of the hour. The caregiver is usually not familiar with the hospital system and undergoes enormous stress, fear and pressure.

Hospitals should employ doctors who can show sympathy and empathy for the care of caregiver to ease their fear especially women, educate them about importance of personnel and oral hygiene, prepare them for the hospital stay, to seek care when in physical or psychological distress, inform about social support mechanism available to help caregivers to minimise the financial burden. Studies involving private hospital, corporate hospital and government hospital covering the entire country is needed for greater understanding of the problem and generalization.

Limitation of this study was that it did not include the caregivers who had lost their loving ones during hospitalization. The study was done in a single territory hospital (private medical college hospital).

CONCLUSION

In conclusion, this study found out that three fourth of the caregivers had one or the other physical symptoms and a half of them had stress and anxiety irrespective of ICU or non-ICU admission. The financial burden was more among the ICU caregivers and the longer duration of stay had affected the health of the caregivers.

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Institutional Ethics Committee

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