EXPERIENCES OF ADULTS WHO HAD A TRAUMATIC BRAIN INJURY

By

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DECLARATION

I, Hallima Ismail, declare that:

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Supervisor: Mrs Xoli Mfene Date: 03 February 2023

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Student: Hallima Ismail Date: 03 February 2023

DEDICATION

For my daughters, Nuha & Imaan Ismail. For your patience, encouragement, and inspiration throughout this journey.

“While we try to teach our children all about life, our children teach us what life is all about.” – Angela Schwindt

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ABSTRACT

A traumatic brain injury is a sudden, unprecedented injury that causes damage to the brain. Impacting an average sixty-nine million people a year, the incidence of traumatic brain injury may be described as a silent epidemic. Therefore, the objectives of this research study were to: investigate the experiences of adults who had a traumatic brain injury, to determine what changes were experienced by adults who suffered a traumatic brain injury and to explore the long-term and short-term challenges of adults who experienced a traumatic brain injury. The study utilised a qualitative research approach, with an interpretive paradigm. Additionally, an exploratory research design was implemented. Purposive sampling was employed to select eight participants for the study. Reflexive Thematic analysis was used to analyze data. The findings of the study indicated that all eight participants experienced negative alterations due to their traumatic brain injuries. The degree of negative experiences varied, and some participants indicated an interleaving of positive impacts post-injury. All participants highlighted a lack of overall awareness and understanding by the general population of their experiences and their plight. Furthermore, the findings of the study highlighted that the traumatic nature of the recovery process was especially challenging for participants, and that some turned to negative coping mechanisms to counterbalance the trauma experienced. An emergent finding of the study revealed gender differences between the seeking of emotional assistance post-injury and indicated that male traumatic brain injury survivors may likely be less inclined to seek assistance, due to the associated stigma. Further research is recommended to assess gender differences in coping with TBI and help seeking.

CHAPTER ONE: INTRODUCTION

1.1. Overview of traumatic brain injury

A traumatic brain injury (TBI) is a sudden, unprecedented injury that causes damage to the brain (Roozenbeek et al., 2013). It differs from a head injury in that a TBI is not always caused by direct trauma to the head. According to Dolman (2021) a TBI may also be caused by concussions, contusions or anoxic brain injuries. To establish the diagnosis of a traumatic brain injury, there should be a presence of neurological symptoms or the demonstration of intracranial pressure (Naidoo, 2013). TBI may occur in childhood and adulthood, but for this study the impact on adults will be focused on. Overall, mortality for TBI survivors has been somewhat reduced, but survivors still require sustained rehabilitation. This is as a result of the various outcomes and impacts of the injury (Dang et al., 2017). TBI has an impact not only on the survivors, but also on their caregivers and loved ones. Webster et al. (2015) refer to the incidence of TBI as a hidden pandemic. The potential cognitive, behavioural and psychological consequences of a TBI are significant. It is one of the leading causes of mortality worldwide and contributes significantly to the national burden of disease and ongoing violent behaviour.

A TBI may be classified as mild, moderate or severe depending on the severity of the injury and outcomes thereof. A concussion is a mild type of traumatic brain injury, however, the effects of a concussion may be serious, although most people have recovered completely in time. Severe traumatic brain injuries can result in severe physical and psychological symptoms, including comas and potentially even death (Webster et al., 2015).

1.2. Problem statement and rationale

According to Dewan et al. (2018) the prevalence of TBI is sixty-nine million injuries per year. Traumatic brain injuries are one of the leading causes of disability in South Africa, and society is not aware of the substantial disability that is caused as a result thereof and the impact that it has on families of survivors (Nicholson, 2016). According to Agarwal et al. (2020) at least 90, 000 people every year experience the onset of long-term disabilities due to traumatic brain injuries. In addition, from 2006, there has been a 53% increase in the total number of traumatic brain injury-related emergency department visits, hospitalisations and deaths (Agarwal et al., 2020).

According to Webster et al. (2015), very few resources are available for the rehabilitation of patients with a TBI in South Africa and access to rehabilitation facilities in the public sector is limited. Consequently, the survivors and families impacted by traumatic brain injuries are left ill-equipped to deal with the complex and potentially long-term and life-changing challenges that accompany the incidence of a TBI (Naidoo, 2013). As described by Khellaf et al. (2019), the incidence of worldwide TBI cases remains high – at fifty million annual cases worldwide. However, despite the high incidence of cases, it is an area which is still under-researched (Jerome et al., 2017). In exploring the global incidence and urgency of traumatic brain injuries, Dewan et al. (2018) concluded that understanding, advocacy and intervention in the field were severely limited. Due to the heterogenous nature of traumatic brain injury, more research is required to gain information on the topic to facilitate appropriate rehabilitation and intervention that may improve the overall quality of life of TBI survivors.

1.3. Research objectives

The research objectives were:

- To investigate the experiences of adults who suffered a traumatic brain injury.
- To determine what changes were experienced (personality, cognitive, emotional psychological) by adults who had a traumatic brain injury.
- To explore the long-term and short-term challenges of adults who experienced a traumatic brain injury.

1.4. Research questions

The research addressed the following questions:

- What are the experiences of adults who had a traumatic brain injury?
- What changes were experienced because of the traumatic brain injury?
- What are the challenges faced by adults who experienced traumatic brain injury?

1.5. Motivation and significance for the study

The study was motivated by the researcher's interest in neuropsychology and the assumption that there is a lack of an account of individualised experiences of TBI survivors. This is due to the comprehensive information available on the clinical nature of the injury, but a gap in information on individuals' emotions, feelings and experiences. Furthermore, the researcher is motivated to disseminate information on TBI experiences, to minimize this gap and improve understanding in the field of traumatic brain injury. This study explores the experiences of adults who had suffered a traumatic brain injury; impacting, on average, sixty-nine million people a year, the incidence of TBI may be described as a silent epidemic (Dewan et al., 2019). According to Nguyen et al. (2016), despite being a very pertinent medical, emotional and social issue, there is a lack of in-depth research into the topic. The research statistics, combined with the lack of detailed information on the topic; elucidated the need to gain information on the experiences of adults who had a traumatic brain injury. This study's findings may improve understanding on the topic, serve as a base for future research and provide foundational knowledge for rehabilitation and intervention.

1.6. Outline of the thesis

Chapter two: the literature review - reviews the relevant research and literature. It provides a strong background into the diagnosis, classification, risk factors, causes, outcomes, prevention and rehabilitation of traumatic brain injury. Furthermore, it relates TBI to trauma and psychological underpinnings, reinforcing the rationale for the study. The theoretical framework is described and motivated for. Following the literature review, chapter three outlines the research methodology of the study. In this chapter, the research methodology, paradigm, design and sampling procedure are described in detail. The procedures of data collection and analysis are explained, and the issues of validity and reliability are addressed. Ethical considerations are expanded upon and how these ensured an ethical study. The findings and results chapter encompass chapter four, wherein the results and findings of the study are designated and briefly expounded upon. Following the analysis of findings and results, within chapter five, the results findings are discussed in detail. Chapter six concludes the research study and makes recommendations for practice and research.

1.7. Definitions of key concepts

The key terms used in the research study are expanded upon, to familiarise the reader with the terminology and concepts relating to the study.

Traumatic brain injury: A TBI may be defined as an "impact, penetration or rapid movement of the brain within the skull that results in an altered mental state" (Prins et al., 2013).

Non-traumatic brain injury: A non- traumatic brain injury causes damage to the brain due to various internal factors. These factors include but are not limited to – lack of oxygen, intracranial pressure or exposure to toxins. Some examples of a non- traumatic brain injury may include – a brain tumor, stroke, an aneurysm or an infectious disease that impacts the brain (Ng & Lee, 2019).

Glasgow coma scale: The Glasgow Coma Scale is administered by a healthcare provider and is typically used to determine the severity of an injury by assessing an individual's ability to speak coherently, follow instructions and move certain body parts. A score of less than 15 indicates that there is some degree of injury, and the patient should be closely monitored for follow-up diagnosis and intervention (Andrade et al., 2011).

Cognitive impairments: Cognitive impairment refers to when a person has trouble with memory, learning new things, concentrating, or making decisions that affect their everyday life. Cognitive impairment ranges from mild to severe (Stocchetti & Zanier 2016).

Social impairment: A social impairment refers to impaired social capacity, often indicated by the inability to form and maintain healthy social relationships (Stocchetti & Zanier 2016).

Mortality: For this study, the medical understanding of mortality is utilized. Mortality is described as the death rate, or number of deaths in a particular group of people within a certain period of time (HarperCollins, 2021).

Multidisciplinary rehabilitation: "Multidisciplinary rehabilitation refers to activities that involve the efforts of individuals from several disciplines. These efforts are disciplinary-orientated and, although they may impinge upon clients or activities dealt with by other disciplines, they approach them primarily through each discipline relating to its own activities" (Melvin, 1980). Singh et al. (2018) reiterates that the complexity of healthcare services and nuanced medical interventions requires a collaboration between several different healthcare professionals.

1.8. Delimitations

A delimitation is a restriction that a researcher enforces before undertaking the study to narrow the study's scope. This study is delimited to adults who experienced a TBI in the province of Kwa-Zulu Natal. Furthermore, the researcher delimited the access of participants to two organisations. This allowed the researcher to focus on relevant participants and find conclusive findings.

1.9. Conclusion

This chapter focused on the outline and orientation of the research problem, elucidated the need for the study and provided a brief overview of the subsequent chapters. The following chapter will expand on the literature relevant to the study.

CHAPTER TWO: LITERATURE REVIEW

2.1. Introduction

This literature review explores several relevant sub-topics and avenues of traumatic brain injury, to provide comprehensive knowledge on the topic. Some of these sub-topics include how it is diagnosed and types of injury, TBI in children, how TBI relates to trauma, rehabilitation and concludes with an in-depth understanding of the impact of TBI on family members and caregivers.

2.2. Overview of Traumatic brain injury

A TBI can be defined as an impact, potential penetration or rapid movement of the brain within the skull that causes an altered mental state (Prins et al., 2013). According to Faul et al. (2010) several factors influence the magnitude of effect; including the severity of injury, the individuals age and gender, type and location. Due to the rising incidence, TBI has been declared a major public health problem (Khellaf et al., 2019). Worldwide cases are estimated to be at fifty million a year – which indicates that approximately half of the global population will experience an episode of TBI in their lifetime (Khellaf et al., 2019). TBI is the leading cause of disability in persons under 40 worldwide (Dang, et al., 2017).

According to Kushner (1998) for a TBI to be diagnosed, there must be several definitive immediate signs present. These signs include “confusion, loss of consciousness, amnesia and focal neurological defects.” Some instant symptoms include imbalance, uncoordinated behaviour, dizziness, nausea and/or vomiting, confusion, delayed verbal and motor responses and a poor attention span. Different tests and measures are used by healthcare providers to diagnose traumatic brain injury. Multiple measures are often used to diagnose as well as form a path for treatment and recovery. These include the Glasgow Coma Scale, imaging tests, blood tests and other relevant tests. The Glasgow Coma Scale is administered by a healthcare provider and is typically used to determine the severity of an injury by assessing an individual's ability to speak coherently, follow instructions and move certain body parts (Andrade et al., 2011). In addition, magnetic resonance imaging (MRI scan). An MRI scan uses strong radio waves and magnets to create a detailed view of the brain. This test is generally used if symptoms do not improve soon after injury. Computerized tomography (CT) scan. This scan uses X-rays to create a comprehensive view of the brain. It is used to determine whether there are any blood clots, brain tissue swelling or bleeding in the brain (Lee & Newberg, 2005). Moreover, according to Valera (2019), blood tests to diagnose TBI is an emerging area of research. Research is being conducted to assist individuals whose injuries are unlikely to show up on CT scans. Blood tests may be an accurate, quick way to diagnose individuals for a mild concussion.

Other tests to determine the extent and prognosis of TBI include: speech and language tests to determine how well the patient can speak and make use of language, and how well the patient can read or write. Verbal skills assessments may include a communication skills test to determine whether a person's behaviour has been impacted. Tests to determine the ability to swallow to assess whether the patient can swallow adequately and receive sufficient nutrition. Breathing ability and lung function tests to determine whether breathing assistance or extra oxygen is necessary. Neuropsychological tests determine the level of thinking, reasoning, understanding, memory and problem-solving abilities (National Institute of Child Health and Human Development, 2020).

According to the Brain Injury Association of America (2020), the Glasgow Coma Scale abilities are scored from three to fifteen in this scale and higher scores translate to less severe injuries. A score of thirteen or higher indicates a mild traumatic brain injury, nine to twelve indicates a moderate injury and eight or below indicates a severe traumatic brain injury. Three key areas are measured: the ability to speak (assessing the manner and appropriateness of speech), the ability to open eyes (including whether the individual can do this on-demand) as well as the ability to move. This scale may also be used to follow up on the effectiveness of treatment (Andrade et al., 2011).

2.3. Experiences of adults who had a TBI

Whilst there is much theoretical information about those who experience traumatic brain injury, the experiences, accounts and emotions of those individuals are lacking. Strandberg (2009) was one of the few studies that illuminated the process, support and consequences experienced by adults who suffered a traumatic brain injury. The data that emerged indicated that experiences of those who had a TBI were both negative and positive. The majority of participants had difficulties in returning to working life after injury and the negatives outcomes were sustained, gradually becoming integrated as part of life (Strandberg, 2009). A significant finding from this study was that significant others were a driving force in recovery.

Jumisko et al. (2009) elucidates that the meaning of feeling well for people with moderate or severe TBI was that although the experience was very unfamiliar, living with the impacts of TBI became familiar. A key aspect to acceptance included seeking meaning, regaining control over everyday life and having a strong support system. Adults who experienced a TBI felt well when they reconciled with the circumstances of their life and created meaning in that circumstance. This study is of clinical significance to enhance professionals' understanding and awareness of people with traumatic brain injuries (Jumisko et al., 2009). Personal accounts of experiences of adults with a TBI are few and far between. The studies that tackle this important topic are limited. This topic is imperative in assisting professionals to better understand the impact of injury, and thereby formulate tailored interventions to effectively rehabilitate individuals, enhancing their overall quality of life and contributing to an overall healthy social setting.

2.4. The changes and challenges experienced following TBI

One of the reasons why TBI is cited to be dangerous and detrimental to both physical and mental health, is the seriousness of impact and outcomes of the injury. Stocchetti & Zanier (2016) differentiated between the potential outcomes of a traumatic brain injury.

The outcomes of TBI may include but are not limited to:

Excess mortality: those who experience a TBI are at higher risk for a shorter life span, compared to those in their age group. This may be as a result of several negative impacts associated with the TBI, notwithstanding the physical injury and the impact thereof.

Cognitive impairments: some common cognitive deficits associated with TBI are a shortened attention span, limited concentration, memory problems, executive functioning deficits, amnesia and confusion. In addition to these cognitive impairments, traumatic brain injuries may cause damage to specific areas of the brain, which may result in localisation of damage.

Physical impacts: Individuals may experience a handicap, paralysis or weakness, impaired balance, poor coordination, weakness of muscles, decreased bladder control and loss of vision or sight.

Mass lesions: hematomas (blood clots) may occur within the brain. Contusions may occur. Ischemia (insufficient blood supply to areas of the brain) may occur.

Language problems: The following language associated problems may occur: aphasia (impairment of language, speech production or comprehension), agraphia (loss of the ability to write) or alexia (a partial or complete inability to read.)

Psychiatric disorders: People who have traumatic brain injuries are more at risk for depressive disorders, anxiety disorders, substance abuse, irritability, decreased motivation and personality changes.

Sexuality: Both physical and psychological implications of TBI may affect sexuality and sexual function aspects.

Social impairment: The combined physical, cognitive and emotional impairments may create an obstacle for re-entering the community. As a result, there is difficulty making and keeping friends and relationships.

Employment: As a result of the physical, cognitive and social challenges associated with traumatic brain injury; a return to a regular working environment is rare, and therefore the unemployment rate amongst those who have suffered a TBI is high (Stocchetti & Zanier, 2016). Trauma: One of the direct impacts of TBI is the traumatic experience associated with the injury.

The range of impacts that arise from TBI may result in severe emotional consequences for the survivors. Understanding that the outcomes of TBI are diverse and each case is highly nuanced emphasizes the need to explore individual experiences of TBI survivors to address this gap in the literature available.

2.5. TBI relation to trauma

The events leading up to a TBI (motor vehicle accidents. acquired brain injuries etc.) are often psychologically traumatic (Vasterling et al., 2017). The distressing nature of the causes of TBI may complicate the recovery and rehabilitation process. Having to emotionally manage the shock of the event that caused the injury and the outcomes resulting from the injury may be overwhelming for the TBI survivor (Vasterling et al., 2017). It is imperative to account for an individual's feelings immediately after the TBI to ascertain the time period of the trauma onset.

In specific cases, including but not limited to motor vehicle accidents, military trauma or ongoing domestic violence, post-traumatic stress disorder may develop. Post-traumatic stress disorder (PTSD) includes behavioural, emotional and cognitive symptoms which may arise following a significant threat to life, serious injury or sexual violence (Vasterling et al., 2017). It is characterized by maladaptive survival responses, behavioural difficulties, experiencing nightmares or flashbacks and heightened arousal. The symptoms must be persistent for more than six months to be diagnosed as PTSD and lead to significant distress or functional impairment (Vasterling et al., 2017).

In a literature review and recommendations of psychosocial and emotional sequelae of individuals with traumatic brain injury, Morton and Wehman (2009) indicate that while physical progress is often made during the first six months following a traumatic brain injury, psychosocial problems remain a long-term challenge. The psychological and emotional challenges of traumatic brain injuries directly relate to trauma. In reference to the risk factors, most individuals who sustain brain injuries are young males. These young males are often in the early stages of establishing their independence in different areas of their lives, including intimate relationships, employment, leisure and friendships. The direct consequences of social isolation and decreased leisure activities relate to a new-found dependence of the survivor on his family members to meet these needs (Morton & Wehman, 2009). This may be described as a traumatic experience and is characterized by frustration, low mood and anxiety (Morton & Wehman, 2009).

Given the varied nature of the injuries, it is important to note that trauma itself may be heterogenous and it is necessary to explore the short and long-term challenges of the survivor to understand the individualised psychological trauma fully. This question is explored in the interview schedule and further elucidates the necessity of the study.

2.6. Rehabilitation

Rehabilitation refers to restoring health or normal functioning following an illness, addiction or imprisonment. The rehabilitation process is often effective in reducing mortality and increasing the chance of normal functioning in the case of many illnesses, TBI included (Wade, 2005). According to Cope (2009), as there is no clear-cut cure for a traumatic brain injury, prevention is the best solution to containing this public health issue. However, in some cases prevention is not possible and it is for this reason that the rehabilitation of TBI has undergone extensive development over the last twenty years. Currently, a much more extended, comprehensive, and direct approach to rehabilitation is clinically accepted (Cope, 2009). Once a TBI has been identified and contained, the rehabilitation phase begins. Rehabilitation may be short or long-term depending on the following factors: nature and severity of the injury, pre-existing conditions and family support (Ylvisaker, 1998). A research study by Khan et al. (2003) emphasizes that recovery from a TBI may continue for up to five years after the injury.

Norrefalk (2003) noted that one of the most imperative factors in rehabilitative medicine is, teamwork. When different professionals are brought together to assess a patient's conditions, it allows for a holistic view of the difficulties, resulting in the best possible outcome. The term "multidisciplinary team" has been given the following definition: "this refers to activities that involve the efforts of individuals from several disciplines. These efforts are disciplinary-orientated and, although they may impinge upon clients or activities dealt with by other disciplines, they approach them primarily through each discipline relating to its own activities" (Melvin, 1980).

A multidisciplinary approach increases personal independence and chances of adaptive functioning for the patient (Goranson et al., 2009). A multidisciplinary approach to rehabilitation may include any of the following approaches: cognitive rehabilitation (memory, problem-solving skills), psychological testing (executive functioning, behavioural and emotional issues), physical rehabilitation and pain management (Khan et al., 2003). Professionals involved in rehabilitation may include neurologists, psychologists, physiotherapists and/or occupational therapists (Khan et al., 2003).

Whilst rehabilitation aims to ensure that the patient will reach an optimal stage of functioning and the highest level of independence possible, all aspects must be considered to facilitate this. This includes emphasizing the psychosocial, personality and emotional impacts of traumatic brain injury. Moreton & Wehman (2009) make a compelling recommendation that rehabilitation should focus significantly more energy on the psychological health of patients with traumatic brain injuries. While reviewing the impact of emotional well-being on long-term recovery and survival in physical illness, Lamers et al. (2011) concluded that "positive emotional well-being is favourably related to the prognosis of physical illness – patients with higher levels of emotional well-being have better recovery and survival rates than patients with low levels of emotional well-being."

Rehabilitating individuals is a long arduous process which requires commitment and determination from the TBI survivor. However, the support of caregivers, family and friends form a strong support system is equally important to health and recovery.

2.7. Family support for TBI survivors

The challenges associated with traumatic brain injuries can be difficult for survivors, however, it is also undeniably challenging for the family and close friends of survivors. A survivor’s life may be usurped by physical and psychological traumatic brain injury-related challenges, while relationships around them may impacted indirectly. These impacts result from having to care for the survivors, showing moral support during trauma, and dealing with the impact of TBI on relationships.

As reported by Verhaege (2005) family members experience stress to such an extent that professional intervention is recommended even a decade or longer after the TBI has occurred. The level of stress experienced is dependent on the nature of the injury as opposed to the severity of the injury. It was found that partners experience more difficulty coping than parents and younger families with financial and medical problems (Verhaege, 2005). Family members of individuals who experience a TBI are at risk for depression, anxiety and somatic symptoms (Kreutzer, 2009). A phenomenological hermeneutic interpretation of data by Ricoeur (1976) revealed that family members battle with their own suffering while showing compassion to their loved ones. It may be deduced that the mental health and well-being of the family members is directly related to the patient’s prognosis. Findings by Jumisko et al. (2007) corroborate the importance of a care system for family members and caregivers. The better family members can cope with the situation, the better the patient’s recovery. Consequently, professionals must pay careful attention to the suffering of close relatives to individuals who experience a TBI (Jumisko et al., 2007).

2.8. TBI in the South African context

Most TBI outcome studies focus on the physical outcomes and have been conducted within developed countries, involving individuals from the dominant culture (Ponsford et al., 2018). This topic is under-researched in South Africa, and yet Nicholson (2016) shares that TBI is one of the leading causes of disability in South Africa. It sometimes results in prolonged or irreversible brain damage which has consequences for patients and their families. This statement aligns with the aforementioned section as well emphasizes the importance of including the *'relationships'* sub-section in the interview schedule. Exploring the support systems of TBI survivors, served as an indicator of positive rehabilitation. It may be understood that the level of family support and rehabilitation process are interlinked.

Kalyan (2007) clarifies that in South Africa, the number of people living with neurological impairments poses an economic burden when considering the cost of hospitalisation, rehabilitation, medication and the inability to work and earn an income. There is a wealth of information on the causes and outcomes of TBI in the South African context, which are consistent with the sub-sections already expanded upon. However, there is a lack of information on the emotional burden of survivors of TBI (Kalyan, 2007). A search of literature indicated that there is limited research reported on the experiences of adults who had a traumatic brain injury. This further clarifies the need for the study, the results of which may facilitate positive change.

2.9. Theoretical Framework

Abend (2008) described a theoretical framework as the structure that can hold or support the theory of a research study. Anfara & Mertz (2015) promulgate that theoretical frameworks provide four dimensions of insight for qualitative research that include: “provide focus to the study, obstruct meaning, connect the study to existing terms and identify strengths and weaknesses.” A theoretical and conceptual framework explores the path of research and grounds in theoretical constructs. Its overall aim is to make research more meaningful and acceptable (Dickson et al., 2018).

Viktor Frankl’s existential approach (1962) is selected as the primary theoretical framework for this study. The existential approach refers to finding meaning in personal existence. The approach brings hope to those who are suffering and those who are faced with challenging situations. It challenges members of society to seek meaning in difficulties and provides a mechanism to attain such meaning (Damianova et al., 2016). This theoretical framework aligns to the study. This is confirmed by the sub-sections of the literature review ‘rehabilitation’ and ‘relating TBI to psychological trauma.’ Furthermore, as confirmed by the sub-section ‘outcomes and impact of traumatic brain injury;’ TBI survivors face unprecedented challenges and may face life-changes. Despite these significant life changes and their suffering, they may still find meaning as understood by the tenets of the existential framework. The core tenets of this theory are:

The freedom to be responsible: individuals must take responsibility for their choices, and external factors should not determine their behaviour. Behaviour is a choice and individuals should be responsible for this choice (Damianova et al., 2016). In applying this tenet to the study, participants would not allow their injury to impact their emotional state but may choose to look forward to rehabilitation. Capacity for self-transcendence: human beings can experience things beyond what animals experience and must strive to find meaning in their lives. This tenet aligns with the study as it is understood that there is a possibility of negative instances, but there is capacity to transcend beyond that meaning toward meanings as human beings. Living a life of meaning: Frankl (1984) posited that “he who has a why to live for can bear with almost any how.” This applies to the study as participants may rely on the purpose and meaning of their lives to assist them through their rehabilitation and recovery. A personally accountable way of being: the meaning of life is unique to each individual. This tenet aligns to the study as each individual may learn and grow from a different aspect of their injury (Damianova, et al., 2016).

According to Frankl (1962) existence comprises of three dimensions: the body, the psyche and the spirit. These three dimensions function as a whole and should be studied in integration. Frankl (1962) explained that there is a strong link between physical and psychological health and that giving up on a psychological level could impact physical health. As indicated by Damianova, et al., (2016) Viktor Frankl rose above his seemingly helpless situation in his concentration camp. While suffering immensely, he was able to transcend beyond this and find meaning in his suffering. In applying the principles of this theory to experiences of adults who had a TBI as a child, it can be assumed that patients may find meaning in their suffering to assist them in striving towards positive rehabilitation. The underpinnings of this conceptual framework links directly to the literature cited by Lamers et al., (2016) on positive well-being and links to the prognosis of physical illness.

Foa and Kozak's (1986) emotional processing theory is selected as the supplementary theoretical framework for this study. Emotional processing theory posits that psychopathology related to traumatic stress is represented through a pathological network of stimuli, response elements and the meaning thereof. Emotional processing occurs when pathological networks are activated, and incompatible information is introduced to promote new learning of adaptive responses. Although, this theory has been utilized primarily in the context of exposure-based treatments, emotional processing was originally proposed as a mechanism of change across many different types of treatments (Foa & Kozak, 1986).

Rachman (1980) defined emotional processing as disturbing events that are so traumatic or overwhelming that one may struggle to process it. These events could be a divorce, a death in the family, a car crash or a major life change emotional processing theory focuses on assisting individuals to fully process disturbing events in order to reach a level where they no longer feel emotionally troubled. An individual's emotional experience is regarded as central to intervention and prognosis. This premise aligns directly to Strandberg's (2009) study which illuminated the process, support and consequences experienced by adults who experienced a traumatic brain injury. This theory further integrates into this research study, as the concept of difficulty with processing traumatic events is consistent with the premises of experiencing a traumatic brain injury.

Several trauma treatments for adults focus on the processing of traumatic experiences (Alpert, et al., 2021). As with pathological responses to trauma, Alpert, et al. (2021) indicates that some research has examined more adaptive responses learned in treatment. Positive emotions reduce the reacquisition of fear, which could have an adverse impact on trauma treatments. One aspect of emotional processing theory relates to PTSD and assessing trauma across domains. The concept of learning new adaptive responses is of particular significance to this study. The study seeks to explore what changes individuals who experienced a traumatic brain may experience. An integral part of this is rehabilitation and acclimatizing to life after injury, which encapsulates the underpinnings of the emotional processing theory.

Several studies have utilized the emotional processing theory in relation to trauma. Rauch and Foa (2006), utilize emotional processing theory in relation to PTSD. The conceptualization of this theory provides an effective framework for treatment and provide theory and suggestions for how to manage difficulties presented. In addition, Alpert et al. (2021) explore the processes of change in trauma-focused cognitive behavioural therapy for youths. This indicates that this theory may be regarded as an appropriate and beneficial theory to utilize whilst exploring the conceptual nuances of trauma. In exploring the experiences of adults who had a traumatic brain injury, emotional processing theory may be used as a framework to study how therapeutic changes occur in adults. This would provide a strong vantage point into further research for interventions and broader literature for adults who suffer a traumatic brain injury, further affirming the need for the study.

2.10. Conclusion

As noted by Demellweek et al. (2006), cognitive skills measured using memory, language or perception neuropsychological tests do not necessarily tap into the emotional difficulties that commonly develop following a traumatic brain injury. This is an issue that is under-researched and requires a deeper understanding. Researching the literature of TBI with the conceptual framework has led to an understanding of the research study and related aspects. This information leads to a broader understanding and greater knowledge of the focus area which serves as a foundation to the next chapter, research methodology.

CHAPTER THREE: RESEARCH METHODOLOGY

3.1. Introduction

The preceding chapter provided a literature review on the various aspects of traumatic brain injury, focusing on sub-sections essential to establish background knowledge on the topic. This chapter expands on the methodology implemented for this study. Research methodology refers to the strategies used to investigate research to create new knowledge (Silverman, 2013). In addition, it refers to the process used for the formal collection and evaluation of information (Terre Blanche et al., 2006). Understanding the research problems and objectives leads to the development of the aim and rationale for the research study. The following sub-topics will be considered in this chapter: research methodology, research paradigm, research design, sampling, data collection, data analysis, validity and reliability and ethical considerations. The conclusion of the chapter summarizes the pertinent information.

3.4. Research approach

A qualitative approach to research was selected for this study. Qualitative research offers a thick and thorough description of the characteristics, processes, contexts transactions (Terre Blanche et al., 2006). The study sought to gain information through a description or account of experiences. An inductive theme of enquiry was adopted in this research study. An inductive enquiry refers to exploring open questions rather than testing theoretically derived hypothesis (Terre Blanche; et al., 2006). The underpinnings of qualitative research mentioned above aligned to the aims of the research study which are to investigate the experiences of individuals who experienced a TBI and ascertain what challenges they are faced with, through individualised accounts. Therefore, a qualitative research approach was therefore deemed appropriate for this research.

3.5. Research Paradigm

A research paradigm refers to how the study is guided by a specific model. Implementing a paradigm is imperative as how the research is structured and organised, influences the design, data collection and data analysis of the research study (Terre Blanche et al., 2006). Four research paradigms may be identified: positivist paradigm, interpretive paradigm, social constructionist paradigm and afro-centric paradigm.

This research study followed an interpretive paradigm. Kaplan and Maxwell (1994) notes that an interpretive paradigm may include interviews and observations and relies on the subjective experience between the researcher and participants. The paradigm assumes that one can understand experiences by interacting with and listening to them and implementing qualitative methods of inquiry (Terre Blanche et al., 2006). Furthermore, instead of measuring people's behavior, this paradigm seeks to understand an individual's internal experiences by inquiring about detailed accounts (Terre Blanche et al., 2006). The underpinnings of this paradigm aligned to the rationale (to explore the experiences of adults with a traumatic brain injury), design (exploratory research design) and approach to research (qualitative approach) in forming a cohesive and coherent approach to the research study. Therefore, it can be inferred that an interpretive paradigm was appropriate for this study.

3.6. Research Design

An exploratory research design was implemented in this study. Exploratory research intends to explore and better understand the research question, as opposed to finding conclusive solutions to existing problems (Saunders et al., 2012). According to Neuman (2011), an exploratory research design is used when there is a minimal amount of information known about the subject or when not many have previously explored the subject. As validated by literature review, there is a gap in research on the experiences and emotional states of individuals who experience traumatic brain injuries. In exploring the experiences of adults who had a traumatic brain injury, this research sought to add to knowledge and bridge this gap.

3.7. Sampling

3.7.1. Type of sampling

Sampling refers to a process of selecting a smaller number of participants who are representatives of a larger population (Gravetter & Forzano, 2012). This research study used a non-probability purposive sampling (Neuman, 2011). Purposive sampling involves the researcher selecting participants based on their own judgement and their relevance to the study (Ames et al., 2019). Following this definition, participants who were relevant to the study were selected.

Through the process of research, it was identified that adults who suffer a TBI may engage with others that have the same diagnosis, through the process of rehabilitation. In this regard, snowball sampling was also used. Snowball sampling may be defined as a sampling method where the researcher asks participants refer to potential participants (Terre Blanche et al., 2006). During the process, participants selected were requested to identify other participants who fit the research description.

3.7.2. Participants and sample size

Due to the time-consuming and in-depth nature of qualitative research, the sample size in qualitative research is smaller than other methods of research (Silverman, 2013). The study's sample size included eight adult participants who were older than 18 years of age and had experienced a traumatic brain injury. Eight participants were sufficient to gain a detailed, in-depth description of experiences without compromising the researcher's ability to thoroughly analyse the data. The specifications of the research topic guided the inclusion criteria of participants. Information on anonymity and confidentiality of participants and other sampling-related considerations are further explained in the ethical considerations.

3.7.3. Sampling procedure

The following sampling process was followed for this research study. Two organisations were approached for possible participants – A private learning institution & a private occupational therapist practice (Appendix six.) These organisations were approached due to the researcher's prior knowledge that the institutions engaged with TBI survivors. Both organisations provided permission to research their clients, respectively. A list of potential participants was identified by both institutions which was used as a base for sampling. Some participants referred others with the same condition (snowball sampling.)

3.8. Data Collection

Data collection is referred to as the process of gathering information on variables of interest (Terre Blanche et al., 2006). According to Silverman (2013), a qualitative research method may use the following tools in data collection: interviews, focus group discussions, questionnaires, observations and visual data. This research study was approved by HSSREC prior to commencing the data collection step ***(appendix one).*** Before conducting the interviews, an information sheet ***(appendix two)*** informed consent form ***(appendix three)*** was shared with all participants and the interviews commenced only once this form was understood and had been signed.

3.8.1. Data collection method

This study used semi-structured interviews as the data collection method. Harrell & Bradley (2009) refer to an interview as a subjective data collection tool used to gather information or opinions and perceptions on specific topics and describe processes. The semi-structured interviews aimed to gain a thick, rich description of participants' experiences, a requisite of qualitative data collection and this research study.

3.8.2 Data collection instrument and process

An interview schedule ***(appendix four)*** was developed by the researcher, grounded in literature (Strandberg, 2009), (Jumisko et al., 2009) and divided into four sub-sections. This included: background questions, any changes that occurred, relationships and experiences as an adult. The interview was conducted in English as all participants and the researcher were familiar with the language. Due to COVID-19 restrictions, all interviews were conducted online via Zoom.

In preparation for the interview, as noted by Kelly (2006) the following was implemented: a quiet space was identified, no distractions were present during the scheduled time and both the researcher and interviewee had sufficient time to complete the process. Each interview was between 30 and 60 minutes in duration. During the interview process, the researcher implemented follow up questions for clarification, asking open-ended questions, remaining neutral in response, no interruptions, exploring rather than probing – as described by (Kelly, 2006). All interviews were recorded on an audio recorder. After the interview, the audio was transcribed verbatim via a Word processing document to proceed with the data analysis process.

3.9. Data Analysis

Upon the conclusion of the data collection phase, data analysis began. Silverman (2013) describes data analysis as: "-working with data which is easy to collect and reliable, focusing on one process within the data, narrowing down to one part of the process and comparing to different sub-sections"

3.9.1. Reflexive thematic analysis

Reflexive thematic analysis research approach is used to ascertain people's views, knowledge or experiences (Caulfield, 2019). Thematic analysis is used to analyze qualitative data and is typically used in the data analysis of interview transcripts and survey responses (Caulfield, 2019). The steps of reflexive thematic analysis proposed by Braun and Clarke (2019) are:

Step one - familiarizing yourself with your data:

The data collected was transcribed and thoroughly examined by reading and re-reading. Initial ideas were noted down, leading to familiarisation with the data.

Step two - generating initial codes:

Interesting features of the data was coded in a systematic matter using CAQDAS software. Relevant codes and labels were ascertained and collated according to the emergent data.

Step three - searching for themes:

Codes were collated into potential themes. Data was gathered according to relevance to potential themes.

Step four - reviewing themes:

Themes were reviewed against the relevant data to ensure that the themes and codes collate. A thematic ‘map’ analysis was created, using the information collated during the initial three steps.

Step five - defining and naming themes:

Themes were refined and clear definitions and themes were stated using the information from the thematic map. Each theme was defined, labelled and expanded upon.

Step six - producing the report:

The steps above resulted in the final analysis of all emergent data, to produce and write the final report.

Throughout the process of reflexive thematic analysis, the researcher adhered to the following criteria for good reflexive thematic analysis, as promulgated by Braun & Clarke (2019): the data transcribed was checked against the tapes to minimize error, each item had been given equal attention throughout the coding process. The coding process was thorough, themes were coherent and checked against each another and against the data set, data was analyzed and not simply paraphrased (search for latent themes). The researcher dedicated sufficient time to analysis.

3.10. Trustworthiness

For qualitative data to be reliable, the following should be implemented: the credibility, transferability of the project, dependability of the participants and the extent to which findings may be confirmed (Lincoln & Guba, 1985).

According to Trochim (2020) credibility is defined as assessing the truthfulness of a study. One way in which credibility is determined in qualitative research may be by using the method of triangulation. Triangulation involves using several methods such as data sources, observers, or theories to gain a deeper understanding of the phenomenon being studied (Noble & Smith, 2015). Analyst triangulation was implemented in this study by the research supervisor cross-checking the data to ensure credibility. In addition, the inclusion criteria for the participants served as another method of ensuring credibility of research. Transferability refers to whether the data applies to other settings or contexts. The person who wishes to transfer the results of this study to another context may decide whether appropriate, based on the thorough description of the research and data analyses processes. Dependability refers to whether the study's findings are consistent and repeatable (Trochim, 2020). To ensure that the study is dependable, the researcher and supervisor both conducted an inquiry audit of the data collection, analysis and results. Confirmability refers to the extent to which results may be corroborated by others (Trochim, 2020). To enhance confirmability in this study, the data was checked numerously before proceeding further.

Researcher bias refers to any form of pre-existing assumptions that the researcher may have towards the study. The researcher bias was mitigated by the researcher adopting an objective approach to research. Reactivity refers to the influence that the researcher may have toward the population. Reactivity was reduced by the researcher remaining neutral in response to interviewee answers. Respondent bias refers to a situation where the participants may answer dishonestly for personal reasons or assume to be expected to answer in a certain way. Response bias was limited by keeping questions short and clear, avoiding leading questions and not interrupting participants Curtin & Fossey (2007).

As per the explanations above, it may be deduced that for the study to be credible, the study should be authentic, consistent and measure what it is supposed to measure. In addition, the study should be credible, transferable and the participants should be dependable. To ensure that the study was trustworthy, the aforementioned procedures were adhered to.

3.11. Ethical Considerations

One of the most important aspects of research is ethical considerations. Key principles initially articulated in the Belmont Report include: autonomy (the respect for individuals, voluntary and informed consent), beneficence (providing benefit to participants) and non-maleficence (do no harm) and justice (Jahn, 2011). Ethical considerations for research initially promulgated by Emanuel et al. (2004) have been adapted for use in social research and outlined by Wassenaar & Mamotte (2012). Amongst several studies, Treffry-Goatley et al. (2021) utilizes these principles in their research study and promulgate the importance of this holistic framework. Each consideration has been outlined and expanded on how these considerations will be considered in the research.

- Collaborative Partnership – This ethical consideration encourages researchers to develop studies by involving the target community within the process. Community participation is advised in planning, conducting and overseeing research as well as in disseminating research results. (Wassenaar & Mamotte, 2012).
- Social Value – A research study is said to have social value if it considers how the research will improve the lives of the participants, the community and the society in which the research is conducted (Wassenaar & Mamotte, 2012). The research study intended to gage the experiences of adults who had suffered a TBI – this serves as valuable information for the participants interviewed. In addition, it may benefit the community at large to gain and build knowledge in the field.
- Scientific Validity – For a study to be scientifically valid, all aspects of the study's design, sample, method, and analysis should be rigorous, justifiable and valid (Wassenaar & Mamotte, 2012). All protocols mentioned in the validity and reliability section were followed to ensure that the design is scientifically valid.
- Fair Participant Selection – This ethical requirement outlines that the study population should be those to whom the research question applies (Wassenaar & Mamotte, 2012). The use of purposive sampling and subsequently snowball sampling, ensured that this ethical consideration is met.
- Risk/Benefit Ratio – A favourable risk/benefit ratio means that the benefits of the research should outweigh the harms/risks and if there are any risks present, there should be safety measures put into place to minimise or deal with any harm (Wassenaar & Mamotte, 2012). In the case of this research, the risk is minimal and should any harm arise as a result of the

research process, participants were referred to the Child & Family Centre for further intervention or had the choice to withdraw from the study at any time **(*appendix five*).**

- Independent Ethics Review – All research must be subject to an independent ethics review to ensure that participants are protected, and that research is beneficial (Wassenaar & Mamotte, 2012). UKZN HSSREC approved this research study ***(appendix one).***
- Informed Consent – Participants must be aware of the purpose of the research. Moreover, participants must give full assent and consent and be aware that they are allowed to withdraw from the research at any point (Wassenaar & Mamotte, 2012). The informed consent form (***appendix three***) signed by each participant before the data collection process, stipulated all necessary information.
- Ongoing Respect – Participants must be treated with respect during the research as well as after the research (Wassenaar & Mamotte, 2012). Implementation of this point means that participants are allowed to withdraw from the research at any point, well-being of participants must be continuously monitored and anonymity and confidentiality be maintained. In this research study, pseudonyms were assigned to participants to ensure anonymity. The information obtained was treated as confidential and stored on a password protected device in the supervisor's office. The results of the study will be disseminated to each participant.

3.13. Conclusion

This chapter provided an overview of the research methodology process. Eight participants were identified using an inclusion criterion – adults who had suffered a traumatic brain injury. Data collection was implemented with the use of semi-structured interviews. The researcher analysed the data collected according to the steps of reflexive thematic analysis and ensured that the study is reliable and valid. The aforementioned processes were elaborated upon in detail throughout this chapter. The next chapter will discuss the findings of the interviews.

CHAPTER FOUR: FINDINGS

4.1. Introduction

The aims of this study were to investigate the experiences of adults who had a traumatic brain injury, to determine the changes experienced (personality, cognitive, emotional, psychological) and to explore the long-term and short-term challenges faces by adults who experienced a traumatic brain injury. In this chapter, the findings of the study are presented, this includes the participant demographic results and the reflexive thematic analysis of the findings. Eight different themes emerged from the data. The themes are: (i) the traumatic nature of the experience, (ii) coping, (iii) psychological changes, (iv) emotional difficulties, (v) cognitive changes, (vi) physical changes, (vii) alterations in relationships and (viii) impact on overall quality of life. Data excerpts are used to demonstrate and support the eight themes. Participants are referred to according to an abbreviation, using their gender and participant number. For example, FP1 means female participant 1 and MP1 means male participant 1.

4.2. Participant characteristics

Eight participants were interviewed. Half of the participants were male (50%) and the other half were female (50%). All participants have a minimum of a Grade 12 level education, but some had gone on to complete their tertiary education (50%). All participants were injured in a motor vehicle accident. Participant demographic information is expanded upon within table 1.

Table 1: Participant biodemographic profile

Participant	Gender	Ethnicity	Education	Marital status
1	F	White	Higher education	Married
2	M	Black	Grade 12	Single
3	F	White	Higher education	Divorced
4	M	Black	Grade 12	Single
5	M	Indian	Higher education	Married
6	F	Indian	Grade 12	Married
7	M	Black	Higher education	Divorced
8	F	Indian	Grade 12	Divorced

4.3. Findings

In line with the tenets of reflexive thematic analysis, the following subsection highlights the themes that emerged from the findings of the data. Each theme has been highlighted and explained in detail, with reference to extracts from participants. The accounts from the data collection process are listed verbatim from participants and thereafter explored in detail. The themes and objectives are seen in table 2.

Table 2: Objectives and themes

Objectives	Themes
To investigate the experiences of adults who had a traumatic brain injury.	• The traumatic nature of the experience Coping
To determine what changes were experienced (personality, cognitive, emotional, psychological) by adults who had a traumatic brain injury.	• Personality and psychological changes • Emotional difficulties • Cognitive changes • Physical changes
To explore the long-term and short-term challenges of adults who experienced a traumatic brain injury.	• Alterations in relationships • Impact on overall quality of life

4.3.1. The experiences of adults who had a traumatic brain injury

All participants experienced negative alterations because of their traumatic brain injuries. The degree of negative experiences varied, and some of the participants indicated an interleaving of positive impacts post-injury. Nevertheless, all participants indicated that they experienced adverse consequences, and highlighted a lack of general awareness and understanding by the general population of their experiences and their plight. These experiences are highlighted in the following two themes:

The traumatic nature of the experience

The impact of the experience integrated with the traumatic nature of the experience was highlighted within the participants interviews. The motor vehicle accidents and collisions proved to be traumatic for those who experienced it. Post-traumatic stress disorder (PTSD) was indicated, together with physiological trauma.

MP 2

> *"Trauma & stress affected me a lot, very very traumatizing…Other people getting my same job, eye problems and that kind of trauma & anger"*

FP3

> *"I think for me the experience is traumatic. As a kid there are things that you constantly do. Sometimes not that focused as an adult. So as a kid there are things that could distract you quiet easily & you will forget the experience. There were things you were used to doing that now you restricted & for me that aspect is to a point of debilitating & so frustrating that I find myself tiring so easily. The fact that I do training at work and I find especially with the mouth injury, I had nerve damage to one side of my mouth. There is a droop to that particular side. Thank God I wear mask so can't really see that visibly."*

FP 8

> *"I would say the difficult thing about it is it's like a huge trauma and it's the kind of thing that people don't have any concept of and there is a lot of prejudice and there is a lot of ignorance and it's really hard work trying to bridge those things."*

As per the extracts above, the actual causes of the traumatic brain injuries proved to cause a significant level of trauma for participants. The participants used different methods of coping to counter these impacts, which will be expanded upon in the following theme:

Coping

Participants employed different mechanisms to cope with the effects and trauma associated with their traumatic brain injury.

FP 6

> *"I had a good support system with my family. My sister stayed with me the whole time…I would think it has made me stronger emotionally. I'm able to deal with everything. I feel that I have conquered a lot, I am emotionally stronger and capable of anything."*

MP 2

> *"Yes. Sometimes to forget what happened in my life, I consume alcohol. Things like that"*

MP 5

> *"When you're a female and have head injuries it's much better to deal with because women are much more empowered to deal with pain and emotion because they're able to speak about it. Our Society looks at them as caregivers as well. So they get support from other family members. They able to cope with it much better."*

While some participants turned to negative coping mechanisms such as substance abuse and 'bottling up' negative thoughts; others indicated that they employed positive coping strategies such as a stronger emotional state and employing the assistance of others. Support from family also seemed to help them cope with their experience and trauma.

4.3.2. Changes experienced by adults who had a traumatic brain injury

All participants experience some form of change because of their traumatic brain injury. The specific changes, as well as its impacts on the participants is expanded upon.

Personality and psychological changes

Most participants indicated that one of the most pertinent changes experienced as a result of the traumatic brain injury, were personality and psychological changes. Some of the personality changes mentioned by participants included increased irritability, loss of spontaneity, being asocial and not feeling like themselves. Psychological changes emerged from the traumatic brain injuries. Participants indicated that they experienced higher levels of anxiety and depression and increased substance use, indicating negative psychological changes. Changes to self-image and identity were also indicated.

FP1

> *"According to my sister I am lot more blunt than I used to be & I get quite frustrated more easily…I think I have lived in very specific routines, I'm not a spontaneous person anymore"*

FP3

> *"Absolutely. I think with the fact that I work. My work is quiet demanding and it's constant where you have to be active and about. The fact that you constantly on medication. I take a lot of anti-inflammatories to alleviate the pain. The moods have changed drastically. I take it out more on my family then work because when I'm home I'm tired. I lost a lot of my energy. I feel like I'm fully drained by the time I reach home and become very moody. Little things agitate & aggravate me…With family I get upset*

quiet easily, so the tolerance level changed quiet drastically for me. Where I used to be accepting of certain things, now I am quick & snappy. I was never quick & snappy. The brunt of everything is with my immediate family. Obviously at work there is a manner in which you have to carry yourself out. Sometimes if I'm snappy at work then I have to remember that I am at work and I can't be that particular individual, so I snap myself out of that but the family aspect definitely. Especially if I am coming from work afternoon time."

MP5

"I tend to be a bit more reserved. I was more of an extrovert so now I've become more of an introvert. Emotionally I have a bit of an anxiety when I get into a vehicle. Accident wasn't caused by me it was caused by somebody else. Someone else drove into my whole family and myself from oncoming traffic. I tend to be more snappy, a little bit more temperamental but with the background that I have I'm able to control it very well. So now when I am in the car I tend to be a bit more apprehensive, overly cautious. I did become sort of an OCD. I had a problem when I came out of hospital, I was having panic attacks. And it carried on for about 1 and ½ to 2 months and I basically started to train myself to control it. From a male perspective it's much more difficult because a man is not able to speak. They tend to put on a brave front because we are the leaders of the house so we have to remove the emotional burden from ourselves. And has dampened my self-esteem because I'm unable to do what I used to do example sports I was extremely sporty, I was a martial arts expert. My job entailed traveling I . Most people get up in the morning and say they hate going to work but I get up in the morning and love going to work because I travel within the country and internationally love speaking to people. I

> *love training so that has taking out a huge, huge chunk out of my life."*

Participants experienced significant personality changes because of their traumatic brain injuries. Some participants described the negative alterations in personality such as high negative emotionality and low frustration tolerance. Some indicated positive changes such as greater organization and positive changes to the brain. However, another participant who indicated positive changes such as greater organization and positive changes to the brain, as seen in the extract below:

FP 8

> *"I have ended up with personality changes that are good, for example, emotional regulation is a whole lot stronger than what it was before the accident because of what I have had to do. I can concentrate for longer. To cope with all the deficits, I have actually needed to become a lot more organized. My anxiety levels are significantly lower than what they were before the accident. I think because I have had so much to cope with that its made positive changes to the brain."*

Emotional difficulties

Whilst every participant differed in the degree of emotional difficulties, the presence of emotional difficulty and angst was evident throughout the interview process.

FP 1

"A lot of emotional changes. More volatile than how I was before."

FP3

> *"There are moments where you are perfectly fine & little things can trigger off an emotional aspect. If you see something on TV, I can become emotional whereas I am not someone who is emotional."*

FP 6

> *"So emotionally I affected. Every time I would go into a car, I would be very terrified to drive the car by myself. Every time I needed somebody to drive me.*

FP 8

> *"I couldn't use my brain and thinking to control my emotions and vice-versa. So I had to find new ways of emotional regulation and the way I got through that was three hours of meditation every single day."*

Emotional difficulties described by participants ranged from lack of emotional regulation to volatility, and even trauma-induced fear in some cases.

Cognitive changes

Half of the sample interviewed indicated some form of cognitive change because of their traumatic brain injuries.

Memory difficulties

FP 1

> *"So when I went to the hospital I couldn't remember and people will ask do yo remember when we did X, Y & Z and I don't have a memory of those things. I remember*

being in hospital and one of my next-door neighbor's walked pass and saw me and waved, I remember saying hello, but I have no idea who you are, and she said I am your next door neighbor. So, it affected my memory quiet badly, my concentration quiet badly. I did have a neuron assessment about 2 years after my accident, my viability to do thing was affected. I couldn't do any kind of computation. I had no contact with time. I couldn't remember what I taught. I could not remember the kid's names. I taught the kids in grade 2 and 3 & now teaching them again in grade 9 and 10 and I could not remember their names. Its very difficult to come into the classroom and have no idea what you have done & even now in terms of my lecturing I need to go back to try and keep track of things."

MP 4

"About a year after the injury, I was what you would call brain folded. When in school, I couldn't remember simple things that I learnt previously, simple words."

FP 3

"The memory aspect drastically changed. There are 2 things that had changed. I got very limited smell; something needs to be very close up where I'm able to smell it. With the memory aspect, I don't remember things as easily as I used to. I use a diary very frequently now in order to remember things."

Other cognitive changes

FP 1

"I couldn't teach all day in the classroom anymore. That was one of the things. I was a teacher, so I was working with kid's disabilities. Because it was a very small school there

was only one teach who teaches a subject, so you teach like the whole school. I was teaching a special class before my accident and then they moved me into teaching at the high school. I taught math's up to grade 8 and math's literacy up to grade 10 and then I was move to the computer class. I could not sustain that kind of intensity. It has been very difficult for me. If you have a very high level of intelligence and loose some of your functions, you feel the difference more. And have literally felt the difference. I am on medication for neuropathic pain and that also doesn't help with some of your functions sometime. I still can't do calculations in my head. So, it has been a lot of hard work, I could not use excel and not use a calculator. Lost contact with time, have to set alarm to ensure I take my medication. If I need to go shopping, I have to put an alarm otherwise it just won't happen. The frustration of knowing what I was capable of and what I was no longer capable of and then I had to work within those limitations. I had to only work with X amount of time and stop because my brain couldn't do anymore and have a rest."

FP 8

"I have had a major problem with processing speed. A big problem is also with vision…My ability to read has been affected. I can read, but after a point it gets too blurry…I would get overstimulated by everyday activities. I would battle to find words and it would look like I was anxious and troubled but it was a cognitive overload when I wasn't able to focus anymore."

MP 4

"I would say based on my results in school at that time I wouldn't have thought that it was my TBI that caused it but looking back it definitely was because prior to this injury, I was a top student & after the injury I can definitely say that it affected my brains. I

> *wasn't able to think. I wasn't able to bring up the right things that I needed. It was very difficult to remember things especially in words. I remember suffering in English, like I forgot the language. It did have an effect because I wasn't performing in school like before."*

All eight participants indicated negative cognitive changes such as memory loss, deterioration in processing speed and reduced performance, as well as academic limitations.

Physical changes

MP 4

> *"I got affected by the right side of my head so the vision on my right side was affected & it actually still is but has recovered. But my right eye is worse than my left eye. I am not sure if that is related to the injury but could be."*

FP 3

> *"With the rib aspect it left you immobilized. Could not walk. Could not bend over. The mouth aspect, I could not even open my mouth because after surgery. The nerve was damaged on the lip area. And I have 3 teeth that are still loose. So, the eating aspect, you can't eat solids and can't eat too much things. There was a droop in my mouth. So immediately after that, the pain with the rib, the pain with the abdominal tear and the pain with the mouth aspect that was immense in the beginning."*

4.3.3. The challenges of adults who experienced a traumatic brain injury

Alterations in relationships

FP1

> *"My husband left me. Physically as well and psychologically. He left me, I had a baby, and my second child was born 2 years after my accident, and he was 9 years old, and my husband left me so definitely it has had a negative impact. It affected friendships and the relationships that I had with my family as well and in some instances, it improved the relationships that I had with my families as well. We have a more understanding ship now."*

MP 2

> *"I don't have my father. I got only 2 brothers who look for their family's as well but sometimes they come to me & see me. I don't have someone who is there around me all the time"*

FP 8

> *"My family empowered me 55%. The remaining percent would be in the early stages when nobody really understood what was going on. I had a whiplash but not even any bruises. There was also my half-sister, to this day it's not something that can be spoken about. It makes relationships quite stressful if I can't communicate what is going on in the moment. My support system was my closest friend – she is a psychologist in the UK. That was very helpful."*

MP 5

> *"Because of my wife it has, she was in the accident so it affected her as well. She had*

> *some sort of head injuries. When a surgeon went to her, she had that exact same tendencies I has. What happened is that we were both at Loggerheads but then I discovered that we both cannot have that so I allowed her to vent and carry on. Because I feel that you need to have a coping mechanism that I'm capable dealing with, so I would say it did affect us but I had to be the one to control it and I let her to go through whatever it is that she's going through. And not for both of us to do that because that will be unhealthy. I had to do a lot of restraint on my part."*

A significant change that individuals experienced were alterations in relationships. Whilst some participants indicated that they had a strong sense of family support, even so they indicated a decline in some aspects of relationships post-injury.

Decreased quality of life

A resounding theme was the impact on the participants' overall quality of life. While the degree and effect of the quality of life differed between participants, all of the participants indicated that their overall quality of life was negatively impacted as a result of their traumatic brain injuries.

MP 2

> *"I don't think I will be able to do or be employed. Like no one will employ me…Like as I told you before I am not normal…It affected me in so many ways…I lost my job, my eyes…" (the participant lost his eyesight due to the accident)*

MP 4

> *"I got affected by the right side of my head so the vision on my right side was affected &*

> *it actually still is but has recovered. But my right eye is worse than my left eye. I am not sure if that is related to the injury but could be.*

FP3

> *"It impacted every single aspect of my life from the sleeping, has changed drastically. It used to be 8 hours, now it is 6 hours. It's not knowing which side to turn because you got injuries & spine constantly sore and the memory aspect, you second guessing yourself constantly whether certain things was done and you have to now make note especially diary notes to make sure that certain things are carried out & the constant pain. It used to be something that was constantly active. I used to do a lot of activities with my kids, now I find myself the more at home person."*

FP 8

> *"It completely slowed me down…I have had to adjust my expectations. It will probably be the reason that I won't ever do a PhD. It's something that would have been an easy route before, but now it will be very difficult."*

The impact on quality of life of participants varied from physical regression to various mental health challenges leading to the theme of emotional difficulties. One participant reported that memory difficulties impacted her ability to work, thereby decreasing her level of independence. This indicated that performance can possibly have an impact on occupation and ambition. A decreased level of performance (being slowed down and having to adjust expectations) may have an impact on occupation and ambition, thereby in avertedly decreasing overall quality of life.

4.4. Conclusion

While there is evidence of resilience and slight positive changes to personality, there is an overwhelming indication of negative consequences because of a traumatic brain injury. Even though different factors have been mentioned, personality changes and the impact on overall quality of life seems to take precedence. Therefore, the findings indicate that the negative impacts associated with the residual effects of TBI (cognitive changes, alterations to relationships, psychological changes etc.) causes significant trauma for the individuals and to those around them.

CHAPTER FIVE: DISCUSSION

5.1. Introduction

This qualitative study explored the experiences of adults who had a traumatic brain injury. The study was guided by the objectives of the research. The objectives of research included investigating experiences of adults who had a traumatic brain injury, determining what changes were experienced by adults who had a TBI and exploring the challenges faced by adults who experienced a traumatic brain injury. This chapter elaborates on the findings of the study, discussing the themes in detail and linking the themes to the objectives of research. In addition, the links between the objectives of research and literature is alluded to.

5.2. The experiences of adults who had a traumatic brain injury

Schwarzbold et al. (2008) indicate that the prevalence of psychological disorders after a TBI are frequent. Major Depressive Disorder and Generalized Anxiety Disorder are considered a common occurrence in TBI survivors. Consistent with these findings, participants indicated that they experienced negative psychological changes because of their traumatic brain injuries. A theme of progression from general positive mental health, to experiencing panic attacks and symptoms of Obsessive-Compulsive Disorder was evident.

The extent of the adverse reactions was that some participants had developed psychological disorders because of their TBI and its residual effects. For example, one of the participants indicated that she has developed depression and PTSD, having experienced no psychological disorders in the past. This has caused her significant distress and she has experienced this trauma as a significant complication in her recovery process. Another participant indicated that the stress that resulted from the injuries causes significant trauma to him. Some of the factors contributing to this stress were other people getting the same job instead of him being able to return to his position, due to him not being able to perform as he did pre-injury. He also alluded to loss of impulse control and becoming angry often, which exacerbated his view of the experience.

As reported in other literature (Bramlett & Dietrich, 2015) the adverse traumatic reactions to the TBI for most participants were linked to changes around their limited functioning and physical changes. For example, participants reported experiencing a frustrating, debilitating and limited ability to perform optimally. This was coupled with self-esteem issues emanating from changes in appearance such as facial drooping, paralysis and others. The lack of independence, together with the physical and emotional challenges of the TBI, lead to a higher likelihood of developing a psychological disorder. The integration of participants responses indicate that trauma is a personal, subjective experience. While TBI survivors may experience the injury in different ways, the underlying experience of trauma is significant and impacts the rehabilitation process.

There is a general lack of education around TBI and a form of prejudice that made those around the participants seem ignorant about this type of trauma. It is evident from the participants' responses and emergent themes that whilst physical rehabilitation takes precedence, psychosocial problems remain a long-term challenge, as further affirmed in literature by Morton and Wehman (2009). Consistent with the findings of the study, there is an ignorance surrounding the personal experiences, individual trauma, and in-depth angst of those who experience traumatic brain injuries.

Based on participant responses, participants who developed psychological disorders also had limited social support. Out of five participants who exhibited symptoms, four had limited social support. As indicated in the study by Morton & Wehman (2009), survivors are forced to depend on family members and friends to meet certain needs, and this may be described as a traumatic experience characterized by frustration, low mood and anxiety. This statement is consistent with the findings of the study and individual participants responses.

It was also identified that those participants who were likely to develop psychological disorders had poor coping mechanisms. The experiences of adults who had a TBI reinforced the coping mechanisms that participants used to manage the physical and psychological changes that they experienced. A range of coping mechanisms were alluded to – both positive and negative.

According to Wardlaw et al. (2018) research on resilience in TBI survivors has been limited, with only one study to date focusing on the association between resilience and participation. It has been noted that resilience after a TBI poses a distinct challenge, as resilience requires emotional stability, a positive outlook, problem-solving skills and social perception. TBI is commonly associated with impaired executive functioning, irritability and aggression and depression (Wardlaw et al., 2018). However, one of the participants in this study indicated that her experience led to acquisition of resilience. The traumatic experience leads to emotional strength and a new-found sense of being able to conquer anything. Family is a significant support structure in post-injury recovery, and this was a key factor in the honing of her resilience.

As indicated by Bjork and Grant (2009) in certain cases, individuals may employ the abuse of substances as a coping mechanism. Correlating to this literature, one participant turned to substance use to manage the impacts of injury to ‘forget’ about the occurrences. Left unchecked, this may impact other aspects of overall wellbeing and even lead to a substance disorder. As elucidated by Sasse et al. (2014) and affirmed by the findings of this study, coping mechanisms after a traumatic experience may vary.

One participant made an interesting statement about gender and coping mechanisms. He indicated that it is more acceptable for females to express their emotions and thus receive the support that they need. The undercurrent of males not being able to express psychological changes or seek help was emergent from the findings of the study. He elaborates that while females have strong support systems in place, males are less likely to seek help due to the stigma that they face thereafter. Consistent with Jumikso et al. (2009) a strong support system is integral to recovery and rehabilitation. However, if these support systems are largely in place for female TBI survivors, then it begs the question: how many male survivors remain quiet and ‘suffer in silence’ for fear of stigma and inadvertently negatively impact their prognosis? Whilst this point had not been cited in literature, it is an interesting and novel observation that elucidates further investigation.

5.3 Changes experienced because of the traumatic brain injury

The findings of the study indicated that one participant presented with positive personality changes, whilst others all experienced negative alterations to personality.

Some of the negative impacts on personality included low frustration tolerance and a marked alteration in mood. Low frustration tolerance was alluded to with one participant indicating that she is more forthright than she used to be. This has impacted her in different aspects of her life. Whilst she used to be a spontaneous person, she now follows very specific routines, which she believes has impacted her overall personality in a negative way. While personality remains fairly consistent over time, those who experience major life changes may have difficulty adjusting to newfound personality traits (Damianova et al., 2016).

A marked alteration in moods was indicated by one participant, with her family bearing the brunt of her low and aggressive moods. Furthermore, she becomes tired very easily. As a result of her traumatic brain injury, she also experiences a low frustration tolerance, which leads her to become irritable with her loved ones. This personality alteration inadvertently causes an alteration in her relationships and impacts several other aspects of her life negatively. Aggression and a low frustration tolerance is consistent with traumatic experiences and recovery thereof (Wardlaw et al., 2018). The theme of a low frustration tolerance persists with other participants indicating that in general, tolerance levels for people has decreased post injury. As a result, it is easy to become angered and upset. These personality changes have residual negative impacts on their family relationships.

Positive self-image actively promotes healthy functioning while an unstable self-concept plays a role in the development of mental health and social problems. Consequently, the personality changes mentioned by participants, specifically a shift in overall self-image in a destructive manner may adversely impact the recovery process. In certain cases, individuals may experience positive changes to personality after being impacted by a TBI (Whiting, 2020). Although, this is a rare occurrence, one of the participants confirmed this by indicating experiencing personality changes for the better. Some of these positive personality changes included being able to regulate better, longer periods of concentration and lowering anxiety levels due to an increased coping ability post-injury.

Whilst the findings of the study indicate majority of participants experiencing adverse personality changes, the single participant who experienced positive changes serves as an indicator that with the correct intervention and coping mechanisms, in certain cases adverse impacts may serve as protective factors. The understanding of this concept directly links to the conceptual framework of the study, which elucidates that human beings have the capacity to transcend beyond what happens to them and find meaning, even in extenuating circumstances (Frankl, 1984). A significant theme that emerged from the findings of the study elaborated on emotional changes experienced because of the traumatic brain injury. Some participants indicated that whilst they were not emotional by nature, they have become easily triggered and can become disproportionally emotional at minor inconveniences. These statements indicate that this may be a residual impact of the traumatic experience.

The pressure placed on males to inhibit emotional expression is alluded to again within this theme, indicating that some males may be experiencing adverse impacts and remaining silent about it, due to the stigma associated with it. Consequently, these males are at higher risk for developing mental health issues due to not seeking early intervention (Sagar-Ouriaghli et al., 2020).

One of the participants alluded to her emotional changes leading to major life changes – to the point where she would refuse to get into her car. This is indicative of dependency on others. Correlating with the aforementioned research and the findings of this study, it is evident that the newfound dependence that the participant has on others relates directly to her negative emotional state. Another participant indicated that she could no longer emotionally regulate as she did so in the past. This resulted in hours of daily meditation, which caused significant lifestyle changes. Some of the changes alluded to by participants included high negative emotionality and adverse impacts post-injury. While the emotional difficulties described were heterogenous, each participants emotional angst was evident throughout the interview process.

One of the impacts of TBI is a decline in overall cognitive potential (Stocchetti & Zanier 2016). This was affirmed by the findings of the research alluding to cognitive overload. Issues with processing speed and ability to read is highlighted, impacting overall quality of life. As indicated by Lovden et al. (2020), cognitive abilities serve as significant predictors of "educational and occupational performance, socioeconomic attainment, health, and longevity." As a result, one can assume that changes in cognitive ability may lead to a decline in the aforementioned areas. Memory loss because of their injuries were mentioned to cause a decline in the overall quality of life. Not being able to remember appointments, schedules or simple everyday tasks causes frustration and despair for participants. Some of the changes experienced by all participants indicated some form of memory loss and deterioration in concentration post-injury, but one participant indicated that her cognitive changes were so severe, that she was unable to continue working as a teacher. In addition to memory and concentration impairment, she indicated that she lost contact with time and had to set alarms just to remember basic, everyday tasks. This indication leads to inadvertently impacting many other aspects of life and influences not only personal independence but leads itself to larger social issues as a rise in the unemployment rate. 25% of participants indicated that they experienced physical changes because of their traumatic brain injuries. Vision difficulties, rib injuries, being unable to eat solids and specific nerve damage renders a feeling of hopelessness and inadvertently impacted her overall quality of life.

5.4. The long-term and short-term challenges of adults who experienced a traumatic brain injury

All participants indicated that their lives were, to some degree, negatively impacted because of their traumatic brain injuries. The support of caregivers, family and friends form a strong support system and is equally important to health and recovery. Some participants indicated that they maintained a strong support system and this was integral to their rehabilitation, other participants indicated experiencing a decline in the overall quality of relationships, or cessation of relationships all together.

A significant life change that one participant alluded to is that her husband left her post-injury. She expanded that he could not manage her caretaking and recovery, and this had severe consequences on her physical and psychological health. The cessation of this relationship filtered through to other relationships, and she had lost touch with mutual friends as a result. Consequently, the loss of this relationship had led to many other relationships terminating, in turn causing even more distressing impacts on her. The resolution of relationships directly impacts individuals' recovery, as family is integral to the rehabilitation process (Jumisko et al., 2007). A recurring theme from the findings was a lack of one specific individual to take care of the participants physical and emotional needs. This was indicated by one participant, who expressed that his brothers have assisted him with his needs however, this was not consistent. They had their own lives to manage and could not commit to his well-being without it having an impact on their personal lives. As a result, they could not afford him the time and energy that he required for optimum recovery. As elucidated by Frankl (1984) and based on the conceptual framework in this study, “he who has a why to live for can bear with almost any how.” This reiterates the importance and significance of family support in the rehabilitation and recovery process of a TBI survivor.

The lack of awareness and insight into the recovery process of TBI was a recurring theme that emerged as a long-term challenge. One of the participants alluded to the initial stages post-injury being particularly challenging and isolating. Due to a general lack of communication and understanding of needs, a deterioration of relationships ensued. As noted by Cloutier & Levert (2009) TBI has a damaging impact on the lives of survivor’s family members.

Other participants indicated that they encountered significant long-term changes, including physical disability which negatively impacted their overall quality of life. One of the physical challenges encountered was vision loss. Being able to see effectively and being healthy prior to the accidents, and thereafter having to manage a disability in addition to the other physical and emotional challenges proved to be very difficult for them. The loss of vision impacted the ability to remain employed, which impacted livelihood.

Males have an expectation to express emotional restraint (McRae et al., 2008). This was affirmed by one of the participants, who indicated that due to him being a male, certain emotional restraint was expected, he was not able to voice the severity of the negative consequences on his overall quality of life was. However, he alluded that this didn't take away from the fact that many aspects of his life had been altered negatively – from his overall personality to the quality of his relationships, to his psychological challenges. This proved to be a long-term challenge for him and may very well be a long-term challenge to other male survivors of TBI who have not spoken out about this issue.

5.3. Summary

This chapter expanded on the findings of the study. Whilst the themes of coping and resilience feature, there is overwhelming evidence that the experiences of adults who had a TBI are negatively inclined. The following chapter will conclude the study.

CHAPTER SIX: CONCLUSION

6.1. Introduction

This study investigated the experiences of adults who had a traumatic brain injury, to determine what changes were experienced (personality, cognitive, emotional, psychological) by adults who had a TBI and to explore the challenges faced by adults who experienced a TBI.

6.2. Summary of the findings

The study revealed that the traumatic nature of the recovery process was especially challenging for participants, and that some turned to negative coping mechanisms to counterbalance the trauma experienced, such as substance abuse. In addition, participants experienced significant changes because of their traumatic brain injuries. Personality changes (low frustration tolerance, marked alteration in mood), psychological changes (the advent of psychological disorders such as anxiety and depression), emotional changes (increased volatility, high negative emotionality), cognitive changes (memory loss and deterioration of concentration,) and physical changes (vision difficulties and nerve damage), impacted the individual's quality of life significantly, to the extent that these changes negatively impacted the participants overall quality of life. Participants also alluded to marked alteration in relationships and the cessation of relationships due to the nature and recovery process of the injuries.

An emergent conclusion drawn from the study is that there are gender differences in seeking help post TBI. While females are likely to seek emotional support, males are less likely to do so, leading to an especially difficult recovery process. All the participants involved in this study were victims of road accidents. According to Kushner (1998) motor vehicle accidents are one of the main contributors to TBI in South Africa. Victims of a road accident can claim for their injuries from the Road Accident Fund (RAF.) This is usually a lengthy process that can take 3-5 years before any compensation is paid up. Whilst the RAF pays the compensation, it neglects to assist the injured with the necessary emotional or psychological rehabilitation during the claim's process. Based on this study findings, most of the participants struggled with adjustment and psychological/cognitive difficulties and did not always have resources or funds available for mental health and cognitive rehabilitation services. By the time the RAF pays up the claim, the opportunity for any cognitive rehab has expired and any psychological difficulties have become too complicated with some family relationships have been destroyed (as evidenced by the noticeable alterations in relationships derived from this study).

6.3. Limitations

Ross & Bibler Zaidi (2019) indicate that limitations of a study indicate weaknesses within a research design that could likely influence the conclusions of the research. It a researcher’s responsibility to include a complete and honest limitations of the study presented. Some of the limitations of this study include:

Sample size and geographical limitation - This study covered the experiences of eight adults who experienced a TBI within KwaZulu-Natal. As such, its reach is limited, and the results may not be generalizable to other countries or populations. However, the study was a qualitative study. The information obtained was significant, relevant and forms a firm basis for future studies.

Recruitment of participants - It was challenging to recruit participants to the study. Many participants who were contacted were hesitant to participate, due to ongoing court cases for claiming from the Road Accident Fund. As a result, they had been instructed by their lawyers to not discuss specifics of their injury with outside parties. However, the use of multiple gatekeepers was advantageous in this case and provided a pool of participants to approach for potential participation.

Age of participants - All participants were within the same age category. This excluded an older population, who may have experienced traumatic brain injuries differently and as such influenced the findings of the study.

Through engaging in reflective practice, the researcher identified no potential biases or distortions that may have discounted the study in any way.

6.4. Recommendations

The study may be conducted in several geographical areas, with an increase in sample size to maximise generalizability. Based on the limitation of the age of the participants, it is recommended that future studies may include a broader age range. Due to the significant changes experienced by participants, a multidisciplinary team should aid participants in every aspect of recovery. This process should begin immediately after the individual has been stabilised and continue throughout the recovery process. Participants indicated not being able to adequately express emotional difficulties. While physical needs are attended to, it is imperative to consider all aspects of the individual’s rehabilitation to facilitate a healthy and positive re-integration into society. It is recommended based on this research study that the Road Accident Fund (RAF) revisit its pay-out timeline and consider the tremendous financial burden placed on TBI survivors and the necessity of funds for effective rehabilitation.

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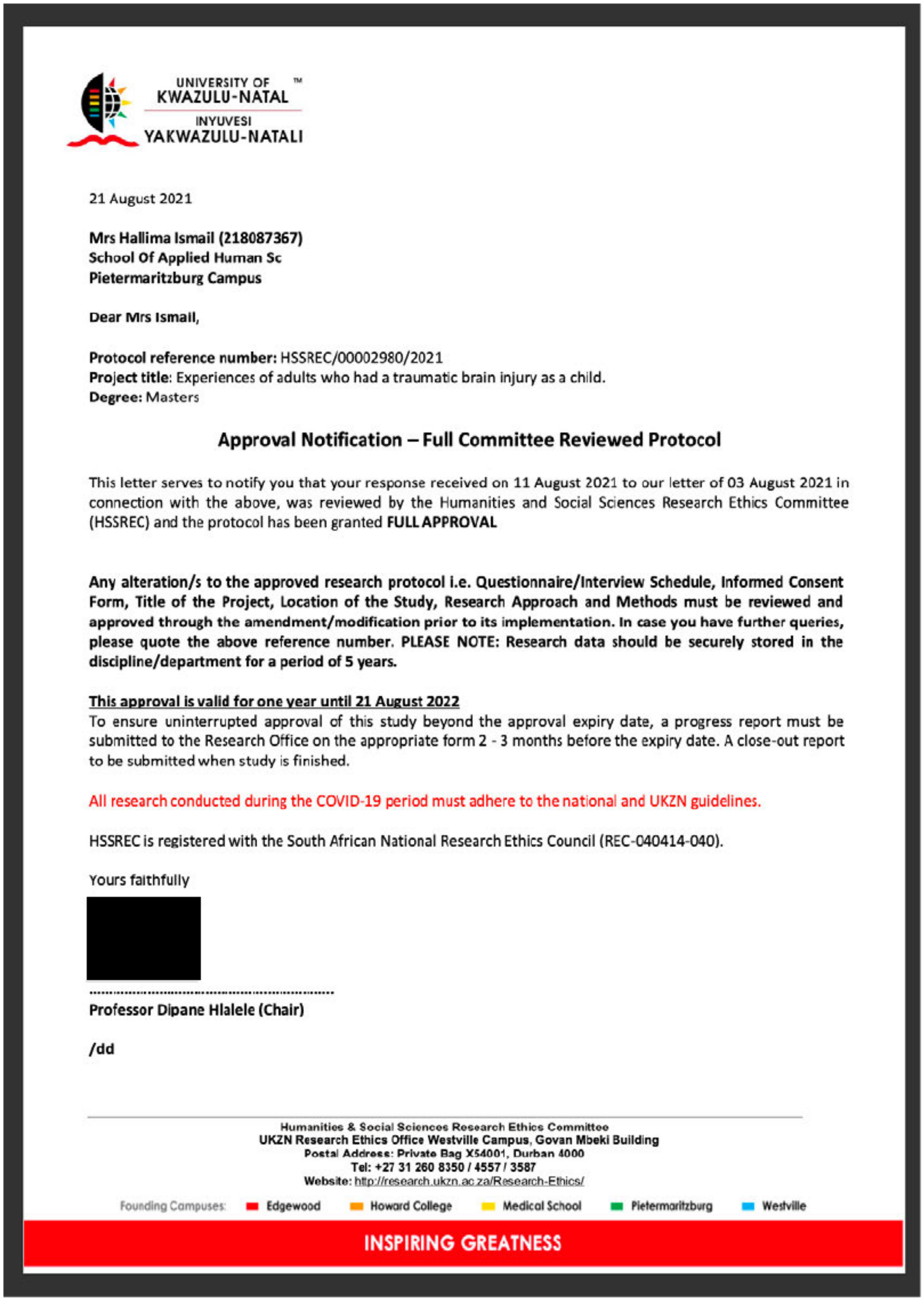
APPENDIX ONE: HSSREC APPROVAL LETTER



UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

21 August 2021

Mrs Hallima Ismail (218087367)
School Of Applied Human Sc
Pietermaritzburg Campus

Dear Mrs Ismail,

Protocol reference number: HSSREC/00002980/2021
Project title: Experiences of adults who had a traumatic brain injury as a child.
Degree: Masters

Approval Notification – Full Committee Reviewed Protocol

This letter serves to notify you that your response received on 11 August 2021 to our letter of 03 August 2021 in connection with the above, was reviewed by the Humanities and Social Sciences Research Ethics Committee (HSSREC) and the protocol has been granted **FULL APPROVAL**

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number. PLEASE NOTE: Research data should be securely stored in the discipline/department for a period of 5 years.

This approval is valid for one year until 21 August 2022
To ensure uninterrupted approval of this study beyond the approval expiry date, a progress report must be submitted to the Research Office on the appropriate form 2 - 3 months before the expiry date. A close-out report to be submitted when study is finished.

All research conducted during the COVID-19 period must adhere to the national and UKZN guidelines.

HSSREC is registered with the South African National Research Ethics Council (REC-040414-040).

Yours faithfully

[redacted]

....

Professor Dipane Hlalele (Chair)

/dd

Humanities & Social Sciences Research Ethics Committee
UKZN Research Ethics Office Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
Tel: +27 31 260 8350 / 4557 / 3587
Website: http://research.ukzn.ac.za/Research-Ethics/

Founding Campuses: 🟥 Edgewood 🟧 Howard College 🟨 Medical School 🟩 Pietermaritzburg 🟦 Westville

INSPIRING GREATNESS

APPENDIX TWO: INFORMATION SHEET

Information sheet and consent to participate in research

Dear participant,

My name is Hallima and I am a Masters of Social Sciences (Educational Psychology) student at the University of KwaZulu-Natal (PMB campus), in the School of Applied Human Sciences; College of Humanities. This study will be supervised by Mrs Xoli Mfene (Clinical Psychologist.)

You are being invited to consider participating in a study that involves research to explore the experiences of adults who had a traumatic brain injury. The aim and purpose of this study is to gain insight on the different experiences of such adults as well as explore challenges faced (if any). The study is expected to enroll eight participants from Kwa-Zulu Natal, South Africa. The following procedure will be followed: After signing this consent form, you will be asked a few questions via interview which will be recorded. The session will be recorded and thereafter manually transcribed to capture responses efficiently. The duration of the interview is expected to be about an hour.

Your participation in the study is voluntary and you may withdraw from the study at any time with no negative implications. In the research you will be assigned an anonymous name to ensure confidentiality. No trace of information collected in the study will link back to your name and participation. All responses will be treated with the strictest confidence.

All data collected will be stored in a safe locked space in the supervisor’s office for a minimum of five years, afterwards will be shredded and destroyed. Participation in the study will not involve any direct benefits but will hopefully add new information to current literature and expand knowledge in the field. The study may involve some questions that may be interpreted as insensitive or upsetting depending on individual circumstances. In the event of discomfort participants will be referred to the Child and Family Centre situated near the School of Psychology at the University of KwaZulu-Natal, PMB campus, where participants may receive psychological intervention if necessary.

In the event of any problems or concerns/questions you may contact the researcher at the following numbers:

Mrs Hallima Ismail – 083 236 6592 (hallimajoosab89@gmail.com)

Or the UKZN Humanities & Social Sciences Research Ethics Committee, contact details as follows:

HUMANITIES & SOCIAL SCIENCES RESEARCH ETHICS ADMINISTRATION

Research Office, Westville Campus

Govan Mbeki Building

Private Bag X 54001

Durban

4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 031 260 4557 – Fax: 031 260 4609

Email: HSSREC@ukzn.ac.za

APPENDIX THREE: CONSENT FORM

I --- have been informed about the study entitled, *Experiences of adults who had a Traumatic Brain Injury* by Hallima Ismail at the University of Kwa-Zulu Natal.

I have been given an opportunity to answer questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any of the benefits that I usually am entitled to.

I have been informed about intervention if injury occurs to me because of study-related procedures.

If I have any further questions/concerns or queries related to the study, I understand that I may contact the researchers on the given contact details.

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact the Humanities & Social Sciences Research Ethics Administration on the contact details provided.

I hereby provide consent to:

Participate in the research study

Audio-record my interview

Give the researcher permission to use the information obtained in the interview for the purpose of the research study mentioned

Signature of Participant

……………………….

Date

…………………………

APPENDIX FOUR: INTERVIEW SCHEDULE:

BACKGROUND

1. What type of TBI did you experience?

2. How old were you when this occurred?

3. How did your TBI impact you immediately after it occurred?

CHANGES

4. Did you notice any immediate/gradual difference in any aspect after the occurrence of your TBI?

5. Did you experience any cognitive changes after your TBI? If so, elaborate.

6. Did you experience any personality changes after your TBI? If so, elaborate.

7. Did you experience any emotional changes after your TBI? If so elaborate.

8. Did you experience any psychological changes after your TBI? If so, elaborate.

RELATIONSHIPS

9. Has your TBI impacted your relationships? If so, how?

10. Did your family empower you after your TBI?

11. Who was your support system throughout your experience?

EXPERIENCES AS AN ADULT

12. Can you describe your experience as an adult who has had a TBI?

13. Do you feel that having a TBI has changed your life? How so?

14. Do you feel as if you have been limited in any way by your TBI?

15. Are there any challenges that you faced?

16. What strategies have you used to cope with these challenges?

APPENDIX FIVE – REFERRAL LETTER

CENTRE for APPLIED PSYCHOLOGY

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

Centre for Applied Psychology, University of KwaZulu-Natal, Durban 4041, South Africa.
Tel: +27 (0)31 260 7425 E-mail: Psychclinic@ukzn.ac.za

---

24 February 2021

TO WHOM IT MAY CONCERN

Student Name: Hallima Joosab Ismail

Student Number: 218087367

Supervisor Name: Ms Xoli Mfene

We herewith confirm that Ms Hallima Joosab Ismail is a Masters Student in MSocSc (Educational Psychology) at the Pietermaritzburg Campus. As part of her studies, she will be required to conduct research.

Her topic is – **Experiences of adults who had a traumatic brain injury.**

There might be potential traumatisation of participants due to disclosing about stressful events that they may have experienced.

We herewith give permission from the Psychology Clinic to allow participants to access clinic services should it be necessary.

Yours Sincerely

[redacted]

Prof D Cartwright

Director: Masters' Clinical \ Counselling Programme

School of Psychology

University of KwaZulu-Natal

Howard College Campus

P. Bag X54001

Durban 4000

031- 260 7425 (Administrator)

Cartwrightd@ukzn.ac.za

APPENDIX SIX – GATEKEEPER LETTERS

Miss Nazmeera Mahomed
Occupational Therapist
B. Occ. Ther. (UKZN) (hon)
Ergoscience Certified
Pr. No. 0549800 **HPCSA Num. OT 0080683**
082 754 0106 **nazmeeraot@gmail.com**
378 Lillian Ngoyi Road, Durban, KwaZulu Natal

Dear Mrs H J Ismail

Thank you for your correspondence and enquiry.

This letter serves as approval for you to contact clients from my practice for participation in your study. Client details will follow shortly.

I wish you all the best in this endeavour, and should you require further assistance, please do not hesitate to contact me.

Kind regards,

[redacted]

Miss N Mahomed

Initials and surname:	H. Ismail
Student number:	218087367
Institution:	University of KwaZulu-Natal (UKZN)
Qualification:	M. Soc. Sci. (Educational Psychology)
Research to be conducted in:	2021
Title of study:	Experiences of adults who had a TBI

Dear Mrs Ismail,

The committee considered your request and have granted permission to conduct research on IIE staff, students, sites or artefacts in accordance with your request – on condition that you strictly adhere to the conditions stipulated below. This approval is based on the assumptions that (1) the information you have provided is true and factually correct and that (2) the study will be conducted in an ethical manner.

Permission is granted to proceed with the above study subject to meeting the conditions listed below. Permission may be withdrawn should any of these conditions not be met.

Standard conditions to be met

1. A copy of the final paper must be submitted electronically to The IIE's Dean for Research and Postgraduate Studies at research@iie.ac.za no later than 30 days post finalisation.
2. The researcher(s) is neither permitted to refer to The IIE or any of its educational brands nor to name, logo, brand or any other identifiers of The IIE or any of its educational brands the in any way, including, but not limited to, in questionnaires, surveys, interviews, proposal or research reports. The IIE or educational brand in question must be referred to in a generic manner, for example 'A private provider'.
3. The researcher(s) will need to obtain informed consent in writing from all of the participants in his/ her sample if the study is not anonymous.
4. If the Learning Management System (LMS) of The IIE is used, the researcher(s) is not permitted to refer to it by name. It needs to be referred to in a generic manner, for example
"the Learning Management System of a Higher Education provider."
5. A copy of this letter must be forwarded to the relevant person(s) at the brand or The IIE that would be involved in the study.

THE INDEPENDENT INSTITUTE OF EDUCATION

6. Resear

oper not interrupted.

Reference: R.15501
Enquiries: bvanwyk@iie.ac.za
research@iie.ac.za

Rd West
da Valley 2196
P.O. Box 2369
Randburg 2125

11 March 2021

**Permission to conduct research on IIE staff, students, sites or artefacts with standa
and additional conditions**

Please note: The panel has not considered the merits, accuracy or ethical soundness of the research. The only merits examined are the use of The IIE as a sample.

7. The principal/ manager of a site must be consulted about an appropriate time when the researcher(s) may carry out the research at the site.
8. The researcher(s) may only use this data for these research purposes and in no other way.
9. Should the researcher(s) wish to publish this research or in any way make the results public, for example by publishing the results on a social media platform, this committee will need to approve a request to this end first.
10. No names or identifying information of participants may be used within the research and the research must be voluntary.
11. Photographs of human subjects may only be taken if relevant to the research and informed consent from the participants or respondents was obtained, and, even with informed consent, the photographs may not be published.
12. The researcher is responsible for supplying and utilising his/ her own research resources, such as stationery, photocopies, transport, faxes and telephones and should not depend on the goodwill of the institutions or the offices visited for supplying such resources.
13. If any of The IIE reports or policies are used as part of the research, all identifying information needs to be removed.
14. Please make it clear that the information will not be used punitively in any way and participants may in no way be counselled or advised based on this.

15. The reference number for this letter must appear, in one format or another, on all research documentation distributed amongst IIE staff or students.

Additional conditions to be met

16. Please inform, in coordination with Dr Quraisha Dawood, the relevant Campus Heads or Managers who have not yet been informed of your study before you commence data collection on the campuses they head.
17. Data collection may only commence once the Research Office at The IIE has acknowledged receipt of an ethics clearance certificate that is issued by the relevant committee at the University of KwaZulu-Natal.

Yours sincerely,

[redacted]

Dr B. van Wyk
Dean: Research and Postgraduate Studies
The Independent Institute of Education

APPENDIX SEVEN – TURNITIN REPORT

Turnitin Originality Report
Processed on: 12-Dec-2022 5:44 PM CAT
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Research Dissertation Draft By
Hallima Ismail

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S. KOSKINEN. "Quality of life 10 years after a very severe TBI(TBI): the perspective of the injured and the closest relative", Brain Injury, 2009

APPENDIX EIGHT – EDITING CERTIFICATE

CERTIFICATE OF EDITING

This certificate confirms that the below listed dissertation was edited by one or more English experts with a Masters in English

Experiences Of Adults Who Had A Traumatic Brain Injury

Manuscript Title

Ismail H

Author

Neither the research content nor the author's intentions were altered. The following items were corrected: grammar, language, spelling, punctuation, sentence structure and referencing.

[redacted]

Muhammed Y Cassim
Director

February 2023

Date Issued