

Psychosocial Quality of Life after Traumatic Brain Injury among Children in Uganda

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Abstract

Background: Traumatic Brain Injury (TBI) is a leading cause of sudden death and disability amongst young people. About 28% of children managed for TBI in Uganda report some degree of physical disability one year post-injury, but little is known about their psychosocial outcomes. We aimed to elucidate the psychosocial outcomes of children with TBI, and associated factors.

Methods: A cross-sectional study carried out in the Neurosurgical Unit of Mulago National Referral Hospital (MNRH), Uganda. The Pediatric Quality of Life Inventory version 4.0 parent proxy was administered to parents/guardians of children aged 6 to 17 years who were previously managed for TBI in MNRH more than a year post-injury; their medical records were also retrieved. Linear regression was used to determine factors associated with psychosocial outcomes.

Results: A total of 116 children were recruited. The overall mean psychosocial functioning was 82 ± 22.74 . Using a standard deviation below the mean score as a cut-off standard, 85.7% of those children had good psychosocial functioning versus 14.3% with poor functioning. A long time of more than 2 years post-TBI (adjusted $\beta=1.36$, $p=0.012$) and absence of associated injuries (adjusted $\beta=0.30$, $p=0.025$) were associated with good psychosocial functioning, while TBI severity was negatively associated with poor psychosocial functioning (adjusted $\beta=-0.36$, $p=0.041$).

Conclusion: Children managed for TBI continue to have psychosocial dysfunctioning after one year following injury, although improving after 2 years. The severity of TBI and the presence of associated injuries are important determinants of the psychosocial quality of life of children. Multi-disciplinary supportive care should be very effective during the first 2 years following the injury to improve the quality of life of children with TBI.

Keywords: Pediatric traumatic brain injury • Psychosocial outcomes • PedsQL • Brain injury

Introduction

Each year, more than 10 million people sustain Traumatic Brain Injury (TBI). TBI is one of the leading causes of sudden death among young people worldwide [1]. According to the World Health Organization (WHO), TBI is also the leading cause of brain disorder and disability, as well as impairment of the physical, cognitive, emotional and social domains [1,2].

Deficits in psychosocial outcomes following TBI are manifest as problems in behavioral and social skills (e.g. aggression, anxiety, depression, inappropriate social integration), as well as impairments in communication, adaptive and school functioning [3,4]. These deficits are more marked in the first year post injury, and tend to improve over time especially in mild to moderate TBI [5,6]. One study reported improvement of the psychosocial functioning 12 months from injury in children managed for mild TBI [7].

Preliminary studies in Uganda have shown that at 1 year post-injury 65% of TBI children had returned to baseline performance, and most children had a good social functioning at 1 year post-injury, and about 28% of those children report some degree of physical disability [8]. However, there are limited studies done to assess the overall psychosocial outcomes in children with TBI long after the injury. To provide insight into for continuous rehabilitative needs for improving the quality of life of children with TBI, this study aimed to elucidate the psychosocial outcomes and associated factors

among children managed for TBI in Mulago National Referral Hospital (MNRH), Kampala, Uganda.

Methods

This was a cross-sectional study carried out in MNRH, a sub-Saharan urban hospital located in Kampala, the capital city of Uganda. It is the country's largest public hospital with a 1500 bed capacity and serving as the main referral trauma center of the country. Our study population comprised of children aged 6 to 17 years at the time of recruitment, and previously managed for TBI in MNRH from January 2017 to December 2018. Children with a known history of neuropsychiatric disorders prior to injury were excluded. Consecutive sampling was used until the targeted sample size was reached. The study's primary predictive variables were nature of the injury, age at injury, severity of TBI, time post-injury (taken as 1-2 years or >2 years post-injury) and presence of associated injuries (musculoskeletal, chest, abdominal trauma, etc...). The study's outcome variable was psychosocial functioning at 1-2 years or >2 years post-injury. To assess the psychosocial outcomes of TBI in the children, their parents/guardians were invited back to the Neurosurgery clinic, and the Pediatric Quality of Life Inventory version 4.0 (PedsQL) questionnaire (parent proxy version) was administered to them. For the parents/guardians unable to return to the clinic, the questionnaire was administered over a phone call. Data regarding severity of TBI (admitting Glasgow coma scale), associated injuries, and type of treatment offered were obtained by reviewing the children's hospital records.

The PedsQL version 4.0 questionnaire consists of four generic core scales namely, physical functioning, social functioning, emotional functioning, and school functioning. Two summary scores namely, Physical Health summary score and Psychosocial Health summary score can be computed from the PedsQL as well as the total score. The Psychosocial summary score is the mean score on emotional, social, and school functioning scales. A 5 point response scale was used to score the children's functioning in each domain over the past one month (0=never, 1=almost never, 2=sometimes, 3=often, 4=almost always) Items were then reverse-scored and linearly

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transformed to a 0 to 100 scale (0=100, 1=75, 2=50, 3=25, 4=0). Mean scores were computed as the sum of the scores divided by the number of items. The higher the overall score, the higher the psychosocial functioning of the patient.

Data were analyzed in STATA version 14.0. Continuous variables were summarized using means, standard deviations, and medians. Categorical variables were summarized into proportions and percentages. Paired t-test and Wilcoxon rank sum tests were used to compare means of the PedsQL domains. Spearman's correlation coefficient was used to relate physical functioning with the overall psychosocial outcome. Linear regression was used to determine factors associated with psychosocial outcomes. Independent variables that were significant in bivariate analysis with $p \leq 0.2$ were considered for multivariate analysis. In multivariate analysis, stepwise backward method was used to identify significant independent variables at $p < 0.05$. Crude β coefficients and adjusted β coefficients, plus their corresponding 95% confidence intervals (CI) were reported for factors that were significantly associated with psychosocial outcome.

Ethical approval was obtained from the School of Medicine Research Ethics Committee (SOMREC) of Makerere University. Informed consent was obtained from the legal parents/guardians who accepted to be physically present, and a detailed phone call consenting process was observed for those who were unable to come.

Results

Patient demographics and disease characteristics

A total of 239 children were admitted to the Neurosurgery ward for TBI between January 2017 to December 2018. Only 209 children had a retrievable phone number in their files. Of these, only 118 children were in service, and two children out of the 118 children had died following their discharge from hospital. Therefore, a total of 116 children were included in our study (Figure 1). The male-female ratio was 2.5, and the mean age was 9.3 ± 4 years. Road traffic crashes (RTC) accounted for most of the injuries (60.3%), and the majority of the children were admitted with the diagnosis of mild TBI.

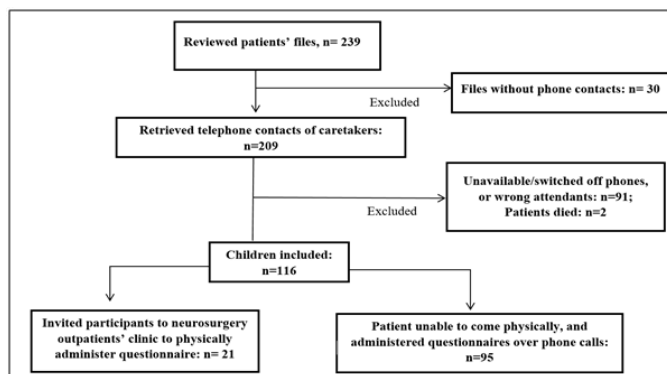


Figure 1. Patients flow chart for study recruitment.

PedsQL domain score characteristics

Children that sustained severe TBI generally reported lower mean scores across all domains of PedsQL in comparison to mild and moderate TBI, but significantly reported lower mean school functioning scores ($p=0.04$). Children that sustained an injury for more than 2 years ago reported better mean social functioning compared to those that had sustained the injury for 1-2 years ago ($p=0.03$). Children that were currently attending school reported higher mean scores across all domains of PedsQL in comparison to those not attending school.

Psychosocial functioning outcomes

Overall, the mean emotional functioning was 79.22 ± 27.34 , mean social functioning was 94 ± 23.75 , and mean school functioning was 79 ± 26.64 . About 18.1% reported poor school functioning by parents with forgetfulness being the most complaint. The overall mean psychosocial functioning score of our study population was 82 ± 22.74 as illustrated in Figure 2. Using one SD below the mean score as the cut-off standard for at risk status for poor psychosocial functioning, 14.3% of the children were found to have a poor psychosocial function. Among them, 8.6% had mild psychosocial dysfunctioning (considered as one SD below the mean), while 5.7% had severe psychosocial dysfunctioning (considered as two SD below the mean). Therefore, 85.7% of children had good psychosocial functioning. A strong correlation was found between physical and psychosocial functioning of children with a history of TBI ($\rho=0.45$) at $p \leq 0.001$.

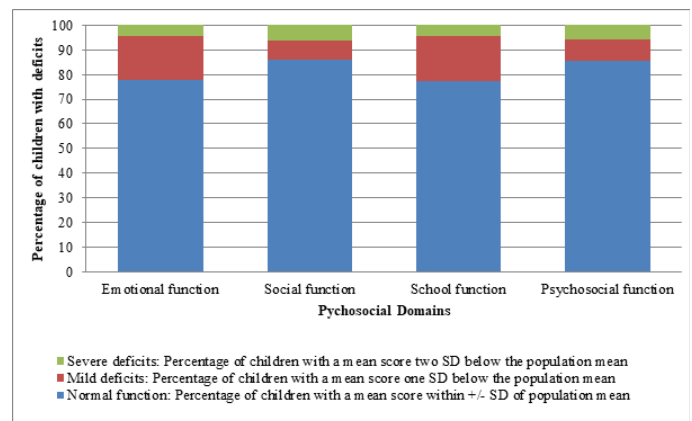


Figure 2. Mean PedsQL scores of children managed for TBI

Factors associated with psychosocial functioning outcomes

From the bivariate analysis, time post-injury, the severity of TBI, associated injuries, home settlement, current school status were considered significant for multivariate analysis at $p \leq 0.2$. At the multivariate analysis, only time post-injury, severity of TBI, and history of associated injury were found to be significantly associated with the psychosocial outcome of children managed for TBI at MNRH. We found that long time of more than two years post-TBI was positively associated with the psychosocial functioning (adjusted $\beta=1.36$ CI [0.22, 1.70], $p=0.012$), moderate TBI was negatively associated with psychosocial functioning (adjusted $\beta=-0.36$, CI [-1.71, 0.03], $p=0.041$), and absence of associated injuries was positively associated with psychosocial outcome (adjusted $\beta=0.30$, CI [0.07, 0.75], $p=0.025$).

Regarding the caretakers characteristics, the marital status, education and employment status of caretaker were found to be significant associated with the psychosocial outcomes of children with TBI from bivariate analysis, but not at the multivariate analysis.

Discussion

Our study demonstrated that indeed children managed for TBI in MNRH do experience psychosocial deficits when assessed 1-2 years after injury. The findings are in concert with many previous studies carried out in different settings that report continued deficits in various domains of quality of life long after TBI (4, 6, 10, 11) The overall psychosocial functioning in our study was good with a mean score of 82, with only 14.3% of children being at risk status for a poor psychosocial outcome.

Of the different domains of psychosocial functioning, we found that social functioning was the most favorable outcome in our children. This compared closely with a previous study done earlier by Vaca et al. in Mulago Hospital, who found that 91% of pediatric TBI patients reported being friendly at 1 year

post-injury. We postulate that the good social outcome may be explained by the strong family and society ties that are still present in African settings. Besides, the parenting style practices in the Ugandan setting may foster recovery and adaptive functioning following TBI. Studies have demonstrated that authoritative parenting facilitates functional recovery following TBI compared to permissive parenting.

Our study also established that TBI greatly affected the school functioning of children with about 15.5% of the children in this study population being unable to resume school following the TBI. About 18.1% of our study population reported poor school functioning with forgetfulness being the most cited complaint by parents. Previous studies have also demonstrated that TBI impacts negatively on the school performance of children. Anderson et al. noted a decline in general intellectual functioning following TBI in children, up to 5 and 10 years post-injury. In South Africa, Dollman et al. examined the academic performance of children following TBI and found that there was a threefold increase in the use of educational services following TBI. Unfortunately, we did not assess the pre-injury school performance of children in our study, and hence our results were only based on the opinion of parents of their children at the time of the interviews. Our study found three factors that significantly affected the psychosocial outcomes of children following TBI. They included length of time post-injury, the severity of TBI, and the presence of associated injuries.

We found that children that had sustained TBI 2 years ago were more likely to have a favorable outcome compared to those who had sustained injury only 1 year ago. Our study, therefore, shows that recovery of psychosocial functioning following TBI continues even after 1 year post-injury. While most studies, like ours, show a trend towards improvement of psychosocial domains with time, a few show conflicting trends. Stocchetti et al. noted that a significant proportion of patients will show significant and continuous improvement in functional outcome during the first 6 months after injury, and then stabilizing thereafter. However, evidence is accumulating that outcomes continue to change over long periods post-injury. A meta-analysis by Babikian et al. examined the impact of time post-injury on functional outcomes in children following TBI. They noted about 0-5 months post-injury represent a post-acute period, where greatest functional impairments are observed; 6-23 months post-injury represent the time of maximum recovery, and 24 and more months post-injury represent a time of minimal change of the established outcome. Furthermore, the severe injury was noted to have the least recovery, and moderate TBI had the greatest recovery of functional outcomes (22). These findings support the notion that adaptive outcomes continue to improve over time post-injury.

Our study also established the impact of severity of injury on the long term outcomes following TBI. We noted that patients with moderate and severe TBI were more likely to suffer from psychosocial deficits long after the injury. The negative effects of more severe forms of TBI have been exhaustively documented by other authors. Babikian et al. in their meta-analysis reported that psychosocial functioning in children with severe TBI continued to deviate so greatly from an uninjured control at more than 2 years post-injury.

Notably, severe injury in children is associated with poorer physical, social, psychological, and academic outcomes as compared to mild TBI. Dollman et al. reported that more than two-thirds of South African children managed for severe TBI reported significant academic deficits requiring special needs education services. Even if our study didn't assess the use of special educational services post TBI, we established that the impact of severity of injury on school functioning of children was significant. Age at injury is another important factor that has been cited by various authors to contribute significantly to long term psychosocial outcomes following TBI in children. Younger age at injury, especially below 5 years, has been reported to be associated with poorer long term psychosocial outcomes. It is postulated that disruption of a rapidly developing brain at an early age leads to an arrest in the development and attainment of new knowledge and skill.

However, despite the above postulations, our study did not find age at the injury to be significantly associated with long-term psychosocial outcomes. The lack of association between age at injury and long term outcomes may be explained by the fact that our study did not include children below 4 years of age at the time of injury. We found that children that had sustained associated injuries had poorer psychosocial outcomes in comparison to those with no associated injury. Children with associated injuries also reported poorer physical outcomes in comparison to their counterparts without associated injuries. Patients that have multiple injuries are at a higher risk of physical deficits in comparison to those with a single injury; this has been reported to be associated with worse long term physical and psychological outcomes. There was a strong correlation between physical functioning and psychosocial outcome of children with TBI ($\rho=0.45$) at $p \leq 0.001$.

Indeed, we acknowledge that the consecutive sampling method used in our study did not provide an adequate proportion of children with severe TBI, probably due to the associated higher rate of mortality. Our study setting receives patients from all over the country especially during the acute phase management of TBI, and some of the potential participants might have been lost to follow-up if they stay far from the capital city, or they did not have a working phone number to be called. It is likely that these results therefore do not give a true representation of outcomes in children with TBI, especially the severe TBI pattern. However, it might have adequately covered a good representation for mild and moderate TBI pediatric patients.

Conclusion

Children managed for TBI continue to have psychosocial dysfunctioning after one year following injury, although this tends to get improved after 2 years. The severity of TBI and the presence of associated injuries are important determinants of the psychosocial quality of life of children. Multi-disciplinary supportive care such as psychotherapy, behavioral therapy, and rehabilitative services should be very effective during the first 2 years following TBI to improve the quality of life of the affected children. Further studies with a qualitative approach could elucidate other associated factors.

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Conflicts of Interest

All authors have declared no conflict of interest.

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