

A Study on Lived Changes Experiences Among Traumatic Brain Injury (TBI) Survivors in Malaysia

NOR'AIN ABDUL RASHID¹, LEE KHUAN^{1*}, ANISAH BAHAROM², MOHD MURSYID ARSHAD³

¹ Department of Nursing, Faculty of Medicine and Health Sciences, Universiti Putra Malaysia, Malaysia

² Department of Community Health, Faculty of Medicine and Health Sciences, Universiti Putra Malaysia, Malaysia

³ Department of Professional Development and Continuing Education, Faculty of Education Studies, Universiti Putra Malaysia, Malaysia

*Corresponding Author: leekhuan@upm.edu.my

ABSTRACT

Traumatic brain injury (TBI) imparts a long-term effect on their survivors. This includes lived changes for the survivors. TBI survivors often have a long-term recovery process that might be influenced by internal and external problems. In order to assist and improve the care of the TBI survivors throughout their recovery period, understanding their 'lived changes' experiences is an important aspect that health care providers and family members need to acquire. The purpose of this study is to understand the 'lived changes' experienced by post-TBI survivors. A hermeneutic phenomenology approach was applied in this study. The recruitment of the participants was done at one rehabilitation hospital in Malaysia from January until August 2021. Ethical approval was given by higher authorities (Medical research committee and hospital) and participants prior started the study. A total of twenty (20) participants were involved in this study of which fourteen (14) were TBI survivors and six (6) were relatives of the survivors. All the interview sessions were held at the hospital and each interview session lasted between 30 to 40 minutes. The data collection was done using semi-structured interviews with both TBI survivors and their relatives. Other data collection method such as field notes, reflective journal, and completion storytelling technique was also used. The data collected using these collection methods were triangulated to obtain rich and thick data. Thematic analysis was applied in the data analysis process using NVivo software Release 1.0. There were two main themes for 'lived changes' experiences as described by the participants; direct and indirect changes. Direct changes were defined as the lived changes directly undergone by the survivors after the injury and could be identified by others such as physical changes, cognitive changes, behavioural changes, post-injury trauma, and fatigue. Indirect changes were defined as the lived changes experienced by the survivors that people could not see directly, although these changes affected the survivor in terms of emotions, stigma, role changes, and financial difficulty. Understanding their 'lived changes' experiences can help the health care provider to be of better assistance and contribute to improved care of TBI survivors. The health care providers can implement patient-centred care by providing the information needed by the survivors and guiding the survivors and those who will be providing post-operation care, on more effective coping practices against those changes for the short-term and long-term period.

Keywords: Traumatic Brain Injury, Lived Changes, Experience, Phenomenology