

Assessing caregiving burden among primary caregivers in a medical intensive care unit setup: Cross-sectional study

ABSTRACT

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Objective: Caregiver burden in caring patients in intensive care unit (ICU) settings are stressful and challenging place. Caregivers also play very important role in doctor–patient relationship. In India, there is a skewed trend in doctor–patient relationship. Without addressing caregiver’s psychological issues, we may not able to deliver good medical services. “Caregiver burden in primary caregivers of patients admitted to medical ICU (MICU) was measured. **Methodology:** Its cross-section observational study. We collected the information from total of 100 caregivers whose patient got admitted to MICU. We took only one caregiver. We administered socio-demographic data, Zarit Caregiver Burden Interview (ZBI) for assessing burden in caregivers. **Results:** The mean age of the caregivers was 38 years with 66% males were being primary caregivers and mean age of education was 8.61 years. The mean duration of patient stay in hospital was 4.67 days with range of 4–18 days. Mean duration of illness in patient was 466 days with range of 4 days to 10 years. Mean score caregivers burden as per ZBI was 5.10 with range of 0–25. Thirty-five percentage of caregiver were felt caregiving was the burden. Correlation analysis shows ZBI negative relationship with caregivers’ age and education and patients total duration of illness. There was a positive co-relationship with the duration of ICU admission. **Conclusion:** Higher burden was observed in caregivers and caregivers felt more burden if patients stays longer duration in ICU. More research is needed in this area.

Keywords: Caregiver burden, caregiver depression, medical intensive care unit, psychological problems

Caregiver burden has been defined as the experiencing physical, emotional, psychological, social, or financial problems because of caring responsibility for a sick member of family.^[1] A fundamental part of giving care is being a good communicator with the person getting care. Care is given with respect for the dignity of the person receiving care. The carer remains in contact with the primary health care provider, often a doctor or nurse, and helps the person receiving care make decisions about their health and matters affecting their daily life It is

considered to be multidimensional task because it involves personal care, mobility, transportation, communication, housework; management and coordination of medical care, administration of medications and therapies, emotional support, assisting with personal care,^[1,2] organizing appointments, social services, assistance with social activities, managing money;^[3] ambulating, transferring, incontinence care, shopping, housework, meal preparation, telephone calls, and managing finances.

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Caregiving is a common task, with one in 10 people having provided hands-on care for someone at the end of life (the majority of whom had cancer) in the past 5 years.^[4] Caregivers experience varying psychological problems such as constant fatigue, anxiety, depression, irritability constant tension, muscle pain, sleep disorders, impaired of attention and concentration, and impatience.

The intensive care unit (ICU) settings are stressful and challenging place for both patients and their families. They must navigate illness and its associated discomforts as well as complex decision making in an environment characterized by tremendous uncertainty.^[5,6] During an ICU stay, it is common for patients to be too ill to participate in decision making in the ICU— and medical decision making will generally be made by the caregivers.^[7,8] Caregivers decision making is stressful and contributes to the development of depression, anxiety, and posttraumatic stress disorder in the caregivers.^[6] Sometimes, this may persists years after their loved one is being discharged from the ICU.^[7,9,10]

Very few studies are available from India on caregiver burden in caring ICU patients. Caregivers play a very important role in doctor–patient relationship. In India, there is skewed trend in doctor–patient relationship. Caregiver mental health is also most important while caring patient in MICU. We aimed to measure caregiver burden in the primary caregivers of patients admitted to the medical ICU (MICU) of a multispecialty hospital.

METHODOLOGY

The objective of the study was “to measure caregiver burden in the primary caregivers of patients admitted in the medical ICU of a multispecialty hospital.” We obtained institutional ethics committee clearance before the beginning of the study with reference no reference number BLDE(DU)/IEC/448/2020-21. We defined caregiver are the relatives (first degree/second degree) who stayed with them for significant period and also knows about the patient illness well and also provide assistance related to an underlying physical illness who are unpaid and have no formal training to provide those services. Then we enrolled 100 caregivers. whose patient got admitted to MICU. We took minimum 4 days of admission as fixed criteria to have its impact on caregiver. We took only one caregiver who is main caregiver in all aspect and should be available for addressing all patient needs. We administered socio-demographic data, Zarit Caregiver Burden Interview (ZBI) to them to look for how much burden do they feel. The ZBI is an assessment tool used for evaluating caregiver burden. Zarit Burden Interview scale is a continuous scale. It has cut off of 10. Less than 10 no burden. more

than 10 burden present. more the score more will be the severity of burden.. This tool is widely used in the world. It was developed in 1980 to evaluate the perceived impact on caregiver’s health, personal and social life, financial situation, emotional wellbeing, and interpersonal relationships. In the international studies, ZBI-12 has been used to evaluate the burden of caregivers in different care contexts and this measure has been proved to be sensitive and effective for evaluating overall burden in caregivers.^[11,12] The ZBI scale is being continuous scale and we analyzed this with a continuous scale of age, education, number of days of ICU stay and total duration of illness (TDI). $P < 0.05$ is being taken as statistically significant. The following were the results.

RESULTS

The mean age of the relatives were [Table 1] 38 years with 66% males were being primary caregivers. The mean education of caregiver was 8.61. mean duration of hospital stay was 4.67 days with range of minimum 4 days to maximum 18 days. The mean duration of illness was 466 days with range of 4 days to 10 years. Mean score of ZBI was 5.10 with range of 0–25. Caregivers’ burden was more in females and urban area [Table 2].

The major occupation of them was labor class, homemakers, and business class [Table 3]. The majority of caregivers were sons, wives, or brothers [Table 4].

In our study, 35 people reported caregiving was a burden to them but the rest did not [Table 5]. It was more among

Table 1: Sociodemographic data

	Mean±SD	Maximum	Minimum
Age (years) (caregiver)	38.50±13.554	70	19
Female (caregiver)	34%		
Male	66%		
Education (years) (caregiver)	8.61±5.818	17	0
ICU stay (days) (patient)	4.67±2.597	18	4
TDI (days) (patient)	466.75±888.206	3570	4
ZBI score (caregiver)	5.10±5.672	25	0

ICU- Intensive care unit; TDI- Total duration of illness; ZBI- Zarit caregiver burden interview; SD – Standard deviation

Table 2: Care giver burden among different sex and urban versus rural

ZBI score	Mean±SD	SEM
Sex		
Male	4.97±5.820	0.716
Female	5.35±5.449	0.934
Urban	6.39±7.358	1.149
Rural	4.20±3.947	0.514

SD – Standard deviation; SEM – Standard error of the mean; ZBI- Zarit caregiver burden interview

laborer group followed by business group and farmer group. Among physical illness, others illness was highest followed by respiratory diseases and infections [Table 6]. The commonest reported problem among burden scale was “Stressed between caring for your relative and trying to meet other responsibilities (work/family)?” 74%. 46% of them were reported Other problem i.e., “That your

health has suffered because of your involvement with your relative?” [Table 7].

Correlation analysis has been shown in Table 8. It shows co-relationship analysis of ZBI score with age, education, TDI and duration of ICU admission.

Table 3: Burden among various occupation

Occupation	Care giver's burden		
	Mean±SD	F	P
Labour	5.8±7.4	0.372	0.895
Farmer	5.6±5.5		
Housewife	5.4±5.9		
Teacher	5.3±2.1		
Business	4.7±7.1		
Engineer	4.7±1.0		
Student	2.5±2.8		
Total	5.1±5.7		

SD – Standard deviation

Table 4: Relation with patient

	Frequency (%)
Son	30 (30.0)
Brother	16 (16.0)
Wife	16 (16)
husband	8 (8.0)
Daughter	8 (8.0)
Friend	4 (4.0)
Grandson	4 (4.0)
Other	14 (14)

Table 5: Zarit burden interview

	n (%)
Felt burden	35 (35)
No burden	65 (65)
Total number of caregivers	100 (100)

Table 6: Care giver's burden in various medical illnesses

Diagnosis in patients in MICU	Care giver's burden as per ZBI score (regression analysis)		
	Mean±SD	F	P
Others	10.8±6.9	2.057	0.048*
Respiratory disease	8.4±10.8		
Infectious	6.0±0.0		
Diabetes mellitus	5.7±2.1		
Heart disease	4.9±5.7		
MDRTB	4.5±0.5		
Neurological disease	4.0±2.2		
Liver disease	3.5±0.8		
Renal disease	1.5±1.8		
Total	5.1±5.7		

*Significant at 5% level of significance (P<0.05). ZBI- Zarit caregiver burden interview; MICU- Medical intensive care unit; MDRTB- Multi-drug resistant tuberculosis

DISCUSSION

This kind of study is very rare in India specially in set up like tertiary care in Northern Karnataka. This study was done in ICU setting where all medical cases require intensive care will be admitted. Many studies have done only in specific setting and certain kind population like cancer or chronic illness while ours was done in general MICU.

We the healthcare professionals were approaching caregivers to speak for ICU patients and providing care, also support patients and caregivers.^[13] Here, involving the caregivers is essential for delivering person-centered care.

In a study done by Sami *et al.* 2016 showed the majority of the caregivers age group was 56.4 years and most of the caregivers were female, Caucasian, married or cohabitating, and helping patients on a daily basis^[14] while ours was 38 years and majority of them were males. It may be cultural differences that exist in India. Caregiving job is most commonly taken up by males when they get admitted to ICU. India is male dominating country where major decision especially like ICU-related issues are taken by males. A study by Shah *et al.* 2019 says^[15] caregivers age >31 years showed higher ZBI score which was statistically significant (P = 0.03). This is likely to be due to increase in maturity. They also say that 52% of the caregiver are mother following grandmother; father's involvement is found to be very less reflected as father being main earning person in family. In our study, sons were major caregivers followed by wife and brothers. Few studies say caregivers are at increased risk of anxiety or depression if they are younger, females, belong to lower socioeconomic status, lower education, spouses, unmarried or in shorter-term marriages.^[15-21]

In our study as per ZBI burden was felt by 35% of caregivers and it was higher in lower age group, less educated and higher duration of ICU admission and long TDI. Its relatively lower compared to a study done by Torres 2017 where a low degree of overburden was reported by 34.5% of caregivers, while 15.5% showed moderate to high levels of overburden was 50%.^[22] It was similar in educational status where lessor education leads to higher stress. Poor education may be associated with

Table 7: Common responses in Zarit Burden Interview-12

	Percent
Stressed between caring for your relative and trying to meet other responsibilities (work/family)?	74
Uncertain about what to do about your relative?	66
That your health has suffered because of your involvement with your relative?	46
That your relative currently affects your relationship with family members or friends in a negative way?	44
That your social life has suffered because you are caring for your relative?	42

Table 8: Correlation analysis

	Care giver's burden (ZBI)	
	r	P
Age	-0.05	0.619
Educn	-0.092	0.365
Durn of ICU admission	0.391	<0.001*
TDI	-0.072	0.476

*Significant at 5% level of significance (P<0.05). ZBI- Zarit caregiver burden interview; ICU- Intensive care unit; TDI- Total duration of illness

feeling of inadequacy of knowledge for disease process, management and outcome.

Caregiver burden was more among labor class people followed by business people. This may sue to poor understanding of ICU setting and patient condition.

In this study, there was a positive correlation between increased ICU admission duration and ZBI score. This may be due to prolonged illness will lead to more perceived burden.

The most common illness for which caregiver feel more burden was other illness such as snake bite, loss of consciousness for unknown reason followed by respiratory diseases and infections. This may due to high fear of death. We do not have any particular study to say the caregiver burden is high among particular illness.

Studies have worked on how to reduce the caregiver's burden and psychological problems. We may need to follow them. Following are the few studies which say we should have interventions for supporting caregivers. This is because if the patient survives, then they are likely to be taken care for prolonged and often difficult recovery period.^[9] The interventions are giving a range of tools or strategies such as family information booklet, dedicated nurse support, bereavement brochure and structured meetings.^[6] Providing written and oral information by nursing and medical staff have significantly increased the satisfaction and reduced anxiety and this reduction has been sustained over time. Reasons for this pattern

are because families were provided with good knowledge about their relative's clinical condition and treatment by attending a family meeting. These meetings ensured families received updated information, had an opportunity to get questions answered and support when difficult decisions needed to be made. They had greater satisfaction with needs met if they received information about the ICU environment and equipment either through leaflets or discussions with staff.^[6]

This study has several limitations. First, this is a cross-sectional study and we do not have information on responsiveness to change and this is important for psychometric property in intervention studies. We should have collected the information at various point of time so that we would have assessed the trend rather than point prevalence.

Implication

- Caregivers feel need for information and assurance by treating team
- One major implication of this study is that medical staff's ability to meet or satisfy these needs are not always achieved
- ICU patient's caregiver experience increased psychological burden, and it has to be addressed to have a better doctor-patient relationship
- Regular structured family meetings using written and oral information are suggested. More research is needed in this area.

CONCLUSION

ICU patient's caregivers feel caregiving is the burden. We need to give more information and reassurance to reduce this burden. However, caregivers' perceived needs were not always met by medical team and this had a negative impact on family satisfaction and their psychological health. More research is needed in this area. We strongly recommend that all ICU set up should have a counselor in place. All persons and their caregivers should be required to visit the counselor and if required, a psychiatrist, to provide management of depression.

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Conflicts of interest

There are no conflicts of interest.

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