After a Child’s Traumatic Brain Injury: An Ethnographic Study of Being a Parent

by

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Abstract

A growing body of literature proposes that parenting can facilitate or hinder a child's recovery after a traumatic brain injury (TBI). Therefore, health care providers need to understand parental experiences so that they can tailor their services to meet child and parent needs. Providing care that is well-suited and developed based on parent experiences may optimize the family environment for a child with a TBI. This thesis includes two studies: 1) a systematic review examining literature on understanding the impact moderate-to-severe TBI in a child has on family functioning (Chapter 2), and 2) an ethnographic study that explored meanings associated with being a parent of a child with a severe TBI (Chapter 4). Overall, it is evident that moderate-to-severe TBI has a long-standing impact on family functioning and parental meanings, and that factors associated with family adaptability vary by parental role. Also included in this thesis is a methodological paper to provide an overview of how ethnography as a methodology evolved over time and how it has been used in health research (Chapter 3).

Preface

This thesis represents original work. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta HREB (Health Research Ethics Board) for the project: “After a Child’s Traumatic Brain Injury: An Ethnographic Study of Being a Parent” [Pro00040127].

Chapter 2 of this thesis has been published as M. Rashid, H.R. Goez, N. Mabood, S. Damanhoury, J.Y. Yager, A.S. Joyce, and A.S. Newton, “The Impact of Pediatric Traumatic Brain Injury (TBI) on Family Functioning: A Systematic Review” *Journal of Pediatric Rehabilitation Medicine*, volume 8, issue 4, 241-54. As lead author, I formulated the review question and designed the review, led relevance screening and data extraction, assessed the quality of included studies, participated in data analysis, and prepared the manuscript. A.S. Newton is the senior author who helped design and supervised the review, and critically reviewed and revised the manuscript. H.R. Goez, J.Y. Yager, and A.S. Joyce provided expertise during data analysis and helped with revisions of the initial manuscript. N. Mabood assisted with relevance screening and data extraction, assessed the quality of included studies, and participated in data analysis. S. Damanhoury assisted with data extraction, assessed the quality of included studies, and helped with referencing.

Chapter 3 has been submitted for publication and is currently under review as M. Rashid, V. Caine and H.R. Goez, “The Encounters and Challenges of Ethnography as a Methodology in Health Research” *International Journal of Qualitative Methods.* As lead author, I was involved in concept formation and drafting and revising the manuscript. V. Caine is the senior author and was involved with manuscript composition. H.R. Goez contributed to manuscript edits.

Chapter 4 is submitted for publication as the following: M. Rashid, H.R. Goez, V.Caine, J.Y. Yager, A.S. Joyce, and A.S. Newton, "After a Child's Traumatic Brain Injury: An Ethnographic Study of Being a Parent" *Brain Injury.* A.S. Newton and I formulated the research question and designed the study, led relevant participant recruitment strategies, the recruitment and data collection, participated in data analysis, and prepared the manuscript. V. Caine supervised all aspects of the study, data analysis and critically reviewed and revised the manuscript. H.R. Goez provided expertise during recruitment, data analysis and helped revise the initial manuscript. A.S. Joyce and J.Y. Yager provided feedback throughout this project and helped revise the manuscript.

Dedication

To my grandmother (RIP).

Acknowledgments

I would have no thesis to call my own without the constant support and guidance of many individuals.

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Chapter 1

Introduction

This paper-based thesis includes three papers based on my graduate research (PhD in Medical Sciences, Pediatrics). The first paper, which has been published, was a systematic review examining the impact of traumatic brain injury (TBI) on family functioning. The second paper, which has been submitted for publication, focuses on the development of ethnography in health research. The third paper is being prepared for submission, and explores parental meanings associated with parenting a child with a severe TBI. This introductory chapter contextualizes my graduate research by providing some background literature on the impact of a child's TBI on families, presenting my personal research interests, describing my chosen study methodology and ethnographic processes, and outlining each chapter's contribution to my thesis work.

Background

Traumatic brain injury often leads to long-term behavioural, cognitive and social deficits in children. Previous studies have observed limited recovery in children with severe TBI during early childhood (age 3 to 6 years) [1,2]. Cognitive deficits in these children are pronounced and generalized [1,3,4], making recovery and family adjustment complex. Parents of children with severe TBI have reported a greater degree of stress associated with the child's injury relative to comparison groups such as moderate and mild TBI [5]. Family functioning and availability of social resources play a significant role to "moderate the relationship of TBI severity to injury-related burden and caregiver distress" [6; page 2] while a higher quality home environment and optimal parenting characteristics have been associated with a child's post-injury cognitive development [7]. Parenting style is crucial in facilitating or hindering behavioural recovery after a TBI, and interventions to address these roles may improve behavioural problems [8,9]; a recent systematic review has recommended that health care providers tailor their services to specific familial needs [10].

The majority of the studies conducted in relation to parental experiences following a child's TBI are based on the experiences of mothers alone [11,12]. Researchers have only recently focused on understanding the fathers' experiences following their child's TBI. A recent study demonstrated that mothers and fathers differ in how they cope with the stress associated with their child's TBI [13]. A study published in 2011 also showed that mothers and fathers differ in how they perceive family related issues, such as child-rearing practices and the overall quality of their married life [14]. While several qualitative studies have explored parent experiences and parental caregiving following a child's TBI [15,16], these studies have mainly focused on daily parenting activities and task-oriented processes. There remains a need to explore how parental meanings, roles, and expectations are constructed from parent-child interactions in the day-to-day lives of families with a child with a severe TBI.

To date, there has been no in-depth exploration of how parents "parent" a child with a severe TBI and the needs of parents of children with a severe TBI are unknown. This is an important knowledge gap to address because of the significance it has on the quality of care received and delivered. With this issue in mind, the purpose of my graduate research was to understand what it means to be a parent of a child with a severe TBI.

Personal Interests

My interests in holistically improving the care provided to families who have a child with a TBI developed while shadowing health care professionals at the Glenrose Rehabilitation Hospital for a year-long period. During this time, I had the opportunity to observe the families who came to the TBI clinic at the hospital. I became well acquainted with some of the problems and struggles the families faced. Parents shared stories about the frustrations they felt in trying to improve their child's health and working with health care providers. These stories sparked my curiosity about parental experiences and meanings. I wondered if by identifying common as well as unique familial experiences whether this information could be incorporated into rehabilitative and family support programs to develop timely and responsive initiatives that address families' challenges. I also became interested in developing recommendations for health care professionals so that they could provide more 'family-centred' care.

Outline of Thesis

My thesis consists of three papers. Chapter 2 presents my systematic review of published literature with the goal of understanding the impact moderate-to-severe TBI in a child has on family functioning. Chapter 3 presents a methodology paper in which I examine the encounters and challenges of ethnography as a methodology in health research. Chapter 4 presents an ethnographic study of families with a child with a severe TBI. This study comprised the bulk of my PhD research and provided an understanding of parenting that has yet to be explored in the TBI field. Recommendations from my study data target support services offered to parents in rehabilitation settings. My thesis concludes with Chapter 5, which presents conclusions based on the findings from my graduate work. Lastly**, Appendix A** includes ethics documents, and **Appendix B** includes the data collection tools I used to conduct my research.

Ethnographic Processes

Ethnography is a complex approach to conducting research. An ethnographer must appraise the practical challenges that he/she may encounter while entering the research field. Throughout the study, an ethnographer must also critically think about their work, having a clear idea of how to access the field, approach gatekeepers/key individuals, and develop strategies to foster trusting relationships with study participants.

As a novice ethnographic researcher, I encountered many challenges in the field. Initially, I had tremendous difficulty in navigating important issues around developing trust with TBI clinic physicians, clinic coordinators, and study participants. I was cautious about the power relation aspect and had concerns about drawing a clear line as to: How much of my perspectives and opinions do I share with study participants? Is it okay for participants to share what they are sharing? Are participants sharing too much personal detail or are they keeping too much to themselves? What needs to be recorded during field notes and interviews? What needs to be kept confidential to ensure that I am not violating participant privacy? In addition, my graduate work taught me that keeping an extensive record of how to conduct ethnographic work is beneficial to entering into the field, and that as an emerging design [17], it is difficult to predict whether the plans in place will unfold in the way imagined.

Connecting with the Participants

Entry into the Clinic

My entry into the clinic involved an important process. One year prior to my entry into the study field, I shadowed a physician at the Glenrose Rehabilitation Hospital working in the TBI clinic. This experience was of tremendous help for me because this enabled me to understand some of the dynamics of the clinic, the relationships that existed between the physicians, neuropsychologists, social workers, coordinating nurses, and other staff. Shadowing allowed me to not only become familiar with the setting, but it also enabled me to get to know the clinic's health care providers and develop a working relationship with the clinic's administration staff. Many of the physicians also became familiar with who I was and my research interests, which helped when it came time for study recruitment. During my year of shadowing, I also developed a clear understanding of some of the complexities that families who had children with TBI were facing. I did not recruit any families into my study during this one year period; however, I did have the opportunity to observe clinic procedures with families, and what a clinic day looked like for a family who came for their child's follow-up appointment. In essence, by the time I was ready to conduct my study, I had a clear idea of what the clinic dynamics were, what to expect and what the needs and demands were of the families who came for the visit. I was also able to identify feasible and appropriate study recruitment strategies, which enabled a smooth recruitment process.

Meeting Families

My interactions with families began in the clinic, and my study had a number of different recruitment strategies to enable contact with potentially eligible participants. Families were either recruited by telephone or email by the coordinating nurse at the TBI clinic at the Glenrose Rehabilitation Hospital. On TBI clinic days, when families would come for appointments, I would visit the clinic. I would have the study information sheet ready for parents to read, and if parents agreed to talk with me about the study, I explained it to them. If a parent (or parents) agreed to participate, I asked for their contact information so that I could book an initial interview. There was no restriction on when and where this interview could take place. If parents were not comfortable with inviting me into their homes, I conducted the interview in the clinic or a place they chose. During study recruitment, a number of families declined study participation with their main reason being the many demands the study asked of the family. As the study was an ethnographic one, it required several home visits. Home is a private space for many individuals and it was not unexpected that families would be hesitant or disinterested in allowing me (as a stranger) into their home.

I was able to conduct home visits with four families (Fiona, Bob, Anna and Rebecca); each family was significant in enriching my study. These families were very different and unique from one another which added to the complexity and variability across my field work. Fiona's family was the first family I met. I learned a lot from this family. Fiona was three years old at the time I met her. She lived in a small town in Alberta with her mother, father and three siblings. She was a very active, happy and social child and she had a severe TBI due to drowning. I was extremely nervous, because it was my first time entering some one's home and I was not sure what to expect. However, with the passage of time these feelings faded and I felt much more confident.

My first encounter with Bob was devastating. I still remember when I tried to say hello to him and he did not respond. I only got a motionless gaze from him. Every time, I looked at him and compared him to his picture from his kindergarten graduation class, placed on the fireplace, it broke my heart. Bob was a ten year old child, who lived in a small town in Alberta with his mother, father and two sisters. Following his TBI his grandmother had moved in with the family and lived with them. Bob had a severe TBI due to drowning. Bob was the center and his family functioned around him and his needs. The living room was the hub of all the activities for them. My experience with Bob's family made me realize that ethnographers face tremendous ethical dilemmas while conducting field work.

Anna was a ten year old, who lived in a small town in Alberta. She lived with her mother, father and two siblings. Anna had a severe TBI due to severe internal bleeding in her brain. My relationship with Anna and her family were of formal nature, often she stayed quiet and did not talk much. This family was significant to my work because, I came to realize how difficult it was to develop close relationships with people. I understood the intricacy associated with the fact that people do not share their inner world with a stranger. This was a turning point in my work, as I came to understand that there are missing gaps and stories in the field work.

Rebecca was ten years old and had a severe TBI. Rebecca lived in a small town in Alberta, with her mother, father and two siblings. My relationship trajectory with Rebecca's family was remarkable. From my work I learned that building rapport with study participants depended on the participants' personality, their willingness to share their life with researchers and the extent to which their needs need to be heard.

Learning from Families

My first encounter with families was when I conducted the individual interview. For six families, this was the only time I learned from them. Other families participated in more than one interview. The individual interview established, for me, an initial understanding of the parents' experiences. During the interviews I realized how different every parent was. I met parents who were extremely sensitive. They had moments of torment and breakdown. Some parents had special requests (for example, they made it clear that they would talk about anything except the time when their child had acquired their injury). Other parents appeared anxious to discuss their issues. The first interview, however, gave me very limited experience with parents 'being parents.'As the interview was an hour long, it provided me with sufficient data to answer my questions, but I had no knowledge of the parent's personality, how s/he reacted in different situations, how s/he went about solving and resolving issues with her/his children, and how they handled stressful situations. It was my home visits/field work that was an eye-opening experience and allowed me to further understand what it means to be a parent of a child with a severe TBI. The home visits and field work allowed me to gain a more comprehensive understanding of how parents ‘parent’ their children. I gained knowledge and understanding about parents’ needs. These needs varied according to many significant factors, such as the severity of their child’s TBI, support that was given to them, and their views about life. I developed an appreciation for how hard it was for parents to deal with their child’s tantrums and how they maintained equilibrium to fulfill the needs of their other children. My field work provided a greater depth of understanding of what parents shared in their individual interviews, and I learned how the severity of a child’s injury could impact the extent to which a family functioned. For instance, in a family in which the child was in constant need of care, there was a great deal of negotiation regarding how the family functioned, and in such instances, the child became the focal point. This experience was not the same for families whose child did not need constant care. Contextual differences also left me with many unanswered questions. In particular, parents differed in their rapport building and approach to trust. I often wondered why some parents had the urge to talk and open up to a stranger during the initial home visit, while other parents did not talk about their parental struggles until after several home visits.

Entry into the family for home visits was the most complex aspect of my study. Entry varied depending on the family. Some families invited me to their home after I first approached them for study participation, while other families waited until after the first in-person interview to agree to the home visits. When I entered the families’ homes, I had to renegotiate the nature of my presence within the field. This was complicated because I am a young, single woman with no personal experiences of parenting a child. I needed to ensure that I developed a mentality that I am a woman who may become a mother one day, and therefore engage with these parents in a sympathetic manner to make sure that I understood what they were going through. This strategy was helpful as it enabled me to establish a reciprocal relationship with parents, allowing a rapport to be fostered and engaging them in a research process where I could gain as much information as I could about their parenting and their day-to-day life with their child.

Within my participants' homes, I had the opportunity to be part of numerous activities. I had the chance to make supper, clean, to study with the children and play games together, whether it was 'go fish' or building a castle out of LEGO®. This time together allowed us to understand each other and with that understanding came a mutual trust. With the passage of time, parents asked me questions and I asked them questions. We answered each other's questions. We tried to understand each other. There were times when I wondered, am I telling them too much about myself? Am I crossing the line? I wondered who draws the line. Do I need to stop somewhere? How much information can I reveal about myself? They tried to understand me as much as I wanted to understand them. This was a process of turmoil, a process where there was internal struggle for me. There were moments when parents cried and they were emotional. This had a strong impact on me and it raised many questions: Do I have to control my internal emotions? Or can I express them to my participants? As a novice researcher, I had no idea what to expect and oftentimes I had no idea how to react.

For some families, I became a significant person in their lives. They trusted me and shared their feelings. I also had very formal relationships with some families. They kept their distance and if that was how it worked for them, I respected that. Within my participants' homes, I was actively involved in most of their activities. There were a lot of activities that unfolded at home and there were a lot of activities that unfolded outside of the home. I went camping and shopping with participants, attended children's swimming competitions and hockey games. In these moments, I gained a deeper understanding about what it means to be a parent of a child with TBI. Through field work, I gained an incredible amount of contextual data, data without which I would not be able to make sense of some of the statements my participants made in their individual interviews. For example, some parents were eager to talk to me and share their experiences. The reason for this willingness was not evident for me until I visited their home and found out that they needed someone to hear what they had to say.

Exiting Families

Exiting families can be difficult, not only for a researcher but also for families as well. In general, this process depended on the type of relationship that I developed with the particular family. I developed a close relationship with some of the young children of participating families. I played with them, went out with them, shopped with them and they felt delighted when I visited their homes. Hence, I felt sad when I hugged them and said a final goodbye. For some children it was a distant relationship and therefore the exit from the family was smoother. Often with children, keeping a formal relationship is difficult to maintain. Some of my relationships with the children grew deeper during my time with them, which made the process of exiting a family more difficult. With one family, in particular, the little girls would not let me go and they wanted to go with me. It was a sad and challenging exit.

References

[1] Anderson VA, Morse SA, Catroppa C, Haritou F, Rosenfeld JV. Thirty month outcome from early childhood head injury: A prospective analysis of neurobehavioural recovery. Brain. 2004; 127(12):2608-2620.

[2] Keenan HT, Hooper SR, Wetherington CE, Nocera M, Runyan DK. Neurodevelopmental consequences of early traumatic brain injury in 3-year-old children. Pediatrics. 2007; 119:616-623.

[3] Taylor HG, Swartwout MD, Yeates KO, Walz NC, Stancin T, Wade SL. Traumatic brain injury in young children: Post-acute effects on cognitive and school readiness skills. J Int Neuropsychol Soc. 2008; 14:1-12.

[4] Anderson V, Catroppa C, Morse S, Haritou F, Rosenfeld J. Recovery of intellectual ability following traumatic brain injury in childhood: Impact of injury severity and age at injury. Pediatr Neurosurg. 2000; 32:282-290.

[5] Wade SL, Taylor HG, Drotar D, Stancin T, Yeates KO. Family burden and adaptation during the initial year after traumatic brain injury in children. Pediatrics. 1998; 102:110-116.

[6] Stancin T, Wade SL, Walz N, Yeates KO, Taylor HG. Family adaptation 18 months after traumatic brain injury in early childhood. J Dev Behav Pediatr. 2010; 31:317-325.

[7] Gerrard-Morris A, Taylor HG, Yeates KO, Walz NC, Stancin T, Minich N, Wade SL. Cognitive development after traumatic brain injury in young children. J Int Neuropsychol Soc. 2010; 16(1):157-168.

[8] Yeates KO, Taylor HG, Walz NC, Stancin T, Wade SL. The family environment as a moderator of psychosocial outcomes following traumatic brain injury in young children. Neuropsychol. 2010; 24:345-356.

[9] Potter JL, Wade SL, Walz NC, Cassedy A, Stevens MH, Yeates K O, Taylor HG. Parenting style is related to executive dysfunction after brain injury in children. Rehabil Psychol. 2011; 56(4):351-358.

[10] Rashid M, Goez HR, Mabood N, Damanhoury S, Yager JY, Joyce AS, Newton AS. The impact of pediatric traumatic brain injury (TBI) on family functioning: A systematic review. J Pediatr Rehabil Med. 2014; 7(3):241-254.

[11] Clark A, Stedmon J, Margison S. An exploration of the experience of mothers whose children sustain traumatic brain injury (TBI) and their families. Clin Child Psychol Psychiatry. 2008; 13:565-583.

[12] DeMatteo CA, Cousins MA, Lin CY A, Law MC, Colantonio A, Macarthur C. Exploring postinjury living environments for children and youth with acquired brain injury. Archives Physical Med Rehab. 2008; 89(9):1803-1810.

[13] Wade SL, Walz CN, Cassedy A, Taylor HG, Stancin T, Yeates KO. Caregiver functioning following early childhood TBI: Do moms and dads respond differently? NeuroRehabilition. 2010; 27:63-72.

[14] Bendikas AE, Wade SL, Cassedy A, Taylor HG, & Yeates KO. Mothers report more child-rearing disagreements following early brain injury than do fathers. Rehabil Psychol. 2011; 56(4):374-382.

[15] Roscigno IC, Swanson MK. Parents' experiences following children's moderate to severe traumatic brain injury: A clash of culture. Qual Health Res. 2011; 21(10):1413-1426.

[16] Jones M, Hocking C, Wright St-Clair V. Parents caregiving for children after a Traumatic Brain Injury: Structuring for security. New Zealand Journal of Occupational Therapy. 2011; 57(1):4-13.

[17] Lofland J, Lofland LH. Analyzing Social Settings: A Guide to Qualitative Observation and Analysis. Belmont, CA: Wadsworth; 1995.

Chapter 2

Title: The Impact of Pediatric Traumatic Brain Injury (TBI) on Family Functioning: A Systematic Review

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Abstract

Purpose: To explore the impact moderate to severe traumatic brain injury (TBI) in a child has on family functioning.

Methods: The search was conducted using 9 bibliographic databases for articles published between 1980 and 2013. Two reviewers independently screened for inclusion and assessed study quality. Two reviewers extracted study data and a third checked for completeness and accuracy. Findings are presented by three domains: injury-related burden and stress, family adaptability, and family cohesion.

Results: Nine observational studies were included. Across the studies, differences between study groups for family functioning varied, but there was a trend for more dysfunction in families whose child had a severe TBI as compared to families whose child had a moderate TBI or orthopedic injury. In three studies, injury-associated burden was persistent post-injury and was highest in families whose child had a severe TBI followed by families with a child who had a moderate TBI. One study found fathers reported more family dysfunction caused by their child's injury compared to mothers. Two studies found that mothers' adaptability depended on social support and stress levels, while fathers' adaptability was independent of these factors and injury severity.

Conclusion: Moderate to severe TBI has a significant, long-standing impact on family functioning. Factors associated with family adaptability vary by parental role.

Key words: family function, family dysfunction, family burden, traumatic brain injury, TBI, head injury.

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Introduction

Traumatic brain injury (TBI) in young children is a frequent cause of disability [1]. The cognitive problems that children with a TBI encounter include changes in memory, problem solving, and planning. After a TBI, children are also more likely to experience difficulties in recognizing facial emotions and emotional prosody [2]. Deficits in self-regulatory abilities associated with a TBI can negatively impact social and behavioural functions and may also be responsible for post-injury difficulties [3]. Severe memory-related problems [4], difficulties with academic achievement [5] and social difficulties [6], lower self-esteem, and aggressive and antisocial behaviours [7] have all been reported for children with a TBI.

Research shows that there is relationship between the child's executive abilities and family functioning, with greater executive dysfunctions associated with higher stress and parental burden [8]. To highlight, a recent study found strong correlations between problems with executive functions/attention, and family function and parenting quality in children with a TBI. Less executive dysfunction and attention problems were experienced by children who had non-permissive parents and those who lived in less dysfunctional families [9].

A TBI may force a family to adapt and adjust by redefining their actions, roles, and meaning of life, and it has been shown that a child's TBI can result in severe psychological problems for parents [10]. Providing care for a family member who has a TBI is challenging and stressful not only due to the injured person's physical or behavioral problems, but also because of personality changes to which the family must adapt [11]. In a study comparing stress levels associated with parenting a child with a TBI relative to a healthy sibling, parents reported significantly more stress parenting their child with a TBI [12]. It has been suggested that parents who have a strong support system experience less life stress than parents who lack such a support system [13] and that the availability of solid social support decreases parental stress [14]. The majority of literature on parental coping strategies related to a child's TBI is based on the experiences of mothers who are most often the primary caregivers [15,16]. Recently, however, researchers have explored how fathers cope with this event. In a study conducted by Wade *et al.* [16] there were marked differences in how mothers and fathers handled the stress associated with their child's TBI—mothers more willingly accepted and used emotional approaches to adjust to their child's injury while fathers reported denial of the injury and believed that their child's injury was more stressful.

The objective of this systematic review was to explore the impact moderate to severe TBI in a child has on family functioning. The goal was to better understand the impact of TBI on global family functioning as opposed to the specific impacts on a parent or sibling. Research conducted in relation to family functioning suggests that better social resources and economic stability are significant factors in preserving a family's function [17,18]. In 1992, Rivara *et al.* [19] showed that the pre-injury family environment is the most effective predictor of family functioning after a child's TBI. It has also been suggested that families who have good communication, a positive home environment, and less pre-injury strain have a higher chance of better adaptation following the injury [20]. Further, longitudinal investigations focusing on TBI in children suggest that the negative impact of severe TBI on family functioning is chronic in nature and may persist for many years following the child's injury [19-22]. To date there has been no systematic review conducted regarding the impacts pediatric TBI has on family functioning. An examination of this body of literature has the potential to identify common and unique familial experiences that can be incorporated into rehabilitative and family support programs to develop timely and responsive initiatives for addressing families' challenges.

Methods

Search Strategies

A literature search was conducted with a librarian to identify studies of the impact of a child's severe or moderate TBI on family functioning. The search strategy was restricted to English language and articles that were published between 1980 and January 8, 2013 (up to date of search). The search was conducted in 9 electronic bibliographic databases: MEDLINE®, EMBASE, CINAHLplus, PsycINFO, Family Studies Abstracts, Web of Science, Child and Adolescent Development, Scopus databases and Proquest Dissertations & Theses. To identify unpublished materials, the 'grey literature' (reports, masters or PhD dissertations, and conference proceedings) was searched. The first author and the librarian conducted a brief search on Google Scholar that consisted of entering limited words that were confined to the review objective (i.e., "TBI", "family" and "pediatric"). The rationale behind conducting this Google Scholar search was to ensure all relevant studies were identified while conducting the electronic bibliographic database search. Comprehensive and complete search strategies used in each database are available in Appendix 1. Key terms such as family function, family dysfunction, family burden, family, family coping, family interactions, family health, family relation, parent-child relation, sibling relation, and family assessment, in combination with traumatic brain injury/TBI, brain damage, head injury, and acquired brain damage, family environment, head or crani* or cerebr* or brain* or skull* or intra-cran* or inter-cran, family conflict, parenting, and sibling relations were used. References cited in the papers that were included in the review were hand-searched to ensure important studies were included.

Inclusion/Exclusion of Studies

The exclusion criteria for this review were as follows: (1) the primary language was not English, (2) studies whose sole population was children with a mild TBI, (3) studies whose population or mean age was not pediatric (>18 years), (4) or studies that examined the impact of family functioning on a child's TBI. This review focused on families whose child incurred a severe or moderate TBI. Two reviewers screened articles retrieved from the search. The first 100 articles were screened by both reviewers to assess the level of agreement between the reviewers, which was quantified with the Kappa statistic (k=0.75; substantial agreement [0.61–0.80]) [23]. Any screening discrepancies were addressed at this stage. Thereafter, the two reviewers screened the remaining articles independently. The full texts of all the relevant articles were retrieved for review. Articles were grouped into three categories: include, exclude, or unsure. Both reviewers met to review the full texts for the 'unsure articles' with a final decision to either include or exclude each article. Studies were included at the screening and inclusion/exclusion stages if the primary objective was to determine the impact of a child's severe/moderate TBI on family functioning. No restriction was placed on study design (qualitative or quantitative).

Quality Assessment

Methodological quality of the studies was assessed by two independent reviewers. Quality was assessed using key sections of a rating tool [24] that follows guidelines for quality appraisal set out by Jadad *et al.* [25]. Studies were rated according to the extent of bias in data collection and analysis, and the proportion of study withdrawals/dropouts. Each study was rated based on these criteria and scored accordingly as weak, moderate, or strong. A particular study was considered strong in quality if there were at least 4 strong ratings and remaining ratings as moderate. A study was considered moderate in quality if there were < 4 strong ratings and one weak rating. A study was considered weak in quality if there were ≥ 2 weak ratings. Reviewers met to review their assessment; if discrepancies occurred, the article was re-reviewed jointly until consensus was achieved.

Data Extraction and Analysis

Data were extracted from all the included articles using a standardized data extraction form. The main components of the form were study publication information (e.g., year of publication, country), general study characteristics, participant characteristics, study methods and findings. Two reviewers extracted data and a third reviewer checked the entries to make sure that the content extracted was accurate. Extraction discrepancies were resolved by consensus. In the case of unclear or unreported information in the original studies, primary authors were contacted. Where studies measured the same outcome using the same outcome measurement, meta-analyses could not be conducted due to the heterogeneity in comparison groups and measurement time points. A qualitative analysis was conducted for the review and detailed findings are presented in summary tables. Results are presented by three domains of family functioning that were measured in the studies: (1) injury-related burden and stress, (2) family adaptability, and (3) family cohesion.

Results

Description of Included Studies

The electronic database search yielded 1,812 potentially relevant articles for screening. After title and abstract review, 150 articles were selected for manuscript retrieval and full review with 9 studies meeting the inclusion criteria after full-text review (see Figure 1). General study characteristics are presented in Table 1. Publication dates ranged from 1992 to 2011. All studies were conducted in the United States. As shown in Table 1, most studies defined the child's TBI based on the Glasgow Coma Scale (GCS) [26]. Six study samples included children and their caregivers [10,17,19,20,22,27], one study sampled mothers and fathers [14], one study reported information from mothers only [28], and one study sampled parents and siblings [29]. Across the studies, the child's mean age ranged from 5 years to 14 years; in three studies, the child's age was older—between 12 [19,20] and 14 years [29]. In four studies, age at injury was reported to be between 5 to 5.9 years for all study groups [14,22,27,28], and in two studies, the age at injury was reported to be between 9 years to 10 years [10,15]. All studies included in the review reported family income while only 6 studies reported parental education [14,19,20,22,27,28]. All 9 studies classified the child's TBI as severe, moderate or mild with the exception of one study that grouped mild and moderate TBI together [27]. The study conducted by *Bendikas et al.* [27] combined the mild and moderate classifications together and we included this group in the review under moderate TBI findings. A summary of study sample demographics can be found in Table 2.

Methodological Quality of Studies

The studies were observational in design: 8 prospective [10,14,17,19,20,22,27,28] and 1 cross-sectional [29]. Five studies used comparison groups to reduce risk of bias [10,14,22,27,29]. All studies were rated as strong for quality of data collection methods using reliable and validated instruments. Eight studies controlled or at least partially controlled for confounders [10,14,17,19,20,22,27,28]. One study did not account for any statistical differences for potential confounders [29]. The most common variables that were considered in analyses were age at injury, race, ethnicity, parental education, family income, and length of stay in the hospital. Two studies also considered the number of children in a family [14,28], which was not accounted for analytically in the majority of studies [10,14,19,20,22,27,29]. No studies reported whether other children in the family had any disabilities or who represented the child's primary caregiver.

In four studies, caregivers were asked to describe pre-injury family functioning [10,14,22,27]. Across the studies, this assessment occurred no later than three months following the child's TBI. Data collected included parent perceptions of injury-related burden, family functioning, parental distress [10,17,22] and marital relationship and child-rearing disagreements [27]. Further, in two studies, family functioning, injury-related burden and child functioning reported at three weeks post-injury were controlled for in the analyses [19,20]. In all the studies included in this review, measures of family functioning, injury-related stress, adaptability and cohesion were administered in a follow-up period.

In terms of methodological quality, most of the studies were "very likely" to be representative of the target population, with the exception of three studies that were rated as "somewhat likely" to be representative of the target population [14,19,29]. The percent of study participants who completed the study (all data collection time points) varied across the 9 studies: 80-100% of participants completed assessments in four studies [14,19,20,28], 60-79% in one study [27], and less than 60% in one study [17]. Three studies did not report the participant completion rate [10,22,29]. The low withdrawal and drop-out rates for four of the studies resulted in strong ratings [14,19,20,28]; in contrast, 5 studies were rated as moderate to weak because of higher withdrawal and dropout rates [10,17,22,27,29].

Impact of a Child's TBI on Global Family Functioning

Global family functioning was measured by six studies using the FAD (Family Assessment Device [30]) [10,17,20,22,27,29], and by two studies using the Family Global Assessment Scale (FGAS [31]) [19,20]. Family functioning was also measured across three other domains: injury-related burden/stress, adaptability and family cohesion. As seen in Tables 3, 4 and 5, studies assessed family functioning at varying time points ranging from the time of injury (usually hospitalization) to 6 years.

As shown in Table 3, the dysfunction reported by families varied from study to study although there was a trend for more dysfunction reported by families whose child had a severe TBI [10,17,19,20]. Three studies reported that families with a moderate and severely brain injured child faced greater family dysfunction in comparison to families whose children sustained an orthopedic injury (Table 3) [10,17,22].] Similarly, in two studies, an examination of functioning among children who sustained severe, moderate or mild TBI indicated that families who had a child with severe TBI faced greater family dysfunction in comparison to the moderate and mild group [19,20]. Overall, across the studies, families who had a child with severe TBI experienced greater family dysfunction in comparison to families whose child sustained an orthopedic injury or mild or moderate TBI.

The frequency and degree of reported dysfunction in studies was modest, however—for example, one quarter of families who experienced a severe TBI and just over 10% of those who experienced a moderate TBI in their child reported dysfunction in one study (Table 3) [10].Three studies found that adverse consequences that a child's TBI have on family functioning lessened over time and dysfunction became comparable between the injury groups [10,22,27]. In two studies, however, this was not the case, and family functioning for those families who experienced a severe TBI deteriorated slightly (2.8 change on a 100-point scale) 3 months post-injury, however, at 1 and 3 years, functioning continued to deteriorate (7.4 and 8.5 scores below pre-injury) [19,20]. Pre-injury functioning has been associated with better family outcomes post-injury [19,20]. In one study, injury severity was not a strong predictor of family functioning post-injury [19], which may help to explain variation across familial outcomes over time [20]. One study found that fathers reported higher levels of family dysfunction in comparison to their spouses ($p<0.001$) [27]. In a comparison of parent and child ratings of FAD domains (roles, problem solving, communication, and affective involvement) to a normative population, one study found that role domain ($p<0.05$) was the only significant difference between parent groups, while children with a TBI faced problems across all FAD domains compared to children without an injury (Table 3) [29].

Injury-Related Burden for Families

Injury-related burden/stress was measured using the Family Burden of Injury Interview (FBII [32]) [10,17,22], Impact on Family Scale (IOF [33]) [10] and Family Inventory of Life Events (FILE [34]) [19,20]. The FBII assesses injury-related stress and burden in relation to (a) the injured child's adjustment and recovery, (b) relationships between spouses, (c) relationships between extended family members and friends [32]. The IOF measures the impact of a child's disability on the family [33]. The FILE measures stress by incorporating the following subscales: intra-family, marital, illness and family care, finance, and legal [34]. Two studies included in this review also used the Family Environment Scale (FES [35]) and Family Interview Rating Scale (FIRS [36]) [19,20] to assess family relationships.

Burden associated with a child's TBI has been found to be chronic in nature, particularly for families whose child has a severe TBI injury compared to other families whose child was diagnosed with moderate TBI and orthopedic injury (Table 4) [10,17,19,20,22]. Family functioning has been found to moderate the association between injury severity and family burden ($p<0.05$) [22]. This suggests that at higher levels of family dysfunction, families who child incurred a severe TBI experience more injury-related burden at all time points (baseline, 6 months, 12 months and 18 months) whereas at lower levels of family dysfunction, families do not experience injury related burden at all time points. One study found that post-injury (study baseline), burden was high for families with a child with a moderate and severe TBI as well as an orthopedic injury [10]. Other studies demonstrated that injury-related burden and stress were sustained over time for families whose child incurred a severe TBI and diminished for families whose child incurred a moderate TBI or other injury [10,17,22]. One study reported a strong correlation between burden for families and stressors ($p<0.01$), resources ($p<0.01$; inverse relationship), and negative life events ($p<0.01$) [22]. Four studies showed that injury-related burden declined considerably post-injury and change in injury-related stress over time did not differ significantly among families whose child incurred a severe or moderate TBI or orthopedic injury [10,17,20,22].

Adaptability and Family Cohesion in Families with Children with a TBI

Adaptability and cohesion were measured by two studies using the subscales of the FACES II (Family Adaptability and Cohesion Evaluation Scale [37]) [14,28]. The adaptability subscale measures the stability and predictability of families' role and rule structures, while the cohesion subscale assesses the nature and quality of relationships in a family.

As shown in Table 5, two studies examined family adaptability and cohesion for mothers and fathers [14] or mothers only [28]. Findings from these studies showed that there was greater consistency in mothers' perceptions of adaptability and cohesion. For mothers, greater adaptability depended on social support and lower levels of psychological stress while family cohesion was related to lower stress and an intact family structure (i.e., both parents resided together) [14,28]. For fathers, social support was the main predictor of family cohesion and their perception of adaptability was not significantly influenced by stress, social support, mental health or the severity of their child's injury [14]. In families whose child had a severe TBI, family cohesion was positively associated with pre-injury levels of general functioning, communication, and coping, and inversely associated with stress, while an increase in social support depended on good communication, flexible family roles, and general functioning [20].

Discussion

This systematic review revealed that significant family dysfunction is experienced by families whose children had a severe TBI immediately after and years after the child's injury. Other literature demonstrates that a child's recovery is dependent on family functioning—better familial function fosters the recovery experienced by children with a severe TBI [38]. Findings from this review, therefore, highlight the need to provide recommendations for TBI programs to address key issues that underpin family functioning in the moderate to severe TBI population: family dysfunction, prevalence of prolonged and high levels of injury-related burden/stress, parental perception of adaptability, and family cohesion. By addressing these issues, the parent and child become the nexus for program development. Further, across studies findings varied and point to important aspects for rehabilitative programs to consider when providing services to families in the post-injury period.

It is vital to note that coping has been identified as a strong predictor of whether stress is experienced by families [19], and a body of literature exists on how parents and caregivers cope following their child's TBI [15,16,39,40]. While these studies [15,16,39,40] have not explored coping or burden in the relation to family functioning, the role of coping is an important aspect to consider for those families experiencing high levels of burden and stress during the post-injury period. Parental perceptions of adaptability, family cohesion, and social support are also important factors to consider vis-à-vis coping. As highlighted in this systematic review, mothers and fathers differed in their perception of adaptability and family cohesion [14], and adaptability and family cohesion depended on lower psychological distress and greater psychological well-being [14,28]. Further, social support was a main predictor of family cohesion for both parents [14,28] and has been found to buffer elevated stress that follows a child's injury [22], and it is well-documented in the existing literature [13,14,22,28] that strong social support is vital for families with children with a TBI to adapt well to their changing family environment. Studies in this review revealed that families experienced worse family functioning as well as elevated stress and burden when they were experiencing a lack of interpersonal resources and social support [17,22]. In sum, while studies varied in the degree to which family functioning was functional and dysfunctional, the extent to which family were adaptive and cohesive, and the amount of burden experienced post-injury, rehabilitative programs will treat families across the spectrum of experiences and should have services tailored to each experience.

For families who have adjusted well post-injury, they may find meaning and value in participating/leading parent-led programs. For successful implementation of recommended parent-to-parent programs, it is further suggested that rehabilitative programs promote strategies that strengthen communication and contact between parents and health care providers to also increase satisfaction with health care services [40]. This may include information/support sessions led by parents to other parents who are in need. Parents can learn peer-tested strategies to adjust to their child's TBI, deal with stress, and burden that is associated with their child's injury. Consistent with this recommendation, Roscigno *et al*. [41] reported that one of the themes that emerged in their qualitative study with parents was "searching for a community." That is, families with a brain-injured child tended to look for assistance from other families who have been through their situation. In this study, parents believed that interacting with other families who had been through a similar experience offered them unique forms of guidance to address the burden and stress associated with their child's injury, that were otherwise unavailable from traditional support/treatment programs.

The findings from this review suggest that a child's TBI impacts the entire family structure and its functions. Based on the evidence outlined in this review, attempts have been made by the researchers to develop family-based interventions for families who have a child with a TBI. Singer *et al.* [42] found that anxiety and depression symptoms improve in parents who receive stress management compared to receiving information/education. These findings suggest that providing the right type of knowledge and services are key for families to adjust well to the child's TBI. In addition, two studies conducted by Wade *et al.*, showed that web-based family interventions reduce injury-related stress, and improve parental knowledge, parent-child relations and psychological states in parents whose child incurred a TBI [43,44]. Several advantages of web-based interventions have been highlighted by the researchers, such as the accessible and flexible nature of online interventions [44]. Indeed, the existence of family-based interventions is vital and it is evident that families will greatly benefit from such intensive programs.

Based on the results of this review, it is also recommended that families whose post-injury experiences include dysfunction, poor adaptation and cohesion and high burden will benefit from more intensive rehabilitative programming. The involvement of social workers and psychologists in assessing families' psychosocial needs and having capacity to recommend and/or provide services that are flexible and family-oriented is critical. Therefore, it is also recommended that service providers educate members involved in the family's social network. To meet that goal, it is suggested that parents of children with a TBI also be actively involved in the training and education of people involved in their social network (i.e., extended family members, friends, other parents who have children with TBI, and support from religious authorities and rehabilitation services) [45]. For families to adapt well to their child's TBI, a strong social network [45] and having a cohesive family [39] is vital.

In addition, based on the findings from this review, clinicians may want to consider the use of family assessment tools, injury related burden assessment and measures of caregiver distress, adaptability and family cohesion to recognize specific familial needs. Incorporating individual measures of family functioning can assist clinicians in isolating strengths and particular challenges for families, which may lead to new intervention strategies for addressing specific familial needs of this patient population.

Based on the variability in outcomes reported across the studies in this review, more study is needed to better understand what factors mediate and moderate family outcomes, and the strength of associations between factors over time. It may be that certain family functioning domains are critical at different periods of time for families. Further, an exploration of the role health system factors play in family outcomes is important to better understand. For example, it may be that to promote family cohesion rehabilitative programs need to increase accessibility (i.e., times when services are offered, location of services) and offer a range of community-based social support for families. Future research is needed to the impact of key variables on family functioning. To highlight, while most studies in this review [10,17,19,20,22,27] included age at injury in their demographic analysis, none examined the impact of age at injury on family functioning. Furthermore, studies did not address developmental variables [19,20].

Limitations

The limitations of this systematic review relate to the studies themselves. While several of the studies had the potential to offer results based on rigorous method implementation and sample size, they were limited by the risk of bias due to poor accounting of relevant confounding variables. Further, it is important to highlight that the samples in a number of studies were not independent. Most studies [17,19,20,22,27] included in our review used overlapping samples, which either belonged to larger studies or were part of already conducted studies. This limits the generalizability of the studies' findings to a larger population, and highlights the need for more research with other families. Another important study limitation was the percent of study attrition. The drop-out rates were low for four studies [10,19,20,28], but for the remaining studies, it was either high or was not reported [10,17,22,27,29]. It is important to note, that two of the studies that had a lower drop-out rate measured family functioning at two weeks [14] and 3 month post-injury [28], as opposed to the other two studies that measured family functioning at time points that ranged from 3 months to 3 years [19,20]. This indicates that the completion rate of studies may not depend on the longevity of a study. However, high drop-out rates in the majority of studies raises an important methodological concern about representativeness of the study samples. It also draws our attention to vital questions about why some families complete a study, how these families may be structurally and functionally different from families that are prone to withdraw or demonstrate an unwillingness to participate, and what the limiting factors are that preclude families being involved in a study over a longer period of time. Importantly, studies of observational design need to be conducted to rigorously assess care efficiency and the incorporation of outcomes that are vital for families. Multi-site research along with a rigorous research design and critical outcomes for families will provide a solid evidence base to lead clinical and rehabilitative practices. A major limitation of our systematic review relates to the lack of bidirectional influences. Our systemic review specifically focused on the impact of child's TBI on family functioning. Thus, our review does not shed light on the impact of family functioning on a child’s TBI. This is indeed an important question that needs to be examined in future systematic reviews to broaden our understanding of TBI literature.

Conclusions

Moderate to severe TBI has a significant, long-standing impact on family functioning. There are different factors that can be considered to assist with families’ adaptability. The evidence from this systematic review provides a strong platform to understand the parental challenges that arise after a child’s TBI, and guide family-based program development that can positively impact the well-being of children with TBI, their families, and their communities.

References

[1] Anderson VA, Morse SA, Catroppa C, Haritou F, Rosenfeld JV. Thirty month outcomes from early childhood head injury: a prospective analysis of neurobehavioural recovery. Brain. 2004; 127(12): 2608-2620.

[2] Schmidt AT, Hanten GR, Li X, Levin SH. Emotion recognition following pediatric traumatic brain injury: longitudinal analysis of emotional prosody and facial emotion recognition. Neuropsychologia. 2010; 48(10): 2869-2877.

[3] Ganesalingam K, Sanson A, Aanderson V, Yeates KO. Self-regulation as a mediator of the effects of childhood traumatic brain injury on social and behavioral functioning. J Int Neuropsychol Soc. 2007; 13(2): 298-311.

[4] Anderson VA, Catroppa C, Rosenfeld J, Haritou F, Morse SA. Recovery of memory functions following traumatic brain injury in pre-school children. Brain Inj. 2000; 14: 679-692.

[5] Ewing-Cobbs L, Prasad MR, Kramer L, Charles SCJ , James B, Stephen F, et al. Late intellectual and academic outcomes following traumatic brain injury sustained during early childhood. J Neurosurg. 2006; 105(4): 287-296.

[6] Yeates KO. Closed-head injury. In: Yeates KO, Ris MD, Taylor HG, editors. Pediatric Neuropsychology: Research, Theory, and Practice. New York: Guilford Press; 2000. p. 92-116.

[7] Andrews TK, Rose FD, Johnson DA. Social and behavioural effects of traumatic brain injury in children. Brain Inj. 1998; 12: 133-138.

[8] Mangeot S, Armstrong K, Colvin AN, Yeates KO, Taylor H G. Long-term executive function deficits in children with traumatic brain injuries: assessment using the Behavior Rating Inventory of Executive Function (BRIEF). Child Neuropsychol. 2002; 8(4): 271-284.

[9] Kurowski BG, Taylor HG, Yeates KO, Walz NC, Stancin T, Wade SL. Caregiver ratings of long-term executive dysfunction and attention problems after early childhood traumatic brain injury: family functioning is important. PM&R. 2011; 3(9): 836-845.

[10] Wade SL, Taylor HG, Drotar D, Stancin T, Yeates KO. Family burden and adaptation during the initial year after traumatic brain injury in children. Pediatrics. 1998; 102: 110-116.

[11] Degeneffe CE. Family caregiving and traumatic brain injury. Health Soc Work. 2001; 26(40): 257-268.

[12] Perrott S, Taylor HG, Montes J. Neuropsychological sequelae, familial stress, and environmental adaptation following pediatric head injury. Dev Neuropsychol 1991; 7(1): 69-86.

[13] Wade SL, Taylor HG, Drotar D, Stancin T, Yeates KO. Interpersonal stressors and resources as predictors of parental adaptation following pediatric traumatic injury. J Consult Clin Psychol. 2004; 72(5): 7767-7784.

[14] Youngblut JM, Brooten D. Pediatric head trauma: Parent, parent-child and family functioning 2 weeks after hospital discharge. J Pediatr Psychol. 2006; 31: 608-618.

[15] Clark A, Stedmon J, Margison S. An exploration of the experience of mothers whose children sustain traumatic brain injury (TBI) and their families. Clin Child Psychol Psychiatry. 2008; 13: 565-583.

[16] Wade SL, Walz NC, Cassedy A, Taylor HG, Stancin T, Yeates KO. Caregiver functioning following early childhood TBI: do moms and dads respond differently? NeuroRehabilitation. 2010; 27(1): 63-72.

[17] Wade SL, Gerry TH, Yeates KO, Stancin T. Long-term parental and family adaptation following pediatric brain injury. J Pediatr Psychol. 2006; 31(10): 1072-1083.

[18] Yeates KO, Swift E, Taylor HG, Stancin T. Short- and long-term social outcomes following pediatric traumatic brain injury. J Int Neuropsychol Soc. 2004; 10: 412-426.

[19] Rivara JB, Fay GC, Jaffe KM, Polissar NL, Shurtleff HA, Martin KM. Predictors of family functioning one year following traumatic brain injury in children. Arch Phys Med Rehabil. 1992; 73(10): 899-910.

[20] Rivara JM, Jaffe KM, Polissar NL, Fay GC, Liao S, Martin KM. Predictors of family functioning and change 3 years after traumatic brain injury in children. Arch Phys Med Rehabil. 1996; 77(8): 754-764.

[21] Max JE, Castillo CS, Robin DA. Predictors of family functioning after traumatic brain injury in children and adolescents. J Am Acad Child Adolesc Psychiatry. 1998; 37: 83-90.

[22] Stancin T, Wade SL, Walz N, Yeates KO, Taylor HG. Family adaptation 18 months after traumatic brain injury in early childhood. J Dev Behav Pediatr. 2010; 31: 317-325.

[23] Altman DG. Practical Statistics for Medical Research. London: Chapman and Hall; 1991.

[24] Thomas BH, Ciliska D, Dobbins M, Micucci S. Process for systematically reviewing the literature: providing the research evidence for public health nursing interventions. Worldviews Evid Based Nurs. 2004; 1: 176-184.

[25] Jadad AR, Moore RA, Carroll D, Jenkinson C, Reynolds DJM, Gavaghan DJ, et al. Assessing the quality of reports of randomized clinical trials: is blinding necessary? Control Clin Trials. 1996; 17: 1-12.

[26] Jennett B, Bond M. Assessment of outcome after severe brain damage. Lancet. 1975; 1: 480-487.

[27] Bendikas AE, Wade SL, Cassedy A, Taylor HG, Yeates KO. Mothers report more child-rearing disagreements following early brain injury than do fathers. Rehabil Psychol. 2011; 56(4): 374-382.

[28] Youngblut JM, Brooten D. Mother's mental health, mother-child relationship, and family functioning 3 months after a preschooler's head injury. J Head Trauma Rehabil. 2008; 23: 92-102.

[29] Montague, E. Multiple perspectives on functioning of families impacted by traumatic brain injury: exploring both parental and injured child's perceptions. Master [thesis]. New Mexico: The University of New Mexico, 2010.

[30] Miller IW, Bishop DS, Epstein NB, Keitner G I. The McMaster family assessment device: reliability and validity. J Marital Fam Ther. 1985; 11: 345-356.

[31] Mrazek D, editor. Family Global Assessment Scale (FGAS): initial reliability and validity. Proceedings from the 32nd annual meeting of the American Academy of Child Psychiatry; San Antonio (TX): 1985; 23-27.

[32] Burgess E, Drotar D, Taylor HG, Wade SL, Stancin T, Schatschneider C, et al. The Family Burden of Injury Interview (FBII): Reliability and validity studies. J Head Trauma Rehabil. 1999; 14: 394-405.

[33] Stein REK, Jessop DT. PACTS Papers/AECOM: Tables Documenting the Psychometric Properties of a Measure of the Impact of Chronic Illness on a Family. Bronx, NY: Albert Einstein College of Medicine, Department of Pediatrics; 1985.

[34] McCubbin HI, Patterson JM, Wilson L. Family inventory of life events and changes (FILE) Form A. In: McCubbin HI, editors. Family assessment for research and practice. Thompson A. Madison: University of Wisconsin Press; 1980.

[35] Moos RH. The social climate scales: an overview. Palo Alto: Consulting Psychologists Press; 1974.

[36] Rivara JB, Fay G, Jaffe KM, Polissar NL, Martin K, Shurtleff HA, Liao S. Family functioning and children's academic performance and behavior problems in the year following traumatic brain injury. Arch Phys Med Rehabil. 1994; 77(4): 369.

[37] Olson DH, Portner J, Bell R. Family adaptability and cohesion evaluation scores [FACES] II. In: Filsinger EE, editor. Marriage and Family Assessment: A Sourcebook for Family Therapy. Beverly Hills: Sage; 1983. p. 299-315.

[38] Yeates KO, Taylor HG, Drotar D, et al. Preinjury family environment as a determinant of recovery from traumatic brain injuries in school-age children. J Int Neuropsychol Soc. 1997;3: 617-630.

[39] Benn KM, McColl MA. Parental coping following childhood acquired brain injury. Brain Inj. 2004; 18(3): 239-255.

[40] Aitken ME, McCarthy ML, Slomine BS, Ding R, Durbin D, Jaffe K, et al. Family burden after traumatic brain injury in children. Pediatrics. 2009; 123: 199-206.

[41] Roscigno CI, Swanson KM. Parents' experiences following children's moderate to severe traumatic brain injury: a clash of cultures. Qual Health Res. 2011; 21: 1413-1426.

[42] Singer GS, Glang A, Nixon C, Cooley E, Kerns KA, Williams D, et al. A comparison of two psychosocial interventions for parents of children with acquired brain injury: An exploratory study. J Head Trauma Rehabil. 1994; 9 :38-49.

[43]Wade SL, Wolfe CR, Pestian JP. A webbased, problem-solving intervention for families of children with traumatic brain injury. Behavioral Research Methods, Instruction, and Computing. 2004; 36: 261-269.

[44]Wade SL, Wolfe CR, Brown TM, Pestian JP. Putting the pieces together: Preliminary efficacy of a Web-based family intervention for children with traumatic brain injury. J. Pediatr. Psychol. 2005; 30: 437-442.

[45] Ramritu P, Groft G. Needs of parents of the child hospitalized with acquired brain damage. Int J Nurs Studies. 1999; 36: 209-16.

Table 1. Study and Sample Characteristics

Study	**Parent participants (n)**	**Traumatic Brain Injury (TBI)**	
		Child TBI (n)	**Definition**
Bendikas (2011)[27]	Parent dyads (n=147)	Severe (n=14) Mild/Moderate (n=39)	Severe TBI: GCS score ≤ 8. Mild to Moderate TBI: GCS score of 9–12 or a higher GCS score with abnormal neuroimaging. The GCS score assigned to the child was the lowest score recorded post-resuscitation.
Montague (2010)[29]	Parent dyads (n=13)	Not reported	Moderate to Severe TBI: GCS score < 12.
Stancin (2010)[22]	Caregivers (n=99)	Severe (n=23) Moderate (n=63)	Severe TBI: GCS score ≤ 8. Moderate TBI: GCS score of 9–12 or a higher GCS score with abnormal imaging.
Youngblut (2008)[28]	Mothers (n=80)	Critical (n=4) Severe (n=17) Serious (n=15) Moderate (n=27)	Injuries by body region classified on a 6-point severity scale using the AIS: 1 (minor), 2 (moderate), 3 (serious), 4 (severe), 5 (critical), and 6 (maximum).
Youngblut (2006)[14]	Mothers (n=97) Fathers (n=37)	Critical (n=4) Severe (n=23) Serious (n=22) Moderate (n=37)	
Wade (2006)[17]	Parent dyads (n=168)	Severe (n=46) Moderate (n=54)	Severe TBI: GCS score ≤ 8. Moderate TBI: GCS score of 9–12, or a GCS score > 12 accompanied by seizures or other signs of neurological dysfunction, skull fracture, intracranial mass lesion, diffuse cerebral swelling, or documented loss of consciousness for more than 15 minutes.
Wade (1998)[10]	Mothers (90% of child sample)	Severe (n=53) Moderate (n=56)	
Rivara (1996)[20]	Parent dyads (n=81)	Severe (n=18) Moderate (n=20)	Severe TBI: GCS score ≤ 8. Moderate TBI: GCS score of 9–12, or GCS score of 13–15 but achieving a score of 15 after 3 days.
Rivara (1992)[19]	Parent dyads (n=94)	Severe (n=19) Moderate (n=25)	

AIS=Abbreviated Injury Scale; GCS=Glasgow Coma Scale; TBI=traumatic brain injury

Table 2. Study Sample Characteristics

Study	Child's age	Race/Ethnicity, n (%)	Family income	Parental education, n (%)	Mechanism of injury, n (%)
Bendikas (2011)[27]	*Age at injury (yrs), mean (SD)* Severe=4.67 (0.81) Moderate=5.02 (1.21) OI=5.09 (1.09)	*White* Severe=10 (71%) Moderate= 32 (82%) OI= 78 (83%)	*Median income* Severe=$57,107 Moderate=$62,147 OI=$67,357	*≤ High school graduate* Severe=9 (64%) Moderate=20 (51%) OI=39 (41%)	Not reported
Stancin (2010)[22]	*Age at injury (yrs), mean (SD)* Severe=5.0 (1.0) Moderate=5.0 (1.2) OI=5.1 (1.1)	*White* Severe=16 (70%) Moderate= 41 (65%) OI= 90 (77%)	*Median income* Severe=$54,300 Moderate=$57,00 OI=$63,900	*High school graduate/GED* Severe=10 (44%) Moderate=24 (38%) OI=45 (39%) *2 years of college* Severe=6 (26%) Moderate=11 (18%) OI=23 (20%) *4 years college* Severe=1(4) Moderate=12 (19) OI=29 (25)	*Fall* Severe=8 (35%) Moderate=35 (56%) OI=92 (79%) *Motor vehicle crash* Severe=13 (57%) Moderate =21 (33%) OI=10 (9%) *Other* Severe=2 (9%), Moderate=4 (6%) OI=8 (7%)
Youngblut (2008)[28]	*Age of child (mo), mean (SD)* Severe=60.7 (12.3) Moderate=61.7 (16.3)	*White* Severe=10 (47.6%) Moderate=14(51.9%) *Black* Severe=6 (28.6%) Moderate=6 (22.2%) *Hispanic* Severe=5 (23.8%) Moderate=6 (22.2%)	*n (%)* *<$20,000* Severe=4 (19%) Moderate=6 (22.2%) *$20,000 - $50,000* Severe=4 (19%) Moderate=8 (29.6%) *>$50,000* Severe=11 (52.4%) Moderate=13 (48.1%)	*High school graduate* Severe=4 (19%) Moderate=7 (25.9%) *> High school* Severe=8 (38.1%) Moderate=7 (25.9%) *≥ 4 years college* Severe=7 (33.3%) Moderate=6 (22.2%)	*Fall* Severe=10 (47.6%) Moderate=16 (59.3%) *Motor vehicle crash* Severe=5 (23.8%) Moderate=2 (7.4%) *Other* Severe=2 (9.5%) Moderate=0 (0%)
Wade (2006)[17]	*Age at injury (yrs), mean (SD)* Severe=9.5 (2.1) Moderate=9.9 (1.9) OI=9.3 (1.9)	*White* Severe=36 (78%) Moderate=42 (78%) OI=41 (60%)	Median income not reported	Not reported	Not reported
Wade (1998)[10]	*Age at injury (yrs), mean (SD)* Severe=9.4 (2.1)	*White* Severe=53 (75%) Moderate=56 (77%)	Median income not reported	Not reported	Not reported

	Moderate=10 (1.9) OI=9.3 (1.9)	OI=80 (57%)			
Montague (2010)[29]	*Total sample age (yrs), mean (SD)* 14.36 (2.31)	*Total sample* *Hispanic*=7 (50%) *Caucasian*=4 (29%)	*Total sample median income* $43,719	Not reported	*Total sample* *Motor vehicle crash* 7 (50%) *Others* 7 (50%)
Youngblut (2006)[14]	*Total sample age (mo), mean (SD)* 60.1 (14.57)	*Total sample* *White* Mothers=47 (49%) Fathers=15 (40%) *Black* Mothers=32 (33%) Fathers=13 (35%) *Hispanic* Mothers=17 (18%) Fathers=8 (22%)	*Total sample, n (%)* *<$20,000*=19 (26%) *$20,000 - $50,000*=27 (37%) *>$50,000* =27 (37%)	*Total sample* *<High school* Mothers=19 (20%) Fathers=7 (19%) *High school graduate* Mothers=24 (25%) Fathers=7 (19%) *>High school* Mothers=54 (55%) Fathers=23 (62%)	*Total sample* *Fall* 55 (53.9%) *Motor vehicle crash* 15 (14.6%) *Other* 7 (6.9%)
Rivara (1996)[20]	*Total sample age (yrs), n (%)* *<12 years* 55 (68%) *≥12 years* 26 (32%)	*Total sample* *Caucasian* 68 (84%) *Of colour* 13 (16%)	*Total sample, n (%)* *$15,000 - $24,000* 12 (15%) *$35,000 - $54,000* 27 (33%)	*Total sample* *<High school* 12 (15%) *High school/GED* 39 (48%) *College degree* 29 (36%)	*Total sample* *Fall* *26 (*32%) *Motor vehicle crash* 36 (44%) *Other* 5 *(*5%)
Rivara (1992)[19]	*Total sample age (yrs), n (%)* *<12 years* 68 (73%) *≥12 years* 25 (27%)	Not reported	*Total sample, n (%)* *$15,000 - $24,000* 14 (15%) *$35,000 - $54,000* 29 (31%)	*Total sample* *<High school* 4 (4%) *High school/GED* 24 (26%) *College degree* 16 (17%)	*Total sample* *Fall* 28 (30%) *Motor vehicle crash* 41 (44%)

GED: general equivalence degree; OI: orthopedic injury; SD: standard deviation

Table 3. Impact of TBI on Family Functioning

Study	Comparison group	Outcome measure (post-injury measurement)	Study Findings
Bendikas (2011)[27]	Families of children with OI	FAD (6, 12, 18 months)	Fathers endorsed higher levels of global family dysfunction (p<0.001) regardless of the nature or severity of the injury. Time since injury was not significantly related to family functioning.
Montague (2010)[29]	Normative/non clinical sample	FAD (time points not reported)	Parent scores were not different between groups with exception of Roles (p<0.05). Injured children reported more problems in all domains (Problem Solving, Communication, Roles, Affective Involvement, Behavioral Control, and General Functioning).
Wade (2006)[17]	Families of children with OI	FAD (6 months; 1, 4, 5, 6 years)	Greater time since injury (p<0.01) and lower levels of social resources (p<0.01) were associated with a higher family dysfunction. Severe TBI families reported significant family dysfunction than OI families, but only in families with low levels of resources and only at the 4 (p<0.01) and 5 (p<0.01) year post-injury time points.
Wade (1998)[10]	Families of children with OI	FAD (6, 12 months)	At 6 months, 25% of severe TBI families, 11% of moderate TBI families, and 7% of OI families reported dysfunction. At 12 months, dysfunction was not significant across the groups and was comparable (p>0.05).
Rivara (1996)[20]	None	FGAS (3 months; 1, 3 years)	For severe TBI families, there was a slight deterioration at 3 months post-injury (2.8 change on a 100-point scale) and continued deterioration at 1 year (7.4 below pre-injury) and 3 year (8.5 below pre-injury) post-injury.
		FES (3 months; 1, 3 years)	For severe TBI families, greater family coherence was predicted by lower control (r=-.4) and conflicts(r=-.6), and high levels of expressiveness(r=.4), problem-solving(r=.6), utilization of resources (r=.7) and good communication(r=.6).
		FAD (3 months; 1, 3 years)	26% to 69% variation in the 3 year outcomes were determined by pre-injury functioning and severity of the child's injury.

Rivara (1992)[19]	None	FGAS (3 months; 1 year)	There was no change in functioning in moderate TBI families. For severe TBI families, at 3 months there was deterioration in functioning and at 1 year there was further deterioration (mean change from pre-injury was -7.2 on a 100-point scale). Family functioning prior to injury was a strong predictor of family functioning in the year 1 post-injury (R^2=.38 to .68) in comparison to injury severity (R^2=.05 to .09)
		FES (3 months; 1 year)	Good pre-injury family functioning was positively and significantly correlated with better family outcomes at 3 years post-injury.

FAD=Family Assessment Device; FGAS= Family Global Assessment Scale; FES= Family Environment Scale; FILE=Family Inventory of Life Events; OI=orthopedic injuries

Table 4. Impact of TBI on Injury-Related Burden and Stress

Study	**Comparison group**	**Outcome measure (post-injury measurement)**	**Study Findings**
Stancin (2010)[22]	Families of children with OI	FBII (6, 12, 18 months)	Family functioning moderated the association between injury severity and injury-related burden (p<0.05). There was higher burden in moderate TBI families at both high and low levels of family dysfunction than OI families with group differences lessening over time. Severe TBI families had the highest injury-related burden. Moderate TBI families had higher burden than OI families. Burden in moderate TBI and OI families declined over time; the proportion of severe TBI families with severe burden remained stable.
Wade (2006)[17]	Families of children with OI	FBII (6 months; 1, 4, 5, 6 years)	Severe TBI families experienced long-standing injury-related burden compared to moderate and OI families (p≤0.001).
Wade (1998)[10]	Families of children with OI	IOF (6, 12 months)	At the time of injury, burden was greatest for all families. At 6 months, burden was diminished for OI families and declined less sharply for TBI families. At 12 months, families with children with both moderate and severe TBI reported more stress related to child's injury than OI families.
		FBII (6, 12 months)	Severe TBI families reported significantly higher injury-related stress compared to moderate TBI and OI families (p<0.05). Injury-related stress diminished over time in all family groups (p<0.001), and change in injury-related stress over time did not differ significantly among the groups.
Rivara (1996)[20]	None	FIRS (3 months; 1, 3 year)	Severe TBI families experienced substantial negative mean changes in comparison to moderate TBI families in relationships at 3 months (mean = -.3), 1 year (mean =-.7) and 3 years (mean = -.8) post-injury. Severe TBI families experienced substantial negative mean changes in comparison to moderate TBI families in coping resources at 3 months (mean

			= -.3), 1 year (mean =-.6) and 3 years (mean = -.6) post-injury.
		FILE (3 months; 1 year)	Lower levels of family activity (r=.-7) increased stress in severe TBI families.
Rivara (1992)[19]	None	FIRS (3 months; 1 year)	At 1 year, pre-injury coping was a strong predictor of stress for TBI families (r=-.51).
		FILE (3 months; 1 year)	Regardless of the severity level, all families experienced increased chronic psychological strain from 3 months to 1 year post-injury. One third to one half of severe TBI families experienced a moderate to severe amount of strain following the injury.

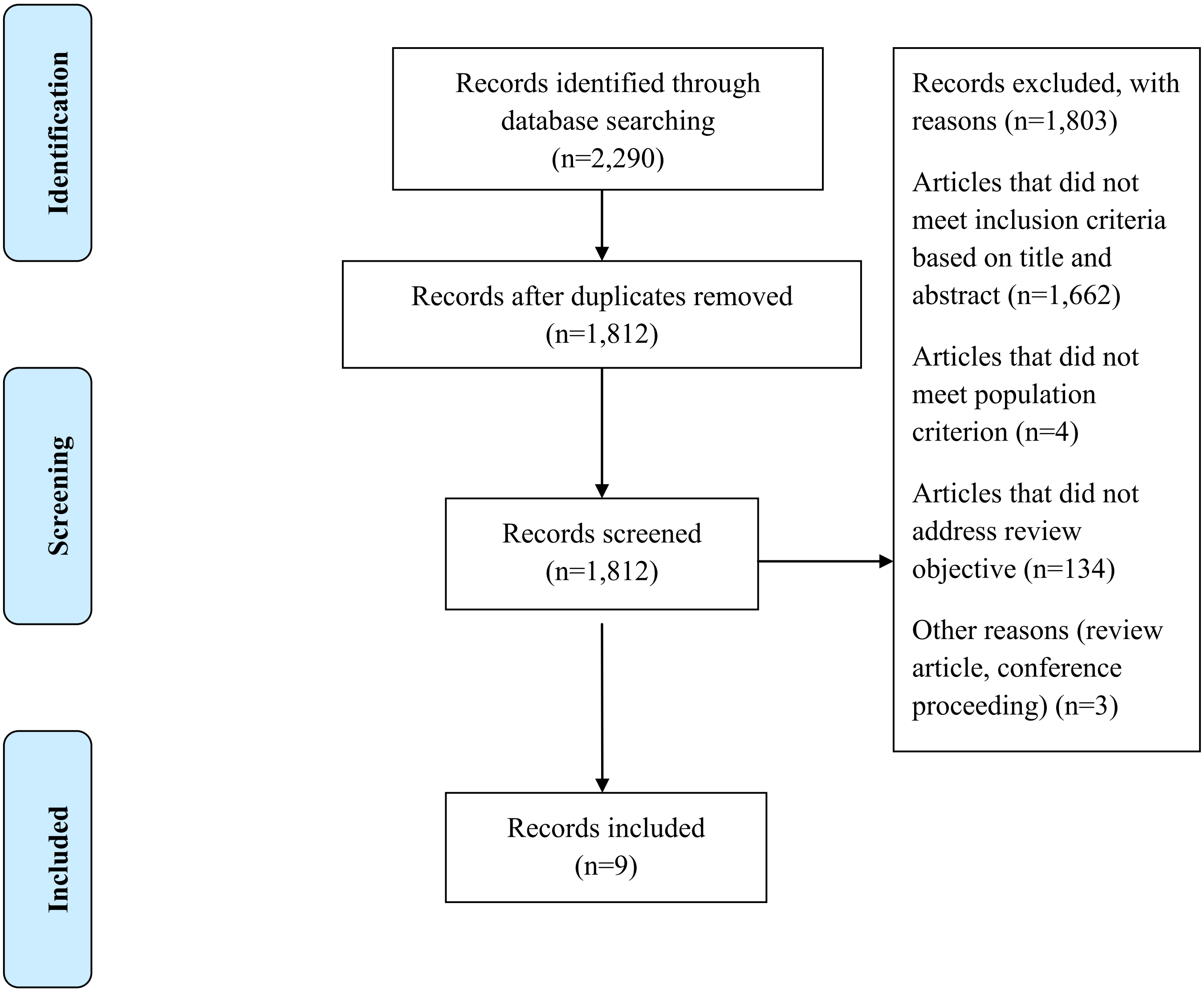
FBII=The Family Burden of Injury Interview; IOF=The Impact on Family (IOF) Scale; FGAS= Family Global Assessment Scale; FIRS= Family Interview Rating Scale; FES= Family Environment Scale; FILE= Family Inventory of Life Events

Table 5. Impact of TBI on Family Adaptability and Cohesion

Study	**Comparison group**	**Outcome measure (post-injury measurement)**	**Study Findings**
Youngblut (2008)[28]	None	FACES II (3 months)	Perceptions of greater family adaptability were related to lower baseline psychological distress (p<0.01), and greater baseline psychological well-being (p<0.05), and social support at 3 month follow up (p<0.01). Perceptions of greater family cohesion were related to lower baseline psychological distress (p<0.01) and being in a two-parent family (p<0.01).
Youngblut (2006)[14]	None	FACES II 2 weeks	Fathers' perceptions of their family's adaptability were not related to injury severity, stressors, parental concern, social support and mental health. Fathers perception of family cohesion correlated with social support at 2 weeks (p<0.05). Mothers' family adaptability was related to more children in the family (p<0.05), greater financial concerns (p<0.01), and greater stress regarding hospital staff behaviour (p<0.01). For mothers, greater family cohesion was related to lower baseline psychological distress (p<0.01) and greater baseline psychological well-being (p<0.01), as well as social supports at 2 weeks (p<0.05) and being in a two-parent family (p<0.05).

FACES II=The Family Adaptability and Cohesion Evaluation Scale

Figure1. PRISMA 2009 Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

Search Strategy

MEDLINE - OvidSP - 1980-present
742 results

1. (((head or crani* or cerebr* or brain* or skull* or intra-cran* or inter-cran*) adj3 (injur* or trauma* or damag*)) or TBI).ti.
2. (brain injur* or head injur*).ti,ab.
3. brain injuries/ or brain injury, chronic/
4. brain damag*.ti,ab.
5. 1 or 2 or 3 or 4
6. Family Health/
7. family relations/ or family conflict/ or exp parent-child relations/ or parenting/ or sibling relations/
8. Family/px
9. *Family/
10. (family function* or family environment* or family relation* or family burden).mp.
11. (family adj3 function*).mp.
12. 6 or 7 or 8 or 9 or 10 or 11
13. 5 and 12

EMBASE - OvidSP 1980 - present
690 results

1. brain injury/ or head injury/ or acquired brain injury/ or brain damage/ or traumatic brain injury/
2. (((head or crani* or cerebr* or brain* or skull* or intra-cran* or inter-cran*) adj3 (injur* or trauma* or damag*)) or TBI).ti.
3. (brain injur* or head injur*).ti,ab.
4. brain damag*.ti,ab.
5. 1 or 2 or 3 or 4
6. exp family relation/
7. family life/ or family coping/ or family functioning/ or family interaction/
8. (family function* or family environment* or family relation* or family burden).mp.
9. (family adj3 function*).mp.
10. *family/ or dysfunctional family/ or family assessment/ or family health/
11. 6 or 7 or 8 or 9 or 10
12. 5 and 11

1 PsycINFO - OvidSP - 1980-present
654 results

1. brain injury/ or head injury/ or acquired brain injury/ or brain damage/ or traumatic brain injury/
2. (((head or crani* or cerebr* or brain* or skull* or intra-cran* or inter-cran*) adj3 (injur* or trauma* or damag*)) or TBI).ti.

3. (brain injur* or head injur*).ti,ab.
4. brain damag*.ti,ab.
5. 1 or 2 or 3 or 4
6. exp family relation/
7. family life/ or family coping/ or family functioning/ or family interaction/
8. (family function* or family environment* or family relation* or family burden).mp.
9. (family adj3 function*).mp.
10. family/ or dysfunctional family/ or family assessment/ or family health/
11. 6 or 7 or 8 or 9 or 10
12. 5 and 11

CINAHL Plus **-** Ebsco
106 results

S3 (S1 AND S2)
S2 ((MH "Family") OR (MH "Family Relations+") OR (MH "Family Functioning+")) OR ("family function*" or "family environment*" or "family burden*" or "family relation*")
S1 (“head injur*" or "brain injur*" or "brain damage" or TBI)
Limiters - Research Articles, Exclude MEDLINE records
Search modes - Find all my search terms

Family Studies Abstracts -Ebsco
77 Results

("head injur*" or "brain injur*" or "brain damage") AND (function* or relation* or burden or environment*)

Scopus
452 Results

(TITLE-ABS-KEY("head injur*" OR "brain injur*" OR "brain damage") AND TITLE-ABS-KEY("family function*" OR "family relation*" OR "family burden" OR "family environment*"))

Proquest Dissertations & Theses
46 results

All (("head injur*" OR "brain injur*" OR "brain damage")) AND all(("family function*" OR "family relation*" OR "family burden" OR "family environment*"))

Web of Science Science Proceedings and Social Sciences Proceedings, Book Citation Index - Science and Social Sciences
9 results
TS=(("head injur*" OR "brain injur*" OR "brain damage")) AND TS=(("family function*" OR "family relation*" OR "family burden" OR "family environment*"))

Child and Adolescent Development
13 results

(("head injur*" OR "brain injur*" OR "brain damage")) AND (("family function*" OR "family relation*" OR "family burden" OR "family environment*"))

Grey Literature in Google
traumatic brain injury , family and pediatric

Chapter 3

Title: The Encounters and Challenges of Ethnography as a Methodology in Health Research

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Abstract

Medical anthropology has existed since the early 1960s, the encounters of ethnography in health research are recent. We will trace key historical markers and highlight several ethnographic studies in health research in this article. In particular, we are interested how aspects of classic ethnographic work have been taken up, and how the use has changed over time, as ethnographies, such as focused ethnographies and other forms of ethnography, have developed in health research. Understandings of culture have shifted and led to re-definitions of culture, and some key elements of ethnographic research have been lost. Ethnographies conducted in health research often do not focus on culture from a broader perspective; instead, the focus is on single health-related issues. Health researchers appear to spend less time in the field, time spent in the field is regarded as less important, and the importance of the context of field notes is underestimated.

Keywords: Culture, ethnography, health care, observation, participant, research, qualitative

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Introduction

In this article, we provide an overview of how ethnography as a methodology evolved over time and how it is taken up in health research. The interest in taking up this challenge emerged from the desire to understand the progression of ethnography as a methodology in health research. We present ethnographic studies to examine how and to what extent ethnographies have been incorporated in health research. We provide a brief history of ethnography and its origin, with a focus on ethnographies that emerged in the field of anthropology in Europe and those that emerged in the era of ethnography in North America, specifically the Chicago School of Ethnography. Looking at this work provides insights on how contemporary forms of ethnographies differ. We then provide an introduction to five major contemporary forms of ethnography, which are extensively used by researchers in the area of health research. Reviewing the range of contemporary forms of ethnography indicates the shift that has occurred in ethnography over time. Further, it shows how difficult it has become to draw specific boundaries in regards to its use. Ethnography is changing and getting popularized in many health scholarships. We also explore future consideration and challenges pertaining to the use of ethnography in health research.

Ethnography in Health Research

The origin of ethnography in health research dates back to the development of a branch of anthropology known as medical anthropology. “Medical anthropology concerns itself with a wide variety of health-related issues, including the etiology of disease, the preventive measures that human members of sociocultural systems have constructed or devised to prevent the onset of disease, and the curative measures that they have created in their efforts to eradicate diseases or at least mitigate its consequences” (Baer, 1997, p. vii). Ethnographic research conducted by anthropologists for many years has included descriptions about health beliefs and practices of different cultural groups (Hill, 1985). For example, Balikci (1963) provided an elaborate account of shamanic practices among the Netsilik. Moreover, Turner (1967) studied rituals for healing among the Ndembu tribe of Africa. Medical anthropologists have also suggested that researchers should incorporate both universal and culturally specific elements of clinical activities in their research (Kleinman, 1981). Brink (2015) who is trained as an anthropologist was one of the first nursing ethnographers engaged in classic ethnographic work.

Medical anthropology emerged in the 1950's and, it was only after World War II that most anthropologists focused directly on health research and issues related to patient and doctor relations (Baer, 1997). A better understanding of patient and heath professional relationships are significant for the healthcare system, since understanding the dynamics of those relations will allow policymakers to provide appropriate information that effectively addresses patients' needs (Goodson & Vassar, 2011). Research conducted by medical anthropologists mainly focused on mental health, public health, biomedical ethics, health improvement, and nursing and global health (Baer, 1997). In addition, medical anthropologists recommended that thorough knowledge acquired by doctors about patients' perception of an illness will enable them to deliver better quality care (Kleinman, 1981).

A huge change in understanding the etiology of diseases and their treatments was also observed at the same time. Hence, traditional medical practices were considered no longer useful in treating modern diseases such as heart related problems, cancer and other injuries (Hill, 1985). New approaches to research and treatments were needed to cure and prevent such diseases. Kleinman was a well-known medical anthropologist in the 1970s. He promoted the need for developing interdisciplinary research teams which collaborate to improve health care (Kleinman, 1981).

In recent years, the focus of many ethnographic researchers and anthropologists has shifted from exploring traditional cultural medical practices to technologically advanced medicine in clinical settings (Geest & Finkler, 2004). In the past three decades ethnographic studies published in health research have increased and ethnographic work has become popular among health researchers (O'Byrne, 2012). Cook (2005) has attributed the increased demand of ethnography in health research to the congruency that exists between the two. In health research the key focus is to understand meanings and patients' experiences of their illness (Morse, 2010). Therefore, researchers suggest that some features (experiences of patients, meanings associated with patients' medical conditions) of the clinical setting are best suited to be examined through methods of data collection such as participant observation common in ethnographic research (Rice & Ezzy, 1999). Ethnography allows researchers to gain deeper cultural knowledge about health and illness (Hodgson, 2000).

The field of medical anthropology has always been rich in ethnographic studies (Bloor, 2002). For instance, there are a vast number of landmark medical ethnographies, including *Boys in White* conducted by Becker, Geer, Hughes, and Strauss (1961). This study particularly focused on understanding the culture of medical students and their day-to-day lives. Another study conducted by Goffman (1961) known as *Asylums* captured the lives and experiences of people in a mental institution. A study conducted by Buckingham, Lack, Mount, MacLean, and Collins (1976) focused on the care provided to dying patients in the general surgical ward/palliative care unit. Buckingham and colleagues explored the topic of family needs using participant observation. These highlighted studies show that ethnography has been a significant methodology in deepening our understanding of health related issues.

Historical Development

The term ethnography emerged from an ancient Greek word for 'folks' (ethnos) and 'written representation' (graphe) (Almagor & Skinner, 2013; Jones, 2010). Ethnography as a field developed at the end of the 19th century and the beginning of the 20th century (Brewer, 2000); it arose primarily in the era of western colonization. In general, ethnography refers to a "formal description of foreign people, their habits, and customs" (Almagor & Skinner, 2013, p.2).

Major ethnographic development was witnessed in Europe, particularly Britain, which included the development of classic ethnographies within the discipline of anthropology (Macdonald, 2002). Renowned ethnographers such as Malinowski, Mead, and Radcliffe-Brown belonged to the field of anthropology (Brewer, 2000). In this era, ethnographic research focused extensively on understanding 'other,' 'primitive,' 'lower culture,' and 'savage' societies (Taylor, 2002; Wolcott, 1999), or an unfamiliar culture. The scope of the research was generally vast and required a long-term commitment to gain an insider's perspective (Richards & Morse, 2007). Many ethnographers travelled long distances where they spent a great deal of time learning about participants' language, understanding unfamiliar ways of life, and most important to be accepted by participants' communities. The primary methods used by ethnographers were interviews, participant observation, and field work to gain an in-depth understanding of their participant's everyday environment and the social meanings attached with being part of a particular culture (Brewer, 2000).

Ethnographers in North America, specifically the work of researchers at the Chicago School of Ethnography (Brewer, 2000; Picken, 2013), contributed and advanced the field of ethnography. It is significant to note that similar to classic ethnographers, the Chicago school researchers were also interested in understanding the ‘other’. However, the focus of researchers from the Chicago school was to examine “the urban ‘other’ where as anthropologist focused on the colonial non-European ‘other’” (Jones, 2010, p.21). Culture is a vital concept to the development of ethnographic anthropology. It is vital to note that there was distinction in how culture was viewed in different disciplines. For instance, sociological and anthropological ethnography have common characteristics but mainly come from distinct traditions. The main subject of investigation in the sociological and anthropological ethnography were groups of people in contrast to psychological and medical research that took the individual as the unit of analysis. Interestingly, health researchers using ethnography often have had a community orientation.

In the beginning, ethnographers were involved in studying underprivileged sections (homeless population, drug dealers, and immigrants) of industrialized cities (Brewer, 2000). A wide range of ethnographic methods were used (Deegan, 2002). For instance, Shaw’s multiple studies on juvenile delinquency in the 1930s exemplified the diversified nature of methods that were used, which included life history or biographical methods. Furthermore, Blumenthal’s (1932) study of small town staff used participant observation methods (Deegan, 2002). Overall, it is evident that the majority of researchers from the Chicago School valued triangulated data, indicating the fact that ethnographies were methodologically more rigorous. In 1990, Brink, one of the first ethnographers in nursing, raised issues of reliability and validity in ethnographic health research studies.

A large number of ethnographies that emerged in the initial stage of ethnographic development in Europe and North America were male oriented (Ardener, 1972; Macdonald, 2002: Jones, 2010). Ethnographers predominately focused on observing male subjects and studied cultures from a single standpoint (Ardener, 1972; Macdonald, 2002). It was only in the 1970's that critics of traditional ethnographic work in anthropology emerged (Macdonald, 2002). The two important areas that were under criticism "included anthropology of women and ethnographic reflectivity" (Macdonald, 2002, p.68). The male centric nature of traditional ethnographic research led most critics to question the universality of their ethnographic work (Macdonald, 2002). In an influential study entitled *Women of Value, Men of Renown* Weiner (1976) examined the position of women in the economic system of Trobriand Island. Weiner's findings suggested that women played a significant role in their communities' economic activities. This study extended the work by Malinowski (1922), whose account of the economic system of Trobriand Island was an incomplete representation.

Often ethnographers' reports were based on representing only small segments of the community (e.g., males). However, the reports that were generated by anthropologists were generalized and were shown to be representative of all the members of a community. Such representational practices resulted in creating silences of some voices, more specifically for woman participants. Following these moments of criticism in the field of ethnography, women, whose voices were silenced in the works of anthropologists, were given more importance. It is vital to note that it was not only women participants whose voices were silent, but also those of female ethnographers. Women's work and their contribution in the field was disregarded and devalued. It was evident that Park, an eminent ethnographer of this era who trained many ethnographers, considered the work of a woman ethnographer Donovan (The saleslady) as not sufficiently academic (Deegan, 2002). Further, Margaret Mead's work entitled as the "Coming of Age in Samoa" was evidence which indicated that regardless of the androcentric nature of the ethnographic work, women continued to contribute to a great extent to the field of ethnography.

In the following section, we will discuss contemporary forms of ethnography that emerged in health research. We want to identify how ethnography has evolved and what might be some of the most important transitions that ethnographers have made in the health sciences. It is important to bear in mind that the contemporary forms of ethnography that we have listed in Table 1 and the studies (examples) in Table 2 are based on an overview of health research and not a systematic review of literature. Our goal was not to conduct a review but rather to critically examine the existing literature to make claims about the progression ethnographic research has made in the health sciences. The Typology in Table 1 was created based on two main criteria: (1) we incorporated ethnography designs used in health research studies that were true to contemporary ethnographic forms, (2) our focus was on health research alone, hence, we did not incorporate existing contemporary forms of ethnography that may be used by researchers in different disciplines. Further, we do not claim that the typology of different forms of ethnography (Table 1) is definitive, as the fluid and ever growing nature of ethnography continues. There are many other forms of ethnography that may be used by the researchers in different disciplines with alternative names (e.g., visual ethnography may be referred to as arts-based ethnography by researchers in other disciplines).

Contemporary Forms of Ethnography

As noted by Boyle (1994) "doing ethnography" has gone through an extensive evolution and has changed significantly. The fact that ethnography has been used by researchers in different disciplines such as medicine, business, public health and nursing (Hughes, 1992) and has been growing in popularity is a noteworthy factor for the diversification of ethnography as a methodology (Boyle, 1994). In addition, O'Byrne (2012) highlighted that ethnography as methodology produced knowledge that was critical for generating health related interventions, which were of significant value to researchers from different disciplines; he concluded that "ethnography becomes a disciplinary and bio-political tool" (p.866) in public health. Furthermore, the field of ethnographic research is diverse and much divided about important factors such as the length and depth of fieldwork, the epistemological/ontological frame work, and data collection (see Table 1 for a comparison of different forms of ethnography). Hence, it is not surprising that a wide range of ethnographic forms are used in health research. In this section, we show the five most common forms of ethnography that have been widely used by researchers involved in health research. We want to emphasize here that we only looked at the most commonly used forms.

Focused Ethnography

Numerous forms of ethnographic practices have been developed including focused ethnography. Focused ethnography is a response to individuals' lives that are "socially and culturally highly fragmented and differentiated" (Knoblauch, 2005, p.1); thus, it is the study of shared experiences of a more confined, pre-determined phenomenon. Important features of focused ethnographies include intense data collection and data analysis, less time spent in the field, occasional participant observation, and technologically advanced (Muecke, 1994; Knoblauch, 2005; Higginbottom, Pillay, & Boadu, 2013). According to Cruz and Higginbottom (2013), focused ethnography is best suited to examine experiences within a culture or a sub-culture in particular settings, such as emergency departments, outpatient clinics or trauma units, as opposed to investigating an entire hospital culture or a community. Furthermore, focused ethnography is pragmatic in nature and offers a proficient means of collecting specific data that is well suited for health care professionals and care providers (Muecke, 1994; Higginbottom et al., 2013). In addition, focused ethnography emphasizes the understanding of participants' perspective (emic or insider perspective). However, emic perspectives are understood from a specific point of view in regards to a culture (Knoblauch, 2005). In comparison, conventional ethnographies emphasize long-term field work, prolonged participant observation and the involvement of larger unknown communities (Hammersley & Atkinson, 1995; Picken, 2013; Atkinson & Hammersley, 1998).

Critical Ethnography

Critical ethnography "is a way of applying a subversive worldview to the conventional logic of cultural inquiry. It does not stand in opposition to conventional ethnography. Instead, it offers a more direct style of thinking about the relationships among knowledge, society and political action" (Thomas, 1993, p. vii). There are numerous similarities between critical ethnography and conventional ethnographies in terms of how data is collected, methods used to collect data and the interpretation of data (Thomas, 1993). It is equally important to underline the distinct features of critical ethnography and conventional ethnography. The central question examined by critical ethnographers is "what could be" whereas conventional ethnographers mainly examine "what is" (Thomas, 1993; Carspecken, 1996). The type of questions examined by critical ethnographers are engraved with political purpose, understanding the depth of social problems with the goal to eradicate power imbalances in a particular culture (Madison, 2012). The main goal of critical ethnography is to understand a culture with the intent to bring about change in the society. Whereas, in conventional ethnography, the main goal is to merely acquire understanding of a particular culture (Thomas, 1993). In critical ethnography the researcher plays a role of advocate for the population under study. As Thomas (1993) noted, critical ethnographers often speak *on behalf* of participants to ensure that participant voices are heard. Critical ethnographers advocate for reflexivity as an important practice that allows researchers to explicitly lay out their subjective opinions that might influence their data interpretation (Thomas, 1993; Lincoln & Guba, 1985). For critical ethnographers the "dynamic and mutual influence of ethnographer and research field on each other is referred to by the term *reflexivity*" (Muecke, 1994, p. 194).

Autoethnography

Historically, autoethnography emerged from the field of anthropology. "Autoethnography shares the storytelling feature with other genres of self-narrative but transcends mere narration of self to engage in the cultural analysis and interpretation" (Chang, 2008, p. 43). A vivid distinction between conventional ethnographers and autoethnographers is presented in the excerpt below:

> We [autoethnographers] think of ethnography as a journey; they [analytical ethnographers] think of it as a destination. Caring and empathizing is for us [autoethnographers] what abstracting and controlling is for them [analytical ethnographers]. We [autoethnographers] want to dwell in the flux of lived experience; they [analytical ethnographers] want to appropriate lived experience for the purpose of abstracting something they call knowledge or theory (Ellis & Bochner, 2006, p. 431).

Autoethnographers are involved in examining their personal experiences in broader external social and cultural contexts; they also examine their self in a "narrow-inward" manner by looking at how cultural interpretations impact their sense of self (Given, 2008).

The existence of personal stories or experiences is essential in understanding oneself in the context of a culture, by comparing personal experiences with others in the same domain, which increases learning from such experience (Ellis, 2004). Autoethnographers write about the most distinct incidences they encounter, experiences that were profound and had life changing meaning (Ellis, 2011). Autoethnographers, on the contrary, mainly evaluate their significant experiences that are related and linked to a culture. While doing so, autoethnographers must connect these to experiences of others in a similar cultural context (Ellis, 2011). There are several intersections between conventional ethnography and autoethnography. For example, both examine how data is collected, the methods of data collection, data interpretation, as well as verification of data through the method of 'triangulation' (Chang, 2008). In sum, the focus in autoethnography is on the personal narratives of people, which are examined in a particular cultural context.

Institutional Ethnography

In institutional ethnography, the focus is on understanding the link between institutions and peoples' experiences. "Institutional ethnography is a method of inquiry that investigates how everyday experiences are coordinated by work done with texts in organizations" (Walby, 2013, p. 141). Therefore it is not the people themselves who are the object of inquiry; rather the institution and their experiences are the target of the investigation (Smith, 2005). Guiding questions that are of interest to an institutional ethnographer are "how does this happen as it does? How are these relations organized?" (Campbell & Gregor, 2002, p. 7). The major theoretical underpinnings emerge from Marx's work and feminist discourses; institutional ethnography also begins with people, their work, and the conditions in which they work (Given, 2008). The rationale behind examining texts is to get an in-depth understanding of how these texts impact the working process of individuals and how it coordinates action among institutions (Mills, 2010). Institutional ethnographers engage in a phenomenon known as 'data dialogue'. 'Data dialogues' occur at two levels (Smith, 2005): the initial stage occurs between the interviewer and the participant who is being observed by the researcher, while at the second level, the dialogue is between the researcher and the text (the transcript/ field notes).

The concept of data dialogue is parallel to the methods of data collection and data analysis used by conventional ethnographers. Once the data is collected the researcher then immerses him- or herself in the text (transcripts /field notes) to look for patterns and themes in their textual data. In explaining the ontological underpinnings of institutional ethnography, Smith (2005) proposed that no individual can be objective since we live in a world of experiences. Smith does not view subjective experiences as undesirable biases; instead, she sees them as vital in shaping our understanding of experiences (Slade, 2010). Institutional ethnography has been used in health research to explore wide range of health related issues ranging from understanding nurses' stress (McGibbon, Peter, & Gallop, 2010) to understanding the production of health care disparities (Sinding, 2010).

Visual Ethnography

During the 1960s to the1980s there was some skepticism expressed by researchers in terms of "whether visual images and recordings could usefully support the observational project of social science" (Pink, 2013, p. 19). The criticism of visual data was based on its lack of meeting standard requirements of social sciences. This was primarily because it was open-ended, unstructured, unsystematic and not objective in nature (Brewer, 2000; Pink, 2013); some have refuted critics by stating that only subjective methods are capable of capturing meanings that shape the everyday lives of people (Hammersley & Atkinson, 1995).

Photographs have been utilized by ethnographers as a major method for data collection, with cameras being the most important element of the 'tool kit' of ethnographers in the 1920s (Pink, 2007). There is no set criterion to determine whether a photograph is ethnographically rich or poor. The analysis of photographic content depends on a number of factors including context, time, who is analyzing them, and when they are being analyzed (Pink, 2013). These aspects are subjective and ambiguous; ambiguity is not viewed as a lax quality "rather, [it is viewed as] multiple meanings negotiated by viewers [which] can be mined for the rich data they yield" (Schwartz, 1989, p.122). Recently, *Photovoice* has gained popularity among ethnographers. It allows participants the flexibility and privacy to photograph certain experiences of their life. This technique could serve two important purposes: first, it assists in resolving the ethical dilemma associated with disrupting a participant's private space, since the participants are free to photograph themselves rather than a researcher. Second, participants and researchers are actively involved in analyzing the photos but with more importance given to the participants' analysis, which will help understand the photographs from the participant's perceptive (Given, 2008).

The use of videos as a vital source of data collection was popularized in the 1980s (Given, 2008) after the technological revolution that gave rise to complex and intricate visual methods (Lomax & Casey, 1998). As Pink (2007) proposed, it is now commonly recognized that videos are not only used to record data but "as a medium through which ethnographic knowledge is created" (p.96). Videos are significant in analyzing the data by enabling an ethnographer to understand fine details about the social and cultural aspects of participants' activities (Heath, Luff, & Sanchex, 2007). Furthermore, the use of videotaping helps ethnographers in capturing the broader array of behavioral data, which is difficult to collect via traditional methods. Nonverbal data such as facial expressions are crucial for interpretation of informants' responses and they can also crystallize the analysis of interviews and field notes. Contextual knowledge is essential in enhancing our understanding (Knoblauch & Schnettler, 2012). Yet, disadvantages of audiovisual methods of data collection remain. Technologically advanced methods of data collection such as cameras are costly and easily noticed (Nastasi,1999).

Looking Across Ethnographic Approaches and Research Studies

We have developed two tables for this article. In Table 1, we highlight some of the main components of the five main forms of ethnography that have been of most interest to researchers in health research. From Table 1 it is evident that the main epistemological and ontological underpinnings of each from of ethnography are distinct; hence, making them diverse in nature. With such diversification, it is not surprising that there is greater variability in how different methods of data collection are tailored to the basic purpose of these ethnographic forms. It is remarkable to note that the modern forms of ethnographies incorporate the basic methods of data collection (interviews, participant observation, and field notes). In terms of functionality these methods differ, because the methods are to a great extent based on the form and main purposes of the type of ethnography a researcher wishes to use. For example, in focused ethnography the use of participant observation is of short duration and time intensive and in autoethnography participant observation might be entirely overlooked. Further, additional approaches such as visual ethnography and institutional ethnography have resulted in enriching the methods of data collection in ethnographic works in health research. For example, in institutional ethnography there is textual analysis, and in visual ethnography there are photovoice or images of everyday life that are the main sources of data collection.

In Table 2, we provide examples of ethnographies in health research. We have selected these studies to show examples of each form of ethnography used in health research. Studies presented in this table were selected based on the methods of data collection, described to provide a comprehensive picture of how different forms of ethnography are incorporated in current health research. The examples of this table also highlight that there is tremendous variability and flexibility in how the methods of data collection can be used. This flexibility might be viewed as a positive feature, because it allows the researcher to use the best method of data collection for their studies. Alternatively, it could also be argued that there is lack of standardized methods of data collection due to the versatile nature of this methodology. From the studies in Table 2, it is apparent that diverse approaches to data collection are used in health research. Each of these approaches involves different techniques. With technological development, studies in health research are depending on modern techniques as means of data collection. Recent studies in health research have used a wide range of advanced techniques to collect data, such as DVD, video recordings (Liu, Manias, & Gerdtz, 2012; McCabe, & Holmes, 2012) and picture/snapshots (Gates, Lackey, & Brown, 2001), Further, journal entries (White & Seibold, 2008), written reflections of the participants' experiences (Bright, Boland, Rutherford, Kayes, & McPherson, 2012) and reflexive focus groups (Lui et al. 2012) are being used as a major sources of data collection in ethnographic health research studies. The use of multiple methods enhances the trustworthiness (i.e., accuracy) of the data collected and guides the ethnographer in making decisions as the study progresses. It is critical to note that the use of the above mentioned methods for ethnographic data collection was not only present in the works of classic ethnographers such as Malinowski, but continues to be utilized in health research.

Future Considerations /Challenges

Blurring of the Field

Field work is an important element of ethnographic research. It is apparent that ethnography as a methodology has progressed and continues to grow. However, with the evolution of ethnography, the dynamic of field work has changed extensively. Researchers in health disciplines do not divulge much about their field work. Vital questions about the field work that are often undermined in ethnographic health research are: how was the field work conducted? What part of the data comes from the field notes? Why and what elements of the research was captured in the field work, which was not achieved through the interviews? As pointed out by Brink in 1990 these questions are related to issues of reliability and validity.

The majority of the studies noted in Table 2 do not reveal much about the field aspects that were undertaken. This might be indicative of the fact that the value of field work is not acknowledged in existing health studies (Bright et al., 2012; Carroll, Iedema, & Kerridge, 2008; Braaf, Manias, & Riley, 2014: Gustafsson, Kristensson, Holst, Willman, & Bohman, 2013). From the studies in Table 2, it becomes apparent that health researchers use the most convenient from of ethnography to explore a particular phenomenon. For instance, focused ethnography used in heath research studies (Gagnon, Carnevale, Mehta, Rousseau, & Stewart, 2013) is quick and convenient in design and autoethnographic design (White & Seibold, 2008) often does not integrate long and complicated field work at all. This may be viewed as a positive aspect of modern ethnography, as ethnography is becoming more manageable as a methodology, which may reflect modern research standards and demands. It is evident that new forms of ethnographies used in health research studies (such as Bright et al., 2012) do not incorporate a wide range of conventional ethnographic features and often result in less time spent in the field. Furthermore, ethnographers are no longer in surroundings that are neither geographically distant nor unknown. They often engage in narrow research topics conducted in familiar surroundings and issues. Time spent in the field is of great importance in ethnographic research and the length of time spent in the field will help the researcher understand their participant's life from a wider range of angles (Boyle, 1994). Nevertheless, this aspect of field work is often disregarded in the current literature. Perhaps this is a reminder of the era of ‘armchair anthropologists’ who worked simply by re-evaluating text books and other archives to understand distinct and unknown cultures in a more convenient manner.

Context

Another issue that is critical in ethnographic work is the context and contextual analysis. Context provides a comprehensive picture of particular issues that are being investigated. It is vital information to correctly analyze the data collected through interviews and observations. To illustrate this point in our own study [unpublished, study ongoing] of parents who have a child with traumatic brain injury, we realize that our potential data and the recommendations we intend to produce will only make sense if presented in the light of extensive contextual background information. “In fact, without contextualization, interpretation of the specialized finding can be dangerously narrow and unethical (the high tolerance of certain cultural group to pain stimuli comes to mind as an example)” (Thorne, 1991, p.182). Solid contextualization will avoid misrepresentation of the participant’s meanings and purposes. We believe that ethnographic work conducted in health research must focus more on contextual components of the data. Researchers who conduct ethnographies in health research might not explicitly state the context in which their data was analyzed (Bright et al., 2012; Kidd & Finlayson, 2010; Carroll et al., 2008; Braaf et al., 2014). Researchers also avoid elaborating on the important contextual question such as: what was the context in which the participant made a statement about the phenomenon under study? Why did they make the statement? What is the main contextual base for driving the study’s themes and sub themes? While researchers provide quotes taken directly from the original data and provide a direct analysis of their quotes, they often avoid contextual background information. Health researchers who conduct ethnographies need to focus on contextual data as much as they focus on what was said.

Missing Depth of Ontological/Epistemological Underpinnings

We have examined a large body of literature in health research which indicates that qualitative studies conducted in health research have overlooked the importance of their ontological and epistemological underpinnings (McCabe & Holmes, 2013; Bright et al., 2012; Kidd & Finlayson, 2010; Carroll et al., 2008; Braaf et al., 2014; Pino, Soriano, & Higginbottom, 2013). Epistemology is the theory of understanding. It is focused on the "relation between the knower and what can be known" (Guba & Lincoln, 1994, p. 108). Ontology focuses on the nature of reality by exploring questions such as what is a reality and how does it function? (Guba & Lincoln, 1994). Therefore, we recommend that researchers pay more attention to elaborating on the ontological and epistemological foundations of their research methods. We note that there is a lack of balance between background and methodology in published ethnographic studies. Researchers should be explicit about their ontological and epistemological stance to better understand the perspective from which they explore and find answers for their research question. Many authors claim that their study is a 'focused ethnography', even though methodological background information commonly focuses on 'qualitative methods' or 'ethnography', in a general manner (Magilvy, McMahon, Bachman, Roark, & Evenson, 1987; Pino et al., 2013; Gustafsson et al., 2013). In conclusion, we recommend that health researchers conducting ethnography be more explicit in detailing their "tradition and paradigm of inquiry" (O'Byrne, 2007, p. 1389).

Re-defining Culture

Since the evolution of ethnography, the meaning of culture has changed. Traditionally, ethnographers explored culture in a broad context. They learned about ethnicity, religious activities and languages of entirely different communities. Inter-cultural differences (differences within cultures) (Fetterman, 2010) were crucial factors for ethnographers. More recently, ethnographers have attended more closely to exploring specific cultures within a broader range of cultures or intra-cultural diversity (examination of subcultures within a culture) (Fetterman, 2010). Similarly, existing ethnographic health research listed in Table 2, (Bright et al., 2012; Carroll et al 2008; Braaf et al., 2014: Gustafsson et al., 2013) does not focus on culture from a broader perspective. For example, in health research the focus is often on a single issue such as understanding experiences of patients with chronic pain (White & Seibold, 2008), exploration of a deaf identity (McIlroy & Storbeck, 2011), or exploring issues of case managers for older persons with multi-morbidity (Gustafsson et al., 2013). This trend was not apparent in classic ethnographies, where the focus was on exploring a whole culture rather than a specific issue. Culture is a core concept in ethnographic research.

Culture has been defined in many different ways by anthropologists. In fact, more than 60 years ago two anthropologists, A. Kroeber and C. Kluckhohn (1952), reviewed all the definitions to date and they numbered in the hundreds. There has been a lot of criticisms of the use of the term 'culture' but most anthropologists continue to use it in a very general way, to refer to ideas, attitudes, values, etc. learned by humans in the course of growing up in a particular community and affecting the way people behave. Human behavior is of course shaped by human biology and is therefore shared by many if not all societies, hence 'culture' tends to be applied to things that vary between societies and which therefore cannot be entirely determined biologically--e.g. what people consider proper food, what times of the day they eat, or with whom they eat. The understanding of culture has become more intricate with the development of different forms of ethnography and theories that emerged in recent years. According to Nuckolls (1998), culture is a problem that can never be resolved, mainly because of its paradoxical nature (individualist / collectivist). This paradoxical element of culture ultimately forces people to compromise with opposing ideas and results in development of new and different forms of defining what culture is. Hence, it is not surprising that there is still an ongoing debate about the concept of culture and how problematic it is among contemporary ethnographers. According to some contemporary ethnographers, culture is viewed as an overly simplistic concept, suggesting an essentialized point of view, a view that recognises that culture is unique to specific social groups while undermining divisions within groups. Culture was and continues to be a contentious concept in ethnography.

Ethics

Ethnographers emphasize that ethical procedures are integral to all aspects of an ethnographic study (Lincoln & Guba, 1985). A substantive amount of attention is given to ethical considerations regarding participants of research studies. However, the issue of ethics extends beyond a consent form, assuring participants that their privacy and confidentiality of information is fully maintained. Studies in health research (Kidd & Finlayson, 2010; Carroll et al 2008; Gagnon et al., 2013) do pay close attention to the requirements involved for appropriate informed consent demanded by institutional review boards. However, approval granted by the institutional review boards does not always mean that ethical issues, which health researchers might encounter are fully addressed.

Health researchers who conduct ethnography often enter an ‘unknown zone’ where they are not aware of what they are looking for or what to expect (Fine, 1993). Hence, spending time in the field, interacting with members of the group, is the best way to gain insight to the phenomenon under consideration (Warr, 2004). This provides context-dependent understanding and allows a better sense of the data collected. The point we want to make here is that it is not surprising that health researchers are often faced with ethical dilemmas. Ethnographers often become much immersed in their data and come to know participants well. Due to their close connections, ethical questions are often encountered. Some of these questions are: How much information can be included in final research texts that are publically accessible? To what extent will the exposure put their participant’s identity in jeopardy, particularly when conducting ethnography on a sensitive topic? Many ethnographers also raise concern about how to give voice to participants in their data? Other questions might include: whose property is the data an ethnographer collects?

However, we found health researchers conducting ethnographic research rarely discuss ethical concerns that they might have encountered during the conduct of their research (Liu et al., 2012; Bright et al., 2012; Kidd & Finlayson, 2010; Carroll et al 2008; Braaf et al., 2014; Pino et al., 2013; Gates et al., 200). In ethnographic research, extensive efforts need to be made to attend more closely to ethical dilemma researchers face while conducting their research. We note that this factor is greatly undermined in the current health literature.

Rigor

Tremendous efforts have been made by classic ethnographers to produce rigorous ethnographic work and this trend continuous in ethnographies produced in health science research. Ethnographic work published in health research show researchers have extensively attended to the issue of rigor in regards to their data. To ensure rigor in their studies, we found that researchers in health research focus on using following wide range of criteria: (1) Triangulation, (2) prolonged engagement, (3) peer debriefing, (4) member checking, (5) thick description and (6) reflexivity.

Researchers often engage in activities such as prolonged engagement, triangulation, and peer debriefing. Triangulation means using different styles of data collection such as observation, photographs, and field notes. Triangulation (Townsend, 1996; Gustafsson et al, 2013; McElroy et al., 2011; Liu et al., 2012; Pesut & Reimer-Kirkham, 2010) and prolonged engagement (Braaf et al., 2014; Liu et al., 2012) were used by health researchers to account for the reliability of their study. Using prolonged engagement and triangulation as approaches for data collection will also serve the purpose of establishing credibility. Further, prolonged engagement will help participants become comfortable with the researchers' presence in their natural settings (McElroy et al., 2011; McCabe & Holmes, 2013).

Peer debriefing is a common technique adopted by health researchers to establish credibility (Braaf et al., 2014; McGibbon et al., 2010; Gates, Lackey, & Brown, 2001). It is significant to note that member checking was widely used in the health research literature to account for rigor (Braaf et al., 2014; Pino et al., 2013; O'Mahony & Donnelly, 2012; Liu et al., 2012; Magilvy et al., 1987).

Thick description was integrated in the majority of the health research studies we reviewed to demonstrate rigor (McCabe & Holmes, 2013; Mahon, 2014; Siddique, 2012; Liu et al., 2012). According to health researchers, thick description of a study and its use in the process of coding is essential as it facilitates contextual evaluation of the data (McCabe & Holmes, 2013; Mahon, 2014). However, several researchers question the transferability/ generalizability of ethnographic findings. For example, Willis (2010) raised issues about the reliability and validity of ethnographic data. Willis (2010) argued that "ethnographers become frozen in time as is his or her account of events in the field" (p.556). Furthermore, Willis (2010) believed that when we return back to the participants for verification, our minds are still frozen in our data whereas, our participants have moved on in their lives. We encountered this issue in our own study examining parental experience of those who have a child with traumatic brain injury [unpublished, study ongoing]. A participant declined to revisit and talk about the initial stage of their child's injury because she has "put it behind them".

Qualitative research has been criticized by the lack of 'objectivity' and the potential influence of the researcher on the data (Ahern, 1999). To help minimize the effects of researcher bias throughout the study, an informal journal of researchers' experiences, views and judgments must be kept (O'Mahony & Donnelly, 2012). The journal is a way to practice reflexive processes. Reflexivity is the ability to note one's personal feelings and preconceptions and be able to think critically about them in relation to the research being conducted (Ahern, 1999). Several health science ethnographic studies (McCabe & Holmes, 2013; Mahon, 2014; Bright et al., 2012; Siddique, 2012; Kidd & Finlayson, 2010; Carroll et al., 2008) have acknowledged the critical role of reflexivity.

Although rigor has been addressed in health research however, the focus on the quality of data and understanding rigor as a process has been undermined. One of the first steps to ensure rigor is by determining methodological congruence (Richards & Morse, 2007). This means evaluating the fit between the various components of the study design. For example questions can be asked: Does the methodology and subsequent methods fit with the research question? Does the type of strategy for data generation fit with the chosen methodology, and is the analysis congruent with the strategy? (Richards & Morse, 2007). However, current health research studies (Gustafsson et al., Bright et al., 2012; Carroll et al 2008; Braaf et al., 2014), to a greater extent, undermine such vital questions in their research design section.

Conclusions

We show that classic ethnographic work has been increasingly taken up in different ways in health research and ethnography as a methodology has changed over time. While new forms of ethnographies have developed as a response to shifting understandings and to re-definitions of culture, some key elements of ethnographic research have been lost. A close examination of multiple ethnographic studies suggests that ethnography continues to be important in the field of health research. There are different contemporary forms of ethnography that have emerged in health research (see Table 1). Ethnography as an approach to research has been in a constant state of development since the 19th century and much of this article points to the many changes over time and that ethnography as a methodology is in constant flux. Health researchers have made ethnography into a more standardized methodology. However, on the other hand, ethnographic that were used traditionally are disappearing. It can be concluded that ethnography is an intricate methodology and with the passage of time it has become multifaceted in nature. However, with all this evolution of ethnography, we fear that it is losing some it is core elements, including the loss of the appreciation of extensive and long term field work.

References

Ahern, K. J. (1999). Ten tips for reflexive bracketing. *Qualitative Health Research, 9,* 407-411. doi:10.1177/104973239900900309

Almagor, E., & Skinner, J. (2013). *Ancient ethnography: New approaches.* London: Bloomsbury Publishing PIc.

Ardener, E. (1972). Belief and the problem of women. In J. L. Fontaine (Ed.), *The interpretation of ritual* (pp. 135-157). London: Tavistock.

Atkinson, P., & Hammersley, M. (1998). Ethnography and participant observation. In N. K. Denzin &Y. S. Lincoln (Eds.), *Strategies of qualitative inquiry* (pp. 110-136). London: Sage.

Baer, H. A., Singe, M., & Susser, I. (1997). *Medical anthropology and the world system.* USA: Bergin & Garvey.

Balikci, A. (1963). Shamanistic behavior among the Netsilik Eskimos. *Southwestern Journal of Anthropology, 19*(4), 380-396. Retrieved from http://www.jstor.org/stable/3629285

Becker, H. S., Geer, B., Hughes, E. C., & Strauss, A. L. (1961). *Boys in White: Student culture in medical school*. Chicago: University of Chicago Press.

Bloor, M. (2002). The ethnography of health and medicine. In P. Atkinson, D. D. Coffey, J. Lofland, & L. Lofland (Eds.), *Handbook of ethnography* (pp. 177-187). London: Sage Publications Ltd.

Boyle, S. J. (1994). Styles of ethnography. In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 159-185). Thousand Oaks, CA: Sage Publications.

Braaf, S., Manias, E., & Riley, R. (2014). The ‘time-out’ procedure: An institutional ethnography of how it is conducted in actual clinical practice. *BMJ Quality & Safety*, *22*, 647-655. doi:10.1136/bmjqs-2012-001702

Brewer, D. J. (2000). *Ethnography.* Philadelphia: Open University Press.

Bright, F. A. S., Boland, P., Rutherford, S. J., Kayes, N. M., & McPherson, K. M. (2012). Implementing a client-centered approach in rehabilitation: An autoethnography. *Disability & Rehabilitation, 34*(12), 997-1004. doi:10.3109/09638288.2011.629712

Brink, P. (1990). Issues of reliability and validity. In J. M. Morse (Ed.). *Qualitative nursing research: A contemporary dialogue* (pp. 164 – 186). London: Sage.

Brink, P. (2015). Experiences of a nurse ethnographer: From student to faculty. In M. de

Chesnay (Ed.). *Nursing research using ethnography: Qualitative design and methods in nursing education* (pp. 121-138). New York: Springer.

Buckingham, R. W., Lack, S. A., Mount, B. M., MacLean, L. D., & Collins, J. T. (1976). Living with the dying: Use of the technique of participant observation. *Canadian Medical Journal*, *115*, 1211-1215. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/63313

Campbell, M., & Gregor, F. (2002). *Mapping social relations: A primer in doing institutional ethnography*. Toronto, Canada: Garamond Press

Carroll, K., Iedema, R., & Kerridge, R. R. (2008). ICU ward round practices using video-reflexive ethnography. *Qualitative Health Research*, *18*(3), 380-390. doi:10.1177/1049732307313430

Carspecken, P. F. (1996). *Critical ethnography in educational research: A theoretical and practical guide.* New York, NY: Routledge.

Chang, H. (2008). *Autoethnography as method.* Walnut Creek, CA: Left Cost Press Inc.

Cook, K. E. (2005). Using critical ethnography to explore issues in health promotion. *Qualitative Health Research*, *15*(1), 129-138. doi: 10.1177/1049732304267751

Cruz E.V., & Higginbottom, G. (2013). The use of focused ethnography in nursing research. *Nurse Researcher*, *20* (4), 36-43. Retrieved from http://dx.doi.org/10.7748/nr2013.03.20.4.36.e305

Deegan, M. J. (2002). The Chicago school of ethnography. In P. Atkinson, D. D. Coffey, J. Lofland, & L. Lofland (Eds.), *Handbook of ethnography* (pp. 11-25). London: Sage Publications Ltd.

Ellis, C., Adams, T. E., & Bochner, A. P. (2011). Autoethnography: An Overview. *Qualitative Social Research, 12*(1), 10-17. Retrieved from http://nbn-resolving.de/urn:nbn:de:0114-fqs1101108

Ellis, C. (2004). *The ethnographic I: A methodological novel about autoethnography*. Walnut Creek, CA: AltaMira Press.

Ellis, C., & Bochner, A. P. (2006). Analyzing analytic autoethnography: An autopsy. *Journal of Contemporary Ethnography*, *35*(4), 429-449. doi:10.1177/0891241606286979

Fetterman, M. D. (2010). *Ethnography: step-by-step*. California: Sage Publications Inc.

Fine, G. A. (1993). Ten lies of ethnography. *Journal of Contemporary Ethnography*, *22*(3), 267-294. doi:10.1177/089124193022003001

Gagnon, A. J., Carnevale, F., Mehta, P., Rousseau, H., & Stewart, D. E. (2013). Developing population interventions with migrant women for maternal-child health: A focused ethnography. *BMC Public Health*, *13*(1), 471-485. doi:10.1186/1471-2458-13-471

Gates, M. F., Lackey, N. R., & Brown, G. (2001). Caring demands and delay in seeking care in African American women newly diagnosed with breast cancer: An ethnographic, photographic study. *Oncology Nursing Forum, 28* (3), 529-537. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/11338760

Geest, S., & Finkler, K. (2004). Hospital ethnography: Introduction. *Social Science & Medicine*, *59*, 1995-2001. doi:10.1016/j.socscimed.2004.03.004

Given, L. M. (2008). *The Sage encyclopedia of qualitative research methods.* California: Sage Publications Inc.

Goffman, E. (1961). *Asylums: Essays on the social situation of mental patients and other inmates.* New York: Doubleday.

Goodson, L., & Vassar, M. (2011). An overview of ethnography in healthcare and medical education research. *Journal of Educational Evaluation for Health Professions, 8*(4), 1-5. doi:10.3352/jeehp.2011.8.4

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research, In N. K. Denzin & Y. S. Lincoln (Eds), *Handbook of Qualitative Research* (pp. 105-117). London: Sage

Gustafsson, M., Kristensson, J., Holst, G., Willman, A., & Bohman, D. (2013). Case managers for older persons with multi-morbidity and their everyday work -- A focused ethnography. *BMC Health Services Research*, *13*, 1-15. doi:10.1186/1472-6963-13-496

Hammersley, M. & Atkinson, P. (1995). *Ethnography principles in practice.* London: Routledge.

Heath, C., Luff, P., & Sanchex Svensson, M. (2007). Video and qualitative research: Analysing medical practice and interaction. *Medical Education, 41*, 109-116. doi:10.1111/j.1365-2929.2006.02641.x

Higginbottom, G. A., Pillay, J. J., & Boadu, N. Y. (2013). Guidance on performing focused ethnographies with an emphasis on healthcare research. *The Qualitative Report*, *18*, 1-16. Retrieved from http://files.eric.ed.gov/fulltext/EJ1005013.pdf

Hill, C. E. (1985). Introduction: Continuity and differences in the old and the new applied anthropology. In C. E. Hill & W. L. Partridge (Eds.), *Training Manual in medical anthropology* (pp. 1-7). Washington: American Anthropology Association.

Hodgson, I. (2000). Ethnography and health care: Focus on nursing. *Qualitative Social Research, 1*(1), 7-14. doi:0114-fqs000172

Hughes, C. C. (1992). "Ethnography": What's in a Word-Process? Product? Promise? *Qualitative Health Research, 2*, 439-450. doi: 10.1177/104973239200200405

Jones J. S. (2010). Origins and ancestors: A brief history of ethnography. In J.S. Jones & S. Watt (Eds.), *Ethnography in social science practice* (pp. 13-27). London: Routledge.

Kidd, J. D., & Finlayson, M. P. (2010). Mental illness in the nursing workplace: A collective autoethnography. *Contemporary Nurse*, *36*(1–2), 21-33. doi:10.5172/conu.2010.36.1-2.021

Kleinman, A. (1981). *Patients and healers in the context of culture: An exploration of the borderland between anthropology, medicine, and psychiatry.* California: University of California Press.

Knoblauch, H., & Schnettler, B. (2012). Videography: Analysing video data as a 'focused' ethnographic and hermeneutical exercise. *Qualitative Research, 12*(3), 334-356. doi:10.1177/1468794111436147

Knoblauch, H. (2005). Focused ethnography. *Qualitative Social Research, 6,* 44-58. Retrieved from http://nbn-resolving.de/urn:nbn:de:0114-fqs0503440

Kroeber, A.L., & Kluckhohn, C. (1952). *Culture: A critical review of concepts and definitions.* Cambridge, Mass: Harvard University Peabody Museum of American Archeology and Ethnology.

Lincoln, S. Y., & Guba, G. E. (1985). *Naturalistic inquiry.* California: Sage Publications Inc.

Liu, W., Manias, E., & Gerdtz, M. (2012). Medication communication between nurses and patients during nursing handovers on medical wards: A critical ethnographic study. *International Journal of Nursing Studies, 49*, 941-952. doi:10.1016/j.ijnurstu

Lomax, H. & Casey, N. (1998). Reordering social life: Reflexivity and video methodology. *Sociologicall Research Online, 3*(2). Retrieved fromhttp://www.socresonline.org.uk/3/2/1/

Macdonald, S. (2002). British social anthropology. In In P. Atkinson, D. D. Coffey, J. Lofland, & L. Lofland (Eds.), *Handbook of ethnography* (pp.60-79). London: Sage Publications Ltd.

Madison, D. S. (2012). *Critical ethnography: Methods, ethics, and performance*. Thousand Oaks: Sage Publications Inc.

Magilvy, J. K., McMahon, M., Bachman, M., Roark, S., & Evenson, C. (1987). The health of teenagers: A focused ethnographic study. *Public Health Nursing, 4*(1), 35-42. doi:10.1111/j.1525-1446.1987.tb00509.x

Mahon, P. R. (2014). A critical ethnographic look at paediatric intensive care nurses and the determinants of nurses' job satisfaction. *Intensive and Critical Care Nursing, 30*, 45-53. doi:10.1016/j.iccn.2013.08.002

Malinowski, B. (1922). *Argonauts of the Western Pacific: An account of native enterprise and adventure in the Archipelagoes of Melanesian New Guinea*. London: Routledge and Kegan Paul.

McCabe, J., & Holmes, D. (2013). Nursing, sexual health and youth with disabilities: A critical ethnography. *Journal of Advanced Nursing, 70*(1), 77-86. doi:10.1111/jan.12167

McElroy, T. A., Davis, A., Hunt, C., Dadul, J., Stanba ,T., & Larson, C. (2011). Navigating a way forward: Using focused ethnography and community readiness to study disability issues in Ladakh, India. *Disability and Rehabilitation*, *33*(1), 17-27. doi:10.3109/09638288.2010.485670

McGibbon, E., Peter, E., & Gallop, R. (2010). An institutional ethnography of nurses' stress. *Qualitative Health Research*, *20*(10), 1353-1378. doi:10.1177/1049732310375435.

McIlroy, G., & Storbeck, C. (2011). Development of deaf identity: An ethnographic study. *Journal of deaf studies and deaf education*, *16*(4), 494-511. doi: 10.1093/deafed/enr017.

Mead, M. (1928). *Coming of age in Samoa: A psychological study of primitive youth for western civilization.* New York: William Morrow.

Mills, A.J., Durepos, G. & Wiebe, E. (2010). *Encyclopedia of case study research*. Thousand Oaks: Sage Publications Inc.

Morse, J. M. (2010). How different is qualitative health research from qualitative research? Do we have a subdiscipline? *Qualitative Health Research*, *20*, 1459-1468. doi: 10.1177/1049732310379116

Muecke, M. A. (1994). On the evaluation of ethnographies. In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 187-209). Thousand Oaks, CA: Sage Publications.

Nastasi, B. K. (1999). Audivisual methods in ethnography. In J. J. Schensul, M. D. LeCompte, B. K. Stephen, & P.Visit Amazon's Bonnie K. Nastasi Pagesearch resultsLearn about Author Central Borgatti (Eds.), *Enhanced ethnographic methods* (pp. 1-50). London: Sage Publications Inc.

Nuckolls, C.W. (1998). *Culture as a problem that cannot be solved.* Madison: University of Wisconsin Press.

O'Byrne, P. (2007). The advantages and disadvantages of mixing methods: an analysis of combining traditional and autoethnographic approaches. *Qualitative health research*, *17*(10), 1381-91. doi: 10.1177/1049732307308304

O'Byrne, P. (2012). Population health and social governance analyzing the mainstream incorporation of ethnography. *Qualitative health research*, *22*(6), 859-867. doi:10.1177/1049732311425049

O'Mahony, J. M., & Donnelly, T. T. (2012). Using critical ethnography to explore issues among immigrant and refugee women seeking help for postpartum depression. *Issues in Mental Health Nursing*, *33*, 735-742. doi:10.3109/01612840.2012.701707

Pesut, B., & Reimer-Kirkham, S. (2010). Situated clinical encounters in the negotiation of religious and spiritual plurality: A critical ethnography. *International Journal of Nursing Studies*, *47*(7), 815-825. doi:10.1016/j.ijnurstu.

Picken, F. E. (2013). Ethnography. In M. Walter (Ed). *Social research methods* (pp. 337-350). Australia: Oxford University Press.

Pink, S. (2013). *Doing visual ethnography*. (3nd ed.). London: Sage Pulication Ltd.

Pink, S. (2007). *Doing visual ethnography*. (2nd ed.). London: Sage Pulication Ltd.

Pino, F. J., Soriano, E., & Higginbottom, G. M. (2013). Sociocultural and linguistic boundaries influencing intercultural communication between nurses and Moroccan patients in southern Spain: A focused ethnography. *BMC Nursing, 12*(14), 1-8. doi:10.1186/1472-6955-12-14.

Rice, P. L., & Ezzy, D. (1999). *Qualitative research methods: A health focus*. Oxford: Oxford University Press.

Richards, L. & Morse, J. M. (2007). *Readme first for a user's guide to qualitative methods.* California: Sage.

Schwartz, D. (1989). Visual Ethnography: Using photography in qualitative research. *Qualitative Sociology*, *12*(2), 119-154. doi:10.1007/BF00988995

Siddique, S. (2012). Being in-between: The relevance of ethnography and auto-ethnography for psychotherapy research. *Counseling and Psychotherapy Research*, *11*(4), 310-316. doi:10.1080/14733145.2010.533779

Sinding, C. (2010). Using institutional ethnography to understand the production of health care disparities. *Qualitative health research*. doi: 10.1177/1049732310377452

Slade, B. (2010). Institutional Ethnography. In A. J. Mills, G. Durepos, & E. Wiebe (Eds.), *Encyclopedia of case study research* (pp. 462-465). Thousand Oaks: Sage Publications Inc.

Smith, D. E. (2005). *Institutional ethnography: A sociology for people*. Toronto, Canada: AltaMira Press.

Taylor, S. (2002). Researching the social: An introduction to ethnographic research. In S. Taylor (Ed), *Ethnographic research* (pp.1-12). California: Sage Publications Inc.

Thomas, J. (1993). *Doing critical ethnography: Qualitative research methods*. Newbury Park: Sage Publications.

Thorne, S. E. (1991). Methodological orthodoxy in qualitative nursing research: Analysis of the issues. *Qualitative Health Research*, *1*(2), 178-199. doi: 10.1177/104973239100100203

Townsend, E. (996). Institutional ethnography: A method for showing how the context shapes practice. *The Occupational Therapy Journal of Research, 16* (3), 179-199. Retrieved from http://eric.ed.gov/?id=EJ525596

Turner, V. W. (1967). *The forest of symbols.* Ithaca: Cornell University Press

Walby, K. (2013). Institutional ethnography and data analysis: Making sense of data dialogues. *International Journal of Social Research Methodology, 16*(2), 141-154. doi:10.1080/13645579.2012.661207

Warr, D. (2004). Stories in the flesh and voices in the head: Reflections on the context and impact of research with disadvantaged populations. *Qualitative Health Research, 14*, 578-587. doi:10.1177/1049732303260449

Weiner, B. (1976). *Women of value, men of renown: New perspectives in Trobriand exchange*. Austin: University of Texas Press.

White, S. & Siebold, C. (2008).Walk a mile in my shoes: an auto-ethnographic study. *Contemporary Nurse: a Journal for the Australian Nursing Profession, 30*(1), 57-68. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/19072191

Willis, M. E. (2010). The problem of time in ethnographic health care research. *Qualitative Health Research, 20*(4), 556-64. doi: 10.1177/1049732310361243

Wolcott, H. F. (199). *Ethnography a way of seeing.* California: Sage Publications, Inc.

Table 1. Contemporary Forms of Ethnography

Major scholars	Epistemology/Ontology	Participants	Participant observation	Field work	Interviews
Hubert Knoblauch and Marjorie Muecke (Focused Ethnography)	-Basic epistemological and ontological underpinnings of focused ethnography are similar to what Glasser and Strauss proposed in the 1960s. Glaser & Strauss (1967) developed a method based on deductive reasoning, which enabled the researcher to generate a theory grounded in data.	-Small group of participants. -Participants have specific understanding or knowledge of the culture/subculture.	-Participant observations are of short duration - Not continuous in nature. -Use traditional form of participant observation but with advanced technical devices.	-Fields are visited in various intervals such after/during an event. - Background knowledge is vital as opposed to insider perspective. -Various recording devices used to collect field data, such as tape recorders, videos, and photo-cameras. - Time and data intensive in nature.	-Interviews are conversational in nature. - Huge amount of data is collected during a short amount of time. -Intersubjectivity is endorsed when analyzing the data.
Phil Carspecken, Jim Thomas and Soyini Madison (Critical ethnography)	- Critical ethnography is rooted in critical theory. In simplest terms critical ethnography is a critical theory at work or in action. Critical ethnography is grounded in claims, which state that critical ethnographers are involved in eradicating power and oppression in the society. -Thomas postulated that "critical ethnography begins with premise that the structure and content of culture makes life unnecessarily more nasty, brutish, and short for some people" (p.33).	-Important question that a critical ethnographer must consider finding an appropriate informant is: where and from whom can we obtain the data that will provide us with meaning which will shape our understanding - The focus must be on participants who possess an insider perspective of the research domain. -Data source can include a person, a group, documents or any other artifacts that bear key cultural meanings.	-Participant observation is a vital method for data collection. -It is suggested to begin a study with passive observation for a period of time. - Rationale for conducting passive observation is to minimize the researcher presence on the day-to-day activities of the study participants.	-Main focus is on conducting intensive and thickly described field notes. -Various techniques are used to collect data in the field such as note taking, audio taping, and videotaping. - Keeping a journal during field work is vital to discover their own biases.	-Face -to-face interviews are conducted with participants. - Interviews are vital in collecting data. -Interviews are flexible, which enables the researcher to revise and adjust their interview guide to better understand the core cultural information employed by their study participants.

Dorothy Smith(institutional Ethnography)	-Epistemologically institutional ethnography is situated in the position undertaken by relativists or interpretists. - Like many relativists, Smith also holds an ontological belief that it is not possible for a researcher to be objective as they are closely integrated and very much present in their research. - Smith also believes that the aim of institutional ethnography is not to generalize findings; rather the focus is on understanding specific aspect of study participants.	- In institutional ethnography participants are not the object of analysis rather they are a means of acquiring and enriching our understanding of the institutional processes.	-Participant observation is a vital component in collecting data in institutional ethnography. -Through participant observation researchers stay in close contact with their participants to build observable relations with their study participants.	-In institutional ethnography field work is vital in collecting and recoding data from participants. -In institutional ethnography documents or texts are a vital medium through which study participants’ experiences could be understood. -Text is defined as any recorded material such as film, pictures, or other medium such as print, television, radio, computer, CDs, DVD.	-Interviews are open-ended. - Institutional ethnography incorporates interviews that are conversational in nature. The researcher has the flexibility to modify their interview guide as their study progresses. This enables them to get as much information as possible. -In some of the work done by Smith, instead of using a standard set of questions, she had developed each of the interview questions based what she had learned from previous interviews.
Sarah Pink (Visual Ethnography)	-Pink’s ontological underpinning focuses on a reflexive theoretical approach to visual ethnography that integrates our everyday, usual and practical involvement with our social surroundings and setting.	-Participants and ethnographers work together to produce data.	-Pink cited ethnographers such as Collier and Collier who advocated for the use of systematic observation, which is supported by theologically advanced methods. - Ethnographers cited by Pink suggest that good videos or films are the product of observation that is organized and reliable in nature.	-Field work focuses on the use of technologically developed mediums such as photographs, video cameras, videotaped recording, audio recording devises, web cam, internet. -Collaborative photography is vital in visual ethnography. Often the researcher is involved in the photographic culture of the study participants.	- Interviews are important means of data gathering in visual ethnography. -Interviews involve talking about the photographs and videos that will enable researchers to again understanding about the nature of the phenomenon under study. -Photo interviews and video interviews are commonly used by the visual ethnographers. - Enable researches to get context-rich data that is vital in understanding their participants’ experiences.

Carolyn Ellis and Heewon Chang (Autoethnography)	-“The "crisis of confidence" inspired by postmodernism in the 1980s introduced new and abundant opportunities to reform social science and reconceive the objectives and forms of social science inquiry. Scholars became increasingly troubled by social science's ontological, epistemological, and axiological limitations” (Ellis et al., 2011, p.1) - Autoethnography is criticized for its canonical ways of doing research by promoting revolution of ideas such as subjectivity existence of multiple realities in research, which is grounded in personal experiences.	-The researcher is examining an autobiographical experience by comparing it with similar experiences faced by the study participants. - In essence, the researcher is also a study participant.	-Personal experiences are used as a major source of data in autoethnographic work. -Participant observation is commonly used to collect data from participants.	-Researcher is involved in note taking during field observation and interviews and these are it is most important source of data collection. -According to autoethnographers, field notes are one selective story, which have been recorded from a particular point of view at a specific period of time. -Field notes comprised of emotions, conversations between different people, sound, colours movements. All these elements that we capture in field notes will craft our final story.	-Two forms of interviews are used: interactive interviewing and reflexive dyadic interviews. -Main features of interactive interviewing are: - Involves active conversation between the participant and researcher, in which both are involved in probing about an issue that is being examined. - What makes interactive interviewing different from context-based face-to-face interviews is the fact that interactive interviewing involves multiple interview sessions. -Reflexive dyadic interviews: Mainly focus on meanings as well as emotional dynamics of the interview itself and on the informants’ story.

Table 2. Exemplary in Ethnographies in Health Research

Methodology/ References	**Participants**	**Participant observation**	**Field work**	**Interviews**
Focused Ethnography Gustafsson et al. (2013)	- Participants were recruited via purposeful sampling. - Study participants were examined in their natural setting which was the hospital setting. -9 participants were involved in individual interviews and 7 in group interviews. -A total of 9 participants were included. -Ages were 40 to 61 years a mean age of 50 years.	-Date was collected via participant observation. - 'Observer as a participant' approach was used to collect data. - Participant observation was conducted to capture different aspects of case mangers' day-to-day work. - There were 36 observation periods. -Duration of these observations depended on the availability of the participant and the type of activity being observed.	- Field notes were taken during observation. -In the field notes the investigator recorded the data, time, place, and sequential order of the events taking place when observing the study participants. - This enabled deeper understating of the case mangers' everyday life. - Field notes were useful in instigating the informal interviews. - Field notes were essential in forming the narrative of the case mangers' daily working life. - Additionally, field notes were also to record researchers' critical reflections.	-Group interviews and individual interviews were conducted. -The rationale behind conducting a group interview was to understand the group mangers' experiences, but within a broader group context. Interviews were recorded.
Gagnon et al. (2013)	-Participants were recruited from postpartum units of hospitals serving a high percentage of migrants to Canadian cities. -The study participants were drawn from an earlier study. -16 immigrant women had provided their contact information for participation in the study.	-Participant observation was used. -Three participant observations were conducted per participant. They were flexible in terms of location. Participant observation was conducted in different place such as: participants' homes, community centers, place of worship, 'ethnic' markets. -The duration of the participant	- Field notes were collected during interviews and participant observation.	-In-depth interviews were conducted with the study participants. -Interviews were conducted during two home visits. They were recorded. -The interviews were tailored to understand processes of care and full range of experiences of early-to- later parenting.

		observation was not fixed (it varied according to the time given by the participants) ranging from 1.5-3.5 hours. -Participant observation was significant in revealing complex overarching findings. -Resulted in a descriptive account of the data collected from participants.		
Visual Ethnography Gates et al. (2001)	-Participants were purposefully selected. -Total number of participants consisted of 13 African American women. -Ages 30 to 66 years. -Sample size depended on saturation point. -Participants were recruited from two oncology clinics in a mid-South metropolitan area.	-Participant observation was conducted. -Main purpose of conducing participant observation was to capture fine details of participants' everyday life, which might not be achieved during individual or group interviews. - Observations were conducted at the sites where participants were getting treatment.	-Field notes were take thought out the study and were transcribed for data analysis.	-Interviews were conducted with the participants. - Interviews focused on caring demands and behaviors during the early breast cancer experience. -Interviews are central in eliciting knowledge about the phenomenon under study. -Pictures and snapshots were taken by participant during their breast cancer experiences. -Snapshot taken by women served as an excellent stimulus to elicit discussion and interviews. -Snapshots representing thoughtful arrangements of specific people as caregivers or care receivers during critical time in their lives.
Carroll et al. (2008)	-Study participant were the ICU medical staffs.	-Participant observation was conducted for 12 days for 193 hours. Out the 12 days, for 7 days the observation was conducted for 24/7. -Observation did not only provide content for the interviews but were also significant in building trustworthy relationships.	Eight, 1-hour formalized medical communication periods were recorded using digital video camera. - Footage formed the basis of a DVD that was used for the purpose of being shown at discussed sessions.	-Semi-structured and unstructured interviews were conducted with nurses, allied health staff, and unit clerks.

		-24/7 observation covered a lot of different activities that were taking place in the unit such as meetings, and handovers	- Filming include four ward rounds, four daily planning meetings, and two periods of general interactions in the ICU.	
Critical Ethnography Liu et al. (2012)	-All registered nurses working in the ward were meeting the inclusion criteria of the study. -The nurses' population comprised of nursing unit managers, nurse coordinators, clinical nurse specialists and staff nurses. - A total of 76 nurses and 27 patients were included for the study.	-290 hours of participant observation was conducted. -The sessions were 2-3 hours in length. - Main purpose was to gain a general understanding of nurses' communication patterns on the ward.	- Field notes made during participant observation and interviews with study participants. - Field noted and conversations between the nurses and the researcher were recorded. - The researcher filmed of 34 hours important activities. - Handovers that occurred during participant observations, such as group handovers, bedside handovers and patient transfers across different wards, were video recorded. - Main purpose of filming was to capture the context in which communications and interactions between the medical personnel took place.	-Individual interviews and reflexive focus groups were also conducted. -In total, 72 interviews were conducted and 5 focus group sessions were held. - Rationale for conducting individual interviews were to obtain nurses' individual perspectives about their experiences. -Reflexive focus groups would encourage a solid interaction in which participants were given feedback about research data and might also allowed the participants to comment on the handover practices.
Mahon (2014)	-31 nurses working in the PICU were recruited. -Their ages ranged for late 20s to 60 years of age and had a minimum of 2 years' experience in PICU and a maximum of 35 years. -Participant pool included 3% males.	-Hallmark of critical ethnography is participant observation. -More than 20 hours of participant observation was used by ethnographers	-Field notes were used during the interview to record details such as: reactions, behaviors of the study participants or events occurring during the interview. - Main purpose of keeping the field notes was to	-Semi-structured interviews were conducted. -Through semi-structured interviews, participants were able to speak freely and they enabled in-depth understanding about their experiences. Interviews were recorded.

			enhance the quality of the observation made about the interview process.	
Autoethnogarpy White et al. (2008)	-The participants were recruited via word of mouth from the researcher's group of patients with chronic, non-malignant pain. - Total number of participants was 5, which included all women between the ages 33 to 44 years. -The intentions of researchers were not to recruit only women participants.	No field work	-Researchers' experience of the chronic pain was recorded in the form of a journal. -In this study the researcher was a participant among the rest of the participants who were interviewed.	-Open ended interviews or conversations were conducted with the participants. -2of the interviews were conducted in the hospital and 3 interviews were conducted in the participants' home.
Bright et al. (2012)	-Personal experience of 3 clinical researchers was explored.	No field work	-Written reflections of the researchers' experiences. -Which were analyzed during and between the focus groups. -Written reflections based on the primary theme of the focus group discussion. These were shared electronically through Google documents and each researcher commented on each other's reflections. -Reflections form the basis for next group discussion sessions. -Reflections were 400-600 words long.	-Data was collected through group discussions (4 sessions over 5 months). -Discussions were 45 minutes long. - This process occurred in an iterative manner and resulted in four written reflections and four focus groups in total.

Institutional Ethnography McGibbon et al. (2010)	-Theoretical sampling was used to recruit participants. -23 nurses agreed to be part of the study.	-Participant observation was conducted in the ICU (PICU) for a period of 3 months. -Participants were observed at different times during their day- to-day work activities, both at night and during the day.	-Field notes were taken throughout the study. - Field notes mainly incorporated a researcher journal and the examination of selected non confidential texts related to the nurses' everyday work	-In-depth interviews were conducted at the time and location that was convenient for the participants. -Interviews enabled researchers to heart the participants' stories throughout the study.
Braaf et al. (2014)	-For this study healthcare professionals were purposely selected -In total, 125 healthcare professionals from the disciplines of surgery, anesthesia and nursing participated in the study.	-Through participant observation the nurses' stories about their practice with children in the PICU were heard. -More than 350 hours of observation was conducted with study participants.	-Field notes were taken through the study and content was used in the data analysis.	-In-depth interviews were significant in revealing important insights for example nurses talked about the feeling that they were tethered to their patients. -20 semi-structured interviews were conducted with study participants. -Interviews were over 30 minutes long.

Chapter 4

Title: After a Child's Traumatic Brain Injury: An Ethnographic Study of Being a Parent

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Abstract

Objective: To explore the meanings associated with being a parent of a child with a severe traumatic brain injury (TBI).

Methods: An ethnographic study was conducted with parents of children aged 3 to 10 years who had acquired a severe TBI. Purposeful sampling was used to recruit parents from the Glenrose Rehabilitation Hospital in Edmonton, Alberta. Data collection involved participant observation, fieldwork and semi-structured interviews. Field notes and interview transcriptions were analyzed using a thematic analysis framework and informed by symbolic interactionism theory.

Findings: 6 parent dyads (mothers and fathers) and 4 mothers participated in the study.

Parents' meanings of 'parenting' a child with severe TBI were shaped by the injury, a wide range of familial dynamics, and interactions. Six main themes related to parental meanings emerged from our data: (1) Getting 'back to normal'; (2) Relying on support system; (3) After injury, parents worry something bad may happen; (4) Parents go through a range of emotions following the injury; (5) After the injury, family dynamics change; and (6) Ongoing performativity.

Conclusions: Parents' meanings of 'parenting' a child are extensively impacted by their child's functioning after the TBI. Having a greater appreciation of these experiences may be beneficial for medical professionals.

Key words: Ethnography, parental meanings, traumatic brain injury, parenting, head injury, qualitative research.

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Introduction

Traumatic brain injury (TBI) represents a significant health risk in childhood [1]. Diffuse brain injury is 3 times more likely to occur in children than adults, making death rates higher in this patient population [2]. It is also predicted that TBI will be a major cause of disability by 2020, exceeding occurrences of many diseases including cancer [3,4]. The detrimental impact of severe TBI on long-term health outcomes among children is well documented. Children who acquire a TBI exhibit linguistic difficulties [5], cognitive problems [6], and both acute and chronic social and behavioral problems [7, 8, 9].

Parents and care givers experience significant injury-related stress and burden after their child's discharge from hospital [10, 11]. Psychological problems [12], imbalances in family routines and roles [13], and concerns regarding overall recovery [14] have been documented. In a recent systematic review we indicated that differences between study groups for family functioning varied, but there was a trend for more dysfunction in families of children who had a severe TBI as compared to families of children with less severe injuries [15]. The results from this review pointed to the intricate functional nature of families with a child with a TBI [15], yet few studies have explored parental experiences to better understand family structure and function. Study of daily parenting activities have provided details of task-oriented processes in families [16, 17], and differences in post-injury stress and adjustment have been noted between mothers and fathers [18]. It has also been reported that following their child's injury, parents re-adjust parenting roles, face tremendous relational conflict, and experience a burden of care [19].

The objective of this ethnographic study was to explore how parental meanings, roles, and expectations are constructed from parent-child interactions in the day-to-day lives of families with a child with a severe TBI. The goals were to generate a better understanding of ‘parenting’, a complex phenomenon [20], made even more complex following a child’s TBI [16,18].

Methods

Study Design

Ethnography was used to explore parental meanings of parenting a child with a severe TBI. The primary methods of data collection were participant observation, field work [21] and semi-structured interviews. This study was guided by Symbolic Interactionism, a theoretical perspective that posits that people interpret and give meaning to their experiences through their interactions with others [22,23]. Ethnographic design, and its use of emic (insider) and etic (outsider) perspectives [24], allowed us to examine parenting beyond the immediate ways of life and activities (e.g., parental roles and responsibilities) to explore the underlying meanings associated with, and symbolic nature of, being a parent of a child with a severe TBI. This approach enabled an in-depth exploration of the internal processes parents experience in relation to their child’s TBI. The study was approved by the Health Research Ethics Board at the University of Alberta (Edmonton, AB, Canada) and received operational approval from Alberta Health Services.

Participant Sampling and Recruitment

Qualitative studies involve purposefully selecting participants who are ‘information rich’ to ensure a thorough examination of the subject under study [25]. In our study, purposeful sampling was used to recruit parents of a child with a severe TBI. A ‘before/after’ reflection was required, as data collection focused on parental role changes and meanings associated with them. Parents of children who acquired a severe TBI (defined by a Glasgow Coma Scale score of 8 or less which was administered upon the patient's first arrival to the hospital) within 24 months of study enrolment were recruited. This study focused on parents of children aged 3-10 years of age. Parents (n=10) were recruited from the TBI Clinic at the Glenrose Rehabilitation Hospital (GRH) in Edmonton, Alberta over a 12-month period (Figure 1).

Study recruitment occurred between February 2014 and April 2015. Potential participants were recruited using the following three strategies: First, an information sheet was offered to families coming to clinic for their child's appointment. The information sheet outlined the details of the study (purpose, background, expectations for participations, risks, benefits, etc.) and invited them to contact the first author for study participation. Second, we used an intermediary (TBI clinic coordinator, administrative personnel) to distribute the information sheet to families attending the clinic. Lastly, recruitment posters were placed throughout the GRH in areas where parents had frequent access.

Data Collection

We used three methods of data collection in this study: (1) participant observation (via home visits), (2) field notes and (3) semi-structured interviews. The first author visited the homes of four parent dyad (mother and father) participants to observe their day-to-day family interactions. The first author also actively participated in family activities (e.g., participating in a parent-child game). A total of eight home visits per family were conducted over a 7 to 12 month period. The visits took place at different times during the day (e.g., after school, afternoon, dinner time, weekend) in order to be able to observe the range of parental roles and activities. Observations were described in the field notes. Field notes, a major source of data, in ethnography, involved an active process of meaning- and sense-making about the phenomenon under investigation [26]. The use of a semi-structured approach allowed the first author to interact with participants in a manner that was less rigid in tone and created a balance in terms of the interviewer-interviewee relationship. Ethnographic interviews are viewed as friendly conversations and flexible in nature [27]. Semi-structured, one-time interviews took place with all parent participants (n=10) through one-on-one meetings; parent dyads participated in a joint interview. Interviews lasted ~60 minutes and took place in the parent's homes, with the exception of one parent who preferred to be interviewed at the GRH while her daughter was receiving care.

Data Analysis

Data analysis and data collection occurred simultaneously [28]. Study data were digitally-recorded and transcribed, and subsequently entered as verbatim transcripts (interviews) or translated transcripts (field notes) into *N-Vivo 10* (2008, QRS International; Melbourne, Australia), a qualitative data management software program. Data analysis was guided by Symbolic Interactionism [22,23] and structured according to a thematic analysis technique [29]. We used Braun and Clarke's (2006) [30] suggested six phases of data interpretation, which are viewed as recursive processes: (1) familiarizing oneself with the data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the reports.

Methodological Rigor

To demonstrate rigor and establish trustworthiness for this study, we attended to four criteria proposed by Lincoln and Guba (1985) [31]: (1) credibility, (2) transferability, (3) dependability, and (4) confirmability. Credibility is comprised of activities that promote authentic and credible study findings. We engaged in three activities: (a) prolonged engagement, (b) consistent (ongoing) observation, and (c) triangulation. The use of triangulation allowed us to examine the data from different angles. Triangulation means using different styles of data collection such as interviews, participant observation, and field notes to inform data analysis. Transferability addresses how relevant a study is to other settings and people. This was achieved by providing a ‘thick’ (comprehensive) description of the study’s methods, sample, and findings. Dependability and confirmability were established through an audit trail. The rationale behind maintaining such records is to help retain documentation of how a researcher recruited participants, collected and analyzed the data. We kept detailed documentation of all the decisions made during the study.

Results

Participants

Six parent dyads (mothers and fathers) and 4 mothers participated in the study. The children of these parents were diagnosed with a severe TBI within 24 months of study enrolment. The parents were between the ages of 26 and 41 years. Most study participants had completed a higher education (ranging from high school to graduate school training). In all families, the household income ranged from $50,000 to $100,000 annually, with the exception of one family who reported their annual house-hold income as less than $ 20,000. All of the study participants were married and had other children with the exception of one family, who had only the one child (Table 1).

The four families who agreed to participate in the home visits were all residents of rural communities. The first author was involved in a range of diverse activities with families, including shopping, attending children’s sports competitions, medical appointments, and school admission, and visiting one family while camping. On the days when the families stayed home, the first author actively participated in day-to-day activities such as playing games, planting vegetables and preparing meals with families. With time, the first author developed trusting relationships with three families, and was able to visit them more than 8 times each (i.e., the families of Bob, Fiona, and Anna). Across all of the families, mothers were the primary caregivers who closely monitored their child's medical appointments, academic progress, and extracurricular activities.

Our findings point to ethnography as an important way to identify parental experiences after a child's TBI. Six main themes emerged during data analysis: (1) Getting 'back to normal'; (2) Relying on support system; (3) After the injury, parents worry something bad may happen; (4) Parents go through a range of emotions following the injury; (5) after the injury, family dynamics change; and (6) Ongoing performativity.

Getting 'Back to Normal'.

While parents described experiencing tremendous tension in the acute period following their child's TBI, most reported that with the passage of time they developed a routine and returned to their usual ('normal') roles and responsibilities. Parents focused on the positive aspect of their child's injury within this routine: "you know what, she can get up in the morning, she can function totally, she can go to school with normal kids and normal activities with normal people. If you didn't know something had happened to her, you would never guess. She's still getting straight A's in school, you know?" (Anna's mother; home visit) Parents found ways to do most of the activities that they would ordinarily do, and they incorporated many previous activities into their everyday routines that they did prior to their child's injury. As reflected in one field note entry, this moved them away from the 'abnormal world' and at the same time allowed them to enter the everyday world:

> I have mentioned in previous field notes that all the families with exception of Bob's (because Bob is in vegetative state) that I have visited so far have one thing in common,

> the families are involving themselves in activities that they used to do before their child's injury. They go for gymnastics, curling, swimming, hockey, basketball… they keep themselves as busy as possible. For example [Anna's family] appears to be operating quite normal and going about their day to day activities, parents make sure that all the other kids and Anna's needs are met. I remember the day when Anna's mother invited me for her swimathon. This was a charity event and Anna participated in a swimathon which was held in the [city name] Recreational Centre. It was a fundraiser for one of their teachers who passed away recently. … It was a big pool packed with people… Right in the front was a hot tub and beside the hot tub there were two huge swimming pools. Today, the pool was booked for the swimathon therefore, only young girls and boys could be seen. The public was not allowed until 7 pm. We grabbed plastic chairs that were piled in one of the corner and we sat to watch the swimathon. In few minutes, Anna came with her partner and they started their laps. Her brother was in charge of counting the laps for Anna's friend and Anna's younger sister was counting the laps for Anna. While the girls were doing their laps her mom, dad, Anna's partner's mother and I watched. Anna's mother was making comments. 'Oh, she's looking, she's resting. That's a lot of swimming. Well she's been swimming pretty straight now for 40 minutes. I see she's on the side of the pool now'. It is quite evident that families try to keep things ordinary and carryout with their everyday schedule. (Anna's family; home visit; multiple field notes)

As their child's recovery progressed, parents treated their child as 'normal' as possible: "We treat Bob as a normal kid because sometimes when I need to go to the washroom and [Bob's youngest sister] is sleeping on the bed, I tell Bob, 'Okay, I need to go to washroom, just watch out, your sister is here beside you,' you know? We just still talk to him so normal." (Bob's mother; home visit). Parents' aspiration to treat their child as 'normal' was not a short-term goal; rather, parents wanted to ensure that their child would be able to participate in society in the long run. As Anna's father stated, "[I]nsuring that she's going to be that person; that she can function normally as an adult and yeah, I think that's one of my biggest fears. I think she's well on her way, provided nothing else happens to her, right?" (Anna's father; interview)

Consistently, parents advocated and displayed the desire to sustain a structure in their life as a family. "[Life is] more structured, more retained, like you know? It's…you just do it, like I do my thing and [Husband] does his thing and you know, at the end of the day we're in the house all together" (Fiona's mother; home visit). In particular, parents in this study wanted stability and structure, and expressed concern about how their other children might be impacted. As stated by one parent: "The fact that we have two other kids, we can't just switch everything because they need the stability, they need the structure, as well as Kevin, so it's… like it's harder when there's other kids involved because it's not just about Kevin, it's… we've got to balance Kevin and the other two and that's where the biggest struggle was at first." (Kevin's mother; interview)

Parental concern about maintaining a structure and healthy equilibrium in the household as well as among their children was most apparent in how parents disciplined their children. Parents ensured that their requests were followed by their children regardless if the child had a TBI. When parents felt that their authority was jeopardized they immediately took action.

> It was my 6th home visit with Fiona's family. Today we headed out to visit her mother's best friend/partner in a small decoration business they operate. Fiona's mother had an order for a small wedding so she wanted to get some wine glasses and table cloths from her friend's storage. While returning from the friend's storage, Fiona's mother and I were talking about her friend and how they have known each other from childhood, when suddenly our attention was diverted to the noise in the back seat where Fiona and her older sister and brother were seated. Fiona's brother and sister were fighting with each other. The sister was telling her younger brother to apologize for spitting on her or she would not give his toy back. Her brother refused to apologize and wanted his toy from his sister. Their mother warned them to behave or she would stop the car and give them both a time out if they didn't stop. In spite of the warning, they continued with their argument for about 5 minutes or so. By this time Fiona's mother got extremely frustrated and stopped the car on the side of the road. She got out and opened the car door; she stood still for a few moments and looked at her children. Then she told them to stop and asked her daughter to sit next to her sister (Fiona) and warned her son that once she got home he would get a time out for being disrespectful to his sister. Her son tried to argue with her. In response, she pulled him out of the car, with a loud tone she told him 'enough [son's name]. Tonight your dad and I need to talk to you. I will make sure that you're not allowed to play with any of the toys and you will stay in the corner for an entire day'. Following this warning he stopped and got back into the car. Fiona's mother got back in the car and started driving again. She was nodding her head and seems extremely frustrated. She told me 'This is what I am talking about. Today is one of those days where I can't take it anymore. When [husband's name] gets back from work he will deal with [son's name]'. For the rest of the drive to their house they all stayed quiet. (home visit, field note)

Relying on Support System

Parents in this study described relief when friends and family provided support and an active involvement, especially in the initial phase of the child's injury. As evident in Rebecca's parents' statement: "So for the most part I had the other two the whole time. So I work out of town, an hour, so I'd have to get them up early and drop them off at friend's houses or take them next door to get ready for school. So I mean in that regard it was more of an issue on them because they had to get up earlier than they normally would if their mother was here. But we still had hockey and hockey practice and all that kind of stuff too then, so I'd still have to look after him for that and then take our youngest to babysitter's or whatever to do that. [Mother interrupting] So we had all kinds of people in the beginning that would help us out though, looking after them and stuff, so we were very lucky in that regard." (home visit) For some parents, the support given by an immediate family member was crucial in managing their everyday life, as evident in the excerpt from our field data:

> I remember the day when Bob's grandmother was unwell. There was a lot of pressure on Bob's mother. She was running up and down trying to dress her daughter for school, pack her lunch, feed Bob and the little one was sitting on the bed mat crying. I asked her if I could help with anything. 'Well ya, if you could take care of [youngest daughter's name] for me it would be great.' I held the baby in my lap and sat her closer to Bob's bed, who was lying down motionless. She touched his face with her little hand and he showed no emotion. As I try to entertain the little girl there is a knock on the door. Bob's nurse comes in and there is sigh of relief on Bob's mother's face. The nurse takes care of Bob while his mother takes her daughter to school and I remain with her baby. (multiple field notes)

Parents acknowledged that the support they received from their family and friends had a positive emotional effect on them: "When we were in the hospital, it was my dad and mom who stepped up and kept the older two… My father-in-law would have to be, has been my biggest support 'cause anything good, bad or otherwise I would phone him and he would either talk to me so I was calmed down… [husband] was a huge support, like I said, my biggest support was my father-in-law and he still is. We have a good friend of ours who lives with us and he's, again, an amazing support." (Kevin's mother; interview)

Parents acknowledged that having a strong support system throughout their child's care was vital. They could not imagine being totally on their own:

> Your family and your friends are there when you need them, right? So yeah, that's huge, like I couldn't imagine being totally on your own, you know? Like there's a lot of people that aren't from here that maybe don't have the family network and I wouldn't imagine, you know? Like it would be just crushing to be totally on your own, you know? So no that's very, very important, so… (Jessica's father; interview)

In some cases, although the level of support from extended family members was reduced, the support from immediate family members continued for a long period following a child's injury. As one parent noted, "My mom… she'll take the kids, like when I need a break, she'll take them and bring them home and they'll have a sleepover and stuff like that and so, oh yeah. She's pretty much here, like she comes here pretty much every day just to see the kids." (Fiona's mother; home visit). Another parent felt that the absence of a reliable support system would have been overwhelming during the acute stage of their child's care. Often, however, parents believed that they were in a better position in comparison to other families who lacked such a support system. As one parent described, "[Other families in the hospital] didn't have a support group with them and it was hard on them. So you know, to see that with us was, wow, what a blessing that we had, really." (Fiona's father; interview)

Several parents reported that without the support of their family and friends it would have been "impossible". For some parents, the support enhanced their own roles and responsibilities following their child's injury: "[W]ithout the support I couldn't have kept working full time, I don't think, and get [kids] home and back and up to the city and visits and so yeah, definitely the six weeks, if there wouldn't have been no family or friends helping out it would have been extremely tough to keep working full time, for sure, and to keep going to hockey and that kind of stuff" (Rebecca's father; home visit). While for other parents, the support ameliorated tense relationships between parents, and was described as leading to better social and familial dynamics: "If we didn't have [the support], you know, so take that question and take it back to our relationship and how it brought us together or pulled us apart, I think without that family support I would say it probably would have pulled us apart. So it would have made things really difficult…" (Fiona's father; interview)

After injury, Parents Worry Something Bad May Happen.

The TBI acquired by their child introduced heightened vigilance and worry into the parent's experiences: "I worry about things a lot more than I used to, like something happening to them, yeah, so, 'cause I mean it's, that's another thing that's hard because with kids there's always, like little accidents and this and that and like that's… And then so now it's trying to not fret about everything but yet be realistic that you want to keep them safe. So I think in a way we do… yeah, I think we're more watchful of them and more, [laughter] you know, like you kind of think things through way more, you know?" (Jessica's father; interview)

Parents reported that they were "scared" all the time following their child's injury, and as a result, they did not take their child for granted. Observational data from field work suggested that parents 'functioned on high alert,' being more watchful and cautious. This parenting role was evident as early as the first home visits with families. For one family,

> In my first home visit with Fiona's family, I noted that her mother was more alert and cautious. Fiona's mother wanted all of us to go for a walk up the hill. We all (myself, Fiona, Fiona's older sister, her sister's friend and her twin brother) wore our shoes and Fiona's mother open the door for us. When we all were out she ensured that door was locked and she told her kids 'let's go up the hill', everyone agreed and I followed them. We started walking up toward a small hill. In few minutes we reached the top of the hill and there was highway ahead. Fiona's sister and her friend were ahead of us. As Fiona and I were little slower, everyone stopped for us so we could cross the highway together.

> While we crossed the highway, I noticed that all of a sudden Fiona's mother became more careful and protective of her children and repeatedly stated 'be careful, all of you hold hands… don't move until [first author] moves. Then you all can follow.' After we had crossed the highway I noticed Fiona's mother was much more relaxed. As we continued walking I asked her 'you seemed quite vigilant with your kids, why is that so?' Fiona's mother responded 'Like you know, like her jumping on the trampoline or her playing on the playground and I'm watching. I'm a little bit more paranoid for her, just because I mean, we don't want her to fall and you know, let's say, hit her head and then what, right? And because she's so fragile right now that… and you know she'll always be a percentage higher for something happening to her than one of my other kids, right? So I mean that fear is always there, or that paranoia." (Fiona's mother; home visit)

Parents reinforced these observations in their interviews. As Dale's mother stated, "I need to focus on the kids, take things slow, they come first. Can't take anything for granted, because one day, you're okay, and the next day—it's a cliché, but it's so true. And all those days of sitting by the bedside hoping that they can take him off these monitors, off these meds, you never forget that." (interview)

Parents of children with a severe TBI also 'parented with fear' following their child's injury. As Anna's mother described, "[A]s a mom 'cause you've got in the back of your mind, she has another angio in grade 7 so because there's still another testing coming up, I don't know, it's just a fear thing and I think as a parent you need to overcome that. So it does make a difference in how you parent, when you parent scared versus parent without fear." (home visit) Parents also described that their fear led them to be assertive and or take risks when their children's health was in question. As Dale's mother recalled, "I'm afraid of everything now. And I make sure they wash their hands all the time! 'But Mom, I just washed it.' 'No, wash it again." (interview). Anna's mother also described, "… now one of the things that I probably do different, like even sledding, on the little tiny hill she will say, 'Do I have to wear my snow helmet?' and I'm like, 'Yes,' 'cause I think part of me thinks to go back to that feeling, I don't know…" (home visit)

Parents Go Through a Range of Emotions Following the Injury.

Parents in this study described a range of emotions that shaped their interactions with others. They felt ‘pulled in many directions’ and experienced a state of uncertainty—not knowing what decisions to make or if the decision they made would be the most effective for their child’s recovery and well-being. As described by Jessica’s mother,

> [Y]ou have doctors coming in for her eye, for her bones, for her brain, for her spine and you have ten different specialists coming in which is stressful and you have one saying, ‘We’re going to shave her head, we’re going to go in her eyeball, we’re going to do all these things,’ and you’ve never been faced with those decisions so you feel pulled constantly and then you also have the other dynamic of our parents, where his parents think one way and my parents think a completely different… for the first time in your life you’re faced with a decision where, you know, you could lose a child, she could lose her eyesight, she could have all these permanent things and you don’t know, as 30-year-old parents, we didn’t know what we were doing, we didn’t know what decisions to make and there was so much outside information and so that part of it was super stressful… (interview)

Parents also described the experience associated with their child’s TBI as ‘painful and hard’: “[Y]ou’re almost blown away. You don’t know what to do or how to react or… right? I know it hit me really hard ’cause you don’t know. You see your child lying in a bed and you know, she can’t talk or move or anything.” (Anna’s father; interview). It was also difficult for parents to see their child suffer. As one parent explained, “That was horrible. Worst thing that we’ve ever had to do. The whole time all we said was we wish we could trade her places. Yeah, it’s just… I would never… I’d never want to do it again. It’s hard and painful to watch them go through that.” (Jessica’s mother; interview) Parents also went through internal turmoil and self-doubt:

> [I]f we’re even doing a good enough job. Like sometimes I feel like, like obviously other parents deal with injuries but I mean, every time something does happen to the kids I feel like maybe it’s because we are irresponsible, maybe we aren’t paying attention, like there is that constant self-doubt in our parenting now. (Bob’s father; field notes)

Parents reported that their child’s injury had an enormous impact and changed their point of view about life. Parents considered life to be ‘ephemera’; they valued the time they spent together as family and described “being closer as a family”. This included being closer with all their children, as they might become future caregivers. In one home visit, Fiona’s mother described: “It’s, like I said, it has brought us all closer to each other, ’cause we do more. We have realized that how quickly everything can change, so we do make a point to be with the kids more now.” Bob’s mother also discussed the idea of being closer in a home visit: “[W]e stay together and we want our son to be with us… you know, even when we are old. But we also teach the girls to understand and help him in the future too and be together always.”

After the Injury, Family Dynamics Change.

As described by the parents in this study, a child’s TBI impacted the relationships and responsibilities of all family members. Families re-adjusted and struggled with appreciating the ‘new person’ in their family. As Anna’s mother noted:

> [Anna’s older brother] had a few cries where he actually said the words, like, ‘I lost my sister to this.’ And we’ve had quite a few conversations about… we just have to accept those changes and you have to form a new bond and a new relationship, right? Like they’re still young and that has to take place because I know, yeah, he very much felt that… in his words, he said it was totally different, yeah. Yeah, we did talk quite a bit. (home visit)

Parents advocated for maintaining a healthy relationship among their children. As a result, they found themselves being more mindful about trying to be “equal” to ensure that they did not single out their injured child and make them feel that they are different, or not as important. Some parents also remarked that despite this balance, what they felt towards their children might be different than what they expressed outwardly. As noted by a parent, “Deep inside that is, my true feeling is, you know, you can’t believe she’s accomplished this… and even if it is the same as your other kids there is kind of… a little more pride for an accomplishment because there was a previous challenge.” (Anna’s mother; interview)

Spousal relationships also changed after the injury. Parents reported that while their child’s injury brought them closer together, it also “pulled them apart”. This dynamic was most often described in the period following the child’s injury: “Like yeah, everything. Just kind of like one person has to stay in the hospital or one person has to stay at home and watch the kids or like, you know, switch off and like we got into a lot arguments then, yeah.” (Kevin’s father; interview) Other parents reported overlooking their spouse’s needs in order to care for their child; any other time they had was allotted to fulfill the needs of their other children. As Anna’s mother described:

> I would definitely say that first, for sure the first six months I didn’t… give back to you [husband] or we didn’t make time for each other. We didn’t… the focus was Anna and then whatever you have left goes to your other kids and then at the end of the day, you’re not going to… when you’re having a hard time letting go as it is, you’re not going to find childcare and go spend time with your spouse because they need it. So there is a point and there is a time that you focus less on your spouse’s needs. (interview)

Some parents reported a greater dependence on their spouse and a sense of harmony in dealing with their child’s TBI following their child’s injury: “I think now we’re both dependent of each other, like we need the help, even with Carla, like yeah, emotionally and physically, yeah. There’s like, no way you can split up now and expect Carla to have a good life later on. Like, yeah.” (Carla’s mother; interview)

Ongoing Perfomativity

Another major aspect of parents’ lives was performativity, or how they ‘made things work’, and what part of this was publicly visible to others. From our field work it became obvious that there was a shift in some families’ physical (home) space. Depending on the child’s injury severity in some families the physical environment of their home was to greater extent altered and re-adjusted following their child's injury. Such shifts in the physical environment invaded the public and private spaces of parents and other family members. This was most evident in Bob's family, where he had become the center of his family. His parents had moved into the living room where they would spend most of their time:

> I mentioned in my previous fieldwork, they don't have enough resources to transport him upstairs to his room and it's difficult because they can't do this every time. So the best and most convenient way is that Bob's bed is permanently kept in the living room, at least for the past year. And, now the parents sleep at his bedside. Things have shifted. His room is no longer used. His mother was telling me today that they haven't slept in their own room for the past 4 months. The entire family dynamics have been shifted towards their son. I have also noted that Bob's mother was talking a little bit about how Bob is the center of attention. He needs more care and therefore she is readily available for him. She also told me that sometimes she gets so carried away in giving him the care that oftentimes she feels that she is not reaching out to her other two daughters, especially Bob's older sister. She goes on by saying that usually she is good and she ensures that her daughters get the care they need. Things have shifted extensively blurring the line of private and public spaces, which is a crucial element of spousal relationships. I have also observed that Bob's grandmother who lives with them after her grandson's injury always stays at the edge of the living room. Bob's grandmother's space is limited to her room upstairs and the kitchen. (Bob's family; home visit)

While in other families the child's injury did not have a huge impact on the physical environment, parents affirmed that if their child's injury was severe enough to cause a permanent disability, they would have re-adjusted their life based on their child's need. As stated by Rebecca's mother: "I mean everybody is different, right? It depends what they need. [Rebecca]'s injury, yes, traumatic but she's back to normal. Not everybody gets that, right? Some kids would end up in a wheelchair or with crutches or whatever for the rest of their life. She didn't end up with that, so it completely depends on those parents and what their situation is. If she was in a wheelchair, yes, that'd be different because she probably can't do everything she used to do and we would adjust it accordingly, but she's not. She's the same kid she was prior." (multiple home visits)

During the fieldwork, the absence of stories was also evident; there were many silences surrounding the impact of a child's severe TBI on parenting. Family interactions during fieldwork were, at times, experienced as ambiguous and raised many lingering questions:

> I have mixed feelings about this family. I want to make it clear that [the family] is really nice, cooperative and always ready to help. In spite of all of this I feel like there is so much I do not understand about this family. I still don't understand the type of relationship that exists between the [wife] and her husband. The main source of this ambiguity is attributed to the fact that there is some contradiction in terms of what is said and what I have witnessed throughout my fieldwork. (Rebecca's family; home visit and multiple field notes)

Discussion

Findings from this study illustrated that parenting a child with severe TBI is shaped not only by the injury experience but the existing relationships between parents and their children, as well as the roles that are expected of them. Parents' responses to the injury were shaped by re-adjusting and adapting to new roles and expectations. Immediately following a child's injury parents were exposed to ambiguity and hardship, and pulled emotionally in many different directions. This also included adapting to sometimes profound changes in parenting roles. During these times, parents relied on others for support while at the same time they had the desire to live a 'normal' life. Parents re-constructed new meanings of parenthood through their interactions with family members, health care professionals and their child in order to adapt.

In this study, parents who had a strong familial support system reported that this was a major factor in maintaining a healthy equilibrium for all family members. Parents' meanings were shaped and informed to a greater degree by relying on interactions with relatives and friends. This finding is consistent with symbolic interactionism, which proposes that we developed a sense of self through the interactions that we have with others which shapes our everyday life [22]. Further, existing literature also suggests that prolonged support is important for families with a child with TBI [32]. Our study also indicated that parents needed support immediately (in the acute phase) after their child's injury. The positive impact of having a support system from immediate family, extended family, friends and community has also been reported by others [10,12,33]. Having support results in less burden and stress on parents and makes life much more manageable for families who have a child with TBI [34]. At the same time, parents have also reported that they lack the energy to address any associated demands from the support offered, and experience guilt as a result [35]. This finding was less consistent with our data; two parents reported feeling both overwhelmed and frustrated by the support they received but this was not a consistent theme across other families. In our work, study participants did not identify health care professionals as part of their support system. While such individuals are key to their child's post-injury care, Kirk and colleagues reported that parents can feel abandoned by service providers once their child is discharged home [36]. Based on the findings from our study and existing literature, we recommend that health care professionals and programs address the context of long-term burden for caregivers by designing services to be available beyond hospital doorsteps.

Parents who have a child with TBI go thought a range of experiences—some do no longer take life for granted; some parent their children on high alert and with fear. The feeling of guilt and self blame experienced by parents has also been reported in numerous studies by other parents following a child's TBI [19,37]. However, in our study parents did not express feeling guilt related to their child's injury. This may be attributed to a few factors. First, the time spent with these families may have not been sufficient for this theme to develop in our study. Secondly, our study sample was small and we may not have witnessed the emergence of this emotion within our study population. In addition, one of the study's inclusion criteria was to include parents whose child had incurred a severe TBI with a Glasgow Coma Scale (GCS) score of 8 or less. Despite these clear neurological criteria, we experienced a great variability in experiences across families. While the GCS may be seen as the best global neurological measure for brain injury severity level, it may not be the most effective measure to evaluate social, emotional and family experiences following a child's TBI. This finding has significant consequences for health care professionals. While providing services to these families, professionals need to bear in mind that the GCS score by no means has any correlation in regards to overall quality of life or other familial dynamics. It is these unique familial, emotional, social dynamics and family functioning that make families distinct in nature. Hence, we recommend that health care professionals incorporate standardized interventions that will evaluate the overall quality of life and family functioning in these families to provide appropriate care based on their specific demands.

Existing qualitative research indicates that parents who have a child with TBI are more likely to experience role changes [16]. Our study findings in relation to role changes among parents were contradictory. The majority of our study participants reported that they did not experience extensive role changes as parents. Few participants reported role changes and role reversal specifically in the acute stage of their child's TBI. Role reversal in some families may bring with it major adjustments and disruptions. Our findings point to a critical issue that the problems parents encounter are much more intricate in nature than expected. In line with other research [16] which suggests that mothers are the primary caregiver of a child, we noticed that fathers were often absent while most mothers took the initiative to provide care for their injured child. This finding has important implication for medical professionals, in that they need to understand the unique and complicated nature of these families. We also recommend that more research is needed to better understand father's perspective in this patient population.

Consistent with symbolic interactionism, parents in this study advocated for normalcy (our image is based on how others imagine us to be). Further, parents engaged in ongoing performativity—being concerned about what was visible to others and what they did not want others to see [23]. Parents in this study acknowledged the importance of being a 'normal' family and emphasized the importance of getting back to the routine of their day-to-day life following their child's injury. While parents acknowledged that their families were drastically impacted by their child's injury, they still insisted on normalcy. Normalization is a suggested style of response that families adopt following a child's chronic illness [38]. Studies of parents with a child with a chronic illness and/or disability [38, 39,40] suggest that parents of such children parent their child as a 'normal child' and focus on activities that they have been involved with in the past [38,41]. Parents of children with chronic illness adopt normalization as a managing style to deal with their child's illness [39]. A qualitative study conducted with adults with a TBI also found that 'getting back to normal' was a central experience [42]. Our study suggests that 'normalcy' for individuals with a TBI is a theme across all ages. However, we fear that the emphasis on such normalcy may hinder the recognition of a diversity of abilities. We also suggest that the urgency for 'being normal' may be underpinned by social expectations to value the 'norm' which, in this instance, is 'to be normal' rather than 'abnormal'. This is a vital finding in the TBI literature and may have important implications for healthcare professionals. Further exploration of this phenomenon will allow the health professional to provide necessary assistance to parents in adopting the most appropriate management styles and strategies while caring for their child. Since exploring normalcy or 'being normal' was not the primary focus of our study, we recommend that future research be conducted in order to investigate this phenomenon in greater depth.

Performativity is embedded in what individuals do, how they engage in meaning-making processes [43, 44], and is a significant part of everyday practices of ‘doing what’s done’ [45]. In our study, parents were involved in an intense meaning-making process. In many cases, these processes were not expressed verbally. Identifying silences in the data was vital as it drew attention to things that were left unsaid—silence may indicate censorship, alternatively it may hold important meanings that cannot yet be articulated [46] or represent a moment when a parent feels that they have shared too much information [47]. We observed that there were many issues which parents avoid or do not address directly. This may represent a degree of self-protection (or parental “role regulation”) and avoidance or denial of difficult realities, which may or may not be conscious. Hence, health care providers need to pay attention to such silences when interviewing or interacting with parents as they may bear vital information that may be significant for suitable service delivery.

Limitations

Our study has several limitations. Our dataset for home visits is small (n=4) and we are unable to provide generalizable findings. Several families refused to participate in home visits mainly due to the time commitment and close involvement of the researcher with families. All four families we worked with over a large time frame lived in rural areas, making our study findings limited as it does not represent parents who live in urban and metropolitan areas. These families may be different from families that live in urban areas, where access to resources and support might differ. In addition, given that we used purposeful sampling to recruit our study population, some may argue that our findings are not free of researcher bias. To reduce bias, we based decisions on accepted criteria and maintained confirmability through an audit trail. In addition, we have mentioned that there were silences in the data. These silences may suggest that we were not always getting "the whole story" from parents, ie, there may have been aspects that were embarrassing.

Limitations aside, our findings contribute to a better understanding of parents and their meanings of everyday life in their home environment. This study is part of growing qualitative research in the area of TBI [17, 18]. However, use of an ethnographic study design with observational data is relatively unique. Findings from our study address the lack of observational data in TBI literature [48].

Conclusions

Parents' meanings of 'parenting' a child are extensively impacted by their child's functioning after the TBI, as well as their familial relationships and the roles expected of them. Following the injury, parents re-define and adjust parenting, roles and meanings. It is important that health care providers understand the evolving and complex nature of parenting a child with severe TBI as well as the multifaceted familial dynamics in this patient population. This will allow health care professionals to tailor their services accordingly in order to address parental needs in the post-injury period.

References

[1] Kan CH, Saffari M, Khoo TH. Prognostic factors of severe traumatic brain injury outcome in children aged 2–16 years at a major neurosurgical referral centre. Malays J Med Sci. 2009; 16: 25.

[2] Aldrich EF, Eisenberg HM, Saydjari C, Luerssen TG, Foulkes MA, Jane JA, Marshall LF, Marmarou A, Young HF. Diffuse brain swelling in severely head-injured children. A report from the NIH Traumatic Coma Data Bank. J Neurosurg. 1992; 76: 450-454.

[3] Hyder AA, Wunderlich CA, Puvanachandra P, Gururaj G, Kobusingye OC. The impact of traumatic brain injuries: A global perspective. NeuroRehabilitation. 2007; 22: 341-354.

[4] Mariotto AB, Rowland JH, Yabroff KR, Scoppa S, Hachey M, Ries Feuer EJ. Long-term survivors of childhood cancers in the United States. Cancer Epidemiol Biomarkers Prev. 2009; 18: 1033-1040.

[5] Ylvisaker M. Communication outcome in children and adolescents with traumatic brain injury. Neuropsychol Rehabil. 1993; 3: 367-387.

[6] Brookshire BL, Chapman SB, Song J, Levin HS. Cognitive and linguistic correlates of children's discourse after closed head injury: A three-year follow-up. J Int Neuropsychol Soc. 2000; 6: 741-751.

[7] Lewis KJ, Morris KM, Morris DR, Krawiecki N, Foster A.M. Social problem solving in children with acquired brain injuries. J Head Trauma Rehabil. 2000; 15: 930-942.

[8] Cole W, Gerring J, Gray R, Vasa RA, Salorio CF, Grados M, Christensen JR, Slomine BS. Prevalence of aggressive behaviour after severe paediatric traumatic brain injury. Brain Inj. 2008; 22: 932-939.

[9] Max JE, Lansing AE, Koele SL, Castillo CS, Bokura H, Schachar R, Collings N, Williams KE. Attention deficit hyperactivity disorder in children and adolescents following traumatic brain injury. Dev Neuropsychol. 2004; 25: 159-177.

[10] DeMatteo CA, Cousins MA, Lin CY A, Law MC, Colantonio A, Macarthur C. Exploring postinjury living environments for children and youth with acquired brain injury. Archives Physical Med Rehab. 2008; 89(9): 1803-1810.

[11] Rivara JB, Fay GC, Jaffe KM, Polissar NL, Shurtleff HA, Martin KM. Predictors of family functioning one year following traumatic brain injury in children. Arch Phys Med Rehabil. 1992; 73(10): 899-910.

[12] Wade SL, Taylor HG, Drotar D, Stancin T, Yeates KO. Childhood traumatic brain injury initial impact on the family. J Learn Disabil.1996; 29: 652-661.

[13] Taylor HG, Yeates K O, Wade SL, Drotar D, Stancin T, Burant C. Bidirectional child–family influences on outcomes of traumatic brain injury in children. J Int Neuropsychol Soc. 2001; 7: 755-767.

[14] Wade SL, Taylor HG, Drotar D, Stancin T, Yeates KO. Interpersonal stressors and resources as predictors of parental adaptation following pediatric traumatic injury. J Consult Clin Psychol. 2004; 72(5): 7767-7784.

[15] Rashid M, Goez HR, Mabood N, Damanhoury S, Yager JY, Joyce AS, Newton AS. The impact of pediatric traumatic brain injury (TBI) on family functioning: A systematic review. J Pediatr Rehabil Med. 2014; 7(3): 241-254.

[16] Clark A, Stedmon J, Margison S. An exploration of the experience of mothers whose children sustain traumatic brain injury (TBI) and their families. Clin Child Psychol Psychiatry. 2008; 13: 565-583.

[17] Jones M, Hocking C, Wright St-Clair V. Parents caregiving for children after a traumatic brain injury: Structuring for security. New Zealand Journal of Occupational Therapy. 2011; 57: 4-13.

[18] Roscigno CI, Swanson KM. Parents' experiences following children's moderate to severe traumatic brain injury: A clash of cultures. Qual Health Res. 2011; 21: 1413-1426.

[19] Brown FL, Whittingham K, Sofronoff K, Boyd RN. Parenting a child with a traumatic brain injury: Experiences of parents and health professionals. Brain inj. 2013; 27: 1570-1582.

[20] Hoghughi MS, Long N. Handbook of parenting: Theory and research for practice. Sage; 2004.

[21] Prus R. Symbolic interaction and ethnographic research: Intersubjectivity and the study of human lived experience. Albany: State University of New York Press; 1996.

[22] Mead GH. Mind, self, and society. Chicago: University of Chicago Press. 1934.

[23] Cooley C H. Social organization and Human nature and the social order. New York: Free Press; 1956. Original work published 1909.

[24] Fetterman MD. Ethnography: Step-by-step. California: Sage Publications Inc; 2010.

[25] Patton QM. Purposeful sampling. In: Bryman A, editor. Ethnography. London: Sage Publications Ltd; 2001. p 106-121

[26] Emmerson RM, Fretz RI, Shaw LL. Writing ethnographic field notes. Chicago: University of Chicago Press; 1995.

[27] Spradley PJ. Interviewing an Informant. In: Bryman A, editor. Ethnography. London: Sage Publications Ltd; 2001. p 331-343.

[28] Erlandson AD, Harris LE, Skipper LB, Allen DS. Doing naturalistic inquiry. California: Sage Publications, Inc.; 1993.

[39] Boyatzis RE. Transforming qualitative information: Thematic analysis and code development. California: Sage Publications Inc.; 1998.

[30] Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006; 3: 77-101.

[31] Lincoln SY, Guba GE. Naturalistic inquiry. California: Sage Publications, Inc.; 1985.

[32] Ylvisaker M, Adelson PD, Braga LW, Burnett SM, Glang A, Feeney T, Moore W, Rumney P, Todis B. Rehabilitation and ongoing support after pediatric TBI: Twenty years of progress. J Head Trauma Rehabil. 2005; 20: 95-109.

[33] Ramritu P, Groft G. Needs of parents of the child hospitalized with acquired brain damage. Int J Nurs Studies. 1999; 36: 209-216.

[34] Verhaeghe S, Defloor T, Grypdonck M. Stress and coping among families of patients with traumatic brain injury: A review of the literature. J Clin Nurs. 2005; 14: 1004-1012.

[35] Aitken ME, Mele N, Barrett K W. Recovery of injured children: Parent perspectives on family needs. Arch Phys Med Rehabil. 2004; 85: 567-573.

[36] Kirk S, Fallon D, Fraser C, Robinson G, Vassallo G. Supporting parents following childhood traumatic brain injury: A qualitative study to examine information and emotional support needs across key care transitions. Child Care Health Dev. 2015; 41: 303-313.

[37] Johansen RK. Listening in the silence, seeing in the dark: Reconstructing life after brain injury. University of California Press; 2002.

[38] Robinson CA. Managing life with a chronic condition: The story of normalization. Qual Health Res. 1993; 3: 6-28.

[39] Knafl K, Breitmayer B, Gallo A, Zoeller L. Family response to childhood chronic illness: Description of management styles. J Pediatr Nur. 1996; 11: 315-326.

[40] Kazak AE, Simms S, Alderfer MA, et al. Feasibility and preliminary outcomes from a pilot study of a brief psychological intervention for families of children newly diagnosed with cancer. J Pediatr Psychol. 2005; 30: 644-655.

[41] Knafl KA, Deatrick JA. How families manage chronic conditions: An analysis of the concept of normalization. Res Nurs Health. 1986; 9: 215-222.

[42] Conneeley AL. Transitions and brain injury: Exploring the journey of people with traumatic brain injury. Brain Impair. 2012; 13: 72-84.

[43] Denzin NK. The call to performance. Symb Interact. 2003; 26: 187-207.

[44] Butler J. Gender trouble: Feminism and the subversion of identity. New York: Routledge; 1990.

[45] Pollock D. “A Response to Dwight Conquergood’s essay: ‘Beyond the text: Towards a performative cultural politics.” In: Dailey SJ, editor. The future of performance studies: Visions and revisions. Washington, DC: National Communication Association; 1998. p 37-46.

[46] Charmaz K. Stories and silences: Disclosures and self in chronic illness. Qual Inq. 2002; 8: 302-328.

[47] Poland B, Pederson A. Reading between the lines: Interpreting silences in qualitative research. Qual Inq. 1998; 4: 293-312.

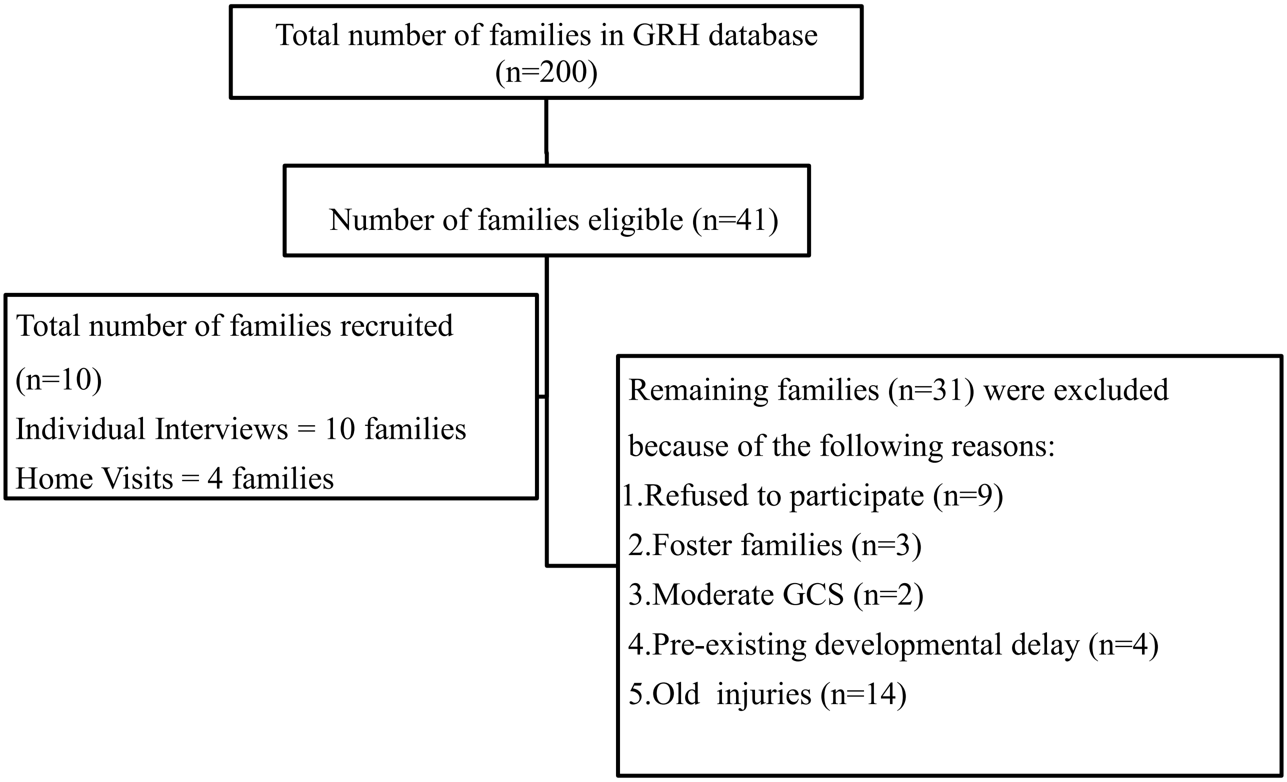
[48] Bendikas AE, Wade SL, Cassedy A, Taylor HG, Yeates KO. Mothers report more child-rearing disagreements following early brain injury than do fathers. Rehabil Psychol. 2011; 56(4): 374-382.

Table I. Demographic Characteristics of Sample

Child code name	Participating parents	Type of participation	Age (yrs)[¥]	Marital status	Household income	Education[¥]	Number of children	Child's age (yrs)	Child's gender	Cause of injury
Dale	Mother	IN	34	Married	\$70,000-\$99,999	Bachelor's degree	2	3	Male	Infection
Sarah	Mother	IN	41	Married	≥ \$100,000	Graduate school	2	5	Female	Tumor
Fiona	Parent dyads	IN/HV	36	Married	≥ \$100,000	High school	4	3	Female	Drowning
Bob	Parent dyads	IN/HV	34	Married	≥ \$100,000	Bachelor's degree	3	10	Male	Drowning
Rebecca	Parent dyads	IN/HV	36	Married	≥ \$100,000	Bachelor's degree	3	9	Female	Spontaneous
Lila	Mother	IN	42	Married	\$50,000-\$69,999	Bachelor's degree	1	3	Female	Tumor
Anna	Parent dyads	IN/HV	39	Married	≥ \$100,000	Graduate school	3	10	Female	Hemorrhage
Jessica	Parent dyads	IN	31	Married	\$70,000-\$99,999	Bachelor's degree	4	7	Female	Fall
Kevin	Parent dyads	IN	26	Married	\$70,000-\$99,999	<High school	3	3	Male	Hemorrhage
Carla	Mother	IN	29	Married	≤ \$19,999	High school	4	9	Female	Mitochondrial

Interview = IN; Home Visit = HV; [¥] Information reflects the data for mothers alone as all the demographic forms were completed by mothers.

Figure 1. Overview of Recruitment.



Chapter 5

Conclusion

Introduction

In this chapter I summarize the major findings from my systematic review (Chapter 2), ethnographic study (Chapter 4) and methodological overview of ethnography in health research (Chapter 3). I also compare and contrast findings between my review and ethnographic study. In addition, I reflect on some of the aspects of these papers and how they came about as well as some of the challenges I faced as a novice researcher during my recruitment, data collection, and data analysis. Finally, I discuss the implications of my work.

Summary of Major Findings

Systematic Review

To date there has been no systematic review of literature studying the impact of a child's TBI on family functioning. By conducting this review I highlighted gaps in the literature and pointed out strengths and weakness of existing studies in this area. My review indicated that moderate to severe TBI has a significant, long-standing impact on family functioning. The review findings indicated that there was a trend for more dysfunction in families of children who had a severe TBI in contrast to comparison/control groups (moderate TBI, mild TBI and orthopedic injuries). Findings from this review highlighted the need for TBI programs to address key issues that underpin family functioning in the moderate to severe TBI population: family dysfunction, prevalence of prolonged and high levels of injury-related burden/stress, parental perception of adaptability, and family cohesion. Further, across studies findings pointed to important aspects for rehabilitative programs to consider when providing services to families in the post-injury period. Based on the review's findings, I noted that family-based interventions for families who have a child with a TBI are vital. I stated that the involvement of social workers and psychologists in assessing families' psychosocial needs and having capacity to recommend and/or provide services that are flexible and family-oriented are critical. I also suggested that families that adjust well following their child's TBI may find meaning and value in participating/leading parent-led programs, and I recommended that families whose post-injury experiences include high levels of dysfunction, poor cohesion, and high burden may benefit from more intensive rehabilitative programs.

Ethnographic Study

The objective of my graduate research was to explore the meanings associated with being a parent of a child with a severe TBI. The main research question that guided this objective was: How are parental meanings, roles, and expectations constructed from parent-child interactions in the day-to-day lives of families with a child with a severe TBI? An analysis of the data from field note/home visits and interviews from parents participants revealed six key components of how parents 'parent' their child with TBI. These components include: (1) Getting back to normal; (2) Relying on a support system; (3) After injury, parents worry something bad may happen; (4) After injury, parents go through range of emotions; (5) After injury, family dynamics change; and (6) Continued performativity. Given these findings, it is vital that health care providers understand the complex nature of this parent population and tailor their services accordingly in order to provide family-centered care.

Comparing Findings across Systematic Review and Ethnographic study

In this section, I highlight some of the similarities and differences across my systematic review and ethnographic study. These two studies complemented each other. The findings from the systematic review helped me to understand what some of the gaps are in this area that needed more attention. Thus, my systematic review not only helped gain in-depth understanding of the exiting TBI literature, but it also focused my ethnographic study objective.

There were key similarities across the results from the two studies. Both studies indicated that parents who have a child with TBI faced tremendous challenges, specifically in the acute stages. With the passage of time families, however, adapted to their daily life. Both study findings showed that families who have a child with severe TBI are more likely to face chronic challenges. Findings from the ethnographic study indicated that there was a great variability across parental experiences, indicating the range of adaptability of these parents. Findings from the studies also indicated that the home environment plays a significant role in overall familial dynamics, which suggests that health care professionals must not only focus on the actual pathophysiological recovery of a child following TBI, but also gain a better understanding of the context in which the child-parents' interactions occur.

One of the major themes that emerged in my ethnographic study was that parents reported how their everyday life has gotten back to 'normal' following their child's injury. However, this was not a facet that emerged in the systematic review findings. This novel finding opens up new research questions about the process of normalization within the pediatric TBI population. Such research could have a significant impact on improving the clinical interactions between health care providers and parents. Health care professionals need to gain a better understanding of the social needs, familial needs, and child's needs in this population.

Considering that qualitative research is scarce in the TBI field, my research adds close accounts from within the everyday lives of participants. This study allows care providers to gain exposure to stories told by parents while in their homes as often, health professionals are not aware of what goes on in these families once a child is discharged from outpatient clinics. As one of the parents in my study stated: “Like we weren’t even home 24 hours and his parents were telling everybody everything was back to normal and everything was fine and maybe to portray that it was good but I just felt like everyone didn’t see all the stuff we were struggling with after and so and I think that people thought, oh you’re so strong and everything’s going so good and then we’d come home and we’d be crying and it would be just… it was hard…” This suggests that parents are left alone to deal with their problems while they return to their homes. Health services need to be tailored towards strengthening family-based interventions to bring about policy changes that should improve the capacity to deliver quality care in outpatient clinics, within homes, and community settings to parents who have a child with severe TBI.

Ethnographic Methodology Paper

I wrote this paper with the goal to gain a better understanding of ethnography as a methodology in health research. My interest in writing this manuscript rose from the confusion I faced with understanding ethnography in health research due to the diverse, evolving, and complex nature of this methodology. In this paper I raised critical questions about the existing status of ethnography as a methodology. In particular, I was interested in how aspects of classic ethnographic work have been taken up, and how its use has changed over time, as ethnographies, such as focused ethnographies, have developed in health research. I explored future considerations and challenges pertaining to the use of ethnography in health research.

This paper demonstrated that understandings of culture have shifted and led to re-definitions of culture, and some key elements of ethnographic research have been lost. Ethnographies conducted in health research often do not focus on culture from a broader perspective; instead, the focus is on single health-related issues. Health researchers appear to spend less time in the field, time spent in the field is regarded as less important, and the importance of the context of field notes is underestimated. It is vital to note that ethnography as a methodology continues to dominate health research and is extensively taken up by researchers.

While writing this paper, I realized that ethnography has changed as a methodology. There are different forms of ethnography such as focused ethnography and institutional ethnography that have emerged for use in health research. This is an important finding as it suggests that ethnography has become more flexible in nature. With the existence of such variation and flexibility in ethnography, there may be a potential to obscure the quality of ethnographic research and data. For example, I noticed that researchers in health research do not pay much attention to the epistemological and ontological underpinnings of their research methodology. This is problematic as the stance and perspective from which the researchers find answers for their research question is lost. Writing this manuscript was of great importance to me, as I was able to see some of the challenges that exist in the current literature. Furthermore, the concept of culture in the context of ethnographic health research has been re-defined. For example, in my ethnographic paper, I focused on understanding culture of parenting a child with TBI. Hence, within this broad culture of parenting, I specifically wanted to study a sub- culture of parents whose child had incurred a severe TBI.

Personal Reflection

On Conducting a Systematic Review

During my first year of my graduate studies, I was enrolled in an independent study course (PEDS 567). This course mainly focused on examining the Traumatic Brain Injury (TBI) literature in relation to children. I had the opportunity to examine several articles related to the pathophysiology of TBI, impact of TBI on language, cognitive abilities, and other physiological and psychological developments in children. Further, I explored an extensive body of literature related to parental stress, burden, social, and familial dynamics in families who have a child with a TBI. While critically examining the TBI literature, I came to realize that there was a need to conduct a systematic review on the impact a child's TBI has on family functioning. Conducting this review was a rewarding experience as it introduced me to the background literature relevant to my dissertation. Further, this was crucial as it allowed me to understand gaps in the literature and what areas needed further exploration.

On Conducting an Ethnographic Study

Prior to conducting the ethnographic study, my exposure to qualitative research was limited. In my last two years of undergraduate work I was mostly exposed to quantitative research in the field of psychology. While conducting this research I wondered if getting a 'significant' p-value was the ultimate answer to conducting rigorous research. It was only after this experience that I began to think more critically about research. During my doctoral research. I was faced with ambiguous situations as a novice researcher and at times felt nervous. I was nervous as I was not sure what to expect. Entering unknown zones can be a nervewracking and scary experience. I tried to conduct my research without any expectations; I wanted to observe things as they unveiled. I was thinking that by adopting this strategy, I would gain two things: First, I would have data free of any predisposed notions. Secondly, I would be strictly committing to the rules of qualitative research by letting things happen naturally. It was hard to restrict myself to such rules! I realized I am naturally curious and have the aspiration to know more and more as my study went on. I also realized that, over time, I did have expectations and notions based on previous interviews and observations of families. In this sense, I began to appreciate the importance of field notes, memoing, and meeting regularly with my supervisors during study conduct.

I conducted an ethnographic study and field work is the hallmark of this study design. My field work was the most exciting part of this study, and yet, the most intricate in nature. Field work allowed me to a gain a better understanding about my parent participants which further enhanced my knowledge about parenting a child with TBI. Frequently, during my field work I had difficulty understanding some of the familial dynamics and this raised many questions for me:

Why do parents say something and then I end up observing something else?

What does this ambiguity tell me?

Does this mean I need more time to get to know parents?

How can I gain their trust?

What implications do my observations have in regards to health care delivery?

As I spent more time with families I learned that the simple answer was that families are a lot more complex than I thought. A child's TBI defined the families I studied and these families looked at everything in the light of their child's injury. During my field work parents often needed help and I tried to understand how helpful I was in their life. What was my role? As I explained more about my research and they became familiar with my work, I almost felt as if this work became their voice. All of the participants showed a keen interest about this work. They often asked me questions such as: how much more data are needed? When will you start writing this work? They were eager to read their own stories and often I felt that they considered this work their own.

This experience has impacted me as person. During my home visits I realized how hard it was to parent a child who has a TBI. I am not a parent, and hence, I was never aware of the complexities that parents of a child with medical conditions face in their everyday life.

Following the home visits, I came to better appreciate what was going on in the lives of these parents. These home visits caused me to think about earlier experiences. For example, in my first shadow shift at the Glenrose Hospital with Dr. Goez (committee member), I met parents who were there for their child's follow up assessments. The first parent I met was a very young mother whose son had incurred a severe TBI. While watching Dr. Goez carry out her medical assessment, I thought about the reasons as to what may have happened to the woman's child. As she appeared very young, I caught myself thinking that she may be not responsible parent and her child is suffering due to her carelessness. As I heard more about her situation during the appointment it became clear that her child had a severe bleed and it had nothing to do with her being young or careless as a parent. On that day, I realized how wrong I was about my assumptions and how easily they could shape my thoughts. It was an eye-opening experience that was important for me to recall as I entered the field. As I became more interactive and familiar with the families in the clinic, I also became more sensitive to their stories and life situations. I also came to understand that my participants' voices were important, and that I needed to communicate their story rather than mine.

My Experiences with the Recruitment Process

I was well aware of the difficulties I might encounter while recruiting study participants. Hence, to overcome challenges, a year prior to the start of my study, I was actively involved in developing relationships with gatekeepers at the study site. I used purposeful sampling to recruit my target population from the TBI Clinic that is located at the Glenrose Rehabilitation Hospital. Despite having well planned recruitment strategies and the vital resources in hand, however, it was extremely difficult to recruit parents. At the outset, I was confident that by having such a well-organized recruitment plan, I would be able to achieve the target sample size for my study.

While I succeeded in achieving the targeted sample size for the face-to-face interviews (n=10), there were several parents who declined to participate in the 8 home visits due to their busy routines and the time commitment these home visits required of them. In order to overcome this problem, I had to re-examine my data collection strategy and ensure that this change did not impact the quality of the data I collected. One of the changes I made was to re-evaluate the inclusion criteria for the study. Following several discussions with members of my supervisory committee, I changed the required time since a child’s injury changed from “within six months of study enrolment” to “within twenty-four months of study enrolment”, and I changed the required child’s age from “3-6 years” to “3-10 years”. Broadening these inclusion criteria increased the pool of eligible participants at the TBI clinic. My committee members and I felt that increasing these ranges still fit with the study’s purpose. These necessary changes were a clear indication that qualitative research is ‘emergent’ in nature [1], but that appropriate strategies must be considered as the project unfolds.

My Experiences with Data Collection

I used participant observation, field notes, and interviews as the sources of collected data. Participant observation is a method of data collection that is well suited for in-depth understanding of everyday life. Further, meanings and interactions of a particular study population are understood through a method described by Cooley as ‘sympathetic introspection’ [2], which is interchangeably used with participant observation [3]. Participant observation is the most complicated qualitative research method of data collection [3]. Consequently, I was very nervous while conducting my first observations. Despite guidance from my supervisors and committee members about what to observe and how to overcome my nervousness, I still felt lost and fragmented while observing study participants. On many occasions I was not sure if I was observing what I was supposed to observe. I had many lingering questions:

Am I observing the most important data?

How do I know what is vital to observe and what is not? Who decides all of this?

What should I do with the silences I encountered? What do they mean?

How much should I participate in my participant's everyday activities?

As I became more familiar with my participants and I was more confident, I adopted a strategy of recording as much detail as possible during my observations. I became more aware of how much and when to participate in certain activities with my participants. However, I still struggled how to deal with spontaneous situations that arose during data collection. Although I have substantially increased my skills of field work and participant observation, I look forward to developing and extending my knowledge in the future.

Information gathered during family visits were collected using field notes to document as much detail as possible related to my observations. The purpose of this strategy was to enable a deeper understanding of parental interactions, meanings, and involvement with their child. It has been suggested that the most effective strategy for writing field notes is to jot main points or words, which can assist in recalling key incidents that occurred during observations [4]. For my study, field notes consist of facts such as the participants in attendance, time and date of the observation, activities observed, as well as both reflective (my thoughts and feelings, interpretations, and conceptual concerns) and descriptive (physical information about the home and parent-child interaction) notes. I constantly struggled with writing field notes and observing at the same time. As time passed, I started thinking about different strategies to make sure that I did not lose my field data. For me the most effective strategy was to record everything I observed immediately after I left the field because my memory of the events that occurred was vivid.

I also used interviews to collect data and these felt less challenging. However, I was concerned about delivering clear questions and probing my participants in an effective manner. I had a well-designed interview guide with many probes to gain as much details from participants as possible in a very short time frame. This was extremely helpful, and with time, I was able to probe study participants in an effective manner when spontaneous questions aroused.

My Experiences with Data Analysis

I was most excited about analyzing my study data. After the first set of field notes and transcripts, however, I realized how complex the analytic process was. I conducted a vigilant review of the text reading paragraph by paragraph, line by line, word by word, which allowed meanings, interactions, and roles to become more defined and pronounced. To become immersed in the data, my first step was an initial reading of the field notes and transcripts to familiarize myself with the content. During a second reading, I began coding by noting the parental meanings, interactions, and roles that emerge from the text. As themes were identified, similar instances or occurrences were aggregated to create a basic coding schema; gaps and contradictory findings were also examined. My supervisors and committee members reviewed the schema and gaps.

My co-supervisor (Dr. Caine) was actively involved during data analysis helping analyze the data and make connections between the meanings, interactions, and roles that parents described and that I observed in my field notes. During this process, I verified my descriptions of the data and to make sure that data were consistent to the reality of the world that was experienced by parents. I compared and contrasted data from different sources to observe similar results across the sources and also look for inconsistencies and gaps in the data. My co-supervisor helped ensure that I produced thick description (comprehensive) of my field notes. She took the time to read my field work and give me feedback on the gaps she noticed in my field data. She and I would discuss my field work immediately after my return from the field to ensure that I had everything fresh in my mind. This was a useful approach as it enabled us not only to generate an inclusive set of field notes but also precise and credible data.

The Implications of My Dissertation Research

My research has shown that parents who have a child with TBI face many challenges once they bring their child home. They go through tremendous struggles of achieving ‘normal’ day-to-day life and encounter many difficulties in relation to family dynamics, relationships, roles and interactions. My ethnographic study, in particular, indicated that the culture of parents who have a child with TBI is extremely intricate in nature. My study provides an important foundation from which to conduct studies aimed at gaining an in-depth understanding of familial dynamics in particular.

1. All the observational data collected in my study were from parents who resided in small towns. Future research needs to be conducted with parents from urban and metropolitan areas to observe how those families may be different form families that live in rural areas, where access to resources and support might differ.

2. My findings related to the process of normalization and normalcy are novel in this area. Hence, researchers in the TBI field need to pay more attention to this phenomenon to better understand such processes within the TBI population and further explore normalcy in these families. Such work will have important clinical implications as it will allow health care

professionals to gain better understanding of brain injured children's families and provide family-centered care.

3. I recommend that more qualitative research be conducted to better understand family dynamics and cultural issues that may have varying effects on families and family members. This research should focus on the role of culture for families in the post-injury period. This could have greater impact on health care policy changes to make culturally grounded programs accessible.

4. Although quantitative research [5] has been conducted with siblings of children with TBI, I feel more research from a qualitative lens would increase the understanding of the needs of siblings of a child with TBI, and could contribute to the improvement of the services provided to families.

5. Examining the culture of school where children with a TBI spend much time is crucial for understanding some of how key dynamics of the school environment interact with children and their families. Findings from this research could facilitate care for children who bring tremendous cognitive, linguistic and social needs during their schooling. Conducting research in this area will help in strengthening community-based interventions and provide psychosocial interventions well suited for the school as well as the child's needs.

6. A prospective study of health care providers' attitudes and beliefs as they provide care to the families who have a child with TBI needs to be conducted. Such a study may examine the attitudes and beliefs of health care providers before and after they treat their patients. This will help us understand the preconceived notions that care providers have about their patients and how they impact health care delivery.

References

[1] Given LM. The Sage encyclopedia of qualitative research methods. California: Sage Publications Inc; 2008.

[2] Cooley C H. Social organization and Human nature and the social order. New York: Free Press; 1956. Original work published 1909.

[3] Prus R. Symbolic interaction and ethnographic research: Intersubjectivity and the study of human lived experience. USA: State University of New York Press; 1996.

[4]Emmerson RM, Fretz RI, Shaw LL. Writing ethnographic field notes. Chicago: University of Chicago Press; 1995.

[5] McMahon MA, Noll RB, Michaud LJ, Johnson JC. Sibling adjustment to pediatric traumatic brain injury: A case‐controlled pilot study. J Head Trauma Rehabil. 2011;16:587-594.

Bibliography

Ahern K J. Ten tips for reflexive bracketing. Qual Health Res. 1999; 9: 407-411.

Aitken ME, McCarthy ML, Slomine BS, Ding R, Durbin D, Jaffe K, et al. Family burden after traumatic brain injury in children. Pediatrics. 2009; 123: 199-206.

Aitken ME, Mele N, Barrett K W. Recovery of injured children: Parent perspectives on family needs. Arch Phys Med Rehabil. 2004; 85: 567-573.

Aldrich EF, Eisenberg HM, Saydjari C, Luerssen TG, Foulkes MA, Jane JA, et al. Diffuse brain swelling in severely head-injured children. A report from the NIH Traumatic Coma Data Bank. J Neurosurg. 1992; 76: 450-454.

Almagor E, Skinner J. Ancient ethnography: New approaches. London: Bloomsbury Publishing Inc.; 2013.

Altman DG. Practical Statistics for Medical Research. London: Chapman and Hall; 1991.

Anderson VA, Morse SA, Catroppa C, Haritou F, Rosenfeld JV. Thirty month outcomes from early childhood head injury: A prospective analysis of neurobehavioural recovery. Brain. 2004; 127(12): 2608-2620.

Anderson V, Catroppa C, Morse S, Haritou F, Rosenfeld J. Recovery of intellectual ability following traumatic brain injury in childhood: Impact of injury severity and age at injury. Pediatr Neurosurg. 2000; 32: 282-290.

Anderson VA, Catroppa C, Rosenfeld J, Haritou F, Morse SA. Recovery of memory functions following traumatic brain injury in pre-school children. Brain Inj. 2000; 14: 679-692.

Andrews TK, Rose FD, Johnson DA. Social and behavioural effects of traumatic brain injury in children. Brain Inj. 1998; 12: 133-138.

Ardener E. Belief and the problem of women. In: Fontaine JL, editor. The interpretation of ritual. London: Tavistock; 1972. p. 135-157.

Atkinson P, Hammersley M. Ethnography and participant observation. In: Denzin NK, Lincoln YS, editors. Strategies of qualitative inquiry. London: Sage; 1998. p. 110-136.

Baer HA, Singe M, Susser I. Medical anthropology and the world system. USA: Bergin & Garvey; 1997.

Balikci A. Shamanistic behavior among the Netsilik Eskimos. Southwest J Anthropolo. 1963; 19(4): 380-396.

Becker HS, Geer B, Hughes EC, Strauss AL. Boys in White: Student culture in medical school.

Chicago: University of Chicago Press; 1961.

Bendikas AE, Wade SL, Cassedy A, Taylor HG, & Yeates KO. Mothers report more child-rearing disagreements following early brain injury than do fathers. Rehabil Psychol. 2011; 56(4): 374-382.

Benn KM, McColl MA. Parental coping following childhood acquired brain injury. Brain Inj. 2004; 18(3): 239-255.

Bloor M. The ethnography of health and medicine. In: Atkinson P, Coffey DD, Lofland J, Lofland L, editors. Handbook of ethnography. London: Sage Publications Ltd.; 2002. p. 177-187.

Boyatzis RE. Transforming qualitative information: Thematic analysis and code development. Thousand Oaks, CA: Sage; 1998.

Boyle SJ. Styles of ethnography. In: Morse JM, editor. Critical issues in qualitative research methods. Thousand Oaks, CA: Sage Publications; 1994. p. 159-185.

Buckingham RW, Lack SA, Mount BM, MacLean LD, Collins JT. Living with the dying: Use of the technique of participant observation. Can Med Assoc J. 1976; 115: 1211-1215.

Burgess E, Drotar D, Taylor HG, Wade SL, Stancin T, Schatschneider C, et al. The Family Burden of Injury Interview (FBII): Reliability and validity studies. J Head Trauma Rehabil. 1999; 14: 394-405.

Butler J. Gender trouble: Feminism and the subversion of identity. New York: Routledge; 1990.

Braaf S, Manias E, Riley R. The 'time-out' procedure: An institutional ethnography of how it is conducted in actual clinical practice. BMJ Qual Saf. 2014; 22: 647-655.

Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006; 3: 77-101.

Brewer DJ. Ethnography. Philadelphia: Open University Press; 2000.

Bright FAS, Boland P, Rutherford SJ, Kayes NM, McPherson K M. Implementing a client-centered approach in rehabilitation: An autoethnography. Disabil Rehabil. 2012; 34(12): 997-1004.

Brink P. Issues of reliability and validity. In: Morse JM, editor. Qualitative nursing research: A contemporary dialogue. London: Sage; 1990. p. 164-186.

Brink P. Experiences of a nurse ethnographer: From student to faculty. In: de Chesnay M, editor. Nursing research using ethnography: Qualitative design and methods in nursing education. New York: Springer; 2015. p. 121-138.

Brookshire BL, Chapman SB, Song J, Levin HS. Cognitive and linguistic correlates of children's discourse after closed head injury: A three-year follow-up. J Int Neuropsychol Soc. 2000; 6: 741-751.

Brown FL, Whittingham K, Sofronoff K, Boyd RN. Parenting a child with a traumatic brain injury: Experiences of parents and health professionals. Brain inj. 2013; 27: 1570-1582.

Campbell M, Gregor F. Mapping social relations: A primer in doing institutional ethnography. Toronto, Canada: Garamond Press; 2002.

Carroll K, Iedema R, Kerridge R R. ICU ward round practices using video-reflexive ethnography. Qual Health Res. 2008; 18(3): 380-390.

Carspecken PF. Critical ethnography in educational research: A theoretical and practical guide. New York: Routledge; 1996.

Chang H. Autoethnography as method. Walnut Creek, CA: Left Cost Press Inc.; 2008.

Charmaz K. Stories and silences: Disclosures and self in chronic illness. Qual Inq. 2002; 8: 302-328.

Clark A, Stedmon J, Margison S. An exploration of the experience of mothers whose children sustain traumatic brain injury (TBI) and their families. Clin Child Psychol Psychiatry. 2008; 13:565-583.

Cole W, Gerring J, Gray R, Vasa RA, Salorio CF, Grados M, Christensen JR, Slomine BS Prevalence of aggressive behaviour after severe paediatric traumatic brain injury. Brain Inj. 2008; 22: 932-939.

Conneeley AL. Transitions and brain injury: Exploring the journey of people with traumatic brain injury. Brain Impair. 2012; 13: 72-84.

Cook KE. Using critical ethnography to explore issues in health promotion. Qual Health Res. 2005; 15(1): 129-138.

Cooley C H. Social organization and human nature and the social order. New York: Free Press; 1956. Original work published 1909.

Cruz EV, Higginbottom G. The use of focused ethnography in nursing research. Nurse Res. 2013; 20(4): 36-43.

Deegan MJ. The Chicago school of ethnography. In: Atkinson P, Coffey DD, Lofland J, Lofland L, editors. Handbook of ethnography. London: Sage Publications Ltd.; 2002. p. 11-25.

Degeneffe CE. Family caregiving and traumatic brain injury. Health Soc Work. 2001; 26(40): 257-268.

DeMatteo CA, Cousins MA, Lin CY A, Law MC, Colantonio A, Macarthur C. Exploring postinjury living environments for children and youth with acquired brain injury. Archives Physical Med Rehabil. 2008; 89(9):1803-1810.

Denzin NK. The call to performance. Symb Interact. 2003; 26.1: 187-207.

Ellis C, Bochner AP. Analyzing analytic autoethnography: An autopsy. J Contemp Ethnogr. 2006; 35(4): 429-449.

Ellis C. The ethnographic I: A methodological novel about autoethnography. Walnut Creek, CA: AltaMira Press; 2004.

Ellis C, Adams T E, Bochner A P. Autoethnography: An overview. Qual Soc Res. 2011; 12(1): 10-17.

Emmerson RM, Fretz RI, Shaw LL. Writing ethnographic field notes. Chicago: University of Chicago Press; 1995.

Erlandson AD, Harris LE, Skipper LB, Allen DS. Doing naturalistic inquiry. Thousand Oaks, CA: Sage Publications, Inc; 1993.

Ewing-Cobbs L, Prasad MR, Kramer L, Charles SCJ , James B, Stephen F, et al. Late intellectual and academic outcomes following traumatic brain injury sustained during early childhood. J Neurosurg. 2006; 105(4): 287-296.

Fetterman MD. Ethnography: Step-by-step. California: Sage Publications Inc.; 2010.

Fine GA. Ten lies of ethnography. J Contemp Ethnogr. 1993; *22*(3): 267-294.

Gagnon AJ. Carnevale F, Mehta P, Rousseau H, Stewart DE. Developing population interventions with migrant women for maternal-child health: A focused ethnography. BMC Public Health. 2013; 13(1): 471-485.

Ganesalingam K, Sanson A, Aanderson V, Yeates KO. Self-regulation as a mediator of the effects of childhood traumatic brain injury on social and behavioral functioning. J Int Neuropsychol Soc. 2007; 13(2): 298-311.

Gates MF, Lackey NR, Brown G. Caring demands and delay in seeking care in African American women newly diagnosed with breast cancer: An ethnographic, photographic study. Oncol Nurs Forum. 2001; 28(3): 529-537.

Geest S, Finkler K. Hospital ethnography: Introduction. Soc Sci Med. 2004; 59: 1995-2001.

Gerrard-Morris A, Taylor HG, Yeates KO, Walz NC, Stancin T, Minich N, Wade SL. Cognitive development after traumatic brain injury in young children. J Int Neuropsychol Soc. 2010; 16(1): 157-168.

Given LM. The Sage encyclopedia of qualitative research methods. Thousand Oaks, CA: Sage Publications Inc.; 2008.

Goffman E. Asylums: Essays on the social situation of mental patients and other inmates. New York: Doubleday; 1961.

Goodson L, Vassar M. An overview of ethnography in healthcare and medical education research. J Educ Eval Health Prof. 2011; 8(4): 1-5.

Guba EG. Lincoln YS. Competing paradigms in qualitative research, In: Denzin NK, Lincoln YS, editors. Handbook of Qualitative Research London: Sage; 1994. p. 105-117.

Gustafsson M, Kristensson J, Holst G, Willman A, Bohman D. Case managers for older persons with multi-morbidity and their everyday work - A focused ethnography. BMC Health Serv. Res. 2013; 13: 1-15.

Hammersley M, Atkinson P. Ethnography principles in practice. London: Routledge; 1995.

Heath C, Luff P, Sanchex Svensson M. Video and qualitative research: Analysing medical practice and interaction. Med Educ. 2007; 41: 109-116.

Higginbottom GA, Pillay JJ, Boadu NY. Guidance on performing focused ethnographies with an emphasis on healthcare research. The Qual Rep. 2013; 18: 1-16.

Hill CE. Introduction: Continuity and differences in the old and the new applied anthropology. In: Hill CE, Partridge WL, editors. Training Manual in medical anthropology Washington: American Anthropology Association; 1985. p. 1-7.

Hodgson I. Ethnography and health care: Focus on nursing. Qual Soc Res. 2000; 1(1): 7-14.

Hoghughi MS, Long N. Handbook of parenting: Theory and research for practice. Sage; 2004.

Hughes CC. Ethnography: What's in a Word-Process? Product? Promise? Qual Health Res. 1992; 2: 439-450.

Hyder AA, Wunderlich CA, Puvanachandra P, Gururaj G, Kobusingye OC. The impact of traumatic brain injuries: A global perspective. NeuroRehabilitation. 2007; 22: 341-354.

Jadad AR, Moore RA, Carroll D, Jenkinson C, Reynolds DJM, Gavaghan DJ, et al. Assessing the quality of reports of randomized clinical trials: Is blinding necessary? Control Clin Trials. 1996; 17: 1-12.

Jennett B, Bond M. Assessment of outcome after severe brain damage. Lancet. 1975; 1: 480-487.

Johansen RK. Listening in the silence, seeing in the dark: Reconstructing life after brain injury. University of California Press; 2002.

Jones M, Hocking C, Wright St-Clair V. Parents caregiving for children after a Traumatic Brain Injury: Structuring for security. New Zealand Journal of Occupational Therapy. 2011; 57(1):4-13.

Jones JS. Origins and ancestors: A brief history of ethnography. In: Jones JS, Watt S, editors. Ethnography in social science practice. London: Routledge; 2010. p. 13-27.

Kan CH, Saffari M, Khoo TH. Prognostic factors of severe traumatic brain injury outcome in children aged 2-16 years at a major neurosurgical referral centre. Malays J Med Sci. 2009; 16: 25.

Kazak AE, Simms S, Alderfer MA, et al. Feasibility and preliminary outcomes from a pilot study of a brief psychological intervention for families of children newly diagnosed with cancer. J Pediatr Psychol. 2005; 30: 644-655.

Keenan HT, Hooper SR, Wetherington CE, Nocera M, Runyan DK. Neurodevelopmental consequences of early traumatic brain injury in 3-year-old children. Pediatrics. 2007; 119: 616-623.

Kidd JD, Finlayson MP. Mental illness in the nursing workplace: A collective autoethnography. Contemp Nurse. 2010; 36(1-2): 21-33.

Kirk S, Fallon D, Fraser C, Robinson G, Vassallo G. Supporting parents following childhood traumatic brain injury: A qualitative study to examine information and emotional support needs across key care transitions. Child Care Health Dev. 2015; 41: 303-313.

Kleinman A. Patients and healers in the context of culture: An exploration of the borderland between anthropology, medicine, and psychiatry. California: University of California Press; 1981.

Knafl K, Breitmayer B, Gallo A, Zoeller L. Family response to childhood chronic illness: Description of management styles. J Pediatr Nurs. 1996; 11: 315-326.

Knafl KA, Deatrick JA. How families manage chronic conditions: An analysis of the concept of normalization. Res Nurs Health. 1986; 9: 215-222.

Knoblauch H. Focused ethnography. Qual Soc Res. 2005; 6: 44-58.

Knoblauch H, Schnettler B. Videography: Analysing video data as a ‘focused’ ethnographic and hermeneutical exercise. Qual Res. 2012; 12(3): 334-356.

Kurowski BG, Taylor HG, Yeates KO, Walz NC, Stancin T, Wade SL. Caregiver ratings of long-term executive dysfunction and attention problems after early childhood traumatic brain injury: Family functioning is important. PM R. 2011; 3(9): 836-845.

Kroeber AL, Kluckhohn C. Culture: A critical review of concepts and definitions. Cambridge, Mass: Harvard University Peabody Museum of American Archeology and Ethnology; 1952.

Lewis KJ, Morris KM, Morris DR, Krawiecki N, Foster A.M. Social problem solving in children with acquired brain injuries. J Head Trauma Rehabil. 2000; 15: 930-942.

Lincoln SY, Guba GE. Naturalistic inquiry. California: Sage Publications Inc.; 1985.

Liu W, Manias E, Gerdtz M. Medication communication between nurses and patients during nursing handovers on medical wards: A critical ethnographic study. Int J Nurs Stud. 2012; 49: 941-952.

Lofland J, Lofland LH. Analyzing Social Settings: A Guide to Qualitative Observation and Analysis. Belmont, CA: Wadsworth; 1995.

Lomax, H. & Casey, N. Reordering social life: Reflexivity and video methodology. Sociol Res Online. 1998; 3(2).

Macdonald S. British social anthropology. In: Atkinson P, Coffey DD, Lofland J, Lofland L, editors. Handbook of ethnography. London: Sage Publications Ltd.; 2002. p. 60-79.

Madison DS. Critical ethnography: Methods, ethics, and performance. Thousand Oaks: Sage Publications Inc.; 2012.

Magilvy JK, McMahon M, Bachman M, Roark S, Evenson C. The health of teenagers: A focused ethnographic study. Public Health Nurs.1987; 4(1): 35-42.

Mahon PR. A critical ethnographic look at paediatric intensive care nurses and the determinants of nurses' job satisfaction. Intensive Crit Care Nurs. 2014; 30: 45-53.

Malinowski B. Argonauts of the Western Pacific: An account of native enterprise and adventure in the Archipelagoes of Melanesian New Guinea. London: Routledge and Kegan Paul; 1922.

Mangeot S, Armstrong K, Colvin AN, Yeates KO, Taylor H G. Long-term executive function deficits in children with traumatic brain injuries: Assessment using the Behavior Rating Inventory of Executive Function (BRIEF). Child Neuropsychol. 2002; 8(4): 271-284.

Mariotto AB, Rowland JH, Yabroff KR, Scoppa S, Hachey M, Ries Feuer EJ. Long-term survivors of childhood cancers in the United States. Cancer Epidemiol Biomarkers Prev. 2009; 18: 1033-1040.

Max JE, Castillo CS, Robin DA. Predictors of family functioning after traumatic brain injury in children and adolescents. J Am Acad Child Adolesc Psychiatry. 1998; 37: 83-90.

Max JE, Lansing AE, Koele SL, Castillo CS, Bokura H, Schachar R, Collings N, Williams KE Attention deficit hyperactivity disorder in children and adolescents following traumatic brain injury. Dev Neuropsychol. 2004; 25: 159-177.

McCabe J, Holmes D. Nursing, sexual health and youth with disabilities: A critical ethnography. J Adv Nurs. 2013; 70(1): 77-86.

McCubbin HI, Patterson JM, Wilson L. Family inventory of life events and changes (FILE) Form A. In: McCubbin HI, editors. Family assessment for research and practice. Thompson A. Madison: University of Wisconsin Press; 1980.

McElroy TA. Davis A, Hunt C, Dadul J, Stanba T, Larson C. Navigating a way forward: Using focused ethnography and community readiness to study disability issues in Ladakh, India. Disabil Rehabil. 2011; 33(1): 17-27.

McGibbon E, Peter E, Gallop R. An institutional ethnography of nurses' stress. Qual Health Res. 2010; 20(10): 1353-1378.

McIlroy G, Storbeck C. Development of deaf identity: An ethnographic study. J Deaf Stud Deaf Educ. 2011; 16(4): 494-511.

McMahon MA, Noll RB, Michaud LJ, Johnson JC. Sibling adjustment to pediatric traumatic brain injury: A case-controlled pilot study. J Head Trauma Rehabil. 2011; 16: 587-594.

Mead M. Coming of age in Samoa: A psychological study of primitive youth for western civilization. New York: William Morrow; 1928.

Mead GH. Mind, self, and society. Chicago: University of Chicago Press. 1934.

Miller IW, Bishop DS, Epstein NB, Keitner GI. The McMaster family assessment device: reliability and validity. J Marital Fam Ther. 1985; 11: 345-356.

Mills AJ, Durepos G. Wiebe E. Encyclopedia of case study research. Thousand Oaks: Sage Publications Inc.; 2010.

Montague, E. Multiple perspectives on functioning of families impacted by traumatic brain injury: Exploring both parental and injured child's perceptions. Master [thesis]. New Mexico: The University of New Mexico, 2010.

Moos RH. The social climate scales: An overview. Palo Alto, CA: Consulting Psychologists Press; 1974.

Morse JM. How different is qualitative health research from qualitative research? Do we have a subdiscipline? Qual Health Res.2010; 20: 1459-1468.

Mrazek D, editor. Family Global Assessment Scale (FGAS): Initial reliability and validity. Proceedings from the 32nd annual meeting of the American Academy of Child Psychiatry; San Antonio (TX): 1985; 23-27.

Muecke M A. On the evaluation of ethnographies. In: Morse JM, editor. Critical issues in qualitative research methods. Thousand Oaks, CA: Sage Publications; 1994. p. 187-209.

Nastasi BK. Audivisual methods in ethnography. In: Schensul JJ, LeCompte MD, Stephen BK, Borgatti P, editors. Enhanced ethnographic methods. London: Sage Publications Inc.; 1999. p. 1-50.

Nuckolls CW. Culture as a problem that cannot be solved. Madison: University of Wisconsin Press; 1998.

O'Byrne P. Population health and social governance analyzing the mainstream incorporation of ethnography. Qual Health Res. 2012; 22(6): 859-867.

O'Byrne P. The advantages and disadvantages of mixing methods: An analysis of combining traditional and autoethnographic approaches. Qual Health Res. 2007; 17(10): 1381-1391.

Olson DH, Portner J, Bell R. Family adaptability and cohesion evaluation scores [FACES] II. In: Filsinger EE, editor. Marriage and Family Assessment: A Sourcebook for Family Therapy. Beverly Hills, CA: Sage; 1983. p. 299-315.

O'Mahony JM, Donnelly TT. Using critical ethnography to explore issues among immigrant and refugee women seeking help for postpartum depression. Issues Ment. Health Nurs. 2012; 33: 735-742.

Patton QM. Purposeful sampling. In: Bryman A, editor. Ethnography. London: Sage Publications Ltd.; 2001. p. 106-121.

Perrott S, Taylor HG, Montes J. Neuropsychological sequelae, familial stress, and environmental adaptation following pediatric head injury. Dev Neuropsychol 1991; 7(1): 69-86.

Pesut B, Reimer-Kirkham S. Situated clinical encounters in the negotiation of religious and spiritual plurality: A critical ethnography. Int J Nurs Stud. 2010; 47(7): 815-825.

Picken FE. *Ethnography*. In: Walter M, editor. Social research methods. Australia: Oxford University Press; 2013. p. 337-350.

Pink S. Doing visual ethnography. (3nd ed.). London: Sage Publication Ltd.; 2013.

Pink S. Doing visual ethnography. (2nd ed.). London: Sage Publication Ltd.; 2007.

Pino FJ, Soriano E, Higginbottom GM. Sociocultural and linguistic boundaries influencing intercultural communication between nurses and Moroccan patients in southern Spain: A focused ethnography. BMC Nursing. 2013; 12(14): 1-8.

Poland B, Pederson A. Reading between the lines: Interpreting silences in qualitative research. Qual Inq. 1998; 4: 293-312.

Pollock D. "A Response to Dwight Conquergood's essay: 'Beyond the text: Towards a performative cultural politics." In: Dailey SJ, editor. The future of performance studies: Visions and revisions. Washington, DC: National Communication Association; 1998. p. 37-46.

Potter JL, Wade SL, Walz NC, Cassedy A, Stevens MH, Yeates K O, Taylor HG. Parenting style is related to executive dysfunction after brain injury in children. Rehabil Psychol. 2011; 56(4): 351-358.

Prus R.Symbolic interaction and ethnographic research: Intersubjectivity and the study of human lived experience. USA: State University of New York Press; 1996.

Ramritu P, Groft G. Needs of parents of the child hospitalized with acquired brain damage. Int J Nurs Studies. 1999; 36: 209-216.

Rashid M, Goez HR, Mabood N, Damanhoury S, Yager JY, Joyce AS, Newton AS. The impact of pediatric traumatic brain injury (TBI) on family functioning: A systematic review. J Pediatr Rehabil Med. 2014; 7(3): 241-254.

Rice PL, Ezzy D. Qualitative research methods: A health focus. Oxford: Oxford University Press; 1999.

Richards L, Morse JM. Readme first for a user's guide to qualitative methods. California: Sage; 2007.

Rivara JB, Fay GC, Jaffe KM, Polissar NL, Shurtleff HA, Martin KM. Predictors of family functioning one year following traumatic brain injury in children. Arch Phys Med Rehabil. 1992; 73(10): 899-910.

Rivara JB, Fay G, Jaffe KM, Polissar NL, Martin K, Shurtleff HA, Liao S. Family functioning and children's academic performance and behavior problems in the year following traumatic brain injury. Arch Phys Med Rehabil. 1994; 77(4): 369-379.

Rivara JM, Jaffe KM, Polissar NL, Fay GC, Liao S, Martin KM. Predictors of family functioning and change 3 years after traumatic brain injury in children. Arch Phys Med Rehabil. 1996; 77(8): 754-764.

Robinson CA. Managing life with a chronic condition: The story of normalization. Qual Health

Res. 1993; 3: 6-28.

Roscigno IC, Swanson MK. Parents’ experiences following children’s moderate to severe traumatic brain injury: A clash of cultures. Qual Health Res. 2011; 21(10): 1413-1426.

Schmidt AT, Hanten GR, Li X, Levin SH. Emotion recognition following pediatric traumatic brain injury: Longitudinal analysis of emotional prosody and facial emotion recognition. Neuropsychologia. 2010; 48(10): 2869-2877.

Schwartz D. Visual Ethnography: Using photography in qualitative research. Qual Sociol. 1989; 12(2): 119-154.

Siddique S. Being in-between: The relevance of ethnography and auto-ethnography for psychotherapy research. Counseling and Psychotherapy Research. 2012; 11(4): 310-316.

Sinding C. Using institutional ethnography to understand the production of health care disparities. Qual Health Res. 2010; 20(12): 1656-1663.

Singer GS, Glang A, Nixon C, Cooley E, Kerns KA, Williams D, et al. A comparison of two psychosocial interventions for parents of children with acquired brain injury: An exploratory study. J Head Trauma Rehabil. 1994; 9: 38-49.

Slade B. Institutional Ethnography. In: Mills AJ, Durepos G, Wiebe E, editors. Encyclopedia of case study research. Thousand Oaks, CA: Sage Publications Inc.; 2010. p. 462-465.

Smith DE. Institutional ethnography: A sociology for people. Toronto, Canada: AltaMira Press; 2005.

Spradley PJ. Interviewing an Informant. In: Bryman A, editor. Ethnography. London: Sage Publications Ltd.; 2001. p. 331-343

Stancin T, Wade SL, Walz N, Yeates KO, Taylor HG. Family adaptation 18 months after traumatic brain injury in early childhood. J Dev Behav Pediatr. 2010; 31: 317-325.

Stein REK, Jessop DT. PACTS Papers/AECOM: Tables documenting the psychometric properties of a measure of the impact of chronic illness on a family. Bronx, NY: Albert Einstein College of Medicine, Department of Pediatrics; 1985.

Taylor HG, Swartwout MD, Yeates KO, Walz NC, Stancin T, Wade SL. Traumatic brain injury in young children: Post-acute effects on cognitive and school readiness skills. J Int Neuropsychol Soc. 2008; 14: 1-12.

Taylor HG, Yeates K O, Wade SL, Drotar D, Stancin T, Burant C. Bidirectional child-family influences on outcomes of traumatic brain injury in children. J Int Neuropsychol Soc. 2001; 7: 755-767.

Taylor S. Researching the social: An introduction to ethnographic research. In: Taylor S, editor. Ethnographic research. California: Sage Publications Inc.; 2002. p. 1-12.

Thomas BH, Ciliska D, Dobbins M, Micucci S. Process for systematically reviewing the literature: Providing the research evidence for public health nursing interventions. Worldviews Evid Based Nurs. 2004; 1: 176-184.

Thomas J. Doing critical ethnography: Qualitative research methods. Newbury Park: Sage Publications; 1993.

Thorne SE. Methodological orthodoxy in qualitative nursing research: Analysis of the issues. Qual Health Res. 1991; 1(2): 178-199.

Townsend E. Institutional ethnography: A method for showing how the context shapes practice. Occup Ther J Res. 1996; 16 (3): 179-199.

Turner VW. The forest of symbols. Ithaca: Cornell University Press; 1967.

Verhaeghe S, Defloor T, Grypdonck M. Stress and coping among families of patients with traumatic brain injury: A review of the literature. J Clin Nurs. 2005; 14: 1004-1012.

Wade SL, Walz CN, Cassedy A, Taylor HG, Stancin T, Yeates KO. Caregiver functioning following early childhood TBI: Do moms and dads respond differently? NeuroRehabilition. 2010; 27: 63-72.

Wade SL, Taylor HG, Drotar D, Stancin T, Yeates KO. Family burden and adaptation during the initial year after traumatic brain injury in children. Pediatrics. 1998; 102: 110-116.

Wade SL, Taylor HG, Drotar D, Stancin T, Yeates KO. Interpersonal stressors and resources as predictors of parental adaptation following pediatric traumatic injury. J Consult Clin Psychol. 2004; 72(5): 7767-7784.

Wade SL, Gerry TH, Yeates KO, Stancin T. Long-term parental and family adaptation following pediatric brain injury. J Pediatr Psychol. 2006; 31(10): 1072-1083.

Wade SL, Wolfe CR, Pestian JP. A webbased, problem-solving intervention for families of children with traumatic brain injury. Behavioral Research Methods, Instruction, and Computing. 2004; 36: 261-269.

Wade SL, Wolfe CR, Brown TM, Pestian JP. Putting the pieces together: Preliminary efficacy of a web-based family intervention for children with traumatic brain injury. J Pediatr Psychol. 2005; 30: 437-442.

Wade SL, Taylor HG, Drotar D, Stancin T, Yeates KO. Childhood traumatic brain injury initial impact on the family. J Learn Disabil.1996; 29: 652-661.

Walby K. Institutional ethnography and data analysis: Making sense of data dialogues. Int J Soc Res Methodol. 2013; 16(2): 141-154.

Warr D. Stories in the flesh and voices in the head: Reflections on the context and impact of research with disadvantaged populations. Qual Health Res. 2004; 14: 578-587.

Weiner B. Women of value, men of renown: New perspectives in Trobriand exchange. Austin: University of Texas Press; 1976.

White S, Siebold C. Walk a mile in my shoes: An auto-ethnographic study. Contemp Nurse. 2008; 30(1): 57-68.

Willis ME. The problem of time in ethnographic health care research. Qual Health Res. 2010; 20(4): 556-564.

Wolcott H F. Ethnography a way of seeing. California: Sage Publications, Inc.; 1999.

Yeates KO, Taylor HG, Walz NC, Stancin T, Wade SL. The family environment as a moderator of psychosocial outcomes following traumatic brain injury in young children. Neuropsychol. 2010; 24: 345-356.

Yeates KO. Closed-head injury. In: Yeates KO, Ris MD, Taylor HG, editors. Pediatric Neuropsychology: Research, theory, and practice. New York: Guilford Press; 2000. p. 92-116.

Yeates KO, Swift E, Taylor HG, Stancin T. Short- and long-term social outcomes following pediatric traumatic brain injury. J Int Neuropsychol Soc. 2004; 10: 412-426.

Yeates KO, Taylor HG, Drotar D, et al. Preinjury family environment as a determinant of recovery from traumatic brain injuries in school-age children. J Int Neuropsychol Soc. 1997; 3: 617-630.

Ylvisaker M. Communication outcome in children and adolescents with traumatic brain injury. Neuropsychol Rehabil. 1993; 3: 367-387.

Ylvisaker M, Adelson PD, Braga LW, Burnett SM, Glang A, Feeney T, Moore W, Rumney P, Todis B. Rehabilitation and ongoing support after pediatric TBI: Twenty years of progress. J Head Trauma Rehabil. 2005; 20: 95-109.

Youngblut JM, Brooten D. Pediatric head trauma: Parent, parent-child and family functioning 2 weeks after hospital discharge. J Pediatr Psychol. 2006; 31: 608-618.

Youngblut JM, Brooten D. Mother's mental health, mother-child relationship, and family functioning 3 months after a preschooler's head injury. J Head Trauma Rehabil. 2008; 23: 92-102.

Appendix A: Ethics Forms

UNIVERSITY OF ALBERTA

Information Sheet

After a Child's Traumatic Brain Injury: A Study of Being a Parent

Study Principal Investigators:
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Study Co-Investigators:
Dr. Vera Caine, Faculty of Medicine & Dentistry, University of Alberta
Dr. Helly Goez, Faculty of Medicine & Dentistry, University of Alberta

Dr. Anthony Joyce, Faculty of Medicine & Dentistry, University of Alberta

Dr. Jerome Yager, Faculty of Medicine & Dentistry, University of Alberta

Background: You are invited to take part in a study that explores parenting a child with a severe head injury. You will be asked about the ways this event has impacted you as a parent. Taking part in this study will help our team better understand what it means to be a parent of a child with a severe head injury so that better post-brain injury services can be provided to families.

Purpose: We want to know how you feel about being a parent, as well as how your parenting roles and expectations are shaped by the day-to-day interactions you have with your child.

Procedures: If you agree to take part in this study, you will participate in an individual interview which will be followed by 8 home visits of ~ 2 hours. An individual interview will last for ~45 minutes and can take place at a time and location that is convenient and preferable to you. A PhD student at the University of Alberta will conduct the interviews, and home visits.

The individual interview will be a semi-structured. That means that investigator will ask general questions to all parents in the study, but depending on your answers, she might also ask other specific questions to better understand what you are sharing. The investigator will digitally-record the interview so that she can go back and listen to your answers. She will also use the recordings to compare and contrast experiences reported by other parents. You can request that the digital recorder be shut off at any time during your focus group/interview.

Study team will not access your child's medical records for this study.

Individual interview will be followed by 8 home visits of ~ 2 hours. These visits can occur over several months depending on your schedule and preference. This means that the study investigator will spend 2 hours at your home over several months learning about your role as a parent and your everyday activities. Occasionally, and if you ask/permit, the investigator could be involved in your day-to-day family interactions and activities (e.g., playing a game with you and your child). During the time spent at your home, the investigator will make notes of the roles and activities she is observing and/or participating in. This is so she does not miss anything important during her visits that will help her understand parenting a child with a severe brain injury. Home visits will be booked with you based on your convenience and for any time and day preferred by you and your family.

If you are interested in participating in this study, we would like you to sign a consent form to show that you agree to take part.

Possible Benefits: You may feel good by answering some of the questions and sharing your experiences as

parent who has a child with severe brain injury. Your experience may be beneficial and contribute to improving the care that parents and children receive when they come to the outpatient clinic at Glenrose Rehabilitation Hospital. By participating in this study, you will better our understanding of how to best help families of children with a severe brain injury.

Possible Risks: You may be asked questions you don't like or don't want to answer. That's fine. You can tell study investigator and she will move on to the next question. If you want to stop answering all the questions, you can let her know that too, and she can stop the interview altogether. This study requires 8 home visits of ~ 2 hours, which means the investigator, will be in your home during those times and for that duration. These visits have the potential to disrupt some of your family routines. Therefore, visits will only be booked with you based on the time and day you prefer.

Confidentiality: Your privacy is important to us. Your name or your child's will never be used in reports from our study. An example of a report we might create based on what we learn is a report detailing recommendations for outpatient care and programs for families and children. Based on the answers to our interview questions, all identifying information will be removed. Access to your personal information will be limited to the principal investigator, Dr. Newton, and Ms. Rashid, which means that only these individuals will have access to your interview and any information they receive from you. All the information received from you will be stored by

Dr. Newton at the Edmonton Clinic Health Academy building at the University of Alberta in an access controlled room in a locked file cabinet. Your information will be digitally encrypted and kept for 7 years. After that time, your interview answers, and any other information about you, will be destroyed.

Voluntary Participation: You don't have to take part in the study at all, but if you agree to participate, you can leave the study any time. These decisions will not affect care or services your child receives from the doctors and health care providers in the outpatient clinic at the Glenrose Rehabilitation Hospital. If you decide after your interview that you would like to withdraw from the study, you need to tell Dr. Newton or Ms. Rashid no later than a week after your interview. After that time, your interview will have had all names removed and there will be no way that they can identify which answers were yours to take out of the study. For the 8 home visits, you can withdraw one week after the final home visit.

For participating in this study, you will receive a $30 gift certificate for interview participation and $90 gift certificate for the 8 home visits to compensate for time and travel. For parents who participate in individual interviews, gift certificates will be provided at the end of the session. For parents who participate in home visits, they will receive a $50 gift card in the end of 4th family visit and final $40 gift card at the end of 8th family visit.

Contact Names and Telephone Numbers: If you have questions, please contact Ms. Marghalara Rashid or Dr. Newton who are the lead researchers on this study. Ms. Rashid can be reached at 780-224-5332. Dr. Newton can be reached at 780-248-5581.

If you have concerns about your rights as a study participant, you may contact the University of Alberta Research Ethics Board (REB) office at (780) 492-2615. This office has no affiliation with Dr. Newton's research team.

UNIVERSITY OF ALBERTA

Consent Form

Title of Project: After a Child's Traumatic Brain Injury: A Study of Being a Parent

Study Principal Investigators:

Marghalara Rashid, PhD candidate, Faculty of Medicine and Dentistry, University of Alberta

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Dr. Amanda Newton, Assistant Professor, Faculty of Medicine and Dentistry, University of Alberta

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Study Co-Investigators:

Dr. Vera Caine, Faculty of Medicine & Dentistry, University of Alberta

Dr. Helly Goez, Faculty of Medicine and Dentistry, University of Alberta

Dr. Anthony Joyce, Faculty of Medicine and Dentistry, University of Alberta

Dr. Jerome Yager, Faculty of Medicine and Dentistry, University of Alberta

Please circle your answers:

Do you understand that you have been asked to participate in a research study? Yes No

Have you received and read a copy of the attached Information Sheet? Yes No

Do you understand the benefits and risks involved in taking part in this research study? Yes No

Have you had an opportunity to ask questions and discuss this study? Yes No

Do you understand that you can refuse to participate or withdraw from the study?

You don't have to give a reason. Yes No

Has the issue of confidentiality been explained to you? Yes No

Who explained this study to you? ____________________________

Do you understand who will have access to the information you provide? Yes No

Do you understand that all the sessions will be recorded? Yes No

I agree to be in this study. **Yes No**

Signature of Participant: ____

Printed Name: ____

Date: ____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee: ______________________________ Date: ________________

AFTER A CHILD’S TRUMATIC BRAIN INJURY: A STUDY OF BEING A PARENT

We are looking for parents of children with severe Traumatic Brain Injury (TBI) to participate in a study called **After a Child’s Traumatic Brain Injury: A Study of Being a Parent**.

You are invited to take part in a study that explores what it means to parent a child with a severe head injury. We want to know how you feel about being a parent, as well as how your roles and expectations are shaped by the day-to-day interactions you have with your child. You will be asked about the ways this event has impacted what it means to be a parent. Taking part in this study will help our team better understand what it means to be a parent of a child with a severe head injury. Interested parents will participate in an individual interview session to discuss your experiences followed by 8 home visits to discuss your experiences in more detail.

For participating in this study you will be compensated for your time. If you participate in an individual interview (a private interview session), you will receive a $30 gift card. You will also receive a $90 gift card for completing 8 home visit sessions.

If you are interested in participating or learning more about the study, please contact Dr. Amanda Newton, in the Department of Pediatrics at the University of Alberta: (780-248-5581) or an6@ualberta.ca.

The University of Alberta Research Team overseeing the conduct of this study includes: Marghalara Rashid, (Department of Pediatrics), Dr. Amanda Newton (Department of Pediatrics), Dr. Vera Caine (Department of Nursing), Dr. Helly Goez (Department of Pediatrics), Dr. Anthony Joyce (Department of Psychiatry), and Dr. Jerome Yager (Department of Pediatrics).

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Appendix B: Data Collection Tools

Screening and Eligibility Form

Date: _______________________ (DD-MM-YYYY)

Parent's First, Last Name: __________________________________

☐ ***Eligibility Criteria*** **(Place X here if all 3 boxes below are checked)**

- ☐ Parent who has a child with a severe TBI (defined by a Glasgow Coma Scale score of 8 or less) within 24- months of study enrolment will be recruited.
- ☐ Parent of a child 2-10 years of age.
- ☐ Parent of a child with any type of bleed (e.g., axonic injury, ischemic or hemorrhagic stroke), **or** space occupying lesion (e.g., tumor) **or** severe infection of the brain (e.g., meningitis)

☐ ***Exclusion Criteria*** **(Place X here if any of the boxes below are checked)**

- ☐ A child within a foster family.
- ☐ Parent of a child with a pre-existing neurological disorder (e.g., CP, autism)
- ☐ Parent of a child with a previous mental disorder.
- ☐ Inability of the parent to speak or understand English.

Demographic Information

Information about you and your family

Date: ________________________ (DD-MMM-YY)

Your First Name: ___________________________________

Your Last Name: _________________________________

Your Age: _____

Gender:

☐ Male

☐ Female

Your Marital Status:

☐ Single, Never Married

☐ Married/Common-Law

☐ Separated

☐ Divorced

☐ Widowed

Can you estimate your total household income?

☐ ≤ $19,999

☐ $20,000-$34,999

☐ $35,000-$49,999

☐ $50,000-$69,999

☐ $70,000-$99,999

☐ ≥ $100,000

Please indicate the highest level of education you have obtained:

☐ <High school

☐ High school

☐ Bachelor’s degree

☐ Graduate school

Please indicate the number of children you have living in your household: ________

Tell us more about your child who attend’s the Glenrose Rehabilitation Clinic

What is your child’s age? ________

Gender:

☐ Male

☐ Female

What was the cause of their brain injury?

☐ Fall

☐ Motor vehicle accident

☐ Bicycle accident

☐ Sports

☐ Other (please indicate): _________________________

Do you know how severe your child’s brain injury is?

☐ Severe Traumatic Brain Injury

☐ Moderate Traumatic Brain Injury

☐ Mild Traumatic Brain Injury

When did your child acquire his/her injury (date)? ____________________

Field Note Guide

Date of Session: ____

Time of Session: ____

Location of Session: ____

Session #: ____

Participants in Attendance: ____

Observation Description:

Type of Observation:

Descriptive	**Reflective**
☐ Basic observation o Who was present during the field experience? o What happened during the observational period? o Notice the overall atmosphere during the observational period. o Pay attention to what events occur during the observational period. o Pay attention to the activities that take place. o Notice how things are done different/same between parents. ☐ Physical information about home environment: o What are the facilities/resources in the home for the child’s TBI? ☐ Parent-child interaction o Notice parent-child communication and interactions. o Type of language used? o Ways of interacting? o Moods/emotions observed? ☐ Parental roles o What are some of the parental role changes? [see interview guide question 5,6] o What are some the different roles that parents undertake?	☐ Consists of my thoughts, feelings, and interpretations. ☐ What are some of the important queries that are raised after my observation of these families. ☐ How do my expectations differ from my data. ☐ What aspects of ‘being a parent’ are still missing that need to be explored? ☐ What are some of the unexpected and stimulating observations? ☐What are some of the events and relationships that I observed that will help me probe/discover parental meanings, roles, and interactions? ☐ What have I learned from my observational data up to now?

Note: Descriptive and Reflective are two types of field notes described by Bogdan and Biklen (2007).

Interview Guide

Opening Questions	Probes
1. Tell me about your son/daughter who is also a patient at the Glenrose Rehabilitation Hospital.	- How old is he/she? - What kind of kid is he/she? (e.g., outgoing, funny, quiet, affectionate, etc.) - What kind of things does he/she like to do/play with? - What are his/her favorite activities? - Is he/she different after the brain injury? How so? - What things have changed about him/her? - How is he/she the same? - How have you dealt with these changes?
Parenting Questions	**Probes**
1. What has it been like as a parent watching your child experience a brain injury?	
2. What has it been like as a parent to observe/be a part of your child's medical care and rehabilitation?	- What roles/jobs have you taken on? What has that been like? - Are there roles/jobs that you are more comfortable with than others? Which roles and why?
3. Tell me about your day-to-day parenting since your child's brain injury.	- In what ways is it still the same? Why do you think these things have stayed the same? - How have you maintained consistency in your parenting roles? - In what ways is parenting different? Why

	do you think these things are different? - Do you have any other children? If yes: Has your child's brain injury changed how you parent your other children? Please explain why/why not.
4. What's it like being a mom/dad of child who has had a brain injury?	- What are the rewards of being a parent to your child? - What are the challenges of being a parent to your child? You can use stories to help explain if you find it easier.
5. Tell me about what it's like to parent your child who is injured.	- What are your new roles and responsibilities? - Are there different things you need to do as a parent because of the injury?
6. (Take each different role/responsibility described above and explore) You mentioned ________ is a new role/responsibility. Tell me more about this change.	How do you view this change – is it easy to do or do you perceive it as hard to do? Why do you think that is?
7. How has your idea of being a mother/father changed since your child was injured?	Why/why not? - In what ways have you changed as a parent/person? - What did being a parent mean to you before your child's injury? - What does it mean to you now after the injury?
8. If the mother/father has other children: I'd like to talk with you about your parenting experiences with your other children. Has your idea of being a mother/father changed with your other children?	- If no, why do you think your idea hasn't changed? Do you think this is important? Why? - If yes, why do you think your idea has

	changed? How do you see this change, is it helpful/not helpful? Why?
9. If the mother/father is married: What impacts have changes in your parenting had on your marriage after your child's injury?	- Tell me more about being a wife/husband/co-parent after your child's injury?
10. If mother/father is not married to child's other parent: What impacts have changes in your parenting had on your relationship with your child's father/mother?	- How have things changed with regard to parenting roles and responsibilities between you and your (ex) husband/wife over time? - Have these changes in your parenting made you independent of or dependent on your (ex) wife/husband? - Have changes in your marriage contributed to how you parent your child? How so? /Why not? - Are there any differences or similarities in how you parent your child relative to your (ex) wife/husband? How so? - If there are differences, how have these differences affected your marriage? - If there are similarities, how have these similarities affected your marriage? - Have your children noticed these similarities/differences? If yes, how do you know this? If no, why do you think that is?
11. Do you feel your relationship with your child has changed as a result of her/his injury?	- If yes, how so? You can use stories to explain these differences. - Can you also tell me how are your relationship is still the same?
12. Have there been any changes to the way that you communicate with your child since their	- If yes, how so?/If not, why do you think that is?

injury?	- What impact has this injury had on the words you use with your child? - How have these changes affected (benefited/limited, etc.) you and your child? If other children: Do you communicate differently with your other kids?
13. How have your immediate family members reacted to the changes in your family since your child's injury?	- What do you think of their reactions? - Have their reactions affected you as a parent? If yes, how so? If not, why not?
14. In what ways has the presence or absences of your immediate family affected you as parent?	- Do you perceive their presence or absences as positive or negative in your life? How so?
15. Have you ever been concerned with how you are perceived by others in relation to your capabilities as a mother/father?	- When have you felt these concerns? Try to describe specific events/places/times. - How did you deal with the situation? - Have the reactions of others affected how you parent? How so? Why/why not? Can you give specific examples of how you parented differently because of someone's reaction?
16. Have you met other parents of children who have sustained a traumatic brain injury?	- If yes, what have those experiences been like? - If no, is that something you would like to do? Why/why not?
Closing Question	
1. Is there anything we haven't talked about today that is important to you as parent that you would like to share?	