



Mood assessments of family caregivers of patients with severe brain injury in China

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Abstract

Objectives Long-term care of severe brain injury patients places a significant mental burden on family caregivers, yet few studies have reported the situation in China. We aimed to describe the mood states of family caregivers of patients with severe brain injury and examine the influencing factors that affect caregivers' moods.

Methods Cross-sectional survey was used to assess the mood profiles of Chinese family caregivers between February 2019 and February 2020. Demographic data of caregivers and patients, the Patient Health Questionnaire (PHQ-9) and the Generalized Anxiety Disorder scale (GAD-7) were used to assess the level of depressive and anxiety symptoms. The quality of life score was also assessed by a visual analog scale, and the Coma Recovery Scale-Revised was used to assess the patient's consciousness.

Result One hundred and one patients with severe brain injury (57 unresponsive wakefulness syndrome, UWS) between the age of 14 and 70 and their main family caregivers were enrolled in the study. Most caregivers displayed depressive ($n=62$) and anxiety symptoms ($n=65$), with 17 and 20 of these family caregivers reporting (moderately) severe depressive symptom and severe anxiety symptom, respectively. The caregiver's depressive symptom level significantly decreased as the patient's injury lasted longer ($r=-0.208$, $P=0.037$). Moreover, the age of the patient negatively related to the levels of depressive ($r=-0.310$, $P=0.002$) and anxiety symptoms ($r=-0.289$, $P=0.003$) in caregivers. There was a significant positive correlation between anxiety and depressive symptoms scores in family caregivers ($r=0.838$, $P<0.001$). The higher the level of anxiety ($r=-0.273$, $P=0.006$) and depressive symptoms ($r=-0.265$, $P=0.007$), the worse the quality of life.

Conclusion Many family caregivers of patients with severe brain injury experience various levels of anxiety and depressive symptoms in China. Tailor-made psychological help seems imperative. Researchers and doctors can provide information about patient's conditions to assist family members in discussing rehabilitation options for patients in different states of consciousness will help to ease anxiety of family caregivers.

Keywords Severe brain injury · Family caregivers · Mood assessment · Anxiety/depressive symptoms

Introduction

Since the development of technology in the intensive care unit, a large number of patients with terminal neurologic diseases, such as severe brain injury, have survived [1]. In China, more than 100,000 new cases of brain injury are reported each year. These patients are generally scattered in various specialized and medium-sized hospitals [2].

In some patients, the brain injury is followed by an impairment of wakefulness and/or awareness, and patients present disorders of consciousness (DoC). In general, DoC can be distinguished into two main categories according to bedside behavioral assessment: unresponsive wakefulness syndrome (UWS)/vegetative state (VS) and minimally conscious states (MCS). UWS characterizes patients who are awake, but who do not present any signs of awareness [3, 4]. In contrast, patients with MCS exhibit repeatable non-reflexive behaviors but are unable to functionally communicate [5]. When the prognosis improves further, patients are diagnosed as emerging from the MCS (EMCS) once they can use objects or communicate accurately [6]. Only 20% of

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patients in UWS may regain signs of consciousness between 14 and 28 months after injury [7], and although the prognosis of patients with MCS is better than that of patients with UWS, these conditions may also last indefinitely [8]. These DoC survivors lose their autonomy in all daily activities and caring for a patient who is completely dependent on others can take up to 20 h of a caregiver's time each day [9]. In developed countries, patients with DoC are taken care of by paid caregivers, and family members cooperate in providing care [10]. In Chinese medical culture, it is common for families to take on the responsibility of caring for the patient's daily needs and making medical decisions on their behalf. This can be challenging for family caregivers and may lead to increased stress.

A recent study from Europe showed that 67% of family caregivers of patients with DoC reported anxiety and 79% reported depressive symptoms [11], which was consistent with previous studies in Western countries [12–14]. These research studies demonstrated the impact of individual characteristics of family caregivers on emotional burden, such as female caregivers exhibiting higher levels of depressive symptom and chronic grief disorder [11, 12]. The patient's diagnosis has also been identified in recent studies as having a significant bearing on the family caregiver's mental burden [15]. In fact, it has been reported in previous work in China that 90% of relatives of patients with DoC had severe or moderate care burden [16]. They also endure emotional stress, face a huge financial burden, and invest a lot of time in the patient. However, no detailed assessment of the mental burden of family caregivers was undertaken in the survey which was done in China. To date, few studies have collected this information on family caregivers of DoC patients, and few studies have examined the impact of patient's conditions (e.g., diagnosis, age, time since injury) on the mood state of family caregivers in Chinese medical surrounding [16]. Understanding the mood state and quality of life of family caregivers is ethically and policy critical, as this may be effective to predict family caregivers' mental health condition and allows for appropriate preventive measures and interventions for caregivers of DoC patients.

Therefore, we carried out a cross-sectional quantitative study using standardized questionnaires to assess first, the mood states of family caregivers of patients with severe brain injury in China and second, their associated factors, including caregiver's and patient's characteristics.

Methods

Ethical statement

Written informed consent to participate in the study was obtained from the patient's family caregiver. This study was

approved by the ethics committee of Hangzhou Normal University (Ref. No 2019–096).

Study design and procedure

We carried out a cross-sectional quantitative survey for the main family caregivers of the patients with severe brain injury. Before the formal survey, preliminary semi-structured interviews with family caregivers and neurologists were used to clarify the relevance and necessity of the research themes, and the study was designed within two weeks of the interviews. The protocol included two parts: patients' condition (e.g., diagnosis, age, sex, etiology, and time since injury) and the information of the main family caregivers of patients (e.g., demographic characteristics including sex, age, religion, education level, income, relationship with patients, weekly care time, type of occupation and care mode, depressive symptom score, anxiety symptom score and quality of life score). The final survey consisted of a socio-demographic information questionnaire, a basic information questionnaire on illness, and three self-reported standardized questionnaires designed to assess anxiety symptoms, depressive symptoms, and the quality of life of the main family caregivers (study design flow program see supplementary 1).

Participants

All the patients were hospitalized in the Hospital of Zhejiang People's Armed Police, and data was collected between January 2019 and February 2020. Patients' inclusion criteria were to present a severe brain injury, in an acute (≤ 28 days) or a post-acute state (> 28 days) [17]. Family caregivers who participated in the study spoke fluent Chinese and read the questionnaire without effort. Only one main family caregiver was included per patient, and when more than one family caregivers took care of a patient, the one who provided the most care was included in the study. Patient recruitment was conducted by the medical staff.

Assessment tools

To define the patients' diagnosis, behavioral assessments were performed with the Coma Recovery Scale-Revised (CRS-R) [18, 19]. The CRS-R was repeated at least three times during the week, using the optimal diagnosis to define the patient's status. Then the family caregivers completed the survey that investigated mood states, quality of life and socio-demographic information and our trained research assistants checked the forms to ensure full completion. According to the CRS-R sub-items, patients were divided into three categories: UWS, MCS and EMCS.

The Patient Health Questionnaire 9 (PHQ-9) was used to measure whether the family caregivers had symptoms of depression in the last two weeks [20, 21]. The Generalized Anxiety Disorder scale 7 (GAD-7) was used to measure whether the family members of patients had anxiety symptoms in the last two weeks [22, 23]. There are nine and seven items to be completed in PHQ-9 and GAD-7, respectively, and the outcome scores are “0 (not at all),” “1 (several days),” “2 (more than half the days),” and “3 (nearly every day)” for each item. Each item score was summed as the final score, with the highest score of 27 for the PHQ-9, and 21 for the GAD-7. The higher the score the more severe the depressive and anxiety symptom levels (PHQ’s grading criteria: 0–4 none; 5–9 mild; 10–14 moderate; 15–19 moderately severe; 20–27 severe. GAD’s grading Criteria: 0–4 none; 5–9 mild; 10–14 moderate; 17–27 severe).

For the self-assessment of quality of life, the main family caregiver was asked to answer the following question, “How would you describe your quality of life in the past two weeks, on a scale from 0 to 10?” The quality of life of family caregivers was assessed by a visual analog scale derived from a questionnaire by Katja Kuehlmeier et al. [24]. Extremely bad moments and extremely good moments in the participant’s life were used as endpoints, scoring 0 and 10, respectively. The main reason for using this simplistic measure of quality of life is the low level of education of our sample (51.5% below junior school), and for this reason we judged it to be more feasible than other more complex options.

Statistical analysis

Statistical analyses were performed using SPSS, Version 20.0 (SPSS Inc., Chicago, IL, USA). Frequencies, percentages, and means were used to describe the demographic characteristics of the family members and the disease information of patients with DoC. Means \pm standard deviations ($\bar{x} \pm s$) were used to describe the score of quality of life, depression symptoms, and anxiety symptoms. One-way ANOVA assessed differences between categorical variables, and LSD/Tukey analyses were used in the post-event pairwise tests. Pearson and Spearman correlation coefficients were applied to measure the association between continuous and categorical variables, respectively. The following criteria were used for the interpretation of the correlation coefficient: 0.00–0.10 = insignificant; 0.10–0.30 = small; 0.30–0.50 = moderate; > 0.50 = large [25]. The study used a two-sided test, $P < 0.05$ was regarded as statistically significant.

Results

Demographic characteristics of patients and their families

One hundred and eight patients and their main family caregivers were included in the study. Seven patients and their family caregivers left in the process. One hundred and one questionnaires were completed, with a response rate of 93.5%. Patients (age: 53 ± 15 years old; male: 74.3%, $n = 75$) were diagnosed with UWS (56.4%, $n = 57$), MCS (36.6%, $n = 37$) and EMCS (6.9%, $n = 7$). The minimum time post-injury was 19 days, the maximum was 821 days, and the average was 141.4 ± 130.6 days (Table 1).

Family caregivers were on average 48 ± 14 years old. Most caregivers were spouses (45.5%, $n = 46$) and the majority of them took care of the patients for at least 5 full days per week in the hospital (71.3%, $n = 72$). The occupations of the largest number of caregivers were freelancers (31.7%, $n = 32$), followed by retirees (22.8%, $n = 23$). There were 58.4% of participants ($n = 59$) whose monthly economic income was less than 463.5 U.S. dollars (Table 2).

Mood assessment of family caregivers

Most of the patients’ families endorsed symptoms of depression (61.6%, $n = 62$) and anxiety (64.4%, $n = 65$) (Fig. 1).

Table 1 Disease information of patients (N = 101)

Items	N (%)
<i>Diagnosis</i>	
UWS	57 (56.4)
MCS	37 (36.6)
EMCS	7 (6.9)
<i>Sex</i>	
Male	75 (74.3)
Female	26 (25.7)
<i>Age (years)</i>	$\bar{x} \pm s$ (Min—Max)
	52.5 ± 14.5 (16 – 80)
<i>Etiology</i>	
Trauma	49 (48.5)
Anoxia	4 (4.0)
Stroke	43 (42.6)
Other	5 (5.0)
<i>Time since injury* (days)</i>	$\bar{x} \pm s$ (Min—Max)
	141.4 ± 130.6 (19–821)

*Time since injury means the time between the brain injury and family caregivers filling the questionnaires

UWS unresponsive wakefulness syndrome, MCS minimally conscious state, EMCS emerging from MCS

Table 2 Demographic information of family members of patients (N = 101)

Demographics	N (%)
<i>Sex</i>	
Male	33 (32.7)
Female	68 (67.3)
<i>Age (years)</i>	
	$\bar{x} \pm s$ (Min – Max)
	48.3 ± 13.9 (23–76)
<i>Relationship with patients</i>	
Children	26 (25.7)
Spouse	46 (45.5)
Parents	18 (17.8)
Siblings	5 (5.0)
Others	6 (5.9)
<i>Weekly care time*</i>	
24 h and below	14 (13.9)
1–2 full days	10 (9.9)
3–4 full days	5 (5.0)
5 full days or more	72 (71.3)
<i>Income (dollar/month) (missing 3)</i>	
< 463.5	59 (58.4)
463.5–772.5	26 (25.7)
772.5–1545	7 (6.9)
> 1545	6 (5.9)
<i>Education level</i>	
Primary school and below	34 (33.7)
Junior school	18 (17.8)
High school	31 (30.7)
Bachelor degree and upon	18 (17.8)
<i>Type of occupation</i>	
Full-time job	23 (22.8)
Part time job	4 (4.0)
Freelance**	32 (31.7)
Student	1 (1.0)
Retired	23 (22.8)
Others	18 (17.8)
<i>Religion</i>	
Non-religion	76 (75.2)
Taoism	1 (1.0)
Buddhism	23 (22.8)
Christianity	1 (1.0)
<i>Care mode***</i>	
Hands-on care	77 (76.2)
Coordinated care	24 (23.8)

*Weekly care time refers to the amount of time family members take care of patients each week

** Freelance: Occupations that are not subject to the jurisdiction of businesses and corporations and are mainly self-employed

***Hands-on care: Family members care for the patient by themselves, without any help other than medical workers. Coordinated care: Family members working with paid caregivers to care for patients

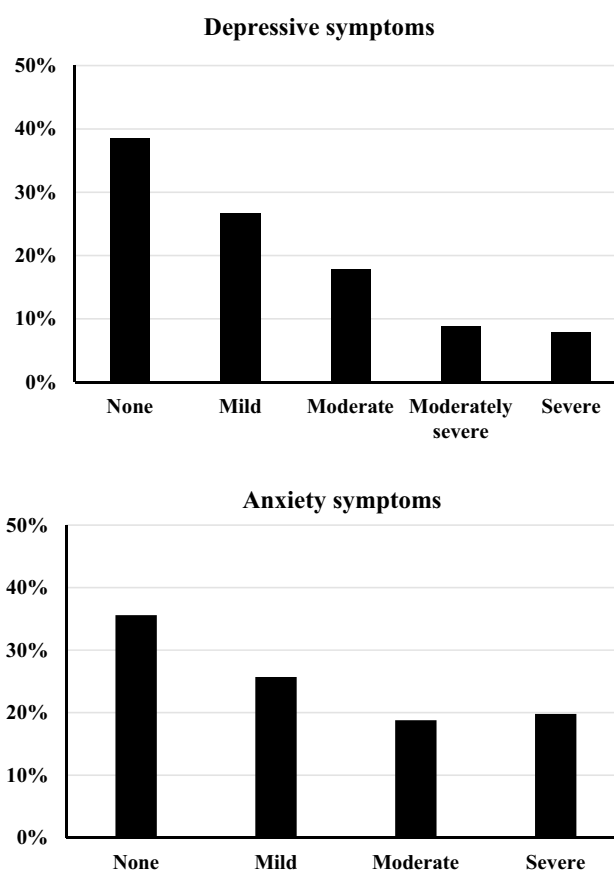


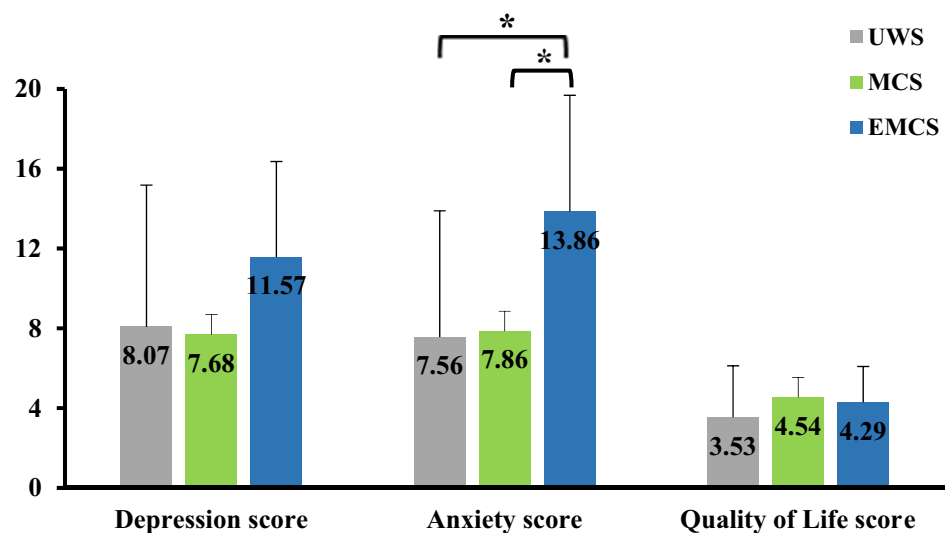
Fig. 1 Levels of depressive and anxiety symptoms of family caregivers (N = 101). Depressive symptoms: PHQ-9's grading criteria: 0–4 None; 5–9 Mild; 10–14 Moderate; 15–19 Moderately severe; 20–27, Severe. Anxiety symptoms: GAD-7's grading criteria: 0–4 None; 5–9 Mild; 10–14 Moderate; 17–27 Severe

Among the family caregivers, 16.8% (n = 17) had severe or moderately severe depressive symptoms, and 44.5% (n = 45) had mild or moderate depressive symptoms in the last two weeks. Regarding anxiety symptoms, 19.8% of the caregivers (n = 20) described severe anxiety symptoms and 44.5% (n = 45) had moderate or mild anxiety symptoms in the past two weeks. The average quality of life score was 4.0 ± 2.5 (0–10 score) (Table 3). The distribution of the frequency of depressive and anxiety symptoms ('not at all' to 'nearly every day') for each item of the PHQ-9 and GAD-7 is summarized in Table 3. The items "little interest", "feeling down", "trouble falling or staying asleep", and "feeling tired" (items 1–4) were common symptoms with high depressive symptom total scores. In the anxiety symptom score, "feeling nervous", "cannot stop or control worrying", "worrying too much", and "having trouble relaxing" (items 1–4) were common symptoms.

Regarding the factors associated with the caregivers' mood states, anxiety symptom scores varied according to the patient's level of consciousness ($F = 3.391$,

Table 3 PHQ-9 score, GAD-7 score, and quality of life score item-by-item results for the total sample (N = 101)

Items	Not at all N (%)	Several days N (%)	More than half the days N (%)	Nearly every day N (%)
<i>PHQ-9 Score</i>				
1. Little interest or pleasure in doing things	37 (36.6)	30 (29.7)	10 (9.9)	24 (23.8)
2. Feeling down, depressed, or hopeless	32 (31.7)	35 (34.7)	17 (16.8)	17 (16.8)
3. Trouble falling or staying asleep, or sleeping too much	28 (27.7)	35 (34.7)	22 (21.8)	16 (15.8)
4. Feeling tired of having little energy	24 (23.8)	41 (40.6)	16 (15.8)	20 (19.8)
5. Poor appetite or overeating	46 (45.5)	38 (37.6)	10 (9.9)	7 (6.9)
6. Feeling bad about yourself – or that you are a failure or having let yourself or your family down	57 (56.4)	22 (21.8)	13 (12.9)	9 (8.9)
7. Trouble concentrating on things, such as reading the newspaper or watching television	56 (55.4)	24 (23.8)	13 (12.9)	8 (7.9)
8. Moving or speaking so slowly that other people could have noticed. Or the opposite being so fidgety or restless that you have been moving a lot more than usual	61 (60.4)	20 (19.8)	11 (10.9)	9 (8.9)
9. Thoughts that you would be better off dead, or of hurting yourself in some way	84 (83.2)	11 (10.9)	3 (3.0)	3 (3.0)
<i>GAD-7 Score</i>				
1. Feeling nervous, anxious, or on edge	22 (21.8)	44 (43.6)	17 (16.8)	18 (17.8)
2. Not being able to stop or control worrying	26 (25.7)	35 (34.7)	21 (20.8)	19 (18.8)
3. Worrying too much about different things	25 (24.8)	33 (32.7)	23 (22.8)	20 (19.8)
4. Trouble relaxing	29 (28.7)	32 (31.7)	20 (19.8)	20 (19.8)
5. Being so restless that it's hard to sit still	48 (47.5)	25 (24.8)	16 (15.8)	12 (11.9)
6. Becoming easily annoyed or irritable	41 (40.6)	32 (31.7)	17 (16.8)	11 (10.9)
7. Feeling afraid as if something awful might happen	50 (49.5)	24 (23.8)	15 (14.9)	12 (11.9)
<i>QOL Score ($\bar{x} \pm s$)</i>				
How would you describe your quality of life in the past two weeks	4.0 ± 2.5			

Fig. 2 Depressive symptoms, anxiety symptoms and quality of life mean score in different groups of family members of patients with severe brain injury (N = 101)* $P < 0.05$

$P = 0.038$) (Fig. 2). After Tukey correction, the mean score of the EMCS group was 5.99 points higher than the anxiety score of the MCS group ($P = 0.049$) and 6.30 points higher than the UWS group ($P = 0.030$).

Depressive symptoms ($F = 1.000$, $P = 0.372$) and quality of life ($F = 1.888$, $P = 0.157$) were not affected by different diagnoses. Increased time since injury was also found to be associated with a lower depressive symptom level

Table 4 Association with family caregivers and patients' characteristics on the family caregivers' mood state and quality of life (N = 101)

Impact on the family caregiver's mood state and quality of life		
Characteristics of patients	Sex	No difference
	Age	Older age: Depressive symptoms ($r = -0.310$, $P = 0.002$) Anxiety symptoms ($r = -0.289$, $P = 0.003$)
	Etiology	No difference
	Time since injury (days)	Longer time: depressive symptoms ($r = -0.208$, $P = 0.037$)
Characteristics of family caregivers	Sex	No difference
	Age	No difference
	Relationship with patients	Spouse, parents, and children: quality of life ($P < 0.05$)
	Weekly care time	No difference
	Income (dollar/month)	No difference
	Education level	Higher education level: quality of life ($r = -0.233$, $P = 0.019$)
	Type of occupation	No difference
	Religion	No difference
	Care mood	No difference

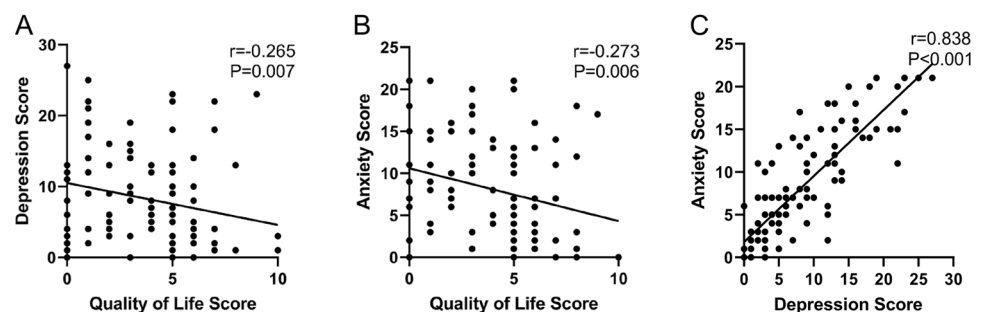
($r = -0.208$, $P = 0.037$) (Table 4) but was not linked to any statistically significant difference in anxiety symptom level ($r = -0.151$, $P = 0.133$). The age of the patient was also correlated with the caregiver's mood state. More specifically, the younger the patients, the higher the depressive symptom level ($r = -0.310$, $P = 0.002$) and the anxiety symptom level ($r = -0.289$, $P = 0.003$).

The quality of life scores negatively correlated with depressive symptom and anxiety symptom scores: the higher the level of anxiety ($r = -0.273$, $P = 0.006$) and depressive symptoms ($r = -0.265$, $P = 0.007$), the worse the quality of life (Fig. 3A and B). Compared with patients' siblings (6.60 ± 1.95) and other relationships (6.67 ± 1.37), the patient's spouse (3.72 ± 2.44), parents (4.17 ± 2.57), and children (3.08 ± 2.35) had a lower quality of life score (all $P < 0.05$) (Table 4). Finally, there was a significant positive correlation between anxiety and depressive symptoms scores in family caregivers ($r = 0.838$, $P < 0.001$) (Fig. 3C). No significant correlation was found when considering other characteristics of the main family caregivers (i.e., age, gender,

income, weekly care time, type of occupation, religion, and care mode) and patients (i.e., sex, etiology).

Discussion

Severe brain injury, as a category of severely disabled clinical patients, has been the subject of considerable research demonstrating the mental burden it causes for caregivers or family caregivers. We used questionnaires to investigate the mood states and socio-demographics information of family members, and disease information of patients. Our results found that more than half family members of severe brain injury patients had some level of depression (61.4%) and anxiety (64.4%), which were linked to some patients' characteristics. Indeed, the younger the patients and the shorter the time post-injury, the worse the emotional distress of the caregivers on the family members. Caregivers also reported a low quality of life, which was negatively correlated with anxiety and depressive symptom levels.

Fig. 3 Correlation between mood state and quality of life of family caregivers (N = 101)

Our results can be understood in the light of other studies. Indeed, previous studies have reported that protracted assistance to DoC patients can lead to psychological disorders, insomnia, and loss of appetite in family caregivers [15]. As 71.3% of caregivers in our sample spent five full days or more a week caring for their relative with DoC, it is thus not surprising that they report depressive symptoms, anxiety symptoms and low quality of life. It was worth noting that we recorded different levels of anxiety and depressive symptoms among the caregivers in our sample. Most of the caregivers who suffered from some level of depressive or anxiety symptoms reported moderate and mild depressive symptoms (42.5%), and moderate and mild anxiety symptoms (43.6%), instead of severe symptoms (16.8% and 19.8% for severe depressive and anxiety symptoms, respectively). While much of the worldwide research on main family caregivers of patients with DoC has focused on severe depressive and anxiety symptoms [26], the latest International Classification of Diseases criteria has recognized the negative impact of mild symptoms of mood disorders, with those with mild mood burdens reporting low levels of social support, resilience, and agreeableness [27, 28]. These adverse effects may exacerbate the social isolation of family caregivers, further worsening quality of life [14]. Based on item-by-item results, little interest, fatigue, insomnia, and worry appeared to be more common in poor mood states. Based on the suggestion of the Lancet Commission on global mental health and sustainable development, psychological counseling and guidance in printed resources and media may provide a degree of protection [29, 30]. In contrast, those participants who reported they would be better off dead or harming themselves, might be more appropriate to personalized, one-on-one counseling as a great option to ease their burden [29].

Recent findings suggest that family caregivers are able to adapt to new events over time and reduce distress through family resilience and cohesion [15, 31]. This is consistent with our results that depressive symptom levels decrease with increasing duration of brain injury. As the study by Francesco et al. (2017) presents, initially, family caregivers complained about a need for some information about patients' condition (prognosis, but also clinical information and rehabilitation goals) and six months later, when these needs were satisfied, the psychological burden on the family caregiver was reduced [31]. Therefore, our results may be explained by the fact that family caregivers receive more detailed medical information over time. However, Moretta et al. (2014) reported the opposite in family caregivers of DoC patients, with more psychological stress on families over time [32]. One possible

explanation is related to patient recovery. In the two-year follow-up study by Moretta et al. no patient had a change in diagnosis [32]. However, the average time after injury of patients in our study was about 141 days (4–5 months), with some patients possibly having a slow recovery [33]. When the patient shows certain signs of regaining consciousness, the family may cradle hope for recovery, even when the odds are bad [34]. In addition, methodological differences may have some influence. We used a cross-sectional survey method rather than a follow-up survey, and in principle, our results cannot explain whether the mood state of each participant changed over time post-injury.

The patient's ages ranged from 16 to 80 years old in this study, and it was negatively correlated with family caregivers' depressive and anxiety symptom levels. Several hypotheses could explain these results. First, in the past decades, most Chinese families had only one child due to the "family planning policy" [35]. Thus, if the child was injured, family members would undoubtedly worry. In addition, in the Chinese cultural context, young adults have the responsibility of both parenting their children and filial piety to their parents. A severe brain injury can leave the patient's parents and children without support, and potentially increase their depressive and anxiety symptom levels. As stated in our results, patients' parents, children, and spouses have lower quality of life score, compared to patients' siblings and other relationships. In addition, younger patients will spend more time in a state of DoC or physical disability than older patients, which undoubtedly creates more concern for finances and care [36]. According to the diagnosis of consciousness, in our study, family caregivers of EMCS patients reported higher levels of anxiety symptom compared to MCS and UWS. On the other hand, we also noticed that other studies have shown no differences in family caregivers of DoC patients with various diagnoses in regard to general burden levels and total scores evaluating depressive symptoms, anxiety symptoms, psychophysiological symptoms, needs, and coping mechanisms [32]. However, this study did not have an adequate sample size and ended up including only 24 family caregivers with DoC. Given the different results, we must remain cautious in interpreting our results, and studies with larger samples are needed to confirm that the mood state between different diagnosis.

Similar to other studies [11, 37], we reported poor quality of life of family caregivers of DoC patients. We also documented that poor quality of life was correlated with more severe levels of anxiety and depressive symptom. In addition to the above, a recent scoping review has documented that financial resources are the other longest-reported aspects

affecting the quality of life of family caregivers with DoC [14]. And our results also recorded that only 26.8% of family caregivers had full-time or part-time jobs, which was similar to a previous study in China [38]. Seventy-nine percent of family caregivers have to give up their jobs to care for their patients, which creates a cycle of poor economic status [38].

Strengths and limitation

Given the paucity of research on family caregivers in severe brain injury patients in China, this study has much to contribute to the development or improvement of interventions on the mental burden of family caregivers. Nevertheless, some limitations should be considered when interpreting the results of this study. Considering the small sample for patients in EMCS in our study ($n=7$), a larger sample of EMCS patients in future studies is warranted to confirm our findings. In addition, all patients were hospitalized, so the sample of caregivers may not be representative of all caregiving situations, especially at home. The unpredictability of the accident, the risk of death of a relative, the effort to accept his/her behavioral disorder, the frustration associated with a prolonged recovery, and the financial difficulties had been shown to add to the mental burden [39]. Therefore, future studies should consider such variables related to the care to be able to identify specific interventions for family members working at home and those providing care for hospitalized loved ones.

Conclusion

Many family caregivers of patients with severe brain injury experience various levels of anxiety and depressive symptoms. This may negatively correlate the family caregivers, including quality of life and social relation. Thus, tailor-made psychological help seems imperative. Healthcare professionals should provide information about the patient's condition in the early stages of the injury and assist the family in discussing rehabilitation options for patients with different states of consciousness as soon as possible [32]. In addition, extra attention should be paid to the young patient's family caregivers and family caregivers close to the patient, such as parents, spouses, or children, so that mild or moderate emotional distress can be addressed through counseling, while one-to-one psychosocial or pharmacological interventions are necessary for severe emotional distress.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s1136-023-03539-2>.

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Author contributions YY contributed to the study conception and design. The first draft of the manuscript was written by ML. Material preparation, data collection was performed by TC, XW, YD, and XH. SL, OG, CG, and HD reviewed and edited the manuscript. All authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Data availability The data that support the findings of this study are available from the corresponding author, Prof. Haibo Di, upon reasonable request.

Declarations

Conflict of interest There is no conflict of interest between all authors.

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