

## **Exploration The Needs of Family Caregivers: Preliminary Finding**

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### **ABSTRACT**

#### **Introduction**

Family caregivers play an important role at home during the rehabilitation phase of severe traumatic brain injury survivor. Understand the survivor's needs was the most crucial thing to focus on. The purpose of this study is to explore the needs of family caregivers towards the care of severe traumatic brain injury survivor at home. The qualitative design was used in this study.

#### **Methods**

A grounded theory, research design by Strauss and Corbin (1990, 1998) were used in this study. The study was done at a family caregiver home. A purposive sampling of ten Malaysian family caregivers from the adult intensive care unit was selected. Data were collected using a semi-structured interview guide which has helped the participants in providing their responses. An open, axial and selective coding was conducted to analyse the data. All the qualitative data were analysed by using NVIVO analysis software.

#### **Results**

Two significant themes emerged from the analysis: (a) Support needed by family caregivers, and (b) the information needed. Data shows that family caregivers certainly need support from the various parties and the participants are lack of information on specific care for the severe traumatic brain injury (sTBI) survivors.

#### **Conclusion**

Family caregivers definitely require full support and seek for more useful information to provide a good care to their loved one. Being aware of the family caregiver's needs will enable them to be better prepared and able to provide an improved customized care.

#### **Keywords**

*Traumatic Brain Injury; Family Needs; Rehabilitation; Family Care; Home-Based Care*

## **BACKGROUND**

Traumatic brain injury (TBI) is a global health epidemic that has harmful consequences for individuals with brain injury, their caregivers and society [1]. Attending to the needs of caregivers of critically ill patients is an important and necessary step in providing appropriate care for both the patient and the caregivers [2]. Lack of nursing care knowledge and training cause improper nursing care of the TBI survivors by their relatives at home hence further complication may occur due to secondary bacterial infections [3]. Major responsibility is placed on the shoulders of a family member who assumes the role of a primary caregiver. This consequence retards the patient's sTBI care at home. Therefore, it is important to explore the needs of family caregivers and give any kind of support for them to provide better care to their loved one.

## **METHODS**

### **Participants**

Participants of the study were family caregivers of severe traumatic brain injury survivors. Family caregivers were defined as parent, child, sibling, and spouse. A researcher has identified the targeted family caregivers from patient admission record in the Intensive Care Unit. Family caregivers who fulfilled the inclusion and exclusion criteria were selected by purposive sampling. Family caregivers looking after patients with severe TBI indicated by Glasgow Coma Score (GCS) from 3–9 after finishing sedation were selected in this study. The researcher made an appointment with participants by phone call and if a participant agrees to meet then the researcher gives them the information sheet during the meet.

All 10 individuals' family caregivers with sTBI gave written consent for demographic and basic medical information to be collected from either family caregivers or through the hospital. (Table1: Family Caregiver' socio-demographic information). The brain injury survivors' family caregivers participating in this study had varying relationship. The most common relationship found in the group of participants was a father-child relationship. The percentage of both groups was also similar. The mean age of all 10 participants was forty-five (45) years old. In this study four (40%) of the participants were fathers; two (20%) were mothers, two (20%) were a daughter, one brother (10%), and one sister (10%). As can be concluded from the table, there is an equal number of respondents that are female 5 (50.0%) followed by male 5 (50.0%). Their occupations were divided into three groups that are government sector, private sector (private, technician, labour, self-employed, and salesgirl) and others (housewife and student). Most of the family caregivers were working in the private sector, five (50%), followed by government sector three (30%) and two (20%) other sectors. The highest education level was the university level with five (50%) participants, LCE with three (30%) participants and college two (20%) participants.

### **Table 1. Family Caregiver' socio-demographic information**

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No	Relationship	Family caregiver Age	Occupation/ Sector	Highest education level
1.	Father	53	Technician	College
2.	Father	47	Government	University
3.	Sister	36	Private	University
4.	Brother	34	Student	University
5.	Father	56	self-worker	LCE
6.	Daughter	28	Salesgirl	University
7.	Daughter	45	Government	University
8.	Mother	47	Government	College
9.	Mother	58	Housewife	LCE
10.	Father	54	Labour	LCE

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\*LCE: Low certificate examination

### Data Collection

The participants living close to a relative with sTBI were asked to describe their daily life and how it had changed since the person sustained sTBI by asking them open-ended questions. Further clarifying questions were asked, for example, "How did you feel then?" or "Please, can you give an example?" The interviews focused on the needs that the close relatives had experienced. All 10 individuals' family caregivers with sTBI gave written consent for demographic and basic medical information to be collected from either family caregivers or through the hospital. Upon confirmation that consent was obtained, the researcher arranged for an interview with the participants. Interviews were conducted in person, wherever possible. They were conducted at an agreed upon locations by both the researcher and participants. During each interview, the researcher reminded the participants of the purpose of the study, as well as the option to stop participating at any time. Each participant signed a consent form before each interview began. The interviews lasted for approximately 40 to 60 minutes with semi-structured interviews and audio recorded. At the end of each interview, the researcher went through a debriefing process with each participant to ensure that upon finishing, their emotional stability was as close as possible to what it was at the beginning.

### Data analysis

The grounded theory, analysis by Strauss & Corbin (1990,1998) describes that the theory derived from data, systematically gathered and analysed through the research process. The method of data analysis requires the researcher to find the themes and select themes according to the semi-structured interview guidelines, the objectives were set before an interview to ensure the finding relates to the point of views of participants. All the data were transcribed verbatim and audio-record was listened to at least 3 times shortly after the interview and the researcher reviewed the transcripts to ensure accuracy. Open coding strategy was used to interpret data and after the coding was complete, the researcher identified themes that emerged from the data, sorting them into meaningful patterns. All the authors known as supervisory committee subsequently evaluated every interview, providing

the opportunity to make improvements in the interviews and the interpretation at an early stage. A copy of the transcript and a summary of the preliminary findings were sent to the participating family caregivers.

## RESULTS

Overall, two significant themes emerged in the analysis, which we will briefly outline here and describe in greater detail later. The thematic analysis identified the following areas: (1) support needs of family caregivers (2) information needs. During the classification of the respondents' statements into different categories within thematic areas, it was observed that some categories were interrelated. During this study, participants were asked questions which facilitated the exploration of the common needs of care during the recovery process.

### Theme 1: Support needed by family caregivers

**Family involvement** in caring the sTBI survivors. Three participants had been discussing the importance of family involvement during the rehabilitation phase. Support from family and relatives are often raising from the interview data. The codes as a sacrifice, respectfulness, teamwork, and trust were showed in the following quotations:

*"My wife and I are together on caretaking. The teamwork is a big, big part of it, although he related it to his son's recovery and not his own well-being"*

*(participant no.1)*

*"My mom and relatives are my supporters, always increase my spirit to look after my younger sister" (participant no.3)*

*"I have to take leave without pay and I looked after my brother every day" (participant no.7)*

**Need for Spiritual** in the care-giving roles were discussed and they are mention almost about prayer:

*"We ask for help in reciting a prayer to our son for each time visitor come to visit our son" (Participant no.3)*

*"...All the way to the hospital, I always pray that my sister will be in good condition, Even though I know that she not stable" (Participant no.4)*

*"I hope that good thing will happen to him. We always hope that he will return to his normal condition by reciting a Prayer at home and mosque" (Participant no.9)*

**Psychological support needs focus on positive thinking and distraction.** The family caregivers are always willing to take care of patients and show their strength in care during the rehabilitation phase, even though their emotions are instable.

*"I was under stress but I still want to give the best care for him" (participant no.8)*

*"She always thinks her son becoming poor. She cries all the time. I advised her to 'isthifar' and remember Allah" (participant no.5)*

*"I'm afraid to look at his condition, but I need to show that I'm strong in taking care of him, I try my best to avoid crying in front of him"(participant no.2)*

**Emotional with bad and good feelings.** Family caregivers express their feeling as bad feeling including anxiety and losing hope towards care after bringing the severe traumatic brain injury survivors home. The following quotations are from three participants:

*"Sometimes I am worried, how she will cope if her son was left disabled because she would be his main caretaker"(participant no.10)*

*"Although she supported everyone else and did not show her feeling, she also had sleepless nights worrying about her dad's condition" (participant no.7)*

*"I thought my sister has no hope, because my friends say, if operation were done to the head, it can be a problem, this situation makes me scared and thinking that her condition will last forever. I only continue to pray that the situation will improve" (participant no.3)*

The good feeling was also identified from family caregivers after sTBI survivors' conditions stabilized, showed by symptom improvement and responding to a command.

*"I felt calm when doctor inform about my father condition become better and show good response" (participant no.6)*

*"I feel so good when I saw his response to my call" (participant no.5)*

**Social concerns** are one of the important functions of social relationships. The participants discussed the needs in social concern in the form of regulating their situation at home and their future provisions. The values of the neighborhood were highlighted as social concerns among family caregivers, feeling good to have the sporting and understanding neighbors as following quotations:

*"I am lucky to have neighbors who come to visit and help, we stay nearer and always meet each other" (participant no.4)*

*"Sometimes I am worried of what relative or friends thought of my son, which could cause feelings of guilt and shame" (participant no.9)*

## **Theme 2: information needs about care**

The caregiver families were seeking the information on the exact problems of the patient, they felt uncertain about care for their patients at home and discussed seeing the healthcare provider when necessary.

*"I was thinking, how long my son will be breathing through that tube (Tracheostomy tube)?" (Participant no.2)*

*"I'm afraid I'll make the situation worse because I do not have the experience of caring a person wounded in the head and with the tube at nose" (Participant no.6)*

They also discussed how to look after the survivors at home and to access to someone or the companies providing medical equipment.

*"When the doctor told me to bring my sister back, I asked him (doctor), where can I get any information on caring my sister at home? It's not easy to take care of her because this is a first time for me, no medical device at home" (Participant no.3)*

*"I was looking for a company selling hospital equipment and ask my colleagues if they know any place that can I refer to" (participant no.4)*

Gaining more knowledge and understanding of the perceived burden of primary caregivers would lead to providing more specific and direct support [4].

## **DISCUSSION**

In this preliminary finding, the result of the interviews focuses on the family caregivers needs during the rehabilitation phase. The shared experiences from a family caregiver of patients ranging from acute phases to rehabilitation phase has provided useful information for researchers regarding the nursing process when taking care of sTBI survivors. The most important part was discussed and concluded the importance to know what kind of support are needed and all the information needed by the family caregivers.

The finding also suggests that family caregivers have similar perspectives that family caregivers needs a strong support. Their needs are highest when preparing to bring sTBI survivors back to home and the first few months at home after that. This finding is supported by a previous study [5] stated that sustaining a Traumatic Brain Injury resulted in families strain due to the significant impact from the injury due to the role and function of individuals and their families at home and in the community. The well-being of the caregiver and families affect their ability and willingness to care for the injured person [6]. Support needed for the social work practitioner includes a greater emphasis on thoroughly assessing the survivor's family function with special attention to gender, family role definitions, the family's ability to appropriately and emotionally respond to each other, and the family's ability to proactively solve family problems [7]. Therefore, in addition to providing patient care, family caregivers must also play their role in family support, through providing information and allowing to be near to the patients [8]. Other important needs on family caregiver were feeling stress and strain were included in emotional support needed by family caregivers who are taking long-term care of sTBI survivors. Caregivers and families play an important, all-encompassing role, in the rehabilitation process of individuals with TBI. This role is often accompanied by an overwhelming sense of stress that is experienced by the individual with TBI and their entire family [9].

In a study [9], it was reported that, the families are struggle to manage the behaviour of TBI-patients that may become a primary determinant of family burden. Inadequate preparation of caregivers and patients to deal with the subsequent personality and behavioural changes is a major complaint. Family members may lack the skills to manage, cope, and provide care in TBI rehabilitation [10]. In our study, family caregivers are faced with difficulty to communicate with survivors and miscommunication always occur during recovery time. This situation affecting the daily care and family caregivers were feeling unsatisfied with care has been given. The published literature about social concern are always focused on community and environment support [11]. The role of peer, relative and neighbour were important in building social support among the caretaker. Family caregivers expressed a major support needed regarding help in social concern. This highlight is importance for deeper integration of social support in the community. Due to this uncertainty, families often exhibit intensive needs for information, emotional support and involvement in care, as they are struggle to

adapt to the changes in their life [12]. The close relatives felt that they themselves were lonelier than they had been before the accident, mainly because now they focus on the person with TBI. If close relatives can receive support in their new situation, they will be able to empower the person with TBI to manage their altered daily life [13]. Current research relative to health outcomes recognizes that positive consumer perceptions of services may be more important than current enacted services. For example, [14] found that perceived support was more beneficial for consumers following TBI than enacted support, where enacted support referred to the actual helping behaviours and perceived social support referred to an individual's cognitive appraisal of his/her social connections. In this research, it was found that the social concerns shown as a key role for family caregivers to adapt the situation to care for their sTBI at home, without the social support the family caregivers feel that they are not a part of the community.

Lack of information provided throughout the continuum is one of the most frequently cited problems in studies reflecting the experiences of carers [14]. There is no standard information on taking care of patients with sTBI and family caregivers, and based on this finding, the healthcare provider needs to provide the information regarding the care of sTBI survivor at the acute and rehabilitation phase. It should further encourage healthcare professionals in helping family caregivers to prepare themselves for the care of their loved one. Thus, family caregivers must also play their roles in upgrading the knowledge on care, through seeking information and allowing patients to be nearer to the patients during the acute phase [15].

## **CONCLUSIONS**

The findings of this study reflect the importance of exploring the general needs of family caregivers for severe traumatic brain injury survivors. Family caregivers may need a full support during the rehabilitation phase and the family members need to help and support these caregivers in solving daily problems faced when dealing with sTBI survivors [16]. Moreover, during a rehabilitation phase, family caregivers are responsible to fulfil additional role of unconscious survivors.

Family caregivers of sTBI survivors have unique needs because sTBI is always a sudden event [17]. The results of this study can be used as a guidance to the healthcare provider in supporting sTBI survivors' family caregivers better, and in this study, family caregivers shared several unfulfilled needs from all dimensions of support. Future studies are needed to reveal the continuing consequences of severe traumatic brain injury and if such consequences exist hence there are needs that can be prevented by support programmes.

## **Declarations**

### **Authors' contributions**

All the authors are responsible for the content and writing of the paper

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### **Ethics approval and consent to participate**

Ethics approval was obtained from the Kulliyah of Nursing (KON) committee, approval of university ethic committee (IREC), International Islamic University Malaysia (IIUM) and approval from Medical ethic through NMRR from Ministry Health of Malaysia.

### **Consent for publication**

“Not applicable”

### **Availability of data and materials**

The data will not be shared, except the demographic data for preliminary study. The authors will still be using the data to obtain full results.

### **Competing interests**

The authors have declared that no competing interests exist.

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\*LCE: Low certificate examination