



The weight of care: exploring the challenges faced by primary caregivers of children with traumatic brain injuries

Hui Ye[#], Jingjing Wei[#], Yuanyuan Miao[#], Liang Gu

Surgical Intensive Care Unit (SICU), Children's Hospital of Nanjing Medical University, Nanjing, China

Contributions: (I) Conception and design: H Ye, L Gu; (II) Administrative support: All authors; (III) Provision of study materials or patients: H Ye, J Wei, Y Miao; (IV) Collection and assembly of data: H Ye, J Wei, Y Miao; (V) Data analysis and interpretation: H Ye, J Wei; (VI) Manuscript writing: All authors; (VII) Final approval of manuscript: All authors.

[#]These authors contributed equally to this work.

Correspondence to: Liang Gu, BM, Surgical Intensive Care Unit (SICU), Children's Hospital of Nanjing Medical University, No. 72 Guangzhou Road, Nanjing 210000, China. Email: ptt84@sina.com.

Background: Traumatic brain injury (TBI) is a leading cause of death and disability in children, yet the full impact on their primary caregivers remains largely uncharted. This study seeks to delineate the current scope of the caregiving burden and to identify the key determinants that shape it, aiming to enhance clinical interventions and caregiving approaches.

Methods: We conducted a comprehensive survey of primary caregivers of pediatric TBI patients admitted to a top-tier children's hospital in China, spanning the period from January 15 to November 15, 2023. The Zarit Burden Interview (ZBI) served as the primary tool for gauging the level of caregiver burden, while the Simplified Coping Style Questionnaire (SCSQ) provided insights into their coping strategies.

Results: Our survey encompassed 284 primary caregivers of TBI children. The average ZBI score for this cohort was 40.57 ± 10.41 , indicating a considerable burden. Correlational analysis uncovered robust links between the burden of caregivers and several pivotal factors: the severity of TBI ($r=0.496$), intensive care unit (ICU) stay ($r=0.525$), monthly household income ($r=0.604$), and reliance on negative coping mechanisms ($r=0.493$), all of which were statistically significant ($P<0.05$). Further, a multiple linear regression analysis affirmed that the severity of TBI, ICU admissions, monthly income, and negative coping styles were independent predictors of caregiver burden ($P<0.05$).

Conclusions: The findings underscore the substantial burden shouldered by primary caregivers of TBI children. It is imperative to direct targeted support towards caregivers from economically disadvantaged backgrounds and those who tend to adopt negative coping strategies, to alleviate their burden.

Keywords: Burden; care; caregiver; children; traumatic brain injury (TBI)

Submitted May 21, 2024. Accepted for publication Sep 04, 2024. Published online Sep 26, 2024.

doi: 10.21037/tp-24-197

View this article at: <https://dx.doi.org/10.21037/tp-24-197>

Introduction

Traumatic brain injury (TBI) has become the main cause of death and disability in children, which affects more than 3 million children every year (1,2). Due to the continuous development of children's brains, the factors affecting the prognosis of TBI children are more complex than those of adult patients (3). The severity of brain damage is a

pivotal determinant; however, the impact of pre-injury developmental status and capabilities, age at the time of injury, and the familial context—including the caregiver's parenting style, family dynamics, and the availability of post-injury resources such as rehabilitation and nursing services—also significantly influence outcomes. These multifaceted factors contribute to the complex interplay affecting recovery and adaptation following brain injury (4).

Caregivers confront the multifaceted challenge of not only effectively managing the symptoms of pediatric TBI patients but also facilitating their physical rehabilitation, educational reintegration, and the acquisition of developmental skills. This complex process encompasses the need for comprehensive medical care, specialized transition services to support the child's return to school, and emotional support, underscoring the necessity for an integrated approach to address the diverse and evolving needs of the child and their family (5,6).

Caregivers' ability, psychological status and adaptability to TBI symptoms of children can predict externalized symptoms such as aggressive behavior, anxiety and quality of life in TBI children, and affect the degree of recovery (7). The parenting behavior and ability of caregivers is an important and changeable factor in the process of child rehabilitation (8). It is of great significance to pay attention to the needs of caregivers, help them understand the strategies and resources conducive to children's rehabilitation, and improve their care ability (9,10). Furthermore, the mean duration of hospitalization for children with TBI ranges from 4 to 15 days, with those suffering from moderate to severe TBI typically requiring a more extended period of inpatient care. The necessity for round-the-clock caregiving during hospitalization imposes a considerable economic and psychological burden on the caregivers, who must provide constant supervision and support to the pediatric patients (11). Currently, scholarly investigations into the burden experienced by

pediatric caregivers have predominantly concentrated on the period following hospital discharge. Conversely, the caregiving demands and associated burdens encountered during the hospitalization phase have garnered relatively scant scholarly focus. Therefore, the purpose of this study was to investigate the burden of the main caregivers of hospitalized TBI children and analyze the influencing factors, so as to provide reference for clinical treatment and nursing interventions. We present this article in accordance with the SURGE reporting checklist (available at <https://tp.amegroups.com/article/view/10.21037/tp-24-197/rc>).

Methods

Ethics

This study was designed as cross-sectional survey. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was approved by Institutional Ethics Board of Children's Hospital of Nanjing Medical University (No. 202406010-1) and informed consent was taken from all the patients' parents or legal guardians. All the data in this survey are anonymized and used only for this research.

Sample size calculation

In this study, a total of 24 variables were examined. Adhering to the principle that the sample size for multiple regression analysis should be 5 to 10 times the number of independent variables (12), and accounting for an estimated attrition rate of 10% as well as practical considerations, the calculated minimum sample size for this investigation was determined to be no less than 132 participants.

Participants

Between January 15th and November 15th, 2023, the study population was defined as the primary caregivers of TBI children within the neurosurgery department of a tertiary-level children's hospital. The eligibility criteria for this survey were delineated as follows: the children (age ≤ 18 years old) met the diagnostic criteria of TBI and were diagnosed by craniocerebral computed tomography (CT) or magnetic resonance imaging (MRI); the TBI children exhibited Glasgow Coma Scale (GCS) scores ranging between 6 and 13; the hospitalization time was more than

Highlight box

Key findings

- The severity of traumatic brain injury (TBI), intensive care unit (ICU) admissions, monthly income, and negative coping styles are the independent predictors of caregiver burden.

What is known and what is new?

- TBI can cause great burden to the caregivers of children with TBI.
- The principal caregivers of children with TBI bear a significant load, which correlates with the severity of the TBI, the duration of the ICU stay, the household's average monthly income, and the adoption of negative coping mechanisms.

What is the implication, and what should change now?

- It is crucial to extend targeted assistance to caregivers hailing from economically disadvantaged backgrounds and those prone to employing negative coping strategies, thereby reducing their substantial burden.

3 days. The caregivers were the main caregivers (care time ≥ 12 h/d) during hospitalization; the main caregivers had the basic understanding and communication ability. The survey's exclusion criteria were specified as follows: children were repeated brain injury; the children complicated with other major diseases such as heart disease; the main caregivers who were unwilling to participate in this survey.

Survey tools

The survey tools used in this survey had previously been published elsewhere and are as follows:

General information questionnaire of children and main caregivers (13). The general data of TBI children included gender, age, medical insurance, home place, TBI classification (we included pediatric patients with TBI who had GCS scores ranging from 6 to 13. Within this range, scores of 9 to 13 were classified as moderate TBI, while scores of 6 to 8 were indicative of severe TBI), admission to intensive care unit (ICU) (children with severe conditions might be transferred to the ICU for intensive monitoring and care). The general data of the main caregivers included age, gender, educational level, average monthly income, relationship with children

Zarit burden interview (ZBI) (14): ZBI encompasses two principal dimensions: personal strain and role strain. Personal strain, assessed through 12 items, pertains predominantly to the effects of caregiving on the caregivers' physical and mental well-being and their interpersonal relationship with the care recipients. Role strain, measured by 6 items, reflects the influence of caregiving responsibilities on the caregivers' social life and leisure time. Item 22 solicits the caregiver's comprehensive appraisal of the caregiving burden. The ZBI utilizes a 5-point Likert scale, with responses categorized as "none", "occasional", "frequent", and "almost always", corresponding to the scale points of 0 to 4, respectively. The sum of the scores on the ZBI ranged from 0 to 88. The scores were categorized into ranges of 0 to 20, 21 to 39, and 40 or above, corresponding to mild, moderate, and severe burdens, respectively. The Cronbach's α coefficient of ZBI scale was 0.83. It has good reliability and validity (15,16).

Simplified coping style questionnaire (SCSQ) (17). SCSQ included two dimensions: positive coping (item 1–12) and negative coping (item 13–20). SCSQ employs a 4-point Likert scaling system, where scores ranging from 0 to 3 correspond to the responses "No", "Occasionally",

"Sometimes", and "Often", respectively. A higher score on a particular coping style indicates a greater inclination towards that style. The scale demonstrated robust psychometric properties, with a Cronbach's α coefficient of 0.90, signifying high reliability and validity (18,19).

Survey process

All the questionnaires were distributed by the two researchers, they explained the filling methods and answered the questions raised by the caregivers, and indicated the detailed filling methods on the questionnaires. The purpose and significance of the survey were explained to the subjects before the survey, and the questionnaire was distributed the day before the child was discharged from the hospital and obtained the consent of the caregiver. The questionnaire was collected on the spot, and we checked the questionnaire for missing items and errors. The primary family caregivers were surveyed independently to mitigate the response bias that might arise from the presence of the child or other family members.

Statistical analysis

In this study, the data obtained were input into SPSS24.0 for analysis. Frequency, percentage, mean and standard deviation were used to describe the general data of TBI children and family main caregivers. And *t*-test, one-way analysis of variance and correlation analysis were used to compare the burden of TBI children and main caregivers with different characteristics. Multiple linear regression was used to analyze the influencing factors of the burden of main caregivers in TBI children. The difference was statistically significant when $P < 0.05$.

Results

A total of 290 questionnaires were initially distributed, finally 284 valid questionnaires were included for analysis. The characteristics of TBI children and 284 main caregivers are presented in *Table 1*.

The average ZBI score of the main caregivers of TBI children was 40.57 ± 10.41 . As indicated in *Table 2*, none, mild, moderate and severe burdens were 10 (3.51%), 68 (23.94%), 159 (55.99%) and 47 (16.55%) cases respectively.

As shown in *Table 3*, univariate analysis results indicated that there were statistical differences in the ZBI score of TBI children with different TBI classification, admission to

Table 1 The characteristics of TBI children and main caregivers (n=284)

Items	Cases	Percentage
TBI children		
Gender		
Male	196	69.01
Female	88	30.99
Age (years)		
0–5	121	42.61
6–12	85	29.93
13–18	78	27.46
Medical insurance		
Yes	201	70.77
No	83	29.23
Home place		
City	215	75.70
Rural areas	69	24.30
TBI classification		
Moderate (GCS 9–13)	220	77.46
Severe (GCS 6–8)	64	22.54
Admission to ICU		
Yes	86	30.28
No	198	69.72
Caregivers		
Age (years)		
<35	192	67.61
≥35	92	32.39
Gender		
Male	66	23.24
Female	218	76.76
Educational level		
Junior high school	68	23.94
Senior high school	82	28.88
University	134	47.18
Average monthly income (CNY)		
<5,000	64	22.54
5000–10,000	161	56.69
>10,000	59	20.77
Relationship with children		
Parents	267	94.01
Non-parents	17	5.99

TBI, traumatic brain injury; GCS, Glasgow Coma Scale; ICU, intensive care unit; CNY, Chinese Yuan.

Table 2 The burden of main caregivers (n=284)

Burden level	Cases	Percentage
No	10	3.51
Mild	68	23.94
Moderate	159	55.99
Severe	47	16.55

ICU and average monthly income (all $P < 0.05$).

As presented in *Table 4*, the correlation analysis results indicated that TBI classification ($r=0.496$), admission to ICU ($r=0.525$) and average monthly income ($r=0.604$) were correlated with the burden of main caregivers (all $P < 0.05$).

The positive and negative coping dimensions of the main caregivers of TBI children were 23.47 ± 5.83 and 11.21 ± 4.98 respectively. The results of correlation analysis showed that the care burden was not correlated with the positive coping style ($r=0.126$, $P=0.16$), but was correlated with the negative coping style ($r=0.493$, $P=0.004$).

As shown in *Table 5*, multiple linear regression analyses indicated that TBI classification, admission to ICU, average monthly income and negative coping were the influencing factors of burden of main caregivers (all $P < 0.05$).

Discussion

Brain damage may force a family to redefine their behavior, roles and the meaning of their lives, placing a great emotional burden on caregivers (20). Previous study has identified that caregivers often experience adverse emotions, including tension, anxiety, and bewilderment, and perceive a deficiency in support systems to alleviate these negative emotional states (21). Some research results (22) have found that caregivers often face uncertainty regarding the duration of cognitive and behavioral alterations in children with TBI. The unique challenges of caring for TBI children, coupled with a perceived lack of understanding from others, can lead to a myriad of psychological issues among caregivers. These may include feelings of uncertainty, anxiety, loneliness, and a diminished sense of security. The absence of adequate support can exacerbate the psychological challenges faced by caregivers, precipitating the adoption of maladaptive coping mechanisms such as neglect, denial, and avoidance. These negative coping styles can, in turn, impair the quality of care provided to the TBI children (23). The findings of this study reveal a significant level of overall burden among the primary caregivers of TBI children. Consequently, it

Table 3 Univariate analysis on the ZBI score of characteristics of TBI children and main caregivers (n=284)

Items	ZBI score (mean ± SD)	t/F	P
TBI children			
Gender		1.285	0.11
Male	40.98±10.72		
Female	40.29±11.23		
Age (years)		2.181	0.07
0–5	41.43±10.29		
6–12	40.26±11.31		
13–18	39.75±10.36		
Medical insurance		1.277	0.09
Yes	40.10±10.87		
No	41.33±11.48		
Home place		1.006	0.10
City	40.21±10.84		
Rural areas	41.08±12.05		
TBI classification		1.280	0.046
Mild	40.34±11.55		
Severe	41.97±10.87		
Admission to ICU		1.124	0.01
Yes	42.14±12.19		
No	39.25±10.49		
Caregivers			
Age (years)		2.084	0.17
<35	41.13±11.96		
≥35	40.20±12.01		
Gender		1.199	0.10
Male	40.17±12.25		
Female	40.88±11.91		
Educational level		2.004	0.21
Junior high school	40.96±12.51		
Senior high school	40.68±11.07		
University	40.04±11.26		
Average monthly income (CNY)		2.115	0.009
<5,000	42.07±12.36		
5,000–10,000	40.84±11.72		
>10,000	39.43±11.07		
Relationship with children		1.203	0.08
Parents	40.60±12.75		
Non-parents	41.03±10.77		

ZBI, Zarit burden interview; TBI, traumatic brain injury; ICU, intensive care unit; CNY, Chinese Yuan; SD, standard deviation.

Table 4 Correlation analysis on the ZBI score and characteristics of TBI children and main caregivers

Items	r	P
TBI children		
Gender	0.1007	0.13
Age	0.116	0.07
Medical insurance	0.279	0.19
Home place	0.201	0.11
TBI classification	0.496	0.04
Admission to ICU	0.525	0.01
Caregivers		
Age	0.104	0.11
Gender	0.290	0.09
Educational level	0.105	0.10
Average monthly income	0.604	0.002
Relationship with children	0.127	0.10

ZBI, Zarit burden interview; TBI, traumatic brain injury; ICU, intensive care unit.

is imperative to focus on the psychological well-being of these caregivers. Interventions should be directed towards enhancing their caregiving knowledge and proficiency through educational initiatives and skill-building programs. Additionally, fostering a robust support system is essential to alleviate the caregiving burden and promote a more positive caregiving experience.

The health problems of a member of the family will affect the function of the whole family, and the family can affect the health of each member through genetic, social, environmental and emotional responses (24,25). The occurrence of TBI is a negative life event for families and patients, which brings a great burden to the families of children (26). The results of this study have shown that the main caregivers of TBI children with severe TBI and ICU admission have heavier burden. In this study, 64 children (22.54%) presented with severe TBI. The patient's admission to the ICU due to a critical condition can elicit a range of adverse emotional responses in caregivers. These may include feelings of separation anxiety, despair, and trepidation, among other negative affective states (27). Upon transitioning from the ICU to a general ward, the caregiving responsibilities often intensify. Concurrently, the primary caregiver may face a dearth of confidence and a perceived inadequacy in caregiving

Table 5 Multiple linear regression analysis on the influencing factors of burden of main caregivers

Variables	Partial regression coefficient	Standard error	Standardized regression coefficient	t	P
TBI classification	4.127	1.403	0.145	1.243	0.007
Admission to ICU	5.218	2.007	0.196	2.139	0.03
Average monthly income	4.077	2.114	0.109	3.055	0.01
Negative coping	6.389	2.560	0.226	2.052	0.01

$R^2=70.31$, adjusted $R^2=68.54$, $F=65.29$. TBI, traumatic brain injury; ICU, intensive care unit.

skills, which can impact their capacity to provide effective care. Some studies (28,29) have shown that strategies such as the distribution of educational materials and the provision of question-answering services to the family caregiver can significantly assist caregivers in managing negative emotions more effectively and in enhancing their caregiving capabilities. Therefore, healthcare providers are encouraged to implement educational programs focused on TBI management and nursing, complemented by the dissemination of informational brochures pertinent to TBI. Such initiatives are designed to bolster the primary caregivers' confidence and competencies in caring for children with TBI.

The lower the average monthly income, the heavier the burden of the main caregivers, which is similar to the results of previous studies (30,31). The hospitalization time of TBI children is long, and the high medical cost may bring heavy financial burden to the main caregivers (32,33). The family economic status of children has an impact on cognitive, behavioral, social and emotional recovery after TBI. Therefore, when formulating the treatment plan for TBI children, we should fully consider the family economic situation of the children, and choose cost-effective treatment and nursing measures to reduce the economic burden. To enhance the well-being of the primary caregivers within a family, it is essential to steer them towards actively engaging with a range of social support mechanisms. This involves not only seeking assistance from family and friends but also tapping into the support offered by community health resources and other societal institutions. By doing so, they can effectively manage stress and navigate the various roles they play with greater ease and resilience (34-36). Social or hospital aid foundations initiate medical assistance programs that encompass a variety of diseases, offering financial support, pharmaceutical aid, and treatment cost reductions to impoverished patients. Volunteers provide psychological solace and emotional support to patients, assisting them in

better coping with the stress induced by illness. Both social and hospital aid foundations and volunteers play pivotal roles in the healthcare sector, each with distinct functions and contributions that collectively foster the advancement of medical services and the enhancement of societal welfare (37).

The results of previous studies (38,39) have shown that patients' negative coping is positively correlated with their burden, and the higher the score of negative coping. Coping is a conscious adjustment behavior made by individuals to the real environment, and different coping styles lead to different results (40-42). Negative coping styles such as avoidance and desalination will lead to the accumulation of negative emotions such as depression and anxiety of caregivers and increase their care burden (43). The outcomes of this investigation have demonstrated that primary caregivers of children with TBI exhibit negative coping mechanisms, including denial and avoidance. Consequently, healthcare professionals are advised to vigilantly monitor for these adverse coping strategies among caregivers. It is essential to delve into the stressors faced by these individuals, address their cognitive and behavioral misalignments, and actively promote a shift towards more adaptive coping methodologies.

This study acknowledges several limitations that warrant rigorous contemplation. Initially, the scope of the caregiver burden assessment was confined to a single comprehensive children's hospital in China, due to constraints in research duration, personnel, and funding, resulting in a modest sample size and a brief cross-sectional design. Secondly, the study's design does not account for the dynamic nature of caregiver burden, which is subject to fluctuation over time. Therefore, it is imperative to implement longitudinal measures and ongoing surveillance of the caregiver burden to discern its temporal patterns. Such insights are critical for informing evidence-based approaches to clinical management and nursing interventions for TBI children.

Conclusions

In conclusion, the burden of the main caregivers of TBI children is heavy, which is related to TBI severity, ICU stay, average monthly family income and negative coping style. It is suggested that nurses should pay attention to the main caregivers of TBI children with severe TBI condition, low family income and high score of negative coping style. It is necessary to improve the social support of the main caregivers of TBI children and improve their social security system to help and encourage caregivers to adopt positive coping styles, so as to reduce the burden and improve the quality of life of the main caregivers of TBI children. At present, there are few studies on the demand of caregivers of children TBI children, mainly qualitative research, and lack of specific assessment tools. Therefore, future studies should focus on the development of targeted assessment scale to understand the burden and needs of caregivers of TBI children. The caregivers of TBI children have a high demand for support services, and there is an imbalance between demand and supply. In the future, it is necessary improve the ability of multidisciplinary coordination and set up teams including medicine, nursing, rehabilitation, psychology and other disciplines to ensure the continuity, coordination and effectiveness of health care services.

Acknowledgments

Funding: None.

Footnote

Reporting Checklist: The authors have completed the SURGE reporting checklist. Available at <https://tp.amegroups.com/article/view/10.21037/tp-24-197/rc>

Data Sharing Statement: Available at <https://tp.amegroups.com/article/view/10.21037/tp-24-197/dss>

Peer Review File: Available at <https://tp.amegroups.com/article/view/10.21037/tp-24-197/prf>

Conflicts of Interest: All authors have completed the ICMJE uniform disclosure form (available at <https://tp.amegroups.com/article/view/10.21037/tp-24-197/coif>). The authors have no conflicts of interest to declare.

Ethical Statement: The authors are accountable for all

aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was approved by Institutional Ethics Board of Children's Hospital of Nanjing Medical University (No. 202406010-1) and informed consent was taken from all the patients' parents or legal guardians.

Open Access Statement: This is an Open Access article distributed in accordance with the Creative Commons Attribution-NonCommercial-NoDerivs 4.0 International License (CC BY-NC-ND 4.0), which permits the non-commercial replication and distribution of the article with the strict proviso that no changes or edits are made and the original work is properly cited (including links to both the formal publication through the relevant DOI and the license). See: <https://creativecommons.org/licenses/by-nc-nd/4.0/>.

References

1. Marklund N, Brody DL. Refined Management of Severe Traumatic Brain Injury in Children. *J Neurotrauma* 2023;40:1027-8.
2. Ijaz S, Scott L, Dawson S, et al. Factors related to adverse long-term outcomes after mild traumatic brain injury in children: a scoping review. *Arch Dis Child* 2023;108:492-7.
3. Coulter IC, Forsyth RJ. Paediatric traumatic brain injury. *Curr Opin Pediatr* 2019;31:769-74.
4. Kochanek PM, Tasker RC, Bell MJ, et al. Management of Pediatric Severe Traumatic Brain Injury: 2019 Consensus and Guidelines-Based Algorithm for First and Second Tier Therapies. *Pediatr Crit Care Med* 2019;20:269-79.
5. Maggard BL, Gies LM, Sidol CA, et al. Online Intervention for Caregivers of Children with Early Traumatic Brain Injury: Pilot Trial. *J Pediatr Psychol* 2023;48:205-15.
6. Miley AE, Fisher AP, Moscato EL, et al. A mixed-methods analysis examining child and family needs following early brain injury. *Disabil Rehabil* 2022;44:3566-76.
7. Antonini TN, Raj SP, Oberjohn KS, et al. A pilot randomized trial of an online parenting skills program for pediatric traumatic brain injury: improvements in parenting and child behavior. *Behav Ther* 2014;45:455-68.
8. Dalgaard NT, Filges T, Viinholt BCA, et al. Parenting interventions to support parent/child attachment and psychosocial adjustment in foster and adoptive parents

- and children: A systematic review. *Campbell Syst Rev* 2022;18:e1209.
9. Ayesha, Ahmad S, Saba S, et al. The Relationship between Psychological Disability and Religious Practice and Coping Strategies in Caregivers of Children with Traumatic Brain Injury in Pakistani Population. *Healthcare (Basel)* 2022;10:2158.
 10. Aitken ME, McCarthy ML, Slomine BS, et al. Family burden after traumatic brain injury in children. *Pediatrics* 2009;123:199-206.
 11. Qadeer A, Khalid U, Amin M, et al. Caregiver's Burden of the Patients With Traumatic Brain Injury. *Cureus* 2017;9:e1590.
 12. Pan Y, Jin A, Wang M. Estimation methods and common errors of clinical study sample size. *Chinese Journal of Stroke* 2022;17:31-5.
 13. Zhang J, Chen H, Fu Q. The burden of main caregivers and its influencing factors in hospitalized children with traumatic brain injury. *Military Nursing* 2022;36:48-51.
 14. Bédard M, Molloy DW, Squire L, et al. The Zarit Burden Interview: a new short version and screening version. *Gerontologist* 2001;41:652-7.
 15. Macchi ZA, Koljack CE, Miyasaki JM, et al. Patient and caregiver characteristics associated with caregiver burden in Parkinson's disease: a palliative care approach. *Ann Palliat Med* 2020;9:S24-33.
 16. Alves S, O'Caoimh R, Ribeiro O, et al. Screening for Caregiver Burden in the Community: Validation of the European Portuguese Screening Version of the Zarit Burden Interview (ZBI-4). *Clin Gerontol* 2022;45:525-37.
 17. Li Y, Cong X, Chen S, et al. Relationships of coping styles and psychological distress among patients with insomnia disorder. *BMC Psychiatry* 2021;21:255.
 18. Xiao H, Li X, Zhou Z, et al. Negative coping style mediates the relationship between negative mental and suicide risk among migrant workers in China. *Sci Rep* 2022;12:305.
 19. Wu Y, Yu W, Wu X, et al. Psychological resilience and positive coping styles among Chinese undergraduate students: a cross-sectional study. *BMC Psychol* 2020;8:79.
 20. Soddors MD, Killien EY, Stansbury LG, et al. Race/Ethnicity and Informal Caregiver Burden After Traumatic Brain Injury: A Scoping Study. *Health Equity* 2020;4:304-15.
 21. Lu M, Huang H, Chen Y. Qualitative study on early psychological experience of main caregivers in children with severe craniocerebral injury. *Hainan Medical Journal* 2015;26:2335-7.
 22. Zhang J, Fu Q. Research progress on supportive needs of family caregivers in children with traumatic brain injury. *Chinese Journal of Nursing Education* 2022;19:668-72.
 23. Zhang J, Chen H, Meng F. Rehabilitation nursing education based on empowerment theory in caregivers of children with traumatic brain injury. *Chinese Journal of Rehabilitation Medicine* 2023;38:1138-41.
 24. De Luca R, Pollicino P, Rifici C, et al. Psycho-Emotional Well-Being in Caregivers of People with Acquired Brain Injury: An Exploratory Study on the Human Immersion Model during the Omicron Wave. *Clin Pract* 2023;13:487-96.
 25. Lee E, Kim Y. How do the influencing factors of health-related quality of life of the injured patient differ according to activity limitations? *Qual Life Res* 2021;30:1103-18.
 26. Hansen C, Battikha M, Teramoto M. Complicated Mild Traumatic Brain Injury at a Level I Pediatric Trauma Center: Burden of Care and Imaging Findings. *Pediatr Neurol* 2019;90:31-6.
 27. Dewan MC, Mummareddy N, Wellons JC 3rd, et al. Epidemiology of Global Pediatric Traumatic Brain Injury: Qualitative Review. *World Neurosurg* 2016;91:497-509.e1.
 28. Hu X, Gao H. Analysis of burden and its influencing factors of main caregivers in patients with stroke. *Nursing Practice and Research* 2018;15:27-9.
 29. Yuan C, Deng S, Ma J. Effect of caregiver self-management support program on psychological resilience, coping style and quality of life of main caregivers of children with epilepsy. *Journal of Qilu Nursing* 2023;29:79-82.
 30. Zhang Q, Song D, Liu Y, et al. Sleep quality, caregiver burden, and individual resilience among parents of children with epilepsy. *Epilepsy Behav* 2022;135:108873.
 31. Camelo Castillo W, Onasanya O, dosReis S, et al. Caregiver Burden in Caregivers of Children With Special Health Care Needs and Association With Chronic Pain. *Med Care* 2022;60:368-74.
 32. Zhang J, Liu N, Wang Y. Analysis of fatigue status and influencing factors of family caregivers in patients with severe craniocerebral injury. *Modern Nurse* 2023;30:8-13.
 33. Huang H, Lu M, Shen S. Qualitative study on early psychological status of main caregivers in children with craniocerebral trauma. *Chinese General Practice Nursing* 2015;13:3280-11.
 34. Shattnawi KK, Al Ali N, Almanasreh AA, et al. Caregiver burden among parents of children with chronic diseases: A cross-sectional study. *J Clin Nurs* 2023;32:6485-93.
 35. Özer Özlü NG, Vural F. Caregiver burden of families of children with corrosive esophageal injuries. *J Child Health*

- Care 2023;27:46-59.
36. Tona JT, Ash J, Brown E, et al. Caregiver Burden, Stress, and Relationship Cohesion Among Self-Identified Caregivers of Children with Pediatric Acute-Onset Neuropsychiatric Syndrome. *J Child Adolesc Psychopharmacol* 2023;33:378-86.
 37. Gan L. Practice of Medical Social Work in Social Service Department of Peking Union Medical College Hospital. *China Social Work* 2024;(10):47-8.
 38. Liu T, Song Q, Xiao Y. Investigation on positive feelings and care ability of main family caregivers of children with congenital heart disease. *Modern Nurse* 2022;29:158-60.
 39. Zhou J, Zhu J, Huang H, et al. Investigation and analysis of care burden and quality of life of caregivers of children with cerebral palsy. *Shanghai Medical & Pharmaceutical Journal* 2022;43:12-5.
 40. Yi M, Jiang D, Jia Y, et al. Impact of Caregiving Burden on Quality of Life of Caregivers of COPD Patients: The Chain Mediating Role of Social Support and Negative Coping Styles. *Int J Chron Obstruct Pulmon Dis* 2021;16:2245-55.
 41. Rasoulpoor S, Salari N, Shiani A, et al. Determining the relationship between over-care burden and coping styles, and resilience in mothers of children with autism spectrum disorder. *Ital J Pediatr* 2023;49:53.
 42. Li N, Fan L, Wang Y, et al. Risk factors of psychological distress during the COVID-19 pandemic: The roles of coping style and emotional regulation. *J Affect Disord* 2022;299:326-34.
 43. Li Y. Analysis on the current situation and influencing factors of nursing service demand of main caregivers of hospitalized children in hospital. *Chinese Journal of Modern Nursing* 2021;27:4864-8.

Cite this article as: Ye H, Wei J, Miao Y, Gu L. The weight of care: exploring the challenges faced by primary caregivers of children with traumatic brain injuries. *Transl Pediatr* 2024;13(9):1551-1559. doi: 10.21037/tp-24-197