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The impact of brain injury on the perceived quality of life of adult survivors of brain injury and caregivers (post-injury): the South African context

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2021
https://hdl.handle.net/10539/33807

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ABSTRACT

Brain injury may result in altered pattern of ability and changes in personality. These changes may impact intimate relationships, friendships, social networks, recreational and vocational activities making it difficult for survivors of brain injury to adjust to post-injury life. The purpose of the study was to investigate the perceived quality of life of adult survivors of brain injury as well as the experiences and challenges faced by their primary caregivers. The study also aimed to gain insight into some lifestyle/role changes that may have occurred for adult brain injury survivors post-injury. The study was conducted under the auspice of Headway. A sample size of 11 adult survivors of brain injury and 7 primary caregivers from different races and gender voluntarily participated in the study. The COVID-19 spread prevention recommendations were exercised with regards to ethical considerations and the study was conducted telephonically i.e. normal phone calls, WhatsApp, and email. The Demographic Background Information Questionnaire and the PQoL scale was utilised to collect data from adult survivors of brain injury and the CRS scale to collect data from caregivers. This research uses a mixed-method approach with a convergent parallel design. Both qualitative and quantitative methods were used to conduct the research and compared the results of each analysis to the other i.e. descriptive analysis, thematic analysis, and content analysis. The SPSS software was used to run descriptive statistics as well as inferential analyses. The results show that most adult brain injury survivors are not satisfied with most aspects in the domains of their perceived quality of life i.e. physical, social, and cognitive functioning. Caregivers indicated to have challenges/difficulties related mostly to relational deprivation, and family beliefs and conflict, however, they also are extremely confident with their competence in their roles as caregivers and have indicated that this journey has increasingly and positively impacted their personal gain. Family finances also showed to have decreased post-injury, however, most caregivers have indicated that finances still work out in the end. The level of satisfaction survivors of brain injury have on their perceived quality of life showed to justify/match with the experiences and challenges/difficulties experienced by their caregivers. It is a general aim of this study is to contribute to the knowledge base of South African research into the phenomenon of brain injury.

Keywords: Brain Injury, Traumatic Brain Injury, Acute Brain Injury, Perceived Quality of Life, Survivors of Brain Injury, Caregivers.