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The Impact of Brain Injury on the Perceived Quality of Life of Adult Survivors of Brain Injury and Caregivers (Post-Injury): The South African Context.

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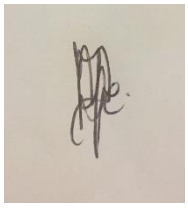
DECLARATION

I declare that this research report is my own, unaided work. It has not been submitted before for any other degree or examination at this or any other university.

Signed: 

Date: 31 July 2021

ABSTRACT

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

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

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CHAPTER ONE: INTRODUCTION

A high quality of life is the ultimate aim of most human beings. Maslowian motivational hierarchy provides an example of the relative necessity of a spectrum of human aspirations. This theoretical model encompasses categories such as basic needs (physiological and safety needs), psychological needs (esteem, belongingness and love needs), and lastly self-fulfillment needs (self-actualization). The Maslowian motivational hierarchy is, however, critisised to not be applicable in many settings in the African continent (Mawere et al., 2016). In the Southern Africa in particular, behaviour motivation is recognised "by pursuit of relationships, strengthening of community, acknowledgement of authority, sharing, and avoidance of shame" (Mawere et al., 2016, p. 1). People who have experienced a traumatic event such as brain injury may no longer have the quality of life that they had prior to the injury; their lives may have completely changed to become less satisfying. However, McLeod (2018) explains that the need for growth does not stem from lack of something, it stems from wanting to be better as a person. Once a person has achieved their growth needs, they are able to reach an optimal level of quality of life.

The WHOQOL Group (1997) stated that Quality of life is defined by the World Health Organization (WHO) as:

> People's perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns. It is a broad ranging concept affected in a complex way by the person's physical state, psychological state, personal beliefs, social relationships, and their relationship to salient features of their relationship. (p. 1)

This definition by WHO highlights the breadth and complexity of the first paragraph as it comprehensively describes the different factors that may be affected by brain injury which therefore in turn affect the quality of life of those who have unfortunately been exposed to brain injury.

To the researcher's knowledge, limited to the South African context, no studies have been conducted that compares the perceived quality of life of brain injury survivors to the experiences that caregivers encounter during the journey of brain injury. The aim of this research therefore was to investigate the perceived quality of life of adult survivors of brain injury, as well as to gain insight into some lifestyle/role changes that may have occurred for adult brain injury survivors post-injury. Survivors of brain injury are not the only ones that may experience changes or difficulties, their families/caregivers prove to also be impacted similarly, therefore, the other area that this research study investigated was the experiences that caregivers encounter. This study is therefore valuable as it sets the first step for local studies to start being conducted on this phenomenon.

The primary research question for this research is: *What is the perceived quality of life of adult brain injury survivors and caregivers post-injury?*

This is explored through the following research questions:

1. *What is the satisfaction level of the perceived quality of life of adult survivors of brain injury?*
2. *What are the themes surrounding the lifestyle of adult brain injury survivors prior and post brain injury?*
3. *What are the experiences that primary caregivers encounter in caring for adult survivors of brain injury?*

4. *Is there a match between adult survivors of brain injury's perceived quality of life and the challenges/difficulties faced by their primary caregivers?*

The study has six chapters; chapter two provides a theoretical framework/literature review on the phenomenon, chapter three outlines the methodology of the study of which outlines the measures and procedure used to derive results of the proposed research questions and how this data was collected thereof. Specific data analyses used in the study is also explained and the results are thoroughly discussed in chapter four. In chapter five, the researcher provides an overall discussion of the study including the strengths, limitations, and recommendations. Lastly, chapter six focuses on the conclusion of the research.

CHAPTER TWO: LITERATURE REVIEW

This chapter provides an overview of the phenomenon of brain injury associated with the quality of life of both the survivors of brain injury and caregivers. It aims to outline context into the physiological mechanism. Thereafter the impact of sequalae on activities of daily living will be discussed. This will be followed by a review of the factors associated with life satisfaction and the specific consequence of role changes associated with dependance and caregiving.

Brain Injury

Broadly speaking, the Brain Injury Association of America (2020) describes an acquired brain injury as an occurrence, unrelated to either genetics or birth trauma and without congenital cause or degenerative consequence, which affects the metabolic activity, physical integrity, or functional ability of nerve cells in the brain. Such injuries can be classified as either non-traumatic or traumatic. The first of these classifications would include hypoxia for example as a result of near drowning or cardiac arrest, cerebrovascular accident either ischemic or hemorrhagic or toxic substance such as in the case of carbon monoxide poisoning (Brain Injury Association of America, 2020). For the purpose of this research report, these will be referred to as acquired brain injuries (ABI). The second classification is that of traumatic brain injuries (TBI). TBI is defined as a brain pathology caused by an external force and could be classified as closed (or non-penetrating) or open (penetrating) (Brain Injury Association of America, 2020). The causes of this kind of brain injury include falls, road traffic accidents, assaults, and accidents that may occur at home or at work (Headway UK, 2020).

Aetiology of Brain Injury

Head injuries differ significantly in their causes, pathophysiology, diagnosic criteria, and optimal treatment strategies (Gennarelli, 1993). More specifically in relation to TBI, Reed-Guy

(2008) mentions that injuries may fall in two categories i.e. closed or open head injuries. Head injuries that do not break the skull are said to be closed head injuries but may result in edema and raised ICP, while an open head injury occurs when the scalp and skull are broken, damaging integrity of protective layers and increasing the possibility of infection (Reed-Guy, 2008). An alternative classification that might be considered is that of focal versus diffuse injury. Commonly when direct blow occurs to the head, it causes focal brain injury associated with contusion, brain laceration, and hemorrhage leading to the formation of hematoma in the extradural, subarachnoid, subdural, or intracerebral compartments within the head (Reed-Guy, 2008). A closed acceleration/deceleration coup/contra-coupe may have both focal and diffuse components. Diffuse brain injuries are normally caused by a sudden movement of the head (for example acceleration/deceleration as mentioned above or rotational forces) and may classically present as cerebral concussion and more prolonged posttraumatic coma associated with diffuse axonal injury (Reed-Guy, 2008). Furthermore, regarding the mechanisms of brain injury, one may distinguish between primary and secondary damage. Mason (2020) argues that primary injury occurs immediately when the incident happens, and it is currently believed to be permanent. In addition to direct mechanical injury to the brain parenchyma, primary injury also causes disruption of brain vasculature. Injury that occurs instantly from the initial trauma triggers a cascade of secondary inflammatory, mitochondrial, metabolic, oxidative stress, and vascular mechanisms that further contribute to cellular injury (Mason, 2020). Primary traumatic effects involve neural or vascular elements of the brain, which can be affected by delayed effects such as deafferentation or secondary events such as swelling, ischemia, cerebral oedema, and heightened intracranial pressure (Gennarelli, 1993). On the other hand, secondary brain injury is maintained and worsened by intracranial and extracranial insults, the combination of these

effects multiply rather than simply adding onto the primary. The continuation of the secondary injury with the skull cavity are due to raised intracranial pressure from cerebral oedema or an expanding space-occupying lesion are the major contributors to continuing the secondary injury cascade (Mason, 2020). Furthermore, accepting that swelling is a natural response to injury, it must be remembered that cerebral oedema and the resultant raised intracranial pressure (ICP) may adversely impact on perfusion and as such the oxygen available to the brain tissue (Gennarelli, 1993). Reduced oxygen availability to neural tissue may account for much of the damage.

Whilst TBI might be caused by traumatic external forces, one might consider non-traumatic ABI to result from internal factors. This difference aside, the mechanism of damage remains the consequence of edema and hypoxia (Sarkar et al., 2017). The leading cause of a non-traumatic ABI is cerebrovascular accident or as it is more commonly referred to, a stroke. Cerebrovascular accidents can be classified as either ischemic or hemorrhagic and both types of injury reduce supply of blood to the brain due to a clot or bleeding (Ellis, 2018). Ischemic includes embolic stroke and thrombotic stroke depending on where the clot that blocks the blood flow originates, on the other hand, hemorrhagic stroke encompasses two reasons that may cause a blood vessel to rupture i.e. weakened blood vessels due to aneurysm or arteriovenous malformation (Joy, 2018). Strokes may cause physical disability and can also lead to emotional and behavioural changes (Ellis, 2018). This can be due to blood vessels of the brain that can be affected by stroke i.e. carotid arteries, vertebral arteries, basilar artery, anterior cerebral artery, middle cerebral artery, posterior cerebral artery, posterior communicating artery, anterior communicating artery, ophthalmic, and retinal (Moawad, 2021). Carotid arteries occupy the front of the neck, vertebral arteries are in the back of the neck, basilar artery merge vertebral arteries

to the brain, anterior cerebral artery embody the left and right branches of carotid arteries and provide blood flow to the brain in the frontal region, middle cerebral artery also has left and right carotid arteries (Moawad, 2021). However, it focuses on supplying blood to dimensions of the brain that control movement, posterior cerebral artery supply blood to the left and right far back regions of the brain, posterior communicating artery, anterior communicating artery, ophthalmic provides blood to regions of the brain that control movement of the eye and vision, whilst retinal supplies blood to the back of the eye (Moawad, 2021). Other causes of ABIs may include space occupying tumors, infection, and poisoning (Gennarelli, 1993).

The Prevalence of Brain Injury

Brain injury is a global health problem. The 2007/2008 Victorian Neurotrauma Initiative (VNI) report showed that globally the TBI incidence was 200/100 000 population (Carron et al., 2020). TBIs are more common in young men, who are normally overrepresented in road accidents (Carron et al., 2020). In South Africa, an estimation of up to 89 000 new cases of TBI are reported yearly (Nicholson et al., 2016). Furthermore, the sub-Saharan Africa prevalence of TBI is 150 - 170/100 000 compared with a global average of 106/100 000 (Jeromel et al., 2017). By way of example, just in Pietermaritzburg which had a population of just over 525 000 between January 2012 and December 2014 a total of 3 301 patients were treated for TBI, whereby there were 2 632 males and 564 females (ratio of 4.7:1) (Jeromel et al., 2017).

Perceived Quality of Life

"Perceived quality of life refers to how people perceive and evaluate their life…the components focus on overall life satisfaction with specific domains of life, for example, marriage, interpersonal relationship, work, leisure activities, and health" (Liao, 2014, p. 205). Demographic and psychosocial characteristics play a crucial role in determining the level of satisfaction one has with their perceived quality of life (Webb et al., 1995). This level of satisfaction, however, can be positively influenced by self-blame (caregivers may blame themselves for the injury and therefore may feel responsible for the survivor) and strong family support of which have a high chance in improving quality of life (Webb et al., 1995). In South Africa, family support has reported to also contribute positively to the recovery process of the brain injury survivor (Mogashoa, 2017). Quality of life may be impacted by brain injury as survivors may experience loss of friends and social isolation of which affect their social life domain (Wedcliffe & Ross, 2001). Loss of sexual relationship in marriages may occur and impact quality of life negatively (Wedcliffe & Ross, 2001). These effects are discussed further below in the sequelae section.

The Sequelae of Brain Injury on the Quality of Life Domains

It is clear from the above discussion of aetiology that brain injury takes many different forms. This given, the longer term sequalae, whether this be physical, emotional, or cognitive and recovery trajectory may vary (Webster et al., 2015).

Physical and Sensory Functioning

During the acute phase survivors of brain injury may experience loss of consciousness, vomiting, seizures, balance or coordination problems, an inability to focus the eyes, abnormal eye movements or a loss of muscle control. Following a brain injury, the individual may not be

able to physically do what they were previously able to do, rendering them dependent on others, whether it be cutting their food, climbing out of the bath or driving (Reed-Guy, 2018), which might prompt for psychological needs such as belongingness and love needs, as well as safety needs.

For any sensory input to be meaningful or for successful execution of output one requires central nervous system processing. For example, damage to the optic or auditory nerves would leave an associated sensory deficit i.e. cortical damage in the occipital region may result in visual deficit or to the temporal region, language deficit (Beck, 2020) of which can affect quality of life of brain injury survivors negatively when it comes to interpersonal relationships. Damage to the somatosensory cortex in the anterior parietal lobe could lead to distortion to touch, whilst damage to the motor homunculus in the frontal lobe may impair motor out-put (Dartmouth Medical School, 2021). When the primary audio cortex located in the temporal lobe becomes impaired, it leads to deafness as an important sequel: loss of hearing may be partial or, when the inner ear is involved, complete and permanent, together with vestibular disturbances (Beck, 2020). Sensory functions that may also be affected include changes in perception of colour, shape, size, blurred vision, diplopia, sensitivity to light, loss of taste (gustatory), not being able to recognize smell (olfactory), and sensitivity to touch whereby loss of physical sensation, in a practical sense, impacts on proprioception or knowledge of your body in space (ASHA, 2020). Furthermore, loss of sense perception can have varied and complex effects, depending on the context in which they would be used and are now absent, for example, loss of olfactory and gustatory senses may imply many challenges, from not being able to detect a fire to not being able to share in eating rituals, and contralateral neglect may also occur as a result of damage to the right parietal lobe i.e. impairment in self-care skills (ASHA, 2020), this prompts for extreme

need for physiological needs and thus quality of life of brain injury survivors may be impacted in that regard.

Cognitive Functioning

"Traumatic brain injury (TBI) results in significant disability due to cognitive deficits particularly in attention, learning and memory, and higher-order executive functions" (Walker & Tesco, 2013, p. 29). Due to brain injury, difficulties such as disorientation, a persistent or worsening headache, memory loss, changes in mood may occur (Reed-Guy, 2018). The quality of life of brain injury survivors can be affected by neurocognitive and behavioural sequelae of frontal lobe injuries that are severe and include poor judgment, impaired problem-solving ability, the loss of ability to think abstractly, poor organisational skills, loss of inhibition, impulsive behaviour, aggression, personality changes, depression, anxiety and reduced social skills (Webster et al., 2015). Left temporal lobe injuries can result in communication difficulties due to disorders of language (receptive aphasia). These deficits affect survivors of brain injury's ability to deal with daily life as well as the ability to construct meaningful relationships (Webster et al., 2015). Other damages to the temporal lobe include difficulty with learning and retaining new information, selective attention, prosopagnosia, impaired factual and long-term memory etc. (Blumenfeld, 2010; Kolb & Whishaw, 2015; Lezak et al., 2012; Mendoza & Foundas, 2011). With cognitive impairments, individuals not only have trouble, but may be unable to operate independently and will require utmost care from loved ones such as their families or spouses. The effect of not being able to cope with daily living activities and the inability to socialize may result in factors such as social-isolation and low self-esteem of which prompts for Maslowian hierarchy esteem needs. Cognitive deficits can affect brain injury survivors' ability to find employment or return back to the jobs they had prior to the injury, and this is linked to

Maslowian hierarchy self-actualisation needs, thus, quality of life can be affected in that aspect. Brain areas such as the occipital lobe and parietal lobe can also be impaired as identified above in the content of the physical and sensory functioning subtitle (i.e. blindness and contralateral neglect) (ASHA, 2020).

Social Functioning

It is clear that many of the scenarios discussed above might impact on social function and change not only the lives of the survivor of a brain injury but also the lives of those with whom they interact on an intimate daily basis. Brain injury can also affect recreational and vocational activities of which can affect the survivor of brain injury's Maslowian hierarchy self-actualisation needs with regards to creative activities and therefore in turn can affect their quality of life. It may even force the person and their family to adapt to a completely new way of life and new kinds of relationships (Synapse: Australia's Brain Injury, 2021). Many survivors may experience mixed emotions; they can feel like brain injury took away their dignity as human beings but then sometimes may feel that they can live positively with TBI (Mason, 2020), this is linked to esteem needs and affects quality of life in that area. The combination of physical, cognitive, and emotional impairments creates a major obstacle for re-entry into the community. Social isolation, loneliness, and depression combined with lack of income/financial stability and disability may severely impact previous social networks (Stocchetti & Zanier, 2016). Brain injury survivors may find themselves in vulnerable positions that pose danger to them due to poor impulse control and difficulty with socialising (Webster et al., 2015). All the above-mentioned factors can affect the overall satisfaction and general happiness of brain injury survivors' perceived quality of life. The Perceived Quality of Life (PQoL) scale was therefore suited for this research as it provided a full picture of the level of satisfaction that brain injury

survivors have with their quality of life. PQoL is a measure that assesses quality of life based on Maslow's hierarchy of needs/Maslowian motivational hierarchy (Patrick & Danis, 2008).

The Impact of Brain injury on Caregivers

Caregivers may experience changes in their well-being (psychological and physical domains) as a result of significant and ongoing care for the TBI survivor. Changes can occur based on the survivor's needs, social support, socio-economic background of the family and severity of head injury. Caregivers may struggle with these changes more than survivors of brain injury and they can be psychologically affected negatively for a very long period of time i.e. years, this could be because they accumulate more responsibility and are normally the silent victims whereby people do not see their sacrifices (Cheatham, 2016). Research also suggests that changes in emotional, behavioural and personality variables result in more subjective caregiver burden than do changes in intelligence and physical disabilities (Goldsworthy, 2015). The impact of TBI on a survivor's family also differs depending on how severe the injury was as well as the socio-economic situation of the family. It is common for family members to not be knowledgeable when it comes to brain injuries. Lack of support and available resources to families can hinder the recovery of brain-injured family member as they may lack of information about available support in South Africa (Chembeni & Nkomo, 2017).

In 2015, Goldsworthy wrote that once an individual acquires brain injury, family members may experience emotional turmoil and be conflicted with the decisions to make for their family member. Feelings of loss and grief may occur due to a significant change of the survivor due to the injury. Significant others and even children may have to exchange roles and become primary caregivers for the survivor of brain injury. They may experience challenges and difficulties associated with the high level of responsibility of providing for the survivor.

The Caregiver Reaction Scale (CRS)

The CRS is a measure that is used to assess the difficulties/challenges faced by caregivers as well as positive experiences (O'Malley & Qualls, 2017). Therefore, this research used it determine the above-mentioned impacts on caregivers. The following variables are imperative to assess when conducting the CRS:

The Situation

The situation category assesses "a) the caregivers' immediate questions, challenges and priorities b) the family's understanding of and approach to the illness/disability, and c) the family's caregiving stage in response to the progression of the illness" (American Psychological Association, 2021, p. 1).

The Context

The context category assesses "a) the family's developmental stage (e.g., family with young children, late-life family), b) individual family members' capacities, personalities, and willingness to take on new roles, c) the family system, including structural and functional characteristics, and d) perceived fairness of the distribution of care responsibilities" (American Psychological Association, 2021, p. 1).

The Meaning

The meaning category assesses "a) the family's previous experiences providing care to an ill or disabled loved one, b) the history and quality of the relationships between the care-recipient and other family members, c) the cultural and spiritual contexts for care, d) perceived choice in providing care among those taking on caregiving roles, and e) motivations for assuming and remaining in the caregiving role" (American Psychological Association, 2021, p. 1).

Rehabilitation

Rehabilitation programmes frequently offer support and have the capacity to gradually improve the quality of life of brain injury survivors little by little. Following extended hospitalisation many survivors may enter a rehabilitation facility, however, following being discharged they may continue to be reliant on outpatient and home-based care (Stocchetti & Zanier, 2016). However, survivors of brain injury that had treatment related to real-life situations lead to significant gains with longevity after discharge (Webb et al., 1995). Brain injury may affect previous relationships negatively and preclude a return to work, with severe economic and social impacts. Rehabilitation programmes can help survivors of brain injury with adjusting back into the community and caregivers may commit themselves in supporting their loved one in this process, however, they also need to make sure that they take good care of themselves as well (Department of Veterans Affair, 2021).

Headway Gauteng (2020) indicated that Headway's counselling and support services dedicate themselves in:

> Understanding that brain injury does not happen to a single individual, it happens to a family. Nobody can be prepared for this, and life seldom gives us the skills to deal with this type of situation. The circumstances resulting from the injury can be exacerbated by the 'disappearance' of friends and family because people do not know how to cope with this 'new' person. Brain injury can be very isolating, and family members need a person who understands what they are going through. Headway's counselling team is made up of volunteers and university students who are familiar with the outcomes and consequences of brain injury, under the guidance and supervision of a Registered Counsellor. (p. 1)

CHAPTER THREE: METHODOLOGY

This chapter provides information of how the study was operationalised, and it begins with a description of the context of the study and the participants. This is then followed by an explanation of the research design that was used, the sampling, data collection techniques that were employed, and the relevant data analysis procedure utilised. Lastly, ethical issues in conducting this study that were carefully considered as was the trustworthiness of the integration of the deeper understanding gained from the qualitative analyses in exploring the trends indicated through quantitative data.

The purpose of the study was to investigate the perceived quality of life of adult survivors of brain injury as well as the experiences impacting primary caregivers through this journey. The study also aimed to gain insight into some lifestyle/role changes that may have occurred for adult brain injury survivors post-injury, for example, (*were you in an intimate relationship before the injury?*) and (*are you now?)*. Dependent upon the answer to the close ended question, participants were invited to provide further detail for qualitative interpretation. The study uses a mixed-method approach with a convergent parallel design. The sample size of the study was 18 participants i.e. 11 survivors of brain injury and 7 caregivers. Together with the Demographic Background Information Questionnaire (see Appendix D), adult brain injury survivors completed the Perceived Quality of Life Scale (PQoL) (see Appendix E), and caregivers completed the Caregiver Reaction Scale (CRS) (see Appendix F).

Research Design

The study is descriptive in nature and used a cross-sectional research design i.e. the study only assessed participants once (Cherry, 2019). The approach the study utilised is mixed-

methods with a convergent parallel design and purpose for this was to have both quantitative and qualitative methods used for analysis and then compare the results of each method to the other (Brodie, 2019; Creswell & Clark, 2007). The quantitative side of the research utilised an ex-post facto research design as the brain injury condition existed before this study (SAGE, 2010).

Study Sample

Participants in this research were drawn from the attendees at Headway Gauteng; a registered non-profit organisation (NPO) that provides support to survivors of brain injury, as well as their families and caregivers through various programmes. The sampling strategy for this study was non-probability convenience sampling.

Inclusion Criteria

Survivors of Brain Injury

Survivors of brain injury included in the study were middle adulthood. The brain injuries sustained by the survivors were unrelated to either genetics or birth trauma and without congenital cause or degenerative consequence. All participants were classified as high functioning by Headway i.e. those who are verbal and mostly independent in their daily living activities but might struggle with paraplegia or hemiplegia, may have dysarthria and/or mildly aphasia, and may struggle with attention and memory.

Caregivers

Caregivers were also of middle adulthood and were those considered as primary caregivers/significant other, in other words, those who spend more time with the survivor of brain injury i.e. spouse or other family member. All participants were telephonically contactable and none of the participants were considered by Headway Gauteng to be emotionally vulnerable or struggled with depression or aphasia**.**

Exclusion Criteria

Survivors of Brain Injury

Survivors that were not included in the study were those not in middle adulthood, those with brain injury related to genetics or birth trauma and with congenital cause or degenerative consequence, not classified as high functioning by Headway, those that suffered from aphasia, those that were not contactable over the phone, and lastly, anyone with a clinical diagnosis of depression, PTSD or other indicators of risk of emotional vulnerability.

Caregivers

Caregivers that were not included for the study were those not in middle adulthood, those that were not classified as primary caregivers of adult survivors of brain injury i.e. those who do not spend substantial time with the survivor of brain injury, those that were not contactable over the phone, and lastly, anyone screened by Headway Gauteng as having a clinical diagnosis of depression, PTSD or other indicators of risk of emotional vulnerability.

Headway Gauteng management identified suitable people as per the above inclusion and exclusion criteria for both the survivors of brain injury and caregivers, contacted them, informed them of the study, invited them to participate and requested their permission to release their contact details to the researcher. The invitation was sent to both the brain injury survivor and their caregiver to participate. These individuals were then contacted by the researcher, the purpose and requirements of the study were explained in accordance with the ethical standards of the university and the participant was then asked for their informed consent to proceed. An appointment was set at each participant's convenience for data collection. The resultant sample of voluntary participants comprised 11 adult brain injury survivors as well as 7

caregivers/significant others. The survivors of brain injury participants revealed that their causes of the brain injury included ruptured aneurysm and Arteriovenous Malformation (AVM) that caused a hemorrhagic stroke and subsequent craniotomy, assault, superbike accident, septicemia, removal of benign fronto-temporal tumour, stroke/blood clot, and lastly five motor vehicle accidents. All the injuries were acquired from the period ranging from 2 to 24 years prior to the study.

Table 1 below depicts the demographic profile of the adult survivors of brain injury who participated in the study.

Table 1.

Demographic Characteristics of Adult Survivors of Brain Injury.

Characteristics	n	%
Sex		
Female	2	18.2
Male	9	81.8
Age Range		
32 - 39	5	45.5
40 - 49	3	27.3
50 – 59	3	27.3
Race		
Black	7	63.6
Coloured	1	9.1
White	3	27.3

Note. $N = 11$.

Data Collection (Measures and Procedure)

Following the Headway screening procedure discussed above, Headway Gauteng provided the researcher with the preferred contact approach and details of willing participants.

The researcher contacted the participants and introduced themself, verified informed consent and set up a time at the participants' convenience on when data would be collected. The participants were informed that the research would be done telephonically, and they could choose between a WhatsApp video call or a normal phone call. The researcher then contacted the participants through their preferred methods, verified the rights of the participants, provided an understanding of what was expected, and requested permission to proceed with the collection of data. Some participants, however, opted to send their completed questionnaires through an email (only the researcher has access to these documents) and none requested for a WhatsApp video call. Adult brain injury survivors completed the Demographic Background Questionnaire, followed by the Perceived Quality of Life Scale (PQoL). Caregivers completed the Caregiver Reaction Scale (CRS). All participants were provided with the scales and therefore they all had copies regardless of their different preferred methods in completing the questionnaires.

The Perceived Quality of Life Scale (PQoL)

The Perceived Quality of Life Scale (PQoL) is described as:

> A measure based on a model defining quality of life as an evaluation of major categories of fundamental life needs. Items on the scale were developed using human needs theory and interviews with various populations of older adults, well persons, and persons with disabilities to establish the content of the instrument. (Patrick & Danis, 2008, p. 1)

Due to the abovementioned information on the scale's development, the scale is considered suitable for this study because it looks to measure the quality of life of adults who have survived a brain injury. PQoL is consistent with the needs-based theory of quality of life and the World Health Organization definition of quality of life (Patrick & Danis, 2008).

The questionnaire took approximately up to 15 minutes to complete. The scale was divided into 3 themes for analysis which are as follows; physical, social, and cognitive functioning that define the quality of life. The scale is an 11-point Likert-type scale and the ratings ranged from 0 (*extremely dissatisfied/unhappy*) to 10 (*extremely satisfied/happy*).

Reliability and Validity of the Perceived Quality of Life Scale (PQoL)

The reliability for PQoL was measured for internal consistency using Cronbach's Alpha i.e. to determine how closely related a set of items are related. The results showed the PQoL scale to have an excellent internal consistency ($\alpha = .88$). The social functioning domain had an excellent reliability ($\alpha = .84$), and the physical functioning domain had an acceptable reliability ($\alpha = .60$), as well as the cognitive functioning domain ($\alpha = .50$). Pearson's correlation coefficient is a statistical test used to measure an association or statistical relationship between continuous variables and it achieves this by focusing on method of variance (Statistics Solutions, 2021). It was used to measure convergent validity of PQoL and there was a significant positive relationship between the general happiness of adult brain injury survivors and their overall perceived quality of life, $r(9) = .793$, $p = .004$. Previous research indicated the intraclass correlation coefficient (ICC) of .84 (Patrick, 2014).

Caregiver Reaction Scale (CRS)

The Caregiver Reaction Scale (CRS) focuses on:

Understanding the difficulties that caregivers experience (O'Malley & Qualls, 2016). The measure includes subscales that assess feelings of role captivity, overload, relational deprivation, competence, personal gain, coping, family beliefs and conflict, job conflicts and financial disruption. Two advantages of this scale for clinical settings include the simplicity of its response format; it is a likert-type scale with ratings ranging from 1 (*not at all*) to 4

(*completely*) and its inclusion of a broad range of possible caregiver responses. In addition to assessing multiple social and emotional impacts of caregiving, the scale taps feelings of competence and self-efficacy as well as family distress and conflict. The CRS is an efficient measure that provides consistent, valid and reliable assessments of multiple reactions to the experience of caregiving, including family-level stresses as well as more traditional burden and role demands, along with a positive-responses to caregiving. (American Psychological Association, 2020, p.1)

This questionnaire took approximately 15 minutes to complete. It is suitable for this study and therefore was utilised in order to understand the types of difficulties that caregivers face in caring for survivors of brain injury.

Reliability and Validity of the Caregiver Reaction Scale (CRS)

Cronbach's Alpha was used to determine the internal consistency of the scale. The subscales/domains of the Caregiver Reaction Scale (CRS) have demonstrated a) very high internal consistency of reliability; competence ($\alpha = .98$), b) high reliability; personal gain ($\alpha = .89$), family beliefs and conflict ($\alpha = .88$), c) good reliability; relational deprivation ($\alpha = .78$), d) acceptable reliability; feelings of role captivity ($\alpha = .68$), coping ($\alpha = .57$), overload scored ($\alpha = .55$) after removing item B7. Previous research demonstrated that the 8 subscales had very good internal reliability ($\alpha \geq .81$) (O'Malley & Qualls, 2016). The convergent validity of the CRS was confirmed through Pearson's correlation coefficient and it indicated that there was a significant relationship between the dimensions/domains of the CRS, and correlations results ranged between -1.0 to 1.0, $p \leq .05$.

The Demographic Background Questionnaire

This questionnaire was tailored by the researcher. The questionnaire asked demographic background questions such as age, race, gender, the duration at which the injury was sustained, and the cause of the injury. The questionnaire also asked open-ended questions related to the lifestyle of survivors of brain injury prior and post-injury. The literature suggests that demographic and psychosocial characteristics play a crucial role in determining the level of satisfaction one has with their perceived quality of life (Webb et al., 1995). Wedcliffe and Ross (2001) showed that quality of life may be impacted by brain injury as survivors may experience loss of friends, social isolation, and loss of sexual relationship in marriages may occur. This was tapped through semi-structured opened ended questions such as (*what were your living arrangements prior to the head injury?*) and (*what are your living arrangements now?*), (*were you in an intimate relationship prior to the head injury?*) and (*are you now in an intimate relationship?*), see Appendix H for the demographic background questionnaires.

Data Coding

The descriptive analysis made use of the PQoL scale of which has 19 items with an additional global item measuring happiness. The 19 items measured three themes i.e. physical, social, and cognitive functioning. The scale items are identified based on the initial letter of the construct followed by a numeric. The descriptive analysis was also conducted for the Caregiver Reaction Scale (CRS) of which has eight themes; feelings of role captivity, overload, relational deprivation, competence, personal gain, coping, family beliefs and conflict, job conflicts and financial disruption. In the original scale, subscales are alphabetically identified. For the present research a numeric label was added i.e. the first item on the scale was numbered as A1 (A is the alphabet that was originally given to the first subscale on the questionnaire and the number 1 was

manually added by the researcher for the first statement under the subscale) (see Appendix J). Participants were coded for anonymity on SPSS for the purposes of running descriptive statistics. Thematic analysis was coded using the storybook theme approach/open coding, whereby the topic of the research is already known and the themes that stemmed from the questions asked on the demographic background information questionnaire were unknown (Maguire & Delahunt, 2017). Lastly, for content analysis, proximity analysis was in place whereby the researcher "evaluated the co-occurrence of explicit concepts in the text […] the result was the creation of a "concept matrix" or a group of interrelated co-occurring concepts that suggested an overall meaning" (Constable et al., 2021, p. 1).

Data Analysis

The quantitative data collected from the Perceived Quality of Life scale (PQoL) and the Caregiver Reaction Scale (CRS) were interpreted through descriptive analyses. These methods were run on the Statistical Package for Social Science (SPSS) version 27 which helped measure the satisfaction level of perceived quality of life on adult survivors of brain injury, as well as measure the degree at which caregivers encounter both positive and negative experiences associated with having to care for adult survivors of brain injury. There are three subscales of PQoL i.e. physical, social, and cognitive functioning. On the other hand, there are eight subscales on the CRS, feelings of role captivity, overload, relational deprivation, competence, personal gain, coping, family beliefs and conflict, job conflicts and financial disruption. The subscales of both the PQoL and the CRS were coded exactly as they are, and the results were then analysed though descriptive analyses.

Secondly, the qualitative data accumulated from the demographic background questionnaire was interpreted through thematic analysis and the demographic background

questionnaire was used for the purposes of this analysis. The thematic analysis made use of an interpretive paradigm which is based on the assumption that social reality is not singular or objective but rather shaped by human experiences and social context (Byun et al., 2019). The data has been coded using a thematic analysis' story book approach/open coding and therefore there were no specific themes set for the study and by following this process, themes were then produced from the data and interpreted as well as explained. There were six steps followed in analysing the data i.e. became familiar with the data, generated initial codes, searched for themes, reviewed themes, defined themes, and finally did the write-up (Maguire & Delahunt, 2017). The researcher became familiar with the data by reading the data obtained in the demographic background questionnaire thoroughly and making sense of it. The data was then organised codes were generated following the story book approach/open coding. This process involved the data being searched for themes, and then reviewing those themes and defining them. Once the storybook approach was completed, the researcher reported the results in this study.

Lastly, the data was interpreted using content analysis incorporated with Pearson's correlation. The specific content analysis utilised is the relational content analysis in order to determine the experiences/challenges that caregivers of adult brain injury survivors face compared to the perceived quality of life of their paired adult brain injury survivor. Relational content analysis involved choosing a concept and examining it by quantifying/counting its presence, then, exploring the relationships between the chosen concepts (Constable et al., 2021).

Ethical Considerations

Ethical clearance for the study was approved by the Faculty Non-Medical Human Ethics committee of the University of the Witwatersrand (see Appendix A). The study was done under the auspices of Headway Gauteng; therefore, the researcher first requested for permission to

conduct the study at their non-profit organisations (NPO) prior to approaching potential participants. A brain-injured population may be considered vulnerable, however, the sample of interest was the adult population classified by the organisation as high functioning, and as such were less likely to be vulnerable and were able to give consent. Informed consent was therefore requested from participants (both survivors of brain injury and caregivers) in order to gain permission from to them to proceed with the research. The researcher informed them about the nature of the study as well as what their rights were, for example, participants had the right to withdraw from the study anytime prior to the final submission of this document The research posed no direct foreseeable risks towards the participants. Other ethical considerations of this study consist of honesty, transparency, voluntary participation, and participants could withdraw from the study anytime without any negative consequences. Although participants' contact details were not anonymous to the researcher as they were provided by Headway Gauteng in order to collect data telephonically, confidentiality as they were in a password-protected document, therefore, the researcher was the only one who had access to these contact details and they were not disclosed to anyone else. No participant was personally identified or identifiable. The data collected from the study was stored on a safe password-protected computer and will be destroyed after 5 years.

The researcher contacted the South African Depression and Anxiety Group (SADAG) and was provided with the organisations' toll-free number that participants could contact in case they experienced any distress from with the study, these phone calls are free; 0800 567 567/0800 456 789. These information was provided to participants through information sheets (see Appendix F and Appendix G).

Participants who wish to have a summary of this report will be provided with one at their request and that will be done through Headway Gauteng to the researcher.

CHAPTER FOUR: RESULTS

The study utilised both quantitative and qualitative analysis to answer the research questions. Descriptive analysis, thematic analysis, and relational content analysis were employed. Descriptive statitistics was conducted to determine the frequencies and average levels of brain injury survivors' perceived quality of life in the physical, social, cognitive functioning domains, and the overall general happiness domain represented in the PQoL scale. Descriptive statistics was also conducted to determine the average levels of caregivers' experiences within the dimensions reflected by the CRS, as well as the assessment of the results through the three variables used to assess the results of the CRS i.e. the situation, context, and meaning. Pearson's correlation was used to determine the convergent validity of the PQoL scale by correlating the overall score with the item reflecting the happiness level of the brain injury survivors (Patrick & Danis, 2008). Convergent validity for CRS was also determined though Pearson's correlation based on all the eight subscales it entails. Thematic analysis then followed, in order to establish themes that stemmed from the demographic background questionnaires that were completed by survivors of brain injury in order to give depth to the findings of quantitative results. Relational content analysis was then conducted for the four pairs of survivors and their caregivers to determine whether the experiences that caregivers of adult brain injury survivors encountered matched to the perceived quality of life of their paired adult brain injury survivor. The chapter will systematically present the results of these analysis starting with the quantitative analyses relevant to the measuring instruments themselves and then moving on to the descriptive analyses of quantitative findings. Thereafter, the results of qualitative analysis which is aimed at providing deeper meaning to the above will be presented.

Quantitative Analysis

Quantitative analysis was conducted in order to answer these two questions: a) *What is the perceived quality of life of adult survivors of brain injury?*

b) What are the experiences that primary caregivers encounter in caring for adult survivors of brain injury?

The Perceived Quality of Life (PQoL) Findings

This scale was completed by 11 adult survivors of brain injury and had 19 items and an additional global happiness item. The scale measured three themes i.e. physical, social, and cognitive functioning. It is an 11-point Likert-type scale with ratings from 0 (*extremely dissatisfied/unhappy*) to 10 (*extremely satisfied/happy*). The descriptive analysis was run on SPSS version 27, see Appendix C for frequencies.

Descriptive statistics in Table 2 below showed the results of the domains of the perceived quality of life of adult brain injury survivors and the overall/general PQoL. Previous research showed a population mean of 7.5 (N=3359) and results were interpreted based on the notion that the mean higher that the average of 7.5 equals *satisfied* and the mean less than 7.5 equals *dissatisfied* (Patrick & Danis, 2008). This study followed the same route when interpreting the results. According to the results, survivors of brain injury are dissatisfied with aspects of their quality of life i.e. physical functioning (M = 6.98, SD = 1.36), social functioning (M = 6.28, SD = 1.60), cognitive functioning (M = 7.09, SD = 1.56), item no.7 (*the kind and amount of food they eat)* (M = 7.36, SD = 2.80). The overall/general happiness of brain injury survivors scored 7.5 indicating that they are satisfied in this area and 95% of the data were within 2 standard deviations of the mean for this domain (M = 7.50, SD = 2.38).

Table 2.

Number of Items, means, and standard deviations of the Domains of the PQoL Scale

Domains	No. of Items	Mean	SD
Physical Functioning	5	6.98	1.360
Social Functioning	11	6.28	1.596
Cognitive Functioning	2	7.09	1.562
No.7	1	7.36	2.803
Overall Happiness	1	7.50	2.381

Note. *N*=11. A mean score above 7.5 indicates satisfaction and the mean score less than 7.5 indicates dissatisfaction.

In this cross-sectional study, the results were measured based on the findings of Patrick & Danis (2008) who developed the PQoL scale, which makes it suitable for this research study. Their results had a population mean of 7.5 (N=3359) (Patrick & Danis, 2008). Table 3 below showed the results for each item of the 19 items of the PQoL scale as well as the mean of the global item which measured happiness of adult brain injury survivors. The reason for this analysis was to identify which areas of the PQoL adult brain injury survivors were satisfied/dissatisfied with in order to determine their satisfaction level of the perceived quality of life.

With regards to the physical domain, survivors were generally confident in their abilities for activities of daily living required for self-care such as basic hygiene, shopping for essentials, preparing meals (item P2). Relative to social functioning, they face challenges with intimate

relationships and report specific disappointment with their sex lives (item S14), their work situation as all of them have indicated to be unemployed according to thematic analysis (item S12), as well as dissatisfaction with their leisure activities (item S13). However, they are pleased with the more general level of interaction with family and friends (item S8), the help they receive from(S9), and are able to offer to these individuals (item S10). The cognitive functioning domain showed that survivors of brain injury are satisfied with how well they can carry on a conversation i.e. speaking clearly, hearing others, or being understood (item C6). Furthermore, thee results suggest that they are happy with their general happiness in life as the global item measuring the general happiness of brain injury survivors indicated that they are well satisfied in that aspect (S20).

Table 3.

The Descriptive Analysis of the PQoL Variables

	P1	**P2**	**C3**	**P4**	**P5**	**C6**	**7**	**S8**	**S9**	**S10**	**S11**	**S12**	**S13**	**S14**	**S15**	**S16**	**S17**	**S 18**	**P 19**	**S 20**
Min.	5	5	1	1	2	4	0	4	3	2	0	1	2	1	1	3	3	3	4	3
Max.	10	10	9	9	10	9	10	9	10	10	10	10	8	10	9	10	10	10	10	10
Mean	6.91	7.64	6.73	6.18	6.82	7.50	7.36	7.50	7.09	7.00	6.09	5.36	5.50	4.50	5.82	6.64	6.73	6.64	7.40	7.50
SD	1.86	1.36	2.24	2.82	2.48	1.57	2.80	1.57	2.34	2.32	3.14	3.04	2.25	3.27	2.99	2.54	1.95	2.06	2.15	2.38

Note. N = 11.

The Caregiver Reaction scale (CRS) Findings

The CRS was completed by seven caregivers of adult brain injury survivors. The scale included the following eight subscales: feelings of role captivity, overload, relational deprivation, competence, personal gain, coping, family beliefs and conflict, job conflicts and financial disruption. It is a Likert-type scale with scores ranging from 1 (*not at all*) to 4 (*completely*). The t-test analysis was run on SPSS version 27, as well as descriptive analysis for measures of central tendency and dispersion, see Appendix D for frequencies. The results were also assessed using the three variables for assessing the caregiver reaction scale i.e. the situation, context, and meaning.

Table 4 below showed the analysis of descriptive statistics/descriptive analysis of which previous research shows an interpretation that a high score on positive dimensions of the CRS indicates a positive impact on caregivers' experiences and the high score on the negative dimensions of the CRS indicates a negative impact on the experiences of caregivers (Nijboer, 2000). The positive dimensions of the CRS include personal gain, competence, and coping. The negative dimensions include overload, feelings of role captivity, relational deprivation, family beliefs and conflict, job conflicts and financial disruption.

The results showed that the personal gain domain indicated to have a positive impact on caregivers as it scored the highest compared to other domains (M = 3.11, SD = .815). Another positive dimension with a positive impact on caregivers experiences is that of competence (M = 3.01, SD = .817). Relational deprivation is one of the challenges/difficulties that caregivers tend to face in caring for survivors of brain injury, this domain indicated a negative impact on caregivers (M = 3.04, SD = .648). Feelings of role captivity had the lowest score (M = 2.29, SD = .796), which

indicates a positive impact on caregivers as they do not feel in captive by their role as caregivers of adult brain injury survivors.

American Psychological Association (2021) indicates that the CRS is assessed based on three variables i.e. the situation, context, and meaning. The results are therefore further analysed based on these variables, see the descriptive analysis table for variables of the CRS in Appendix E.

The Situation

With regards to the personal gain, item E20, caregivers indicated to have become more aware of their inner strengths as it has shown to have increased during this journey (*M* = 3.29, *SD* = .756). The competence domain revealed a positive perception of caregivers' experiences (*M* =3.01, *SD* =.817). Responses indicate that caregivers treat caring for survivors of brain injury as a priority and appreciate the positive gains that also come with this responsibility. Most challenges/difficulties include relational deprivation as item C10 indicated that caregivers do feel that they have lost someone they used to know (*M* = 3.71, *SD* = .488). Furthermore, the family beliefs and conflicts domain showed that caregivers indicated to have family conflicts mostly related to family members not spending sufficient time with the brain injury survivor demonstrating a negative impact on their experiences (*M* = 3.17, *SD* = .753). Responses to items on the demographic background questionnaire indicated that survivors of brain injury sustained brain injury from 2 years ago to 24 years prior to assessment. This may have provided an opportunity for caregivers to achieve some level of understanding of their loved one's condition. Assimilation of this understanding may explain why caregivers do not experience feelings of role captivity as indicated on item A3 (*wish you could just run away*) which scored in the lower range (*M* = 1.71, *SD* = 1.11).

The Context

Caregivers include parents, older children, as well as siblings of the survivors of brain injury. Contextualising the responses to items in the domains of job conflicts and financial disruption domain, the majority of the caregivers reported being employed in the open job market but experience some financial strain. Illustrating this, for item 49, the mean score indicated that the financial situation at month-end was “somewhat” okay” (M = 2.00, SD = 1.15). Their willingness to take on this role is also remarkable as it showed in their competence i.e. item D17 indicated that they are believe that they have confidence in their caregiving (M = 3.17, SD = .690), however, with family beliefs and conflict, the distribution of care responsibilities showed to not be balanced/equal between family members as caregivers have indicated a negative experience with this domain.

The Meaning

As indicated and explaining their motivations for assuming and remaining in the caregiving role, caregivers were predominantly immediate family members of the survivors of brain injury. Coping mechanisms showed to contribute in their willingness to continue with their roles as caregivers for survivors of brain injury as it impacts them positively by helping them deal with the situation or stress. Participants came from different races and background and, therefore, cultural and spiritual contexts may in addition contribute, for example, thematic analysis showed that most survivors of brain injury indicated to read the bible.

Table 4.

Number of Items, Means, and Standard Deviations of the Domains of the CRS Scale

Domains	No. of Items	Mean	SD
Feelings of Role Captivity	4	2.29	.796
Overload	4	2.71	.529
Relational Deprivation	7	3.04	.648
Competence	4	3.01	.817
Personal Gain	4	3.11	.815
Coping	11	2.38	.334
Family beliefs and conflict	12	2.46	.872
Job conflicts and Financial Disruption	3	2.71	.559

Note. *N*=7. A high score on the negative domains of the scale indicate a negative impact on the experiences of caregivers and a high score on the positive dimensions of the scale indicate a positive impact on the experiences of caregivers.

Qualitative Analysis

Qualitative analysis was carried out with the purpose of gaining depth understanding of the quantitative results. Thematic analysis and content analysis were therefore carried out. Interpretive research design was suitable to be used as this design helped with understanding and describing the constructs of the impact of brain injury on adult brain injury survivors and caregivers.

Trustworthiness of Thematic Analysis

The trustworthiness of the thematic analysis was examined on the 4 primary criteria by (Whittemore et al., 2001) i.e. credibility, authenticity, criticality, and integrity. The study is credible and reliable in a sense that the researcher ensured to reflect the results in the experiences of participants, different voices/participants are used for interpretation, assessment of the results, and humble presentation of the results (Whittemore et al., 2001).

Thematic Analysis

The thematic analysis made use of an interpretive paradigm which is based on the assumption that social reality is not singular or objective but rather shaped by human experiences and social context (Levers, 2013). This analysis was conducted to answer this question: *What are the themes surrounding the lifestyle of adult brain injury survivors prior and post brain injury?*

"Demographic characteristics are likely to affect quality of life by reflecting populations with particular life problems" (Webb et al., 1995, p. 1113), hence the construction of open-ended questions on the demographic background questionnaire measuring the life of adult brain injury survivors before and post-brain injury was used for the purpose of this analysis.

The interpretation of these thematic analysis results makes an emphasis on Maslow's hierarchy of needs of which encompasses categories such as basic needs (physiological and safety needs), psychological needs (esteem, belongingness and love needs), and lastly self-fulfillment needs (self-actualisation). These categories account for the perceived quality of life of brain injury survivors as they fall under the PQoL domains/subscales i.e. physical, social, and cognitive functioning.

Theme 1: Unemployment Amongst Brain Injury Survivors

"There are eight out of ten persons with a disability who are unemployed. Statistics in South Africa shows that only about 1.8% of persons with disabilities are employed" (Soeker et al., 2018, p. 303). There are several barriers that may contribute to the unemployment of brain injury survivors i.e. lack of knowledge on their condition, loss of memory or inability to retain memory, and misconception of TBI from employers and employees (Soeker & Darries, 2019).

The results showed that unemployment is significant issue among brain injury survivors. All but one of the participants indicated that they were employed prior to the injury, however, but have not continued in this employed capacity post-injury despite having had long work records at good companies before i.e. "*I worked at…for almost 8 years*", and *"…had a job with an Information Technology (IT) company*". Some survivors continue to engage in volunteer work and financially support themselves through disability grant or trust funds. One participant mentioned that they are "*On permanent medical disability"* and *"…volunteer administrator…*". This suggests that although unemployment is a problem for adult brain injury survivors, they do make sure that they keep themselves active and productive through volunteer work, however, it does not take away the fact that it affects their self-actualisation need of which can affect their quality of life satisfaction negatively.

Theme 2: Social Relationships After Brain Injury

Subtheme: Self-Isolation by Adult Brain Injury Survivors

The results of this research revealed that all the participants did not immediately return to being as sociable as they were previously, which is in line with Mogashoa (2017) and Trask (2019) who suggest that they may not have as many friends as they used to previously, and that survivors of brain injury may experience isolation after the incident due to changes in cognitive,

behavioural, and emotional functions. The results showed that some survivors of brain injury transitioned from living with their family to living on their own after brain injury occurred i.e. "*Living with son*" to "*now living alone*" and "*My daughter lived with me*" to "*I stay alone*". This indicates that most social relationships may change after brain injury and in turn, may impact on the belongingness and love needs aspect of quality of life. On the other hand, this may reflect normal aging and development if it is a transition brought about by older children leaving the parental home.

Subtheme: Family Support after Brain Injury

Some brain injury survivors indicated that their living arrangements remained the same after brain injury occurred. On questions asking about previous and current living arrangements, participants made statements such as "*Same as now; living with my life partner*", "*Still staying with mom*", and "*I still live with my wife and two kids*". This explains the high level of satisfaction survivors of brain injury demonstrated in the descriptive analysis with regards to the frequentness at which they see or talk to their family and friends (M = 7.45, SD = 1.69). They also indicated that they were very satisfied with the help in which family members and friends provide to them indicating a positive impact their quality of life (M = 7.09, SD = 2.34). These findings may also be because roles tend to change after brain injury has occurred between family members and couples, and that crucial and the majority of the decisions that the survivor of brain injury used to make may now be made by someone else (Godwin, 2018).

Theme 3: Leisure Activities of Adult Brain Injury Survivors

Leisure activities may change depending on age maturity, however, physical health has proven have a stronger relationship with change in leisure activities than age (Paggi et al., 2016).

The findings of the present study show that brain injury has affected the type of leisure activities engaged in by survivors as their favourite leisure activities before acquiring the injury differ from the current ones they have. Most of the new leisure activities involve the internet, social media, as well as reading as opposed to the more active ones they used to have such as hiking and playing golf. This could be due to the negative impact on their physical functioning of which may in turn impact on their quality of life. This elaborated on the subthemes below. However, it is important to consider that restriction on activities imposed by the COVID-19 pandemic may also have played a role.

Subtheme: Transition from Active Leisure Activities to Passive Leisure Activities

Brain injury survivors have shown that after brain injury, people may not be able to physically do what they were previously able to do (Reed-Guy, 2018). Many of the survivors had active leisure activities before the injury, for example, playing golf. After brain injury, there has been a significant shift in their vocational activities and not only have the activities changed, they have also changed to a different category as well. Adult brain injury survivors stated that they moved from playing "*Golf*" to using "*Facebook*", "*Playing cricket*" to "*Reading and surfing the internet*", "*Outing with family and friends*" to "*Watching movies at home, email, Whatsapp, Instagram, and Facebook*". These findings support the below average level of satisfaction reported relative to the amount and kind of recreational activities in their lives (M = 5.45, SD = 2.25). This indicates a negative impact in the self-actualisation needs of brain injury survivors as well as their physical functioning (Paggi et al., 2016).

Subtheme: Leisure Activities Improving Cognitive Functioning

Results indicate that although leisure activities of adult brain injury survivors significantly changed after brain injury, there was an increase in reading as a leisure activity. The consequence may reflect positively on cognitive function if through reading they increase mental stimulation (Watkins, 2012). Some survivors of brain injury went from active recreation such as "*Gaming, playing soccer, and road trips*" to "*…reading*". One participant went to the extent of joining a book club. Some participants indicated that they spent time reading their bibles which may speak to spiritual context, which impacts their belongingness and love needs.

Theme 4: Intimate Relationships after Brain Injury

Intimate relationships of adult brain injury survivors vary in a sense that some are still with the same partner they were with before the injury, some were in intimate relationships before the incident and that changed post-brain injury, lastly, some were never in intimate relationships and are currently still not. It has been reported (Godwin et al., 2020) that following a brain injury, the dynamic of intimate relationships may change and both the survivors of brain injury and their partners may have to change many aspects of their lives including responsibilities, relationship roles, and communication challenges.

Subtheme: Devotion of Partners of Brain Injury Survivors After Brain Injury

According to Headway UK (2018) intimate relationships do not end as much as people may assume after brain injury, instead, brain injury tends to strengthen some of the couples' relationships. Results indicated that those that are still in relationships are those who are married and had been married before brain injury occurred i.e. "*living with my life partner; same as now*". Those who were in intimate relationships before brain injury and who were not married,

indicated that they became single after the incident, i.e. "*I was staying with my better half; I had to move back with my mother and father*". This is explained by the findings by (Headway UK, 2018) where they indicated that survivors of brain injury that mentioned that their relationships collapsed or ended was because of the lack of knowledge their partners had with regards to partner the impact of the injury on the survivor and therefore they could not embrace it.

Subtheme: Level of Sexual Activity or Lack of Sexual Activity

Brain injury may have effects that affect their sexual life such as physical, emotional, cognitive, and behavioral problems, the physical effects include fatigue, pain, hormonal changes, and limited mobility. Emotional effects on the other hand, may include loss of self-esteem and emotional lability. Lastly, the cognitive effects may include problems with motivation (Headway UK, 2017). The level at which most of the survivors are not in intimate relationships is shown by the findings in the descriptive analysis which showed very poor score for the level of sexual activity and lack of sexual activity of brain injury survivors and 99.7% of the data for this item were within 3 standard deviation of the mean (M = 4.50, SD = 3.27). However, this could also be influenced by factors such as the fact that participants were of middle adulthood and therefore sexual activity may have changed over the years.

Content Analysis

Relational content analysis was conducted to determine the experiences/challenges that caregivers of adult brain injury survivors face compared to the perceived quality of life of their paired adult brain injury survivor. Relational content analysis involves choosing a concept and examining it by quantifying/counting its presence, then, exploring the relationships between the chosen concepts (Constable et al., 2021). This analysis answered the following question: *Is there*

a match between adult survivors of brain injury's perceived quality of life and the challenges/difficulties faced by their primary caregivers?

There were four pairs which constituted of the adult brain injury survivor and their caregiver. The relationships included three females and one male (three of comparable age and one much older).

Adult brain injury survivors' quality of life may have significantly changed after brain injury, and this may have an impact on caregivers' lives as they would have to adjust to the new life of becoming primary caregivers of brain injury survivors. Whilst small sample sizes resulting from the limitations impose on data collection by the advent of COVID-19 is an obvious cause of concern for the validity of quantitative analysis, a Pearson's correlation coefficient was calculated as a means to observe the relationship the variables/domains of the PQoL scale and the CRS scale for the paired survivors of brain injury and caregivers. PQoL encompasses three domains/subscales i.e. physical, social, and cognitive functioning, item 7 does not fall under any of the subscales and is therefore used on its own, and general happiness is measured as a global item on the scale (Patrick & Danis, 2008). The positive dimensions of the CRS scale include personal gain and coping, whilst the negative dimensions include family beliefs and conflict, relational deprivation, overload, job conflicts and financial disruption and feelings of captivity.

With due cognisance for the small sample size, the Pearson's correlation coefficient was used merely as a framework to guide qualitative understanding. The Pearson's correlation analysis in Table 5 below suggested a significant negative relationship between the cognitive functioning domain of adult brain injury survivors and the caregivers' overload domain, $r(6) = -.981$, $p = .019$. This is supported by (Devi et al., 2020) who found that caregivers' overload/burden is associated with cognitive impairment of the survivors of brain injury.

There was, however, a significant positive relationship between the cognitive functioning domain of adult brain injury survivors and the caregivers' family beliefs and conflict domain, $r(6) = .990$, $p = .010$. Literature revealed that inappropriate, embarrassing, or impulsive behaviour of the survivor can affect them and the family negatively in social situations (Neumann & Lequerica, 2021). There was a significant positive relationship between the relational deprivation domain of caregivers and the coping domain, $r(6) = .977$, $p = .023$. Caregivers' ability to cope may be impaired by stress such as domestic upset, feelings of negativity toward the survivor, as well as personal distress in relation to the survivor (Byun et al., 2019). Lastly, family beliefs and overload indicated to have a significant negative relationship, $r(6) = -.990$, $p = .010$, this is in line with Akosile et al. (2018) who suggested that caregivers tend to face more burden when they have low/lack of social support. Caregivers of survivors of brain injury's burden could be due to factors such as stress and financial burden (Devi et al., 2020).

Table 5.

Descriptive Statistics and Correlations for Variables of the Paired Survivors of Brain Injury and Caregivers

Variable	*n*	*M*	*SD*	1	2	3	4	5	6	7	8	9	10	11	12	13
1.Physical Functioning	4	7.25	1.088	—												
2.Social Functioning	4	6.14	2.371	.934	—											
3.Cognitive Functioning	4	7.63	.479	.944	.901	—										
4.Item No.7	4	8.75	.957	.720	.674	.455	—									
5.Overall Happiness	4	7.25	3.403	.554	.779	.690	.128	—								
6.Feelings of Role Captivity	4	2.38	.924	.274	.111	-.047	.800	-.490	—							
7.Overload	4	2.81	.554	-.864	-.827	-.981*	-.275	-.718	.224	—						
8.Relational Deprivation	4	2.68	.513	-.098	-.446	-.170	-.024	-.811	.439	.178	—					
9.Competence	4	3.25	.500	.705	.831	.522	.870	.539	.451	-.376	-.510	—				
10.Personal Gain	4	3.44	.515	-.349	-.053	-.464	.127	.154	.066	.529	-.686	.404	—			
11.Coping	4	2.50	.410	.116	-.247	.039	.116	-.684	.480	-.017	.977*	-.370	-.771	—		
12.Family Beliefs and Conflict	4	2.33	1.114	.899	.897	.990*	.365	.777	-.175	-.990*	-.278	.499	-.411	-.077	—	
13.Job Conflicts and Financial Disruption	4	3.00	.544	-.525	-.188	-.426	.426	.360	-.552	.368	-.795	.000	.792	-.905	-305	—

*$p < 0.05$.

In summary, the results above suggested that cognitive functioning stresses the family and increases the load on the family and when the caregiver feels that the pre-accident relationship has been compromised (possibly because of the survivors cognitive function), they may have more difficulty coping and also may receive less support from the family.

Table 2, Table 3, Table 4, and Appendix E were further analysed for descriptive analysis in order to determine which specific items of the scales matched for the pairs and the following themes were drawn thereof.

The Positive Impact of Personal Gain and Competence on Caregivers Associated with Survivors' Physical and Cognitive Functioning

All the pairs had different relationships ranging from intimate relationships to immediate family members. Caregivers indicated to have had positive experiences in this journey with regards to personal gain and competence. These domains may be associated with the physical and cognitive functioning of the survivors of brain injury as caregivers indicated that despite all, they personally have learned to cope with a difficult situation and thus experience personal growth, for example, scored high in item D16 on the CRS descriptive analysis (*believe you've learned how to deal with this very difficult situation*) (M = 3.14, SD = .690).

The Negative Impact of Job Conflicts and Financial Disruptions Associated with Survivors' Physical and Social Functioning

Although there were positive experiences for caregivers, there were also aspects that impacted them negatively. Job conflicts and financial disruptions indicated to also have a negative impact on caregivers, this is also explained by the unemployment issue of the survivors raised in the thematic analysis results. Job conflicts and financial disruption is also associated

with the social functioning of the survivors, for example, item S15 on the PQoL scale (*How dissatisfied or satisfied are you with the way your income meets your needs?*) indicated that survivors were not satisfied in this regard as suggested by the descriptive analysis (M = 5.82, SD = 2.99).

The Negative Impact of Family Beliefs and Conflicts and Relational Deprivation Associated with Survivors' Social Functioning

The combination of negative experiences such as family beliefs and conflict and relational deprivation for caregivers suggests that they feel that the level of isolation they as caregiver perceive relative to their personal relationships with both the survivor and the extended family may reflect in the survivors level of general happiness. Survivors of brain injury's low scores on social functioning may imply that an oppositional unsupportive extended family impacts negatively on the survivors' satisfaction of their social world.

The Impact of Experiences of Caregivers Associated with Survivors' General Happiness

The positive and negative aspects of caregiver experience, for example, relative to positive experiences, the perception of competence that a caregiver feels relative to their role appears to be reflected in the overall sense of happiness of the survivor. Furthermore, a caregiver with positive experiences relative to family support, as well as lack of feelings of relational deprivation reflected to have a positive impact on the general happiness of the survivor of brain injury. Whilst a caregiver experiencing a negative impact with regards to relational deprivation appeared to impact the overall happiness of the survivor negatively.

Integration of Quantitative and Qualitative Analysis Results

Descriptive analyses, thematic analysis, as well as content analysis results revealed that aspects of quality of life of brain injury survivors are affected by brain injury, and so is the experiences of caregivers of which can be impacted both positively and negatively. Self-isolation does exist for some survivors post-brain injury with statements showing that some used to live with their loved ones before the incident, however, they stated to be living alone after the incident of which affects the social functioning domain negatively. Relational deprivation also proved to exist after brain-injury occurred to the survivors as all the caregivers indicated to feel grief of having lost someone they used to know, this proved a negative impact on the experiences of caregivers. Caregivers have also indicated have negative experiences with regards to family beliefs and conflict as problems arise often when it comes to dealing with the survivor's condition of brain injury, many face disagreements in terms of giving unwanted advice, not visiting or calling enough, and not visiting the brain injury survivor enough. However, survivors of brain injury indicated to be satisfied with the support they receive from family, and they could be referring to their caregivers and immediate family members. Although finances in the household have decreased for some and expenses have increased, some families still manage to make it work at the end of every month. Furthermore, many caregivers have shown to have extremely gained personal growth from this journey and are confident in their competence as caregivers of which showed a positive impact on their experience. Caregivers indicated to not experience feelings of role captivity of which showed a positive impact on them. Most adult survivors have shown to not be satisfied with their physical, social, and cognitive functioning domains/subscales. However, they have shown good physical functioning in the aspect of being able to do things for themselves without assistant. They are also satisfied with their social lives

in terms of receiving the necessary help from family. The brain injury survivors have also indicated fair cognitive functioning as they were able to read and complete the scales indicating no presence of aphasia as the results also indicate that they are able to communicate well with others. The two factors that are mostly negatively impacted the quality of life of the survivors is employment and sexual activity. The results showed that all the adult brain injury survivors are unemployed and have been since the occurrence of brain injury, they are therefore not satisfied with their current work situation which explains some caregivers indicating that finances in the household have since decreased. Vocational or leisure activities of the brain injury survivors proved to have significantly changed post the injury as they have transitioned from active leisure activities to passive leisure activities i.e. many are now interested in social media, the internet, and reading as opposed to their previous leisure activities such as playing golf or hiking. However, with regards to adjusting to the society, many are fairly satisfied with the respect they receive from others and their purpose and meaning in life. All the Maslowian motivational hierarchy needs have been impacted in one way or another since brain injury for both the survivors and caregivers.

CHAPTER FIVE: DISCUSSION

This chapter aims to discuss the results of the research by referring to the existing literature on brain injury and quality of life and interrogating the results of this research with the emphasis of the impact of brain injury on the perceived quality of life of adult brain injury survivors and caregiver (post-injury). This chapter provides a brief context of the overall picture of the study, and then looks into the aspects of quality of life that are impacted by brain injury, and lastly, engages with the aspects of life/experiences of caregivers that are impacted.

The adult brain injury survivors who participated in the study were those with brain injury unrelated to either genetics or birth trauma and without congenital cause or degenerative consequence (Brain Injury Association of America, 2020). The races of participants included Black, White, and Coloured. The survivors' injuries involved both Acquired Brain Injury (ABI) and Traumatic Brain Injury (TBI). The culminative effect of multiple TBIs can be devastating but can be quite successfully avoided. On the other hand, one ABI may suggest a very real vulnerability for another. This given the impact on stress levels and anticipatory anxiety may differ (Gennarelli, 1993). The causes for TBIs for survivors of brain injury in this study included assault, motor vehicle accidents, as well as a superbike accident. For this study this has implications for gender differences in coping strategies, for example, the four pairs assessed for content analysis in this study encompassed all men as survivors of brain injury, and three women as caregivers together with one man. Carron et al.,(2020) found TBIs to be more common in young men, who are normally overrepresented in road accidents, of which the results of this study confirmed as only men showed to be the ones with TBIs caused by all the 5 motor vehicle accidents and the superbike accident. This is also supported by the fact that, for example, one of these survivors' brain injury occurred 23 years ago and the survivor is currently 48 years old, the

other is 55 years old and the incident occurred 24 years ago, another one is 36 years old and the incident occurred 12 years ago, and lastly the other is currently 37 years of age and the incident occurred 9 years ago, therefore this shows that at the time of the incident, they were still in their younger ages/were young men. This reflects early adulthood development which indicates that during this phase, people's physical abilities are at the peak i.e. muscle strengths, whilst in middle adulthood and aging this decline (Horton et al., 2008). The developmental trajectory and expected life experiences for different ages, therefore, might impact on life satisfaction, for instance, poor sexual activity reflected in the results may be due to age as one of the factors.

Physical and Sensory Functioning of Adult Brain Injury Survivors

Reed-Guy (2020) stated that some brain injury survivors may experience a loss of muscle control i.e. a person may not be able to physically do what he or she was previously able to do, making them dependent on others, whether it be cutting their food, climbing out of the bath or driving. ASHA (2020) stated that loss of olfactory and gustatory senses such as not being able to share in eating rituals may also occur, however, participants in the present study indicate that they are very well satisfied with their ability to do things for themselves without assistance, for example, shopping, driving, and preparing meals. This may impact on the generalisabilty of the research. In addition, participating survivors of head injury did not indicate severe long term visual, auditory, olfactory or gustatory sensory fallout as a result of the injury. This could be because for some, it might have occurred at the time of the injury with minimal severity (Beck, 2020). Again, this impacts on the generalisability of present findings which are specific to the Headway Gauteng's classification of high functioning brain injury survivors. It was recorded, however, that even for this group, survivors indicate severe dissatisfaction with their sex lives, and this could be because of physical, emotional, and cognitive effects as a result of brain injury.

It could additionally be due to role changes and the negative impact brain injury might have had on the opportunity of establishing intimate relationships due to the occurrence of brain injury at a young age.

Cognitive Functioning of Adult Brain Injury Survivors

Webster et al.,(2015) stated that brain injury survivors may have different deficits that may affect their ability to deal with daily life as well as the ability to construct meaningful relationships. The adult brain injury survivors who participated in the study did not have cases of aphasia. However, the results showed that they were dissatisfied with their cognitive functioning in terms of how well they think and remember as well as the way they are able to communicate with others and carry conversations well, this indicates dissatisfaction with esteem needs. The findings showed that many of them can operate independently as some even stay alone. However, staying alone after the brain injury incident may also indicate social isolation of which impacts quality of life (ASHA, 2020).

Social Functioning of Adult Brain Injury Survivors

Sarkar et al. (2020) found that brain injury can affect intimate relationships, friendships, social networks, recreational and vocational activities. It may even force the person and their family to adapt to a completely new way of life and new kinds of relationships. The results of the study confirm these findings as caregivers have indicated to experience relational deprivation with their loved ones that have suffered brain injury. They showed to strongly feel they have lost someone they used to know and confide in and whom could do same with them, as well as the opportunity to do things they had planned, and also loss of contact with others. Furthermore, adult brain injury survivors have shown to have completely different leisure or vocational activities now than they did before the brain injury occurred. They mostly now read, visit social

media and the internet often for leisure. Before brain injury, their leisure activities involved outside activities such as playing golf or hiking, this is an indication that their physical functioning may have been affected, in turn, impacting on their quality of life. Mason (2020) stated that many survivors can feel like brain injury took away their dignity as human beings but then sometimes may feel that they can live positively with TBI. This explains the research findings as they show that brain injury survivors are not satisfied with the way in which they feel respected by others as well as their meaning and purpose in life. The research results show most caregivers have indicated that finances in the home have decreased and that expenses have increased ever since brain injury occurred to their loved ones. This is supported by Stocchetti & Zanier (2016) who found that re-entry into the community may be a major obstacle for brain injury survivors. Living arrangements for some survivors remained the same, others, however, did change post-brain injury and some of the survivors moved to stay alone. Although some survivors have indicated to have had long work records at good companies before, circumstances have now changed since brain injury occurred and unemployment has proven to be a problem among all of them as they have indicated to not have employment anymore due to the injury and this affects their self-actualisation needs aspect (Soeker et al., 2018).

Challenges/Difficulties Faced by Caregivers

Results show that caregivers experience changes in their well-being (psychological and physical domains), for example, they mostly feel exhausted when they go to bed at night as a result of their roles as caregivers to the adult brain injury survivors. Goldsworthy (2015) states that caregivers may struggle with these changes more than survivors of brain injury. The impact of TBI on a survivor's family also differs depending on how severe the injury was, which explains the research findings whereby the brain injury survivor has indicated to be extremely

satisfied with their perceived quality of life, which contradicted with the results of their paired caregiver whereby they indicated to experience challenges of relational deprivation as well as family disagreements and conflict due to the survivor's condition. Goldsworthy (2015) found that once an individual acquires brain injury, family members may experience emotional turmoil and be conflicted with the decisions they are required to make on behalf of their family member. This explains the family disagreements such as feelings of no appreciation for caregivers by relatives, unwanted advice, and lack of sharing in taking care of the brain injury survivor. Feelings of loss and grief also occurred chiefly due to a significant change of the survivor due to brain injury as many caregivers feel that they have lost someone they used to know. Significant others and even children also had to exchange roles and become primary caregivers for the survivor of brain injury (Goldsworthy, 2015). The present study indicates that although some caregivers are parents of the survivors, other caregivers proved to be their children, younger siblings, as well as their wives. Caregivers continue to use a range of coping mechanisms to deal with the condition of their loved ones. By way of example, personal gain for caregivers has, however, showed to have increased during this journey in their lives. They have reported to have become more aware of their inner strengths, they are more self-confident, have grown as a person during this journey, as well as have learned to do things they did not do before. They have also reported to be confident in their competence as caregivers for the brain injury survivors.

Rehabilitation and Support Services

Adult brain survivors of brain injury in the study are clients of the Headway Gauteng Non-Profit Organisation (NPO) and some have indicated to still be undergoing therapy. Some have also indicated to be doing volunteer work at the organisation. Headway does not only offer services to brain injury survivors only but also offers support to their families as they believe that

brain injury does not happen to a single individual, it happens to a family (Headway Gauteng, 2020).

CHAPTER SIX: CONCLUSION

This research study relates to and contributes/adds to the existing literature. It contributes to the existing literature on brain injury as well as studies conducted internationally on the perceived quality of life of survivors of brain injury and caregivers. The study also closes the gap of studies not conducted on this phenomenon locally. The study shows that indeed brain injury does not only affect the survivor but the household/families as well. The research reported that most adult brain injury survivors classified as high functioning by Headway are not satisfied with most aspects of their perceived quality of life in terms of their physical, social, and cognitive functioning. This suggests that brain injury has a negative impact on the quality of life of survivors of brain injury as they in addition, acknowledge that many aspects of their lives have changed after brain injury occurred i.e. their social lives, leisure activities, and livelihoods have showed to have been affected negatively after brain injury occurred. This has an implication on external validity as the research constituted of a small sample and therefore the results cannot be applied to the quality of life all brain injury survivors in South Africa. Caregivers reported to face challenges/difficulties mostly related to relational deprivation, family disagreements and conflict with regards to the brain injury survivor's condition, and even through these difficulties, caregivers indicated to have positive experiences such as personal gain. This suggest that difficult experiences can help one with life growth. This journey indicated to have been difficult for both the survivors and caregivers, however, adult brain injury survivors indicated to be satisfied with the help they receive from others and caregivers have improved personal gain significantly through their roles of caring for the survivors.

Strength, Limitations and Recommendations

Strengths

The study made use of a mixed-method approach, and this helped strengthen the findings. A combination of both quantitative and qualitative results is advantageous as it provided insight into multiple facets of the phenomenon explored allowing for further gaps for future research to be exposed. The measures/instruments used for the study were not difficult and could easily be completed, they were not time consuming, and required no cost. Most importantly, the study closes the gap in research by establishing if there is a match between the quality of life of survivors of brain injury and that of caregivers. This can assist support facilities such as Headway in being able to address and tackle relevant issues that require attention between survivors of brain injury and caregivers.

Limitations

Due to COVID-19 constraints, the research methods had to rely solely on the use of methods that do not require human interaction, which takes away the ability to observe and analyse non-verbal communication. COVID-19 restrictions may have reduced life satisfaction across global populations. The study may have response bias as some participants might have falsely answered some questions on the questionnaires as they were Likert-scale type. Due to COVID-19 constraints again, as well as Headway Gauteng's capacity, the study had a small sample size of 11 adult brain injury survivors and 7 caregivers, which therefore cannot be generalised to the broader of South African population. Lack of research studies on brain injury in South Africa is also a limitation of the study as we currently do not know what the current incidence of brain injury is in the country.

Recommendations

Recommendations to Caregivers and Family Members

Family members and primary caregivers should acknowledge that the incident of brain injury to their loved ones does not only affect the survivors, but it also affects them as well. They should be open to receiving counselling and use support services available to them. It is of utmost importance for them to gain more knowledge on brain injury, how to deal with the situation, as well as how to care for themselves too during this process. Counselling can help them with the ability and skills on dealing with having a brain injury survivor in the family.

Recommendations to Headway Gauteng

Headway Gauteng has proved to be doing an important job in not only supporting the survivors of brain injury but their families as well. Some survivors reported to have volunteer jobs at Headway of which is a great method in assisting them in adjusting themselves back into the community. Moving forward, Headway might consider collaborations with Organisational Psychologists and other representatives of the employment field to assist in a transition to possible gainful employment as results have shown that adult brain injury survivors struggle in finding employment. The other option is to also not only offer counselling services but to also offer programmes that can assist brain injury survivors with obtaining skills that will make them eligible to join the working force again.

Recommendations to the Public and the Community

It is important for the public/community to not rely on the government in educating us about brain injury. It is our responsibility to learn about brain injury and understand that there is life after brain injury, that people with brain injury are more than capable in adjusting back into

the community and live independently. Helping brain injury survivors and supporting them through this process is of utmost importance.

Recommendations to Government and NGOs

The government can assist greatly in building more facilities in the country dedicated to the rehabilitation and support services of brain injury. The government can also help greatly by ensuring that survivors of brain injury who are still capable to work obtained employment. Both the government and NGOs need to promote awareness on brain injury to communities. NGOs, however, can assist greatly by strengthening social and political change, encouraging communalities to participate in programmes that help build knowledge on the phenomenon, and to reach out to places with less media coverage on brain injury. The government should enforce the improvement of research on brain injury and ensure that more research is conducted on the phenomenon in the country, which will contribute to the sustainable development goals (SDGs) of South Africa. The purpose of this should not only be to conduct the research but to also use this research as a source in helping to deal with issues of brain injury in the country.

Recommendations for Future Research

This research suggests that the level of the perceived quality of life of the survivor of brain injury has an impact on the experiences of caregivers, and that those experiences also affect the level of quality of life of caregivers. However, this research was limited to Headway Gauteng, therefore, future research should consider adding to this study by targeting a broader South African population. Secondly, future research should consider other supporting facilities, rehabilitation facilities, as well as hospitals. This research targeted adults, therefore, future research should consider a younger group. The results revealed that cognitive functioning of

survivors of brain injury has a negative impact on the overload/burden caregivers face, future research should engage and investigate this in a broader manner. Family beliefs and conflict indicated to be at the peak of the negative experiences that caregivers encounter in caring for the survivor of brain injury, future research should target families of survivors excluding caregivers to examine if lack of family support or good family support is determined by the closeness of the family, as well cognitive functioning of the survivor.

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Appendices

Appendix A: Ethical Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

Research Office

HUMAN RESEARCH ETHICS COMMITTEE (NON-MEDICAL)
R14/49 Thupe

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER: H20/08/42**
PROJECT TITLE	The Impact of Brain injury on the Perceived Quality of Life of Adult Survivors of Brain Injury and Caregivers (Post- Injury): The South African Context
INVESTIGATOR(S)	Miss M Thupe
SCHOOL/DEPARTMENT	Human and Community Deveopment/
DATE CONSIDERED	21 August 2020
DECISION OF THE COMMITTEE	Approved Risk Level: Low
EXPIRY DATE	17 September 2023

DATE 18 September 2020 **CHAIRPERSON** _____
(Professor J Knight)

cc: Supervisor : Prof E Schutte

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University. Unreported changes to the application may invalidate the clearance given by the HREC (Non-Medical)

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to completion of a yearly progress report.**

_____ _____/_____/_____
Signature **Date**

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES

Appendix B: Formal Letter of Permission from Headway

HEADWAY GAUTENG
CELEBRATING 25 YEARS

21 July 2020

To Whom it May Concern,

Headway Gauteng is a registered NPO that aims to provide information and support to survivors of brain injury and their families. We are currently working with over 400 families, providing online group activities, online support groups and telephonic counselling. As such, we are able to facilitate our members' participation in research projects conducted through tertiary institutions.

This letter serves to confirm that we are granting permission for Matlhogonolo Thupe to invite our members to participate in her research project entitled 'The impact of brain injury on the perceived quality of life of adult survivors of brain injury and caregivers (post-injury): the South African context.'

We are giving our permission for our organisation's participation on condition that Ms Thupe receives clearance for her project from her ethics committee, and on condition that there is continued communication and co-operation between our two parties.

Yours faithfully,

Mia Pienaar
Counselling and Support Services

Love your life
Positive mind . Positive vibes . Positive Life

Headway Gauteng (The Brain Injury Association)
Registration Number 001-304 NPO | PBO Number 930 001 688
PO Box 500 Sasanwold 2132 | Telephone 011 442 5733 | Fax 086 723 8051
E-mail: headway@iafrica.com Website: www.headwaygauteng.co.za

Appendix C: Descriptive Statistics of the Perceived Quality of Life Scale

Characteristics of the Perceived Quality of Life of Adult Survivors of Brain Injury, where n is the number of participants (Adult Survivors of Brain Injury).

Characteristics	n	%
P1		
5 - Neither Satisfied/happy or dissatisfied/unhappy	3	27.3
6 - A little satisfied/happy	3	27.3
7 - A little satisfied/happy	1	9.1
8 - Somewhat satisfied/happy	2	18.2
10 - Extremely Satisfied	2	18.2
P2		
5 - Neither Satisfied/happy or dissatisfied/unhappy	1	9.1
6 - A little satisfied/happy	1	9.1
7 - A little satisfied/happy	2	18.2
8 - Somewhat satisfied/happy	5	45.5
9 - Somewhat satisfied/happy	1	9.1
10 - Extremely Satisfied	1	9.1
P4		
1 - Somewhat dissatisfied/unhappy	1	9.1
2 - Somewhat dissatisfied/unhappy	1	9.1
4 - A little dissatisfied/unhappy	1	9.1
5 - Neither Satisfied/happy or dissatisfied/unhappy	1	9.1
6 - A little satisfied/happy	1	9.1
8 - Somewhat satisfied/happy	4	36.4
9 - Somewhat satisfied/happy	2	18.2

P5		
2 - Somewhat dissatisfied/unhappy	1	9.1
4 - A little dissatisfied/unhappy	1	9.1
5 - Neither Satisfied/happy or dissatisfied/unhappy	1	9.1
6 - A little satisfied/happy	1	9.1
7 - A little satisfied/happy	3	27.3
8 - Somewhat satisfied/happy	1	9.1
9 - Somewhat satisfied/happy	1	9.1
10 - Extremely Satisfied	2	18.2
P7		
0 - Extremely dissatisfied/unhappy	1	9.1
5 - Neither satisfied/happy or dissatisfied/unhappy	1	9.1
7 - A little satisfied/happy	1	9.1
8 - Somewhat satisfied/happy	5	45.5
9 - Somewhat satisfied/happy	1	9.1
10 - Extremely satisfied/happy	2	18.2
P19		
4 - A little dissatisfied/unhappy	1	9.1
5 - Neither Satisfied/happy or dissatisfied/unhappy	2	18.2
6 - A little satisfied/happy	1	9.1
7 - A little satisfied/happy	1	9.1
8 - Somewhat satisfied/happy	3	27.3
10 - Extremely Satisfied	3	27.3
S8		
4 - A little dissatisfied/unhappy	1	9.1
5 - Neither Satisfied/happy or dissatisfied/unhappy	1	9.1
7 - A little satisfied/happy	3	27.3
8 - Somewhat satisfied/happy	2	18.2
9 - Somewhat satisfied/happy	4	36.4

S9		
3 - A little dissatisfied/unhappy	1	9.1
5 - Neither Satisfied/happy or dissatisfied/unhappy	3	27.3
7 - A little satisfied/happy	2	18.2
8 - Somewhat satisfied/happy	1	9.1
9 - Somewhat satisfied/happy	2	18.2
10 - Extremely Satisfied	2	18.2
S10		
2 - Somewhat dissatisfied/unhappy	1	9.1
5 - Neither Satisfied/happy or dissatisfied/unhappy	1	9.1
6 - A little satisfied/happy	2	18.2
7 - A little satisfied/happy	3	27.3
8 - Somewhat satisfied/happy	1	9.1
9 - Somewhat satisfied/happy	1	9.1
10 - Extremely Satisfied	2	18.2
S11		
0 - Extremely dissatisfied/unhappy	1	9.1
1 - Somewhat dissatisfied/unhappy	1	9.1
5 - Neither satisfied/happy or dissatisfied/unhappy	2	18.2
7 - A little satisfied/happy	3	27.3
8 - Somewhat satisfied/happy	2	18.2
9 - Somewhat satisfied/happy	1	9.1
10 - Extremely satisfied/happy	1	9.1
S12		
1 - Somewhat dissatisfied/unhappy	1	9.1
2 - Somewhat dissatisfied/unhappy	1	9.1
3 - A little dissatisfied/unhappy	2	18.2
5 - Neither satisfied/happy or dissatisfied/unhappy	3	27.3
7 - A little satisfied/happy	1	9.1
9 - Somewhat satisfied/happy	2	18.2
10 - Extremely satisfied/happy	1	9.1

S13		
2 - Somewhat dissatisfied/unhappy	1	9.1
3 - A little dissatisfied/unhappy	2	18.2
5 - Neither satisfied/happy or dissatisfied/unhappy	4	36.4
8 - Somewhat satisfied/happy	4	36.4
S14		
1 - Somewhat dissatisfied/unhappy	2	18.2
2 - Somewhat dissatisfied/unhappy	1	9.1
3 - A little dissatisfied/unhappy	2	18.2
5 - Neither satisfied/happy or dissatisfied/unhappy	3	27.3
10 - Extremely Satisfied	2	18.2
S15		
1 - Somewhat dissatisfied/unhappy	2	18.2
3 - A little dissatisfied/unhappy	1	9.1
5 - Neither satisfied/happy or dissatisfied/unhappy	2	18.2
8 - Somewhat satisfied/happy	5	45.5
9 - Somewhat satisfied/happy	1	9.1
S16		
3 - A little dissatisfied/unhappy	2	18.2
4 - A little dissatisfied/unhappy	1	9.1
5 - Neither Satisfied/happy or dissatisfied/unhappy	1	9.1
7 - A little satisfied/happy	2	18.2
8 - Somewhat satisfied/happy	3	27.3
10 - Extremely Satisfied	2	18.2
S17		
3 - A little dissatisfied/unhappy	1	9.1
5 - Neither Satisfied/happy or dissatisfied/unhappy	2	18.2
6 - A little satisfied/happy	2	18.2
7 - A little satisfied/happy	1	9.1

8 - Somewhat satisfied/happy	4	36.4
10 - Extremely Satisfied	1	9.1
S18		
3 - A little dissatisfied/unhappy	1	9.1
5 - Neither Satisfied/happy or dissatisfied/unhappy	3	27.3
6 - A little satisfied/happy	1	9.1
7 - A little satisfied/happy	2	18.2
8 - Somewhat satisfied/happy	2	18.2
9 - Somewhat satisfied/happy	1	9.1
10 - Extremely Satisfied	1	9.1
S20		
3 - A little dissatisfied/unhappy	1	9.1
5 - Neither Satisfied/happy or dissatisfied/unhappy	2	18.2
6 - A little satisfied/happy	1	9.1
8 - Somewhat satisfied/happy	3	27.3
9 - Somewhat satisfied/happy	1	9.1
10 - Extremely Satisfied	3	27.3
C3		
1 - Somewhat dissatisfied/unhappy	1	9.1
5 - Neither Satisfied/happy or dissatisfied/unhappy	1	9.1
6 - A little satisfied/happy	1	9.1
7 - A little satisfied/happy	4	36.4
8 - Somewhat satisfied/happy	2	18.2
9 - Somewhat satisfied/happy	2	18.2
C6		
4 - A little dissatisfied/unhappy	1	9.1
6 - A little satisfied/happy	1	9.1
7 - A little satisfied/happy	4	36.4

8 - Somewhat satisfied/happy	1	9.1
9 - Somewhat satisfied/happy	4	36.4

Note. N = 11. The average Perceived Quality of Life scale score was 131.10 (SD = 27.509).

Appendix D: Descriptive Statistics of the Caregiver Reaction Scale (CRS)

Characteristics of the experiences that caregivers of adult survivors of brain injury, where n is the number of participants (Primary Caregivers of Adult Survivors of Brain Injury).

Characteristics	n	%
A1		
1 - Not at all	3	42.9
2 - Somewhat	1	14.3
3 - Quite a bit	2	28.6
4 - Completely	1	14.3
A2		
1 - Not at all	2	28.6
2 - Somewhat	2	28.6
3 - Quite a bit	2	28.6
4 - Completely	1	14.3
A3		
1 - Not at all	4	57.1
2 - Somewhat	2	28.6
4 - Completely	1	14.3
A4		
2 - Somewhat	3	42.9
3 - Quite a bit	1	14.3
4 - Completely	3	42.9
B5		
2 - Somewhat	1	14.3
3 - Quite a bit	4	57.1
4 – Completely	2	28.6

B6		
2 - Somewhat	5	71.4
4 – Completely	2	28.2
B7		
2 - Somewhat	3	42.9
3 - Quite a bit	3	42.9
4 – Completely	1	14.3
B8		
1 - Not at all	2	28.6
2 - Somewhat	2	28.6
3 - Quite a bit	1	14.3
4 – Completely	2	28.6
C9		
1 - Not at all	1	14.3
2 - Somewhat	1	14.3
3 - Quite a bit	3	42.9
4 – Completely	2	28.6
C10		
3 - Quite a bit	2	28.6
4 – Completely	5	71.4
C11		
2 - Somewhat	1	14.3
3 - Quite a bit	3	42.9
4 – Completely	3	42.9

C12		
3 - Quite a bit	3	42.9
4 – Completely	4	57.1
C13		
1 - Not at all	1	14.3
2 - Somewhat	2	28.6
3 - Quite a bit	2	28.6
4 – Completely	2	28.6
C14		
1 - Not at all	3	42.9
2 - Somewhat	1	14.3
3 - Quite a bit	1	14.3
4 – Completely	2	28.6
C15		
1 - Not at all	1	14.3
2 - Somewhat	2	28.6
3 - Quite a bit	1	14.3
4 – Completely	3	42.9
D16		
1 - Not at all	1	14.3
2 - Somewhat	1	14.3
3 - Quite a bit	3	42.9
4 – Completely	2	28.6
D17		
2 - Somewhat	1	14.3
3 - Quite a bit	4	57.1
4 – Completely	2	28.6

D18		
2 - Somewhat	2	28.6
3 - Quite a bit	3	42.9
4 – Completely	2	28.6
D19		
2 - Somewhat	1	12.5
3 - Quite a bit	3	37.5
4 – Completely	1	12.5
E20		
2 - Somewhat	1	14.3
3 - Quite a bit	3	42.9
4 – Completely	3	42.9
E21		
1 - Not at all	1	12.5
2 - Somewhat	1	12.5
3 - Quite a bit	3	37.5
4 – Completely	1	12.5
E22		
2 - Somewhat	1	14.3
3 - Quite a bit	4	57.1
4 – Completely	2	28.6
E23		
1 - Not at all	1	14.3
3 - Quite a bit	3	42.9
4 – Completely	3	42.9

F24		
2 - Somewhat	1	14.3
3 - Quite a bit	5	71.4
4 – Completely	1	14.3
F25		
2 - Somewhat	2	28.6
3 - Quite a bit	4	57.1
4 – Completely	1	14.3
F26		
3 - Quite a bit	5	71.4
4 – Completely	2	28.6
F27		
1 - Not at all	1	14.3
2 – Somewhat	3	42.9
3 - Quite a bit	3	42.9
F28		
2 – Somewhat	4	57.1
3 - Quite a bit	3	42.9
F29		
1 - Not at all	5	71.4
3 - Quite a bit	1	14.3
4 – Completely	1	14.3
F30		
1 - Not at all	1	14.3
2 – Somewhat	4	57.1
3 - Quite a bit	2	28.6

F31		
2 - Somewhat	3	42.9
3 - Quite a bit	2	28.6
4 – Completely	2	28.6
F32		
2 - Somewhat	3	42.9
3 - Quite a bit	3	42.9
4 – Completely	1	14.3
F33		
1 - Not at all	3	42.9
2 – Somewhat	3	42.9
3 - Quite a bit	1	14.3
F34		
1 - Not at all	7	100
G35		
1 - Not at all	1	14.3
2 - Somewhat	2	28.6
3 - Quite a bit	3	42.9
4 – Completely	1	14.3
G36		
1 - Not at all	1	14.3
2 - Somewhat	1	14.3
3 - Quite a bit	2	28.6
4 – Completely	3	42.9
G37		
1 - Not at all	1	14.3
2 - Somewhat	3	42.9
3 - Quite a bit	3	42.9

G38		
1 - Not at all	5	71.4
2 - Somewhat	1	14.3
4 - Completely	1	14.3
H39		
2 - Somewhat	1	12.5
3 - Quite a bit	3	37.5
4 – Completely	2	25.0
H40		
2 - Somewhat	2	25.0
3 - Quite a bit	3	37.5
4 – Completely	1	12.5
H41		
1 - Not at all	2	25.0
2 - Somewhat	1	12.5
3 - Quite a bit	2	25.0
4 – Completely	1	12.5
H42		
2 - Somewhat	4	50.0
3 - Quite a bit	1	12.5
4 – Completely	1	12.5
H43		
1 - Not at all	1	12.5
2 - Somewhat	2	25.0
4 - Completely	3	37.5
H44		
2 - Somewhat	2	25.0
3 - Quite a bit	3	37.5

4 – Completely	1	12.5
H45		
1 - Not at all	1	12.5
2 - Somewhat	1	12.5
3 - Quite a bit	2	25.0
4 – Completely	2	25.0
H46		
1 - Not at all	1	12.5
2 - Somewhat	1	12.5
3 - Quite a bit	2	25.0
4 – Completely	2	25.0
I47		
1 - Not at all	1	14.3
3 - Quite a bit	4	57.1
4 – Completely	2	28.6
I48		
2 - Somewhat	2	28.6
3 - Quite a bit	2	28.6
4 – Completely	3	42.9
I49		
1 - Not at all	3	14.3
2 - Somewhat	2	28.6
3 - Quite a bit	1	14.3
4 – Completely	1	14.3

Note. $N = 7$. The average score of the Caregiver Reaction scale was 129.50 ($SD = 8.505$).

Appendix E: The descriptive analysis of domains of the Caregiver Reaction Scale (CRS)

D18	D17	D16	C15	C14	C13	C12	C11	C10	C9	B8	B7	B6	B5	A4	A3	A2	A1	
2	2	1	1	1	1	3	2	3	1	1	1	2	2	2	2	1	1	**Min.**
4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	**Max.**
3.00	3.14	2.86	2.86	2.29	2.71	3.57	3.29	3.71	2.86	2.43	2.71	2.57	3.14	3.00	1.71	2.29	2.14	**Mean**
.816	.690	1.069	1.215	1.380	1.113	.535	.756	.488	1.069	1.272	.756	.976	.690	1.000	1.113	1.113	1.215	**SD**

H 39	G 38	G 37	G 36	G 35	F 34	F 33	F 32	F 31	F 30	F 29	F 28	F 27	F 26	F 25	F 24	E 23	E 22	E 21	E 20	D 19
2	1	1	1	1	1	1	2	2	1	1	2	1	3	2	2	1	2	1	2	2
4	4	3	4	4	1	4	4	4	3	4	3	3	4	4	4	4	4	4	4	4
3.17	1.57	2.29	3.00	2.57	1.00	1.86	2.71	2.86	2.14	1.71	2.43	2.29	3.29	2.86	3.00	3.14	3.14	2.67	3.29	3.00
.753	1.134	.756	1.155	.976	.000	1.069	.756	.900	.690	1.254	.535	.756	.488	.690	.577	1.069	.690	1.033	.756	.707

I 49	I 48	I 47	H 46	H 45	H 44	H 43	H 42	H 41	H 40
1	2	1	1	1	2	1	2	1	2
4	4	4	4	4	4	4	4	4	4
2.00	3.14	3.00	2.83	2.83	2.83	2.83	2.50	2.33	2.83
1.155	.900	1.000	1.169	1.169	.753	1.329	.837	1.211	.753

Appendix F: Telephonical Study information Sheet and Informed Consent (Survivors of Brain Injury)

Research Title: The Impact of Brain injury on the Perceived Quality of Life of Adult Survivors of Brain Injury and Caregivers (Post-Injury): The South African Context.

Good day,

My name is Matlhogonolo Thupe, I am a Master of Arts in Social and Psychological Research student at the University of the Witwatersrand. I believe that brain injury does not only occur to an individual but rather to a household. I am investigating the perceived quality of life of adult brain injury survivors and their caregiver under the supervision of Ms. Enid Schutte. The aim of this research study to find out and understand how survivors of brain injury as well as their caregiver, for example, a parent, spouse or other member of the household who has been through this journey with you experience, and cope with the challenges of daily life in South Africa in partial fulfillment of my degree.

As part of this project, I would like to invite you as the survivor of brain injury to take part in answering two questionnaires which will take around 10 - 20 minutes each. The first questionnaire will ask you about your background information and the second questionnaire will ask you about your perceived quality of life.

There will be no personal costs to you if you participate in this project. You will not receive any direct benefits from participation but there are no disadvantages or penalties if you do not choose to participate or if you withdraw from the study. Participation is entirely voluntary, and you may withdraw from the study at any point before the report is submitted for examination without any negative consequences. Due to the COVID-19 (novel coronavirus) pandemic the study will be conducted through a Whatsapp video call or a normal phone call. If you choose a Whatsapp video call, you will be able to see the

researcher, however, you will have the option to redirect your camera should you not wish to be seen by researcher. Although confidentiality and anonymity cannot be guaranteed as I, the researcher have your contact details, those details will not be reported anywhere and data that may be reported in the research report will not include any information that reveals your identity. There are no names required on the questionnaires, only the researcher will have access to the data collected and it will not be disclosed to anyone else. If you experience any distress or discomfort at any point in this process, we will stop and resume at another given time. If you need some support or counselling services following answering the questionnaires, you can contact the South African Depression & Anxiety Group (SADAG) free of charge on 0800 567 567/0800 456 789.

If you have any questions during or afterwards about this research, feel free to ask me. If you wish to receive a summary of this report, I will be happy to send it to you. The data collected from this research project will be stored in password-protected computer and will be kept for five years. If you have any concerns or complaints regarding the ethical procedures of this study, you are welcome to contact the University Human Research Ethics Committee (Non-Medical), telephone +27(0) 11 717 1408, email hrecnon-medical@wits.ac.za

Appendix G: Telephonical Study information Sheet and Informed Consent (Caregiver)

Research Title: The Impact of Brain injury on the Perceived Quality of Life of Adult Survivors of Brain Injury and Caregivers (Post-Injury): The South African Context.

Good day,

My name is Matlhogonolo Thupe, I am a Master of Arts in Social and Psychological Research student at the University of the Witwatersrand. I believe that brain injury does not only occur to an individual but rather to a household. I am investigating the perceived quality of life of adult brain injury survivors and their caregiver under the supervision of Ms. Enid Schutte. The aim of this research study to find out and understand how survivors of brain injury as well as their caregiver, for example, a parent, spouse or other member of the household who has been through this journey with you experience, and cope with the challenges of daily life in South Africa in partial fulfillment of my degree.

As part of this project, as the primary caregiver of the survivor of brain injury, I would like to invite you to take part in answering a questionnaire which will take around 10 - 20 minutes. The questionnaire will ask you about the challenges/difficulties you experience as a caregiver of the survivor of brain injury.

There will be no personal costs to you if you participate in this project. You will not receive any direct benefits from participation but there are no disadvantages or penalties if you do not choose to participate or if you withdraw from the study. Participation is entirely voluntary, and you may withdraw from the study at any point before the report is submitted for examination without any negative consequences. Due to the COVID-19 (novel coronavirus) pandemic the study will be conducted through a Whatsapp video call or a normal phone call. If you choose a Whatsapp video call, you will be able to see the researcher, however, you will have the option to redirect your camera should you not wish

to be seen by researcher. Although confidentiality and anonymity cannot be guaranteed as I, the researcher have your contact details, those details will not be reported anywhere and data that may be reported in the research report will not include any information that reveals your identity. There are no names required on the questionnaires, only the researcher will have access to the data collected and it will not be disclosed to anyone else. If you experience any distress or discomfort at any point in this process, we will stop and resume at another given time. If you need some support or counselling services following answering the questionnaires, you can contact the South African Depression & Anxiety Group (SADAG) free of charge on 0800 567 567/0800 456 789.

If you have any questions during or afterwards about this research, feel free to contact ask me. If you wish to receive a summary of this report, I will be happy to send it to you. The data collected from this research project will be stored in password-protected computer and will be kept for five years. If you have any concerns or complaints regarding the ethical procedures of this study, you are welcome to contact the University Human Research Ethics Committee (Non-Medical), telephone +27(0) 11 717 1408, email hrecnon-medical@wits.ac.za

Appendix H: Demographic Background Information Questionnaire

1. **Sex** ☐ Male ☐ Female
2. **Race** ☐ Black ☐ White ☐ Coloured ☐ Indian
3. **Age** ☐

The following questions apply to the survivor of brain injury:

4. How long has it been since you acquired brain injury? _____
5. What was the cause of the head injury? _____
6. What were your living arrangements prior to the head injury? _____
7. What are your living arrangements now? _____
8. Were you gainfully employed prior to the accident? _____
9. Are you presently gainfully employed? _____
10. Were you in an intimate relationship prior to the head injury? _____
11. Are you now in an intimate relationship? _____
12. What was your favourite leisure activity prior to the head injury? _____
13. What is your favourite leisure activity now? _____

Appendix I: Perceived Quality of Life Scale (PQoL)

0 - Extremely dissatisfied/unhappy

1 or 2 - Somewhat dissatisfied/unhappy

3 or 4 - A little dissatisfied/unhappy

5 - Neither satisfied/happy or dissatisfied/unhappy

6 or 7 - A little satisfied/happy

8 or 9 - Somewhat satisfied/happy

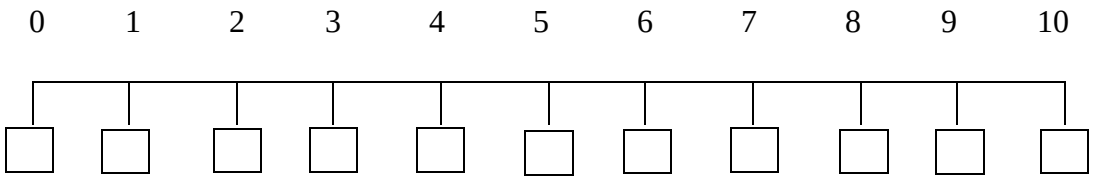
10 - Extremely satisfied/happy

We would like to know how satisfied you are with different aspects of your life. Each item below has a scale where "0" is Extremely Dissatisfied and "10" is Extremely Satisfied. For each item, mark an **X** in the box of the number that shows your own level of satisfaction.

How dissatisfied or satisfied are you with:

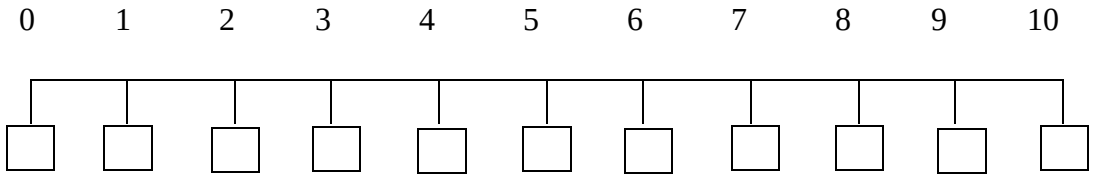
P 1. How dissatisfied or satisfied are you with your physical health (the health of your body)?

Extremely dissatisfied	Extremely satisfied



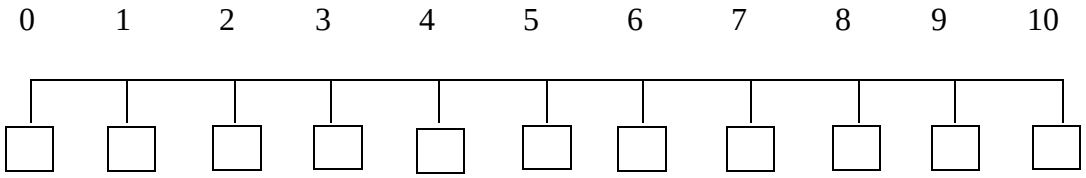
P 2. How dissatisfied or satisfied are you with how well you care for yourself, for example, preparing meals, bathing, or shopping?

Extremely dissatisfied	Extremely satisfied



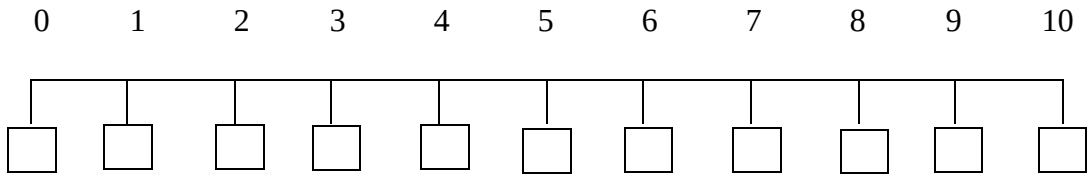
C 3. How dissatisfied or satisfied are you with how well you think and remember?

Extremely dissatisfied	Extremely satisfied



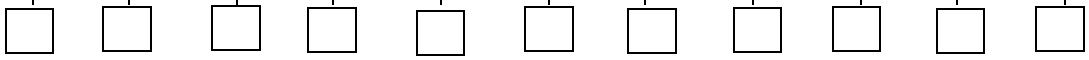
P 4. How dissatisfied or satisfied are you with the amount of walking you do?

Extremely dissatisfied	Extremely satisfied



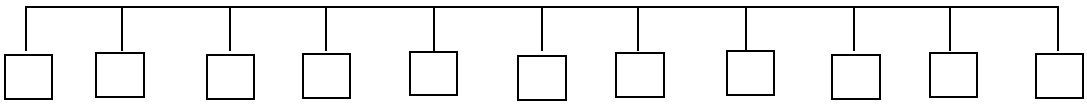
P 5. How dissatisfied or satisfied are you with how often you get outside the house, for example, going into town, using public transportation, or driving?

Extremely dissatisfied										Extremely satisfied
0	1	2	3	4	5	6	7	8	9	10



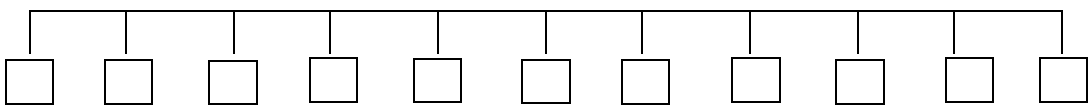
C 6. How dissatisfied or satisfied are you with how well you carry on a conversation, for example, speaking clearly, hearing others, or being understood

Extremely dissatisfied										Extremely satisfied
0	1	2	3	4	5	6	7	8	9	10



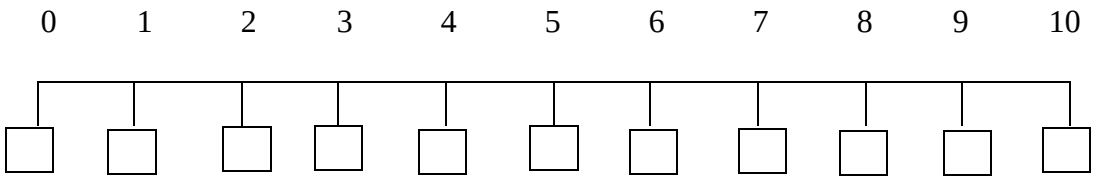
P 7. How dissatisfied or satisfied are you with the kind and amount of food you eat?

Extremely dissatisfied										Extremely satisfied
0	1	2	3	4	5	6	7	8	9	10



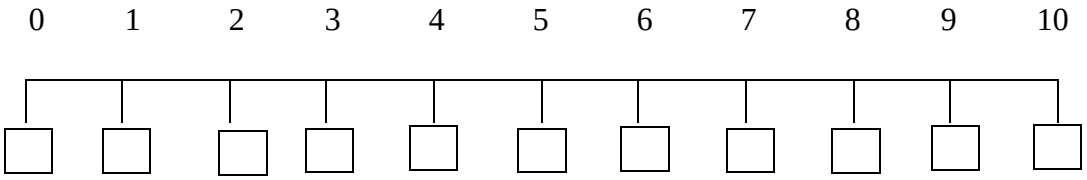
S 8. How dissatisfied or satisfied are you with how often you see or talk to your family and Friends?

Extremely dissatisfied	Extremely satisfied



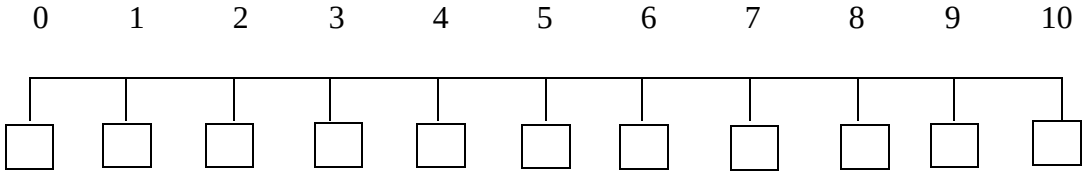
S 9. How dissatisfied or satisfied are you with the help you get from your family and friends, for example, helping in an emergency, fixing your house, or doing errands?

Extremely dissatisfied	Extremely satisfied



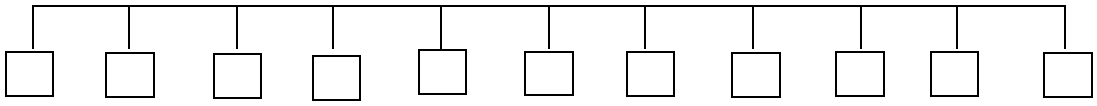
S 10. How dissatisfied or satisfied are you with the help you give to your family and friends?

Extremely dissatisfied	Extremely satisfied



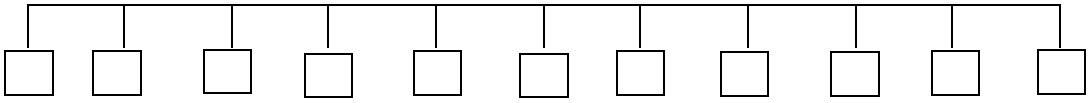
S 11. How dissatisfied or satisfied are you with your contribution to your community, for example, a neighborhood, religious, political or other group?

Extremely dissatisfied										Extremely satisfied
0	1	2	3	4	5	6	7	8	9	10



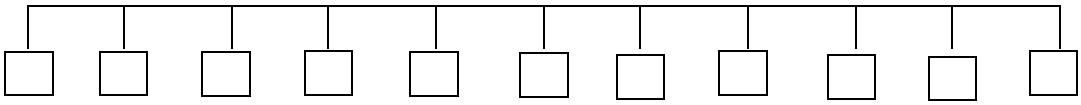
S 12. How dissatisfied or satisfied are you with your work situation, for example, your current job, retirement for any reason, or never having worked?

Extremely dissatisfied										Extremely satisfied
0	1	2	3	4	5	6	7	8	9	10



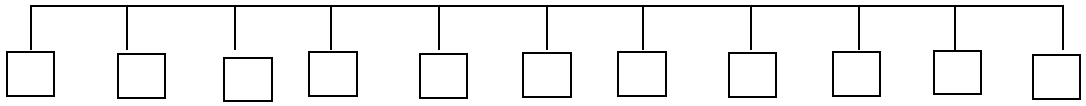
S 13, How dissatisfied or satisfied are you with the kind and amount of recreation or leisure you have?

Extremely dissatisfied										Extremely satisfied
0	1	2	3	4	5	6	7	8	9	10



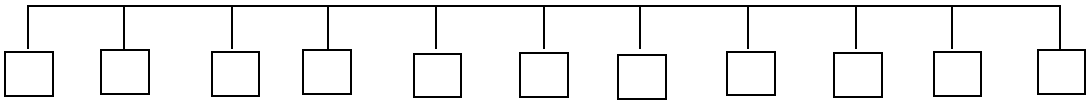
S 14. How dissatisfied or satisfied are you with your level of sexual activity or lack of sexual activity?

Extremely dissatisfied										Extremely satisfied
0	1	2	3	4	5	6	7	8	9	10



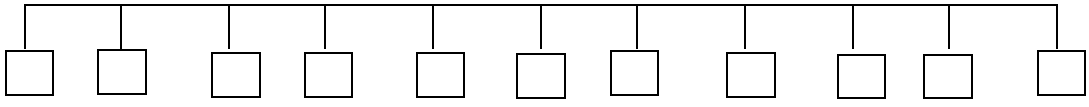
S 15. How dissatisfied or satisfied are you with the way your income meets your needs?

Extremely dissatisfied										Extremely satisfied
0	1	2	3	4	5	6	7	8	9	10



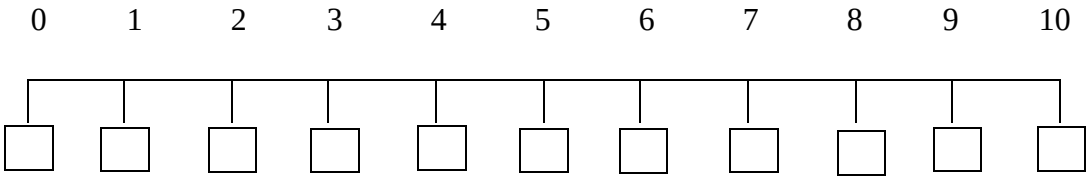
S 16. How dissatisfied or satisfied are you with how respected you are by others?

Extremely dissatisfied										Extremely satisfied
0	1	2	3	4	5	6	7	8	9	10



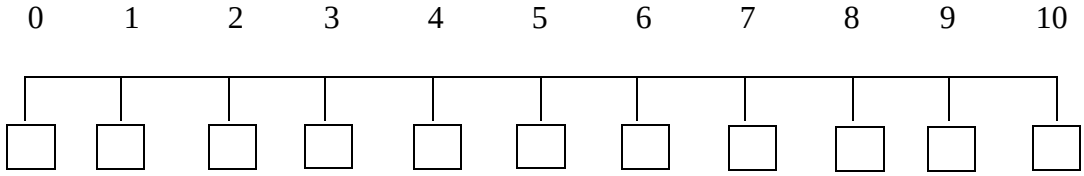
S 17. How dissatisfied or satisfied are you with the meaning and purpose of your life?

Extremely dissatisfied	Extremely satisfied



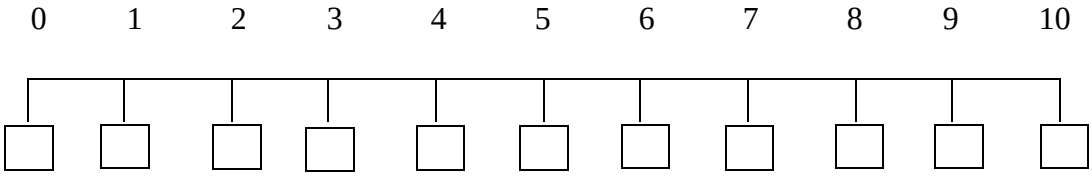
S 18. How dissatisfied or satisfied are you with the amount of variety in your life?

Extremely dissatisfied	Extremely satisfied



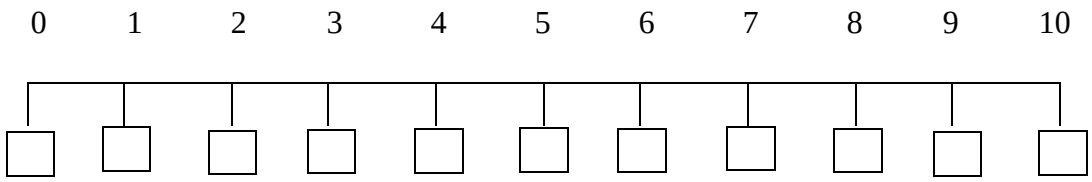
P 19. How dissatisfied or satisfied are you with the amount and kind of sleep you get?

Extremely dissatisfied	Extremely satisfied



S 20. How happy are you?

Extremely unhappy	Very Happy



Appendix J: Caregiver Reaction Scale (CRS)

The following questions are designed to help us understand the types of difficulties you and your family face as caregivers.

Each item is rated on a 1 to 4 scale. 1 (not at all) 2 (somewhat) 3 (quite a bit) 4 (completely)

Please respond to all items by checking the appropriate box:

(A)	Here are some thoughts and feelings that people sometimes have about themselves as caregivers. How much does each statement describe your thoughts about your caregiving?	1 – Not at all	2 – Somewhat	3 – Quite a bit	4 – Completely
1	Wish you were free to lead a life of your own				
2	Feel trapped by your relative's illness				
3	Wish you could just run away				
4	Feel stressed by your relative's illness and needs				
(B)	How much does each statement describe you?	1 – Not at all	2 – Somewhat	3 – Quite a bit	4 – Completely
5	You are exhausted when you go to bed at night				
6	You have more to do than you can handle				
7	You don't have time just for yourself				
8	You work hard as a caregiver but never seem to make any progress				
(C)	Caregivers sometimes feel that they lose important things in life because of their relative's illness. To what extent have you personally lost the following:	1 – Not at all	2 – Somewhat	3 – Quite a bit	4 – Completely
9	Being able to confide in your relative				
10	The person whom you used to know				
11	Having someone who really knew you well				
12	A chance to do some of the things you planned				
13	Contact with other people				
14	A sense of who you are				
15	Lost an important part of yourself				
(D)	People can often learn things about themselves from taking care of a relative. How much do you:	1 – Not at all	2 – Somewhat	3 – Quite a bit	4 – Completely
16	Believe you've learned how to deal with this very difficult situation				

17	Feel that, all in all, you're a good caregiver				
18	In general, feel competent as a caregiver				
19	Feel self-confident as a caregiver				
(E)	Since becoming a caregiver, how much have you:	1 – Not at all	2 – Somewhat	3 – Quite a bit	4 – Completely
20	Become more aware of your inner strengths				
21	Become more self-confident				
22	Grown as a person				
23	Learned to do things you didn't do before				
(F)	There are many different ways of coping with the stress of caregiving. How often do you:	1 – Not at all	2 – Somewhat	3 – Quite a bit	4 – Completely
24	Try to accept your relative as he/she is, not how you wish he/she could be				
25	Try to think about the present rather than the future				
26	Try to keep your sense of humor				
27	Spend time alone				
28	Eat				
29	Smoke				
30	Get some exercise				
31	Watch TV				
32	Read				
33	Take some medication to calm you down				
34	Drink some alcohol				
(G)	Family members don't always see eye-to-eye when it comes to dealing with a relative who is ill. How much disagreement have you had with anyone in your family about the following issues:	1 – Not at all	2 – Somewhat	3 – Quite a bit	4 – Completely
35	The seriousness of your relative's memory problems				
36	The need to watch out for your relative's safety				
37	What things your relative is able to do for him/herself				
38	Whether your relative should be placed in a nursing home or assisted living				
(H)	How much disagreement have you had with people in your family because they:	1 – Not at all	2 – Somewhat	3 – Quite a bit	4 – Completely
39	Don't spend enough time with your relative				
40	Don't do their share in caring for your relative				
41	Don't show enough respect for your relative				
42	Lack patience with your relative				

43	Don’t visit or telephone you enough				
44	Don’t give you enough help				
45	Don’t show enough appreciation for your work as a caregiver				
46	Give you unwanted advice				
(I)	These questions ask about your household expenses and your standard of living. Compared with just before you began to take care of your relative how much would you agree, with the following statements:	1 – Not at all	2 – Somewhat	3 – Quite a bit	4 – Completely
47	Total household income has decreased				
48	Total monthly expenses have increased				
49	In general, family finances work out at the end of the month				