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STUDENTS' CORNER

Assessing the Need for Support in Post-Concussion Patients and Their Families

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Abstract

Background: The purpose of this paper is to outline my experiences investigating the need for additional support among post-concussion patients and their families. A growing volume of research has continued to demonstrate the significant health consequences of concussions on youth and adolescents, with studies emphasizing the need for increased support during the post-concussion recovery period. It was proposed that one way to provide this support may be through family-based peer support. **Results:** In this study, I interviewed 25 families with a child who had experienced a concussion in the past two years and received care from BCCH. The findings showed that individuals from this sample typically reported that they did not need additional support. While additional support was not indicated for this sample, it is important to note that all participants reported their concussion symptoms had resolved within a month. **Conclusions:** Results may have differed in a population with longer-lasting or more severe concussion symptoms. Additionally, this paper outlines my experience with conducting research during a global pandemic, additional findings regarding education surrounding concussions, and suggestions for future research.

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Introduction

In recent years, a growing volume of research has demonstrated the significant health consequences of concussions on youth and adolescents (Carman et al., 2015; Pfister et al., 2016; Tator, 2013; Turner, Lucas, Margolis, & Corwell, 2017). Given the increase in concussion awareness and subsequent diagnoses in North America, there is a need for widespread advancements in concussion treatment protocols and resources (Hickling et al., 2020). The impact of a concussion often goes beyond just the individual themselves, as the recovery and management from this injury can be emotionally tolling on the family (Graves et al., 2020). Numerous studies have emphasized the need for increased support during the post-concussion recovery period (Hibbard et al., 2002a; Minney, Roberts, Mathias, Raftos, & Kochar, 2019). Consequently, is it essential that there are appropriate services in place to support both the individual who suffered the concussion, as well as those supporting their recovery (Hibbard et al., 2002a; Minney et al., 2019). Recently, researchers have demonstrated the immense value peer support programs can have for families who face a wide array of medical challenges, including recovery from mild traumatic brain injury (mTBI) (Haines et al., 2018; Hibbard et al., 2002a; Minney et al., 2019).

Peer support systems are emotional and practical networks based on the principle of giving and receiving non-professional, non-clinical help from individuals who have shared a related experience (Ainbinder et al., 1998). Many forms of peer support have been found to be crucial in mediating healing through fostering understanding and support from individuals in a similar situation (Haines et al., 2018).

I began my research on family peer support programs in 2018 when I completed a study (unpublished) assessing whether family-to-family support would be a feasible option for families facing a recent neurosurgical diagnosis in the BC Children's Hospital (BCCH) Neurosurgery Department. This topic has personal meaning to me, as I grew up watching my sister undergo 14 brain surgeries for complications related to hydrocephalus. I know from my experience how important it is to have appropriate supports and how beneficial talking to someone who has been through a similar challenge can be. The results from this project indicated a clear need for enhanced support within the neurosurgical population; thus, I founded a family-to-family support group which created connections between those undergoing similar treatments or procedures. This previous research provided the foundation for the current study, in which I aimed to understand whether similar supports would be needed for pediatric patients recovering from a concussion.

Project Overview

This qualitative study used semi-structured interviews that I conducted with parents/children over the phone. The sample included 25 families with children under 18 years of age, who had experienced a concussion in the past two years and received care from BCCH. The interview outline was constructed based on the interview guide from my work in the Neurosurgery Department, and included 14 open-ended questions to explore the families' experience as their child recovered from a concussion. In each interview, patient families were asked about the support and resources they received in the hospital, if they had felt adequately supported throughout the child's concussion (both through the hospital and in their personal lives), and what type of support they would have preferred, if they expressed the need for additional support. Patient families were offered examples of different types of support including support from other parents, medical professionals, support in a group setting, and online groups. Examples of group and online support include support groups led by a trained professional or less formal groups made up of peers who had previously undergone a similar situation.

Participants were recruited via convenience sampling using a database of patients who had previously consented to be contacted by researchers, which was provided by the Canadian Hospital Injury Reporting and Prevention Program (CHIRPP). The CHIRPP is a surveillance system that gathers information and data on individuals presenting with injuries who are seen in emergency rooms in hospitals (11 pediatric and 9 general) around Canada (Government of Canada, 2023). Verbal consent was obtained from both the caregiver and child prior to interviews. The interviews were conducted with a total of 21 parents and 4 children.

Experiences With Interviews

Participant recruitment for this project was challenging, as this research was conducted during the COVID-19 pandemic lockdown period. Consequently, families often did not answer the calls, had forgotten that they consented to be contacted for research, or were confused about why they were getting a call about their child. Furthermore, due to patient confidentiality protocols and the nature of the recruitment framework, I did not know anything about the patient's situation prior to calling them, making it difficult to determine if patients would fit the inclusion or exclusion criteria prior to the phone call. For example, as I did not have access to patient files, I did not know how the patient sustained the concussion, how long after the concussion the patient visited the emergency room, or if the patient had any lasting symptoms from the concussion. Multiple families reported that they would have participated in the research but did not feel their participation would have been impactful, as their child either had not experienced any residual concussion symptoms or experienced a very minor concussion and recovered uneventfully without complications. If additional studies wish to explore this topic further, it may be useful to employ inclusion/exclusion criteria such as a minimum length of recovery and include more information to the researcher on the patient's concussion history and recovery prior to conducting interviews. Lastly, multiple families reported not remembering much about the concussion as it had happened more than a year prior. In the future, it may be beneficial to approach families sooner after the initial injury to ensure they can recall details of their hospital visit and the subsequent recovery.

While initial recruitment was difficult, participants were eager to participate once they understood the aim of the study. Results from this study suggest that individuals from a pediatric population treated at BCCH generally feel that they received adequate support from the medical staff and their personal support networks after being diagnosed with a concussion. Only one participant (4%) felt they needed additional support throughout their child's recovery, whether from medical resources, family members, or some type of peer support. This parent participant reported that their child experienced long-term post-concussion symptoms following their concussion. The majority of participants (n = 24, 96%) reported that they were satisfied with the support they received, both from their physician and in their personal lives.

Unlike my prior research, in which we investigated the support needs of neurosurgical patients who reported needing more tangible support with activities of daily living, participants in this population felt well-supported in managing at-home recovery post-concussion. Participants reported that if they required additional support, they would have preferred medical advice from physicians or nurses (n = 13, 52%). Only three participants (12%) reported that if they had needed more support, they believed that some type of peer support would have been beneficial. Notably, 13 participants (52%) did report that they talked to someone else in their life who had gone through a similar experience, suggesting they had used a form of informal peer support.

While peer support was not indicated in this population, it is important to note that only four interviews (16%) were conducted with the patient themselves. Interviews were primarily conducted with the mother of the child (*n* = 14, 56%). The support needs of the child may have differed from the experience of their parents, and researchers may wish to explore this further in the future. Secondly, the population interviewed includes a relatively homogenous sample of patients who reported suffering only minor concussions with fast and uncomplicated recoveries. Most patients (*n* = 15, 60%) reported their concussion symptoms were resolved in under a month, and thus it was unsurprising that they did not report an extensive need for support. The need for additional support may have differed in a group of patients who suffered persistent symptoms beyond 30 days. Many participants (*n* = 13, 52%) in this study sustained a concussion between the ages of 11-15 years. Recent research has suggested there may be a link between age and recovery time from concussion, indicating future research may wish to explore the support needs of children throughout different stages of development (Ledoux et al., 2019). Lastly, the results from this research demonstrate that most participants (*n* = 11, 44%) reported their concussion was due to a sports-related injury. Future research should aim to investigate the need for post-concussion support and education among youth athletes.

Additional Findings

Results from the interviews indicated that thorough, evidence-based concussion education may be beneficial for parents of young children. Only five (20%) parents reported having a comprehensive understanding of concussions at the time of their child's injury. This is particularly significant as every participant reported someone in the household had completed at least a diploma or undergraduate degree, indicating a highly educated sample. Additionally, multiple participants voiced concerns that their child did not receive any definitive testing, such as imaging, to diagnose their child's concussion; however, imaging is typically not needed for a mTBI (Guenette et al., 2018). Increasing concussion education and awareness may help families understand what concussion assessment, treatment, and management typically entail. An example of a tool families could be pointed towards in the future is the Concussion Awareness Training Tool (CATT; https://cattonline.com/). The CATT provides online eLearning modules and educational resources for various audiences including parents or caregivers, medical professionals, youth, athletes, and multiple other populations (Babul & Turcotte, 2015). Ensuring parents and caregivers have the right tools can better prepare them to assist their child through concussion recovery.

Conclusions

Moving Forward

While the results of this study did not indicate a need for enhanced peer support within a population of pediatric post-concussion patients, the study provided insight into opportunities and suggestions for future research and highlighted the need for enhanced education for caregivers of a child with a concussion. Central recommendations for additional research include assessing the need for family and peer support networks in populations with individuals who have post-persistent symptoms from their concussion beyond the expected course of recovery, as well as for patients who were treated in other hospitals. Additionally, given that this research was conducted at a large, urban hospital, it may be of interest to compare these findings to support the needs of families in rural/remote settings. It is well established that individuals in rural/remote areas have limited access to healthcare resources, and thus often face poorer health outcomes than individuals in urban settings (Wilson et al., 2009). Furthermore, potential initiatives may wish to interview both the parent/caregiver and the child who experienced the concussion themselves. Interviewing the child and caregiver will allow researchers to gain a more comprehensive understanding of the recovery experience and support needs from the viewpoint of the individual who suffered the concussion, as well as family members involved in the recovery. Lastly, this study suggested that enhanced education and tools may help to relieve some of the anxiety faced by caregivers of children recovering from a concussion.

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Authors' Qualifications

The authors' qualifications are as follows: Kheya McGill BKin; Shazya Karmali PhD; Shelina Babul, PhD.

References

Ainbinder, J. G., Blanchard, L. W., Singer, G. H., Sullivan, M. E., Powers, L. K., Marquis, J. G., & Santelli, B. (1998). A qualitative study of parent to parent support for parents of children with special needs. Consortium to evaluate parent to parent. *Journal of Pediatric Psychology*, *23*(2), 99–109. doi:10.1093/jpepsy/23.2.99

Babul, S., & Turcotte, K. (2015). Concussion awareness training tool for parents, players & coaches: Evaluation report [R]. doi:10.14288/1.0400212

BC Injury Research and Prevention Unit. (2022). *Concussion Awareness Training Tool.* Retrieved from https://cattonline.com

Carman, A. J., Ferguson, R., Cantu, R., Comstock, R. D., Dacks, P. A., DeKosky, S. T., . . . Fillit, H. M. (2015). Expert consensus document: Mind the gaps- advancing research into short-term and long-term neuropsychological outcomes of youth sports-related concussions. *Nature Reviews. Neurology*, *11*(4), 230. doi:10.1038/nrneurol.2015.30

Government of Canada. (2023). *Canadian Hospitals Injury Reporting and Prevention Program.* Retrieved from https://www.canada.ca/en/public-health/services/injury-prevention/canadian-hospitals-injury-reporting-prevention-program.html

Graves, J. M., Moore, M., Kehoe, L., Li, M., Chan, A., Conrick, K., . . . Vavilala, M. S. (2020). Family hardship following youth concussion: Beyond the medical bills. *Journal of Pediatric Nursing*, *51*, 15-20. doi:10.1016/j.pedn.2019.11.016

Guenette, J. P., Shenton, M. E., & Koerte, I. K. (2018). Imaging of concussion in young athletes. *Neuroimaging Clinics of North America*, *28*(1), 43–53. doi:10.1016/j.nic.2017.09.004

Haines, K. J., Beesley, S. J., Hopkins, R. O., McPeake, J., Quasim, T., Ritchie, K., & Iwashyna, T. J. (2018). Peer support in critical care: A systematic review. *Critical Care Medicine*, *46*(9), 1522–1531. doi: 10.1097/CCM.0000000000003293

Hibbard, M. R., Cantor, J., Charatz, H., Rosenthal, R., Ashman, T., Gundersen, N., . . . Gartner, A. (2002a). Peer support in the community: Initial findings of a mentoring program for individuals with traumatic brain injury and their families. *The Journal of Head Trauma Rehabilitation, 17*(2), 112-131. doi:10.1097/00001199-200204000-00004

Hickling, A., Mallory, K. D., Wilson, K. E., Del Fernandes, R., Fuselli, P., Reed, N., & Youth Concussion Awareness Network (You-CAN) Team. (2020). The youth concussion awareness network (you-CAN) - a school-based peer-led intervention to improve concussion reporting and social support: The protocol for a cluster randomized trial. *BMC Public Health*, *20*(1), 186. doi:10.1186/s12889-020-8244-5

Ledoux, A. A., Tang, K., Yeates, K. O., Pusic, M. V., Boutis, K., Craig, W. R., ... Zemek, R. L., & Pediatric Emergency Research Canada (PERC) Concussion Team. (2019). Natural progression of symptom change and recovery from concussion in a pediatric population. *JAMA Pediatrics*, *173*(1), e183820. doi:10.1001/jamapediatrics.2018.3820

Minney, M. J., Roberts, R. M., Mathias, J. L., Raftos, J., & Kochar, A. (2019). Service and support needs following pediatric brain injury: Perspectives of children with mild traumatic brain injury and their parents. *Brain Injury, 33*(2), 168-182. doi:10.1080/02699052.2018.1540794

Pfister, T., Pfister K., Hagel, B., Ghali W.A, & Ronksley P.E. (2016). The incidence of concussion in youth sports: a systematic review and meta-analysis. *British Journal of Sports Medicine, 50*(5)*,* 292-297. doi:10.1136/bjsports-2015-094978

Tator C.H. (2013). Concussions and their consequences: Current diagnosis, management and prevention. *Canadian Medical Association Journal, 185*(11)*,* 975-979. doi:10.1503/cmaj.120039

Turner, R. W., Lucas, J. W., Margolis, L. H., & Corwell, B. N. (2017). A preliminary study of youth sport concussions: Parents' health literacy and knowledge of return-to-play protocol criteria. *Brain Injury*, *31*(8), 1124-1130. doi:10.1080/02699052.2017.1298003

Wilson, N. W., Couper, I. D., De Vries, E., Reid, S., Fish, T., & Marais, B. J. (2009). A critical review of interventions to redress the inequitable distribution of healthcare professionals to rural and remote areas. *Rural and Remote health*, *9*(2), 1060. Retrieved from https://www.rrh.org.au/journal/article/1060