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The lived experience of people with brain injury living in long term care facilities: Specific implications for social isolation

by

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A research report submitted in partial fulfilment of the requirements for the degree of Master of Arts in Social and Psychological Research

to the Department of Psychology,
School of Human and Community Development,
The University of the Witwatersrand,
Johannesburg, South Africa,
2017

DECLARATION

I, Emma Jane Walland, hereby declare that this is my own unaided work. It is submitted for the degree of Masters in Social and Psychological Research at the University of the Witwatersrand, Johannesburg. It has not been submitted for any other degree or examination at this or any other university.

Signature: **Date:**

_____ _____

Emma Jane Walland

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LIST OF TABLES

Tables		Page
1.	Participant Characteristics	37
2.	Overall Evaluations	48
3.	General Lived Experience	50
4.	Sources of Well-being	56
5.	Social Isolation	58
6.	Sources of Isolation	60

LIST OF FIGURES

Figures Page

1. Bronfenbrenner's Ecological Systems Theory..... 10

2. Maslow's Hierarchy of Needs..... 12

3. Procedure..... 41

TABLE OF CONTENTS

DECLARATION..... i

ACKNOWLEDGEMENTS..... ii

LIST OF TABLES..... iii

LIST OF FIGURES..... iv

CHAPTER

1 **INTRODUCTION**..... 1

Overview..... 1

Definitions..... 2

Rationale..... 4

Significance..... 5

Research Problem Statement..... 6

Research Aims..... 7

Research Questions..... 7

2 **LITERATURE REVIEW**..... 9

Theoretical Framework..... 9

Aetiology of ABI..... 13

Nature and Severity of ABI..... 15

Incidence of ABI..... 15

Consequences of ABI..... 16

Psychosocial Consequences of ABI..... 17

Life in Long Term Care Facilities..... 21

Social Isolation in Long Term Care Facilities..... 25

Transitions for People with ABI..... 26

Methodological Challenges in Brain Injury Research..... 27

METHODOLOGY..... 31

Research Design..... 31

Recruitment..... 32

Ethical Considerations..... 34

Participants..... 36

Data Collection..... 38

Procedure..... 40

Data Analysis..... 41

Rigour..... 43

4 FINDINGS..... 47

Overall Evaluations..... 47

General Lived Experience..... 49

Sources of Well-being..... 56

Social Isolation..... 57

Sources of Isolation..... 60

5 DISCUSSION..... 66

Overview..... 66

General Discussion of Aims, Research Questions and Findings..... 66

Lived Experience of People with ABI in Long Term Care Facilities..... 68

Fulfilment of Needs..... 72

Experience and Sources of Social Isolation..... 76

Sources of Well-Being..... 78

Summary of Discussion 79

6 CONCLUSION..... 80

Limitations and Strengths..... 82

Recommendations for Future Research..... 83

REFERENCES..... 85

APPENDICES..... 96

Appendix A: Interview Guide..... 96

Appendix B: Informed Consent Form..... 98

Appendix C: Ethical Clearance Certificate..... 102

Appendix D: Institutional Permission..... 103

CHAPTER 1: INTRODUCTION

Overview

Between 89,000 and 170,000 people acquire a traumatic brain injury (TBI) each year in South Africa (Department Health: Province of KwaZulu-Natal, 2010; Naidoo, 2013; Statistics South Africa, 2015) and about 10 million people acquire one each year globally (Hyder, Wunderlich, Puvanachandra, Gururaj & Kobusingye, 2007), making brain injury a leading cause of disability worldwide (Hyder et al., 2007; Kneafsey & Gawthorpe, 2004).

Whilst some people who sustain brain injuries can continue living independently, others remain dependent on assistance for the rest of their lives. In cases where family members cannot accommodate their needs, placement into long term care facilities is often the only option. Unfortunately, there is a dearth of long term care facilities for people with brain injury globally (Winkler, Farnworth, Sloan & Brown, 2011) as well as in South Africa. Therefore, many people with acquired brain injury (ABI) who require assisted living end up in potentially inappropriate facilities, such as aged care and homes for people with physical and mental disabilities (Winkler et al., 2011).

According to Winkler et al. (2011, p. 153) “the inappropriate placement of people with acquired brain injury (ABI) in residential aged care (RAC) is an international issue”. However, no previous research has investigated the lived experience of people with brain injury in long term care facilities internationally or in South Africa. Thus, it is unclear to what extent these facilities are suitable for people with ABI and how they feel about living there.

Although results from research into the experiences of the elderly in long term care facilities varied, the findings often revealed poor quality of life and low levels of well-being among participants (Street, Burge, Quadagno & Barrett, 2007; Zimmerman et al., 2005).

People in long term care are also often socially excluded (Meyer, Marx & Ball-Seiter, 2011; Winkler et al., 2011) and this, in turn, can have devastating effects on their well-being.

Social isolation is known to have deleterious effects on a person's psychological and physical well-being (Meyer et al., 2011; Mezuk, Rock, Lohman & Choi, 2014) and has even been correlated with suicide risk among people in long term care facilities (Mezuk et al., 2014). People with ABI are more likely to experience social isolation after their injury (Conneeley, 2012; Levack, Kayes & Fadyl, 2010). This is due to a variety of factors including personality changes, loss of employment and being unable to drive a motor vehicle (Levack et al., 2010). This may be compounded by living in long term care facilities. Therefore, exploring potential social isolation among people with ABI living in long term care facilities is essential.

Definitions

It is important to define the concepts that are used in this study; namely social isolation, well-being, long term care facilities, acquired brain injury and brain injury rehabilitation.

Social isolation. Social isolation refers to loss of relationships in terms of quantity and quality, lack of feelings of belonging, living without companionship, loneliness, lack of social support and feelings of marginalisation from society (Levack et al., 2010; Zavaleta, Samuel & Mills, 2014).

The opposite of social isolation is social inclusion. According to Winkler et al (2011), "social inclusion is when people have the opportunity and support they need to participate in community life, access goods and services, develop their own potential and be treated with dignity and respect" (p.161).

Well-being. Well-being is a term that is difficult to define and consists of many dimensions (Dodge, Daly, Huyton & Sanders, 2012). In this study, well-being is understood to be a combination of a cognitive sense of satisfaction with life, a sense of happiness, an abundance of positive affect and low levels of negative affect (Dodge et al., 2012). Other important elements are having autonomy, positive relationships with others and a purpose in life (Ibid).

Long term care facilities. In this research, a long term care facility is defined as any facility that offers long term residential care for people who are unable to live independently for reasons of physical or mental ill health and/or disability. The definition encompasses assisted living, nursing homes, residential facilities for older persons (or residential aged care) and residential facilities for persons with disabilities (Department of Social Development, 2017).

Acquired brain injury. Brain injury refers to any damage to the tissue in the brain. Acquired brain injury (ABI) refers to brain injury occurring after birth and comprises traumatic brain injury (TBI) and non-traumatic brain injury (N-TBI). TBI is caused by trauma to the brain from acceleration/deceleration forces or a blow to the head that result in loss of consciousness, confusion and disorientation (Ruff, Iverson, Barth, Bush & Broshek, 2009), while N-TBI is due to a medical condition, such as a stroke or a tumour.

Brain injury rehabilitation. Rehabilitation addresses the consequences of brain injury in an attempt to return the person to a satisfactory level of function as far as possible (Khan, Baguley & Cameron, 2003). The acute phase of brain injury rehabilitation consists of inpatient management in a hospital setting. This is followed by outpatient rehabilitation that assists the person in gaining independence and participation in the community (Khan et al., 2003). Successful community re-integration is an important goal of brain injury rehabilitation (Conneeley, 2012).

Rationale

Brain injury can happen to anyone at any time. The onset is sudden, often with no forewarning, and it can result in previously healthy and productive members of society becoming disabled and dependent on long term care. Brain injury is a global concern but is far more common in developing countries.

In South Africa, brain injury is a major public health issue as the incidence of traumatic brain injury is higher than that reported in other countries (Badul, 2012). In 2017, the National Institute for Occupational Health estimated that the incidence of TBI in South Africa was 316 per 100 000 people compared with 180 to 250 per 100 000 in the United States. Possible reasons for this trend include the high incidence of interpersonal violence, motor vehicle accidents, pedestrian injuries and aggravated crime in South Africa (Levin, 2004; Naidoo, 2013). Since interpersonal violence, pedestrian injuries and aggravated crime are higher among people with lower socio-economic status (SES) in South Africa (Seedat, Van Niekerk, Jewkes, Suffla & Ratele, 2009), it is likely that ABI is more common amongst this demographic, although no studies were found that interrogated this question. People with lower SES are more likely to receive poorer quality health care in South Africa, and may therefore also suffer more severe consequences of ABI.

Thus, the need for appropriate care and rehabilitation for people who have sustained ABI is immense. Due to advances in medical technology, more people are surviving ABI each year and their life expectancy is improving (Ogden, 2005). Studies indicate that the life expectancy of people with ABI is only 3 to 7 years lower than the general population (Winkler, Farnworth, Sloan, Brown & Callaway, 2010). Furthermore, a large percentage of ABI survivors are under the age of 30 (Winkler et al., 2010). The International Brain Injury Association reported that the highest rate of brain injury in the United States occurs in individuals between the ages of 15 and 24 (Brain Injury Facts,

n.d.). While South African statistics are lacking, the trends in age are likely to be similar (Naidoo, 2013). Therefore extended time periods for appropriate long term care and rehabilitation are required. Yet countries worldwide have failed to respond to this need.

Long term care options globally are limited and often inadequate for people with ABI (Winkler et al., 2011). Inadequate living arrangements can lead to a reduction in quality of life and sense of well-being and can therefore have a deleterious effect on rehabilitation (Mezuk et al., 2014). On the other hand, suitable assisted living arrangements can have the opposite effect. For example, Winkler et al. (ibid) found several positive outcomes in people with ABI who moved out of aged care into community based settings, such as greater social inclusion, independence and overall sense of well-being.

Significance

The significance of this research is both practical and theoretical. Practically, the findings could be used to petition for the provision of appropriate long term care facilities for people with ABI and to inform the design of such long term care models. At a more immediate level, the findings could be used as a resource for the brain injured person and others involved in their care (Conneeley, 2012). Counsellors and family members who are preparing a person for a move into long term care could be made aware of the effects on rehabilitation and could take steps to mitigate this. Managers and staff who run homes with brain injured residents could gain greater understanding of specific issues they are facing.

In addition to practical significance, the research should fill a theoretical gap in the understanding of the lived experience of brain injured people within the context of long term care facilities. Previous research has clarified some psychosocial issues faced by people with brain injury, such as social isolation, loss of independence and deterioration in

relationships amongst others (Levack et al., 2010). This research could build on this knowledge by investigating how these psychosocial issues pan out in the context of a long term care facility.

Research Problem Statement

As previously stated, there is a global paucity of research exploring the experiences of people with ABI living in long term care facilities. Despite extensive review of local and international research, no studies were found that examined day-to-day life experiences in a long term care facility of adults with acquired brain injury. Furthermore, their experience of social isolation in a long term care setting has not been explored globally or in South Africa.

The suitability of living arrangements for people with ABI is a global issue that deserves attention. Inappropriate living arrangements can impact negatively on well-being and quality of life and can exacerbate social isolation. In their studies, Mezuk et al. (2014) and Winkler et al. (2011) found that inappropriate living arrangements can lead to increased depression and suicidality. Mezuk et al. (2014) reviewed 37 research reports of empirical studies of suicidal behaviour in long term care facilities. It was found that depression and suicidal thoughts were common in these facilities. Winkler et al. (2011) conducted interviews with people with ABI who had moved away from aged care settings into community based settings and found that overall well-being and social inclusion increased after the move.

Research Aims

In line with a study of elderly residents in long term care facilities by Iwasiw, Goldenberg, MacMaster, McCutcheon and Bol (1996), the purpose of the study was to listen to and analyse the particular experiences of people with ABI living in a long term care facility and thereby fill a gap in the literature.

The primary aim of this research was to explore the lived experience of people with ABI in long term care facilities and to understand more about their well-being and the appropriateness of these living arrangements.

The secondary aim was to discover how living in a long term care facility may contribute to social isolation of adults with ABI. Various components of social isolation were explored, such as relationships, a sense of belonging, companionship, loneliness, social support and marginalisation.

Both the primary and secondary aims were explored using semi-structured interviews and an interpretive phenomenological epistemology was adopted.

Research Questions

The following specific research questions were posed:

1. What is the lived experience of an adult with ABI in a long term care facility?
    a. What are the sources of unhappiness or distress?
    b. What are the sources of happiness or well-being?
2. How do adults with ABI perceive the suitability of their living arrangements: i.e. what needs do the long term care facilities fulfil and what needs are neglected?

3. How does the long term care home influence social isolation amongst adults with ABI?

The introduction of this report has served to explain the rationale, significance, context, aim and specific research questions of this study. The remainder of this report will cover the literature review (Chapter 2), methodology (Chapter 3), findings (Chapter 4), discussion (Chapter 5) and conclusion (Chapter 6).

CHAPTER 2: LITERATURE REVIEW

Literature from a variety of disciplines has explored the many facets of acquired brain injury. Insights have been gained from medicine, occupational therapy, nursing and psychology amongst others. The following topics will be covered in the literature review: theoretical underpinnings of this study, aetiology of ABI, nature and severity of ABI, incidence of ABI, general consequences of ABI, psychosocial consequences of ABI, life in long term care facilities, social isolation in long term care facilities, transitions for people with ABI and the methodological challenges associated with conducting research with people with ABI.

Theoretical Framework

Understanding the way in which a person with ABI experiences living in a long term care facility is complex and multifaceted, therefore, a complex theoretical model is required. The researcher believes that no one can be understood in isolation and that, to understand an individual one examine their social context. Therefore, a systems approach was opted for as the optimal method of approaching the problem, in the form of Bronfenbrenner's Ecological Systems Theory (1979). Theories that remove the individual from their context, such as psychoanalytic theory, were not appropriate for this purpose and were therefore discarded.

In addition, the research is concerned with optimising quality of life and fostering conditions in which people can reach their potential. The theory that was most compatible with this aim was Maslow's Hierarchy of Needs (1943). The researcher could not find another theory to explain how people reach their potential based on need fulfilment in this manner. Aspects of these two theories were taken into consideration when developing

questions for the interview schedule and to enhance the interpretation of the findings. The theories are discussed in detail below.

Bronfenbrenner's ecological systems theory. As a systems theorist, Bronfenbrenner (1979) understands human development to occur within a set of "nested structures, each inside the next" (p.3.). The nested structures or levels, the Microsystem, the Mesosystem, the Exosystem, and the Macrosystem are depicted in Figure 1.

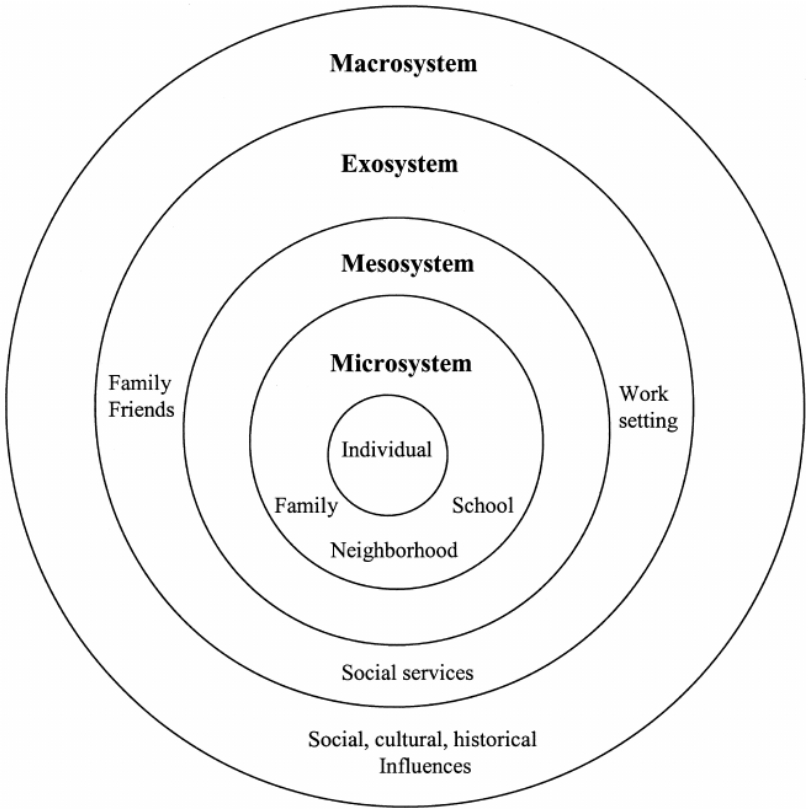


Figure 1: Bronfenbrenner's Ecological Systems Theory (Swanson et al., 2003). This figure illustrates the different levels of an individual's social context.

The essence of Bronfenbrenner's model is the idea that the individual cannot be understood in isolation. Instead, the individual is studied in relation to the various contexts that exert influence on them. The structure or level closest to the individual is the Microsystem, representing the immediate environmental setting and the significant others who have direct interaction with the individual. The crux to understanding the individual at

this level is how they perceive their Microsystem and the associated relationships. In this study, the long term care facility is the immediate environmental setting that forms the Microsystem for the person with ABI. According to Bronfenbrenner's model (1979), the physical setting and the other people within that setting have a profound impact on their life. Therefore, the way in which the person with ABI perceives the long term care environment and the others with whom they interact in this setting will undoubtedly play a powerful role in their well-being.

In addition to the Microsystem, there are three other levels that influence human interaction. These levels are: the Mesosystem; the Exosystem; and the Macrosystem. The second level, the Mesosystem, represents interconnections between different Microsystems, such as the interconnections between the long term care facility and activities outside. The third level, the Exosystem, consists of settings in which the individuals themselves are not present but that nevertheless influence them, for example, the caregiver's home situation. The final level, the Macrosystem, consists of broader cultural and contextual factors in which the other levels are embedded. For example, the economic situation, general long term care practices and people's beliefs towards people with brain injury. An additional element of Bronfenbrenner's theory is the Chronosystem, which refers to how development can be influenced by changes over time. For example, experiences in long term care facilities may change as a function of time.

In the case of a person with ABI living in a long term care setting, a large majority of their time is spent in their Microsystem. This is often due to their inability to drive a motor vehicle, their restriction from walking freely in and out of the facility and unemployed. Consequently, this research focused on exploring the Microsytem of the individual, while acknowledging that the other systems also exert influence.

Maslow's hierarchy of needs. Maslow formulated the well-known hierarchy of needs in relation to human motivation (1943). He argued that people have various levels of needs that occur in a hierarchy, as depicted in Figure 2.

According to the hierarchical nature of human needs, basic needs must be fulfilled first before higher level needs can be met. The lowest two levels on the Hierarchy of Needs are concerned with physical survival and safety. Physiological needs refer to basic human drives, such as hunger, thirst and sexual activity whilst safety needs refer to living in a safe, predictable and orderly world. The third and fourth levels are regarded as psychological needs of, respectively, belongingness and love, and esteem. The fifth level involves the drive towards self-actualisation.

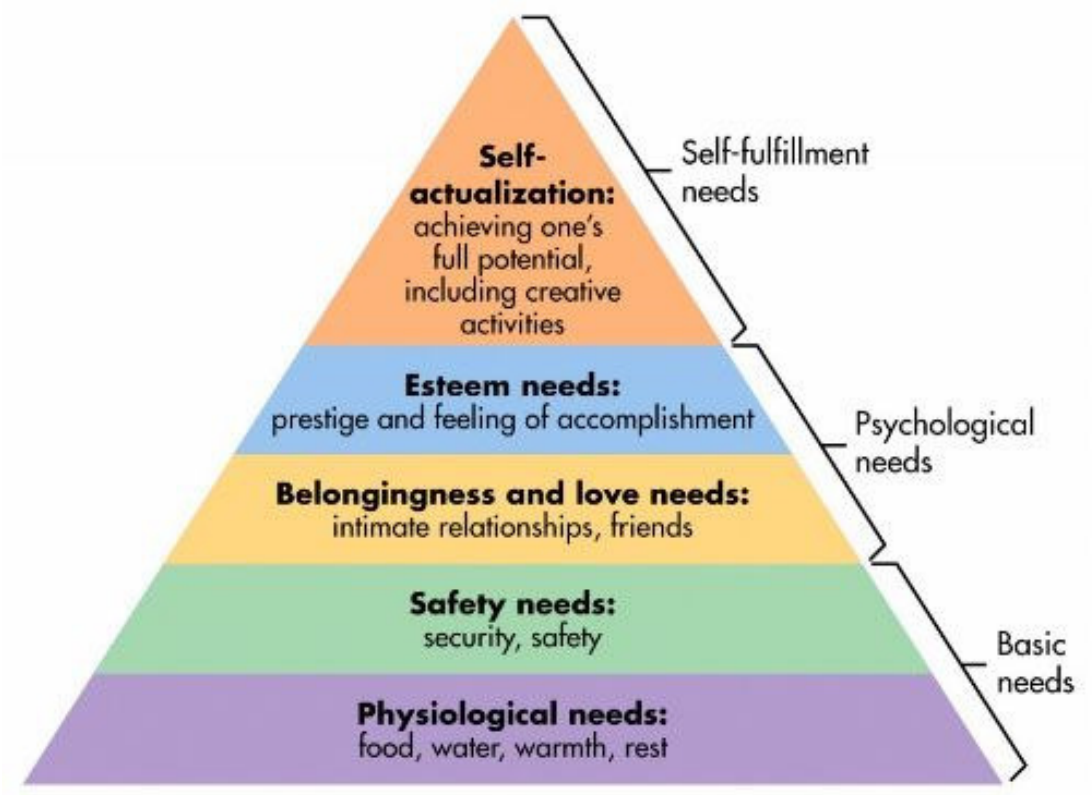


Figure 2. Maslow's Hierarchy of Needs (McLeod, 2016). This figure illustrates the hierarchical organisation of human needs.

Love needs involve love, affection and a sense of belonging, such as the need for companionship and a place to fit in. Esteem needs encapsulate having a stable and positive evaluation of the self, the need for freedom and independence, and prestige or respect from others. Having self-esteem needs met can be manifested in feeling useful and needed and, often, this is achieved through finding meaningful work or related roles.

The final need is that of self-actualisation, which refers self-fulfilment and reaching one's potential. Maslow believed that the achievement of self-actualisation could only occur once all other needs are fulfilled.

Maslow's theory of motivation provides a useful framework for considering whether a person with ABI can still reach their full potential and achieve satisfaction of higher level psychological needs that are essential for well-being. Having an ABI may generally lead to a person being less able to meet these higher level psychological needs so it is important that their immediate Microsystem, in which they spend majority of their time, provides them with opportunities to realise their potential. Therefore, Maslow's Hierarchy of Needs was considered an appropriate theory to address the research question of which needs are met in people with ABI living in long term care facilities.

Aetiology of ABI

The aetiologies of traumatic and non-traumatic brain injuries are different and are, therefore, discussed separately.

Traumatic brain injury (TBI). According to research by Hyder et al. (2007), the most common cause of TBI globally is motor vehicle accidents, followed by falls, interpersonal violence and work- and sports-related injuries. In South Africa, motor vehicle accidents and interpersonal violence are the most common causes of TBI, although

percentages vary, depending on location (Alexander, Fuller, Hargovan, Clarke, Muckar & Thomson, 2010). Pedestrian accidents are also a common cause of TBI in South Africa (Naidoo, 2013).In a sample of 150 people with TBI at a particular hospital in KwaZulu-Natal, Alexander et al. (2010) found that 41% of TBI patients sustained their brain injuries as a result of blunt force head trauma during assaults whilst 28% were from injuries in motor vehicle accidents. Only 3% had gunshot wounds to the head and another 3% had fallen from a height.

TBI can be classified into three main types based on aetiology, namely: penetrating, crushing and closed head injuries (Brown, 2010; Ogden, 2005). The most common are closed head injuries, which refer to damage caused when brain tissue moves inside the skull as a result of sudden forces of acceleration, deceleration and/or rotation (Brown, 2010). Examples of a closed head injury include motor vehicle accidents and falls. According to Ogden (2005), crushing head injuries are the least common and occur when the head is compressed between two objects, for example, in workplace accidents. Lastly, penetrating head injuries occur when an object pierces the skull and the brain and are usually caused by gunshot and knife wounds (Odgen, 2005).

Non-traumatic brain injury. In contrast with traumatic brain injuries, non-traumatic brain injuries are related to medical conditions, such as cerebrovascular accidents, diseases and tumours. Cerebrovascular accidents, more commonly known as strokes, may lead to brain injury by preventing blood flow to brain tissue or as a result of bursting of blood vessels in the brain (Brown, 2010). Diseases that affect brain tissue include meningitis and encephalitis (Soeker, 2011).

The Nature and Severity of ABI

Damage to the brain produces diffuse and/or focal lesions in brain tissue (Khan et al., 2003). Brain injuries are classified as primary when they occur on impact, for example, a diffuse axonal injury, and secondary when they develop thereafter, often due to swelling of the brain or pooling of blood from a slow leak in a blood vessel (ibid).

Various methods are used to assess the nature and severity of ABI's (Brown, 2010). Technology available to medical science includes radiological techniques, such as computed tomography (CT) and magnetic resonance imaging (MRI). Rating scales are used by medical staff in acute and chronic patient care to assess level of consciousness and posttraumatic amnesia following impact. They provide information that can be used for prognoses of survival and outcome (Khan et al., 2003). Commonly used scales include the Glasgow Coma Scale (GCS; Teasdale & Jennett, 1974), Galveston Orientation and Amnesia Test (GOAT; Levin, O'Donnell & Grossman, 1979) and the Westmead Post Traumatic Amnesia Scale (WPTAS; Shores, Marosszeky, Sandanam & Batchelor, 1986). In addition, various batteries of neuropsychological tests are used to assess the nature and severity of sensorimotor, cognitive and psychological deficits (Brown, 2010).

Incidence of ABI

As previously stated, traumatic brain injury is far more common in developing countries, such as South Africa, than in developed countries (National Institute for Occupational Health, 2017). Worldwide, incidence statistics show that traumatic brain injury is most prevalent in individuals between 15 and 35 years of age and is more common among males than females (Khan et al., 2003).

Some of the most commonly occurring non-traumatic brain injuries are cerebrovascular accidents (CVA's), brain aneurysms, tumours and infections (The Rehab Group, 2017) and these injuries often lead to disability. Statistics show that more than 50% of survivors of a CVA in the United Kingdom have a disability (The Stroke Association, 2015). More than a third of survivors of CVA's are dependent on others and only one in five of those are cared for by family and friends. Previously, CVA's were thought to occur primarily in the elderly, but the United Kingdom statistics show that CVA's have increased in people aged 20 to 64 by 25% from 1990 to 2010. People residing in developing countries, including South Africa, are at an increased risk of having a CVA at a younger age (Ibid). Adeloye (2014) reported that the incidence and number of survivors of CVA's in South Africa have increased by 10.8% and 9.6%, respectively, from 2009 to 2013.

These statistics show that acquired brain injury is likely to place the greatest burden on countries with limited resources as patients often have disabilities from a relatively young age that require long term care. The challenge is then for the system to provide suitable alternative long term living arrangements.

Consequences of ABI

ABI can lead to a combination of physical, cognitive and psychosocial sequelae that depend on factors, such as the age of the person at the time of the injury and the location and severity of the injury (Alston, Jones & Curtin, 2012; Odgen, 2005). Physical sequelae can affect mobility, balance and coordination with the result that a person with ABI may require assistive devices to walk, such as a walking stick or walking frame, or they may be confined to a wheelchair. Cognitive sequelae most commonly include deficits of attention, memory, communication and executive functions (Ogden, 2005).

Psychosocial Consequences of ABI

Commonly reported psychosocial sequelae of ABI are: personality changes; mood disturbances; low self-esteem and loss of sense of identity; social isolation; loss of employment; loss of independence, including the ability to drive a car; and decreased leisure activities (Conneeley, 2012; Di Battista, Godfrey, Soo, Catroppa & Anderson, 2014; Gauvin-Lepage & Lefebvre, 2010; Levack et al., 2010; Liddle, Fleming, McKenna, Turpin, Whitelaw & Allen, 2012; Norup, Welling, Qvist, Siert & Mortensen, 2012; Ogden, 2005; Soeker, 2011). These consequences are discussed in more detail in the following paragraphs.

Personality changes. Following a brain injury, people with ABI and their family members often complain about personality changes (Bodley-Scott & Riley, 2015). The most challenging are aggression, irritability, mood swings, loss of motivation and interest, socially inappropriate behaviour, impulsivity and changes in emotional responsiveness (Badul, 2012; Bodley-Scott & Riley, 2015). They cause distress to the person with the brain injury as well as caregivers, family members and other loved ones (Bodley-Scott & Riley, 2015). Often, they lead to family breakdown and loss of intimate relationships (Levack et al., 2010).

Mood disturbances. Depression is common after mild, moderate and severe brain injuries (Fann, Hart & Schomer, 2009). Associated with depression, people with ABI commonly report high levels of negative emotions such as fear, regret, grief, anger and guilt (Levack et al., 2010).

Depression goes hand in hand with suicide risk. Studies have shown that people with ABI are at a greater risk of committing suicide than the general population (Leon-Carrion, De Serdio-Arias, Cabezas & Rolda, 2009; Teasdale & Engberg, 2001). Of 39 brain injury survivors assessed by Leon-Carrion et al. (2009), 48.6% were depressed and

68% of them were at risk of committing suicide (33% of the total). Teasdale and Engberg (2001) found that suicide rates were not evenly distributed among the brain injury population. They were higher for males and lower for people who sustained their brain injury before 21 or after 60 years of age. Thus, younger and middle-aged men were most at risk for suicide after brain injury.

Anxiety is another common emotional problem after brain injury and can take various forms (Moore, Terryberry-Spohr & Hope, 2006; Williams, Evans & Fleminger, 2003). Anxiety can be general (generalised anxiety disorder) or it can manifest in specific disorders such as panic disorder and obsessive compulsive disorder (Williams et al., 2003).

Low self-esteem and changed identity. People with ABI often report low self esteem that is often associated with loss of their sense of identity (Levack et al., 2010). Reductions in self-esteem have also been linked with changes in body image and cognitive ability. For example, Cooper-Evans, Alderman, Knight and Oddy (2008) found that people with ABI who were less cognitively impaired reported higher levels of self-esteem. Having low self-esteem was linked to negative outcomes in health, well-being, occupational success and social relationships.

Along with reductions in self-esteem, family members of people with ABI reported that the identities of their loved ones changed after the injury (Bodley-Scott & Riley, 2015). Their participants with ABI reported feelings of disconnect with their pre-injury personal identity and a desire to re-construct this identity. Levack et al. (2010) discovered that their participants with ABI felt unable to connect with the person they were prior to the injury, and often reported feeling “reborn” or having become a different person. Re-constructing this lost identity was important for recovery and involved acceptance and changing the way the self is viewed.

Social isolation. Social isolation is a commonly reported challenge and people with ABI often struggle to maintain a social support network of friends and family (Coneeley, 2012; Winkler et al., 2010). Studies have demonstrated that numbers of friends decrease following a brain injury and social integration may also deteriorate (Winkler et al., 2011). Levack et al. (2010) found that people with brain injury experienced reductions in and disruptions to their social world, often feeling abandoned by others. This was sometimes understood to be the result of stigma and discrimination towards people with brain injury.

Experiencing social isolation is associated with negative outcomes among people with ABI. For example, Winkler et al. (2010) found lower levels of satisfaction with life and reduced well-being among participants with ABI who experienced social isolation.

Loss of employment. According to a systematic review conducted by Diaz et al. (2014), 60% of people who have acquired a traumatic brain injury do not return to work. According to Soeker (2011) this rate is even higher in South Africa with an estimated 97% of people with ABI being unfit to return to work. After interviewing people with mild to moderate brain injury, Soeker (2011) found the following barriers to returning to work: uncertainty about the future, loss of confidence in their worker role and loss of functions necessary to perform in the workplace.

Loss of independence. Dodge et al. (2012) noted that a sense of independence and autonomy are considered to be important facets of well-being. However, there are many factors related to brain injuries and their sequelae that may lead to decreased independence. These factors include problems with health as well as environmental factors, such as an increased need for supervision (Nadler, Fleming, Cornwell, Shields & Foster, 2013).

Loss of ability to drive a car. Liddle et al. (2012) opined that being able to drive is an important means of achieving independence in modern society. These researchers

estimated that about 50% of people with ABI are unable to drive a motor vehicle after their injury due to physical, cognitive, visual, behavioural and/or functional impairments associated with brain injury. They pointed out that the effects thereof can be devastating and can lead to greater social isolation and changes in mood and identity. From interviews they conducted with people with ABI and their families, they found that not being able to drive and the associated loss of independence caused sadness and anger. Their participants felt isolated and they reported low self-esteem and a lack of out-of-home activities. Outcomes were better when participants had other means of accessing their community, such as walking and using public transport.

Decreased leisure activities. Often, people with ABI are not integrated back into the community and, as a result, they experience a decline in leisure activities (Winkler et al., 2010). In a study of 149 people with ABI, Johansson, Hogberg and Bernspang (2007) found that less than half the participants were satisfied with their current leisure activities.

The above psychosocial sequelae paint a grim picture of life after ABI. Often, the sequelae interact with, and exacerbate, each other. For example, loss of ability to drive leads to loss of independence, which then leads to social isolation and results in depression. However, Levack et al. (2010) identified psychological resources that enable people with ABI to cope with their challenges. These include hope and optimism; strength of will; spirituality; and appreciation of both the good and the small things in life.

It is plausible that the context in which a person lives may either exacerbate or alleviate some of these psychosocial challenges, which is why appropriate long term placement is essential. For example, Winkler et al. (2010) wrote that the psychosocial sequelae of brain injury may be exacerbated by living in inappropriate accommodation, such as residential aged care. The next section will discuss the literature on life in long term care facilities.

Life in Long Term Care Facilities

Winkler et al. (2010) note that the psychosocial sequelae of brain injury may be exacerbated by living in inappropriate accommodation such as residential aged care. From a functionalist perspective, long term care facilities can be viewed as social institutions that serve to fulfil certain societal needs. According to the websites of some of the long term care facilities that accommodate people with ABI in South Africa, they aim to fulfil the need for support, care, dignity, accommodation, stimulation, improved quality of life, development of skills and self-esteem, and the creation of a happy and homely environment.

However, long term care facilities are not always happy and homely places. A study conducted by Zimmerman et al. (2005) investigated quality of life in residents of residential care and assisted living facilities. The sample included residents with and without cognitive impairments related to Alzheimer's disease and dementia. Quality of life was assessed twice over a six-month period using measures of positive and negative affect, engagement in activities, ability to participate in meaningful activities, self esteem, feelings of belonging, physical condition, mood, interpersonal relationships and financial situation (Zimmerman et al., 2005). They found that the residents with greater cognitive impairment experienced a greater reduction in quality of life, suggesting that quality of life may be linked to cognitive impairment in some way. Thus, people with ABI with significant cognitive impairment may experience a similar reduction in quality of life when living in long term care.

Well-being has also been studied among residents of assisted living facilities. In their study, Street et al. (2007) evaluated well-being across three dimensions: life satisfaction; quality of life; and perception that assisted living feels like home. It was found that the residents who had adequate privacy reported greater well-being across all dimensions than those who shared rooms with people. Most importantly, "the most

consistent findings concerned internal social relationships" (p.129). The residents who scored higher on internal social relationship measures experienced greater well-being in all areas.

Meyer et al. (2011) investigated the degree of depression among 33 residents of three rural nursing homes in the United States. Results of assessments using the Geriatric Depression Scale found that 46% of the residents experienced mild or moderate levels of depression. The data also showed evidence of loneliness and social isolation amongst residents. In a review on existing empirical studies into suicide risk among residents of long term care facilities, including nursing homes and assisted living facilities, Mezuk et al. (2014) found that suicidal thoughts were common and correlated with depression, social isolation and loneliness.

Iwasiw et al. (1996 used qualitative techniques to explore the experiences of 12 elderly residents who had moved into a long term care facility, focusing specifically on the experience of the first two weeks of residence and the process of adjustment that occurs during this transition. They found that residents adjusted to long term care more easily if they had actively participated in the decision to move. The experiences of these residents were described in four main categories: emotional reactions, transitional activities, reflecting on their situation and connecting with a personal philosophy, and are discussed below.

Emotional reactions. The residents experienced many different emotions, including fear and relief. Relief was the result of not being alone anymore, not having to prepare one's own meals and feeling safe. Feelings of sadness, depression, powerlessness and betrayal were common, especially in residents who did not choose to move into long term care. Only one participant experienced positive emotions, namely a

feeling of liberation and an improvement in self-esteem. The variation in emotional reactions showed that control over decisions was an important facet of well-being.

Transitional activities. They fell into the following categories:

1. Trying to make the long term care facility feel like home: the residents reported personalising their rooms and engaging in activities that they found enjoyable.
2. Maintaining new relationships and beginning new ones: some residents kept in contact with friends from outside and tried to build new relationships inside the facility. However, those residents who did not want to move experienced negative emotions, such as anger, shock and depression. They isolated and emotionally distanced themselves from other residents in the facility.
3. Fitting in: the residents fitted in largely by observing and adhering to the rules of the long term care facility. Some of the residents were bothered by other cognitively impaired residents.

Reflecting on their situation. The residents expressed a range of appraisals of the facility, from disapproval, to guarded approval and enthusiastic endorsement. Commonly, participants described their experience as different.

Connecting with a personal philosophy. Participants expressed tolerance for and acceptance of their situation, for example, by making the most of their living arrangement and expressing faith in God's plan. These philosophies helped to give meaning to their experiences.

Other studies looked at quality of life and well-being in residents of assisted living and residential care facilities from a quantitative perspective. However, as Maslow and

Heck (2005) point out, there is no single or easy way of measuring quality of life among residents in long term care facilities. Studies into the quality of life in such populations tend to yield different results depending on the instrument used and whether the residents or their caregivers complete the instrument. Therefore, no definitive conclusions can be drawn from these studies and more research is needed. Furthermore, none of these studies investigated the well-being of people with ABI in long term care.

There is an Australian study by Winkler et al. (2011) that described the effects of moving away from residential aged care. The study explored how young people with ABI experienced a transition from aged care to community-based settings. These settings referred to shared supported accommodation, homes with parents and homes with partners. Shared supported accommodation included facilities that were either privately owned or run by community service organisations that housed four to six residents who shared disability support workers (Winkler et al., 2010). Their results revealed that living in community-based settings had several benefits for people with ABI. It resulted in greater independence, social inclusion and overall well-being as discussed below.

Independence. One of the reasons the participants wanted to leave aged care was to have more independence. Their independence was enhanced in several ways, such as: improved continence; improved mobility; improvements in speech and communication; and improvements in eating independently.

Social inclusion. Participants could participate more meaningfully in social activities, including: having things to do, being known in the community and interacting more with friends and family.

Overall well-being. Participants experienced a greater sense of well-being after moving away from aged care, which manifested in a reduction in difficult behaviour such as aggression and attention seeking behaviour. Consequently, they required less

behaviour controlling medication. Overall feelings of distress were reduced and participants generally felt happier. Winkler et al. (2011) postulated that this was due to having more control, being able to choose with whom to live and being able to do the things they enjoyed.

Winkler et al. (2011) also found that people with ABI in aged care experienced boredom and loneliness and they reported a lack of age appropriate activities. Not being able to engage in meaningful activities also led to distress in a study conducted by Strettles, Bush, Simpson and Gillet (2005, as cited in Winkler et al., 2011). In the context of aged care, "younger people miss opportunities for exercise, socialisation with people like themselves, engaging in activities that contribute to a positive sense of self and added purpose to life" (Winkler et al., 2011, p.160). These findings again point to the importance of social inclusion and independence for well-being among people with ABI.

Social Isolation in Long Term Care Facilities

As previously stated, social isolation was a critical issue for elderly residents of long term care (Meyer et al., 2011). Meyer et al. (ibid) found that less than half of 33 residents living in nursing homes were happy with levels of communication with family and friends. They also found that residents of nursing homes were more likely to experience social isolation than the elderly living in the community.

Winkler et al. (2011) argued that social isolation in people with ABI was aggravated when they lived in aged care facilities. Participants with ABI in their study found it difficult to invite friends visit them in aged care facilities because of the conditions, such as the smell of faeces. Furthermore, younger residents in aged care struggled to make friends with other residents due to age differences and having little or nothing in common with

older residents. Living in aged care facilities generally excluded people from community life, which was exacerbated by limited access to transport. In contrast, moving back into the community provided some people with ABI better access to transport allowing them to reconnect with past neighbourhood friends.

Transitions for People with ABI

Research has shown that recovering from a brain injury entails a number of transitions in the affected individual's life (Conneeley, 2012; Nadler et al., 2013). One significant transition is moving from acute hospital care back home (Conneeley, 2012; Nadler et al., 2013; Turner et al., 2007). The following themes were important for people with ABI when returning home: wanting to return to normality, moving forward, changing views on the self and life and wanting to regain independence, autonomy and control (Conneeley, 2003; Conneeley, 2012; Nadler et al., 2013).

Wanting to return to normality. For many participants in Coneeley's (2012) and Nadler et al.'s (2013) research, the focus was on getting home and returning to normality. This included "re-establishing life roles, activities and relationships and making the transition through to integration within the community" (Coneeley, 2012, p.79). Returning to work was a high priority for many of the participants and being unable to return to work impacted negatively on participants' sense of self (Coneeley, 2012). Wanting to return to normality was also linked with gaining independence in Nadler et al.'s (2013) study.

Moving forward. Participants in Coneeley's (2012) study could recognise that their lives were moving forward one year after discharge from hospital. This included aspects such as gaining autonomy and control over decision-making and problem-solving.

Changing views of the self and life. Many participants in Nadler et al.'s (2013) study showed a change perspective on life. They acknowledged the need to accept changes in their life because of the sequelae of their injuries, which had often changed their priorities. As for changing views of the self, Levack et al. (2010) conducted a meta-synthesis of the lived experience of people with brain injury. It was found that people with brain injury expressed a need to reconstruct themselves and their place in the world by transitioning from an 'old' to a 'new' self. Hence brain injury resulted in a change in personal identity.

Wanting to regain independence, autonomy and control. Coneeley (2012) found that regaining a sense of independence, autonomy and control was important for participants when moving from hospital back home. In Nadler et al.'s (2013) study, regaining independence was perceived as an important step towards returning to a normal life.

The literature discussed above shows that people with ABI struggle with the psychosocial consequences of their injury in various contexts in their lives. Thus, it is important to investigate how these issues play out in various forms of long term care. However, conducting interview based research with people with ABI poses a range of methodological challenges, which form the focus of the next section.

Methodological Challenges in Brain Injury Research

Various researchers (Boylan, Linden & Alderice, 2016; Carlson, Paterson, Scott-Findlay, Ehnfors & Ehrenberg, 2007; Paterson & Scott-Findlay, 2002) identified challenges in conducting qualitative interview based research with people with ABI. They were fatigue,

cognitive deficits, memory problems and communication difficulties. Because of these difficulties, many researchers gather information from caregivers and/or family members instead of the people with ABI (Boylan et al., 2016).As a result, they are often marginalised when it comes to research and their views are not represented in published literature, even though it is important to listen to their perspectives for methodological and ethical reasons. In the words of Iwasiw et al. (1996), “Because individuals who enter a LTCF are affected most, it is essential that their views are heard” (p.382). Philpin, Jordan and Warring (2005) discovered that the information gained from caregivers and family differs from the information provided by the person experiencing the phenomenon. In a study conducted by Iwasiw et al. (1996), issues raised by residents of long term care facilities were unfamiliar to the nursing staff and other caregivers. Thus, relying on information from caregivers could jeopardise the trustworthiness of findings. Since the person with ABI is the one experiencing the living conditions, they are in the best position to provide data on these experiences.

Although there are real challenges to interviewing people with ABI, there are methodological strategies that can be used to ensure rigour. In qualitative research rigour corresponds to validity and reliability in quantitative research and refers to methods of ensuring confidence or trust in the qualitative research findings (Thomas & Magilvy, 2011). Articles published by Boylan et al. (2016), Carlson et al. (2007) and Paterson & Scott-Findlay (2002) provide methodological recommendations for conducting interview-based research with ABI.

The challenges identified by researchers and the recommendations to address them are discussed below.

Fatigue. One of the biggest challenges when interviewing brain injured people is fatigue (Carlson et al., 2007; Middleton, 2001). People with ABI can become mentally and

physically tired during an interview (Paterson & Scott-Findlay, 2002). Paterson and Scott-Findlay (2002) reflected on their experience of interviewing people with ABI. They found that their participants became tired and distracted as the interview progressed, rendering their responses less focused and more concrete towards the end of the interview. Signs of fatigue that were noted included the person looking tired, slurring their words and slumping in their chairs. The participants admitted that focusing for a long time on the interview questions was challenging especially in the presence of other distracting stimuli, such as noise. Therefore, Paterson and Scott-Findlay (2002) recommend that interviews are divided into shorter sessions, that the interviewer watches participants closely for signs of fatigue, and that the interviewer is flexible in terms of the interview schedule.

Cognitive difficulties. Cognitive difficulties can vary widely in people with ABI depending on the severity and location of their injuries (Ogden, 2005). Because an interview requires a certain level of cognitive functioning, doing interview-based research is limited to those who can function at an adequate cognitive level. This means the personal views of those who are most impaired are seldom represented in the literature. Participants with ABI may struggle with open ended questions, may have difficulties with concentration and may be easily distracted (Egan, Chenoweth & McAuliffe, 2006). It is important to adapt the methodology accordingly, for example, by using semi-structured interviews and by taking steps to minimise distractions.

Memory problems. Brain injury often affects a person's ability to recall events (Paterson & Scott-Findlay, 2002). While memories for events prior to the injury are often intact, people with ABI can struggle to encode, retain and retrieve new information due to damage to the memory circuits and centres of the brain. Therefore, depending on the location and extent of the injury, some participants may not be able to recall some events

after the injury. Therefore, research design should not rely on this but should focus on familiar, everyday experiences.

Related to memory difficulties, is the possible issue of confabulation that occurs when a person cannot remember an event and creates a false memory. This phenomenon is rare in people with ABI (Demery, Hanlon & Bauer, 2001) and research has shown that "the critical deficit for confabulation has its anatomical location in the inferior medial frontal lobe" (Turner, Cipolotti, Yousry & Shallice, 2008 p. 637).

Communication difficulties. In addition to cognitive and memory issues, people with ABI may also have communication difficulties. Following brain injury, a person may experience word finding difficulties (dysphasia), or expressive communication difficulties such as dysarthria. These issues can interfere with fluency of speech during the interview, so participants with communication difficulties are often excluded from research. Including people with dysphasia and dysarthria is important as they too can contribute important personal information and their difficulties can be overcome with time and patience (Paterson & Scott-Findlay, 2002).

Therefore, conducting interviews with people with ABI is not an easy task. However, they have valuable insights to offer on their life experiences and it is up to the researcher to address the challenges to enable them to tell their stories.

CHAPTER 3: METHODOLOGY

The research design and methodology was informed both by the aims of the study, which were to understand the experiences of people with ABI living in long term care facilities, and how they are affected by social isolation, and by the known challenges one can encounter when interviewing people with ABI. The methodology section will discuss the following topics: the research design, recruitment, ethical considerations, participants, data collection, procedure, data analysis and rigour.

Research Design

A qualitative research design was chosen to explore life experiences of people with ABI in long term care facilities. By using this approach, the researcher hoped to uncover rich and meaningful insights into the lives of the participants. A qualitative approach was chosen as an initial means of exploring the phenomenon in depth, since it is an understudied topic. The study can then be followed by quantitative approaches to add breadth to these findings.

This study followed the epistemology of interpretive phenomenology, based on the philosophy of Heidegger (Duckham & Schreiber, 2016). The interpretive phenomenological approach places emphasis on the perspectives of people living through the phenomenon under investigation (Horrigan-Kelly, Millar & Dowling, 2016). It focuses on the person's existence within their social context and aims to uncover the meaning of their lived experience as a means to understanding the phenomenon (Duckham & Schreiber, 2016). The researcher actively looks for themes in people's stories and attempts to interpret and understand what is meaningful for participants.

This approach was chosen because it was compatible with the overall research aims of this study, namely to understand the individual with ABI within their context of long term care facilities through exploring their everyday lived experience.

Recruitment

Convenience sampling was used to recruit participants. Convenience sampling refers to selecting participants that are most accessible to the researcher (Robinson, 2014). The participants were recruited from a brain injury support organisation called Headway Gauteng. Participants who were familiar with the phenomenon being studied, namely living in long term care, and who were willing and able to share their experiences during interviews were invited to participate.

To ensure the suitability of participants, the following inclusion criteria were used:

1. The participant had to have sufficient cognitive ability to participate meaningfully in an interview. This was assessed using a combination of objective and subjective measures:
    a. Subjective measures:
        i. The researcher knew many of the participants prior to the study and was familiar with their cognitive abilities;
        ii. The researcher discussed potentially suitable candidates with other staff members at Headway; and
        iii. The researcher observed the participants' abilities during the informed consent procedure.

b. Objective measures:

i. With the relevant consent from the Therapy Manager at Headway Gauteng, the researcher was granted permission to examine their files for the results of cognitive assessments done at Headway Gauteng. There were no exact criteria for deciding who could participate based on the assessments, but the files provided information on participants' executive functioning, which was analysed holistically in combination with the subjective measures and the assessment notes.

2. The participant had to have had an ABI, either traumatic or non-traumatic, more than two years prior to the interviews. Two years is generally accepted as the time it takes for maximum medical improvement following brain injuries (Monnett, 2017). Participants with different types of ABI's were included in the study so as to understand the experiences of people with ABI in general.
3. The participants had to be residing in a long term care facility for at least 6 months to ensure that they were relatively settled in their new residence and would have enough experience to contribute during the interviews.
4. The participants had to be less than 65 years of age (retirement age) because the aim of the study was not to focus on experiences of the elderly.
5. The participants had to be conversant in English and be able to communicate well enough to answer interview questions.

The only exclusion criterion was if the participant was known to confabulate. This information was found in their files.

Ethical Considerations

The participants of this research could be considered vulnerable as a result of their brain injury. Therefore, very careful attention was paid to ensuring the research was conducted in an ethical manner at all stages. The study was approved by the Human Research Ethics Committee (Medical) at the University of the Witwatersrand. The ethical clearance certificate can be found in Appendix C.

The following ethical considerations were taken into account: informed consent, voluntary participation, confidentiality, institutional permission and minimisation of harm. These ethical considerations are presented in more detail below.

Informed consent. A thorough and ethically compliant informed consent procedure was developed. The informed consent documentation can be found in Appendix B. The informed consent procedure involved reading through the information sheet with potential participants on an individual basis in a quiet room at Headway Gauteng. After each section of the informed consent document was read aloud, the researcher asked the potential participant if they understood the contents and if they had any questions. The following sections were covered: introduction, purpose of the research, type of research intervention, participant selection, voluntary participation, procedures, duration, risks, benefits, reimbursements, confidentiality, permission to audio-record, sharing of results, right to refuse or withdraw and who to contact.

Thereafter, the researcher asked if the potential participant would like to participate. They were advised that they were not expected to answer immediately and were given the opportunity to give the matter some thought and discuss it others before making a decision. If they agreed to participate, they were asked to sign the consent form and were given a copy thereof, along with the information sheet containing the researcher's contact

details. The participants were told that they could contact the researcher at any time should they have any questions or concerns, of if they wanted to withdraw from the study.

Voluntary participation. The voluntary nature of participation was emphasised and it was made clear that there would be no negative consequences as a result of failing to participate. It was made clear to participants that they were free to withdraw at any time during the research process with no consequences. Participants were also informed that they did not have to answer questions if they did not wish to do so and they were reminded of this at the beginning of each interview. No coercion was used and no incentives were offered for participation.

Confidentiality. The participants were allocated pseudonyms and only the researcher knows the participants' real names. The interviews were conducted in a private place. The audio files and transcriptions were kept on a password protected computer and will be destroyed after completion of the study. The researcher took care to remove any identifying details from the transcripts. The characteristics of the participants were described in a way that would not lead to their identification, for example, the names of the facilities in which they reside were not provided.

Institutional permission. Permission was obtained in writing from the Therapy Manager Headway Gauteng to recruit their members and access their files (see Appendix D).

Minimisation of harm. To ensure psychological well-being, the participants were encouraged to say if they felt any distress as a result of the interview and wished to speak to a counsellor. A qualified counsellor from Headway was on call should this need arise. Care was taken to schedule interviews at a time that did not interrupt the participants' rehabilitative activities.

Participants

A total of eight participants volunteered to take part in the research, however, one volunteer dropped out before the first interview. The remaining seven participants were adults with a history of ABI who were living in long term care facilities. However, they were not a homogenous group due to divergent demographic characteristics and the nature of their brain injuries. Six of the participants were male and one was female. The age of participants ranged from 28 to 61 years. Six had a history of traumatic brain injuries and one of non-traumatic brain injury. The intervals from the time of the injuries until the time of the study ranged from four to 15 years. The time spent living in long term care ranged from two to eight years.

Most of the participants lived in facilities for people with various disabilities. One participant had lived in residential aged care prior to moving into an assisted living facility. Their files at Headway showed that none of the participants had inferior medial frontal lobe damage or any signs of confabulation. They all spoke English, although some had speech difficulties in the form of dysphasia and/or dysarthria. The characteristics of the participants are summarised in Table 1.

Participant's Pseudonym	Age	Nature of injury	Years post-injury	Type of long term care facility	Years in long term care facility
Richard	28	Fall	14	Cerebral Palsy	6
Henry	61	CVA	4	Disabilities and previously aged care	2
James	55	Bicycle Accident	7	Physically Disabled	2
Kevin	34	Gun shot	9	Physically Disabled	8
Brandon	48	Motorbike Accident	9	Physically Disabled	6
Ian	41	MVA	9	Cerebral Palsy	5
Charlene	57	MVA	15	Disabilities	7

Table 1. Participant Characteristics. This table shows the characteristics of the seven participants of this study. MVA = motor vehicle accident, CVA = Cerebrovascular Accident

The characteristics in Table 1 are the ones deemed essential for this study, and any extra information, for example, family circumstances and status prior to the ABI, was not recorded in order to protect the participants' confidentiality. The researcher stopped recruiting after seven participants because there was enough data to draw meaningful themes from analysis, and it was difficult to find more participants that met the selection criteria.

Data Collection

Data was collected from the participants using serial semi-structured, face-to-face interviews as recommended by Jumisko, Lexell and Soderberg (2009), who found this to be the best approach to interviewing people with ABI. A semi-structured interview schedule (Appendix A) was designed using questions and probes that were relevant to the research questions of this study. The interview schedule was informally piloted using three members of Headway who functioned on a similar cognitive level to potential participants. They were asked whether they would understand the questions. All the questions were found to be suitable and were not changed.

Since people with ABI are known to struggle with open-ended interview questions (Egan et al., 2006), a funnel type method of questioning was used. The interviewer began with a relatively open ended question and if the participant struggled to respond, the question was made more specific. To limit possible effects of memory problems, the questions focused on what the person felt and experienced in their current situation, and were not based on recall of past events, although many of the participants were able to recall and reflect on past events.

The questions in the interview schedule were theoretically informed, using Maslow's Hierarchy of Needs (1943) and Bronfenbrenner's Ecological Systems Theory (1979), and were developed in collaboration with two experts in the field of brain injury. According to Bronfenbrenner, a person's reality cannot be seen directly, but can be inferred from their activities, roles and relationships. With this in mind, the interview schedule included questions about the activities, roles and relationships of participants to develop an understanding of the experience of living in long term care. Incorporating Maslow's (1943) hierarchy of needs, questions were asked to elucidate possible feelings of love and

belonging, to investigate what needs the facilities met or neglected and to understand participants' feelings related to social isolation.

Many probes were used to encourage the participants to speak about their experiences and ensure that the researcher had understood correctly what the person was trying to convey. Throughout the interview, the researcher ensured that participants understood the questions and they were rephrased whenever necessary. The researcher remained flexible with the interview schedule at all times and investigated important subjects that arose for participants.

To minimise the possible effect of fatigue, the interviews were divided into thirty minute sessions were conducted in the morning as much as possible. The interviews were carried out in a place that was as quiet and private as possible to minimise the possibility of distractions. During the interview, the researcher continually observed for signs of fatigue and the participants were encouraged to say if they felt tired. It was made clear to participants that the interview could be terminated if this was the case.

In addition to reducing the effect of fatigue, the technique of serial interviewing also aided in ensuring reliability and consistency of the responses, as some of the questions were repeated in subsequent interviews. The participants answered in the same way across interviews and some of them also recalled being asked the question before and mentioned this. The serial nature of interviews also allowed the researcher to probe on any points that were unclear or any apparent inconsistencies, as recommended by Paterson and Scott-Findlay (2002). A break between sessions enabled the researcher to reflect after each interview and design appropriate follow up questions.

During the interviews, some of the participants had speech difficulties, for example, dysarthria. The researcher has experience working with people with communication difficulties and was therefore able to minimise the impact on data quality. To limit the

possibility of misunderstanding when communication difficulties were present, the researcher checked her understanding of what the participants had said to ensure that this was what they meant.

The interviews took place in a quiet and private room either at Headway Hyde Park or at the participants' long term care facilities, depending on the participants' preferences. The interviews were conducted in two to four thirty minute sessions depending on how long it took to get through all the questions. The participants were reminded at the beginning of each interview that their responses were confidential and they were encouraged to provide open and honest responses.

The researcher audio-recorded each interview using a password-protected tablet device. The interviews were loaded onto a password-protected computer and were transcribed verbatim by the researcher.

Procedure

The entire research process, including conceptualisation, planning, operationalisation, analysis and write-up occurred between November 2015 to March 2017, with interviews taking place in July and August 2016. The steps taken are summarised in Figure 3. They have all been explained in detail in the relevant sections elsewhere in this chapter.

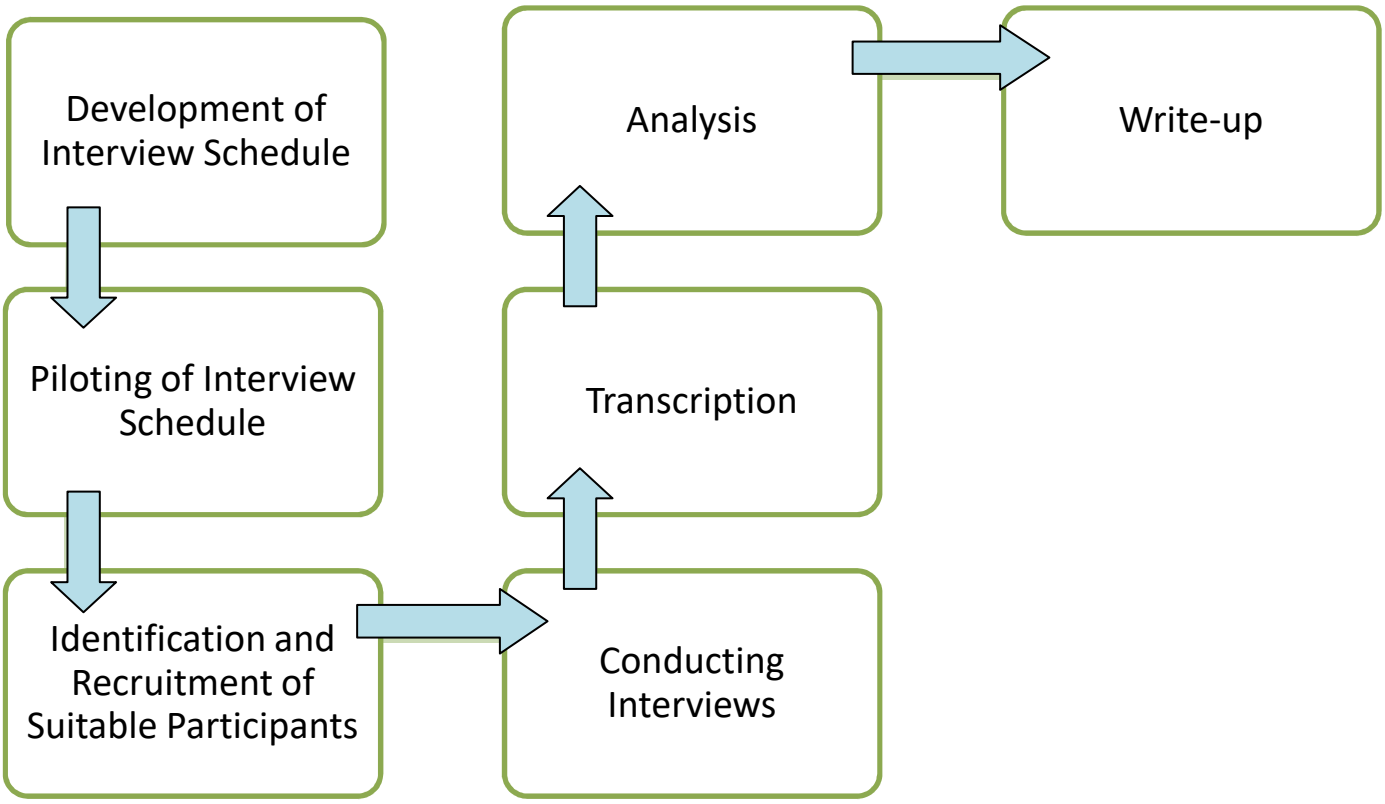


Figure 3: Procedure. This figure summarises the main steps followed in this study.

Data Analysis

Thematic Content Analysis was used to analyse the data according to the six phases as recommended by Braun and Clarke (2006), which are described in detail below.

Phase 1: familiarising yourself with the data. Prior to analysis, the researcher already developed a level of familiarity with the data through having conducted and transcribed each interview herself. The researcher further enhanced this familiarity by reading through the transcripts repeatedly to gain a sense of the information contained therein. During this phase, the researcher read the content actively, taking down initial notes and ideas in the process (Braun & Clarke, 2006).

Phase 2: generating initial codes. The next phase consisted of generating initial codes from information found within the transcripts. This was done manually without the aid of analysis software. The researcher went through each transcript repeatedly, highlighting parts of the data that captured something important in relation to the research questions. These parts of the data were given short names (codes) to describe the essence and meaning of what was being said. The coding was done thoroughly and systematically, paying equal attention to all parts of the data.

Phase 3: searching for themes. Themes were extracted by looking for commonalities amongst the initial codes between participants. The different codes were sorted into potential themes and the researcher gave thought to the potential relationships between themes and different levels of themes. The themes were grouped together under categories that represented the nature of the themes.

Phase 4: reviewing themes. The themes were then reviewed, refined, defined and named before being presented. Themes that had insufficient supporting data were abandoned and themes that seemed to refer to the same underlying theme were combined. Larger themes were broken down into smaller themes and the resulting themes were revised for coherence.

Phase 5: defining and naming themes. This phase consisted of identifying the essence of each theme and giving it an appropriate name. Thereafter, an individual analysis and write-up was conducted for each theme, reflecting on what was interesting about the theme and explaining what the theme conveyed.

Phase 6: producing the report. The data was written up to provide a concise, coherent and interesting account of the data. In the write-up, quotes from the transcripts were used to provide evidence of the themes. The write up of the themes is presenting in the next Chapter (Chapter 4: Findings).

Rigour

Based on the model of trustworthiness of Lincoln and Guba (1985), the following four areas of rigour were addressed in this study: credibility, transferability, dependability and confirmability. In addition and as discussed above, steps were taken during recruitment, instrument design and data collection to ensure rigour and to address the specific challenges posed by interviewing people with ABI.

Credibility. Credibility refers to the truth-value of findings and the extent to which the findings represent an accurate interpretation of the phenomena (Thomas & Magilvy, 2011). To enhance credibility the following steps were taken:

1. Peer debriefing and examination: This refers to the process of going over the coding and interpretation of data with peers. The researcher discussed the experience of the interviews afterwards with a peer, who was the researcher's supervisor (Lincoln & Guba, 1985). The discussion was in the form of formal supervision sessions, and covered issues relating questioning techniques and anything that caused an emotional reaction. For confidentiality reasons, the peer did not know the identities of participants. Throughout data analysis, the peer assisted with generating, refining and organising codes and themes, and added another perspective to the data interpretation, which served to enhance rigour.
2. Prolonged engagement: This refers to spending extensive time with participants in various settings. The researcher conducted two to four interviews with each participant and in some cases visited the long term care facilities. The researcher has also spent a lot of time with the participants outside of the interviews through volunteer work at Headway Gauteng. This served to establish rapport with the participants so that they were more likely to share their experiences with the researcher.

3. Interview technique: The researcher made sure that she understood what participants were saying and asked questions whenever clarification was necessary. The researcher avoided leading questions and followed up on any important issues raised during the interviews.
4. Thick description: The researcher used the words of participants as much as possible when presenting the results and quotes were used as supporting data.
5. Deviant case analysis: To enhance credibility, efforts were made to analyse and present parts of the data that contradicted or did not support the dominant analysis (Lincoln & Guba, 1985).
6. Theory triangulation: This involves using multiple theories and perspectives to provide a richer and more balanced interpretation of the findings (Lincoln & Guba, 1985). Both Maslow's Hierarchy of Needs and Bronfenbrenner's Ecological Systems Theory were used to view the findings from different perspectives.

Transferability. Transferability entails the extent to which the research findings can be applied to different groups or settings (Cope, 2014). To this end, the selection criteria and characteristics of the participants and the long term care facilities have been presented in as much detail as possible without compromising confidentiality.

Dependability. Dependability is present when the study has been described in enough detail so that another researcher would be able to replicate the study (Thomas & Magilvy, 2011). The methodological process followed in this study is described in detail and efforts were made to achieve an audit trial, meaning that all data, notes, summaries, themes, personal and reflexive notes and instruments have been kept by the researcher (Lincoln & Guba, 1985).

Confirmability. Confirmability is present when all the other aspects of rigour have been established. It pertains to how the researcher is able to show that what was found represents the views of participants and not the biases of the researcher (Cope, 2014; Thomas & Magilvy, 2011). This was achieved through illustrating themes using participants' own words. It also compels the researcher to be reflective of the research process and open to the unfolding results, whatever they may be (Ibid). In this study, the researcher maintained an open and flexible attitude to data collection. She followed up on issues raised by participants in the interviews, tried to not lead participants and sought clarification of participants' views.

In some cases during the interviews, the participants appeared tangential, and this has been noted in previous studies with people with ABI (Egan et al., 2006). In such cases, the researcher tried to determine the link between these apparently tangential thoughts and the interview material and found that they often revealed important and valuable insights.

Reflexivity is also an important element of confirmability (Egan et al., 2006). This involves the researcher reflecting on the impact of their own personal characteristics, feelings, insights and biases on the research process. These components of reflexivity are discussed in the following paragraphs.

Personal characteristics. In qualitative research, the researcher herself is an instrument of data collection and it is possible for the personal characteristics of the researcher to have an effect on the data collected. In this study, participants may view the researcher as sensitive due to her relative youth, femininity and small stature. However, many of the participants know the researcher through her volunteer work at Headway and were, therefore, aware that she could handle strong emotional content. Having undergone

training in counselling people with ABI was an asset in this regard, since the researcher had the skills to help participants feel at ease during interviews.

Feelings. The researcher often felt saddened about the living arrangements of the participants. She made explicit efforts to not allow personal feelings to interfere with data collection and analysis though debriefing with her supervisor.

Insights. The researcher had some insight into brain injury from working as a volunteer for two years at Headway Gauteng. This was advantageous during the interviews when it came to asking relevant probing questions and to understanding what the participants with speech difficulties were saying. In addition, the researcher went to some of the participants' facilities, which helped to give insight into the phenomenon. Thus, it was useful to see the conditions in the long term care facilities first hand as well as to hear about participants' experiences.

Biases. Possible biases could have resulted from the researcher caring for the welfare of people with ABI and wanting to help them. This could have led to focusing more on the negative aspects of their lives in long term care at the expense of the positive aspects. Therefore, explicit efforts were made to ask participants about their positive experiences and include these in the write-up. Furthermore, the data from deviant cases were also included in the write-up. If participants did not respond expected ways during interviews, these responses were valued and embraced.

CHAPTER 4: FINDINGS

In this chapter, the themes generated from analysing the participants' responses to the interview questions on living in long term care facilities are presented. They fell into five categories, namely, 'Overall Evaluations', 'General Lived Experience', 'Sources of Well-Being', 'Social Isolation' and 'Sources of Isolation'. The first three categories have to do with participants' individual beliefs, attitudes and perceptions based on their experiences of living in such facilities whilst the latter two categories focused on interpersonal communication and relationships. Various themes were identified under each category and are presented below.

Overall Evaluations

In terms of their overall evaluations of living in long term care facilities, some participants expressed guarded approval whilst others expressed disapproval. Guarded approval referred to tentative endorsement whilst disapproval was voiced in negative terms. No participants expressed outright approval of their living conditions. The themes pertaining to overall evaluations are summarised in Table 2 below and are presented in detail thereafter.

Themes	Supporting Data
Guarded Approval	*"It's fine ... it's alright"* (Richard).
	"I don't feel any negativity when I think about going back" (Henry).
	"but it's a place to stay ... I don't mind staying there" (Charlene).
Disapproval	*"I found it quite depressing"* (Henry).
	"it can get quite depressing" (Charlene).
	"basically I don't live there I exist there" (Brandon).

Table 2. Overall Evaluations. This table shows the themes relating to participants' overall evaluations of their long term care facility.

Guarded Approval. Majority of the participants used weakly positive or neutral adjectives when speaking about their experiences in their long term care facility, such as "fine" and "alright" as reported by Richard. Charlene said "*but it's a place to stay and I've made my room how I like it so I don't mind staying there".* The use of phrases such as "I don't mind" and "it's alright" indicates that the participants viewed their living conditions as tolerable rather than favourable.

One participant, James, seemed somewhat unsure of his feelings towards his residence and said, *"But I think I'm happy with the place. I do think I am happy with it"* and then added, *"But being in the home now is actually very pleasant. It's actually, I can say it is actually very pleasant".* The use of the term "*I do think*" points to guarded approval.

Disapproval. Some participants reported disapproval of their living situation. The most negative experience was reported by Henry when reflecting on his experience of living in residential aged care. Henry said *"Yeah because I mean I went from a home to an old age home. And I found it quite depressing to be around all these old people. And some people were sitting there asking for Matron to kill them you know. And then somebody*

would die at the dining room table they would just (snaps fingers) die you know what I mean. They'd just stop. And often you'd see - my room was right by the main entrance - and often you'd see a truck coming in and picking up furniture and you could never tell if there's people moving in or out you know? Because often people died and they come fetch their furniture. So you weren't living amongst the young and healthy. You're living amongst the old and dying".

This made Henry feel depressed and even suicidal. In his view, his residence was *"not the best environment for getting better if I can put it that way. Because your mind is like I must get better so I can become like that? So it's like get better so you can start dying again. It's like what's the point, let me just rather die now".* Henry then moved to a care facility for people with disabilities. Although this was better than aged care, he still battled with depression from being around people with disabilities. He said *"I mean they are very nice people here but um we're all battling with something you know what I mean. I just think sometimes that can become a little bit, just a little bit depressing"*.

Charlene also opined that living in a long term care facility for the disabled could lead to feelings of depression. As she put it, "Believe me it can get quite depressing to see these people [the other residents]". The other residents were often in a worse condition than her, which saddened her. Ian also expressed negative feelings towards his long term care facility by saying that *"I don't like being there"* and *"I'm not happy there".* Brandon berated the low quality of life in his facility when he said *"I'm just existing there".*

General Lived Experience

The general lived experience of participants with brain injury living in long term care facilities was encompassed in the following themes: lack of autonomy, choice, freedom,

burden, boredom and basic needs. They are summarised in Table 3 below and then are presented in detail.

Themes	**Supporting Data**
Lack of Autonomy	*"Sometimes I want to wake up late but the home must run by structure. You cannot do whatever you want"* (Kevin). *"I don't have any decision making for anything … the one who pays is the King"* (Ian).
Choice	*"Where else am I going to go?"* (Richard). *"I live at the home because I have to"* (Brandon). *"you know you are not really there by total freedom of choice it is by circumstances that you are there"* (Henry).
Freedom	*"I go out the gates. I'm not a prisoner"* (Kevin). "*it is not like a prison you are free to come and go as you like"* (Charlene). *"[I feel] like a prisoner"* (Ian). *"[If I had my driver's licence] I could escape"* (Richard).
Burden	*"I don't want to put that burden on [my family], I'd rather stay where I am"* (Charlene). "*I don't want to be a burden to someone else"* (Kevin).
Boredom	*"at the workshop … it's good … because it keeps me busy [but] it gets boring … it's not stimulating enough"* (Richard). *"I get terribly bored there because they don't have any extracurricular activities"* (Charlene). *"They've got Bingo on a Thursday but to me Bingo is an old people's thing ... I don't get any joy out of playing bingo"* (Henry).

Basic Needs	*"And when it's gets to night time you realise look I have a warm bed I have a safe room what more do I really need"* (Ian). *"the positives are it is secure"* (Charlene).

Table 3. General lived experience. This table shows the themes relating to participants' general lived experience.

Lack of Autonomy. The subject of lack of autonomy was a prominent theme when participants referred to the rules and structure of the facilities. For example, there were complaints about set times to wake up in the mornings, for meals and for showers, and for having to follow rigid procedures before they could leave the facility. Some participants accepted, and/or got used to, the rules and regulations whilst others found ways around them. Kevin confessed that he would like to wake up late, but was aware that, "*The home must run by structure. You cannot do whatever you want. If everybody does what they want it will be berserk".* When reflecting on set meal times Henry pointed out that, *"At the old age home that's how it used to be, five o' clock. In hospital too five o' clock was the meal time. So, your body sort of gets used to that time".* James had to adjust his personal showering schedule to fit in with the structure of his facility. He said "*now I take a shower after my late medicine I go and have a shower at 8 o' clock in the evening because there is no one because at 5 o' clock they shower the people that can't shower themselves so then you rather, I rather leave them to shower then I wait until 8 o' clock when everyone is in the bed".*

While most participants were only slightly perturbed by their lack of autonomy, this seemed to cause Ian distress. Because his family paid for his accommodation, he bemoaned the fact that they were the ones in charge and he could not make any decisions on his own. He had to ask permission if he wanted to leave the home, whereas the other participants could decide that for themselves.

Choice. Most of the participants had little choice of long term care facilities due to factors, such as financial constraints and a lack of alternative options. In keeping with the lack of suitable facilities for people with ABI in South Africa, participants confirmed that there were very few options available.

Charlene chose her long term care facility because it is the only one she could afford. She said *"I actually chose the place because of the amount of money I pay them. It's all I could afford".* James made his choice based on the fact that the facility allowed his dog to live with him, saying *"when we were looking for a place it was the only place that allowed me to go with my dog"*. Brandon likewise chose his facility because it was the only one that enabled him to keep his car, saying *"[Name of Home] is the only one that's allowed me to take my car to [Name of Home] to leave my car at [Name of Home]".*

Furthermore, participants reported that they did not choose to live in a long-term care facility. According to Richard, "*I'm just put there and it's expected of me to just accept it"*. When asked where he would live if he had the choice, Brandon raised his eyebrows and enquired, *"if I had the choice?"* and added, *"Basically, I live at the home because I have to"*. Kevin reiterated this sentiment saying, *"I have no choice".* As Henry explained, *"You are not really there by total freedom of choice it is by circumstances that you are there".*

Freedom. Having freedom of movement was important to the participants. Charlene valued being able to walk around freely and confided *"That's one thing I do like about that place it is not like a prison you are free to come and go as you like. Because I've got a friend that lives in a retirement village which is about 400 yards from my front door and he meets me at the side gate and he has got a key for the side gate and I go and see him there. We are always doing favours for one another and we swop parcels whatever which is nice … at least I can exercise which is good".* As a result, she is able to

visit a friend who stays nearby in a retirement village, thereby enabling her to maintain relationships outside the home. Kevin was also free to come and go, and thereby take part in religious activities outside of the home. He stated *"I go out, out the gates. I'm not a prisoner".*

Those participants who were prevented from walking around freely were very unhappy about this and it reduced their sense of freedom. Ian was not allowed to walk to the local shopping centre and this made him feel *"very upset"* and *"like a prisoner"*. He believed that he wasn't allowed freedom because *"they don't trust us".* Ian was terrified that the place would *"keep me there for life".* Richard also felt trapped in the home. He said that if he had his driver's licence *"I could escape"*.

Therefore, there was a disparity of opportunities to exercise freedom between the participants. Those that felt a sense of freedom perceived this as a positive aspect of their life in long term care and those that did not experience freedom found this to be very distressing.

Burden. Some participants felt as though they were a burden to others, especially family members. As Kevin said, *"I don't want to be a burden to someone else".* One consolation of living in a long term care facility was the reduction in participants viewing themselves as burdensome. Charlene would rather stay in her facility than with her children, saying *"I don't want to put that burden on them, I'd rather stay where I am"*. As far as Henry was concerned, *"At the end of the day it is a safe environment so for children you know if you can put somebody that's had um in my situation in an environment where they safe, they're warm, they're fed, they're assisted, it's much better for them as well because they've got jobs to do they can't spend their time looking after you. So it's a better situation for all. It's a better option for all concerned in the family".*

Some participants expressed resentment towards family members for placing them in long term care facilities. Although they could appreciate that it made it easier for their families, they fell short of expressing this in terms of not being a burden. For example, Ian retorted, *"My mother and them think it's a bloody miracle that it is such a nice place, doing such nice things, but it also makes it very much easier for them because the home looks after me".* James recalled that, *"In the beginning I felt sort of my family left me behind, it sort of felt like my family kicked me out of the house".*

Boredom. Participants often felt bored and un-stimulated living in their long term care facilities. They complained about both insufficient and unsuitable leisure activities. Although some of the facilities did offer a limited range of things to do, they were not perceived as being stimulating by participants. Richard lived in a home that required the residents to work in a workshop. His job was very basic and repetitive (removing plastic from a screw). While he acknowledged that it kept him busy, he did not enjoy it because *"It gets boring".* Another resident in the same home, Ian, initially disliked working in the workshop because of the monotony. After he had been given varied tasks to do he changed his mind, declaring that he liked *"working in the workshop a lot more than I used to".*

When Richard was asked what he did for fun, he said he *"sits in the sun",* suggesting that there was nothing better to do. Charlene admitted, *"I get terribly bored there because they don't have any extracurricular activities except for bio on a Monday and then a church meeting on a Thursday. Besides that you just entertain yourself. It's actually quite bad".*

Kevin felt that activities were needed to keep the residents occupied and healthy. He wondered, "*Did you ask me whether I want a job or not? Ja, something to keep me busy. There are different people, something to keep them busy because we are not doing*

something … Being forced, being able to make the time go and not thinking about yourself too much. Not a job necessarily, a hobby or something to do because …some of the residents they over-smoke because they don't have anything to do".

Henry believed that the activities provided were not suitable for his age, such as Bingo on a Thursday. In his view, *"Bingo is an old people's thing, you know what I mean. I don't get any joy out of playing Bingo".* He preferred tasks that challenged him mentally and added, *"I prefer to go on my iPad and do brain puzzles, word search or play a solitaire game that you get a new challenge everyday".* James came up with his own creative tasks to keep himself occupied, stating, *"I make my own activities".*

Brandon was the only participant who found the home's activities beneficial. His home offered art classes each week, which he felt enabled him to develop his artistic abilities. He said, *"I think the advantage is you get, it depends on the home, you get a chance to enhance your abilities. I mean, I could never draw and at least they have art sessions with artists that come to you on a Monday and a Friday to the home and I can actually draw ... I have actually developed a bit of a talent".*

Basic needs. The participants described how their particular long term care facility met only some of their basic living needs. For Kevin it was *"cleanliness, your own room, privacy and they do not force you to do anything that you don't want. And the food is not bad, the nurses are not that bad, there are bad apples but that's life"*. When probed further on what he liked about living there he said "*Mm security. What I mean by security is you know you have got shelter and you have got food, that's important".* For Charlene, the only positive attribute she mentioned was the security. For Henry it was the security and care. In his words, "*when it gets to night time you realise look I have a warm bed I have a safe room what more do I really need".* When asked what he liked about living there he said *"It's*

safe, you've got assistance if you need it, if you fall or something. So you've got help you've got in my case they help me dress".

Sources of Well-Being

Besides the above mentioned negative experiences, some participants appeared more resilient and reflected on the importance of being positive about their situation. This contributed to their sense of well-being.

Another source of well-being was the recognition received and sense of purpose imbued when participants helped more disabled residents. The themes relating to sources of well-being are summarised in Table 4 where after they are presented in more detail.

Themes	Supporting Data
Positivity	*"I try to do my best to be positive"* (Charlene).
	"but I want to look at life in the positive way. Because if I don't I die. I will be still living but I am dead" (Kevin).
Meaning	*"You know what I do? At mealtimes, they have gotten so used to it that there are a couple of ladies waiting for my help. The ones in wheelchairs I push … they appreciate it so much. That makes me happy"* (Ian).
	"basically what I do and it's not a chore but if there's somebody paraplegic or quadriplegic that's in a wheelchair that's battling I push the wheelchair around. I help push the wheelchair around, I help where I can … It's just part of my job to do it. Because my purpose in life is to help where I can" (Brandon).
	"It brings back old memories feeling good memories … I think it's good if I can help somebody" (James).
	"I don't mind helping … it doesn't bother me, actually I feel like I am doing something helpful" (Charlene).

Table 4. Sources of well-being. This table shows the themes that constituted sources of well-being for participants.

Positivity. Several participants expressed the need to be positive about their circumstances. Brandon, for example, said *"I try to do my best to be positive"*. Kevin tried to *"look at life in the positive way".* Charlene advised that *"you just got to be thankful for what you've got. You can't carry on life thinking of what you haven't got"*

Meaning. Living with people who were physically disabled provided some participants with opportunities to help others which made them feel good about themselves. Ian said "*You know what I do? At mealtimes, they have gotten so used to it that there are a couple of ladies waiting for my help. The ones in wheelchairs I push … they appreciate it so much. That makes me happy".* Brandon revealed that *"basically what I do and it's not a chore but if there's somebody paraplegic or quadriplegic that's in a wheelchair that's battling I push the wheelchair around. I help push the wheelchair around, I help where I can … It's just part of my job to do it. Because my purpose in life is to help where I can".* James said *"It brings back old memories feeling good memories … I think it's good if I can help somebody".* Charlene said *"I don't mind helping … it doesn't bother me, actually I feel like I am doing something helpful".*

The above participants went out of their way to assist other residents of their own volition as the long term care facilities rarely provided opportunities for residents to feel useful. Unfortunately, those participants who were wheelchair-bound themselves were not able to offer assistance and could not share in the meaning this provided.

Social Isolation

Despite living with other people, social isolation was a prominent issue among residents. Participants reported feelings of loneliness and a lack of quality contact with

others, living without companionship, and ambivalent feelings of belonging. These themes are summarised in Table 5 and are discussed thereafter.

Themes	Supporting Data
Loneliness	*"loneliness is a problem"* (Henry).
	"So I think the worse thing about being like this is being lonely" (Brandon).
Companionship	*"I would love to be in a relationship with somebody and living with her and having that companionship more than anything"* (Henry).
Belonging	*"Sometimes [I feel like I belong] but sometimes not ... It's hard to live without anyone you know"* (Kevin).
	"Sometimes [I feel like I belong] … Where else am I going to go?" (Richard).

Table 5. Social isolation. This table shows the themes relating to social isolation amongst participants.

Loneliness. Majority of the participants felt lonely and lacked quality social contact with other residents. Although they were surrounded by many people in the long term care facility, they still often felt lonely and struggled to connect with the other residents. As Henry put it *"loneliness is a problem"* whilst Brandon went so far as to say *"I'm lonely to death".*

Companionship. Many participants expressed a longing for companionship, love and physical affection. In Henry's words *"I mean I do miss being in a home environment, I would love to be in a normal house, I would love to be in a relationship with somebody and living with her and having that companionship more than anything, that's what I think I miss the most"*. He also missed the physical affection his family could provide. He said *"Ja because [if you lived at home] you'd I mean you'd see your kids everyday to some degree*

and get a hug or something or a kiss. I get that when they visit but as soon as they leave I want them to come back".

Brandon was the only participant who experienced close companionship with other residents of the home. According to him, *"Well basically I always joke about it [Name of Fellow Resident] is actually my brother ... Not by marriage or anything but he's my brother and [Name of Fellow Resident] is my great Aunt".* He added *"I'd say the thing I like about living there is I've got two or my or two of my closest friends there that's [Name of Fellow Resident] and [Name of Fellow Resident]. We look after each other help each other where we can".*

Only one of the participants was allowed to have a pet and this provided a great source of companionship for him. He said *"if it wasn't for him [the dog] I think I would have been at home a long time ago. I would not have been able to be here without him. Because he is really a very very good companion … he is a fantastic companion".*

Belonging. Some participants reported ambivalent feelings of belonging. For Kevin, his sense of belonging was linked to payment of the rent, *"Sometimes [I feel like I belong] but sometimes not. When I haven't got money to pay my rent I don't think it that way … when I've got arrears then I've got I think the reality is that comes to me here it's just renting".* For James, the lack of ownership diminished feelings of belonging. He said *"I think it would be more belonging if I lived at my house again because it is MY house. I can do things there, still little things that I can do. So yes, it might be better".* Richard felt obliged to belong because he had nowhere else to go. He said *"Sometimes [I feel like I belong] … Where else am I going to go?"*

Charlene tried to make the best of her situation by decorating her room according to her preferences in an attempt to make it feel more like home. She said *"I suppose yes it does [give you a sense of belonging] because that's where my home is. But you don't feel*

like comfortable not like a family sort of home type thing … [A family home is] more personal and I don't know it's a different feeling. Like this one is you get to know it's where you live but it's like I try make it my room as much as possible I've put like different pictures on the wall and that so it feels comfortable to me". She was not the only one to draw comparisons with living at home with one's family. Even after living in his facility for eight years Kevin revealed that *"It's hard to live without anyone you know… If you are living with your parents or your sisters you know them all well, you know them well, but this …I know them but I don't know them well".* Brandon would like to "*live in a home where the people they are actually true friends of mine, true blood of mine".*

Henry did not feel he belonged at all and gave the absence of choice as the reason for this saying, *"Ag, you don't really [feel a sense of belonging] because you know you are not really there by total freedom of choice…It's like people here will say they don't want to be here, you know like Sam [a fellow resident], he'd rather be dead than here".*

Sources of Isolation

Certain conditions in the long term care facilities exacerbated the participants' feelings of social isolation, including living with people with disabilities, having a different disability to others in the residence, age differences, an absence of pets, and the layout of the facility. These themes are summarised in Table 6.

Themes	**Supporting Data**
Living with people with disabilities	*"I think sometimes if you spend too much time with people who aren't well it also sort of affects you"* (Henry). *"I don't necessarily want to be with people, they've all got their own problems and I just think I've got enough of my own problems, I don't need to carry everybody else's as well"* (Charlene).

Different disability	*"No [I don't get enough chance to socialise with people] because they don't understand … sometimes I get cross and the people there don't understand why … They don't know how to treat me … they just give me funny looks and think I'm mad … I know what they think … I am getting cross at nothing"* (Richard). *"people think that because you are brain injured it's all hypothetical … people seem to think I'm an idiot or something like that. They just back off from me"* (Brandon). *"I am one of the walkers, a very good walker why the hell would they want me there forever?"* (Ian). *"I think the residents generally hate me"* (Brandon)
Age Differences	*"I mean I was 57 when my kids put me in the old age home, I was by far the youngest there… and they're sweet old people but they're different"* (Henry). *"The age difference matters because I'm the second youngest. And she's too young ja those are too old"* (Kevin).
Pets	*"Since I was small I have always had a dog … And dogs are so warm you know if they hop up on your lap and give you a kiss …that pet supplies a sense of belonging or companionship or what"* (Henry). *"if it wasn't for him [the dog] I think I would have been at home a long time ago. I would not have been able to be here without him"* (James).
Facility Setup	*"I mean you don't have a dining room as such, you eat in your room. So it becomes a little bit isolated"* (Henry).

Table 6. Sources of isolation. This table shows the themes that formed sources of social isolation for participants.

Living with people with disabilities. A couple of the participants found themselves intentionally withdrawing socially from the other residents of the long term care facilities as they found living with people with disabilities depressing. Charlene revealed, "*Well I get on with most of them but lots of times I feel, like, please just leave me alone now. I get a book and I go and close my door and I just read. Maybe I do too much of that*

but … I don't necessarily want to be with people". Henry believed he would be more socially active if he was around healthy people. He admitted, *"It would be nice to spend more time with people that are well, you know. I think sometimes, if you spend too much time with people who aren't well, it also sort of affects you".*

Brandon expressed the view that the other residents treated him differently because he was not in a wheelchair, which upset him to the point that he believed that other residents did not like him. He said *"Ja, I think the residents generally hate me... they're bombastic. They talk to you like they expect you to do things, like if you can drive, they expect you to go to the shops for them. What they do is come to me and say, 'Go to the shops and buy me something' and the answer is 'no'. Very simple. I'm not running around for them. I think the big problem is that they believe, because they're disabled, somebody that's enabled owes them something".*

Different disability. Being brain injured in a home where majority of residents are not brain injured often made the participants feel as though they were misunderstood and, as a result, they could not connect with other residents. Brandon said *"So I think the worse thing about being like this is being lonely. Because people don't understand your intellectual level they don't understand that you're bright enough to do anything yourself… people think that because you are brain injured it's all hypothetical. I mean yes I forgot a lot of things but I tell you I'm not being arrogant now or something but my IQ is very high …I'd like to find somebody who actually will tolerate me on the same level and wants me on the same level that understands to communicate with me and to bond with me … people seem to think I'm an idiot or something like that. They just back off from me … The thing is I think that's why I can talk to Mark [fellow brain injured resident] because they know what it is about. Because they were in the same situation as me".* Brandon felt that

having other brain injured people at the home was helpful because they understood each other better but he felt misunderstood by majority of the other residents.

Richard also felt misunderstood and this contributed to his social isolation. In his case he experiences angry outbursts as a result of his brain injury and said *"No [I don't get enough chance to socialise with people] because they don't understand … sometimes I get cross and the people there don't understand why … They don't know how to treat me … they just give me funny looks and think I'm mad … I know what they think … I am getting cross at nothing".* Because of his social inappropriate behaviour he was considered a *"pervert"* and wished that the staff and other residents were more patient and understanding. He said *"the people there don't understand me … [it would help] if they were more patient".*

Some participants with ABI reported that living in facilities for other disabilities was a potential source of conflict. Ian confided that a social worker had told other residents that if they *"get rid of all the brain damaged residents you will get rid of a lot of the problems. That pissed me off a lot".* He also felt that did not belong there because he was more physically able than the other residents (he could walk while the other residents were all in wheelchairs). He said *"I am one of the walkers, a very good walker why the hell would they want me there forever?"*

Age differences. Differences in age contributed to feelings of alienation and loneliness in some participants. Previously, Henry had lived in an old age home where he was the youngest by far. He reported that their version of a sing-along was *"to sing songs from World War 2",* adding that they had nothing in common as *"they're all talking about life past. My intentions was about getting better and trying to have a life forward … so the two are at odds".* Kevin was the second youngest at his facility and he also found it difficult to communicate with older residents. According to him, "*When I talk to you and I talk to a*

fifty-year-old, the conversation will be different". Brandon emphasised how differing interests interfere with relationships. For him, "*Lonely is a sense of mind for people you can bond with".* He had met someone who promised to speak to her husband about taking him riding and added, "*At least they are bikers … that can bond with me … I mean it's no use talking to people at the home…The rest have no idea what I'm talking about … it's because of their age and attitude".*

Pets. For James, being allowed to keep his dog provided companionship and a buffer against social isolation from other residents. He told the researcher, "*I've got my dog I spend a lot of time with him"*. He was the only participant who was allowed to have a pet and confided that, "*I would not have been able to be here without him. Because he is really a very very good companion … he is a fantastic companion".*

Other participants felt that having a pet would provide them with much needed companionship, affection, warmth and love. As Henry said, *"So I think companionship is the biggest thing I miss, a combination of a person or a pet. Since I was small I have always had a dog… and dogs are so warm you know if they hop up on your lap and give you a kiss …that pet supplies a sense of belonging or companionship or what. There is a lot of positives with having a pet. In my case I find that it's been an understated therapy, the therapy that can be derived from having a pet".* Charlene reported being quite sad because *"I would have liked to have had a little dog or something … They are such good company and I love having something close to me like that … they don't ask for anything but a bit of love, they don't expect anything else"*. Richard wanted to have a pet because *"he will be my best friend*".

Layout of facility. The facility where Henry stays does not have a dining room so meals are served in the residents' rooms. As a result, he has almost no contact with other

residents and revealed "*So it becomes a little bit isolated".* In contrast, other participants identified meal times as a major opportunity for social interaction with other residents.

In summary, analysis of the data revealed themes that were organised into five main categories: overall evaluations, general lived experience, sources of well-being, social isolation and sources of isolation. In the next chapter, these themes will be discussed in relation to the theoretical frameworks of the research as well as the relevant literature.

CHAPTER 5: DISCUSSION

Overview

The present study was devised in an attempt to address the dearth of research into personal experiences of people with ABI who live in long term care facilities worldwide. Motivation for this study was the number of people with ABI who are rendered incapable of independent living as a result of the residual physical and/or cognitive sequelae to their traumatic and non-traumatic brain injuries. These people then require long term residential care. With particular reference to South Africa, there are no long term facilities for them and they are then placed in homes for the aged and the disabled. These homes are inappropriate and have detrimental psychological and social consequences for people with ABI as was suggested in overseas studies (Winkler et al., 2010).

The primary aim of this study was to explore the lived experience of people with ABI in long term care facilities with a view to gaining insight into their quality of life and the suitability of their long term care facilities. Research questions related to this broad aim concentrated on the psychological effects of living in these facilities and whether or not their needs were met. The secondary aim of this study was to establish if living in these facilities contributed to social isolation, one of the more devastating consequences, not only for people with ABI, but for residents of residential homes in general as reported by other researchers (Meyer et al., 2011; Mezuk et al., 2014).

General Discussion of Aims, Research Questions and Findings

A convenience sample of seven participants with ABI was recruited to take part in the study. The participants provided information on their experiences in long term care during serial, semi-structured, face-to-face interviews using a qualitative research design.

Other researchers warned of challenges relating to brain injury sequelae that occur when conducting qualitative interview based research (Boylan et al., 2016; Carlson et al., 2007; and Paterson & Scott-Findlay, 2002). However, these researchers also devised methods of dealing with these challenges and this researcher used their suggestions. In this way, each participant was able to answer questions in their own unique way and to provide valuable insights into their perceptions of what it is like to live in long term care facilities, the psychological and social consequences of such living arrangements and whether they were appropriate and met their needs. Thus, under controlled conditions, it is possible to give people with ABI 'a voice' as proposed by Philpin et al. (2005, p 299).

Thematic analysis of the data captured from these interviews was organised into five categories of themes, namely, 'Overall Evaluation', 'General Lived Experience', 'Sources of Well-being', 'Social Isolation' and 'Sources of Social Isolation'. Themes associated with the categories were as follows:

- Overall Evaluation: Guarded Approval and Disapproval.
- General Lived Experience: Lack of Autonomy, Freedom, Choice, Burden, Boredom and Basic Needs.
- Well-Being: Positivity and Meaning.
- Social Isolation: Loneliness, Companionship and Belonging.
- Sources of Isolation: Living with People with Disabilities, Different Disabilities, Age Differences, Pets, Facility Layout.

Each category and its constituent themes will be discussed in relation to the aims of this study and within the theoretical framework of Bronfenbrenner's Ecological Systems Theory (1979) and Maslow's Hierarchy of Needs (1943), taking existing relevant literature into consideration.

Lived Experience of People with ABI in Long Term Care Facilities

Long term care facilities as Microsystems. As per Bronfenbrenner's Theory of Ecological Systems (1979), the long term care facilities in which dependent people with ABI find themselves constitutes their Microsystem. This comprises both the immediate physical environment and persons therein who interact directly with them on a regular basis. While a person is influenced by many levels of their ecological system, according to Bronfenbrenner, the Microsystem exerts the most powerful influence. In the case of people with ABI living in long term care facilities, they spent the majority of their time within their Microsystem, as they have limited mobility compared to the general population and do not engage in official employment. Thus, it stands to reason that long term care facilities and their residents have a marked effect on the person with ABI. Likewise, they have a reciprocal effect on that environment and its residents.

As demonstrated by Winker et al. (2011), comparative age differences due to inappropriate placement of people with ABI in long term care facilities produced negative mood states. They reported increased levels of depression in younger people with ABI who lived in old age homes with elderly and demented residents where deaths were common. Henry could identify with this as witnessing the deaths of elderly residents made him depressed and suicidal. Age differences also affected the type of activities that were offered by the homes and opportunities for social integration, leaving some participants in the current study (Henry and Kevin) feeling bored, alienated and alone.

Differences in disabilities in residents of long term care facilities were also reported to give rise to negative emotions in the affected participants with ABI in this study. The four participants who live in homes for disabled people (Henry, Charlene, Ian and Brandon) were all unhappy about their living arrangements and fellow residents and resorted to avoidant behaviour and social withdrawal, leading to social isolation. As

reported by Levack et al. (2010), reduction in social circles can give rise to feelings of abandonment. Some participants (Henry and Charlene) were personally affected by the severity of disability in residents and reported having suffered severe bouts of depression as a result of this, which would have a deleterious effect on their sense of well-being. In some instances, participants (Richard and Ian) reported stigmatisation of people with ABI at their facilities, both from members of staff and residents who were physically disabled. Levack et al. (2010) reasoned that this could be due to discrimination against people with ABI. Unfortunately, this has the potential to cause conflict that could get really unpleasant as people with ABI generally do not have good emotional and behavioural control (Badul, 2012; Bodley-Scott & Riley, 2015). In contrast, participants felt that they would have greater levels of well-being if they spent more time with well people and with family members who understood them better.

A common complaint associated with inappropriate placement in long term care facilities amongst the people with ABI in general as well as the participants was social isolation (Coneeley, 2012; Winkler et al., 2010). This was usually due to their having little in common with other residents, such as those who were elderly and physically disabled. Accordingly, this prevented them from forming friendships and they reported a longing for the companionship that friendships would bring. Only one participant (Brandon) had a fellow resident with whom he could relate. In the absence of human companionship, Henry, Richard and Charlene wished they could have a pet. Due to rules and regulations in the various facilities, only James was allowed to keep a dog. In Brandon's case, the loneliness was extreme and led him to confide that there were times that he was "lonely to death". As pointed out by Mezuk et al. (2014), loneliness is associated with depression and an increase in suicidal thoughts. Of grave concern were the findings of Leon-Carrion et al. (2009) and Teasdale and Engberg (2001) who reported increased risk of suicide compared with the general population in their participants with ABI who were depressed.

When it came to evaluating their living arrangements, disapproval was high in those participants who lived in inappropriate long term care facilities and who experienced their living conditions as being negative. It so happened that these participants also reported emotional, social and/or behavioural problems, all of which are common sequelae to ABI (Bodley-Scott & Riley, 2015; Fan et al., 2009, Levack et al., 2010; Ogden, 2005). However, if the work of Winkler et al. (2010 & 2011) can be extrapolated to this South African sample, placement in inappropriate facilities could have exacerbated these sequelae. Winkler et al. (ibid) reported various physical, cognitive, emotional and social benefits in their participants with ABI when they were transferred from an old age home to a facility in the community. In addition, they detected greater sense of well-being in their participants with ABI who were subsequently placed in community settings (Winkler et al., 2011).

Clearly, inappropriate placement of people with ABI in long term care facilities negatively affects their mood and general sense of well-being. At times, this could have potentially lethal consequences, such as the increased risk of suicide (Leon-Carrion et al., 2009; Teasdale & Engberg, 2001).

From data collected from the current participants it appears that some of them resigned themselves to living in their long term care facility and tried to make the best of it. These participants expressed guarded approval when giving their overall evaluation of their facilities. At best, their responses were weakly positive and, at worst, they were neutral, whilst others were ambivalent. Although still not entirely happy with their facilities, this acquiescence could suggest acceptance as reported by Levack et al. (2010), which forms part of reconstructing one's identity following a brain injury and is regarded as an important part of recovery.

Some participants (Charlene and Kevin) tried to see their situation in a positive light. Others (Ian and Brandon) found a way of being helpful by assisting residents in wheelchairs. Their efforts were appreciated and this made them feel good and provided them with a sense of meaning and purpose. It seems the disabled residents acknowledged the fact that they are 'helpers'. In each case, their efforts enhanced their sense of well-being, which Street et al. (2007) found correlated with what they termed, "internal social relationships" (p. 129).

None of the current participants endorsed their long term care facilities when asked for their overall evaluations. The reason for this could be that none of them were in facilities that catered for people with ABI or in assisted living facilities in the community. If one considers the results of the Winkler et al.'s Australian studies (2010 & 2011), one has to wonder whether placement in similar community settings with shared accommodation or with family members is a viable alternative for higher functioning people with ABI in South Africa. In fact, one of the participants in the current study raised the point that he felt it would be beneficial to his well-being to spend more time with 'well' people and many of the participants felt they would prefer to live with family in order to feel more love, affection and belonging. Living in community settings would enable people with ABI to spend more time with healthy individuals and to avoid the depressing effects of living around the elderly, demented or disabled. One suspects this would engender feelings of social inclusion and a sense of belonging, thereby reducing social isolation.

In line with Bronfenbrenner's Ecological Systems Theory (1979), the Microsystem in the context of people with ABI in long term care has a significant effect on overall quality of life and well-being. Inappropriate placement has the potential to exacerbate and/or result in serious psychosocial problems and disorders, whilst suitable placement could give rise

to improvement. Thus, it is vital that people with ABI who cannot live independently are placed in a long-term care facility that can cater to their needs.

Fulfilment of needs.

It was found that many of the participants of the study had entered into the long term care facility because they had become less able to meet their own basic needs as a result of their injuries. For example, their reasons for doing so included needing help with preparing meals, getting dressed, getting showered, taking medication, looking after financial matters and having someone to help out should a fall occur. However, these basic needs were often found to be the only needs being met by the facilities and very few opportunities were provided for the fulfilment of higher level psychological needs, as explained by Maslow (1943). In accordance with Maslow, these basic needs constitute physiology needs and safety needs, and there was little opportunity to fulfil the higher order psychological needs for love and a sense of belonging as well as self-esteem.

All the participants agreed that their lowest-level needs that are necessary for survival were met. They had shelter and a place to sleep, and received food and care. Most participants mentioned their rooms which provided privacy and safety in addition to shelter. Henry referred to his “warm bed” and the food was “not bad” according to Kevin. They also received assistance with self-care activities when necessary. Kevin noted that the nurses were also “not that bad” and Henry received help with dressing. Participants also agreed that their needs for safety and security were met at their respective facilities, which was important, especially to Charlene. However, Maslow (1970) believed fulfilling these physiological and safety needs was not enough for a satisfying life as an adult. This means that among this group of participants, they are less likely to be able to achieve self-actualisation, or to reach their potential.

With regard to psychological needs, participants seemed ambivalent about whether or not their living arrangements imbued a sense of belonging. Aspects, such as a lack of choice (Richard and Henry) and ownership (James), and being different to other residents (Henry, Richard and Charlene) affected their capacity to feel as though they belonged. Not having meaningful relationships with other residents or regular contact with friends, family and loved ones resulted in feelings of social isolation and loneliness. Even Brandon, who had a friendship with a fellow resident, missed having a "true friend". Henry missed the love and companionship he received at home from his children. Some participants (Charlene and Kevin) were able to maintain relationships with either friends or social groups outside of the facility. One participant (James) felt rejected by his family. Generally, however, there are difficulties with maintaining prior social and support networks after brain injury (Coneeley, 2012). The end result of the lack of affection, companionship and a sense of belonging in the participants could exacerbate social isolation and depression, both common psychological sequelae to brain injury (Coneeley, 2012; Fan et al., 2009; Winkler et al., 2010).

Esteem needs are also regarded as psychological needs (McLeod, 2016) and incorporate freedom, independence, and respect from others as well as a positive self-evaluation. Having freedom, choice, autonomy, self-esteem, self-fulfilment and meaningful leisure activities are essential components to well-being according to Coneeley (2012) and Trenberth (2005).

The findings concerning lack of freedom and autonomy in this study were in line with previous research demonstrating that people with ABI often experience a reduction in, and place value on, their freedom and autonomy (Coneeley, 2012). Some participants described varying degrees of freedom and autonomy. For example, Charlene could walk to visit a friend, Kevin could attend meetings and Brandon had the use of a car. However,

this was not always the case in that some participants were not allowed to move in and out of the facility. Ian was not allowed to walk to the local shops and suspected this was because the staff did not trust the residents. Other participants were physically challenged and unable to move about on their own. Liddle et al. (2012) emphasised the importance of mobility out-of-home activities in people with ABI to maintain a sense of freedom and autonomy to prevent isolation. In extreme cases, participants went so far as to use prison metaphors, such as 'prisoner', 'escape' and 'keep me there for life' when describing their experiences. This appears excessive when compared to other accounts of loss of freedom in the literature (Coneeley, 2012). Individual freedom and autonomy was curtailed as part of facility rules and regulations, for example, old age homes often implement rules to prevent residents from wandering off and getting lost. However, it is important to ensure that people with ABI in long term care facilities have opportunities to exercise freedom, to leave the home to foster social connectedness.

Having choices when it comes to make decisions that are potentially life-changing are important for autonomy and self-esteem. Responses from participants varied - some took exception to not being able to make decisions whilst others were resigned to having choices made on their behalf or settling for situations where they had no choice. As for the choosing to move into a particular long term care facility, some participants' choices were restricted (James – to keep his dog; Brandon – to keep his car). Others accepted their fate as they did not want to be a burden to their family and loved ones, in line with reasons given by elderly residents of long term care facilities in a study done by Iwasiw et al. (1996). In the same study, Iwasiw et al. found that elderly residents adjusted better to long term care if they had participated in the decision to move. It seems possible that the lukewarm approval and disapproval ratings of their long term care facilities by the participants are partly related to not being involved in choosing where they want to live.

Meaningful work and leisure activities are important for self-esteem, autonomy and independence and the motivation to self-actualise according to Maslow (1970). Thus, the lack of suitable activities may inhibit self-actualisation in terms of Maslow's theory as well as reduce well-being and hamper cognitive and physical rehabilitation as reported by Bier, Dutil and Couture (2009) and Trenberth (2005). Most of the participants complained about the lack of appropriate activities. Either they were more suited to other residents or they were 'boring'. Henry complained about Bingo and Richard, about his tedious job in the workshop. In some cases, there was nothing to do and participants either did nothing or tried to keep themselves busy. One participant (Brandon) enjoyed the art classes. This could be due to facilities gearing their activities towards the majority of residents and was problematic for young people living in aged care facilities (Strettles et al. (2005), as cited in Winkler, 2011). People with brain injury often lose self-motivation and spontaneity (Bodley-Scott & Riley, 2015) and, thus, require structured activities as they may struggle to entertain themselves. This could give rise to doing nothing and boredom.

Boredom was an issue amongst participants in this study could be consistent with a decrease in leisure activities following ABI described by Levack et al. (2010). A study conducted by Zimmerman et al. (2005) among residents in residential care and assisted living facilities found that residents experienced better overall quality of life when they lived in a facility that encouraged greater participation in activities. When planning activity programmes suited to pepole with ABI, however, the effects of brain injury on factors, such as motivation, need to be taken into account.

In this study, only basic physiological and safety needs were provided for in the participants' long term care facilities. Provision for psychological and self-esteem needs that are important for well-being and quality of life was lacking. This could lead to mood disorders, boredom, apathy and general lack of approval for the facilities. This was in

keeping with Winkler et al.'s findings (2010) of low levels of satisfaction with life in general and reduced levels of well-being in people with ABI living in inappropriate long term care facilities.

When participants were questioned about whether they thought they would have more of their higher level needs fulfilled in a different setting, they often expressed that they would. For example, Henry felt that being around other people with ABI would be beneficial because he could have better quality social interactions with them. Richard felt that being at home with his family would be better for his sense of belonging because his family had a better understanding of the nature of his injury. He also expressed that having access to internet at his family home would enable him to connect more with other people and to pursue leisure activities. Brandon felt that he would experience greater belonging in a family home with people he was physically related to and he would be able to develop his talents further in a family home. Ian reflected on the greater mobility and freedom he would experience if he lived with his mother, as he would be able to walk around the block. Henry expressed that he would received more love and physical affection if he lived with his family. Therefore, many of the needs that are not being met in the long term care facilities were expressed by participants to be better met if they were to live in a different setting.

Experience and Sources of Social Isolation

Social isolation is common in people with ABI (Coneeley, 2012) and the participants of the current study were no different. They reported feeling lonely, lacking companionship and ambivalent feelings of belonging. A study done by Stanley, Conwell, Bowen and Van Orden (2014) reported that feelings of loneliness and social isolation were associated with negative outcomes, such as heart disease, early mortality, Alzheimer's disease,

depression and suicide. As indicated previously, loneliness is associated with depression and an increase in suicidal thoughts (Mezuk et al., 2014) and there is an increased risk of suicide in people with ABI (Leon-Carrion et al., 2009; Teasdale & Engberg, 2001).

The sources of the loneliness and social isolation in the current study seems to be related to the fact that the participants were placed in inappropriate long term care facilities. Placement in alternative settings, such as community-based homes or facilities specifically designed for people with ABI, may offset the loneliness, boredom and social isolation. Furthermore, living with people the same age may have positive effects in terms of facilitating social inclusion since age differences were a barrier to social integration this in the study. As noted by Winkler et al. (2011) younger residents in aged care struggle to make friends with other residents because of the age differences and having little or nothing in common. One participant, James, reflected on how he was less able to see his old friends because he was now living further away, and was therefore separated, from his old community.

The participants of the study opined that having a pet would help to meet their needs for love and companionship. Research has shown that having pets has therapeutic benefits as they counter loneliness and provide a source of social connectedness (Stanley et al., 2014). Pet owners in their study were 36% less likely to report loneliness than non-pet owners. Owning a pet in a facility can contribute to well-being in various ways. For example, they may give their owners a sense of responsibility and self-worth, they may help foster human interactions through providing a conversation point, and they can encourage greater levels of exercise, such as taking a dog for a walk (ibid). Many participants had previously owned pets in their family homes prior to living in long term care, and the rules of the facility prevented them from owning pets, which may not be the case in a different living arrangement.

In terms of Maslow's Hierarchy of Needs (1943 and 1970) and Bronfenbrenner's Ecological Systems Theory (1979), neither conditions in the long term care facilities or the other residents in the participants' Microsystem were able to fulfil their needs for companionship, love and affection. There were barriers to in-house and outside friendships and feeling that they did not belong that bordered on discrimination at times. Only one participant was allowed to keep a pet. Love, affection and companionship are important elements of well-being according to Shaw (2007). Thus, living arrangements that are suited to the needs of people with ABI where they are allowed to keep a pet could provide for their needs for love, affection, self-worth and companionship.

Sources of Well-Being

Some of the participants developed coping mechanisms that involved positive thinking and helping other residents to enable feelings of well-being. Considering the positive psychological benefits, these coping mechanisms are to be promoted and encouraged.

Positive thinking is known to be a resource used by people with ABI, as shown by Levack et al. (2010). By engaging in positive thoughts, certain participants (Charlene and Kevin) were able to make themselves feel better about their situation. By helping other residents Ian and James gained recognition, appreciation and a sense of purpose. Therefore, encouraging this positive thinking could be a constructive therapeutic goal to assist people with ABI in long term care contexts.

Summary of Discussion

The findings of this study were clear when it came to answering the research questions on general lived experience in the facilities and whether they were suitable when it came to catering for the needs of the participants. There was overall dissatisfaction with the facilities, which were inappropriate as people with ABI were mixed with the elderly, demented and/or people with other disabilities and they failed to meet their higher-level needs. Psychological distress and social isolation were reported. Despite this, some participants devised ways of keeping themselves occupied and coping mechanisms to enhance well-being.

CHAPTER 6: CONCLUSION

Acquired brain injury is a major global public health problem and the World Health Organisation (WHO) estimates that approximately 10 million people are affected annually. This burden is spread throughout the world, but is especially problematic in developing countries. Statistics show that South Africa has a significantly higher incidence of TBI (316 per 100 000) compared to a rate of 280 to 250 per 100 000 in the United States (National Institute for Occupational Health, 2017).

Brain injury can leave previously healthy individuals suddenly dependent on long term care. In South Africa and globally, there is a lack of long term care facilities designed specifically for people with brain injury. People with brain injury often end up living in inappropriate facilities such as homes for the disabled and residential aged care. According to Bronfenbrenner (1979), a person's immediate environment, the Microsystem, exerts the most powerful influence on an individual. Therefore, having a suitable home to live in is of vital importance for well-being and rehabilitation.

The findings of this study addressed the aims and research questions by providing valuable insights into the lived experience of people with ABI who are living in long term care facility settings. Themes relating to overall evaluations, general lived experience and social isolation together provided a rich and in depth understanding of life in a long term care facility for a person with ABI.

When interpreting the findings from the perspective of Bronfenbrenner's Ecological Systems Theory (1979) those participants who were placed in homes for the elderly and demented or people with disabilities reported negative emotions, disapproval of their living arrangements and social isolation. Some participants made an effort to improve their sense of well-being through positivity and creating meaning in their lives by helping others.

From the point of view of Maslow's Theory of Hierarchy of Needs (1943), basic physiological and safety needs were met for all participants. However, all the participants reported that psychological needs to do with relationships, belonging and self-esteem were not satisfied. The lack of facilities for pets was also a contributing factor. Other themes that were identified included a lack of autonomy, freedom and choice and boredom. In most cases, participants reported depression and in some, suicidal ideation. Thus, there long term care facilities only addressed basic needs such as shelter, food and safety with little evidence that higher-level needs were even considered.

The data collected from the participants provided insight into factors contributing to social isolation for people with ABI in long term care facilities. Age differences were a major issue, as was placement in long term care facilities that were geared for people with other kinds of disabilities. When asked to evaluate their facilities, participants gave either guarded approval or disapproval, suggesting that these facilities were not suitable and did not cater to their needs.

Overall, the findings of this study provided valuable information about the lives of people with ABI in South Africa who cannot live independently and reside in long term care facilities. In particular, they provide a unique understanding of their overall lived experience and that of social isolation in such facilities. It is hoped that the results from this study can be used to inform the development of suitable models of long term care for people with ABI that can improve on current facilities.

Limitations and Strengths

A limitation of the research is that it is not possible to draw causal links between the themes extracted from the data and living in long term care. For example, the psychosocial difficulties the participants are experiencing may have been present in similar ways in other settings. Collateral information pertaining to posttraumatic changes over time from reliable sources, such as family members, medical doctors and therapists would be advisable. This could allow comparisons to be drawn.

The small number of interview participants in this study also constitutes a limitation in terms of generalising the findings. However, it is difficult to recruit participants who function at the required cognitive level to participate in the research and who reside in long term care facilities. Finding themes among a small sample, however, perhaps points to the strength of these themes. However, a more nuanced understanding may be achieved by conducting further interviews.

Due to the cognitive requirements of an interview, the views of those who are more severely impaired could not be included in this study. Therefore, the findings only represent the experiences of people with less severe brain injuries.

The sampling method also has implications for transferability of the findings because the participants were selected on a convenience basis from Headway Gauteng's Hyde Park Branch. Membership involves nominal costs and so the findings may only represent the views of people with ABI from middle class or higher socio-economic status.

Furthermore, the findings may have limited utility for people with brain injury from different communities and belief systems. In rural communities in South Africa, family members of people with ABI usually look after the person at home (Mokhosi & Grieve, 2004). In their study, Mokhosi and Grieve (ibid) found that this was related to belief

systems that the ancestors instructed family members to look after the person with ABI and they felt privileged to carry out the ancestors' will. Therefore, it is unlikely that such families would consider placement of a family member with ABI in a long term care facility. Thus, the findings of this study would not apply to them.

A strength of the research findings was that the participants were from different long term care facilities, different age groups, different genders and difference cultural groups. Therefore, the results could reflect views from a diverse group of people with ABI, thereby strengthening the transferability.

Another strength is that the methodology was carefully designed to enable optimal quality data to be gathered, taking the well known challenges of interviewing people with ABI into account.

Interviewing people with ABI who live in long term care as opposed to their caregivers or family members constitutes another strength since they are the ones experiencing the phenomenon first hand. Therefore, the findings are likely to be closer to their real experiences.

Recommendations for Future Research

The research into people with ABI living in long term care facilities can be expanded and enhanced with the following recommendations:

1. Explore the lived experiences of people with brain injury living in various other settings, such as with family members, living on their own or with a partner. This would enable comparisons to be made between the experiences of people with ABI in different settings.

2. Measure the variables that arose as themes in this study quantitatively using a larger sample size to assess generalisability of the concepts.
3. Interview the other residents of long term care facilities to assess whether they are experiencing similar issues and to understand their perspective of having people with brain injury in the facilities.
4. Conduct a longitudinal study to see how these themes develop and change as a function of time in the facility.

REFERENCES

Adeloye, D. (2014). An estimate of the incidence and prevalence of stroke in Africa: a systematic review and meta-analysis. *PLoS One*, *9*(6), e100724.

Alexander, T., Fuller, G., Hargovan, P., Clarke, D., Muckar, D., & Thomson, S. (2009). An audit of the quality of care of traumatic brain injury at a busy regional hospital in South Africa. *South African Journal of Surgery*, *47*(4), 120-126.

Alston, M., Jones, J., & Curtin, M. (2012). Women and traumatic brain injury: "It's not visible damage". *Australian Social Work, 65*(1), 39-53. Doi: http://dx.doi.org/10.1080/0312407X.2011.594898.

Badul, A. (2012). The prevalence of traumatic brain injury in a South African, juvenile delinquent sample, Honours Thesis, University of Cape Town.

Bier, N., Dutil, E., & Couture, M. (2009). Factors affecting leisure participation after a traumatic brain injury: An exploratory study. *The Journal of Head Trauma Rehabilitation*, *24*(3), 187-194.

Bodley-Scott, S. E., & Riley, G. A. (2015). How partners experience personality change after traumatic brain injury: Its impact on their emotions and their relationships. *Brain Impairment*, *16*(3), 205-220.

Boylan, A., Linden, M., & Alderice, F. (2016). Interviewing children with acquired brain injury (ABI). *Journal of Early Childhood Research, 7*(3). 264-282. Doi: 10.1177/1476718X09336970.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. Doi: 10.1191/1478088706qp063oa.

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design.* Cambridge, UK: Harvard University Press.

Brown, B.P. (2010). *Salem health Magill's medical guide*. New York, NY: Salem Press.

Carlson, E., Paterson, B.L., Scott-Findlay, S., Ehnfors, M., & Ehrenberg, A. (2007). Methodological issues in interviews involving people with communication impairments after acquired brain damage. *Qualitative Health Research, 17*(10), 1361-1371. Doi: 10.1177/1049732307306926.

Conneeley, A.L. (2003). Quality of life and traumatic brain injury: A one-year longitudinal qualitative study. *British Journal of Occupational Therapy, 66*(10), 440-446. Doi: http://bjo.sagepub.com/content/66/10/440.abstract.

Conneeley, A.L. (2012). Transitions and brain injury: A qualitative study exploring the journey of people with traumatic brain injury. *Brain Impairment, 13*(1), 72-84. Doi: 10.1017/BrImp.2012.3.

Cooper-Evans, S., Alderman, N., Knight, C., & Oddy, M. (2008). Self-esteem as a predictor of psychological distress after severe acquired brain injury: An exploratory study. *Neuropsychological Rehabilitation*, *18*(5-6), 607-626.

Cope, D.G. (2014). Methods and meanings: Credibility and trustworthiness of qualitative research. *Oncology Nursing Forum, 41*(1), 89-91. Doi: 10.1188/14.ONF.89-91.

Demery, J. A., Hanlon, R. E., & Bauer, R. M. (2001). Profound amnesia and confabulation following traumatic brain injury. *Neurocase*, *7*(4), 295–302. Doi: http://doi.org/10.1093/neucas/7.4.295.

Department Health: Province of KwaZulu-Natal (2010). *World head injury awareness day.* Retrieved from http://www.kznhealth.gov.za/headinjury.htm.

Department of Social Development. (2017). *Facilities listed by category.* Retrieved from https://www.westerncape.gov.za/dept/social-development/facilities.

Di Battista, A., Godfrey, C., Soo, C., Catroppa, C., & Anderson, V. (2014). Depression and health related quality of life in adolescent survivors of a traumatic brain injury: A pilot study. *PloS One*, *9*(7), e101842.

Diaz, A. P., Schwarzbold, M. L., Thais, M. E., Cavallazzi, G. G., Schmoeller, R., Nunes, J. C., ... & Walz, R. (2014). Personality changes and return to work after severe traumatic brain injury: A prospective study. *Revista Brasileira de Psiquiatria*, *36*(3), 213-219.

Dodge, R., Daly, A. P., Huyton, J., & Sanders, L. D. (2012). The challenge of defining wellbeing. *International Journal of Wellbeing*, *2*(3), 222-235.

Duckham, B. C., & Schreiber, J. C. (2016). Bridging worldviews through phenomenology. *Social Work & Christianity*, *43*(4), 55-67.

Egan, J., Chenoweth, L., & McAuliffe, D. (2006). Email-facilitated qualitative interviews with traumatic brain injury survivors: A new and accessible method. *Brain Injury, 20*(12), 1283-1294.

Fann, J. R., Hart, T., & Schomer, K. G. (2009). Treatment for depression after traumatic brain injury: A systematic review. *Journal of Neurotrauma, 26*(12), 2383-2402.

Gauvin-Lepage, J., & Lefebvre, H. (2010). Social inclusion of persons with moderate head injuries: The points of view of adolescents with brain injuries, their parents and professionals. *Brain Injury, 24*(9), 1087-1097.

Horrigan-Kelly, M., Millar, M., & Dowling, M. (2016). Understanding the Key Tenets of Heidegger's Philosophy for Interpretive Phenomenological Research. *International Journal of Qualitative Methods, 15*(1), 1609406916680634.

Hyder, A. A., Wunderlich, C. A., Puvanachandra, P., Gururaj, G., & Kobusingye, O. C. (2007). The impact of traumatic brain injuries: A global perspective. *NeuroRehabilitation*, *22*(5), 341-353.

Iwasiw, C., Goldenberg, D., MacMaster, E., McCutcheon, S., & Bol, N. (1996). Residents perspectives of their first 2 weeks in a long-term care facility. *Journal of Clinical Nursing, 5*(6), 381-388. Doi: 10.1111/j.1365-2702.1996.tb00271.x.

Johansson, U., Hogberg, H., & Bernspang, B. (2007). Participation in everyday occupations in a late phase of recovery after brain injury. *Scandinavian Journal of Occupational Therapy*, *14*(2), 116-125.

Jumisko, E., Lexell, J., & Soderberg, S. (2009). The meaning of feeling well in people with moderate or severe traumatic brain injury. *Journal of Clinical Nursing, 18,* 2273-2281. Doi: 10.1111/j.1365-2702.2008.02738.x.

Khan, F., Baguley, I. J., & Cameron, I. D. (2003). Rehabilitation after traumatic brain injury. *Medical Journal of Australia*, *178*(6), 290-297.

Kneafsey, R. & Gawthorpe, D. (2004). Head injury: Long-term consequences for patients and families and implications for nurses. *Journal of Clinical Nursing, 13,* 601-608. Doi: 10.1111/j.1365-2702.2004.00903.x.

Leon-Carrion, J., De Serdio-Arias, M. L., Cabezas, F. M., & Rolda, J. M. D. (2001). Neurobehavioural and cognitive profile of traumatic brain injury patients at risk for depression and suicide. *Brain injury*, *15*(2), 175-181.

Levack, W.M., Kayes, N.M., & Fadyl, J.K. (2010). Experience of recovery and outcome following traumatic brain injury: A metasynthesis of qualitative research. *Disability and Rehabilitation, 32*(12), 986-999. Doi: 10.3109/09638281003775394.

Levin, H.S., O'Donnell, V.M. & Grossman, R.G. (1979). The Galveston Orientation and Amnesia Test: A practical scale to assess cognition after head injury. *Journal of Nervous and Mental Disease, 167*(11), 675 – 684.

Levin, K. (2004). Paediatric traumatic brain injury in South Africa: Some thoughts and considerations. *Disability & Rehabilitation, 26*, 306-314.

Liddle, J., Fleming, J., McKenna, K., Turpin, M., Whitelaw, P., & Allen, S. (2012). Adjustment to loss of the driving role following traumatic brain injury: A qualitative exploration with key stakeholders. *Australian Occupational Therapy Journal*, *59*(1), 79-88.

Lincoln, Y.S. & Guba, E.G. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.

Maslow, A. H. (1943). A theory of human motivation. *Psychological Review*, *50*(4), 370-396.

Maslow, A.H. (1970). *Motivation and personality.* NY: Harper & Row.

Maslow, K., & Heck, E. (2005). Dementia care and quality of life in assisted living and nursing homes: Perspectives of the Alzheimer's association. *The Gerontologist*, *45*(1), 8-10.

McLeod, S. (2016). *Maslow's hierarchy of needs.* Retrieved from http://www.simplypsychology.org/maslow.html.

Meyer, D., Marx, T., & Ball-Seiter, V. (2011). Social isolation and telecommunication in the nursing home: A pilot study. *Gerontechnology*,*10*(1), 51-58.

Mezuk, B., Rock, A., Lohman, M. C., & Choi, M. (2014). Suicide risk in long-term care facilities: A systematic review. *International Journal of Geriatric Psychiatry*, *29*(12), 1198-121.

Middleton, J. A. (2001). Brain injury in children and adolescents. *Advances in Psychiatric Treatment, 7*(4), 257-265.

Mokhosi, M. T., & Grieve, K. W. (2004). African families' perceptions of traumatic brain injury. *South African Journal of Psychology*, *34*(2), 301-317.

Monnett, C.G. (2017). *Effective representation of individuals with traumatic brain injury: An overview.* Retrieved from https://www.hg.org/article.asp?id=7462.

Moore, E. L., Terryberry-Spohr, L., & Hope, D. A. (2006). Mild traumatic brain injury and anxiety sequelae: A review of the literature. *Brain Injury*, *20*(2), 117-132.

Nadler, E., Fleming, J., Cornwell, P., Shields, C., & Foster, M. (2013). Reflections of life: Experiences of individuals with brain injury during the transition from hospital to home. *Brain Injury, 27*(11), 1294-1303. Doi: 10.3109/02699052.2013.823560.

Naidoo, D. (2013). Traumatic brain injury: The South African landscape. *South African Medical Journal, 103*(9), 613-614. Doi: 10.7196/SAMJ.7325.

National Institute for Occupational Health, 2017. Retrieved from http://www.nioh.ac.za/?page=topical&id=13&rid=214.

Norup, A., Welling, K. L., Qvist, J., Siert, L., & Mortensen, E. L. (2012). Depression, anxiety and quality-of-life among relatives of patients with severe brain injury: The acute phase. *Brain injury*, *26*(10), 1192-1200.

Ogden, J.A. (2005). *Fractured minds: A case-study approach to clinical neuropsychology, 2nd ed.* New York, NY: Oxford University Press.

Paterson, B & Scott-Findlay, S. (2002). Critical issues in interviewing people with traumatic brain injury. *Qualitative Health Research, 12*(3), 399-409.

Philpin, S., Jordan, S., & Warring, J. (2005). Giving people a voice: Reflections on conducting interviews with participants experiencing communication impairment. *Journal of Advanced Nursing*, *50*(3), 299-306.

Robinson, O. C. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative Research in Psychology, 11*(1), 25-41.

Ruff, R. M., Iverson, G. L., Barth, J. T., Bush, S. S., & Broshek, D. K. (2009). Recommendations for diagnosing a mild traumatic brain injury: a National Academy of Neuropsychology education paper. *Archives of Clinical Neuropsychology*, *24*(1), 3-10.

Seedat, M., Van Niekerk, A., Jewkes, R., Suffla, S., & Ratele, K. (2009). Violence and injuries in South Africa: Prioritising an agenda for prevention. *The Lancet, 374*(9694), 1011-1022.

Shaw, R. (2007). Relating: family. In S. Matthewman, C.L. West-Newman, & B. Curtis (Eds.) *Being sociological*. Palgrave: Macmillan.

Shores, E.A., Marosszeky, J.E., Sandanam, J., & Batchelor, J. (1986). Preliminary validation of a clinical scale for measuring the duration of post-traumatic amnesia. *Medical Journal of Australia, 144,* 569-572.

Soeker, M. S. (2011). Occupational adaptation: A return to work perspective of persons with mild to moderate brain injury in South Africa. *Journal of Occupational Science*, *18*(1), 81–91 11p. Doi: http://doi.org/10.1080/14427591.2011.554155.

Stanley, I. H., Conwell, Y., Bowen, C., & Van Orden, K. A. (2014). Pet ownership may attenuate loneliness among older adult primary care patients who live alone. *Aging & Mental Health*, *18*(3), 394-399.

Statistics South Africa. (2015). Mid-year population estimates (Statistical Release PO302). Retrieved from https://www.statssa.gov.za/publications/P0302/P03022015.pdf.

Street, D., Burge, S., Quadagno, J., & Barrett, A. (2007). The salience of social relationships for resident well-being in assisted living. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *62*(2), 129-134.

Swanson, D. P., Spencer, M. B., Harpalani, V., Dupree, D., Noll, E., Ginzburg, S., & Seaton, G. (2003). Psychosocial development in racially and ethnically diverse youth: Conceptual and methodological challenges in the 21st century. *Development and Psychopathology*, *15*(03), 743-771.

Teasdale, G., & Jennett, B. (1974). Assessment of coma and impaired consciousness: A practical scale. *The Lancet*, *304*(7872), 81-84.

Teasdale, T. W., & Engberg, A. W. (2001). Suicide after traumatic brain injury: A population study. *Journal of Neurology, Neurosurgery & Psychiatry*, *71*(4), 436-440.

The Rehab Group. (2017). *The ABI manual.* Retrieved from http://www.acquiredbraininjury.com/abi_manual.

The Stroke Association. (2015). *State of the nation stroke statistics.* Retrieved from https://www.stroke.org.uk/sites/default/files/stroke_statistics_2015.pdf.

Thomas, E., & Magilvy, J. K. (2011). Qualitative rigor or research validity in qualitative research. *Journal for Specialists in Pediatric Nursing*, *16*(2), 151-155.

Trenberth, L. (2005). The role, nature and purpose of leisure and its contribution to individual development and well-being. *British Journal of Guidance & Counselling, 33*(1), 1-6.

Turner, B., Fleming, J., Cornwell, P., Worrall, L., Onsworth, T., Haines, T, Kendall, M., & Chenoweth, L. (2007). A qualitative study of the transition from hospital to home for individuals with acquired brain injury and their family caregivers. *Brain Injury, 21*(11), 1119-1130. Doi: 1080/026990500701651678.

Turner, M. S., Cipolotti, L., Yousry, T. A., & Shallice, T. (2008). Confabulation: Damage to a specific inferior medial prefrontal system. *Cortex: A Journal Devoted to the Study of the Nervous System and Behavior*, *44*(6), 637–648. Doi: http://doi.org/10.1016/j.cortex.2007.01.002.

Williams, W. H., Evans, J. J., & Fleminger, S. (2003). Neurorehabilitation and cognitive-behaviour therapy of anxiety disorders after brain injury: An overview and a case illustration of obsessive-compulsive disorder. *Neuropsychological Rehabilitation*, *13*(1-2), 133-148.

Winkler, D., Farnworth, L, Sloan, S., & Brown, T. (2011). Moving from aged care facilities to community-based accommodation: Outcomes and environmental factors. *Brain Injury, 25*(2), 153-168. Doi: 10.3109/02699052.2010.541403.

Winkler, D., Farnworth, L., Sloan, S., Brown, T., & Callaway, L. (2010). Comparison of people with ABI living in two accommodation settings: Shared supported accommodation and residential aged care. *Brain Impairment*, *11*(03), 313-325.

Zavaleta, D., Samuel, K., & Mills, C. (2014). *Social isolation: A conceptual and measurement proposal, 67*(3), OPHI Working Papers [Online]. Retrieved from http://www.ophi.org.uk/wp-content/uploads/ophi-wp-67.pdf.

Zimmerman, S., Sloane, P. D., Williams, C. S., Reed, P. S., Preisser, J. S., Eckert, J. K., ... & Dobbs, D. (2005). Dementia care and quality of life in assisted living and nursing homes. *The Gerontologist, 45*(1), 133-146.

APPENDICES

Appendix A: Interview Guide

Hello Participant. Thank you very much for your willingness to participate in this research. (Re-confirm consent). If at any point during the interview you do not understand me, please tell me. It is my job to make sure you understand what I am asking. Also, if I misunderstand anything you say, please correct me. If you no longer want to take part in this research at any time during the process, you are free to leave. Please tell me if you are getting tired and we can continue on another day. Remember that whatever we talk about is confidential and will not be linked back to you. Do you have any questions before we start?

As you know, I want to talk about your experiences of living in long term care. I am going to ask you a series on questions on this topic. Please stop me if you do not understand the question. If you feel uncomfortable answering a question, we can skip it and move onto the next question.

General Lived Experience

1. What is it like for you living here?
2. What do you like about living here?
3. What don't you like about living here?
4. If you had the choice, would you choose to live here or somewhere else?
5. What are some of the challenges you have living here?
6. What do you think are the benefits of living here?
7. What are the disadvantages of living here?
8. Do you feel that this is a suitable place for you to live? Why or why not?
9. What activities do you do here?
10. What do you do for fun?

Social Isolation

1. What kind of relationships do you have with the other people that live here?
2. How does living here affect your relationships with your family?
3. How does living here affect relationships with your friends?
4. What are the other people that live here like?
5. How do you get on with the other people that live here?
6. What opportunities do you have for interaction with others?
7. Do you find you can relate to the others that live here? In what way?
8. Does living here give you a sense of belonging? In what way?
9. Do you have loving relationships with people here? Please elaborate.
10. Do you have friends here? Please elaborate.
11. How often does your family visit and are you happy with how often they visit?
12. How often do you communicate with your family and are you satisfied with this?
13. What do you have to offer the other residents living here?
14. Where do you spend most of your time and with whom?
15. How often do you go out and where do you go? Would you like to go out more?
16. If you have a personal problem do you have someone you can talk to about it?

Anything else you feel is important to tell me about living here that I have not asked?

Probing Questions:

Where appropriate, participants will be asked to elaborate on certain answers given, using some of the following probes.

- Could you please tell me more about that?
- Can you tell me more about …?
- In what way?

Appendix B: Informed Consent Form

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Principle Investigator: Emma Walland
Organisation: University of the Witwatersrand
Supervisor: Marilyn Adan
Name of Project: *The lived experience of people with brain injury living in long term care: Specific implications for social isolation*

This Informed Consent Form has two parts:

- Information Sheet (to share information about the study with you)
- Certificate of Consent (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form

Part I: Information Sheet

Introduction

My name is Emma Walland and I am a student in Social and Psychological Research at the University of the Witwatersrand. I am passionate about learning more about the experiences of people with brain injury. I am doing research on what it is like to live in a care home and would like to invite you to participate in this research. You may talk to anyone you feel comfortable with about the research and you may take time to think about whether you want to participate or not. If you do not understand some of the words or concepts, I will take time to explain them to you as we go along and you can ask me questions at any time.

Purpose of the Research

The aim of this research is to understand your experience of living in long term care and also how living here impacts on your social relationships.

Type of Research Intervention

This research will involve your participation in approximately one to three face to face interviews with me, lasting approximately half an hour each. The interviews will be arranged at a time and place convenient to you.

Participant Selection

You are being invited to take part in this research because we feel that your experience of living in a home is valuable and can contribute much to our understanding of what this experience is like.

Voluntary Participation

Whether you want to participate in this research is entirely your choice and there will be no negative consequences at all should you choose not to take part. Whether you participate or not will not have any bearing on the services you receive at your home or support group. If you decide to participate, you can choose to stop participation at any time during the process.

Procedures

A. If you accept, you will be interviewed about how living in a long term care home affects your social relationships and your view of yourself.

B. The interviews will be conducted by me. I will conduct the interviews in a private place. I will begin by making sure you are comfortable and asking you if you have any questions about the research. Then, I will ask you questions about your experience of living in a care home. We will talk about things such as the challenges of living here, what you like about living here and the opportunities you have for social relationships.

You may possibly find some of the topics upsetting to talk about. If you do feel upset by something raised in the interview, I will arrange a counseling session for you with a Registered Counsellor, Christine Buchanan, 011 442 5733. If you do not wish to answer any of the questions during the interview, you may say so and we will move on to the next question. No one else will be present in the interview unless you would like to have someone with you.

The interview will be audio-recorded but no one will be identified by name on the recording. The recording will be password protected and kept secure at all times. The information recorded is confidential and no one else except me and my research team will have access to the recordings. The recordings will be destroyed after the research is complete.

Duration

Each interview will take approximately 30 minutes. If we run out of time in answering the questions, we may schedule more interviews, with a maximum of three interviews.

Risks

We are asking you to share with us some personal information and some of the questions may make you feel uncomfortable. We do not wish for that to happen. You do not have to answer any question or take part in the interview if you don't wish to and that is fine. You do not have to give any reason for not responding to a question or for refusing to take part in the interview.

Benefits

The research may benefit you through sharing your experience. Many people in South Africa have brain injuries and it is a life changing event. One of the challenging aspects of living with a brain injury is living arrangements. Research on living in a long term care home can potentially help the all the

people involved to better understand this. You will be able to get a report on the research findings when the research is complete if you wish.

Reimbursements

You will not be provided any incentive to take part in the research.

Confidentiality

We will not share any information about you to anyone outside of the research team and the information we collect will be kept private. Any information about you will not reflect your name; we will use a pseudonym. Only the researchers will know your pseudonym and the data will be kept under lock and key. Any information that may lead others to identify you will not be included in the research.

Sharing the Results

After the research is completed, you will have the opportunity to receive a summary of the research findings. We are aiming to share the research with other community members through publications and conferences.

Right to Refuse or Withdraw

Remember that participation in this research is entirely your choice and you have the right to refuse or withdraw your participation at any time during the research process. There will be an opportunity after the interview(s) to review your comments and make changes to them if you wish.

Who to Contact

If you would like to discuss the research further or if you have any questions, please contact me:

Emma Walland
University of the Witwatersrand
emma.walland@gmail.com

This proposal has been reviewed and approved by Wits Human Research Ethics Committee (Medical), which is a committee whose task it is to make sure that research participants are protected from harm. If you wish to find about more about this committee, contact Zanele Ndlovu (Zanele.ndlovu@wits.ac.za).

You can ask me any more questions about any part of the research study, if you wish to. Do you have any questions?

Part II: Certificate of Consent

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Print Name of Participant_____

Signature of Participant _____

Date _____

Day/month/year

If illiterate [1]

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness_____ Thumb print of participant

Signature of witness _____

Date _____

Day/month/year

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

1. Participate in one to three 30 minute long interviews about their experience of moving to their home

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent _____

Signature of Researcher /person taking the consent _____

Date _____

Day/month/year

[1] A literate witness must sign (if possible, this person should be selected by the participant and should have no connection to the research team). Participants who are illiterate should include their thumb print as well.

Appendix C: Ethical Clearance Certificate

R14/49 Miss Emma Walland

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M160319

NAME: (Principal Investigator)	Miss Emma Walland
DEPARTMENT:	Psychology Headway, Gauteng
PROJECT TITLE:	The Lived Experience of People with Brain Injury Living in Long Term Care: Specific Implications for Social Isolation
DATE CONSIDERED:	01/04/2016
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Marilyn Adan
APPROVED BY:	Professor P. Cleaton-Jones,Chairperson, HREC (Medical)
DATE OF APPROVAL:	22/04/2016

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 10004,10th floor, Senate House/2nd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand. I/We fully understand the the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated,from the research protocol as approved, I/we undertake to resubmit to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. in this case, the study was initially review in March and will therefore be due in the month of March each year.

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix D: Institutional Permission

HEADWAY GAUTENG

15 January 2016

Ms Emma Walland

RESEARCH: The meaning of a transition to long term care after acquired brain injury: an interpretative phenomenological analysis

This letter serves to confirm that you have permission to peruse the files of Headway attendees at our Hyde Park premises and to interview attendees with their informed consent. Please respect the anonymity and confidentiality of our members and attendees.

I wish you all the best in your research study.

If you require further information or have any questions please feel free to contact me on 011 442 5733 on Mondays to Fridays between 08h00 and 17h00.

Yours sincerely

Christine Buchanan
Therapy Manager
Headway Hyde Park

Registered Counsellor (PRC 0010804)
MA Research Psychology (WITS)
Member: South African Neuro-Rehabilitation Association
Member: British Psychological Society

The Brain Injury Association
Welfare Reg. Number 001-304 NPO PBO NO 930 001 660
PO Box 502 Sasorwold 2132 • Telephone (011) 442 5733 • Fax 086 723-8051
E-mail: headway@iafrica.com Website: www.headwaygauteng.co.za

Governing Body: Quentin Sussman (chairman) – June Cruickshanks (vice chairman) – Jonathan Davis (treasurer) – Carol Cannel – Monica Dube
Rozanne Gevers (Alt: Ron Gevers) – Brian Mallinson – Prof Mochichi Samuel Mokgokong – Dr Thobeka Nkomo – Dr Nilesh Patel
Patrons: Gareth Cliff – Nkombi Mailela

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