Factors associated with strain among informal care providers of patients with traumatic brain injury in Malaysia

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ABSTRACT

Purpose: This study aims to investigate the level of strain and various influencing factors among informal care providers of traumatic brain injury (TBI) patients. Methods: A cross-sectional study was conducted in a single center in Malaysia via recruiting care providers of patients with TBI. The modified caregiver strain index (MCSI) questionnaires were utilized to ascertain the level of strain. The demographic data of informal care providers were also obtained. Independent sample t-test, analysis of variance (ANOVA), and a linear regression model were processed for data analysis. Results: A total of 140 informal care providers were included in the study. More than half of informal care providers claimed to have strain (54.3%). Factors associated with increased strain include receiving tertiary education, being of Chinese background, and employed experience higher strain level. Informal care providers with characteristics such as being single, retired and provided care for 5 years experienced a lower level of strain. Conclusion: Guidance on integrating the TBI knowledge into practice, assessing the care provider’s level of strain regularly and providing supportive measures may aid in supporting informal care providers at risk.

Keywords: Brain injury, care, informal, provider, strain

Introduction

Traumatic brain injury (TBI) is a chronic disease process that requires an informal care provider’s involvement for several years.¹,² By the year 2050, the number of informal care providers is estimated to increase by 85%.³ Informal care providers of patients with chronic illness who possess a good attitude, knowledge, and awareness about the illness will experience better well-being compared to those with poor knowledge and awareness.⁴ It has been reported previously that many informal care providers with poor knowledge and skills were still involved in providing sustained care for individuals with chronic illness. As a result, they have reduced confidence levels and feel unprepared.⁵ Further, informal care providers reported receiving insufficient guidance from formal clinical care providers, contributing to their inability to assume caregiver role, being unfamiliar with type and amount

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of care needed, and ineffective utility and accessibility of resources.[9]

The involvement of informal care providers in providing care results in making them distressed, burdened and influences their lifestyle, daily activities, and responsibilities.[10] It has been suggested that informal care providers are more likely to develop future illnesses than formal care providers, thus, approximately 59% of informal care providers experience clinical depression at one point of time.[11] It seems that cognitive and behavioral challenges of TBI patients put informal care providers at high levels of strain compared to physical malfunctions.[12] Ponsford et al. found that behavioral challenges in patients with TBI up to 5 years post-injury were strong predictors of anxiety and depression in informal care providers.[13]

In Malaysia, TBI is the third leading cause of admission to hospitals, and the fifth cause of death.[14] Motor vehicle accidents or motorcycle crashes were found to be the leading cause of TBI in Malaysia.[15] In view of the informal care providers’ experience in literature, and the increased occurrence of TBI in Malaysia, the quantity and quality of informal care providers for TBI patients is significant. Herein, our study aims to determine factors predicting strain levels among informal care providers in Malaysia.

Methods

This is a cross-sectional and single-centered study that was performed to determine the level of strain among informal care providers using a self-administered questionnaire. The study participants were selected as they accompanied the patients during follow-up or outpatient therapy sessions at University Malaya Medical Center (UMMC). A total of 140 informal care providers were recruited from October 2018 to January 2019 in a teaching hospital in Kuala Lumpur, Malaysia (the department of rehabilitation medicine, University Malaya Medical Center).

The inclusion criteria were: (1) informal care providers of patients with TBI who act as primary care providers for the patients; (2) care for the TBI patients for at least 6 months because informal care providers experience long-term challenges from 6 months to several years post-injury; and (3) age 18 years of age or older. The exclusion criteria were: (1) nurses and paid maids (paid personnel), and (2) informal care providers with mental illness.

The instrument used in this study is composed of a demographic section and the modified caregiver strain index (MCSI). Various demographic data were obtained from informal care providers that include age, gender, ethnicity, marital status, level of education, employment status, monthly income, relationship to the patient, duration of caregiving, caring for another disabled person, and the patient’s severity of the injury.

MCSI is a self-administered, 13-question tool that is utilized to measure the level of strain among informal care providers. It was developed by (Robinson, 1983) and was later modified by (Thornton and Travis, 2003).[10][11] Scoring is 2 points for “yes,” 1 point for “sometimes,” and 0 for “no.” The higher the test score, the higher the level of the caregiver’s strain.

The statistical analysis was performed starting with the frequency distribution of demographic features. The reliability of data was measured using Cronbach’s alpha. Independent sample t-test was used to evaluate gender, marital status and caring for another disabled person in relation to the level of strain. One-way analysis of variance (ANOVA) followed by post hoc least significant difference (LSD) examined the relationship between ethnicity, marriage and employment status, and level of strain. A multivariate linear regression model was structured by placing informal providers’ age, gender, education level, monthly income, time since injury, duration of caregiving, caring for another disabled person, and severity of the injury as independent variables and level of strain as a dependent outcome. A P value of less than 0.05 was considered statistically significant. The continuous variable data are represented as mean ± SD. All statistical analyses were processed using SPSS for Windows, version 23 (IBM).

Ethical considerations

Signed consent was obtained from the informal care providers prior to the study. Ethical approval was obtained from the Research Medical Ethics Committee of the hospital. Permission to use the MCSI was obtained. Approval was obtained in May 2018.

Results

Demographic characteristics of study participants

A total of 140 care providers were included in the study. The mean age of informal care providers was 47.8 ± 10.51. The average monthly income of the informal care providers was RM 3,719 ± 4107 with the majority having a monthly income of less than RM 3,000 (750 USD). Most of the informal care providers were married, caring for patients with severe TBI, and they are not caring for another disabled person (n = 114, 81.4%) (n = 125, 89.3%) (n = 126, 90%), respectively. The demographic data is demonstrated in Table 1. The internal consistency of the questionnaire is shown to be acceptable with Cronbach’s alpha of 0.86.

Factors associated with the high level of informal care provider’s strain

The total mean score of the level of strain was 12.30 ± 5.67 and the majority of the informal care providers reported scores greater than 10 indicating a higher level of strain (n = 76, 54.3%).

Using ANOVA with post hoc LSD test, informal care providers from Malay ethnicity had a lower level of strains compared to Chinese and Indians with P values of <0.01. Furthermore, single informal providers have reported a higher strain score compared to those who are married (P = 0.001). In addition, providers who are retired tend to be more strained than those
Table 1: The demographic profile of the informal care providers (n=140)

| Demographics                      | n (%) | Level of strain Mean±SD | P    |
|-----------------------------------|-------|-------------------------|------|
| Gender                            |       |                         |      |
| Male                              | 48 (34.3%) | 12.29±5.49              | 0.99 |
| Female                            | 92 (65.7%) | 12.30±5.79              |      |
| Ethnicity                         |       |                         |      |
| Malay                             | 77 (55%)  | 10.83±6.06              | 0.006|
| Chinese                           | 44 (31.4%) | 13.97±5.34              |      |
| Indian                            | 19 (13.6%) | 14.71±1.90              |      |
| Marital status                    |       |                         |      |
| Single                            | 63 (45%)  | 13.65±2.67              | 0.01 |
| Married                           | 77 (55%)  | 11.67±2.50              |      |
| Employment status                 |       |                         |      |
| Employed                          | 65 (46.4%) | 14.80±6.32              |      |
| Private sector                    | 36 (25.7%) | 11.33±3.96              | <0.001|
| Unemployed                        | 9 (6.4%)   | 11.22±4.55              |      |
| Retired                           | 30 (21.4%) | 8.37±3.11               |      |
| Education level                   |       |                         |      |
| Primary school                    | 13 (9.3%)  | 8.08±5.14               |      |
| Secondary school                  | 84 (60%)  | 10.84±4.31              | <0.001|
| Tertiary                          | 28 (20%)   | 15.17±6.44              |      |
| Graduate                          | 15 (10.7%) | 18.73±4.00              |      |
| Duration of caregiver             |       |                         |      |
| <1 year                           | 27 (19.3%) | 16.51±6.27              |      |
| 1-5 years                         | 51 (36.4%) | 12.86±5.15              | <0.001|
| >5 years                          | 62 (44.3%) | 10.00±4.60              |      |
| Caring for another disabled person|       |                         |      |
| Yes                               | 14 (10%)   | 12.71±4.81              | 0.77 |
| No                                | 126 (90%)  | 12.25±5.77              |      |
| Relationship to the patient       |       |                         |      |
| Spouses                           | 32 (22.9%) | 13.75±5.98              |      |
| Siblings                          | 19 (13.6%) | 15.89±5.64              | <0.001|
| Parents                           | 76 (54.3%) | 10.06±4.25              |      |
| Children (son/daughter)           | 13 (9.3%)  | 16.53±6.45              |      |
| Patient's Severity of injury      |       |                         |      |
| Mild                              | 5 (3.6%)   | 10.00±4.00              |      |
| Moderate                          | 10 (7.1%)  | 14.90±4.17              | 0.23 |
| Severe                            | 125 (89.3%) | 12.19±5.79              |      |

who are either employed (P < 0.001) or work in the private sector (P = 0.02). Furthermore, informal care providers who are employed have a higher strain rating compared to their peers who work in private sectors with P value of 0.02. With the utilization of independent sample t-test, informal care providers who are single tend to procure a higher level of strain compared to their married counterparts with P value of 0.01. All other findings are depicted in Table 1.

The multivariate regression model has shown that older care providers have a reduced level of strained compared to younger peers (B = −0.10, P = 0.037). Additionally, those with a higher educational background manifest an increased level of strain (B = 2.14, P < 0.001). All other results are illustrated in Table 2.

### Discussion

According to the MCSI used in this study, informal care providers experience overwhelming feelings due to sleep deprivation, TBI patients’ behaviors, or physical challenges. Informal care providers being overwhelmed may be due to their refusal to seek help within the family or available community services. Further, the imbalance between TBI patient’s needs and one’s own needs could possibly contribute to exacerbating overwhelming behaviors and feelings. This result is consistent with previous investigations showing that the physical and emotional consequences associated with such overwhelming feelings could lead to severely insufficient caregiving needs.\[13,14\] The MCSI has no cutoff score to indicate higher levels of strain. In order to obtain low and high levels of strain, a cutoff point was determined by considering the median score as the cutoff point, which was obtained from the pilot study by Juni et al. and Karim et al.\[13,14\] The median score was 10. Respondents with a high level of strain scored equal or above the median score, while those with a low level of strain scored below the median score of the level of strain.

One of the goals of the current study was to determine factors associated with strain among informal care providers for TBI patients in Malaysia. In Malaysia, TBI patients are usually cared for at home by family members who act as primary care providers. Cultural values can play a role in the well-being of the care provider in this study. Individuals of the Chinese race, representing 23% of the Malaysia population, experience a high level of strain according to the current study. It might be due to the Chinese culture and traditions which considerably perceive the family as the foundational unit of any society. Confucian and Buddhist value systems defend the perspective that caring for older people is a family responsibility. It has been well documented that the Chinese, because of the strong impact of their cultural values and traditions, exhibit certain personality characteristics and unique values.\[13,14\] Such a belief system makes Chinese families caring for older people to less likely to seek paid care providers. This could be attributed to the quality of external paid services, and hesitancy to depend on unconnected individuals to provide support.\[13,14\]

Informal care providers spend a considerable amount of time during the week to provide care for individuals with chronic illnesses. In the United States, an average of 24.4 h spent per week by family care providers. Such an amount of time is expected to increase to 40 h per week when the informal care provider resides in the same place as the TBI patient.\[17\] Distal factors such as socioeconomic status may influence the time spent by informal care providers and hence contributes to the higher strain level. In our current study, employed individuals were found to have a higher strain level compared to unemployed individuals. Our finding contradicts previous studies that showed employed individuals did not possess a high strain compared to unemployed individuals. Such findings could be attributed to the fact that employed individuals are younger, healthier and more likely to be...
a child of the patient than a spouse. For example, Taylor and Chatters reported that elderly African Americans would be more likely to request assistance from a child rather than a spouse.

On the other hand, informal care providers who completed a tertiary education tend to have a high level of strain. However, studies found out contrasting results where informal care providers who did not have advanced education levels were at least seven times more likely to induce high stress than those who had high levels of education. This may be potentially linked to financial related reasons, as individuals with lower education level are expected to be unemployed and may not be able to afford to care for TBI patients.

Our study aligns with previous studies that spousal caregiving seems to experience a greater strain compared to other forms of relationships. Yet, several lines of other investigations demonstrated otherwise. In our context, this finding can be explained that spouses may experience the feeling of uncertainty, anxiety, and other psychosocial factors that may contribute to such a high level of strain. Further, caring for a spouse may partly impact the resources of income for a family which may explain susceptibility to being subjected to high strain level because of financial reasons. However, further studies should examine closely the psychosocial factors that may participate in high strain in this specific population.

In our study, it was found out that informal care providers who are single, retired, or provided care for over 5 years had a lower level of strain compared to married care providers, employed, or less than a year of caregiving, respectively. The marital status has been examined before by chatters and it was found out that married individuals seem to be in less strain. This is attributed possibly to the social network size and the accessibility and availability to care, providers. Being retired allows informal care providers to spend some of their free time doing something meaningful and valuable. It could be possible that retired informal care providers decided to retire and care for their other significant. Such feeling of dedication and determination may influence the strain level to be lower as such informal care providers are willingly providing care. Informal care providers who spent over 5 years seemed to have a lower level of strain. This suggests that the duration is a key factor in influencing the strain levels. Over the course of years, informal care providers become adapted to the process more and develop a set of skills, experiences, attitudes and knowledge they make the strain level minimal.

The findings from this study demonstrate significant implications for future research, policy, and practice in the Malaysian context. Regardless of the socioeconomic characteristics of the informal care providers, those who are subjected to be in high levels of strain should be targeted to improve outcomes on a larger scale. It may be useful to implement strategies to screen and monitor informal care providers’ strain and stress levels in the clinical setting. Health and social services should be involved in identifying and managing high-risk informal care providers. The development of programs for informal care providers by national agencies in Malaysia that support caregivers is worth considering. The role of primary care has not been proactive in providing enough support for informal care providers’ needs, health, and challenges. Primary care staff is not certain if they are equipped with skills, resources and time to provide care for informal care providers. Thus, the role of primary care should be boosted in providing support for informal care providers to achieve progress. Future research should be directed toward a better understanding of the effect of care providing on health outcomes. Focusing on characteristics of informal care providers only may mislead future policy and practices rendering them ineffective. Despite the currently available interventions to reduce informal care providers’ strain, a low to moderate success was achieved.

The present study has several limitations that should be considered when interpreting the results. First, as the participants were recruited from a single-center, the findings may not be representative of TBI informal care providers throughout Malaysia. The cross-sectional method also decreases the generalization of the findings. However, UMMC is one of the main referral centers for TBI rehabilitation in West Malaysia. Thus, the findings still make a significant contribution as a baseline in identifying knowledge and strain among informal care providers in this country.

### Conclusion

In the Malaysian context, socioeconomic factors and cultural values seem to influence the level of strain among informal care providers.
providers of TBI patients. Informal care providers from the Chinese race, being employed and received tertiary education possessed a high level of strain. On the contrary, informal care providers who were single, retired, and cared for TBI patients 5 years or more possessed a lower level of strain. This study illustrates that the socioeconomic, cultural and belief system may moderate the strain in a specific population which may differ from findings from other studies reported. Guidance on integrating the TBI knowledge into practice, assessing the care provider's level of strain regularly and providing supportive measures may aid in supporting informal care providers at risk.

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Conflicts of interest
There are no conflicts of interest.

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