



Exploring Psychosocial Concerns and Needs of Ventilator and Nonventilator Caregivers in the Emergency and Trauma Care Setting

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Abstract

Introduction Caregivers of traumatic brain injury (TBI) survivors in ventilators and nonventilator undergo psychological distress and their concerns and needs are secondary to patient care. Thus, this study aimed to explore the day-to-day concerns of the caregivers of ventilator and nonventilator survivors of TBI.

Materials and Methods A descriptive research method with a qualitative and quantitative approach was adopted. Overall, 100 adult caregivers (ventilator care, $n = 50$), (nonventilator care, $n = 50$) providing care for patients diagnosed and suffering from TBI were recruited using a cross-sectional survey method. Percentage, mean, standard deviation for continuous variables, and the simple thematic analysis were used for qualitative data.

Results The results showed that mild depression (9.54 ± 3.83) and mild anxiety (9.90 ± 4.22) were present in caregivers who were providing care for ventilator patients. However, no signs of depression (4.78 ± 2.30) and anxiety levels (2.90 ± 2.60) were found in the nonventilator caregivers. The qualitative results showed that social concerns such as marriage, work, psychological worry, and difficulty in decision making were highly present in caregivers.

Conclusion The study findings indicates that psychosocial intervention to be considered as an essential service in the neurotrauma unit to address crisis and support for the caregivers, family members, and patients from the holistic care perspective by medical and psychiatric social workers.

Keywords

- ▶ neurotrauma
- ▶ caregivers
- ▶ ventilator and nonventilator

Introduction

Traumatic brain injury (TBI) is increasing due to which considerable number of patients with TBI require ventilator and nonventilator care. Although the ventilator and nonventilator services have saved many lives of TBI survivors,

these services have made them dysfunctional and their health care needs complex.¹ Therefore, TBI survivors depend on caregivers for activities of daily living. Caregivers are defined as the family members or friends responsible for providing or coordinating the ventilator-assisted or

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nonventilator-assisted individuals' care without financial compensation. Caregivers providing care for ventilator patients have experienced significant physical, psychological, social, and financial burdens.² Further, studies have revealed that increased psychological stress and fear of handling emergencies have led to provide home care after discharge.³ The environment of ventilator care is highly stressful for caregivers at intensive care unit (ICU) due to which more than 50% caregivers develop psychosocial problems such as stress, anxiety, depression, hypochondriasis, complicated grief, and suicidal tendency especially higher in spouses of TBI survivors. Studies also suggest exploring the differences related to culture, geographic regions considering the variability in values, preferences and support available to the caregivers is needed.⁴ However, caregivers of nonventilator patients do experience psychosocial problems but still severity is not known and their psychosocial problems are unaddressed. The number of studies report that caregivers' psychosocial needs of ventilator and nonventilator TBI survivors are given little attention in the field of TBI.⁵⁻⁸ Therefore, the present study aimed to understand the severity of psychological distress and explore the day-to-day psychosocial concerns between caregivers of ventilator and nonventilator patients.

Methodology

The study was conducted in emergency and trauma care center at the tertiary care, Bengaluru, after receiving ethical approval from the ethics committee. The study had followed the descriptive research design with a qualitative and quantitative approach. Overall, 100 adult caregivers (50 ventilator care and 50 nonventilator care) providing care for TBI survivors were recruited. Adult caregivers who were providing care for TBI survivors at ICU unit (ventilator) and step-down ward (nonventilator), who could speak vernacular languages such as Kannada, Telugu, Tamil, and Hindi were recruited after obtaining the written informed consent. Caregivers who had expressed unwillingness to participate were excluded from the study.

Qualitative Approach

The qualitative approach was used to understand the caregiver's psychosocial concerns. In the present study, caregivers providing care at ICU and stepdown ward patients were considered as ventilator and nonventilator caregivers. One-to-one in-depth interviews were conducted with caregivers of ventilator ($n=33$) and nonventilator ($n=22$) patients. The in-depth interviews were guided by the pre-designed interview guidelines to understand the day-to-day caregiving concerns, caregiver needs, caregiving experience, and caregivers' difficulties concerning decision making. The following open-ended questions were asked to both the groups to bring homogeneity in the data.

1. What are your current concerns?
2. What are your current needs?
3. How are you feeling in the ICU/non-ICU care?

4. How difficult and easy while making a decision during hospitalization? And Why?

Quantitative Approach

The modified Kuppuswamy socioeconomic scale (SES), Depression, Anxiety and Stress Scale (DASS-21), and semi-structured interview schedule were used for the data collection.

Modified Kuppuswamy Socioeconomic Scale (2020)

The modified Kuppuswamy SES was used to measure the SES of the caregivers in the study. It includes parameters such as education, occupation, and total income of the family pooled from all resources. Each parameter has subcategories and is classified into subgroups such as "upper class, upper-middle-class, lower middle class, upper lower and lower socioeconomic class." The total score of Kuppuswamy SES ranges from 3 to 29.

Depression, Anxiety, Stress Scale

To measure the caregiver distress, DASS-21 (¹³DASS-21) was administered on caregivers. DASS is a set of three self-report scale designed to measure the negative emotional states of depression, anxiety, and stress. The DASS was used for screening "normal" adolescents and adults. The DASS was constructed to measure the presence of significant emotional states usually described as depression, anxiety, and stress. Each of the three DASS-21 scales contains seven items, divided into subscales of two to five items with similar content. Subjects are asked to use four-point severity/frequency scales to rate the extent to which they have experienced each state over the past week. The severity is represented as 0—did not apply to me at all, 1—applied to me to some degree, or some of the time, 2—applied to me to a considerable degree, or a good part of the time, and 3—applied to me very much, or most of the time. The scoring for DASS-21 is as follows: depression—normal (0–9), mild (10–13), moderate (14–20), severe (21–27), and extremely severe (28 above); anxiety—normal (0–7), mild (8–9), moderate (10–14), severe (15–19), and extremely severe (20 above); and stress—normal (0–14), mild (15–18), moderate (19–25) severe (26–33), and extremely severe (34 above).

Semistructured Interview Schedule

A semistructured interview schedule was used to collect the patient's demographic and illness characteristics, caregivers' demographic details, and social support available for caregivers while providing ventilator and nonventilator care.

Data Analysis

The qualitative data that was collected in the vernacular language through in-depth interviews was summarized soon after the interview and translated into English. The simple

thematic analysis was used to analyze the qualitative data. Thematic content analysis method is used for identifying, analyzing, reporting themes that come from the qualitative data. These concepts or categories are derived from within the data in an inductive or deductive manner.⁹ In the process of analysis and to maintain qualitative rigor, the qualitative data were first read and reread word by word, line by line multiple times by two authors independently to become familiar with content of qualitative data and generate an initial code. The coding was done independently by two authors. The codes were developed along with creation of mutually exclusive rules for inclusion criteria. The meaningful coded transcripts were carefully analyzed, compared, and refined their coding categories and developed the final themes in a systematic manner adhering to guidelines of thematic analysis. Further, disagreement between the two authors was resolved by consensus with the input of third reviewer who was not involved in the coding process. Based on the reviewers' consensus, the codes' subcategories were merged into four major themes that were reassessed to ensure that they represented the data. Finally, a selection of powerful and specific verbatim illustrations was selected within the context to represent each theme. In addition, the researcher's field observations and caregivers' facial expressions were added whenever necessary. With regard to quantitative data descriptive statistics was used for nominal, categorical and continues variables. For qualitative data analysis, free Atlas. ti software was used and for quantitative data analysis, R software was used.

Results

This study revealed that male patients received ventilator care 74% ($n = 37$) and nonventilator care 76% ($n = 38$). Female patients received ventilator care (26%; $n = 13$) and nonventilator care (24%; $n = 12$). Total number of male patients in ventilator care who had a history of road traffic accident (RTA) that caused trauma and nontrauma were (68% $n = 34$) and (32%; $n = 16$), respectively, while total number of male patients in nonventilator care who had a history of RTA that caused trauma and nontrauma were (74%; $n = 37$) and (26%; $n = 13$), respectively. The Glasgow Coma Scale (GCS) scores revealed that the majority of patients who were on ventilator care had severe GCS score of 15 (30%), moderate GCS score of 30 (60%), GCS score of 5 (10%), whereas nonventilator patients had severe GCS score of 22 (44%) moderate GCS score of 21 (42%), and mild GCS score of 7 (14%). ► **Table 1** depicts the demographic and illness details of ventilator and nonventilator patients.

The results depicted that male caregiver provided care for 35 ventilator patients (70%) and for 40 nonventilator patients (80%), while female caregivers provided care for 15 ventilator patients (30%) and 10 nonventilator patients (20%). The educational grade achieved by the Ventilator and non-ventilator caregivers were illiterate [20% ($n = 10$) v/s 26% ($n = 13$)], primary education [4% ($n = 2$), v/s 12% ($n = 6$)], secondary education [30% ($n = 15$) v/s 14% ($n = 7$)], [PUC 26% ($n = 13$)

v/s 26% ($n = 13$)] and [20% ($n = 10$) v/s 22% ($n = 11$)] for ventilator and nonventilator caregivers, respectively. The majority of caregivers providing care for ventilator patients were working as daily wagers (48%; $n = 24$), and whereas the total number of nonventilator caregivers working as daily wagers were 14 (28%). The majority of ventilator caregivers belonged to lower middle class (56%; $n = 28$) and nonventilator caregivers belong to upper lower (60%; $n = 30$) SES.

The results further showed that nonventilator caregivers (100%; $n = 50$) had better primary support when compared with ventilator caregivers (92%; $n = 46$). Ventilator caregivers had better secondary support (68%; $n = 34$) when compared with nonventilator caregivers (66%; $n = 33$). For tertiary social support, nonventilator caregivers reported they had adequate tertiary social support (100%; $n = 50$) and ventilator caregivers reported that they did not have adequate tertiary social support (100%; $n = 50$) in caregiving. Ventilator caregivers had good amount of emotional support (62%; $n = 31$) when compared with nonventilator caregivers (52%; $n = 26$). Ventilator caregivers reported they had adequate instrumental support (50%; $n = 25$), whereas nonventilator caregivers reported less instrumental support (46%; $n = 23$). ► **Table 2** gives the demographic details, SES, and the level of social support received by ventilator and nonventilator caregivers.

The results showed that the average age of ventilator patients was 40 years (40 ± 19.57) and nonventilator patients' average age was 37 years (37 ± 18.40). The average of ventilator's caregivers was 40 years (40 ± 19.57) and the average age of nonventilator caregivers age was 37 years (37 ± 18.40).

Further, the results showed that mild depression (9.54 ± 3.83) and mild anxiety (9.90 ± 4.22) was present in caregivers of ventilator patients. However, no signs of depression (4.78 ± 2.30) and anxiety levels (2.90 ± 2.60) were found in the nonventilator caregivers. And no significant stress was perceived by neither of the caregivers. ► **Table 3** showed the descriptive statistics of patients' and caregivers' age, and caregiver's distress levels.

Qualitative Themes

The major themes that emerged from qualitative data with respect to psychosocial concerns of ICU caregivers and non-ICU caregivers are described below.

Theme 1: Day-to-Day Concerns of Caregivers on TBI Survivors Life

One of the themes derived from qualitative data was concerns of caregivers during hospital care. Both ventilator and nonventilator caregivers expressed social concerns such as resume back to work, marriage and education concerns, recovery of the patient, continuity of care, and having positive hope for a better life.

"My brother is a very intelligent student and he is interested in studies very much, considering his current

Table 1 Sociodemographic details of the patients

Variable	Category	Ventilator	Nonventilator
		n (%)	n (%)
Gender	Male	37 (74%)	38 (76%)
	Female	13 (26%)	12 (24%)
Education	Illiterate	6 (12)	9 (18%)
	Primary	11 (22%)	11 (22%)
	Secondary	12 (24%)	16 (32%)
	PUC	11 (22%)	8 (16%)
	Degree	8 (16%)	5 (10%)
	Children below 2 years	2 (4%)	1 (2%)
Occupation	Home maker	4 (8%)	4 (8%)
	Student	10 (20%)	11 (22%)
	Daily wager	24 (48%)	15 (30%)
	Private employee	6 (12%)	5 (10%)
	Farmer	6 (12%)	8 (16%)
	Self-employment	–	7 (14%)
Marital status	Unmarried	16 (32%)	17 (34%)
	Married	31 (62%)	31 (62%)
	Separated/Diverse	3 (6%)	2 (4%)
Religion	Hindu	40 (80%)	44 (88%)
	Muslim	9 (18%)	6 (12%)
	Christian	1 (2%)	–
Domicile	Within Karnataka	38 (76%)	46 (92%)
	Outside Karnataka	12 (24%)	4 (8%)
Diagnosis	Trauma	34 (68%)	37 (74%)
	Nontrauma	16 (32%)	13 (26%)
GCS	Mild	5 (10%)	7 (14%)
	Moderate	30 (60%)	21 (42%)
	Severe	15 (30%)	22 (44%)

Abbreviations: GCS, Glasgow Coma Scale; PUC, pre-university course.

situation we are really worried that whether he will continue his education or not.”

“We have started looking for marriage proposals for our son soon after he started going to work, this unexpected incident made us in a dilemma when he will become normal and get ready for his marriage.”

Theme 2: Day-to-Day Concerns during Hospitalization

Another theme derived from the data was the current needs of the caregivers during the hospital stay. Most of the caregivers required basic facilities such as seating facilities and charging ports for mobiles. Besides, information, neuroeducation, emotional, psychological, and financial support were their needs.

One of the caregivers had expressed that “We have spent a huge amount of money as of now, taken debts from the relatives for the treatment; me and my wife we both have to earn to manage the family daily. Don’t know how to manage the financial issues.”

Another caregiver had expressed that “my son (the patient) is the breadwinner of our family; our family is meeting all the needs upon his salary only. Now he has admitted here, don’t know how long he will be like this and go back to work, which is very shock and difficult experience for us to deal with.”

Theme 3: Day-to-Day Emotional Concerns of Caregivers

All the caregivers who had expressed while seeing their patients with life support made them worried, anxious,

Table 2 Caregivers demographic details of ventilator and nonventilator patients

Variable	Category	Ventilator	NonVentilator
		n (%)	n (%)
Gender	Male	35 (70%)	40 (80%)
	Female	15 (30%)	10 (20%)
Education	Illiterate	10 (20%)	13 (26%)
	Primary	2 (4%)	6 (12%)
	Secondary	15 (30%)	7 (14%)
	PUC	13 (26%)	13 (26%)
	Degree	10 (20%)	11 (22%)
Occupation	Home maker	6 (12%)	6 (12%)
	Student	2 (4%)	2 (4%)
	Daily wager	24 (48%)	14 (28%)
	Private employee	9 (18%)	9 (18%)
	Farmer	6 (12%)	7 (14%)
	Self-employment	3 (6%)	12 (14%)
Marital status	Unmarried	7 (14%)	12 (24%)
	Married	43 (86%)	37 (74%)
	Separated	–	1 (2%)
	Spouse	13 (26%)	4 (8%)
	Daughter/son	15(30%)	15 (30%)
	Parents	12 (24%)	17 (34%)
	In-laws	7 (14%)	9 (18%)
	Brother/sister	3 (6%)	5 (10%)
Socioeconomic status of caregivers (Kuppuswamy scale)	Upper class	2 (4%)	2 (4%)
	Upper middle	16 (32%)	4 (8%)
	Lower middle	28 (56%)	13 (26%)
	Upper lower	3 (6%)	30 (60%)
	Lower	1 (2%)	1 (2%)
Primary social support	Adequate	46 (92%)	50 (100%)
	Inadequate	4 (8%)	0 (0%)
Secondary social support	Adequate	34 (68%)	33 (66%)
	Inadequate	16 (32%)	17 (34%)
Tertiary social support	Adequate	0 (0%)	50 (100%)
	Inadequate	50 (100%)	0 (0%)
Emotional support	Adequate	31 (62%)	26 (52%)
	Inadequate	19 (38%)	24 (48%)
Instrumental support	Adequate	25 (50%)	23 (46%)
	Inadequate	25 (50%)	27 (54%)

Abbreviation: PUC, pre-university course.

fearful, and at times feeling relaxed because the patient was under care and treatment. This theme was derived from the following illustrations.

“I have never experienced these situations in my life, which is unexpected and shocking to me, I am very

much worried about the current health condition of my husband.”

“We are anxious about my son-in-law’s health; he has recently married our daughter and my daughter is pregnant now. She needs his support and affection during this time. We don’t know when he will become normal.”

Table 3 Distress levels among caregivers of ventilator and nonventilators

Variables	Ventilator	Nonventilator
	Mean \pm SD	Mean \pm SD
Patients age (in y)	40 \pm 19.57	37 \pm 18.40
Caregivers age (in y)	40 \pm 19.57	37 \pm 18.40
Variables	Distress levels among ventilator caregivers	Distress levels among nonventilator caregivers
	Mean \pm SD	Mean \pm SD
Depression	9.54 \pm 3.83	4.78 \pm 2.30
Anxiety	9.90 \pm 4.22	2.90 \pm 2.60
Stress	9.50 \pm 3.74	5.04 \pm 2.64

Abbreviation: SD, standard deviation.

"I am fearful about my father's current condition, my mother is alone at home and I have to manage her and look after my father at the hospital. She is also a diabetic patient; don't know when the things will become alright."

Theme 4: Day-to-Day Concerns of Caregivers in Making a Decision

The final theme derived was difficulties faced while deciding the hospitalization. The caregiver had faced difficulty in making a timely decision during treatment. Consent for unexpected surgery, affordability of medical expenditures, the decision regarding alternative caregivers, long stay in the hospital, and continuity of care after discharge were the main areas of difficulties that emerged.

"It's been more than a week that I have stayed here in the hospital and looking after all the needs for my brother, but my manager has told me that I need to join back to the work immediately, my parents are very old and they don't know how to manage all these things, I am very much distressed and worried."

"I and my wife both are in the hospital since the time of admission, we have left our two children at my relative's house; we are concerned that how are they doing without us and missing them. We have no idea that more how many days we should be here."

– **Tables 4 and 5** provide the various psychosocial concerns of caregivers and differences observed between ICU caregivers and non-ICU caregivers.

Discussion

This study was aimed to understand the psychological distress of caregivers providing care for ventilated and non-ventilated TBI survivors and also explore the psychosocial concerns of caregiving between ICU caregivers and non-ICU caregivers. Most of the earlier studies focused to understand

the psychological impact of family members or caregivers of ventilated TBI survivors but very minimal studies investigated the psychosocial concerns of caregivers of ICU and non-ICU setting in Indian context. In this connection, this study holds significance and contributes to caregiver literature especially ICU and non-ICU setting in the field of TBI from a psychosocial perspective.

This study results highlighted that caregivers providing care for ventilator patients experienced mild depression (9.54 \pm 3.83) and mild anxiety (9.90 \pm 4.22). However, no signs of depression (4.78 \pm 2.30) and anxiety levels (2.90 \pm 2.60) were found among caregivers of nonventilator patients and no significant stress was perceived by neither of the caregivers. On the other hand, the qualitative results depicted caregivers had expressed anxiety, fear, worry during caregiving and at times felt relaxed because the patient was under care and treatment by ICU treating team. This finding is supported by earlier studies report that stress, anxiety, depression, grief, burden posttraumatic stress disorder, and hypochondriasis are common in caregivers who provide care for ventilator patients. Findings are inconsistent on psychological distress among caregivers.^{4-8,10} The qualitative results emphasized caregivers of ventilator and non-ventilator had common psychosocial concerns such as patient's recovery, resume back to work, marriage and education concerns, continuity of care, and optimism toward the recovery. Further, caregivers had various expressed needs such as lack of basic facilities to take rest, lack of general information hospital services, neuroeducation, unmet psychological needs, and financial constraints. Besides, they had difficulties and worries associated with providing consent for unexpected surgery, affordability of medical expenditures, arranging alternative caregivers, long stay in the hospital, and continuity of care after discharge. This study finding is supported by earlier study on caregivers who have faced various psychosocial difficulties in giving consent and inability to afford medical expenses.¹¹ The result identified caregivers who were providing care for nonventilator patients had adequate primary social support, whereas ventilator caregivers had secondary social support.

Table 4 Ventilator and nonventilator caregiver needs during hospitalization

Variable	Category	Ventilator caregivers (n)	Nonventilator caregivers (n)
Caregivers' concerns	Recovery of the patient	20	33
	Financial problems	14	18
	Continuation of the patient education	9	8
	Continuation of the patient job	12	14
	Marriage concern	4	7
Caregivers' supportive needs	Spiritual need	3	9
	Financial need	20	18
	Emotional need	8	11
	Psychological need	3	13
	Psychosocial need	26	22
Caregivers' feelings	Worried	20	29
	Anxious	14	16
	Fearful	6	5
Educational needs of caregivers	Neuroeducational needs	30	48
	Informational needs	22	7
	Treating team like doctors, nursing staff, social workers	30	48
	Not preferred	21	2
	Treatment decision	10	11
Caregivers' difficulties in decision making	The decision about the stay of caregivers in the ward	17	34
	The decision to sell the property financial aid	15	15
	The decision about the shifting of the patient	8	12
Caregivers' difficulties during hospitalization	No practical difficulties	25	45
	Seating facilities, charging facilities	5	5

Concerning tertiary social support, nonventilator caregivers had perceived adequate support compared with ventilator caregivers. This perception may be differed based on the severity of the illness and the duration of stay in the ICU. Studies also report that during crisis time accessing social support is difficult for caregivers providing care in trauma care.¹² Further studies can be explored in this area to strengthen the social support and family-based interventions.

Differences in ICU and Non-ICU Caregivers

Financial Burden

Caregivers of patients under ventilation express more distress and helplessness about the situation as compared with caregivers of nonventilator patients. Second, what

we majorly observe is that the financial burden tends to increase as the duration of the ventilation is extended. Furthermore, many of the ventilator patient's caregivers will be waiting outside the emergency ICU throughout the day worrying about the patient's condition without proper sleep and food. This subsequently takes a toll on both their physical and mental health. Apart from that, we see that the degree of distress is more prevalent in the caregivers of ventilator patients. Due to the busy setting and lack of proper communication about the illness and current condition to the caregivers of ventilator patients, the tension and stress among the caregivers are further exacerbated. They also express their helplessness as they are unable to convey adequate information about the patient's status to their other family members who are expecting from them.

Table 5 The major themes and subthemes of caregivers of ICU and non-ICU care

Questions asked	Subthemes	Major themes
1. What are your current concerns?	<ul style="list-style-type: none"> • Recovery of the patient • Financial problems • Concern regarding patients' studies • Concern regarding return to work or resume to job • Marriage concern 	Day-to-day concerns of caregivers on TBI survivors' life
2. What are your current needs?	<ul style="list-style-type: none"> • Educational needs • Informational needs • Spiritual needs • Financial needs • Emotional needs • Psychological needs • Psychosocial needs 	Day-to-day concerns during hospitalization
3. How are you feeling in the ICU/non-ICU care?	<ul style="list-style-type: none"> • Worried • Anxious • Fearful • Uncertainty 	Day-to-day emotional concerns of caregivers
4. How difficult and easy while making a decision during hospitalization? And Why?	<ul style="list-style-type: none"> • The decision about the stay of caregivers in the ward • The decision to sell the property financial aid • The decision about the shifting of the patient 	Day-to-day concerns of caregivers in making a decision

Abbreviation: ICU, intensive care unit.

Psychosocial Issues and Concerns on Prognosis and Recovery

The concerns of caregivers on TBI prognosis and recovery were significantly different. Most importantly, the study observed the psychosocial concerns expressed by caregivers regarding the prognosis and recovery of the TBI survivor along with financial concerns in the ICU and non-ICU setting. Another concern was related to the caregiving role and needs of the patients after discharge from the hospital. Many TBI survivors who were admitted tend to be the breadwinner of the family due to which they lost their only source of income and were left with no earning source in the family. In some cases when the woman of the family was bedridden, the husband expressed concern and worry regarding the rearing of their children especially when infant or young children were present in the family. Moreover, in the hospital many TBI survivors discharged soon after the surgery due to reasons like shortage of beds and various emergency cases. Hence, the caregivers were left clueless and engulfed in a state of confusion about what to do next. The other social factors such as poverty, unemployment, lack of adequate social support and fear about the disruption in family functioning, presence of disability, concern for long term care, and accessibility of rehabilitation also contributed to increase the psychosocial issues among caregivers. As a result of this, the caregivers can experience immense levels of stress, anxiety, depression, and burden.

Potential Needs

The study also identified potential differences between ICU caregivers and non-ICU caregivers. The potential needs of the caregivers comprise of financial needs, supportive and psychological needs. Arranging after care supporting aids such

as wheel chair, special beds, and other equipment also became one of the needs of the caregivers. Other than that, caregivers also express the utmost need for communication of adequate information regarding the patient's condition that was not provided to them by the treating team most of the times due to language barriers. The caregivers need someone who could listen to them and their respective concerns. Most of the caregivers ventilate their feelings and emotions during sessions with the psychiatric social worker. However, there is severe shortage of trained medical and psychiatric social workers. There is a high need to ignite special courses to fill this manpower gap in the emergency and trauma care. At times, the caregivers had mental and physical issues that could make them feel overburdened and underwhelmed in providing support and care to the TBI survivor and sometimes they ignored their personal care.

Social Support

Another frequently made observation in the study was lack of social support. In many cases, only one caregiver was present to take care of the patient on ventilator and they had to run around to collect medications and test reports, which also contribute to the caregiving burden. On the other hand, patients under ventilation suffer from other comorbid illnesses that add on to the poor prognosis of the patient due to which many caregivers increase concerns regarding the recovery and functionality of the patient. Therefore, future studies should focus to understand psychosocial predictors of caregiver burden, caregiver's perception on prognosis and recovery, availability of social support, and understanding potential needs in a systematic manner. ► **Table 6** provides the psychosocial differences and its triggering factors between ICU caregivers and non-ICU caregivers.

Table 6 Various psychosocial factors that increase the psychosocial concerns among ICU and non-ICU caregivers

Psychosocial Issues	Ventilator caregivers	Nonventilator caregivers
Financial burden	<ul style="list-style-type: none"> Caregivers are overburdened with the additional and miscellaneous expenses that add to the hospital care, treatment, and transportation When the patient is the breadwinner of their family, then it becomes a challenge as the family faces a financial crunch 	<ul style="list-style-type: none"> Caregiver being the sole breadwinner of the family has to bear multiple expenses, arrange money for the patient's treatment, and simultaneously contribute toward the rest of the members in the family
Psychosocial concerns and distress	<ul style="list-style-type: none"> Improper communication between medical staff and caregivers can cause them distress Inadequate information about the diagnosis and health condition When other family members are facing health conditions, it adds to the distress factor 	<ul style="list-style-type: none"> Caregiver's feel concerned regarding the slow recovery rate and poor prognosis Due to the patient's hospitalization, the caregiver who is a breadwinner might tend to lose their daily wage Distress is more among caregivers who are parents with younger children as the hospitalization leads to separation from their children Caregivers coming from distant places feel distressed about coordinating the treatment process, making the required arrangements for post discharge general care
Uncertainty regarding prognosis and recovery	<ul style="list-style-type: none"> Caregivers feel uncertain about the improvement in health condition and time period needed for patient's complete recovery 	<ul style="list-style-type: none"> The amount of uncertainty is slightly low when it comes to nonventilator caregivers except for patients with extreme health conditions
Potential needs, home care, and social support	<ul style="list-style-type: none"> Affects caregiver's activities of daily living Caregiving needs of patients with elderly caregivers differ in nature Emotional and financial needs Home care needed on a higher level Primary support is more prevalent in ventilator patients 	<ul style="list-style-type: none"> Adequate communication on patient's condition and information about the illness home care is required to a lesser level among nonventilator patients. Social support differs from case to case among nonventilator patients and more of secondary support seems to be prevalent

Abbreviation: ICU, intensive care unit.

Conclusion and Implications on Clinical Social Work Practice

The current research implies systematic psychosocial intervention needs to be provided for the caregivers at ventilator and nonventilator care. There is a need to establish psychosocial care services round the clock in the ventilator and nonventilator setting. Therefore, the psychosocial unit needs to be considered as an essential service provider in the neurotrauma unit to address the caregiver and patients' psychosocial needs from a holistic care perspective and hospital management should take appropriate steps to fill the man power gap to address psychosocial concerns and reduce the caregiver burden at the earliest.

Conflict of Interest
None declared.

References

- Dale CM, King J, Nonoyama M, et al; CANuVENT group. Transitions to home mechanical ventilation: the experiences of Canadian ventilator-assisted adults and their family caregivers. *Ann Am Thorac Soc* 2018;15(03):357–364
- Liu JF, Lu MC, Fang TP, Yu HR, Lin HL, Fang DL. Burden on caregivers of ventilator-dependent patients: a cross-sectional study. *Medicine (Baltimore)* 2017;96(27):e7396
- Hui C, Lin MC, Liu TC, Wu RG. Mortality and readmission among ventilator-dependent patients after successful weaned discharge from a respiratory care ward. *J Formos Med Assoc* 2010;109(06):446–455
- Choi J, Donahoe MP, Hoffman LA. Psychological and physical health in family caregivers of intensive care unit survivors: current knowledge and future research strategies. *J Korean Acad Nurs* 2016;46(02):159–167
- Pérez-San Gregorio MA, Blanco-Picabia A, Murillo-Cabezas F, Domínguez-Roldán JM, Sánchez B, Núñez-Roldán A. Psychological problems in the family members of gravely traumatised patients admitted into an intensive care unit. *Intensive Care Med* 1992;18(05):278–281
- Davidson JE, Jones C, Bienvenu OJ. Family response to critical illness: postintensive care syndrome-family. *Crit Care Med* 2012;40(02):618–624
- Pochard F, Azoulay E, Chevret S, et al; French FAMIREA Group. Symptoms of anxiety and depression in family members of intensive care unit patients: ethical hypothesis regarding decision-making capacity. *Crit Care Med* 2001;29(10):1893–1897
- Schmidt M, Azoulay E. Having a loved one in the ICU: the forgotten family. *Curr Opin Crit Care* 2012;18(05):540–547

- 9 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3(02):77–101
- 10 Kanmani TR, Thimmappur RM, Birudu R, Reddy NK, Raj P. Burden and psychological distress of intensive care unit caregivers of traumatic brain injury patients. *Indian J Crit Care Med* 2019;23(05):220–223
- 11 Kanmani TR, Raju B. Caregiver's psychosocial concerns and psychological distress in emergency and trauma care setting. *J Neurosci Rural Pract* 2019;10(01):54–59
- 12 Birudu R, Reddy K. Role of medical and psychiatric social workers in improving follow-up care in surgical settings: Medical and psychiatric social work perspective. *Int J Health Allied Sci* 2018;7(02):120–120
- 13 Lovibond FP, Lovibond HS. The structure of negative emotional states: Comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. *Behaviour research and therapy* 1995;33:335–43