THE CHALLENGES EXPERIENCED BY TRAUMATIC BRAIN INJURY SURVIVORS WITH REGARD TO FAMILY REINTEGRATION POST-HOSPITALISATION

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Date: 25 November 2021

DECLARATION

I declare that the work in this thesis titled "*The challenges experienced by traumatic brain injury survivors with regard to family reintegration post-hospitalisation*" is my original work. I declare that I have not plagiarised, all the sources of information used in this study were acknowledged.

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ABSTRACT

Recovery from traumatic brain injury (TBI) can be a lengthy and challenging process for survivors, their families, and health and welfare services. Globally, South Africa has the second-highest prevalence of TBI that is due to road traffic accidents. The growing challenges for TBI survivors are the financial constraints, health implications, and the psychosocial support required by survivors of TBI and their families, which impacts family reintegration, post-hospitalisation. The aim of the study was to understand the challenges experienced by TBI survivors with regards to the psychosocial support services for family reintegration. A qualitative approach, using an exploratory-descriptive design was used. The person-centred perspective was chosen as a theoretical framework. The study setting was a selected community in the Cape Metropole in the Western Cape, South Africa. The population was TBI survivors in the selected community. Using purposive sampling, 20 TBI survivors from a non-profit organization (NPO) participated in face-to-face semi-structured individual interviews, all COVID-19 protocols were adhered to. Thematic data analysis was conducted, developing themes, subthemes. Six main themes emerged from the data analysis along with three to five subthemes under each theme. The findings indicated a number of challenges related to family reintegration for survivors and their families. Those challenges relating to financial, health, psychosocial, biopsychosocial issues, access to services and reintegration related challenges for TBI survivors post-hospitalisation. Recommendations for social welfare policy, social work practice, social work education and future research were made. Ethics approval was received from the Biomedical Research Ethics Committee at UWC and permission to conduct the study was obtained from the NPO where participants were recruited.

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LIST OF ACRONYMS

BSW = Bachelor of Social Work

NPO = Non-Profit Organisation

PCA = The Person-centred approach

PTE = Post-traumatic epilepsy

PTS = Post-traumatic seizures

PTSD = Post-traumatic stress disorder

RAF = Road Accident Fund

RDP = Rural Development Programme

SACSSP = South African Council for Social Service Professions.

SAPS = South African Police Services

SASSA = South Africa Social Security Agency

TBI = Traumatic Brain Injury

UWC = The University of the Western Cape

CHAPTER ONE

OVERVIEW

2.1.Introduction

Traumatic brain injury (TBI) can cause death and permanent disability (Eapen & Cifu, 2018). It can also result in psychological challenges in survivors, depending on the nature and severity of the injury (Cohen, 2018). These include prolonged behavioural changes and mental health issues such as post-traumatic stress disorder (PTSD) (Eapen & Cifu, 2018). Recovering from TBI can be a lengthy and taxing experience for the survivor and his/her family (Cohen, 2018, p. 21).

South Africa has a high prevalence of penetrative injuries owing to a high rate of road traffic accidents (Buitendag, Ras, Kong, Bruce, Laing, Clarke & Brysiewicz, 2019). Previous research on psychosocial support for TBI survivors and their families have mostly been conducted from a medical point of view, by medical doctors, in nursing and occupational therapy (OT) (Berger, 2019; Soeker& Ganie, 2019; Varghese, 2020). This study aims to understand the challenges experienced by TBI survivors and the psychosocial support services required for improved family reintegration, from a social work perspective.

2.2. Literature Review

2.2.1. Rehabilitation of TBI survivors

TBI contributes to the burden on the healthcare system of South Africa and on rehabilitation services in the public sector. Furthermore, the scarcity of rehabilitation services leads to family members having to assume the responsibility of taking care of and rehabilitating loved ones with TBI with no formal training (Soeker & Ganie, 2019). Persons who have suffered TBI often require inpatient and later outpatient rehabilitation. “For effective treatment, an interdisciplinary team approach to rehabilitation is preferred. Occupational therapists (OTs) and physiotherapists offer rehabilitation programmes to patients following injury on an inpatient and/or outpatient basis” (De Klerk, Eloff, Naude, Boon, Carelse, Sterward & Zaidi, 2019, p. 54). The rehabilitation process is meant to address physical pain, enhance functionality and foster self-care, along with promoting family reintegration to improve the quality of life of the TBI survivor (Soeker & Pape, 2019). According to Berger (2019), rehabilitation for patients with TBI combines several treatments to improve the recovery of patients. “Moderate and severe TBI typically require significant medical resources along the continuum of care from acute care to rehabilitation”(Sima, Yu, Marwitz, Kolakowsky-Hayner, Felix, Barguest, Whiteneck, Kreutzer & Johnson-Green, 2019, p.321). According to Van Praag, Cnossen, Polinder, Wilson and Maas (2019), TBI can result in major psychological challenges that most often require rehabilitation for an extended period. Rehabilitation involves the holistic healing of the survivor, which includes physical, emotional and social needs being attended to. Addressing such needs is aimed at improving the quality of life of TBI survivors (Gomez-de-Regil, Estrelo-Castillo & Vega-Cauich, 2019).

It is imperative to place the TBI survivor’s needs and wants at the centre of the rehabilitation process in order to promote self-determination and foster a sense of empowerment (Cisneros, Morino, Leveille, Charette, Guarrette & McKerral, 2019). Cisneros et al. (2019) suggest that an ideal rehabilitation process involves an inter-disciplinary approach that involves a doctor, OT, physiotherapist, nurse, psychologist and social worker, all working in collaboration with the family.

In the Western Cape, South Africa, rehabilitation services for survivors of TBI are limited and not without challenges (Mlenzana, Eide & Frantz, 2018). Mlenzana et al. (2018) indicate that caregivers have expressed dissatisfaction with the management of patients at rehabilitation centres, often related to overcrowding. The study highlights the importance of caregivers' input in the rehabilitation process, while the input of the service users helps to create informed interventions for professionals and the management of the patients. According to Clark-Wilson and Holloway (2020), it is of great importance for caseworkers such as social workers and OTs to build relationships with the families, to equip them with the necessary knowledge about caring for TBI survivors at home, as it is not easy to deal with a loved one whose life has been drastically changed owing to TBI.

2.2.2. The effect of TBI on family and caregivers

TBI can cause physical, psychosocial and cognitive challenges or deficits in the survivor for a long time (Soeker & Pape, 2019). The long-term effects of TBI on an individual's health and psychosocial wellbeing are mostly followed by neuropsychological deficits, including language, information processing, and working memory (Schwartz, 2019). These deficits can be devastating as they do not only affect the emotional wellbeing of the TBI survivor but also their quality of life owing to their physical limitations and resultant inability to carry out daily activities (Martino, Russo, Santonastatso, Gamberini, Bertoni, Padovani, Tosatto, Ansaloni Agnoletti, 2020). According to Clark-Wilson and Holloway (2020), the reality of having a TBI survivor return home after hospitalisation can place a strain on family norms and relationships, often leaving family members feeling trapped and helpless. The physical and emotional challenges caused by TBI can create health problems and psychosocial suffering for both survivors and their families (Sima et al., 2019). The aggression that is often displayed by TBI survivors affects their quality of life and that of their loved ones, remaining one of the most difficult problems to manage (Deb, Leeson, Aimola, Bodani, Li, Weaver, Sharp & Cawford, 2018). TBI can cause a survivor to be in a vegetative state, leading to a permanent dependency on family and loved ones (Ostermann, Joestl, Tiefenboeck, Lang, Platzer & Hofbauer, 2018). This vegetative state can have huge psychological and financial effects on families of TBI survivors (Oberholzer & Müri, 2019). Studies conducted in the Western Cape, South Africa, show that after TBI patients are discharged from medical facilities, family members take on the responsibility of caring for and rehabilitating them and, these family members take on the caregiver role have no formal training on how to provide daily care to a TBI survivor (Arnold-Day & Semple, 2020; Soeker &Ganie, 2019; Soeker & Pape, 2019; Webster,Taylor & Balchin ,2015). Regardless of these limitations, family members play an important role in supporting survivors, which helps survivors to cope after the traumatic experience (Machisa, Christofides & Jewkes, 2018).

2.2.3. Family reintegration

Family reintegration is the process of preparing or rehabilitating a person back into the family after inpatient or residential care, through the provision of biopsychosocial support to the person who has been away from the family for an extended period. Biopsychosocial services are provided to the family to enable the person to return to the family as quickly as possible, to enhance self-reliance and to promote optimal social functioning (RSA, 2007; Eapen & Cifu, 2018).

From a social work perspective, family reintegration is generally associated with the process of counselling (children and their families) and returning children to their family home after being removed from the parental home owing to neglect or abuse (Cardoso, Bhattacharjeeb, Codyc, Wakiad, Mensonb & Tabbia, 2020; RSA, 2005). Family reintegration is also associated with the returning to home of persons who have been in a substance abuse rehabilitation facility for a prolonged time (Prevention of and Treatment for Substance Abuse Act No. 70 of 2008, RSA, 2008). The term and practice of family reintegration is also used in the case of prolonged hospitalisation and the subsequent return of a person to the family home environment (O'Neal, Lucier-Greer, Duncan, Mallette, Arnold & Mancin, 2018), as is the case with the participants in this study. Community integration is generally the term used in the medical fraternity for reintegration (into the family) after hospitalisation; it involves re-entering every aspect of community life, such as family, the neighbourhood, community organisations (church, sports clubs, etc.) (Clark-Wilson & Holloway, 2020). However, this study focuses on the integration of the TBI survivor in the family home specifically and uses the term 'family reintegration' as proposed in social work practice (Hepworth, Rooney, Rooney, Strom-Gottfried & Larsen, 2013; Kirst-Ashman & Hull, 2008).

The study aimed to understand the lived experiences of TBI survivors and their families regarding the challenges of family reintegration after hospitalisation, from a social work perspective.

2.3. Theoretical framework

The person-centred approach (PCA) was chosen as the theoretical framework for this study. Developed by Carl Rogers (1961), the PCA is based on the notion that a person can develop and grow towards self-actualisation when provided with a nurturing context (Symonds, Miles, Steel, Porter & Williams, 2019). Symonds et al. (2019) explain that PCA is based on the idea that every individual possesses internal resources for self-understanding, for altering her/his self-concept, for shaping attitude, and for behaving in a self-directed way. These internal resources may be tapped into in a definable climate where the psychological attitude of the individual is properly facilitated (Brodley, 2019). This theory further assumes that a nurturing environment promotes a positive self-concept, thereby boosting an individual's development (Bachkirova & Borrington, 2018). According to the World Health Organisation (WHO) (2019), a PCA takes into consideration the individual's daily life, environment and needs, as well as the needs of loved ones. This suggests that the TBI survivor's recovery is subject to and determined by the environment. In terms of this study, the family context created after hospitalisation is critical in the recovery process. In other words, TBI survivors do not exist in a vacuum.

The concept of person-centeredness in PCA confirms its applicability for this study because it implies that, creating a safe and nurturing environment for the individual, and has been applied and used in similar studies (Terry & Kayes, 2019). However, studies have shown that there are gaps or limitations to using this approach, as it is often romanticised; it is not easy to implement it, especially in individuals with formed egos (Bachkirova & Borrington, 2018). Nonetheless, the main premise on which this approach is built suited the phenomenon under investigation in this study, with regard to placing the TBI survivor and his/her family context at the centre in the process of family reintegration.

2.4. Problem statement

Globally it is estimated that TBI affects 69 million individuals annually (Bedry & Tadele, 2020). TBI causes disability which causes a lack of productivity in the individuals' work environment, making it difficult for survivors to go back to work (Soaker & Darries, 2019). According to Bedry & Tadele (2020), there is a high burden of TBI in low and middle-income countries mostly in Africa, compared to high income countries. "More than 90% of trauma mortality occurs in low and middle-income countries, especially in sub-Saharan Africa" (Purcell, Reiss, Eaton, Kumwenda, Quensey & Charles, 2020, p. 597). In South Africa, approximately 89 000 new TBI cases are reported annually, for which the three most common causes are motor vehicle, bicycle or vehicle-pedestrian accidents, falls, and violence (South African Government, World Head Injury Day, 2018, cited from the National Institute for Occupational Health, 2011). As such, TBI has significantly contributed to the burden of healthcare as there are few resources available for rehabilitation in the public sector (Soeker & Ganie, 2019). The scarcity of rehabilitative resources results in families having to take care of and rehabilitate TBI survivors on their own, usually without proper training to do so (Mlenzana et al., 2018).

TBI survivors often suffer lifelong comorbidities that cause hindrances in their physical, cognitive and functional skills (Purcell et al., 2020). Alarmingly, individuals with moderate TBI are often misdiagnosed, as their symptoms cannot be observed easily and they often have an undiagnosed disability (Soeker & Pape, 2019). Furthermore, the outcome of TBI may vary depending on many factors, including the age of the victim, comorbidities, time in treatment, type, quality and appropriateness of care received, level of support given for rehabilitation (including psychological support), and integration back into family, job and society (Varghese, 2020, p. 69).

In South Africa, there is a gap in research, particularly on the experiences of TBI and the psychosocial services rendered by social workers. Much attention has been paid to the challenges faced by families with regard to disability and work rehabilitation for TBI survivors, but mostly from a medical perspective in disciplines such as OT and physiotherapy (Berger, 2019; Soeker & Pape, 2019; Soeker & Darries, 2019; Soeker & Gannie, 2019). Perceptions of TBI survivors about their own lived experiences have been under-reported (Buitendag, et al., 2019).

Family reintegration is an essential part of the rehabilitation of TBI survivors (Clark-Wilson & Holloway, 2020). As such, the role played by family members, post-hospitalisation of TBI survivors is important in the rehabilitation and recovery process that continues in the home environment. This is an under-researched area in social work and in need of scrutiny. Also, the psychosocial interventions by social workers regarding TBI survivors have been poorly reported. Therefore, this study aims to understand the experiences of TBI survivors regarding family reintegration post-hospitalisation from a social work perspective.

2.5. Research question, aim and objectives

The research question was; “What are the challenges experienced by TBI survivors regarding family reintegration, post-hospitalisation”? The study aimed to understand the challenges experienced by TBI survivors regarding family reintegration, post-hospitalisation, from a social work perspective.

The objectives of the study are:

- To explore and describe TBI survivors’ challenges and experiences regarding the reintegration process into their families, post-hospitalisation;
- To explore and describe the vulnerabilities and the resilience of survivors in the process of adapting to the home environment, post-hospitalisation;
- To explore and describe the challenges that come with TBI and how it affects family dynamics and roles, post-hospitalisation; and
- To explore and describe the coping resources and protective factors needed for the process of family reintegration post-TBI.

2.6. Research methodology

2.6.1. Research approach and design

A qualitative research approach was selected for this study because it is appropriate when a researcher wants to study people in their natural settings, to identify how their experiences and behaviour are shaped by their context (Hennink, Hutter & Bailey, 2020, p. 10). Also, qualitative research involves discovering the deeper meaning of phenomena, by exploring phenomena in their entirety (Edlund & Nickols, 2019). A combination of explorative and descriptive research design was used in this study (Krysik, 2018). The purpose of explorative designs is to gain deep insight into and knowledge about a problem, while descriptive designs describe the issue and the effect of the problem on the participants (Kumar, 2014). The combination of the two designs was therefore appropriate, in view of the aim of the study, which was to understand the challenges experienced by survivors of TBI regarding family reintegration.

2.6.2. Research setting

The study was conducted at a non-profit organisation (NPO) that offers support services to TBI survivors, situated in a township in the Western Cape, South Africa. The NPO runs a weekly support group and provides psychosocial interventions by an interdisciplinary team which includes a social worker.

2.6.3. Population and sampling

The population of the study was TBI survivors living in the Cape metropole. The specific township or community where the study was conducted comprised mostly isiXhosa-speaking residents, most of whom understand English and some Afrikaans, since these three are the dominant languages spoken in the Western Cape (Western Cape Government, 2021). The researcher made a written request to the manager of the NPO to access the NPO to recruit participants. Upon receiving permission to do so, the researcher conducted an introductory information session with clients of the NPO, explaining the aim and objectives of the study.

Purposive sampling was used to select 20 participants. This is a type of sampling is characterised by the selection of participants based on certain characteristics that they possess (DeVos, Strydom, Fouche & Delport, 2011). The inclusion criteria: had to be male or female, older than 18 years of age; had to be a resident of the selected community; had to be a TBI survivor with mild, moderate or severe injuries; had to be able to understand questions and articulate responses; had to be a service user at the selected NPO. Exclusion criteria were male and female survivors of TBIs who were 18 years and older and who were clients at the selected NPO, but unable to talk and who had severe mental health challenges, and thus unable to discuss the challenges of family reintegration.

2.6.4. Data collection

Data collection in the qualitative approach makes use of different methods, including open-ended, closed and semi-structured interviews, focus group discussions and document analysis (Aspers & Corte, 2019). In this study, semi-structured individual interviews were conducted, which Carey (2013) defines as pre-planned interviews that are flexible and allow participants to express their views freely. The participants were therefore able to expand on the topic of questions as they saw fit, regarding their perceptions and experiences of living with TBI. An interview schedule and information sheet (see Appendix 2A and 2B) was used, giving information on the study and 27 open-ended questions. The use of these open-ended questions in interviews allowed participants to elaborate on their own experiences, which closed-ended questions would not have allowed (Copley, 2019). The researcher requested participants to sign a consent form (Appendix 3A and 3B) in which they agreed to participate in the study voluntarily.

All interviews were planned to last approximately an hour and were held at the selected NPO on a date and time convenient to the participants. Babbie (2013, p.275) asserts that interviews assist the researcher to have direct personal contact with participants. Participants had the choice of responding to the interview questions in the language of their choice as the researcher is fluent in isiXhosa and English. Interviews were recorded on a voice recorder with the permission of the participants. The researcher proposed to interview 20 participants who met the sampling criteria, or until data saturation was achieved.

2.6.5. Data analysis

The researcher used the eight steps for data analysis proposed by Tesch (1990), cited in Creswell (2014, p. 198). These are as follows:

Step1: The researcher read through the transcriptions to get a feeling of all interviews, formulating ideas about themes that arose while doing do.

Step 2: The researcher read through each transcribed interview in turn while trying to establish the underlying meaning. All relevant thoughts that arose were noted in a memo. This process was repeated with all 20 transcripts.

Step 3: The researcher sought out and organised the patterns of meaning that emerged into themes and subthemes. Similar themes and subthemes were then arranged in columns and labelled as ‘major’, ‘unique’ or ‘leftover topics’.

Step 4: The data was revised in terms of the list of topics. The researcher used abbreviations to identify the themes and noted these abbreviations next to the appropriate text. This was followed while going through the texts again to search for possible new themes that might emerge from the data.

Step 5: The researcher decided on the most descriptive wording for the identified themes and subthemes, and decided on a semi-final list of themes to reduce the total list. Related topics were put together, and links between themes were indicated.

Step 6: The researcher made final decisions about wording of the themes and subthemes and where to place them.

Step 7: The themes and sub-themes were subjected to a literature control to support each theme and subtheme.

Step 8: The researcher recorded existing data where necessary.

2.7.Pilot study

A pilot study refers to small-scale test of the approach, methodology and instrument to determine their suitability, in preparation for a bigger study (De Vos et al., 2011). The researcher conducted a pilot study to evaluate the effectiveness of the data collection methods and interview schedule, using one participant who met the sampling criteria. The interview schedule was slightly adjusted based on the outcomes of this pilot study. Considering the current COVID-19 pandemic, the researcher wore a mask during the pilot study and all subsequent interviews. The researcher kept a 1.5-meter space between her and participants. Extra masks were brought as a precaution in case any participant did not have one.

2.8. Data verification and trustworthiness

The purpose of data verification and a trustworthiness check in a qualitative inquiry is to ensure that the findings are accurate, convincing and worth paying attention to, and that all inconsistencies and errors have been addressed (Levitt, Bamberg, Creswell, Frost, Josselson & Suarez-Orozco, 2018).

The researcher maintained trustworthiness in the study in the following ways: **Credibility** refers to the researcher's ability to prove that the data collected is presented correctly (Korstjens & Moser, 2018). The researcher ensured credibility by making sure that the data collected was presented truthfully, which involved asking the supervisors and participants to read through the transcripts and correct any inaccuracies that they might discern. **Transferability** refers to ensuring that the qualitative research could be applied in slightly different contexts and with other participants (De Vos et al., 2011). A detailed description of the research setting, approach and methods for data collection and analysis were provided to assist future researchers to select whether a similar study would be feasible in a similar context. **Confirmability** is grounded on the researcher's ability to prove that the findings of data can be established by other researchers (Creswell, 2014). The researcher attained confirmability when interpreting the data collected from participants. Each participant would be provided with the transcription of his/her interview and would be asked to confirm or refute the content. **Dependability** refers to the accuracy of the findings (De Vos et al., 2011), which requires that the researcher ask a selection of participants to evaluate the interpretations, findings and recommendations to confirm that it is supported by the data received from participants. In addition to the aforementioned, **reflexivity** was applied to rule out any bias on the part of the researcher and to eliminate preconceptions or ideas of how the participants would respond (Korstjens & Moser, 2018). Self-reflexivity was enhanced in that the researcher consulted with her supervisors to get objective opinions and guidance about the research process, especially regarding data collection and analysis.

2.9. Ethical considerations

Ethical approval was sought from the Biomedical Research Committee at the University of the Western Cape, and was granted. The researcher provided an information letter in isiXhosa and English (see Appendix 1A and 1B) to inform the participants about the purpose of the study, their rights during the study, and what their involvement would entail (Carey, 2012). Carey (2012) emphasises that informed consent is about making sure that participants are well informed, and that they give their consent to participate in the study. Participants were asked to sign a consent form (see Appendix 3A and 3B), indicating whether they agreed to be audio recorded. It was made clear to all participants that participation was voluntary and that no one would be coerced to participate; their participation was of their own accord (De Vos et al., 2011). The researcher was cognisant of the possibility of causing emotional harm to the participants and tried to prevent this (Levitt et al., 2018). The precaution was taken of arranging for a trained counsellor to assist with debriefing if this was required. Lastly, the researcher ensured that all interviews were confidential and that identities were not written on the interviews notes; instead, codes were used to identify audio recordings and transcripts (De Vos et al., 2011). All documents related to the study were kept on a password-protected computer to which only the researcher had access. These will be kept for five years, after which they will be destroyed.

2.10. Delimitation/limitations of study

The study was a qualitative exploratory-descriptive study, where participants were asked to share their challenges regarding family reintegration after a TBI. The study was limited to TBI survivors with mild to moderate injuries, and those with severe TBI whose injuries occurred over five years ago and who were able to function cognitively and express themselves with varying levels of difficulty.

This was a small-scale and context-specific study and the results should not be considered generalizable to social work services aimed at family reintegration for all TBI survivors. Social workers could, however, draw on the study for practise and policy development aimed at services to TBI survivors and their families.

2.11. Structure of the thesis

Chapter One: presented an overview of the research study. The chapter briefly indicated the research methods, ethical considerations and the theoretical framework used in the study **Chapter Two:** presents an extensive literature review on the topic of TBI and its effects on the survivor and the family. The chapter also articulates the rationale and application of the person-centred approach as the selected theoretical framework to contextualise the phenomenon**.** **Chapter Three:** provides a detailed description of the research methodology that was chosen and used in this qualitative study. **Chapter Four:** presents the main findings of this study that emanated from the data analysis of the transcripts of participants.

Chapter Five: is the final chapter of the thesis and provides a summary, conclusions and recommendations for social work policy, practice and further research.

2.12. Definition of key words

Family reintegration is a process of preparing or rehabilitating a person back into the family, after inpatient or residential care by providing biopsychosocial support to the person who has been away from the family for an extended period of time. Biopsychosocial services are provided to the family to enable the person to return to the family as quickly as possible to enhance self-reliance and optimal social functioning (RSA, 2007; Eapen & Cifu, 2018).

Post-traumatic stress disorder is a psychological condition that is triggered by an incident, a condition that is disabling causing functional limitations and, or lack of productivity in daily activities (Mavranezuoli, Megnin-Viggars, Grey, Bhutani, Leach, Dally, Dias, Welton, Katona, El-Leithy, Greenberg, Stockton & Philing, 2020).

Rehabilitation is a process that included services that help to address emotional or physical pain aimed at enhancing wellness and social functionality, to promote self-care as well as family reintegration to improve the quality of life of the person suffering emotional and, or physical trauma or injured. Services are provided in a wide range of settings, including the home, service agencies and residential facilities (Andreea, Teoibaş-Şerban, Mandu, Băilăl, Badiu, Razvan-Laurentiu, Oprea & Onose, 2018; RSA, 2007).

Trauma can be an emotional response to an incident that we have no control over (Reutter, 2019). Trauma also refers to a physical injury to the body caused by accidents, physical assault, or loss of oxygen to the brain (Clark-Willson & Holloway, 2020).

Traumatic Brain Injury is an altering of the brain by an external force or impact to the head, causing a change in the neuro-functioning to the brain (Teutsch, Jones, Kaiser, Gardner & Lim, 2018).

2.13. Chapter conclusion

This chapter provided an overview of the thesis. It explained the rationale for the study, and gave a brief literature review to introduce the topic on the challenges experienced by TBI survivors with regard to family reintegration post-hospitalisation. The chapter also explained the reasons for the selected theoretical framework, its relevance in social work and how it relates to the research topic. The research methodology and the reasons for the specific approach and design were also presented, along with a fairly detailed discussion on the various ethical considerations that were observed, and the steps taken to ensure the study's trustworthiness.

CHAPTER TWO

THE LITERATURE REVIEW

2.1. Introduction

The previous chapter presented an overview of the study. This chapter presents the literature review to conceptualise the study. According to Henning, Van Ransburg and Smit (2004), a literature review is a combination of voices or perspectives of researchers that have studied the same topic, and lays the groundwork for the research; in its absence, social science research would be incomplete.

While TBI causes death and disability to survivors all over the world, new medical interventions have been developed to increase chances of recovery, and in the area of psychological interventions for TBI patients (Gómez-de-Regil et al., 2019). TBI affects health and welfare systems all over the world, owing to the fact that survivors have a disability and low functionality in daily activities, making them dependent on others (Stålnacke et al., 2019). TBI survivors require long-term follow-up of the disability and experience cognitive and emotional impairments (Sima et al., 2019). Eapen and Cifu (2018), in discussing rehabilitation after TBI, state that TBI can cause permanent damage on many levels, including socially, emotionally and physically, in addition to having many financial and health implications for survivors and family members. Cohen (2018), in a study the reliability and construct validity of the TBI-QOL communication for children with TBI, state that TBI has many symptoms that can be permanent, some of which are not visible in the early stages of recovery. The number of symptoms is solely dependent on the severity of the injury. “Every individual with a brain injury has a personal history and identity, making each recovery process unique” (Cisneros et al, 2019, p. 2). Cisneros et al. (2019) wrote a study person-centered tool to support goal setting during interdisciplinary neurorehabilitation’.

This means that the recovery process also depends on the severity of the injury and the intervention strategy has to suit the needs of a TBI survivor. Some individuals may require a great deal of medical or health intervention and some might require few intervention strategies, if at all. “Many patients with mild TBI will have an uncomplicated recovery within three months post-injury without any medical intervention”(Yuea, Ricka, Morrisseya, Taylora, Denga, Suena, Vassara, Cnossenc, Lingsmac, Yuhb, Mukherjeeb, Gardner, Valadkaf, Okonkwog, Cagea, Manleya & TRACK-TBI Investigators, 2018, p.170). This statement was made in the paper their paper on the pre-injury employment status as a risk factor for symptomatology and disability in mild TBI.

Cancelliere and Mohammed (2019, p.1), studied the psychosocial factors influencing recovery following a mild TBI, stated that “mild TBIs 90 % of TBI cases in the United States of America alone , with over 1.5 million cases reported every year”. Deb et al.(2018) studied aggression following a TBI, state that in the United Kingdom, previous studies have shown that TBI is a major health issue with 1.4 million people admitted every year, 80% of them with a mild TBI, and only 200 000 people admitted to hospitals for other medical interventions.

A study by Buitendag et al. (2019), on penetrating traumatic brain injuries at a major civilian trauma centre in South Africa, indicate that Africa has the second-highest prevalence of TBI owing to road traffic accidents and penetrative injury. Those injuries add to trauma cases for local hospitals in South Africa. According to Purcell, Reiss, Eaton, Kumwenda, Quinsey and Charles (2020), in their study about the survival and functional outcomes at discharge post TBI for children versus adults in Sub-Saharan Africa, they indicate that 90% of trauma mortality occurs in the region’s low-and middle-income countries. In South Africa, 89 000 cases of TBI are reported every year (South African Government, World Head Injury Day, 2018, p.1, cited by the National Institute for Occupational Health, 2011). A study by Zaidi, Dixon, Lupez, De Vriese, Wallis, Ginde and Mould-Millman (2019), studied the burden of trauma cases in hospitals in the Western Cape Province of South Africa, state that Of the 3299 cases of trauma reported, most were males between ages of 18 to 34, with 251 (44.4%) cases of intentional wounds, including gunshots, stab wounds and assault. These authors further state that 324 (55.6%) trauma cases were caused by road accidents and unintentional injuries.

According to Leeper, Lahri, Myers, Patel, Reddy, Marting and Van Hoving (2019), in a study assault-injured youth in the emergency centres of Khayelitsha, state that 80% of traumatic injuries in Khayelitsha occur in males, mostly in the form of assaults to the head and face caused by interpersonal violence. Soeker and Ganie (2019), in a study titled: “The experiences and perceptions of employers and caregivers of individuals with mild-moderate TBI in returning to work”, state that TBI has increased the burden on the health system, which has scarce resources for rehabilitation, particularly for TBI survivors. They further argue that the scarcity of rehabilitative resources causes families to take care of and rehabilitate survivors on their own, with no proper training.

2.2.TBI

Bangirana, Giordani, Kobusingye, Murungyi, Mock, John and Idro (2019) studied patterns of TBI and neurological outcomes in Uganda, they state that TBI is indeed a health concern due to the number of symptoms that TBI is a health burden due to the number of symptoms that come with it more so to the elderly. Kumar, Kumar and Singh (2019), studied the psychosocial impact of TBI and found that TBI is often referred to as a silent pandemic owing to its hidden and delayed symptoms, many of which do not show in the early stages of recovery, with many more symptoms becoming apparent apart from physical disability and blindness.

2.2.1. What is TBI?

TBI refers to an altering of the brain by an external force, causing loss of consciousness and neurological deficits in memory, speech and balance; it interrupts the normal functioning of the brain and causes disorientation in the state of mind at the time of injury (Teymoori, Gorbunova, Haghish, Real, Zeldovich, Wu, Polinder, Asendorf & Menon, 2020), in 'Factorial structure and validity of depression and anxiety scales after TBI'.

Nkoana, Williams, Steenkamp, Clasby, Knowler and Schieffa (2020) conducted a study to better understand the educational needs of young offenders with TBI,they indicate that the severity of the injury is determined by the depth of losing consciousness and the extent of post-traumatic amnesia. Mechanisms of TBI include: closed head injury caused by a blow, fall or strike to the head; open head injury caused by a penetrating object to the head; and deceleration injury caused by an impact on the head causing the brain to move inside the skull (Overview of TBI, no author, 2020).

"TBI can be primary or secondary. Primary brain injury occurs as a result of the main injury, while secondary brain injury occurs as a consequence of primary or initial injury" (Mushtaq, Durrani & Artif, 2018, p. 610). This is indicated in their study about post-traumatic epilepsy in TBI survivors and is supported by Berger (2019) and Varghese (2020) who conducted their studies on TBI from a medical perspective. Abdemelek, Draghic and Ling (2019), studied management of TBI and agree that the most common type of TBI is closed head injury, usually caused by a blunt object with a non-penetration of the skull. They further state that another type of TBI is a blast injury, which occurs when a patient is exposed to forces associated with detonation, often constituting a severe injury. Koehmstedt, Lydick, Patel, Cai, Garfunkel and Weinstein (2018, p.1), in a study about the health status and difficulties for caregivers and TBI survivors who are war veterans, found that "TBI is a type of injury that affects several body systems and is not always visible. It is normally followed by several symptoms, including a combination of headaches, confusion, agitation, slurred speech, fatigue, sleep disturbance, vestibular disturbances, sensory problems, memory concentration difficulties, irritability, aggression, vomiting or nausea, problems with judgment and executive control, and convulsions or seizures".

A study by Rashno, Ghaderi, Nesari, Khorsandi, Farbood and Sarkaki (2020) studied TBI along with the memory decline and depression, indicated that long-lasting and permanent disability from TBI can be so devastating that it causes survivors to become suicidal, as they find it hard to cope with their new reality. The seriousness of the consequences of TBI across the globe and the scarcity of effective medical intervention has caused a huge burden on survivors and their families, and remains a major concern, according to Marklund, Bellander, Godbolt, Levin, McCrory and Thelin (2019) in their study about treatments and rehabilitation for acute TBI. A study in South Africa 'Beta-blocker therapy in severe TBI', indicated that TBI is a major health and economic problem with a high prevalence in young adults (Naidoo, Enicker & Hardcasle, 2020). Cancelleire and Mohammed (2019), in a study about the influencing factors following a mild TBI, indicate that symptoms for mild TBI include depressive symptoms and cognitive symptoms such as headaches, memory loss and information processing difficulties. Yuea, et al. (2018), in study tittled'Pre-injury employment status as a risk factor for symptoms and disability in mild TBI', indicate that cases of mild TBI are often under-reported since many patients or victims do not seek medical intervention. It is therefore not easy to determine the prevalence of mild TBI cases, but the estimate is that four million people in the United States are affected every year.

Huet, Dany and Apostolidis (2018), studied 'the representations of the caregivers of brain-injured people', state that severe traumatic injuries cause permanent symptoms including social deficits, communicative and behavioural disorders in a survivor. A study by Pozzato, Tate, Rosenkoetter and Cameron (2019), entitled 'Epidemiology of hospitalised TBI in, Australia' found that the healing process of survivors often requires access to treatment and rehabilitative services; however, many survivors cannot afford such services and recovery for them will depend on the nature of the injury and the medical treatment available. Delgado, Peacock, Elizondo, Wells, Grafmanand Pugh (2018) in ‘Families caring for veterans with penetrating TBI’, indicate that there has been a huge increase in the survival rate from deadly injuries associated with TBI over the years. Naidoo, Enicker and Hardcaslte (2020), state that there are still major challenges with the shortage of propanol manufacturing in USA, UK, South Africa and across the globe. They further state that propanol is an affordable medication with proven results that is known to decrease death rates post-TBI. Shortages thereof are therefore a huge concern to survivors, their families and health systems.

2.2.2. Causes of TBI

According to Wang, Wong, Wu, Chiang, Chiu, Chen and Chang (2019), indicated that causes of TBI are mostly road accidents and interpersonal violence, including being hit by a heavy object causing blood-forced trauma to the head. Specific causes of TBI include domestic violence, recreational or sports injuries to the head, gunshot to the head, military blasts and child abuse or abusive head trauma (Overview of TBI, 2020). A paper entitled ‘What impact will moderate or severe TBI have on a person’s life?’ (BrainLine, 2019), cites similar causes of TBI, mentioning blows, jolts to the head and falling. In low and middle-income countries, road traffic crashes are the leading causes of TBI in young people, while falls are the leading cause in the elderly. According to Bangirana, et al. (2019) studied TBI in Uganda, state that countries with a developing economy are more likely have a high prevalence of TBI owing to the high use of vehicles, which leads to road accidents. In the United States of America (USA), there has been a proven connection between criminal lifestyles, significant violence and TBI, as indicated by Schwartz (2019) in a longitudinal study on the assessment of head injuries. According to Liu, Bush, Koyutürk and Karakurt (2020) in their study on the interplay between TBI and intimate partner violence, another common cause of TBI is domestic violence from intimate partners, usually caused by severe beatings to the head. In South Africa, the most common causes of TBI are falls, interpersonal violence, including assaults, and vehicle accidents, according to Nkoana, Williams, Steenkamp, Clasby, Knowler, Schrieffa (2020), in their study on the prevalence of TBI and learning disabilities.

2.2.3. Physical effects of TBI

TBI causes death and morbidities leading to physical effects across the globe (BrainLine, 2019). Purcell et al. (2020), writing on survival and functional outcomes at discharge after TBI, mention that there is still a huge risk of mortality for survivors, and that over the years there has been a 7% increase in the prevalence of death during the 13 years post-TBI. That speaks to the quality of life and health related complications of TBI survivors post hospitalisation. Martino et al. (2020), on long-term outcomes in major trauma patients and correlations with the acute phase, state that severe TBI is a catalyst for permanent disability on survivors, leading to many psychosocial effects. Gómez-de-Regil et al. (2019), in their study on psychological intervention in TBI patients, indicate that physical symptoms of TBI may include sensitivity to noise, fatigue and headaches, which affect the quality of life and decrease functionality, but that these can be moderated by rehabilitative services. TBI survivors are likely to experience challenges in completing work tasks owing to physical effects and may not be able to perform activities that they once completed before the injury (BrainLine, 2019). Taylor and Seebeck (2020), who studied pre-injury psychological factors and case formulation in mild TBI rehabilitation, state that another physical effect of TBI is a loss of stamina or fatigue post-injury, which affects an individual's ability to perform tasks for an extended period. Another study by Tomar, Sharma, Jain, Sinha and Gupta (2018) on fatigue and associated factors in TBI, state that TBI is commonly associated with insomnia and depression, post-TBI fatigue. They further state that, the occurrence of insomnia and depression may change but fatigue remains for a number of years post TBI.

2.2.4. The effects of TBI on health and welfare systems

The symptoms of TBI are mostly undetected immediately after the incident, but lead to increasing health, social and economic burdens across the globe (Wang et al., 2019). TBI has added to the burden in the health and welfare system in South Africa and there are not enough rehabilitative services in the public sector (Soeker & Ganie, 2019). Adediran, Drumheller, McCunn, Stein and Albrecht (2019) who studied sex differences in in-hospital complications among older adults after TBI, found that TBI has a long-lasting effect on survivors and families, with high costs for healthcare and emotional wellbeing. Tandean, Jarpadi, Loe, Riawan and July (2019) who studied the use of propolis extract in relation to TBI, state that not only is TBI a global problem, it also causes huge economic problems for families, owing to the fact that many survivors are unable to work and become dependent on families. Ned, Tiwari, Buchanan, Van Niekerk, Kate Sherry and Chikte (2020) studied changing demographic trends among South African occupational therapists and found that there is a high demand for professionals who can deliver essential rehabilitative services to South Africans. They state that rehabilitation professionals are instrumental in the improvement of physical functionality and the quality of life of beneficiaries, and draw attention to the huge gap that still exists between the private and public healthcare sectors. These authors point out that there is an enormous public healthcare burden and high inequality when it comes to social, health, economic and political systems, with 84% of the population depending on the public sector and only 16% of the population afford medical insurance, which gives very few people access to top-quality healthcare. A South African Government (2020) publication on disability grants states that a care dependency grant of R1 860.00 per month is awarded to parents or primary caregivers who earn R48 000 per annum or less and are taking care of severely disabled children from birth to the age of 18. The disability grant (also R1 860. 00) can be applied for by South African citizens with a medical document that proves the mental or physical disability of an individual. This shows that TBI has a financial effect on the healthcare and welfare system, as also stated by Soeker and Ganie (2019).

2.3. The prevalence of TBI (globally, Africa, South Africa and Western Cape)

2.3.1. The prevalence of TBI globally

Eapen and Cifu (2018) indicate that TBI is a huge cause of disability and death, with over 1.4 million cases in the United States and 10 million cases around the globe reported every year. Soeker and Darries (2019) state that TBI is often serious enough to lead to death and hospitalisation. Kumar et al. (2019, p.1), discussing the psychosocial impacts of TBI, state that in developing countries the prevalence of TBI is likely to be 341 per 100,000, and that the delayed effects of TBI are estimated to cost over $56 billion. “In comparison to other parts of the world, Asia has the highest percentage of TBI-related outcomes as a result of falls (77%), unintentional injuries (57%) and road traffic accidents (48%)” (Ghosh, Desai, Halder, Ghosh, Das, Saldanha, 2020.p.77). “In European countries, an overall incidence of 262 hospitalisations per 100,000 inhabitants per year was derived from a meta-analysis. About 10% of TBI are considered as severe. The weighted average mortality for severe traumatic brain injury was 39%.” Ruet, Bayen, Jourdan, Ghout, Maude, Lalanne, Pradat-Diehl, Nelson, Charenton, Aegerter, Vallat-Azouvi & Azouvi, 2019, p. 2). These studied are indicative of the prevalence rate of TBI across the world.

2.3.2. The prevalence of TBI in Africa

Onyemaechi (2020) studied road traffic injuries in Nigeria , indicate that the prevalence of trauma emergency cases is very high in low and middle-income countries including Africa, with 85% of death rate caused by road traffic accidents. Bedry and Tedele (2020), state that TBI affects 69 million people across the globe, but the burden of TBI is three times higher in Africa owing to its’ low-income status. “A study in one of the African countries yielded the following results: TBI 317 (7.4%) cases, documented. Most of the TBI cases presented within 24 hours of injury, 258 (81.4%)"(Bedry & Tedele, 2020).

In total, 90% of trauma mortality occurs in low-and middle-income countries, especially in sub-Saharan Africa (Purcell et al., 2020). Brown, Belli, Qureshi, Davies, Toman, Upthegrove (2019, p. 2) state: "The incidence of TBI varies between 150–300 cases per 100,000 populations per year, and is associated with younger age and male gender. The three most common causes of TBI are falls, road traffic collisions (RTC) and assault, with assaults accounting for around 18% of all cases in western populations, and around 40% of cases for younger patients".

Samanamalee, Sigera, De Silva, Thilakasiri, Rashan, Wadanambi, Jayasinghe, Dondorp, Haniffa, (2018), who studied TBI outcomes in a tertiary care centre, found that low and middle-income countries, where 85% of the world's population live, are burdened with a high prevalence of TBI with high chances of death post-injury and a high prevalence of permanent disability. Adjorlo (2018) studied diagnostic accuracy, sensitivity, and specificity of executive function tests in moderate TBI in Ghana, finding that TBI remains a huge public health issue and a socioeconomic challenge owing to its high cost to the health system. This author further states that in sub-Saharan Africa, TBI is a major cause of death, especially in Ghana, which has many road accidents. Bundu, Lowsby, Vandy, Kamara, Jalloh, Scott and Beynon (2019), in a study about the burden of trauma and the referral path for government hospitals in Sierra Leone, state that trauma cases often lead to death and disability in most African countries and are still relatively under-reported in these countries. Awua, Kwarteng, Ofosuhene-Mensah, Krafona (2019) , studied the 'Psychosocial , cognitive and behaviour after- effects of TBI', state that despite the high number of TBI cases in low and middle-income countries, there is a huge limitation with regard to accessing healthcare services.

2.3.3. The prevalence of TBI in South Africa

A study on TBIs by Webster, Taylor and Balchin (2015) state that the high prevalence of violence in South Africa and the Western Cape contributes to the burden of disease with 76 653(9.7%) deaths due to intentional injuries. “Globally every year more than 5% of people suffer serious brain injury after an accident or as a result of accidentally bumping their head”(World Head Injury Awareness Day 2018 ,South African Government, 2018 as cited in the National Institute for Occupational Health, 2011). In South Africa, despite a generally perceived high level of TBI in adolescents and adults, few hospital-based studies are available to substantiate the perception (Habtemariam, 2019).The above figures are reiterated by Jacobs-Nzuzi, Swart and Soeker (2019) in their study on the role of occupational therapy in school transition practice for high school learners with TBI. “South Africa accounts for 89 000 of the 10 million people affected by TBI globally per year. There are peaks identified in TBI incidence throughout the life span” (Jacobs et al., 2019.p. 1).According to Maasdorp, Swanepoel and Gunter (2020), studied the ‘Outcomes of severe TBI and discharge in Bloemfontein’, they state that there is a gap in studies regarding the prevalence of TBI in South Africa. These authors continue to say that in South Africa, a TBI occurrence rate of 316 per 100 000 people is reported annually. Soeker & Pape (2019), stated that a previous study indicated a six times higher prevalence of death rate in South Africa, owing to trauma related injuries. These authors further state that individuals from low socioeconomic backgrounds and male gender are often at risk of TBI.

The three most common causes of head injuries are motor vehicle, bicycle or vehicle-pedestrian accidents (50%), falls (25%) and violence (20%) (South African Government, 2018). There is a huge gap in the literature regarding TBI in South Africa, with TBI studies very scarce in relation to the number produced in other developing countries (Sallie, 2020). Sallie (2020, p. 7) states: “A study done in Pietermaritzburg Metropolitan Trauma Service (public institution) reported an overall mortality of 38%, Baragwanath Hospital (a public institution in Johannesburg) reported 27%, and Milpark Hospital (a private institution in Johannesburg) reported 58%”.All of these figures are evidence of the prevalence of trauma cases are high in South Africa, as in other developing countries.

2.3.4. The prevalence of TBI in the Western Cape

Studies by Leeper et.al (2019) and Tylor (2018), conducted at different times in Khayelitsha, both came to the conclusion that violence has reached worrying levels in the Western Cape. These authors further state that, trauma injuries accounted for 14% (6 770) of all deaths in the Western Cape in 2016, with over 80% of these being males, in particular 20-39-year-olds. Of the 6 770 injury-related deaths, 3 385 (51%) were homicides and half of them tested positive for alcohol.

Mbombo (2019, p.1) delivered a speech in February 2019 titled ‘Violence, trauma and alcohol has devastating effects on Western Cape Health system’ and stated;

> “During this period, over 30 000 emergency cases were transported to hospitals by emergency medical services. Of these cases, 23% (8 069) involved injuries which ranged from violent trauma such as stabbings and gunshots to physical and interpersonal violence, as well as accidental injury”.

Webster, Taylor and Balchin (2015), indicate that the high rate of violence in South Africa and the Western Cape leads to trauma cases including TBI, which contribute to the burden of disease, with 76 653 deaths (9.7% of all deaths) caused by intentional injuries. Another study in the Western Cape by Zaidi, Dixon, Lupez, De Vries, Wallis, Ginde and Mould-Millman, (2019, p.14) states;

> “Of 3299 total cases, 565 (17.1%) presented with trauma, of which 348 (61.6%) were male. Of the trauma patients, 256 (47.6%) were aged 18–34 and 298 (52.7%) presented on the weekend. Intentional injuries (assault, stab wounds, and gunshot wounds) represented 251 (44.4%) cases of trauma. There were 314 (55.6%) cases of injuries that were unintentional, including road traffic

> injuries. There were 144 (60%) intentionally injured patients that arrived overnight (7 pm–7 am)".

Despite these alarming figures, there remains a gap in the literature on TBI survivors, particularly in the Western Cape.

2.4. The effects of TBI on survivors

Taylor and Seebeck (2020), examining pre-injury psychological factors and case formulation in mild TBI rehabilitation, state that most mild TBI cases are often not accounted for because survivors do not go to the hospital and the recovery period takes less than three months in cases of mild TBI. They further state that with mild TBI, common symptoms are memory loss, headaches, fatigue, functional deficits and cognitive deficits, among others. Soeker and Pape (2019), in 'The use of the model of self-efficacy for work retraining', indicate that it is not uncommon for TBI survivors to experience psychosocial and physical effects, occurring over an extended period of time, depending on the severity of the injury. The effects of TBI are felt in the survivor's psychosocial wellbeing, caused by various neuropsychological impairments including language, information processing and working memory, to name a few (Schwartz, 2019). "It is possible that many patients with a severe TBI die before reaching the hospital, considering the long delays in transfer from the scene and between hospitals which are inherent in developing countries" (Sallie, 2020, p.7). This justifies the devastating effects of TBI; as some lose their lives before receive medical attention, which speaks to the huge burden in the health and welfare systems (Soeker & Ganie).

2.4.1. Stress, mental health issues and TBI

Martino et.al (2020) state that most trauma patients show problems in their emotional, physical and cognitive domain that need to be carefully monitored by trauma specialists in the trauma system. Weiss, Becker, Hanna, Shazly, Gao and Ventevogel (2019, p.119) support this finding, stating: "These emotional, cognitive, physical and behavioural reactions are normal adaptive reactions to severe stressors; these are more likely to resolve if a supportive family or community environment is available”. Tyreman (2018) states that dealing with the impact can be devastating but it helps if the patient is resilient, appreciates and accepts their difficulties, has coping tools and a supportive family, and receives professional support. Furthermore, TBI survivors are not immune to post-traumatic stress disorder, which exacerbates behavioural cognitive dysfunction, causing anxiety and a magnified startle response (Teutsch, Jones, Kaiser, Gardner & Lim, 2018, p.1). Post-traumatic stress disorder is an emotional or psychological condition that disables the victim and hinders his or her functionality, leading to low productivity in daily activities, according to Mavranezouli, Megnin-Viggars, Grey, Bhutani, Leach, Daly, Dias, Welton, Katona, El-Leithey, Greenberg, Stockton and Pilling (2020), writing on the cost effectiveness of psychological treatments for post-traumatic stress disorder in adults. People with PTSD experience emotional highs and lows, including re-living the event, avoidance, hypervigilance, fear, low self-esteem and a sense of being emotionally drained (National Institute for Health and Care Excellence, 2019). TBI and PTSD can lead to devastating emotional and psychological consequences in survivors, especially if the effects of the incident are not addressed through psychological intervention (Teutch et al., 2018). The combination of TBI and PTSD has been linked to reduced quality of life, poorer productivity, and reduced insight (Wang et al., 2019). Wang et al. further ascertain that TBI is accompanied by many persistent symptoms including depression, anxiety and sleep disturbances, some of which develop later on in the process of recovery. Shepherd-Banigan, Shapiro, McDuffie, Brancu, Sperber, Van Houtven, Kosinski, Mehta, Nagi and Williams (2018), who studied interventions that support families of patients with TBI, expand on this, stating, “Symptoms may include flashbacks, nightmares, and severe anxiety, as well as uncontrollable thoughts about the event (Mehta et al.,2018,p.1178)”. Tyreman (2018) concurs that depression is not uncommon to TBI survivors, being an emotional response to the trauma of the injury and, in some cases, caused by the inability to accept long-term deficits of TBI, including permanent disability. Tyreman (2018) further states that the changes or loss in social skills and personal relationships, loss of functionality, increased dependency and decreased chances of returning to work can be predisposing factors for depression in TBI survivors. Depression may also be linked to fatigue or loss of stamina and may lead to sleep disorders, depending on the severity of the injury, according to Tomar, Sharma, Jain, Sinha and Gupta (2018), who studied the correlation between TBI, insomnia and depression. One extra emotional effect of TBI is anxiety disorder, which often goes hand in hand with TBI; its prevalence ranges from 31% to 61% post-hospitalisation, according to Leong Bin Abdullah and Sidi (2019), who studied depression and anxiety among TBI patients in Malaysia.

It seems therefore that TBI survivors are likely to experience anxiety and feelings of nervousness or fear, often feeling out of place in the process of adapting to the new reality.

2.4.2. Cognitive and behaviour changes post TBI

Following a TBI, a survivor may experience significant cognitive deficits that may last up to ten years or longer, especially in cases of moderate and severe injuries (Psychosocial considerations for TBI, no author, 2019). They further ascertain that over the years there has been an increase in the number of TBI survivors, with 60% of them reporting changes in behaviour and cognitive functioning.

Cognitive and behavioural challenges are to be expected in a TBI survivor, although many are invisible at first and may not be noticed in the initial stages of recovery. This makes it difficult to grasp and deal with them (Stålnacke, Saveman & Stenberg, 2019). With improvements in medical care, there has been an improvement in the survival rate of TBI survivors; however, survivors suffer long-term cognitive deficits that cause functional limitations, as indicated by Kanchan, Singh, Khan, Jahan, Raman and Sathyanarayana Rao, (2018), who studied the impact of neuropsychological rehabilitation on the daily living and community reintegration of patients with TBI.

Cognitive-communicative deficits are often present following a TBI, although their severity will depend on the severity of the injury. These affect the person’s ability to make conversations, maintain a sense of identity and maintain relationships, as indicated by Brunner, Palmer, Togher and Hemsleyn (2019), who studied the experiences of people with TBI. Tyreman (2018, p.8) expands on this, stating, “This means that conversations can be frustrating and unrewarding for others, particularly when the same conversation is repeated several times”. It may be hard for a person with a brain injury to identify and analyse problems, think of possible solutions, make decisions, and implement coping strategies. Milders (2018), who studied the relationship between social cognition and social behaviour following a TBI, report that other studies have shown that the prevalence of behaviour change ranges from 25% to 88% in moderate TBI cases, with a higher occurrence among those with severe or penetrative injuries.

Aggressive behaviour, as well as agitation, are common among TBI survivors’ post-hospitalisation. Kumar, Kumar and Singh (2019, p. 13) define aggression as “damaging, threatening, or intimidating behaviour that may be impulsive or premeditated or episodic, with recurrent crises of out-of-proportion fury owing to provocation or frustration, along with antisocial behaviour, with inconsideration of moral and social principles”. Aggressive behaviour causes suffering for family members and sometimes results in family breakdown, in which case proper intervention by relevant service providers is needed (Deb et al., 2018). In addition to aggression and agitation, TBI survivors often experience anger which greatly impacts caregivers and family dynamics, as they are often on the receiving end of it (Naidoo, Eniker & Hardcastle, 2020).

Apathy and egocentrism are common in survivors and have been shown to be part of neuropsychiatric disturbances post-injury, according to Semple, Zamani, Rayner, Shultz and Jones (2019), who examined affective, neurocognitive and psychosocial disorders associated with TBI and post-traumatic epilepsy. These neuropsychiatric disturbances can cause a survivor to be self-centred, to lack an understanding and have no regard for other people's needs and emotions (Tyreman, 2018). Williams, Wood, Alderman and Worthington (2020, p. 119), studied the psychosocial impact of neurobehavioral disability, state that neurobehavioral disability

> … "can take many forms, some of which involve a lack of social cognition (often involving problems of emotion-recognition and expression), or a lack of inhibitory control (such as labile mood, impulsivity, low tolerance, irritability, and poor temper control), while other forms present as diminished patterns of behaviour (characterized by a lack of arousal-drive-motivation".

In a study by Stålnacke et al. (2019), survivors experienced memory problems as one of the consequences of TBI, with participants scoring low on problem-solving skills, memory, concentration, speech and language. These authors believed that there was a need for further cognitive investigation of TBI survivors. Cardoso, Faleiro, de Paula, Kummer, Caramelli, Teixeira, de Souza and Miranda (2019) studied mild acute TBI on survivors and how it causes cognitive impairments post-injury; they state that it is not uncommon for survivors to experience deficits with their cognitive performance, naming, incidental memory, and delayed recall and executive functioning.

2.4.3. Epilepsy and sleep disorders post-TBI

Epilepsy is one of the long-lasting inherent complications of TBI, mostly occurring in survivors of severe TBI. It is a clinical condition that disturbs the electrical activity of the brain and is evident and recurrent, unplanned seizures which are 24 hours apart. (Mushtaq, Durrani & Artif, 2018). There is a high risk of developing epilepsy following TBI, with the incidence varying between 1.6% and 4.2 % in moderate injuries and 25.3% to 53% for severe or penetrative injuries (Ghadiri, Gorji, Vakilzadeh, Hajali, Khodagholi & Sharifzadeh, 2020).

“Post-traumatic seizures (PTS) may occur as a result of a complication of severe TBI. If the PTS occur within 7 days of the injury they are classified as early; they are late PTS when they occur for the first time more than 7 days following injury” (Sallie, 2020, p. 11). According to Tubi, Lutkenhoff, Blanco, McArthur, Villablanca, Ellingson, Diaz-Arrastia,Van Ness, Real, Shrestha, Engel, Paul and Vespac (2019), in ‘prediction of PTS by early seizures and trauma to the temporal lobe’, stated that severe TBI is known to be a major risk factor for post-traumatic epilepsy; however, the injury location and how it impacts the tendency of seizure development has yet to be proven.

Wolfe, Sahnib and Attarianc (2018), who studied sleep disorders in TBI, indicated that sleeping disorders are common amongst TBI survivors with severe TBI, who often experience abnormal sleeping patterns, although after eight days they may once again demonstrate normal sleep patterns and ‘consolidate day and night’. Cronin and O’Loughlin (2018), who studied sleep and fatigue after TBI, state that sleep disturbances often lead to post-TBI fatigue, causing tiredness in survivors. A study by Kaufmann, Orff, Moore, Delano-Wood, Depp and Schiehser (2019), on psychometric characteristics of the insomnia severity index in veterans with a history of TBI, found that lack of sleep is to be expected post-injury and is linked with psychological issues including suicide, alcohol and drug abuse, all of which cause huge disruptions in the process of recovery for survivors. They further state that sleep dissatisfaction post-TBI leads to poor physical health, interference in daily functions and decreased quality of life. Medical interventions are needed for such disturbances, in order to moderate sleep patterns for TBI survivors.

2.4.4. The effects of TBI on relationships

Martino et al. (2020) and Tyreman (2018) state that TBI impairments have a huge impact on the individual’s ability to maintain relationships, among other things. In addition, injury can cause many social dysfunctions in survivors including a feeling of wanting to be left alone, low self-esteem and difficulties with intimate relationships (Cohen, Holdnack, Kisala & Tulsky, 2018). Cohen et al. (2018) study on depression measures among individuals with TBI, they found that the physical and verbal aggression that is common to TBI survivors has a direct effect on relationships with family members and loved ones, as might be expected.

“Readjustment after brain injury is perhaps most difficult for partner relationships, particularly where there are marked changes in the personality of the injured partner” (Tyreman, 2018, p. 19). Tyreman (2018) further states that most partners become the caregivers of TBI survivors, which changes the dynamics of their relationships, affecting social activities, leisure, sex and intimacy. Douglas (2020), who studied loss of friendship following TBI, states that having a close relationship with someone can be one of the key factors for overcoming the long-term effects of TBI, since good relationships form one of the protective factors that help with overcoming stress and promoting wellbeing. Part of socialising requires communication skills. Survivors with communicative disorders may be at risk of losing friends, as they are apt to repeat ideas and do always make sense to others (Tyreman, 2018).

These factors can cause survivors to isolate themselves, exacerbating the problem of loneliness and depression (Douglas, 2020). Survivors may end up misusing alcohol as a coping mechanism as they are not sure about the possibility of returning to work or studies, and may find themselves bored, sitting at home with nothing to do (Psychosocial considerations for TBI, no author, 2019). It is further stated that families and friends might enable survivors with money to buy alcohol in an attempt to cheer them up or to try to make them feel better. TBI remains a huge problem as it changes survivors, often making them feel like strangers to their loved ones; many spouses experience rejection, detachment from survivors and emotional isolation post-TBI (Williams et al., 2020).

2.4.5. Return to work post-TBI

Martino et al. (2020) state that many people who sustain a brain injury cannot go back to their previous work because of impaired functionality which may last an indeterminate period. Ostermann, Joestl, Tiefenboeck, Lang, Platzer and Hofbauer (2018), writing on risk factors predicting prognosis and outcomes of elderly patients with isolated TBI, state that it is not enough to just survive TBI; a good quality of life is also important, where an individual is able to function in society. Severe TBI is usually followed by several symptoms which cause reduced functionality, permanent disability and cognitive and behavioural impairments which make it difficult for survivors to return to work post-injury, as most workplaces require cognitive skills (Sigurdardottir, Andelic, Wehling, Anke, Skandseng, Holthe, Manskow & Roe, 2018). Sigurdardottir et al. (2018) further state that communicative disorders, memory loss, and changes in information processing, as well as inappropriate social behaviour, are difficult disorders that negatively impact a survivor’s chances of returning to work. A TBI survivor is liable, for example, not to complete tasks at work or to omit doing them altogether because he or she simply forgets to do so. Interestingly, a study by Andelic, Howe, Hellstrom, Sanchez, Lu, Lovstad and Roe (2018), on disability and quality of life 20 years after TBI, found that there was a 52% improvement rate amongst participants who returned to work. However, their study showed that there were many functional limitations in survivors to one degree or another, and that those limitations got in the way of their return to work. Welk (2019), who studied employment outcomes following TBI, highlights the importance of access to vocational rehabilitative services for TBI survivors, as this reinforces cognitive skills including: memory, information processing, reasoning, attention to detail and improved communication skills, all of which are essential for workplaces. Welk (2019) further states that vocational skills programmes focus on enhancing cognitive functions (memory, attention and reasoning) in individuals to increase their chances of employment; however little has been done for more training of the brain function. Soeker and Ganie (2019) indicate that the severity of the injury and the period of recovery determines the chances of going back to work. They further state that, factors that have an impact on this process include the level of education, the level of stress tolerance, and the cognitive functions of the survivor. A study by Ruet, Bayen, Jourdan, Ghout, Meaude, Lalanne, Pradat-Diehl, Nelson, Charanton, Aegerter, Vallat-Azouvi and Azouvi (2019), on long-term outcomes in severe TBI eight years post-injury, found that there is a need to manage cognitive disorders and socio-professional reintegration to help improve the vocational skills and cognitive functioning of TBI survivors. These authors state that the chances of returning to work after TBI are very low, and that those with jobs may have challenges with maintaining long-term employment after TBI. In some cases, colleagues can be indifferent to the survivor's challenges post-injury at work, and may be annoyed with the survivor's inability to work at a fast pace, leading to financial losses and not meeting workplace deadlines (Williams, Wood, Alderman & Worthington, 2020). Williams et al. (2020) study on the psychosocial impact of neuro-behavioural disability also found that there are substantial reasons why most survivors cannot return successfully to the workplace post-injury.

All of these studies indicate the limitations for TBI survivors with regard to returning to work post-hospitalisation, and further highlight the importance of gaining access to vocational rehabilitation programmes to enhance the skills of TBI survivors.

2.4.6. Psychosocial effect of TBI on family members and caregivers

According to Corallo, Di Cara, Lo Buono, De Salvo, Cannistraci, Algana, Fifici, Bramanti and Marino (2019), who studied religious coping in caregivers of patients with acquired brain injuries, primary caregivers are the most likely to experience emotional suffering after a family member's TBI, and tend to suffer from mental health issues including anxiety, trauma and depression. This indicates that caregivers are also victims of trauma and need psychological help. Family members have a huge role to play in supporting survivors and that role helps to moderate the stress, assisting them to cope and adapt to the aftermath of TBI, in the absence of long-term professional assistance (Machida, Christofides & Jewkes, 2018). Shepherd-Banigan et al. (2018, p. 1177) studied the interventions that support or involve caregivers or families of patients with TBI, and point to the high numbers of caregivers who care for TBI survivors on their own. They state: "Almost 40 million family caregivers care for a loved one with severe physical or cognitive impairments". Ostermann et al. (2018), indicate that is not always easy for family members to accept change in survivors, as they can be completely disabled and dependent on others for basic needs post-injury. According to Oberholzer and Müri (2019), studying the neurorehabilitation of TBI patients, state that the vegetative state of survivors and other symptoms of TBI often increases the financial burden on family members and caregivers. According to Huet, Lionel, Dany and Apostolidis (2018), who conducted a qualitative enquiry on the representations of the caregivers of brain-injured people state that, a caregiver is any person, relative, neighbour, friend, close family member, wife or husband who takes it upon themselves to care for an adult with a long-lasting disability. This indicates that anyone can be a caregiver for another person with physical challenges. Soeker & Ganie (2019) point out that most family members have to undertake this caring with no training. Koehmstedt, Lydick, Patel, Cai, Garfunkel and Weinstein (2018), in 'Health status, difficulties and desired health information and services for veterans with traumatic brain injuries and their caregivers', indicate that even though some families may receive instructions on how to care for survivors upon the family member's discharge from the hospital, they still need to continue to receive education and support to adapt to the adversities and challenges of this care, especially given the after-effects of TBI. These authors state that family members have an all-encompassing role, having to care for survivors while experiencing high levels of stress. Caregivers struggle to process and accept the drastic changes in their loved ones, especially in cases where survivors lose their ability to function. Changes include fundamental changes in the survivor's personality, with new characteristics emerging such as difficulty with cognition, all of which cause suffering to families, along with the survivors themselves, as indicated by Sima et al. (2019), who studied outcome prediction from post-injury resilience in patients with TBI. It is pivotal for family members and caregivers to have enough information on the mental healthcare of survivors, as lack thereof can lead to misunderstandings of survivors' wishes and needs, causing caregivers to experience a range difficulties and frustrations (Huet, Lionel Dany & Apostolidis, 2018). Fully informed caregivers will understand the health effects of TBI on survivors, their difficulties with social interaction, changes in behaviour, attitude, skills and inability to go back to work, and they may be better prepared to seek financial support for families as stated by Awua, Ofosuhene-Mensah and Krafona (2019). A survivor's inability to return to work adds to the stress of the family members, causing an emotional and financial burden on families who struggle to deal with the aftermath of TBI (Williams et al, 2020). Corallo et al. (2019) state that, these challenges lead to an increasing burden on caregivers who experience anxiety, depression and stress for years, and often require psychological intervention and caring. A study in India by Kanmani and Raju (2018), on caregivers' psychosocial concerns and psychological distress in emergency and trauma care settings, showed that caregivers experienced several psychological problems such as physical ailments and unmet psychosocial needs, post-hospitalisation, which contributes to the burden on families. They further state that healthcare professionals should attend to the needs of caregivers and educate them, as some might be illiterate and have no understanding of how to manage the symptoms of survivors at home. These days it is common to find survivors discharged into the care of informal caregivers, who receive no guidance and formal training on managing the condition, leading to several psychological and financial challenges to caregivers (Cox, Schepers, Ketelaar, Kruithof, Van Heugten & Visser-Meily, 2018). Cox et al. (2018) conducted a validation study of the caregiver mastery scale for partners of patients with acquired brain injury. Caregivers of TBI survivors are usually on the receiving end of major effects from caring for TBI survivors and were found to have increased rates of depression and anxiety in study by Anderson, Daher and Simpson (2020). These authors state that it is important for caregivers or family members who support survivors post-TBI to get the relevant health and emotional support to improve their wellbeing.

All of these studies speak to how TBI directly affects caregivers and indicate that caregivers may benefit from psychosocial and educational support to cope with caring for TBI survivors.

2.5. Psychosocial services available for TBI survivors

2.5.1. Holistic rehabilitation

A holistic approach to rehabilitation is key for addressing all the symptoms of TBI, and implementing the multidisciplinary approach is ideal, according to Birudu, Kanmani and Devi (2020) in their study on psychiatric social work management of rehabilitation needs of TBI. Combs, Richfield and Soble (2018), who studied a yoga-based mindfulness intervention in a residential military brain injury rehabilitation programme, concur that the ideal treatment is holistic in nature. Combs et al., 2020, p.82) state that“First-line treatments for TBI primarily include medication and rehabilitation therapies such as physical therapy, speech therapy, occupation therapy and psychological intervention”. Soeker and Ganie (2019) report that in South Africa there is a scarcity of rehabilitation centres for TBI survivors, especially in the public sector. Thus lack of care facilities potentially disenfranchises TBI survivors who are dependent on the public health system. Bohanna, Fitts, Bird, Fleming, Gilroy, Esterman, Maruff and Clough (2018), who studied the transition from hospital to home, state that the first six months after hospitalisation are crucial and require inpatient and outpatient rehabilitation, as it is not easy for survivors to adapt to their homes and communities after sustaining TBIs. They further state that rehabilitation helps with dealing with difficulties of adjusting, maintaining relationships and attaining independence. Sima et al. (2019, p. 321) state: "Moderate and severe traumatic brain injuries (TBI) typically require significant medical resources along with the continuum of care from acute care to rehabilitation". The ideal rehabilitation programme cuts across several disciplines to address all the deficits in survivors, with a team of experts assisting with "physical medicine and rehabilitation, speech-language pathology, social work, and (neuro) psychology, among others" (Gómez-de-Regil et al., 2019, pp.1-2). Elderly TBI survivors are the most vulnerable and need the most rehabilitation, since they stay longer in hospitals and are at risk of death and disability (Ostermann et al, 2018). A study by Andreea et al.(2018,p.326), entitled 'Methods and results for therapeutic rehabilitative approaches of a patient with a behaviour and psycho-cognitive status after severe TBI', states: "The objectives of rehabilitation are to fight pain and regain functionality [to] allow the patient self-care and locomotion; treating diseases and preventing complications, improving the patient's psycho-cognitive status and emotional, socio-professional, family reintegration and improvement of quality of life". The occupational therapist and physiotherapist play a big role in rehabilitation, enhancing a patient's functionality as well as preparing them to return to work as inpatients or outpatients" (De Klerk, Ellof, Naude, Boon, Carelse, Steward & Zaidi, 2019, p. 54). The multidisciplinary approach to the rehabilitation of TBI may help prevent the occurrence of a secondary injury and other complications (Huijben, Wiegers, Lingsma, Citerio, Maas, Menon, Ercole, Nelson, van der Jagt, Steyerberg, Helbok, Lecky, Peul, Birg, Zoerle, and Carbonara, Stocchetti & CENTER-TBI investigators and participants, 2020). Huijben et al.'s (2020) study was on changing care pathways in intensive care for TBI in Europe. However, not all survivors get access to rehabilitative services owing to financial constraints, environmental factors and geographical limitations (Bohanna et al., 2018). It is imperative to make use of the person-centred approach to rehabilitation as it promotes self-determination and brings a sense of empowerment, according to Cisneros, et al. (2019). Cisneros et al. (2019) further state that each individual is unique and requires specific rehabilitation strategies that are designed for that specific patient. Welk (2019) ascertains that it is important for TBI survivors to access vocational rehabilitation to enhance skills and prepare them for a return to work. Soeker and Darries (2019) state that many factors impede TBI survivors from returning to work post-hospitalisation, including the nature of the injury and progress in recovery. Those who do have the possibility of returning to work require vocational rehabilitation to improve their work skills. These authors further state that the vocational rehabilitation process yielded positive results in the female TBI survivors they studied, and stress the importance of such services. Soeker and Pape (2019) tested a rehabilitation model for vocational rehabilitation purposes and found that not all survivors were able to cope in the work environment. They state that TBI remains a huge cause of unemployment. Gómez-de-Regil et al. (2019) emphasis the need for psychological interventions for survivors of TBI to help them to cope and adapt to the new reality and ultimately enhance resilience. Tyreman (2018) further states that as part of rehabilitation, survivors and family members need psychological counselling for their long-term mental health. Combs et al. (2018), who studied a yoga-based mindfulness intervention, found positive result in survivors who underwent the intervention and concluded that mindfulness training should be considered part of the multidisciplinary rehabilitative services offered to TBI survivors. Mersky, Topitzes and Britz’s (2019) study, ‘Promoting evidence-based, trauma-informed social work practice’, found that trauma-informed social workers are needed to support victims of trauma and their families, equipping them with relevant tools to cope and linking them to services for further intervention.

Symonds et al. (2020) and Safodien (2021) point to the role of social workers in assisting people with TBI, finding that there is a close connection between social work and the person-centred approach. Social workers can be instrumental in the rehabilitation process of TBI survivors, as they play many roles, including advocating for survivors and families, providing education and addressing issues of stigma and discrimination (Zastrow & Kirst-Ashman, 2007).

2.6. Psychosocial services for family members and caregivers

Studies on caregivers and war veterans with TBI show that receiving plans post-hospitalisation can help with caring for a survivor and with continuous education, and are needed by caregivers (Koehmstedt, Lydick, Patel, Cai, Garfunkel & Weinstein, 2018). Anderson, Daher and Simpson (2020) studied health status, difficulties and desired health information and services for veterans with traumatic brain injuries and their caregivers. They found that it is essential that caregivers or family members of TBI patients have access to the relevant health and emotional support to improve their wellbeing and combat burnout.

“Rehabilitative programmes addressing the patients’ level of functioning and participation can reduce the level of emotional stress in the caregiver”(Corallo et al., 2019, p.4). In addition, a multidisciplinary approach to rehabilitation has been proved to have a great effect on moderating stress for caregivers and promotes a high rate of successful reintegration into the community and home for the TBI survivor, even assisting with the work-life balance for survivors (Bohanna et al., 2018). Azman, Jali, Singh, Abdullah and Ibrahim (2020) concur that support for caregivers is crucial and should include financial support for medical costs, self-care management for caregivers. These authors further state the importance of a support group for caregivers to share experiences with others and get good advice, and to receive emotional and social support from professionals so as to equip them with coping tools to cope with the challenges caring for TBI survivors. Sodders, Killien, Stansbury, Vavilala and Moore (2020) studied race/ethnicity and the informal caregiver burden after TBI, and found that the support for caregivers of TBI survivors has to be ongoing in order to tackle all aspects of the challenges of caregiving. They further found that there is a huge gap between the demand for caregiver support and the available and affordable support from healthcare professionals. Clark-Wilson and Holloway (2020) studied the family experience of brain injury, and indicate that caseworkers and social workers, among others, need to play a big role in equipping families of TBI survivors with coping mechanisms and linking them to relevant services that will help in the process of reintegration into the home post-hospitalisation. It is not easy for families to cope with changes in a TBI survivor, especially in cases of severe injury that cause permanent disability, as pointed out by Tyreman (2018). Tyreman (2018) further states that therapy can be instrumental for the health and emotional wellbeing of family members; hence family therapy is an important aspect of the post-hospital care of survivors. Sodders et al. (2020) state that previous research has shown that there is a need for unpaid family caregivers to get educational support to know how to care for survivors, and that they also need emotional support to help them cope with the burden of caring for survivors, especially the permanently disabled.

Shepherd-Banigan et al. (2018, p.1178) state that “caregiver supportive services can offset these negative effects by reducing caregiver burden and mental distress, and improving patient functionality and symptoms.Therefore, standardized support and training may be important to optimize patient and caregiver well-being and functioning”. It is further stated that “Psychological intervention contributes to building resilience in caregivers, and resilience is needed, as it is the ability to adapt to hardships or adversity and ongoing significant life stressors” (Anderson et al., 2020, as cited in Newman, 2005, p. 227).

Family reintegration for survivors and their caregivers is vital as it helps moderate the stress of caring and helps family members adapt to the new reality, as stated by Tyreman (2018). This process of helping the person to return home and adapt applies in cases of children who are removed owing to risk factors in the home, including neglect and/or abuse, as stated by Cardoso, Bhattacharjeeb, Codyc, Wakiad, Mensonb and Tabbia (2020). These authors studied ways to promote learning in the reintegration of children into family-based care. They state that the process of family reintegration helps to reinforce adaptability, resilience and healing and helps create a sense of belonging in a child. Similar findings apply in the case of adults returning home after prolonged absence in hospital and dealing with the traumatic changes that result from TBI.

Post-hospitalisation, survivors often change and can become total strangers to their family and caregiver, leading to feelings of rejection, misunderstanding and emotional isolation (Williams et al, 2020). According to Sauls and Esau (2015), who evaluated family reunification services in the Western Cape, social workers' perceived the process of reintegration as a process of helping children re-unite with their families after they have been removed because of home circumstances. These authors state that there is a strong need to equip families and the child to cope and adapt, thereby enhancing successful family reintegration. The same would apply to adults who have been separated from their families because of TBI. A study by Koehmstedt et al. (2018) states that caregivers of TBI war veterans benefitted from receiving care plans from the hospital, which helped with their caring role; they also appreciated continuous education and support from health professionals over the long term. Family reintegration is clearly crucial in the process of rehabilitating survivors into their family contexts post-hospitalisation. When provided, biopsychosocial services help to support families and survivors and reinforce independence, promoting social skills (Eapen & Cifu, 2018; RSA, 2007).

There is limited literature on this topic when it comes to TBI survivors and their families in South Africa. Most studies focus on social reintegration and community reintegration, but for survivors, all of this remains a challenge, particularly in the absence of well-informed family support. Family members clearly become exhausted and drained from the stress of caring the survivors, who can be short-tempered, abusive, forgetful and unable to communicate. All of this points to the need for a special focus on ‘supporting the supporter’.

2.7. The theoretical framework (The person-centred approach)

The person-centred approach (PCA) was chosen as the theoretical framework for this study. This framework has been used in many disciplines, and is ideal for social work and education studies, as it puts the client at the centre of practice.

2.7.1. Origins of the theoretical framework

The person-centred approach (PCA) developed from the work of the psychologist Dr Carl Rogers (1902 to 1987). He advanced an approach to psychotherapy and counselling that, at the time (the 1940s to 1960s), was considered ‘extremely radical if not revolutionary’ (The Person-Centred Association, no author, 2020, p. 1). In this approach, it is assumed that a nurturing environment promotes a positive self-concept, which boosts the individuality in the perceptions of each person, based on their perspective and experiences (Bachkirova & Borrington, 2018). Carl Rogers’s theory is based on his experience of working with people as a clinical psychologist and on his personal experiences, particularly in his childhood. His work constitutes a theory for personality development (Meyer, Moore & Viljoen, 2008). The main purpose of the PCA as a therapeutic approach is to foster a facilitative environment, whether in counselling, education or psychotherapy, that enables constructive change or self-actualisation (Symonds et al., 2019). “The central hypothesis is that every human being has in themselves vast resources for self-understanding and for altering their self-concepts, basic attitudes, and self-directed behaviour; these resources can be tapped if a definable climate of facilitative psychological attitude can be provided”(Cornelius-White, Motchnig-Pitrik & Lux, 2013, p.10). PCA is a humanistic phenomenological approach in that it recognises the unique experiences of individuals and their perceptions, and takes into consideration people's views of their world and their unique reactions to different experiences (UK Essays, no author, 2018).“The counsellor provides the conditions for self-exploration in a safe, trusting environment which provides the framework for self-initiated and self-directed reappraisal and modification of existing behaviours, attitudes, thought processes, values and habitual modes of coping”(Coghlan,1993,p.12). One of the key strengths of this approach is that it encourages therapists to have a non-judgemental attitude to and acceptance of their clients, and not to put pressure on them, but to show empathy (UK Essays, no author, 2018). Over the years, the person-centred approach has broadened beyond the scope of therapy and is applied in education, family life, administration and leadership, healthcare settings, international settings, politics, interracial activities and many more settings (Corey, 2009). “What the humanistic psychology of Carl Rogers brings along with its emphasis on human potential and concern for the welfare of people is its view of human beings, with the implication to empower and free people, to create no hierarchal and democratic structures, in the expectation that this was in the best interests of not only the people involved but also ultimately the organisations” (Joseph, 2019, p. 280). The PCA aims to create a nurturing environment that promote positive self-concepts and thereby boosts an individual's development (Bachkirova & Borrington, 2018). Lastly, the person-centred approach emphasises establishing a warm and caring relationship between the client and the counsellor or facilitator (Mbedzi, 2011).

2.7.2. Assumptions and principles of the framework

According to Meyer et al. (2008), Carl Rogers established 19 propositions to better understand human behaviour. Three propositions were chosen as relevant to this study: propositions 1, 7, and 12. Each of these is discussed below in relation to its relevance in this study. **Proposition**

1: ‘All individuals exist in a continually changing world of experience of which they are the centre’ (Meyer et al., 2008, p.367).

This proposition means that every person is unique, living in a world that is constantly changing, and each individual knows more about themselves and their unique experiences than the counsellor does (Mbedzi, 2011). This is relevant to the study, as the researcher did not make assumptions about the experiences of TBI, but rather listened to how survivors perceived their experiences in a continually changing world. The idea of a changing world was especially relevant in this study as survivors themselves had all experienced post-TBI changes personally and were having to adapt to new realities and contexts, as stated by Tyreman (2018).

Proposition 7: “The best vantage point for understanding is from the internal frame of reference” (Meyer et al., 2008, p. 367).

This proportion means that the counsellor has to have a high regard for the client and strives to understand the client from the client’s frame of reference, not their own (Mbedzi, 2011). This proposition was applied to this study, as the researcher opted to understand the survivor’s interpretations of their own experiences from their frame of reference.

Proposition 12: “Most of the ways which are adopted by the organism are those which are consistent with the concept of self” (Meyer et al., 2008, p. 368.)

This proposition highlights the importance of the self-image and how it affects an individual’s behaviour. The concept or perception that an individual has will lead him to behave in a way that is in line with his, perceived image (Wade, 2009). This proposition was relevant to this study as it allowed the researcher to evaluate whether survivors saw themselves as victims or as survivors of a most unfortunate life-changing injury. In this study, the researcher attempted to show how self-concepts affected the behaviour of TBI survivors post-hospitalisation.

2.7.3. The core condition of Carl Rogers's theory

a) Congruence

According to Corey (2009), counsellors who are person-centred embrace congruence, which is described as an attitude of openness and acceptance of the client's experiences, without judgement. Corey (2009) further states that congruence means that the counsellor or facilitator is real and transparent. This genuineness of the counsellor can be instrumental in creating a space for transparency and genuine presence, which enables clients to feel safe enough to express themselves without fear of judgement or of not being accepted (Maurer & Daukantaite, 2020). Congruence was embraced by the researcher to create a safe space for TBI survivors to express themselves, and to talk openly about their experiences without fear of being judged.

b) Unconditional positive regard

Meyer et al. (2008) state that unconditional positive regard is characterised by showing appreciation, admiration and respect to others. The facilitator or counsellor accepts the client and treats him or her with utmost respect and dignity, devoid of any conditions (Mbedzi, 2011). Unconditional positive regard is about embracing the client's inherent worth as a whole, acknowledging who they are (Maurer & Daukantaite, 2020). This principle was embraced in this study; participants were treated with the utmost respect and dignity, with no conditions attached.

c) Empathy

"Empathy is a continuing process whereby the counsellor lays aside her way of experiencing and perceiving reality, preferring to sense and respond to the experiencing and perceptions of her client. This sensing may be intense and enduring, with the counsellor experiencing her client's thoughts and feelings as powerfully as if they had originated in herself"(Mearns & Thorne, 2007, p. 67). This means that the facilitator or counsellor adopts an empathic understanding of the client, reflecting on a client's words and listening carefully so that the client's point of view is heard and so that they feel heard and seen (Maurer & Daukantaite, 2020). Empathy was embraced in the study; the researcher listened attentively as survivors talked about their experiences from their frame of reference.

2.8. The history and development of the framework

2.8.1. Non-directive therapy

Carl Rogers and his colleagues were the first to employ the process of recording, transcribing and publishing their comprehensive psychotherapy cases. Rogers then embarked on a journey of more research than he had before (Kirschenbaum & Jourdan, 2005). In the 1940s, Rogers established non-directive therapy, which parted from the notion of the counsellor as the expert; instead, in non-directed therapy, the counsellor is a facilitator. This approach moved towards trusting that people, enabling them to flourish in a conducive climate of therapy, and to grow and develop towards self-actualisation (Brodley, 2019).

2.8.2. Client-centred therapy

"In the second period, during the 1950s, Rogers renamed his approach client-centred therapy, to reflect its emphasis on the client rather than on directive methods. Also he started a counselling centre in the University of Chicago."This period was characterised by a shift from a clarification of feelings to a focus on the phenomenological world of the client" (Corey, 2009, p. 167). Apart from renaming his non-directive approach, in the year 1951 Rogers emphasised how the therapist becomes a facilitator, allowing the client to grow without using the typical techniques of counselling (UK Essays, no author, 2019). Rogers then formulated his 19 propositions which contributed to the advancement of personality and behaviour theory.

2.8.3. Widening applications

“The third period, which began in the late 50s and extended to the 1970s, addresses the necessary and sufficient conditions of therapy. He published a book on becoming a person, based on openness to experience, a trust in one’s experience and an internal locus of evaluation” (Corey, 2009, p. 167). According to ‘Person-centred development’ (2018), this period was characterised by the spread of Carl Roger's work in different settings, including business, medical, academic and professional groups. Rogers and his colleagues used this approach to facilitate larger groups and workshops with hundreds of people in attendance, emphasising the full humanisation of the professional relationship between psychotherapist and client. This paved the way for widespread applicability of the theory, which really caught on during this time. Human relationships became more and more understood in experiential terms.“Stay in touch with what you experience and try to get in touch with what others experience”, said Holdstock (1978). Rogers developed the approach as a way of conducting psychotherapy, but in 1963, he and his colleagues transferred the theory to numerous contexts where people were in relationships, including childcare, patient care, conflict resolution and management.

2.8.4. The person-centred approach

The fourth phase was characterised by the spread of the approach and its renaming as the person-centred approach in the 1980s (Corey, 2009). Corey (2009) states that, in addition to applying the approach to business, education, management, Rogers then moved the approach to address intercultural and interracial activities and moved towards person-centred politics.

The legacy of Carl Rogers continues to this day as many academics in different disciplines of psychology, business and management embrace the empathic understanding and the genuine approach to fostering healthy social contexts (Cornelius-White et al., 2013). “Rogers has helped to initiate and develop what might be called a person-centred approach, not only in counselling, psychotherapy and education, but also in marriage and family relationships, in intensive groups, and to a lesser extent in administration, in the problems of minority groups, and interracial, intercultural and even internal relationships. “The principles underlying the theory are of relevance in every aspect of the behaviour of human beings” (Holdstock, 1978, p. 26). After he died in 1987, the influence of Carl Rogers’ work continued to spread.

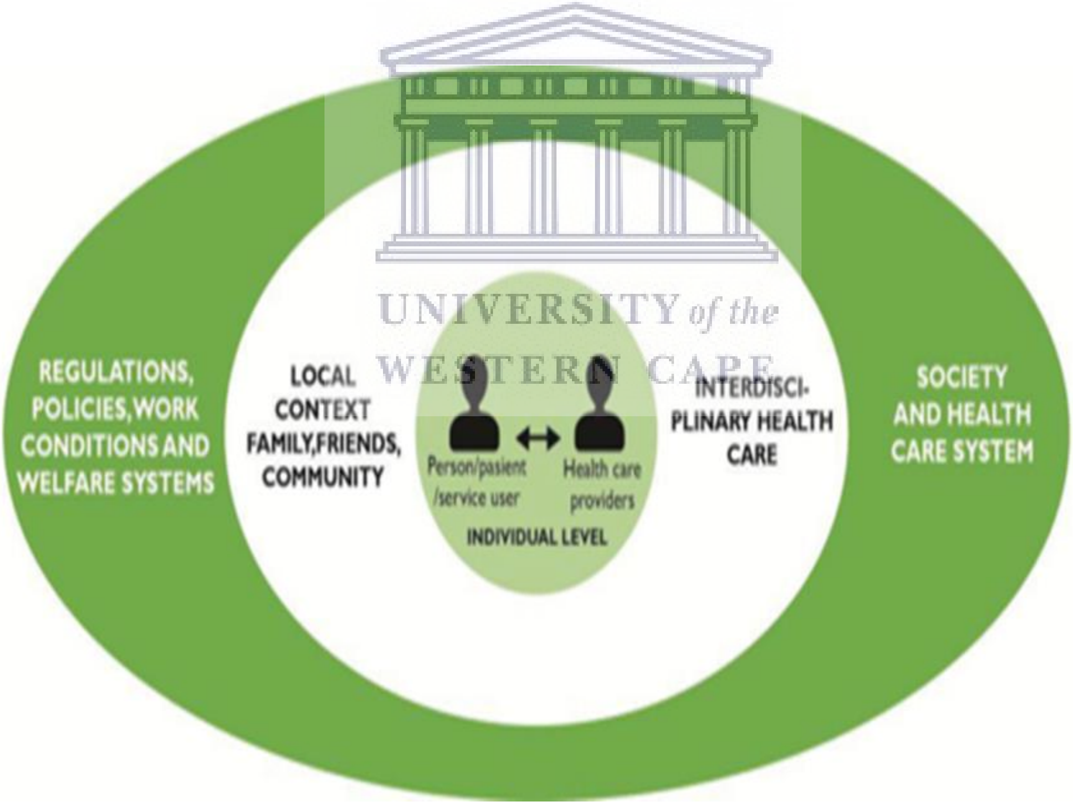
Kirschenbaum and Jourdan (2005) state that Roger’s work has spread all over the world and has saturated many professionals environments, including social work, group leadership, education and pastoral counselling.

2.9. The application of the framework to social work, and psychosocial services to survivors and families affected by TBI

Dealing with a TBI can be onerous for families and survivors, and to address the symptoms, a multi-disciplinary approach is crucial. Studies have shown that there is a huge need for medical and psychiatric social workers (Birudu et al., 2020). The person-centred approach is one of the approaches used by social workers in practice, with the intent of aiding self-determination and empowerment in clients (Engelbrecht, 1999). This approach is relevant and has many benefits for TBI survivors. The survivors in this study all came from a community that is afflicted by low socio-economic conditions, as well as crime and high levels of violence, as pointed out by Taylor (2019). It is essential that social workers incorporate this approach in their practice as it puts the clients’ needs at the centre, and helps the social worker to guide clients towards self-actualisation, using a great deal of empathy and genuine listening (Corone, 2019). When employing this approach, the social worker acts in a non-directive manner and accepts the client unconditionally (Engelbrecht, 1999). The notion of person-centeredness means that counselling is personalised for each client, and takes place in a safe and nurturing environment that is deliberately created to reinforce healing and recovery (Terry & Kayes, 2019). “In utilising the client-centred approach, the personal qualities of the social worker are stressed more than the specific techniques, since the social worker employs his/her personality to bring about growth and change. Techniques such as interpreting and advising are not used. Empathic responding, active listening and reflecting [are used in preference]" (Engelbrecht, 1999, pp. 84-85). Social workers go above and beyond the normal requirements of a job as they are trained to challenge any power imbalances, advocate for clients and promote justice and fairness, as well as safeguarding human rights (Zastrow & Kirst-Ashman, 2007).

Figure 1.1 below illustrates the various applications of the person-centred approach.

Figure 2.9.1 Areas of person-centred research



Source: University Southern Eastern of Norway (no author, 2016).

The above framework is relevant to the study, as it puts the client or person at the centre of practice with the health provider as the facilitator. The intervention starts with the person, with the healthcare provider or social worker focusing on the individual in order to properly assess the needs of that individual (Dhavaleshwar, 2016). It then moves outward to the family, community and broader society. Interdisciplinary interventions may be provided by different professionals for the benefit of the client. This framework mostly relates to healthcare providers but is very relevant to this study, since it expresses the need for intervention at all three levels – the micro, mezzo, and macro levels, all of which are relevant for social work interventions. Addressing all three levels promotes healing and recovery for survivors and can be applied in many disciplines (Hepworth, et al., 2013).

Figure 1.2: The framework of the person-centred approach

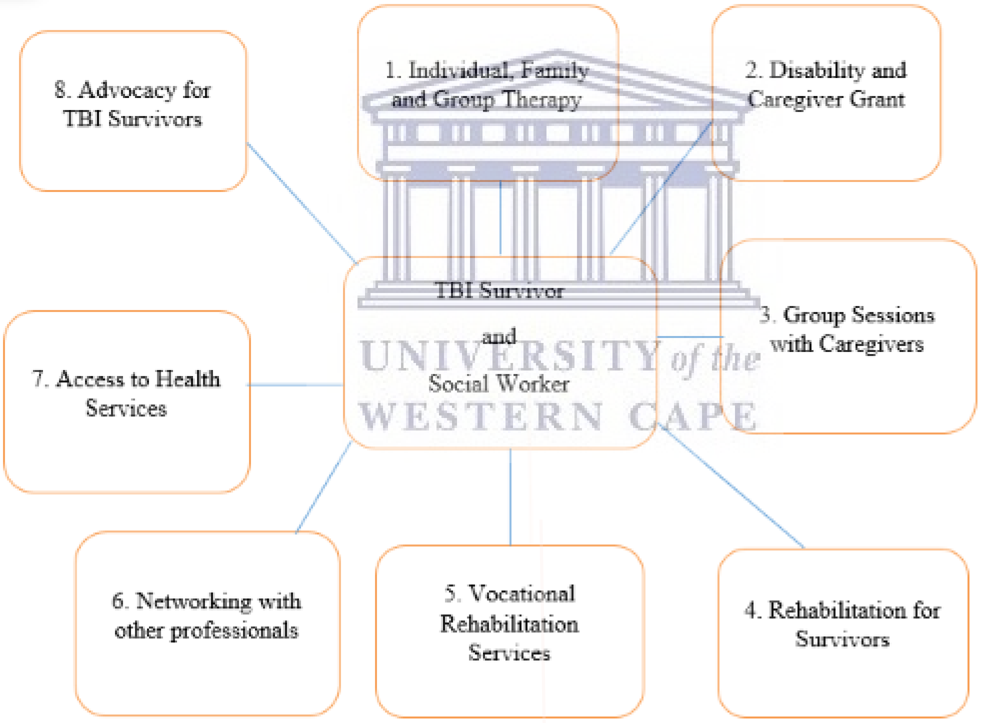


Figure 2.9.1 The framework of the person-centred approach

Source: Rearcher's Illustration (2020).

Figure 1.2 shows how the social worker plays the role of facilitator in the process of creating a safe and nurturing environment for clients who are TB survivors, when using the PCA (Mbedzi, 2011). According to Birudu, Kanmani and Devi (2020), several services are required for the healing and recovery process of TBI survivors post-hospitalisation.

2.10. The application of the person-centred approach in the study

2.10.1. Individual, family and group therapy

A social worker would focus on two of the social work intervention levels – the micro level, in the form of individual therapy, and the mezzo level, in the form of family and group therapy, as indicated by Hepworth et al. (2013). In the case of TBI survivors, this intervention would mostly be trauma intervention to help TBI survivors and their families establish coping mechanisms. This requires social workers to be trauma informed, as pointed out by Mersky, Topitzes and Britz (2019). Through the role of a facilitator, a social worker will form a support group for survivors and families and facilitate discussions about their challenges and successes (Mbedzi, 2011). All the above-mentioned intervention strategies are relevant in healing and creating a nurturing environment for TBI survivors.

2.10.2. The disability grant

Dhavaleshwar (2016) states that one of the roles of the social worker is that of 'needs analyser', able to assess the needs of clients, families and communities and actively link people to the resources that they need. A study on the impact of moderate or severe TBI on a person's life found that TBI often leads to permanent disability, especially in cases of severe injury, thereby causing functional limitations on an individual (BrainLine, 2019). Therefore the role the social worker is paramount in terms of assessing the need for a disability grant and referring clients to a medical doctor for medical assessments, then a referral is made to South African Social Security Agency (SASSA) to apply for the grant.

2.10.3. Support groups for care-givers

Sodders et al. (2020) state that support for caregivers of TBI survivors is crucial and is needed for a lengthy period to address the inherent challenges or caring for survivors. A social worker can establish such a group, comprising caregivers of TBI survivors, and can facilitate these group sessions (Dhavaleshwar, 2016). These sorts of groups are beneficial for both survivors and families, helping to reinforce positive relationships at home, since the caregivers receive informal psycho-education on behavioural changes to expect in survivors and emotional support from people who are experiencing the same stresses and strains.

2.10.4. Rehabilitation for survivors

Rehabilitative services for survivors need to be arranged; these should include access to an occupational therapist, physiotherapist or audiologist, to name a few, in the local day hospital. The social worker can connect or refer survivors to such services based on the need. This means that a social worker link survivors to community resources to promote mutual interests (Engelbrecht, 1999).

2.10.5. Vocational skills rehabilitation

Vocational skills are needed for those survivors who are still young and capable of returning to work. Welk (2019) indicates that vocational skills are pivotal, but due assessments have to be done to determine the capability of TBI survivor in preparation for their return to work. The social worker may play the role of a broker, linking survivors to resources including workshops to train survivors and make them ready to return to or seek work (Zastrow & Kirst-Ashman, 1997).

2.10.6. Professional networking

“Social work is a collaborative enterprise. Building strong operational, personal and strategic social work networks benefits not only your career but your clients as well” **(**Professional networking in social work, 2019, p.1). In cases of TBI survivors, professional networking helps the social worker to establish a good referral path for survivors, so that the social worker keeps abreast of any new developments in practice and theory.

2.10.7. Access to healthcare

De Klerk et al. (2019) ascertain that TBI survivors often need a multidisciplinary approach to address challenges, including their medical needs. Access to healthcare can be facilitated by a social worker, as some survivors may have several symptoms that require medical attention such as epilepsy, stroke and other medical complications caused by TBI. At this point, the social worker will link the survivor to available and affordable health resources, bearing in mind their socio-economic background, again assuming the role of a broker, as stated by Zastrow and Kirst-Ashman, (1997).

2.10.8. Advocacy

Zastrow and Kirst-Ashman (1997) state that advocacy involves speaking on behalf of a person, group or community to address social ills and difficulties faced by people in their respective communities. In the case of TBI survivors, a social worker's role is to raise awareness to educate the public (schools, communities, hospitals and clinics) about the effects of TBI on individuals. In doing so, the social worker advocates for the TBI survivors, educating the public about many aspects, including where to refer survivors for services and how to improve treatment of survivors in communities.

2.11. Gaps and shortcomings of the theory and the study

It has been indicated that there are gaps or limitations in using the person-centred approach. It is often romanticised but is not easy to implement, especially among individuals with already-formed egos or those in the reformed ego stages (Bachkirova & Borrington, 2018). It is not always easy to accept an individual unconditionally. The person-centred approach is non-directive, which means that the counsellor has to confine herself to being supportive without challenging or using 'techniques' (Corey, 2009). Person-centred therapy does not have the kind of arrangements that may exist between therapist and client, in that the therapist may not offer help; this makes it almost impossible to apply in situations of crisis where a therapist is required to make a plan and assist an individual in a particularly stressful situation (UK Essays, no author, 2018). “This ideal is rarely if ever, encountered, since individuals are not unconditionally accepted by others. What this means is that the environment lays down certain conditions for accepting the individual. This influences individuals’ self-concepts, and they then act, not per the conditions set by significant others” (Meyer et al., 2010, p. 366). Joseph (2019) states that the person-centred approach is based on the notion that people will move towards self-determination, growth and self-actualisation, which might not apply to some people. The person-centred approach in social work may well have limitations, since social workers play many roles that are not limited to PCA; for example, they educate, enable and initiate actions and are called upon for crisis intervention, where sometimes decisive actions are required. In social work practice, the person-centred approach can only be employed to a certain extent when dealing with clients, as some cases do not call for the non-directive approach, especially situations of crisis where a client is at risk (Murphy, Duggan & Joseph, 2013). These authors state that in such instances, social workers may need to be more directive with clients, which may be in their best interests.

2.12. Chapter summary

The literature indicates that TBI is indeed a silent pandemic with life-altering consequences for TBI survivors and their families. However, there are very few studies on TBI in South Africa. The literature in this chapter has shown that TBI causes death and disability, and that survivors often experience several biopsychosocial deficits, including physical, emotional, cognitive and behavioural challenges as they struggle to adapt to a new reality. It became apparent during this literature review that TBI survivors need far more than hospital-based medical and physiotherapy support; after release from hospital, there is a great need for long-term assistance with adjusting and creating a new way of life. In addition, caregivers and family members need as much support as do the survivors themselves. Families need to be equipped and educated about TBI, as the real challenge starts after hospitalisation. Survivors struggle to function in their communities and many are unable to return to school or find employment. The person-centred approach is deal for rehabilitation and for any support provided by social workers. This type of rehabilitation is holistic and consists of a multi-disciplinary team of professionals who address the impairments of TBI survivors; however, most of the time this ideal is far from possible, owing to issues of affordability. Many South Africans depend on the public healthcare system, and public rehabilitation centres are rare, meaning that in most cases, TBI patients leave hospital and go straight home to their families, who suddenly face enormous challenges they are usually ill-equipped for. The literature has also made it clear that over the years, with the advances in medical care, recovery rates from TBI are higher than before, which means that there is a higher prevalence of TBI survivors living with debilitating conditions. Family members would benefit from ongoing support from health professionals, including nurses and social workers, to educate them on how to care for TBI survivors, while providing psychosocial support. The next chapter describes the methodology used in this study, addressing ways in which data was collected and analysed. It also discusses the study design and approach.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1. Introduction

The goal of this study was to explore and describe the challenges experienced by TBI survivors regarding family reintegration post-hospitalisation. The previous chapter presented the literature review and the theoretical framework of the study. This chapter describes the research methodology used including; the research approach, the research design, the research setting, the data collection methods, population sampling, data analysis processes, and trustworthiness of the data, and the ethical considerations.

3.2.Aim and objectives of the study

The study aimed to understand the experiences of TBI survivors regarding the challenges they experienced regarding family reintegration, post-hospitalisation. The objectives of the study were:

- To explore and describe TBI survivors' challenges and experiences regarding the reintegration process into their families, post-hospitalisation;
- To explore and describe the vulnerabilities and the resilience of survivors in the process of adapting to the home environment, post-hospitalisation;
- To explore and describe the challenges that come with TBI and how it affects family dynamics and roles, post-hospitalisation;
- To explore and describe the coping resources and protective factors needed for the process of family reintegration post-TBI.

3.3.Research methodology

The researcher chose the qualitative research method as it was deemed suitable to accomplish the goal of the study and to answer the research question. "Methodology in the research process refers to the coherent group of methods that complement one another and that have the "goodness of fit" to deliver data and findings that will reflect the research question and suit the research purpose" (Henning, Van Ransburg & Smit, 2004, p. 36). The qualitative research approach was selected and found suitable for yielding an understanding of the experiences of TBI survivors and their challenges post-hospitalisation.

Qualitative research is characteristically more in-depth than quantitative research, enabling the researcher to explore a situation in its entirety; it is therefore appropriate when a researcher wants to know more about the phenomenon being investigated (Edlund & Nichols, 2019). In qualitative research, the goal is to give a voice to those whose lived experiences, feelings and emotions may not have been told (Lapan, Quartaroli & Riemer, 2012). This was useful in the researcher's journey of uncovering the lived experiences of TBI survivors. "Qualitative methods are an umbrella phrase that refers to the collection, analysis and interpretation of interviews, participant observation, and document data to understand and describe meanings, relationships, and patterns" (Tracy, 2014, p. 36).

It was important for the researcher to make use of language to unearth and better understand the circumstances participants experienced. "The term qualitative research is used to describe a set of approaches that analyse data in the form of natural language and expressions of experiences" (Levitt, Bamberg, Creswell, Frost, Josselson, & Suarez-Orozco, 2018, p.27). This approach coincided with the researcher's interest in exploring and describing the experiences of TBI survivors, as she wanted participants to express themselves in their own words. The researcher conducted all the interviews herself, so that she was able to observe the participants' non-verbal behaviour and communication (Creswell, 2014). This confirms assertions by Berg

(2009), who states that conducting interviews allows the researcher to seek answers to challenges experienced by participants, which in this case were TBI survivors. Interviewing and observing them in their social settings enabled the researcher to observe and understand their unique reactions and experiences.

3.4. Research design

The researcher saw fit to employ the explorative and descriptive design often used in qualitative studies to understand more about the experiences of an observed group, in this case, TBI survivors. Descriptive research design in a qualitative study is used to describe the problem and to further gain insight into its impact on the phenomenon (Kumar, 2014). The researcher used this research design to gain insight into the impact of TBI on participants along with their lived experiences post-hospitalisation. The exploratory research design is used in qualitative studies to explore the origin of a problem, especially in cases where little is known about it (Krysik, 2018). Through a combination of the explorative and descriptive research designs, the researcher was able to describe and explore the impact of TBI on the participants, which is what the researcher had envisioned for this study. These designs well served the purpose of the study.

3.5. Research setting

According to Tracy (2013), the research setting refers to a site or the exact space where the study takes place. For this study, the researcher selected a non-profit organisation (NPO) in a township in the Cape Flats as the research setting. In South Africa, all NPOs are registered under the Non-Profit Organisations Act No 71 of 1997. Section 15 under subsection 1(a) clearly articulates the process of obtaining a registration certificate and receiving a registration number for the NPO; the selected NPO in this study is registered under this Act (Republic of South Africa; Non-Profit Organisation Act, 1997).

The NPO was purposefully selected because it is one of only a few organisations that render outpatient rehabilitation and psychosocial services to TBI survivors and their families/caregivers post-hospitalisation. The NPO was developed to accommodate TBI survivors who did not receive full rehabilitation in hospital that addressed all the impairments of TBI post-hospitalisation, and to assist TBI survivors and their families adapt to changes post-hospitalisation. The selected NPO is located in a community that is burdened with social ills including poverty, gang violence and domestic violence, along with a general shortage of basic resources (Leeper et al., 2019).

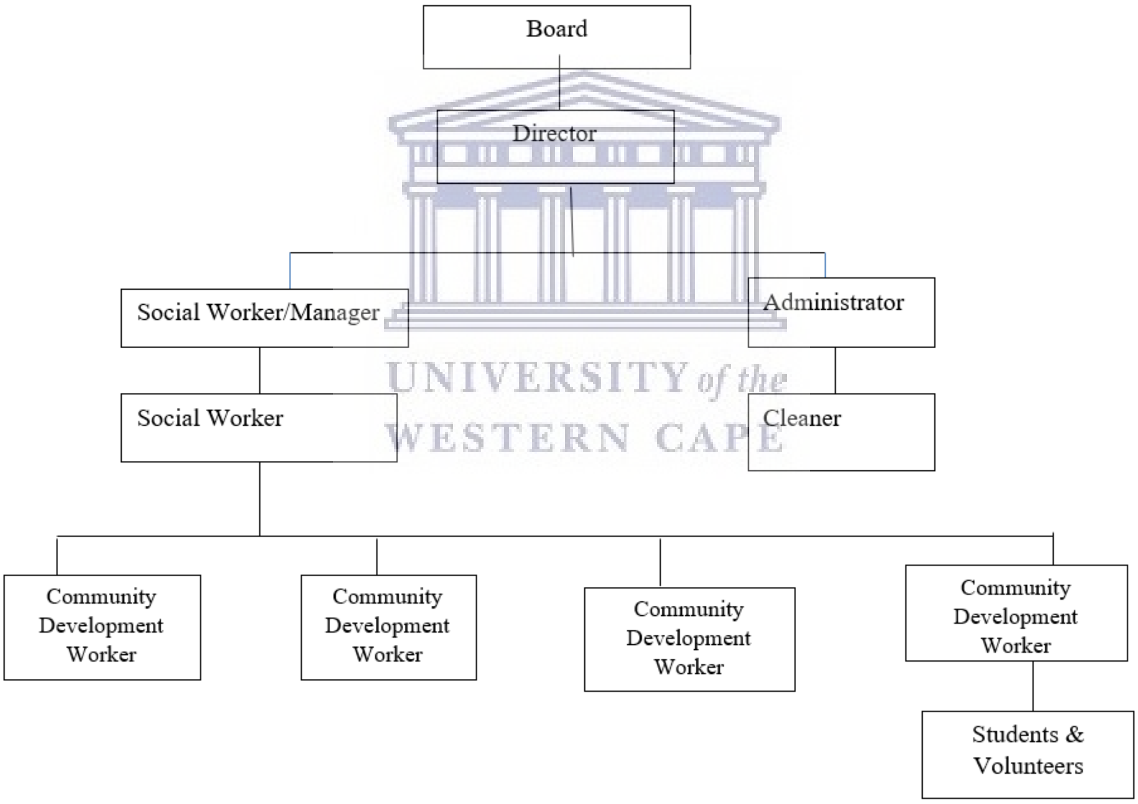


Figure 3.5.1 Organogram of the selected NPO

Source: Heads UP (2016).

The board oversees the ergonomics of the organisations' operations and its vision and mission, planning, organising, leading, controlling and formulating the policies of the organisation. The director is responsible for building partnerships and networks with other organisations and developing strategic implementation plans for the organisation. The manager oversees' the everyday running of the office. The social worker provides social work services to clients and coordinates support group sessions. The social worker is registered with the South African Council for Social Service Professionals (SACSSP) in terms of Act no 110 of 1978. Section 17(10) states, "the council may, on application made in the prescribed manner, register as a social worker any person who holds the prescribed qualifications and satisfies the prescribed conditions, and who satisfies the council that he is a fit and proper person to be allowed to practise the profession of social work" (Social Service Professions Act 110 of 1978, p.15). The administrator controls the day-to-day office management, technology and finance, keeping records of all finances of the organisation. The community developmental workers (CDWs) ensure early identification, early prevention and continued support to people with brain injury disabilities. They raise awareness about brain trauma issues and facilitate support groups. The students and volunteers work under the guidance of community developmental workers and are monitored by the social worker at the NPO.

3.5.1. Services offered by the NPO

Currently, the NPO offers psychosocial interventions including: individual counselling, group sessions, family conferencing, raising awareness at the local clinics, stress relief sessions for caregivers and training/workshops for professionals (teachers, nurses, social workers, social auxiliary workers, doctors, nurses, occupational therapists) as well as educating families about TBI. The services in the NPO include prevention work in primary schools in the community, to teach young children about TBI and to prevent them from engaging in gang violence, which often leads to TBIs at a young age. The NPO provides psychosocial care and counselling to family members of TBI survivors, support groups and advocacy platforms for brain injured person, and manages cases that apply to the Road Accident Fund for support (Western Cape Government, 2021). As part of their prevention work, the NPO facilitates dialogues with men in the community, to prevent behaviours that could potentially put men at risk of TBI through violence and substance abuse. This is done in collaboration with other NPOs that work with men in the community and with government entities such as the South African Police Service.

The NPO currently runs two weekly support group sessions from 12 pm to 1 pm, having split the former larger group into two because of COVID-19 restrictions on the size of gatherings. There were 30 support group members in total at the time of data collection; however, the group is open-ended, and new members are allowed to join at any time. The NPO renders services to at least 60-65 people per month, and 780 people per annum, according to the NPO's statics in March 2020 (Patala & Ntlokombini, 2021, unpublished data). The numbers had dropped since the beginning of the COVID-19 pandemic to 30-40 per month, numbers which tend to vary according to the level of national lockdown regulations as stipulated by the South African Government. The NPO uses a tool called the S-Plan to address the following issues for survivors and families post-TBI: sustenance, sleep, sexuality, sensitivity to noise, stimulation, speech, social life, safety and security (Webster, Taylor & Balchin, 2015). These areas were shown to be the most troublesome for survivors post-TBI, and families often struggle to provide the right care for survivors that will address these. The tool is further used to structure their days to maintain a routine post-hospitalisation. The S-Plan helps to normalise their experiences and to address the nine issues to improve the quality of life of survivors post-hospitalisation. The S-Plan was developed in 2015 by the board members and the director of the NPO, based on their research. Figure 3.2 shows the S-Plan.

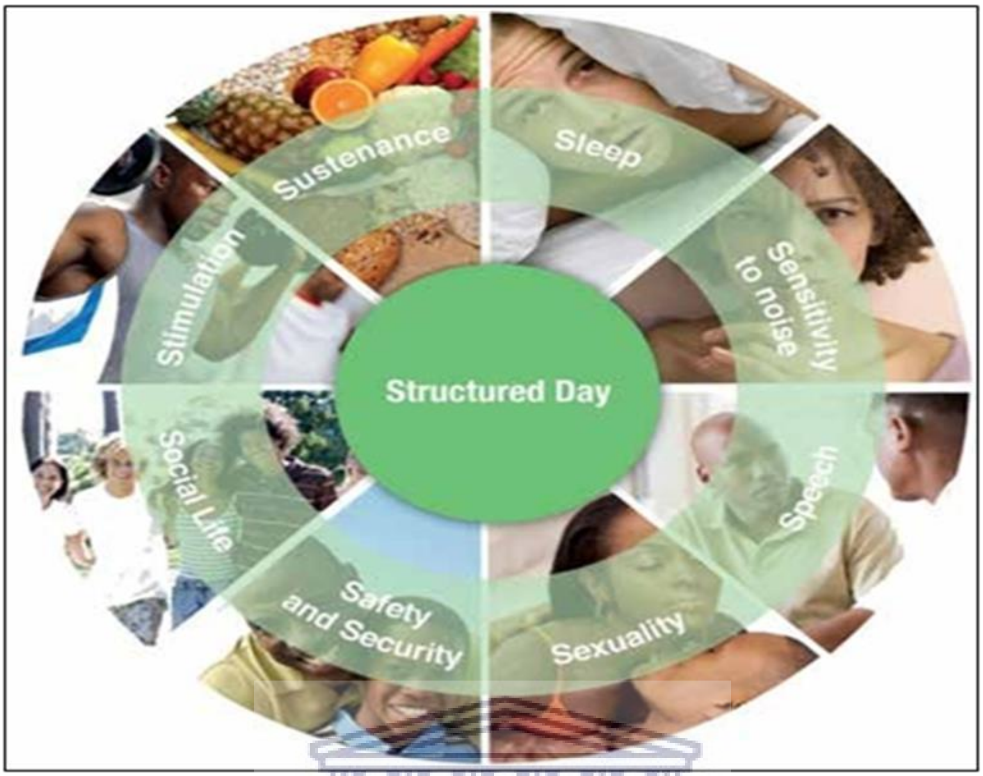


Figure 3.5.2 The S-PLAN

Source: Webster, Taylor and Balchin (2015).

Webster, Taylor and Balchin (2015, p.197), who studied emergency and trauma cases and head injuries in Khayelitsha, state “Some of the more experienced family members interviewed described their coping strategies to avoid and manage the most distressing survivor behaviours, noting that, as with parenting a child, survivors needed to have a balanced and structured day to ensure a sense of wellbeing and safety, and that they needed regular sleep, a healthy diet, stimulation and friendship”. The S-Plan tool has been used for many years at the NPO, with all nine areas focussed on during support group sessions. For example, in one session they might discuss the social life of TBI survivors, and in the next, sexuality or challenges related to that. After survivors open up about their challenges, the social workers provide the necessary intervention strategies, including referral to other organisations if needed.

The setting was selected because of its convenience to the TBI survivors who attend group sessions twice a week and are therefore familiar with the area. Most participants lived close to the NPO, but travel by public transport to ensure their safety and convenience and to accommodate their disabilities. Participants were provided with financial assistance for travelling to the venue for the interviews, with each participant receiving R22.00. The researcher travelled to the organisation by car and merely had to negotiate a convenient time with the social worker and participants for the interviews. Twenty-one interviews were conducted in a period of a little over a month from 26 October 2020 to 23 November 2020, with some unexpected delays. The goal was to complete the data collection in a week during the school holidays in 2020, but because of Covid-19, many were simply not coming to the organisation. The researcher was told by the programme manager of the NPO that the participants would come and that some just needed to be reminded. Staff members at the NPO then made arrangements for new participants to come after work from 2:30 pm to 4:30 pm. The staff members would notify the researcher every day about who was coming at what time and the researcher would drive from work to conduct interviews, five days a week. This process happened until the desired number of participants was reached. The NPO venue was the best option for the participants that were chosen for this study.

3.5.2. The clientele of the NPO

The NPO renders services to children, youth and adults. For children from the age of 10, staff mostly equip parents with knowledge on how children sustain injuries while playing outside. They make referrals for children to access medical attention after head injuries, especially in cases where children sustain concussions. For teenagers (13-19 years), the NPO mostly provides preventative strategies to prevent young boys from sustaining head injuries, which would lead to disability causing academic challenges. The NPO also renders services to adult TBI survivors, male and female. Lastly, older people from the ages of 40-65 are catered for;

most of these are family members or caregivers of TBI survivors. Most of the TBI survivors live with their immediate families, with many having several impairments that render them very dependent post-TBI. Most receive disability grants and do not work owing to their disabilities from TBI. Only a few clients are married; most are unmarried or divorced as a result of their TBI impairments. Many live in RDP houses where a two-bedroomed house may be crowded with eight to ten family members, while some live in informal settlements with their families where they suffer extreme lack of basic resources. Clients are often victims of violence; the high prevalence of violence hinders the work of social workers in some areas as they fear being mugged. This being the case, the social workers do not conduct home visits for clients in such areas, but make arrangements for clients to come to the organisation and access their services. The services are free to all clients at the NPO. Using the NPO as a base and interviewing clients of the NPO was the best option in this study, as the organisation formed both a central venue and a useful point of contact to reach out to TBI survivors.

3.6. Population and sampling

3.6.1 Population

Population refers to the people or participants that are the focal point of the study and the analysis (Lapan et al., 2012). The population of this study was adult TBI survivors living in a selected township on the Cape Flats in the Cape metropole. The community where the study was conducted consists of mostly isiXhosa-speaking residents; however, they understood English and some Afrikaans, as these are the three dominant languages spoken in the Western Cape (Western Cape Government, 2021).

According to Clarke (2015), Khayelitsha (which is an isiXhosa name for ‘new home’) was developed in 1983 during apartheid times as a result of an influx of African people who came to Cape Town seeking work opportunities. The, community is poverty stricken. Clarcke (2015) points out that the township was created in the tempestuous context of conflict and change that prevailed towards the end of the apartheid era in South Africa.

> “Khayelitsha has a population of 391,749 [as of 2011] and runs for a number of kilometres along the N2. Current estimates of the population size is said to be in the region of 1, 2 million. The ethnic makeup of Khayelitsha is [mixed] with Xhosa being the predominant language of the residents. Khayelitsha has a relatively young population with fewer than 7% of its residents being over 50 years old and over 40% of its residents being under 19 years of age. In 2011 around 62% of residents in Khayelitsha were rural to urban migrants, most coming from the Eastern Cape. In the communities of Enkanini and Endlovini over 85% of the residents were born in the Eastern Cape. About 75% of residents identify themselves as Christian while about 20% follow traditional beliefs; a small minority of residents identify themselves as Muslim” (The Khayelitsha Developmental Forum ,2021, p.1).

According to Maasdorp et al. (2020), there are few epidemiological studies on TBI in South Africa and the incidence is under-reported. They further stated that in South Africa, the reported prevalence of TBI is 316 people per 100 000 people. This indicates that TBI is a silent pandemic and is still under-reported in South Africa.

> “The Western Cape Province is emphasised in 2013 admissions data from the two tertiary hospitals servicing the province – Groote Schuur Hospital (GSH) and Tygerberg Hospital (TBH); 2 851 patients with TBI were admitted (1 855 at TBH and 996 at GSH). Likewise, an internal audit conducted in 2009 at GSH revealed the high prevalence of TBIs among trauma admissions (n=10 046) where 24% of patients were TBIs, of which 27% (n=654) were classified as moderate to severe and resulted in in-patient admission” (Arnold-Day and Semple,2020, p. 27).

This speaks to the lack of studies related to TBI in the Western Cape; however, the prevalence of TBI is relatively high. There is therefore a relatively high prevalence of TBI in Khayelitsha compared to other communities. A few TBI-related studies have been conducted in the Western Cape, including on emergency and trauma cases and head injuries in Khayelitsha and Mitchells Plain (Balchin et al., 2015; Soeker & Ganie, 2019). The research population was selected from this community, burdened with a history of violence and other social ills, as confirmed by Clarcke (2015). This was the best option for this study because the researcher wanted to explore and understand the experience of living with TBI is a place burdened with vulnerability and poverty. The researcher wanted to understand how these individuals navigated life with TBI in light of the many difficulties they face at home and in their environment. Khayelitsha was therefore the best place from which to draw the population and the sample.

3.6.2 Gaining access

In research, it is not always easy to gain access to the relevant population, and in many cases, researchers depend on their own resources and strategies to gain access to a target population (Hamersley & Atkinson, 1995). In this case, the researcher had a good relationship with the NPO, making it easy to gain entrance and recruit participants for the study. The researcher made a written request to conduct the study to the director and the programme manager months before data collection (see Appendix 4) and they gave their consent via email upon receiving the request. The agreement between the researcher and the management team of the NPO was made in February 2020 before the national Covid-19 lockdown. The researcher then contacted the manager of the NPO a month before collecting data, to make sure that their agreement was still in place. It was such a relief to hear that the NPO was still open and that the researcher could come at any time. The researcher then proceeded to make new appointments with the director and management team to discuss the logistics of the data collection process. The meeting went well; the researcher was given permission to meet with the participants during a support group session, where she introduced the research topic and recruited participants for the study. The researcher did this for two consecutive days, introducing the topic of the study to the TBI survivors, introducing herself to potential participants, and explaining the purpose of the study. The process went well and the recruitment process was successful. In total 20 TBI survivors agreed to participate in the study.

3.6.3 Sampling

Purposive sampling was selected for this study as it was the most suitable means to recruit the kinds of participants who would be able to help answer the research questions. This type of sampling is characterised by the selection of participants based on certain characteristics they possess that are relevant for the study (Johnson & Christensen, 2014). The researcher wanted to recruit TBI survivors who came from that community and who had good communication skills because she wanted to explore and describe their lived experiences. “When developing a purposive sample, researchers use their special knowledge or expertise about some group to select subjects who represent this population” (Berg, 2001, p.32). The researcher knew the NPO and the services they render to TBI survivors, which dovetailed well with the purpose of this study. The researcher purposefully chose TBI survivors because they are experts about their own their lives and experiences; no one would be able to tell their stories better than they would. This was the best sampling option for this study and participants produced rich data.

Table 3.6-1 Sample of the study

Participant	Age	Gender	Cause of Injury	Nature of Injury	Living Arrangements	Duration of injury
P1	47	Female	Car accident	Severe	Family	33 years
P2	37	Male	Car accident	Moderate	Family	4 years
P3	53	Male	Road accident	Moderate	Family	8 years
P4	41	Male	Interpersonal violence	Severe	Alone in a Shack	10 years
P5	34	Male	Interpersonal violence	Moderate	Family	17 years
P6	24	Male	Domestic violence	Severe	Family	17 years
P7	44	Male	Car Accident	Severe	Family	10 years
P8	33	Male	Road Accident	Severe	Family	8 years
P9	36	Male	Road Accident	Severe	Family	19 years
P10	46	Male	Interpersonal violence	Moderate	Family	5 years
P11	22	Male	Car accident	Moderate	Family	4 years

P12	39	Male	Interpersonal violence	Severe	Family	10 years
P13	55	Male	Gunshot	Severe	Family	44 years
P14	34	Male	Interpersonal violence	Severe	Family	5 years
P15	35	Male	Road Accident	Mild	Family	3 years
P16	37	Female	Pedestrian accident	Severe	Family	5 years
P17	38	Male	Road Accident	Moderate	Family	4 years
P18	46	Male	Road Accident	Moderate	Family	11 years
P19	56	Female	Domestic violence	Severe	Family	28 years
P20	34	Male	Road Accident	Severe	Family	28 years

Twenty participants were purposefully selected for this study; 17 males and three females. In total, 19 participants lived with their families and one participant lived on his own in an informal settlement. Twelve participants suffered from severe TBI, seven participants had sustained moderate TBI and one participant had sustained mild TBI. Their ages were as follows; two participants were in their twenties, ten were in their thirties, five were in their forties and three were in their fifties. Participants thus ranged in age from 22 to 56. The causes of TBI among participants were road accidents, car accidents, interpersonal violence, domestic violence, a gunshot and a pedestrian accident. All participants spoke in isiXhosa and English, two of the three dominant languages in the Western Cape (Western Cape Government, 2021).

Participants had to be TBI survivors because the study was on the challenges experienced by TBI survivors. Both male and female TBI survivors were interviewed because the researcher wanted to explore the experiences of both sexes. Participants had to be between the ages of 18 and 65 because the researcher was interested in interviewing adult TBI survivors, and not children. TBI survivors with mild and moderate injury were selected because they were able to comprehend language and communicate. Participants with severe injury were selected only if they had sustained their injury at least five years earlier, so that they would be able to communicate and articulate their experiences in a coherent manner. Having lived with their condition for a long time, these participants were able to supply rich data on their lived experiences. Lastly, all the survivors were from a selected NPO, which ensured that they had detailed documentation as proof of injury and the NPO provided convenience and accessibility for the participants and the researcher.

Community developmental workers at the NPO assisted with the selection of TBI survivors who fit the criteria for this study. Students assisted with the signing in of participants on arrival, assisted participants with signing consent forms as they waited to be interviewed. This was necessary owing to the overwhelming number of participants who came on the first and second day of data collection.

The researcher was given permission by the director to use one of the counselling rooms at the NPO to conduct the interviews. The room provided good ventilation, with enough space to keep a social distance of 1.5 meters as per the Covid-19 regulations.

3.7 The data collection instrument

In qualitative studies, the researcher is the key instrument in the process of data collection and data analysis (Creswell, 2014). The researcher collected the data and used her interpersonal skills to engage in conversations with participants during the interviews, which produced rich data. “Since understanding is the goal of this research, the human instrument, which can be immediately responsive and adaptive, would be the ideal means of collecting and analysing data” (Merriam, 2009, p.15). In the process of collecting data, the researcher made efforts to be warm, friendly and relatable to, which made it easy to establish rapport with participants. Establishing rapport was done through the researcher’s expressed appreciation for their participation as well as the fact that she communicated in isiXhosa, the mother tongue of participants. The interviews were recorded on a voice recorder with the permission of the participants, and stored in a password-protected computer. The researcher interviewed 21 participants (including one pilot interview) who met the sampling criteria. She kept a notebook in which she wrote down any interesting information that emerged during the interviews, to enable deeper reflection on what she learnt during the interviews.

The researcher wanted to develop questions that would produce answers to the research questions and the objectives of the study, and so the interview schedule was developed with these in mind. The researcher worked on three drafts of the interview guide with the guidance of her academic supervisor and finally decided on the right questions. These were translated into isiXhosa to accommodate participants. The researcher tested the interview schedule during the pilot interview before finalising the questions. Being the key instrument in a qualitative study was rewarding for the researcher; it gave her a sense of responsibility and was the best option for this study.

3.8 The pilot study

The researcher conducted a pilot study to assess her capabilities as a research instrument, and to test the value of the research questions. A pilot study refers to testing or experimenting via a smaller study to prepare for a bigger study (De Vos et al., 2011). “This is typically used as a feasibility study; a pilot study can test a research protocol, such as a data collection method and a sample recruitment strategy” (Kim, 2010, p.191). The researcher interviewed one participant to assess the usefulness of the qualitative data collection method, tools and interview schedule that the researcher had chosen for this study. All COVID-19 regulations were followed during the interviews. On the one hand, the researcher was happy that the participant had come during a pandemic; on the other hand, the researcher was worried about whether her interviewing skills were good enough to extract rich data from the participant. The interview went well, which boosted the researcher’s confidence to conduct twenty more interviews with the remaining participants. It was the best option to conduct a pilot interview before interviewing the rest of the participants for this study.

3.9 Data collection

The researcher made use of qualitative data collection methods since this was a qualitative study. Qualitative data collection methods include focus groups, document analysis, open-ended, closed and semi-structured interviews (Aspers & Corte, 2019). The researcher used an interview schedule and information sheet (see Attachment 1), which contained detailed information on the study as well as a set of open-ended questions that allowed participants to elaborate on their own experiences, as would not have been possible with closed-ended questions (Cropley, 2019). The researcher requested participants to individually sign consent forms (see Attachment 2), in which they indicated that they agree to participate in the study voluntarily. A schedule was developed to keep track of interviews and to plan interviews accordingly. Before each interview, participants were provided with a copy of the information sheet and the interview schedule, so that they could familiarise themselves with the questions before the interviews began. The first interview was conducted on 26 October 2020 and the last interview was conducted on 28 November 2020; the process thus took just over a month to complete. The information sheet was made available to the director and the manager of the NPO, in order to maintain transparency throughout the data collection process. This was deemed the best option for this study in light of the ethical requirements of trustworthiness and transparency during research.

3.9.1 Individual interviews

Qualitative research is centred on understanding information that is presented through language and expressed experiences (Levitt, Bamberg, Creswell, Frost, Josselson, Suarez-Orozco, 2018). To understand the experiences of the participants, the researcher conducted individual interviews, which would enable rich data produced through language and suited the goals of the research. “Many if not most qualitative research studies rely on interviews with participants. The data collection method is an effective way of soliciting and documenting, in their own words, an individual’s or group’s perspectives, feelings, opinions, values, and attitudes, in addition to factual information about their lives” (Saldana, 2013, p. 32). The researcher found this style of interviewing very useful as it allowed for probing. Because the interview schedule was flexible, TBI survivors were able to express their views on their experiences and challenges in connection with the process of family reintegration post-hospitalisation. “Researchers record information from interviews by making handwritten notes, by audiotaping and by videotaping” (Creswell, 2014, p.244). The researcher used an audio recorder to record the interviews and kept a notepad to write notes on important things that emerged during interviews. All the recordings were kept in a password-protected computer to ensure confidentiality and the protection of data.

The researcher wanted to conduct interviews that lasted one and a half hours each, but some participants were very quick to answer the questions and their interviews lasted less than an hour. Babbie (2013) states that individual interviews enable the researcher to have one-on-one contact with participants. Before each interview, the researcher would establish rapport with participants to make them feel comfortable. “The interviewer often also has an extended time in which to get informants to relax and become accustomed to the recorder” (Taylor, Bogdan & De Vault, 2016, p.130). Before each interview, the researcher would test the audio recording with the participants to ensure that it was able to capture their voices. To accomplish that, the researcher would ask each participant to say their names and where they lived. It was a fun exercise and made participants laugh a little.

The researcher would start each interview by introducing herself and expressing appreciation to the participant for having taken the time to participate in the study. At the end of each interview, participants were thanked for taking part. Christensen, Johnson and Turner (2014) support the idea of establishing rapport with the interviewees to create a safe and comfortable space. Through establishing rapport with participants, the researcher was able to gain more in-depth data, and thus develop a better understanding of the experiences of TBI survivors. All participants expressed themselves in isiXhosa with a little English spoken here and there. There were unforeseen interruptions by staff members a few times during the interviews, as they took something from the interview room; at such times, the researcher would pause and resume after the staff member had left. The first question in the interview schedule was: "Please tell me about where you come from, what you do for a living.' The last question on the schedule was: 'Has the support group helped you? Please elaborate". At the end of each interview, the researcher would thank the participants for their time. The individual interviews served the purpose of this study which was to explore and describe the challenges experienced by TBI survivors. This was the best data collection method for this study.

3.10 Qualitative data analysis

"Data analysis is a process of making sense of the responses you have received as a result of various methods of data generation" (D'Cruz & Jones, 2014, p.133). After interviews, the researcher embarked on the journey of making sense of the data. The eight steps for data analysis as proposed by Tesch (1990, in Creswell, 2014, p.198) were followed. These are described below.

Step1: The researcher read through all the transcriptions to gain an overall sense of the data, noting interesting ideas that emerged during this review. The most interesting interview was read first. The researcher then listened to the recordings a few times, listening attentively for underlying messages, as may be conveyed through silences and areas of emphasis, particularly when it came to the challenges experienced by the interviewee. This was a process that required going back and forth in the voice recordings, stopping at certain intervals and rewinding to listen again in order to ensure that the interpretation of the words was correct. Merriam (2009) described the complexity of this process; it often requires the researcher to go back and forth while trying to ‘connect the dots’ and make sense of data.

Step 2: The researcher read through one transcribed interview at a time to establish the underlying meaning in each. All thoughts that arose were noted in the form of memos. This process was repeated with all 20 transcripts.

Step 3: The patterns that emerged from the 20 transcripts were organised into themes and subthemes. Similar themes and subthemes were clustered together in columns and labelled as major, unique and leftover topics. Six themes relevant to the objectives of this study emerged.

Step 4: The themes were checked and revised, with the researcher making use of abbreviated codes for each theme, which were written next to the appropriate text. This was followed by searching for possible new themes that might emerge from the data. Only a few new themes emerged. Final decisions were made by the researcher and her supervisor about those themes.

Step 5: The researcher decided on the most descriptive wording for the identified themes and subthemes. Related topics were put together, with links to other topics. There were six themes with two to five subthemes each.

Step 6: The consistency of coding was evaluated and decisions were made regarding the wording of the themes and subthemes, as well as where to place them. The codes were represented by six colours (red, yellow, green, blue, grey and pink) that were used to highlight themes and subthemes; this helped the researcher to remember which code referred to which theme. The researcher gained clarity and guidance from her supervisor; she provided support and encouragement that the researcher needed at the time.

Step 7: The themes and subthemes were subjected to a literature control to support each theme and subtheme. It was then easy to write up the findings, bearing in mind the findings of other researchers as described in Chapter Two of this study.

Step 8: The researcher recorded the existing data to report the findings. The data was kept in a password-protected computer and saved on the cloud. A few unforeseen traumatic incidents caused some delays in the process of data analysis.

Supervision came at the right time to boost this researcher's confidence, as she was starting to doubt herself and her capabilities, for some reason. It took over four months for the researcher to complete the process of making sense of data. The transcripts were in isiXhosa, and there were challenges in transcribing because Microsoft Word did not recognise the language; as a result, there were many errors which had to be rectified. It was challenging to have to play each recording over and over again to ensure that the exact words, which were not always clear, were captured and transcribed. Finally, the researcher wrote up the findings that emanated from the data analysis. The first draft of the findings was complete and submitted to the supervisor. Making use of the eight steps in data analysis was the best option for this study.

3.11 Data verification and trustworthiness

Data verification and a check of trustworthiness in a qualitative inquiry is conducted in order to prove or support that the findings are accurate and convincing, and are worth paying attention to, and that all inconsistencies and errors have been addressed (Levitt et al., 2018). In the process of verifying data, the researcher checked five aspects: credibility, dependability, transferability, confirmability and reflexivity, in order to ascertain that the findings are worth paying attention to.

Credibility is ensured when the researcher embarks on the process of proving that the data collected is presented correctly and reflects the true experiences of participants (Korstjens & Moser, 2018). To ensure credibility, the researcher kept the audiotapes and the transcriptions of the interviews and checked that what was reported was a true representation of participants' experiences and challenges post-hospitalisation, and that they would be available on request.

Dependability is based on the accuracy of the findings (De Vos et al., 2011). This required the researcher to ask some participants to evaluate the written interpretations, findings and recommendations to confirm that these were supported by the data received from participant. The researcher went back to the organisation and read through the transcripts for participants to ensure what she had written was a true representation of their experiences. The participants expressed that they were satisfied with the transcripts; they concurred that the transcripts were true representations of their interviews with the researcher.

Transferability is based on the notion that there needs to be a level of transferability of qualitative research to other contexts and other participants (De Vos et al., 2011). The researcher kept a detailed description of the research setting, research approach and methods for data collection and analysis, for future researchers to review so that they might decide whether a similar study would be feasible in a similar context. This ensured transferability in this study.

Confirmability is grounded on the researcher's ability to prove that the findings could be established by other researchers and that the findings are based on participants' narratives (Korstjens & Moser, 2018). The researcher used narratives and quotes from the transcripts of participants. The transcripts were in isiXhosa because the interviews were in that language; the narratives used for findings were translated into English with the help of academic peers to ensure objectivity in the data interpretation process.

Reflexivity. The researcher made use of reflexivity as a way of acknowledging her own biases that might have affected the way she selected the research approach, research design, data collection and data analysis for the study. She used this method of trustworthiness to consider whether her own background and viewpoints might have influenced the findings, and took trouble to ensure that this possibility was eliminated as far as possible (Tracy, 2014). "As a qualitative researcher, you have to acknowledge the importance of being self-aware and reflexive about your role in the process of collecting, analysing and interpreting the data, and in the pre-conceived assumptions you bring to your research" (Korstjens & Moser, 2018, p. 123). There was a possibility of bias, as the researcher had prior knowledge of TBI as an ex-employee and ex-programme manager at the NPO that was selected for the study. She had vast experience in rendering services related to TBI, was previously responsible for delivering training and workshops for other professionals to establish a referral path, and for educating the public about TBI. The researcher had also facilitated and coordinated the weekly support group sessions, and individual and family sessions. She had trained staff once a month with new information on TBI, to help improve their knowledge and practice, and to enhance high-quality service delivery to TBI survivors and their families.

Since the researcher was trained and experienced in rendering services to TBI survivors, having left the NPO in 2015, it was not possible to remain entirely objective or neutral, or to eliminate prior knowledge. In research, subjectivity is always present and serves as a bias that needs to be controlled by the researcher to enhance objectivity in the study (Flick, 2018). The researcher managed to control her biases in this study but could not be completely objective. Going back to the organisation after some years and meeting new participants who did not know the researcher may have helped to ensure objectivity. The researcher found herself far more engaged and interested in participants' stories than before; perhaps because she came as an outsider and not as an employee of the NPO. She established rapport with all the participants, and ensured confirmability, thereby producing rich data as indicated by Johnson & Christensen (2014).

Creswell (2014) states that in qualitative research it is important for the researcher to acknowledge how their experiences can potentially drive the interpretation of data and the formulation of themes. That was true in this study; the researcher's background of working with TBI survivors from 2013 to the end of 2015 shaped the way she formulated data analysis. She had already developed some themes before interviews were completed, based on the many common issues that arose, which may well have been an indication of some bias.

For the data collection process, the researcher decided to use her leave during a one-week school holiday to interview as many participants as possible. On the first day of data collection, five participants were interviewed, which turned out to be physically and emotionally draining. She found herself conflicted between reaching her target number of participants in five days and being realistic about the emotional effects of the interviews.

She used reflexive memos and jotted down all her interpretations of the interviews and how she was able to function as a research tool to ensure proper data collection. The researcher assessed how she transcribed the audios, to ensure that they were not based on her interpretation but were a true reflection of the views of participants. The memos played a part in contextualising and interpreting quotes, and were used during the write-up of the findings. Leavy (2017) supports this idea and states that qualitative researchers write reflexive memos to keep track of and assess their positions in their qualitative studies.

After the first day of data collection, the researcher could not stop thinking about what the participants had said in the interviews; their struggles in dealing with disabilities that they were not born with. The experience was very affecting. It was not only their stories that stirred strong emotion; it was also the way that may have been physically disfigured, with scars on their faces and heads.

At times during the interviews, the researcher was tempted to intervene with the kinds of advice or referrals that a social worker might give, especially where it was felt that participants could benefit from particular health services or they did not know about places that would help them with their needs. The researcher made a few referrals after the interviews with another social worker at the NPO and to other organisations for the benefit of participants. Part of this may have been related to a sense of guilt, as the researcher felt that she was using these participants for her dissertation, and wanted to help them in some way. However, she was careful to ensure that this sort of help was given only behind the scenes and did not form part of the interviews in any way.

In this regard, the researcher sought out supervision from her academic supervisor who is an experienced social worker and researcher. The supervisor was able to conduct a debriefing session and give guidance. This boosted the researcher's confidence and mental health which was starting to plummet from listening to the stories of TBI survivors. This was to be expected, in light of Tracy's (2013) remarks about researchers having to be cognisant of their own strengths and weaknesses during research. When the researcher became aware of her own weaknesses, she sought her supervisor's help.

The researcher had completed only fifteen interviews before her leave was over. After that, she made arrangements with participants and staff members of the NPO to interview the remaining participants after working hours from 2:30 pm to 4:30 pm. She would drive from work to interview the remaining participants; this meant that the data collection process took slightly over a month to complete.

The researcher then embarked on the process of analysing data. She began transcribing interviews in December 2020, having the goal of completing this task by the end of January. However this goal was set without taking into consideration the many distractions of the Christmas period, and only one transcript had been done by the end of December. In January 2021, personal trauma put the process on hold, in the form of a family bereavement. The researcher started again at the end of February 2021, completing the transcriptions by April 2021. A delay occurred in late April and early May, after the researcher was robbed at gunpoint. The trauma caused delays in achieving other milestones connected with the writing up of the research.

It was therefore late May 2021 when the researcher started the process of writing up the findings, having overcome a number of hurdles along the way. She used Google Translate to help translate quotes from participants that were from isiXhosa to English. However, Google Translate was not useful as had been expected. Eventually, all quotes were translated, based on the researcher's own knowledge of the two languages and her understanding of participants' contexts and states of mind, which helped to ensure that the data was rich and nuanced. Translation and transcription were time-consuming, at times a quote was found not to be suitable for the point being discussed and had to be replaced with another.

The researcher drew on the literature (Korstjens & Moser, 2018; Levitt et. al., 2018; De Vos et al., 2011) to ensure the trustworthiness and validity or credibility of the data. The findings of this study reflect what the selected participants said during the interviews, and are not generalisations of what people living with TBI in South Africa might say. The study was conducted in a specific setting with a certain population group. In this study, the researcher tried to be as objective as she could be to ensure a true representation of the lived experiences of TBI survivors regarding family reintegration post-hospitalisation.

3.12 Ethical considerations

“There are moral and legal codes in place regarding the ethical treatment and care of people involved with research studies. The classic principle “But first, do no harm”, is primary when working with human participants”(Saldana, 2011, p.24). The researcher adhered to research ethics to ensure that the participants were protected from any form of harm during the interviews. To achieve this, the researcher focused on the following areas: informed consent, voluntary participation, avoidance of harm and anonymity. The researcher adhered to the Bill of Rights enshrined in the Constitution because the participants are protected under South African law; she maintained their rights to privacy, equality, human dignity and respect (The Bill of Rights of the Constitution of the Republic of South Africa, 1996).

The researcher also made sure that all regulations were followed as per government regulations to sure the safety of participants during the data collection process. The researcher was also cognisant of the injunction against causing any emotional or psychological harm to participants. This aspect was challenging as the objectives of the study required probing participants about past traumatic events, a process which could have caused emotional pain.

The researcher was granted permission to research by the Biomedical Research Ethics Committee at the University of the Western Cape (see Attachment 4). The granting of permission was exciting to the researcher, and it energised her to move quickly on to the interviews.

She forwarded the Ethics Approval Letter (BM20/8/11) to the director and the programme manager of the NPO as proof and legitimacy of her study and for their record keeping. After receiving permission from the NPO’s programme manager, the researcher provided an information letter and asked whether she could present her request to participants as part of a workshop in one of the support group sessions at the NPO. Once permission was granted, an information letter (Appendix 1a and 1b) was disseminated to all participants in which the researcher explained all the ethical guidelines of the study. Many participants requested the researcher to read the information to them so that they could fully grasp what the study was about. This she did at workshops held over two consecutive days. That process did not take more than 30 minutes; the researcher was very cognisant of their attention spans and cognitive deficits.

"Informed consent means the knowing consent of individuals to participate as an exercise of their choice, free from any element of fraud, deceit, duress, or similar unfair inducement or manipulation" (Berg, 2001, p. 56). All the participants were well informed about the nature and goals of the study, thanks to the reading out and explaining of the information sheet. The researcher spoke isiXhosa throughout, to ensure that everyone knew what the study was all about.

The participants were asked to sign a consent form (Appendix 3a and 3b) in which they agreed to be audio recorded during the process of data collection. The consent form was written in English and isiXhosa. The researcher noticed that three participants struggled to sign their names owing to their physical disabilities, mostly from strokes. She asked them to relax and take their time in writing their signatures, and after some time they were able to sign. The researcher felt guilty for not providing other options, such as the option of supplying a thumbprint; however, she did not have the facilities to do so. These limitations will be considered by the researcher in future studies with persons living with disabilities.

Voluntary participation was embraced in this study; no participants were coerced to participate and no false promises were made to entice participants. De Vos et al. (2011) state that voluntary participation is vital in research studies and that participants should not be forced or threatened to participate. Participants seemed excited to be part of the study, with many saying that this gave them a chance to do something other than sit at home. Most were unemployed and not studying; they wanted to do go out during national lockdowns which had kept them confined for some time. Avoidance of harm is another key ethical aspect in research. In this study, no participants were harmed. It was vital that the researcher ensured this aspect, as there was potential for emotional harm , however, the researcher had made provision for that (Levitt et al., 2018), having arranged for a trained counsellor to be available should the need arise. As it turned out, one female participant was very emotional during the interview; the recording was paused as the researcher helped her do a breathing exercise to calm her down. She was then referred her to one of the social workers for a few minutes. When the participant was ready to proceed with the interview, she returned. After the interview, the researcher made a referral for the participant to receive trauma counselling from one of the two social workers at the NPO.

The researcher ensured the anonymity of participants, keeping the identities of all participants confidential. Discussions were anonymous, as codes, not names, were used to identify audio recordings and transcripts (De Vos et al., 2011). All documents from this research were kept safe in a password-protected computer to which no one else had access. After five years the documents will be discarded. Participants were assured that personal identifiers would be removed or changed in the written data and the presentation of the data analysis (Flick, 2014, p. 209). The researcher mentioned that participants would be referred to as Participant 1 or Participant 2, in the order of their interview schedules.

The researcher maintained transparency with the participants throughout the process of recruiting them; all questions regarding this study were answered. A few participants were concerned that their names might be mentioned in the study, and the researcher assured them that they would not be used.

3.13 Delimitation /limitations of study

There are some limitations to this exploratory-descriptive study in which participants were asked to share their views and experiences on challenges that they faced post-hospitalisation for TBI regarding family reintegration. The study is limited to TBI survivors who had mild and moderate impairments or, in the case of severe TBI, had sustained the TBI at least five years before the time of the study, to avoid the complex symptoms that might have caused hindrances in their communication. Communication skills and language comprehension of survivors was a big factor in the process of selecting participants. This was done to ensure that the qualitative data was attainable and suitable for this study. Even though participants were able to communicate, there were still underlying speech problems, mostly in the form of slowed speech. However, this had been expected and the researcher was able to accommodate these participants in this study. Only TBI survivors participated in this study and not their family members; this may be construed as a limitation. It would have been interesting to gain the perspective of caregivers as well, since TBI affects family members deeply. The recordings were made in isiXhosa and transcribed in isiXhosa, and then quotes or narratives were translated to English. This dual process of transcription might have meant that some nuances of language were lost, although every precaution was taken to ensure that this did not happen. The findings were written up with the guidance of the supervisor, and the findings were found to suit the objectives of the study. The findings were compared and contrasted with the literature in Chapter Two as well as other literature that was referred to during the process of analysis. The study was small-scale and should not be used for generalisation. This was a small-scale, context-specific study and it would not be feasible for social workers to generalise the findings as they may not be relevant in other settings. However social workers can still learn from this study to add to their practises and the findings may be considered during policy development for services to TBI survivors, caregivers and their families.

3.14 Conclusion

A qualitative research approach and an explorative and descriptive research design were used in this study. Purposive sampling was employed to ensure that participants would be able to assist in attaining the objective of the study; criteria were: five years post-TBI for severe cases, and any period for those who had suffered mild or moderate injuries; male or female adults residing in the selected community; willingness to participate, and able to verbally communicate.

Twenty-one interviews were conducted, one being a pilot interview to assess the effectiveness of the selected qualitative research methods. The researcher collected the data through individual interviews using a list of semi-structured open-ended questions to produce rich data.

The researcher followed the eight steps of data analysis to derive the findings. The researcher ensured that the findings represented what the participants had said by using a data verification and trustworthiness test; i.e. transcripts were given or read to participants to check and verify. The researcher was very cognisant of her own biases throughout the study and endeavoured to limit these. She was deliberately reflexive during the process so that she was able to examine her own emotions, biases and weaknesses, and address these.

The researcher was granted permission by the Biomedical Research Ethics Committee at the University of the Western Cape to conduct research. The researcher also received permission from the NPO management to recruit participants for the study and to use one of their counselling rooms for individual interviews. All participants gave their written consent to freely participate in the study. All ethical considerations were adhered to; no harm was inflicted on any of the participants.

The following chapter presents the findings of the study.

CHAPTER FOUR

RESEARCH FINDINGS

4.1 Introduction

This chapter presents the research findings that emerged from the semi-structured interviews that were conducted with the 20 participants, all of whom were TBI survivors and clients of an NPO in a selected community in the Cape metropole.

The chapter is structured in the following way: First the demographic profile of the participants is presented in Table 4.2-1, followed by a discussion of the demographic profile. Next, the study findings are presented, arranged according to six main themes. Under each theme, two to five subthemes are presented. The themes and subthemes are shown in Table 4.2-1. After the table, each theme is discussed in detail along with its subthemes, with relevant quotes from the participants' narratives included to support the discussion. Each subtheme is briefly summarised and compared and contrasted with the relevant literature. The last part of this chapter is a summary of the chapter.

4.2 Demographic profile of participants

The demographic profile and selection criteria for the participants in this study were discussed in Chapter Three. Participants were purposefully selected for this study, based on their experience of having experienced a TBI. They all attended weekly support group sessions in an NPO in a selected community, as discussed in Chapter Three. The data collection was done via individual semi-structured interviews with 20 participants. One participant who met the sampling criteria participated in a pilot interview. In total 21 interviews were conducted, with 20 being used for data collection, at which point data saturation was achieved. Table 4.2-1 shows the demographic profile of the 20 participants.

Table 4.2.1 Demographic profiles of participants

Participant	Age	Gender	Cause of Injury	Nature of Injury	Living Arrangements	Year of Injury	Employment status
P1	47	Female	Car accident	Severe	Family	33 years	Unemployed
P2	37	Male	Car accident	Moderate	Family	4 years	Unemployed
P3	53	Male	Road accident	Moderate	Family	8 years	Unemployed
P4	41	Male	Interpersonal violence	Severe	Alone in a Shack	10 years	Unemployed
P5	34	Male	Interpersonal violence	Moderate	Family	17 years	Unemployed
P6	24	Male	Domestic violence	Severe	Family	17 years	Unemployed
P7	44	Male	Car accident	Severe	Family	10 years	Unemployed
P8	33	Male	Road accident	Severe	Family	8 years	Unemployed
P9	36	Male	Road accident	Severe	Family	19 years	Unemployed
P10	46	Male	Interpersonal violence	Moderate	Family	5 years	Unemployed
P11	22	Male	Car accident	Moderate	Family	4 years	Unemployed
P12	39	Male	Interpersonal violence	Severe	Family	10 years	Unemployed
P13	55	Male	Gunshot	Severe	Family	44 years	Unemployed
P14	34	Male	Interpersonal violence	Severe	Family	5 years	Unemployed
P15	35	Male	Road accident	Mild	Family	3 years	Unemployed
P16	37	Female	Pedestrian accident	Severe	Family	5 years	Employed
P17	38	Male	Road accident	Moderate	Family	4 years	Unemployed
P18	46	Male	Road accident	Moderate	Family	11 years	Unemployed
P19	56	Female	Domestic violence	Severe	Family	28 years	Unemployed
P20	34	Male	Road accident	Severe	Family	28 years	Unemployed

Table 4.2.1shows that 17 males and three females participated in this study. The ages of the participants ranged from 22 to 56 years old. Of the 20 participants, two were in their twenties, ten in their thirties, five in their forties and three in their fifties. Most of the participants were in their thirties. With regard to the causes of TBI, most were owing to road accidents (7), interpersonal violence (5) and car accidents (4). A few were domestic violence (2), one was caused by a pedestrian accident and one was the result of a gunshot to the head. Regarding the nature of the TBI, most participants had severe injuries (12), some participants had moderate injuries (7) and one participant had a mild injury. Regarding the living arrangements, most participants lived with their families (19) and one participant lived alone in a shack. The duration of the injuries ranged between 3 and 44 years. In terms of ethnicity, all the participants were black and isiXhosa speaking, and most were very keen on speaking in English during the interviews. Most (19) participants were unemployed, and one was employed.

In South Africa, TBI cases are mostly the result of vehicle accidents, interpersonal violence and assaults (Nkoana et al., 2020), which support the findings in Table 4.2-1with regard to the common causes of TBI.

4.3 Presentation of the research findings

The process of data analysis was presented in the previous chapter, Chapter Three. From the data, six themes were developed, all centred on the experiences of TBI survivors regarding family reintegration post-hospitalisation. Several subthemes under each theme emerged from the data. The data analysis and findings were developed based on the interviews, the literature reviewed and the theoretical framework, as presented in Chapter Two.

Table 4.3.1 Overview of the themes and subthemes

THEMES	SUBTHEMES
1. Biopsychosocial challenges experienced by TBI survivors post-hospitalisation	1.1 Cognitive deficits or challenges experienced by TBI survivors 1.2 Physical challenges experienced by TBI survivors 1.3 Psychological and emotional challenges experienced by TBI survivors 1.4 Education challenges experienced by TBI survivors 1.5 Challenges regarding employment and sustaining jobs
2. Biopsychosocial adjustments of TBI survivors post-hospitalisation	2.1 Lack of family conferencing before reintegration 2.2 Reintegration of TBI survivors 2.3 Rehabilitation of TBI survivors
3. Vulnerabilities experienced by TBI survivors	3.1 The physical infrastructure is not conducive 3.2 Impact of TBI on survivors' health 3.3 Access to the disability grant for TBI survivors
4. Resilience and coping resources for TBI survivors post-hospitalisation	4.1Support group as a coping resource 4.2 Religion as a coping resource 4.3 Psychosocial services for TBI survivors and their families post-hospitalisation
5. The impact of TBI on family dynamics	5.1 Impact of TBI on family roles 5.2 Family conflicts
6. Recommendations to improve services for TBI survivors and their families	6.1 Recommendations for TBI survivors 6.2 Recommendations for families of TBI survivors

Table 4.3.1 gives an overview of the themes and subthemes that emerged during interviews.The themes and subthemes presented in Table 4.3-1 emerged during the interviews which were based on the following broad questions:

1. Tell me how it was for you to return home to your family after being hospitalised for a TBI.
2. What were some of the vulnerabilities or difficulties that you experienced in the process of adapting to the home environment after being discharged from the hospital?
3. How did the rehabilitation programme at the hospital prepare you for returning home after your hospitalisation?
4. What psycho-social services did you receive post-injury after you came out of the hospital?
5. What suggestions would you make regarding the improvement of services for TBI survivors and their families?

4.4 Discussions of themes and subthemes

4.4.1. THEME 1: Biopsychosocial challenges experienced by TBI survivors post-hospitalisation

This first theme is linked to the first objective of the study which was to explore and describe TBI survivors’ challenges and experiences regarding the reintegration process into their families after hospitalisation. The theme emanated from the interview question regarding how it was for the participants to return home to their family after being hospitalised for TBI. The five subthemes that emanated regarding the challenges experienced by TBI survivors were the cognitive, emotional, physical, education and employment challenges experienced by TBI survivors post-hospitalisation. Theme 1 is the biopsychosocial challenges experienced by TBI survivors post-hospitalisation.

Most participants mentioned that they experienced speech problems at some point owing to the TBI. Some quickly recovered from that, while others were still experiencing the problem to some degree. Some participants mentioned that they experienced bodily pain daily since the TBI and that they had become sensitive to cold and hot weather, also owing to the TBI. Lastly, some participants stated that they were experiencing sleep problems, mostly insomnia, which had not been present before the TBI.

These are some of their views regarding the biopsychosocial challenges that they experienced post-TBI:

> *"At the time of the injury, I was not able to talk ... um… I think I was only able to talk after a month in a private hospital* [he was on medical aid paid for by his employer*]. I was then able to talk ... but ... what I said didn't make sense at the time. And no one could understand what I was saying".* P8
>
> *"First of all, I have this pain in my whole body that I cannot explain … for instance, when the weather is too hot and when it is too cold ... I have this pain in my body even if I do not have my normal seizures".* P5
>
> *"When I go to sleep at night, I do not go to sleep right away … I stay up and play with my phone ... around 11 pm ... but somehow I will wake up again ... I can count 1…2...3… by half-past 2 in the morning I am still awake … and I can't go back to sleep".* P20

According to Tyreman (2018), a study on the psychological effects of brain injury indicated that it was not uncommon for people with TBI to have severe communication difficulties, and challenges with language comprehension and making complex statements. Similarly, Bruijel, Vermeeren, Ponsford and Van Heugten (2018), who studied the biopsychosocial factors of fatigue and sleep problems after TBI, found that the likelihood was high of developing highly complex symptoms following TBI, which hinders the process of recovery for survivors. That is consistent with the participants' expressed experiences with speech challenges post-TBI, causing communication breakdown between participants and society.

Lefkovits, Hicks, Downing and Ponsford (2020), in their study on surviving the 'silent epidemic' of TBI, highlighted physical pain as a common impairment caused by TBI. The findings in this study support this finding. Some of the challenges experienced by participants are not necessarily visible and cannot be seen at first. This finding confirms that TBI is truly a ‘silent pandemic’ owing to the delayed and hidden symptoms that survivors may experience post-hospitalisation, as highlighted by Kumar et al. (2019), in their study on the psychosocial impact of brain injury.

According to Teymoori et al. (2020), who studied the structure and validity of depression and anxiety after TBI, it is common for survivors to develop sleep disturbances, insomnia in particular, which is a catalyst for psychiatric problems and fatigue. They further state that communicative disorders, memory loss and changes in information processing, as well as inappropriate social behaviour, are difficult disorders that negatively impact survivors’ chances of returning to work. Most of the participants experienced sleep problems post-TBI. Findings from a study by Wolfe et al. (2018) and Poulsen et al. (2020), on sleep disorders post-TBI, also indicate that sleep disorders or impairments are likely to develop in survivors especially in cases of severe TBI. They further indicated that these sleep disorders can be caused by physical pain post-hospitalisation that requires more medical attention. These attention would benefit from a person-centred intervention that is suited for their biopsychosocial need. This is supported by Bachkirova and Borrington (2018), who state the importance of creating a nurturing environment in person centred practice, thereby creating positive self-concepts.

It became apparent from participants’ narratives and the supporting literature that biopsychosocial challenges are inherent in cases of TBI survivors; these include sleep disorders, speech problems and physical pain, to name a few.

4.4.1.1 Subtheme 1: Cognitive deficits or challenges experienced by TBI

The first subtheme under theme one was the cognitive deficits or challenges experienced after the TBI. The theme emanated from the research question about how it was for them when they returned home after hospitalisation.

Most participants complained about memory problems, and of forgetting important things such as switching off a tap to stop water from flooding their homes. Some participants stated that they struggled to remember things or names of people and needed to be reminded. Some had noticed that after the injury, they were forgetful to the point of feeling out of place and disoriented.

These quotes express the participants' experiences with cognitive deficits or challenges:

> *"Eh, all I can say is that I didn't understand the sudden forgetfulness that I experienced* [Post TBI]. *At times I would forget to turn off the tap in the bathroom and leave the water running. One time I went to hang out with my friends, leaving the tap running water, my aunt called me frantically telling me that, there was water on the bathroom floor, she demanded that I mop the floor and I did".* P10
>
> *"Yes, I have noticed a lot of changes in me, like this thing of not remembering things. It is one of the things that I have noticed about me ... I am losing my memory and I struggle to remember some people, I forget people's names … but I remember you* [Reffering to the researcher] *from last week".* P11
>
> *"You know, I have noticed that after the injury I forget things easily. I would set out to another room to fetch something but when I get there I ask myself what am I doing here and where was I going?"* P19

Participants reported that they experienced cognitive challenges, particularly with memory, which was not a problem before the TBI. It became apparent that these cognitive challenges are long lasting in survivors as all participants complained about being forgetful. Several studies (Devi, Khan, Rana, Deepak, Dhandapani, Ghai, Gopichandran & Dhandapani, 2020; Stålnacke et al., 2019; Psychosocial considerations of TBI, 2019) highlight that cognitive deficits are common after TBI and affect information processing, attention, memory issues and decision making or executive functions. These can last up to ten years post-hospitalisation, particularly in moderate and severe cases of TBI. This theme is thus consistent with previous research on the cognitive challenges related to memory problems for TBI survivors. From a person-centred approach, it seems that these participants could benefit from cognitive and neuro-rehabilitation to combat these challenges, as highlighted by Stålnacke et al. (2019). In terms of the current study and from a person-centred approach, a social worker could make referrals for TBI service users to affordable cognitive rehabilitative services, assuming the role of a broker and linking TBI survivors to available resources, as highlighted by Kirst-Ashman and Hull (2008), in their writings on adaptation, human behaviour and the social environment.

It became apparent from the narratives of the participants and the supporting literature that cognitive impairments or challenges are common in TBI survivors across the globe, regardless of the different contexts of such survivors.

4.4.1.2 Subtheme 2: Physical challenges experienced by TBI survivors

The second subtheme under theme one was physical challenges experienced by TBI survivors post-hospitalisation. This theme emerged from the interview question regarding some of the vulnerabilities or difficulties of adapting to the home environment after being discharged from hospital. Most of the participants had a physical disability as an inherent symptom of TBI. They mentioned that they had physical challenges caused by different disabilities following the TBI. Most had experienced a stroke as a result of the TBI, which added to their physical challenges. In addition, some participants mentioned the physical challenge of bowel and bladder dysfunction; some experienced this while in hospital and during the beginning stages of their recovery, and for two participants, this persisted.

These are some of their views concerning the physical challenges that they experienced post-hospitalisation:

> *"After that* [TBI] *I noticed something … I noticed that my arm … the right arm, could not function at all … it became loose … and just like that, my arm gave up … I use it at times but not too much. I started to have a tingling feeling on this very arm … especially when I try to hold something on this side* "[points to left arm]. P6
>
> *"Then I decided to go play with my friends just like before when I got there ... you know ... my friends knew me as a strong boy with no weak side, with no paralysis* [referring to stroke] *on my left side or stroke. We would play soccer outside … as I was in the middle of the field, I noticed that I wasn't as strong as before … and I lost balance … especially on my left side".* P13
>
> " *Sister* [Referring to the researcher] *this* [uncontrolled bowel and bladder dysfunction] *is the nature of my disability … the fact that I can't control my urine and that I soil myself … that means … that means I am loose".* P18

Severe TBI is usually followed by several symptoms which cause reduced functionality or permanent disability, such as cognitive and behavioural impairments, which make it difficult for survivors to return to work post-injury Sigurdardottir et al. (2018), in their study on returning to work after severe TBI.

From these findings it appears that participants had various physical challenges or disabilities that they noticed only after leaving the hospital. A study by Othman et al. (2021), on the neuro-rehabilitation of TBI, had similar findings, indicating that TBI has a direct effect on survivors' ability to function both psychologically and physically, which causes functional limitations in survivors. Studies on TBI confirm that survivors experience physical challenges and disabilities that continue to hinder their abilities to complete their daily tasks and cause functional limitations throughout their lives (Covington & Duff, 2020; Soeker & Ganie, 2019; Taylor & Seebeck, 2020). In this regard, the findings in the current are therefore in line with findings in the literature.

Stroke, as a consequence of TBI was not discussed in Chapter Two of the study; however, it was prevalent in most participants, a finding which is in line with the finding of an international study by Turner et al. (2021), on stroke risk following TBI. These authors mention that TBI can causes stroke, disability and death, and affect the quality of life and life expectancy of TBI survivors. Olaoye, Soeker and Rhoda (2020), in a study on the development of a 'return to work' intervention programme for stroke survivors, indicate that stroke has many neurocognitive challenges, leading to a high risk of unemployment in survivors who do not receive proper vocational rehabilitation.

Similarly, bowel and bladder dysfunction were not discussed in Chapter Two of this study, but were mentioned during the interviews with participants. According to Headway: The Brain Association (2021) and Albayram, MacIver, Mathai, Verstegen, Baxle, Qiu, Bell, Caldarone, Zhou, Lu and Zeidel (2019), who studied TBI complications, the loss of control of one's bladder and bowel is very common post-TBI, and can last for several weeks and even months. These authors further state that this is a complex issue, affecting the dignity of TBI survivors, and likely to cause depression and low self-esteem. From a person-centred approach, a social worker can create warm and caring relationships, thereby promoting self-determination in participant. This is emphasised by Mbedzi (2011), who talks about the importance of establishing warm relationships between client and counsellor or facilitator.

The researcher found that this was true for some participants. One participant was still experiencing this bowel and bladder dysfunction and it was puzzling that he had not sought medical help for this. The researcher thus assumed that he may have been too embarrassed to seek such help. This issue was not explored further during the interview because the researcher's role was not that of social worker but she encourage the participant to seek medical help at the local day hospital.

It became apparent from both participants' narratives and the literature that disability or physical challenges are prevalent among TBI survivors across the globe and continue to cause many limitations for survivors.

4.4.1.3 Subtheme 3: Psychological and emotional challenges experienced by TBI survivors

The third subtheme under theme one was psychological/emotional challenges experienced by TBI survivors. The responses emanated from the interview question relating to the mental health issues that participants experienced post-hospitalisation. Most participants mentioned that they had experienced some form of emotional or psychological challenge owing to not being able to reconcile with the permanent deficits that followed TBI. Most mentioned that they experienced post-traumatic stress disorder (PTSD) as a result of the incident that caused the TBI. In addition, some participants said that they had been suicidal at some point in their lives, feeling that their lives had no meaning as a result of their disabilities. Some participants mentioned that they became extremely depressed because of not being able to accomplish their goals in life, and feeling stuck. These are some of their views regarding the psychological challenges that they experience post-hospitalisation:

> *"You know, when I am on my way to the Centre* [Mall] *... when the bus approaches ... I try to avoid it, walk far from it, even when I am walking with someone ... I do the same thing and they often ask me, 'Why are you standing and why are you scared of the bus?'... I try not to ride on a bus because of what happened ... and I mostly commute by taxis …*"P16

> *"You know it is one of those things ... one day I was sitting at home and I thought of just giving up on life, because I do not enjoy life anymore .. .I was at my lowest ... I even thought of killing myself, but I told myself to wait for the day that I will die, but not take my own life".* P6

> *"That* [Referring to being depressed] *happens to me sometimes, like ... just thinking about how much people of my age have accomplished in life ... and I am alone. I am still stuck here ... with no progress".* P20

It became apparent from these findings that the incident that causes the TBI can cause post-traumatic stress disorder (PTSD), as was apparent in the words of the first speaker. PTSD was also found by Ilijazi, Ashina, Al-Khazali, Lipton, Ashina, Schytz and Ashina (2020), in their study on post-traumatic stress disorder after TBI. These authors state that it is not uncommon for TBI survivors to experience PTSD, often in the first three months after TBI. This is supported by other researchers (Wang et al., 2019; Rauen et al., 2020; Psychosocial considerations of TBI, 2019). These studies concur that the psychological effects of TBI include PTSD, anxiety and depression.

According to Kaufmann et al. (2019), in their study on the psychometric characteristics of insomnia in veterans with a history of TBI, there is a high possibility of suicide ideation in TBI survivors. These authors state that psychological and emotional impairments can lead to an unpleasant lifestyle, filled with bad choices that impact negatively on health and reduce the quality of life for TBI survivors. This supports the finding in this study, that some participants felt suicidal and wanted to give up on life.

Tyreman (2018) highlights the importance of receiving counselling to boost the mental health of brain injury survivors; thus acknowledging the psychological turmoil experienced by many TBI survivors. Based on the findings of the current study, the researcher believes that the participants could benefit from interventions based on the person-centred approach, as highlighted by Coghlan, (1993). Mental health is one of the invisible challenges that need paying attention to. It was interesting and saddening to hear that some participants had not received trauma counselling and cognitive therapy, and that some were still at risk of taking their own lives owing to the psychological effects of TBI that had not been addressed.

Participants’ narratives and the supporting literature indicate that the mental health of TBI survivors can plummet owing to the many psychological challenges of dealing with drastically altered circumstances, and not having received the necessary therapeutic intervention to deal with these.

4.4.1.4 Subtheme 4: Educational challenges experienced by TBI survivors

The fourth subtheme under theme one was the educational challenges experienced by TBI survivors. This subtheme emerged when participants were asked about some of the vulnerabilities or difficulties they experienced in the process of adapting to the home environment after being discharged from hospital. Most participants indicated that they had returned to school after the injury but experienced difficulties that led them to drop out of school. Some indicated that they were open to short courses to enhance their abilities. Some stated that they were not able to go back to the mainstream schools but were sent to schools for disabled persons.

These are some of their views in relation to educational challenges post TBI:

> *"So I mean … it's not possible to go back to studying … I used to really enjoy school. I am not that person anymore now. Even if I want to do a course, I have to make sure that it is an easy course, a basic course or a very short course for at least two weeks … I cannot study now".* P11
>
> "*I was not able to go back to the same school as before the injury … I was referred to a school for the disabled. I continued to study there and most of the work that we did in our classes was mostly hand work and at times we would go do our practical"* .P13
>
> *"I am trying to find something to do with my life … I was not able to cope at school even though I really wanted to study … because of the injury. I wouldn't say I was delayed because what happened had to happen, but I am grateful that I made it out alive. I went back to school and I noticed that things have changed … and I ended up here at HeadsUP because of my curiosity".* P2

These findings indicate that most participants struggled to cope in mainstream schools, post-hospitalisation and stopped going to school altogether. Ezer, Wright and Finsp (2020), who studied the neglect of persons with severe brain injury in the United States, concur that in cases of severe TBI, survivors are often at risk of not reaching their full potential in their education, which infringes on their right to education, especially when there are no rehabilitative services for survivors. That is supported by Headway: The Brain Association (2020), which reports on returning to school after TBI. The authors highlight the importance of returning to school after the TBI as it brings meaning and helps to obtain the skills and expertise necessary for future employment purposes. This issue of educational challenges applies to some participants in the current study. Many of the participants in this study tried to resume schooling post-injury but gave up owing to cognitive challenges. The lack of infrastructure coupled with the diverse challenges of TBI had clearly impacted participants' ability to attain their Constitutional (RSA, 1996) right to education. The findings show that participants have limitations regarding academic endeavours, and are not able to access education suitable for their needs post-hospitalisation. In Chapter two, the person-centred approach was presented, which have significance in terms overemphasising inclusivity in educational settings (Cornelius-White et al., 2013).

Some participants in the current study had left school since the educational setting was not sufficiently inclusive and could not accommodate their needs. This is due both to a lack of knowledge about resources, and the limited educational resources that exist in the participants' environment. Educational challenges were very apparent in these findings. At the same time, participants mentioned that their own cognitive challenges with regard to information processing, problem-solving and memory made it almost impossible to continue schooling. Processing, problem-solving and memory are all essential skills in education (Cardoso, et al., 2019; Tyreman, 2018).

It was interesting to notice the many areas of commonality in the responses by participants with regard to the challenges they experienced; for instance how cognitive, speech and insomnia problems affected them, and how memory and learning ability were impaired to the point where they stood little chance of finding employment. This confirms the need for a person-centred approach to combat these challenges, focusing on each individual's needs.

Participants' narratives and the supporting literature indicate that many TBI survivors struggle to stay in school after injury, and that owing to a dearth in educational resources, many remain unemployable.

4.4.1.5 Subtheme 5: Challenges regarding employment and sustaining jobs

The fifth subtheme under theme one is challenges regarding employment and sustaining jobs after TBI. This subtheme emerged when participants were asked about some of the vulnerabilities or difficulties that they experienced in the process of adapting to the home environment after being discharged from hospital. Most participants expressed that they were not able to return to their previous jobs after sustaining a TBI or that they had been unable to cope or keep up in their respective workplaces, which led to their unemployment. Most participants were young and had not given up on looking for jobs, despite the issues that they experienced.

These are some of their sentiments regarding employment and sustaining jobs:

> *"You see, my spinal cord was also affected. As a result I can't stand in the cold for a long time. You see I went back to work after the injury with the doctor's letter stating the health risks involved on my return. My boss said it would be illegal to take me back to work and they would go to jail ... so they didn't take me back".* P3

> *"The TBI really affected me ... as I am not able to do many tasks ... it ruined my life. I used to work at the construction site as a cleaner but things changed* [Post- TBI]. *I couldn't perform like before. As a result, I ended up being too slow and I felt like my colleagues would be delayed because of me, because they would try to help me ... which is something I wasn't used to before".* P9

> *"I do not have one* [referring to a job] *at the moment, but I am applying via my phone because I have a soft copy of my CV on my phone".* P15

The findings reflect the challenges that participants experienced with employment and employability post-TBI, including losing jobs as a direct result of the TBI. As presented in Table 4.1 of this chapter, 19 out of 20 participants were unemployed at the time of the interviews. The level of unemployment of participants is in line with the high unemployment rate in South Africa. The Department of Statistics South Africa (2021) indicates that the prevalence of unemployment in the fourth quarter of 2020 was at 7,2 million, an increase of 8 000 on the previous quarter. The findings also indicate that the participants needed not just to survive, but to function in society and have a good quality of life working for a living. This corroborates what has been found by other researchers (Ostermann et al., 2018; Martino, et al., 2020; Williams et al., 2020).

Many participants in the current study have found that the impairments of TBI lead to challenges for survivors with regard to working, particularly their ability to keep up with the pace of job demands, which often lead to termination of employment sometime after the survivor resumes work. This confirms both the high rate of unemployment amongst TBI survivors and the dearth of vocational rehabilitative services that might increase the chances of employment for persons with TBI. It also became apparent in these findings that the younger participants were still interested in finding jobs that are suitable for the neurocognitive and physically challenged. A longitudinal study on TBI survivors conducted over 20 years by Andelic Howe, Hellstrom, Sanchez, Lu, Lovstad and Roe (2018), on disability and quality of life 20 years after TBI, found that there was a 52% improvement rate in the abilities of survivors who returned to work, but that many had persistent functional limitations. Their finding supports what was found in this study. According to Welk (2019), Soeker and Ganie (2019) and McDonnall, Cmar and McKnight (2020), there is a possibility of TBI survivors returning to work post-hospitalisation, but this depends on the severity of the injury, the level of education, the levels of stress tolerance and the cognitive skills of the TBI survivor. A study by Soeker and Pape (2019) on the effectiveness of a model of occupational self-efficacy in TBI survivors in the Western Cape found that the model under review was suitable for some but that not all survivors are able to cope in the work environment. These authors further highlight the need for TBI survivors to be given support to enhance their cognitive skills, memory, communications skills, reasoning and attention, through vocational rehabilitative services. Ideally this is done soon after leaving hospital so that survivors stand a chance of re-entering the workplace successfully. The need for such service ties in with the fact that very few participants on this study were actively seeking work; most felt they had no chance. Libeson et al. (2020), in a qualitative study on the experience of returning to work in individuals with TBI, highlight that vocational rehabilitation increases the rate of employment for TBI survivors.

According to the person-centred approach, clients ought to be linked to vocational rehabilitation resources by a social worker assuming his/her role of being a broker (Zastrow & Kirst-Ashman, 1997), cognisant that some TBI survivors can in fact return to work, with the right support. There will of course be challenges in regard to TBI survivors returning to work which Shafi and Colantonio, (2021), in their study on the effectiveness of workplace facilitation of return to work for persons with TBI, concur. From the interviews and from the literature, it is apparent that employment remains a huge challenge for TBI survivors, many of whom have a low socio-economic status because of unemployment. This raises a question about the quality of life that is possible for these participants, given that the desire to work is inherent in most people, regardless of injury. Participants' narratives and the supporting literature indicate that TBI survivors across the globe face challenges regarding their return to work post-hospitalisation. It is apparent from these findings that not all TBI survivors can return to work, but nevertheless, many could, given the right support.

4.4.2. Theme 2: Biopsychosocial adjustments of TBI survivors post-hospitalisation

Theme two was in line with the first objective of this study; to explore and describe TBI survivors' perceptions and experiences regarding the reintegration process into their families, post-hospitalisation. This theme emanated from answers given regarding participants' experiences of biopsychosocial adjustments post-hospitalisation. The theme speaks to how survivors adjust or attempt to live their lives post-hospitalisation. The specific question that gave rise to this theme was 'How was it to return to your family and home after hospitalisation?' Most reported a negative experience in this regard. Some mentioned name-calling by community members owing to their disabilities, and that they were made fun of at places like churches and local meetings, owing to speech problems that developed as a result of the TBI. Most male participants mentioned that they were not in romantic relationships because they had previously experienced rejection and were made fun of because of their decreased libido after the TBI.

These are some of their views about their experiences regarding biopsychosocial adjustments post-hospitalisation:

> *"All I can say … in my community, there was this one guy but unfortunately he passed away. That guy used to call me crazy, in fact he used to call me a mental case... I tell you … people with disabilities have been given such names in our communities"*. P6
>
> *"There is a lot of things* [incidents where people with disabilities are mistreated] *… and those things have caused many changes in my life. Now I really do not want to meet or engage with people who always put me down … people who always crush me … and make fun of how I speak …this is common in places like … at church and meetings in my community"*. P13
>
> *"How do I put it … how do I say this in isiXhosa … I noticed that if I am going to have sex with a woman … It takes time for me to be in the mood or in that form … this is something that never happened before the injury… So the girls end up leaving me … because I am wasting their time … they often leave me for other people. I have had relationships but when it comes to sexual intercourse … I have a problem … the other person often feels like I am wasting their time"*. P5

According to Rauen et al. (2020), who studied quality of life up to ten years after TBI, adapting to the environment post-TBI is mostly about the process of recovery and slowly gaining control over one's life. They found that TBI survivors would benefit from having early rehabilitation treatment to promote resilience and adaptation post-hospitalisation. Gómez-de-Regil et al. (2019) in their study on psychological intervention in TBI patients, highlight the importance of access to psychological help to assist TBI survivors with the process of adapting to their homes post-hospitalisation. Tosatto, Ansaloni and Agnoletti (2020), in a study on long-term outcomes for major trauma patients, attest that TBI has a long-term impact on the survivor and that various impairments have a huge impact on the individual's ability to maintain relationships, among other effects. This corroborates participants' views on their challenges with adjusting and adapting to the 'new normal' post-hospitalisation.

In addition, the injury can negatively impact social relationships, with survivors often preferring to be left alone as a consequence of their communication difficulties. They tend to have low self-esteem and experience difficulties with intimate relationships, as highlighted by Tyreman (2018), who wrote on the psychological effects of brain injury.

According to Douglas (2020), who studied loss of friendship following TBI, having a close relationship with someone can be one of the key factors to overcome the long-term effects of TBI, because relationships form part of a set of protective factors that help with overcoming stress and promoting wellbeing in survivors. TBI survivors could benefit from having early rehabilitation treatment to promote resilience and adaptation post-hospitalisation (Rauen et al, 2020). A study by Headway: The brain association (2018), on sex and sexuality after brain injury, highlights that damage to some parts of the brain can lead to several sexual dysfunctions in men and women. They further state that TBI survivors often experience low libido as a side-effect of the medication they take to combat the complex impairments of TBI post-hospitalisation. This confirms the finding in this study that participants did not have a smooth transition from hospital to home. It was puzzling for the researcher to comprehend the depth of the challenges that these participants faced in their attempts to adapt to life post-TBI. Also, based on the participants narratives coupled with the literature reviewed it seem that biopsychosocial adjustments for TBI survivors post hospitalisation are extremely challenging to TBI survivors. However these participants could benefit from the person centred rehabilitation to address psychosocial issues. This is supported by (Combs et al., 2018), who emphasises the person-centred approach and a holistic approach to addressing all TBI related impairment.

4.4.2.1 Subtheme 1:   Lack of family conferencing before reintegration

The first subtheme under theme two is the lack of family conferencing in families of TBI survivors before they were reintegrated into their homes and communities. This subtheme emerged when participants were asked to reflect on how it was for them to return home after hospitalisation. Most participants mentioned that they were discharged into families that were not trained in how to care for them, which led to a variety of hurdles in their respective recovery processes. The participants were not aware whether their families had sought out social work interventions to be equipped for their return post-hospitalisation, but they did notice that their families did not know what to do and were unprepared. The participants further stated that their families were not aware of the permanent disabilities of TBI survivors, including stroke, which speaks to the lack of family conferencing before the reintegration process.

These narratives attest to the lack of family conferencing or training before reintegration:

> *"My family had no idea how to help me after hospitalisation. They were really confused and they had no idea where to begin and how to take care of me"*. P6
>
> *"They were not ready for my return. They didn't know anything. There was no preparation to equip them. No steps were taken to seek help from social workers. They did not seek any help from social workers"*. P4
>
> *"My family reacted differently because they did not understand anything about my stroke. It took a very long time for them to accept that there were changes in my body after the injury. At first they had no idea about what was happening to me"*. P14

TBI has added to the burden on the health and welfare system in South Africa and there are not enough rehabilitative services in the public sector (Soeker & Ganie, 2019). It is apparent from these findings that the families did what they could to take care of TBI survivors despite the lack of formal training. As a result, they struggled to understand the changes in their loved ones, and their specific needs. Families could benefit from person-centred psychosocial services to enhance resilience and help them cope with the stress that comes with caring for TBI survivors (Anderson et al., 2020). These findings support findings in the literature in Chapter Two which speak of an international lack of family conferencing before reintegration. Studies by Rasmussen, Arango-Lasprilla, Andelic, Nordenmark and Soberg, (2020) and Azman et al. (2020) show that families are often overwhelmed with caring for survivors, especially where they are not trained to do so (which applies to all participants in this study). The problem is therefore one that is common across the globe. It becomes apparent from these findings that there are still gaps in the healthcare system regarding acute interventions or rehabilitation for TBI and proper training for families of TBI survivors. Thus, the findings under this subtheme are substantiated by the lack of family conferencing and training before reintegration of TBI survivors globally. The lack of family conferencing in the treatment plan of TBI survivors highlights a gap in the healthcare system. Participants' narratives in this study therefore back up findings in the literature that a there is a great lack of family conferencing for families of TBI survivors before the process of reintegration into homes and communities.

4.4.2.2 Subtheme 2: Reintegration of TBI survivors

The second subtheme under theme two is participants' views on the reintegration process post-hospitalisation. This subtheme emerged from the interview question about how it was for TBI survivors when they returned home after hospitalisation. Some participants expressed that they were discharged prematurely to accommodate new, more critical patients, as there were not enough beds in hospitals for emergency cases. Most mentioned that they had experienced disorientation; a state of being completely lost and unaware of who and where they were, from time to time. Some participants expressed that they felt neglected by their family members, and had the sense that they no longer mattered.

These are the views of participants about their reintegration experiences post-hospitalisation:

> *"I was discharged from the hospital and told to go home as there were not enough beds for patients at the hospital. I had no idea how the process of discharging someone works. I was also told to make frequent visits to the local day hospital".* P18
>
> *"There were times where I would be going somewhere but somehow I would be disoriented to a point of not knowing where I am and where I am going. I still experience that, suddenly not knowing where I am going and where I am".* P4
>
> *"I didn't do this* [TBI] *to myself so I had to be strong. At times I would feel neglected by my family. At times I would say something and they wouldn't pay attention to me and carry on with their daily lives and that really hurt me deeply. I would tell myself, no, it's not that these people hate me. They are helping me behind the scenes or making decisions that will help improve my life. I can't be the same as I was before the injury".* P2

These statements indicate that participants had no formal reintegration programme set out for them and their families to combat the challenges of TBI post-hospitalisation. This supports the finding that globally there is a dire lack of integration programmes. These programmes are needed in view of the increasing numbers of TBI survivors whose lives are saved because of medical advances; however, higher numbers of survivors means an increased burden on global healthcare systems (Alqahtani, Assiri, Mohany, Imran, Javaid, Rasool, Shakeel, Sivandzade, Alanazi, Al-Raijaie, Alshammari, Alasmari, Alanazi & Alamri, 2020). Alqahtani et al. (2020) studied how the co-administration of ketamine and perampanel improves behavioural function and reduces inflammation in acute TBI in mice. Their general observations on the nature of TBI globally corroborate the finding in this study.

Tyreman (2018) urges that reintegration strategies be put in place for survivors to enhance adaptability post-hospitalisation. Community reintegration is usually a process followed to enhance the adaptability and participation of TBI survivors in the community post-hospitalisation (Lama, Damkliang & Kitrungrote, 2020). The findings of this study also support the findings of Lama et al. (2020) that there is a lack of community reintegration for TBI survivors. This reveals the lack of a much-needed service for TBI survivors.

There is not a great deal of literature about the family reintegration of TBI survivors. Most of the literature covers community reintegration, which is a rehabilitation process that helps to enhance community and social participation for TBI survivors (Lama et al., 2020). TBI survivors often experience challenges with social integration and maintaining other aspects of their lives, according to Ang and Wasserman (2021), who studied TBI among the guests at a low-barrier homeless shelter. This social integration challenge links with the vulnerabilities that are highlighted in Theme 3, 'Vulnerabilities experienced by TBI survivors' where participants spoke of being subjected to maltreatment by community members. This complete unpreparedness of both family members and community to understand and deal with the changes in TBI survivors partially explains participants' challenges with creating and maintaining relationships; these challenges only add to their sense of being completely outside of social circles and a social life. It became apparent to the researcher that TBI affects survivors on many levels, and that survivors would really benefit from community or family integration services. These services would need to be tailored to the needs of the TBI survivors through social work services that are person-centred. Participants' narratives in the current study back up findings in the literature that there is a dire lack of reintegration programmes tailored to assist TBI survivors move from hospital to home.

4.4.2.3 Subtheme 3: Rehabilitation of TBI survivors

The third subtheme under theme 3 covered the diverse views of participants about rehabilitation. This theme emanated from the interview question about how the rehabilitation programme at the hospital had helped with their return home after hospitalisation. Some participants were fortunate in having family members with medical knowledge, who were able to seek services, including physiotherapy, at the hospital; however, this sort of help was not forthcoming for most of the participants. Some were referred to their local day hospitals for physiotherapy post-hospitalisation. Many mentioned that they had never had access to any kind of rehabilitation, and were not aware that they were supposed to receive any.

These are some of the participants' views regarding their experiences regarding with the process of rehabilitation:

> *"When I was discharged from the hospital I was told to go home. We* [the family] *asked to gain access to a physiotherapist from that hospital and they agreed. I would attend sessions with the physio from time to time".* P10

> *"Today I can say that it took time for me to realise that there were changes in my body. I only realised when I was already going to a physio, I was then told to practise at home what we did in the sessions … to do activities like standing up and sitting down. And then I was advised* [by the doctors] *to change my lifestyle and not do the things I used to do".* P14

> *"I never received any rehabilitation services. I was discharged from hospital and went straight home. I didn't even go for the appointments after that. I was told to have a bandage and wrap it around my legs to keep them warm, and I do not remember much but I remember that I was discharged with a lot of bandages and rubbing stuff"* [ointment]. P1

Most participants who said that they had received physiotherapy from their local hospitals highlighted that family members had to request this service, which only happened if the family member had some medical background or knowledge about the importance of physical rehabilitation. A study by Mlenzana et al. (2018), on perceptions and satisfaction levels of caregivers with rehabilitation services from selected rehabilitation centres in the Western Cape, highlighted the important role of caregivers in helping persons with a disability be part of the rehabilitation process. These authors found some level of dissatisfaction amongst caregivers regarding access to services and perceived disorganisation in the rehabilitation process. This finding is in line with other findings in the literature (Borgen, Løvstad, Andelic, Hauger, Sigurdardottir, Søberg, Forslund, Kleffelgård, Winter & Røe, 2020; Mlenzana et al., 2018; Soeker & Ganie, 2019),that highlight the scarcity of rehabilitation and the fact that rehabilitation usually does not include cognitive and vocational rehabilitation, it focuses only on the physical aspect. This is supported by the participants' statements above, in which one makes it clear that physical rehabilitation through physiotherapy was received only when asked for at a local clinic or day hospital.

The findings show that some survivors had no access to rehabilitation, which points to the scarcity of rehabilitative services in the Western Cape for TBI survivors. This leaves untrained families or caregivers with the responsibility of providing all services, which they are not equipped to do (Soeker & Ganie, 2019). Several studies (Birudu et al.,2020; Combs et al., 2018; De Klerk et al., 2019; Naess et al., 2020) support the person-centred approach and the multidisciplinary approach to rehabilitation for TBI survivors to address the many complex impairments of TBI patients, including speech, cognitive and psychosocial challenges, and medical needs. This needs to be done by a multidisciplinary team, comprising social workers, doctors, speech therapists and dieticians, to name only a few. The findings under this theme point to the need for such multidisciplinary rehabilitation processes to be offered to TBI survivors; these processes need to focus not only on the physical but also on other aspects of combating the complex impairment of TBI. This, however, may not be possible, given constraints in the healthcare system in South Africa, which again speaks to the burden caused by TBI on the health and welfare system. The high number of TBI survivors means that some inevitably fall between the cracks of the health system. It became apparent from the narratives and the reviewed studies that a holistic and person-centred rehabilitation programme is needed for every TBI survivor to combat the complex deficits they experience.

4.4.3. Theme 3: Vulnerabilities experienced by TBI survivors

Theme three was the vulnerabilities experienced by TBI survivors, in line with the second objective of this study to explore and describe the vulnerabilities and resilience of TBI survivors in the process of adapting to the home environment, post-hospitalisation. This theme emerged from the interview question about the vulnerabilities or difficulties that participants experienced in the process of adapting to their home after hospitalisation. Under this theme there are three subthemes: infrastructure not conducive for TBI survivors, post-hospitalisation, the impact of TBI on survivors' health, and access to disability grants for TBI survivors. The participants had different views about their vulnerabilities post- hospitalisation. Most reported that they were not safe in their communities, owing to high levels of violence. Some participants talked about how badly they were treated in their communities, which had not been the case before they sustained TBI. Most participants mentioned that there was no accountability with regard to the people who caused their TBIs; some families did not report the incident to the police and nothing was done. These are some of their views with regard to the vulnerabilities that they experienced:

> *"No, it is not safe, the risk is too high* [referring to the rate of violence] *because my place is very close to the road, my shack is here and the road is here … a lot happens on that road, so I have decided to use an alternative route to get home ... I mostly walk on the pavement and I skip one street and then I arrive at home".* P17

> *"I had a terrible experience that changed my life. TBI completely changes one's life. Society and the community treat us badly. I am only speaking about where I live, because communities are not the same. People in my community treat you badly if you are disabled and that for me is a challenge that I face most of the time"*. P8
>
> *Nothing was done about it. There was no accountability for what happened to me* [The person responsible for his accident was never brought to justice]. *The only thing I remember is that someone* [referring to an official from Road Accident Fund] *used to come home and take me somewhere and talk to me"*. P20

According to Ackley and Brown (2020), who studied speech-language pathologists' practices for addressing cognitive deficits in college students with TBI, disability causes particular vulnerabilities that is felt by most TBI survivors. This was supported by the experiences of participants in this study, who spoke of how disability from TBI made them vulnerable to several violations in their communities. The literature speaks at length about the social ills that survivors are subjected to in their communities, such as poverty, crime and high levels of violence, as stated by Taylor (2019) in an ethnographic study bout violence and trauma in Khayelitsha. The high prevalence of violence in the community in which these participants lived increases the number of trauma emergency cases, as stated by Leeper et al. (2019) who studied assault-injured youth in the emergency centres of Khayelitsha. These authors state that many of these assaults result in head injuries in young men in Khayelitsha. This confirms the statements made by participants in this study who spoke of feeling physically unsafe in their community. South Africans have the right to an environment that does not cause harm to their health or their wellbeing (RSA, 1996). This right was not upheld in the case of these participants, as they felt unsafe and at risk in their own neighbourhoods, including from traffic.

The findings highlight that survivors suddenly found themselves subjected to discrimination, ridicule and mockery in their communities owing to their disabilities. According to Mustapha et al. (2021), who studied the experience of individuals with physical disabilities regarding stigma and discrimination, people with disabilities are often exposed to discrimination and their rights are often violated. This finding from the literature is supported by what participants mentioned about being mistreated, and how the people responsible for their TBIs were never brought to justice.

This is where the social worker can assume the advocacy role from a person-centred approach, educating the public and local communities about TBI and disabilities and helping to address other social ills (Zastrow & Kirst-Ashman, 1997). This would help educate people about the needs of TBI survivors and enhance the support they receive in their communities.

The findings show how TBI changes a person's life, and how the vulnerabilities caused by TBI remain unaddressed. It was interesting that these participants had little sense of agency and seemed somehow to accept that their human rights were violated in their communities. The narratives given by the participants and findings in the literature both speak to the issue of increased vulnerability among TBI survivors, in a variety of contexts, and of being both unsafe and subject to ridicule for their disabilities.

4.4.3.1 Subtheme 1: Physical infrastructure not conducive for TBI post-hospitalisation

The first subtheme under theme three was participants' views on how the physical infrastructure that was not conducive to their mobility post-hospitalisation. This subtheme emerged from the interview question about the vulnerabilities and difficulties that they faced as a result of TBI post-hospitalisation. Most participants mentioned that they experienced challenges with regard to infrastructure. Most participants were disabled and stated that infrastructure did not help their recovery. They experienced challenges with regard to having disabilities in informal settlements where they struggled with basic services including access to toilets. Most participants lived in informal settlements close to the road and found themselves at risk of road accidents, which added to their vulnerability. These were some of their comments:

> *"The biggest challenge for me was to walk in between shacks; you see there is not enough space between shacks in the informal settlements. I really struggled to walk a distance there. At times I would be walking with my crutches and I would really struggle".* P3
>
> *"Things like taking a bath I struggled with that because we stay in shacks or informal settlements, you see. So we use plastic washbasins to bathe. After I was discharged from the hospital. I struggled to use such facilities and my family members did not understand that at all".* P11
>
> *"You know I have been hit by three cars already. The first one was driven by my neighbour who lives in the same street as me ... He hit me with his car and after that, he didn't pay attention to me. I remember he was arrogant and not apologetic at all. The second car hit me next to the railway station. I was trying to cross. I remember after that my leg was swollen. The driver took me to the hospital. The third time I was hit by a taxi. The driver was swerving for another car. I thought it was going to stop but it was turning towards P-Section and I was hit".* P7

The comments show that the infrastructure and environments in which these participants live is not conducive to their ease of movement and does not accommodate their needs. Leeper et al. (2019) and Taylor (2018) support this finding, both stating that TBI survivors feel unsafe and find it difficult to move around owing to an inadequate infrastructure and the high prevalence of violence in their community. A particular vulnerability related to infrastructure was the lack of adequate housing, with small shacks and in rural development programme (RDP) houses in no way being adequate for the needs of physically disabled people. The Constitution of the Republic of South Africa (1996) highlights the right to adequate housing, within available resources. It was interesting to hear from the participants how inadequate housing directly affected their recovery post-TBI. A great deal of research has been conducted on the infrastructural challenges experienced by people living in informal settlements by (Jooste and Mathibela, 2020; Mutyambizi, Mokhele, Ndinda and Hongoro, 2020; Wang, Bertrand, Beshir, Kahanji, Richard, Walls and David Rush , 2020) have all studied informal settlements in South Africa, and have found that people living in informal settlements lack access to basic services, and the adverse living conditions contribute to the high level of crime. These authors show how infrastructure can either ameliorate or exacerbate crime and violence. In this study, the design and placement of informal housing was a definite risk factor for participants, given their physical vulnerabilities. The above authors also refer to the risk of fire in informal settlements, owing to the closeness of the structures and the light materials used to build shacks. This is consistent with this theme of the vulnerabilities experienced by the participants, and how living in informal settlements was not conducive to their long-term recovery from the impairments of TBI. It is interesting how lack of proper housing adds to the long list of challenges for these TBI survivors, who have no choice or means to better their living arrangements. The narratives related by these participants, together with the findings of research conducted in different parts of South Africa, confirm that inadequate infrastructure in informal settlements contributes to the many challenges and risks faced by TBI survivors. It became apparent that living in informal settlements, is not conducive for survivors and causes a vulnerability that impedes the recovery processes of TBI survivors post-hospitalisation. The views of these participants clearly indicate the need for more person-centred approach practice, so as to put their needs at the centre in the process of rehabilitation. This is supported by Cisnero et al. (2019), they make an emphasis to providing services that are designed for each patient.

4.4.3.2 Subtheme 2: Impact of TBI on survivors' health

The second subtheme under theme three was the views of participants on the impact of TBI on survivors' health. This theme emanated from the interview question about the vulnerabilities or difficulties that they experienced in the process of adapting to their home environments post-hospitalisation. Most participants mentioned that they had epilepsy as a result of TBI, a delicate condition that requires medication or treatment from their local day hospitals. Most participants mentioned that there were inherent deficits and medical complications that followed TBI, including headaches that needed medical attention. Some participants talked about the medical complications that warranted some form of surgery, but most were not able to afford surgeries owing to their economic backgrounds and unemployment.

These are some of their views regarding the impact of TBI on their health:

> “ *I get this strong headache and when I have it, I just want to keep quiet. Then I see that me being quiet doesn’t reduce the pain from the headache. Even at home. I get such headaches. I have noticed that but I didn’t notice it earlier. Even the people in my family have noticed this”.* P2
>
> *“Hmm ... yes I have epilepsy sometimes when I lie in bed … I can feel that something is happening* [seizures] *to my body and I call out to my children for help … I have been receiving treatment for it at the clinic … but they have lost my folder … they steal folders for their families … that has been happening a lot”.* P19
>
> *“I was referred back to Groote Schuur Hospital owing to a medical complication that I had* [post-discharge]. *I remember the doctors there told me that there was a complication related to my nerves from my brain that affected my legs, and they couldn’t help me. They said that this required a specialist to operate on me. They mentioned that in England the procedure would cost around R300 000.00 and in America, it would cost R200 000.00, and they proceeded to tell me that no doctor would be able to help me in Africa. The only thing they could do was to drain all the blood clots and stop the bleeding”.* P12

Most participants mentioned that they had developed chronic headaches that were not present pre-injury. Borgen et al. (2020), who studied TBI needs and treatment options in the chronic phase, state that TBI has been referred to as a chronic disease that requires long-term planning for medical care. For example, headaches are highlighted as a consequence of TBI in many studies (Koehmstedt et al., 2018; Sigurdardottir et al., 2018; Sima, et al., 2019). This finding was corroborated by participants in this study.

According to Ghadiri et al. (2020), who studied neuronal injury and death following mild brain injury, and Zhang et al. (2019), whose study was on the efficacy and safety of intrathecal meropenem and vancomycin in the treatment of postoperative intracranial infection in patients with severe TBI', TBI survivors are at a high risk of developing epilepsy, especially in severe cases of TBI where there is a lot of haemorrhaging in the brain. Mushtaq et al. (2018), writing on post-traumatic epilepsy, also highlight epilepsy as a clinical and medical condition characterised by spontaneous seizures that affects cases of moderate to severe TBI. These studies support the findings in the current study, in which most participants indicated that they had epileptic fits that they had not experienced before TBI. Many received medication for epilepsy from their local clinics.

Findings relating to high medical costs are supported by the literature, which corroborates the finding in this study that complications post-TBI are common and have a lasting impact on families, who mostly cannot afford high-quality healthcare (Adediran, Drumheller, McCunn, Stein & Albrecht, 2019). Adediran et al. (2019) studied sex differences in in-hospital complications among older adults after TBI. They found that TBI can cause permanent damage on many levels, and carries many financial and health implications for survivors and family members. It became apparent in this study that participants experienced limitations with regard to accessing healthcare, as is common in lower-middle-income countries, as highlighted by Awua et al. (2019) in their study on the psychosocial, cognitive and behavioural after-effects of TBI in Ghana. TBI adds to the high burden of disease in developing countries like South Africa and there are still many limitations to accessing comprehensive healthcare services for those who lack financial resources. This is in contradiction to the Constitution of South Africa's Bill of Rights, which speaks of the right of all who live in South African to have access to quality healthcare, no matter what their income (RSA, 1996). Addressing these medical issues post-TBI remains a challenge for those who lack the means. This lack of heath care access affects TBI survivors' recovery progress and their long-term quality of life, as highlighted by Rauen et al. (2020), in a study on quality of life ten years after TBI. These authors concur that it is common for TBI survivors to experience challenges regarding their health and quality of life post-hospitalisation. Krentz et al. (2021), who studied health-related quality of life after paediatric TBI, attest to the health-related challenges following TBI. It was interesting to hear from these participants how TBI lead to health-related issues that required constant medical attention, and yet how they were prevented from getting the attention they needed because of a lack of resources. This means that there are many people living with TBI who simply suffer the consequences and have a quality of life below that which is possible for survivors of TBI. These medical challenges could be addressed through the person centred approach to health care. This can be facilitated by social worker 'a broker', linking participants to the participants to relevant and affordable health services (Zastrow & Kirst-Ashman, 1997). Although the narratives related by participants and several other studies all took place in different countries, there was a great deal of overlap regarding the difficulties of access to much-needed medical services and the health impacts experienced by TBI survivors. All concur that TBI directly causes health complications post-hospitalisation.

4.4.3.3 Subtheme 3: Access to the disability grant for TBI survivors

The third and last subtheme under theme three was the views of participants on their experiences regarding access to the disability grant. This subtheme emanated from the interview question concerning the vulnerabilities or difficulties experienced by TBI survivors on their return from hospital to home. Some participants mentioned that they received the disability grant monthly and that it was permanent. Some survivors said that they received it but it was not permanent they had to go through the process of renewal every six months, some every twelve months. They further stated that while they waited for the disability grant to be renewed, they often depended on the old age grants of elders in their families.

Lastly, some participants mentioned that they had been denied access to the disability grant. Given their visible disabilities and the effects of stroke, it was hard to understand why they had been denied access.

These are the views of participants regarding access to the disability grant post-TBI:

> *"Yes, I receive the disability grant every month. It is permanent and I have never been asked to go and renew it".* P14
>
> *"Sometimes I receive disability … the disability grant for a limited amount of time. Sometimes for 12 months or six months and I often have to go back to renew it at SASSA* [South African Social Security Agency] *offices. The process of renewing a disability grant can be lengthy and takes time. In cases where my disability grant lapses … we depend on my mother's old age grant".* P5
>
> *"When I went to the doctor to ask for a letter* [proof of disability after the assessment] to *apply for the disability grant, he refused and said that I am now fine and I can breathe on my own. He read the letter from the hospital which explained how I got injured, from how I was stabbed, to not being able to walk and breathe properly. He proceeded to tell me that he will not help me in the process of re-applying for a disability grant".* P10

The findings regarding access to disability grants support the findings of a study by Awua, et al. (2019) who found that TBI contributes to a huge burden on the welfare and health system because of the complex impairments experienced by survivors. When one considers how many people survive TBI and how many other conditions qualify people for grants, it is not surprising that the welfare system in South Africa is burdened.

Studies by (Jiang, Hao, Zhang and Pang , 2020; Ritter, Dawson and Singh, 2021; Rauen et al., 2020) that TBI is one of the leading causes of disability and death across the globe, which fits the findings in this study as all of the participants who had experienced TBI were disabled in some way. This is why it was puzzling that some participants in the current study found it hard to access the disability grant. To apply for a disability grant in South Africa, one must undergo a medical assessment by a medical practitioner, to evaluate the extent and severity of the disability and whether that person qualifies to receive the grant or not (South African Social Security Agency, 2021). However, SASSA makes the final decision on who receives the disability grant, not the medical practitioner. In terms of the Bill of Rights, participants have the right to social security; however, the availability of resources and certain measures determine the realisation of this right (The Constitution of the Republic of South Africa, 1996). It could be those participants whose applications were denied were due to a lack of resources on the part of the State.

Dhavaleshwar (2016) states that one of the roles of the social worker is ‘needs analyser’ which involves being able to assess the needs of clients, families and communities, and actively linking people to the resources they need. A social worker can assess the need for a disability grant and refer clients to a medical doctor for medical assessment, then to SASSA to apply for a disability grant, intervening from a person centred-approach. Participants continue to experience vulnerabilities in this regard; perhaps it is time to include neurological disabilities in the list if disabilities that qualify for a disability grant or to redefine disability so that TBI survivors have access to this grant. It was also interesting how some participants were not considered disabled enough to receive the disability grant, yet were not functioning well enough to maintain jobs, meaning that they fell through the cracks of the welfare system. The narratives related by participants and the findings of the studies show how common it is for TBI to cause a huge burden on the health and the welfare system across the globe, and how many still fall through the cracks.

4.4.4. Theme 4: Resilience and coping resources for TBI survivors post-hospitalisation

Theme four aligned with the fourth objective of this study, which was to explore and describe the coping resources and protective factors needed for the process of family reintegration post-TBI. This theme is based on the resilience and coping resources for TBI survivors, post-hospitalisation. It emanated from the interview question on the psychosocial services that survivors received post-hospitalisation. Under this theme there are three subthemes: the support group as a coping resource for TBI survivors, religion as a coping resource for TBI survivors, and psychosocial services for TBI survivors and their families' post-hospitalisation. Participants indicated that they were able to use different coping skills to establish resilience. Most talked about acceptance as the centre and the beginning of their emotional healing and a great coping resource. They further stated that their children and some family members formed part of their coping resources and their motivation for not giving up on life. Lastly, some participants expressed that they used alcohol as a coping resource; these participants were aware that alcohol is a negative coping tool and that it is not good for their healing process after hospitalisation.

These are some of their views with regard to resilience and coping resources:

> "*I felt really terrible and I was in pain because of my circumstances. So now I have finally decided to accept what has happened to me*. P13
>
> *One other thing that keeps me going is my child. I have a daughter, her father died when she was only a one-month-old baby. I keep fighting for her so that she doesn't feel the absence of her father. I am her mother and father. So [that] when she needs something, I can provide it for her"*. P16
>
> *"No, I can't sleep properly and I drink* [alcohol] *a lot to deal with the stress. And the sad part is I never really got the help I needed"*. P17

These findings indicate positive and negative coping tools. Corey (2009), in his study on the adaptation of theory and practice in counselling and psychotherapy, highlights the person-centred approach as one that recognises the individual's innate ability to move towards self-actualisation, growth and self-determination. This applies to some participants, the majority of whom had learned to accept who they were and their circumstances after the TBI. This acceptance was to them an innate coping resources, enabling a measure of resilience against the adversities of TBI.

Machisa et al. (2018) conducted a study on social support factors associated with psychological resilience among women survivors of intimate partner violence in Gauteng. They indicated that family members are protective factors that help survivors to cope and adapt after violent incidents. The findings in this study concur; many participants had family members and children who acted as their protective factors and coping resources, motivating them to keep going and not give up on life.

Some participants struggled to cope with stress and drank alcohol as a way of coping with TBI. The literature by (Simske, Rivera, Breslin, Hendrikson, Simpson, Kalina, Ho and Vallier ,2020; Van de Horn, De Koning, Mayer, Spikman, Sommer and Van de Naalt, 2020; Kaufmann et al., 2019) state that trauma patients, especially TBI survivors, are likely to use substances as a coping mechanism to adjust and deal with stress post-trauma. Mbombo (2019), in a speech on the 'effects of violence, trauma and alcohol on the Western Cape health system', highlights alcohol as the main catalyst for many trauma cases and health issues in the Western Cape. The statements by participants in this study who used alcohol therefore back up international and local trends regarding alcohol as a means to cope for TBI survivors and a catalyst for many health-related problems. The participants would almost certainly benefit from more from a person-centred intervention, where social workers assess and make referrals to other organisations, including rehabilitation centres tailored for each participant, as mentioned by Hepworth et al. (2013), in their study on the adaptation of direct social work practice. The narratives in this study, together with the literature, are representative of common positive and negative coping strategies for human beings globally, in different contexts. The narratives and the reviewed studies flag alcohol as a negative coping resource, especially for TBI survivors, who suffer many debilitating impairments already.

4.4.4.1 Subtheme 1: Support groups as a coping resource for TBI survivors

The first subtheme under theme four is the support group as a coping resource for TBI survivors. This subtheme emerged from the interview question about the psychosocial services that participants received post-hospitalisation.

Most participants indicated that they attended weekly support group sessions as a psychosocial service and a coping resource. They further expressed that attending the support group sessions creates a space of trust where they can share their excruciating experiences and get support and motivation, which helps to reinforce a sense of resilience and ability to cope. Some participants mentioned that attending the weekly support group session enhanced their self-esteem and that they had learned to refer to themselves as 'survivors' and not 'victims' of TBI, which speaks to their empowerment and continued motivation. The participants reiterated that they received advice from other survivors on how to cope with certain challenges related to TBI, thereby becoming better educated and equipped to deal with their own challenges.

These are some of their views on having a support group as a coping resource:

> *"It helped me a lot, now I have people that I can trust ... people I can share my deep and painful experiences with and they support and motivate me. At times they make me realise that my problem is small compared to theirs ... which makes me realise my circumstances".* P5

> *"I gained my self-confidence by coming here at HeadsUP. I have been coming here to attend the support group and we talk about things. We are called 'survivors', meaning that we can continue to live life just like other people, have jobs and continue living life".* P8

> *"I receive sound advice from there* [the support group]. *We advise each other and find solutions to different challenges. Sometimes I go there and do not say what my problem is, but someone else would suggest how to deal with the very same problem that I have. I leave that session equipped with knowledge and tools on how to cope".* P2

Participants were selected from an NPO that provides psychosocial services to TBI survivors and their families, as mentioned in Chapter Three of this study. Birudu et al. (2020), writing on the rehabilitation needs of ‘unknown’ TBI survivors from a medical and psychiatric social work perspective, indicated the need for psychosocial interventions for TBI survivors to address the diverse psychosocial needs from a social work perspective. This is in line with the findings of this study, as participants attend weekly group sessions at the NPO with other people that they can identify with, and find the sessions highly motivating, informative and supportive. Another study by Hughes, Fleming and Henshall (2020), on peer support groups after acquired brain injury, highlights the importance of support groups, stating that they form an essential part of psychosocial intervention, creating a sense of support to help promote healing and recovery for TBI survivors, post-hospitalisation. Azman et al. (2020) highlight the importance of creating support groups for TBI survivors; however, they are just as important for the families of TBI survivors to participate in support groups. With support groups for both parties, both TBI survivors and their caregivers would receive the psychosocial support they need. These findings concur with national and international social work practices of mezzo-level interventions and group facilitation, as discussed by Hepworth et al. (2013), and Kirst-Ashman and Hull (2009). The findings show that participants gain confidence, support, advice, and a sense of belonging from support groups, and that the group format helps survivors air their emotions and become, in the end, more resilient. From the point of view of the person-centred approach, attending support groups enhances participants’ sense of unconditional positive regard, a state of receiving admiration or respect, as highlighted by Meyer et al. (2008) in their study on the adaptation of personology from an individual to an ecosystem. It became apparent from the narratives and the supporting literature that support groups form part of positive coping resources for TBI survivors, helping them to deal with the complex impairments of TBI.

4.4.4.2 Subtheme 4.2: Religion as a coping resource for TBI survivors

The second subtheme under theme four was religion as a coping resource for TBI survivors. This subtheme emerged from a probing interview question concerning other coping resources that survivors drew from, that helped them to keep going and not give up on life.

Most participants said that their religious beliefs helped them to cope with stress and other challenges that come with surviving TBI. They further highlighted the importance of believing, praying and asking God to be with them wherever they went. Most participants attended church regularly and held the belief that they would receive deliverance and healing from TBI. Many participants expressed a sense of gratitude at being given a ‘second chance’ in life, having survived the TBI incident. They believed that God had a greater purpose for them; this belief motivated them and helped them to cope with their symptoms.

These are the views of three participants regarding coping enhanced by their religious beliefs:

> *“All I can say is that to worship is not necessarily about carrying a bible and gathering with other people, but when you leave your house, pray to God. I ask for this and that from God. I also ask Him to be with me everywhere I go”*. P2
>
> *“The church is very supportive because ... how do I put it? You have people to pray for you so that you can have hope that you will receive deliverance from my current situation. There is also hope that I might be healed or to be completely cured and saved from many things, including gangs”*. P5
>
> *“You find yourself being grateful to God for making it out alive from the accident, knowing that God has a greater purpose for your life, so be grateful. You see, minor things have caused death to other people and I have heard of incidents where a person could die from being slapped in the face”*. P12

Most participants found religion to be a coping tool and a protective factor, which helped them to adapt, accept and make sense of the changes in their lives caused by TBI. An international study on mental health issues caused by the Covid-19 pandemic by Prazeres, Lígia Passos, Simões, Simões, Martins and Teixeira (2021) also found that religion was a coping resource, and instrumental in reducing depression and anxiety. This is supported by Szcze´sniak, Kroplewski and Szałachowski (2020), who studied the mediating effect of coping strategies on religious/spiritual struggles and life satisfaction. These authors state that religion has been shown to have a positive effect, helping to decrease levels of stress and anxiety, and making it easier to bear suffering and pain. Although religion was not highlighted as a coping resource in the literature discussed in Chapter Two of this study, it became apparent in these findings that it was a significant and effective coping tool for participants. From a person-centred point of view, a social worker can assist to reinforce this positive coping resource, thereby creating a safe and nurturing environment that reinforces healing and recovery, as stated by Terry and Kayes (2019), who studied person-centred care in neurorehabilitation. The narratives and the literature highlight the importance of a positive, practical religious faith as a coping resource to improve survivors' mental health, helping them to deal with the effects of TBI. It was interesting that this was a finding in a number of studies in different contexts around the globe.

4.4.4.3 Subtheme 3: Psychosocial services for TBI survivors and their families post-hospitalisation

The third subtheme under theme four was the psychosocial services for TBI survivors and their families post-hospitalisation. This subtheme emanated from the interview question about the psychosocial services that participants received after being discharged from their different hospitals.The participants had diverse views about the psychosocial services that they received post-hospitalisation, apart from attending the support group. Some participants expressed that they had access to psychosocial services at other NPOs in Khayelitsha, including Nkosinathi, an NPO that renders services to youth struggling with substance abuse. They found this help because, they indicated, they were relentlessness in seeking help to combat the impairments of TBI. Some participants mentioned that they received psychosocial services at HeadsUP NPO, which helped address family issues and provided caregiver training for families of TBI survivors. This training helped family members to understand survivors' behaviours and to treat them better. Some participants, however, were not aware of the wide range of psychosocial services at their disposal, to the point where they did not seek individual counselling because they were not aware of such a service. Some of their remarks were:

> *"Yes, I have received that kind of help* [psychosocial services] *… I have also gone to another NPO called Nkosinathi, they render different services ... but they mostly deal with youth with drug problems. No one told me to go there ... I went there on my own, going there helped me to identify with other young people who were experiencing different problems"*. P2
>
> *"I go here at HeadsUP because there were a lot of things happening at home that I didn't like, things that would upset me. Those issues were in the family and I struggled because I am not well-spoken and I didn't know how to express myself. I then came here to HeadsUP, they helped me a lot. They encouraged my aunt to go for caregiver training. That helped to equip her to understand me and my behaviour"*. P8
>
> *"No, I never received such services* [referring to counselling]. *All I do is come here occasionally* [for the support group] *… but never had any individual counselling, I haven't had that one-on-one talk with these people* [referring to social workers and community developmental workers] *here"*. P15

These findings indicate that participants benefit from psychosocial services post-hospitalisation at the NPOs. A social worker acts as a team member, helping to provide psychosocial services to survivors and their families that address the devastating effects of TBI, as stated by Birudu, et al. (2020). According to Anderson et al. (2020), who studied the predictive model of resilience among family caregivers supporting relatives with TBI, psychological interventions contribute to enhancing resilience in family members and caregivers.

These authors stress the importance of conducting home visits to families of TBI survivors, so that social workers know the living conditions and circumstances of survivors. This was supported by the findings of this study, as some participants sought psychosocial services from social workers to help them adapt to and address issues with their families.

In addition, social workers tend to be well informed and well connected, able to make the right referrals for survivors, thereby creating a nurturing environment and catering to the needs of survivors, as was found by Terry and Kayes (2019), whose study was on the person-centred care in neurorehabilitation, in which secondary analysis, disability and rehabilitation was the focus. Psychosocial interventions are beneficial both to survivors and their families, as they help survivors cope with changes and slowly take control of their lives, while families are strengthened with knowledge on what TBI is and how to handle survivors when they get angry; also what they need to eat and their need for regular sleep patterns, etc. Naess et al. (2020), who studied the effect of early interdisciplinary rehabilitation for trauma patients, found that social workers play a very important role in the rehabilitation of TBI survivors and their families, since they provide psychosocial services that help, and also link people to other resources needed for the process of adaptation post-hospitalisation.

It was interesting that some survivors did not access these services, but only attended the support group. They had never asked a social worker to intervene and help repair the dynamics in their families. The findings in this study concur with those in the literature that it is important for survivors of TBI, and their families, to access psychosocial services to help address the many physical and emotional effects of TBI.

4.4.5. Theme 5: The impact of TBI on family dynamics

This theme was in line with the third objective of this study: To explore and describe the challenges that come with TBI and how it affects family dynamics and roles post-hospitalisation. This theme emerged from comments by participants about the impact of their

TBI on their families. It also emerged from the interview question related to how it was for participants when they returned to their homes after hospitalisation.

Most participants mentioned that the injury strongly affected their family dynamics post-hospitalisation. Those who had been married before the TBI had been abandoned or divorced by their respective spouses. Some stated that their families became overprotective of them, since they felt that they had almost lost them in the incident that caused the TBI. The overprotectiveness was coupled with a sense of control, and made some participants feel that they were treated as minors, which had not been the case before the TBI. Most participants expressed that they often felt that they were burdening their families, and that they did not like being completely dependent on their families for so many things. This was a huge change for them and a challenge, even after some years after sustaining the TBI.

These are the views of participants regarding the impact of TBI on their family dynamics:

> *"My wife left me because I became dependent on her; I had no financial contribution towards family responsibilities. She is a teacher so she decided to leave me while we were in the Eastern Cape. I was called by my doctor to come back to Cape Town to apply for a disability grant ... So I came back. When I had left for Eastern Cape I had no idea about applications for a disability grant and things like that"*. P3
>
> *"No, I won't lie, it's just that my family was too overprotective of me after the injury. If we are walking in the road they would put me in the middle and they would be on both sides. I would really get frustrated and tell them it's too much and I can see where I am going. They really keep a close watch on me … and decided that I should return to Kraaifontien. They feel it's not safe for me there"*. P15
>
> *"No … I feel like I am a burden on them* [his family] *because even now … I am stressed because this other hand of mine doesn't work at all ... and … I really feel like I am a burden on these people ... I really wish and would like to be able to do my own thing"* [referring to providing for himself or having a job]. P9

Tyreman (2018) highlights the changes in dynamics that occur after TBI in areas such as intimate relationships like marriage, where a wife or husband becomes the carer of the survivor, leading to low intimacy, among other things. That is in line with the comments of participants in this study whose partners had left them because the changes were too great to cope with.

Participants' comments made it very clear that family dynamics are sensitive and easily affected by TBI in a family member. The person's disability affects everyone in the home, hitting especially hard when family members have no training in how to care for survivors, post-hospitalisation. This was also found by Soeker and Ganie (2019), in a study on the experiences and perceptions of employers and caregivers of individuals with mild to moderate TBI in returning to work.

Rasmussen et al. (2020), in a study on the mental health and family functioning of patients and their family members after TBI, indicate that the behavioural change experienced by survivors often causes stress and disruption in the functioning of the family and that family members are often on the receiving end of survivors' frustrations and anger, receiving insufficient help from professionals. Carlozzi et al. (2020), who studied family disruption in caregivers of persons with TBI, there is a great deal of stress on caregivers, particularly those who take care of dependent survivors with permanent morbidities. From the point of view of the person-centred approach, the participants would benefit from social work interventions to work with families of survivors to re-establish healthy family dynamics, which is part of meso-level social work intervention, as highlighted by Hepworth, et al. (2013), in their study, adaptation of direct social work practice.

Participant narratives and the literature concur that families experience disruptions and stresses post hospitalisation of TBI survivors, in every context and country.

4.4.5.1 Subtheme 5.1: The impact of TBI on family roles

The first subtheme under them five was the impact of TBI on family roles. This theme emanated from the interview question about how it was for the participants when they returned home after hospitalisation for the TBI, from being breadwinners and contributors to being dependents.

Most participants mentioned that they were completely dependent on their families after the TBI, which created a huge shift in the roles that were played in their families. Some spoke of playing important roles in the family before their incident, having been big brothers, breadwinners or husbands, and told how these roles had been upended after the TBI. They felt the loss of their roles keenly, and spoke of no longer being respected, having no position in the family. This loss seemed especially felt by the males in the group.

Some of their views regarding the impact of TBI on family roles were:

> *"I used to stay alone before the injury and I knew that had to send money home every month to assist with the school expenses for my child. Due to that, I used to send money very often ... I had a job at the time and I made sure to send money to my family ... but after the injury, I was not able to do that anymore"* [became completely dependent on his family]. P15
>
> *"All I can say about this thing is that at home I have a brother who comes after me ... the age difference is small between us. We are brothers. We are five siblings in total. My siblings have all grown up and I helped to raise them when my mother used to go to work. So everything changed* [after TBI] *and now I have noticed that my younger brother has been given the status and the responsibilities of being the older brother"*. P11
>
> *"There were changes in my life post-injury. At the time my dad was still alive. He would help support me and buy me the basic things ... important things that I needed at the time"*. P4

Most participants had similar things to say about how roles had changed in their families, post-TBI. The issue was raised to some extent in the literature discussed in Chapter 2 Two. It became apparent that most participants were taken care of by their family members after hospitalisation. It was also apparent that for the male survivors, roles seemed to have changed the most, and they were consequently the most affected. They spoke of loss of a sense of identity, status and position in their families. The dependency which is a normal result of moderate to severe TBI places financial and other burdens on family members and caregivers, who have to cover the costs of visits to clinics and for various medical needs of survivors, as well as cope with the loss of a responsible or working member of the family. This was also found by Oberholzer and Müri (2019) who studied neurorehabilitation in TBI.

Apart from playing the all-inclusive role of being caregivers, family members often experience a lot of stress as they struggle to process and accept the drastic changes, especially in cases where survivors are permanently disabled. This was found by Awua et al. (2019), in their study on psychosocial, cognitive, and behaviour after-effects of TBI. Othman et al. (2021, p.1) in a study on the needs of TBI survivors' caregivers, especially during the Covid-19 pandemic, state, “The results of brain injury often cause the roles and responsibilities within a family to change, because individuals with TBI often rely on caregivers for long-term and life-long assistance”. This concurs with comments by participants in this study. There are often disruptions in family roles post-TBI, leading to emotional suffering for families of survivors, as was found by Carlozzi et al. (2020), in a study on family disruption in caregivers of persons with TBI. Participants’ narratives are therefore supported by the literature and indicate that it is common to experience family disruptions that radically alter roles in the family as a result of TBI.

4.4.5.2 Subtheme 5.2: Family conflicts

The second subtheme under theme 5 was views of participants on family conflicts that erupt post-hospitalisation. This theme emerged from the research question about how it was for participants when they returned home from the hospital.

Some participants mentioned that there were conflicts in their families and that TBI was the catalyst of those conflicts. They further stated that there were disagreements among family members regarding the money received from the Road Accident Fund (RAF), which applied to survivors who were victims of road accidents. Most participants highlighted that they had anger problems as a result of TBI, and that their anger caused arguments and conflicts in their families, where they felt they could not control themselves. Some participants mentioned that the conflicts would sometimes escalate into physical fights with their family members. They spoke as follows:

> *"There were issues and conflicts between mother and aunt. Aunt used to complain about not receiving a share from the Road Accident Fund money. The two of them would constantly have arguments regarding the money issue. At some point, the social workers from KTC were involved and made a few suggestions but my mother would often say that she hasn't received any money. Not even a cent"*. P1
>
> *"Conflicts and arguments are kind of my thing now. I always get into arguments and fights at home, I have anger problems. Children at home would try to reason with me and say, 'Brother, what is it?' and I would tell them off. This happens randomly. Out of nowhere, I get angry. This started after the injury. Before the injury, I was always calm and enjoyed playing with the children at home … now I have this tendency to just switch and they can't recognise who I am"*. P10
>
> *"You see when I come back from a certain place …they* [his family] *ask me why I left or why I exited through the window. We get into those arguments and then they beat me up. My only mistake is that I fight back and do not let them overpower me … and I end up sustaining more injuries that way … you see. That's how I continue to get injured"*. P6

Participants expressed diverse views on conflicts that occurred at home post-hospitalisation. The findings correspond with the literature on the behavioural changes of survivors, including the aggression and agitation that they often experience, with their anger causing disruption and conflicts in their families (Naidoo et al., 2020). Naidoo et al. (2020) in their study on beta-blocker therapy in severe TBI found that many factors lead to conflict in families, including finances, behavioural issues of survivors and, in some cases, the dependency of survivors on their families.

Kumar et al. (2019), writing on the psychosocial impact of brain injury, found aggression and irritability to be very common post-TBI, along with impulsivity, and intimidating and threatening behaviour. Deb et al. (2018), writing on aggression following TBI, add that the aggression shown by TBI survivors often leads to breakdown and suffering, and that skilled family interventions can help improve such families.

From the point of view of the theoretical framework, family therapy conducted by a person skilled in the person-centred approach would be beneficial for these cases, and assist the family to understand their own trigger points and deal with anger and related emotions more appropriately. A knowledgeable social worker would also link these families to resources that might bring about positive change in family dynamics. Rasmussen, Andelic, Pripp, Nordenmark and Soberg (2021), in a study on the effectiveness of family-centred intervention after TBI, state that disruptions and dysfunctions are expected in families of survivors, owing to their inability to cope with the effects of TBI. They further mention the importance of survivors and their families having access to support services, to address the many challenges caused by TBI. Participants' narratives and the literature on TBI therefore concur that conflict is common in families of TBI survivors, the only differences being in the immediate context.

4.4.6. Theme 6: Recommendations to improve services for TBI survivors and their families

Theme six aligns with the fourth objective of this study, which was to make recommendations and suggestions for improving services for TBI survivors and their families. This theme emanated from the interview question about recommendations to improve services to survivors and their families. Under this theme there are two subthemes: recommendations for TBI survivors and recommendations for families of TBI survivors.

The participants had access to psychosocial serviced at the NPO that renders services for TBI survivors and their families. They recommended that TBI survivors who return home after hospitalisation access the psychosocial services offered at HeadsUP. They further highlighted the importance of receiving counselling and home visits, among other social work services, to combat the challenges related to TBI. Most participants recommended services that would help create job opportunities for them. Those job opportunities would help them with their boredom, keep them busy and bring some meaning to their lives.

These are some of their views regarding their recommendations for social work interventions for survivors and families:

> "*All I can say is that I recommend for survivors to come here* [HeadsUp] *after hospitalisation. I remember the support I got from the social workers at HeadsUP, one time I had a personal problem I went to them and received counselling and they really helped me. When my father passed away, the social workers did a home visit and I will never forget that*". P7

> *"One of the things I would like to have more is job opportunities … the social workers here contacted me saying that since I have basic education, I can apply for a learnership, you see. It is important to keep yourself busy. It helps your mind to be at ease. So I would recommend creating more job opportunities for people like us".*

It became apparent from participants' comments that although the TBI survivors appreciated the help provided by this NGO, there was need for far more in-depth services for survivors and their families. Rasmussen et al. (2020) state that families play a huge role in the rehabilitation of TBI survivors, and can therefore benefit from training and workshops on how to care for survivors. Lastly, participants highlighted the importance of having someone to support them during the early stages of recovery. The literature concurs with this (Brancu, Sperber, Van Houtven, Kosinski, Mehta, Nagi and Williams, 2018; Clark-Wilson & Holloway, 2020; Krenz, et al., 2021; Shepherd-Banigan et al., 2018). It became clear from both the participants and the findings of other authors that families of survivors need support and basic training to minimise the stress levels and to foster healthy family dynamics. From the person-centred point of view, survivors and their families would benefit from home visits to assess the needs of survivors and their living conditions, and link survivors and their families to services and resources suitable for their needs. This suggests that social workers are indeed ‘brokers’.Based on participants’ narratives and the supporting literature, it would seem that psychosocial intervention is pivotal for TBI survivors and their families, post-hospitalisation.

4.4.6.1 Subtheme 6.1 Recommendations for TBI survivors

The first subtheme under theme six was in line with the fourth objective of this study: To explore and describe coping resources and protective factors needed for the process of family reintegration post-hospitalisation. This theme is based on recommendations made by the participants for TBI survivors, and emerged from responses to the interview question on what participants could suggest for other TBI survivors who are discharged from the hospital.

Most participants highlighted the need for other survivors to seek medical help as soon as possible after they sustain a TBI, and to receive the right diagnosis early to avoid further complications later in life. Most participants highlighted the importance of having someone, a caregiver or a family member, who is well aware of the nature of the injury and knows about the resources needed to combat the impairments of TBI. This person needs to be someone close and supportive, as they should, ideally, accompany survivors to their check-ups or appointments at the local clinics. Most participants talked about how important it is for survivors to be resilient and not to give up on life because of the challenges related to TBI, and to refrain from using recreational drugs and alcohol, as these delay the healing process of the brain.

These are some of their recommendations for fellow TBI survivors:

> *"Hey, sister* [referring to the researcher*], the first advice I would give to someone who has had a TBI … is that they must seek medical help and get treated as soon as possible. The problem that we* [TBI survivors] *have is that, when someone is hit in the head with an object, they do not seek medical help immediately. I recommend seeking medical help so that any possible complications can be diagnosed and treated early to avoid further complications on the survivor's life"*. P11
>
> *"To a TBI survivor, I would say find someone close to you, someone who is aware of the resources needed to address TBI impairments. That person can then accompany you to your appointments because it is not easy for survivors to know where to go for help, especially in the early stages after hospitalisation"*. P17
>
> *"Firstly I would tell the person about my experience with TBI, also tell them that I am just like them* [TBI survivor] *and to not look down upon themselves. I would tell them to be strong, not to lose hope, 'this too shall pass'. I would tell them about the things that I had to stop, including drinking alcohol and using drugs. If that person is not ready to give up alcohol, then I would tell him about the implications of consuming alcohol after the injury"*. P2

The statements made by participants highlight the importance of seeking help immediately after sustaining a TBI; however, this is subject to one's knowledge and access to health resources, as highlighted in subtheme 3.2 in this chapter. According to Taylor and Seebeck (2020), in their case report on pre-injury psychological factors in mild TBI rehabilitation, many TBI survivors do not seek medical attention, which causes medical complications, rendering survivors vulnerable to more long-term impairments. Ezer, Write and Fins (2020), in their study on the neglect of persons with severe brain injury in the United States, indicate that in previous years there was a high death rate amongst TBI patients, and that more recently there have been developments in the medical field that have increased the survival rate of people who suffer from TBI. This means that there are many more people suffering from the impairments of TBI than before. This in turn supports the contention by participants in this study that people who have sustained a TBI need to seek medical attention as quickly as possible, as new medical knowledge keeps evolving and more can be done to help people who have suffered such injuries. More is also known about the long-term effects of untreated TBI.

Shepherd-Banigan et al. (2018) stress that caregivers need to be supported, trained and informed on the services needed for survivors. Sodders et al. (2020), on race/ethnicity and informal caregivers' burden after TBI, indicate the need for families of unpaid caregivers to access educational support, to be equipped for caring for TBI survivors. This supports the view of the participants in this study who stressed the important of having a knowledgeable caregiver post-hospitalisation. The cognitive challenges indicated under theme 1.1 – memory loss, forgetfulness, problems with information processing and decision making – can make participants forget their appointments; hence it is important to have caregivers to help survivors in this regard. Krenz et al. (2021), who studied health-related quality of life after paediatric TBI, support the idea of having caregivers or parents of survivors who are trained in how to care for survivors, and stress that the caregivers themselves need to receive support to enhance their coping. A social worker can be an enabler, helping the client by providing support and encouragement, and helping them to solve their problems (Kisrt-Ashman & Hull, 2008, p. 82). The idea of an 'enabler' or facilitator is pertinent, as this is really what TBI survivors need; someone who does not do things for them, but enables or empowers them to better help themselves, in keeping with the person-centred approach. Such a person (which can be family member, if willing and well trained, but would usually be a social worker) would be of tremendous benefit to TBI survivors, helping them to make good life choices that will benefit their health in the long run. The participants' own comments suggest the need for someone fulfilling that role in their lives.

4.4.6.2 Subtheme 6.2: Recommendations for families of TBI survivors

The second subtheme under theme six was participants' recommendations for families of TBI survivors. This subtheme emanated from the interview question about participants' recommendations for families of TBI survivors.

Most participants in this study lived with their families and had been taken care of by a family member since the early stages of their healing from TBI. The participants highlighted the importance of having family members who are trained in TBI and who know how to care for survivors. This knowledge and training would assist both the caregiver and the TBI survivor. Participants spoke of the need to be accepted and understood; they clearly needed family members who were patient with them and would remind them to take their medication, for instance. Family members and TBI survivors also needed to have a shared understanding of the disabilities and medical conditions of the survivor, including epilepsy and what to do in the event of epileptic seizure.

These are some of their recommendations for families of TBI survivors:

> *"To a person who has had a TBI, I would recommend that they accept themselves and learn to ask some of the family members or one person in the family to remind them about when to come for group sessions, medications and other things related to treatment after hospitalisation, most importantly the person,* [family member] *must be trained how to take care of the survivor".* P16
>
> *"So when someone has a disability, the family of that person need to know the nature of that disability and accept it. I accept other people's disabilities and learn how to help them. For example, I have learned how to help someone who is suffering from epilepsy when they have seizures. The families need to know about our* [TBI survivors] *disabilities so that when you have those headaches and pains … then they already know it is the headache caused by the injury* [TBI]". P4

The comments highlight the need for caregivers or family members of survivors to be well prepared for the many effects TBI and be active in supporting them both physically and in terms of cognitive skills. The best way to train caregivers is for them to be slotted into caregiver support groups, which would need to be organised by social workers. According to Huet et al. (2018), who studied representations of caregivers of brain-injured people, it is essential for family members/caregivers to have enough information on mental healthcare of survivors.

Lack thereof can lead to misunderstandings about survivors' wishes and needs. New caregivers often struggle to help the TBI survivors in ways that the survivor wishes to be helped. They also struggle with understanding the survivor's verbal communication at times. Dhavaleshwar (2016) highlights the role of the social worker as a facilitator. A skilled and caring social worker could benefit caregivers in many ways, serving as facilitator of debriefing and enabling caregivers to share their experiences of caring for TBI survivors. From a person-centred perspective, providing support to caregivers would indirectly create a nurturing and conducive environment for TBI survivors, as suggested by Terry and Kayes (2019).

'Inadequate health literacy also may contribute to caregivers feeling overwhelmed by the demands of assisting the person with TBI with health management tasks' (Hah, Boileau, Hanks, Sander, Miner & Carlozzi, 2020, p. 402). This observation further supports the recommendation that families be trained on how to care for TBI survivors. With proper training, and ideally a support group to assist over the long term, family members would be informed and prepared, and might be able to offer a better quality of care to their TBI survivor at home. This kind of support would also greatly relieve the stress felt by caregivers, which inevitably places a burden on their own physical and mental health and can add to conflicts in the home. Social work has always been person-centred and has been instrumental in combating a variety of social ills affecting people (Safodien, 2021, p.257). These observations are supported by the recommendations made by participants that caregivers are trained and equipped to assist. The narratives and the literature under this subtheme therefore indicate that families of TBI survivors need both adequate training and emotional support to provide a better quality of care for TBI survivors.

4.7 Chapter summary

This chapter has presented an overview of the participants and their many challenges and needs as TBI survivors. The demographic profile of participants was presented in Table 4.1, with discussion on the six themes and subthemes forming the bulk of this chapter. Each theme and subtheme were discussed in light of comments made by participants and in light of the literature; where new ideas emerged that had not been revealed in the literature discussed in Chapter Two, new literature was consulted to verify findings.

The findings indicate that TBI survivors experience a range of challenges, at all levels, in every area of life, many of which are not immediately apparent and may go unaddressed for years, particularly in resource-constrained environments. Participants' comments further highlight the many difficulties experienced with reintegration and psychosocial adaptation post-hospitalisation. TBI survivors are vulnerable, yet all develop coping strategies and resilience in one way or another. The impact of TBI on family dynamics, roles and conflicts was described in light of the theoretical framework selected for the study. The sixth theme highlights that survivors have ideas on how to improve services for their care; TBI survivors made suggestions for both family members and, indirectly, for the healthcare and welfare system, particularly revealing the need for caregivers to be well supported with knowledge and emotional support so that that they can better care for TBI survivors and not become emotionally drained by the experience. All the findings presented in this chapter were interpreted using the person-centred approach, and were substantiated by findings from the literature on TBI.

CHAPTER FIVE

CONCLUSIONS AND RECOMMENDATIONS

5.1.Introduction

The study aimed to explore and describe the challenges experienced by TBI survivors with regard to family reintegration post-hospitalisation. This chapter presents the conclusions of this study, drawing conclusions about each chapter in turn. The chapter also summarises the six main themes that were discussed in Chapter Four. In addition, recommendations for policy, practice, education and future research are given. The chapter ends with a final conclusion.

5.2.Summary and conclusion of the literature review

Chapter two of this study presented a comprehensive review of the literature on TBI, highlighting the definitions and mechanisms of a TBI. The effects of TBI on the health and welfare systems in a few countries, including South Africa were articulated. Chapter Two also defined and explained the mechanisms of TBI, the different types of injuries and the long-lasting effects of TBI on survivors. The common causes of TBI included falls, road accidents and violence. The chapter also discussed the effects of TBI on families, caregivers and relationships. The various impairments that result from TBI were discussed, along with the prevalence of TBI across the globe and regionally. A holistic and multidisciplinary approach to rehabilitation for TBI survivors was presented as the ideal approach to combat the many impairments of TBI post hospitalisation. The literature in Chapter Two was used to validate the finding in Chapter Four of this study. The extensive literature reviewed in Chapter Two showed areas of commonality on the challenges experienced by TBI survivors across the globe

5.3.Summary and conclusion of the theoretical framework

The person-centred approach was the theoretical framework used in this study, because it is the approach most likely to assist TBI survivors and has wide applicability to healthcare workers, social workers and family members. TBI requires a multi-disciplinary team to combat the long-lasting effects of TBI, as discussed in Chapters One and Two of this study. The person-centred approach focuses on the person seeking help, rather than the person involved in providing help; it stresses that each person ultimately knows his or her own story, history, needs, strengths and weaknesses better than anyone else. The approach put the person and their needs at the centre of practice. The researcher could have used the biopsychosocial approach that is mostly used in health or medical-related studies such as the current study. The strengths-based approach could also have been used, which mostly focuses on creating community support for TBI survivors. The researcher could also have adopted the "Batho Pele" principles or systems theory, both of which are often used in social work studies. All of these approaches were relevant, yet the researcher opted for the person-centred approach (PCA) because it puts the person – in the case the TBI survivor – at the centre of the recovery process, and views TBI-related services and interventions in light of the felt needs of TBI survivors. The approach was reflected in the central roles placed by survivors' verbatim comments in Chapter Four, which discussed the findings.

Social work is, in its very nature, a person-centred practice. The approach suits all interventions engaged in by social workers, including referrals for TBI survivors to all the relevant services needed to address TBI-related issues. From the person-centred approach, the TBI survivor is at the centre and the social worker acts as a facilitator, enabler or 'broker', linking that survivor to other professionals or services to combat the impairments of TBI. The social worker also links the families of TBI survivors to services such as family counselling to deal with the emotional stress that accompanies caring for TBI survivors. The person-centred approach was therefore the best option for this study, and served its purpose of guiding the researcher to see all findings from a person-centred perspective.

5.4.Summary and conclusion of research: Problem, question, aim and objectives

The **research problem** that ignited the topic of this study is the fact that TBI is a silent pandemic that causes death and disability across the globe. In developing countries such as South Africa, there are many causes of TBI, including road accidents, falls, assaults and interpersonal violence. The high prevalence of TBI puts a strain on the health and welfare systems of many countries, including South Africa, owing to the many deficits experienced by TBI survivors. Most TBI survivors are hospitalised and receive the immediate medical care they need, but when they return home, other problems begin to manifest, many of them psychosocial or cognitive in nature. Survivors struggle to adjust in their families and communities, as do their untrained family members who quickly have to adjust to being caregivers. The study was conducted in a low-socioeconomic community that is affected by poverty and violence, among other social ills. The researcher wanted to explore and describe how TBI survivors from such a community experience their challenges and how these affect their low-income families. In addition, the researcher wanted to explore how survivors cope with the challenges of TBI and the resources that they have access to for addressing the many TBI-related deficits post-hospitalisation.

The research question was: What are the challenges experienced by TBI survivors with regard to family reintegration post-hospitalisation? This question was answered through the six themes that were presented and discussed in Chapter Four of this study.

The **research aim** was to understand the challenges experienced by TBI survivors regarding family reintegration post-hospitalisation, from a social work perspective. The aim of this study was achieved; the themes in Chapter Four discussed the challenges in details, in light of participants' input and the literature.

The research objectives

Objective 1: To explore and describe TBI survivors' challenges and experiences regarding the reintegration process into their families, post-hospitalisation.

This objective was achieved in themes one and two in Chapter Four, where the bio-psychosocial challenges experienced by TBI survivors were stated and discussed. Theme one had five subthemes: cognitive, physical, psychological/emotional, educational and employment-related challenges. Theme two was the biopsychosocial adjustments of TBI survivors post hospitalisation. The three subthemes here were lack of family conferencing before reintegration, the reintegration of TBI survivors, and the rehabilitation of TBI survivors.

Objective 2: To explore and describe the vulnerabilities and the resilience of survivors in the process of adapting to the home environment, post-hospitalisation.

This objective was achieved in theme three of Chapter Four, which discussed the vulnerabilities and resilience of survivors at length. Theme three articulated the vulnerabilities experienced by TBI survivors, including the high rate of violence they experienced in their community. Theme three had three subthemes: Physical infrastructure not conducive for TBI survivors, post-hospitalisation, the impact of TBI on survivors' health, and access to the disability grant for TBI survivors. Theme three provided an accurate description of the vulnerabilities of TBI survivors, thereby achieving the second objective.

Objective 3: To explore and describe the challenges that come with TBI and how it affects family dynamics and roles, post-hospitalisation**.** This objective was achieved in theme five of

Chapter Four of this study, which articulated the impact of TBI on family dynamics. Under theme five there were two subthemes: The impact of TBI on family roles, and family conflicts.

Objective 4: To explore and describe the coping resources and protective factors needed for the process of family reintegration post-TBI. This objective was achieved and highlighted in themes four and six of Chapter Four. Theme four discussed resilience and coping resources for TBI survivors post hospitalisation. This theme had three subthemes: support as a coping resource, religion as coping resource, and psychosocial services for TBI survivors and their families. These were some protective factors that kept survivors going in their journey post-TBI. Under theme six, TBI survivors gave recommendations that would help survivors cope with TBI deficits. The two subthemes were: Recommendations to improve services to TBI survivors and recommendations to improve services to families of TBI survivors. The participants mentioned that TBI survivors need to seek medical attention and get an early diagnosis to avoid further complications. They also mentioned the importance of having caregivers or family members who are trained to care for them.

All the objectives of the study were therefore attained.

5.5.Summary and conclusion of research methodology

The research methodology was presented in Chapter Three, which discussed the research methods, data collection methods, research setting and ethical considerations of this study.

A **qualitative research approach** was used in the study because the researcher wanted to capture rich and detailed data in the form of language; it was the best option for this study as it served the aim of exploring and understanding the experiences of TBI survivors with regard to reintegration post-hospitalisation. The qualitative research approach was chosen for the sole purpose of getting a deep understanding of the issues related to TBI, and was more appropriate for the goals of the study than the quantitative approach that quantifies a phenomenon.

Since this was a qualitative study, the researcher employed an **explorative–descriptive design** to uncover new information that is not readily available. Through this research design, the researcher was able to describe and shed light on the challenges experienced by TBI survivors. **The research setting** was an NPO that offers free services to persons affected by TBI of all ages. The NPO also renders services to families and caregivers of TBI survivors to assist them to cope and care for their loved ones at home after hospitalisation. The participants attend weekly support groups at the NPO, so conducting the interviews there was a good option as the setting was conducive and familiar to participants.

Population and sampling

Participants were chosen for this study through purposive sampling. Random sampling would not have suited, as participants had to have certain characteristics that served the purpose of this study. Through purposive sampling, the researcher was able to select TBI survivors from the ages of 18 to 65, who were able to talk and comprehend language, and yield rich data through interviews. TBI survivors with severe, moderate and primary injury were all included in this study to ensure variety and inclusivity.

Data collection

Semi-structured individual interviews were used as a method of collecting data. This instrument was very effective as it allowed participants to share their challenges in a safe space and yielded rich data. Through semi-structured individual interviews, the researcher was able to capture the lived experiences and challenges of TBI survivors, post-hospitalisation. Semi-structured interviews allowed probing of responses and produced rich data. Structured interviews would not have suited, as they would not have allowed for probing and may have constrained responses. The researcher used this type of data collection because the space was conducive for individual interviews and not for focus groups. Semi-structured interviews were the best option for this study and happened to be best suited in terms of Covid-19 regulations, which prohibited the gathering of many people in a small space. Data collection was done in October and November 2020.

Data analysis: The researcher used the eight steps for data analysis and opted to use thematic analysis to make sense of the data. Following these steps assisted in conducting a systematic and rigorous research process. As mentioned in the methodology chapter, these steps were not followed in a neat, chronological order; the researcher went back and forth to various steps as she navigated the data analysis process. Thematic analysis was the most suitable option and yielded the themes and subthemes which could be supported by rich and thick descriptions from the participants' narratives.

Data verification: The researcher engaged in data verification and a trustworthiness check to ensure that the findings of the study are convincing and worthy of paying attention to. Credibility, validity, transferability, confirmability and reflexivity all formed part of this check. **Credibility** was ensured by keeping the recordings and the transcripts from the individual interviews, and ensuring that the findings were true representations of the participants' experiences. **Dependability** was ensured by evaluating the findings to ensure that they were accurate. The researcher read the findings back to participants and they were satisfied that the findings were indeed true representations of their experiences. **Transferability** was ensured by providing accurate descriptions of the research methodology used in this study, so that future researchers might ascertain whether a similar study in a similar context might achieve the same results. **Confirmability** was ensured by making use of the participants' true narratives and quotes from the transcripts. The transcripts were written in isiXhosa, then translated to English with the guidance of peers who are academic scholars, to ensure credibility and objectivity.

Reflexivity: Reflexivity on the part of the researcher was highlighted by several researchers in the literature. The researcher used personal reflexivity as a method of ensuring the trustworthiness of the study, being aware of her own biases and weaknesses, and acknowledging the possible role that these might play in the study. Detailed information was given on the researcher’s career background which might have contributed some bias. The researcher had a background understanding and training on social worker interventions for TBI survivors, having worked as an employee of the NPO from 2013 to 2015. This experience gave her some ideas on how to formulate questions that would yield good answers. The problem statement for this study stemmed from the researcher's past experience in working with TBI survivors. During the process of data collection, the researcher felt overwhelmed and affected by the traumatic experiences of TBI survivors, which challenged her ambition to complete twenty-one interviews in one week. On the first day of data collection, the researcher interviewed five participants back to back with no breaks in between. This had a strong emotional effect, and the supervisor was sought to help with de-briefing and guidance on the data collection process. Thereafter, the number of interviews conducted per day was reduced from five to three. That helped, but the researcher was not able to complete the data collection in one week. The rest of the interviews were conducted two weeks after the targeted completion date. The researcher experienced a couple of delays during data analysis, owing to unseen personal problems. The researcher was, however, able to complete the process in four months.

5.6.Summary and conclusion relating to the ethical considerations

The researcher adhered to all ethical considerations required in research, and ensured that participants were not harmed in any way. Participants were not coerced to participate in this study, and they were well informed about what the study would entail. Each gave signed informed consent to participate. The anonymity of the participants was maintained, with participants referred to as Participant 1 or Participant 2, in the order of their interviews. Transparency was maintained through reading the transcripts to them and informing them about the preliminary findings. As a social worker the researcher prides herself to be ethically responsible and have conducted this study in a manner that protects her own professionalism and upheld the dignity of the social work profession to the best of her ability.

5.7.Summary and conclusions of research findings

Chapter Four presented the qualitative study of the challenges experienced by TBI survivors regarding family reintegration post-hospitalisation. Six themes emerged and were discussed in detail, with verbatim quotes from participants given and reference made to relevant findings in the literature.

Survivors and their families experience many challenges post-hospitalisation which require a person-centred approach and a multidisciplinary team for appropriate intervention. It was also highlighted that survivors and their families would greatly benefit from improved social work interventions to address the psychosocial effects of TBI on families and TBI survivors.

5.7.1. Summary and conclusion relating to Theme 1

Biopsychosocial challenges for TBI survivors after hospitalisation include speech, sleep and pain. The subthemes of cognitive, physical, psychological, educational and employment challenges highlighted their many areas of difficulty. Physical challenges were one of the most common results of TBI, leading to functional problems in the home. Many experienced emotional and psychological challenges post-hospitalisation, which remained unaddressed as most survivors do not seek individual counselling or therapy. Most had dropped out of the educational system owing to their cognitive deficits, and most were unemployed for the same reason. These challenges remain and make life difficult for TBI survivors, directly affecting their caregivers and their families and making it hard for survivors to function independently daily. TBI therefore indirectly results in unemployment, mental health issues and school dropout. There is a gap in services that might help combat these deficits and improve quality of life for survivors. Lack of information about accessible and affordable services was prevalent.

5.7.2. Summary and conclusion relating to Theme 2

Survivors experience many biopsychosocial hurdles in trying to adjust to their new reality. Communities are uneducated and unprepared, and many survivors were subjected to ridicule and mockery for their disabilities, which naturally exacerbated feelings of low self-esteem. TBI survivors and their families did not receive any family reintegration training; survivors were discharged from hospital and sent home to families that knew little about their condition and how to assist them. This was found to be common across the globe and TBI was found to be a significant burden on global health and welfare systems. There are not enough rehabilitation services to address the impairments caused by TBI, which forces untrained families to care for these survivors on their own. The literature in Chapter Two highlights the ideal person-centred rehabilitation process, which would involve a multidisciplinary team that is equipped to address a range of deficit and impairments and support both survivor and family. This remains the ideal and is not evident in the Western Cape, which also suffers a dearth of rehabilitation centres. Lack of these services has led to conferencing as a means to prepare family members and TBI survivors, but this is a once-off session held in hospitals and is inadequate to address the many impairments and problems that become apparent after some months of living with TBI.

5.7.3. Summary and conclusion relating to Theme 3

TBI survivors are vulnerable to all the social ills that plague low-income communities, including overcrowding, hazardous traffic conditions, flimsy and inadequate housing, alcohol abuse and violence. Violence is one of the causes of TBI as highlighted in Chapter Four, and many survivors suffer the risk of sustaining another further TBI from living in an unsafe environment. Infrastructure is inadequate and creates great difficulties for survivors who cannot manoeuvre easily between informal shelters, wash with any ease or, in many cases, stray far from their homes, owing to unsafe conditions on the roads (and, of course, the ever-present threat of violent attack). TBI survivors also suffer health issues that often require further medical attention for conditions such as stroke, epilepsy and severe headaches. These vulnerabilities impair survivors’ quality of life. Access to the disability grant was also a challenge for survivors; some had been refused access to the grant despite their obvious disabilities. Others had to renew the grant regularly, causing great discomfort, inconvenience and expense. Difficulties with attaining or keeping grants forced families to suffer financially, and to depend on the old age grants of elderly people in the family.

5.7.4. Summary and conclusion relating to Theme 4

Survivors have developed coping strategies to deal with the emotional, financial and other consequences of TBI post-hospitalisation. Survivors in this study attend weekly support groups that help them to cope, affording them the chance to swap stories and coping strategies with one another. Survivors reported feeling encouraged and supported by these sessions, one commenting that he had learned to see himself as a survivor and not a victim through his support group. Many find comfort in strong religious beliefs which give them a sense of being loved and valued, with many holding onto the hope that their conditions would eventually be cured by God. The hope they held in the regard may have been a strong motivator to keep going in the face of all odds. Religious faith also gave them a sense of appreciation for their lives, and a sense of being given a ‘second chance’. These TBI survivors had access to some psychosocial services through social workers in other organisations and their own NPO. Very few had access to social services such as home visits that serve the important function of strengthening family relationships and dynamics, and teaching the families about what to expect from a TBI survivor.

5.7.5. Summary and conclusion relating to Theme 5

The participants spoke about changes in family dynamics post-hospitalisation, recognising dysfunctions in their families that emerged as result of the strain their condition imposed on others. Some survivors had aggression and anger issues which affected family members. There were distinct changes in family roles, with former breadwinners now being completely dependent on their families. Many spoke of a sense of being invisible or disrespected in their families. Most of those who had been married were now single, indicating the stress associated with living with a TBI survivor. Tensions often led to conflicts over money and other issues. The changed family dynamics experienced by participants in this study were noted on the literature as common in relation to TBI, no matter what the setting or context.

5.7.6. Summary and conclusion relating to Theme 6

The participants made recommendations for improvements in services for TBI survivors and their families, post-hospitalisation. They expressed appreciation for the social work services that they had received but mentioned the need for more home visits, more in-depth counselling and more access to a variety of resources. That would help them and their families address the impairments of TBI. They highly recommended that fellow TBI survivors seek medical help immediately and post-discharge, in light of the many TBI complications that develop post-hospitalisation. They emphasised the need for family members to receive training and support, to lessen their burden and help reduce tensions at home. The recommendations made by the TBI survivors are supported by previous research on TBI and the effects on family members, which calls for an improvement in social work practice to new TBI survivors and their families.

5.8.Recommendations

The findings of this study give rise to recommendations required for policy, practice, social work education and future research. These recommendations are presented below.

5.8.1. Recommendations for policy

- While there are comprehensive policies that guide service delivery and eligibility for disability grants, policymakers could review existing policies relating to the medical assessment and means tests to determine disability and eligibility for social grants.
- Policymakers in the medical field should develop guidelines for the reintegration of TBI survivors, which should be facilitated by a multidisciplinary team while the TBI survivor is in the hospital. This should include a policy on assistance to family members in the form of education on the nature of TBI, training and how best to care for TBI survivors, and tips for helping to reintegrate survivors into the community post-hospitalisation.

5.8.2. Recommendations for practice

- Social workers should be trained on TBI and related complications and how it affects survivors and their families. This could be facilitated through continuous professional development workshops and seminars. Such training would enhance social workers' knowledge and skills, enabling them to provide more effective services to TBI survivors and their families.
- Survivors and families need to be educated about the resources and services from which they can benefit. Such awareness raising needs to be done by social workers and interested groups in the field of disability. Social media could be used as a platform to create such awareness. Medical practitioners could also facilitate education and

information sessions regarding integration to patients and their families during hospitalisation.

- Social workers working with TBI survivors in NPOs could partner with protective workshops programme coordinators who cater for persons with disabilities, to facilitate programmes that are aimed at developing clients' work skills.
- Social workers should advocate on behalf of TBI survivors who are victims of road accidents so that they may access the Road Accident Fund (RAF).
- Social workers should provide TBI survivors with information on how to manage funds paid out to them, to avoid financial exploitation by family members of TBI survivors.
- Social workers should advocate on behalf of TBI survivors by working in partnership with trauma counsellors from the South African Police Service (SAPS) to encourage survivors who are victims of violence and assaults to report the perpetrators and seek justice.

5.8.3. Recommendations for education

- The Bachelor of Social Work (BSW) training should prioritise curricula that focus on social work services to persons with disabilities.
- The BSW should prioritise training on policy and legislation relating to persons with disabilities, with a specific emphasis on inclusion and social cohesion.
- The curriculum should encourage students to look critically at existing policies relating to persons with disabilities to create debate around this topic and begin raising awareness of the need for reform in this area.

5.8.4. Recommendations for future research

It is recommended that future studies focus on:

- The medical complications caused by TBI, including stroke and epilepsy and how these affect quality of life of TBI survivors.
- The availability and accessibility of rehabilitation services for TBI survivors from low socio-economic backgrounds, through the biopsychosocial approach.
- The effectiveness of current social work and other services to family members and caregivers of TBI survivors.
- Community reintegration services for TBI and stroke survivors from low-socio-economic backgrounds in the Cape Metropole.
- Statistics relating to the knowledge, skills and experience of social workers; a quantitative study that would report statistics on trauma intervention strategies used for mental health issues experienced by TBI survivors in the Western Cape and South Africa.
- The employability of persons with disability, stroke and epilepsy; both a quantitative study and qualitative study that uses a biopsychosocial theoretical framework.
- Comorbidities caused by TBI and how to combat them, with a focus on the services available for TBI survivors and their families who are from low-socioeconomic backgrounds.

5.9.Chapter summary

This study aimed to explore and describe the challenges experienced by TBI survivors regarding family reintegration post-hospitalisation. In this final chapter, summaries and conclusions were presented, highlighting the main features of the study in terms of the literature reviewed, the research methodology employed and, of course, the findings of the study. This chapter ends with recommendations for policy, social work practice, education and future research in general, not specific to social work.

5.10. Final conclusion

The study sought to understand the challenges experienced by TBI survivors regarding family reintegration post-hospitalisation from a social work perspective. The goals and the objectives of this study were accomplished by employing an explorative-descriptive design, common in qualitative studies. The participants, all selected from one NPO, provided rich and detailed data on the challenges they and their families experience in a number of areas.

Families of survivors have to care for them without adequate preparation, which negatively impact on quality of life of both survivors and family members. There is a need for ongoing training on intervention strategies for social workers and other professionals to enhance service delivery to TBI survivors and their families. Many recommendations emerge from the findings that, if implemented, would ease the burden on families and survivors and better equip new social workers to handle the needs of TBI survivors, whose numbers are rising owing to advances in medical care.

The researcher is hopeful that the findings and recommendations from this study will be used by stakeholders to address the gaps in services for TBI survivors and their families. As a social worker, the researcher specifically hopes that the findings will assist social workers to improve service delivery for TBI survivors and their families.

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Appendix 1a): Information Sheet (English version)

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INFORMATION SHEET

Project Title: The challenges experienced by traumatic brain injury survivors with regards to community reintegration post- hospitalization

What is this study about?

This is a research project being conducted by Sanda Sogoni, a Masters student in the Department of Social Work at the University of the Western Cape. We are inviting you to participate in this research project because you are a traumatic brain injury survivor, and you have first-hand experience of what you went through and what you continue to face on a daily basis due to the injury. The purpose of this research project is to shed light on the experiences and challenges that are faced by traumatic brain injury survivors regarding family reintegration after hospitalization. The knowledge and information being sought is very important, because it can be used to improve support services from social workers to traumatic brain injury survivors and their families.

What will I be asked to do if I agree to participate?

You will be asked to participate in an interview to share your experience of the challenges ou have experienced after you was discharged from hospital and how you managed to cope at home. The interviews will be held at the HeadsUP in Site B Khayelitsha. Covid 19 regulations will be followed (social distancing, sanitation and social distancing) during the interview. The interview will be approximately 1 hour. You will be asked to sign a consent form stating that you agree to participate in the study and choose whether the researcher may record the interview session on a voice recorder.

Would my participation in this study be kept confidential?

The researcher undertakes to protect your identity and the nature of your contribution. To ensure your anonymity, your name will not be mentioned in the study. Only the researcher will have access to the identification key. All the information gathered in the research will be stored on a password protected computer to which only the researcher has access. If we write a report or article about this research project, your identity will be protected.

There are however limits to confidentiality. Therefore, in accordance with legal requirements and professional standards, we will disclose to the appropriate individuals and/or authorities any information that comes to our attention concerning child abuse or neglect or potential harm to you or others. In this event, we will inform you that we have to break confidentiality to fulfil our legal responsibility to report to the designated authorities.

What are the risks of this research?

All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the researcher learn more about the challenges experienced by traumatic brain injury survivors with regards to family reintegration post hospitalization. We hope that, in the future, other people might benefit from this study through improved understanding of psycho –social support services for traumatic brain injury survivors.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by Sanda Sogoni at the University of the Western Cape. If you have any questions about the research study itself, please contact Sanda Sogoni at: 2951217@myuwc.ac.za/ssogoni05@gmail.com or on 081 266 5479. You may also contact the research supervisor, Dr Shernaaz Carelse at scarelse@uwc.ac.za or on 021 959 2859

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

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REFERENCE NUMBER:
This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.

Appendix 1 b): Information Sheet (IsiXhosa Version)

UQEQESHO 1

Iphepha lolwazi

Isihloko seProjekhthi: Imiceli mngeni ngokubhekisele ekumiselweni kwakhona kosapho okwenzeka kumaxhoba okonzakala kwengqondo ebuhlungu

Lufundelwa ntoni olu phando?

Le yiprojekthi yophando eqhutywa ngu-Sanda Sogoni, umfundi we-Masters kwiSebe lezeNtlalontle kwiDyunivesithi yeNtshona Kapa. Siyakumema ukuba uthathe inxaxheba kule projekthi yophando kuba wena ulixhoba lokulimala kwengqondo ebuhlungu, kwaye unamava okuqala wento oyenzileyo kunye nento oqhubeka ujongene nayo mihla le ngenxa yokulimala. Injongo yale projekthi yophando kukukhanyisela ngamava kunye nemiceli mngeni abajamelene nayo abahlengi abenzakaliswa kukulimala kwengqondo ngokubhekisele ekukhulisweni kosapho emva kokulaliswa esibhedlele. Ulwazi kunye nolwazi olufunwayo lubaluleke kakhulu, kuba lunokusetyenziselwa ukuphucula iinkonzo zenkxaso ezivela kubasebenzi bezentlalo ukuya kwixhoba lokulimala kwengqondo kubuhlungu kunye neentsapho zabo.

Yintoni endiza kucelwa ukuba ndiyenze ukuba ndiyavuma ukuthatha inxaxheba?

Uza kucelwa ukuba uthathe inxaxheba kudliwanondlebe ukuze wabelane ngamava akho ngemiceli mngeni oye wayifumana emva kokukhululwa kwakho esibhedlele nendlela oye wakwazi ngayo ukusombulula imeko ekhaya. Udliwanondlebe luza kubanjwa e-HeadsUP e-B B eKhayelitsha. Kuya kulandelwa imigaqo eyi-19 kwi-Covid 19 (kummango woluntu, ucoceko kunye nokuncitshiswa kwezentlalo) ngexesha lodliwanondlebe. Udliwanondlebe luya kuba malunga neyure. Uya kucelwa ukuba usayine ifomu yemvume echaza ukuba uyavuma ukuthatha inxaxheba kwisifundo kwaye ukhethe ukuba umphandi unokurekhoda iseshoni yodliwanondlebe kwirekhoda yezwi.

Ngaba ukuthatha inxaxheba kolu phando kuya kugcinwa kuyimfihlo?

Umphandi uzinikela ukukhusela ubuwena kunye nohlobo lwegalelo lakho. Ukuqinisekisa ukungaziwa kwakho, igama lakho aliyi kukhankanywa kuphando. Kuphela ngumphandi oya kuba nako ukufikelela kwiqhosha lokuchonga. Lonke ulwazi oluqokelelwe kuphando luya kugcinwa kwikhompyuter ikhuselekile kwikhompyuter apho kuphela umphandi efikelelekayo. Ukuba sibhala ingxelo okanye inqaku malunga nale projekthi yophando, isazisi sakho siya kukhuselwa.

Kukho imida yokuba yimfihlo. Ke ngoko, ngokweemfuno zomthetho kunye nemigangatho yobungcali, siya kwazisa kubantu abafanelekileyo kunye / okanye nabasemagunyeni ngolwazi oluzisa ingqalelo yethu malunga nokuphathwa gadalala kwabantwana okanye ukungahoyi okanye ingozi enokubakho kuwe okanye kwabanye. Kule meko, siya kukwazisa ukuba kufuneka sophule imfihlo ukuze sizalisekise uxanduva lwethu lwasemthethweni lokunika ingxelo kwabasemagunyeni.

Buphi ubungozi bolu phando?

Lonke unxibelelwano lomntu kunye nokuthetha ngesiqu sakho okanye abanye bathwala umngcipheko othile. Nangona kunjalo siyakucutha ubungozi obunjalo kwaye sisebenze ngokukhawuleza ukukunceda ukuba ufumana naliphi na ingxaki, ingqondo okanye enye into ngexesha lokuthatha kwakho inxaxheba kolu phando. Apho kukho imfuneko, ukuthunyelwa okufanelekileyo kuyakwenziwa kwiingcali ezifanelekileyo ngoncedo olungaphezulu okanye ungenelelo.

Zithini izibonelelo zolu phando?

Olu phando alwenzelwanga ukukunceda wena, kodwa iziphumo zinokunceda umphandi ukuba afunde ngakumbi malunga nemiceli mingeni abahlangabezana nayo abo basinde kwingozi yokulimala kwengqondo malunga nokukhubazeka kosapho esibhedlele. Sinethemba lokuba, kwikamva elizayo, abanye abantu banokufumana lukhulu kolu phononongo ngokuphuculwa kokuqonda kweenkonzo zenkxaso yengqondo yengqondo yabasindileyo abenzakeleyo engqondweni.

Ngaba kufuneka ndibekho kolu phando kwaye ndingayeka ukuthatha inxaxheba nangaliphi na ixesha?

Ukuthatha kwakho inxaxheba kolu phando kukwenza ngokuzithandela. Unokukhetha ukungathathi nxaxheba. Ukuba uthatha isigqibo sokuthatha inxaxheba kolu phando, unokuyeka ukuthatha inxaxheba ngalo naliphi na ixesha. Ukuba uyeka ukuthatha inxaxheba nangaliphi na ixesha, awusohlwaywa okanye uphulukane naziphi na izibonelelo ozifaneleyo.

Kuthekani ukuba ndinemibuzo?

Olu phando luqhutywa nguSanda Sogoni kwiYunivesithi yeNtshona Kapa. Ukuba unayo nayiphi na imibuzo malunga nesifundo ngokwaso, nceda uqhakamshelane noSanda Sogoni kule nombolo: 2951217 @ myuwc.ac.za / ssogoni05 @ gmail.com okanye kule nombolo 081 266 5479. Ungaqhagamshelana nomphathi wezophando, uGqr Shernaaz Carelse kwi-scarelse @ uzc.ac.za okanye kule nombolo ye-021 959 2859

Ukuba unemibuzo malunga nolu phononongo kunye namalungelo akho njengomthathi-nxaxheba ophando okanye ukuba unomdla wokuxela naziphi na iingxaki onazo ezinxulumene nesifundo, nceda uqhagamshelane:

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Prof Anthea Rhoda
Dean: Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17
Bellville 7535
chs-deansoffice@uwc.ac.za

Humanities and Social Sciences Research Ethics Committee
University of the Western Cape
Private Bag X17
Bellville
7535
Tel: 021 959 4111
e-mail: research-ethics@uwc.ac.za

REFERENCE NUMBER:
This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.

Appendix 2 a): Research Questions (English version)

SEMI-STRUCTURED INTERVIEW SCHEDULE

Participant details

Participant code__________

Male/Female ________ Age_____________ Date of interview________

Duration hospitalised after TBI?

How long ago were you discharged from hospital?

For how long were you in the hospital rehabilitation program?

What professionals were involved in your rehabilitation while you were in hospital?

Interview question

1. Tell me how it was for you to return home to your family after being hospitalised for a TBI.
2. What were some of the vulnerabilities or difficulties that you experienced in the process of adapting to the home environment after being discharged from the hospital?
3. How did the rehabilitation programme at the hospital prepare you for returning home after your hospitalisation?
4. What psycho-social services did you receive post-injury after you came out of the hospital?
5. What suggestions would you make regarding the improvement of services for TBI survivors and their families?

Appendix 2b): Research Questions (IsiXhosa version)

ISHEDYULI YOKUQWALASELWA KWENKCAZO YOKUGQIBELA

Iinkcukacha zabathathi-nxaxheba

Ikhowudi inxaxheba

Indoda / Ibhinqa ________ Ubudala ________ Ubudala ____ _ Udliwanondlebe ________

Ixesha elide ndilalisiwe emva kweTBI?

Kudala wawukhutshwa esibhedlele?

Ude ixesha elingakanani kwinkqubo yokuvuselelwa kwesibhedlele?

Zeziphi iingcali ezazibandakanyeka kulungiso lwakho ngelixa usesibhedlele?

Umbuzo wodliwanondlebe

6. Kha undichazele ngokubanzi ngokukulimala entloko namava akho emva kokuba uphumile esibhedlele waya ekhaya?

7. Zeziphi izinto eziye zayimiceli mingeni kwaye zenza bomi bubenzima kuwe kwela xesha ubuzama ukwenza izinto owuzenza ngaphambili lokulimala?

8. Ingaba ikuncede njani I rehabilitashini esibhedlele uku kulngiselela ukuba amalungu omzimba asebenze ngaphambi kokuba ugoduke uye ekhaya?

9. Yeyiphi iminyango yoncede lwezentlalo othe wafumana uncedo kuyo emva kukuba ulimele ukuncedana nawe?

10. Zeziphi iingcebiso ongazixela kuntu ongenwalwazi ngokulimala entloko, nezinto ezinganceda ukukhuphula amaziko oncedo lwezentlalo ku maxhoba engozi yentolo kunye nabantu abalusapho kumaxhoba engozi?

Appendix 3A): Consent Form (English version)

UNIVERSITY OF THE WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa
Ph: 021 959 2849 ***Fax: 27 21-959 2854***
E-mail: 2951217@myuwc.ac.za/ssogoni05@gmail.com

CONSENT FORM

Title of Research Project: (***The Challenges experienced by traumatic brain injury survivors, with regards to community reintegration post-hospitalization)***

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

I agree that the interview may be audio recorded ……..

I do not agree that the interview be audio recorded ……..

Participant's name……………………..

Participant's signature……………………………...

Date………………………..

Appendix 3B): Consent Form (IsiXhosa version)

UNIVERSITY OF THE WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa
Ph: 021 959 2849 ***Fax:* 27 21-959 2854**
E-mail: 2951217@myuwc.ac.za/ssogoni05@gmail.com

Iphepha le Mvume ngoPhando

Isihloko Sophando: *Uphando lwendlela abaphila ngazo abantu abakhe balimala entloko, nendlela ababuyela ngayo kumphakathi emva kokuphuma esibhedlele.*

Ndicaciselwe ngokupheleyo kwaye ndiyaqonda kakuhle ngoluphando. Imibuze ebendinayo, iphendulekile. Ndiyayiqonda kakuhle ukuba izakuba yintoni inxaxheba yam kolu phando, kwaye ndizakuthabatha inxaxheba ngokwe mvume yam, ndinganyanzeliswanga. Ndiyaqonda ukuba akukho mntu ozawkulazi igama lam, nokuba ndingubani na ngenxa yoluphando. Igama lam alizoku khankanywa nakanye kolu phando. Ndiyayazi ukuba nanini na ndinga rhoxa kulophandlo ngaphandle kokwazisa nabani na, kwaye akukho mntu unako ukundinyanzela okanye andigrogrise .

Ndiyavima ukuba lu rekhodwe olu dliwano ndlebe..
Andivumi ukuba kurekhodwe kolu dliwano ndlebe..

Igama lakho..
Tyikitya apha..
Umhla..

Appendix 4: Request for Permission to Conduct Research

No 58780, Khayamnandi STR
Green-Point, Khaylitsha
Khayelitsha
7784
20 May 2020

Programme Manager

HeadUp!

REQUEST FOR PERMISSION TO CONDUCT RESEARCH

Dear Sir/ Madam

My name is Sanda Sogoni, a registered social worker with registration number: 10-34052. I am a School Counsellor/Social Worker at Groote Schuur Primary School. I am currently studying towards a Master's degree in Social Work (Full Thesis) at The University of the Western Cape. My student number is 2951217.

The topic of study is "**The challenges experienced by traumatic brain injury survivors with regard to family reintegration post-hospitalisation**"This research will be conducted under the supervision of Dr S. Carelse at the University of the Western Cape, South Africa.

I hereby request your permission to conduct this research at your Khayelitsha branch. This study requires 20 (and 1 more for Pilot Study) traumatic brain injury survivors both male and female from 18 to 65 years of age. I will provide any documentation that you might need to verify (Certified ID copy and all the necessary documentation for participation, including consent forms).

Upon completion of the study, I will furnish HeadsUP with a full report and I will acknowledge the organization in my study.

Should you require any further information, please do not hesitate to contact me at Work: 0216857295, Mobile: 0609919538/0812665479 and email: 2951217@myuwc.ac.za & ssogoni05@gmail.com

Thanking you in advance for your assistance.

Kind Regards,

Miss S. Sogoni

Appendix 5: Editorial Letter

ProsePerfect

54 Blakeway Road Mthatha 5100
Tel. number (047) 532 2303 or (071) 217 7489
e-mail Janemqamelo@gmail.com
http://janemqamelo.wixsite.com/proseperfect

6 October 2021

To Whom It May Concern

I, Peta Jane Mqamelo, ID number 611120 0014 08 and a member of the Professional Editors' Guild, do herewith confirm that I have conducted an English proofreading and grammar edit on a dissertation by Ms Sanda Sogoni, student number 2951217, entitled

The challenges experienced by traumatic brain injury survivors with regard to family reintegration post-hospitalisation

Professional
EDITORS
Guild

Jane Mqamelo
Associate Member

Membership number: MQA001
Membership year: March 2021 to February 2022

071 217 7489
janemqamelo@gmail.com
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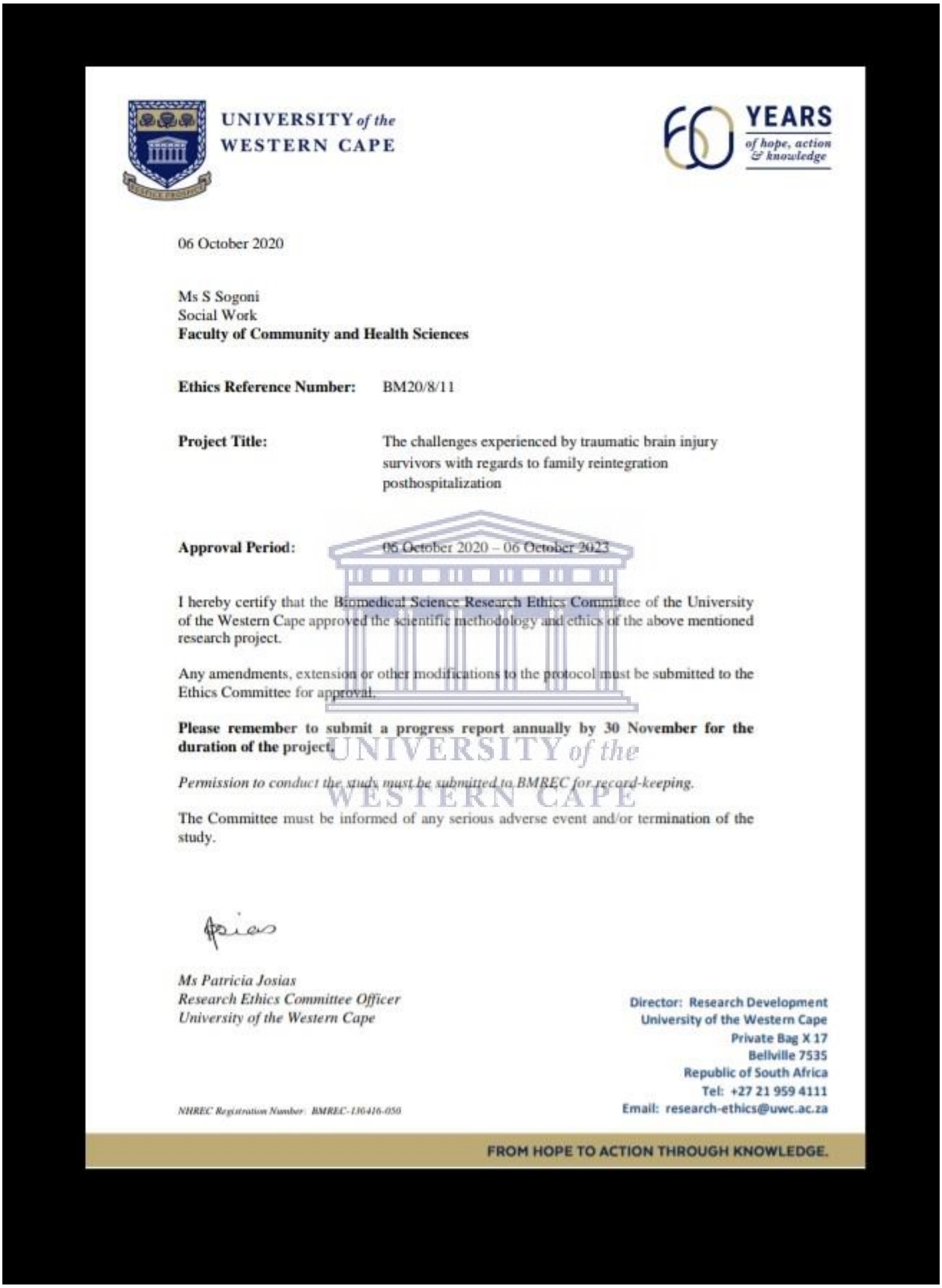
Appendix 6: Ethics Clearance Letter



UNIVERSITY of the
WESTERN CAPE

60 YEARS
of hope, action
& knowledge

06 October 2020

Ms S Sogoni
Social Work
Faculty of Community and Health Sciences

Ethics Reference Number: BM20/8/11

Project Title: The challenges experienced by traumatic brain injury survivors with regards to family reintegration posthospitalization

Approval Period: 06 October 2020 – 06 October 2023

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report annually by 30 November for the duration of the project.

Permission to conduct the study must be submitted to BMREC for record-keeping.

The Committee must be informed of any serious adverse event and/or termination of the study.

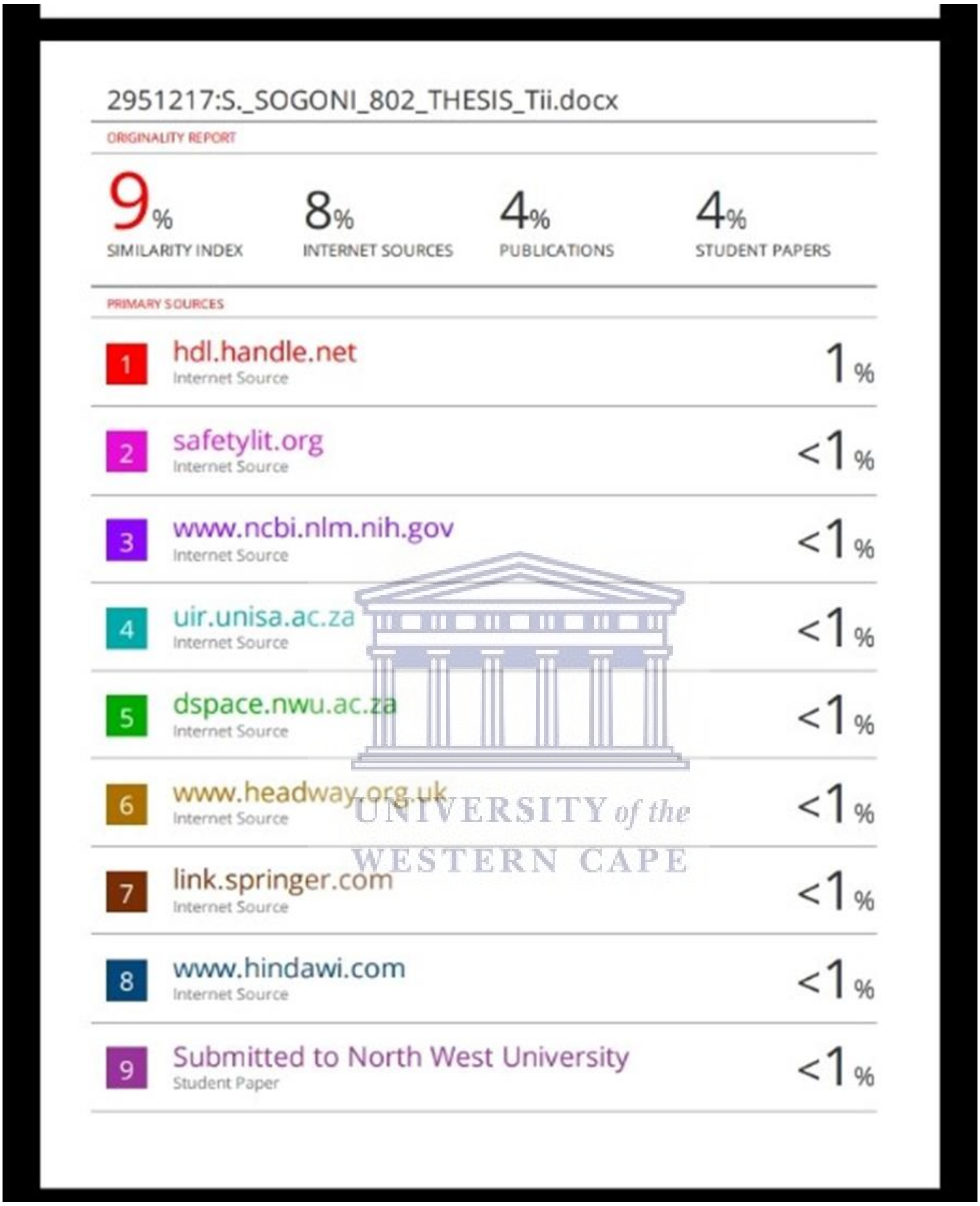
Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

Director: Research Development
University of the Western Cape
Private Bag X 17
Bellville 7535
Republic of South Africa
Tel: +27 21 959 4111
Email: research-ethics@uwc.ac.za

NHREC Registration Number: BMREC-130416-050

FROM HOPE TO ACTION THROUGH KNOWLEDGE.

Appendix 7: Similarity Index



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