

Family roles, challenges and needs in caring for traumatic brain injury (TBI) family members: a systematic review

Caring for TBI
family
members

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Abstract

Purpose – Advanced medical technology has reduced the mortality rate among traumatic brain injury (TBI) patients. This, however, has led to an increasing number of surviving patients with a major disability. As a consequence, these patients need attentive care which becomes an important issue for the society, particularly family members. Thus, this paper aims to review some of the salient roles, challenges and needs of the family caregivers in caring or nursing for their family members diagnosed with TBI.

Design/methodology/approach – An inclusive search of the literature was undertaken to identify the family roles, challenges and needs in supporting and nursing TBI patients.

Findings – Previous studies have shown that the family needs to address two important aspects of taking care of TBI patients, which involve emotional and physical affairs. Hence, it is essential for the family members to have adequate information on healing treatment, nursing and care methods, financial support, support groups, managing self-care and, more importantly, emotional and social support.

Originality/value – This paper is not currently under consideration, in press or published elsewhere. In Malaysian culture, nursing disabled patients have always been a family responsibility. The role of nursing the patients has been done domestically and is considered a private affair. In order to execute the role, some put the patient needs as their priority and leave aside their needs and matters.

Keywords Family roles, Caregiver roles, Nursing, Traumatic brain injury (TBI) family members

Paper type Review

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Introduction

Traumatic brain injury (TBI) is an unexpected health problem [1]. In Malaysia, road accidents are the cause of most TBI incidences [2]. Road accidents usually involve means of transport such as bicycles, cars and motorcycles as well as pedestrians. TBI causes cognitive and sensory processing disorders, communication problems and behavioral changes [3]. TBI patients can experience permanent life-limiting disabilities, thus causing permanent suffering [4, 5]. Due to these permanent disabilities, TBI patients are highly dependent on their family members to take care of them and manage their daily needs.

In the Malaysian context, most caregivers are family members. This is because societal expectation entails that the responsibility of caring for TBI patients will fall on immediate family members; hence, it is considered a private affair. In most cases, these family members are not well trained in nursing procedures related to TBI patients. Furthermore, TBI patients are usually informally cared for at their family's residence or the caregiver's house. This creates a challenge for them to provide the best care for TBI patients [6, 7]. As caring for TBI patients requires a full-time commitment, informal caregivers including family members often face mental strain, as they are physically, emotionally and economically not ready to cater to the often demanding needs of TBI patients. Studies have found negative impacts on the physical and mental health of the patient's family members [8, 9], especially the designated primary caregiver. Providing long-term care for TBI patients causes stress, depression and anxiety among caregivers [6, 7].

Even though the issue seems to garner minimal public attention, it is a critical issue that needs to be addressed, as it concerns the well-being of the caregivers and, in turn, could improve the care and recovery of TBI patients [10, 11]. This review will highlight studies on the social well-being of the caregivers, highlighting the challenges and needs of the family caregivers in caring or nursing for their family members diagnosed with TBI. The findings from this review will help guide efforts to reduce stress among caregivers of TBI patients as part of the post-discharge rehabilitation program.

Method

The literature for this systematic review was derived from an extensive search of different databases such as PubMed, Science Direct, EBSCHOhost, SAGE Online, ProQuest Family Health, Scopus, Public Health, Taylor & Francis Online, Humanities, Social Sciences Collections, Wiley Online Library and Health Collections. The systematic review included studies published from 1995 to 2018. The search terms used for the review included TBI, increasing family roles, challenges and needs in supporting and nursing TBI patients. The search was also narrowed down to find studies focusing on Malaysia and the Southeast Asian region. However, the search only found a few studies specific to the Malaysian and Southeast Asian contexts, and so studies from other countries, including Western countries, were also included.

Overall, 65 articles including books, masters research papers and reports were obtained from the database search. The details of these articles were imported into Endnote version 7.1 reference manager software. Endnote was then used to remove all duplicates, and a total of 27 articles deemed as irrelevant were removed. The remaining 38 articles were then reviewed by all the authors, and the relevant data were extracted to support this systematic review.

Ethical consideration

Ethical approval was obtained from the Universiti Sains Malaysia ethics board (USM/JEPeM/17010001) prior to the commencement of writing this paper.

Results

The literature search revealed several different studies that focused on issues such as TBI care, caregiver roles and family needs. In this review, the discussion focused mainly on

studies regarding caregiver roles and the emotional and physical demands, as well as overall family needs involved in the care of TBI patients. The findings of the studies were then checked for relevance and applicability in the context of this review.

Caregiver roles

The studies reviewed found that the responsibility as the primary caregiver of TBI patients mostly relied on immediate family members [4, 12, 13]; this is also highlighted in several Malaysian studies [6, 7]. The prime guardian refers to the family member who lives with the patient and is responsible for providing, supporting and managing the patient's daily needs [8]. The function of a family institution to provide nursing and care for its member who suffers TBI is based on their free will. The nursing process includes serving and providing for the patient's physical, psychological and social needs [8, 14]. The nursing and care provided by a family system is of benefit to the patient, particularly in the case of long-term nursing provision [8]. Family caregivers are characterized as nurturing. The patient tends to feel more comfortable under the continuous care of their loved ones, compared to the patient who is nursed by an institution which causes them to feel isolated and alone [15]. However, studies have found that being a primary caregiver to a family member creates a high level of stress and emotional strain [4, 7, 16]. To address this issue, this review will focus on the emotional and physical aspects of the patients, as these aspects are the main determiner of the patients' rate of recovery.

The role of family caregivers in the recovery of TBI patients

Family plays an important role in the nursing of the TBI patient, particularly in the treatment and healing process, as they are responsible for providing for all the patient's needs and necessities [17]. Family caregivers tend to have trouble handling and nursing TBI patients due to the difficulty in obtaining access to health and treatment services. As caregivers, the family should have a solid understanding of the treatment costs in managing TBI patients. Therefore, access to information that is understandable, honest and regularly updated is vital [8, 15]. The information regarding the services available is very important to help the family to gain an in-depth understanding of the process of treatment and healing.

Taking care of the TBI patient is a very demanding responsibility [18], and the long-term nursing process can affect the livelihood of primary caregivers. Hence, caregivers should not neglect their needs and desires. Studies [6, 13, 17, 19] have documented that family members have experienced various difficulties such as anxiety, financial hardship and social isolation, and these challenges have affected their ability to provide adequate care for TBI patients. Having a supportive environment could help caregivers in providing quality care for their TBI family members. Thus, creating a support group for TBI caregivers might help to ease the emotional strain they experience.

Moreover, the recovery process for TBI patients is time-consuming and requires the family to provide an efficient system in managing the patient to aid the healing process. The task as primary caregivers to TBI patients requires some medical and nursing knowledge and skills including adequate knowledge and information regarding the illness, the treatments and the patient behavior.

Therefore, to prepare and provide for the patient's needs, the family needs to fulfill their own needs and necessities [16]. However, most of them tend to neglect their needs as they are burdened with the challenging task of taking care of the TBI patient [20]. The primary caregivers of TBI patients need to equip themselves with information related to treatments and nursing methods and must be aware of any available financial aid and emotional and social support that they are able to access. They should also be provided with guidance on

issues such as safety and hygiene to manage the TBI patient [8]. In this regard, medical institutions can provide talks and courses on how to take care of these patients [16].

The emotional aspect of caring for TBI patients

The role of the key caregiver of a TBI patient requires a lot of patience and dedication. There are numerous challenges that the family needs to face such as a lack of knowledge and skills in nursing and care methods, financial constraints and lack of mental and physical preparation to handle and care for the patient [17]. Despite these challenges, the family needs to put these constraints and limitations aside and fully engage with the patient's emotions and their healing process [21].

According to one study [22], the most pressing concern for family members is the communication problem, as the patient usually has trouble communicating verbally. However, efficient communication can help resonate and stimulate the patient's brain activities. Thus, the family member caregiver is encouraged to engage in communication with the patient to reduce their boredom and stress levels [17]. In addition, the family member also needs to be very strong emotionally, as taking care of the patient could be devastating and can often challenge patience levels [19, 23]. The behavior changes in TBI patients are often unexpected, and their emotions can be unstable as they experience mood swings. There are many other symptoms that might be displayed by the TBI patient that require the family to learn, adapt and manage the patient. As the primary guardian, the task of looking after the patient is a responsibility, and therefore the family needs to understand the demands which will be placed upon them.

Supportive emotional care of TBI patients by their family gives them the motivation to feel alive, comfortable and protected [24]. In the healing process, other than physical treatment, what matters is the moral support from close relatives. Emotional support can lighten the patients' mood, and consequently reduce their stress and pains [25, 26]. The nursing and care of the TBI patient by their family are based on love and a sense of responsibility, as they have an emotional attachment. In practice, caregivers should be given emotional support, as their well-being helps ensure the success of their TBI family member's recovery. Without, or if lacking in emotional support, these caregivers can feel stressed and demotivated, and this can affect the recovery process of their TBI family member.

The physical aspect of caring for TBI patients

According to Ryan [24], the support that a family might get from taking care of TBI patients is dependent on the functional and capability levels of the patient. Nursing the TBI patient means that the family caregivers need to manage and fulfill all the basic needs of the patient, especially if they suffer a total loss of physical capabilities [15]. In such cases, the family needs to fully manage the patient from moving to bathing and changing clothes. For more mobile patients, they still may need help going to the bathroom, but for patients who have lost all physical abilities, they require constant assistance including changing bedsheets multiple times a day when soiled.

In order to physically attend to all the TBI patient's needs, family caregivers are required to supervise the patient's medicinal and medical needs, including ensuring that the patient takes their medication on time [20]. It is also the family caregiver's responsibility to provide meals and to feed the patient if they are unable to eat unaided [12]. As the primary caregiver, the family must also ensure that the meal provided is a healthy and balanced diet. They also need to ensure that the living environment of the patient is always clean and safe. Nursing the TBI patient can be exasperating if the patient suffers physical limitations which can severely disrupt the nursing flow. The task is even harder if there is only one primary caregiver who must continuously care for the patient [27]. The family caregivers who have to take care of the

patient for a very long time suffer compromised health, as they find themselves experiencing exhaustion through a lack of rest. This compromises the family's ability to manage the patient as well as they would like. Thus, as mentioned in Mazlan *et al.* [6], hospitals could provide greater support in terms of health care, physical activities and courses for TBI patient's carers to help keep them physically healthy and capable of providing the assistance that their TBI family member requires.

Available support for primary caregivers of TBI patients

Financial support

Significantly, the most crucial aid that family caregivers can access is financial support [16, 28, 29]. Regrettably, many of them suffer financial constraints in providing all the basic needs and treatments needed for the TBI patient under their care. Often, families need financial aid to support the long-term treatment cost [3, 15]. The treatment cost increases, as more treatment procedures and medicines are needed to relieve the TBI patient's pain. The economic state of a household depends on its net income. For the family of a TBI patient, not only do they spend on their usual monthly household expenses, but they also need to allocate a large part of the monthly income for the patient's treatment costs. Most Malaysian families only earn just enough for their household needs, especially those who live in the city, and this often means that TBI medical costs are too expensive to purchase every month [30]. Therefore, many families need financial aid due to the escalating cost of taking care of TBI patients, particularly for those families with lower incomes [31]. Due to these financial constraints, the caregivers might have to stop essential follow-up treatment required by the patient.

Therefore, family caregivers need financial aid to cover the costs of taking care of TBI patients [22]. These costs involve hospital fees, costs for the follow-up treatment and other hidden costs. However, the process of obtaining financial aid can be difficult. Moreover, the qualification for a financial subsidy depends on the level of the patient's disability, economic status, and location. Financial aid is not always balanced with financial status, as there is always a hidden cost every time the patient goes for treatment. According to other studies [32, 33], without financial aid, the family might fail to provide proper treatment for the patient. In other words, financial aid helps to lighten the burden of managing a TBI patient.

Support groups

Support groups should focus not only on the patients but also on family members who carry out their roles as caregivers. According to Nik Jit [16], support groups that exist in the community can provide special support to the patient and their family. The support group is a medium for caregivers comprising of family members of TBI patients who meet with other family members of TBI patients. The support group can be a place to share opinions and experiences of care in helping the recovery of the patient. According to Roscigno *et al.* [15], families need a positive outlook, supporting each other to maintain the hope that the patient will recover as usual. According to a study conducted by Ryan [24], the family requires support groups to gain moral support to enhance the level of patient acceptance and preparation whilst providing care. The study showed that 78% of respondents who consisted of caregivers to TBI patients stated that participation in the support group helped to reduce the burden of care. Also, they hoped that more support groups would be provided for the benefit of the patients and their family members.

Managing self-care

According to Roscigno *et al.* [15], during the initial period of injury, family caregivers give full attention to the injured person, while other responsibilities are postponed or delegated. As the

recovery period is prolonged, family members begin to realize that they have other responsibilities such as work and community life. As a guardian, family members do not have enough time and resources to meet the responsibilities of the various roles they are expected to perform. When the responsibilities of taking care of patients overlap with other social roles, the caregiver experiences difficulties and stress that affects their well-being. Patient care is an additional commitment that reduces the performance of a career. DeBaillie [30] stated that family members who act as caregivers exhibit lower productivity compared to those who do not serve as caregivers. This is because family caregivers must allocate more time to take care of the patients, thus affecting any other roles they are expected to perform. Family caregivers are often forced to take frequent leave to care for patients, work less than the period prescribed by the employer and often face harassment during work due to their focus on the responsibility of providing the necessary care to the TBI patient. Therefore, families affected by TBI need self-care guidance to ensure that they have enough time to sleep, focus on health care, carry out other roles and also spend time on relaxing activities [15].

Emotional and social support

The TBI patient's caregivers who are family members require a lot of support including emotional and social support [15, 22, 24]. Dealing with all the issues regarding nursing matters can be very stressful, and therefore the caregivers need support, especially from their family members [15]. Lack of support in emotional and social aspects might exert a negative impact on the quality of their life [30]. Besides taking care of the TBI patient, the caregivers also have other responsibilities that they need to balance at the same time. These heavy workloads can easily cause them stress. Receiving emotional and physical support from others will help the caregiver with their motivation and help manage their stress levels throughout the nursing period. The ability of the family to look after the TBI patient is parallel to the emotional and social support that they receive. This support is especially helpful when facing the personality changes of the TBI patient. Even though the family knows that the changes are due to psychological disorders, the behavior changes displayed by the patient can be very upsetting to deal with.

Family members caring for TBI patients need emotional and social support, particularly from the health community and social services [16]. Roscigno *et al.* [15] urged families to seek professional help from doctors, nurses and social workers to ensure that the nursing they provide is working. In addition, the support given can create a positive environment as professional help builds trust and confidence so that the family can maintain the treatment and healing process of the TBI patient.

Challenges of caring for TBI patients

Family caregivers are often required to provide care for TBI family members for many years. This brings numerous challenges to family caregivers. The articles reviewed found that family caregivers face financial problems, increasing amounts of additional family roles and social isolation that may affect their social functioning.

Financial problems

Wong and Tay [34] found that financial problems present the biggest burden for family caregivers of TBI patients in Malaysia. This is especially true when the TBI patient was the main breadwinner in the family. In this regard, a family's stability will be threatened, and financial resources can decline as other family members struggle to find other sources of income [35].

DeBaillie [30] posited that some family members have to quit their jobs to care for TBI patients. Losing a job and a source of income will affect a family's financial position, and some might have to use personal savings to pay for the high cost of treatment [3]. As a result, most families have to cut down their family expenditure to pay for medical treatments. The lack of financial resources leads to stress as they pay for TBI patient's bills and at the same time pay for household expenses.

Ketzeback [35] further described that many families have difficulty in obtaining financial assistance. DeBaillie [30] mentioned that despite the availability of government or privately funded financial assistance for the treatment of terminal diseases, not all families are eligible for financial assistance, and this has severely affected many families [31]. In some cases, financial problems have forced families to cut back or even stop providing the necessary treatment for TBI patients.

Increasing roles

TBI patients often find difficulties in finding jobs [12] due to their poor health. As a result, they are unable to take on the role of the income-earner in the family, and this threatens the stability of the family. In this case, for many families caring for TBI patients, there is an inevitable restructuring of family roles and responsibilities. Smith and Godfrey [36] posited that the shift in the social roles and functions in a family occurs gradually. In this regard, this shift can be difficult, as some individual family members need to take on extra responsibilities to replace those left void by the TBI patient. Keenan and Joseph [14] mentioned that some family members are reluctant to share care responsibilities, putting an even greater burden on those that do.

Family caregivers of TBI patients often think that the increased roles in a family system create a challenge for them, especially if the family members need to take care of all matters on their own without any help. According to the National Alliance for Caregiving in Collaborating of AARP [37], approximately 44 million family members over the age of 18 are forced to take on extra responsibilities including earning income to cover daily expenses and treatment bills and managing the needs of the TBI patients.

In this regard, family members forced to replace the family roles of TBI patients experience changes in their social functioning due to the burden of care during the care process [30]. Younger family members may be forced to take on extra roles, such as providing extra income for the family, in addition to their preexisting family routines.

Social isolation

Families play a very important role in maintaining the health and care of their incapacitated members. Studies found that families caring for TBI patients experience social isolation [22, 30]. Kat *et al.* [20] mentioned that the injuries suffered by TBI patients often cause patients to be highly dependent on their caregivers, as they experience radical changes in all aspects of their lives following their injuries. Consequently, family members are often obliged to care for the patients at all times [23].

As caring for TBI patients is a full-time responsibility, families who take the responsibility as primary caretakers often find themselves isolated from others, as they find it difficult to find time to socialize or participate in family activities [23]. These families are not able to participate in social activities, as it can be difficult for families to leave TBI patients to join community activities. This causes emotional distress among family members. Furthermore, family caregivers feel distressed because they find it difficult to find time to socialize with other people as they need to prioritize caring for TBI patients over their social needs. DeBaillie [30] also mentioned that society often alienates families of TBI patients, as they do not fully understand the caregiving role of TBI patients, and this has created gaps that have led to social isolation [30, 38].

Conclusions

In conclusion, healthy individuals are essential to generating a peaceful and harmonious community. However, at times, the family unit is challenged with unexpected health issues. Families are then expected to take on primary carer responsibilities when a member of the family is incapacitated. In the Malaysian culture, the family is the backbone that undertakes the role of carer. The responsibilities that the family may experience can be very complex when nursing a TBI patient, with research documenting the long-term deleterious effects on caregivers when providing care for an individual with TBI.

Research indicated that caregivers with limited support will be challenged with physical and mental health burdens. Therefore, health professionals need to play their role in aiding the family to attend to their social functions alongside their nursing obligations in order to enhance the caregiver's social functioning and well-being. This paper suggests several strategies that can be implemented by TBI caregivers. For instance, caregivers should consider engaging in self-help and support groups. By involving themselves in these types of groups, they would be able to learn about constructive coping strategies that are being used by other families in caring or nursing for their family members diagnosed with TBI. This paper strongly recommends that health professionals from government-based agencies, especially the medical social work departments in hospitals and related non-governmental organizations (NGOs), continue to provide appropriate training related to coping strategies for TBI caregivers. Such training is vital to enhance the existing knowledge of the family members so they can implement possible coping strategies when dealing with and caring for their TBI family members. Improving caregivers' support reduces the caregivers' burden, thus helping their mental health which helps them with the quality of the informal care that they provide to their family members diagnosed with TBI.

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