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An exploration into the pathways of care and support followed by persons with post-acute traumatic brain injuries living in Soweto, Johannesburg

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An exploration into the pathways of care and support followed by persons with post-acute traumatic brain injuries living in Soweto, Johannesburg.

A research dissertation by:

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for the degree

Master of Arts in Speech Pathology

in the

Department of Speech Pathology and Audiology

Faculty of Humanities

at the

University of the Witwatersrand

Supervised by:

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DECLARATION FORM

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Date: 5 June 2023

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ABSTRACT:

Background: Persons with Traumatic Brain Injuries (TBI) require care and support from various sources during the post-acute phase. Seeking care and support is crucial for persons with TBI to cope with their new realities and deal with the consequences of their injuries. However, little attention has been paid to the care-seeking behaviours of persons with TBI in the African context, and how these behaviours are impacted by cultural and belief structures.

Methodology: To guide the narrative interviews of eleven adults with post-acute traumatic brain injuries living in Soweto, Johannesburg, an exploratory qualitative research design was utilized, underpinned by the biopsychosocial model (Engel, 1977). The sample included both male (N=9) and female (N=2) participants who were fluent in isiZulu, English, or Sepedi, and were selected through purposive and convenience sampling. Participants had sustained TBIs from motor vehicle accidents, pedestrian vehicle accidents, assaults, or falls. The data were analysed using Braun and Clarke's (2017) six-phase framework in an inductive manner.

Findings: The pathways of care and sources of support for persons with TBI are influenced by various biological, psychological, and social factors, including impairments resulting from the TBI, personal values, beliefs and preferences, financial issues, interpersonal relationships, family culture and religion, and education. The study revealed that post-hospitalisation, persons with TBI primarily seek care from family members, as well as from other sources such as friends, the community/neighbours, support groups, therapists, the church, and traditional healers, based on the roles these sources play in their healing process. However, the COVID-19 pandemic and subsequent restrictions prevented participants from accessing the support they needed.

Conclusion: This study sheds light on the importance of decolonizing research methods when studying TBI. It advocates for a holistic approach to the management of persons with TBI, by considering their spiritual, emotional, physical, and cognitive needs when providing support. Through exploring the impact of various factors on care-seeking behaviours, the study provides insight that can help foster ideal health outcomes and improve the health status of persons with TBI.

Key words: Traumatic Brain Injury (TBI), holistic, post-acute phase, biopsychosocial model

CHAPTER 1: INTRODUCTION AND RATIONALE

1.1 Introduction

Chapter one introduces the study by presenting the background information. The research problem is then stated, followed by the research questions and objectives. The rationale for the study is explained, and the main concepts that will be covered are clarified. Finally, the structure of the research dissertation is outlined.

1.2 Background

South Africa has a high prevalence of traffic accidents and other types of mishaps, such as assaults, falls, and gunshot wounds, that can result in individuals sustaining a TBI (Road Transport Management Corporation, 2021). Recovering from TBI can be lengthy process, and individuals often seek medical attention as well as various forms of care and support. The choice of care providers is influenced by a range of biopsychosocial factors, including the individual's impairments resulting from the injury, personal values and beliefs, financial considerations, interpersonal relationships, family culture and religion, and education.

This study aimed to investigate the pathways of care followed by persons with TBI living in Soweto during the post-acute phase of their injuries. The decision to focus on a predominantly Black and African community was motivated by the limited availability of research exploring care-seeking behaviours and beliefs about TBI in African populations (Mbakile-Mahlanza et al., 2017). Unfortunately, persons with TBI have often been excluded from research due to impairments in cognition, language, and communication, which were perceived as hindrances to providing personal narratives (Neille & Penn, 2017). Moreover, individuals with limited proficiency in English or who whom English is not their first language have also been excluded from research (Neille, 2021).

This study explores the care and support-seeking behaviours of persons with TBI, with a focus on the biological, psychological, and social factors that influence help-seeking from various sources and health outcomes associated with these factors. The impact of each factor on care-seeking behaviours is not well understood, and it is crucial to consider the interconnection of these factors to promote optimal health for persons with TBI in African communities. The lack of understanding regarding the impact of different factors on care-seeking behaviours in persons with TBI hinders the development of culturally appropriate and effective interventions that could improve clinical outcomes for this population. The biopsychosocial model seeks to address the limitations of the biomedical model, which

considers health as being independent of the sociocultural context in which it occurs (Rocca & Anjum, 2020). By considering the interplay between biological, psychological, and social factors, the biopsychosocial model offers a more complete insight of the health of persons with TBI and can guide the development of more effective interventions.

The biopsychosocial model which was developed by George L. Engel in 1977 (Turabian, 2018), serves as the theoretical framework for this study. This model recognizes the interdependence of "thoughts, beliefs, behaviours, social context and interactions with biological processes" (Turabian, 2018, p.1) in understanding and managing disease and disability. Engel (1977) argues that biological, psychological, and social processes cannot be separated from one another and must be integrated when providing care. A more in-depth discussion of this model will be provided in the background section of the research.

Persons with TBI often experience impairments in speech, swallowing, cognition, motor skills, and emotional disturbances, which can significantly impact their quality of life. Providing support can be crucial in helping them lead more fulfilling lives and become more independent (Kreutzer et al., 2016). TBI can also affect their ability to return to work successfully and participant socially, hindering their integration into their communities. TBI may also result in various emotional disturbances, such as anxiety, depressions, anger, feelings of worthlessness, and sadness (Weber, 2015). Seeking care and support is therefore seen as critical in helping individuals learn to live with their new realities and providing them with an opportunity to become as independent as possible, thereby promoting a sense of usefulness and self-sufficiency (Kreutzer et al., 2016).

The primary goal of all support systems available to persons with TBI should be to help them achieve the highest level of independence possible (Kohrt et al., 2018). This may involve modifying the home environment to enable them to perform tasks independently, providing job skills training, or educating them on social interactions. With proper care and attention, persons with TBI can achieve remarkable outcomes and create their own happiness (Kohrt et al., 2018). It is important to note that persons with TBI can access various sources of support. However, some sources may be more beneficial or more commonly used than others (Lambert et al., 2020). Individuals with disabilities often turn to their families, friends, community members, traditional healing practices, and religious institutions for support (Awosan et al., 2011). This could be attributed to the fact that those closest to the person with TBI are likely to know the type of support they require, and the persons with TBI may feel more comfortable disclosing

their feelings to those in their innermost circle (Tramonti et al., 2015). This circle would include family members, friends, and community members.

In many parts of Africa, it is commonly believed that disabilities and illnesses can be caused by supernatural forces such as ancestors and God (Claassens et al., 2019). As a result, some people may seek out mediums who are believed to be able to connect them with these forces. These mediums may include traditional healers, as well as priests and pastors in churches (Claassens et al., 2019). According to some persons with TBIs' belief structures, ancestors play a role in causing misfortune when ceremonies are not done to appease them. Ancestors also serve a purpose in warning people about danger and punishing them if they do not follow their commands (Lambert et al., 2020; Moshabela et al., 2017). For instance, if an individual refuses to perform ceremonies advised by their ancestors, he or she may be punished by means of making the individual ill or become involved in an accident, and this may be interpreted as resulting from the ancestors' anger towards that person. Therefore, traditional healers are seen as being able to help the persons with TBI to understand the causes of their brain injuries as well as what rituals or ceremonies need to be completed to reverse this sudden misfortune or to avoid further punishment from the ancestors (Moshabela et al., 2017).

It is not uncommon for persons with a disability in Africa to attribute their injuries, disabilities, illnesses, and misfortunes to supernatural causes such as God's punishment for bad behaviour or divine will (Lambert et al., 2020). For those who have experienced injuries or disabilities, these beliefs can serve as coping mechanisms or facilitators for everyday participation. As a result, church leaders such as priests and pastors are often sought out to help, as they are seen as godly figures who can offer deliverance and salvation to persons with TBI (Claassens et al., 2019). Priests and pastors are often sought out by persons with TBI because they can pray to God to release them from any perceived punishment that led to their disability. The church is viewed as a place where individuals can mend broken relationships with God to reverse sinful behaviour (Claassens et al., 2019). Consequently, persons with TBIs who hold religious and traditional beliefs may be less likely to seek help from medical professionals such as psychologists, rehabilitations teams, and support groups because they may believe that these care provers cannot help them to achieve the desired health outcomes (Lambert et al., 2020; Tramonti et al., 2015) compared to traditional healers, priests, and pastors.

The support available to persons with TBIs in South Africa is largely based on Western rehabilitation principles and may not meet the needs of people in Black South African communities (Tramonti et al., 2015). While some persons with TBI may receive Western-style consultations with healthcare providers such as counsellors and therapists, as well as participate in support groups, these may not always be preferred options for some persons with TBIs (Tramonti et al., 2015). Support groups provide a space for individuals with similar disabilities to come together and share their experiences of living with these disabilities, with the hope of supporting each other to overcome their challenges and achieve better health outcomes (Worrall et al., 2018). However, some persons with TBI may feel uncomfortable being vulnerable and sharing their feelings with strangers in support groups, which can make these groups less appealing as a source of support (Worrall et al., 2018). This discomfort may lead to reluctance to participate in support groups as a means of receiving the necessary support (Worrall et al., 2018). Moreover, if these interventions fail to produce the desired health outcomes, individuals may become unwilling to engage in support group activities (Moshabela et al., 2017).

Counselling and consultation with psychologists and/or counsellors can be effective in helping persons with TBIs understand why they behave in certain ways, as well as improving their stress management, emotional strain, and behaviour (Liu et al., 2017). In fact, consulting with psychologists and/or counsellors can be a successful way to ensure that individuals with head injuries can lead more successful lives, build better relationships, gain self-confidence, and improve their overall quality of life (Khan, et al., 2013). Western medical practitioners, such as occupational therapists, speech-language therapists, and physiotherapists, are primarily involved in the rehabilitation process for persons with TBI, including improving speech and swallowing, reintegrating them into activities of daily living, and improving motor control and movement (Khan, et al., 2013). While they may also provide counselling to persons with TBI, they generally refer them to disciplines that have greater expertise in providing counselling and support.

Data collection was conducted at Headway, located in Soweto, a township in the City of Johannesburg, that is renowned for its rich cultural and linguistic diversity. The languages spoken in Soweto include isiZulu, isiXhosa, Afrikaans, Sesotho, Setswana, English, Xitsonga, SiSwati, Tshivenda, and isiNdebele. The population is primarily Black, and the most spoken first language in isiZulu (37.1%). Soweto is the largest township for Black people in South Africa (City of Johannesburg, 2018; Ramchander & Wilson, 2004). It was established in the

1930s during Apartheid, a period when Black people were forcible separated from White people, resulting in the development of Black townships. The name Soweto is an English abbreviation for South-Western Townships. The township is predominantly Black African, with approximately 98.5% of the population being Black, 1.0% Coloured, and 0.1% Indian and White (City of Johannesburg, 2018; Ramchander & Wilson, 2004).

The researcher's choice of Soweto was due to her interest in the interplay of different factors such as cultural contexts, the impairments resulting from the TBI, cultural beliefs, religion, access, and level of education of persons with TBI living in Soweto. The researcher also chose Soweto due to her interest in participants who are from various cultures and can communicate in various languages being isiZulu, IsiXhosa, Afrikaans, Sesotho, Setswana, English, Xitsonga, SiSwati, Tshivenda, and IsiNdebele. In the African context, little is known about how different cultural contexts, language variances, and belief structures influence care-seeking behaviours (Claassens et al., 2019). Therefore, it is fundamental to understand how these various aspects impacted care-seeking from the various sources that spoke to the indigenous worldviews of people in the South African context.

1.3 Research problem

Care and support for people with TBI is not limited to biomedical care. Many service users are believed to also utilise non-biomedical avenues in the pathway to care and support. These non-biomedical treatments include indigenous and faith healing methods. Although some studies have already examined the available support by different streams in different contexts, the reasons for and use of the different pathways (including factors which influence the decision to use a particular pathway) is not well explored among people with TBI. There is a plethora of reasons why people choose certain pathways to care, and it is the purpose of this research to explore the pathways of care and support followed by persons with post-acute traumatic brain injuries living in Soweto and which of these reasons impact their help-seeking behaviours. It is the purpose of this research to also provide a more nuanced understanding of what informs these choices, so that people with TBIs can get an adequate and appropriate provision of healthcare services.

1.4 Purpose of study

The purpose of the study was to investigate the care and support seeking pathways followed by adults with post-acute traumatic brain injuries living in Soweto, Johannesburg, who receive help at a care facility (Headway). The study aimed to elicit individual responses

from participants to gain a better understanding of the reasons behind their choices, and to advocate for the need for diverse sources of care and support for persons with TBI.

1.5 Research questions

The main research question is stated thus:

- What care and support seeking pathways are followed by persons with post-acute traumatic brain injuries living in Soweto, Johannesburg?

The sub questions are:

- What factors influence persons with TBI to seek care and support pathways?
- How have impairment needs of persons with TBI influenced their care seeking and support pathways?
- How has the COVID-19 pandemic restrictions influenced care seeking behaviours and access to care and support

1.6 The Theoretical framework of the study

The biomedical model focuses on diagnosing and treating illnesses based on their physical symptoms and underlying biological causes. It often relies on medical interventions, such as medications or surgery, to cure or manage illnesses (Rocca & Anjum, 2020). While the biomedical model has led to significant advancements in medical treatments and technologies, it has been criticised for overlooking the social and psychological factors that can contribute to illness and recovery. In contrast, other models of healthcare, such as the biopsychosocial model, consider the collaboration between biological, psychological, and social factors in illness and recovery (Rocca & Anjum, 2020).

George Engel was concerned about the challenges that psychiatry faced in the 1970s, particularly the absence of an established illness model to inform and direct its practice. In 1977, he published a paper that highlighted a limitation in the biomedical model (Engel, 1977). Engel proposed that psychiatry embrace the biopsychosocial model of illness. He argued that the biomedical model did not account for the social, psychological, and behavioural aspects of illness. He recognised that the limitations of the biomedical model were that it does not include the patients and their attributes as a person. Hence, Engel (1977) presented an alternative model, of a systems approach, the biopsychosocial model. He suggested that physicians should strive to understand their patients' contexts in order to develop personalised intervention plans

that consider pertinent biological, psychological, social, cultural, and spiritual factors that impact health, longitudinal care, and outcomes (Engel, 1977, as cited in Saxena et al., 2022).

He recognised that illness and health arise from the interplay between biological, psychological, and social factors. For instance, for a person to be fully healthy there is an interplay of different factors like biological factors such as the nature of the injury, psychological factors such as the persons mental state and emotions about the illness/disability as well as social factors such as availability of resources around where the person lives, their interpersonal relationships, economic status, belief structures, and culture. According to Engel (1977), as cited in Turabian, 2018, patients and their families often face multi-factorial problems that cannot be easily categorised under the biomedical model. Instead, Engel (1977) advocates for the biopsychosocial model which supports a person-centered approach to care that can improve patient outcomes (Saxena et al., 2022).

This model also promotes a more holistic approach to healthcare, which could lead to a more sustainable health system by emphasising patient-centered care and better cooperation and sharing of resources. In adopting a more holistic approach to intervention, there is often more than one source of support that is available to persons with TBI. For instance, families and peers can be seen as better able to understand the person with TBI and can help reintegrate them back to their normal lives, since they know the person's way of living or condition prior to the injury (Awosan et al., 2011). In addition, it may feel safer for the person with TBI to seek help from a family member or a friend whom they know would not judge them or misrepresent their values (Tramonti et al., 2015). Whom they also know will understand how their spiritual values can help manage their impairments. Therefore, to protect themselves from the misrepresentation of their identities, values, and experiences, many individuals seek help from people who are aware of and responsive to their cultural identities, being their families and/or peers (Awosan et al., 2011).

In the same vein, when a person gets involved in an accident and ends up having a TBI, they will end up seeking care from health professionals and non-professionals alike (Awosan et al., 2011). Persons suffering from TBI seek help so that they get better both medically and psychologically (Awosan et al., 2011). Psychologists, for example, are well-equipped to provide support, although some persons with TBI may not necessarily turn to them for support for various reasons. Awosan et al. (2011), highlights two reasons why some persons with a disability are reluctant to receive support from psychologists or members of the healthcare

sector. These are the lack of cultural understanding and the stigma attached to attending therapy or counselling. People with disabilities often point to healthcare professionals' lack of understanding of Black cultures and this prevents them from consulting these fraternities. This notion is attributed to historical experiences of racial oppression and marginalization as well as the providers of counselling being mostly white (Awosan et al., 2011). Many individuals become mistrustful of attending sessions with individuals who they perceive would not understand things from their perspective or their indigenous worldviews (Awosan et al., 2011).

Aspects such as the misrepresentation of cultural identities and values based on subconscious assumptions by counsellors, influences the unwillingness of persons with TBI to participate in these therapy sessions (Moshabela et al., 2017). Cultural identities entail characters that are unusual to other people to the degree that these cultural identities mark them out from other people. These traits include people's languages, religion, social norms, and values. Values are to be comprehended "as beliefs that are held about what is right and wrong and what is important in life" (Idang, 2015, p.102). Persons with any disability often fear that their counsellors will not fully understand their cultural experiences or even respect these experiences (Lambert et al., 2020).

Subsequently, communities from which people come from, may have certain stigma regarding the consultation of Westernised healthcare providers, based on the idea that Westernised healthcare providers may not understand the persons with TBIs' values and therapy being for certain people. This stigma reinforces the need to seek help from people who are not therapists. Hence many people from African communities turn to family members, friends, communities, and/or religious or traditional leaders for care and support (Awosan et al., 2011). In addition, this reinforces the notion that the awareness of and culturally informed clinical skills are crucial in making healthcare more accessible and approachable to African communities.

1.7 Researcher Positionality

The researcher is an African female, qualified in speech-language therapy and audiology. As part of the profession, the researcher has worked with adult persons with TBI before and has conducted research on their experiences of living with TBI in her fourth-year research study (Maleka, 2019). The previous research study was conducted with the same TBI population but different participants and focused on describing their experiences of living with

TBI and what perceptions they had regarding the events that might have led to TBI as influenced by their African cultural beliefs.

The researcher is fluent in English, Sesotho, Sepedi, Setswana, isiZulu, and isiXhosa and comes from a Sepedi cultural background in Limpopo. The researcher's entire family has strong beliefs in ancestors as well as in God. A sudden illness or disability in the researcher's family is not usually accepted as just any other illness. A traditional healer would be consulted to ensure that the family is not cursed or that it is the ancestors' way of communicating a message to the family, such as them not being pleased. As such the illness or disability presents itself as a form of punishment. On the other hand, an illness or disability may be perceived as punishment from God for sinful and wrongful doings hence consultation with a priest, to reverse the sin, would be vital.

Furthermore, the researcher has been exposed to people from different cultures, in Limpopo as well as in the researcher's community where she currently lives, that hold similar beliefs in ancestors and in God and attribute their injuries to witchcraft or to not pleasing their ancestors. Hence, they are getting punished and would consult a traditional healer or a priest to receive their healing. However, the researcher acknowledges that not all people hold beliefs in ancestors or even in God, yet many do and this impacts on our understanding of people with TBI's experiences and the ways in which they can be engaged in therapy.

1.8 Definition of Terminology

Traumatic Brain Injury (TBI): Traumatic Brain Injury is a change in the function of the brain (Maasdorp et al., 2020; Malec et al., 2017) presenting as altered level of consciousness, confusion, sensory and motor neuron neurological deficit (Barman et al., 2016) that results from a penetrating (open head) or blunt (closed head) force to the head (Maasdorp et al., 2020; Malec et al., 2017).

Holistic treatment: Refers to the treatment of the whole person, taking into consideration mental and social factors rather than focusing on the symptoms of a disease (Sarajuuri et al., 2018).

Post-acute phase: A phase where a patient receives a variety of medical facilities that support sustained recovery from an illness or disability (Burke et al., 2017).

Biopsychosocial model: A model that suggests that to fully comprehend a person's medical condition, it is essential to consider not only biological factors but also psychological and social factors (Bolton & Gillett, 2019).

Sangomas: A healer that diagnoses, prescribes and performs rituals to heal people physically, mentally, emotionally, or spiritually (Bila & Carbonatto, 2022)

Ukugcatshwa: The act of cutting someone with a razor that has *muthi* (Ngwenya, 2019).

Muthi: A traditional medicine prescribed by a *sangoma*, an *inyanga* or a herbal healer (Ngwenya, 2019).

Ukupeita/Ukuchatha: A method of clearing out the colon using an injection of fluid (loosening impacted bowels to be able to poop) (Nawe, 2021).

Ukugabha: The act of forcefully expelling the stomach's contents out of the mouth (Nawe, 2021).

1.9 Outline of Chapters

The dissertation comprises 6 chapters which are organised as follows:

Chapter 1: The first chapter introduces the study and the rationale for conducting the study. In this chapter, the researcher discussed the aims of the study being an investigation into the pathways of care followed by persons with TBI in the post-acute phase as well as the impact that COVID-19 may have had on support and care-seeking. The researcher also discussed the origin and application of the theoretical framework as well as the research site and area/region where the study took place. Moreover, in this chapter, the importance of offering support to persons with TBI and the different sources of support based on various factors was highlighted.

Chapter 2: In the second chapter, the researcher reviewed the literature on the definition of TBI and the prevalence and incidence of TBI both locally and globally. The researcher also reviewed literature on the consequences of TBI such as impairments resulting from TBI, for example impairments in speech, mobility, cognition, emotions, and vision. Moreover, the classification of TBI was also discussed into the different categories being "mild, moderate, and severe, using the Glasgow Coma Scale (GCS)" (Hawryluk & Manley, 2015, p.17). As well as the various sources of support that persons with TBI sought post hospitalisation. Also, the researcher looked at COVID-19 and the effect that the pandemic had on care-seeking. In addition, previous methods used to study TBI as well as the need for the decolonization of research methods in studying TBI was also discussed in the literature review.

Chapter 3: The third chapter of the study focuses on the methodology. The research methodology chapter also discussed the research paradigm, the qualitative research design, the research site, and its location as well as participant demographics. A table on inclusion and exclusion criteria is also included in this chapter. Moreover, the research outlines all the data collection procedures as well as the data collection instruments used. The data analysis methods used in the study are also discussed. Additionally, the researcher highlighted the ethical considerations for the study being informed consent, autonomy, non-maleficence, justice, beneficence as well as confidentially and anonymity.

Chapter 4: The fourth chapter outlined and described the results of the study where the researcher discussed the findings obtained from the interviews conducted as well as direct quotations obtained from the participants. The results of the study were presented in relation to the themes and subthemes that emerged in the study. The researcher presented the objective on COVID-19 in all the themes and subthemes that emerged, as this objective influenced most of the participants' responses. Lastly, in this chapter, the researcher also included figures on care and support pathways post discharge as well as a decision-making model indicating the influence on the participants' decision to seek care from different sources.

Chapter 5: The fifth chapter focused on a detailed discussion of the results in relation to the theoretical framework and the literature in the field. In this chapter, the researcher provided an in-depth discussion on the influence of biological, psychological, and social factors on the care-seeking behaviours of persons with TBI. This chapter also outlined how the different factors impacted the choices of sources of support, to provide the person with TBI with optimal health outcomes.

Chapter 6: The sixth chapter provided a conclusion of the entire study and the implications thereof. In this chapter, the researcher provided an overview of the aims of the study as well as a summary of the research findings. The researcher also discussed the implications for research and practice, for instance the researcher provided an overview of which social factors impact help-seeking behaviours and the decolonisation of research methods in studying TBI. This chapter also included the strengths and limitations of the study.

1.10 Conclusion

This chapter situated and introduced the research by giving the background to the problem before focusing on the research problem. After stating the research problem, attention shifted to the purpose and rationale of the research before stating the research questions and

the research objectives. The theoretical framework was outlined before the main terms that are used in the research were conceptualised. The research dissertation format was then given. Chapter 2 below focuses on reviewing the literature as well as a detailed discussion on the decolonisation of research methods used to study TBI and the impact that COVID-19 has had on access to health care.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

In terms of causes and prevalence, this chapter highlight the range of factors that can lead to TBI, such as falls, assaults, and road traffic accidents. The prevalence of TBI is also explored, with statistics showing that it is a significant public health concern globally.

Various forms of care for persons with TBI are discussed, including acute care, rehabilitation, and long-term care. The chapter also highlights the importance of psychological and emotional support for persons with TBI and their families.

Reflections on previous methods used to study TBI are discussed, with an emphasis on the need to adopt a more inclusive and culturally sensitive approach to research. The importance of decolonising research methods in studying TBI is also highlighted, to recognise and incorporate the perspectives of diverse communities affected by TBI.

The chapter also explores the impact of the COVID-19 pandemic on access to healthcare for persons with TBI, with a focus on the challenges faced by vulnerable communities and the need for innovative approaches to care during the pandemic.

2.2 Traumatic Brain Injury

TBI is an acquired injury to the brain that is caused by an outer force applied to the head leading to psychosocial impairment as well as deficits in daily functioning (Libeson et al., 2018; Malec et al., 2017; Maasdorp et al., 2020). TBI can lead to impairments in cognition, behaviour, physical function, language, and emotional changes (Mbakile-Mahlanza et al., 2017). A brain injury can either be diffuse, meaning that it is caused by acceleration and/or deceleration forces or it could be focal, meaning that only a certain part of the brain would have sustained a damage. A diffuse type of injury is a closed head injury, that is a brain injury sustained due to a blow to the head or rapid acceleration/deceleration of the head, for instance, a car accident or a fall; and a focal type of injury is an open head injury which is due to the penetration of a foreign body to the skull such as a knife or a gunshot wound (Saban et al., 2014).

2.3 The causes and prevalence of traumatic brain injury

TBI is seen as the foremost cause of disability and death globally (Nguyen et al., 2016). Road traffic accidents and falls are the leading causes of TBI in the United States of America (USA) (Nguyen et al., 2016). Also, in the African context a tenth of deaths is secondary to

motor vehicle injury and violence (Wonga et al., 2015). Similarly, in Europe, the leading causes of TBI are road traffic collisions, and falls (Brazinova et al., 2021). Each year, more than 10 million people worldwide suffer from TBI (Clasby et al., 2018).

While violence and industrial accidents account for a significant number of TBIs, road traffic accidents are by far the largest contributor, estimated to contribute to 60% of the total TBI burden (Dunne et al., 2020). Moreover, road traffic accidents account for 2.5% of deaths worldwide, and the World Health Organization (WHO) predicts that "by 2030, road traffic accidents will become the seventh leading cause of death, with an increase from 2.5% in 2015 to 2.6% in 2030 of total world deaths" (Dunne et al., 2020, p.287).

In a study conducted by Nguyen et al. (2016), in the USA, it was revealed that approximately 1.7 billion TBIs occur every year and these are related to 30.5% of injury related deaths. In their study, they conducted a systemic review and "meta-analysis of 15 studies on the prevalence of TBI in the adult population, which reported that 12% of adults in developed countries had a history of TBI" (Nguyen et al., 2016, p.775). This study further revealed that the more common degree of TBI in USA is a mild than moderate or severe TBI and that the incidence of TBI is much higher in males at the lower extremes of age (Nguyen et al., 2016).

Brazinova et al. (2021) conducted a review "to determine the incidence, mortality, age, and sex distributions of TBI in Europe along with severity" (p.1411). The study revealed that there are variations in TBI incidence and mortality rates among different countries and populations. Incidence rates for all ages, sexes, and "TBI severities ranged from 47.3 per 100,000 to 694 per 100,000 population per year, and from 83.3 per 100,000 to 849 per 100,000 population per year. Meanwhile, mortality rates ranged from 9 to 28.10 per 100,000 population per year and from 3.3 to 24.4 per 100,000 population per year" (Brazinova et al., 2021, p.1411). Although there is a scarcity of studies that address the incidence of TBI in the South African context, "an incidence of 316 per 100 000 per year has been reported recently" (Eaton et al., 2017, p.650). In previous years, statistics for TBI in South Africa were found to be three times higher than those of developed countries such as the USA.

In a study conducted in 2010 in Pietermaritzburg, the spectrum of head injuries at a regional hospital for patients aged between 8 and 78-years-old revealed that the leading causes of TBI included interpersonal violence (41%) as well as motor vehicle accidents (28%) (Alexander et al., 2010). In 2015, a study conducted in Bloemfontein, South Africa, found that

injury-related mortality and morbidity rates in the country were alarmingly high, largely due to violence and road traffic accidents.

The study revealed that the rate of road traffic accidents in South Africa was up to 2.5 times higher than the global average (Rossouw, 2015). Additionally, the study found that cities in developing countries, such as Johannesburg in South Africa, Sau Paulo in Brazil, and particularly Nwewi in Nigeria, had very high rates of TBI incidence (Rossouw, 2015). These high rates were attributed to post-apartheid and social issues, such as unemployment, poverty, crime, and substance abuse, which were identified as contributing factors to the high rates of accidents and interpersonal violence in South Africa (Rossouw, 2015).

A more recent study in Sub-Saharan Africa by Eaton et al. (2017) revealed that the likelihood of mortality in TBI patients in low to middle-income countries, including those in the Sub-Saharan Africa region, is more than twice that of patients in high-income countries. The main causes of TBI in these areas are violence and road traffic accidents, which are associated with high mortality rates (Dunne et al., 2020). This can be attributed to the lower level of acute healthcare provision in these areas, as well as a lack of access to prevailing healthcare systems (Dunne et al., 2020).

The incidence of TBI "ranges between 150 and 316 cases per 100,000 inhabitants per year in the low to middle income countries" (Eaton et al., 2017, p. 650). Also, the growing incidence of deaths due to TBI is caused by a mixture of urbanization, accessibility to affordable cars and motorbikes, as well as an increase in the geriatrics population in the absence of a well-established health care system (Eaton et al., 2017; Wong et al., 2015). In addition, it is important to highlight that the epidemiology of TBI is changing worldwide and TBI remains a rising health concern, particularly in the low to middle income countries (Eaton et al., 2017).

2.4 Classification and consequences of TBI

The classification of a brain injury is essential for the diagnosis and effective treatment of related symptoms (Hawryluk & Manley, 2015). The classification of TBI is split into a closed (diffuse) and penetrating (focal) head injury. Brain injuries can also be classified into mild, moderate, and severe categories using the Glasgow Coma Scale (GCS) (Hawryluk & Manley, 2015). The GCS is a system that is used to classify TBI severity. The scale is used to assess the gravity of the brain injury based on three behavioural characteristics being motor movement, verbal performance as well as eye opening (Maasdorp et al., 2020; Savitsky et al., 2016). The scale also aims to grade an individual's level of consciousness on a scale of 3 – 15,

for example a brain injury with a GCS of 13-15 is mild, a GCS of 9 – 13 is moderate and a GCS of 3-8 is severe (Andriessen et al., 2011; Barman et al., 2016; Maasdorp et al., 2020; Savitsky et al., 2016).

TBI may result in chronic disability and may significantly influence an individual's life, in terms of cognitive, behavioural, psychosocial, physical factors, and vocational issues (Barman, et al., 2016). Impairments resulting from TBI include verbal communication difficulties, neuromotor impairments as well as cognitive impairments such as memory, attention, and concentration, information processing, planning as well as problem solving difficulties (Barman et al., 2016; Malec et al., 2017). In addition, TBI can also lead to behavioural and emotional difficulties and the person may not be able to function self-sufficiently or cope with daily functioning (Kreutzer et al., 2016). For instance, a person with a TBI may no longer be able to drive, work, integrate back into the community, and maintain overall quality of life. Moreover, the person with TBI goes through several adjustments in their everyday lives including psychosocial/emotional adjustments such as depression and anxieties (Webster & Taylor, 2015). Lastly, TBI can also result in swallowing difficulties at any of the stages of swallowing, oral phase, pharyngeal phase, and oesophageal phase (Bremare et al., 2016).

2.5 Support/care for persons with TBI

Outlined below are some of the more common sources of care and support followed by persons with TBI. Some persons with TBI may use a combination of sources depending on variables such as their impairments from the TBI, traditional beliefs, cultural contexts, access and individual choices and preferences.

2.5.1 Religious and spiritual spaces

"Religion is defined as the institutionalized and organized patterns of beliefs, morals, rituals, and social structures that people create to help fulfil their spiritual journey" (Claassens, et al., 2019, p.). There is rising evidence to suggest that an individual's inner world of beliefs, inspirations, and values plays a vital role in determining their ability to cope with life's misfortunes (Claassens et al., 2019). In a recent study by Lambert et al. (2020), "the treatment of mental illness in faith-based and traditional healing centres in Ghana, Africa was investigated" (p.3). The findings showed that faith-based centres are often the primary point of contact for individuals with mental illness in Ghana, utilizing Bible scriptures, fasting, and praying as part of their treatment approach. There is a growth in evidence to suggest that it is

an individual's internal beliefs, values, and inspiration that helps determine the process of coping with life's misfortunes (Lambert et al., 2020; Claassens et al., 2019).

Additionally, some studies have shown that religion and spirituality can also play a role in the coping and adjustment process for persons with TBI. For example, a study conducted by Perrin and colleagues (2011) found that spirituality was a key factor in the coping process for persons with TBI, providing a sense of meaning, purpose, and hope. Similarly, a study by Cullen and colleagues (2018) found that spiritual practices, such as prayer and meditation, were commonly used by persons with TBI to manage symptoms and improve well-being. These findings suggest that religion and spirituality can play an important role in the care and support of persons with TBI.

Subsequently, in a study conducted by Badu et al. (2019), they suggested that religion serves important functions for people who are ill as it provides people with a framework to make meaning of their illness and to further provide them with hope. The meaning people with disabilities attribute to the causes of their sudden misfortunes and symptoms has implications for care seeking and is facilitated by beliefs in spiritual and supernatural forces as the main causes of their injuries so the problem is often seen as needing a spiritual cure (Badu et al., 2019; Lambert et al., 2020) thus should be dealt with in a pastoral counselling context.

According to Fregh et al. (2019), spirituality, particularly the belief in God's will, can help many families positively accept an injury or illness. They may see it as a test of faith, a trial to be endured, or even as punishment for wrongdoing. Similarly, Zhang and Bennett (2018) suggested that families may turn to cultural or spiritual traditions to help them make sense of sudden injuries. Moreover, some churches would attribute causes of an illness to the work of Satan or demons, or because of personal sin (Lambert et al., 2020). Therefore, people would receive their healing if they deepened their faith in God. Therefore, some people who have suffered an illness have a strong belief in going to church to receive prayer and be relieved from their illness. Additionally, an affirming religious support system can be seen as playing a vital role not only in recovery but also in the prevention of illnesses (Kpobi et al., 2018, as cited in Lambert et al., 2020).

2.5.2 Community support and support groups

People with disabilities encounter various physical and attitudinal obstacles that limit their involvement in their communities (Grossman & Magaña, 2016). To enhance support for them, it is critical to gain a better understanding of how formal services and community-based

support systems provided by disability networks and wider community organizations can influence the quality and accessibility of support services (Grossman & Magaña, 2016). Chappell and Johannsmeier (2009) conducted a study that discovered that psychological services that are accessible to persons with disabilities are few and far between, with rehabilitation programmes frequently focusing exclusively on addressing their physical requirements. Chappell and Johannsmeier (2009) further presented that communities are essential in that they provide significant intervention entailing giving advice and counselling. Therefore, it can be said that communities are able to address a major gap with regards to the psychological needs of persons with disabilities.

According to Clasby et al. (2018), providing access to effective community-based rehabilitation services and treatment for persons with TBI can support long-term intensive care and recovery while promoting positive outcomes for their overall well-being. With regards to support groups, Worrall et al. (2018) presents that they have been used for many years as a means of providing an opportunity for persons with TBI to discuss issues and share knowledges and information. In their study, Worrall et al. (2018), aimed to investigate current research on the effectiveness of support groups for families and people who have experienced illness or disabilities themselves.

Their findings revealed that by being part of support groups, individuals with TBI had an increase in resilience and community assets and this facilitated participation in their communities and promoted social inclusion. Prior to joining support groups, these individuals often felt isolated and lacked hope (Worrall et al., 2018). The literature proves that support groups for people with disabilities (TBI) are efficient and have optimistic products. Support groups have been found to be an "effective modality of intervention to improve care, family, and patient functioning" (Worrall et al., 2018, p. 8).

2.5.3 Traditional healers

Regardless of the influence of Western cultures, the majority of indigenous people of Southern Africa hold on to their traditional cultural values (Lambert et al., 2020). According to a study conducted by Moshabela et al. (2017) in Eastern and Southern Africa, it was discovered that people with HIV often chose their primary interventionists, be it medical, faith-based leaders or traditional healers and the decision to uphold or change their source of care depended on their experience of enhancement in the status of their health. The same can be said about persons with TBIs, when a pathway of care that had been previously chosen fails,

they are more likely to change sources of care (Moshabela et al., 2017). The choice of care pathways depends on three aspects, the first being health beliefs, the second being whether they are more inclined towards medical, faith-based, or traditional sources of care, or the third being what they consider to be the cause of their disability, and this influences their preferred source of care (Moshabela, et al., 2017).

Traditional healing cultural heritages remain the realities people have come to understand and embrace. Traditional healing practices have existed in many or most cultures since their beginnings as a culture (Moshabela et al., 2017). Traditional healing practices in Southern Africa have roots dating back to the foundations of their cultures. In this regard, traditional treatment appeals to many patients largely because traditional healing practices are linked to African beliefs in ancestors (Lambert et al., 2020). In a study conducted by Van der Merwe (2019), it is revealed that counselling and spiritual help given by traditional healers is important in dealing with patients with disabilities (in this case living with TBI). From the moment that a person sustains a brain injury until the time they learn to adjust to their new way of living, there is a need for psycho-social support for that person (Tramonti et al., 2015).

From the foregoing discussion it follows that there is a need to consider the contexts of counselling and the people for whom counselling is provided, to be able to comprehend the support required and valued by persons with disabilities. Accordingly, when providing care cross-culturally, health care providers should avoid being seen as demeaning African cultural values but explore and acknowledge their own prejudices, stereotypes, and cultural assumptions (Van der Merwe, 2019). Thus, traditional healers are seen as competent and sincere within their communities and are the first (and sometimes only) resource to which many people turn for their healthcare and psychological/emotional needs (Lambert et al., 2020).

2.5.4 Western practitioners

Regardless of severity, an acquired injury can disrupt normal life, as the person with a TBI is challenged by a fundamentally new and different set of conditions, which may intensely change preceding family, professional, and social roles (Liu et al., 2017). During sudden and drastic changes, people may turn to health professionals and institutions with the expectation that the condition can be reversed or transformed. Consequently, there is a growing recognition that counselling is an important component of a rehabilitation treatment program for survivors of TBI. Therefore, it is recognised that psychotherapists have a role in treating an increasing number of TBI victims (Liu et al., 2017).

In a study conducted by Aragão et al. (2014), they investigated psychotherapy as a medium of support for physically disabled patients. It was revealed that healthcare interventions are increasingly tailored to help each patient achieve their maximum recovery potential. This is particularly important in cases of TBI, where the spectrum of lesions and resulting disabilities is wide-ranging, and each person has unique premorbid and psychosocial circumstances. As a result, rehabilitation must be individualized, holistic, and focused on the long-term needs of the survivor and their family (Aragão et al., 2014; Khan et al., 2013).

As there is a long-time frame for improvement, endurance of care is one of the most significant objectives in dealing with a person with TBI. Thus, the rehabilitation of TBI is best accomplished by the involvement of a multidisciplinary team of healthcare professionals, namely rehabilitation health professionals such as occupational therapist, physiotherapist, speech pathologist, social worker as well as neuropsychologist or clinical psychologist and vocational rehabilitation counsellors (Khan et al., 2013). In the post-acute phase, it is the role of these health professionals to help persons with TBI to return to maximum independence and participation in the community whilst incorporating family support, education, and counselling for a prolonged period (Liu et al., 2017). Hence, psychotherapy, counselling, and rehabilitation are essential in providing support for the person with TBI to address the consequences of TBI.

Additionally, to enhance outcomes during recovery, rehabilitation services tailored to the needs of persons with TBI, along with community-based non-health services, are essential. It is important that both the person with TBI and their social support networks have access to rehabilitation services throughout the entire path of recovery, which can last for a long time after the injury (Khan et al., 2013).

2.5.5 Peer support and family support

Peer support and interaction can help individuals with disabilities refine their social skills, build relationships, and learn social norms. Which ultimately increases their self-confidence and ability to succeed in their societies (Carter & Hughes, 2005, as cited in Shippy, 2015). Providing opportunities for individuals with disabilities to interact with others can increase their self-esteem and ability to succeed in society. Peer interaction has been shown to have a permanent, positive, and life-changing impact on individuals with disabilities (Shippy, 2015). Shippy (2015) conducted a study which noted that peer support can be one of the most effective resources for enabling individuals with disabilities to succeed. Furthermore, peer

support can help them to cultivate personal traits such as flexibility, patience, and an appreciation of diversity (Shippy, 2015).

Globally, members of the family are a principal, and frequent source of support for people with disabilities (Grossman & Magaña, 2016). Family members play a significant role in assisting with activities that encourage living and integration across a person's life span (Grossman & Magaña, 2016). As adults acquire impairments in mid-and late life, family dynamics undergo changes as spouses, partners, and family members renegotiate relationship boundaries within the caregiver role. In this context, families become an essential source of assistance, helping individuals lead meaningful lives within the community. Grossman and Magaña's (2016) study summarizes and "evaluates literature on the care, support, and services provided by family members. Their study found that a combination of sociocultural and economic factors makes families a more frequent source of care in the recovery from TBI for African Americans and Latinos" (Grossman and Magaña, 2016, p.239)

It is essential to note that family caregivers' provision of care, support, and services can significantly impact outcomes for persons with TBI, including "community participation, employment, health and wellness, and independent living" (Tam et al., 2015, p.3). As such, family caregivers play a crucial role in managing challenging behaviours after TBI (Tam et al., 2015). Tam et al. (2015) identified these challenging behaviours as aggression, absconding, inappropriate sexual and social behaviours, lack of initiation, and perseveration. While rehabilitation services are crucial in dealing with behavioural problems during the initial stages following TBI, families usually take on the role of primary support for dealing with challenging behaviours once the individual returns to living in the community. Therefore, "family caregivers are essential in providing ongoing support for persons with TBI, including monitoring and supervision, physical assistance, and assistance with activities of daily living" (Malec et al, 2017, p.1236).

By comprehending the needs of persons with TBI, the multiple sources of care and support mentioned above can promote feelings of empowerment (Coco et al., 2011; Sigurdardottir et al., 2015), thereby lessening the sense of burden experienced by persons with TBIs (Sakanashi & Fujita, 2017).

2.6 The impact of COVID–19 on access to healthcare

Coronavirus disease (COVID-19) is an infectious disease caused by the SARS-CoV-2 virus. The initial outbreak of the virus was reported in Wuhan, China, in December 2019, and

since then, the disease has rapidly spread worldwide. COVID-19 is “highly contagious and can spread during the incubation period, making it challenging to identify suspected cases without clinical symptoms and epidemiological history” (Mbunge, 2020, p.1809).

In South Africa, the first COVID-19 cases were reported to be from nine adults on the 29th of February 2020 (Mbunge, 2020) who were later confirmed COVID-19 positive. The repercussions of these cases prompted the President of the Republic of South Africa, Mr. Cyril Ramaphosa, to declare a national state of disaster to mitigate the potential spread and impact of the COVID-19 pandemic. With increasing COVID-19 cases, the authorities and health system in South Africa executed drastic measures. These measures included the national total lockdown, travelling restrictions, bans on large gatherings (music, sports, religious and other social gatherings) as well as the prohibition of selling alcohol and cigarettes. Moreover, campaigns for practicing social distancing and good hygiene, implementation of curfew and staying at home were implemented (Mbunge, 2020; Wilkie et al., 2021).

The COVID-19 pandemic’s far-reaching effects have complicated the health service landscape in South Africa (van Staden et al., 2022). The response to the COVID-19 pandemic in South Africa has had both direct and indirect impacts on support structures. Specifically, “it has shifted healthcare resources towards combatting COVID-19, exacerbated or introduced additional barriers to healthcare and limited access to available support structures” (van Staden, et al., 2022, p.2). Moreover, COVID-19 had many effects including “increased mortality rate and deaths, mental health and substance abuse, closure of schools and universities, increasing cases of gender-based violence, increased social unrest and demonstration, a sudden change of lifestyles and reduced physical activity levels” (Mbunge, 2020, p.1810) these significantly changed people’s lives.

The increasing infections, unemployment and fatality rates, financial constraints, lockdowns, and restrictions on movement caused by the virus changed daily living and significantly brought on mental health problems (Mbunge 2020; Wilkie, et al., 2021). The consequences of the responses to the virus, as well as the financial implications, have affected the ability to access services. Headway conducted a survey for more than 1000 survivors of brain injury and their families during the COVID-19 period and 57% of them reported inability to access rehabilitation services and 42% reported that rehabilitation was negatively affected (Tyerman, 2020).

Therefore, the restructuring of healthcare services, linked to COVID-19, has disrupted services for vulnerable groups, such as persons with TBIs. Persons with TBI who needed to access support services post-hospitalisation were largely affected by lockdown and the restrictions that followed. Persons with TBI were not able to attend therapy to help alleviate the consequences of their TBIs. They were faced with limited movement and unavailability of transportation to clinics and hospitals, and this reduced out-patient services.

The pandemic also had a huge knock-on the global economy, resulting in loss of employment and reduced incomes for people who were employed. Further increasing poverty in developing countries (EL-Chaarani, 2021). The economic fallout from COVID-19 resulted in lower incomes and increased unemployment rates for the general population (EL-Chaarani, 2021). The poverty level has amplified, and the socio-economic conditions have gotten worse largely in the poor regions. In such circumstances of instability, most businesses faced financial issues therefore unable to pay their financial dues such as wages and people's salaries (EL-Chaarani, 2021). Without employment and any source of income, the public is not able to sustain their livelihoods and spend on daily expenses.

Subsequently, the spread of the pandemic has had weighty consequences on food security and food supply chains, this disruption has a possibility of resulting in adverse consequences for people's health and overall nutrition (High Level Panel of Experts (HLPE), 2020). This has had profound implications on food security and nutrition (HLPE, 2020). The ongoing crisis has had an impact on food systems and has threatened access to food through various dynamics. Along with offering a safe space to share life's transitions and express one's feelings and emotions, support groups that persons with TBI attend also offer food packages (Worrall et al., 2018). However, with the pandemic and shortages of food supply this meant little to no provision of food for the vulnerable populations and for persons with TBIs (Kakaei at al., 2022). Many people were already suffering from poverty and hunger before the virus and now the combined effects of COVID-19 on food supply could disrupt the functioning of food systems (HLPE, 2020). This disruption has a possibility of resulting in unfavourable consequences for people's health and overall nutrition. In South Africa, the continued restrictions on travelling, lockdowns, and increase in poverty without sustainable COVID-19 relief food aid, has led to social unrest and confrontation due to lack of food supply (Mbunge, 2020).

The COVID-19 pandemic has also had a significant impact on the availability and accessibility of healthcare services for persons with TBI. Due to the increased demand for healthcare resources to manage COVID-19, there may be a shortage of healthcare professionals and equipment available to provide adequate care for persons with TBI. In addition, due to social distancing regulations and lockdown measures, access to healthcare facilities may be limited, resulting in delayed or postponed care. These factors may have a detrimental effect on the quality of care and recovery outcomes for persons with TBI.

In addition, the COVID-19 pandemic has influenced general mental health and has been associated with psychiatric complications (Vindegaard & Benros, 2020). In a study conducted by Zhang et al., (2020a), it was found that depression, stress, and anxiety rates were higher during the pandemic. This is also particularly true for persons with TBI. Persons with TBI are faced with emotional challenges as a result of their brain injuries. Likewise, not being able to attend support services that help them overcome these emotional challenges led to further depression, fear, stress, and anxiety (Yao et al., 2020). Furthermore, there were differential levels of psychological distress in people infected with COVID-19 living under quarantine as well as the public. The Headway survey (Tyerman, 2020) reported that 65% of persons with acquired brain injuries reported feeling isolated, fear for the future, and increased anxiety due to lockdown and 60% of them stated that this had an undesirable effect on their overall mental health. The susceptibility to mental distress across populations during the COVID-19 pandemic could be attributed to a variety of factors such as "gender, social support, specific experience with the COVID-19 infection, length of isolation, and amount of exposure to the media" (Brooks et al., 2020, as cited in Zhang et al., 2020, p.49).

In conclusion, the pandemic has had a major impact on the provision of services for people, especially for the vulnerable populations that relied on support services during this time. During the COVID-19 epidemic, persons with TBI were not able to access rehabilitation services, they had shortages of food, lived with emotional difficulties with no availability of platforms to share emotional experiences with other survivors of TBI. This era of the virus presented barriers in accessing timely health services and had a great consequence on their wellbeing and overall progress and outcome (Yao et al., 2020).

2.7 The need to decolonise research methods in studying TBI

A decolonising research methodology "is an approach that is used to challenge the Eurocentric research methods that undermine the local knowledge and experiences of the

marginalised population groups" (Barnes & Siswana, 2018, p.298; Keikelame & Swartz, 2019, p.2). Research conducted with local people with TBI has been largely confined to methods from the global North, in which procedures in the research do not consider participants' indigenous worldviews, the participants' cultural beliefs and values, languages and interpreters, elements of translation, and transcription (Keikelame & Swartz, 2019). In some instances, procedures in research also do not consider the full involvement of the participants from the identification of the research problem, the development of the research proposal, and the design and methods used (data collection, data analysis, sampling procedures) (Keikelame & Swartz, 2019).

Also, there have been numerous ethical issues following previous research with people with TBI, such as issues of trust, obtaining consent, justice, beneficence, and power dynamics (Keikelame & Swartz, 2019). Keikelame and Swartz (2019) propose that trust is another important aspect in research. Building trust between the researcher and the study population in a decolonising research process is crucial and should be founded on values of respect, exchange, teamwork, and collaboration. Consequently, ongoing engagement with study participants can enable researchers to acquire a deeper comprehension of the culture and history of the population being studied, foster trusting relationships, and promote the concept of research 'with' the researched rather than research 'on' them.

In looking at a previous study for instance, Hunt et al. (2021) conducted a study in Kenya, where they aimed to investigate whether "parenting stress experienced by caregivers in a household with a disabled member is greater when the disabled member is the caregiver, or the child, and how much of these respective relationships is explained by poverty" (p.1). They collected cross-sectional data with the use of a demographic survey, questions on adult disability and on child disability as well as the Parenting Stress Index-Short Form. Their data were collected in the caregiver's preferred languages being Luo and Swahili (Hunt et al., 2021). The results revealed that parental stress and poverty was higher in households with a disabled member than households without a disabled member. This study was conducted on the local population in Kenya and was conducted in the person's preferred languages. However, this study only looked at caregiver accounts or responses and no accounts by the individual with the disability was enforced. Which is contrary to what the decolonisation approach is about and essentially people with disabilities' views were disregarded in this case.

In a study conducted in Australia, Libeson et al. (2018), investigated the experiences of returning to work in people with TBI. They conducted semi-structured interviews with the use of open-ended questions to allow the participants to talk freely about their experiences which were transcribed verbatim. The study highlighted the significance of non-injury related factors, such as family and employer support, that could facilitate successful return to work. It also highlighted that injury related factors were found to hinder return to work and this information can inform the development of effective return to work programmes and further improve employment outcomes following TBI (Libeson et al., 2018). The study does not indicate whether programmes were thus developed to improve the participants' outcomes and ethical issues were not addressed in the study. Which can be seen as a limitation in decolonising research methodologies.

Webster and Balchin (2015), conducted a study in Cape Town, South Africa, looking at healthcare challenges and the number of rehabilitation services available for people with TBI in the post-acute stage. They conducted interviews with families of TBI survivors and the survivors themselves highlighting their experiences of living with TBI and caring for persons with TBI (Webster & Balchin, 2015). It has been uncovered that in South Africa, insufficient information and support have placed a significant care burden on family members and community care workers. Hence, the experiences of TBI survivors and their family members have been instrumental in informing the development of coping strategies in conjunction with counselling and support group processes (Webster & Balchin, 2015).

Although their study encourages the engagement of the participants in the study as well as the improvement of the quality of life of people with TBI and their caregivers in Cape Town, it is not driven by cultural values and a language relevant to the participants. The participants in Webster and Balchin (2015) study were interviewed predominantly in their home language though there was code-switching between the home language (IsiZulu and Sepedi) and English. The different cultures from which they come were not considered, in terms of investigating how their cultures may have influenced their experiences with TBI or even how healthcare challenges were exacerbated by their cultural values and beliefs. The study also aims to advocate for more rehabilitation services being made available to the individuals, however it does not consider other more culturally appropriate forms of support or care that this group of people may turn to cope with their sudden realities.

However, in more recent years researchers have begun to make research more relevant to the population being studied. Mbakile-Mahlanza et al. (2017) conducted a study in Botswana aimed to investigate caregiving for people with TBI. The researchers conducted interviews with participants with moderate to severe TBIs and their caregivers. The interviews were not conducted in the native language of the Batswana people. Data were collected and transcribed in English, which is one limitation of this study conducted amongst people in the African context. This is a limitation of the study because when transcribing a language into English, the researchers may have lost the true reflection of their participants' utterances as well as the emotions behind everything that the participants may have said in Setswana. There is also no direct translation of native languages into English, therefore by restructuring or rephrasing what had been said, researchers risk losing the true meaning of native languages. Translation is also culture related and can be difficult because of cultural differences. The words used often imitate the culture and people that utilise them. Some words and concepts are usual in one language but in another language, researchers may require a lot of effort to find an equivalent (Dlamini & Dlamini, 2021).

Furthermore, in the results of Mbakile-Mahlanza et al. (2017)'s study it was revealed that caregivers of people with TBI reported receiving limited information on TBI and management methods. They also reported high demands placed on them with little support from the healthcare system and the wider community (Mbakile-Mahlanza et al., 2017). Caregivers in this study were devoted to their faith and beliefs in God to alleviate the burden and distress placed on them. By reporting on this point, the researchers in this study took into consideration the different worldviews that indigenous Batswana people hold. Also, they continuously engaged with the participants to gain a deeper understanding of their cultural and religious beliefs which is an important aspect in the decolonisation of research procedures.

Mohatt et al. (2021) conducted a study in Colorado (USA), in which they examined processes used to identify techniques to enhance engagement with TBI survivors and caregivers. In the study, it was acknowledged that the patient experience is relevant to improving the development of interventions for people with TBI. This study acknowledges that research conducted on people with TBI needs to result in improved health outcomes of the people being researched by trying to find interventions that would be most relevant to them.

Furthermore, this study used community-based participatory research to improve research engagement with people with moderate to severe TBI and their caregivers (Mohatt, et

al., 2021) as a method of collecting the data to emphasize shared decision making between the researchers and the researched. The participants were included in all phases of the study to support their participation and to collaboratively learn from one another ways to improve patient engagement for future endeavours. Moreover, during the data collection procedure, semi structured interviews were conducted with participants living with moderate to severe TBI and their caregivers. The interviews were conducted in English by two researchers, one taking notes and one being the interviewer. Both the interviewer and the note taker took detailed notes and combined their notes in a single transcript for accuracy and completeness (Mohatt et al., 2021), this is important as it ensured overall rigour of their study.

In summary, procedures in research have been shown to not always consider participants' local worldviews, their cultural beliefs, and values as well as languages. There have been several ethical issues following previous research on people with TBI which includes issues of trust, obtaining consent, justice, beneficence, and power dynamics (Keikelame & Swartz, 2019) and participants not being included in all phases of the study in order to support their participation. Moreover, previous studies have focused a lot on research about the provision of healthcare, for instance, for people with disability but there is quite a limited amount of research on the provision of healthcare for people with cognitive-communicative disorders like TBI. Take authors like Tshaka et al. (2023) for instance, they looked at the difficulties that persons with disabilities experience when accessing healthcare due to several environmental and personal barriers which led to non-use of such services (Tshaka, et al., 2023). Although their participants were interviewed in isiXhosa, they still translated their data to English which is a research method believed to undermine the local knowledge and experiences of the population studied (Barnes & Siswana, 2018; Keikelame & Swartz, 2019). Since meaning may change during translation, it may be preferable to present findings in the language in which data are elicited.

In addition, the researcher of this study, engaged with previous research conducted by researchers in the global South to note the methodologies used to study local populations. Researchers such as Ned and Lorenzo (2016) conducted a study that aimed to look at the "capacity of service providers in facilitating the participation of disabled youth in economic development opportunities" (Ned & Lorenzo, 2016, p.1). They conducted their interviews with service providers, persons with disabilities, and their families and translated and transcribed all isiXhosa interviews. Although they are researchers from the global South, in this study, they used accounts from all three groups of people being the service providers, persons with

disabilities and their families. Responses were not only by the persons with disabilities. The researchers also did not preserve the interviews in the source languages. Rather they translated it and transcribed the interviews in English.

On the other hand, Ned et al., (2022) conducted research focusing on the "challenges and opportunities of centring African voices in disability research" (Ned et al., 2022, p.1). These researchers suggest that reimagined disability studies depend on centring African experiences, voices, and knowledges. Their study advocates for the decolonisation of methods used by global North researchers on people with disabilities worldwide, that are mostly located in the global South (Greening, 2015, as cited in Ned et al., 2022). They are also arguing for a term they refer to as "African Renaissance" (Ned et al., 2022, p.3) which posits that when thinking about disability we need to not only focus on the historical and contemporary constructs of disability but think of the inclusion of people with disabilities where they can exist within society as worthy and valued human beings (Ned et al., 2022).

Grut et al. (2012) explored challenges faced by poor people with disabilities who live in rural areas in South Africa. They conducted interviews with people with disabilities, family members, and health personnel. They aimed to investigate how the difficulties experiences by people with disabilities may interact and influence access to and use of health services (Grut et al., 2012). The researchers used an interview guide from similar studies conducted in Kenya and adapted it to the South African setting. Adapting their interview guide to the South African context ensured that they made their research specific to a population they were studying. This forms part of the accommodations they had to make to include their global South participants in research. This study was conducted in the participants' mother tongue but later translated to English. The researchers applied colonial methods of conducting research. Their findings show that "access to health services for people with disabilities who live in poor communities was influenced by multiple factors which unfold throughout the person's life course" (Grut et al., 2012, p.4). Similar to an interplay of factors that influence persons with TBIs' pathways of care.

The aim of this current study was to conduct a study not only amongst persons with a disability but specifically persons with TBI, presenting with cognitive-communicative difficulties, in the African context. According to Nhemachena et al., (2016), research conducted among local people in Africa has most of the time not resulted in improved health outcomes for the people who are being researched due to the use of Eurocentric methods that do not

magnify the importance of local worldviews. “African research is still largely dominated by epistemological and methodological frameworks that find their origins in the global North” (Nhemachena et al., 2016, p.16). Therefore, there is still a need for a series of contexts that could simplify the expansion of contextually applicable methods to research (Nhemachena et al., 2016). This is what the researcher of this current study aimed to tackle and to challenge throughout the entire research process.

2.8 Conclusion

In conclusion, based on the above literature, the researcher provided a thorough definition of what TBI is, followed by the causes and prevalence of TBI. The discussion then shifted to highlighting the classification of TBI as well as the different sources of support for persons with TBI. The researcher went on to outline how the COVID-19 pandemic impacted persons with TBIs’ access to healthcare services. The need to decolonise research methods was also emphasised, whereby the researcher stated the need for other researchers to start examining their own approaches throughout the research processes by looking at existing power dynamics, the study’s design, their interview questions, and data collection techniques used, as well as to start paying attention to their actual responses to participants’ comments. For example, researchers need to avoid the issue of finding local worldviews to be absurd because of having their own values and beliefs that overpower how information obtained from the researched (participants) is interpreted. With this current research, the researcher acknowledged the population being studied and that being of African descent, certain cultural and traditional worldviews regarding care seeking may be held based on historical experiences. Hence these beliefs were encouraged and were crucial in understanding what African people believed to be satisfactory sources of care or support that led to the desired improvement in their health status.

The following chapter details the methodology of the study. In the chapter, the research paradigm and the research design are outlined and discussed. The research questions, aims and objectives of the study are also delineated. Focus is also placed on rigour and trustworthiness and ethical considerations of the study.

CHAPTER 3: METHODOLOGY

3.1 Introduction

This chapter discusses the methodology that was employed in this study. The chapter focuses on the research paradigm before discussing the research design that was used in this study. The study site is also discussed. Focus then shifts to a discussion of the demographics of the research participants as well the rationale behind selection of participants. The data collection instruments that were used in the study are also discussed before a discussion of the ethical issues that guided this study.

3.2 Research Question

What care and support seeking pathways are followed by persons with post-acute traumatic brain injuries living in Soweto, Johannesburg?

3.3 Research Aim

To elicit responses from persons with TBI regarding the different support pathways that they followed and continue to follow during their journey of seeking care post hospitalisation.

3.4 Research Objectives

- To explore when, where and for what purpose, persons with TBI seek care and support as influenced by cultural, beliefs, contextual and linguistic variables.
- To explore how have impairment needs of persons with TBI influenced their care seeking and support pathways.
- To explore how the COVID-19 pandemic restrictions influenced care seeking behaviours and access to care and support.

3.5 Research paradigm

There are three main paradigms that researchers rely on: positivism, interpretivism, and pragmatism. According to Kamal (2019), a paradigm refers to a set of beliefs that focus on how problems arise, exist, and how researchers can study these problems to produce solutions. Every researcher has an explicit or implied perspective that guides how they approach research problems. These perspectives are centered on the nature of the social world and the way in which it can be studied. The study by Antwi and Hamza (2015) suggests that each paradigm has three important facets: ontology, epistemology, and axiology.

The main tenet of epistemology is the connection between the researcher and the nature of human knowledge and understanding. The questions that are at the centre of epistemology are: “What is the relationship between the knower and what is known? How do we know what we know? What counts as knowledge?” (Antwi & Hamza, 2015, p.219). On the other hand, ontology deals with the nature of reality and focuses on whether entities should be viewed as subjective or objective. Ontology therefore deals with how an individual makes sense of what constitutes reality or fact (Al-Saadi, 2014). Lastly, axiology deals with the role of values and the way they influence the process of creating knowledge (Biedenbach & Jacobsson, 2016). The research is based on the interpretivist paradigm which is suitable for qualitative research.

3.6 The Interpretivist paradigm

In this study, the interpretivist paradigm was selected because it recognises that knowledge is socially constructed, and that both the researcher and the participants are integral to the research process (Riyami, 2015). Interpretivists contend that knowledge is subjective. The interpretivist paradigm was chosen to undergird the research, given that it is amenable to the chosen qualitative research approach (Pulla & Carter, 2018). The qualitative approach allows the researcher to use data collection methods which include inter alia; semi and unstructured interviews, diaries, open ended questionnaires, and immersion.

Gemma (2018) states that interpretivism is primarily concerned with how people make sense of their lived experiences, issues, and phenomena. This approach emphasises the importance of understanding the subjective meanings that individuals ascribe to their experiences. Given that human and societal problems are complex and multifaceted, the interpretivist approach is often used in qualitative research to explore and capture the nuances and complexities of these issues. Unlike quantitative research, which prioritises objective and measurable data, interpretivism acknowledges that human experiences and behaviours are shaped by subjective interpretations and meanings.

The interpretivist approach recognises that each person and society in which they live are unique, and therefore, when studying them, the researcher should examine them based on their distinctiveness and circumstances. According to Saunder et al. (2012), qualitative research is challenging to generalize because of the unique social, political, economic, and cultural nuances that are specific to each research. However, the interpretivist approach is valuable because it enables a better understanding of how people create meaning in the context of their

lived circumstances. This understanding is essential for obtaining a more profound and nuanced understanding of the human condition.

The interpretivist epistemology posits that knowledge can only be understood in the context of the experiences of the participants involved in the research (Saunders et al., 2012). This is because knowledge is not something that is simply objective and measurable but is shaped by the subjective experiences of the participants (Creswell & Poth, 2018). The interpretivist approach recognises that the researcher is not an objective observer, but an active participant in the research process. As such, the researcher's own subjectivity and biases may influence the research outcomes (Kivunja & Kuyini, 2017). Therefore, the interpretivist approach emphasises reflexivity and encourages researchers to acknowledge their own values and biases, and how they might impact the research process and outcomes.

This paradigm was chosen for this study because it allowed for the collection of multiple views, providing a nuanced understanding of the events studied within the participants' community and lived circumstances using approaches like case studies. Semi-structured interviews were used to probe on issues related to values, biases, feelings, and insights. The data that was collected is therefore unbelievably valuable data and helped the researcher to gain insights into how persons with TBIs chose their pathways of care (Pham, 2018).

3.7 Research design

This study utilized an exploratory qualitative research design. Qualitative research involves the exploration of meanings and insights in each situation (Levitt et al., 2017). It encompasses a variety of data collection and analysis techniques that use purposive sampling and semi-structured, open-ended interviews (Gopaldas, 2016). Qualitative research is considered an effective model as it occurs in a normal location and allows the researcher to develop a level of detail from involvement in actual experiences (Creswell, 2009). Additionally, qualitative research is a multi-method and involves an interpretive, naturalistic approach to its subject matter (Denzin & Lincoln, 2005, as cited in Haradhan, 2018).

The researcher adopted a qualitative, cross-sectional design (Lincoln & Guba, 2018). A cross-sectional study is a type of research design in which data is collected from different individuals at a single point in time and is not collected repeatedly from the same subjects overtime, as with longitudinal studies (Thomas, 2022). For instance, the researcher aimed to investigate care-seeking pathways of persons with TBI in Soweto to gain an understanding of

the biological, psychological, and social factors that influence help-seeking from various sources and health outcomes associated with these factors. Therefore, a cross-sectional design provided the researcher with this required data.

The choice of the qualitative research design was that it is flexible and is a key component in developing effective health promotion strategies and interventions. Also, the researcher used a semi-structured interview approach. This is a data collection approach that is guided by a list of open-ended questions with follow-up questions that emerge from the dialogue between the interviewer and interviewees as well as probes and comments (DeJonckheere & Vaughn, 2019). The purpose of using semi-structured interviews for data collection is "to gather information from key informants who have personal experiences and beliefs related to a research topic of interest" (DeJonckheere & Vaughn, 2019, p.2). The use of semi-structured interviews was appropriate for this research because the researcher wanted to have an open-ended discussion with the participants on their pathways of care as well as go through predetermined interview questions with them.

In addition, for research to be meaningful and applicable to the local community involved in this research project, it should be guided by indigenous worldviews, cultural values, and a language that is relevant to the local group (Keikelame & Swartz, 2019). For the purpose of this research study, the researcher aimed to follow ways to decolonise the entire research process. By exploring a local perspective as well as establish how the research findings can be translated into actions that promote social justice as well as promote a culturally appropriate research practice. Also, the researcher valued the participants' cultural and traditional worldviews about the pathways of care they seek in the post-acute phase. These were quite central to the entire project and assist in the development of culturally appropriate services for persons with TBI in the African context.

In so doing, the researcher aimed to follow a research design and methodology that spoke to or was relevant to the population being studied (Laher & Kramer, 2019). Also, seeing as this research project involved people of the marginalised population groups, the researcher is fluent in the languages of the participants being isiZulu, isiXhosa, Sesotho, Sepedi, and Setswana and therefore interviewed them in their first languages and transcribed the data collected in those respective languages. Although the participants were interviewed in their home languages, some of them still chose to speak English or to code-switch. This highlighted decolonisation of research methods as it was valuable to give participants an option of language

and this was aided by the researcher speaking multiple languages. Moreover, the researcher took into consideration issues of language in research by using her own knowledge and fluency of the languages spoken by the participants. The researcher also gave the participants who have been historically excluded from research, a voice to speak about their help-seeking behaviours, regardless of them being considered unreliable sources of information (Ned et al., 2022). Including persons with TBI, with cognitive-communication difficulties, (not their caregivers) in research and giving them a voice is seen as a significant way that challenges Eurocentric methods to research (Ned et al., 2022).

Furthermore, the researcher did not rely on translated data which would have made the study contrary to the concept of decolonisation but used raw data and preserved the participants' direct quotations in the source languages. Essentially, translating the participants' spoken words into English would have resulted in the loss of this voice that the researcher aimed to preserve (Ned et al., 2022) and further losing the gist of what the participants had reported on, to a certain extent. In the same breath, the data obtained was first person narratives, the researcher did not rely on proxy accounts such as caregiver and healthcare provider accounts to speak on behalf of the persons with TBI, they were allowed to speak for themselves and that on its own agrees with the tenets of decolonisation.

This research also took into consideration issues of ethics, of religion, faith-based and traditional beliefs from the persons with TBI. By highlighting other sources of care that were followed based on African belief structures. These issues are of great importance to consider and are of special relevance to research conducted in the African context. The researcher acknowledged the importance of African perspectives on disability and support seeking as told by the participants themselves. This was essentially important as it informs culturally appropriate forms of support for persons with TBIs.

Subsequently, structures such as power dynamics, trust-building, cultural competency, respect for local cultural practices, recognition of individual and community assets, and ethical research practices are crucial considerations when conducting research among marginalized populations. These factors can significantly impact the research process and outcomes and must be taken into account to ensure that the research is conducted in an ethical and culturally appropriate manner (Mertens, 2014; Wallerstein & Duran, 2010; Keikelame & Swartz, 2019). Furthermore, to decolonise research, the researcher acknowledged that she is not the sole producer of knowledge but both the researcher and the researched make rightful and valuable

contributions to the entire research process. With this, the researcher aimed to reduce any acts of power that may be portrayed by the researcher on the population studied. For instance, the researcher assured the participants that they could be comfortable to express whatever opinions and views they may have had, as these are valued by the researcher and that they would be involved in checking the information they had provided to the researcher for accuracy and for them to recognise their role in this research project as important.

3.8 Research site

The participants were recruited from the Soweto Branch of Headway Gauteng. Soweto has a racial makeup of approximately 98.5% Black African, 1.0% Coloured and 0.1% Indian and White (City of Johannesburg, 2018). The population is predominantly black and the most common first language is isiZulu (37.1%) (City of Johannesburg, 2018). Other languages spoken in Soweto include IsiXhosa, Afrikaans, Sesotho, Setswana, English, Xitsonga, SiSwati, Tshivenda and IsiNdebele. Soweto was created in the 1930s during Apartheid, when black people were separated from white people leading to the creation of black townships. Soweto then became the largest township for black people in South Africa (City of Johannesburg, 2018).

The research site for this study, Headway Gauteng, is a registered non-profit organisation in Soweto, dedicated to providing support programmes for adults who have suffered TBI, as well as their families and caregivers. The fact that most members have sustained TBI from a range of causes, including motor vehicle accidents, sporting accidents and assaults, indicates that the organisation caters to a diverse group of people. Additionally, Headway Gauteng offers support for survivors of other acquired brain injuries such as stroke, further highlighting its commitment to providing comprehensive care. Headway Gauteng also offers various support programmes to persons with TBI (through strokes, tumours, or illness such as meningitis) and their families (Headway, n.d.).

Headway Gauteng offers a variety of services, including Headway Friendship Circle. This group consists of families from diverse cultural and socio-economic backgrounds, each with a loved one with a brain injury. In addition, Headway Gauteng provides counselling and support services that include face-to-face and telephonic counselling, as well as regular family support group meetings and caregiver workshops. Group therapy and activity programs are also available to provide injured members with a structured, productive day. These programs aim to provide stimulating and enjoyable activities and social skills practice.

Complimentary services are also available, such as social gatherings for families and assistance with community resources and referrals (Headway, n.d.). During the COVID-19 pandemic, these activities were put on hold as members attended sessions telephonically and they were slowly being brought back to the site in smaller groups to attend therapy sessions, mainly physiotherapy sessions/ Then they would receive food packs and leave for home to minimise the length of contact as much as possible as well as to adhere to the COVID-19 regulations put forth by the South African government.

3.9 Participants

Eleven participants were recruited from Headway. They consisted of two females and nine male adults who have experienced a TBI (see Table 3.2 for demographic details). The sample size of eleven participants was determined by the willingness of the members to participate in the study, the availability of participants who met the researcher's inclusion criteria (see Table 3.1 for participant selection criteria) as well as data saturation, which is explained in the data collection section below. Accessing the participants was also challenging as it coincided with the COVID-19 restrictions which were still in place at the time. The participants were only able to come to the site on specific days and times to maintain social distancing and limit crowded gatherings.

The researcher used pseudonyms to identify the participants. Given that confidentiality and anonymity are paramount in research, pseudonyms in qualitative research are important to consider and are an ethical requirement of research (Allen & Wiles, 2016). Pseudonyms are "self-chosen or participant approved" (Salmon, 2007, p.992, as cited in Allen & Wiles, 2016) and researchers may choose them based on gender, ethnicity, or age. The pseudonyms used for this research were determined by the researcher and were guided by the participants' ages, gender, and race.

For the purpose of this study, the researcher used a combination of purposive sampling and convenience sampling with maximum variation to recruit participants from Headway in investigating the help seeking pathways of persons with TBI in Soweto. That is, samples were selected to serve an investigative purpose rather than to be statistically representative of a population (Ritchie et al., 2003). Purposive sampling is the most common sampling technique and involves the identification and selection of people or groups of people that are particularly knowledgeable about a phenomenon of interest (Clark 2011, as cited in Palinkas, 2013). Within this form of sampling the researcher chose the sample (as determined by the inclusion criteria)

to best answer the research question and this also allowed for the selection of participants according to the shared common features that this study aimed to investigate. According to Palinkas et al. (2015), purposive sampling involves different subtypes that entail "selecting cases with maximum variation to document unique or diverse variations that have emerged in adapting to different conditions" (p.534). The purpose of this approach is to identify important common patterns that cut across these variations. Convenience sampling was also used in the study, this method of sampling was used to select the target population that met the researcher's inclusion criteria as well as the population of participants that were spatially situated in one site (Etikan et al., 2016).

Table 3.1: *Participant Selection Criteria*

Inclusion criteria	
Criteria	**Rationale**
All the participants were required to be over the age of 18.	Persons over the age of 18 are legally able to consent to participating in research. The South African Department of Health states that adolescents defined as "persons who have reached puberty, may consent unassisted to research so long as the research poses no more than minimal risk to the adolescent" (Zuch, et al., 2012).
The participants were required to be able to engage in a conversation with the researcher.	Communication difficulties have the potential to affect the person with TBI's everyday life and this can lead to reduced social contact and interaction (Ahmad, 2017). For the purpose of this research the participants needed to be able to converse, this is done to give the participants an opportunity to explain and make sense of their life experiences using their own words.

The participants were required to be isiZulu, isiXhosa, Sesotho, Sepedi, Setswana, or English speakers.	This is due to the proficiency of the researcher in these specific languages as well as some of the languages being common and easily understood in Soweto e.g., isiZulu and Sesotho (City of Johannesburg, 2018).
The participants were required to have been living with TBI for 2 years or more.	The number of years that they have been living with TBI suggests that they have some experience with TBI as they are past the acute stage and spontaneous recovery no longer happens after more than 2 years post TBI (Nudo, 2013).
The participants were required to have been diagnosed with TBI as a result of either a closed or open head injury.	The injuries needed to be as a result of motor vehicle accidents, pedestrian vehicle accidents, assaults, falls, or gunshot wounds to note possible variations in narratives. Also, these are the leading most common causes of TBI in South Africa (Chembeni & Nkomo, 2017) and this is related to the availability of such participants at the site. The manager at the site has also indicated that people with brain injuries come on specific days at the site therefore this will enable the researcher to know which participants have a closed and open head injury.
Exclusion criteria	
Participants who have severe communication and cognitive impairments as determined by current communication ability guided by the manager at Headway.	Participants with severe communication and severe cognitive impairments may not be able to use their higher-order functioning to mutually engage in meaningful conversation with the researcher given their underlying condition as such self-reporting, in this case,

	would not be suitable (Stocchetti & Zanier, 2016). The researcher aims to obtain this information from the research site manager and from observation of current communication ability of the participants.

3.10 Participant demographics

The participants in the study included nine males and two females. For most of the participants their highest level of education was high school and a few of them were unemployed before the TBI and are still unemployed even after the TBI. The length of time since their injuries ranged from 3 to 20 years ago and their ages ranged from 25 – 65 years. The participants had chronic impairments and none of the participants were diagnosed during the COVID-19 pandemic.

Table 3.2: *Demographic Details of Participants*

Participant no.	Age	Gender	Home Language	Language of Choice	Highest level of education	Employment status before and after TBI	Causes of TBI	Length of time since injury	Immediate support
1	29	Male	English	English	High School	Unemployed	Motor vehicle accident	11 years	Family
2	59	Male	isiZulu	IsiZulu	College	Criminal Investigating Department Police officer, Unemployed	Motor vehicle Accident	20 years	Family
3	49	Male	Sesotho	IsiZulu	High School	Handyman, Unemployed	Assault	4 years	Family
4	36	Male	Sepedi	Sepedi	High School	Mechanic, Unemployed	Pedestrian vehicle accident	9 years	Family
5	59	Male	Xitsonga	IsiZulu	High School	Taxi driver, Unemployed	Pedestrian Vehicle Accident	18 years	Headway
6	58	Male	isiZulu	IsiZulu	College	Salesman, Unemployed	Assault	6 years	Prophets
7	29	Female	Sepedi	Sepedi	High School	Unknown, Unemployed	Pedestrian Vehicle Accident	11 years	Family

8	32	Male	isiZulu	IsiZulu	College	Taxi driver, Unemployed	Assault	6 years	Rehab
9	65	Female	isiZulu	IsiZulu	High School	Unknown, Unemployed	Fall and hit the head	24 years	Family
10	32	Male	isiZulu	IsiZulu	High School	Unknown, Unemployed	Pedestrian Vehicle Accident	12 years	Family
11	25	Male	isiZulu	IsiZulu	High School	Unemployed	Pedestrian Vehicle Accident	5 years	Rehab

3.11 Data collection procedures

After permission was obtained, interviews were scheduled to take place at Headway Soweto. The site manager allowed the researcher to gain access to the research site. She then explained that due to the COVID-19 pandemic, members come on specific days and certain times. For instance, some of the participants came to the site on Tuesdays, Wednesdays, and some on Fridays from 11:00am. When all the members that were scheduled for a particular day arrived for group therapy sessions, the manager allowed the researcher to present the purpose of the research to them and to further explain what participation in the research study would entail. The study was also explained in depth using supportive or assistive techniques (APPENDIX F) such as the use of gestures, drawings, pictures and/or photos for participants who may have had language impairments. The manager also indicated to the members that the researcher would be stationed outside the therapy rooms, and they were free to come find out more about the research and indicate to the researcher whether they would be interested to participate or not, when they were finished with their group therapy sessions.

The interviews were conducted outside the therapy rooms, in the garden, when the other members had left. The researcher used guiding, semi-structured interview questions (APPENDIX D) in the sessions to gather first person narratives and accounts on help-seeking behaviours. Participants were allowed to use the languages that they were most comfortable with for the interviews. Participants' languages ranged from isiZulu, Sepedi, and English. The interviews were conducted on the 1st, 16th and 23rd of February 2022 at Headway in Soweto. Each interview lasted between 20 minutes and 30 minutes. The participants required a lot of probing upon being asked a question and were encouraged to add more detail to the information they provided. However, not all the participants were able to do this, which led to shorter interview sessions, but the essential information was obtained.

With semi-structured interviews, the participants have the freedom to respond to open-ended questions however they wish, and the researcher can probe for more responses if any further elaboration is needed (Tshaka, et al., 2023). During data collection, the researcher may have resonated with some of the things that the participants were saying based on prior knowledge and experiences. However, on some accounts the researcher did not share the same values or beliefs as the participants. This, however, did not influence the data collection process

or analysis of the data. The researcher did not impose own beliefs and worldviews on the participants, which is an important aspect of decolonisation.

The dates of the interviews were decided upon by the site manager and the members who agreed to participate. This was based on the availability of the participants and whether they had group sessions arranged on those specific days at Headway. Lastly, the researcher followed the questions on the interview schedule (APPENDIX D) to ensure that the interviews followed the same format for each of the participants. The researcher asked the participants to recall the sources of help and support they received post hospitalisation. Probing and prompts were used to encourage participants to elaborate on their responses and the interviews continued until saturation was reached. Data saturation is reached when "there is enough information to replicate the study when the ability to obtain additional new information has been attained, and when further coding is no longer feasible" (Fusch & Ness, 2015, p.1409). This was the case with this research study, no new information and codes were being obtained from the interviews therefore saturation was reached, and the interviews were concluded.

3.11.1 Working cross-linguistically and cross-culturally

As part of the decolonisation of research methods approach, the study participants were interviewed in their home languages. The researcher was proficient in all the participants' home languages. Eight participants were interviewed in isiZulu, one in English, and two in Sepedi to explore the support and care-seeking pathways they pursued. These included religious spaces, community, peers, family members, traditional healers, and Western practitioners. This was done to gain a better understanding of which pathways of care were perceived as more beneficial. For the participants, being offered the opportunity to participate in an interview in their home languages may have seemed unusual due to the perception that interview sessions are formal and that proficiency in English is required. This belief is highlighted by Anderson and Killenbeg (2009). Cross-cultural and cross-linguistic studies, however, aim to understand how individuals from diverse cultural and linguistic backgrounds comprehend their situations and behave in their environments within their cultural context (Lopez et al., 2008). Conducting research studies in languages other than English is limited due to the assumption that "meaning cannot be sufficiently ascribed by an investigator whose primary language differs from the study's participants" (Lopez et al., 2008, p.1729).

Although the participants were interviewed in their home languages, there was some code-switching between English and their respective languages at both the word and sentence

level. Code-switching refers to the practice of alternating between two or more languages during the same conversation between multilingual speakers. This phenomenon is influenced by a variety of factors, such as a person's environment, linguistic background, educational background, social networks, and age (Jose et al., 2020; Rich, 2016).

Following a brain injury, a person's ability to code-switch may be influenced by their premorbid bilingual or multilingual skills. In cases where the participants knew that the researcher was bilingual or multilingual, code-switching could be perceived as a facilitatory approach that improved communication, rather than indicating a language deficit (Rich, 2016). Similarly, in the present study, some participants were observed code-switching between English and their African languages when communicating with the researcher. It is possible that the participants code-switched because medical terminology did not exist in their home languages or based on who they were speaking to, considering the researcher's appearance and profession. They may have also code-switched to identify with the researcher or the situation of being in an interview session.

Furthermore, some of the participants chose not to use their home languages in an interview session. The researcher in the interviews may have code-switched between English and the participants' home languages when asking about the support pathways "*Kukuphi la uye wathola isupport khona uma uphuma esbhedlela*" ["Where did you get support after discharge from the hospital"] so the use of English words like "support" may have influenced the participants' use of English as well. Although the option of being interviewed in an African language was available, three of the participants reverted to English. For some of the participants, it may have just been a personal preference to code-switch between English and their home languages.

Although all participants understood that they would be interviewed in their home languages, several of them still code-switched during the interviews. However, eight other participants were comfortable speaking their home languages and did not feel that they needed to speak only English in a formal interview setting. The fact that the researcher was able to converse with them in their home languages was reassuring for these participants. Ultimately, it was important for the participants to feel comfortable and be able to express themselves in their own languages during the interviews, allowing them to be heard in the languages that felt most natural to them.

3.12 Data collection instruments

To capture the exact vocal responses of the participants, the researcher used a mobile phone to record the interview sessions and had written notes. This approach allowed for more thoughtful responses from the participants and gave them the impressions that the researcher was concerned with capturing their responses accurately. Using a mobile phone to record the interviews and writing notes are both useful methods for highlighting key points and ensuring that important information is not missed (Creswell, 2009).

In addition to using notes and a mobile phone to record the interviews, the researcher also employed supportive strategies such as gestures, drawings, and pictures or photos (APPENDIX F) to assist participants who may have had difficulty understanding the purpose of the research and their role in it. The researcher also administered a questionnaire at the beginning of the interviews to collect demographic information such as the participants' age, gender, ethnicity, and other relevant descriptors (APPENDIX C). COVID-19 regulations were also adhered to throughout the study, with measures such as always wearing masks, sanitization, social distancing, and ensuring proper ventilation during the interviews, most of which were conducted outdoors.

3.13 Data analysis

For this research study, the researcher employed thematic analysis, using an inductive approach that allows the data to determine the themes during analysis (Patton, 2002; Le Roux et al., 2021). There are various ways to conduct thematic analysis, but the researcher followed Braun and Clarke's (2017) six phase framework as it provides a clear and practical guide. Braun and Clarke's (2017) framework include five phases for data analysis, as outlined below, and the sixth phase involved the final analysis and write-up of the report, journal, or dissertation (Delahunt & Maguire, 2017; Tshaka et al., 2023).

3.13.1 PHASE 1: familiarising yourself with the data

The researcher was working with verbal data, it was transcribed into written form in order to conduct a thematic analysis. The researcher transcribed the interviews in the languages that they were collected in and analysed them in those languages. The researcher then translated the quotes used in the results section into English and back translated them from English to the source/input languages, as indicated in the above sections to make sure that no meaning was lost. Further, the researcher read and re-read the responses to gain a sense of the data, continually moving between description and explanation, as it is important to be absorbed

in the data to be familiar with the content. “Immersion usually involves repeated reading of the data and reading the data in an active way - searching for meanings, patterns and so on” (Delahunt & Maguire, 2017, p.3351). The researcher also took notes while reading the data and marked ideas for coding to go back to in subsequent phases.

3.13.2 PHASE 2: generating initial codes

After the researcher had read and became familiar with the data, codes were extracted manually from each data set. Codes identify a feature of the data that can be semantic content or latent, that appears interesting to the analyst, and refer to “the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon” (Boyatzis, 1998, p.63). To ensure rigour during coding, the researcher worked thoroughly through the collected data, giving careful consideration to each data item as well as recognizing interesting features in the data items that may be part of the repeated themes of the whole data set. To code extracts, the researcher used highlighters. Each code was identified with a different colour highlighter (APPENDIX H), then matched up with data extracts that demonstrate that code.

3.13.3 PHASE 3: searching for themes

Next, the researcher began sorting the various codes into possible themes and collating all the appropriate codes within the identified themes. The researcher sorted the codes into themes on a table format to conduct a tabular analysis of the data obtained. This is when a relationship between themes was established, the researcher then separated the themes into main and sub-themes. At this stage, certain codes did not seem to belong anywhere and did not seem to fit into the main and sub-themes, these were discarded.

3.13.4 PHASE 4: reviewing themes

The researcher then began to refine the themes that were identified and combined others to form one theme (see Table 4.1), for instance all the sources of care and support were put under one theme.

3.13.5 PHASE 5: defining and naming themes

Subsequently, the researcher further refined and defined the final themes for the overall thematic analysis to analyse the data within them. The following themes, sub-themes and sub sub-themes emerged from objectives one to four of the study:

1. Pathways of care and support followed post-hospitalisation and influence on decision-making on which pathways of care and support to follow
    1.1 family, peers, and community support
        1.1.1 Support with activities of daily living
        1.1.2 Social and emotional support
    1.2 Allied and Medical Health Professions Support
    1.3 Religious and Traditional Support
    1.4 Headway Support Groups-Rehabilitation
        1.4.1 Social interactions and activities
2. Influence on support sources / support-seeking pathways

3.14 Rigour and trustworthiness

To ensure the trustworthiness of the research process, the researcher applied Guba and Lincoln's (1989) criteria for ensuring rigour, as described by Maher et al. (2018). Trustworthiness is an important criterion for evaluating qualitative studies. Guba and Lincoln (1989) propose four criteria that must be met to ensure the trustworthiness of a research process: credibility, transferability, dependability, and confirmability. The researcher ensured the research credibility by using different data collection instruments and methods such as semi-structured interviews, audio recordings, supportive communication techniques, and notes that were suitable in revealing the true representation of the findings.

As well as ensured that the study investigated what it intended to investigate being the pathways of care participants followed post-hospitalisation. The researcher also used prolonged engagement with the data set and used a research assistant fluent in the languages that the participants used during the interviews. This was done to confirm the themes obtained and interpret what was said together with the researcher to increase transcription and translation accuracy. Post each interview session, to further ensure credibility, the participants listened to their recorded audio to check for accuracy of the data collected and the notes that were taken by the researcher (Le Roux et al., 2021; Ned & Lorenzo, 2016; Ned et al., 2022).

The goal of confirmability is to minimise researcher bias by acknowledging the researcher's own predispositions (Maher, et al., 2018). To ensure confirmability the researcher used a reflexive journal to describe experiences from her perspective, reactions to situations or what participants were reporting on and reflections on the research process as a whole (Barry & O'Callaghan, 2008). This enabled the researcher to reduce any biases through reporting on

her own thoughts and feelings related to her subjective experience. The research conducted can also be repeated by other researchers ensuring dependability and transferability, as the researcher has described the processes and procedures in detail and has advocated for the decolonisation of research methods in studying TBI that can be replicated and continued by other researchers conducting research on local people that live with a TBI.

The results obtained are applicable and can be transferred to other settings. To ensure transferability, the researcher described the research context in detail as well as clearly outline the assumptions that are central to the research. Lastly, this research valued persons with TBI and their perspectives on the kind of support or care they sought after based on their cultural beliefs, traditional beliefs, and their values as a community of people with TBI. The researcher recognised that people's cultural beliefs should not be viewed as barriers to research, but rather as an integral part of local research methodologies. As such, these beliefs should be explicitly incorporated into the methodology and reflected upon in a transparent manner.

The process of transcription helps researchers to familiarise themselves with the data (Delahunt & Maguire, 2017). "There is no one way to conduct thematic analysis, there is no one set of guidelines to follow when producing a transcript. However, at a minimum it requires a rigorous and thorough transcript – a verbatim account of all verbal (and sometimes nonverbal [e.g., coughs]) utterances" (Regmi et al., 2010, p.20). For this research, the researcher used verbatim transcription (APPENDIX H) which is to transcribe everything from tape recordings of each participant word for word (verbatim) and involved writing an utterance as it is even with grammatical errors including aspects like pauses, emotional expressions, elisions, mispronunciations, slang, nonverbal sounds, and background noises in order to retain the information needed from the verbal account (Regmi, et al., 2010). The researcher used Brislin's 1970 back-translation process for cross-cultural research, this process entails the translation of the input language into the target language (forward) and then translation of the target language into the input language (backward) this allows for addressing concerns regarding interpreter bias as well as cultural variations, ensuring the accuracy and meaningfulness of the data reported (Shigenobu, 2007; Squires, 2008).

The researcher also used a research assistant qualified in speech therapy and audiology and fluent in all 4 source languages to confirm if the transcriptions, by the researcher, were a true reflection of what was on the audio recordings. The research assistant also assisted with the translation process and to cross-check the translated data against the data in the different

languages to ensure that the meaning was not lost through translation. Also, raw data in the source languages was presented in quotations and the researcher kept raw data and transcripts (APPENDIX H). This was done to add rigour and trustworthiness to the research. Then, key themes and/or quotes from the transcripts were translated into English using forward and backward translation outlined above, which entailed the translation from the source/input language to the target language (English) and the other to back-translate from English to the source/input language to check for accuracy and equivalence (Brislin, 1970, as cited in Regmi et al., 2010; Lopez et al., 2008; Shigenobu, 2007).

There are different ways in which data can be translated from one language to the other, but the process of translation changes the original use and structure of the participant's language (Squires, 2009). Also, for this research, there seems to be a complexity of translating African words into English as they do not have a direct comparable translation (Twinn, 1997, as cited in Lopez et al., 2008). Therefore, in the current study, the researcher has alternated between the source languages and the target language (English). The source language is written in italics and quotation marks and the English translation and/or interpretation of the original quotes in square brackets next to the source language (Nikander, 2008) for preservation of the participants' voice. Some of the information cannot be translated directly into English therefore the researcher restructured the word order in English and interpreted the original transcripts to still capture the essence of the narrated information (Squires, 2008).

With regards to reflexivity, the researcher used a reflexive journal to write her experiences with the research study and what she has encountered during the interview sessions, such as the different beliefs that people with TBI may have, the researcher's own values and beliefs, anything that the researcher found confusing as well as how the participants respond to a Western practitioner enquiring about their pathways of care. A reflective journal was also kept to record any critical incidences, as well as the researcher's thoughts, experiences, emotions and what was learnt throughout the research process (Ned & Lorenzo, 2016; Tshaka et al., 2023).

3.15 Ethical considerations

Ethics approval for the study was received from the University of the Witwatersrand Human Research Ethics Committee Non-Medical (**protocol number H21/09/21**) (APPENDIX G).

Sabati (2018) emphasizes that in the context of decolonisation, ethical issues need to be reframed to foster institutional commitments that shift resources and research practices

towards anti-colonial forms of knowledge. These considerations should be central to how researchers engage with ethical issues. In particular, "when conducting research in global South community contexts, special attention should be paid to issues related to limited resources, power relations between researchers and participants, and participants' ability to consent given language barriers" (Sabati, 2018, p.3). These concerns need to be fundamental to ethical considerations, especially in research that aims to improve communities and contexts (Sabati, 2018).

Indigenizing research methods is essential to the development of social sciences in the global South, in addition to ethics and rigour (Keikelame & Swartz, 2019). Local research practices must be carefully examined to guarantee that they are culturally relevant and ethical for research that is conducted with and among local people. Research practices that are unethical have been reported, such as disrespect of cultural beliefs and values, dishonesty, unfair treatment, and injustice (Keikelame & Swartz, 2019). The use of scientific language during research is also a major concern. Language barriers can impact access to appropriate care and informed consent to participate in research.

Participants may consent without fully understanding the research (Keikelame & Swartz, 2019). To address these concerns, the researcher refrained from using technical language when framing questions. When necessary, the research clarified questions and explained the rationale behind them to ensure that participants fully understood the research. Beauchamp and Childress (2001) outline the following ethical principles that need to be taken into consideration in research, autonomy, justice, non-maleficence, confidentiality and anonymity, beneficence as well as informed consent.

3.15.1 Informed consent

The participants who were included in the study based on the researcher's inclusion criteria were given informed consent forms that the researcher went over with them in the language they were most comfortable with. The participants gave verbal assent and signed consent for the researcher to proceed with the research. Informed consent is a concept that is central to research with human participants (Penn et al., 2008), it is a process that rests on the principles of autonomy, confidentiality, beneficence, and non-maleficence. Moreover, all research projects need consent from the participants involved who can make a decision to be part of the study based on them being educated on and able to comprehend the possible benefits and risks of their participation. The information provided to participants needs to be in a

language they are competent in and through written information and interaction face-to-face (Penn et al., 2008).

To account for misunderstanding, language, and literacy issues, the researcher used the supportive communication techniques (APPENDIX F) to explain the purpose of the study in the participants' languages and to obtain verbal assent and written consent where participants would need to verbally agree to participate in the study and sign the sheet, tick yes or no on the informed consent sheet (APPENDIX B) upon explanation. The researcher also explained the overall study to the participants using the participant information sheet, with this the researcher allowed a question-and-answer session where the participants learnt more about what is expected from them. The participants indicated on the informed consent sheet that they understood the study and that there would be no direct benefits from their participation (APPENDIX B). Lastly, the participants were required to give their consent for the researcher's use of an audio recorder as well as taking notes during the session.

3.15.2 Autonomy

Autonomy refers to respecting one's independent actions and choices including their dignity, worth and rights in terms of choosing whether or not to participate in the study (Beauchamp & Childress, 2001). The participants are classified as a vulnerable population, which is defined as those who are "relatively/absolutely incapable of protecting own interests – insufficient power, intelligence, education, strength of other needed attributes to protect their own interests" (Penn & Watermeyer, 2017, p.111).

The researcher explained in the participants' languages what the research was about and provided possible implications for being participants in the study using the supportive communication techniques (APPENDIX F) where necessary. For participants who had difficulties understanding, the researcher made use of supportive or assistive techniques such as the use of photos, pictures, gestures, and drawings (APPENDIX F). Furthermore, the researcher took necessary steps to ensure the participants that their participation in the study was not an obligation but was voluntary and that they were free to withdraw or decline from the study altogether.

3.15.3 Non-maleficence

To ensure non-maleficence, the researcher established an atmosphere of trust and openness with the participants as well as ensured the participants of any potential harm or risk

from their participation in the study. This was done through holding the interviews in a space that was free from disturbance. The researcher encouraged the participants, in the interview sessions, that they could be comfortable to tell their stories to the researcher and any information shared in the sessions would not be spoken of elsewhere to build trust between the researcher and the participants. The researcher assured the participants that the information that they gave during the interview would only be used for academic purposes and would not have a bearing on their continued care at the centre.

3.15.4 Justice

Justice refers to the state of being fair (Orb et al., 2001). To exercise justice, the researcher avoided any exploitation and abuse of participants by promoting a clear understanding of the researcher's role during data collection as well as the participants' role to ensure that any power gradients were deliberately levelled. Also, to ensure that the participants freely exercised choice regarding their continued involvement in the study. The researcher explained in depth to the participants what her role was as well as what was expected from the participants in the interview sessions which was to tell their stories and answer the interview questions truthfully. Lastly, the participants, who met the inclusion criteria, were given an equal opportunity to participate in the study. Participants who did not meet the inclusion criteria were not afforded the opportunity, since they could not be able to use their higher-order functioning to mutually engage in a meaningful conversation with the researcher, given their underlying condition. As such self-reporting, in this case, would not be suitable.

3.15.5 Beneficence

It is the responsibility of the researcher to ensure that participants are referred to counselling services whenever the need arises. The researcher also took into consideration the sensitivity of the research questions and possible implications it may have on the participants. Therefore, to address any emotional distress, a distress protocol (APPENDIX E) was followed. The researcher developed strategies to minimise distress by referring one of the participants to a counsellor trained to address psychological distress during the study. The researcher discontinued discussion on a topic that seemed distressing to the participants to ensure that the participants were not treated unfairly, and their feelings were not disregarded in the process. For instance, one of the participants was not comfortable to provide information on a particular topic or question, the researcher discontinued discussion on that topic and moved on the next topic.

3.15.6 Confidentiality and Anonymity

The researcher ensured the participants of their confidentiality and anonymity throughout the research process as a way of honouring and respecting their integrity. The researcher informed the participants, in their languages, that their participation in the research would remain anonymous and that the researcher would use pseudonyms (fake names) chosen by the researcher to identify them (Tshaka et al., 2023, Ned & Lorenzo, 2016; Booysens et al., 2015).Their participation would remain strictly confidential and no one else besides the researcher will be able to identify them during or after the interview sessions had been completed.

3.16 Conclusion

The chapter discussed the methodology that was employed in this study. The research paradigm and qualitative approach that was used as the research design was unpacked before focus shifted to a discussion on data collection procedures and instruments. The researcher also discussed an application of decolonised research methods to the entire study. Thematic analysis, which is the chosen data analysis approach, was discussed and the steps that were followed to come up with the codes as well as the themes was delineated. The ethical issues that guided the entire research process was discussed and the steps that the researcher took to navigate the ethical issues were presented.

The next chapter will look at the results of the study where the researcher will discuss findings from the semi-structured interviews as well as the participants' direct quotations written in their home languages with an English translation in brackets. The researcher will present the results of the study in relation to the themes and subthemes that emerged in the study. The objective that speaks about COVID-19 will be presented in all the themes and subthemes that emerged as this objective influenced most of the participants' responses.

CHAPTER 4: RESULTS

4.1 Introduction

This study sought to explore the care and support-seeking behaviours of persons with TBI in the post-acute phase in Soweto by eliciting responses from persons with TBI regarding the different support pathways that they followed and continue to follow during their journey of seeking care post hospitalisation. Participants in the study reported receiving assistance and support from family members, peers, community members, church, traditional healers, Headway support groups, and Western practitioners such as speech-language therapists, psychologists, occupational therapists, and physiotherapists in that order, following their discharge from the hospital. Seeking help from these various sources was determined by their needs at the time, family traditions and religious beliefs, accessibility to different forms of support and care, and their individual preferences. This chapter will present the results from the interviews conducted with the eleven participants.

4.2 Participants' Languages

A total of eleven participants took part in the study. The participants included nine males and two females. The home language of most of the participants was isiZulu, although there were other languages like Sepedi and English. English was spoken by 1 participant and others used English to code-switch. Sepedi was spoken by 2 participants. The participants chose to be interviewed in three languages namely English, Sepedi and isiZulu. However, during the interview process, code-switching was used to accommodate the preferences of the participants.

4.3 Emergent themes

Using Braun and Clarke's (2017) inductive data analysis procedure, two major themes emerged from the study. The first theme was the pathways of care and support that the participants followed being discharged from the hospital. Several sub-themes also emerged under this theme, including family, peers, and community support, allied and medical health professionals support, religious and traditional support, and Headway support groups-rehabilitation. Within the sub-theme of family, peers, and community support, two minor themes emerged: support with activities of daily living and social and emotional support. Within the Headway support groups-rehabilitation sub theme, the minor theme that emerged was social interactions and activities. The second theme explored the influence on support

sources/support-seeking pathways and highlighted what and who influenced the participants' decisions to seek help from certain sources of support.

Table 4.1 (below) presents the total number of times that participants referenced the themes and sub-themes. The table provides an overview of the main themes and sub-themes identified in the study, as well as the participant numbers and the frequency in which each participant referred to a particular theme. Figure 4.1 (below) also presents a visual representation of the themes identified in the study.

Table 4.1: *Summary of the total number of times that participants made reference to the themes and subthemes*

	Pathways of care and support followed post-hospitalisation.				Influences on support sources / support-seeking pathways
Participant no.	Family, peers & community support	Religious & Traditional support	Allied & Medical HPS	Headway Support Group-Rehabilitation	
	Subtheme: Support with ADLs & socio-emotional support			Subtheme: Social interaction & activities	
1	5	3	3	0	3
2	5	4	2	0	2
3	4	5	1	2	1
4	7	5	1	0	1
5	2	3	2	2	2
6	2	8	1	0	1
7	2	3	1	0	1
8	6	0	1	0	1
9	2	4	2	1	2
10	2	3	2	2	2
11	6	3	1	2	1
12	4	1	1	0	1
N	**47**	**42**	**18**	**9**	**18**

n = total number of times that participant made reference to themes and subthemes

The diagram below (figure 4.1) outlines the main themes and subthemes obtained from the participants.

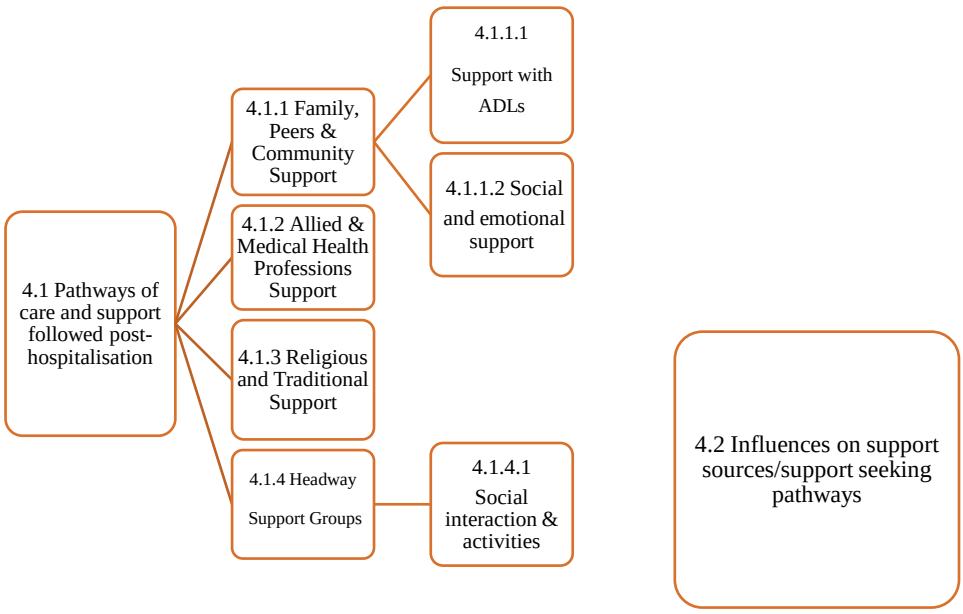


Figure 4.1: *Care and support pathways post-discharge (researcher's creation)*

The following sections present the findings of the study in relation to the themes that emerged. Due to the impact of the COVID-19 pandemic on the participants' responses, the objective related to the pandemic is presented across all themes. To protect the participants' identities, pseudonyms are used consistently for each participant throughout the study. Eleven pseudonyms are used in total.

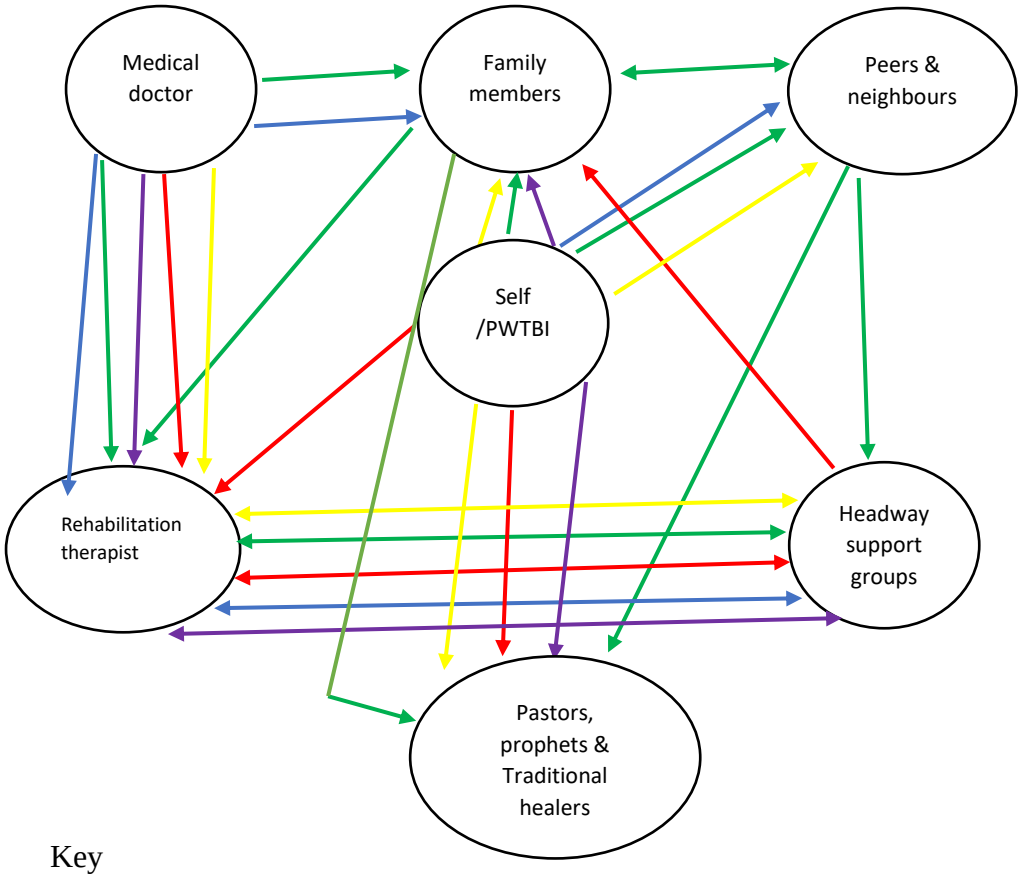
4.4 Pathways of care and support followed post-hospitalisation

Most of the participants reported experiencing multiple difficulties related to their brain injury, such as problems with speech, memory, eating and swallowing, walking, balance, emotions, behaviour, voice, and vision. These impairments influenced the type of care and support sought after discharge, with some seeking consultations with Western healthcare practitioners as out-patients. Some participants viewed rehabilitation provided by speech therapists, psychologists, physiotherapists, and occupational therapists as a successful means of regaining premorbid abilities following a TBI.

The decision to seek help from Western healthcare practitioners was primarily influenced by doctors, as well as family and friends who had knowledge of the rehabilitation required for full recovery from TBI-related impairments. For example, Martin, an English-speaking man who lived with his mother and brother, sought support from family members and peers first, followed by church and traditional healers, and then the community and other sources of care and support, including medical practitioners. Support groups were followed inconsistently or not at all. Five participants followed a pathway of support and care that included family members, peers, neighbours, traditional healers, churches, Western healthcare practitioners such as rehabilitation therapists, and Headway support groups (see Figure 4.2).

Figure 4.2 illustrates how the participants' pathways of care were influenced by different individuals based on the impairments they had sustained post their brain injuries. The figure also highlights the pathways of care that the participants pursued independently when they were not satisfied with the help they had received from other sources of care. Additionally, the figure indicates the different people involved in the decision-making regarding support pathways to follow for persons with TBI. The different coloured arrows represent the various groups of participants and the process of decision-making that occurred (see Figure 4.2 for details).

For instance, the green arrows in Figure 4.2 indicate group A consisting of six of the participants who reported that medical doctors referred them or suggested further help seeking from rehabilitation therapists within the hospital or outside the hospital. Doctors also advised family members to continue giving care and support at home. Family members also discussed and referred between themselves and the peers of the person with TBI for overall social and emotional support. Likewise, family members and peers were also influential in suggesting that the person with TBI be taken to churches and to traditional healers to reverse the disability, whilst also adhering to the medical advice of seeking help from rehabilitation therapists. Moreover, the therapists within the hospitals also referred the participants to Headway for further support and vice versa.



Key

	Group A Green: 6 of the participants
	Group B Blue: 2 of the participants
	Group C Red: 1 of the participants
	Group D Yellow: 1 of the participants
	Group E Purple: 1 of the participants

Figure 4.2: *Decision-making model (researcher's creation)*

4.4.1 Family, peers, and community support

Most participants reported receiving a lot of help and support from their families, friends and/or the community at large. Family support was reported to be centered around self-help and activities of daily living. The family focused largely on helping the person return to their previous self. Hence, they assisted them with mobility, eating, and bathing. For most participants in the study, peers (friends) and the community provided social and emotional support. Their peers used to visit them and assist them outside the home environment with transportation, spending time outside, and motivating them to work harder in attaining premorbid abilities. However, not all participants had positive experiences with regards to the

support they had hoped to receive from their significant others. Some participants reported experiencing abandonment and feeling like a burden to their families and peers.

4.4.1.1 Support with activities of daily living

The section below presents the results on the support that the participants received with activities of daily living provided by their family members, peers, and community members.

Sibusiso, an isiZulu speaking man living with his parents reported that: "*But ekhaya they were very supportive, family yah namanje kakhulu, bangincede ngokudla ukudla healthy*" ["But at home they were very supportive, family yah even now a lot, they helped me to eat, to eat healthy'] and reported that "*Even my ex-girlfriend that assaulted me was supportive bekangiphonela now and then*" ["Even my ex-girlfriend that assaulted me was supportive she used to call me now and then"].

Martin also stated that: "*My family helped a lot like eish a lot with everything, feeding me, wiping me, washing me you see all those things cause when I got out of hospital I couldn't uhm bathe myself, wash myself, they had to do it for me. I couldn't use the toilet by myself uhm like move around in the house alone I couldn't eat by myself nothing I was like a new-born baby".*

Mduduzi, an isiZulu speaking man living with his family reported that: "…*angisho bengingakhoni ukuhamba, ngingakhoni nokukhuluma uncedo kakhulu beluse khaya yabo…"* ["…seeing as I was not able to walk, not able to speak I received help a lot at home you see"]. He added why it was necessary for him to seek help, he said that: "*ehh uncedo luyasiza like luyamakha umuntu eqinisweni usizo luyamnceda umuntu, angeke ululame ngoba eskhathini esiningi uhlala maybe ucabanga izinto eziningi and maybe ezingekho right, tholukuthi like maybe ziyakuphazamisa ngomqondo ugcina manje sowaba crazy so usizo luyenza ukuthi ungacabangi kakhulu like makukhona into engaku phathi kahle you have to go out nje uthathe iwalk nje uzihambele ushaye umoya*" ["getting help is quite beneficial like it builds you as a person, most of the time you always think about a lot of things that are mostly negative and they disturb you mentally and you end up being crazy so getting help prevents you from overthinking, if something has hurt you, you have to go out and take a walk and get some fresh air"].

Likewise, Jabulani, an isiZulu speaking man living with his wife and kids reported that: *"Ngathola uncedo kakhulu endlini especially ekhaya my wife and first born oyi ntombazane*

we are four in the house. Banginceda ngokukhuluma cause ispeech sami sasi ngekho right bengikhuthaza mengikhuluma ukuthi inqondo ibuye yonke into nje, bangigcokisa, bangigeza umfazi wam until nami sengikwazi ukuzigeza" ["I received help a lot at home especially in the house my wife and first-born daughter, we are four in the house. They helped me speak because my speech was not good, they motivated me when I speak, also so that my memory can come back, everything, they dressed me, they bathed me until I was able to bathe myself"].

Additionally, Sipho also mentioned receiving help from his family, he reported that: "*The first line of help I received was from my family they helped me with things of like washing myself, washing me, cooking for me, clean for me they looked after me in general nje. My mother, my brother and sister yibo banginceda kakhulu. My extended family also helped me they used to go to the shops and buy me stuff that I wanted*" ["The first line of help I received was from my family they helped me with things of like washing myself, washing me, cooking for me, clean for me they looked after me in general. My mother, my brother and sister are the ones who helped me a lot. My extended family also helped me they used to go to the shops and buy me stuff that I wanted"].

Lesetja, a Sepedi speaking man, living with his family, also mentioned receiving support from his family, "*Then ho tloha mouwe ka thola support ko ngwaneshu le buti, ne ba nthusha ka hore ke seke ka fela pelo, ne kele motho wa ho fela pelo le ho ntlisetsa tsa hoja batle batlo ntlatswetsa*"["Then from there I got support from my brother, they helped me not to be impatient, I used to be very impatient, they also helped with bringing me food and to wash for me"].

Lebone reported that: "*mama waka family yaka hantle ne ba kase nseye ke le one maybe ba nyaka hoya somewhere ne ba tsamaya le nna le hore ba nrute ho tsamaya le ho hlapa cause ne ke sa kgone ho hlapa, ne ba njesa*" ["my mother, my family actually would not leave me alone if they wanted to go somewhere they would take me with, they taught me how to walk again, to bath because I was not able to bathe myself, they fed me"]. Ntombikayise, an isiZulu speaking woman living with her children reported that: "*Ngathola isupport kakhulu ekhaya abantwana bami mhm bebeza everyday bangiyenzela yonke into ebengiyidinga*" ["I received support a lot at home, my children used to come every day and did everything for me that I needed"].

Nhlanhla, an isiZulu speaking man living with his father and stepsisters reported that: "*Endlini bengincedwa abantu base khaya, ubaba wami nama step sister wami, ubaba kakhulu*

bekanginceda kodwa abo sister bebeza nabo bazonceda ubaba ngalokhu bengikudinga"["At home I was helped by my family, my father, and my stepsisters, especially my father he helped a lot, but my sisters used to come help him(father) out with regards to things that I needed"]. Additionally, seeking care from family members, peers and neighbours was almost automatic for most of the participants after getting discharged because these were the people closest to them and could rely on for care and support.

4.4.1.2 Social and emotional support

This section of the results outlines the social and emotional support provided by families, peers, and community members to persons with TBI. Only three of the participants reported on the support they received from their fellow community members.

Sibusiso reported that: "*ama friends wami…bashaya iround bangithathe bablome nami siphuze ama drinks so braai inyama sihlale bafike bazongibona*" ["my friends…they visited, they took me to go chill with them, have drinks, braai meat, we would chill they would come see me"]. Martin added that: *"My friends just visited me a lot yah and took me out to take a walk and that time I was still in a wheelchair they pushed me around yah. I needed that and appreciated that at the time".* Sipho also added that he received support from his friends *"There were some friends who supported me, they motivated me in fact I was brought by a friend here at Headways."*

Mthokozisi mentioned that he received support a lot from his friends as well as his girlfriend, "*Nabangani bami they were there for me bebeza bazongbona yabona mhm yah bangi encourager ukuthi hai uzoba right. Ne medi yam nayo lomuntu ngihlala naye ngabe kudala wahamba kodwa she didn't bengingekho right so wahlala since the incident yabona, ngaba ne mali ngizomshada*" ["my friends were there for me they used to come visit me you see mhm, they encouraged me that I will be okay. Even my girlfriend I live with her she could have left me a long time ago, but she didn't, I wasn't okay, but she stayed since the incident you see, when I have money, I am going to marry her"].

Mduduzi added that: "*abangani bebangivakashela bazongibona bona bebeza bazongibona iqiniso angeke ngiphosise namanje baseza. Abanye basuka maybe basemsebenzini plus angithi ama lockdown before mara manje bese kuncono ngoba besikhona ukubonana"* ["my friends used to come visit me, it's the truth I will not lie even now they still come. Others are sometimes at work plus it was lockdown before but now it is a better because we can see each other"]

Moreover, three of the participants also mentioned receiving support from their neighbours. Neighbours were seen to offer support and help to the family of the person who had sustained an injury or to the individuals themselves by provision of social connection, inclusion, less feelings of loneliness and increased quality of life. Martin reported that: *"And people in my community also helped me here and there. Like they knew what happened to me, so they supported my family they offered their help when I was still in hospital, they offered their help like offering to take my family to the hospital to come see me."*

Jabulani added that: "*Omakhelwane bami esisebenza nabo beza njalo bazongikhuthaza ukuthi I must pick it up, bangithathe bathi asambe maybe siye ku funeral eEastern Cape bayenza ukuthi lezindawo ngizibone all over again, ngikhumbule ukuthi endaweni ethile konje kuhanjwa kanjani yah, bayibuyisa yonke imemory yami*" ["My neighbours that I work with used to come every day to encourage me to pick up, they would take me and go with me to a funeral in Eastern Cape, they did that so that I can see these places again so that I can remember certain places yah, they helped jog my memory"]. Lesetja further reported that he had a neighbour who also took him to church to receive help, he reported that: "*Kreke keya motho o mong mo ke dulang mo teng o tsena kereke ya zion jwanong ne ana le hore haya kerekeng aye lenna, he le gona aya krekeng Sunday ne keya le yena krekeng ya zion mara nou akesaya*" ["That church is the one my neighbour used to go to. It's a zion church so sometimes when he went to church, he would take me with, when he went on Sundays, I used to go with him at that zion church but now I don't go anymore"].

Even though families and peers were a very strong source of support for most participants in the study, some participants experienced abandonment from their friends, family, spouses and/or children in their time of need. Lesetja reported that he was only supported by one friend and the rest had left after his brain injury, he reported that: "*friend ke e one (1) ene eng supporta ba bang ba tsamayile like onale koloi nna akena koloi o kgona ho ntseya keye leyena Limpopo*" ["I had only one friend that supported me the rest of my friends left me, like he has a car and I don't so whenever I needed to go to Limpopo he would drive me there"].

Ntombikayise was desperate to share her experiences of living with a TBI but often felt misunderstood or that other people who did not know what it was like to live with TBI would not be able to relate with how she felt. She reported that: "*ba siza kakhulu ngoku exercise siyakhuluma sinabangani angithi abanye abantu mawukhuluma nabo abazwisisi so lana*

siyakhuluma ngokuthi wena ulimale kanjani nomunye ulimale kanjani mhm…lokho kuyakhuthaza ukukhuluma nabantu abakhe balimala ngoba nabo balimele bakuzwile lokho okuzwile" ["Headway helped a lot with exercises we talk we have friends here (Headway), other people when you talk to them they don't understand so here we spoke about how we each got injured mhm…talking to people who also got injured encouraged us because they know and understand the pain that one also felt"]. Other participants reported receiving support from their friends and their relationships were not altered by their brain injury, and support from friends was seen as crucial for their overall emotional health and wellbeing.

In conclusion, the above findings revealed that the participants valued the support they had received from their families, friends, and communities. Families were able to provide support in the home environment in terms of helping with manoeuvring the house as well as with emotional support. Friends were also able to offer social and emotional support to the participants. Some participants, albeit a minority, did however report experiencing abandonment from their family members and friends after sustaining a TBI and presenting with different impairments that had proven to be a challenge to deal with or a burden for other people.

4.4.2 Support received from Allied and Medical Health Professionals

With this sub-theme, the focus is on the support that the participants received from the health professionals. Health professionals are a broad grouping of people who offer treatment, psychological, social, and emotional support. The professions that are included in this category are doctors, sociologists, psychologists, physiotherapists among others. In this sub-theme a few of the participants reported on how much they valued the support they had received from the specialised interdisciplinary team of health care professionals, namely rehabilitation health care professionals such as physiotherapist, occupational therapists, speech therapists and psychologists/counsellors mostly due to the impairments they sustained because of their TBI.

The participants who used the route of allied and medical health professional to obtain care and support, mentioned attending therapy that had been suggested by their doctors and/or their families or friends because they were told that therapists would be able to help them recover from their impairments. The participants also reported that they attended therapy sessions with each different discipline for the specific impairments they had, for instance the participants that reported difficulties with their mobility reported having attended physiotherapy as out-patients at the hospital or at Headway. It was also noted that some of the

participants did not necessarily attend therapy as regularly as it was recommended but rather resorted to other sources of care that spoke to their cultures and traditions.

The participants have difficulties with mobility, balance and cognition motivated seeking care from therapists that specialise in that field, as suggested to them by their medical doctors and/or their families/friends. Lesetja reported changes with his memory and speech, he reported that: "*ke kreile accident ka timela ke monahano…ke dutsi 6 months ke sa kgone go bolela*" ["I got involved in an accident and I lost my memory…I spent 6 months not being able to speak"]. Sipho, further reported that: "*my left side beyingasebenzi therefore bengingakhoni ukuhamba kahle, benginenkinga nge speech sami ne vision nayo beyingasafani I started using glasses after my brain injury*" ["my left side was not working anymore therefore I could not walk properly, I had problems with my speech, my vision was also not the same anymore I started using glasses after my brain injury'].

Martin reported difficulties with his mobility, "*everything I do is a bit slower now because I can't walk fast, I can't carry a lot of things you see, now it's just what they call it…my mobility, at first when I just came out of hospital my speech was bad my eating was a little bad also*". Nhlanhla added the significant role that Western professional played in his recovery, he reported that: "*ngiye ngasizwa abantu basesbhedlela ba lokhu banginceda bangihambisa ama physiotherapy ukuthi ngikhone ukuhamba but manje ngiyabona ukuthi kulesimo engikuso sengikhona ukuzenzela zonke izinto*" ["I got help from the professionals at the hospital they helped me walk, physiotherapists helped me to be able to walk but now in my current situation I am able to do most things independently"].

Sibusiso alluded to the support he received at the hospital, he reported that: "*they are supportive esbhedlela khohlwa noma ungena lapha uhleli nama physiotherapist uyabona ukuthi they focus on you they know umsebenzi wabo that's where I saw iadvantage ye skolo ukuthi kwangisiza ukuya eskolweni nami ngine diploma so ngafunda ukuthi ulalele*" ["they are supportive at the hospital even when you go in there you sit with the physiotherapists and you can see they focus on you, they know what they are doing that's where I saw the advantage of being educated, that it helps to be educated, I have a diploma, I learnt to listen"]. He further added that *"…isbhedlela singincedile yonke iprocess yami yasesbhedlela, physio, OT and Speech, yonkinto eyenzeke esbhedlela from eBara ngazitshela ukuthi I am going to stick to what these doctors are telling me, esbhedlela kukhona ukuphola ungabhilivi kuzinto zesintu kakhulu*" ["the hospital helped with the entire process, physio, OT and speech, everything that

happened at the hospital from Bara I told myself I am going to stick to what these doctors are telling me, there is healing at the hospital you mustn't believe in traditional things a lot"].

Sibusiso said that: "*Ukuhamba I was not good; I came out of hospital ngihamba nge-wheelchair. Bekubheda nokukhuluma I attended speech at Bara"* ["I was not good with walking; I came out of hospital using a wheelchair. It was difficult to even speak I attended speech at Bara"]. Jabulani added that: *"Ngangihambe nge-wheelchair kodwa kancane kodwa ngikwazi ukusukuma ngiqothoze. La (points to neck) ngangifakwe ipipe ngiphefumula ngalo"* ["I used a wheelchair for a short period of time, but I was able to get up and walk slowly. Here (points to neck) I had a pipe that helped me to breathe"]. Sibusiso further said: "*Bangiyenzela ireferral yase Bara mara tholukuthi kune lockdown yabona so I couldn't go but ekhaya they were very supportive*" ["They gave me a referral for Bara, but this was during lockdown you see so I couldn't go but at home they were very supportive'].

Mduduzi said in his response that: *"angikwazi nokuhamba, ekhaya baze bangifunela intsimbi zokuthi ngikhone ukuhamba ehh, ngithathe isikhathi ukukhuluma, ngiye ngakwazi ukukhuluma sengihamba lana e Headway, ukudla bengidla kodwa bebangifundza ngoba izandla zami bezinga sebenzi kahle"* ["I cannot even walk, at home the found crutches that would enable me to walk ehh, I took a while to speak, I was only able to speak properly when I started attended Headway, I was able to eat but they used to feed me because my hands did not work properly].

Lebone averred that "*Ne bangrutisa ho buwa ke le spetlele ke leka ho buwa hanyane slow ke moka ka discharger kaya ntlung ke moka bangruta ho tsamaya le ho buwa*" ["They taught me how to speak when I was at the hospital, I tried to speak, I was then discharged and went home then they continued to help me to walk and speak"]. Sibusiso added: "*mina ngifuna abantu aba professional nje ngani hai lezinto zokuya ehostela kunomuntu oso uzoyenza kanje ugcatshwe kaningi ningi no I needed professional help not ukuchata lapha uyenza izinto ezisnux phela nami ngiyile eskolweni kancane angifuni ukubizisa ilife yami*" ["I wanted people who are professional like you not being told to go to the hostel there's a certain person who will do this and that, ugcatshwe (cutting with a razor) a lot no I needed professional help not ukuchata (enema), doing nonsensical things, I went to school a bit so I don't want to endanger my life"].

Speech, language, and swallowing impairments were also commonly reported for the majority of the participants. They reported that their families and therapists helped them to

overcome these impairments. Ntombikayise reported that: "*Bengingakhulumi kahle bengikhuluma mara hai kahle nokuhamba namanje angikwazi ukuhamba kahle mhm*" ["I could not speak properly, I spoke but not clearly, I cannot walk properly even now mhm"]. Lebone also added that she could not speak properly, and they assisted her with this, she said that: "*Ne bangrutisa ho buwa ke le spetlele ke leka ho buwa hanyane slow ke moka ka discharger kaya ntlung ke moka bangruta ho tsamaya le ho buwa*" ["They taught me how to speak when I was at the hospital, I tried to speak, I was then discharged and went home then they continued to help me to walk and speak"].

Lebone reported that: *"Before kea kwa hae ne kese buwi and ke saje ka molomo ne kena le operation mo maleng mo mpeng le ho tsamaya ne kesa kgone ho tsamaya ne ke tsamaya ka wheelchair ehh"* ["Before I returned home, I could not speak and I could not eat with my mouth, I had an operation on my stomach, I could not even walk I used a wheelchair"]. Martin reported that: "*at first when I just came out of hospital my speech was bad my eating was a little bad also…*". Jabulani added that: "*Banginceda ngokukhuluma cause ispeech sami sasi ngekho right bengikhuthaza umangikhuluma ukuthi inqondo ibuye…"* ["They helped me with speaking because my speech was not good, they motivated me to speak so that my memory comes back"].

Very few of the participants reported experiencing emotional impairments. Lebone reported that her social worker helped her a lot with her emotions, she said: "*Le social worker/counsellor yaka ne enthuse oa nthekga ka ntho engwe le engwe wa encourager ore ska wara*" ["even my social worker/ counsellor used to help me a lot, she supported me with a lot of things and encouraged me not to worry"]. The participants did, however, indicate that the COVID-19 pandemic had a huge impact on attending therapy to receive help with any emotional difficulties they may have experienced and to talk about their feelings and emotions with their peers. One of the participants mentioned that the COVID-19 lockdown protocols brought on feelings of loneliness because he was not able to socialise with people anymore and this brought on a lot of negative thoughts and emotions. He reported that: "*during lockdown bengiboreka to be bored ucabanga kakhulu ukuba ne stress maan ukungabonani yabona umuntu ofuna ukumbona not even umtana wami bekunzima so leyonto beyingilimaza enhlizweni yabona izinto ezinjalo*" ["during lockdown I was bored I was thinking a lot I had stress, I couldn't see the people I wanted to see not even my child, it was hard so that broke my heart you see things like that"].

To avert the spread of the virus, online telerehabilitation services were introduced as they guaranteed social distancing. Telerehabilitation services, however, presented new challenges to accessing rehabilitation services for the participants such as the need for purchasing airtime and data to be able to access these services. Lebone alluded to the issue of not having data on some days to access the online services that were provided to them and this meant on those specific days she would not attend the sessions, she reported: "*ne ba romela di exercise ko phonong hobane ne ke satle mo so ntho eo ele ya thusa haholo hore ke practise ko ntlung but ka matsatsi a mang ne ke sana data ya ho sheba di exercise ko phonong*" ["they used to send exercises on my phone because I was not coming here that that helped a lot in terms of practising at home but on some days I did not have data to look at the exercises on my phone"]. Sipho further added that: "*I was attending my sessions using my phone whatsapp groups but sometimes angina data*" ["I was attending my sessions using my phone whatsapp groups but sometimes I don't have data"].". Therefore, during the pandemic they had no platform to share their emotional experiences with people or to attend therapy sessions where they got to do a lot of activities with other survivors of TBI.

The above-mentioned impairments in mobility, cognition, speech, and language as well as mental health challenges motivated the decision to seek help from therapists who had prior knowledge of how to work on these impairments in therapy. Although, it was noted that the pandemic and the protocols that surfaced had a major impact on the participants' ability to access services that helped them deal better with the changes they were undergoing. It can be said that some people who have sustained TBI did not necessarily disregard referral to and consultation from Westernised healthcare providers and may therefore not see it as important to seek help from people who are not therapists or rather people who are not trained to deal with impairments resulting from TBIs. Hence, they adhered to attending therapy from the various rehabilitation therapists. The therapists were realised as important in helping the persons with TBI to overcome what had befallen them and because rehabilitation was suggested to them by doctors and families, they believed this to have been a useful pathway to follow. The section shows that most of the participants had access to health professionals who not only attended to them immediately after the accidents but were also available post their recovery. The participants had a choice of a number of health professionals of varying specialisations, this indicated that people who have TBI had access to holistic recovery pathways.

4.4.3 Religious and Traditional Support

In this theme, participants mentioned seeking care and support from the spiritual and traditional mediums such as traditional healers, priests and prophets given their cultures, identities, values and beliefs regarding sudden disability and the cause of a disability being from mystic forces such as ancestors and God as well as witchcraft. They reported that the decision to seek help from churches and traditional healers was initially influenced by family members and friends. Eight of the participants reported consulting churches and traditional healers to be able to get the abilities that they had lost because of the TBI. One of the participants reported that he sought help from spiritual mediums from the onset because he was a traditional man from long ago.

Sipho reported that he believed God and the ancestors caused his injury, so he consulted both the church and traditional healers. He reported that, *"I believe that God had a hand in my accident. He wanted to direct me somewhere that I needed to be, not in the direction I was thinking."* and added that "*I went to the Sangomas after I came back from the hospital, my cousin is a sangoma so I went straight to him to clarify things for me like why would the ancestors take away my gift why would they give me a gift and take it away again, my gift of being an artist. I wanted to get help from the spiritual world."*

Mthokozisi added that: "*ngaya ge wangisiza loya baba wangisiza besengiya shuthi everyday ngabo half past 8 da uyiprophet yena yabona so wangisiza kakhulu…ngaya eZCC for lendaba ye khanda eZCC bazama kodwa azange ngibe right yabona so… bayathandaza banginikeze izinto zakhona zokuba ncono angithi bayasho ukuthi mawuphuza into eso uzoba right uhambe uyogabha yabona mhm ai bangizama serious bengiya lapha bayothandaza khona ngithathe 2 years lapha ngilokhu ngiya ngagcina ngaba yi member yase ZCC*" ["I went to this man and he helped me. I went every day at half past 8 at his home he is a prophet you see so he helped me a lot…I went to the ZCC church for my head, they tried but I was not okay you see so…they pray they gave me their stuff to help me get better, they said if I drink a certain drink I will be okay after vomiting you see mhm ai they tried seriously I went there to get prayers I took 2 years there constantly going I ended up becoming a member of the church"].

Furthermore, Martin reported *"My family also took me to church, the church also supported me because at first I couldn't go to church they came to my house and chatted with me about things, prayed with me yah and had conversations about you know just life yah".* He

also added: *"I am a Christian and have strong belief in God so I felt my church can help me connect with God. I also went to traditional healers here and there just because Sangomas they speak to the dead and the ancestors let me say ancestors so maybe just by having help from the ancestral side and help me connect with them and heal faster".*

Jabulani also mentioned that he received support from the church, he said that, "*So esontweni bangisupporta kakhulu ukuthi bangifundise yonkinto ezenzwa ama sonto ukuthi nami ngikwazi ukubonisana nabantu mabangivakashele nokuthi I must always pray for ukuphola kwami so that God can give you power to be healed*" ["So at church they supported me a lot, they taught me everything that has to do with the church so that I can be able to communicate with people when they visit me and they also said I must always pray for my healing so that God can give you power to be healed"].

Sipho added on receiving help from church as well as traditional healers, "*I got spiritual help at church you understand, they helped me to believe in myself that I will get better, abafundisi helped me to believe in God that God will heal me. I also went to traditional healers as well because at home they are traditional healers as well yah so at home they helped me by giving me muthi African medication and the readings from them ukuhlola from amadlozi*" ["I got spiritual help at church you understand, they helped me to believe in myself that I will get better, the pastors helped me to believe in God that God will heal me. I also went to traditional healers as well because at home they are traditional healers as well yah so at home they helped me by giving me African medication and the readings from them, consultation from ancestors"].

Lastly, Lebone added "*Ne ke tsamaya kereke hore bangrapelle. Ba ile ba nkisa ngakeng nako e ke sa kgone ho tsamaya hantle ke moka bare ba tshwantse ba nthobe ka metsi a tjhesang le ditlhare*" ["I was attending church to get prayers. They took me to a traditional healer when I couldn't walk properly then from there the traditional healer advised that they should use warm water and African medicine to heal me"]. Ntombikayise added that her church members would come offer support to her at home, "*Nase sontweni bebeza bazong culela"* ["The church used to come sing for me"]. Nhlanhla reported that he did not consult traditional healers but went to church instead, "*Angihambi inyanga kodwa ichurch ngiyile ngoba ngibelieva ku Nkulunkulu nokuthandazelwa ukuthi ngiphole*" [I don't consult traditional healers, but I went to church because I believe in God as well as in prayer for me to get healed"].

Nine of the participants mentioned that they believed their brain injuries were due to witchcraft from their friends and/or family members. They also reported that they believed their ancestors had a hand in their injuries and as a result, they needed to consult traditional healers to be able to find out if any ceremonies needed to be performed to reverse what they believed to be a curse or punishment from their ancestors. Ephraim, an isiZulu speaking man, mentioned that he suspected that there was an underlying cause to him getting an accident, he stated that: "*ngiye ngabuza amathambo inyanga nge ngozi yami, hai zithi abantu bakhona abantu bangizondayo so bayenza ukuthi ngithole ingozi*" ["I consulted the bones, traditional healers about my accident, they told me there are people who hated me and were the root cause of my accident"].

Mthokozisi further added that he was given something to drink by his friend at work and from there on he started getting sick, "*ngavula ngaphuza half then from there I was not okay shukuthi it was made yabo eish angisakwazi ukukhuluma yabona angikho right…so nje I went to that sangoma and that prophet and the ZCC church basho ukuthi yinto yangabomo le*" ["I opened it and I drank it half then from there I was not okay it was done on purpose you see I couldn't speak anymore I wasn't okay…so I went to that sangoma and that prophet and the ZCC church and they confirmed it"]. Furthermore, Mduduzi mentioned that: "*siyakhonza eZion and esontweni bangipropheta ukuthi hai ngizoba ncono makuya kuya, nami ngizinakekele ehh, hai ngincono ngoba ngiyakwazi ukuzigeza manje*" ["we attend Zion church, and they gave us a reading from the prophets that I will be healed as time went on, I just need to take care of myself ehh, I am better because I can wash myself now"].

Lesetja mentioned that he and his family suspected his girlfriend to have had a hand in the accidents occurring in the family. This was following his brother's accident that led to his death. He reported that: "*Abuti waka o ele a kreya accident je kanna so family ya kgona ho e bona mouwe, o ele a kreya accident athlokofala yaba family e thoma ho bona hana mou…ha re nyakisisa le family yaka re kreya hore dilo tse kamoka tse ditswa mo girlfriend yaka…ba nyaka ho diya hore re se ka ra surviva mo bophelong*" ["my brother got involved in an accident like me and we started realising there that something was wrong, he got involved in an accident and passed away…when we went to consult with my family we were told that all of this was caused by my girlfriend…she wanted to make sure that we never survive in life"] he added that "*Ke motho o believelang haholo mo culture ya rona so ne ke nyaka ho tseba hore accident ebakile ke eng*" ["I am a person that believes in our culture so I wanted to know what caused my accident"]. Also, Lesetja and Lebone reported that their families were the ones that took

them to a traditional healer. Lesetja said: "*Family yaka ele ya nkisa mothong wa setso ba kreya hore accident e hase accident fela…"* [*"*My family took me to a traditional healer, and they found that this accident wasn't just an accident…"].

With the above findings, it was revealed that the participants attended churches and traditional healers as influenced by their families and their friends or merely as a decision they took based on their own beliefs and values. These spaces provided them with opportunities to be healed spiritually or to amend errors they had done to the ancestors and to God. The belief here was that, if the person with TBI goes to church to get prayed for or to receive a prophecy they would know what direction to take to alter the punishment from God. Likewise, the belief was, traditional healers would be able to reveal to them any communication from their ancestors and if any traditional rites needed to be performed to be cured from their injuries.

4.4.4 Headway Support Groups

The participants in this study mentioned that they attended Headway shortly after discharge from hospitals. Headway was either suggested by their doctors and therapists at the hospitals and their friends who had heard of Headway and the services they offer to people with TBI. This section of the results mentions the participants' reports on how Headway provided them with support groups where they got to engage and interact with other people who had sustained a TBI. The participants reported that being immersed in support groups and doing activities with other people going through the same ordeal as them, helped them to be able to deal with their impairments and recover from any feelings attached to the TBI. Headway also provided them with meals and food packages to take home, especially for participants who had no means of getting food at home.

4.4.4.1 Social interactions and activities

The participants come to Headway on their appointed days during which they take part in social activities. Participants reported on the different activities they did at Headway within their support groups as well as the interaction they had with other people in the groups who were going through the same experiences of living with a TBI.

Martin reported that he received help from support groups like Headway, *"You know support groups because they also helped me like games and stuff, we need those things uhm to be with other people in the same situation you see yah they give us therapy like speech and physio…"*. Mthokozisi further added: "*ngiyafosta I can't speak so banginikeza umuntu uspeech*

therapist usisi bekangisiza yabona…" ["I am forcing I can't speak so they gave me a speech therapist lady she helped me you see"].

Sipho reported: "*Headway supported me a lot in terms of support groups since I came to Headway I have gained my confidence, I was able to socialise with other people, the therapists also helped a lot ama OT…OT used to do writing exercises and puzzles, physiotherapy I did it at Mofolo Clinic and here at Headway as well*" and further added that: "*Headways inceda kakhulu ngama support groups because I felt I was with family here at Headways, we talk about our experiences and how to cope with our problems so that was very helpful for me and how to handle conflicts all the time conflicts that we have with people who do not understand our situation"* ["Headways helped a lot with support groups because I felt I was with family here at Headways, we talk about our experiences and how to cope with our problems so that was very helpful for me and how to handle conflicts all the time conflicts that we have with people who do not understand our situation"].

Ntombikayise reported that "*Nala eHeadway banginceda ngokuthi bangi-exercisisise ngakhuluma ne therapist eye speech*" ["Even at Headway they helped with exercises and helped me speak with the speech therapist"]. She added that: "*ba siza kakhulu ngoku exercise siyakhuluma sinabangani angithi abanye abantu mawukhuluma nabo abazwisisi so lana siyakhuluma ngokuthi wena ulimale kanjani nomunye ulimale kanjani mhm…lokho kuyakhuthaza ukukhuluma nabantu abakhe balimala ngoba nabo balimele bakuzwile lokho okuzwile*" ["they helped a lot with exercises we talk we have friends here (Headway), other people when you talk to them they don't understand so here we spoke about how we each got injured mhm…talking to people who also got injured encouraged us because they know and understand the pain that one also felt"].

Ephraim mentioned that no one was employed at home therefore he relied on support services like Headway to provide food for him even before the pandemic hit. When COVID-19 started to spread, and restrictions were put in place it meant little to no access to food and the slowing down of economic activity did not make it any easier for him. He reported: "*ukudla kuncane endlini so ngiphatheke kabi ngoba ne Headway beyivaliwe and ngihlala ekhaya ngedwa kwezinye inkathi akuna muntu engikhuluma naye akuna no kudla*" ["there is little food at home so that hurts me because even Headway was closed, and I am sometimes alone at home and there is no one to talk to there is even no food"]. Jabulani, reported that: "*at Headway we were doing a lot of activities, lockdown yavimba yonkinto, eHeadway babuyisa inqondo uthola*

siyenza ipuzzle, bengibuza imibuzo ethile ukuthi inqondo ibuye, ukhumbule la eHeadway senza ingadi sitshale…so Headway beyinginceda ngama activities amaningi" ["at Headway we were doing a lot of activities, lockdown prevented all of that, at Headway they helped with getting back my memory by doing puzzles and asking me certain questions to help jog my memory, remember here at Headway we did the garden and planting…so Headway helped with a lot of activities"]. Jabulani further added that: "*Safety precautions were put in place a lot but leyonto yayenza ngingwakzi ukuza eHeadway*" ["Safety precautions were put in place a lot but that thing of implementing safety precautions prevented me from being able to come to Headway"].

Lesetja also added that: "*since covid ithoma mo Headway bare ne bakwala ke ka se kgone ho hlola ke tla, ba romela di message hore ketle ka di Friday kare neh akena tjhelete ya hotla mo ka Fridays so ne ke sa kgone hotla*" ["since covid started Headway told us they are closing therefore I couldn't come, they sent messages that I must come on Fridays I said no I don't have money to come so I couldn't come"]. Martin reported that: "*with covid it was a little more difficult to get help like coming to Headway you know support groups because they also helped me emotionally…we need those things uhm to be with other people in the same situation you see…*".

The support groups at Headway were reported to have been beneficial for the participants who attended them. They reported on the significance of the activities and interactions they had with other people at Headway. As well as the importance of attending group therapy with other members who had a TBI. The participants also added on the impact that COVID-19 had on attendance at Headway and how this affected them negatively and resulted in emotional and financial difficulties.

In addition, even though the majority of participants in the study reported receiving adequate support from various sources including family, friends, and peers, not all participants had a positive experience, with some of the participants reporting significant challenges in their spousal and parental relationships, with some of the challenges leading to separation and/or divorce. Some participants reported that there were changes in how their spouses received them after their brain injuries and this altered their relationships and negatively impacted on their spouses' abilities to give them the much-needed support.

Ephraim reported that both his wife and his daughter abandoned him post injury and the only support he had received was from Headway. He stated that: "*nganginomfazi uhambile, siyele sa hlukana, ngangihlala nomtana wami we ntombazane uzishadisile (laughs) angikatholi*

imali yama lobola so manje uhlala ne boyfriend yakhe ngihlale ngiyi one so ngiyazenzela endlini yikho ngithi uncedo ngiluthola lana eHeadway kakhulu" ["I had a wife, she left, we got a divorce, I lived with my daughter she now lives with her boyfriend, I didn't even receive lobola money, I live alone now so I do most things by myself that's why I am saying I get the most help from Headway"].

Lesetja reported that his in-laws had taken his child from him, and he was not able to see her, but he was expected to only send her clothes home, "*ke nale ngwana December ba mpuditse hore ba nyaka diaparo ka mo rekela le hane bjale ha ba mpotse hore neh diaparo tseo diya molekana or hadimolekane mhm*" ["I have a child. In December, they told me that they want her clothes, I bought them but even now they have not even communicated with me to say whether or not the clothes fit my child"].

4.5 Influences on support sources/support-seeking pathways

This section of the results highlights the influences on care seeking behaviours. Participants reported on seeking care from various sources as suggested to them by their families, friends, doctors, and hospital therapists. In this section, the participants also reported that the decision to seek care from these various sources was a decision they took themselves based on their own values, beliefs, and preferences. The decisions were also taken when they (the participants) were not satisfied with other sources of support that had been previously suggested. Moreover, the decision on pathways of care was also based on their psychological needs at the time as well as the influence of family traditions, social circumstances, and social institutions. The section highlights what influenced the participants to seek certain support pathways while avoiding certain providers of support services.

Seven of the participants (green arrows on Figure 4.2), mentioned that their doctors influenced the decision to seek care and support from family members and therapists, family members influenced the decision to seek help from peers and/or neighbours. Peers influenced the participants to seek care from their families, Headway as well as from pastors, prophets, and traditional healers. Family members also influenced seeking care from therapists as well as from pastors, prophets, and traditional healers.

For Sibusiso and Mduduzi, (blue arrows in Figure 4.2), the doctors and therapists influenced the decision to seek help from their families, therapists, and Headway for extra support. Sibusiso did not believe in seeking help from pastors, prophets, and traditional healers but also relied on his friends for support. He mentioned that Bara Hospital told him to attend

therapy at another hospital, he reported that: "*Umabangi-discharger eBara they organized physio at South Rand, eSouth Rand ngahlala 8 weeks*" ["When I got discharged at Bara they organized physio at South Rand, I spent 8 weeks at South Rand"] and Mduduzi reported that the family helped him but his doctors also encouraged him and his family to go seek further help at Headway, *"…ekhaya bangisiza kuze udokotela wami wangithumela lana eHeadway*" ["…at home they helped me then my doctor sent me here at Headway"].

Nhlanhla (purple arrows in Figure 4.2) reported that he was influenced by his doctors to seek help from his family and therapists who then referred him to Headway. He also decided to seek care from therapists, he reported that: "*ngiye ngasizwa abantu basesbhedlela ba lokhu banginceda bangihambisa ama physiotherapy ukuthi ngikhone ukuhamba but manje ngiyabona ukuthi kulesimo engikuso sengikhona ukuzenzela zonke izinto*" ["I got help from the professionals at the hospital they helped me walk, physiotherapists helped me to be able to walk but now in my current situation I am able to do most things independently"].

Other participants mentioned that the decision to seek help from various sources was solely a decision they made themselves. For instance, Mthokozisi, an isiZulu speaking man living with his girlfriend (yellow arrows in Figure 4.2), mentioned trialling different traditional healers and prophets when one did not satisfy him. He stated that: *"…ngazama omunye umama mara ngabona ukuthi hai la after 3 days nyana ngabona ukuthi yazin akangisizi lo yabona*" ["I tried one female traditional healer, but I realized after 3 days that she was not helping me"]. He also went back and forth to doctors who then referred him to therapists who later suggested he attends Headway. The participant also sought help from his peers and neighbours.

Ephraim, an isiZulu speaking man, living alone (red arrows in Figure 4.2) reported that: "*iyangifundisa iHeadway, siyaya eSpeech therapy ngoba angikwazi ukukhuluma kahle, futhi ingisiza ngoku gyma abo physio, baningi*" ["Headway teaches me, we attend speech therapy because I cannot speak clearly, it also helps with exercising, the physio, they are a lot"]. Ephraim also mentioned that his doctors suggested therapy at the hospital for further management as well as Headway. Headway also encouraged further support seeking from his family. He also consulted traditional healers because he believed he had been bewitched. He said that: "*iHeadway beyikhuluma nomtanami ukuthi angincede endlini*" ["The people at Headway would speak to my daughter for her to help me at home"].

Martin mentioned that his family members are the ones that took him to church, he reported that: "*My family also took me to church, the church also supported me because at first*

I couldn't go to church…". Lebone, a Sepedi speaking woman living with her mother and sister, also added that the decision to go to a traditional healer was influenced by her family, she said: "*Ba ile ba nkisa ngakeng nako e ke sa kgone ho tsamaya*" ["They took me to a traditional healer when I could not walk"]. Moreover, Lesetja, a Sepedi speaking man living with his parents, added that: "*Family yaka e le ya nkisa mothing wa setso…"* ["My family took me to a traditional healer"]. Mduduzi reported that he had to listen to his family and went with what they decided, he said: "*ahh mina ngingasho ukuthi ekhaya zikhona lezinto zesintu vele according to umama ne vele ifamily yabo nami kukhona ezinye izinto engizilandelelayo according to bona uyangthola because of ngimamela amagama aphuma from bona abazali nami bengifollow-upa wona*" ["at home they are more traditional according to my mother and my family, I also follow traditional things according to them because I listen to whatever they say and I follow their suggestion"].

He further added that: "*Saya emuntwini ehh umuntu wasitshela wathi yinto endala le eyenzeka ukuthi ngilimale, uaunty wami wuye owangigangela yikho ngiso, lomuntu wasipha izinto nemithi ukuthi ngibe ncono wasipha ama chemicals*" ["we went to a traditional healer, and he told us that my injury was planned a long time ago, my aunt bewitched me, and I ended up disabled, this healer gave us muthi for me to get better and he gave us chemicals"].

Sipho reported that: "*There were some friends who supported me, they motivated me in fact I was brought by a friend here at Headways*" and that "*Headways took me to dokotela wa mehlo to get help for my vision and my glasses as well*" ["Headways took me to an optometrist to get help for my vision and my glasses as well"]. The therapists also recommended Headway and vice versa. The eight participants also decided to seek support from their families as well as from peers and neighbours. Lesetja further reported that he had a neighbour who also took him to church to receive help, he reported that: "*Krekeng like key a motho o mong mo ke dulang mo teng o tsena kereke ya zion jwanong ne ana le hore haya kerekeng aye lenna, he le gona aya krekeng Sunday ne keya le yena krekeng ya zion mara nou akesaya*" ["That church is the one my neighbour used to go to. It's a zion church so sometimes when he went to church, he would take me with, when he went on Sundays, I used to go with him at that zion church but now I don't go anymore"].

4.6 Conclusion

The chapter presented the results that arose from the interviews that were held with the eleven participants. The chapter started by highlighting the languages of the respondents. In total nine males and two females were interviewed. The themes and the subthemes that arose from the data analysis were highlighted and the results were presented by highlighting the responses from the participants. The next chapter discusses the results in relation to the theoretical framework and available literature.

CHAPTER 5: DISCUSSION

5.1 Introduction

The previous chapter presented the findings that emerged from the semi-structured interviews with the eleven participants, which led to the identification of two major themes and four sub-themes. This chapter will discuss the results by drawing on relevant literature and the theoretical framework, specifically the biopsychosocial model. First, the biopsychosocial model will be restated to provide context, followed by a discussion of the results in relation to this model.

5.2 Biopsychosocial model and pathways of care

This research was underpinned by the biopsychosocial model, which is an interdisciplinary model that examines the interconnectedness between biology, psychology, and socio-environmental factors (Taukeni, 2020). The biopsychosocial model was chosen for this research to provide a holistic understanding of how biological, psychological, and social factors contribute to the care-seeking behaviours or the pathways of care of persons with TBI. Through this model, the study was able to identify and conclude that a range of factors influence the choice of care pathways for persons with TBI, including personal attitudes, values, beliefs, injury-related impairments, financial circumstances, family beliefs and cultures, education, and societal organisations. For example, participants reported that their decision to seek care from rehabilitation therapists was influenced by their own preferences, their impairments, or recommendations from organisations like Headway.

The biopsychosocial model recognises that patients' beliefs and attitudes about their illness or disability are important factors that can influence their ability to cope and adhere to treatment recommendations (Turabian, 2018). By taking these factors into account, healthcare providers can develop more effective treatment plans that consider not just the patient's physical symptoms, but also their psychological and social well-being. Engle (1977) proposed this theory outlining that, specific systems, including the biological, psychological, and social systems, are interdependent and interact with each other to determined health outcomes. In his theory, Engel (1977) emphasized the importance of recognizing the interaction between these systems in understanding and treating illnesses (Engel, 1977).

Additionally, healthcare science and other system sciences primarily focus on specific areas. Biomedicine, in particular, focuses on biological systems. Whilst psychology deals with

specific psychological systems such as motivation and fear, and social systems examine the societal influences on patients' health outcomes. The biopsychosocial model emphasises the interplay of these systems, suggesting that clinicians must consider and address all of them to fully comprehend and respond effectively to a patient's suffering and provide them with a sense of being understood.

This model helps us to comprehend the interconnection between persons with TBIs' physical health (biology), mental health and behaviour, associated beliefs, attitudes and values and social and cultural context that governs the path of their health outcomes (Bolton & Gillett, 2019). This interplay of factors also determined their help-seeking behaviours and the pathways of care that they chose. For instance, as discussed with the literature in this study, persons who have suffered a TBI undergo various feelings and emotions and this psychological state motivates them to seek care and support from various available sources of care or medical professions that are trained to deal with these impairments. However, due to social beliefs, family traditions or even lack of finances to access such services, help-seeking behaviours may change and pathways to seeking care may also change to seeking help from more accessible sources or sources suggested by families due to generational traditional beliefs.

The analogy above helps us understand that a person with a TBI is faced with several factors in their lives that ultimately influence their healthcare pathways and outcomes. This is something that care providers, such as therapists and doctors need to be cognisant of when a person is discharged from the hospital. The biopsychosocial model enables us to take account of the person with TBI, the person's experience of, account of and attitude towards the condition, as well as whether they or others in their life view it as a disability or a result of ancestral or divine curse (Lambert et al., 2020).

In their study, Bolton, and Gillett (2019) noted that Engel (1977) advocated for a new biopsychosocial model to broaden the biomedical approach and account for all the factors that contribute to both illness and patienthood (Bolton & Gillett, 2019). The biopsychosocial model is effective in identifying and integrating different aspects of care for the patient's life, disease, and management. This model supports the motivation of multidisciplinary teams and the growing acknowledgment of the value of the patient's opinions in providing effective healthcare in a decolonised context. Essentially, this model values the patient's views in what constitutes the provision of good and effective healthcare and is in line with the concept of decolonisation.

Participants in the study mentioned receiving help and support post-discharge from family members, peers, support groups, community members, church, traditional healers, and western practitioners such as speech therapists, psychologists, occupational therapists, and physiotherapists. Seeking help from these various sources was based on an interplay of different factors, their needs at the time, access to these various sources of support and care, what they valued to be most important to them and personal choice. The decision to seek care from the different sources was also influenced by other people such as doctors at the hospital, family, friends, rehabilitation therapists and Headway.

This study also rests on the principles of decolonisation of research methods when studying persons with TBIs. The researcher advocated for the need to decolonise research methods by means of making the research specific to the population studied and respecting participants' views irrespective of their impairments. The researcher achieved this by hearing the participants' worldviews regarding care seeking as well as what influences the decisions about the care that they seek. By highlighting their worldviews, the researcher was able to draw up conclusions regarding the care that persons with TBI seek and which factors influences those choices. It brought on the understanding that, the provision of healthcare does not only rest on Western biomedical approaches but rests on a more holistic approach that caters for every aspect of the persons with TBIs lives. This knowledge also enabled decolonisation on a broader scope by bringing to the attention of medical healthcare providers the important factors that need to be considered and that potentially have an impact on persons with TBIs help seeking patterns and behaviours.

The model below depicts the different biological, psychological, and social dimensions that influence a condition such as TBI. As well as influenced the participants' help-seeking behaviours and pathways of care. These three dimensions encompass an individual's biological and personal history, interpersonal relationships, and the community settings in which persons with TBIs lives, and a broader sociocultural environment. A more in-depth discussion of each factor and how it influenced pathways of care is to follow in relation to the results obtained in the study.

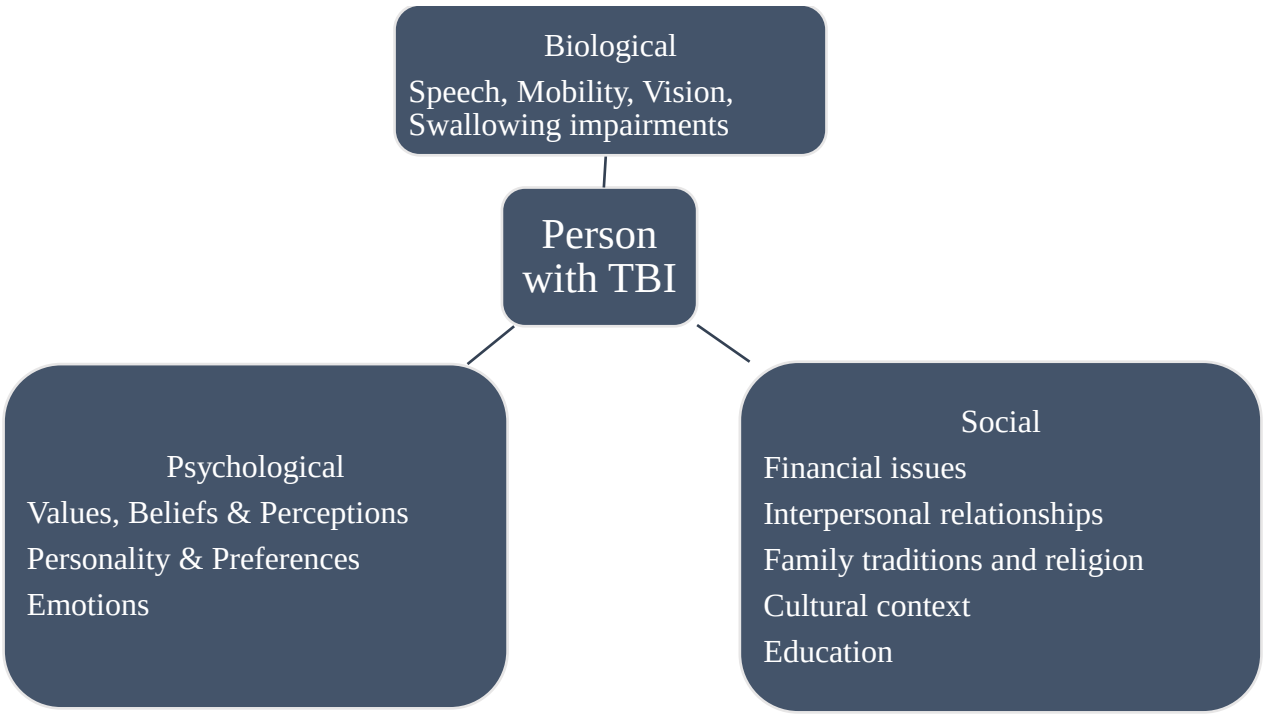


Figure 5.1: *biological, psychological, and social factors that impacted care-seeking.*

5.2.1 Biology

The concept of biology in the biopsychosocial model speaks to one's disability, general vulnerabilities, and physical health (Turabian, 2018). In relation to this study, it speaks to the injury-related impairments resulting from sustaining a TBI. Sustaining a TBI impacts on an individual's cognition, psychosocial and physical factors, and vocational issues. The findings of this study regarding TBI related changes are consistent with the implications of TBI recognised in the literature. Malec et al., (2017) reported that impairments resulting from TBI include verbal communication difficulties, neuromotor impairments, visual difficulties, swallowing and/or eating difficulties as well as cognitive impairments such as memory, attention and concentration, information processing, planning and problem-solving difficulties.

This is consistent with the findings in this study where the participants indicated that they had impairments in communication, mobility, cognition, emotions and in behaviours. These impairments determined the decision on pathways of care or support to follow after discharge. Such that consultations with Western healthcare practitioners as out-patients was seen as a successful way of ensuring that persons living with a TBI can attain premorbid abilities through rehabilitation and lead successful lives, build relationships, and gain more self-confidence (Khan, et al., 2013). Research has identified that people with TBIs present with

a range of changes post their injuries. This meant that an increased support system is required even with decision-making, because at the time of discharge the individual may not be ready to make decisions about the care they needed at the time (van Dijck et al., 2019). This was also the case for the participants in the study since they mentioned that their families mostly influenced where they went to seek help.

The pathways of care followed post-discharge, concerned with addressing these impairments in communication, swallowing, mobility, cognition, emotions and in behaviours, were influenced by different people mainly medical doctors and family members of persons with TBI. Since the person with a TBI was not able to make sound decisions about the care they needed due to the head injury and the impairments that followed. This meant that they required help to alleviate the consequences of the impairments and needed help with deciding which pathways to follow and which sources would be better suited to work on cognition, mobility, speech, and swallowing difficulties (van Dijck et al., 2019).

The doctors in the hospitals consulted with family members regarding the person's progress and what further interventions needed to be performed to help the person in the home environment. This warranted the family to transition into the role of making decisions for their family member with TBI in terms of what further care they needed at home and from other sources (Knox et al., 2016a). The family was most influential in decision-making on pathways of care to follow because they had prior knowledge of the person prior to the injury, and they knew what the individual valued and believed in.

According to Hooft, et al., (2020) doctors often refer the patients to multidisciplinary teams for them to receive specialised rehabilitation. The impairments sustained meant that they needed additional support (van Dijck et al., 2019), be it at home, therapy sessions or from spiritual mediums, based on various cultural beliefs, context, and identities. The doctors knew that rehabilitation post brain injuries was essential for recovery thus they advised the participants to seek help from rehabilitation therapists to help them with their injury related impairments. The rehabilitation therapists within hospitals and out of hospitals also cross-referred the participants within their different disciplines based on the person's needs at the time and they also suggested joining support groups to further cope with and manage emotional impairments for instance. The participants' decision to seek help from a speech therapist, for instance, was influenced by doctors and families and it was brought on by their own understanding that a speech therapist would be better suited to work on speech, language and

swallowing impairments and a physiotherapist would be better suited to work on impairments with mobility, i.e., Jabulani, Martin, Sipho, Nhlanhla. These findings emphasise that decision making is a complex process that often involves the person with TBI and several people around the person with TBI (Knox et al., 2016).

Likewise, rehabilitation therapists or allied healthcare professionals occupy a central role in referring persons with TBI for rehabilitation following acute care. Due to the consequences of TBI, persons with TBI need adequate lifelong care to optimize their health outcomes. For persons with TBI, post-hospital care pathways are vital in enabling optimistic outcomes (Mellick, et al., 2003) and these can include discharge to home, to in-patient rehabilitation facilities or residential care facilities. Early rehabilitation interventions have been shown to be of benefit for physical improvement and regaining skills (Khan, et al., 2013). The findings of this study reveal that participants were referred for rehabilitation by their doctors, families and/or friends. Likewise, rehabilitation therapists co-referred to their colleagues within the multidisciplinary teams or to other organizations that could offer support.

Rehabilitation therapists "use clinical and non-clinical patient factors" (Khan et al, 2013, to suggest further intervention (Khan et al., 2013, p.293). For instance, most of the participants mentioned that their therapists referred them to Headway most likely to address the non-clinical factors that might affect improvement such as poor familial backgrounds and socio-economic status. Headway was seen as an organization that can provide support in that regard by the provision of utilities that the persons with TBI could use at home especially for the participant who reported to be living alone and had no means of getting food except through Headway (Ephraim).

Therapists also suggested Headway and the psychologists on-site for clinical factors such as the emotional impairments that most of the participants had following their TBI (Khan, et al., 2013). Additionally, post-discharge therapists may talk to the family members regarding ways to improve functionality in the home environment, this may be done with or without the person with TBI's knowledge or approval. However, this is done for the benefit of the person with TBI and does not intend to cause harm. Hence it is discussed with family members first who will then approve the procession of interventions (Stuntzner & Hartley, 2014).

Furthermore, it is important to note that in the findings, few of the participants preferred the care and support they had received from the allied team of health care professionals, mostly due to the impairments they sustained because of their TBI. From the findings, it can be said

that some of the participants, such as Sibusiso and Nhlanhla, did not necessarily hold certain stigma regarding the consultation of Westernised healthcare providers. Therefore, they did not see it as important to seek help from people who are not therapists or rather people who are not trained to deal with impairments resulting from TBIs. Essentially, in the post-acute phase, it is the role of the above-mentioned health care professionals to help persons with TBI with these impairments and to help them to return to maximum independence and participation in the community (Khan et al., 2013).

The participants mentioned that these professionals offered words of encouragement, valuation of the person's outcome and motivated why the person needed the suggested help at the time and this encouraged the decision by some of the participants to seek help from physiotherapists, speech therapists, psychologists, and occupational therapists. However, for some of the participants there was a bit of uncertainty and little knowledge on the benefits of rehabilitation, which resulted in them being reluctant to seek help from Western professionals but rather sought help from various other sources, than the ones suggested by their medical doctors.

5.2.2 Psychological

The concept of psychology is concerned with an individual person's values, beliefs, and perceptions about their disability. It also looks at preferences and emotions surrounding their disability, in this case, TBI (Turabian, 2018).

5.2.2.1 Personality & Preferences

In the current study, it was noted that some of the participants had their own preferences with regards to pathways of care they sought. They mentioned that in most cases it was their families who decided on what was best for them and because they trusted their families had their best interests at heart, they complied with any decisions made. After having trialled different sources of care with their families initially, some of the participants decided on the pathways of care they wanted to follow. For instance, Mthokozisi mentioned that he sought help from the prophets, and this is the help that he needed seeing as he was a traditional man. Ephraim also wanted to follow the pathway of seeking help from traditional healers to confirm his suspicions of his TBI being caused by witchcraft.

This speaks to another important finding that emerged from the study being that the nature of the decision-making process changed as time goes by because persons with TBI and

their families have transitioned towards increased independence. One participant, Sibusiso mentioned going to traditional healers but realising later that this was not what he preferred or believed in or what he needed at the time when he had acquired a bit more independence. He had a unique knowledge of his own health and desired outcomes and exercised freewill to decide on the care he wanted to follow henceforth, being rehabilitation from therapists.

Mthokozisi also revealed that he was a traditional man and was only focused on receiving help from traditional sources of support. Such that he trialled different prophets and traditional healers, when he was not satisfied with one source of support, he moved on to the next one or rather when he was not satisfied with what had been initially suggested he moved to sources of care that spoke to his beliefs and personal choice. He made those decisions, and these decisions were not influenced by his family or his friends. Initially, his doctors, family and friends suggested seeking medical help from doctors and therapists. However, he only got exposed to therapy when he later joined Headway. Moreover, these findings provide evidence that personal preferences, as a psychological factor, is enough to impact on the pathways to care-seeking. Also, making choices and decisions about one's own life and pathways of care is seen as essential both for individual welfare and sense of identity (Helmrich et al., 2021).

In the same vein, some of the participants may not have wanted to participate in decision-making because of feeling like they lack the knowledge and experience to develop informed preferences and might also be afraid to make the wrong decision. Ideally, increasing patient involvement in decision-making about their own pathways of care, can be seen as important for quality improvement and is associated with improved health outcomes for the person with TBI (Krist et al., 2020). Therefore, it is imperative for care providers to realise the importance of involving patients in treatment decisions, recognising them as experts with a unique knowledge of their own health and their preferences for treatment, health states and outcomes. At the time of discharge, it is understandable why decisions are taken for the person with TBI but as time progresses and with noticeable improvement, persons with TBI should be more involved in decision-making processes.

5.2.2.2 Values, Beliefs & Perceptions

The findings of this study indicated that religious and spiritual beliefs that the participants had played an important role in predicting care-seeking and outcomes after TBI. The participants mentioned seeking care and support from the spiritual and traditional mediums given their perceptions, values and beliefs regarding sudden disability and the cause of a

disability being from supernatural forces, such as ancestors and God as well as witchcraft. These belief structures led some of the participants to seeking care and support from mediums that can connect them with their ancestors and God. These mediums being traditional healers as well as priests and/or pastors in churches. For them to better understand the underlying cause of the injury and the ceremonies or rituals that need to be completed to appease ancestors or to reverse the punishment (White, 2015). With regards to witchcraft, some of the participants believed that the bewitchment which resulted in the brain injury was from some family members who had evil intents and ill wishes upon their lives.

Some of the participants revealed that they had strong beliefs in God. Due to their belief in God and having attended church prior to the injuries, the participants believed in returning to church to get prayed for and become healed by God, i.e., Jabulani. This would have been observed by the return of their pre-morbid abilities which would suggest the forgiveness of sin. The participants also reported using religion or their spirituality to cope with the stress associated with the effects of brain injury. The conflation between sin and disability confirms the notion that, disability is viewed as a punishment inflected upon a person or their family by God because of sin (Retief & Letšosa, 2018). These findings are consistent with prior research on TBI populations that believed spirituality predicted health outcomes (Waldron-Perrine et al., 2011). Specifically, the participants' feelings of connectedness to God predicted their own experiences of distress and overall well-being. Such that, when this connection was strengthened, it reduced negative emotions about their injuries and provided them with a more positive outlook on their recovery.

The participants therefore relied on pastors, priests, and prophets to help strengthen their connection with God through prayer and supplication. They believed that receiving prayers or praying to God themselves would ensure that they are forgiven for sins committed and as a result reverse their injuries and the overall disability (Retief & Letšosa, 2018). Moreover, praying to God suggested their need for a meaningful explanation for their sudden injury and being attuned to their spiritual beliefs as supported by pastors and prophets. Who were perceived to being able to identify the source of the problem and give the solution, being to overcome the causative spiritual power of God.

Some revealed beliefs in ancestral powers. The participants believed that there were other alternative causes of their accidents such as their ancestors and this influenced their help-seeking, Sipho, for instance, thought his ancestors were trying to communicate something to

him through his injury and them taking his gift of being an artist away. He, therefore, consulted traditional healers to confirm this. They reported that they went and consulted traditional healers to help them clarify if these accidents were merely just accidents or warnings and/or punishment from their ancestors. Beliefs about causality and help seeking were intertwined, such that if a participant believed the cause of a brain injury to be from witchcraft and/or ancestral anger he/she sought help or consulted traditional healers to confirm the cause of the injury and the ceremonies that needed to be performed thereof to reverse the curse or the punishment.

The results show that some persons with TBI who have deep traditional beliefs on ancestors and causes of TBI, sought help from traditional healers. Whilst Christians sought help from God via the church. However, the results also show that there are some respondents who sought care from both traditional healers and the church. This according to Latif (2010) is because of the fact that, the church and traditional healers are perceived as giving spiritual help that takes into account cultural imperatives.

5.2.2.3 Emotions

Two participants reported on emotional impairments (Lebone and Lesetja) and highlighted that they underwent counselling to deal with the emotions attached to having a brain injury. The one participant reported that he experienced feelings of boredom and stress when he was not able to socialise with his friends and other people anymore. This highlights the importance of the emotional support he was receiving from his friends that helped him reduce having negative thoughts about his injury and his impairments. Sener (2011) study demonstrates that the provision of emotional support has an impact on one's well-being and overall health and that people that receive emotional support proved to have an increase in morale and life-satisfaction. Such that the absence of emotional support may result in "loneliness, anxiety, uncertainty, a sense of meaningless and vulnerability to stress" (p.81) as is the case with the two participants that reported on emotional impairments.

Howlett et al., (2022) found mental health problems, such as "impulsivity, severe irritability, affective instability, and apathy" (p.1) as consequences of TBI that adversely affect quality of life and day to day functioning. As well, increased levels of anxiety, stress, and depression reduced levels of positive wellbeing, quality of life, and overall life satisfaction. The same can be said with the two participants in this study regarding the changes they underwent because of their brain injuries i.e., psychosocial/emotional adjustments such as

depression, anger, and anxieties. Although the participants reported improvements, especially with attending therapy, these challenges were seen to continue during the pandemic, putting a strain on their overall wellbeing. Perez de la Cruz (2021) indicated that due to loss of functional status because of TBI, psychologists and support groups are able to assist the person with TBI with feelings of depression and frustration that follow post the injury as well as failure to accept their new life.

The current findings suggest that psychological support, amongst other forms of support, was deemed helpful in enabling the participants to cope with their own emotional challenges and feelings of depression, sadness, anger, and anxiety (Stuntzner & Hartley, 2014). Another setting that helped the participants deal with emotional impairments was support groups, found within the Headway site. Previous research reveals that support for a person with TBI from someone with the same condition or similar circumstances has proven to be essential for emotional, informational, and appraisal support (Lauckner & Hutchinson, 2016).

The participants in the study revealed that they did not know about Headway, and it was suggested to them and their family members by their doctors as well as by therapists and some friends. Likewise, when participants began attending Headway, it was also suggested to them that they seek further support at home and from external therapists by the facilitators of programs within their support groups. In the findings, support groups were reported to be a space where the participants got to chat about their experiences, and these were spaces where they related with each other. To help alleviate feelings of anger, depression, and anxiety and led to the desired health outcomes. Participants further reported that they learnt a lot of skills such as behaviour management skills. They were taught to be able to regulate the emotions they felt towards their condition. Some participants alluded to the fact that receiving support from another person with TBI within the support groups was particularly empowering (and therefore gratifying) for persons with TBI.

Their support groups were concerned with helping the person with TBI to recover and attain premorbid abilities whilst also sharing their experiences with people who underwent the same ordeal. Upon learning about what Headway and support groups can offer to persons with TBI, participants gravitated towards seeking help at Headway for further support. Like any other organisation, interventions that were implemented needed to be further practised at home with families or with peers. Hence these support groups worked hand in hand with the

participants' families and caregivers to encourage participation and keep the participants motivated to return to their old selves.

Support groups do not only help the persons with TBI, but they also help alleviate the burden placed on family members with having to deal with all the impairments following TBI. By provision of adequate support on how to deal with impairments in the home environment. Hence, the participants in the study also found it beneficial and motivating to attend sessions with their family members at Headway to learn more about ways the family can help them at home and to also receive some encouragement in dealing with the consequences of the TBI. Some of the participants reported that being part of support groups ensured that they felt like they had an increase in resilience and this facilitated participation in their communities and promoted social inclusion. This agrees with Hughes et al. (2020) study which found that support groups are essential in ensuring that persons with acquired brain injuries gain a sense of connectedness, interact with people going through the same situation as theirs, as well as assisting with promoting emotional adjustment following a brain injury.

However, during the pandemic, the participants reported having no platform to share their experiences with people or to be in a group session where they got to do a lot of activities with other survivors of TBI. It was rather difficult for them to continue with the same activities while sitting at home and it was challenging to share experiences with people who have never experienced living with a TBI. Therefore, this period of COVID-19 and the restrictions that followed thereof had a prominent effect on the participants' mental health and overall lifestyles.

5.2.3 Social

This concept looks at all the social factors that influenced persons with TBIs' pathways of care. It is concerned with the influence of interpersonal relationships, family traditions and religion, education, and financial issues as well as the overall cultural context.

5.2.3.1 Family Traditions and Religion

The participants reported having generational traditional views regarding sudden disability, causes of the disability as well as how it is diagnosed and treated. They reported that they and their families consulted Sangomas and performed some sort of ancestral offering rituals to help alleviate the consequences of the TBI, as a common belief in their families. White (2015) study found that, when the ancestors are not treated well, they could punish people with disease. Ancestors are seen to play a role in causing adversity to families when

rituals are not done by families to appease them (White, 2015). They also serve a purpose in warning families about danger and punish them if they do not follow their commands. For instance, if an individual refuses to follow an ancestral calling he/she may be punished by the ancestors by making the individual ill, get involved in an accident, and this may be interpreted as resulting from the ancestors' anger towards this person.

Some of the participants reported on witchcraft as being caused by family members. Mduduzi, mentioned that the idea of witchcraft was brought on by his mother who had consulted a sangoma and it was revealed that her son was bewitched by his aunt. Lesetja also revealed that his girlfriend had a hand in his injury, she was bewitching him, and the traditional healer revealed this information to him and his family. Witchcraft was also seen as a cause of injuries, disabilities, illnesses, and the misfortune experienced. Bewitchment in the form of putting muthi in food was reported to have resulted from jealous family members, friends and even co-workers who did not want the individual to succeed in life. Mthokozisi also revealed that he accepted a drink from his co-worker, and he started becoming ill. The findings are consistent with previous research on the role of ancestors in causing adversity to people who do not follow their commands as well as on witchcraft resulting from thoughts of evil intent (Lambert et al., 2020; Moshabela et al., 2017).

Family cultural and religious beliefs led the participants to seek care or support from prophets and traditional sources of support. These sources of support were more able to address the participants' cultural and traditional needs as well as helped them understand the underlying causes of their injuries. For example, Sipho reported that he believed that God and the ancestors caused his injury, so he consulted both the church and traditional healers. This shows that for people like Sipho when faced with the need to get care they resorted to consultation with prophets, priests, and traditional healers to connect them with God and their ancestors.

Additionally, in the findings, we see that the family's religions or ongoing church attendance influenced the participants' faith in God and beliefs in a greater power and these beliefs became a part of who they are and impacted on how they perceived their brain injuries and what they ultimately prioritised as a successful way of receiving help. For example, Martin reported that his family believed in God, and he also believed in God, so his family took him to church to receive prayer for his disability. This encouraged the choice of the pathways of care he chose being pastors and prophets through the church. This knowledge enables the understanding that, persons with TBI prioritised certain sources i.e., pastors and prophets based

on what had been enforced to them by their family members over the years, even prior to their injuries. This is true of Mthokozisi, Martin and Sipho, to name a few, who relied on prophets, pastors, and the church to reverse their impairments because of it being a common practise in their families that they had automatically adopted.

5.2.3.2 Interpersonal Relationships

Following a TBI, many families find themselves in a significant role of providing care and support to their family member with TBI. Successful coping during the early adjustment period with TBI has been associated with obtaining satisfactory social support and information, attending support groups, involvement in work, engagement in recreational activities as well as the use of religion (Knox et al., 2016a). In this study, participants reported seeking care and support mostly from their families and friends. This could be attributed to the fact that these are the people closest to the individual with a TBI and would most likely know the kind of support or help they need at home after getting discharged.

Family members also play an important role in the care of people with TBI including contributing to decision-making and assisting medical healthcare professionals to provide care (Jazieh et al., 2020). The results discovered that family members encouraged the participants to seek care from various sources and influenced their pathways to healthcare. This might have been due to family members' prior knowledge about the benefits of seeking help from different sources as well as based on their own beliefs about sudden disability. For instance, one of the participants, amongst others, mentioned that his family took him to church post-discharge. This could be attributed to the reason that the family believed that the church had the ability to heal their family member and help them recover and regain functionality again.

Families hold their own expectations on the person's outcome and these expectations on the person's outcomes post injury encouraged them to be part of the decision-making process. In essence, the family can shape individual decisions to reduce risk or to ensure an outcome that they perceive to be in the best interests of the person with TBI (Jazieh, et al., 2018). The results obtained agree with the claims of Perez de la Cruz (2021) that families are seen as the first source of support because when the individual gets home, families are available to provide assistance with daily activities and routines. The family can improve outcomes over time due to increased and more efficient home practice (Perez de la Cruz, 2021).

Like family, friends also made suggestions to their friends with an injury to seek help from various sources including traditional healers and therapists. Friends' knowledge of

personal characteristics of the individual and an understanding of their history, achievements, aspirations, and self-narrative (Knox et al., 2016) warranted them to advise their friends on trialling different sources for their improvement with their impairments. Levy et al., (2019) proposed that friends offer continued support and care to help the person with the brain injury to feel positive about themselves and their circumstances which can have a positive impact on recovery.

This was observed in the findings of the current study where the participants reported that their friends played a crucial role in making them feel positive about their current situation. Being able to do the same activities they did with their friends prior to the injuries such as having braai and drinks sessions, going out a lot more often meant a lot to them. For most of the participants being out with other people reduced any feelings of depressions, anger and anxiety about their condition as opposed to being at home alone which brought on a lot of thoughts about their injuries and feelings of abandonment (Yao et al., 2020). Peer support had also been reported to be an effective intervention for the participants. For example, peers were the ones who mostly visited the participants and often checked on them at home. They also helped to alleviate feelings of demotivation from their friends with a TBI, as reported by Martin, Mthokozisi and Sibusiso.

Some of the participants reported that in as much as their family members took them to traditional healers and church, their friends were no different to their family members. They also influenced seeking care from the traditional route and the person with TBI would choose whether or not they follow up with what had been suggested to them. Friends in this regard, provided supported decision making whilst also recognizing that ultimately it was the person with TBIs' choice whether or not they wanted to seek help from traditional healers or from the church. Ephraim, amongst others, mentioned that his friend introduced him to Headway and saw it beneficial for him to attend to receive further support from people who had also sustained a brain injury. As well, friends can offer support to the person with TBI or work hand in hand with their family members in offering support outside the home environment. With friends, it can be said that persons with TBI could express choices because nothing felt forced or imposed on them (Shippy, 2015). Friends were just recognised as offering suggestions about pathways to follow but did not necessarily obtrude certain pathways on the participants.

Even though support was provided by their families and peers, there was an issue of abandonment reported by the participants in the current study. Some participants felt

abandoned by their friends, family, spouses and/or children. They indicated that post their brain injuries, their relationships with their friends have not been the same. They reported losing contact with friends, giving up on friends and vice versa. Mainly, Ntombikayise reported feeling misunderstood when she shared their experiences with their friends due to her friends not having sustained a TBI therefore not relating to the emotions and feelings attached to TBI. Ephraim further reported that after his brain injury his wife had divorced him and moved on with another man. Lesetja mentioned that he was not able to see his children after the injury. Douglas (2019) found that interpersonal relationships have a significant impact on one's wellbeing and maintenance of self-confidence. For persons with TBIs, life is frequently characterised by declining interpersonal relationships which was reportedly the case for some of the participants in the study who indicated that friendships and spousal relationships began to decline shortly after they had sustained a brain injury and affected the willingness to seek help.

In the same vein, the disruption of neighbourly and friendly bonds intensifies the sense of loneliness and isolation, as such the genuine upkeep of close neighbourly contacts and the delivery of support becomes even more limited (Górnicka, 2021). Only three of the participants reported receiving help from their neighbours and the community at large, Martin, Jabulani and Lesetja. The other participants did not report receiving support from their neighbours or rather this was substituted by support from other sources which masked the need for community support. These findings support the notion that upon an individual sustaining a disability, communities are subject to transformation and may constitute an invaluable source of support for a person with disability.

Kriegel et al., (2020) suggested that while family and friends provide important sources of support, neighbours "can facilitate support through anonymous, but meaningful interactions. These interactions can help to compensate for increased social isolation and smaller networks of peers" (p.285). The neighbourhood can be defined as "community of people inhabiting a limited and relatively isolated territory, possessing and appreciating a common tradition, common values and symbols and service and cultural institutions, being aware of their unity and distinctness and ready for community action and living in a sense of belonging and internal safety" (Górnicka, 2021, p.52). In the study, communities and neighbours were reported to have offered support and help to the family of the person who has sustained a TBI as well as offer support to the individual themselves by provision of assistance with transportation to the

hospital, attending therapy sessions with them and going to church or traditional healers with them.

Fundamentally, interpersonal relationships impact on the decision-making process of persons with TBI, with regards to which pathways of care they need to follow post-discharge. A disruption in these relationships, rendered persons with TBI vulnerable to feelings of neglect and isolation, as mentioned by the participants. Thereby, affecting help-seeking behaviours, such that the participants who felt that their friends were not present in their lives anymore had to seek support elsewhere and form bonds elsewhere. Where they would feel empowered and obtain a sense of belonging with fellow TBI survivors. Therefore, interpersonal relationships, as a social factor, are important to consider when thinking about pathways to healthcare for persons with TBI as they ultimately affect where persons with TBI go to for help.

5.2.3.3 Cultural Contexts

Family cultural beliefs and traditions have also been found to have influenced persons with TBIs' cultural beliefs and customs from generations to generations (Grossman & Magaña, 2016). For instance, if one's family believes that a sudden disability has an underlying cause and therefore requires a more traditional approach to intervention, this has the potential to influence persons with a disability and their perceptions about disability and intervention thereof (Kamalia, et al., 2019; Idang, 2015), especially the younger generation. Younger members of the family internalize beliefs in family customs and practises because this is what has been learnt and has been passed down by their families (Kamalia, et al., 2019). However, these values and beliefs in customs and rituals, depend on time and location and are often not static, meaning they can change overtime (Idang, 2015).

For instance, two of the participants, Sibusiso and Nhlanhla revealed that they come from families that held strong beliefs in ancestors and rituals to reverse a disability and this was something they grew up believing in. However, for them, being young men living in modern times, they understood other causes of disability. They also understood what they were required to do to heal from the impairments from their TBI. Take Sipho, amongst others for example, he, from the onset, reported that he believed God and his ancestors were behind his injury. Therefore, he consulted traditional healers and went to church to confirm his suspicions. They did not necessarily follow what their families had been following for several years. However, these were beliefs they also had in sudden disability.

Families of some of the participants in this study viewed traditional healers as better suited to advise on ceremonies that needed to be performed to reverse the disability, as reported by the participants. At this time, the participants with the TBI did not decide to seek help from traditional healers, the family somewhat stepped in or overrode the participants' preferences (if any) to manage risks because of the longevity of the relationship they have had with the person with TBI and because of knowing what is best for them at the time. Previous literature has identified that minimising risk is often a key factor that influences the outcome of decisions about life after TBI (Know, et al., 2017). Here we see that, decisions taken for the person with TBI are mostly based on knowing a person well enough and on historical family cultural practices. That automatically becomes a prerequisite for providing support and deciding on the best form of support that the person with TBI needs.

This aligns with previous research by Knox et al, (2016), that people contributing to decisions about pathways of care, are usually those who know the individual well and understand the consequences of the brain injury for the person (Knox, et al., 2016). The families mentioned in this study might have realised the debilitating impact that TBI has therefore came up with means to offer help and support. Also knowing the person well, meant understanding their cognitive capacity, life experiences, strengths, and weaknesses at the time and this warranted taking decisions to improve all of the areas that had deteriorated because of the TBI.

Saint et al. (2018) is in support of the researcher's findings that, cultural determinants such as symptom experience, beliefs and interpretation, and cultural contexts can influence people's perceived need and help-seeking behaviours. People's cultural beliefs and practices affect how they seek care and from whom, such that these beliefs can influence the communication and interaction between the person with a disability and different healthcare providers. Seeing that some people in African cultures and contexts believe that a sudden disability is the will of a higher power, this may make them a bit more reluctant in receiving health care from other sources outside their usual, historical, generational customs and beliefs (Saint et al., 2018). Following their family customs, led persons with TBI to seek help from prophets and/or traditional healers because of the belief that they can come up with divine interventions which will help them heal.

Likewise, while many people of a culture hold common beliefs and practices, there can be many variations between individuals of the same culture and context (Idang, 2015). Idang (2015) mentions that in talking about African cultures and values, the presupposition must not

be that all “African societies have the same explanation(s) for events…” (Idang, 2015, p.97). In the findings, it is noted that some of the participants did not necessarily follow the cultural route of seeking help. Some of the participants mentioned not believing in consulting traditional healers to get help rather they understood that there were other professionals trained to help with TBI and the impairments sustained thereof. These participants used primary care physicians and other sources of health care to assist with their impairments. Therefore, people’s individual identities and what they valued, outside their families, were seen to also influence care-seeking behaviours, as mentioned above in the psychological factors that influenced help-seeking.

5.2.3.4 Education

Education is a stable aspect of socio-economic status that is established in early adulthood and can be easily measured. Regions with low levels of education and poverty often have limited access to and lower quality of healthcare (Ihaji et al., 2014). It is widely acknowledged that education has a positive impact on the use of Westernised healthcare. Mahgoub (2020) study indicated that, individuals’ level of education can influence where they go to for help. Mahgoub (2020) study aimed to investigate the relationship between education level and attending traditional healers. Their study found that 57.9% of people who did not graduate from higher education sought help from traditional healers, whereas 51.6% of people who graduated did not seek help from traditional healers.

The findings of their study agree with many studies that, people who consult with traditional healers usually have low socioeconomic status and are usually not educated (Mahgoub, 2020). The results of Mahgoub (2020) study agree with this current study, as some of the participants indicated unwillingness to attend or to seek care from traditional forms of intervention due to their level of education. Sibusiso alluded to being educated, he indicated that he had a diploma. This brought the understanding that his level of education motivated him to seek care from Westernised medical facilities. Being educated and having a certain level of education influenced his outlook on disability and the help that he required to fully recover and be healthy again.

These results agree with some available findings from Ihaji et al. (2014) study. They aimed to look at “the impact of educational level, sex and church affiliation on health seeking behaviour” (p.314) using a questionnaire that was self-constructed to elicit responses from participants on their health seeking behaviour. Their results revealed that educational level was

significant on health seeking behaviour. Specifically, participants who had high educational level obtained higher scores on health seeking behaviour. This implies the acceptance of their first hypothesis which stated that "participants with high educational level will differ significantly on health seeking behaviour from those with low educational level" (Ihaji, et al., 2014, p.314). A study by Monazza and Greta (2010) as cited in Ihaji et al., (2014) also found that better educational levels were positively related to better attitudes toward healthcare.

It was also noted that the participants' level of education was affiliated with their ages. It was found that their ages seemed to have influenced where they went to seek help and support. For instance, the older participants believed in going to traditional healers to receive help because of the long-standing traditional beliefs they had in sudden injury, i.e., Ephraim a 65-year-old man. Whilst, the younger participants, due to being educated, understood the roles that western practitioners had to play with brain injury and impairments, hence they consulted them for help. For instance, from the results section we learnt that one of the participants, Nhlanhla, was a 25-year-old man and he did not believe in receiving help from traditional healers, although his father took him there. He instead believed in consulting Western practitioners to help him recover from his impairments. Sibusiso, is a 32-year-old man, he spoke quite intensely about having a diploma hence knowing the help he needed due to being educated. Therefore, it can be concluded that the participants' ages and level of education, as social categories or constructs did indeed have an influence on support-seeking behaviours or rather pathways of care and support.

There are some people who preferred biomedical providers rather than traditional providers of care. Primarily because of their ability to provide tests that guide diagnosis and treatment (Hooft, et al., 2020). In a study conducted by Nyundu and Naidoo (2016) it was revealed that the main reason for young people to visit traditional healers was because it was part of their family tradition or culture, or they were largely encouraged by their parents to do so. Hence, alluding to socialisation and strong parental influence (Nyundu & Naidoo, 2016). The study also found that young people seldom use the services of Sangomas or traditional healers because they are aware of the benefits of education. In a sense, this outlook resonates with the claims that young people who are generally better educated than their parents are less inclined to go to Sangomas or traditional healers to seek help and support (Nyundu & Naidoo, 2016).

In conclusion, the participants who are younger, who have some level of education and who understand the role of therapists or physicians in helping with the recovery from TBI impairments in speech, language, swallowing, mobility, cognition, emotions, are more likely to seek help from people who are professionally trained to help with these impairments (Hooft, et al., 2020). It is therefore argued that young people who are more educated, know of health complications, the availability of different healthcare facilities, and use this information more successfully to sustain and accomplish a good status of health.

5.2.3.5 Financial issues

The COVID-19 pandemic negatively affected the economy, both locally and globally. The provision of support services was utterly disrupted, and these are support services that were crucial, especially for persons with TBI who relied on support services. The restriction and lockdown following the pandemic resulted in a discontinuation of face-to-face therapy sessions. Attendance of sessions telephonically and via social media platforms was encouraged. However, this resulted in high and rising costs and expenditure, and this left persons with TBI in strained conditions and not being able to access the therapy services they were initially receiving. In the findings, Lesetja, Lebone and Sipho reported that due to the lack of money to purchase data and airtime, to attend therapy sessions online, receiving help and support during this period was rather difficult or impossible.

A study conducted by Friedman (2022) investigated the financial challenges experiences by individuals with disabilities during the COVID-19 pandemic. The study found that people with disabilities tend to have lower income and experience greater financial insecurity compared to those without disabilities. They are more likely to lack basic needs than people who are not disabled. Their study also found that it is possible for people with disabilities to be "unemployed, underemployed, paid lower wages, and have fewer advancement opportunities than nondisabled people" (Friedman, 2022, p.2) as is the case with the participants in this study who were unemployed after their injuries. Their financial issues affected their access to healthcare and help-seeking, especially during the pandemic. "People with disabilities' increased likelihood of living in poverty not only resulted in them experiencing more financial hardship, but it also contributed to other forms of hardship, such as food insecurity" (Friedman, 2022, p.2). As Ephraim mentioned that he was not able to get food from his providers of help (Headway) because he was not able to attend Headway during the pandemic. Headway provided the participants with food packages and them not being able

to go to Headway impacted on help-seeking patterns and in turn affected mental health, well-being, and overall quality of life.

In conclusion, this was difficult especially for poor populations and had negative outcomes, affecting participation in activities and overall quality of life (Adebiyi, et al., 2021). Online services required financial capability and technical support, therefore, for participants who had no prior experience with technology or who did not have money to access these platforms experienced challenges in accessing help via digital platforms. Thus, they reported not being able to attend online sessions and this further delayed their improvement in therapy.

5.3 Conclusion

In conclusion, the findings from this study revealed that for most of the participants, at the time of discharge, it was either the family or the physicians or a combination of both, that played a role in deciding on the pathways of care that the persons with TBI needed to follow to regain functionality. It was later in the progression of the injury or in the recovery stages where the person with TBI was then able to also decide on which pathways of care that they personally wanted to follow based on various psychological factors such as existing emotions, their personal beliefs, their values, and identities as an individual. In the findings, we also see that, persons with TBI follow various pathways of care post hospitalisation. This was also based on biological and social factors such as impairments from TBI, financial circumstances, family traditions, education level and age. Also, the participants did not necessarily follow one source of support but rather combined them to suit the various factors at play during their time of discharge and throughout the progression of their healing journeys.

The biopsychosocial model enabled the comprehension that a patient's decision on pathways of care is guided by several factors that ultimately impact each aspect of the patient's life. The above findings support the hypotheses that not only one source of support is pursued after hospitalisation, as each source has a different role to play in the person with TBI's life. Each of the participants had a different pathway they followed based on the various systems at play surrounding their disabilities. Therefore, the integration of the different support sources has proven to result in valued outcomes for the participants in the study. As well, the decolonised method of research employed by the researcher, enabled the understanding of local people's perceptions of their injuries and psychosocial factors affecting their help-seeking behaviours. By not only focusing on Eurocentric methods to research and Western principles of healthcare, the researcher was also able to obtain local people's worldviews, experiences,

and voices on care-seeking. As well as advocate for the need for healthcare providers to extend healthcare beyond just biological aspects and consider the psychosocial and spiritual processes involved.

CHAPTER 6: IMPLICATIONS AND CONCLUSIONS

6.1 Introduction

The previous chapters served different purposes in this research. Chapter 1 provided an overview of the study, contextualising the research problem and stating the aims. Chapter 2 presented a comprehensive review of the existing literature on TBI and explored how persons with TBI seek help and care after hospitalisation. In chapter 3, the research methodology used in the study was described. Chapter 4 contained the presentation of the results. Chapter 5 discussed the results by referring to the theoretical framework, specifically the biopsychosocial model. The main goal of this chapter is to provide a summary of the whole research and highlight the main findings, conclusions, and recommendations.

6.2 Summary of findings

The purpose of the study was to explore help seeking behaviours of persons living with TBI in Soweto, Johannesburg, South Africa. The study aimed to elicit individual responses from adults with post-acute TBI living in Soweto, Johannesburg regarding the care and support seeking pathways they follow. The main research objective was thus to elicit responses from persons with TBI regarding the different support pathways that they followed and continue to follow during their journey of seeking care post hospitalisation in their home languages. The theoretical framework was the biopsychosocial model that rests on the premise that biological, psychological, and social factors need to be integrated and considered when thinking about a holistic approach to healthcare for people with disabilities (Turabian, 2018). Patient's values, beliefs, social circumstances as well as biological vulnerabilities need to all be considered to promote positive health outcomes. From a care seeking perspective, it means that the choices that the persons with TBI make when choosing a pathway of care are influenced by a plethora of factors and the choice that one ultimately chooses is because of the interplay of these factors.

This study also rests on the concept of decolonization of research methods in studying disability, particularly TBI. "Disability studies are still characterised by the supremacy of ideas from the global North to the exclusion of experiences and understandings of those in the global South" (Ned et al., 2022, p.2). Although most people with disabilities globally are found in the global South, their voices, knowledge, and experiences are unknown and are not often encouraged by global North researchers. This is evident in our country, South Africa where, as Ned et al. (2022) puts it, "disability research and provision have been historically interlinked with the hierarchical racialised power which has informed issues of access and use" (p.3). The

researcher of this study aimed to decolonize previous research methods in studying African populations with disabilities, i.e., TBI.

The researcher conducted the study in the participants' home languages to allow for authentic voices in providing a broad description of support seeking after hospitalisation. The researcher aimed to preserve the participants' voices and knowledge in relaying the pathways of care they followed, without being spoken for by their caregivers and/or healthcare providers. Participants in the study were recognized as being a crucial part of the entire research process and their worldviews on care-seeking were encouraged and welcomed by the researcher. The participants mentioned receiving help and support post discharge from family members, peers, support groups, community members, church, traditional healers, and western practitioners such as speech therapists, psychologists, occupational therapists, and physiotherapists. Seeking help from these various sources was based on an integration of various factors.

From the results section, it was revealed that persons who suffered from TBI do not seek help from one source. The participants sought help from several sources. In some instances, one would seek help from both Western methods of care as well as traditional methods of care. These are sources of help that operate differently, for example prophets and traditional healers generally practice divination based on their belief systems which posits that, illnesses and mishaps have a spiritual element to them. The traditional healers can sometimes prescribe rituals and give muthi when helping persons suffering from TBI (Lambert et al., 2020; Moshabela et al., 2017). On the other hand, Western medicine practitioners do not believe in divination and often use methods such as various forms of therapy and counselling to help persons with TBI on their journey back to health (Liu et al., 2017). The overarching reason for choosing a particular pathway of care is the need to get well, hence persons with TBI would do anything in their quest to get well. In some instances, it is the person with TBI that makes the decision independently, while in some cases the decision can be influenced by family, friends and/or physicians.

Due to the nature of their brain injuries, the participants in this study may not have been involved from the onset in the decision-making about which pathways of care to follow post discharge. Their doctors and family members took on the role to decide on the best care and support for the person with TBI, be it receiving care from the family, friends and neighbours, rehabilitation therapists and support groups after hospitalisation. Participants may have been involved in decision-making later in their recovery stages. However, the initial choice of a

pathway of care was often influenced by doctors and immediate family members and the choice of the person with TBI would come at a later stage when they would have recovered enough to make own decisions. This is not to discount the influence of other factors embedded in the theoretical framework of the study.

It was also revealed that the impairments resulting from TBI, which include among others, impairments in speech, swallowing, mobility, as well as emotional impairments motivated them to seek care from Westernised medical facilities as out-patients because they were more familiar with the effectiveness of Westernised care in private or even public medical facilities as advised by medical physicians and/or significant others. For example, speech therapists were consulted and seen as useful in helping them work on their speech and swallowing impairments, physiotherapists to help with physical impairment or counsellors to address their emotional impairments. Essentially, as the biopsychosocial model proposes, disability is not only about the impairments that follow but it is also about the "sociospatial, environmental, cultural, and economic constructs that produce and reproduce it" (Ned et al., 2022, p.3). Beliefs held about disability should be integrative and people with disabilities should be given active roles in society to exercise own beliefs, values, and attitudes. This is integral to the participation and inclusion of people with disabilities.

The biopsychosocial model enabled the researcher to draw up a conclusion that indeed there are various processes at play when persons with TBI decide on pathways of care to follow post discharge. It is not only biomedical processes that need to be considered to understand help-seeking behaviours. All these processes are interconnected and cannot be viewed separately. Processes such as the participants' social contexts, beliefs, religion, finances, cultural norms, impairments, level of education, are not to be disregarded as they enable us to understand the help-seeking patterns of persons with TBI. As well as guide us towards more holistic interventions to disability.

Lastly, on the COVID-19 pandemic, alternatives were put in place to ensure service delivery and help provision for persons with TBI. However, COVID-19 was noted to have affected support seeking and had a prominent effect on the participants' progress, mental health, lifestyles, finances, and food security. Some of the participants averred that the COVID-19 pandemic impacted their ability to attend therapy sessions as well as receiving food from Headway and help when they experienced emotional difficulties and did not have people to talk to about their feelings and emotions. COVID-19 lockdown protocols brought on feelings

of loneliness because they were not able to socialise with people anymore and this brought on a lot of negative thoughts and emotions.

6.3 Strengths

The study is particularly valuable because it provides first-hand accounts of the experiences of persons with TBI and cognitive-communicative disorders. The researcher gave persons with TBI a voice. Persons with cognitive-communicative disorders who have been previously excluded from research due to the nature of their impairments (Neille, 2021) were given a voice to speak for themselves. By allowing these individuals to express their own perspectives and experiences, the study sheds light on the unique challenges they face and the factors that influence their decision-making processes when seeking healthcare. Neille (2021) further adds that the experiences of persons with TBI have historically been provided by proxy accounts. They have often been excluded based on their "cognitive-communicative disability and language proficiency" (Neille, 2021, p.1).

In agreement with the tenets of Neille (2021)'s study, the researcher did not rely on proxy accounts of caregivers and/or healthcare workers to speak for the persons with TBI, instead these were first person narratives written in their home languages. In this study, the researcher preserved the quotes from the participants as they were. Often researchers rely on translated material and present participants' utterances in a different language from the source language (Ozolins, et al., 2020) and essentially losing the participants' own voice. The researcher also put reasonable accommodations for this study to ensure that she can have a conversation with persons with TBI, such as the use of supportive communication techniques.

The researcher held a perspective from both a traditional and a western point of view due to her being a Black African woman who is also practising as a Western practitioner. This was regarded as advantageous because the researcher was aware of the care that we speech therapists offer from a medical perspective and aware of African people's reasons of seeking care traditionally. So, this enabled the researcher to avoid disregarding people's beliefs with regards to their care-seeking behaviours based on their definite worldviews and it ensured that the researcher avoids imposing her own beliefs on care-seeking on the participants. By understanding that we, the researcher, and the participants, may all be from African backgrounds but that did not mean we all held certain values and beliefs with regards to seeking help and support.

6.4 Implications for research and practice

Firstly, this study aimed to advocate for the need of the decolonisation of lenses that are used when studying TBI. The researcher of this study used methods to decolonise research with persons with disabilities, TBI. They were held central to the entire research and governed the outcome of the study. In the findings, it was highlighted that it is not always proper to focus on therapy and rehabilitation as defined in the medical sense but to also focus on culture, for example, as it might impact the choices that the persons with TBI ultimately make. Hitherto, research methods in studying TBI have predominantly used Western lenses and have failed to consider the impact that the person's lived realities have on the choices made. The researcher emphasized the importance of self-reflection among other researchers throughout the research process. This includes understanding the power dynamics, designing the study, formulating interview questions, selecting data collection techniques, and attentively considering their responses to participants' comments.

Thus, future research especially in an African setting should consider the impact that culture, family settings, level of education and beliefs in witchcraft and religious beliefs, individual preferences, values, attitudes have on the choice of pathways to care. According to Ned et al. (2022), the challenges faced in disability research require disability scholars and activists to engage in more dedicated activism and critical scholarship. The findings of this study can be transformed into actionable steps that advance social justice and promote culturally appropriate research practices by decolonizing research methods. With this study, the researcher advocates for research on persons with TBI to be centered around them and that their impairments should not hinder them from being given an opportunity to provide personal accounts of living with a TBI. Researchers and disability activists should aim to adopt strategies and techniques that will accommodate persons with disabilities (TBI) in research.

Moreover, there needs to be an adequate understanding of their cultural context including beliefs and attitudes they have towards a disability i.e., mental illness, TBI, to enable effective implementation of care and support interventions (Lambert et al., 2020). To address gaps in research, it is important to note that, persons with TBI must not only be exposed to certain sources of support but be allowed to express or explore other pathways they may follow to seek support. They need to be managed holistically in terms of their spiritual, emotional, physical, and cognitive needs in order to be able to provide appropriate services and support to ensure their desired health outcomes and desired health status.

A holistic understanding of the help-seeking behaviours of persons with TBI is necessary to assist service providers like rehabilitation therapists and medical doctors, in recognising impairment and functional needs. Whilst also being aware of the belief structures of persons with TBI. This holistic focus will reconceptualise TBI and disability as a whole within an expansive framework and may contribute to appropriate healthcare provision (Wright et al., 2016). Furthermore, this study advocated for care providers to develop an understanding of the power dynamics at play when suggesting sources of care and support post discharge for persons with TBI and how these power dynamics by doctors, therapists, families and/or friends, ultimately impact on the choices made on which pathways of care to follow post-discharge, earlier on in the recovery stages.

Persons with disabilities, particularly TBI need to be given access and not just physical access but emotional and supportive access as a way of ensuring that they feel empowered to participate in their communities. Supportive and emotional access is embedded in how patients are advised on care pathways that are available to them. For instance, the focus should not just be on Western practices but should take into account other factors that may impact on their emotions and outlook, such as their actual impairments, their social circumstances, cultural and religious beliefs, education, individual preferences, and values. All of these have a bearing on the ultimate choice and all these factors were reported to have impacted the help-seeking behaviours of persons with TBI.

Furthermore, the study aimed to create an understanding of the various help seeking pathways that persons with TBI, in Soweto, follow in the post-acute phase, such as their families, communities, their peers, support groups, psychotherapists or rehabilitation therapists, churches and traditional healers. Soweto was chosen to extend to the knowledge of the makers of policies and service providers on contextual issues that impact care-seeking for persons with TBI living in these communities. The findings of this study can be used by health researchers and practitioners, particularly health promoters, to develop programs that promote health and are culturally relevant to individuals from these communities.

The study's findings enable the understanding that for some people with TBI, their reduced level of functioning and sudden impairments would be attributed to punishment from supernatural forces thus they believed attending to those in terms of performing ritual ceremonies and receiving prayers was important to them to eliminate the punishment. Thus, for them to embark on the journey to wellness, they would require interventions that cater not

only for their impairments but interventions that allow them to choose the pathways to care as they deem fit. The wishes of the patients, while remaining sacrosanct, should be balanced with the culture, religion, beliefs, and family as well as medical and rehabilitation considerations. It behoves practitioners and all the other stakeholders to be considerate of the interplay of biological, psychological, and social factors which have been found to influence pathways to healthcare seeking.

As this study has proven, biological, psychological, and social factors do indeed impact help-seeking behaviours and pathways of care. Practitioners need to be aware of these factors to prevent culturally inappropriate and ineffective interventions to be able to improve clinical outcomes for persons with TBI. Also, it is not sufficient that persons with TBI have access to care but that the care should be provided in an environment that is comfortable for the patients and that the care is holistic (Wright et al., 2016). It might therefore be necessary for more research to be carried out not only with persons with TBI but also with survivors who have undergone rehabilitation and healing so that there can be more nuanced understanding of the whole process and not just the choice of pathways to care.

At an educational level, the researcher recommends training practitioners to take into account the needs of the patients while at the same time being cognisant of *inter alia* the religious, spiritual, social, and cultural needs and imperatives of the persons with TBI. It might be prudent to include, into the medical curriculum, modules that focus on culture, religion, and spirituality So that medicine and allied health sciences become more holistic and also be able to take into account the plethora of factors; physical, mental, social, spiritual and others which impact not only a person's health and psychological wellbeing but also the pathways of care that are chosen.

Medical care is still very Eurocentric, and it would be very helpful if policy makers would take steps to make sure that medical practice becomes more Afrocentric by considering the various factors that impact on care-seeking and overall health outcomes for persons in Black African communities. Policy makers may also recognize the factors that have an influence on help-seeking behaviours of persons with TBI and plan to enhance policies that will inculcate patterns of help-seeking behaviour amongst this population. The policies should put at the centre of practice and thinking, the lived realities of the persons with TBI and their beliefs system to the extent that they have an influence on the pathways of care that are eventually chosen. This is to say, policy should put African traditional religion, culture, and

spirituality at the same footing with Western medicine, with a view to allowing patients to move seamlessly between various methods and approaches of healthcare.

6.5 Limitations

The sample of the study was small, and it was limited to a specific group of people, namely those with TBI living in Soweto. This implied that the study's findings only apply to this particular population and may not be generalizable to all populations with TBI residing in other areas. The only research site that was used for the study was Headway, this may have potentially influenced the mention of Headway by the participants in their responses, especially since these were people with TBI who were contextually bound. The study also had more males than females therefore additional perceptions on help-seeking behaviours, by females, that may influence care may not have been fully elucidated. The study being qualitative cannot be generalised and therefore has limited applicability and reproducibility to other situations. The sample size also meant that the findings cannot be generalised. However, it should be noted that qualitative data aims not to be generalisable but to provide "a rich, contextualized understanding of some aspect of human experience through the intensive study of particular cases" (Polit & Beck, 2010, p.1451) and this was achieved with this study.

It might be necessary to carry out research that involves a bigger population and would involve more rigour so that general conclusions can be arrived at. This would allow for a more comprehensive understanding of the unique challenges faced by persons with TBI and how they differ from other disabled populations. In the same vein, it might be advisable to carry out quantitative research so that the results can be generalisable, as well as conduct research using multiple case-studies instead of focusing on just one research site, as is the case with this study. It might also be prudent to carry out longitudinal research so that, instead of getting participants at a point in time, views can be elicited over a long period of time to see if considerations that are made when choosing pathways to care change over time and as the needs of persons with TBI change.

6.6 Research conclusions

The research focused on people who are helped a care facility for people with TBIs that is in Soweto, Johannesburg, South Africa. The study aimed to elicit individual responses from adults with post-acute traumatic brain injuries living in Soweto, Johannesburg regarding the care and support seeking pathways they follow. The study was conducted using the biopsychosocial model as the framework. The study was also conducted using qualitative

approach and semi-structured interviews to elicit responses from the persons with TBI. The interviews were transcribed verbatim, and participants' quotes were preserved in their home languages with English translations in brackets. The results were presented using the themes generated. The results were then discussed with reference to the theoretical framework and referring to literature.

The research found out that when persons with TBIs are deciding on pathways to care the route is not always linear and there are many considerations that are made and various factors that are considered. The choices of care providers range from Western practitioners, pastors, traditional healers, prophets, family, and friends among others. The choice is determined by an interplay of factors that include impairments from TBI, individual attitudes and values, family traditions and culture, religious beliefs and social circumstances and institutions. The study also found out that COVID-19 pandemic had an impact on the persons with TBI's ability to seek and get care and resulted in feelings of loneliness, depression, and anxiety. The study also found out that the care that is available to persons with TBIs is usually Western medicine practice based and there is a need to decolonise medicine and all other practices that help persons with TBI on their paths to wellness. There is a need to be more cognisant of the importance of culture, religion, and social beliefs on healthcare.

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APPENDIX A

PARTICIPANT INFORMATION SHEET

Dear Sir/Madam

My name is Lethabo Maleka. I am a speech therapist and audiologist, pursuing my Masters research in Speech Pathology at the University of the Witwatersrand. In fulfilment of my studies, I have to undertake a research project. The title of my project is: *An exploration into the pathways of care and support followed by persons with post-acute traumatic brain injuries living in Soweto, Johannesburg.*

What is involved in the study?

I would like to invite you to take part in an interview telling me about the various help-seeking pathways you have followed since your Traumatic Brain Injury (TBI), TBI is defined as an alteration in brain function (Maasdorp, et al., 2020; Malec, et al., 2017) presenting as altered level of consciousness, confusion, sensory and motor neuron neurological deficit (Barman, et al., 2016) that results from a penetrating (open head) or blunt (closed head) force to the head (Maasdorp, et al., 2020; Malec, et al., 2017). This activity will involve telling me, about any pathways you have followed to get support as well as when and for what purpose you chose to follow these specific care and support pathways. The interview will last approximately one hour. With your permission, I would also like to record the interview using an audio recorder and only I will have access to the recordings. With your permission I would like to keep anonymised copies of the interview transcripts to potentially re-analyse in the future.

What does your participation entail?

You will not have any direct benefits for participating in this study, and there will be no costs to you if you do decide to participate in this project. There also will be no disadvantages or penalties for not participating. You may withdraw at any time and do not have to answer questions if you do not want to. I will keep any identifying information confidential. The information you give to me will be kept securely and I will not disclose it to anyone else. For my final report I will use a pseudonym (fake name) to represent your participation. Should you experience any discomfort during the interview we will stop and resume another time. You will be talking about a topic that may bring up negative emotions and make you upset, if you do feel this way, I will arrange for you to speak to a counsellor online or in person at Headway,

Umthombo Building – 1st Floor, Room U132, Braamfontein East Campus , Private Bag 3, WITS 2050
T +27 11 717 4577 | E sppa.SHCD@wits.ac.za | www.wits.ac.za/shcd/speech-pathology-and-audiology/

Ms Mia Pienaar, during and after the study without charge. Her contact number is 011 442 5733, and her email address is counselling@headwaygauteng.co.za, I will facilitate your access to the counsellor.

Should you have any ethical concerns regarding the study you may contact the Human Research Ethics Committee (Non-Medical), telephone +27(0) 11 717 1408, email hrecnon-medical@wits.ac.za.

Yours sincerely,



Masters Researcher

Lethabo Maleka, 840320@students.wits.ac.za, 074 574 8698

Research supervisor

Dr Joanne Neille, joanne.neille@wits.ac.za, 011 717 4574

Research supervisor

Dr Khetsiwe Masuku, khetsiwe.masuku@wits.ac.za, 011 717 4584

APPENDIX A:1

PROXY PERMISSION SHEET FOR CAREGIVER

Dear Sir/Madam

My name is Lethabo Maleka. I am a speech therapist and audiologist, pursuing my Masters research in Speech Pathology at the University of the Witwatersrand. In fulfilment of my studies, I have to undertake a research project. The title of my project is: *An exploration into the pathways of care and support followed by persons with post-acute traumatic brain injuries living in Soweto, Johannesburg.*

What is involved in the study?

I would like to invite possible persons with TBI from the Headway site in Soweto to take part in an interview as well as a questionnaire regarding their demographic information. I would like to invite them to take part in an interview telling me about the various help-seeking pathways they have followed since their TBI. This activity will involve telling me, the researcher, about any pathways they have followed to provide support for them as well as when and for what purpose they chose to follow these specific support pathways. The interview will last approximately one hour. I would also like to record the interview using an audio recorder and only I will have access to the recordings. With their permission and yours as their caregiver, I would like to keep anonymised copies of the interview transcripts to potentially re-analyse in the future.

What will participation entail?

The participants will not have any direct benefits for participating in this study, and there will be no costs to them if they do decide to participate in this project. There also will be no disadvantages or penalties for not participating. They may withdraw at any time and do not have to answer questions if they do not want to. I, as the researcher, will keep any identifying information confidential. The information provided to me will be kept securely and I will not disclose it to anyone else. For my final report I will use a pseudonym (fake name) to represent their participation. Should any discomfort be experienced during the interview I will stop and resume another time. I understand that they will be talking about a topic that may bring up negative emotions therefore I will arrange for them to speak to a counsellor online or in person at Headway, Ms Mia Pienaar during and after the study without charge. Her contact number

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is 011 442 5733, email address is counselling@headwaygauteng.co.za, I will facilitate access to the counsellor.

Should you have any ethical concerns regarding the study you may contact the Human Research Ethics Committee (Non-Medical), telephone +27(0) 11 717 1408, email hrecnon-medical@wits.ac.za.

Yours sincerely,



Masters Researcher

Lethabo Maleka, 840320@students.wits.ac.za, 074 574 8698

Research supervisor

Dr Joanne Neille, joanne.neille@wits.ac.za, 011 717 4574

Research supervisor

Dr Khetsiwe Masuku, khetsiwe.masuku@wits.ac.za, 011 717 4584

APPENDIX B

CONSENT FORM FOR PARTICIPANT

The title of project: *An exploration into the pathways of care and support followed by persons with post-acute traumatic brain injuries living in Soweto, Johannesburg.*

Name of researcher: Lethabo Maleka

I, _____, agree to participate in this study about the care-seeking pathways that I have followed since my TBI. In giving consent I understand and agree to the following:

- I understand and agree that I will be asked to participate in an interview session that will last for about an hour with the researcher to discuss the different help-seeking pathways that I have followed since my TBI.

YES	NO

- I understand and agree that the interviews will be audio recorded and the researcher will be taking notes throughout the sessions and that another researcher may be used to help translate the information.

YES	NO

- I understand that I can choose to leave the research whenever I want to, and I have no obligation to participate.

YES	NO

- I understand the potential risks and that there are no immediate benefits involved in the research study.

YES	NO

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- I understand that my identity will be kept anonymous and will be replaced with a pseudonym (fake name) throughout the whole research process.

YES	NO

- The researcher has also thoroughly explained the research to me in a language that I understand, and I was given an opportunity to ask questions about the research project.

YES	NO

Participant Name (Print) **Participant Signature**

_Lethabo Maleka _____ __ _____

Name of person seeking consent **Researcher's Signature**

Date

APPENDIX B:1

CONSENT FORM FOR CAREGIVER

The title of project: *An exploration into the pathways of care and support followed by persons with post-acute traumatic brain injuries living in Soweto, Johannesburg.*

Name of researcher: Lethabo Maleka

I, _____, the caregiver of _____agree to participate in this study about the care-seeking pathways that_____ has followed since his/her TBI. In giving consent I understand and agree to the following:

- I understand and agree that I will be asked to participate in an interview session that will last for about an hour with the researcher to discuss the different help-seeking pathways followed since his/her TBI.

YES	NO

- I understand and agree that if it happens that she/he is unable to remember some of the help-seeking pathways followed I can assist in answering the interview question.

YES	NO

- I understand and agree that the interviews will be audio recorded and the researcher will be taking notes throughout the sessions and that another researcher may be used to help translate the information.

YES	NO

- I understand that I can choose to leave the research whenever I want to, and I have no obligation to participate.

YES	NO

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- I understand the potential risks and that there are no immediate benefits involved in the research study.

YES	NO

- I understand that his/her identity and mine will be kept anonymous and will be replaced with a pseudonym (fake name) throughout the whole research process.

YES	NO

- The researcher has also thoroughly explained the research to me in a language that I understand, and I was given an opportunity to ask questions about the research project.

YES	NO

_____ _____

Caregivers Name (Print) **Caregivers Signature**

_Lethabo Maleka _____ __ _____

Name of person seeking consent **Researcher's Signature**

_____

Date

APPENDIX C

BIOGRAPHIC QUESTIONNAIRE

GENDER	○ Male ○ Female
AGE	○ 18-25 ○ 26-45 ○ 46-66 ○ 67+
HIGHEST LEVEL OF EDUCATION	○ No schooling completed ○ High school ○ College ○ University ○ Other
CAUSES OF TBI	○ Motor Vehicle Accident ○ Pedestrian Vehicle Accident ○ Gunshot ○ Other
EMPLOYMENT STATUS	○ Unemployed ○ Self-employed ○ Student ○ Retired ○ Unable to work

APPENDIX D

SCHEDULE FOR INTERVIEWS

The interview will be conducted in the following way:

Introduction: The researcher will introduce herself and provide information about herself and her interest in this area of research.

Permission to record: The researcher will request and obtain permission from the participant to audio record their interview for later transcription and analysis.

Purpose of the study: The researcher will describe why they have been asked to participate in the study and will provide the participant with the aims and objectives of the research study and how their information will benefit the findings of the study.

The largest part of the interview will be guided by questions designed to elicit specific information, as detailed below:

Interview questions for the person with TBI:

- What are your experiences of living with a TBI?
- Where did you seek care and support after hospitalisation/ Which sources of care and support did you go to after hospitalisation?
- For what purpose or reason did you seek care and support from those sources that you mentioned?
- What kind of treatment/intervention/support did they provide you with?
- How did COVID-19 affect your care-seeking behaviours?
- What kinds of support would you like or would have been helpful?

APPENDIX E

COUNSELLOR INFORMATION SHEET

Dear Sir/Madam

My name is Lethabo Maleka. I am a speech therapist and audiologist, pursuing my Masters research in Speech Pathology at the University of the Witwatersrand. In fulfilment of my studies, I have to undertake a research project. The title of my project is: *An exploration into the pathways of care and support followed by persons with post-acute traumatic brain injuries living in Soweto, Johannesburg.*

What is involved in the study?

I would like to invite possible participants at the Headway site in Soweto to take part in an interview as well as a questionnaire regarding their demographic information. I would like to invite the participants to take part in an interview telling me about the various help-seeking pathways they have followed since their TBI. This activity will involve telling me, the researcher, about any pathways they have followed to provide support for them and their families as well as when and for what purpose they chose to follow these specific support pathways. The interview will last approximately one hour. I would also like to record the interview using an audio recorder and only I will have access to the recordings. With their permission I would like to keep anonymised copies of the interview transcripts to potentially re-analyse in the future.

What participation entail?

The participants will not have any direct benefits for participating in this study, and there will be no costs to them if they do decide to participate in this project. There also will be no disadvantages or penalties for not participating. They may withdraw at any time and do not have to answer questions if they do not want to. I, as the researcher, will keep any identifying information confidential. The information provided to me will be kept securely and I will not disclose it to anyone else. For my final report I will use a pseudonym (fake name) to represent their participation. Should any discomfort be experienced during the interview I will stop and resume another time. I understand that they will be talking about a topic that may bring up negative emotions. To account for the possibility of this happening, I would like to refer them to a counsellor after the study. With your permission I would like you to be the available counsellor and I would like to ask permission for you to see them without charge.

Umthombo Building – 1st Floor, Room U132, Braamfontein East Campus , Private Bag 3, WITS 2050
T +27 11 717 4577 | **E** sppa.SHCD@wits.ac.za | www.wits.ac.za/shcd/speech-pathology-and-audiology/

Should you have any ethical concerns regarding the study you may contact the Human Research Ethics Committee (Non-Medical), telephone +27(0) 11 717 1408, email hrecnon-medical@wits.ac.za.

Yours sincerely,



Masters Researcher

Lethabo Maleka, 840320@students.wits.ac.za, 074 574 8698

Research supervisor

Dr Joanne Neille, joanne.neille@wits.ac.za, 011 717 4574

Research supervisor

Dr Khetsiwe Masuku, khetsiwe.masuku@wits.ac.za, 011 717 4584

AGREEMENT WITH COUNSELLOR

I, _Mia Pienaar_____ agree to be the counsellor or make a counsellor available for the study undertaken in the event of topics discussed being too difficult for some of the participants. I agree that the researcher can refer participants to me, and I will see them without charge.



Mia Pienaar

Counsellor Name (Print) **Counsellor Signature**

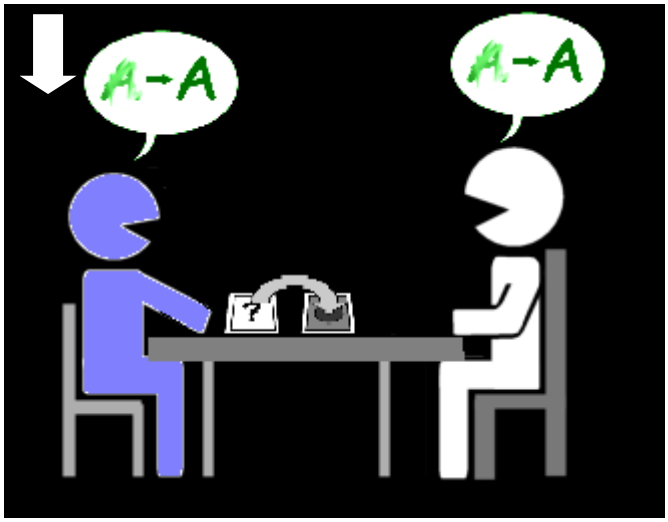
20/08/2021

APPENDIX F

SUPPORTIVE COMMUNICATION TECHNIQUES (PARTICIPANT INFORMATION SHEET AND INFORMED CONSENT)

HELLO, MY NAME IS **LETHABO.**

I AM **A SPEECH THERAPIST AND AUDIOLOGIST**. I AM DOING MY MASTERS RESEARCH AT THE UNIVERSITY OF THE WITWATERSRAND.



I AM **REQUIRED TO DO A RESEARCH PROJECT**.



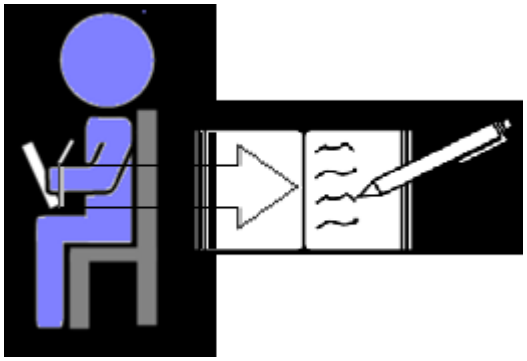
YOU ARE **INVITED** TO PARTICIPATE IN MY STUDY AND I WILL TELL YOU MORE ABOUT IT.



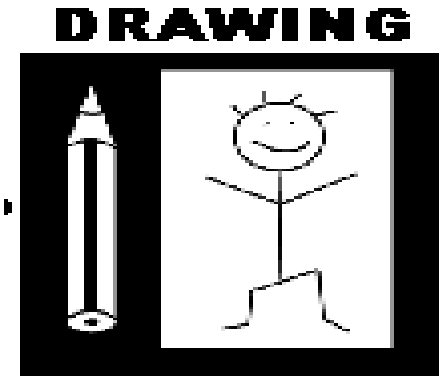
I AM INTERESTED IN **THE CARE PATHWAYS YOU FOLLOWED AFTER HOSPITALISATION**. IF YOU WOULD LIKE TO PARTICIPATE, I WOULD LIKE TO INTERVIEW YOU FOR APPROXIMATELY ONE HOUR.

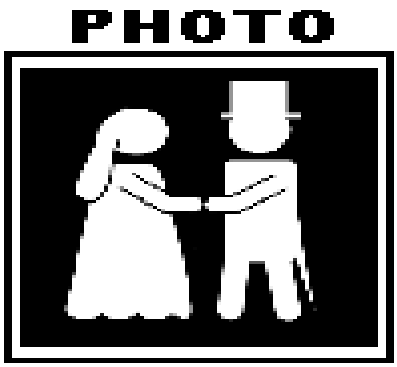


I WILL **AUDIO RECORD** THE INTERVIEWS AND
I WILL TAKE **NOTES**.



IT MAY BE HELPFUL TO USE **GESTURES, DRAWINGS** AND **PICTURES/PHOTOS** TO HELP YOU TELL ME YOUR STORY.





THE RAW INTERVIEW INFORMATION WILL BE HEARD AND SEEN BY **ME AND MY SUPERVISOR**





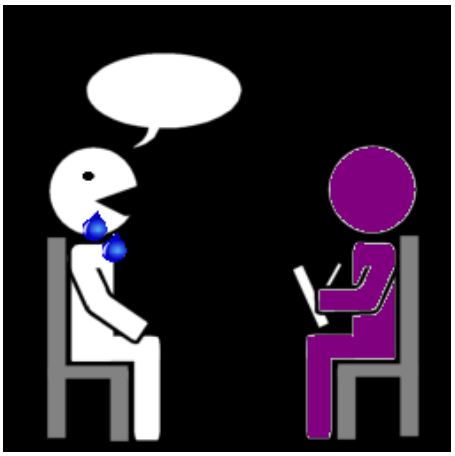
ONLY MY SUPERVISOR AND I WILL KNOW YOUR NAME. I WILL NOT USE YOUR NAME IN THE WRITTEN DOWN INTERVIEWS OR THE RESEARCH REPORT YOU CAN CHOOSE TO TAKE PART OR NOT.



YOU CAN STOP AT ANY TIME WITHOUT A PROBLEM. **IT IS OK TO QUIT**.



IF YOU BECOME EMOTIONALLY UPSET DURING THE STUDY A COUNSELLOR/ SOCIAL WORKER, MS MIA PIENAAR AT HEADWAY (CONTACT 011 442 5733, WILL BE THE COUNSELLOR OR WILL MAKE COUNSELLORS AVAILABLE TO SEE YOU, **FREE OF CHARGE.**



Acknowledgements: Phillips, M. (2011). Identity Life Narratives: Revelation of Self in Aphasia.

APPENDIX G

ETHICS CLEARANCE CERTIFICATE

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Research Office

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

CLEARANCE CERTIFICATE — **PROTOCOL NUMBER: H21/09/21**

PROJECT TITLE — An exploration into the pathways of care and support followed by persons with post-acute traumatic brain injuries living in Soweto, Johannesburg

INVESTIGATOR(S)	Miss L Maleka
SCHOOL/DEPARTMENT	Human and Community Development/
DATE CONSIDERED	17 September 2021
DECISION OF THE COMMITTEE	Approved Risk Level: Medium
EXPIRY DATE	11 October 2024

DATE 12 October 2021 **CHAIRPERSON** (Professor J Knight)

cc: Supervisor : Dr J Neille and Dr K Masuku

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 submit an amendment of the protocol to the Committee. **I agree to completion of a regular progress report. For Minimal and Low studies, this is due annually on 31 December. For Medium and High Risk studies, this is due twice annually on 30 June and 31 December.**

Signature

21 / 10 / 2021
Date

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES

APPENDIX H

PARTCIPANTS' TRANSCRIPTION

1. PARTICIPANT ONE

HOW HAS LIFE BEEN WITH LIVING WITH TBI?

BAD YAH… ITS JUST A LITTLE BAD NOW BECAUSE IM STRUGGLING TO FIND WORK ITS HARD TO FIND A JOB IN MY SITUATION BECAUSE IM SLOWER NOW EVERYTHING I DO IS A BIT SLOWER NOW BECAUSE I CANT WALK FAST I CANT CARRY A LOT OF THINGS YOU SEE. NOW ITS JUST WHAT THEY CALL IT MY MOBILITY THATS ALL NOW, AT FIRST WHEN I JUST CAME OUT OF HOSPITAL MY SPEECH WAS BAD MY EATING WAS A LITTLE BAD ALSO

WHAT CAUSED YOUT TBI WHAT HAPPENED?

CAR ACCIDENT, I WAS DRIVING, NO NO I WASN'T DRIVING

WHERE DID YOU GO TO FIND SUPPORT OR HELP AFTER HOSPITALISATION?

MY FAMILY, MY FRIENDS. MY FAMILY HELPED A LOT LIKE EISH A LOT WITH EVERYTHING, FEEDING ME WIPING ME WASHING ME YOU SEE ALL THOSE THINGS CAUSE WHEN I GOT OUT OF HOSPITAL I COULDN'T UHM BATH MYSELF, WASH MYSELF THEY HAD TO DO IT FOR ME, I COULDN'T USE THE TOILET BY MYSELF I COULDN'T UHM LIKE MOVE AROUND IN THE HOUSE ALONE I COULDN'T EAT BY MYSELF NOTHING I WAS LIKE A NEW BORN BABY. MY FAMILY ALSO TOOK ME TO CHURCH, THE CHURCH ALSO SUPPORTED ME BECAUSE AT FIRST I COULDN'T GO TO CHURCH THEY CAME TO MY HOUSE AND CHATTED WITH ME ABOUT THINGS, PRAYED WITH ME YAH AND HAD CONVERSATIONS ABOUT YOU KNOW JUST LIFE YAH

MY FRIENDS JUST VISITED ME A LOT YAH AND TOOK ME OUT TO TAKE A WALK AND THAT TIME I WAS STILL IN A WHEELCHAIR THEY PUSHED ME AROUND YAH. I NEEDED THAT AND APPRECIATED THAT AT THE TIME. AND PEOPLE IN MY COMMUNITY ALSO HELPED ME HERE AND THERE. LIKE THEY KNEW WHAT HAPPENED TO ME SO THEY SUPPORTED MY FAMILY THEY OFFERED THEIR HELP WHEN I WAS STILL IN HOSPITAL THEY OFFRED THEIR HELP LIKE OFFERING TO TAKE MY MY FAMILY TO THE HOSPITAL TO COME SEE ME.

FOR WHAT PURPOSE DID YOU SEEK HELP OR SUPPORT?

CAUSE YOU KNOW WHEN YOU'VE HAD A BRAIN INJURY AND YOU JUST ALONE NO SUPPORT YOU TAKE YEARS TO HEAL AND COME TO TERMS WITH YOUR SITUATION NOW GETTING SUPPORT YOU LAUGH NOW AND THEN, WITH FRIENDS WITH YOUR FAMILY YAH THEY MAKE THE HEALING MUCH FASTER YAH. WHEN YOU GOING THROUGH SONETHING LIKE THAT YOU ANGRY MOST OF THE TIME YOU SEE YAH SO THEY HELPED TO EASE THAT ANGER FOR ME. I AM A CHRISTIAN AND HAVE STRONG BELIEF IN GOD SO I FELT MY CHURCH CAN HELP ME CONNECT WITH GOD. I ALSO WENT TO TRADITIONAL HEALERS HERE AND THERE JUST BECAUSE SANGOMAS THEY SPEAK TO THE DEAD AND THE ANCESTORS LET ME SAY ANCESTORS SO MAYBE JUST BY HAVING HELP FROM THE ANCESTORAL SIDE AND HELP ME CONNECT WITH THEM AND HELP ME HEAL FASTER. WITH COVID IT WAS A LITTLE MORE DIFFICULT TO GET HELP LIKE COMING TO HEADWAY YOU KNOW SUPPORT GROUPS CZ THEY ALSO HELPED ME EMOTIONALLY LIKE GAMES AND STUFF WE NEED THOSE THINGS UHM TO BE WITH OTHER PEOPLE IN THE SAME SITUATION YOU SEE YAH THEY GIVE US THERAPY LIKE SPEECH AND PHYSIO, WITH COVID THEN WE COULDN'T BE TOGETHER ANYMORE AND TALK ABOUT OUR PROBLEMS NOTHING. AT HOME ALSO MY FRIENDS COULNT VISIT AS OFTEN ANYMORE

2. PARTICIPANT TWO

BEKUNJANI UKUPHILA NE BRAIN INJURY?

IMPILO YACHANGER BECAUSE INTO EZININGI EBENGIZENZA ZANGE NGIPHINDE NGIZENZE FANA NOKU VISITOR AMA FRIENDS NOKU BHEMA UGWAYI NOKU PHUZA UTSHWALA. NGANGIHAMBA NGE WHEELCHAIR KODWA KANCANE KODWA NGIKWAZI UKUSUKUMA NGIQOTHOZE. LA (POINTS TO NECK) NGANGIFAKWE IPIPE NGIPHEFUMULA NGALO.

UTHE MAWUPHUMA ESBHEDLELA KUKUPHI LA OYE WATHOLA UNCEDO KHONA?

NGATHOLA UNCEDO KAKHULU ENDLINI ESPECIALLY EKHAYA MY WIFE AND FIRST BORN OYI NTOMBAZANE WE ARE FOUR IN THE HOUSE. BANGINCEDA NGOKUKHULUMA CZ ISPEECH SAMI SASI NGEKHO RIGHT BENGIKHUTHAZA MENGIKHULUMA UKUTHI INQONDO IBUYE YONKE INTO NJE BANGIQOKISA, BANGIGEZA UMFAZI WAM UNTIL NAMI SENGIKWAZI UKUZIGEZA AYITHATHANGA NAMA VIKI LEYONTO, KODWA BENGIKWAZI UKUZIDLISA KANCANE KODWA MY WIFE BEKANGIZAMA NJE.

OMAKHELWANE BAMI EBESISEBENZA NABO BEZA NJALO BAZONG KHUTHAZA UKUTHI I MUST PICK IT UP, BANGTHATHE BATHI ASAMBE MAYBE SIYE KU FUNERAL EEASTERN CAPE BAYENZA UKUTHI LEZINDAWO NGIZIBONE ALL OVER AGAIN, NGIKHUMBULE UKUTHI ENDAWENI ETHILE KONJE KUHANJWA KANJANI YAH, BAYIBUYISA YONKE IMEMORY YAM.

KUNGANI KUSEMQOKA UKUFUNA UNCEDO EMVENI KOKUTHI ULIMALE?

BENGIDINGA UNCEDO BECAUSE MY MIND WAS OUT OF ORDER I FORGOT EVERYTHING WHAT WAS GOING ON NGAKHOHLWA YONKINTO SO I NEEDED HELP TO REGAIN MY MEMORY I EVEN WENT BACK TO WORK BUT THEY DECLARED ME UNFIT AFTER 2 MONTHS BECAUSE I WASN'T DOING A GOOD JOB MOST OF THE TIME I FORGOT EVERYTHING I WAS EVEN TAKEN TO DISCIPLINARY COMMITTEE BECAUSE I COULDN'T GUARD THE PRISONERS SO LEYONTO YANGIYENZA NGIFUNE UKUNCEWA KAKHULU NGEMEMORY YAMI. EKHAYA SIKHOLELWA KAKHULU KWI SINTU NE SONTO BECAUSE EVERY SUNDAY SIJWAYELE UKUYA ESONTWENI SO ESONTWENI BEYA BANGISUPPORTA KAKHULU UKUTHI BANGIFUNDISE YONKINTO EZENZWA AMA SONTO UKUTHI NAMI NGIKWAZI UKUBONISANA NABANTU MABANGIVAKASHELE NOKUTHI I MUST ALWAYS PRAY FOR UKUPHOLA KWAMI SO THAT GOD CAN GIVE YOU POWER TO BE HEALED. KODWA NGOKWESINTU ENYANGENI ASIYANGA TO SEE WHAT WAS THE REASON PLUS THEY WERE JUST THANKFUL TO GOD UKUTHI NGISINDILE, KODWA SINGABANTU ABAJWAYELE KAKHULU UKUHLABA GE THINA SBONGE AMADLOZI UKUTHI YEY NGASINDA KULEYA NGOZI SO NGAWISA IMBUZI UKUBONGA AMATHONGA WAMI UKUTHI ANGINCEDILE KULEYA NGOZI. NGINGUMZULU WASE NATAL SHUKUTHI SATHATHA ISLWANE SAKHULUMA NASO UKUTHI SIYABONGA KAKHULU UKUTHI NIKWAZI UKUSINDISA AFTER THAT SAFAKA ISPHANDLA ESANDLENI, SASHISA NEMPEPHO UKUKHULUMA NAMATHONGA WETHU.

SAFETY PRECAUTIONS WERE PUT IN PLACE A LOT BUT LEYONTO YAYENZA NGINGAKWAZI UKUZA EHEADWAY BECAUSE THE SUPPORT I AM GETTING AT HEADWAY WAS TOO MUCH, AT HOME IT WAS JUST BUYING NEWSPAPER AND BE BUSY WITH IT NOTHING ELSE BUT HEADWAY WE WERE DOING A LOT OF ACTIVITIES, LOCKDOWN YAVIMBA YONKINTO EHEADWAY BABUYISA INQONDO UTHOLA SIYENZA IPUZZLE BENGIBUZA IMIBUZO ETHILE UKUTHI INQONDO IBUYE UKHUMBULE LA EHEADWAY SENZA INGADI SITSHALE EBE RIGHT NJE INGADI YAKHONA SO HEAWAY BEYINGINCEDA NGAMA ACTIVITIES AMA NINGI ISIKHATHI ESININGI NGINGASHO UKUTHI ICHURCH, THEY EVEN SAY CHOOSE A SCRIPTURE WHICH ENCOURAGES YOU TO RETURN TO YOUR NORMAL LIFE BENGIFUNDA LAWO MA SCRIPTURE KAKHULU TO BE ABLE TO TRUST IN GOD AGAIN, MANGIVUKA MANJE NGIYATHANDAZA AND MANGILIMALA NGIYE KAKHULU ECHURCH UKUTHOLA ITHEMBA ELISHA

3. PARTICIPANT THREE

BEKUNJANI UKUPHILA NE BRAIN INJURY?

BEKUNZIMA KAKHULU KHONA BECAUSE ANGISAKHONI UKUYENZA EZINYE IZINTO BENGIZENZA KUDALA YAH MORE ESPECIALLY BENGIWUMUNTU OSEBENZA NGEZANDLA MANJE ANGISAKHONI UKUYENZA ANYTHING NGEZANDLA, I USED TO DESIGN LEATHER PRODUCTS FOR PEOPLE. BANGIKAPA NGESTINA EKHANDA IT WAS DELIBERATE, I WAS FIGHTING NGABA DIZZY AND I COLLAPSED AND I COULDN'T DO ANYTHING WITH MY LEFT SIDE I WENT TO THE HOSPITAL THAT VERY DAY I WENT TO JOBURG GEN YAH THEN FROM JOBURG GEN THEY TRANSFERRED ME TO THIS HOSPITAL IN BOKSBURG, CHARLOTTE MAXEKE WHAT IS IT YAH YAHI STAYED FOR 3 MONTHS THEN I CAME BACK A LOT OF THINGS HAD CHANGED, MY LEFT SIDE BEYINGASEBENZI THEREFORE BENGINGAKHONI UKUHAMBA KAHLE, BENGINENKINGA NGE SPEECH SAMI NE VISION YAMI NAYO BEYINGASAFANI I STARTED USING GLASSES AFTER MY BRAIN INJURY, IMEMORY KODWA WAS STILL INTACT, I COULD FEED MYSELF FROM THE HOSPITAL

UTHE MAWUPHUMA ESBHEDLELA KUKUPHI LA OYE WATHOLA UNCEDO KHONA?

THE FIRST LINE OF HELP I RECEIVED WAS FROM MY FAMILY THEY HELPED ME WITH THE THINGS OF LIKE WASHING MYSELF, WASHING ME, COOKING FOR ME, CLEAN FOR ME THEY LOOKED AFTER ME IN GENERAL NJE, MY MOTHER, MY BROTHER AND SISTER YIBO BEBANGINCEDA KAKHULU. MY EXTENDED FAMILY ALSO HELPED ME THEY USED TO GO TO THE SHOPS AND BUY ME STUFF THAT I WANTED.OUTSIDE THE FAMILY…THERE WAS NO ONE ELSE BUT THERE WERE SOME FRIENDS WHO SUPPORTED ME, THEY MOTIVATED ME IN FACT I WAS BROUGHT BY A FRIEND HERE AT HEADWAYS

HEADWAY SUPPORTED ME A LOT IN TERMS OF SUPPORT GROUPS SINCE I CAME TO HEADWAYS I HAVE GAINED MY CONFIDENCE SELF CONFIDENCE, I WAS ABLE TO SOCIALISE WITH OTHER PEOPLE, THE THERAPISTS ALSO HELPED A LOT AMA OT, I DIDN'T SEE A SPEECH THERAPIST BECAUSE MY SPEECH BESESILUNGILE IT CAME BACK, OT USED TO DO WRITNG EXERCISES AND PUZZLES, PHYSIO THERAPY I DID IT AT MOFOLO CLINIC AND HERE AT HEADWAYS AS WELL. HEADWAYS TOOK ME TO DOKOTELA WA MEHLO (OPTOMETRIST) TO GET HELP FOR MY VISION AND MY GLASSES AS WELL.

I AM A RELIGIOUS MAN, IM A PERSON WHO USUALLY GOES TO CHURCH I READ THE BIBLE MOST OF THE TIME, I GOT SPIRITUAL HELP AT CHURCH YOU UNDERSTAND, THEY HELPED ME TO BELIEVE IN MYSELF THAT I WILL GET BETTER, ABAFUNDISI HELPED ME TO BELIEVE IN GOD THAT GOD WILL HEAL ME. I ALSO WENT TO TRADITIONAL HEALERS AS WELL BECAUSE AT HOME THEY ARE TRADITIONAL HEALERS AS WELL YAH SO AT HOME THEY HELPED ME BY GIVING ME MUTHI AFRICAN MEDICATION, AND THE READINGS FROM THEM UKUHLOLA FROM AMADLOZI, AT MY HOME WE HAVE THAT GIFT OF HAVING VISIONS SINGABANTU ABANJALO. I BELIEVE THAT GOD HAD A HAND IN MY ACCIDENT HE WANTED TO DIRECT ME SOMEWHERE THAT I NEEDED TO BE NOT IN THE DIRECTION I WAS THINKING. I WENT TO THE SANGOMAS AFTER I CAME BACK FROM THE HOSPITAL, MY COUSIN IS A SANGOMA SO I WENT STRAIGHT TO HIM TO CLARIFY THINGS FOR ME LIKE WHY WOULD THE ANCESTORS TAKE AWAY MY GIFT WHY WOULD THEY GIVE ME A GIFT AND TAKE IT AWAY AGAIN MY GIFT OF BEING AN ARTIST. I WANTED TO GET HELP FROM THE SPIRITUAL WORLD.COVID 19 AFFECTED MY ABILITY TO BE AT HEADWAY AND DO EXERCISES AT MOFOLO CLINIC WITH MY PHYSIOS I COULDN'T GO ANYMORE HEADWAY WAS ALSO CLOSED AS WELL SO SUPPORT WAS LIMITED AND NO ACCESS TO THERAPISTS WAMI, I WAS ATTENDING MY SESSIONS USING PHONE WHATSAPP GROUPS BUT SOMETIMES ANGINA DATA. SO I ALWAYS READ THE BIBLE AT HOME WHEN I AM NOT ATTENDING HEADWAYS.HEADWAYS INCEDE KAKHULU NGAMA SUPPORT GROUPS BECAUSE I FELT I WAS WITH FAMILY HERE AT

HEADWAYS, WE TALK ABOUT OUR EXPERIENCES AND HOW TO COPE WITH OUR PROBLEMS SO THAT WAS VERY HELPFUL FOR ME AND HOW TO HANDLE CONFLICTS ALL THE TIME CONFLICTS THAT WE HAVE WITH PEOPLE WHO DO NOT UNDERSTAND OUR SITUATION.

4. PARTICIPANT FOUR

HO NE HOLE JWANG HO PHELA KA TIMALO YA HLOHO?

KE KREILE ACCIDENT KA TIMELA KE MONAHANO BA NKESA SPETLELE SA CHARLOTTE MAXEKE KA MOGWA O KE KWELENG KA GONA KE DUTSI 6 MONTHS KE SA KGONE GO BOLELA NE KE LE CHECK UP CHARLOTTE MAXEKE BA MPOTSA HORE KE DULA KAE KARE KE DULA SOWETO BARE BA TLA NYAKELA PLEKE MO KGAUSWI LE SOWETO…HEADWAY KA TLO DULA MO TENG KA THOMA HOTLA HANA MO. KE LEMETSE KE DULA ALEXANDER KA MOGWA O KE KWELENG KA GONA KE NE KE NA LE KOLOI NE KO REKA DI PARTS TSA HO LOKISA KOLOI DURING THE WEEK MOTHO YA LOKISANG DI KOLOI AMPOTSE HORE NEH DINTHO TSE DIREKISWA MO KAE KARE OKAY NEH KAORE NNA AKEGO TSEBE KE TLA TSAMAYA LEWENA ATSAMAYA LENNA AMPHOLOSHA MO IMMEDIATELY ASENO JEKA HA KERE KE JUMPA DIROBOTO OKWA GUU (SOUND OF A CAR HITTING SOMEONE) HA BUYA AKREYA E LE NNA KE THUTSI KE KOLOI HONA MOKHI BA MMATHISETSA SPETLELE SE KGAOSWI, SPETLELE BANKENYA MO WARDING BA SA NTHLOKOMELE SO KAYA CHARLOTTE MAXEKE

O ITSE HA OTSWA SPETLELE KE KAE MO O ELE OA THOLA THUSHO GONA?

THEN HO THLOHA MOUWE KA THOLA SUPPORT LE NGWANESHO LE BUTI (FAMILY YAKA), NE BA NTHUSHA KA HORE NE KE SEKE KA FELA PELO NE KELE MOTHO WA HO FELA PELO LE HO NTLISETSA TJA HOJA BATLE BA TLO NTLATSWETSA.

FRIEND KE E ONE ENE ENG SUPPORTA BA BANG BA TSAMAYILE LIKE ONALE KOLOI NNA AKENA KOLOI O KGONA HO NTSEYA KEYE LEYENA LIMPOPO KE YENA NA NTRANSPORTA HAHOLO.

FAMILY YAKA ELE YA NKISA MOTHONG WA SETSO BA KREYA HORE ACCIDENT E HASE ACCIDENT FELA BA NE KENA LE GIRLFRIEND GIRLFRIEND YE KE BONA BA HO DIYA HORE NEH KE THOLE KE KOLOI MHM NE ELE PLAN YA BONA NE NTSE RE KWANA RE THOMA HO SOKOLA KGANI BJALE HA KE SENO KREYA ACCIDENT RA THOMA HO SE KWANE GANA MOUWE. KORE HA KE ELE MOTHONG O NO MPUTSA HORE DILO TSE KAMOKA TSE DITSWA KO HABO GIRLFRIEND YA HAO.

KE ELE KA DULA NYANA KORE NTHWE E BONAHETSE BOTSE BOTSE NE KESA THLOKOMELE FAMILY NE SOKA E THLOKOMELA, ABUTI WAKA O ELE A KREYA ACCIDENT KORE NNA LE FAMILY RA KGONA HO E BONA HANA MOUWE. O ELE A KREYA ACCIDENT ATHLOKOFALA YABA FAMILY ETHOMA HO BONA HANA MOU. ABUTI HA KREYA ACCIDENT ATLHOKOFALA RA THOMA HO NYAKISISA HANA MOU HORE ACCIDENT YE ETLHAHILE BJANG. HA RE NYAKISISA NNA LE FAMILY YAKA RA KREYA HORE DILOTSE KAMOKA TSONA TSE DI TSWA MO GIRLFRIEND YAKA EEHH NNA LE ABUTI YAKA NE RE JOLA KA MO MOTSENG O MO TII (0NE) EE YENA AJOLA LE O MOHOLO NNA KE JOLA LE O MONYANE DITLHAHILE HONA MOU DILO TSE KAMOKA. BA NYAKA HO DIYA HORE RE SKA SURVIVA MO BOPHELONG KA BOBEDI YA BONA KE NGWANA MAMHOLO LE WA MMANE NTHO E HLALA KA MO FAMILYING E TII (ONE). NNA KE KREILE ACCIDENT PELE RA SEBE AWARE KA YONA HORE NEH ACCIDENT YE ETHLAHILE BJANG RE THOMILE HO NYAKISISA BOTSE BOTSE HA ABUTI WAKA ASENO THLOKOFALA HORE HA BOTSE HO DIA HETSENG KA BUTI BARE NE MOTHO OUWE NGAKA EO YA BOLELA HORE NEH DITSWA KO BARATANI BA LENA KAMO KA NTLUNG. HO BONTSHA HORE NEH BATHO BA NTHO E BAE DIYANG BA SERIOUS HANA KA MOU HABO GIRLFRIEND YAKA KE NALE NGWANA KA MOU DECEMBER NGWANA O MPUDITSE HORE KEYA GAE ARE KEYA GAE KARE HA GENO KE RUSTENBURG ARE HABO KOKO ARE O NYAKA DIAPARO KA MO REKELA DIAPARO HA KE FETSA LE HANE BJALE HA BA MPOTSE HORE NEH DIAPARO TSEO DIYA MOLEKANA OR ADIMOLEKANE MHM. KE MOTHO O BELIEVELANG HAHOLO MO CULTURE YA RONA SO NE KE NYAKA HO TSEBE HORE ACCIDENT EBAKILE KE ENG, KREKENG LIKE KEYA MOTHO O MONG MO KE DULANG MO TENG O TSENA KEREKE YA ZION JWANONG NA NA LE HORE HAYA KEREKENG AYE LENNA, HA LE GONA AYA KREKENG SUNDAY NE KEYA LEYENA KREKENG YA ZION MARA NOU AKESAYA. COVID.. MHM…EHH NNA NKA NORE KA COVID NE KE PHELELA KA MO NTLUNG KE NOE TIBELLA TV ANYAKANG HO TLO MPONA A ETLA MO KO NTLUNG, NE KESA KGONE HO YA HO BATHO, HO TSWA HAKA NE KETSWA KEYA SHOPONG KO REKA BOROTHO. SINCE COVID ITHOMA MO HEADWAY BARE NO BAKWALA KA SE KGONE HO HLOLA KE TLA BA ROMELA DI MESSAGE HORE KE SKATLA KA DI FRIDAY KARE NEH AKENA THJELETE YA HOTLA MO KA FRIDAYS SO NE KE SA KGONE HOTLA. MO BA RE THUSHA KA…RE KGONA HO CONCENTRATER LE HORE RE SKA FELA PELO KE MOTHO WA HO FELA PELO, MEMORY YAKA EYA E BOYA HANYANE HANYANE HE KETLA MO HEADWAY. FAMILY HOBANE NE BA DULA BA NA LENNA AND KE BONA BA PHONELANG HEADWAY HO ARRANGER DI VISITATION TSAKA FAMILY YAKA INTHEKGILE KUDU KUDU KAORE KE MOTHO OILE A THOLA ACCIDENT NE HOSE EASY HORE KE KREYE TJHELETE YA ACCIDENT SO BA KGONE HO NTSEYA RE TSAMAYE DI LAWYER FOR TJHELETE YA ACCIDENT.

5. PARTICIPANT FIVE

BEKUNJANI UKUPHILA NE BRAIN INJURY?

NGIBA NGIBUYA E NGASE ESPAR YANGISHAYISA IMOTO, ANGITHI THINA SIHLALA E EVERTON, NGIBUYA E SPAR SASE EVERTON YANGISHAYISA IMOTO NGIHAMBA EQELENI KO MGWAQO IBALEKILE IMOTO NGAWA KHONA LAPHO NGILE NGAVUZWA ABANTU BANGISA ESBHEDLELA. NGAPHUMA NGALE LANGA ELILANDELAYO ESBHEDLELA.

KUKUPHI LA WA THOLA KHONA UNCEDO BABA SINCE WA LIMALA?

HEADWAY MHM MHM (LAUGHS) AKEKHO OMUNYE ENGINGASHO UKUTHI MHM IHEADWAY. EY EY EY (LAUGHS) INGINCEDA NGOKUNGIPHA UKUDLA NGIYATRAINA ISUPPORTA YONKE INTO. IHEADWAY BEYIKHULUMA NOMTANAMI UKUTHI ANGINCEDE ENDLINI

EKHAYA NGIHLALA, NGANGINO MFAZI OHAMBILE UMFAZI SIYELE SA HLUKANA NGANGIHLALA NOMTANA WAMI WE NTOMBAZANE UZISHADISILE (LAUGHS) AKAKA THOLI IMALI YAMALOBOLA (LAUGHS) SO MANJE UHLALA NE BOYFRIEND YAKHE NGIHLALA NGI ONE SO NGIYAZENZELA ENDLINI YIKHO NGITHI UNCEDO NGILUTHOLA LANA E HEADWAY KAKHULU. NGOBA NGIYAKHONA IYANGIFUNDISA IHEADWAY, SIYAYA ESPEECH THERAPY NGOBA ANGIKWAZI UKUKHULUMA KAHLE, FUTHI INGISIZA NGOKU GYMA ABO PHYSIO, BANINGI (LAUGHS). NGIYE NGABUZA AMATHAMBO (LAUGHS) INYANGA NGE NGOZI YAMI, HAI HAI EHH ZITHI ABANTU BAKHONA ABANTU BANGIZONDAYO SO BAYENZA UKUTHI NGITHOLE INGOZI. EY ANGITHI UMNTANAMI MHM MNTANAMI MHM UNE BOYFRIEND UTHENGISA AMA VEG UYEZA KUZONGIPHA AMA VEG KODWA UKUDLA KUNCANE ENDLINI SO NGIPHATHEKE KABI NGOBA NE HEADWAY BEYI VALIWE AND NGIHLALA EKHAYA NGEDWA KWEZINYE INKATHI AKUNA MUNTU ENGIKHULUMA NAYE AKUNA NO KUDLA

6. PARTICIPANT SIX

KWAYENZAKALANI KUWE BABA?

NO MINA BENGIKHAPHA UMUNTU WAM ESPANINI FOR A TAXI LAPHA EBARA MINA NGISEBENZA E BARA PROP MANGIFIKA E BARA PROP NGIKHULUMA NOMUNTU ANGISAKHONI UKUKHULUMA SO SAYA EKOS EKOS BANGITHUMELA EBARA EBARA NGAHLALA ABOUT 6 DAYS NYANA LAPHANA BUT BANGANGISIZI YABONA SO I LEFT I LEFT NGAYA ENDLINI AFTER 6 DAYS SO NGATHI MANGIFIKA ENDLINI I HAD UKUTHI NGISEBENZISE ISINTU..

WAYAPHI UKUTHI UTHOLE UNCEDO?

I HAD UKUTHI NGISEBENZISE ISINTU UYASAZI ISINTU BANGIZAMA GE BANGIZAMA NGAZANYA OMUNYE UMAMA MARA NGABONA UKUTHI HAI LA AFTER 3 DAYS NYANA NGABONA UKUTHI YAZIN AKANGISIZI LO YABONA ANGITHI UYAZI BASEBENZISA ISDARKI ISINTU UYASAZI ISINTU ANGITHI PHELA KHONA INTO AZONGINIKEZA UKUTHI NGIPHUZE NGIYENZENI YABONA SO AFTER 3 DAYS NYANA NGIYABONA UKUTHI AKANGISIZI KAHLE KAHLE YABONA SO SAVUMELANA NGAMA PRICE NGALE MALI EKUMELE NGIMUBHADALE NGAYO YABONA SO BUT I HAD UKUTHI NGIMBHADALE EVERY MONTH YABONA SO MARA NGEKE NGIKUTSHELE UKUTHI MALINI ANGISHO YAH HA MARA NGAMBHADALA NGACEDA BENGISABA MANJE UKUTHI YAZIN NGATHI KUZOBULAWA MINA MANJE UYA UNDERSTANDA EISH HA BUT NGIPHUME NGITHATHE IWALK GE NGAHLANGANA NOMUNYE UBABA WATHI HAI MAAN MELE UZE NGIZUKUBONA MARA ANGITHI ANGIMAZI LOBABA BUT NGIJWAYELE VELE UKUMBONA NGAMBUZA UKUTHI UHLALAPHI WASHO UKUTHI UHLALA ENDAWENI ESO UZE GE UPHETHE IR20. SO NGAYA GE WANGISIZA LOYA BABA WANGISIZA BESENGIYA SHUTHI EVERYDAY NGABO HALF PAST 8 DA KWAKHE UYI PROPHET YENA YABONA SO WANGISIZA KAKHULU NGASALA NGABA NALE PROBLEM YOKU LUMA NGAPHAKATHI EKHANDA SO WAZAMA WAZAMA WAZAMA NAYE WAIBONA UKUTHI YAZIN NAYE LE AKAKHONI UKUYILUNGISA SO…NGAYA EZCC (CHURCH) FOR LENDABA YOKULUMA IKHANDA EZCC BAZAMA KODWA AZANGE NGIBE RIGHT YABONA SO…BAYATHANDAZA BANGINIKEZE IZINTO ZAKHONA ZOKUBA NCONO ANGITHI BAYASHO UKUTHI MAWUPHUZA INTO ESO UZOBA RIGHT UHAMBE UYOGABHA YABONA MHM AI BANGIZAMA SERIOUS BENGIYA LAPHA BAYOTHANDAZA KHONA NGITHATHE 2 YEARS LAPHA NGILOKHU NGIYA NGAGCINA NGABA YI MEMBER YASE ZCC AND THEN…UKUKHULUMA GE OH NGABA NE PROBLEM NYANA LA (POINTS TO CHEST) NGABA NA SOMETHING NYANA LA (POINTS TO CHEST) ENKULU NGAYA LAPHAYANA BANGILALISA FUTHI EBARA YA THATHA 3 DAYS MARA BAYIKHATHA BAYIKHIPHA LENTO LE YABONA MHM HAA NGIMNANDI MANJE JUST NJE ISLUNGU KUPHELE ASIKHO, NABANGANI BAMI THEY WERE THERE FOR ME BEBEZA BAZONGBONA YABONA MHM YAH BANGI ENCOURAGER UKUTHI HAI UZOBA RIGHT. NE MEDI YAM NAYO LOMUNTU NGIHLALA NAYE NGABE KUDALA WAHAMBA KODWA SHE DIDN'T BENGINGEKHO RIGHT SO WAHLALA SINCE THE INCIDENT YABONA, NGABA NE MALI NGIZOMSHADA

BEKUYINI INTLOSO YOKUTHI UYE LAPHO?

YOU KNOW WHAT HAPPENED LAPHA YA E BARA NGAFIKA EBARA PROP LAPHO BENGISEBENZA KHONA YABONA BENGIKHULUMA NO SOMEBODY YABO MASIQOQA SOMEBODY ONE OF MY FRIENDS GAVE ME ICOKE YABONA COKE LE YE CAN SO YOU UNDERSTAND NGAVULA NGAPHUZA HALF THEN FROM THERE I WAS NOT OKAY SHUKUTHI IT WAS MADE YABO EISH ANGISAKWAZI UKUKHULUMA YABONA ANGIKHO RIGHT. ANGIKHO RIGHT SERIOUS MANJE NJENGOBA NGALALA EBARA NGIBONA NGATHI THEY WERE NOT HELPING ME SO I WENT TO TRADITION ROUTE SO NJE I WENT TO THAT SANGOMA AND THAT PROPHET AND THE ZCC CHURCH BASHO UKUTHI YINTO YANGABOMO LE. HEADWAY NGINA 3 YEARS NGIQALILE, THE TIME NGIYOKHATHA LENTO (POINTS TO CHEST) AND NGIYAFOSTA I CANT SPEAK SO BANGINIKEZA UMUNTU USPEECH THERAPIST USISI BEKANGISIZA YABONA WANGITSHELA NGE HEADWAY NJALO MANGIYA NGIYOMBONA WATHI BAZONGSIZA KHONA MORE THAN YABONA YAH SO I CAME IN. YOH HAI COVID ISISHAYILE YOH ANGITHI PHELA ASIHLANGANI NABANTU ABANINGI MANJE YOU UNDERSTAND ISHAYILE YONA ANGIFUNI UKUSHO UKUTHI UBANI ONGINCEDE KAKHULU (LAUGHS) BUT THE PROPHET WUYE ONCEDILE KAKHULU

7. PARTICIPANT SEVEN

HO ETSAHETSENG HOTLE O LEMALE?

NNA KE TLILE MO JOBURG NTATE WAKA ARE OTLONG REKELA DIPHAHLO TSA CHRISTMAS KE MOKA HANTHI ONALE MANGWANE LE NGWANA WA HAE MO KE MOKA KE RALOKA LE NGWANA WA MANGWANE KA MO KANTLE

RE BAPALA BOLO KE MOKA NTHO BOLA YAYA KO STRATENG NGWANA HESO ARE O BATLA HO E LATA KARE HAI SKAE LATA NNA KE TLAE LATA KE MOKA HA NE KE LATA HANTHE HOTLA KOLOI KA MO YANG THULA NE ELE KITIMA YANGITSHAYISA KAYAWA KAYA SPETLELE. KE DUTSI NAKO SPETLELE KE MOKA BA TRANSFERA KO GIYANI. BEFORE KEYA KWA HAE NE KESA BUWI AND KESAJE KA MOLOMO NE KENA LE OPERATION MO MALENG MO MPENG LE HO TSAMAYA NE KESA KGONE HO TSAMAYA NE KE TSAMAYA KA WHEELCHAIR EHH.

KE BO MANG BA HO FELENG THEKGO HA OTSWA SPETLELE?

NE BANGRUTISA HO BUWA KE LE SPETLELE KE LEKA HO BUWA HANYANE SLOW KE MOKA KA DISCHARGER KAYA NTLUNG KE MOKA BANGRUTA HO TSAMAYA, MAMA WAKA FAMILY YAKA HANTLE HANTLE KAORE AKERE NE KE TSAMAYA KA WHEELCHAIR NE BA KASE NSEYE KE LE ONE MAYBE BA NYAKA HOYA SOMEWHERE NE BA TSAMAYA LE NNA LE HORE BA NRUTE HO TSAMAYA LE HO HLAPA CZ NE KE SA KGONE HO HLAPA, NE BA NJESA. LE SOCIAL WORKER/COUNSELLOR YAKA NE ENTHUSA OA NTHEKGA KA NTHO ENGWE LE ENGWE WA ENCOURAGER ORE SKA WARANE KE NA LE CHOMI MARA NE ESE THAKA YAKA. NE KE TSAMAYA KEREKE HORE BANGRAPELLE. BA ILE BA NKISA NGAKENG NAKO E KE SA KGONE HO TSAMAYA HANTLE KE MOKA BARE BA TSHWANTSE BA NTHOBE KA METSI ATSHESANG LE DITHLARE, AKEMOTHO YA KGOLWA DINTHO TSE KE FAMILY YAKA ENKISETSENG MOU. KA COVID 19 AKERE NE HO KWETSE NAKO E TELELE MO KE MOKA RA BULA RETLA KA ONE ONE KA TWO TWO SO EO NE ESE SHAP BECAUSE NE RE SA KGONE HO BUA KA DI EXPERIENCES TSA RONA HA KETLA KE LE ONE AND NOT LE BATHO BA BANG. NE BA RUMELA DI EXERCISE KO PHONONG HOBANE NE KE SATLE MO SO NTHO EO ELE YA THUSA HAHOLO HORE KE PRACTISE KO NTLUNG MARA KA MATSATSI AMANG NE KE SANA DATA YA HO SHEBA DI EXERCISE KO PHONONG.

8. PARTICIPANT EIGHT

NCELA USHO UKUTHI KWAYENZEKALANI KUWE BABA?

SISI IT WAS DURING LOCKDOWN YABO 2020 AT THE END OF MARCH LAPHO SISI I WAS DRUNK NE NGISUKA EKHAYA NE GIRLFRIEND YAMI NE NGISHIYE AMA BEER WAMI KUYE EISH NGAFIKA NGAWATHATHA NGILOKHU NGIHLELI NAYE NGAPHUZA YINDAWO YAKHE UQHASHILE LAPHO NGAPHUZA AMA BEER SEKUSE BSUKU KWAZE KWA SHAYA U22:00 ISKHATHI SE LOCKDOWN ANGISAKWAZI UKUHAMBA NGATHI KUYE AI NGATHI NGIZOLALA NGAPHANDLE PHAKATHI KWE MOTO KWE TAXI YABONA SENGIDAKILE EBSUKU NGEZWA UKUTHI SENGIDAKIWE MANJE NGISELE NGE SIX PACK MANGIPHAPHAMA NGILALE FUTHI EMOTWENI NGISABA UKUTHI BAZOYI TSHONTSHA NGIPHAPHAME EBSUKU NGABO 1 NGIYAGODOLA NGIPHUME EMOTWENI NGIHAMBE NGIYOMKOKOTELA ENDLINI YABANTU LA BA QHASHE KHONA BANGVULELE NGIMTSHELE UKUTHI NGIYAGODOLA ASAMBE NGIZOTHI NIYISA MINA ESBHEDLELA NGATHI NGIDAKIWE HAI WAHALA UKUTHI UHAMBA NAMI WATHI YENA AKAHAMBI ATHI NGILALE ECOUCHINI HAI LAPHO SISI KUSILE NGITHATHE IMPAHLA ZAKHE NAMA BAG NGENKANI EY SESIYAPHIKISANA ECOFFEE TABLE KUNE SIDE PLATE ATHATHE ISIDE PLATE ANGISHAYE NGAYO LA EKHANDA YOH SISI NGIBLEEDE NGIHAMBE NGIYIHLALA ECOUCHINI MANGILOKU NGIHLELI ECOUCHINI NGILOSE AMANDLA NGIPASSE OUT YOH SHE REALISED UKUTHI LOMUNTU ULOSA AMANDLA UPASSA OUT ANGIPHAKAMISE ANGAZI ANGIBEKE ITOWEL BESE AFONELE IAMBULANCE LAPHO NGAPHAPHAMA SENGISESBHEDLELA AFTER A WEEK BANGIYISA EHIGH CARE EBARA NGAHLALA EBARA FOR 6 WEEKS. MABANG DISCHARGER EBARA THEY ORGANISED PHYSIO AT SOUTH RAND ESOUTH RAND NGAHLALA 8 WEEKS.

KUKUPHI LA WATHOLA KHONA UNCEDO?

BANGIYENZELE IREFERRAL YASE BARA MARA THOLUKUTHI KUNE LOCKDOWN YABONA SO I COULDN'T GO BUT EKHAYA THEY WERE VERY SUPPORTIVE, FAMILY YAH NAMANJE KAKHULU, BANGINCEDE NGOKUDLA UKUDLA HEALTHY, UKUHAMBA I WAS NOT GOOD, I CAME OUT OF THE HOSPITAL NGIHAMBA NGE WHEELCHAIR, BEKU BHEDA NOKUKHULUMA I ATTENDED SPEECH AT BARA BUT BEFORE DECEMBER BA CANCELLA AMA SESSIONS AMANYE YABONA BATHI BAZOFOUNA AND AZANGE BA FOUNA BECAUSE OF COVID KODWA NGATHI AT LEAST KU SPEECH ANGISEKHO BAD INTO ENGI ATTENDAYO YI OT NE PHYSIO YABONA. BESENGIYENZA IGROUP SESSION YE SPEECH EBARA NGAMISA AMA APPOINTMENT BATHI BAZONTHINTA FOR APPOINTMENT NGA FOCUS KU OT NE PHYSIO BE SE NGIKHATHELE AMA UP AND DOWN UKUKHATHALA KOMZIMBA. AMA FRIENDS WAMI NABANTWANA BAMI AMA JITA ENGIKHULA NABO NABA KHULA PHANTSI KWAMI BASHAYA IROUND BANGITHATHE BABLOME NAMI SEPHUZE AMA DRINKS SO BRAAI INYAMA SIHLALE BAFIKE BAZONGBONA KODWA ANGISAPHUZI ANGISABHEMI I WAS DRINKING KAKHULU NGAYEKE AFTER NGILIMALE. MY FRIENDS THEY RESPECT ME BAYAZI NGUMUNTU OTHANDA UKUKHULUMA MHM BA RIGHT KIMI YAZI THEY DIDN'T CHANGE BAYANGAZI NGIWUMJITA BENGIHLANGANISA MHM. EVEN MY EX GIRLFRIEND THAT ASSAULTED ME WAS SUPPORTIVE BEKANGI PHONELA NOW AND THEN

KUNGANI UYE LAPHO UKUTHOLA UNCEDO?

AYIBO ABA DECIDELE NGISHAP MINA SISI NGIYINDODA MINA SISI I MUST MAN UP IM A GUY FANELE NGIPROVE UKUTHI NGIYI AUTHI THAT'S WHY NGILA (HEADWAY) KUBE ANGIKHO LA KUBE ANGISI YI AUTHI LIKE IF UZA NE SUGGESTION UTHI BHUTI YENZA KANJE UZOTHOLA UNCEDO NGIYAYA MINA YABONA MHM NGIBELIVELA KIMI. MINA BENGIBELIVA UKUTHI UNKULUNKULU UNGINIKE ISECOND CHANCE YABO UKUTHI NGIPHILE YABONA THAT'S WHY UMUNTU OZA NE SUGGESTION UKUTHI NAYI INTO ESO IZOKUPHILISA I TOOK THAT THAT SUGGESTION YABONA UKUTHI NGIZOHLULEKA KHONA YABONA NJENGOBA NGISHO ISPEECH BENGI ENJOYA BUT BESENGIKHATHELE SISI YAZ I WAS ENJOYING BUT IT WAS TOO MUCH AND THE EXERCISE BENGIWAYENZA EKHAYA SO NGABONA NGATHI THEY ARE PILING UP NGATHI HAI UKUKHULUMA NGIYAZAMA AND KUZOLUNGA KUZOBUYA NGOKUHAMBA KWE SKHATHI YABONA NGABONA UKUTHI NGIYA IMPROVA EVEN NOKUHAMBA FROM WHEELCHAIR TO THIS I CAN MOVE FAST NOW.

NO NOT CULTURE, ISBHEDLELA SINGINCEDILE YONKE IPROCESS YAMI YASE SBHEDLELA, PHYSIO, OT AND SPEECH YONKINTO EYENZEKE NGISESBHEDLELA FROM E BARA NGAZITSHELA UKUTHI IM GOING TO STICK TO WHAT THESE DOCTORS ARE TELLING ME, ESBHEDLELA KUKHONA UKUPHOLA, UNGABELIVE KUZINTO ZESINTU KAKHULU MINA ANGINAYO LEYO NQONDO LEYO UKUTHI FANEKE NGIKHOTHANE NE MITHI NGIYENZENI UKUTHI NGIPHOLE NO SISI ISBHEDLELA IS WHERE UNCEDO LUTHOLAKALA KHONA LEZINTO ABAZENZANGA FOR MAHALA YABONA BUT MINA NGIBELIVELA UKULANDELA IPROCEDURE YASE SBHEDLELA THAN LEZINTO ZESINTU UHAMBE UKHOTHA ZONKE LEZINTO LEZI. MINA NGIFUNA ABANTU ABA PROFESSIONAL NJE NGANI HAI LEZINTO ZOKUYA EHOSTELA KUNOMUNTU OSO UZOYENZA KANJE UGCATSHWE KANINGI NINGI UZOBA RIGHT NO I NEEDED PROFESSIONAL HELP NOT UKUPEITA OR UKUCHATA LAPHA UYENZE IZINTO EZISNUX PHELA NAMI NGIYILE ESKOLWENI KANCANCE ANGIFUNI UKUBIZISA ILIFE YAMI. BUT KHONA UBABA WAYE NCEDILE WOKUQALA LOYA BABA AMA QUALIFICATIONS WAKHE WAWA THOLA EWITS BAMNIKA ICERTIFICATE SOBU DOKOTELA HE WAS AN INYANGA AS WELL WAYE GOOD YONKINTO. ISBHEDLELA NUMBER ONE PLUS WONKE LAMA PROFESSIONALS WAKHONA OT, PHYSIO NE SPEECH YABONA KULANDELE IFAMILY YAM THEY MAKE SURE UKUTHI NGIDLA IBREAKFAST LUNCH SUPPER YABONA. UNGADELELI ISBHEDLELA SISI BENGIZWANA NO CHERRY WE NURSE E BARA YANG SUPPORTA MANGIPHUMA ESBHEDLELA LEYA CHERRY ABANTU BASESBHEDLELA THEY ARE SUPPORTIVE ISBHEDLELA KHOHLWA NOMA UNGENA LAPHA UHLELI NAMA PHYSIOTHERAPIST ABANTWANA UYABONA UKUTHI THEY FOCUS ON YOU THEY KNOW UMSEBENZI WABO THAT WHERE I SAW IADVANTAGE YE SKOLO UKUTHI HAI KWANGISIZA UKUYA ESKOLWENI NAMI NGINE DIPLOMA SO FUNDA UKUTHI ULALELE.

9. PARTICIPANT NINE

KWENZAKALANI KUZE UYE ESBHEDLELA

BEKUYI 14 ZIKA MAY 2016 NGALIMALA IKHANDA ECLINIC AZANGE BAKWAZI UKUNGINCEDA NGAZE NGANCEDWA YI SBHEDLELA NGAYA EMILNER PARK ESBHEDLELA NGANCEDWA UDOKOTELA UDOCTOR BANI KONJE LOYANA NGIYAMKHOHLWA UKUTHI UDOCTOR BANI WE NDIA WUYE UDOCTOR WANGINCEDA LOYO NGAHLALA ESBHEDLELA NGIYABONA FOR 3 MONTHS NGASE NGIYAPHUMA. MANGIPHUMA ESBHEDLELA BENGIVELE NGIKWAZI UKUKHULUMA, NGIKWAZI UKUDLA BENGINGAKHULUMI KAHLE BENGIKHULUMA MARA HAI KAHLE NOKUHAMBA NAMANJE ANGIKAKWAZI UKUHAMBA KAHLE MHM

MASE UPHUMA ESBHEDLELA MAMA KUKUPHI LA UYE WATHOLA KHONA ISUPPORT

NGATHOLA ISUPPORT KAKHULU EKHAYA ABANTWANA BAMI MHM BEBEZA EVERYDAY BANGIYENZELA YONKE INTO EBENGIYI NEEDA NASE SONTWENI BE BE BEBEZA BAZONG CULELA MHM NALA EHEADWAYS BANGINCEDA NGOKUTHI BANGI EXCERSISISE NGAKHULUMA NE THERAPIST EYE SPEECH

YINGANI KUBALULEKILE FOR UMUNTI OKHE WALIMALA UKUTHI ATHOLE UNCEDO

KUBALULEKILE UKUTHOLA UNCEDO NGOBA KUYENZA UKUTHI INQONDO YAKHO UKUTHI IBUYE BACK…MHM YABUYA BACK NGAKWAZI UKUKHULUMA KAHLE NABASE NDLINI BANGINCEDA NGOKUTHI BANGIKHULUMISE. ABANTU BESONTO BONA BE BEZA BANGICULELA MHM ICHOIR YASE SONTWENI BEBETHANDAZA BECULA MHM NGIKHOLELWA KU NKULUNKULU MINA KAKHULU THAT'S WHY AZANGE NGIMBLAME UNKULUNKULU FOR UKULIMALA KWAMI NGAYITHATHAT NGOKUTHI BEKUMELE KUYENZEKE KIMI MHM BEKUYI SKHATHI MHM. ESONTWENI YIBO BEZA KIMI NGANGINGA ATTENDI ISONTO KUQALA KODWA MANJE YISONTO LAMI NGISONTA KULO MHM EHEADWAY NGESKHATHI SE COVID BESINGEZI BEBE KHULUMA NATHI OVER THE PHONE MHM EY LEYONTO INGAFFECTILE NGOBA BESINGASEZI KUYO BENGIYITHANDA KAKHULU YANG AFFECTA NGOBA ANGISAKWAZI UKUZA NAMANJE NGIJABULILE NJENGOBA SESIZA FUTHI. BA SIZA KAKHULU NGOKU EXERCISE, SIYAKHULUMA SINABANGANI ANGITHI ABANYE ABANTU MAWUKHULUMA NABO ABAZWISISI SO LANA SIYAKHULUMA NGOKUTHI WENA ULIMALE KANJANI NOMUNYE ULIMALE KANJANI MHM UMUNYE UYASHO UKUTHI EY BEKE WORSE OMUNYE UNCONO KUNAWE NAWE UYAZIBONA UKUTHI EY NAMI BENGIWORSE KODWA MANJE SENGINCONO LOKHO KUYAKHUTHAZA UKUKHULUMA NABANTU ABAKHE BALIMALA NGOBA NABO BALIMELE BAKUZWILE LOKHO OKUZWILE LOBOBHLUNGU LOBO (HEADWAY SUPPORT GROUP AND HOW IT HELPED). NGIBONA UKUTHI UNKULUNKULU WUYE ONGINCEDILE UKUTHI NGIZE NGIBE LA MHM NOKUFUNDA IZWI.

10. PARTICIPANT TEN

WALIMALA NINI?

ANGIKWAZI NOKUHAMBA EKHAYA BAZE BANGIFUNELA INTSIMBI ZOKUTHI NGIKHONE UKUHAMBA EHH, NGITHATHE ISKHATHI UKUKHULUMA NGIYE NGAKWAZI UKUKHULUMA SENGIHAMBA LANA E HEADWAY, UKUDLA BENGIDLA KODWA BEBANGIFUNDZA NGOBA IZANDLA ZAMI BEZINGA SEBENZI KAHLE

ABANGANI BONA BEBANGIVAKASHELA BAZONGIBONA BONA BEBAZA BAZONGIBONA IQINISO ANGEKE NGIPHOSISE NAMANJE BASEZA ABANYE BASOKU MAYBE BASEMSEBENZINI PLUS ANGITH AMA LOCKDOWN BEFORE MARA MANJE BESEKUNCONO NGOBA BESIKHONA UKUBONANA. YAH UNCEDO EKUQALENI THE TIME NGISAHAMBA NGELONA ANGISHO BENGINGAKHONI UKUHAMBA NGINGAKHONI NOKUKHULUMA UNCEDO KAKHULU BELUSE KHAYA YABO BECAUSE BEKUNGANA SKHATHI SOKUTHI KUNOMUNTU OPHUMAYO, BENGISHAKER, EKHAYA BANGISIZA KUZE UDOKOTELA WAMI WANGITHUMELA LANA EHEADWAY

MAWUPHUMA ESBHEDLELA UNCEDO WALITHOLAPHI KAKHULU?

ANGISHO BENGINGAKHONI UKUHAMBA, NGINGAKHONI NOKUKHULUMA UNCEDO KAKHULU BELUSE KHAYA YABO

ABANGANI BEBEKHONA BEBEZA ABANGANI BAMI MHM BAZONGIBONA KODWA ALUKHO USIZO ABANGINCEDE NGALO ABANGANI

UMQONDO WAMI UYALAHLA NGIYAKHOHLWA

UNGASHO UKUTHI KUBALULEKE NGANI UKUTHI UMUNTU OKHE WALIMALA EKHANDA ATHOLE USIZO?

EHH UNCEDO LUYASIZA LIKE LUYAMAKHA UMUNTU EQINISWENI USIZO LUYAMNCEDA UMUNTU CZ WITHOUT USIZO ANGEKE ULULAME ANGEKE ULULAME NGOBA ESKHATHINI ESININGI UHLALA MAYBE UQABANGA IZINTO EZININGI AND MAYBE EZINGEKHO RIGHT THOLUKUTHI LIKE MAYBE ZIYAKUPHAZAMISA NGOMQONDO UGCINA MANJE SOWUBA CRAZY SO USIZO LUYENZA UKUTHI UNGACABANGI KAKHULU LIKE MAKUKHONA INTO ENGAKU PHATHI KAHLE YOU HAVE TO GO OUT NJE UTHATHE IWALK NJE UZIHAMBELE USHAYWE UMOYA

AHH MINA NGINGASHO UKUTHI EKHAYA ZIKHONA LEZINTO ZESINTO VELE ACCORDING TO UMAMA NE VELE IFAMILY YABO NAMI KUKHONA EZINYE IZINTO ENGIZILANDELELAYO ACCORDING TO BONA UYANGTHOLA BECAUSE OF NGIMAMELA AMAGAMA APHUMA FROM BONA ABAZALI NAMI BENGIFOLLOW UPA WONA.SAYA EMUNTWINI EHH UMUNTU WASITSHELA WATHI INTO ENDALA LE EYENZEKA UKUTHI NGILIMALE UAUNTY WAMI WUYE OWANGIGANGELA YIKHO NGISO, LOMUNTU WASIPHA IZINTO NEMITHI UKUTHI NGIBE NCONO WASIPHA AMA CHEMICALS.

SIYAKHONZA EZION AND ESONTWENI BANGIPROPHETA UKUTHI HAI NGIZOBA NCONO MAKUYA KUYA NAMI NGIZINAKEKELE EHH, HAI NGINCONO NGOBA NGIYAKWAZI UKUZIGEZA MANJE

HAI AZANGE AA NGOBA BESIHLALA STILL AZANGE ATHOLE ISSUPORT NGENKATHI YE COVID BEBAPHONA NJE, KODWA MAKUVUKA EKUSENI BEKAYENZA AMA EXERCISE UMUNTU WE BOLA BE DLALA IBOLA UKWAZILE UKU EXERCISE. AHH TO BE HONEST EKUQALENI BENGINGAZI NEX ABOUT COVID 19 NGOBA UMQONDO WAMI BOWU DIZZY SO LOCKDOWN ABANGANI BEBANGAKHONI UKUVAKASHA LIKE BEFORE. DURING LOCKDOWN BENGIBOREKA TO BE BORED UCABANGA KAKHULU UKUBA NE STRESS MAAN UKUNGABONANI YABONA UMUNTU OFUNA UKUMBONA BENGAKHONI UKUMBONA NOT EVEN UMTANA WAMI BEKUNZIMA SO LEYONTO BEYINGILIMAZA ENHLIZWENI YABONA IZINTO EZINJALO. AHH MINA TO BE HONEST FIRST OF ALL FAMILY COMES FIRST YAH FAMILY COMES FIRST CAUSE OF SUDDENLY NGINE NGANI NAYO IZA KUQALA, IHEADWAY NAYO IDLALA INDIMA YAYO THAT IFAMILY YAMI INGAKHONI NAYO IYAMAKHA UMUNTU NJENGOBA ISAKHILE KANJE YAH SO ZOYI TWO BESI IMPORTANT NGENDLELA YAZO

11. PARTICIPANT ELEVEN

KWENZAKALENI KUWE BHUTHI?

THE THING THAT MADE ME LIKE THIS IS THE ACCIDENT AND MY ACCIDENT IT HAPPENED IN 2007 NGILIMALE NGO 2007 NGISASE ESKOLWENI NGIQHAMUKA ENORTH WEST NGIZA NGAPHA. UMAMA WAMI LO BENGIHLALA NAYE USHONILE BESA NGATHOLA ESINYE ISTEP MOTHER ENORTH WEST. NGIHLALE AMALANGA AMANINGI ESBHEDLELA ANGAZI UKUTHI HOW LONG WAS IT NISE SBHEDLELA NGOBA IBHEDLELA ENGIZIHMABILE ZININGI ABAO LERATONG, NGAYA EPERDE KRAAL NGAHLALA ISKHATHI. NGILIMALE IRIGHT SIDE YONKE KWAMOSHEKA NE NQONDO YAMI BEYIKHOHLWA NGESPITI, UKUKHULUMA BENGINGAKWAZI NOKUHAMBA BENGINGAKWAZI NOKUYENZA EVERYTHING BENGINGAKWAZI

KUKUPHI LA UYE WATHOLA UNCEDO KHONA

NGIYE NGASIZWA ABANTU BASE SBHEDLELA BA LOKU BANGINCEDA BANGIHAMBISA AMA PHYSIOTHERAPY UKUTHI NGIKHONE UKUHAMBA BUT MANJE NGIYABONA UKUTHI KULESIMO ENGIKUSO SENGIYAKHONA UKUZENZELA ZONKE IZINTO NE MARA IRIGHT HAND SIDE YAMI ILIMELE MARA INYAWO SELIRIGHT MANJE, NAMA SEIZURES BEWANOKUNGI PHATHA BEFORE SEWARIGHT. DOCTOR NAYE WANGINCEDA KAKHULU, ENDLINI BENGINCEDWA ABANTU BASE KHAYA, UBABA WAMI NAMA STEP SISTER WAMI, UBABA KAKHULU BEKANGINCEDA KODWA ABO SISI BEBEZA NABO BAZONCEDA UBABA NGALOKHU BENGIKUDINGA

KUNGANE UBUDINGA UNCEDO?

UKUTHI NGITHOLE UNCEDO KUBALULEKILE NGOBA MANGIBUYA ESBHEDLELA UKUTHI NAMI NGIKHONE UKUBA RIGHT UKUTHI NGIBUYELE KULE SIMO EBENGIKUSO BEFORE UKUTHI NGIKWAZI UKUFANA NJE NGABANYE ABANTU. ICULTURE YAMI AYIZANGE IDLALE INDIMA KULOKHO ANGIHAMBI INYANGA KODWA ICHURCH NGIYILE NGOBA NGIBELIVA KU NKULUNKULU NOKUTHANDAZELA UKUTHI NGIPHOLE. EHEADWAY BASITSHELA NGAYO ICOVID-19 NOKUTHI BAZOCANCELA AMA SESSION WETHU SO BEBAPHONELA UBABA WAMI UKUSETA AMA APPOINTMENT NGE PHONE. YENA MAKABUYA EMSEBENZINI UYANGITSHELA UKUTHI EHEADWAY BATHINI SOR SOR SOR.

APPENDIX I

SITE PERMISSION LETTER

HEADWAY GAUTENG
CELEBRATING 25 YEARS

University of the Witwatersrand,
School of Human Communication and Development

11 August 2021

To whom it may concern

Re: Permission to conduct research at Headway Gauteng

This letter serves to confirm that Ms Lethabo Agnes Maleka has been granted permission to conduct her research i.e. **An exploration into the pathways of care and support followed by persons with post-acute traumatic brain injuries living in Soweto, Johannesburg**, at Headway Gauteng.

The above permission is dependent on approval from the University of the Witwatersrand's Ethics Committee.

Yours sincerely

Bianca Burger

Bianca Burger
General Manager
Headway Gauteng

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 502 Saxonwold 2132 | Telephone 011 442 5733 | Fax 086 723 8051
E-mail: headway@iafrica.com **Website:** www.headwaygauteng.co.za

Governing Body: Brian Mallinson (chairman) | Carol Cannel (vice-chairman) | Waldek Wasowicz (treasurer) | Bianca Burger | Monica Dube | Rozanne Gevers (Alt: Ron Gevers) | Jerry Nkeli | Dr Thobeka Nkomo | Patron: Gareth Cliff

APPENDIX J

PROTECTION OF PERSONAL INFORMATION (POPI): USE AND STORAGE OF RESEARCH DATA

'Raw' or unprocessed data, especially where the identity or personal data of research participants is included, must be safeguarded, and preserved from unauthorised access. Data may be destroyed after use, but preservation in an archive or personal collection may also be appropriate, desirable, or even essential. All data should be preserved in a way that respects the nature of the original participants' consent.

Name of student: Lethabo Agnes Maleka

Student number: 840320

Title of project: An exploration into the pathways of care and support followed by persons with post-acute traumatic brain injuries living in Soweto, Johannesburg.

Name of supervisor(s): Dr. J. Neille & Dr. K. Masuku

Nature of raw data (e.g., test score sheets; audio recordings of interviews): Audio recordings of narrative

What is to be done with the raw data after completion of the project?

_____ Stored securely in supervisor's office

__X___ Stored in a password protected computer (specify whose computer: Researcher)

_____ Stored in digital form with all identifying features removed (e.g., in the case of interview transcripts, these should be anonymised)

_____ Stored in an archive (specify where: _____)

_____ Stored in an on-line data base (specify where: _____)

_____ Destroyed (indicate when data is to be destroyed: _____)

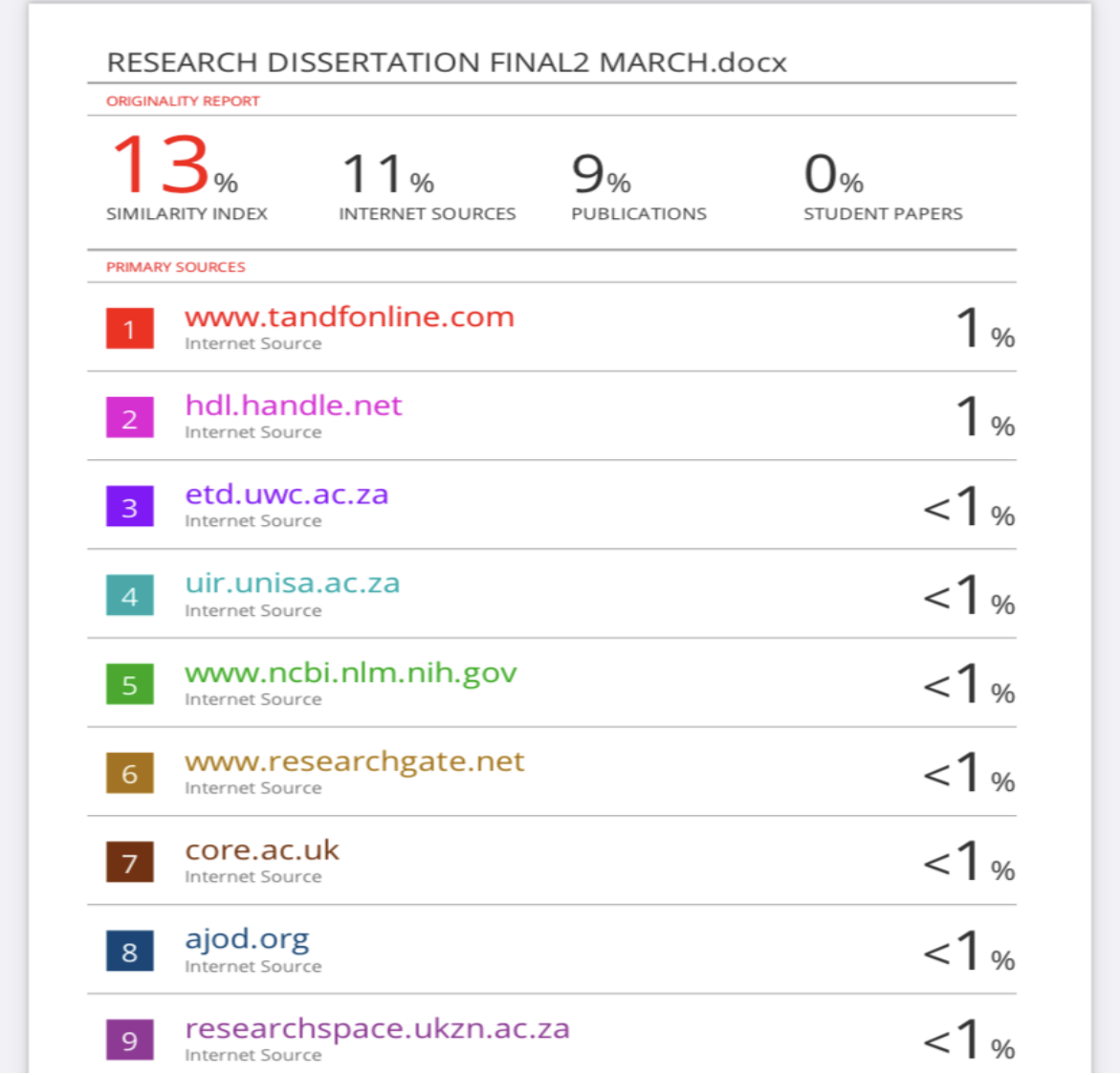
What is to be done with the signed informed consent sheets?

_____ Stored securely in supervisor's office

__X___ Scanned and stored in a password protected computer (specify whose computer: Researcher_; original copies should then be destroyed

APPENDIX K

TURNITIN REPORT



RESEARCH DISSERTATION FINAL2 MARCH.docx

ORIGINALITY REPORT

13%	11%	9%	0%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	www.tandfonline.com Internet Source	1%
2	hdl.handle.net Internet Source	1%
3	etd.uwc.ac.za Internet Source	<1%
4	uir.unisa.ac.za Internet Source	<1%
5	www.ncbi.nlm.nih.gov Internet Source	<1%
6	www.researchgate.net Internet Source	<1%
7	core.ac.uk Internet Source	<1%
8	ajod.org Internet Source	<1%
9	researchspace.ukzn.ac.za Internet Source	<1%