Long-Term Outpatient Therapy: Perspectives from Acquired Brain Injury Survivors, their Caregivers and the Therapy Team: A KwaZulu-Natal Study

Shivani Reddy

Student Number | 208508433

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DECLARATION

I, **Shivani Reddy**, a student at the University of KwaZulu-Natal, declare that, regarding this dissertation titled,

"Long-term outpatient therapy: Perspectives from acquired brain injury (ABI) survivors, their caregivers and the therapy team. A KZN study"

1. That the work described in this thesis has not been submitted to the UKZN or another tertiary institution for purposes of obtaining an academic qualification, whether by myself or any other party.

2. That my contribution to the project was as follows: conceptualisation, design, data collection, analysis of the raw data and write up of the dissertation.

3. That the contributions of others to the project were as follows: I was assisted with advice and guidance at each step of the way by my supervisors.

Signed _______________________ Date: 20 November 2017

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ABSTRACT

Introduction: Acquired brain injuries often result in persistent residual impairments which negatively impact the individual for years after the injury, contributing to difficulty in the acquired brain injury survivor reintegrating into the community. A non-government organisation in KwaZulu-Natal provides long-term outpatient therapy to this population, with involvement from their caregivers, and the therapy team. This study aims to gain more insight into the stakeholders' experiences of this type of the therapy, and whether there is a need for it. **Aim:** To explore the experiences and perceptions of acquired brain injury survivors, their caregivers and the therapy team involved in this long-term therapy programme. **Methods:** An exploratory, qualitative research design was used. The study was conducted at the non-government organisation providing long-term outpatient therapy for the acquired brain injury survivors in the province of KwaZulu-Natal, and the sample was recruited from participants attending this facility, using purposive sampling. Face-to-face and telephonic interviews were conducted with participants who met the inclusion criteria, with a total of 11 participants recruited. Data was then analysed using thematic analysis. **Results:** Three main themes emerged, namely: the impact of an acquired brain injury indicating the need for long-term therapy; the benefits of long-term therapy for acquired brain injury survivors; and the challenges of long term therapy for acquired brain injury survivors. The acquired brain injury survivors still had residual deficits which impacted on their ability to engage in occupations, and as a result required continued intervention. Furthermore, participation in groups and long-term therapy reduced the participants' feeling of social isolation and contributed toward the acquired brain injury survivors' perceptions of being engaged in meaningful occupations. However, some changes to the programme were suggested. **Conclusion:** Acquired brain injury is a complex condition which can result in residual impairments, and which requires care on a long-term basis. The provision of long-term therapy for this population appears to have numerous benefits, and some challenges that need to be addressed. The provision of this service assists in bridging the gap between hospitalisation and community reintegration for the acquired brain injury survivors.

Keywords: *Acquired brain injury, ABI survivor, long-term therapy/rehabilitation, caregiver, therapy team*

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ABBREVIATIONS

ABI	Acquired brain injury
ADL	Activity of daily living
CVA	Cerebrovascular disease
ICF	International classification of functioning
TBI	Traumatic brain injury
WHO	World Health Organisation

OPERATIONAL DEFINITIONS

Acquired brain injury

"*A non-progressive acquired injury to the brain with sudden onset*" (Headway, 2011, p. 1).

Activities of daily living

"*Activities of daily living (ADLs), often termed physical ADLs or basic ADLs, include the fundamental skills typically needed to manage basic physical needs, comprised the following areas: grooming/personal hygiene, dressing, toileting/continence, transferring/ambulating, and eating*." (Mlinac & Feng, 2016).

Caregiver / carer

"*The term 'caregiver' encompasses a wide range of experiences and situations. Caregiving may include caring for a loved one in the caregiver's home, the care recipient's home or in an institutional setting. It may include attending to an individual's emotional well-being and/or physical health. It may involve long-term caregiving for an individual with a chronic illness or physical disability, or may be intermittent and sporadic as in the case of caring for someone with an acute illness or an acute episode of a chronic illness*" (Greenlee & Scharlach, 2003, p. 7).

Cerebrovascular accident (stroke)

"*Cerebrovascular accident is the medical term for a stroke. A stroke is when blood flow to a part of your brain is stopped either by a blockage or a rupture of a blood vessel*." (Ellis, 2013, p. 1).

Disability

"*Disability is defined as impairments in body function or body structure, limitations in the performance of activities and restriction in participation in life situations"* (Johansson & Bernspang, 2001, p. 475).

Impairment

Problems with body function and structure such as significant deviation or loss. (World Health Organization [WHO], 2001).

Occupation

According to Brown & Hollis (2013; cited by Crepeau et al., 2003) '*occupations* "*include the day-to-day activities that enable people to sustain themselves, to contribute to the life of their family, and to participate in the broader society*."'.

Occupational therapy / therapist

"*Occupational therapy is a client-centred health profession concerned with promoting health and well-being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by working with people and communities to enhance their ability to engage in the occupations they want to, need to, or are expected to do, or by modifying the occupation or the environment to better support their occupational engagement*." (World Federation of Occupational Therapy, 2012, p. 1).

Rehabilitation

"*A set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments*" (World Health Organization [WHO], 2011).

Stroke (see cerebrovascular accident)

Traumatic brain injury

"*Traumatic brain injury or craniocerebral trauma may be defined as an occurrence of injury to the brain (arising from blunt or penetrating trauma or acceleration- deceleration forces).*" (Kalyan et al., 2007, p. 32).

CHAPTER 1

INTRODUCTION AND ORIENTATION TO THE STUDY

1.1. INTRODUCTION

This chapter provides a brief orientation to the study on long-term outpatient therapy based on the perspectives of acquired brain injury (ABI) survivors, their caregivers and the therapy team. It begins with an explanation of the term ABI followed by an overview of the research study. This includes positioning the study within the background literature, a problem statement, research questions and objectives of the study. The chapter is concluded with a brief outline of the subsequent chapters in this research report.

1.2. BACKGROUND

ABI can be defined as an injury to the brain with sudden onset, which is non-progressive (Headway, 2011) and did not occur at or before birth (The Rehab Group, 2015). An ABI is not in itself one condition, but the term for a collection of conditions which can be divided into traumatic and non-traumatic brain injuries. Traumatic brain injuries (TBIs) include motor vehicle and pedestrian accidents, assaults, penetrating head injuries, falls, sports injuries and concussions. Alternatively, non-traumatic brain injuries include cerebrovascular accidents (CVAs), also referred to as a stroke, brain tumours, brain aneurysms, hypoxia, anoxia, metabolic disturbances resulting in harmful toxins damaging brain tissue, infections and damage as a result of alcohol and drug use (The Rehab Group, 2015). For the purpose of this study, the focus will be on TBIs and CVAs, the latter more commonly referred to as strokes, due to the high prevalence of these conditions at the facility where this study was conducted.

An ABI can result in various impairments and or disabilities, and in most cases, survivors will experience physical, cognitive and or behavioural changes, which often impacts upon their level of independence. Many are left wheelchair bound, and those able to ambulate may experience residual cognitive impairments which might also prevent independent living. These changes not only have an effect on the individual, but their family members too, who are generally required to take on the role as the caregivers; a role that typically lasts for many years (Jaracz et al., 2015).

Sudden trauma to the brain results in a TBI, which may be a closed or penetrating injury of the head, and which may damage one or more areas of the brain (Ribbers, 2010). In South Africa, approximately 89 000 new cases of TBIs are being reported annually, according to the Department of Health, KwaZulu-Natal (2015) and "*anecdotal information suggests that the incidence is high*" in KwaZulu-Natal (Kalyan et al., 2007, p. 35). Despite the pervasiveness of traumatic brain injuries, there is a lack of specific statistics available on the prevalence of this type of brain injury. There is also a shortage of evidence of rehabilitation available for this condition, specifically in KwaZulu-Natal.

A CVA is defined by the World Health Organization (WHO) as "*rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin*" (Truelsen et al 2000, p. 1). In 2000, this condition was the second highest cause of mortality in KwaZulu-Natal, affecting more women than men. The highest prevalence of deaths was in the over 60 age group, with stroke being the second highest cause of death in males for this age group, and highest cause of death in females (Bradshaw et al., 2006). The Department of Health in KwaZulu-Natal (2011) noted that an estimated 243 out of every 100 000 people will experience a stroke and approximately 50% of these individuals are left with chronic disabilities. Dworzynski et al. (2015), indicated that more than 30% live with persisting disability and require long term services. Long term rehabilitation for a stroke survivor refers to therapy that is required by the individual for as long as he/she continues to show functional improvement. Long term rehabilitation is seen to have positive effects on stroke survivor's psychosocial and physical functioning. Re-hospitalisation and deterioration in functioning and quality of life have been noticed to occur if rehabilitation is not received (Paolucci et al., 2000).

Post injury, there are generally three levels of care for an individual with a brain injury, namely inpatient management, community rehabilitation and adapted lifestyle-sustaining services (Horn 1992; Khan et al., 2003). The initial phase, inpatient management, refers to therapy whilst in hospital for the retraining of basic activities of daily living (ADLs), ordering of necessary equipment/assistive devices required upon discharge, and family education. The second phase, community rehabilitation, occurs after hospital discharge, involves family support, counselling and training the individual to function independently within society. The third phase, adapted lifestyle-sustaining services, encompasses daily activity programmes, residential living programmes and home-based services. This third phase is the main focus of the current study, where the aspect of daily activity programmes is explored, within the domain of community reintegration.

Living with a brain injury results in various challenges, and some of those documented include having less social contacts and friends than they did pre-morbidly, poor social support and feeling isolated (Johnson & Davis, 1998). This contributes to challenges in community reintegration. TBI survivors have been known to experience poor integration into the community, including aspects such as reduced participation within the community, integrating socially, and their life satisfaction (Juengst et al., 2014). ABI is thus more prevalent, and provision of long-term services is an essential need. This is particularly relevant in a country such as South Africa which has human resource and financial constraints. This study aims to explore the perspectives of stakeholders involved in a long-term programme to explore the positive and challenging aspects of attending a long-term programme after having an ABI.

1.3. PROBLEM STATEMENT

Brain injuries generally result in impairments which negatively compromise the survivor for many years and often a lifetime, post injury (Kapoor, 2004). These impairments often contribute to their social exclusion, and poor integration into their communities. In KwaZulu-Natal, a non-government organisation exists, which provides long-term outpatient therapy to this population, and requires involvement from their caregivers, and the therapy team. This study aims to gain more insight into this type of therapy from the perspective of the stakeholders involved. This type of service is generally lacking in KwaZulu-Natal, and only one known facility was providing daily outpatient support to these individuals and their families in KwaZulu-Natal in 2007 (Kalyan et al., 2007). There is a scarcity of information available about the number and type of these services available in this province. It is hoped that, by exploring ABI survivors’ experiences regarding reintegrating into their communities, the outcome of this study will create an awareness regarding the need for long-term care for this population. This is particularly significant given this limited literature in the field of long term therapy for ABI survivors, within South Africa and particularly the KwaZulu-Natal context.

1.4. RESEARCH QUESTIONS

a) What are the experiences and perceptions of *ABI survivors* attending a long-term outpatient therapy programme?

b) What are the experiences and perceptions of the *therapy team* involved in the long-term therapy of ABI survivors?

c) What are the experiences and perceptions of the *caregivers of ABI survivors* attending a long-term outpatient therapy programme?

1.5. OBJECTIVES

a) To explore the experiences and perceptions of *ABI survivors* attending a long-term outpatient programme by looking at the long-term effects of an ABI from the perspective of the survivor, and describing the positive and challenging experiences of attending a long-term outpatient programme.

b) To explore the experiences and perceptions of a *multidisciplinary team* working in a long-term outpatient therapy programme by describing the perceptions of the therapists on the benefits and challenges of a long-term outpatient programme for ABI survivors.

c) To explore the experiences and perceptions of *caregivers of ABI survivors* who attend a long-term outpatient programme, by describing their role in the process, as well as the caregivers’ experiences of the long-term outpatient therapy programme for the ABI survivors.

1.6. SUMMARY

This chapter provided an overview of the context of ABI survivors and background of long term therapy. The problem statement highlights the paucity of available literature in this area within the context of KZN in South Africa and the purpose statement is formulated with research questions and objectives towards an exploration of these individuals' experiences and perceptions. The following chapter will outline the available current literature on ABI and long-term therapy.

1.7. OUTLINE OF THE STUDY

Chapter 1: This chapter introduces the study, by a synopsis of the background and rationale, problem statement, aims and objectives of the study, and the significance and contribution of this study.

Chapter 2: This chapter discusses the literature available on aspects relating to the current study. The literature review focused on the following areas: ABI statistics, the impact of an ABI, community reintegration challenges, long-term therapy for ABI survivors, the role of the caregiver of an ABI survivor, and the therapy team involved in ABI rehabilitation.

Chapter 3: This chapter details the way in which data was collected and the study conducted, by exploring the study design, the study location, and the sampling and recruitment strategies utilised. Furthermore, the criteria used for selection of participants will be discussed, along with the data collection strategies and procedure, data analysis and management, and the ethical principles underpinning the study.

Chapter 4: This chapter discusses the data that was obtained through coding and thematic analysis, with three emergent themes, those being the impact of an ABI, the perceived benefits, and the perceived and challenges of long-term therapy for ABI survivors. The subthemes emerging from each theme will also be detailed.

Chapter 5: This chapter makes use of the findings which emerged through interviews conducted with the three participant groups, namely the ABI survivors, the caregivers and therapy team in an attempt to critically discuss the relevance of the three themes in relation to available literature.

Chapter 6: This chapter concludes the study, discussing the overall key findings of the study in relation to the aims and objectives, as well as the limitations of this study. Recommendations based on the outcome of this study are also detailed in this chapter.

CHAPTER 2

LITERATURE REVIEW

2.1. INTRODUCTION

This chapter reviews and summarises the literature available on ABI statistics both globally and locally, and the impact of having an ABI on the survivor. It provides an overview of the issues surrounding community reintegration, long-term therapy for ABI survivors, and the role of the caregiver and therapy team in ABI rehabilitation. The main search engines utilised for perusal of relevant articles were EbscoHost and google scholar, with the key search items being long-term care for ABI survivors, caregivers of ABI survivors, and the therapy team in long-term care of ABI's.

2.2 ACQUIRED BRAIN INJURIES

An ABI occurs after birth (Toronto ABI Network, 2015) and includes head trauma, complications after surgery and cerebrovascular accident (Kapoor, 2004). Based on this description, the term excludes conditions such as congenital disorders and developmental disabilities (Toronto ABI Network, 2015).

ABI was found to be one of the foremost causes of disability and death in North America *(*Mackenzie et al., 2015). Disability after an ABI presents as a multitude of physical and psychological symptoms (Pentland et al., 2003), and while natural recovery can take up to one year, many survivors are left with multiple residual impairments for years to come (Kapoor, 2004) and often for the rest of their lives.

The focus of this literature review revolves around stroke and TBI, (conditions falling under the category of ABI) due to the nature and location of the study, and the participants recruited.

2.3 BURDEN OF DISEASE

2.3.1 Global cerebrovascular accident / stroke statistics

CVA results in more than five million deaths every year (Lopez et al., 2006). Roughly 795 000 people experience a stroke yearly, with 70% of these being over the age of 65 years (Kapoor, 2004) and of this number, approximately 610 000 are new strokes and 185 000 are recurrent (Mozaffarian et al., 2015).

CVA is said to be the "*leading cause of chronic disability*" (Kapoor 2004, p. 1667) and the third main cause of death in America (Smith-Johnson et al., 2015). Mozaffarian et al. (2015), reports that strokes were the cause of approximately 1 in every 20 deaths in the United States in 2011, occurring approximately every 40 seconds. A decrease was seen in this high mortality rate over the past few decades, as the population had started to show changes in health behaviour, including improved risk factor control in cardiovascular diseases, hypertension, high cholesterol levels and diabetes mellitus. Similarly, in Europe, there was a high incidence of stroke, with the condition being named the third most common cause of disability and death (Stables, 2010). Roughly 110 000 people living in England, 4 000 in Northern Island and 11 000 in Wales experience their first or recurrent stroke each year (Dworzynski et al., 2015).

The number of individuals who have experienced a stroke has been increasing since the 1990s, with the number of people with disabilities and deaths due to stroke subsequently increasing (Krishnamurthi et al., 2013). Globally, there are approximately 33 million individuals living with a stroke and a large number living with a disability because of it (Feigin et al., 2014). If this continues, it is estimated that there will be approximately 20 million stroke deaths yearly and 70 million individuals who have experienced a stroke throughout the world by the year 2030 (Maredza et al., 2015). Studies show that 40 to 45% of stroke survivors experience severe limitations in their functional abilities within a few months of suffering the stroke (Wolf, 2000; Carod-Artal et al., 2000) and approximately 30% experience this after 5 years (Luengo-Fernandez et al., 2013; Pallesen et al., 2014).

These statistics indicate that not only is stroke common in all parts of the world, but that the incidence of disability due to a stroke is very high.

2.3.2 CVA / Stroke in South Africa

Norman et al (2006, cited by Bertram et al., 2013, p. 1) noted that in 2000, "*stroke was the third leading cause of death in South Africa after HIV/AIDS and ischemic heart disease*". In South Africa, the risk is great due to the population's high consumption of salt, a large percentage of the population (29% men and 56% women) are either obese or overweight, and strategies to decrease these risk factors have not yet been put into place in this country (Bertram et al., 2013). Human immunodeficiency virus (HIV) is a growing and significant problem in South Africa with an estimated two thousand people from the country contracting the disease on a daily basis (Karim & Karim, 2010). In turn, this virus is known to increase the risk of suffering from a stroke (Cole et al., 2004; Evers et al., 2003; Hoffman et al., 2000; Tipping et al., 2007).

In 2007, approximately 35 000 individuals were living with a stroke in South Africa, with 35% of this population left with moderate to severe disabilities (Bertram et al., 2013). This number increased in 2008 as 75 000 new cases of strokes were reported, with approximately 25 000 of these being fatal within 28 days. Not only is the mortality rate of stroke high, but the economic burden due to those left with disability after a stroke is also high, with approximately 50% of stroke survivors being left with chronic disabilities (Naidoo, 2013).

In 1991, the cost of stroke annually in South Africa was R4.1 - R5 billion, excluding rehabilitation (Pestana et al., 1996) however this cost has now escalated to R13 - R16 billion (Bertram et al., 2013). The above information therefore shows that stroke is a growing problem in this country, and that sufficient care should therefore be provided for those affected.

The above statistics indicate that the number of strokes seen in South Africa is increasing annually, once again demonstrating that adequate and efficient care is required to handle this burden on the health system.

2.3.3 Global (TBI) statistics

The World Health Organization (WHO) reports that a TBI is not an event, but rather a chronic illness and should be managed as one by health care professionals (Masel & DeWitt, 2010). In 1999, 1.5 million people were experiencing a TBI every year (Thurman et al., 1999, cited by Kalyan et al., 2007), however this number increased to 1.7 million by 2012 (Chen et al, 2012). This is supported by data from the Centre for Disease Control and Prevention (2015) which reported that from 2001 to 2010, an increase in the number of emergency department visits and number of hospitalizations due to TBIs was noted. TBI was seen to be the primary cause of brain damage globally (Van der Merwe, 2004). Each year, roughly 2.5 million people in America experience a TBI, and as 2% of the American population is living with a disability due to TBI (Chen et al., 2012), these individuals will require assistance in their activities of daily living for a long time to come (Centre for Disease Control and Prevention, 2014). Similarly, in Europe, trauma resulting in brain injuries was the leading cause of disability in 2010 (Stables, 2010).

There appears to be commonalities in the causes of TBI around the world: in America, the three main causes were motor vehicle accidents, falls and gunshot wounds (Geddes et al 2001), in the United Kingdom, motor vehicle accidents resulted in approximately half to two thirds of the severe injuries (Murray et al., 1999 [a]); and in Singapore, falls were the main cause (Murray et al., 1999 [b]).

As seen with CVAs, the global number of TBIs seen annually is increasing, and it is therefore imperative that adequate care is provided for individuals who are affected.

2.3.4 TBI in South Africa

The three leading causes of TBI’s in South Africa were identified to be; motor vehicle, vehicle-pedestrian or bicycle accidents, which accounted for more than 50% of all TBI’s reported, falls resulting in a TBI which accounted for approximately 25% of all reported TBI’s and physical assaults which accounted for an estimated 20% of all reported TBI’s (Wilson et al., 2015). One of the main causes of a TBI and mortality in South Africa was also found to be interpersonal violence (Corrigan et al 2010; Norman et al 2007) possibly due to the high crime rate in this country. The incidence of TBI’s peaks from 15 to 35 years old, and it appears that this injury is more common in males than females, presumably so due to male risk-taking behaviour (Khan, 2003).

In the province of KwaZulu-Natal, very few studies on the epidemiology of TBI have been published (Lalloo & Van As, 2004; Reed & Welsh, 2002; Naidoo, 2013). The morbidity rates, mortality rates, number of people with a TBI living with a disability and the effect on the health care system in South Africa are all unknown (Kalyan et al. 2007). This therefore indicates that the impact and incidence of TBI in KwaZulu-Natal remains under researched.

2.4 THE IMPACT OF AN ABI

2.4.1. Impairment in body function

ABI impairments can be divided into four broad categories, namely: neurological impairments, cognitive impairments, personality and behavioural changes, and lifestyle consequences (Khan et al., 2003).

Neurological impairment includes motor dysfunction such as problems with coordination, balance, walking, hand function and speech; sensory loss affecting taste, touch, hearing, vision and smell; sleep disturbances such as insomnia and fatigue; and medical complications such as post-traumatic epilepsy, hydrocephalus and heterotopic ossification (Khan et al., 2003). Paralysis is a common neurological impairment, leading to hemiparesis or hemiplegia (Gil-Gomez et al., 2011) as well as spasticity, where “*Damage to areas of the brain that control movement may result in uncontrollable muscle spasms*.” (Zasler, 2007 p. 7), which can affect one’s ability to walk and perform daily tasks. Contractures are another possible impairment, caused by spasticity and immobility of a body part, resulting in shortening of body tissues and structures, with consequent deformities of that body part (Zasler, 2007).

Cognitive impairments include problems with memory, attention and concentration, thought processing, problem solving skills, planning, organising, making decisions, language, judgement and safety awareness (Khan et al., 2003). Personality and behavioural changes include problems with social skills, self-esteem, frustration tolerance, anger management, insight, disinhibition, impulsivity, anxiety, depression and apathy (Khan et al., 2003). "*Acquired brain injury is referred to as the hidden disability because its long term problems are often in the areas of thinking and behaviour and are not as easy to see and recognise as many physical disabilities*." (Headway, 2011 p. 1). Finally, common lifestyle consequences include unemployment, financial difficulties, lack of transport, problems with recreational alternatives, difficulties maintaining relationships, loss of independence and pre-injury life roles (Khan et al., 2003).

The above-mentioned impairments can lead to a decrease in functional independence and challenges performing daily activities. Hartman-Maeir et al. (2007), pointed out that these difficulties may reduce the ABI survivors' activity participation, leading to social isolation, and an overall decline of their health, subsequently negatively impacting their well-being and quality of life.

The International Classification Framework (ICF) is a model with its three main health components related to disability, which are the impairment in body structure or function, such as paralysis of a limb, activity limitation, for example, being unable to walk, and participation restrictions, such as an inability to participate in a social situation (Scott et al., 2012). Kostanjsek (2011), pointed out that only in recent years has there been a shift from health being seen as concerning mortality and morbidity, with disability being excluded from the equation, but recently the two are being integrated and understood as inter-related. This is through the ICF considering various aspects and dimensions relating the two, such as biological, psychosocial, and environment components. This framework explains that disability and functioning are the result of interactions between the condition and the environment, or context. It is understood that the condition, or disease or disorder, can impact an individual's functioning in relation to the three core aspects mentioned above: their body, their participation or limitation in activity participation.

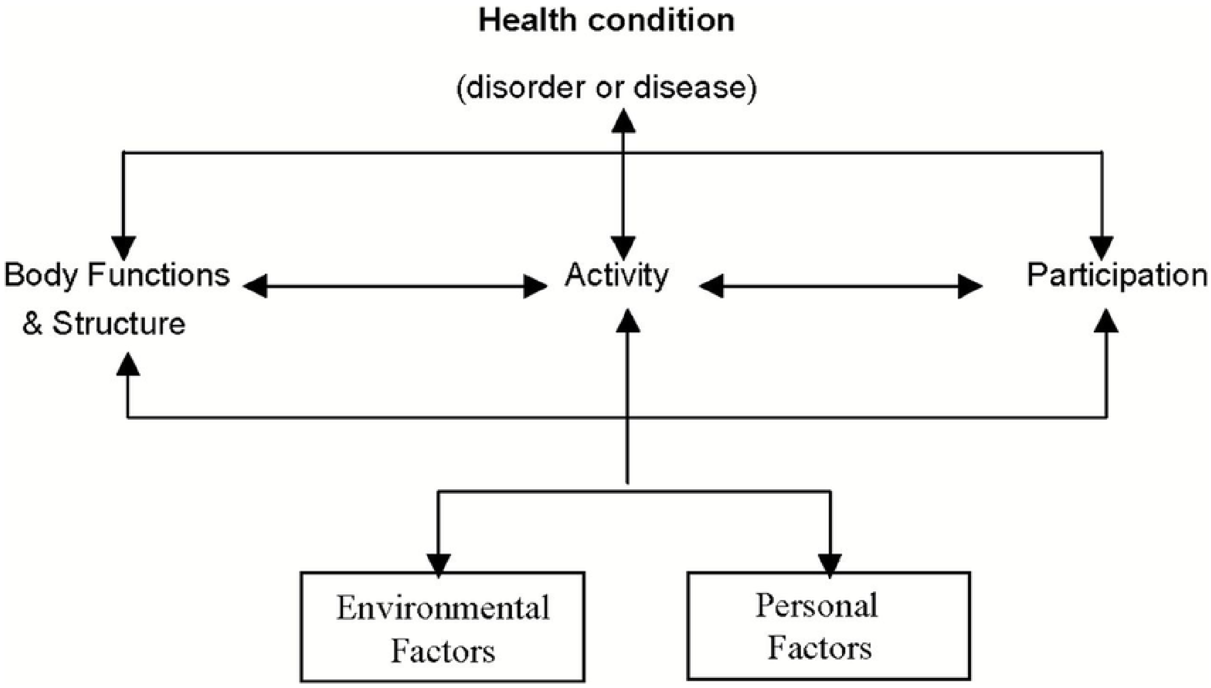

Figure 1: The International Classification Framework

2.4.2. Impact on ADLs

The chronic neurological impairments which can occur after a stroke, may lead to a decrease in functional independence, bringing about an inactive lifestyle as the individual may experience various symptoms such as poor balance, spasticity and overall weakness which can limit their level of participation in activities of daily living (Mamabolo et al., 2009). Hackett et al. (2000), conducted a survey on individuals who had experienced a stroke six years prior to the study, and revealed that approximately 60% of the sample still required assistance for certain activities of daily living (ADLs) such as dressing and transferring to the shower. The participants reported their quality of life to be significantly lower than the 40% who were independent in basic ADLs (Hartman-Maeir et al., 2007), suggesting that a sense of independence has an influence on one’s quality of life. Similar findings were noticed in a study conducted by Mayo et al (2002), where 33% of the participants reported difficulty in their basic ADLs: 51% in household / domestic tasks, 50% in travel and 53% in meaningful occupations such as socialisation, recreation and work. Hartman-Maeir et al. (2007, p. 560) also reported that their review of current literature “*reveals high percentages of disability one year and more post stroke*.”. These difficulties could potentially lead to a decrease in the overall activity participation of this population which may result in social isolation and a decline of their health, contributing weight to the fact that long term care and activity groups are essential to increase the quality of life of ABI survivors (Hartman-Maeir et al., 2007).

Many of the impairments experienced may resolve or be treated within a few years post injury; however, there are also impairments that may never resolve. Vaishnavi et al. (2009) concur with this by reporting that once an individual has experienced a moderate to severe TBI, often full recovery does not occur and even after two years the individual may still be experiencing difficulty with functioning at their most basic level. Many individuals who have experienced a TBI have challenges securing employment, often due to cognitive problems such as difficulty concentrating and poor memory. Behavioural problems such as poor anger control, inappropriate language use and change in personality due to injury can also negatively affect interpersonal relationships at work, resulting in challenges sustaining employment.

2.4.3. Social exclusion

"*Although many individuals are well enough to attempt reintegration into the community, this population is especially vulnerable to homelessness and incarceration*" (Centre for Disease Control, 2009, cited in Mackenzie et al., 2015 p. 10), which contributes to negatively impacting their quality of life.

Several studies have found that being unable to perform certain activities due to impairments and a feeling of being excluded by society has contributed toward the social isolation of many ABI survivors (Laatsch, Little & Thulborn 2004; Powell & Malia 2003; Sander et al. 2012; Winkler et al., 2006). When there is damage to the frontal lobe area of the brain, often symptoms such as disinhibition, lability, poor anger control, aggression, impulsivity, inappropriate sexual behaviours and poor social judgement can be seen (Ylvisaker et al., 2005), which could also lead to social isolation. According to Linden and Boylan (2010), when an individual is denied the right to inclusion, this contributes to compromising the social bonds tying society together.

People with disabilities are often deprived of opportunities to participate in social activities, due to their limitations and impairments (Tough et al., 2017). This deprivation is seen as a contradiction of basic human rights, and compromises the individual's health and well-being. Tough et al. (2017) noted that being able to participate in one's social life, such as with family, friends and at work, had positive effects on the individual's health and well-being. On the other hand, being socially excluded or having few social connections was linked to poor health, as well as an increase in the risk of mortality. While this applies to the general population, it is especially true for people with disabilities. Janzen et al. (2015) mentions that some of the challenges brain injury survivors face are isolation, lack of support and having less friends and people to interact with.

Social inclusion can be defined as the act of making all groups of people within a society feel valued and important. For the ABI survivor this may include the ability to once again participate in work, friendship and leisure activities, as well as being included in education, having access to health amenities, community services and welfare support (Johner, nd). Social inclusion is linked to a person's well-being, socially and economically, and their quality of life (Johner, nd). The term exclusion implies being distant from conventional society, and dealing with difficulties preventing one's engagement in aspects of social life such as relationships and being involved in decision-making (Linden & Boylan, 2010). Social inclusion, according to Linden & Boylan (2010) involves inter and intrapersonal relationships, and includes acceptance by others, and has a huge impact on community reintegration of brain injury survivors. Linden & Boylan (2010) maintain that TBI survivors can experience a decrease in their friendships; less opportunity to form new friendships; a reduction in participation of leisure pursuits; and a high risk of suffering from depression and anxiety. They further suggest that because of this, TBI survivors have a challenge with upholding social networks. Social participation is a concept referring to engaging within various life situations, such as leisure pursuits, social events and work. However, stroke survivors generally experience a decrease in social participation, evidenced by their lack of involvement in social activities. This, in turn, negatively impacts their self-rated quality of life (Scott et al., 2012).

Some of the long-term effects of an ABI are social exclusion, abuse of substances, difficulties with mental health, suicidal ideation and inappropriate behaviour. Due to these, as well as other problems such as depression, their ability to be accepted by their community is compromised and leads to a deterioration in their social networks, as well as challenges in their ability to form new relationships (Mahar & Fraser, 2012). Eisenberger & Lieberman (2005, cited by Allman, 2013), indicate that being connected socially is as crucial to our lives as our basic needs such as sustenance, fire and shelter, and that without these, literal pain could be experienced.

The above literature indicates that ABI survivors are often left with residual impairments years after the injury, which negatively impacts their participation in daily activities, and can lead to social exclusion, which in turn contributes to poor integration into their communities.

2.5. COMMUNITY REINTEGRATION

According to Janzen et al. (2015), the ultimate goal of rehabilitation for an ABI survivor, is community reintegration. Gretschel (2016) agrees with this and adds that it is the most meaningful outcome. Gretschel (2016) further explains that all individuals ought to be a contributing member in their community, and the recommencement of one’s roles within the community is also important. Many studies agree that recommencement of one’s roles in the community includes a social, physical and psychological component (Dijkers, 1998; Parvaneh & Cocks, 2012; Sander et al., 2012; Wolfensberger, 1993; Wong & Solomon, 2002). Community reintegration could be comparable to the element of participation in the ICF model, which can be defined as being actively involved in life situations (Gretschel, 2016).

Several studies agree that most South Africans living with disabilities are still not always provided with equal rights and opportunities, both socially and economically, and are not being re-integrated into their communities (Heap et al., 2009; Maleka et al., 2012; Mudzi et al., 2013; Schneider & Nkoli, 2011). Some of the reasons leading to ostracism of individuals with disabilities in South Africa include difficulty in physically accessing the environment, stigma surrounding disability, restricted access to certain services such as health, poverty, the lack of basic education and the high unemployment rate (Gretschel, 2016). In South Africa, the programmes developed for rehabilitation are generally focused on impairment, and subsequently not targeting community reintegration. There is also a lack of literature in South Africa quantifying community reintegration after rehabilitation (Gretschel, 2016).

According to Lux (2007), the term autonomy refers to the concept of self-governance, and refers to both an act, such as a choice, and a person, where they are liberated from any external control. Shames et al. (2007), reiterating this, maintained that a large number of individuals with moderate to severe head injuries experience persistent impairments which negatively impact upon their participation in tasks such as self-care and mobility, as well integrating back into society. Because of these limitations, some of the common lifestyle consequences which result from a brain injury include unemployment, problems with recreational alternatives, and a loss of independence and pre-injury roles in life (Khan et al., 2003). Barnes (2012) agrees that people with disabilities are significantly disadvantaged when it comes to the open labour market and, that people with disabilities are at a higher risk of being unemployed than the average population.

2.5.1 Meaningful occupation

Quality of life was found to be low for individuals who had experienced a TBI, and appears to remain low throughout their lives (Andelic et al., 2009; Hoofien et al., 2001; Horneman et al., 2005; Mackenzie et al., 2015; Man et al. 2004; Nestvold & Stavem, 2009; Powell et al. 2007). Factors that contribute to a low quality of life are depression (Andelic et al., 2009; Hart et al., 2011), stress (Strom & Kosciulek, 2007), fatigue (Cantor et al., 2008), and decrease in productivity and social difficulties (Heinemann & Whiteneck, 1995). However, there are ways to increase the quality of life of a TBI survivor, which include: having a good social support system (Tomberg et al., 2005), being employed (Man et al., 2004), feeling integrated within the community (Kalpakjian, et al., 2004), participation in work and leisure activities (Steadman-Pare et al., 2001), and participating in activities of daily living, which are the biggest predictors of a good quality of life (Pierce & Hanks, 2006). Eakman & Eklund (2012), refer to several articles which clearly linked wellbeing with occupation, and occupation is steadily linked to life satisfaction, as well as purpose and meaning in life. The term occupational value is one referring to the concrete, abstract and gratifying attributes of daily occupations. Eakmand & Eklund (2012), commented on numerous studies which revealed a link between meaningful or purposeful occupation, occupational value, and well-being. This is an indication of the significance of the latter three concepts to health and well-being, as well as the meaning of one’s life, life satisfaction, a sense of reason, self-mastery, intrinsic motivation, self-esteem, quality of life, depression, anxiety and stress.

According to the WFOT Position Statement of Human Rights (WFOT, 2006), there are several rights that should be adhered to in relation to human occupation and participation. These include the following, which are relevant to this study:

- *“People have the right to participate in a range of occupations that enable them to flourish, fulfil their potential and experience satisfaction in a way consistent with their culture and beliefs*
- *People have the right to be supported to participate in occupation and, through engaging in occupation, to be included and valued as members of their family, community and society*
- *The right to occupation encompasses civic, educative, productive, social, creative, spiritual and restorative occupations. The expression of the human right to occupation will take different forms in different places, because occupations are shaped by their cultural, societal and geographic context*
- *At a societal level, the human right to occupation is underpinned by the valuing of each person’s diverse contribution to the valued and meaningful occupations of the society, and is ensured by equitable access to participation in occupation, regardless of difference”*

These human rights highlight the significance of participation in meaningful occupations, to allow one to be, or feel like, a contributing member of society.

According to Scott et al. (2012), several studies involving recovery from a stroke proposed that stroke survivors focus more on the goals of social integration with the community, their family and their occupations, rather than overcoming their physical impairments. Similarly, the World Health Organization (WHO) views successful rehabilitation as reintegration of the survivors into their social networks, and active participation within their communities (cited in Scott et al., 2012). Parvaneh et al. (2014), agree that after experiencing a brain injury, resuming their place in the community, as well as being productive within, was the most significant objective of rehabilitation.

Parvaneh et al. (2014) concur with WFOT’s position that participating as a member of society was a human right. In the United Nations, accessibility and equality of opportunity were seen as two of the rights for people with disabilities (Parvaneh et al., 2014). WHO has expressed the significance of community integration, through development of a policy which was named, "*Health for all by the year 2000*" and which maintains that individuals worldwide should have access to health at a level which allows for productive work and active participation within the social life of their community (Parvaneh et al., 2014). Parvaneh et al. (2014) also noted that people living with disabilities prefer to participate within their community, without being judged or labelled due to their impairments, rather than in an isolated rehabilitation environment. Parvaneh et al. (2014) further found that the following dimensions of community integration were explored by various researchers, namely: participation in leisure, contact with family, acceptance, occupation, environment in which one lives, social support, life satisfaction, social engagement, interaction with community members and a feeling of belonging. The three most commonly expressed aspects were having relationships with others, being independent, and participating in activities.

2.6. LONG-TERM REHABILITATION

"*The ultimate objective of treatment and rehabilitation is to maximize activity and participation*." (Varjačić et al, 2010, p. 158).

Long term therapy for stroke survivors is rehabilitation "*as long as stroke survivors need the service*" (Nordin et al., 2014; p. 1-2) and functional improvement continues to be seen during receipt of these services. Further rehabilitation may increase an individual's functional independence, improve their participation in their daily roles and assist with re-integrating them into their community (Nordin et al. et al., 2014). Paolucci et al., (2000, cited by Nordin et al., 2014) indicate that individuals receiving long-term therapy found that it benefitted their psychosocial and physical functioning, and that without further rehabilitation, deterioration in function, re-hospitalisation and a decrease in the quality of life of survivors was observed. Similar findings were found in two other studies: Varjačić et al., (2010) reported that outpatient and home-based rehabilitation for individuals with TBI's three to five years post in-hospital rehabilitation, was found to be beneficial, as functional improvement was seen; and Mayo et al., (2000, cited by Mamabolo et al., 2009) stated that rehabilitation after discharge, especially home-based rehabilitation, improved functional recovery and community and home integration.

Deciding on the most advantageous intervention approach to use is one of the biggest challenges in TBI rehabilitation, due to the complex nature of this type of injury, as well as the various impairments (Hammond et al., 2015). There are several factors which can be considered when determining whether the individual would benefit from group or individual therapy, such as: their level of functioning, the goal of therapy, availability of therapists, and financial aspects.

Group therapy is one way of combating the above mentioned social challenges such as difficulty re-integrating into the community and social exclusion. Participants of a study attending group therapy expressed that the group setting was the first form of social interaction that many of them had experienced where they felt that they were not being judged and were instead supported. This, in turn, resulted in more liberal interaction (Wilson et al., 2015). TBI survivors may experience great difficulty in forming new relationships and maintaining old ones, due to deficits in their social perception such as poor understanding of emotional signals given by others (Ylvisaker et al., 2005). Therefore, group therapy would be a platform for assisting with this as it provides the opportunity for social interaction (Wilson et al., 2015). Ylvisaker et al. (2005), state that having good social skills is also vital for a fulfilling social life. However, Arigo and Haggerty (2016), note that, should patients compare themselves to others functioning at a lower level, this could lead to dissatisfaction with their own situation, or anxiety about ending up in that position.

Even after discharge from inpatient care, ABI survivors are often still limited in their independence, quality of life and participation (Bender et al., 2016) and usually require additional medical and rehabilitation services for many years after the injury (Chen et al., 2012). Rehabilitation of an individual with an ABI generally focuses on pain management, increasing independence in ADLs, behavioural therapy, cognitive rehabilitation and pharmacological care. The survivor, and their family and caregivers play an integral part in the process (Khan et al., 2003). Waehrens & Fisher’s (2007) study found that after attending a rigorous rehabilitation programme, ABI survivors with moderate to severe disabilities displayed an improvement in their participation in familiar ADLs.

Similar findings were seen in a study by Bender et al., (2016) where patient-specific goals were attained in an intensive rehabilitation programme lasting four weeks, in patients with serious acquired brain injuries that were sustained approximately four years prior. According to Kwakkel et al. (2002), this information is significant as it is generally assumed that, in the chronic phase, a plateau, instead of dynamic improvement is expected. Research indicates that it is possibly to achieve significant functional or activity-related goals more than six months post injury (Duncan et al., 2011; Reisman et al., 2013). Other researchers indicate that there can be improvement in level of functioning. Trombly & Randomski (2002) found that CVA survivors displayed an improvement in their participation in ADLs after three months of rehabilitation. Duncan & Min Lai (1997) report that improvement could be seen "*as far as 6-12 months after stroke*" (Mamabolo et al., 2009, p. 15).

Several studies were found regarding long-term therapy for CVA survivors, such as those by Dam et al., (1993), Dworzynski et al. (2015), and Nordin et al. (2014) , however TBIs have received limited attention. Marion (1999) reports that long-term outpatient care of brain injuries is under-served while Van der Merwe (2004) indicates that more development and research is required in this area. Abelson cited in Van de Merwe (2004), found that "*the resources available in South Africa for the comprehensive care and rehabilitation of traumatic brain-injured individuals, were inadequate*" (Van de Merwe, 2004, p.35).

However, even though long-term therapy has been introduced to many developing countries, sustainability is one of the biggest obstacles due to a lack of funds for maintenance of the service (Turmusani et al., 2002, cited by Nordin et al., 2014). These countries, such as Malaysia, have thus been focusing more on acute care for non-communicable and communicable illness, rather than on rehabilitative services such as those necessary for individuals with strokes (Nordin et al. 2014). In most cases, rehabilitation for an individual with a stroke ceases after a year, and in those areas providing care for longer periods, optimal service provision is hampered by factors such as shortage of trained professionals in the field of rehabilitation, and a lack of commitment and dedication on the part of the wards responsible for stroke rehabilitation. Nordin et al. (2014), suggest that rehabilitation for longer periods may be more advantageous for optimal recovery as many patients do not reach their optimal level of recovery despite being in therapy for more than six months. After receiving rehabilitation (such as occupational therapy and physiotherapy) at the community level, clients who had previously complained of problems such as poor hand function as well as overall functional deterioration, showed improvement in these areas (Greenberg et al., 2004, cited by Mamabolo et al., 2009).

Nordin et al. (2014) conducted focus group interviews with rehabilitation professionals working with stroke survivors, and with individuals who had attended rehabilitation and had experienced a stroke more than one year prior to commencement of the study. The majority of the participants in both groups felt that continuity of care for stroke survivors was lacking and greatly needed. Participants were questioned about their beliefs regarding long term rehabilitation, and the majority maintained that motivation was a factor; as long as clients attending therapy are motivated for therapy to continue, then it will be beneficial. The stroke survivors themselves also felt that participating in exercises for a longer period was beneficial, especially for maintenance of strength. Some of the rehabilitation professionals did have their doubts about the benefits of long term care; one participant mentioned that chronic stroke patients would have reached a plateau in therapy and that therapy would be focused more on preventing complications rather than achieving new goals (Nordin et al., 2014). Some participants from this group also expressed certain barriers or limitations that they found with this type of care, such as not being able to determine clear goals for long term therapy and what the expected outcome would be; limited resources which often compromises the provision of long term services; a lack of community based programmes for integration into the community after hospital discharge; shortage of staff at the hospitals; and a lack of volition on the part of the stroke survivors (Nordin et al., 2014). Other barriers included the lack of transport services to and from the hospital, which made mobility to the hospital difficult for those with low socio-economic statuses who were unable to afford frequent public transport to the hospital. Another barrier was the lack of education provided to patients and families on the need for rehabilitation for optimal recovery after a stroke, which resulted in poor compliance. Participants in this research provided the following suggestions regarding the provision of long term rehabilitation services: that community-based rehabilitation services be provided to maintain long term therapy; the number of staff positions increase to tackle the shortage problem; and ensure that caregiver training is included in the rehabilitation process (Nordin et al., 2014).

Overall, the study by Nordin et al. (2014) revealed a general agreement from all participants: that further therapy or long-term therapy would benefit stroke survivors and assist them in achieving maximal recovery. The study did, however, find that long term care would be better provided at a community level (such as at community based rehabilitation centres) which would allow for hospitals to deal with the acute case. Stroke rehabilitation at community-based level has been shown to maintain and even improve participation in one's activities of daily living, and decreases the risk of functional deterioration (Legg et al., 2004). The above-mentioned study shows that there is a lack of continuity of care once individuals with strokes are discharged from hospitals, and that this service is one that both professionals and patients find is needed.

In South Africa, Green et al. (2005) found that the average hospital stay of stroke patients in private hospitals was roughly 30 to 34 days, whereas in Chris Hani Baragwanath Hospital, a government-funded hospital, the length of stay was approximately 12 days (Hale & Eales, 1998, cited by Mamabolo et al., 2009). Mamabolo et al. (2009), suggested that the time periods were not sufficient, and that patients were discharged "*before they are functionally independent*" (Mamabolo et al., 2009, p. 15).

The above literature highlights the necessity and importance of continuation of care for individuals with a brain injury. According to Cameron et al., (2008), there are very few studies which focus on individuals a year after their injury, and it is very rare to find a study focusing on more than five years post injury (Colantonio et al. 2010; Dikmen et al., 2003; Dunn et al 2000; Whitlock & Hamilton, 1995, cited by Cameron et al., 2008). The above information also demonstrates the vast difference in the availability of literature on long-term TBI and stroke rehabilitation.

2.7. CAREGIVERS OF ACQUIRED BRAIN INJURY SURVIVORS

Brain injured survivors and their families may have difficulty adjusting to the transition of the survivor going from independence to complete dependence on their family for assistance in all aspects of their lives, which can result in high levels of stress for the family, emotionally as well as financially (April, 1997; Bekker, 2000). This is supported by Wilson et al. (2015) who remarked that a brain injury survivor may not be able to participate in or contribute to work or school settings, which results in dependence on government grants as they are not able to support themselves financially. A study was conducted in the United Kingdom on the psychological and physical health effects of carers for individuals with ABIs, which found that the carers had more than double the levels of depression, stress and anxiety than the general population (Headway, 2012).

A caregiver may experience ‘caregiver burden’, which occurs when their tasks are very strenuous, or the carer has had a short time to prepare themselves for this change in role and has not received sufficient support or education. Burden can be seen as “*the extent to which a caregiver perceives emotional, physical health, social life, and financial consequences that impairs one’s ability to provide care*” (Headway, 2012, p. 6). This, in turn, negatively affects their health, social life, finances and spiritual life. (Adelman et al., 2014). Several studies reported that approximately 25% to 46% of caregivers experience a high amount of burden in the first 6 months of providing care (van Exel et al., 2005; Ilse et al., 2008; Blake et al., 2003; Tooth et al., 2005; Hung et al., 2012, cited by Jaracz et al., 2015).

According to Van de Merwe (2004), extensive research has been conducted on the impact of TBI on the family members. Most of the time, the position of caregiver is taken up by a member of the family, as the individual is generally discharged back home (Jaracz et al., 2015). The family plays an integral part of the recovery process. A study by Sander et al., (2012) found a direct link between the “*emotional functioning of caregivers to TBI survivor’s productivity and social integration*” (Wilson, 2015, p.5). Caregivers experience a sense of pride and fulfilment when the family member is motivated and participates in therapy (Wilson, 2015). When caring for a stroke survivor, the caregiver’s duty includes providing assistance, involving the individual’s activities of daily living, and communication impairments as well as any cognitive difficulties such as depression and changes in personality (Smith-Johnson et al., 2015). Caregivers have been found to receive very minimal support from health care professionals (Jeggels, 2006). It is important that caregivers are educated about how to care for the individual, because if they provide too much assistance and protection for the individual, this can result in a decrease in the functional ability of the individual (Mamabolo et al., 2009). Caregivers were also noted to benefit from social support, and those who socialised with friends less, and who did not have a good support system, often felt more isolated and burdened (Coy et al., 2013; Davis et al., 2009; Manskow et al., 2014).

Additionally, Calvete & de Arroyabe (2012) noted that having access to information and education also impacted caregiver burden, as they felt information on health, especially in the acute phase of a TBI, to be very beneficial. Conversely, not receiving this type of support could negatively affect their mental health.

The above literature emphasises the importance of caregivers in the rehabilitation process, and their inclusion at each phase of care, to educate them on effective handling of the patient in order to reduce the risk of burnout. It is also important to ensure that care and support is available for them, should they require it.

2.8. THE THERAPY TEAM IN ABI REHABILITATION

Rehabilitation for brain injury patients requires a team of healthcare professionals, due to the variety of symptoms seen, where treatment of mobility difficulties, cognitive deficits and communication problems requires expertise from different members of the team (Pentland et al., 2003). A multidisciplinary approach is necessary in the treatment of a stroke (Dworzynski et al., 2015) and this applies to TBIs as well (Khan et al., 2003). The professionals involved in this team generally include the client and their family, nurses, general practitioners, physiotherapists, occupational therapists, physicians, speech and language therapists, clinical psychologists, neuropsychologist and social workers (Dworzynski et al, 2015; Khan et al., 2003). Examples of the some of the therapist's roles are detailed below.

Khan et al. (2003) describes the role of the occupational therapist in the various stages, such as inpatient treatment, which generally focuses on increasing independence in ADLs, cognitive therapy, provision of necessary assistive devices and home adaptations. After discharge, the occupational therapist will provide ways to allow for them to be as independent as possible within their community setting, in a stage which Khan et al. (2003) term as community rehabilitation.

Physiotherapists generally focus on respiratory care, reducing spasticity and maintaining passive movement of the joints in the acute phase. In the later phases, therapy concentrates on aspects such as functional training and mobility, and education on compensatory methods (Carr & Shepherd, 2003).

Davee (2014) noted that speech and language therapists assess aspects such as swallowing, all areas of communication, and determine the appropriate intervention and goals for the client’s functional recovery.

Du Plessis et al. (2014) indicated that therapists working in rehabilitation centres were particularly exposed to stressful situations, and emotionally draining interactions with the clients and their family. As therapists are generally seen as compassionate and dedicated individuals, they are vulnerable to burnout. Schlenz et al. (1994) also mentions that when working with head injury clients, emotionally draining interactions are to be expected. Burnout is a state of exhaustion, physically and emotionally (Du Plessis et al., 2014), and this occurs when one works in conditions with stressors on a chronic basis, and frustrations which they are unable to tolerate and cope with. Du Plessis et al. (2014) noted that this occurs frequently with health care providers due to the emotionally demanding nature of their work. Burnout can have a negative effect on the employee’s working ability.

2.9. SUMMARY

As indicated by the above literature, ABI (specifically TBI and stroke) is a growing problem in South Africa. Rehabilitation is vital and does not end once the ABI survivor has been discharged from the hospital. Review of existing literature reveals that the focus has been mainly on acute rehabilitation for individuals with brain injuries, indicating a lack of research on the outcomes of long-term therapy. Long-term therapy is an aspect of treatment imperative for the wellbeing and quality of life of the individual with an ABI, therefore this study aims to contribute to this sparse area in literature.

Chapter 2 explored the current and relevant literature surrounding ABI statistics both globally and locally, the impact of an ABI on the survivor and effect on community reintegration, long-term care for ABI survivors, and roles of the caregivers and the therapy team involved. The study methodology will be explored in the next chapter.

CHAPTER 3

METHODOLOGY

3.1 INTRODUCTION

This chapter describes and justifies the design utilised in this study, provides a description of the study location, the sample and recruitment strategies used. The inclusion and exclusion criteria are discussed, as well as the strategies and procedure of data collection. The process of data analysis is outlined. The ethical principles considered in the study are also detailed herein.

3.2. STUDY DESIGN

This study made use of a qualitative exploratory design. This research design is suitable for this particular study since qualitative research allows for a process of creating a holistic picture of the content of a study, to seek deeper meaning, with the aim of gaining an understanding of a problem, be it human or social, from many perspectives (Abawi, 2008). "*Qualitative inquirers bring to their studies a different lens toward validity than that brought to traditional, quantitative studies*" (Creswell & Miller, 2000, p. 125). In this study, the experiences of the participants were explored using face-to-face and telephonic semi-structured interviews, with open-ended questions to elicit deeper responses.

An exploratory design is one which addresses a topic with minimal existing literature available on the subject, and where there may be uncertainty and/or ignorance around it. This type of design permits flexibility and a lack of strict structure (Van Wyk, 2012), and is relevant in this study as it allows for unrestricted exploration of the long-term therapy programme provided by an NGO.

3.3. STUDY LOCATION

The study was located at a NGO situated in an urban area, in KwaZulu-Natal. This facility provides chronic daily outpatient therapy (both individual and group therapy) for ABI survivors, at lower rates than those in private settings. This is possible because the facility is an NGO, attempting to provide affordable care for those who may not be able to afford private care. The therapy team consists of physiotherapists, occupational therapists, social workers, psychologists and speech therapists. Group therapy includes, but is not limited to, cooking, gardening, exercise, communication, support, life skills, recreational, music, family and support groups. Those ABI survivors discharged from individual therapy are still able to continue with group therapy on an ongoing basis for maintenance of their current level of functioning. The majority of the ABI survivors attending the programme are cared for by formally employed caregivers or family caregivers who accompany them to the NGO. The therapy programme is offered daily from 08:30 am to 13:00pm, five days a week (Monday to Friday), with most ABI survivors attending daily, or several times in a week. Annual events are held to monitor progress of the ABI survivors, such as swimming galas and sports days, and the organisation hosts bi-annual fundraisers, with the sale of items that are produced by the ABI survivors in group therapy.

This location was selected as the researcher was employed there at the time the study was conducted, and because it is the only known facility providing long-term outpatient therapy for ABI survivors, known to the researcher currently in KwaZulu-Natal.

3.4. STUDY SAMPLE

According to Kolakowsky-Hayner et al. (2001) many studies indicate long-term as being more than two years, therefore only those survivors who had acquired a brain injury more than two years prior to the commencement of the study, which was in January 2015, were selected. The study sample was recruited using purposive sampling. This is a non-probability sampling technique most often used in qualitative research, where individuals are selected based on certain criteria relevant to the study and the research questions being posed (Teddlie and Yu, 2007). Three participant groups were included in this study, namely

- Group 1: ABI survivors
- Group 2: Caregivers of the ABI survivors who were attending therapy at the long-term outpatient NGO
- Group 3: Therapists from various disciplines that offer a service at the long-term out-patient NGO

3.4.1. Recruitment

Participation in the study was voluntary. Individuals who met the inclusion criteria, which are detailed in the following section, were presented with information documents and consent forms, and only those who had read both and signed the latter, were interviewed. Times for scheduling of the interviews were arranged during those periods convenient to both the participant and researcher.

3.5. SAMPLING PROCEDURE

The selection criteria that were relevant in the recruitment of participants in this study are highlighted below:

3.5.1. Group 1: ABI survivors

A group of five ABI survivors who had been attending the programme at the study site were recruited for participation in the study, as they met the inclusion criteria, which included:

Inclusion criteria:

- ➢ ABI survivors who had suffered a brain injury more than two years prior to the commencement of this study;

- ➢ Participants with adequate cognitive level/ ability who were able to understand all questions posed;

- Participants who were able to communicate verbally.

Exclusion criteria:

- Participants with significant cognitive fallout;
- Severe impairment in receptive and/or expressive communication skills of the individuals with acquired brain injuries, resulting in the participant not being able to understand questions posed and/or verbally provide appropriate responses;
- Participants who had suffered a brain injury less than two years prior to commencement of this study.

3.5.2. Group 2: Family/caregivers

Three caregivers of ABI survivors attending the programme at the study site were recruited to participate in the study, to explore their experiences of long-term therapy for an ABI survivor, as they met the following inclusion criteria:

Inclusion criteria:

- An individual who is formally employed as a caregiver, or a family member who has taken on the role as a caregiver. A caregiver is one who attends to the needs of an individual's health, be it emotional well-being or their physical health (Greenlee & Scharlach, 2003);
- The participant had to have cared for or be caring for ABI survivor during attendance at the programme at the study location.

Exclusion criteria:

- Participants who were not employed as caregivers, or who had not taken on the caregiving role in the family;
- Participants who were not caring for ABI survivors attending the programme at the study site.

3.5.3. Group 3: Therapy team

Three members of the therapy team working with the ABI survivors at the study site were recruited for participation in the study, namely an occupational therapist, physiotherapist and speech therapist, as they met the following inclusion criteria:

Inclusion criteria:

- Participants who were qualified health professional practitioners registered with the Health Professionals Council of South Africa (HPCSA);
- Participants who were employed at the study site, and were involved in the therapy/programme offered to the ABI survivors.

Exclusion criteria:

- Participants who were not qualified as health professional practitioners.

3.6. SELECTION STRATEGY

Once ethical clearance was obtained from a Biomedical Research Ethics Committee (BREC), reference number (BE202/16), the gatekeeper of the study location was contacted in writing, and informed of the study purpose and procedure, to allow for access to the ABI survivors and their medical records, the caregivers, and therapy team. The study commenced once gatekeeper permission (*Appendix 3, pg. 110*) and BREC approval was obtained.

3.7. SAMPLE SIZE

A total of 11 interviews were conducted. Five individual, face-to-face interviews were conducted with the ABI survivors and three with the caregivers. One face-to-face interview was conducted with a therapy team member, and two of the interviews in the therapy team group were conducted telephonically. It was envisaged that a wider sample would be included in this study. However, due to particular circumstances associated with the nature of the phenomena being explored, the numbers of the participants were lower than intended. Some of the challenges leading to the limited sample were as follows: the therapy team participants could not always be interviewed at the NGO, due to their work hours and the ethics of not affecting their schedule with patients. Additionally, availability of the ABI participants was a challenge as they could not be interviewed during their therapy time, and a handful of ABI survivors met the inclusion criteria, specifically due to the cognitive impairment. However, given the nature of qualitative research, as discussed in section 3.2, a large sample is not necessary for valid analysis since the focus is on in-depth data rather that extensive data. "*Saturation is used in qualitative research as a criterion for discontinuing data collection and/ or analysis*" (Saunders et al., 2017, p.2) and was achieved when interviews began to reveal redundant information.

3.8. DATA COLLECTION STRATEGIES

As mentioned previously, the main data collection strategies employed were face-to-face and telephonic interviews. The interviews were conducted in a private room at the study location at a time that was convenient to the participant. The dialogue was audio-recorded, with written consent from the participants, and notes were taken by the researcher during the interviews. The telephonic interviews were audio-recorded while on speaker mode. The interviews varied in length, that is, approximately 20 to 35 minutes. The interview questions were formulated based on the research questions, using an exploratory design, and were refined following the pilot studies. (*See Appendix 1, pg. 108 for the interview schedule*).

As the participants were familiar with the researcher, rapport had already been established. In this type of research, it is essential for a trusting relationship between the researcher and the participants to be established. The implications of this relationship and rapport is discussed further in Section 3.14 under trustworthiness (*pg. 35*). Optimal responses were obtained through open-ended questions posed, and prompting when required, for a more in-depth discussion.

3.9. PILOT STUDY

A pilot study was conducted with one participant from each participant group, three in total, for refining of questions, to ensure that the interview schedules were in response to the aims and objectives of the study. These participants were provided with informed consent forms, and interviews were audio-recorded and transcribed. Once coded, the data was noted to be useful, and aspects from the pilot studies were included in analysis of the body of data, given that the sample accessed for the pilot met the same criteria as for participants in the main study and given the qualitative nature of the study. Questions were amended, not in terms of content, but the way in which they were phrased, so as to prompt more open-ended responses, and to provide extended prompts in cases where the participants required clarification.

3.10 RESEARCH PROCEDURE

3.10.1. Administration of informed consent forms and scheduling of interviews

Informed consent forms *(See Appendices 4, 5, & 6 pg. 111 to 114*) were presented either directly, or via e-mail to participants who met the inclusion criteria. Three separate informed consent forms were drafted, for each of the three participant groups. Once consent was provided, interviews were scheduled with participants, in a time and place that was convenient to both parties. Face-to-face interviews were held in the private boardroom at the study location, and telephonic interviews were conducted with the two therapists after working hours.

3.11 DATA ANALYSIS

Thematic analysis was utilised for analysis of the data. Each interview was transcribed manually, and relevant quotes (or initial codes) were retrieved. Within each participant group, a coding table was drawn up. This consisted of three columns: initial codes, categories, and themes (Clarke & Braun, 2014). The researcher utilised deductive reasoning in the analysis of the data, matching these to the objectives of the study.

Clarke & Braun (2006) identified six phases of thematic analysis. In this study, these phases were adopted in the following ways:

1) **Familiarising one’s self with the data:** The researcher initially familiarised herself with the data, by listening to the audio-recordings of each participant in each participant group several times, manually transcribing the recordings, reading these several times and documenting (writing memos) during this process.

2) **Generating initial codes:** The transcriptions were re-read several times, and within each transcription, relevant quotes were highlighted as the initial codes. The codes of all transcripts in each participant group were then separated and grouped according to their commonalities, meaningful to the aims and objectives of the study, which were labelled as categories.

3) **Searching for themes:** The categories within each transcript were then clustered, once again according to the aims and objectives of the study, to form larger themes. This was done for each participant group, and common themes were generated between participant groups.

4) **Reviewing themes:** The themes were generated by grouping of the initial codes and categories were scrutinized, to determine whether they were answering the research questions initially created. Additionally, a backward approach was used where the themes were looked at against the categories and then initial codes, to ensure that there was a link between the three and to ensure that in the thematic analysis, the core initial codes and meanings were not lost.

5) **Defining and naming themes:** Each theme was then separately analysed, in order to determine its essence and relevance to the study (Braun & Clarke, 2006). The themes were further analysed to determine whether they needed to be subdivided into subthemes.

6) **Producing the report:** Each theme was then analysed further with regards to literature surrounding the topic, and the meaning in the context of the current study.

The data was linked to the research question, aims and objectives of the study, and the findings and relevance are detailed in the results and discussion chapters of this thesis.

3.12 DATA MANAGEMENT

Data obtained in this study has been stored on an external hard drive and password protected laptop which are accessible only to the researcher and supervisors when necessary. Hard copies of data have been stored within a lock-up cabinet, and will remain there for a period of five years, after which they will be incinerated. Data on the external hard drive and laptop will then also be deleted.

3.13 TRUSTWORTHINESS

3.13.1 Reflexive statement

The researcher qualified as an occupational therapist in 2011, and had been working at the study site providing outpatient therapy for ABI survivors at the time of data collection. Through group and one-on-one therapy sessions with the clients, the researcher grew curious as to why ABI survivors who had been attending the programme for several years, some for more than 10 years, continued to do so. This was the only type of facility providing this type of care in the province known to the researcher, which is why it was selected as the study location. The researcher was also interested in finding out what the experiences of the caregivers and therapy team were, as they were an integral part of the therapy process at the study location.

Throughout the research process, the researcher was conscious of suspending any judgement, bias, and influence over the participants, as well as during the analysis of the data, to ensure that reliable and objective findings were ascertained. To enforce trustworthiness, the perspectives of a peer (an Occupational Therapist with a Masters Degree), was engaged so as to ensure that the data analysed and themes generated were not biased by the researcher’s positionality. The advantage of the participants being familiar with the researcher, was that rapport had already been built, and participants were able to share their stories more easily given this rapport. A disadvantage was that, at times, the participants assumed that the researcher understood and could make deductions from an explanation of their experiences which led to responses not always being as in-depth as would have been preferred. This necessitated more prompting, paraphrasing of responses, and repetition of questions during the interviews.

3.13.2. Credibility, dependability and confirmability

Trustworthiness was ensured by following the principles of credibility, dependability and confirmability (Shenton, 2004).

Credibility was ascertained through the use of purposive sampling for the recruitment of participants, which ensured that relevant data from relevant stakeholders were collected. Audio recorders were used during the interviews to ensure that verbatim responses were gathered, which were transcribed verbatim, and thick descriptions (verbatim quotes) were used in the analysis of this study. Additionally, source triangulation was adopted as three participant groups were interviewed, to ensure that the perceptions of all groups of individuals involved in the long-term therapy programme were explored. Each participant was provided with an information document and consent form, and given the opportunity to withdraw from the study at any given point. Frequent debriefing sessions were held between the researcher and supervisors, which allowed for those with more experience to detect gaps or omissions in the analysis, and ensured an objective perspective when looking at the data.

Peer review was done with a colleague, who scrutinized the data prior to analysis by the researcher, and discussed their views with the researcher from a non-biased perspective. During the interview process, member checking was applied at random, where a participant’s point would be summarised or paraphrased back to them to ensure that no miscommunication occurred, and that they were satisfied with their responses. This allowed for clarification had they felt that there was misinterpretation of their responses. The pilot study was conducted with individuals from each participant group to ascertain whether questions were phrased appropriately, and to sort out any logistical matters for later running of the interviews, such as operating the audio-recorder.

Dependability was applied by ensuring that should another researcher attempt to conduct this study, they would acquire similar findings. This was ensured by the researcher documenting the specific steps and methods used in the study, and subsequently documenting a comprehensive audit trail.

Confirmability is the principle where investigator bias needs to be removed. This was ensured by triangulation, as mentioned above with the three participant groups, a reflexive statement was made to divulge all potential biases, which the researcher was constantly conscious of, and how these were managed, and by scrutiny of the audit trail. (Shenton, 2004).

3.14 ETHICAL CONSIDERATIONS

Ethical clearance was applied for and approved by a Biomedical Research Ethics Committee (BREC) prior to commencement of the study (reference number: BE202/16). Additionally, an online ethics course was completed (*Appendix 7, p. 112*). The gatekeeper of the study site was e-mailed to request authorisation for the study and permission was granted (*Appendix 2 p. 104 and Appendix 3, p. 107).* The ethical principles followed throughout the study were as follows:

3.14.1 Informed Consent and respect for persons

All participants, including those involved in the pilot study, were provided with an informed consent form detailing all relevant information about the study and what participation entailed, including that they were able to withdraw at any time without prejudice, and all were informed of audio-recording. Only those participants who voluntarily provided consent after perusal of these forms, were included in the study.

3.14.2 Beneficence

The outcomes of this study did not and will in no way cause any harm to the participants, but may benefit those attending the long-term therapy programme in the following ways. The study findings may be used to increase awareness of long-term therapy for ABI survivors, their needs and the challenges, and could also indicate possible recommendations for the current programme, which could benefit the ABI survivors, their caregivers and therapists at the facility, as well as potential future programmes that may be similar.

3.14.3 Non-maleficence

There was no anticipated or direct harm to any of the participants involved in this study. Due to the sensitive nature of the questions, face-to-face interviews were held with the ABI survivor participants in place of the focus groups, to ensure that they were free to share any information in an intimate but safe space. The face-to-face interviews were held at the study location, for convenience of their attendance, and with adherence to their schedule within the programme. No costs were required on the part of the participants. And there was no payment to participants for participating.

3.14.4 Confidentiality

Confidentiality of participants and the NGO was maintained throughout the study. The study location remained anonymous, and pseudonyms were used in place of the participants' names during both the data collection and analysis. Data collected in the study will be permanently disposed of after a five-year period. All 3 participant groups were informed of this in their consent information letters. (*See informed consent letters in Appendices 6, for ABI survivors (pg. 113-114), for caregivers (pg. 115-116) and the therapy team (pg. 117-118)).*

3.14.5 Scientific Honesty and Integrity

The reliability of the study findings is based on the fact that scientific integrity and honesty were upheld throughout. The Singapore Statement points to the characteristics required in integrity of a study, highlighting the principles of honesty, accountability, professional courtesy and fairness, good stewardship (Collste, 2015). These principles were considered from commencement to completion of the study, as follows: in terms of honesty, the participants were provided with informed consent forms prior to data collection, highlighting all aspects of their participation. This data was transcribed verbatim by the researcher, to ensure validity of the findings. The participants were each treated with professional courtesy and fairness and given the opportunity to withdraw from the study at any given time. Good stewardship was also followed in that the data was managed responsibly, and upon completion of the study, a report will be drafted and the findings published to ensure accessibility to all who are interested in the field.

3.15 SUMMARY

Chapter three details and motivates for the methodological process followed in this study and describes the manner in which data were collected and analysed in this study. The study design, sampling and recruitment of participants, data analysis and management, and the ethical considerations have been described within the context of this study with implications highlighted where necessary. Trustworthiness and credibility were adhered to, to ensure validity of the study findings.

This study followed a qualitative exploratory design in order to describe the experiences of the ABI survivors, caregivers and the therapy team, around a long-term outpatient NGO in KwaZulu-Natal. Sampling of the three above-mentioned stakeholder groups included in this study have been provided with details of their participation. Issues around the ethics in research have been described, taking into consideration the vulnerability of this population. Trustworthiness, which demonstrates the rigour of the research, has been described with strategies that were employed to ensure authenticity in the research process. Chapter 4 elucidates the findings of the study which are combined to describe the lived experienced of these three stakeholder groups.

CHAPTER 4

RESULTS

4.1 INTRODUCTION

Chapter 4 presents an analysis of the findings that emerged from the analysis of data obtained through interviews with the three groups of participants, namely the ABI survivors, caregivers of ABI survivors and the therapy team involved. Three main themes emerged, which included the impact of an ABI, indicating the need for long-term therapy, the benefits of long-term therapy, and the challenges of long term therapy. The demographic profiles of the participants are summarised and thereafter the three themes are outlined.

4.2. PROFILES OF PARTICIPANTS

The following three tables detail the profiles of the three groups of participants, namely, ABI survivors (n=5); caregivers of ABI survivors (n=3) and the therapy team (n=3).

Table 4.1 Profile of the ABI survivor participants

Participant Alias	Age	Gender	Race	Type of ABI	Year of ABI
Harry	54	Male	White	CVA	2002
John	48	Male	White	CVA	2012
Ted	27	Male	White	TBI	2007
Sam	45	Male	Indian	CVA	2007
Doug	43	Male	White	CVA	2014

Table 4.2 Profile of the caregiver participants

Participant Alias	Age	Gender	Race	Type of caregiver
Mandy	54	Female	Indian	Formally employed
Amanda	48	Female	White	Family member
Beth	35	Female	African	Formally employed

Table 4.3 Profile of the therapy team participants

Participant Alias	Age	Gender	Race	Designation
Kate	24	Female	White	Occupational therapist
Martha	56	Female	White	Physiotherapist
Nancy	34	Female	Indian	Speech and language therapist

Figure 4.1 below provides a diagrammatic presentation of the themes and sub themes that emerged from the study.

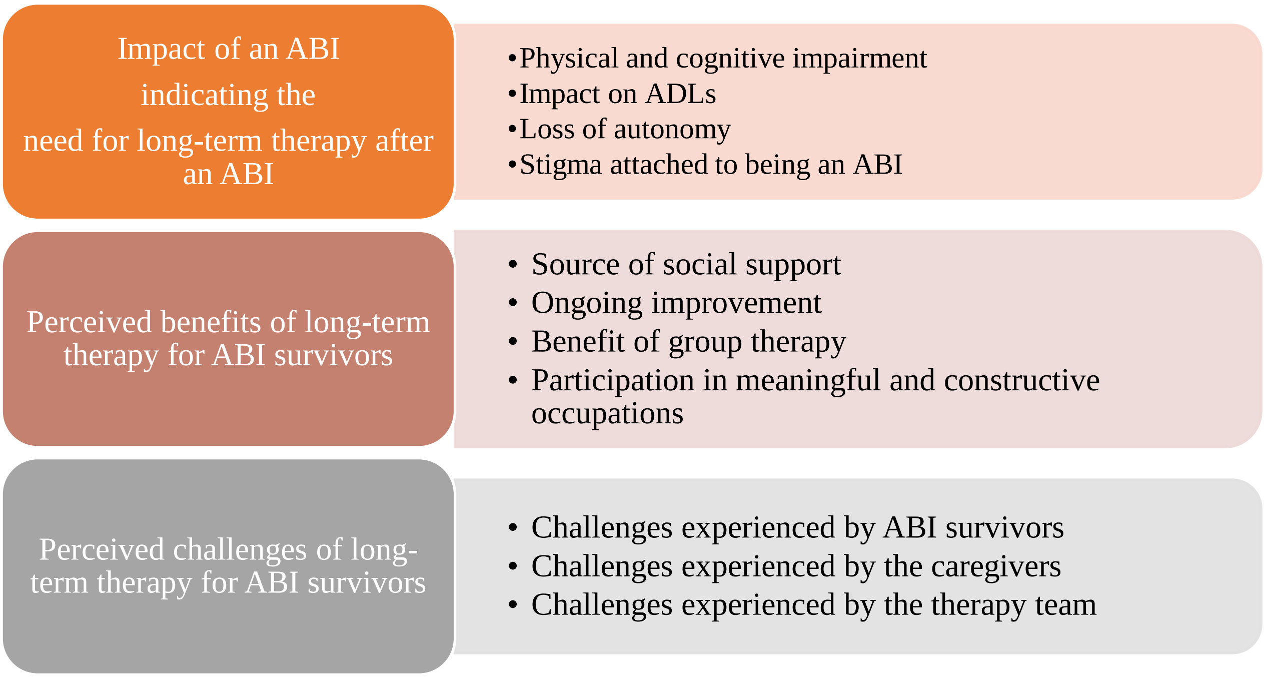

Figure 4.1 The themes and sub-themes that emerged from this study

4.3. THEME 1: Impact of an ABI indicating the need for long-term therapy

ABI survivors' experiences were elicited regarding the impact that the condition had on their daily lives, in order to gain insight into the need for long-term therapy. The common problems that were expressed were regarding their physical and cognitive functioning, in their ADLs, with their autonomy, and the stigma that was attached to this condition.

4.3.1. Physical and cognitive impairment

The participants revealed that difficulty in upper limb mobility was a significant restriction and activity limitation to their daily participation. Participants expressed not having complete use of one of their upper limbs, years post injury.

> *"although I've recovered..uhh a enormous amount, I still don't have full strength on my left arm and left hand" (Harry, 54, CVA survivor)*

> *"With my fingers not working, that's even the worst, more difficult part. The arm can lift up and stuff like that, but the fingers doesn't work and I always say, I dunno one day if the fingers start working, what's gonna happen, I'm gonna have such a shock" (Sam, 45, CVA survivor)*

One of the participants mentioned the difficulty that using one hand posed.

> *"it's especially with uh, with the left hand, that's been uh not working, there's – I only got one hand you know, I mean if you take yourself, you know, and you tie your hand up, it's difficult to just all of a sudden, and especially with my left hand, doesn't work so well" (Sam, 45, CVA survivor)*

However, he still had hope that he would have return of function of his upper limb/hand and often tried several intervention strategies recommended by other survivors to improve his hand function.

> *"Because you know, they just don't wanna work. I've done everything, people has given me balls to play with in my hand, and it just doesn't want – I went for massages at uh people that they say uh made other people's hands work and, and I just, it just doesn't wana work for me, you know" (Sam, 45, CVA survivor)*

The ABI survivors reported that lower limb impairments often severely impacted on their functional mobility. This being particularly relevant in the initial stages of therapy when sitting balance and posture were also affected.

> *"That stroke gave me umm total paralysis on my left side. And it actually, it put me in a wheelchair. That's why when I came to [name of NGO], I came in a wheelchair. I couldn't stand, I couldn't even sit like the way I'm sitting today. They had to tie me up onto the chair so I don't fall over" (Sam, 45, CVA survivor)*

> *"I had to be taught how to walk again and that's about a four-month process at a rehab centre" (Harry, 54, CVA survivor)*

However, some ABI survivors reported that they still faced challenges with mobility years after the brain injury was sustained. Impairments in balance was a factor that contributed to difficulties experienced with walking.

> *"I mean walking and so on is quite difficult uhh for me I think umm, although around the house I walk without a crutch. Uhh the thing about walking around the house is there's – you can't go too far without touching a surface of some sort in case you lose your balance or something" (John, 48, CVA survivor)*

A caregiver participant mentioned that the gains achieved in walking were not always functional, but rather only achievable for short periods.

> *"it's just the walking that he can do for that particular time only, it's not something that he can do permanently or like it's something that's gonna make huge changes to him" (Beth, 35, employed caregiver)*

An ABI survivor and therapist both reported impairments in speech as creating challenges in communication with others.

> *"if it's post stroke and they have aphasia, umm it makes it very difficult for them to, to express themselves. And sometimes it's also difficult for them to understand what's being spoken about them" (Nancy, 34, speech and language therapist)*

> *"And I heard myself on people's recordings before I started at [name of NGO], and I could hear that my voice sounded very broke, I, and I couldn't string my sentences together" (Ted, 27, TBI survivor)*
> *"and my left jaw, um my mouth sagged on the left side so I started sort of slurring my words" (Harry, 54, CVA survivor)*

The ABI participants reported their main cognitive impairment as short-term memory, which affected their participation in ADLs.

> *"well uh when it comes to my memory uh I do forget things. Like uh I mean when it comes to medication, you know my tablets" (Sam, 45, CVA survivor)*

> *"I just can't handle the-I can't- I do the exercise but, it just gets too much for me after-because I think I start forgetting of what I must do" (Sam, 45, CVA survivor)*

One of the ABI participants mentioned that he had initially experienced difficulty controlling his emotions, another remarked that he remained with residual visual impairment, and another commented on the difficulty that he still had with swallowing.

> *"the first couple of years were quite difficult to control, uh my emotion and such and-but I'm slowly I'm uhh better able to control them" (John, 48, CVA survivor)*

> *"other thing that was affected is my peripheral vision" (Harry, 54, CVA survivor)*

> *"when I swallow and I involuntarily cough because of it uh and it's something I can't control still, so if anything, uh that is, uh, it can be, a-a bit uh, a bit problematic" (John, 48, CVA survivor)*

4.3.2. Impact on ADLs

The ABI participants reported that their ability to participate in certain ADLs was severely affected, which was a marked difference from their pre-morbid level of functioning. The restriction in participation was attributed to the physical and cognitive impairments experienced by the ABI participants.

One of the participants felt that his ability to participate in simple basic activities of daily living, such as meal preparation and toileting, was affected by his impairments, but had learnt to adjust and cope due to his intrinsic motivation and need for independence.

> *"just normal stuff, uhh like in breakfast lunch and dinner and going to the toilet and making my bed and so on. It's actually, it takes a bit longer so I, I've just slowly adjusted, but I keep telling myself that, well, it doesn't matter that it takes twice as long, as long as you get it done." (John, 48, CVA survivor)*

Two of the ABI participants voiced restrictions in their ability to participate in ADL tasks such as participating in constructive leisure tasks, and in vocational pursuits, and expressed a feeling of loss due to not being able to participate in premorbid activities.

> *"so my previously, umm joy of playing musical instruments – pianos and keyboards and things like that – I can still play about 400 tunes by heart with my right hand, but my-the-accompaniment from my left hand is not available." (Harry, 54, CVA survivor)*

> *"unfortunately one of the requirements of my job is that I need to be able to drive a motorcar. And with the impaired vision and impaired left leg, uhh, and uhh I'm not able to drive which means I was therefore medically boarded" (Harry, 54, CVA survivor)*

> *"so uh, it was quite difficulty from that point of view to let that go, I mean I've been consulting for about 20 years, and all of a sudden it comes to an end, just like that." (John, 48, CVA survivor)*

> *"I was umm..uhh I had a private pilot's license so I couldn't fly anymore, I was a squash player and I couldn't play squash anymore, windsurfer – your balance is quite critical in everything, in those things especially. And uh, I was also a golfer and obviously it's quite difficult to play golf because uh, my right side is affected, and so I found that it's quite difficult to swing through, and hit a golf ball" (John, 48, CVA survivor)*

4.3.3. Loss of autonomy

The ABI participants reported that their loss of independence and autonomy was one of the biggest effects of having an ABI. This loss of independence resulted in a new-found need for assistance and fostered reliance on others to be able to complete ADLs and other tasks that they were independent in pre-morbidly.

> *"so uhh, the loss of independence, and for me the loss of driving – driving a car – was a big deal because you, you have to rely on someone else" (John, 48, CVA survivor)*

> *"I'm quite an independent person so it was quite difficult to get used to the uhh, depending on a person, someone else" (John, 48, CVA survivor)*

> *"I still have a problem dressing myself. That's why I got a carer at home, uh she, she does, every morning she's there to-she help me with-like even with brushing my teeth, I can't brush my teeth on my own, so she's there to help me you know, to give me water to wash my face and all that" (Sam, 45, CVA survivor)*

One of the participants felt that, due to the upper limb impairment, he was unable to participate in certain tasks without assistance, resulting in him opting to not participate in the task.

> *"but now because the other hand doesn't work it's very difficult for me, I always need a partner, you know, to help me. Like one of the volunteers they will normally help me too, when I used to do the beading. But now-then afterwards I*

> *said no, I rather give up the beading, you know, don't do it at all" (Sam, 45, CVA survivor)*

He also felt restricted in his ability to access amenities.

> *"I'm restricted to where, you know wherever I wana go, I need somebody to be with me or, accompanying me like, if it's not my wife it's one of my sons. Somebody has to accompany me" (Sam, 45, CVA survivor)*

4.3.4. Stigma attached to being an ABI

One of the ABI participants voiced that the general population viewed them as different. The ABI participants and the therapists indicated that individuals who may have not previously interacted with a person with a disability, often viewed and interacted with the ABI survivor differently.

One of the ABI participants mentioned that people in society frequently make assumptions and undermine their abilities, which he found frustrating, and added that he would assisted in tasks when he did not need the assistance.

> *"People often assume that you can't do much, which is the wrong thing-you should actually give the person a bit of space and see what they can do. And that I found frustrating for me, in the beginning. I think there are a lot of things that uh would be done for me that I could do for myself" (John, 48, CVA survivor)*

> *"the thing is that people often assume you can't do something – you can't do this and you can't do that" (John, 48, CVA survivor)*

One of the therapists explained that the study location was seen as a place of comfort and security, as society generally judges and discriminates against people with disabilities.

> *"I think they just feel comfortable [at the NGO] because out in the world, people can be very harsh, and if you got a physical disability people look at you strangely and don't always interact nicely with you" (Martha, 56, physiotherapist)*

One of the ABI participants expressed concern that society had misconceptions of brain injuries and how it affected the survivor

> *"I think that I enjoy it because, I enjoy it because people they often think once you have a brain injury, that's it, life stops, but I'm a testimony to that. I'm proof that it doesn't stop. Life is what you make it" (Ted, 27,* TBI survivor)

Having presented and discussed the main findings on physical and cognitive impairment within this theme, the next theme examines the data on the participants' perceived benefits of long term therapy for ABI survivors.

4.4 THEME 2: Perceived benefits of long-term therapy for ABI survivors

This theme explores the positive experiences of long-term therapy for the ABI survivors. The ABI participants frequently reported that the social support system provided by this type of care was beneficial. Additionally, they indicated that they believed they were gaining from ongoing improvement, and through participation in meaningful activities, which was motivating.

4.4.1 Source of social support

All the participant groups expressed the view that the social support provided for the ABI survivors was the most beneficial aspect of long-term therapy. Many of the participants were not employed, and thus attended the long-term therapy programme most days in the week. This appeared to serve as a supportive environment, where they could share ideas, advice and stories, in a non-threatening setting.

Many of the ABI participants appreciated the ability to interact with others who had experienced similar challenges or were experiencing similar problems. These shared experiences are expressed below.

> *"I have plateaued in terms of my physical mobility, but I like coming here because you can always talk and share with people who have had similar injuries to you. I mean, they may not be the same, but we are all brain injured people. So it's nice to hear, to hear about things from other people's perspectives" (Ted, 27, TBI survivor)*

> *"the big thing for me about [name of NGO] is, you know, coming here and spending time with people that's in the same position as me, you know. We got the same stuff in common, you know, that we can talk about, and stuff like that. And that's what makes my uh, you know, my train tick over." (Sam, 45, CVA survivor)*

> *"the reason why I would say I enjoy coming to [name of NGO], interacting with the therapist and the patients here, you know they can converse with me, and they know where I come from and they know how I feel because they also in the same boat, you know" (Sam, 45, CVA survivor)*

> *"and we can, you know we can share, because what problems they have, I also have the same problems, you know" (Sam, 45, CVA survivor)*

Two of the therapy team participants reinforced long-term therapy as beneficial and supportive to ABI survivors, and perceived it as an opportunity for individuals with ABI to interact with people who had experiences similar to their own.

> *"I think that being in a place where there are lots of people who are going through the same thing" (Kate, 24, occupational therapist)*

> *"um and I think there's obviously, for some patients it's where they're being in an environment where people understand their difficulties, and also they can*

> *meet other people that have similar difficulties as well. So I think it's the whole socialisation and support that [name of NGO] offers." (Nancy, 34, speech and language therapist)*

Both a caregiver and therapist participants maintained that a long-term programme provided an opportunity for the ABI survivor to interact with a variety of people, instead of being isolated at home. Additionally, another therapy team participant reinforced that, in this type of environment, the ABI survivors could socialise without the stigma attached to their condition. One of the ABI participants reported enjoying being able to share his story, and in having the opportunity to meet new people, which he likely otherwise would not have had the opportunity to do, had he been at home all day. Some of the survivors also chose to spend the entire day at the organisation.

> *"I think with some people I do see that it is, it's the social aspect and the social support because if they just at all, all they-they just only interacting with carers or nobody's there interacting with them, whereas if they come to [name of NGO], there's a lot going on" (Nancy, 34, speech and language therapist)*

> *"socially because at home, there's not much people who are around, during the day, so being here, he gets to be around people, chat with them, socialise and all that" (Beth, 35, employed caregiver)*

> *"I think with communication um a lot of, being able to communicate is social, so I think sometimes if you're only in an environment where you, you now, you only have, a carer to communicate with or a family member or-it can be-I think it can lead to some, a bit of social isolation, and um, uh so I think, I think with communication, because it-again I'm saying it's so social, it usually involves a lot of people." (Nancy, 34, speech and language therapist)*

> *"I think socially it provides a huge platform where they interact, and they are treated as 'normal' people, if I can put it like that, and they expect to do and maintain certain things under strict rules." (Martha, 56, physiotherapist)*

One of the therapy team participants remarked that this type of organisation and programme exuded positivity which was seen as beneficial for the ABI survivors. Additionally, a familiar environment was created, where the ABI survivors, the therapy team and the caregivers were accustomed to one another thus forming a shared community, where individuals know each other by name. A caregiver participant mentioned that the participants in the long-term therapy programme and the therapy team felt like family.

> *"I don't know what it is exactly but there just generally is a warmth and positivity here – I-I can't put my finger on it, but there's definitely something in the way people interact, the way everyone greets each other so cheerfully and um, knows everyone by name, that just-is sort of infectious in think." (Kate, 24, occupational therapist)*

> *"I know not everyone is motivated, but what I've found about here is that generally there's a very positive attitude uhm, I find that in the groups, they encourage one another um, and have fun together, which makes my job a lot easier because I don't have to be sitting there cheering them on and-the whole time-and running out of steam and even in individual therapy. I feel like they come in-most of them come in positive, with a goal in mind, and that's been really rewarding, really encouraging" (Kate, 24, occupational therapist)*

> *"she likes the company she's in. she enjoys that. She laughs and talks with everybody. Tries and verbalise with them. And umm.. yah the company that she's with uh they are very caring, like we are one big happy family when we come out here" (Mandy, 54, employed caregiver)*

One of the ABI participants stated that he valued being able to provide the social support, not just receive it, reinforcing this mutual connectedness.

> *"so you feel that, although you severely injured compared to where you were, you are still..your life is still making a contribution towards uh other people because there's a lot of comradery and also because you experience something*

> *quite profound, you're able to assist or advise other patients and also discuss matters with the therapists." (Harry, 54, CVA survivor)*

What was interesting to discover was that the caregivers of the ABI survivors also benefitted from the social support. The caregiver participants and therapy team participants reported that caregivers gained knowledge on how to care for their family member, and were able to interact with others who had similar experiences and who faced similar challenges. Additionally, the caregiver participants reported finding relief and freedom in having some time for themselves and being able to interact with someone other than the ABI survivor.

> *"we sort of forget about them often and focus only on the client, but um I think it's really nice for the caregivers to meet other caregivers and to know that their loved one-their-that the client is fine-having support from other people so I think it can sort of make-ease their minds a bit and also be-form education for them about what's going on" (Harry, 54, CVA survivor)*

> *"just to see also, to see that you not the only one going through whatever that you going through with the family-you realise that actually, other people are going through worse than what you going through" (Beth, 35, employed caregiver)*
>
> *"Because most of the time we stuck, just the two of us, so we end up not saying anything at all to each other, we just sitting there, so.. being out and about, talking to other people, it also makes a difference" (Beth, 35, employed caregiver)*

> *"I think for me it's much more of a relief, because then-you can imagine us stuck at home, just the two of us the whole flippen week (laughs).. I'll go crazy too. So being here, it also gives us a breath of fresh air" (Beth, 35, employed caregiver).*

> *"Oh I've learnt a lot. I've learnt extremely a lot because uhh.. I never did what I can do now, like I've watched you guys doing the occupational therapy, the physio – I help out with the physio and I also help out with the various uh.. things around here and uhh – she's – with uhh speech therapist she's improved. We've*

> *given – they've given us material to go over with the patient. Yah and I've learnt a lot. I've learnt extremely a lot from here." (Mandy, 54, employed caregiver)*

One of the therapists also felt that working within a multidisciplinary team was beneficial, as she received support from the other therapists.

> *"when you sit down with the individual therapists in a group meeting that you start appreciating that sometimes we can, we work together towards the same goal maybe in a different route, and that if we have a shared goal and we push together, we can often achieve something better. So it's much easier to share that kind of information and have a positive outcome, than try and struggle along on your own and come up with all the ideas and all the input." (Martha, 56, physiotherapist)*

> *"It does help to be working in an environment where there's more than one therapist. So um sometimes you are really stuck-what do I do now, I'm not achieving what I'm trying to achieve and we do share ideas and get ideas from each other so, it is much easier than if you were working completely on your own." (Martha, 56, physiotherapist)*

4.4.2 Ongoing improvement

The ABI participants reported that they experienced improvements, albeit small and slow, in their overall ability. At the study location, progress was also regularly monitored via open events such as sports days. Improvement was noted in physical functioning and mobility, speech, and ADLs such as toileting.

> *"I find with brain injury patients particularly, there is no quick fix. It is a long slow process and there is ongoing improvement, umm I dare to stick my head out and say six, ten years down the line they can still improve." (Martha, 56, physiotherapist)*

"you see um people, you know a year down the line, the-the way that patients will actually improve, and you think, you think like a year of therapy and yes they're doing okay, but it's actually in the second year and the third year that you actually see more uhh you see more improvement with the patients, so it's a long-term process" (Nancy, 34, speech and language therapist)

"I think that umm even if you are, if you don't see, the thing I've learnt with the stroke group, with a stroke, is that things take longer to get done. Umm though in the first two years you might see some changes, after that the changes are very slow. Because then you start to give up hope, and that doesn't mean that you shouldn't-you stop doing what you are doing uhh because you don't see the progress" (John, 48, CVA survivor)

"the whole process is like walking up a flight of steps. You go forward and initially you improve quite a lot and the longer you stay obviously the steps are smaller, but they lasting and they very beneficial" (Harry, 54, CVA survivor)

"I think I'm coming up to two years, and there's patients I'm seeing from the beginning, and now I'm in to the first and second year-the second year working with them. And I'm still discovering things from them, you know, their, their abilities, what's working. I still see recovery" (Nancy, 34, speech and language therapist)

"I've learnt over a period of time that you can achieve an incredible amount with some of the patients, some more than others, but that satisfaction of achieving that, even with the small, with the minority of patients, makes it extremely rewarding and worthwhile trying" (Martha, 56, physiotherapist)

"with our group exercise patients, in other words those that have moved on from individual to long term, we run-we have been running regular umm, uh galas and sports days and we've kept records of how they've um, with certain items-their progress in that, and we regularly and-see uh ongoing improvement in

> *those, in the long-term patients, which is uh often a good indication of the fact that there is improvement in the long-term" (Martha, 56, physiotherapist)*

> *"I've been doing it for a year and I feel like.. yah a lot of things I've achieved, as I said like I'm independent at home, I go to the Jon by myself-the toilet" (Doug, 43, CVA survivor)*

Therapy team participants revealed that long-term therapy also aimed at maintaining what had already been achieved, and in preventing further deterioration. In addition, the ABI participants reported that having a long-term programme offers the ABI survivor the opportunity to access the various therapists in one facility rather than having to access each discipline separately.

> *"I think it offers a good guidance for the patient to understand that it's ongoing, it needs to become a lifetime thing so I think if you working with the patient and you know that they now, after five, six years, they understand if they don't stretch their hands, they're going to get contractures for example, then they will, they do see benefit of that constant input" (Martha, 56, physiotherapist)*

> *"I think that the patients do plateau out as to the amount of improvement they can achieve, um in certain areas. But without an intervention of maintenance such as um, regular exercise, they would lose strength for example, or other aspects of their improvement." (Martha, 56, physiotherapist)*

> *"I think that if we don't see improvement we do see maintenance through the long-term intervention. And they quickly see a deterioration if they stop, even for a couple of months, they seem to find that, they gravitate back to us because of this issue that they, they lose what, what they've gained, quickly" (Martha, 56, physiotherapist)*

> *"there are multiple disciplines at [name of NGO] which is also beneficial because you don't have to go to four different therapists at four different*

> *locations, cause moving is difficult as well, you can do it all in one place, within a couple of metres" (Harry, 54, CVA survivor)*

One of the therapists indicated that therapy is a two-way process: not only is the ABI survivor discovering and re-learning skills after their injury, but the therapist is also discovering new things and new abilities and potential as they work with the ABI survivor and see progress after many years.

> *"the process of therapy, it's not umm, it's not recovery but it's discovery" (Nancy, 34, speech and language therapist)*

4.4.3 Benefits of group therapy

The ABI participants found benefit in the variety of groups offered by the study site, and reported gaining stimulation from participation in the groups. Some ABI participants mentioned that they enjoyed the outings, which they would have otherwise not been able to participate in, due to the obstacles posed by their disabilities, in accessing various facilities. The ABI participants found that the high turnover of staff, which allowed for new ideas and activities, and the variety of activities offered at the study site, allowed them to remain stimulated.

> *"just the variety of umm, of games we play, the interaction, the umm, the opportunity to, to contribute some or other umm bit of knowledge or just to, just to stimulate my mind for a bit-with different things. And so uhh that's an important thing I believe. It's something you wouldn't get anywhere um so yah, I think that's actually important I think. It's also-the thing I like about [name of NGO] is that you can do all these things in a non-competitive way or non-threatening way, which is uh, which is a good thing I believe" (John, 48, CVA survivor)*

> *"a valuable idea is the outings that we have and those.. those are set out to explore a various number of different things. Some are like..uhh..sailing around the bay and others are going to nature reserves, so those are sort of things that*

> *so called disabled or impaired people normally don't get the chance to do..or having scones at the botanical gardens and things, you know, those are fun things" (Harry, 54, CVA survivor)*

> *"we had a stroke group where items which are specific to uh say a group of 6 to 8 people..uh.. can voice what's happened in their situation and what they've achieved or what they found useful or how they've got past a problem- you know we've discussed even matters about toilet etiquette and how to deal with catheters and things like that, which are quite personal, but uh if one knows especially when you start, that somebody else's been there done that and they can ex- they can help you by their own experience – I've tried that and I've tried that and don't do that. So you know that sort of thing is real and it's very helpful." (Harry, 54, CVA survivor)*

> *"they also have the stroke group that she attends and she understand everything, although she cannot verbally express it, but she do understand every word they say." (Mandy, 54, employed caregiver)*

> *"I think there've been different things they're doing-they not doing the same thing every year" (Amanda, 48, family member caregiver)*

> *"but we've been very fortunate at [name of NGO] in that, on about a three and a half, or four-year cycle, the therapists have changed..so there's been an opportunity for new ideas and new therapists to impact on the programme so although the programme is similar, it's not the same. So therefore the patients' point of view it's like a breeze of fresh air" (Harry, 54, CVA survivor)*

4.4.4. Participation in meaningful and constructive occupations

The ABI participants and the caregiver participants reported that the ABI survivors found the creation of products, learning new skills and participation in leisure pursuits beneficial. The ABI participants viewed their participation in group therapy as their vocational activity for that day. This was seen to provide a sense of accomplishment which most of the ABI survivors would be denied, given their difficulty in securing employment, due to their physical and cognitive impairments.

> *“also the craft work-the craft groups, they do because at least they keep him busy, he got something to look forward to do” (Beth, 35, employed caregiver)*

> *“I think she gets more satisfaction in herself and seeing what she can actually make. And seeing it afterwards, what she’s applied to it, what- her teamwork she’s put into it, that obviously she feels satisfied, you know, and rewarding for her” (Amanda, 48, family member caregiver)*

> *“it’s a whole new venture. She’s gotta get dressed, she’s going out and it’s a big thing in her life to go in the car with mum, you know, we’re going out, I’m going to do hard work at [name of NGO].” (Amanda, 48, family member caregiver)*

> *“I think the programme that they have had of skills development has also been an area which I personally have found extremely enjoyable because it’s taught you something” (Harry, 54, CVA survivor)*

> *“there was a skills development, uh that they taught us a skill where you know, with our disabilities, we’ll be able to make the soap and sell it, and make income” (Sam, 45, CVA survivor)*

> *“the last thing we want is for people to become-to sit at home and do nothing, and it can be really helpful for recoveries to engage in things and to find enjoyment” (Kate, 24, occupational therapist)*

> *“I feel, she needs that independence as much as possible at home, but when we come here, it’s an outing and she’s gotta work” (Amanda, 48, family member caregiver)*

> *"That's why I enjoyed the pottery so much and I'm a bit bunged that we've had to terminate that, dealing with your hands which is something I needed and dealing with clay-you've gotta put in quite a lot of effort which you don't think you're putting in. So that's… you're sort of doing a good job without even realising it. You know…so..and I think that's good therapy, because uh you're doing therapy and then you have a prize at the end of it..which is always motivational for anybody." (Harry, 54, CVA survivor)*

> *"my role is individual and group therapy, so um, individual therapy, basically focussing on rehabilitation, and that can be physical and cognitive with the purpose of regaining function and ability for the per-the client to go back to daily living, to do the things that they need to do. Um, the groups are…some of them are creative, some of them are more um, specifically more therapeutic, there are outings, so that really varies a lot and I'm responsible for doing some of those." (Kate, 24, occupational therapist)*

4.5 THEME 3: Perceived challenges of long-term therapy for ABI survivors

Several challenges were expressed by each of the participant groups. These are discussed in further detail below.

4.5.1. Challenges experienced by the ABI survivors

The ABI participants maintained that the most common concern was engaging in therapy that was seen as repetitious or routine. This led to feelings that the programme had become monotonous and part of the daily routine, hence not of benefit. Additionally, ABI participants reported feelings of boredom due to attending one facility and programme. One ABI participant even voiced trying to find alternatives to his attendance of the programme.

> *"why don't I just move in here? You drive all the way here, and then tomorrow I'm back again" (Doug, 43, CVA survivor)*

> *"Yes, what I've noticed with John, a routine gets boring for him" (Beth, 35, employed caregiver)*

> *"for me it seems like he's not gaining anything from it, because now he feels like it's something that he has to do everyday, but not for any benefit" (Beth, 35, employed caregiver)*

> *"coming here it's more like a routine to him because he knows that, if I go on Monday we're gonna be cooking, then exercise then we done, or whatever else and then we done. Tuesday it's this. So he knows exactly what's going on so it's like now, to him it's a routine rather than a.. activities to help him recover" (Beth, 35, employed caregiver)*

> *"eventually as he gets to knowing that okay, on Monday I'm doing cooking and.. and group exercise, as the time gets-goes on, he gets bored, and even when it's time for exercise group he's not looking forward to it because he knows exactly okay I'm going there, I'm going to be doing this and this and this" (Beth, 35, employed caregiver)*

> *"I'm actually trying to find something to replace [name of NGO] with. You know, I need to find something constructive to do, you know" (Sam, 45, CVA survivor)*

> *"yah this is boredom, you know, I'm doing the same thing every day and every week, and it's uh like uh repeating the same thing every week, you know" (Sam, 45, CVA survivor)*

> *"as therapists as well we also wanna see progress, we wanna do the best that we can with the patients and umm, I think there's a possibility that it can become a bit, it can become a bit tedious" (Nancy, 34, speech and language therapist)*

Two of the participants from the therapy team group were concerned about the long-term attendance and subsequent risk of institutionalisation.

> *"and then sometimes I think people, if they feel that actually, you know, if they start to see [name of NGO] as an institution then I think that's going to be something that's, will put them off, and then they will stop coming, I think" (Nancy, 34, speech and language therapist)*

> *"there's always a risk of institutionalisation, as in any day centre or rehabilitation centre where people can come for years, and years, and years. I think that's a big risk" (Kate, 24, occupational therapist)*

One of the therapists also commented on the financial aspect of sustaining attendance at a long-term programme.

> *"obviously the biggest challenge is the financial. Financial aspect, which have a certain part… the kind of patient's you're getting with head injuries and those patients that just don't get better quickly, it is a long term. And they find it difficult sometimes to maintain that financial output." (Martha, 56, physiotherapist)*

4.5.2. Challenges experienced by the therapy team

The therapy team participants expressed that long-term care was at times emotionally taxing, and that performing the same types of interventions on a chronic basis was not something that they always preferred. Additionally, working with clients with an ABI for an extended period, without extensive improvements, as well as trying to find innovative ideas for therapy constantly, was also seen as dissatisfying and challenging.

> *"we work with very complex uh patients, and also it's, you know, emotionally as well, um it can actually, not take its toll but I mean obviously it does affect you" (Nancy, 34, speech and language therapist)*

> *"with anything like a brain injury, everything is so complex you know, your communication, your cognitive abilities, and I find that, there's always something that's challenging, there's something that you discover-along the*

> *therapeutic process, you know, as you go along with it" (Nancy, 34, speech and language therapist)*

> *"and umm, coming up with new ideas, you know I don't want to bore the clients, and I want to make therapy interesting for them, but if they're not improving you kind of-I feel like I often end up doing the same thing over and over again and I don't really like that, you know, and if I'm not seeing progress that's really discouraging." (Kate, 24, occupational therapist)*

> *"but certainly you do get in a rut, and it's hard to become innovative (laughs) over a long extended work with the patient" (Martha, 56, physiotherapist)*

> *"when you're working with a TBI or you're working with a stroke, it's so complex, and it's also, you know there's so much that you unravel that, in your therapy, so I always find, I don't find that I get to the point where I'm not sure what to do next, or I find that umm, we're getting nowhere" (Nancy, 34, speech and language therapist)*

The therapy team participants found that ABI survivors had the tendency to become dependent on the therapists, thus losing their intrinsic motivation and autonomy, and becoming passive in the therapy process. This was attributed to the fact that ABI survivors engage in therapy for an extended period of time. Some of the therapy team participants felt that the survivors' attendance for a prolonged period may result in them becoming discouraged or demotivated.

> *"the negative aspects if.. perhaps the dependency of the patient on the therapist to, um, keep them on track so.. sometimes the whole process umm is wasted once they stop [name of NGO], all the gains is lost because they don't have the motivation and-to keep that up." (Martha, 56, physiotherapist)*

> *"their dependency on us, is always to choose what therapies to do and force goals on them. You know, they are so passive sometimes that they-no you choose,*

> *you decide what, what you are doing with me. There's no choice from their side." (Martha, 56, physiotherapist)*

> *"I think, if it goes on for a long time, whether then patients start to feel demotivated. And then they think, umm I'm not getting better, I'm not getting back to normal, um, you know it's been a year now and I should have, I should have progressed more." (Nancy, 34, speech and language therapist)*

> *"the longer they're here the more they just sit back and let you make the choices, or given them choices. They don't initiate them" (Martha, 56, physiotherapist)*

> *"and I guess you can also become despondent because some clients can make really rapid recovery, but then others can take years, and years, and years, and they still are never 100 percent again, and I think that can be really discouraging and people can sort of give up" (Kate, 24, occupational therapist)*

One therapy team participant indicated that "skewed boundaries" occurred when working with an ABI survivor on a daily basis for several months or years. This refers to the relationship between therapist and ABI survivor moving beyond the professional relationship, to a more friendship-based one, which at times affected their discharging of the client from therapy.

> *"we get a bit too close and too attached to the patient, and even if they've reached their physical improvement limit, if I can put that, in our um feelings, it's sometimes quite hard to say you know what, it's time to stop therapy. It's very hard to cut off" (Martha, 56, physiotherapist)*

> *"Because you've formed maybe too close a bond and we, we feel sorry for the patient and we often realise that once they move off from us, they will not maintain the levels that they've achieved, because they don't have that constant guidance." (Martha, 56, physiotherapist)*

Family expectations emerged as a challenge in this study. One of the therapy team participants noted that family members often had unrealistic expectations, which put pressure on the ABI survivor. One caregiver participant agreed with this sentiment.

> *"there's always the thing, you know people do have that, that date, that this happened to me a year ago and look at me now, you know, like a year later, what-it's like their expectation uh, compared to what-it's the expectation of the family, compared to what is actually, um, the patient is presenting with, a year later. Umm so I think there's, it can be, it can be uh difficulty for them" (Nancy, 34, speech and language therapist)*

> *"I think a lot of the families' expectations usually in the beginning, when you start off the process, people are more positive so the family is positive because they feel oh I'm starting something now, therapy is going to make them better, uh with rehab they're going to become better. And then, as time goes by and then the progress is slow or they not achieving what they would expect, you know, the client to achieve, then I think that also can be a bit draining on patients" (Nancy, 34, speech and language therapist)*

> *"the families normally make un-they make too much expectations for the patient, so-which makes it so difficult, even for them to cope, because now, they make them expect things that they not even sure they going to happen, and then at the end of the day when they don't happen, the patients are so frustrated." (Beth, 35, employed caregiver)*

Family expectations were also noted as a source of frustration by one of the therapists, as therapists had to explain to family members that the process would be a long-term one.

> *"I always make that clear to families so that they do understand, you know that, in three months' time, you not gona get-they not going to be talking, walking, eating, you know" (Nancy, 34, speech and language therapist)*

One of the ABI participants saw therapy in two contradicting ways: with the therapist assisting in increasing their independence, but the with the ABI survivor being dependent on the therapist.

> *"you people are the model builders, and we are the clay, and you have to form-build us up…and it's true, it's basically what's happening" (Doug, 43, CVA survivor)*

4.5.3 Challenges experienced by the caregivers

One caregiver participant noted that it was difficult working with the same client throughout the day, as many caregivers work long shifts with their clients, and that the ABI survivor's behaviour may differ from when they were at the study site. Another caregiver participant expressed the view that the higher turnover of therapists negatively influenced the ABI survivor's progress, which differs from that of the ABI survivor earlier mentioning that the high turnover was seen as a benefit, resulting in new ideas and activities.

> *"I so wish when we get here, we are made to work with different patients, not with the patient that we come here with, because I'm stuck with this person at home 24 hours, then I get here and I still have to work with him, it's so frustrating, I feel like pulling my hair" (Beth, 35, employed caregiver)*

> *"then they must understand that when we get home, it's completely different to how they are when they here – the patient" (Beth, 35, employed caregiver)*

> *"if we get here maybe during exercise then they [should] just swap us around, just to be with someone different you know, even if I was angry with John, then when I'm working with someone else, then that's just gona go, go away" (Beth, 35, employed caregiver)*

> *"we had a lot of change of occupational therapists at [name of NGO]. It's always been-she'd get used to one, I mean I found she was very uneasy with the whole thing, you know, and likewise at physio" (Amanda, 48, family member caregiver)*

4.6. SUMMARY

The three main themes that emerged from the interviews with the three main groups of participants have been described in this chapter, and have been supported with verbatim quotes from the various participants to ensure the veracity of the data. What was evident, was that, although those involved in the long-term therapy may feel that progress is slow, and tasks may be repetitive, there is a large social support system that they benefit from. Chapter 5 will outline the discussion of the key points that emerged from the findings.

CHAPTER 5

DISCUSSION

5.1. OVERVIEW

This chapter discusses the findings that emerged from the data obtained through interviews with the three groups of participants in this study, namely the ABI survivors, caregivers of the ABI survivors and the therapy team involved in their care.

As stated in Chapter 1, the research questions for this study are:

a) What are the experiences and perceptions of ABI survivors attending a long-term outpatient therapy programme?
b) What are the experiences and perceptions of the therapy team involved in the long-term therapy of ABI survivors?
c) What are the experiences and perceptions of the caregivers of ABI survivors attending a long-term outpatient therapy programme?

The findings were synthesised and are discussed according to the themes that emerged.

The three major themes of this study included the impact of an ABI indicating the need for long-term therapy, perceived benefits of long-term therapy for ABI survivors, and perceived challenges of long-term therapy for ABI survivors, which are discussed in the context of available empirical literature.

5.2. THEME 1: IMPACT OF AN ABI INDICATING THE NEED FOR LONG TERM THERAPY

5.2.1. Physical and cognitive impairment

It is evident from this study, that years after the injury had been sustained, the ABI participants continue to experience residual impairments, which compromise their overall well-being. The Centre for Disease Control and Prevention (2016), describes 'well-being' as a concept that is generally accepted as including positive moods and emotions, fulfilment and satisfaction with life, and the absence of negative emotions. In public health, physical well-being is also viewed as crucial to overall well-being. The ABI participants in this study reported restrictions in upper and lower limb mobility, residual cognitive impairment such as memory impairments, as well as challenges with swallowing which affects eating, speech which affects communication, and visual impairments. Khan et al., (2003) concurs that deficits with memory is one of the common cognitive impairments experienced by ABI survivors. Incidences of impairments experienced years post injury, are also well-documented in stroke-related literature (Haartman-Maeir et al., 2007; Hackett et al., 2000; Mamabolo et al., 2009; Mayo et al., 2002).

Pentland et al., (2003) and Kapoor (2004) further provide evidence that individuals who sustain an ABI often present with many physical and psychological symptoms. Likewise, Gil-Gomez et al., (2011) indicate that paralysis is a common neurological impairment, which can lead to hemiplegia or hemiparesis. Similarly, in this study, ABI participants reported compromise in their physical functioning, specifically in upper limb function which was noted to limit their participation in occupations, and their lower limb impairments which negatively impacted on their functional mobility. These impairments, they noted, were limiting their participation in their daily activities, and subsequently, their well-being and quality of life.

5.2.2. Impact on ADLs and subsequent loss of autonomy

Restriction in tasks such as meal preparation, constructive leisure tasks, and vocational pursuits were particularly affected, and the ABI participants expressed a sense of regret at not being able to participate in these tasks as they had done pre-morbidly. Similarly, studies by Hackett et al., (2000) and Mayo et al., (2002) also found that ABI survivors were being restricted in their participation in daily activities years after the brain injury had been sustained.

The ABI participants mentioned difficulty coping with their loss of independence and autonomy, and subsequent dependence on others. Autonomy, in medical ethics, is seen as the individual’s ability to make logical decisions, and is defined as the ability of the patient to independently make decisions and participate in activities, as well as to determine their own course of action in their lives (American Nurses Association, 2011). Autonomy is closely related to the notion of patient well-being (Varelius, 2007). It is not solely about allowing one to make their own decisions, but also providing them with the opportunity to do so, and respecting their right for independence (Pantilat, 2008). Although it is considered an element of independence in the occupational therapy field (Collins & O'Mahony, 2015), independence and autonomy are seen as two separate concepts in rehabilitation: the former being the ability to perform tasks without the assistance of others, and doing what one chooses, and the latter referring to being able to make one's own decisions, and can be defined as self-determination (Arcuri et al., 2013). It does not only refer to performing an activity without assistance, but also relates to the ability to make decisions about one's life. It involves motivation, the ability to identify one's goals and needs, and devising plans using this motivation to ensure that they are achieved (Arcuri et al., 2013). By being autonomous and making decisions, one is seen as being in control of their life, in that they are forming and creating themselves, are agents of their lives, and allow their lives to have some purpose, meaning and uniqueness (Varelius, 2007).

In this study, an ABI survivor preferred not to participate in certain tasks if he could not perform them independently, and restrictions in accessing community facilities were also voiced. This contributes to dependence on others, and a subsequent loss of one's own autonomy, as they are no longer able to freely choose the community amenities that they wish to access. This loss of autonomy, and the ability to make their own choices and act on them, is what contributes toward preventing this population from being independent and contributing members of society. A study by Knox et al. (2017), found that decision-making plays an important role in ABI survivor's self-conceptualisation. The ability in making decisions reinforces one's self-concept which could lead to the ABI survivors revising their sense of self, positively or negatively (Knox et al, 2017).

5.2.3. Stigma related to an ABI

The ABI participants were aware of the stigma surrounding disability, and acknowledged that they were not always treated equally by society. They felt that they were viewed differently by the general population, were treated unfairly because of their disability, and were often underestimated. They found this frustrating, feeling that their independence and abilities were being undermined. Block et al. (2016) noted that stigmatisation often leads to discrimination of individuals with disabilities, including TBI survivors, which then leads to social exclusion. According to Johner (nd), often the most disabling aspect for the individual with the impairment, is the ignorance of society regarding their equal needs, rights and responsibilities. The ICF also indicates that disability is not just a condition or biological aspect, but recognizes that the societal obstacles are more disabling that the condition (Johner, nd). Several studies revealed that a lack of participation and feeling excluded by society often led acquired brain injury survivors to social isolation and exclusion (Laatsch et al., 2004; Powell & Malia, 2003; Sander et al., 2012; Winkler et al., 2006). The ABI participants mentioned that people in society would assume that they required assistance when they did not, and displayed misconceptions regarding their disability and abilities. This stigmatisation further contributes towards their exclusion from society, and subsequent challenges with reintegration back into their communities' post-injury, as they are misjudged and misunderstood.

Janzen et al. (2015) and Gretschel (2016) noted that the essential goal of ABI rehabilitation is community reintegration. The majority of South Africans living with disabilities have not always been provided with equal rights and opportunities, and are still not re-integrated into their communities (Schneider & Nkoli 2011; Maleka, Stewart & Hale, 2012; Heap, Lorenzo & Thomas 2009; Mudzi, Stewart & Musenge 2013). Stigma was one of these reasons highlighted, as was difficulty with mobility, and subsequent access to community amenities.

This aligns with the findings of this study as the ABI participants experienced similar problems. They expressed the stigma related to their condition and how they are perceived by society, and having difficulty accessing community amenities due to mobility impairments was also voiced. Barnes (2012) noted that individuals with disabilities had a great disadvantage in re-entering the open labour market, and had a higher risk of unemployment. The ABI participants in this study maintained that they were unable to return to their pre-morbid vocational roles, due to their impairments.

The World Health Organisation also believes that the key to successful rehabilitation is reintegration of ABI survivors within social networks, and active participation in their community (Scott et al., 2012). Tough et al. (2017) highlighted that the lack of integration, and opportunity for people with ABIs to participate within their community, is seen as being contrary to basic human rights and compromises the ABI survivors' health and well-being. ABI survivors face challenges with social inclusion, which involves being accepted by others, and forming inter and intra personal relationships (Linden &Boylan, 2010) due to the fact that they are often misunderstood and judged by society. According to Christiansen, (1999), having control over the possibility of facing rejection by avoiding social situations is seen as the easiest way of eluding rejection. Hartman-Maeir et al., (2007) re-iterated this, indicating that the residual impairment and compromise in functioning experienced by brain injury survivors could result in a decrease in participation, leading to social isolation. Taking this into account, it makes sense why people with overt disabilities prefer to keep their interaction limited to the closest people around them. The residual impairment, loss of independence and autonomy, stigma and resultant social exclusion and reduced community reintegration indicates the need for provision of a setting where the ABI survivor can feel accepted.

5.3. THEME 2: PERCEIVED BENEFITS OF LONG-TERM THERAPY FOR ABI SURVIVORS

This study was located in a non-government organisation that was established in KwaZulu-Natal, providing outpatient therapy for ABI survivors on a long-term basis. This organisation is unique, dealing with the impairments and challenges experienced by ABI survivors through the provision of individual and group therapy. The organisation requires active involvement from the family and caregivers, and allows for access to a multidisciplinary therapy team. The programme covers issues around social inclusion and community reintegration, through provision of a space where individuals with similar challenges and experiences can interact, and actively participate in meaningful occupations.

5.3.1. Social support and group therapy

In a study by Rudman et al. (2006), several stroke survivors and their caregivers explained how their social life had reduced since the injury, and the occupations that they focused on most when expressing loss of same, were leisure and social activities. In this study, the most common reason for attendance of the long-term therapy programme, was the social support provided by this type of organisation, as well as the group therapy, which allows the ABI survivors the opportunity to interact and form relationships with others who are able to relate to their problems, and communicate without judgement. Similarly, Wilson et al. (2015) mentioned that the group setting allowed for a space where they felt that they were not judged, and were instead supported.

The supportive environment of this study location allowed for those who are unable to secure employment in the open labour market, due to their limitations, to attend a daily programme with other ABI survivors, where they are being stimulated, mentally and physically, are included in a community where they feel that they belong, and are able to actively participate and contribute to that community. They felt that, within this programme, they are able to share advice, stories and ideas in a setting where they are not judged, but accepted for their differences. They valued the ability to be able to interact and build relationships with others alike, who could relate to their challenges and experiences. One participant enjoyed being able to meet new people through the programme, which he otherwise would not have been able to do, had he remained at home. Another participant took pleasure in being able to not only receive support, but provide support to others, and mentioned the term ‘comradery’, indicating a sense of mutual trust and friendship. By attending this programme for an extended period, a sense of community and family was created, as expressed by the ABI participants.

Kessler et al. (2014) notes that although it is important for stroke survivors to receive support from their family, friends and healthcare professionals, having support from peers, which is generally centred round their similar experiences, can assist in reducing feelings of fear and isolation, and also increase their awareness regarding services provided by the community. Support from peers is commonly recommended, as it is a source of educational, emotional, and positive support for those with long-term conditions, and can also endorse feelings of empowerment. Peer support is generally linked to feelings of reduced loneliness, increased social acceptance and competence, and a sense of acceptance of chronic conditions. Both individuals receiving and providing the support are seen to benefit (Kessler et al., 2014). Some of the therapy team participants in this study reinforced long-term therapy as essential in providing support to ABI survivors, by allowing them the opportunity to interact with people who had experiences similar to their own. They mentioned that this type of facility and environment radiates a sense of warmth and positivity, and that the stakeholders involved in the programme communicated on a personal and familiar basis, reinforcing the sense of family and community.

According to Tomberg et al. (2005) several studies have noted that some ways of increasing quality of life were having a good social support system, feeling integrated within the community (Kalpakjian, et al., 2004), participating in work and leisure activities (Steadman-Pare et al., 2001), feeling independent (Anderson et al., 2010) and participating in activities of daily living (Pierce & Hanks, 2006). The participants in this study confirmed that these aspects were being addressed by their attendance at this type of long-term facility. The type of therapy within this organisation adheres to the rights formed by the WFOT in 2006, in their Position Statement of Human Rights, which highlight the significance of participating in meaningful occupations, allowing one the opportunity to be a contributing member of society. Group therapy is a large part of the programme at the study location, which encompasses a variety of activities and serves as a vocational pursuit for many. Which would have otherwise most likely not been possible for them, as acquiring work after sustaining a disability is not a common occurrence. Pre-morbidly, the ABI survivors would have in all probability had the potential to be active and contributing members of society. Most of the participants were employed prior to their injury. Post-morbidly, however, their ability to secure employment in the open labour market has been compromised due to their impairments. The group sessions and activities within this NGO can therefore be seen as a substitute for this gap in their lives, where they are able to participate in occupations that are meaningful, productive and purposeful. In a study by Rudman et al., (2006) stroke survivors and their caregivers generally expressed a reduction in their contact with friends, and occasionally family, as well as a decrease in social outings, and the ABI survivors in this study mentioned the programme catered for outings, allowing them to access community amenities that they otherwise would have been unable to access.

Similar findings were seen in a study by Kessler et al. (2014), where the stroke survivor participants reported that by participating in a group, they felt enjoyment and understood by others. Morris & Morris (2012) investigated experiences of the stroke survivors and their care partners, who had participated in in-hospital support groups. The results indicated the significance of peers in encouragement, belonging, empowerment and connecting to others. These findings reinforce those found in this study. Some of the participants in the Morris & Morris (2012) study expressed positive feelings with regard to their feeling helpful towards others through participating in group sessions. However, other participants in the Morris and

Morris study expressed both positive and negative feelings towards activities such as open-ended discussions. Hancock (2009) explored the experiences of stroke survivor participants in a local support group in Canada. Some of the main themes which emerged were as follows: reducing feelings of isolation; allowing the survivors to understand the condition in ways that health professionals could not relate to; assist in combating depression; and adjusting their time frame regarding recovery and improvement. These key points indicate the value of group therapy for this population. Malec (2014) mentioned that group members are willing to respond to other members more willingly than they are with the therapists. The support and guidance that they received from each other was seen to be as more effective than that received from the therapist (Malec, 2014). According to Patterson et al. (2016), there had been no other reviews on rehabilitation groups in the treatment of TBIs published.

Hammond et al. (2015) noted that group therapy could have more distinctive benefits than individual therapy. Some of those advantages which were frequently mentioned, were the ability to interact with individuals who had similar experiences, which could improve learning and allow for a sense of support, increase their motivation, and reduce their feelings of depression and isolation. A study by Gauthier et al. (1987) also mentioned that group therapy could increase coping skills, and mood.

Hammond et al. (2015) further highlighted that, from a resource perspective, group therapy allowed for reduced staff, which could decrease treatment fees, and assist in addressing problems of staff shortages. One of the disadvantages of group therapy is the difficulty with personalising the sessions for each member, because many of the brain injured survivors would be functioning at different levels (Hammond et al., 2015). This makes it very challenging to decide on the best approach to use, due to the complexity and diversity of a TBI.

This study concurred with the literature as the participants found that group therapy was beneficial and helped reduce their feeling of social isolation. In addition, the caregiver participants felt that they were also benefitting from the social support provided by this type of programme as they were able to socialise with other caregivers with similar challenges, interact with individuals other than the ABI survivor, and also gain knowledge from the therapists on how to care for their client or family member. They also expressed relief and a sense of freedom at having this opportunity, and to have time away from their client or family member, for example when they are in therapy. One of the caregiver participants also mentioned that, by attending this programme as often as they did, the stakeholders felt like family. Jeggels (2006), in their study, found that caregivers were receiving minimal support from health care professionals, and that this type of support is necessary for relief of their caregiving burden, which will indirectly also benefit the ABI survivor. A caregiver participant in this study maintained that she had acquired a great amount of knowledge from attendance at the study location, from the various disciplines, with home programmes to carry over with the ABI survivor, and expressed a great passion for her occupation as a caregiver. The therapy team participants also emphasised that it was important for the caregiver to be able to interact with other caregivers, and have the opportunity to be educated on how to care for their client or family member.

Gurayah et al. (2016), mentioned that some of the key components which encouraged positive outcomes when working as a caregiver, were having an internal locus of control, social support, resilience and positivity. This, in turn, can improve a caregiver's self -esteem, and activity or job satisfaction. A study by Moghimi (2007), found that working as a caregiver brought a sense of companionship, fulfilment in being able to help others, and meaning and spiritual satisfaction to one's life.

5.3.2. Ongoing improvement

While it appears that long-term therapy has a strong basis for maintenance of functional ability and prevention of future deterioration, many participants noted that they were still experiencing improvements for years following the injury. The ABI participants were aware of functional abilities that they would not be able to achieve independently, but appreciated that they could exercise certain skills at the long-term outpatient NGO. An example of this is walking, which cannot be achieved by many ABI survivors due to their mobility impairments, but which one participant expressed being able to participate in during his therapy sessions. This opportunity allows for a sense of achievement, albeit temporarily, and a sense of hope.

A common sentiment expressed by the therapy team participants, was that the process of rehabilitation of an ABI survivor was a long and slow one. However, although some of the

ABI survivors had been attending therapy for many years, the therapy team participants maintained that small improvements were still possible, which was reinforced by one of the therapy participants who mentioned that she was still seeing improvements, albeit small, in the second year of therapy after the injury. Similarly, in a study by Varjačić et al. (2010), TBI survivors who had experienced the injury three to five years prior, reported functional improvement after outpatient and home-based rehabilitation. Additionally, Mayo et al. (2000) noted that individuals receiving therapy after being discharged were still noticing improvements in their functional recovery, as well as in their home and community integration.

The therapy team participants also mentioned that one of the indications of continuous improvement was through the ABI survivors' participation in special events such as galas and sports days, which generally measured their physical abilities, and allowed for monitoring and assessing the ABI survivor's physical progress and /or deterioration. These types of events also assisted in providing the ABI survivors goals to constantly work towards. Interestingly, they felt that the process worked two ways: that the ABI survivor was provided with skills from the therapist, but that the therapist also learnt more about the ABI survivor and their condition and abilities as therapy progressed, especially after a few years. This points to the complexity of an ABI, and that the therapists continue to learn with the survivor through the therapy process.

A key aspect of this type of programme appeared to be that of maintaining those skills and abilities that had been achieved, and preventing future deterioration. Conversely, a therapy team participant voiced that when the ABI survivors stopped attending therapy, even for a few months, signs of deterioration were often displayed which indicates that gains are not maintained without reinforcement received from attending therapy. Paolucci et al. (2000) similarly revealed that individuals who were receiving long-term therapy were able to notice benefits both psychosocially and physically, and without further therapy, experienced re-hospitalisation, a deterioration in functioning, and a decrease in their quality of life was noticed.

5.3.3. Participation in meaningful and constructive occupations

According to Christiansen (1999), occupations are significant in forming a particular type of person, and can formulate and maintain one's identity. He added that it involves the relationships that one has with others, providing that individual with some purpose, and a sense of structure in their lives. They contribute towards creating meaning in one's life, which in turn leads to well-being, and which is seen as the essential goal in occupational therapy. Christiansen (1999) further indicates that when one believes that one does not have an identity, or that it has been tainted, their life can feel less meaningful, or even become meaningless.

Other aspects influencing well-being include economic, social, developmental, emotional and psychological well-being, as well as engaging in work and activity (Centre for Disease Control and Prevention, 2016). Considering the latter two, many of the ABI participants attend this programme daily as it serves to form the most part of the normal working day in their lives, and viewed their attendance and participation in therapy, specifically the group therapy, as their vocation for the day. This provides them with a sense of achievement. Most of the ABI survivors attending the programme are unemployed, and thus attend the programme for several days or every day of the week. Should they not have been granted this opportunity, and remain at home during the day, this could likely lead to social isolation. In KwaZulu-Natal, sheltered and protective workshops are available for those individuals who are unable to secure employment in the open labour market, however this would be a challenge for many of the ABI survivors due to their physical and cognitive impairments. Further, they would not receive the support provided by the programme that they are attending.

There are several factors which can lead to a decrease in participation in occupations after a stroke, such as a reduction in physical functioning (Lawrence & Christi, 1979), not being able to leave one's house (Pound et al., 1998), depression (Feibel & Springer, 1982), not being satisfied with one's performance and relationships between the survivor, their family and friends which may not be supportive (Morgan & Jongbloed, 1990). Christiansen (1999) further speaks of occupation as activity which is goal directed, and adds that goals are seen as motivational forces, as one generally thinks of how their lives will be impacted on when they have met that goal. "*If our identities are crafted by what we do and how we do it, then it follows that any threat to our ability to engage in occupations and present ourselves as competent people becomes a threat to our identity*." (Christiansen, 1999, p. 553). Threats to one's identity can include aging, injuries, disorders or diseases which may result in persistent disability, so much so that it hinders efficient performance in certain activities, which may jeopardize the identity one has established, which may be based on competence (Christiansen, 1999).

Rudman et al. (2006) noted that descriptions of daily life by stroke survivors and their caregivers centred on an overall lack of purposeful activity, and limitations which were experienced by the survivors. There was significant narrowing in their occupational choices due to their limitations, which led to the stroke survivors participating in any occupation that they were able to, instead of what they preferred to. Rudman et al. (2006) noted that studies which had analysed the effects of having a stroke, indicated that the cognitive, physical and communication impairments, along with the environmental challenges experienced, often led to sudden changes in one's roles, routines and daily occupations or activities. In the Rudman et al. (2006) study, participating in a community group or therapy session was the only time that stroke survivors would go out into the community. Other than that, they generally engaged in activities which were sedentary in nature, at home, and most of the time related to self-care tasks, often with assistance. Additionally, the stroke survivors spent their time performing tasks such as watching television, reading, practising their mobility skills or sleeping. Rudman et al. (2006) also noted that overall, the stroke survivors participated in those occupations which were easily accessible in their homes, or those which were essential to complete. Similarly, as indicated above, many of the ABI survivors in this study attended the programme daily, or several days a week, so as to fill the gap in their day with meaningful and purposeful activity. The caregiver participants in this study also viewed the long-term therapy programme as the ABI survivor's vocational pursuit for the day, as they were able to be productive, and feel as if they had accomplished a goal for the day.

5.4. THEME 3: PERCEIVED CHALLENGES OF LONG-TERM THERAPY FOR ABI SURVIVORS

5.4.1. Challenges experienced by the ABI survivor

Due to its chronic long-term nature, one of the risks of a long-term therapy institution is institutionalisation. This is a term referring to an individual's restriction to a certain institute, with no or limited relationships with society (Parvaneh et al., 2014). In this type of programme, although the ABI participants do not live within the institute, the programme is repetitive, and some participants have been attending for several years, interacting with the same people. One of the most commonly expressed concerns, expressed by all the participant groups, was the repetition of tasks on a weekly basis, and that because of this boredom was likely to set in. Although the survivors are involved in meaningful and constructive activities, the benefit of this may be contraindicated when they are participating in the same activities on a regular basis, and one can argue that they may not be receiving benefit at some stage. This boredom may contribute to negatively affecting the ABI survivor's well-being, and in turn their life satisfaction and quality of life.

Johnson & Rhodes (2007) define institutionalisation as a group of symptoms, or syndrome, which generally involves lethargy, apathy, poor self-initiative, reduced compliance, submissiveness, passivity, social isolation and withdrawal, being dependent on the structure of the institution and decreased feelings of personal value and worth. In this study, one of the therapy team participants expressed a sense of frustration at the passivity and lack of motivation that the ABI survivors were showing, as they were becoming more dependent on the therapist, suggesting commencement of the initial signs of institutionalisation.

Johnson & Rhodes (2007) discussed a study which found that patients can lose their desire to want to take responsibility for their lives, as the institution may be caring for their basic needs, and this was seen as the first step towards institutionalisation. The second step was the sense that the patient did not need to think or plan for themselves, as the institution may have a structure which was followed.

5.4.2. Challenges experienced by the therapy team

Similarly, one of the concerns of a therapy team participant was that, by attending one programme on a long-term basis, institutionalisation of the ABI survivor could occur. As mentioned above, there is a risk of this occurring, especially with those ABI survivors attending for a prolonged period. Additionally, a therapist noted that the ABI survivors could at times lose their intrinsic motivation, and become dependent on the therapist, contributing to their loss of autonomy. A concern was that this, as well as their attendance on a long-term basis, could result in the ABI survivor becoming demotivated or discouraged, which, one of the therapists has experienced. Although a high turnover of staff was mentioned, this could be seen as positive and negative, as it allows for the introduction of new ideas, but the programme overall generally remains the same, resulting in boredom and routine.

The therapy team participants did express that working with the ABI survivors on a long-term basis could become tedious, and emotionally draining, and that they did not always enjoy performing the same types of activities on a long-term basis. Although they mentioned that small improvements were seen, they also mentioned that, when working with the ABI survivor on a long-term basis, finding novel ideas for sessions was at times difficult, and when seeing no improvements, disappointing. On the other hand, one therapy team participant felt that, as brain injuries are so complex, there was always something new to learn, and she never found that she reached a point where she did not know what to do with them, or that they were not improving. Another therapist felt that communication on long term basis led to unhealthy boundaries, where they had built almost a friendship with the ABI survivor, and felt guilty to discharge them. These skewed boundaries could also compromise the efficiency of their therapist-client relationship, and consequently the rehabilitation process. They also mentioned that family members often had unrealistic expectations, which put pressure on the ABI survivor, and this was also agreed upon by the caregiver participants.

Interestingly, two therapy team participants differed in their opinions of the ABI survivor’s attitudes towards therapy. One participant felt that they were motivated with a positive attitude, making her job easier and rewarding for her, while another therapy team participant expressed that the ABI survivors could be passive at times, and dependant on the therapist in goal-setting. A study by Johnson (2007), mentioned that in chronic settings which are at risk of institutionalisation, there is often apathy, passivity, compliance and submissiveness.

The above challenges could contribute to burnout experienced by the therapists. Burn-out is a state of exhaustion, physically and emotionally (Du Plessis et al., 2014), and occurs when an individual is employed in an environment with chronic stressors, and frustrating aspects that they have difficulty coping with. Schlenz et al. (1994) also indicated that emotionally draining interactions were expected when working with head injury clients. Another challenge was the financial aspect, which was mentioned by a therapy team participant, and a by the ABI participants. The cost of sustaining attendance on a long-term basis, by the ABI survivors is often difficult, however, it is fortunate that many disciplines are available for them to access within one facility, which assists in saving costs for therapy.

Nordin et al. (2014) found that some rehabilitation professional participants maintained that their difficulties with conducting long term therapy included having limited resources, having a scarcity of community-based programmes to integrate the survivors back into society once they had been discharged, not being able to decide on clear goals and what the expected outcomes are, and a lack of volition from the stroke survivors. The latter two challenges were also both expressed by the therapy team participants in this study. Nordin et al. (2014) further found that, some participants who were rehabilitation professionals, were doubtful of the benefit of long-term therapy for stroke survivors, being concerned that the individual would have reached a plateau, and that therapy would be focusing more on preventing complications instead of achieving new goals.

5.4.3. Challenges experienced by the caregiver

The caregivers of the ABI survivors attending the long-term facility were either formally employed, or were dedicated family members who take on the role of caregiver. One of the caregiver participants in this study mentioned that attending the same programme on a long-term basis was repetitive and boring for the clients, and that she felt that the ABI survivor was no longer gaining from attendance in the programme. She expressed discontent at the daily routine, and it appeared that she was also experiencing a sense of boredom by the repetitive programme.

Due to the complexity of stroke, including the emotional, cognitive and behavioural impairments, provision of care may be very demanding, and this may have a negative impact on the caregiver's health, physically and emotionally and aspects such as their social life. This is what is referred to as caregiver burden or strain (Jaracz et al., 2015).

The caregivers also mentioned that unrealistic expectations of the family members was a challenge, and as noted above, this was also expressed by some of the therapy team participants. Family members are often unaware of the consequences of a brain injury, the long-term effects, and that therapy is a long process. This adds strain and stress to both caregivers and the therapy team, also putting the caregivers at risk of burnout, and one of the caregiver participants even expressed relief at having freedom away from the client, and the ability to interact with someone who was not the ABI survivor. As caregivers are prone to physical and emotional burden, for example if their tasks are strenuous in nature, this can negatively affect their ability to efficiently care for the ABI survivor.

Gurayah et al. (2016), mentioned that caregivers are recently being seen as the 'invisible client' who are also in need of care, in terms of health and occupation, which may have previously been neglected. The tasks of a caregiver, particularly in the care of a severe brain injury, can be manually intensive in nature, requiring heavy lifting and handling of the client. Due to caregiver burden, they may additionally experience emotional challenges, fatigue, and social isolation (Gurayah et al., 2016). This points to the need for support for the caregiver, to reduce the risk of this burden and strain.

5.5. CONCLUSION

It is evident that there are both benefits and challenges in long-term outpatient therapy for ABI survivors, however, when one considers the fact that, without this type of service, these individuals would be at home, quite possibly experiencing poor integration within their community, and subsequently social exclusion. In this study, the benefits of long term therapy appeared to outweigh the concerns and challenges as expressed by the stakeholders. This type of programme is seen as the bridge for the ABI survivors, allowing for them to be a part of, and integrated into a community where they are not judged, can relate to others, are able to form social networks and support systems, and can contribute by participating in meaningful and purposeful occupations. Overall, and most importantly, this type of programme contributes to ensuring and improving their well-being, and quality of life.

CHAPTER 6

CONCLUSION

6.1. INTRODUCTION

As described in this study, an ABI refers to a group of conditions leading to residual, physical, cognitive, behavioural and emotional impairments, which often negatively impact upon the survivor for the remainder of their lives. In a long-term outpatient NGO in KZN, ABI survivors are able to receive therapy and support on a long-term basis. The ABI survivors are generally accompanied by their caregivers, and can access the services of a multidisciplinary rehabilitation team in one venue. In this study, the experiences of these three stakeholder groups were explored within this setting. This chapter concludes the study by highlighting key findings related to the experiences of the ABI survivors, therapy team and caregivers, limitations of the study and recommendations arising from it.

6.2. SUMMARY OF KEY FINDINGS

This study is unique in that it investigates the experiences of individuals who have been attending a long-term outpatient therapy programme for several years, some for more than ten years, whilst other studies generally explore a shorter time frame post-injury (Mayo et al., 2002; Eriksson et al., 2006). Moreover, the long-term outpatient NGO in which this study was located, is the only well-known type of organisation providing this service to ABI survivors in KwaZulu-Natal. When considering the high statistics of brain injury in South Africa, particularly of stroke cases, the residual impairment which requires long-term care, and the benefits expressed by the participants in this study, such a facility is considered a necessity. This study was approached with the hope of increasing the awareness of the severity of the long-term effects of an ABI, the need for consistent care and therapy, the services available, and the need for the provision of similar services around the province of KwaZulu-Natal. It will further contribute by increasing the evidence base for intervention through providing personal experiences of ABI survivors in the long-term phase of rehabilitation, which will assist with development of programmes and treatment of ABI survivors, and also create awareness around the risk of burnout of the therapy team, to ensure that measures are put in place to reduce the risk of same. Additionally, this study will ensure mindfulness of the caregivers' needs and challenges, and the risk of burden.

The objectives of this study were to explore the experiences of the ABI survivors, caregivers and therapy team involved in a long-term outpatient therapy programme for chronic ABI survivors, specifically in terms of the benefits and challenges of long-term therapy.

This study found that the ABI survivors in this study were experiencing numerous residual post-morbid impairments, which were compromising their mobility, participation in daily activities, overall independence, and which led to stigmatisation by the community. This, in turn, contributed to challenges with their reintegration back into their various communities.

Through attendance at this long-term outpatient NGO, they were allowed the opportunity to be actively contributing members of a different society, one in which they were made to feel accepted. The ABI survivors voiced various benefits gained through attendance of a long-term outpatient therapy programme such as this. They were able to interact with others who could relate to their challenges, and found this environment to offer a wealth of social support. Although some ABI survivors have been attending therapy at the NGO for many years, they still see small improvements, and enjoy the opportunity to attend group therapy sessions, where they are able to participate in meaningful and constructive activities. This, they felt, gives them a sense of achievement, and purpose, especially since many of the participants are unable to secure employment in the open labour market. This contribution to well-being is imperative, as it leads to satisfaction in and quality of life.

The caregivers in this study also felt that they received social support by interacting with other caregivers, and expressed relief at having time away from the ABI survivor for which they cared. As caregiver burden is a reality, especially with caring for chronic conditions such as an ABI, their attendance at this long-term outpatient NGO assisted them by reducing the risk of burden, and also provided a platform for caregivers to be consistently educated on how to care optimally for their client. The therapy team expressed a sense of reward by seeing improvements in ABI survivors' abilities years post-injury, sometimes even after ten years of living with the residual impact of the ABI.

The ABI survivors at this long-term NGO are involved in a weekly programme which is run throughout the year, and may continue attending potentially for years. Some challenges and concerns were expressed with this, one of these being that some ABI survivors and caregiver participants felt that, after attending the programme for many years, boredom eventually set in and the activities were seen as repetitive and not optimally benefitting all ABI survivors. For the therapy team, an ABI was seen as a complex condition, and the therapy process a long and tedious one. They found difficulty in creating or innovating new activities and ideas, to prevent boredom and repetition, and felt that working with individuals with this type of condition on a long-term basis could become emotionally taxing. These factors suggest the risk of burnout amongst health professionals, which is not uncommon in the care of individuals with chronic conditions.

An ABI is a long-term and complex condition, often resulting in residual impairment and the need for consistent care for those affected. While there are challenges with receiving therapy on a long-term basis, the benefits outweighed these in this study, and contributed to the well-being and life satisfaction of these individuals. The provision of more organisations like this particular NGO, specifically in the rural areas in KwaZulu-Natal, would allow for a larger population of ABI survivors to access this type of service, and assist in bridging the gap that the ABI survivors are experiencing between hospitalisation and community reintegration.

6.3. STUDY LIMITATIONS

No study is without limitations and it is important for researchers to acknowledge them and minimise them.

- The ABI participants were all males, as this gender grouping forms the majority of the population attending the long-term programme at the NGO and who met the inclusion criteria regarding cognitive ability. It is possible that inclusion of female participants may have contributed differing opinions to those of the male participants in this study.

- The location of the facility was a middle class residential area which was historically a predominantly “White” area in the apartheid era, and continues to have a large population of White residents, thus the ABI participants in this study, even though was not the intention of the researcher, were mainly White. The experiences and perceptions are therefore likely unavoidably skewed in that cultural direction.

- The study was limited to a single site, but provides insights that are valuable to translate to ABI populations in other locations. Saturation of data relevant to the purpose of this study, was achieved, in that redundant data was noted in the interviews conducted with the study participants towards the end of the data collection phase. Furthermore, in the chosen qualitative research design, generalisability of the findings is not intended.

- The sample size for each of the groups was less than was originally planned, due to difficulty interviewing the ABI survivors at the study location when they were involved in therapy sessions, and the availability of the caregivers and therapy team members who were on duty at the study location. Some of the challenges leading to the limited sample were as follows: the therapy team participants could not always be interviewed at the NGO, due to their work hours and the ethics of not affecting their schedule with patients. This limitation was minimised by focussing on the meaning and the depth of the data rather than the number of the participants

6.4. RECOMMENDATIONS

The following recommendations are offered as a result of the processes and products of this study:

- The provision of more long-term outpatient facilities for ABI survivors in KZN, specifically in the rural areas to ensure greater accessibility to the service by many ABI survivors.

- Meetings can be held with the therapy team and ABI survivors on a 6-monthly basis, to re-visit their goals and challenges.

- Awareness of funding needs should be increased for these types of organisations, to ensure sustainability and provision of necessary resources;

- The entire programme at the long-term outpatient NGO should be reviewed on at least an annual basis, to minimise the risk of boredom and institutionalisation;

- Psychosocial support in the form of group sessions or individual psychotherapy for the therapists could be conducted, to prevent and manage burnout and for the caregivers to prevent and manage caregiver burden;

- Family education on an ABI is recommended, to minimise unrealistic expectations by the family members;

- Further research is required on the burden of ABI in South Africa and specifically KwaZulu-Natal, and the research should include a diversity of race, class and gender.

6.5. DISSEMINATION OF RESEARCH

It is the intention of the researcher:

- To publish this study in an accredited an appropriate journal, so as to ensure dissemination of the findings in order to increase awareness on the need of this type of organisation and programme for long-term outpatient therapy for ABI survivors.

- To compiled a summarised report of this study for the NGO that the study was located at, to share findings with the staff members and management, which may assist them in updating and addressing possible recommendations for the facility.

6.6. CONCLUSION

This chapter summarised the significant findings of the study, considering the research questions, aims and objectives. The limitations were discussed, as well as recommendations based on the findings, and dissemination of this study. The outcomes from this research has led to possible recommendations for the facility and the programme, which will assist with providing the best care for the ABI survivors.

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APPENDICES

APPENDIX 1	Schedule of interview questions for the ABI survivors
APPENDIX 2	Schedule of interview questions for the caregiver participants
APPENDIX 3	Schedule of interview questions for the therapy team participants
APPENDIX 4	Letter requesting gatekeeper permission
APPENDIX 5	Letter granting gatekeeper permission
APPENDIX 6	Informed consent document for the ABI survivors
APPENDIX 7	Informed consent document for the caregivers
APPENDIX 8	Informed consent document for the therapy team
APPENDIX 9	Letter granting full ethical clearance
APPENDIX 10	Ethics course certificate of completion

APPENDIX 1 Schedule of interview questions for the ABI survivors

1. Can you explain why you started to attend the NGO?

2. Why do you still attend the programme at the NGO?

3. Are there are other reasons that you attend the programme?

4. What parts of the programme do you enjoy the most?

5. What parts of the programme do you enjoy or benefit from the least?

6. You have been attending the programme here for more than 2 years. Can you share with me any negative aspects or challenges of attending the programme for this length of time?

7. What would you change in the programme?

8. If you could tell a person one thing about long term therapy for brain injury, what would it be?

APPENDIX 2 Schedule of interview questions for the caregiver participants

1. Can you explain your connection to the client/ your family member?

2. Why did your client/family member start to attend the NGO?

3. What is your client/family member still having difficulty with now?

4. What difference have you noticed in your client/ family member since they started to attend the NGO?

5. What parts of the programme do you think benefits your client/ family member and yourself the most and why?

6. What parts of the programme do you and the client/ your family member enjoy or benefit from the least?

7. Your client/ family member has been attending the programme for more than 2 years. Are there any negative aspects or challenges with him/her attending for this length of time?

8. Does your client/ family member attending benefit you in any way? (and if so please explain?)

9. Is there anything in the programme that is of benefit to you, the caregiver? If yes / no please explain. What are some of the challenges?

10. What would you change in the programme?

APPENDIX 3 Schedule of interview questions for the therapy team participants

1. Can you share with me your role in the programme?

2. Can you share with me if you believe that there is benefit in long term therapy for acquired brain injuries?

3. Why do ABI survivors attend the NGO for an extended period of time? (e.g. more than 2 years)

4. Do you see progress in ABI survivors who have been attending for longer than 2 years, if yes please elaborate.

5. What parts of the programme do you feel benefit the ABI survivors the most and why?

6. What parts of the programme do you feel benefit the ABI survivors the least, or that they enjoy the least and why?

7. What are the negative aspects or challenges and benefits of a long-term therapy programme for the therapy team?

8. What do you feel can be done or included to further benefit the ABI survivors attending?

9. What is it like for you, working in a programme that provides long term therapy?

APPENDIX 4 Letter requesting gatekeeper permission

The Manager,

Re: Gatekeeper permission for study at this facility

I have just completed registration processes and am in the final stages of protocol development towards a study for a Master's Degree in Occupational Therapy at the University of KwaZulu-Natal. My research topic is based on; *The Experience of Daily Long-Term Therapy for Individuals with Acquired Brain Injuries, their Caregivers and the Therapy Team.*

The aim of this study is to explore the perceived impact of long term therapy on the clients and their families/caregivers. A site such as this NGO will prove to be valuable in me realising the objectives of this study.

I therefore seek your permission as gatekeeper to locate this study at this NGO. Methods of data collection for this study will involve a document analysis, focus group discussions or interviews with consenting clients, their families/caregivers and the therapy team. The interviews will be audio recorded with the consenting participants. I will ensure confidentiality and anonymity by the use of pseudonyms throughout my research report and any ensuing publications as well as by ensuring the research protocol is approved by the institutional research board of the UKZN. I anticipate this study as contributing significantly to the area of rehabilitation and care that this NGO as a long-term facility uniquely provides in KwaZulu-Natal. Recommendations of the research may contribute to increasing the awareness of this type of facility and the services that it provides; pointing to possible recommendations for the facility; and increasing knowledge in this under-researched field of long term therapy for acquired brain injuries.

May I kindly request this in writing so that I am able to submit this as part of the ethical clearance procedures of UKZN. I look forward to a favourable response.

Kind regards,

Shivani Reddy

Masters Candidate
Tel.: 0312668644
Cell.: 0726727122
E-mail: reddyshivani22@gmail.com

XXXXXXX
Research Supervisors
Tel: 031 2607310
E-mail: xxxxx

Ms Phindile Nene
Postgraduate Administration
Tel: 031 2608280
E-mail: nenep1@ukzn.ac.za

APPENDIX 5 Letter granting gatekeeper permission

"Making Headway to a better future"

HEADWAY NATAL

14 December 2015

Ms. Shivani Reddy
Masters Candidate
reddyshivani22@gmail.com

Dear Shivani

<u>Re: Gatekeeper permission for study at Headway-Natal</u>

In response to your mail of 10.12.2015 you have permission to use Headway information provided it is kept confidential and no names are used. In addition, any discussion with the member, family and any staff members should be done outside of Headway hours.

Good luck with this study.

Best regards

[redacted]

Ian Vowles
Manager
Headway Natal

11 Menston Road,
Westville, 3629
Tel: 031 266 2709 / 13
031 266 0045
Fax: 086 558 2348
Email: headway@dbn.stormnet.co.za
www.headway.org.za

Fr 001-305NPO

A NON-PROFIT ORGANISATION TO ACQUIRED BRAIN INJURY AND STROKE SURVIVORS AND

APPENDIX 6 Informed consent document for ABI survivors

STUDY TITLE: The experiences of long term outpatient therapy for individuals with acquired brain injuries, their caregivers and the therapy team

PURPOSE OF THE STUDY: I am currently conducting a study towards my Masters' Degree at the University of KwaZulu-Natal. There is a lack of information on long term care for individuals with acquired brain injuries, therefore I would like to explore your experiences of the long-term outpatient programme run here at this NGO, as well as the experiences of the family / caregivers and the therapy team.

STUDY PROCEDURES: I would like to hear from you, the clients attending the programme, and will give you the opportunity to share your experiences with me, the researcher. I would also like to access your medical files at the facility, to ascertain biographical information (such as your age, gender, date of birth), information about your injury (type of brain injury), the length of time that you have been attending this programme and if you have been / are being cared for by a caregiver.

Either an interview with the researcher or a focus group will be conducted with the consenting caregivers of the clients, and will run for approximately 60 minutes. If the group is conducted, it will allow for you to share your experiences with the researcher and other participants that can relate to you, in a safe environment. Questions asked in the focus group or interview will be centred around positive and negative experiences of attending the programme and your experience of living with an acquired brain injury. Responses given will be recorded via an audio recorder which will be controlled by myself, the researcher and may be replayed later on during the data collection process.

Please note that you are able to withdraw from the study at any given time, and should you wish for your responses to be removed from the study, this will be done so immediately. All information shared is confidential, and this will be reinforced before the start of the focus group. Your name will not be used in the study, to ensure anonymity; an alias will be used in place. All data gathered from the focus group and medical files will be stored safely, and will only be accessible to me, the researcher.

In the event of any problems or concerns/questions you may contact me, the researcher at 0726727122 or the UKZN Biomedical Research Ethics Committee, contact details as follows:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus
Govan Mbeki Building, Private Bag X 54001, Durban, 4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za

Thank you for your time, and for your interest in this study.

Regards,

Shivani Reddy

B. Occupational Therapy (UDW) Occupational therapy (UKZN)

Consent Form for Clients

- I have been informed by the researcher about the content of the study, what will be required of me, and any risks involved in participation
- I understand that my participation is voluntary and that I am able to withdraw from the study at any given time
- I understand that my responses will be given in a focus group with other clients at the facility present, or in a face-to-face interview
- I understand that my responses will be recorded via an audio recorder, which will be controlled by the researcher, and may be used at a later stage when the data is being used in the study or may be played back for the supervisors of the study
- I acknowledge that my name will not be used to identify me in the study, and that an alias will be used instead
- Any and all questions that I have had about my participation in the study have been answered by the researcher
- I acknowledge that all data used will be kept in a secure location accessible only to the researcher, and kept confidential
- I acknowledge that the outcomes of this study will result in a research dissertation (report) and may be sent for publication
- I acknowledge that a Psychologist will be on standby during the focus group, in the event that I require support during or after the discussions held

I agree to have the focus group / interview audio taped yes ☐ no ☐

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus
Govan Mbeki Building, Private Bag X 54001, Durban, 4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za

Participant's name: ______________________ (Please print)

Participant's signature: ______________________ Date: ____________________

APPENDIX 7 Informed consent document for the caregivers

STUDY TITLE: The experiences of long term outpatient therapy for individuals with acquired brain injuries, their caregivers and the therapy team

PURPOSE OF THE STUDY: I am currently conducting a study towards my Masters' Degree at the University of KwaZulu-Natal. There is a lack of information on long term care for individuals with acquired brain injuries, therefore I would like to explore your experiences of the long-term outpatient programme run here at this NGO, as well as the experiences of the clients attending and the therapy team.

STUDY PROCEDURES: I would like to hear from you, the family member/friend/caregiver of the client at the facility, and will give you the opportunity to share your experiences with me, the researcher. Either an interview with the researcher or a focus group will be conducted with the consenting caregivers of the clients, and will run for approximately 60 minutes. If the group is conducted, it will allow for you to share your experiences with the researcher and other participants that can relate to you, in a safe environment. Questions asked in the focus group or interview will be centred around positive and negative experiences of the client attending the programme and your experience of living with or caring for an individual with an acquired brain injury. Responses given will be recorded via an audio recorder which will be controlled by myself, the researcher and may be replayed later on during the data collection process.

Please note that you are able to withdraw from the study at any given time, and should you wish for your responses to be removed from the study, this will be done so immediately. All information shared is confidential, and this will be reinforced before the start of the focus group. Your name will not be used in the study, to ensure anonymity; an alias will be used in place. All data gathered from the focus group / interview and medical files will be stored safely, and will only be accessible to me, the researcher.

In the event of any problems or concerns/questions you may contact me, the researcher at 0726727122 or the UKZN Biomedical Research Ethics Committee, contact details as follows:

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Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za

Thank you for your time, and for your interest in this study.

Regards,

Shivani Reddy

B. Occupational Therapy (UDW) Occupational therapy (UKZN)

Consent Form for Caregivers

- I have been informed by the researcher about the content of the study, what will be required of me, and any risks involved in participation
- I understand that my participation is voluntary and I am able to withdraw from the study at any given time
- I understand that my responses will either be given in a focus group with other caregivers at the facility present, or in an interview with the researcher
- I understand that my responses will be recorded via an audio recorder, which will be controlled by the researcher, and may be used at a later stage when the data is being used in the study or may be played back for the supervisors of the study
- I acknowledge that my name will not be used to identify me in the study, and that an alias will be used instead
- Any and all questions that I have had about my participation in the study have been answered by the researcher
- I acknowledge that all data used will be kept in a secure location accessible only to the researcher, and kept confidential
- I acknowledge that the outcomes of this study will result in a research dissertation (report) and may be sent for publication
- I acknowledge that a Psychologist will be on standby during the focus group, in the event that I require support during or after the discussions held

I agree to have focus group / interview audiotaped yes ☐ no ☐

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus
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KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za

Participant’s name: ______________________ (Please print)

Participant’s signature: ______________________ Date: ____________________

APPENDIX 8 Informed consent document for the therapy team

STUDY TITLE: The experiences of long term outpatient therapy for individuals with acquired brain injuries, their caregivers and the therapy team

PURPOSE OF THE STUDY: I am currently conducting a study towards my Masters' Degree at the University of KwaZulu-Natal. There is a lack of information on long term care for individuals with acquired brain injuries, therefore I would like to explore your experiences of the long-term outpatient programme run here at this NGO, as well as the experiences of the family / caregivers and the clients attending the programme.

STUDY PROCEDURES: I would like to hear from you, a member of the multidisciplinary team at the facility, and will give you the opportunity to share your experiences with me, the researcher. Either an interview with the researcher, or a focus group will be conducted with the consenting therapists, and will run for approximately 60 minutes. If a focus group is conducted, it will allow for you to share your experiences with the researcher and other therapists in a safe environment. Questions in the interview and focus group will be centred around your role in this multidisciplinary team at this NGO and your perceptions of the benefits and challenges of a long-term therapy programme. Responses given will be recorded via an audio recorder which will be controlled by myself, the researcher and may be replayed later on during the data collection process.

Please note that you are able to withdraw from the study at any given time, and should you wish for your responses to be removed from the study, this will be done so immediately. All information shared is confidential, and this will be reinforced before the start of the focus group. Your name will not be used in the study, to ensure anonymity; an alias will be used in place. All data gathered from the focus group / interview and medical files will be stored safely, and will only be accessible to me, the researcher.

Should you have any questions about this study or your participation in the study, please do not hesitate to ask. In the event of any problems or concerns/questions you may contact me, the researcher at 0726727122 or the UKZN Biomedical Research Ethics Committee, contact details as follows:

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Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za

Thank you for your time, and for your interest in this study.

Regards,

Shivani Reddy

B. Occupational Therapy (UDW) Occupational therapy (UKZN)

Consent Form for Therapy team members

- I have been informed by the researcher about the content of the study, what will be required of me, and any risks involved in participation
- I understand that my participation is voluntary and that I am able to withdraw from the study at any given time
- I understand that my responses will be given either in a focus group with other therapists at the facility present, or in an interview with the researcher
- I understand that my responses will be recorded via an audio recorder, which will be controlled by the researcher, and may be used at a later stage when the data is being used in the study or may be played back for the supervisors of the study
- I acknowledge that my name will not be used to identify me in the study, and that an alias will be used instead
- Any and all questions that I have had about my participation in the study have been answered by the researcher
- I acknowledge that all data used will be kept in a secure location accessible only to the researcher, and kept confidential
- I acknowledge that the outcomes of this study will result in a research dissertation (report) and may be sent for publication

I agree to have focus group / interview audiotaped yes ☐ no ☐

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researchers then I may contact:

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Durban
4000
KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za

Participant’s name: ______________________ (Please print)

Participant’s signature: ______________________ Date: ____________________

APPENDIX 9 Letter granting full ethical clearance

UNIVERSITY OF ru
KWAZUW-NATAL
INYUVESI
YAKWAZULU-NATALI

22 April 2016

Ms S Reddy (208508433)
Discipline of Occupational Therapy
School Of Health Sciences
reddyshivani22@email.com

Protocol: The experiences of long term outpatient therapy for individuals with brain acquired injuries, their caregivers and the therapy team. Degree: M Occupational Therapy
BREC reference number: BE202/16

EXPEDITED APPLICATION

The Biomedical Research Ethics Committee has considered and noted your application received on 04 March 2016.

The study was provisionally approved pending appropriate responses to queries raised. Your response dated 20 April 2016 to queries raised on 12 April 2016 have been noted and approved by a subcommittee of the Biomedical Research Ethics Committee. The conditions have now been met and the study is given full ethics approval.

This approval is valid for one year from 22 April 2016. To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (201 5), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at http:/[research.ukzn.ac.za/ResearchEthics/ Biomedical-Research-Ethics.aspx.
BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

The sub-committee's decision will be RATIFIED by a full Committee at its meeting taking place on 10 May 2016.

We wish you well with this study. We would appreciate receiving copies of all publications arising out of this study.

Yours sincerely

[redacted]

1910

Founding Campuses

Professor V Rambiritch
D$uty Chair: Biomedical Research Ethics Committee

cc supervisor:
Naidoope@ukzn.ac.za cc
postgrad: nenepl@ukzn.ac.za

Biomedical Research Ethics Committee
Professor J Tsoka-Gwegweni (Chair)
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
Telephone: +27 (0) 31 260 2486 Facsimile: +27 (0) 31 260 4609 Email: breg@ukzn.ac.za
Website: http://reseatch.ukzn.ac.za/ResearchÆthics/BiqmedicAl„ResearGh-Ethiqs.aspx

2040 too YEARS OF ACAOEUc
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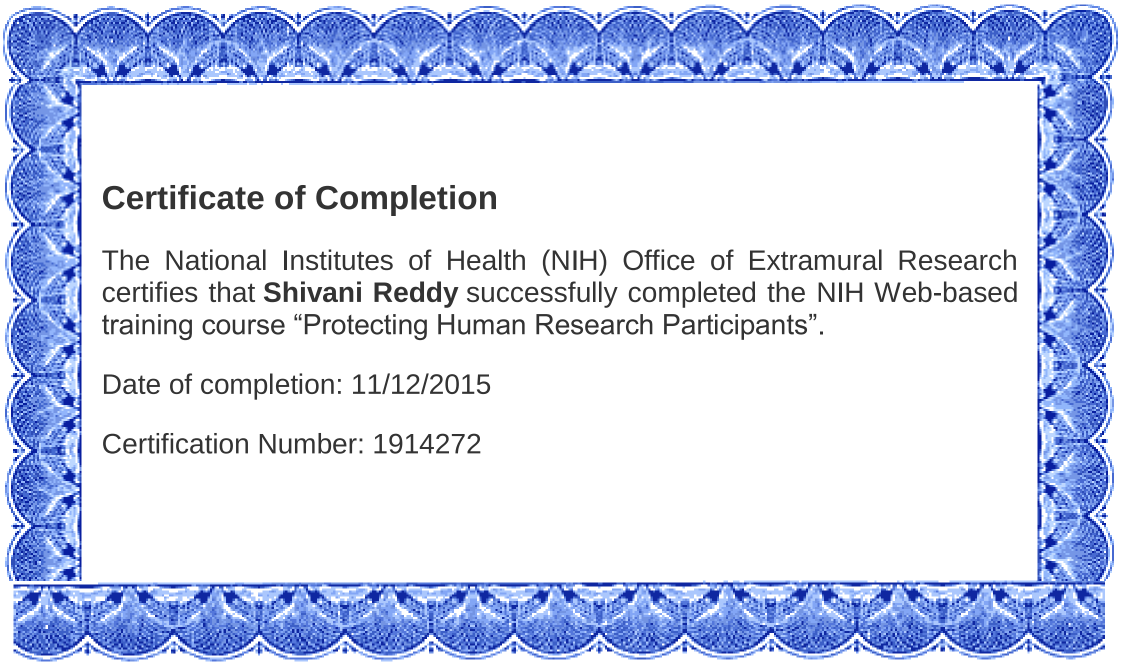
Edgewood Hcnasd Cdleqe Mediel School Pietermatitzbura Westville

Appendix 10 Ethics course certificate of completion



Certificate of Completion

The National Institutes of Health (NIH) Office of Extramural Research certifies that **Shivani Reddy** successfully completed the NIH Web-based training course “Protecting Human Research Participants”.

Date of completion: 11/12/2015

Certification Number: 1914272