The Perceptions of Community Integration One Year Post Rehabilitation for Survivors of Traumatic Brain Injury and Their Significant Others: A South African perspective.

Jade Calogridis

9 November 2017

A Masters Dissertation submitted to the Department of Speech Pathology
and Audiology School of Human and Community Development
Faculty of Humanities
University of Witwatersrand
Johannesburg

Supervised by Dr Jaishika Seedat

In fulfillment of the requirements for the degree Master of Arts in Speech Pathology

Declaration

I hereby declare that this thesis is my own unaided work and that the assistance obtained has been only in the form of professional guidance and supervision. It is submitted for the degree Master of Arts in Speech Pathology to the Faculty of Humanities, Department of Speech Pathology and Audiology at the University of Witwatersrand, Johannesburg. It has not been previously submitted for any other degree or examination to any other university.

Jade Calogridis

9th day of November 2017

Acknowledgements

Many people have contributed in different ways to making the completion of this dissertation possible.

I would like to thank all the participants in the study for their time and willingness to share their experiences and thoughts. I've learnt much from each of you.

To my supervisor, Dr Jaishika Seedat, I cant thank you enough for your guidance, availability, constant encouragement and excitement for the study. You pushed me just the right amount at just the right times. I've gained so much from working with you.

Leon, your support, love, patience and encouragement has aided tremendously in the completion of this study. Thank you for making the best 'late night cup of tea' in the world. I love you.

To my family, Mom, Luke, Dad, Den, By, Margot, Amy and Ally, thanks for your constant interest in what I'm doing, your belief and pride in me and your endless encouragement. I appreciate and love you all.

To my angel girl Sophia, you gave me the energy I needed to finish and submit in the end. I love you more than words can say.

To my friend Sherianne thank you for your constant advice and absolute passion for research. Your guidance and constant availability to lend an ear and share your knowledge is appreciated more than you know.

I would like to thank my employer, Rita Henn and Partners Inc. for the support and time you've given me over the last 2 years which has allowed me to complete this study.

Abstract

Background**:** Traumatic Brain Injury (TBI) is a serious public health problem worldwide. It is a major cause of death among younger adults and is a leading cause of lifelong disability in persons who survive it. There are a large number of young adults living with life-long disabilities as a result of traumatic brain injury worldwide, with higher numbers existing in South Africa. Whilst previous research internationally has examined issues of community integration and difficulties experienced by persons with traumatic brain injury and their significant others or caregivers, a paucity of research of this nature exists in South Africa. This study intended to explore whether a gap in clinical practice exists with regard to aspects of intervention and support, underpinned by an ambiguous definition of community integration for survivors of traumatic brain injury and their significant others

Method: The main aim of the study was to explore existing feelings of community integration and active participation in patients with traumatic brain injury who have been discharged from rehabilitation services in private practice in Johannesburg, South Africa. In this study, the sample comprised of 10 survivors of TBI and 10 significant others (SOs). The objectives were to describe and compare participants and significant others' or caregivers experience of community integration and factors that influenced the perceptions by each (i.e. the patient and the caregiver) as well as to document barriers and facilitators to community integration and active participation within the, familial, social and work context. Lastly the study aimed to determine if the qualitative analysis of formal assessment measures (FIM and CIQ-R) match perceptions of persons with TBI with regard to Community Integration (Landrum et al., 1995).

Results: Across various areas of comparison, participants who scored higher in the CIQ-Rand FIM measures, often expressed more subtle difficulties or challenges that landed up going undetected and ultimately contributed to their personal feelings of poorer community integration. Various studies, including the current study reveal that significant others have many unmet needs in terms of what they know and what they should expect with regard to handling their loved one with a TBI.

Implications: This research has highlighted the fact that our South African context is lacking with regard to ongoing management of individuals surviving TBI, with reduced funding available for outpatient therapies, a lack of post discharge programmes and a general lack of education and information given to family members of TBI survivors upon discharge. As such this should be a major focus of health care providers in the future. This research revealed many subtleties that impact perceptions of community integration but go undetected by formal measures. Such subtleties could be used to direct specialised programmes, which should be made available to TBI survivors post discharge from rehabilitation services.

Keywords: traumatic brain injury; community integration; rehabilitation; functional outcomes; private practice, developing countries, community resources, south Africa

Table of Contents

List of Figures

List of Tables

Abbreviations

ADL-	Activities of Daily Living
CDTP-	Comprehensive Day Treatment Programmes
CIQ-R-	Community Integration Questionnaire- Revised
D/C-	Discharged
DRS-	Disability Rating Scale
FIM-	Functional Independence Measure
GCS-	Glascow Coma Scale
HPCSA-	Health Professions Council of South Africa
ICF-	The International Classification of Functioning, Disability and Health
IPA-	Interpretative Phenomenological Analysis
MAEC-	Medical Advisory Ethics Committee
MDT-	Multidisciplinary Team
NHS-	National Health Service
OT-	Occupational Therapist
PABIR-	Post-Acute Brain Injury Rehabilitation
PT-	Physiotherapist
PVA-	Pedestrian Vehicle Accident
QOL-	Quality Of Life
RA-	Research Assistant
SCI-	Spinal Cord Injury
SO-	Significant Other
ST/SLP-	Speech Therapist/ Speech Language Pathologist
TBI-	Traumatic Brain Injury
WHO-	World Health Organisation

Overview

This section introduces concepts surrounding prevalence and management of Traumatic Brain Injury (TBI) in both developed and developing countries. It provides a rationale for the research as well as some insights into various aspects that have contributed in the culmination of this research. The literature review covers areas including The International Classification of Functioning, Disability and Health (ICF), community integration and the assessment thereof, medical schemes in South Africa (SA), caregivers and the transition from hospital to home following TBI, as well as the methodological framework of phenomenology.

1. Introduction

According to the World Health Organisation, Traumatic Brain Injury (TBI) will exceed many diseases as the significant cause of death and disability by the year 2020 (Hyder, Wunderlich, Puvanachandra, Gururaj & Kobusingye, 2007). With an estimated 10 million people affected by TBI annually, it is rising as a significant threat for society (Hyder et al., 2007). Low and middle-income countries are more at risk as they are underprepared and largely under-resourced to manage the health outcomes associated with TBI (Hyder et al., 2007). Following acute and outpatient rehabilitation for TBI, many people discharged home experience significant difficulty with the transition back into life roles. In order to improve quality of life and provide adequate services for individuals undergoing this complex transition, it is important to understand the perspectives of people with TBI as well as their significant others regarding this life phase (Nalder et al., 2012).

There are numerous older as well as on-going studies internationally that have investigated TBI and its long-term effects i.e. the transition back into the home environment; integration into the community following TBI; re-conceptualising 'self' and maintaining social connection following TBI as well as quality of life (QOL) issues in living with TBI (Dijkers, 2004; Douglas, 2013; Nalder et al., 2012; Wehman, Gentry, West, & Arango-Lasprilla, 2009). The current study sought to describe the perceptions of a small sample of TBI survivors and their significant others (SO) or caregivers in South Africa, with regard to such issues, most specifically focusing on these individuals' perceptions of their own integration back into the community following a TBI. Existing research has highlighted a variety of resources that exist in developed countries with regard to post-rehabilitation support and programmes (Douglas, 2013). A study conducted in Australia that aimed to investigate social connectedness as well as the conceptualisation of self following TBI, made reference to the post-discharge activities and programmes the participants were involved in (Douglas, 2013). The study describes disability sheltered workshops, volunteer programmes, community based leisure activities with attendant care support and activities in the community with attendant care (Douglas, 2013). The results of this study highlighted the need for increased facilitation of engagement in social activity as well as the need for improved community-based support services (Douglas, 2013). This research demonstrated how such engagement allows for increased feelings of participation and integration into the community, contributing to positive quality of life (QOL) feelings of TBI survivors in these areas (Douglas, 2013). Limited research of this nature exists in South Africa and more significantly limited research detailing the availability or efficacy of such programmes exists.

In a resource-constrained country like South Africa (Hyder et al., 2007) with limited support services for survivors of TBI and their SOs or caregivers, understanding the perceptions of community integration against this backdrop may facilitate a more tailored approach to rehabilitation from the perspective of the allied health professionals, and inform community integration initiatives. Whilst focus is often placed on investigating larger populations of people in the government sector or low social economic settings in South Africa, this study investigated a smaller sample of TBI survivors who have had access to private health care. In observing the perspectives of survivors of TBI and their SOs, this research highlighted areas of strength and weakness in current practice, particularly post-rehabilitation support. It examined whether inpatient and outpatient rehabilitation services in private practice leave individuals with TBI feeling adequately equipped to subjectively and objectively achieve levels of integration into community or active participation in life.

1.1. Rationale

There is a large proportion of young adults living with life-long disabilities as a result of TBI worldwide, with higher numbers existing in South Africa (Corrigan, Selassie & Orman, 2010). This study gained insight into aspects of the TBI intervention and post-intervention process that are lacking. In a developing country such as South Africa which is already subject to low income and economic strain (Naidoo, 2013), the financial costs of managing the long-term health and rehabilitative needs of TBI survivors paired with increasing unemployment rates among the TBI population, places an even more serious burden on society as a whole (Evans & Brewis, 2008). Internationally, although some support structures are available for TBI survivors, there is a trend toward fewer provisions being made for inpatient and outpatient rehabilitation (Benson Yody & Strauss, 1999; Evans & Brewis, 2008) and as such there is a higher burden placed on primary caregivers (Paterson, Kieloch & Gmiterek, 2001; Evans & Brewis, 2008). One can expect that such issues are exacerbated in developing countries such as South Africa. It was therefore vital to investigate existing support structures as well as understand the needs and perceptions of TBI survivors and their SOs or caregivers living in South Africa.

This study highlighted and examined aspects of community integration of persons with TBI and how this condition impacts on quality of life and participation in the long term. Integration back into the community following a TBI impacts on an individual's quality of life (McCabe et al., 2007). In defining quality of life (QOL), Dijkers (2004) asserts that the starting point is in understanding that each individual has needs and desires, aspirations and future plans. When reality matches these needs, individuals are likely to feel content and thus have a positive perception of their own quality of life (Dijkers, 2004). If however a persons' real life situation falls short of their needs and wishes, or in the case of TBI, an injury leads to failure to meet these needs, the conceptualisation of a persons' QOL can be negatively impacted (Dijkers, 2004).

In addition to understanding the levels, factors and processes of transition and community integration for individuals with TBI, this study gained insight into elements that would make the process more successful according to a small sample of people with TBI living in South Africa as well as their significant others. This research provided further insights that may help in informing clinicians to better prepare patients and caregivers when they leave outpatient rehabilitation. It could assist in the institution of possible fading out programmes that slowly integrate patients back into their previous lives.

1.2. Literature Review

1.2.1 The Epidemiology of Traumatic Brain Injury

Traumatic Brain Injury (TBI) is a serious public health problem worldwide (Langlois, Rutland-Brown & Walds, 2006). It is a major cause of death among younger adults and is a leading cause of lifelong disability in persons who survive it (Roozenbeek, Maas & Menon, 2013). TBI can be defined as an alteration to brain function that may present itself as confusion or altered consciousness; it can result in seizure, coma as well as sensory/motor neurological deficits (Bruns & Hauser, 2003). TBI results from a blunt or penetrating force to the head and may vary in degree of severity. Milder forms of TBI may result in subtle behavioural or neuropsychological changes; these may even be the only notable changes (Bruns & Hauser, 2003).

Roozenbeek and colleagues (2013) describe TBI as having the following disabling effects on survivors (See figure 1.).

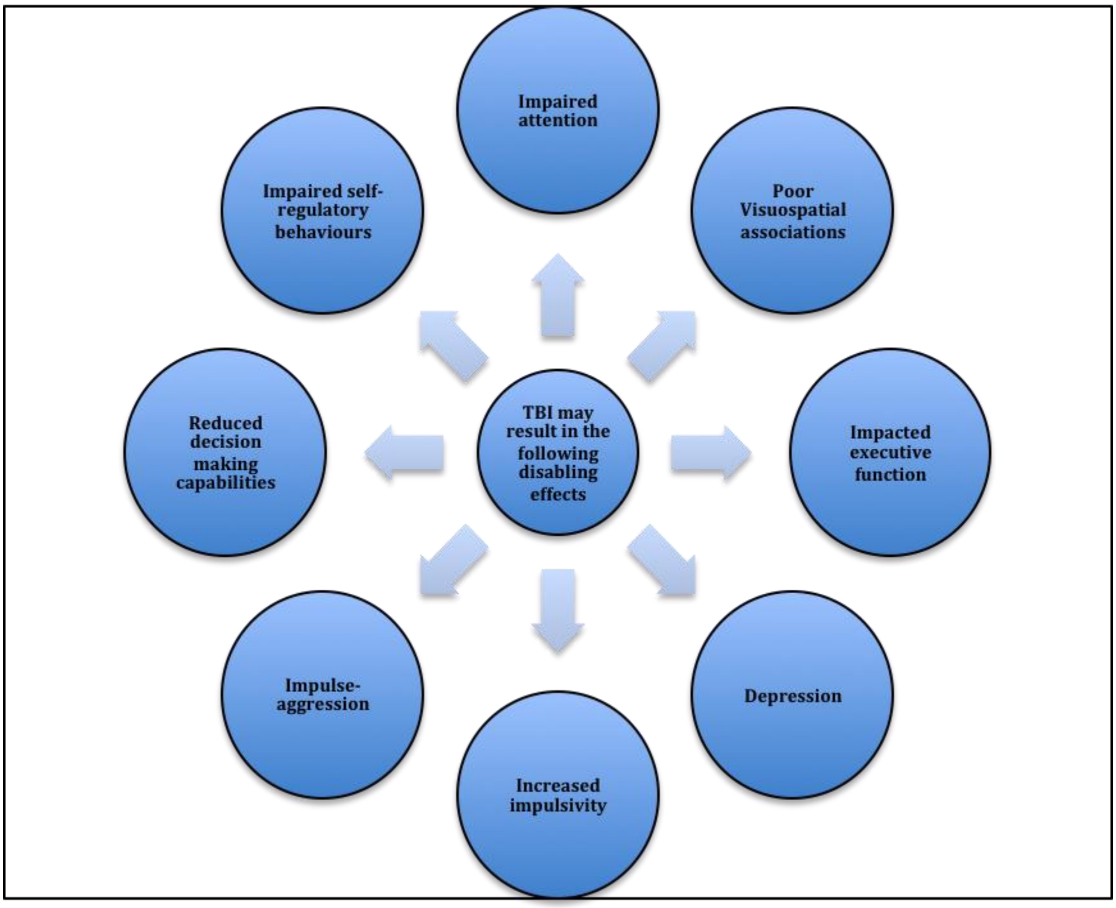


Figure 1. The effects of Traumatic Brain Injury (TBI) (Roozenbeek et al., 2013)

Such difficulties as those described in Figure 1 can impact on the ability of survivors of TBI to maintain interpersonal relationships and integrate into the community, social and work environments. Often such individuals are unable to live independently and may require long-term institutional placements (Roozenbeek et al., 2013).

The incidence of TBI is rising worldwide mainly as a result of increased motor vehicle use. This is so particularly in middle-income and low-income countries (Roozenbeek et al., 2013). There are an estimated 235 000 hospitalisations for non-fatal TBI in the United States (US) each year (Corrigan et al., 2010). Corrigan and colleagues (2010) report that recent estimates indicate that 124 000 persons discharged from acute hospitals with TBI in the US develop long-term disability. Population-based studies from South Africa (SA), India and Taiwan suggest that these rates are higher in developing countries (Corrigan et al., 2010). These statistics raise questions as to whether developing countries are adequately equipped and resourced to manage the increasing incidence of TBI.

South Africa does not have a TBI databank and as such data related to prevalence and incidence of TBI in SA are lacking (Naidoo, 2013). A study by Watt and Penn (2000), illustrated how increases in TBI due to motor vehicle accidents (MVA) and violence are particularly high in SA. Brown and Nell (1991) reported a TBI incidence of 316 per 100 000 persons in Johannesburg. These statistics were assembled using data collected from all trauma hospitals in Johannesburg at the time and whilst the statistics are dated, many of the factors that the study refers to, such as incomplete and unreliable hospital records, poor research funding and overcrowded and poorly resourced public hospitals, are still relevant today (Naidoo, 2013; Bruns & Hauser, 2003; Watt & Penn, 2000). Another feature unique to SA is the prevalence of TBI cause by pedestrian vehicle accidents (PVA) (Naidoo, 2013). Bryan-Hancock and Harrison (2010) reported that the global incidence rate of TBI is estimated at 200 per 100 000 people per year; however, the incidence rate of TBI in SA has been estimated at 1.5 to 3.5 times that of the estimated global rate (Bryan-Hancock & Harrison, 2010). Aligning with the need for epidemiological data, research pertaining to the long-term effects and management of the condition is also required. The economic consequences and burden on society due to loss of productivity (Corrigan et al., 2010) are further outcomes of TBI. A shortage in adequate long-term care following TBI is likely to trigger progressive cognitive decline in survivors as well as the acceleration of health conditions associated with age-related cognitive decline, essentially increasing this burden (Corrigan et al., 2010; Roozenbeek et al., 2013). The current study explores factors that may hinder or facilitate the long-term management of the condition given the increase in its prevalence.

1.2.2 Theoretical Framework: The International Classification of Functioning, Disability and Health (ICF)

The International Classification of Functioning, Disability and Health (ICF), was developed in order to produce a standard language and framework for the understanding and classification of health related issues (World Health Organisation [WHO], 2002). The ICF looks at classifying individuals with a health condition according to a variety of domains; it highlights and aims to understand the discrepancies between what the person with a health condition can achieve in a 'standard' environment (their capacity level) as well as what they actually manage to achieve in their typical day to day environment (their performance level) (WHO, 2002). The ICF broadens the term ‘functionality’ to refer to all body functions, activities and participation; it also expands the definition of ‘disability’ to include a person’s impairments, activity limitations and participation restrictions (WHO, 2002).

The understanding and conceptualisation of the ICF framework is vital for the current study. The ICF highlights that diagnosis alone is insufficient in the prediction of service needs; length of hospital stay; level of care required or functional outcomes (WHO, 2002). It establishes the need for further investigation and more accurate domains of measuring outcomes for individuals with chronic disability (WHO, 2002). It moves away from ideas, that individuals are only restricted by the physical disabilities directly caused by the disease. It broadens to look at service provision for such persons at an individual level, an institutional level and at a social level (WHO, 2002). The ICF looks at barriers and resources for individuals with disability in different domains and attributes levels of disability to all aspects; personal, institutional and environmental, which contribute to the disability of such individuals (WHO, 2002).

Against this backdrop, this study interrogates what happens in South Africa following discharge from inpatient and outpatient therapy. There is a paucity of information that is available to practicing neurological rehabilitation allied health professionals, with regard to the challenges and facilitators persons with TBI and their families experience once rehabilitation ceases. This niche required investigation from a social, employment and home integration perspective. Equipped with this insight from a first person perspective, rehabilitation clinicians may be better informed to incorporate principles of the ICF into their rehabilitation programmes so that outcomes may be improved for those needing to be integrated into community and work situations.

The ICF as a theoretical basis supports the notions that disability is multifaceted (Stucki, 2005). As previously mentioned the ICF establishes a standardised language for describing and delineating various health conditions (Stucki, 2005). In doing so, it indirectly acknowledges the depth of disability and how it extends to include not only body functions and structures, but also levels of activity and participation of the individual after considering the particular health condition (Stucki, 2005). Considering such levels is pertinent when looking at integration into the community following a traumatic brain injury. As previously described, community integration and the rehabilitation to achieve this, requires that disability be viewed more holistically to include and understand levels of activity and participation into various aspects of life (McCabe et al, 2007).

The ICF is based on a biopsychosocial model that integrates medical and social approaches in its view of disability (WHO, 2002). Figure 2 below is a representation of the model of disability that forms the basis for the ICF.

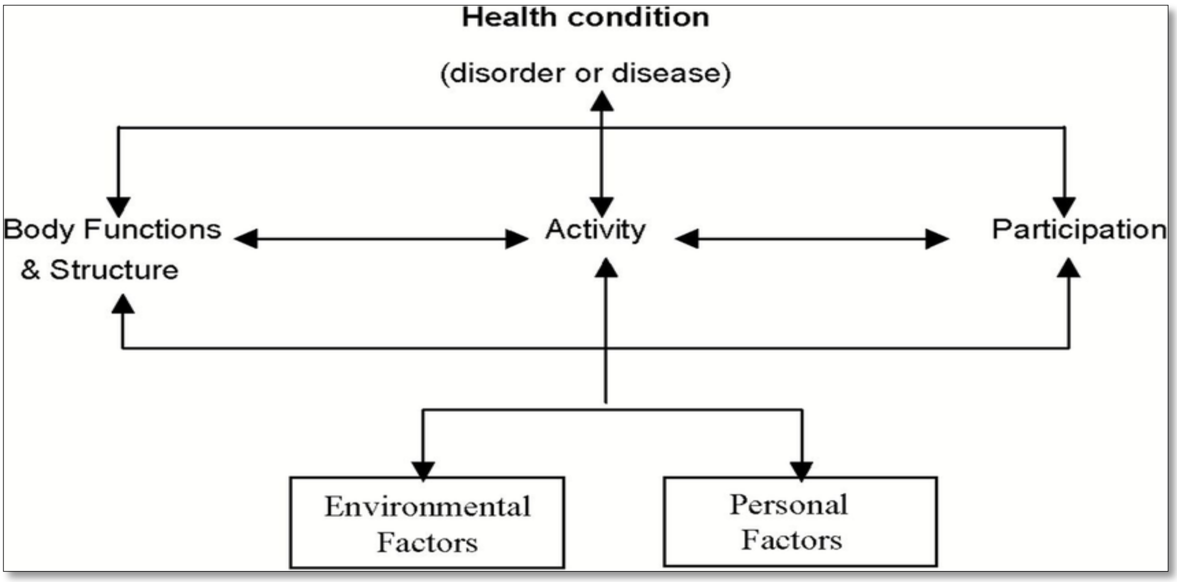


Figure 2. ICF model (WHO, 2002).

Figure 2 above shows how disability and functioning are multi-dimensional and not hierarchical (WHO, 2002). This diagram details the complex interactions between health conditions and contextual factors. Functional ability can impact participation and activity levels and visa versa (WHO, 2002). A first hand account from TBI survivors as provided by this research, as well as an account of the SOs of the participants with TBI, helps to establish a greater understanding of these factors and how they vary for each individual with differing environmental and personal factors. In further describing the above diagram, the following terms will be defined; body functions, body structure, impairments, activity, participation, activity limitations, participation restrictions, environmental factors and personal factors (WHO, 2002).

Body Functions	• Refers to the functions of body including mental and sensory functioning, voice and speech functioning as well as the functioning of the various systems in the body
Body Structures	• Refers to the parts of the bodies anatomy including organs, limbs and the components of the various body systems
Impairments	• Refers to loss or deviation in body functions or structures
Activity	• Refers to the performance of a task or action • Examples of activities include; learning and applying knowledge; completion of general everyday tasks and fulfilling demands; communication and mobility.
Participation	• Refers to the process of being involved in a life role • Examples of participation include; participation in domestic life; maintaining interpersonal interactions and relationships as well as participation in community; social and civic life.
Activity Limitations	• Refers to difficulty executing activities
Participation Restrictions	• Refers to difficulty with involvement in life situations
Environmental Factors	• Refers to support from family and friends in the form of relationships and attitudes as well as modification of the environment and support services, technologies, systems and policies in place to support the individual with disability
Personal Factors	• Refers to factors like gender, age, social and cultural background, eductaion, experience, beahvioural and character traits that may impact on how the disability is perceived and experienced by the individual.

Figure 3. Defining aspects of the ICF model (WHO, 2002).

> *In clinical settings, ICF should always be used with the full knowledge, cooperation, and consent of the person whose level of functioning are being classified… Wherever possible, the person whose level of functioning is being classified (or the person's advocate) should have the opportunity to participate, and in particular to challenge or affirm the appropriateness of the category being used and the assessment assigned,* (WHO, 2001, p.244)

The above quotation from the WHO (2001), touches on the importance of involving patients as well as SOs in setting relevant goals for rehabilitation as well as in life thereafter. The ICF is a useful tool for identifying potential outcomes for rehabilitation and tailoring them to suit individuals, whilst including the patient and significant others in the process (Threats, 2006). Implementing the ICF and using it effectively allows for the setting and development of personally relevant goals for patients (Threats, 2006). In a clinical setting, successful implementation of the ICF allows for an interactive process of goal setting and intervention that considers a variety of functional levels and personal factors. (Threats, 2006). Such an approach aims to ensure greater functional outcomes for patients (Threats, 2006). The current study allows for the personal accounts of patients who have been discharged from rehabilitation. Looking at a small South African sample, the current research gains insight into the rehabilitation outcomes for survivors of TBI. The ICF framework is useful in discussing these outcomes and establishing perceptions of activity and participation in a community setting. The current research looks at specific accounts and reveals how each patient or SOs goals and or ideas of 'community integration' are different and personal.

1.2.3 Community Integration

Community integration, referred to in some of the literature as 'community reintegration' refers to the process of transition back into previous roles and relationships. It refers to the re-establishment of an individuals' former identity as well as the process of resuming former roles (Wood, Connelly & Maly, 2010). Successful community integration is the ultimate goal of rehabilitation for brain injury (McCabe et al, 2007). Transition back into the community following rehabilitation requires significant and varied supports (McCabe et al, 2007). Understanding these supports and the needs of survivors of TBI and their SOs is vital for ensuring quality of life after TBI (McCabe et al, 2007).

McColl and colleagues (1998) developed a theoretical framework for conceptualising community integration. Their study compared a model that was derived from a review of previous research, with feedback of a sample of people with TBI who were engaged in detailed interviews with the researchers. Ideas and words used by the participants were consolidated into restructuring the definition of community integration (see figure 4).

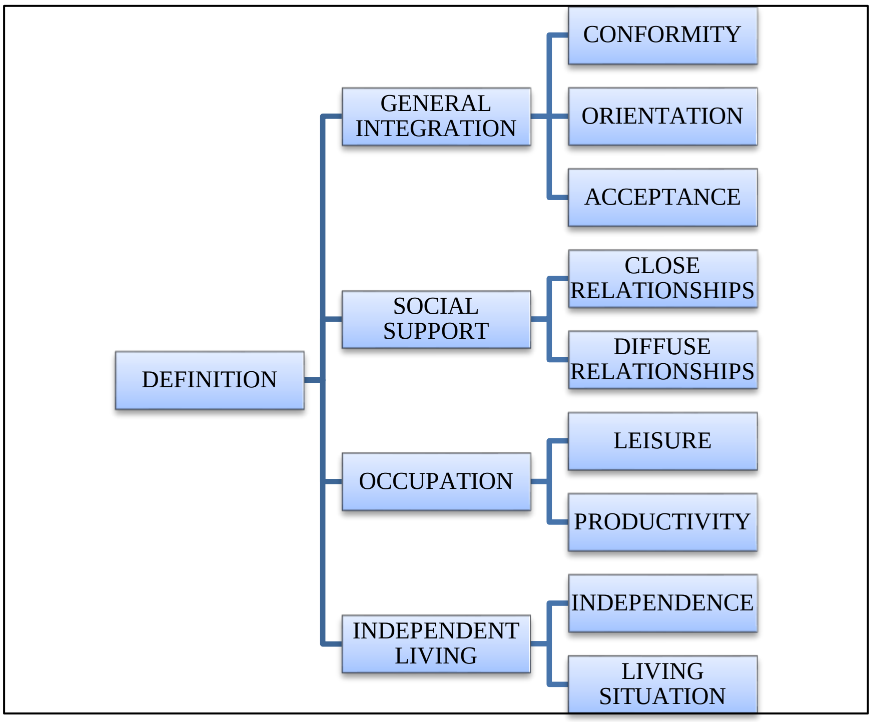


Figure 4. Consumer model of community integration as cited in McColl et al., (1998)

According to this model, community integration includes:

a) General integration: being able to fit in with and be accepted by other people, as well as knowing your way around the environment;

b) Social support: having relationships with family, friends and acquaintances;

c) Occupation: having roles to fulfill each day as well as the ability to meaningfully participate in various activities and

d) Independent living: being independent in daily tasks as well as having independence in decision/choice making

(McColl et al., 1998 as cited in Winkler, Unsworth, & Sloan, 2006).

These aspects of community integration can be easily incorporated or understood using the ICF framework.

Wood and colleagues (2010) concur that for an individual who has experienced a neurological injury, integrating back into the community refers to their ability to return to work as well as maintain occupational, family, social and recreational roles. It is clear that there is a need for the person to be viewed holistically and all aspects of the person's life to be given due consideration.

McCabe et al. (2007) view community integration as a multidimensional concept pertaining to various aspects of human functioning. These include yet are not limited to aspects such as independence, social relationships, leisure and productivity (McCabe et al, 2007). McCabe et al. (2007) look at elements such as independence and social integration, caregiver burden, satisfaction with quality of life, productivity, and return to driving when examining 'community reintegration'. Many survivors of TBI reportedly have restricted social and home lives post-injury (McCabe et al, 2007). McCabe et al. (2007) purport that effective community integration strategies are needed in order to ensure 'recovery'.

In SA, while these parameters may be acknowledged by independent clinicians, or by teams at specific rehabilitation institutions, the complex needs of individuals who have suffered a TBI remain undocumented at a national level. Hence, there is no avenue for standardisation of information or comparison from one institution to the next. By being more cognizant of a community integration model and what it entails, incorporating the principles of the ICF, and obtaining direct input from the patient and family, one may be able to provide more patient-centered guidelines that need to be addressed during rehabilitation and thereafter, that will adequately prepare the patient to encounter these different contexts (as described in figure 1). This study delves into some of these issues.

1.2.4.Factors affecting transition, conceptualisation of 'self' and Quality Of Life (QOL) issues

Dijkers, 2004, explores a number of QOL factors that can easily be related to earlier mentioned constructs that influence community integration. In his study, he reviews literature detailing the approaches and findings of research on QOL factors. He highlights areas requiring further research in the field and draws attention to particular links that can be made between an individual's QOL and levels of rehabilitation and reintegration. He makes reference to the way that research in these areas has been conducted, finding that the majority of literature reviewed makes reference to the negative impact of TBI on QOL and outcomes (Dijkers, 2004).

Despite the fact that TBI is the leading cause of morbidity and disability in the United States demanding high financial costs to society, limited research has been conducted into the costs of alternative treatment and rehabilitation programmes (Dijkers, 2004). The majority of studies reviewed by Dijkers, highlight a lack of services available to individuals who have chronic needs following TBI. Dijkers (2004) mentions that the under utilisation of services may be due to a lack thereof, a lack of awareness of existing services, or lack of access to such services in the way of poor medical insurance coverage.

The current research drew on such literature that establishes links between QOL factors, community integration, and how they influence and benefit one another as well as interrogate limited long-term resources available to TBI survivors (Dijkers, 2004).

Figure 5 summarises QOL achievement factors impacted by TBI, in research reviewed by Dijkers, 2004. QOL factors detailed here include; Satisfying work; Learning; Material comforts; Close relationship with a significant other, Having or rearing children; Relationships with relatives; Having close friends- socializing; Helping and encouraging others; Active and passive recreation; Understanding oneself; Expressing oneself and Health and personal safety.

Satisfying Work (Occupation)

- Studies have found that people with moderate or severe TBI are unable to regain employment despite vocational rehabilitation services
- Employment is a major determinant of QOL in that it often affects standard of living, financial security and opportunities to meet people
- In western societies employment and marriage are seen as major markers in being a 'responsible adult'

Learning

- Individuals who were studying at the time of the TBI often experience an interruption in their studying process and may not return at all, only return to a less intense programme or require special assistance

Material Comforts

- Due to loss of employment, individuals who experience TBI may encounter financial difficulties and therefore a reduction in material comforts

Close Relationship With a Significant Other, Having or Rearing Children

- TBI may result in the termination of relationships that offer support and intimacy
- Individuals who experience TBI may decide against having children due to financial restraints as a result of the injury

Relationships With Relatives

- Often following TBI, interactions with relatives become more frequent, replacing relationships with work friends, romantic partners and even spouses
- Studies have shown that relationships with relatives may become stressful and conflictual

Having Close Friends: Socialising

- Forming new relationships may become challenging often due to restricted interactions with others such as those which may be formed in a work or school environment
- Studies have shown that factors such as poor self control, reduced interpersonal and communication skills , may impact this further

Helping and Encouraging Others

- TBI subjects may have limited opportunity to help or guide other people
- If subjects are involved in volunteer work, one study conducted showed that this was not reported to compensate for the loss of the worker role

Active and Passive Recreation

- Studies have shown that people with moderate or severe TBI have lower levels and lower 'quality' of leisure activity
- The shrinking of a social network often results in decline of recreational activities

Participation in Public Affairs

- No results from other studies indicated that TBI results in decreased participation in political social and religious freedom

Understanding and Expressing Oneself

- Studies have shown that individuals with TBI may have decreased awareness of cognitive emotional and behavioural deficits
- In light of impoverished leisure, unemployment or employment in jobs that do not allow for creative expression, one can assume that individuals with TBI have less opportunity to express themselves

Health and Personal Safety

- Numerous studies have indicated that TBI survivors report many more symptoms and health problems than comparison groups

Figure 5. Summary of literature reviewed on QOL factors for persons impacted by TBI (Dijkers, 2004)

Douglas (2013) engaged in a qualitative study in order to examine the self-concept of adults, who sustained very severe TBI, several years post injury. The intention of the study was to uncover concepts that may be useful in guiding rehabilitation practices in facilitating TBI survivors with self-conceptualisation (Douglas, 2013). This study too, draws on QOL factors and makes clearer links between such factors and community integration. The sample of the particular study was made up of sixteen men and four women who sustained severe-very severe TBI as a result of motor vehicle accidents (Douglas, 2013). Interestingly average QOL ratings in the particular study were high, however this could be linked to their levels of participation. Of the studied sample, none of the participants were employed however one person was actively engaged in a disability sheltered workshop for 20 hours per week, three participants were engaged in weekly volunteer work, two of the participants were enrolled in vocational rehabilitation programmes and thirteen of the participants participated in group community based leisure activities, the remaining participants engaged mainly in family activities or individual community activities with a disability support worker (Douglas 2013). It is clear from this study that high levels of participation resulted in greater QOL ratings and as previously discussed, higher QOL ratings are linked to successful community integration (Dijkers, 2004).

Understanding QOL factors that positively impact on self-concept is highly valuable for the current study, which delves into first-hand accounts of TBI survivors and their SOs. These first-hand accounts allow for a subjective understanding of what impacts on the ability to feel ‘community integrated’ whether it be the ability to participate in previous activities, new activities or various QOL factors as listed above (Dijkers, 2004). Using the ICF framework may assist with establishing the necessary links between what activities or levels of participation will link to feelings of successful community integration for each individual (Threats, 2006). The current study gains insight into the feelings of each individual and what activities or acts of participation are most meaningful and ‘integrating’ for them.

1.2.5 Assessing Community Integration

In assessing community integration it is important to factor in how individuals who have experienced TBI perceive themselves, how their SOs or caregivers perceive them as well as how objective measures depicting their functioning and participation, compare against that of a population unaffected by TBI. A number of scales have been developed to measure outcomes after TBI (Johnston, Shawaryn, Malec, Kreutzer & Hammond, 2006). Some of these include the Glasgow Outcome Scale (GOS) and the Ranchos Los Amigos Scale of Cognitive Function, the Disability Rating Scale (DRS), the Comprehensive Assessment Inventory for Rehabilitation, The Community Integration Questionnaire (CIQ) as well as general scales of disability and participation developed for a variety of populations not limited to survivors of TBI such as the Functional Independence Measure (FIM), to name a few (Johnston et al., 2006). By employing formal measures one can gain an understanding of TBI outcomes, providing objective insights into the presenting impairments of a survivor of TBI; their disability, neuro-behavioural dysfunction and community participation (Johnston et al., 2006).

The results of formal assessment measures are most useful as a means of comparison against subjective feedback from participants in a study. One of the objectives of this study was to compare and contrast subjective experience of survivors of TBI and their SOs or caregivers against objective feedback found using formal assessment measures namely the FIM and the CIQ-R. Employment of formal measures was geared at providing traditional TBI outcomes or scores, however utilising semi-structured interviews as well, helped to provide deeper and more personal insight into the factors that influence community integration. Aligned with similar studies internationally, using semi-structured interviews with survivors of TBI and their SOs, as well as the FIM (describing a functional level of independence) and CIQ-R (providing an objective description of the level of community integration) results, this study was geared at gaining insight into 'perceived' levels as well as 'objective' levels of community integration. The FIM and CIQ-R formal assessment measures are described in greater detail in the methodology.

1.2.6 Medical Schemes in South Africa

Healthcare provision and financing in South Africa occur within two essentially different systems, the public healthcare system and the private healthcare system (Harrison, Bhana & Ntuli, 2007). In a discussion paper by McIntyre (2010) it was found that approximately 15% of the South African population are contracted within medical schemes. Membership of such medical schemes is weightily concentrated within the higher earning socio-economic groups (McIntyre, 2010). An extensive literature review did not reveal a current published standard of South African medical aid standards or guidelines related to post rehabilitative services. However a review of three (not cited to protect anonymity) popular medical aid schemes revealed, limited services for both inpatient and out-patient rehabilitation services and no provisions following discharge for support or community based services aimed at ensuring outcomes such as community integration.

The United Kingdom (UK) National Health Service (NHS) provides assessment to patients for what is known as NHS continuing healthcare. This is a service designed to fund ongoing care and support needed by individuals who have returned home or back to the community following illness or injury and continue to require ongoing support and care (NHS Continuing Healthcare, 2015). This care is offered to ensure that home based needs, community access needs and social needs are met, and that the required support for patients with disability is offered and funded (NHS Continuing Healthcare, 2015). In a similar vein, the South Africa Government has initiated legislative policies toward improving equitable access to healthcare for all persons in the way of National Health Insurance (NHI) (Harrison et al., 2007). In examining potentials of such a system, it should be noted that the move toward an NHI approach aims to promote issues such as prevention of ill health, limiting mortality and reducing the effects of disability (Harrison et al., 2007). This system aims to promote mandatory rehabilitation and vocational training programmes to ensure the reintegration of diseased and injured workers into the workplace (Harrison et al., 2007). This research highlights the importance of such initiatives, given the current shortage of funding available for issues of reintegration into the workplace or community integration programmes following acquired disability.

In a review of some of the larger private medical aid schemes in South Africa, inpatient and outpatient therapy services are covered according to the type of plan held by the member with the higher the plan the greater the benefits i.e. less limits regarding outpatient therapy services. This has adverse implications for those on lower plans or standard hospital plans that would limit if not prevent access to outpatient rehabilitation services. Rule and colleagues (2006) assert that in the public health care sector in South Africa, a move in the direction of community-based rehabilitation is becoming a growing area of promise for persons with disability. The current study exposes limited provisions that are made available to persons with disability in this regard, from a private healthcare perspective.

Despite the fact that TBI is the leading cause of morbidity and disability in the United States demanding high financial costs to society, limited research has been conducted into the costs of alternative treatment and rehabilitation programmes (Dijkers, 2004). The majority of studies reviewed by Dijkers, highlight a lack of services available to individuals who have chronic needs following TBI. Dijkers (2004) mentions that the under-utilisation of services may be due to a lack thereof, a lack of awareness of existing services or lack of access to such services in the way of poor medical insurance coverage.

This research drew on such literature that interrogates reasons for limited long-term resources available to TBI survivors (Dijkers, 2004). This research highlights these elements within a South African context.

1.2.7 Transition from Hospital to Home after TBI

The transition from hospital into the community environment is a challenging step for individuals with TBI. Research from developed countries confirms that transition back into the home environment is particularly challenging whilst individuals with TBI attempt to reconnect with their previous routines and occupational roles (Turner, Fleming, Ownsworth & Cornwell, 2007a). Reasons contributing to this difficulty include reduced independence in activities of daily living (ADLs), greater reliance on family members or caregivers, limited access to or knowledge of post-discharge services, difficulty re-engaging in premorbid social and occupational roles as well as emotional distress (Gage, Cook & Fryday-Field, 1997; Mistiaen, Francke & Poot, 2007; Nalder et al., 2012).

While numerous studies have been conducted in developed countries examining the life experiences of individuals with TBI throughout the acute, post-acute and long-term community integration phases of rehabilitation (Turner et al., 2007b), similar studies have not been conducted in developing contexts. There is a paucity of such research in developing countries and particularly in South Africa, a country that was found by Watt and Penn in the year 2000, to have a prevalence and increasing incidence of TBI. Such research is vital in guiding rehabilitation practice in South Africa, as well as patients and families in effective planning for post-hospital life (Nalder et al., 2012). It is necessary to see if the barriers and facilitators that exist for patients in developed countries, are similar to that for people from developing contexts.

Studies conducted in developed countries indicate that rehabilitation and recovery success definitions are largely correlated with higher levels of community integration (Nalder et al., 2012). To determine whether similar trends exist for persons with TBI in SA, empirical evidence is needed. The need for post-hospital support systems, support groups for family members and caregivers and the need for patients to engage in meaningful activities post-discharge were highlighted as important factors (Turner et al., 2007b). This research aimed to establish whether a small sample of TBI survivors and their SOs or caregivers experience similar feelings with regard to their discharge and life after private rehabilitation in South Africa.

1.2.8 Caregivers

Sander et al., (2002) found that family functioning had a significant impact on patients' progress following TBI with regard to various factors such as overall independence level and employability. Similarly, patients with supportive families are said to reap greater benefits from rehabilitation than those who do not (Sander et al., 2002). Research by Sander et al., (2002), concluded that survivors of TBI who have supportive families tend to achieve greater outcomes. This is important when considering the current study that explores the perspectives of SOs and their experiences in supporting their loved ones with TBI. In a study by Arango-Lasprilla et al., (2010) it was identified that due to the significant burden placed on caregivers resulting from a TBI, the caregivers have important needs. Kreutzer, Serio & Bergquist (1994) identified the following important caregiver needs; provision of information pertaining to the problem; having someone who can answer relevant questions truthfully and having professional guidance and respect from health professionals. Similarly Leith, Phillips and Sample (2004) found the following five major family needs in TBI; support services to help in the facilitation of placement and treatment; access to information and education on TBI; support and encouragement from health professionals; positive environment and lastly emotional support and enhanced community integration. Many studies also describe how families and caregivers often report unmet needs, the current study attempts to gain insight into caregiver perspectives in dealing with TBI.

1.2.9 Methodological Framework: Phenomenology

The philosophical basis of phenomenology forms part of all qualitative research and allows for a rich description needed to understand human complexities (Lichtman, 2006; Denzin & Lincoln, 2008; Padilla-Diaz, 2015). There are various types of phenomenology; descriptive phenomenology which refers to the study and description of an individuals' personal experience; eidetic phenomenology which analyses consciousness of individual experiences and egological phenomenology which examines the analysis of the 'self' (Padilla-Diaz, 2015). Using phenomenology to analyse data, as in the case of the current research, allows for the analysis of the descriptions, contexts as well as hidden meanings and discourses, which are so vital when attempting to understand subjective human experiences (Padilla-Diaz, 2015). Interpretative phenomenological analysis (IPA) is useful for critical analysis. It tends to allow for the interpretation of beliefs and the acceptance of participants' stories allowing for a greater depth of analysis (Pringle, Drummond, McLafferty & Hendry, 2011). IPA accounts are advantageous for the individual, making direct reference to specific accounts through direct quotes and metaphors obtained from the transcriptions (Pringle et al., 2011). Theme titles are often derived in IPA using the direct words of the participants, which goes beyond a 'standard thematic analysis' (Brocki & Wearden as cited in Pringle et al., 2011). IPA recognizes the important role of the researcher in placing the collected data in context during the analysis process (Pringle et al., 2011). The current study makes use of IPA as it allows for a degree of creativity and adaptability whilst still ensuring that the richness of the data and personal accounts of the participants is expressed (Pringle et al., 2011).

Problem Statement

TBI is a leading cause of disability worldwide and given its increasing prevalence in developing countries such as South Africa, it is essential to consider the long-term effects and management of the condition. The concept of disability is expanding and as such it is essential that current practice and management thereof expand simultaneously to view disability, support structures and long-term rehabilitative services. This will allow for a more holistic view in order to cater for the needs of people with disability living in our society. In understanding the perceptions of individuals living with TBI and their significant others, it is vital to be aware of facilitators and barriers to their community integration.

It is important to highlight factors such as financial resources and availability thereof for post-rehabilitative services in order to fully grasp the current situation. Equally important is to identify accuracy of outcome level prediction by rehabilitation specialists following the use of formal assessment measures and outcome level descriptor scales, the transition home from hospital, difficulties experienced through increased caregiver burdens, or reduced access in and around the community and what factors are influencing these.

In South Africa, there is limited, if any research that monitors or describes what happens to TBI survivors discharged from private rehabilitation facilities upon termination from outpatient therapy. Survivors of TBI may be assessed using functional independence measures or standardised community integration measures however their personal accounts are not commonly taken into consideration. Little is known about how they manage once they have returned home and are attempting to rediscover and integrate into life roles, or whether they deteriorate as a result of poor integration. This study sought to answer the following research question, ‘What are the perceptions/experiences of people with TBI and their SOs about community integration post-rehabilitation?

2. Methodology

Overview

This section contains information on the methodology of the study. It describes the research design, the participants, the type of sampling used and the data collection tools and procedures. Details on data analysis and trustworthiness is also included as part of the methodology.

2.1 Main aim

To explore existing perceptions of patients with TBI (regardless of the initial severity level) as well as the feelings of their significant others (SO) regarding community integration post-rehabilitation.

2.2 Objectives

2.2.1 To describe the experience of community integration by the person with TBI and their SO/caregiver,

2.2.2 To document barriers and facilitators to community integration and participation within the:

2.2.2.1 Familial
2.2.2.2 Social and
2.2.2.3 Work context

as reported by the person with TBI and his/her SO/caregiver,

2.2.3 To determine if the qualitative analysis of formal assessment measures (FIM and CIQ-R) match perceptions of persons with TBI with regard to Community Integration (Landrum et al., 1995).

2.3 Design

This research took the form of a qualitative exploratory design with a retrospective record review component (Brink, van der Walt & van Rensburg, 2012). This design enables one to understand and make sense of a variety of phenomena affecting certain manifestations, rather than attempting to explain or predict them (Babbie & Mouton 2001). Specific to this study, the researcher aimed to understand and describe how and to what extent persons affected by traumatic brain injury (regardless of the initial severity level) are able to integrate into the community i.e. their family environment, work environment and social environments, once his/her period of rehabilitation is terminated as well as what factors are believed to have impacted this. This information was gained from the perspective of the person with TBI him/herself as well as his/her caregiver and was validated against outcome measures from the FIM and CIQ-R scale, which provided descriptions of the participants' functional independence levels as well as descriptions of their degree of participation in everyday life roles.

Qualitative research takes into consideration meaning, experience and understanding in an attempt to conceptualise and draw conclusions on human experience from the viewpoints of the participants within their context (Brink et al., 2012). It allows for the accumulation and analysis of rich and detailed data. Furthermore, it allows for a thorough analysis of the various perceptions offered by participants (Brink et al., 2012). For these reasons a qualitative design was appropriate for this study.

The study was deemed exploratory in that despite studies that have been done in developing countries, paucity of literature exists in the current exploration of patient integration into the community at a minimum of 1-year post discharge from rehabilitation institutions especially in South Africa. The literature review process involved a series of literature searches based on a combination of key words, including: *Traumatic Brain Injury, community integration, reintegration, participation, developing countries, community resources* and *South Africa.* National and international articles were sourced through the University of Witwatersrand Library intranet. Articles were also sourced by means of the following search engines: EBSCO HOST, JSTOR, Science Direct, PubMed Central, Google, Google Scholar, and Springerlink. The searches were originally performed in the English language only for the period 2010-2015 in order to access the most recent research material. However, the search period was extended to include the1990s and early 2000s, which allowed for access to more foundational literature.

A retrospective record review was conducted to access information from the medical files of the participants in the study. Hospital records can be rich and valuable data sources and are advantageous in that they serve as an economical source of information (Brink et al., 2012). Review of such records allow for the examination of trends over time and also eliminate the need for the researcher to obtain cooperation from participants at every step of the study (Brink et al., 2012). Hospital record reviews should be utilised with caution however, as they may contain biases of the particular institution and record keeping may be inconsistent with omitted or distorted facts (Brink et al., 2012). Nonetheless, the review of hospital records for the purposes of this study was essential in obtaining biographical information as well as retrospective views on patient functioning at the time of discharge, hence the limitations were considered.

2.4 Site

This study was conducted with patients who had been discharged from therapy at a private rehabilitation hospital, in Johannesburg. This hospital is a specialised healthcare facility forming part of a large hospital group in South Africa. It offers comprehensive physical rehabilitation services focusing on persons with the following conditions:

- Spinal Cord Injuries (SCI) ,
- Traumatic Brain Injuries ,
- Cerebrovascular Accidents (Stroke) ,
- Polytrauma, Amputations,
- Joint Replacements,
- Neurological Conditions,
- Burns,
- Near drowning cases,
- General Weakness after lengthy hospitalisation

The hospital houses 102 adult beds and 8 paediatric beds making it one of Gauteng’s largest rehabilitation hospitals. A specialized rehabilitation team, including physiotherapists; speech therapists, occupational therapists, doctors, rehabilitation nurses, dietician, social workers, psychologists, neuro-psychologists and orthotists comprise the fabric of the hospital and work in close co-operation with each other, the patient and his/her family, to ensure that the rehabilitation process offers optimal recovery in an attempt to attain a high level of independence in all spheres of life.

Apart from inpatient rehabilitation services, the hospital offers outpatient therapy the purpose of which being to prevent complications; minimize impairments to achieve maximum functionality; establish activity so that the individuals maximise their re-integration and participation in life; improve the client and family's quality of life as well as to ease the burden of care. Vocational rehabilitation consists of an interdisciplinary team, which focuses on clients with physical disabilities, and is also offered as part of the hospitals therapy services.

Vocational services include:

- Early intervention for return to work
- A sensitisation programme for employers and colleagues
- A work visit
- A work hardening programme
- Recommendations regarding reasonable workplace accommodations
- Work ability assessment and report (interdisciplinary)
- Functional Capacity Evaluation (occupational therapist)
- Ergonomic assessment and recommendations for office, industrial and home
- Identification of resources to accommodate clients that require re-skilling

2.5 Sampling

Purposive sampling was used to recruit all participants into the study (described below). The participants with TBI were purposively selected from the population of traumatic brain injured patients in Gauteng who have undergone, both inpatient and outpatient rehabilitation therapy at the chosen site. The significant others (SOs) or caregivers were selected based on their daily interactions and caregiver responsibilities toward the participants with TBI. Research assistants (RA) were utilised in the study however did not form part of the participants for the study.

Purposive sampling is based on researcher judgment (Brink et al., 2012). It is concerned with identifying a sample of participants who are characteristic or representative of the study phenomena and/or are experienced regarding the particular topic of concern (Brink et al., 2012). Although this type of sampling allows the researcher to identify participants with particular knowledge of the studied phenomena, there remains a high potential for sampling bias as the data does not adequately represent the population and thus is not generalisable (Brink et al., 2012).

The depth and richness of information obtained however, added new insight into the lives of persons with TBI in terms of their integration back into home, family, work, and social contexts, after rehabilitation. This insight can thus inform the rehabilitation and discharge from rehabilitation process amongst health professionals.

2.6 Sample

2.6.1 Sample description

The sample for study included individuals who attended inpatient and outpatient rehabilitation at a Johannesburg Rehabilitation Hospital, as well as their significant other (SO) or caregiver.

Inclusion criteria for the participants with traumatic brain injury diagnosis were:

- Male or female between the ages of 18-65 years old
- Have suffered a traumatic brain injury, regardless of the severity level
- Married or single
- Living alone or with other people
- Employed or unemployed
- Have undergone at least a 6-8 week period of inpatient acute rehabilitation followed by an average of 2-3 months of outpatient rehabilitation
- Live in Gauteng
- Have a basic understanding of English
- Have abstract communication skills in English, even if scaffolding is required by a communication partner
- Have been discharged from rehabilitation for a minimum period of 1 year but not more than 2 years

Exclusion criteria for persons with TBI

- Individuals who have been readmitted to acute facilities due to further neurological/other complications since discharge.
- Persons with co-existing neurological conditions or impairments

Inclusion criteria for significant others

- Must spend at least 4 working hours with the person with TBI per day in order to have adequate knowledge regarding overall functioning in both residential and community environments.
- Have a basic understanding of English
- Should be able to express him/herself in English at a discourse level

Exclusion criteria for significant others

- Should not be under 18 years of age

2.6.2 Sample size

In purposive sampling, the researcher is unable to specify how many participants will be required in order to obtain data saturation (Brink et al., 2012). Data saturation refers to the point at which no new data is emerging during the data collection procedure (Brink et al., 2012). During the data collection process, the researcher remained mindful of data saturation, and the number of participants was modified accordingly.

2.6.3 Describing the Sample

(Refer to Table 1: Participant with TBI Demographic Information and Table 2: Significant Other Demographic Information)

Although the sample size was relatively small, it is reflective of a varied socioeconomic group as well as varied ethnic groups. Socioeconomic status was determined based on how participants described themselves with regard to access to food, amenities and regular income. A total of 10 patients and 10 significant others comprised the sample. In describing the sample of participants with TBI further; 60% of the patient cohort were over the age of 30 whereas the remaining 40% were between the ages of 20-30 years old. All of which are appropriate work going and productive ages (van Velzen, van Bennekom, Edelaar, Sluiter & Frings-Dresen, 2009). Despite this, 70% of the patient cohort was unemployed following the TBI with the other 30% working in different roles with reduced demands than before.

Males comprised of 90% of the sample and the race classifications were as follows; 60% white, 30% black, and 10% coloured.

With regard to the significant others that participated in the study 70% of the participants were the primary caregivers to the survivors of TBI. The other 30% were made up of close friends and co-workers. Of the sample of significant others 70% were female, made up of mothers and wives and 30% were male, this 30% was made up of fathers and friends of the survivors of TBI. 80% of the SO sample were individuals over the age of 30 and 70% of the SOs were employed. The race classifications were as follows; 50% white, 30% black and 20% coloured.

Table 1: Participant with TBI Demographic Information

Table 1 below describes the demographics of the participants with TBI featured in this study. A detailed description and discussion of the sample can be found in the results and discussion section. As mentioned above, socioeconomic status was determined based on how participants described themselves with regard to access to food, amenities and regular income.

Participant	**Sex**	**Ethnicity**	**Marital Status**	**Current Employment**	**Living Status**	**Age**	**Time since Injury**	**Time since discharge from Outpatient therapy**	**Socioeconomic Status**
1	Male	White	Divorced	Unemployed	Alone	>30	>2 Years	Between 1-2 years	Middle
2	Male	White	Single	Employed	Alone	>30	>2 Years	Between 1-2 years	Middle
3	Male	Coloured	Divorced	Employed	With Parent	>30	>2 Years	Between 1-2 years	Low
4	Male	Black	Married	Employed	With spouse	>30	>2 Years	Between 1-2 years	Low
5	Female	White	Single	Unemployed	With Parent	20-30	>2 Years	Still Attending	High
6	Male	Black	Single	Unemployed	With Parent	20-30	<2 Years	Less than 1 year	Low
7	Male	Black	Separated	Unemployed	Alone	>30	>2 Years	Between 1-2 years	Low
8	Male	White	Married	Unemployed	With Spouse	>30	>2 Years	Still Attending	High
9	Male	White	Married	Unemployed	With Spouse	20-30	>2 Years	Still Attending	High
10	Male	White	Single	Unemployed	With Parent	20-30	>2 Years	Between 1-2 years	Middle

Table 2: Significant Other Demographic Information

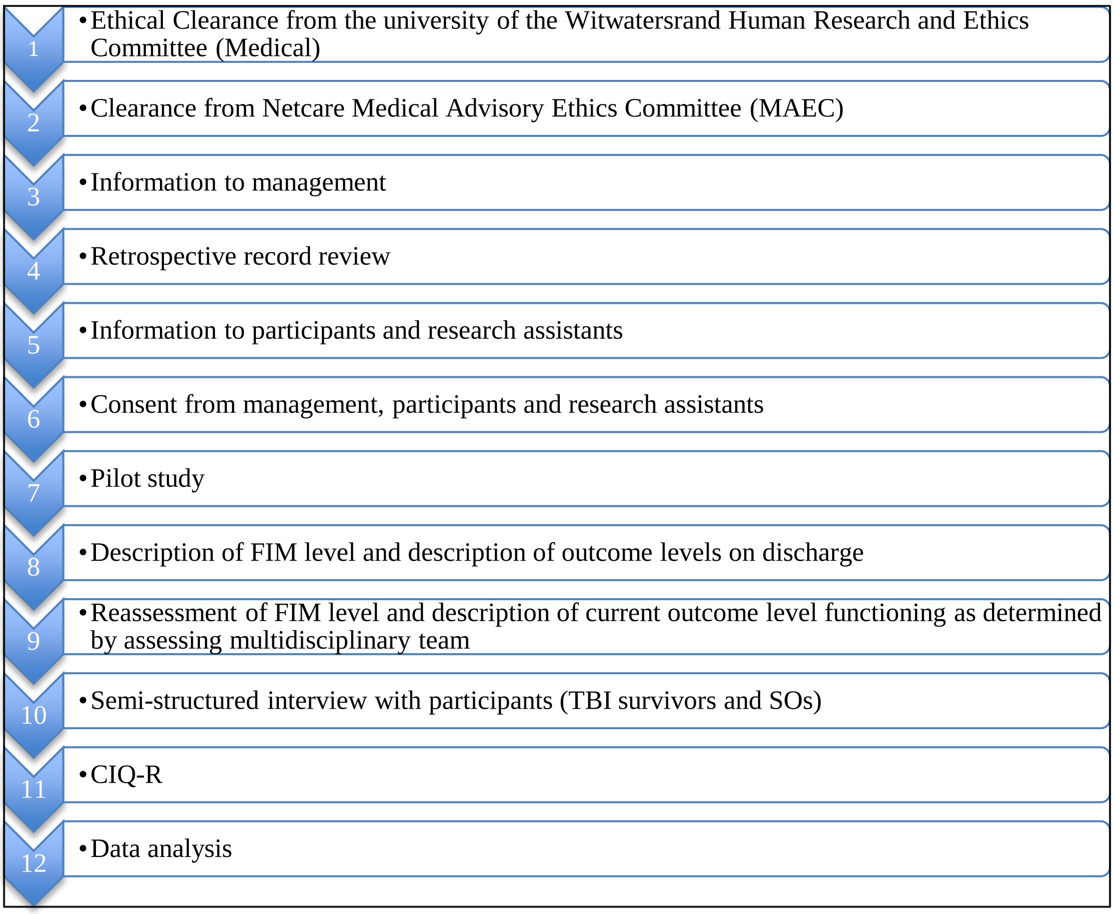
Table 2 below describes the demographics of the Significant Other (SO) featured in this study. A detailed description and discussion of the sample can be found in the results and discussion section.

Significant Other	Sex	Ethnicity	Current Employment	Primary support/caregiver	Age	Relationship to survivor of TBI
1	Female	White	Employed	Yes	>30	Partner
2	Male	Coloured	Employed	No	>30	Friend
3	Female	Coloured	Unemployed	Yes	>30	Mother
4	Female	Black	Unemployed	Yes	>30	Wife
5	Female	White	Employed	Yes	>30	Mother
6	Female	Black	Unemployed	Yes	>30	Mother
7	Male	Black	Employed	No	20-30	Friend
8	Female	White	Employed	Yes	20-30	Wife
9	Male	White	Employed	No	>30	Father
10	Female	White	Employed	Yes	>30	Mother

2.7 Data collection tools

A combination of tools were utilised to obtain the required data, namely semi-structured interviews, retrospective record review from which a Functional Independence Measure (FIM) level as well as a general outcome level on discharge was derived (Outcome levels according to Landrum, Schmidt and McClean, 1995) which gave insight into the participants level of functioning at the time of discharge from rehabilitation. In addition the Community Integration Questionnaire-Revised (CIQ-R) was administered at the time of the interview and a functional independence level (FIM level) was re-established. Formal measures were utilised for data triangulation purposes. This will be discussed in further detail below. The FIM was utilised as a measure in this study as it is used to track functional independence at the rehabilitation center of the studied sample. A detailed description of each tool is provided when discussing the research procedure.

2.8 Research procedure



1. Ethical Clearance from the university of the Witwatersrand Human Research and Ethics Committee (Medical)
2. Clearance from Netcare Medical Advisory Ethics Committee (MAEC)
3. Information to management
4. Retrospective record review
5. Information to participants and research assistants
6. Consent from management, participants and research assistants
7. Pilot study
8. Description of FIM level and description of outcome levels on discharge
9. Reassessment of FIM level and description of current outcome level functioning as determined by assessing multidisciplinary team
10. Semi-structured interview with participants (TBI survivors and SOs)
11. CIQ-R
12. Data analysis

Figure 6: The research process

2.8.1 Ethical clearance

Prior to commencing with the study, ethical clearance from the University of the Witwatersrand Human Research and Ethics Committee (Medical) was obtained (Refer to appendix A).

In addition ethical clearance was obtained from the Hospital Medical Advisory Ethics Committee (MAEC) (Refer to Appendix B). This committee is made up of a body of specialists specifically chosen for their expertise as advisors, negotiators and members of various regulatory, decision making and ethical bodies in the medical field (Netcare, 2015a). Obtaining ethical clearance from this committee was vital for this study, in that its members are geared toward advising how to maintain the highest standards of quality care possible in relation to international research and best clinical practice. In addition they ensure that clinical outcomes of quality care are measured and corrected and clinical risks are investigated and minimised. Lastly, this committee advises on ethical issues related to patient care, patient information, patient confidentiality and record keeping (Netcare, 2015a). Within these guidelines best ethical practice was ensured and maintained for the study

2.8.2 Information to management

An information sheet was given to the hospital management detailing the nature of the research and what it hoped to achieve. In addition the information sheet detailed the ethical considerations taken into account by the researcher. It provided information regarding the potential benefits as well as the potential risks of conducting such research (Brink et al., 2012). Refer to Appendix C.

2.8.3 Retrospective record review

The retrospective record review was done initially to identify persons with TBI who met the inclusion and exclusion criteria. This allowed the researcher access to biographical information of the participants, information that was useful in the data analysis process, as well as to establish a formal representation of the functional independence level of the participants using the Functional Independence Measure (FIM) and Outcome Levels (outcome levels according to Landrum et al., 1995) determined by the clinicians for the patient upon discharge. For the purposes of this study, the researcher analysed the FIM qualitatively to obtain richer and more holistic descriptions of each participant. The descriptions elicited from the particular scores for each patient were used qualitatively to link the results from the various data collection tools for that patient.

The minimum record inclusion criteria for files being reviewed were as follows:

- Files should have had notes documenting functioning in all domains mentioned in the FIM (See Table 2) that enabled the ST/PT/OT to obtain a FIM level and exit outcome level for each patient.
- Only files of patients 1-2 years post discharge from outpatient therapy services were reviewed.

2.8.4 Information to participants and research assistants

The primary goal of a participant information sheet is to provide the participants with clear and comprehensive information about his/her participation in the study and to invite them to participate (Brink et al., 2012). It was important to consider the cognitive abilities and literacy levels of the participants especially taking into consideration their status as TBI survivors. As such information sheets were made available in a written form with use of an aided pictorial representation to ensure understanding by all participants. Refer to Appendix F.

The researcher's contact details, the data gathering procedure as well as patient's rights and role were included in this information sheet. Patients were assured that they were free to withdraw from the study at any point with no consequence, privacy assurance that pertained to personal information and data obtained during the study was also explained. Once participants agreed to participate, they were asked to sign a consent form.

2.8.5 Consent from management, participants and research assistants

Refer to appendices C-K.

2.8.6 Pilot Study

A pilot study was conducted. This was completed to identify unforeseen problems with the main study and allowed the researcher to improve the study as necessary (Brink et al., 2012). One participant was used for the pilot study. The participant was selected in accordance with the inclusion criteria. The aims of the pilot study were as follows:

- To confirm the period of time required to complete the record review, obtain a FIM level and description of outcome level at the point of discharge.
- To confirm the length of time required to administer the CIQ-R
- To determine the length of time necessary for the interview with the participant and their significant other.
- To identify challenges and facilitators around communicating with the participant with TBI in order to implement necessary accommodations during the main study.
- To monitor participant fatigability and make necessary modifications
- To confirm the content validity of the interview, use of terminology and overall validity of the interview to obtain the required info.
- To confirm the feasibility and flow of the research process including the administration of the different data collection procedures and record review.

The findings of the pilot study were interpreted with caution given that the presentation of the effects of TBI is unique from one person to the next (Roozenbeek et al., 2013). General conclusions from analysis of the findings were:

- The semi-structured interview required more time than expected. Some questions were noted as being vague and ambiguous. These were modified to be more specific.
- Open-ended questions while providing the opportunity to acquire info with depth and richness, were not found to be appropriate as they facilitated tangential speech. Thus the use of open-ended questions was limited to only essential areas of exploration. Adaptations were thus made to the semi-structured questionnaire for participants with TBI. (Refer to Appendix L)

2.8.7 Functional Independence Measure (FIM) level description

As noted, a retrospective record review was conducted for each participant. Information from the medical and rehabilitation notes were used to describe a FIM level for each participant as well as to derive what outcome level (outcome levels according to Landrum et al., 1995) was determined for each patient on discharge. The FIM was created as a ‘universal language’ used for describing function and outcomes and to address weaknesses of the Barthal Index (Cournan, 2011). It is aimed at assisting in a universal understanding between healthcare professionals regarding a patient's functional abilities and goals especially when transitioning through different levels of care (Cournan, 2011). It was initially created with an 18-item, 7-level ordinal scale, 1 indicating dependence and 7 indicating independence (see table 3 below). The FIM is a measure that was designed to be sensitive to change in functional ability over the course of a rehabilitation programme (Hall, Bushnik, Lakisic-Kazazic, Wright & Cantagallo, 2001). Scores for each item are added to give an overall score. It is widely accepted that higher FIM scores are associated with greater patient functional abilities (Hall et al., 2001). The rehabilitation center of the current study makes use of FIM levels as well as outcome level determination in order to establish readiness for and placement following discharge. The outcome levels according to Landrum et al., (1995) and how they are used will be discussed further below.

Whilst the FIM is known to be sensitive to improvements in physical and cognitive status, it holds reduced ability to track changes in vocational and psychosocial functioning (Hall et al., 1996; Sanders et al., 1999). It was designed as a burden of care measure as well as a tool to determine the type and amount of assistance an individual with a disability may require (Cournan, 2011).

Table 3: Functional Independence Measure Items (as cited in Cournan, 2011).

Motor Items	**Cognitive Items**
Eating	Comprehension
Grooming	Expression
Bathing	Problem solving
Dressing uppers	Social interaction
Dressing lowers	Memory
Bladder	
Bowel	
Toileting	
Transfer bed/chair/wheelchair	
Toilet transfers	
Tub/shower	
Walk/wheelchair	

Stairs	

Procedure for record review and establishment of FIM level:

The current protocol of the rehabilitation practice research site is as follows;

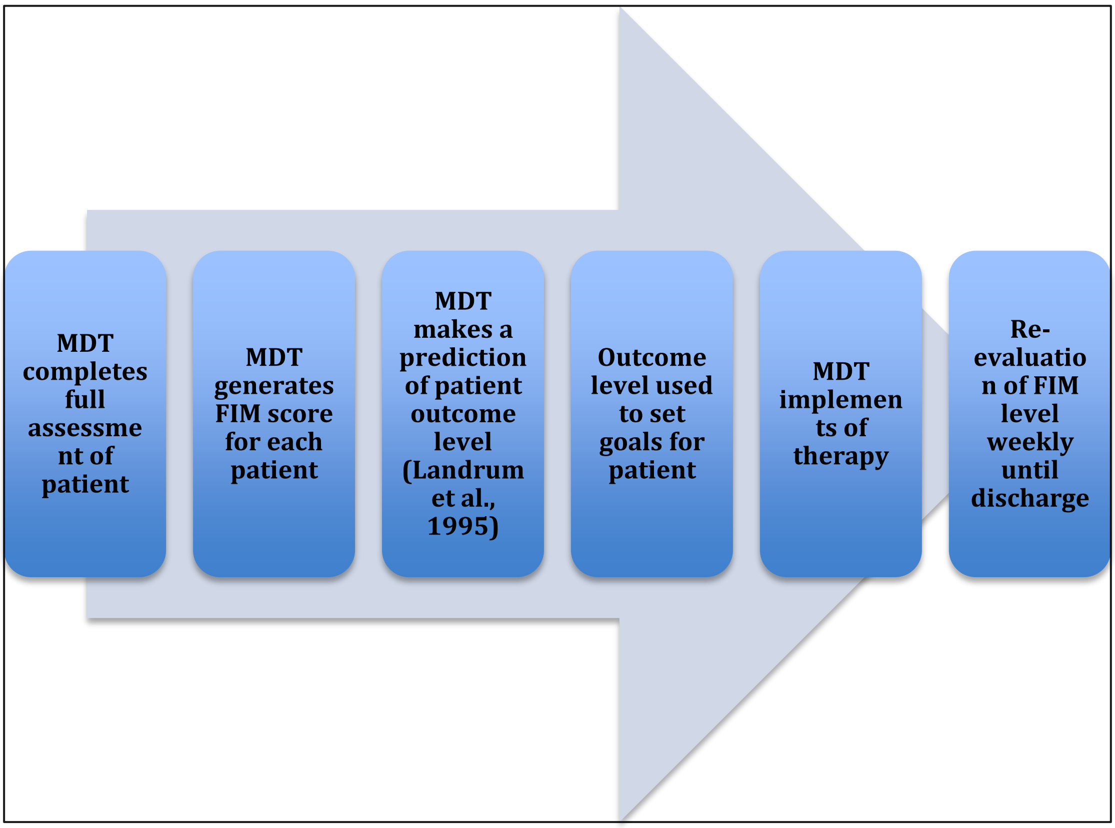


Figure 7: Description of current protocol of rehabilitation practice research site

The outcome levels discussed above, are those outlined by Landrum, Schmidt & McClean (1995). Landrum and colleagues (1995) established six outcome levels as well as a broad description of what areas should be targeted or achieved at each level (Hassan et al., 2012). Broadly, the outcome levels are as follows; Level 0: Physiologic Instability; Level I: Physiologic Stability; Level II: Physiological Maintenance; Level III: Residential Integration; Level IV: Community Integration and Level V: Productive Activity (Landrum et al., 1995). See table 4 for better understanding of the outcome levels described.

Table 4: Outcome levels according to Landrum, Schmidt and McClean, 1995 (as cited in Hassan et al., 2012)

Level	**Description**	**Tasks that must be achieved to achieve the level**
Level 0: Physiologic instability	Acute diagnostic and medical issues are not addressed and managed.	Directly following a health incident such as stroke.
Level I: Physiologic stability	All major acute diagnostic and medical issues are appropriately addressed and managed.	• Diagnosis made • Treatment plans decided on and implemented e.g. Hypertension controlled through medication.
Level II: Physiologic maintenance	Achievement of basic rehabilitation outcomes necessary to preserve long-term physiological health.	• Client and family educated and trained • Rehabilitation and long-term management plans in place • Strategies to prevent secondary complications in place: - Bladder and bowel - Diet, swallowing and aspiration - Prevention of chest infections - Pressure sore prevention - Prevention of contractures - Emotional support - Pain management Limited physical and cognitive outcomes such as mobility and communication can be achieved but are not the focus of this level.
Level III: Residential integration	Achievement of status where the person can function reasonably and safely in a residential setting.	• Self-care tasks performed • Mobile in and around dwelling • Effective general communication system • Safe in home Activities such as self-care can be performed by another person, but must be directed by the client
Level IV: Community integration	Achievement of an appropriate level of function within the person's community, i.e. participate in social activities such as shopping, church and sport according to individual needs.	• Manage personal affairs & finances • Socially competent • Community mobility • Complex home-making abilities • Self-directed health management
Level V: Productive	Work at a competitive level within physical, functional, and/or	• Environment, disabilities & job requirements play a role

activity	cognitive capabilities and appropriate to life stage & interests. This can be vocational, avocational or educational.	• Work & skills assessment • Vocational training • Employer education • Reasonable accommodations
* Note that at all levels, tasks can be performed by another i.e. a care giver, but all must be client-directed		

As mentioned briefly above, it is the protocol of the rehabilitation center of the current study, to allocate an outcome level for each patient. This outcome level is determined based on the patients' functional independence level as well as his or her ability to participate in premorbid activities. This protocol is based largely on the ICF taking into consideration what the patient was doing before and considering what he/she is able to do now. It should be noted however that treating therapists, who are responsible for assessing function and asking about participation within a therapy session solely determine these levels. Neither patients nor their caregivers are consulted as to what outcome level they feel they are at, which is largely what the current study delves into.

During the retrospective record review of each participant, a description of the FIM level and discharge outcome level, were drawn from the file and used to inform the study. Following this, participants who were at least 1-year post discharge from outpatient rehabilitation were reassessed on both of the above-mentioned scales i.e. given a FIM level and assigned an outcome level (according to Landrum et al., 1995) based on their performance. The FIM was utilised as a descriptive tool. It aimed to highlight the functional independence level of the participants upon discharge as well as their current level. This was necessary in order to establish a clear picture of how the participant is functioning currently. Taking the FIM factors into consideration, in a qualitative manner allowed the researcher to establish a more holistic understanding of factors that may have negatively or positively impacted on community integration. A physiotherapist, speech therapist and occupational therapist (researcher and research assistants) from the rehabilitation practice conducted the assessments. These measures were applied in order to establish whether a difference exists in the FIM level and outcome level 1-2 years post discharge from a rehabilitation setting. Any changes discovered, were probed during the interview process, and themes of factors that either facilitate or impede community integration were identified.

2.8.8 Semi-structured interviews:

Semi-structured interviews are a formal means of ensuring that all participants hear the same questions in the same manner (Brink et al., 2012). They involve the use of an interview schedule and are aimed at reducing bias held by the researcher (Brink et al., 2012). The interview schedule is the instrument containing details of the open-ended or fixed questions (See Appendix L) (Brink et al., 2012). Open-ended questions were used to explore and describe aspects of the participants' experiences and perceptions regarding their current community integration. As noted from the pilot study, the use of open-ended questions was monitored as necessary. The interview took the form of a discussion wherein the participants were able to provide information pertaining to their experience, feelings of integration and participation in previous life roles following their discharge from outpatient rehabilitation services. The use of interviews permitted the researcher to explore the structures and faculties that permit greater feelings of integration in patients who have experienced a traumatic brain injury as well as identify conditions perceived to hinder integration and active participation.

Similarly, semi-structured interviews were used with SOs or caregivers (See Appendix L) where they were encouraged to share information regarding elements that they believe have contributed to higher levels of integration for the chosen participants as well as elements that appear to hinder this. The interviews were conducted at prearranged times which were suitable for the participants and their SOs or caregivers as well as the researcher. The interviews with the caregiver and the person with TBI occurred one after the other. All participants were reimbursed for transport to and from the research site if required.

2.8.9 Community Integration Questionnaire- Revised (CIQ-R) (See appendix M)

Whilst the combination of the FIM as well as the outcome levels defined by Landrum and colleagues (1995) offer information specific to 'functioning' (as cited in Hassan et al., 2012), further detail with regard to how 'integrated' the participants are was obtained through the use of the CIQ-R. The CIQ-R (Willer, Ottenbacher, & Coad, 1994) was administered with each participant in order to establish more detailed information regarding home integration, social integration, productivity and electronic social networking (Willer et al., 1994). It provides simplistic answers to questions pertaining to ones ability to fulfill everyday roles in the home, work and school environments as well as in relationships (Seale et al., 2002). In scoring the CIQ-R, the potential score range falls between 0 and 35, with a higher score being more closely linked with better community integration (Willer et al., 1994). The administration of this questionnaire also served as a more structured tool that aimed to either establish trustworthiness in the information obtained via the interviews and the FIM or reveal a contrast in the feedback obtained. The process of approaching a research study and obtaining data from a number of different angles and asking different questions is termed triangulation. Triangulation allowed for a higher level of reliability of the study (Brink et al., 2012). Various avenues were used to obtain an indication of the level of community integration of the participants of this study. Figure 8 below depicts these various avenues.

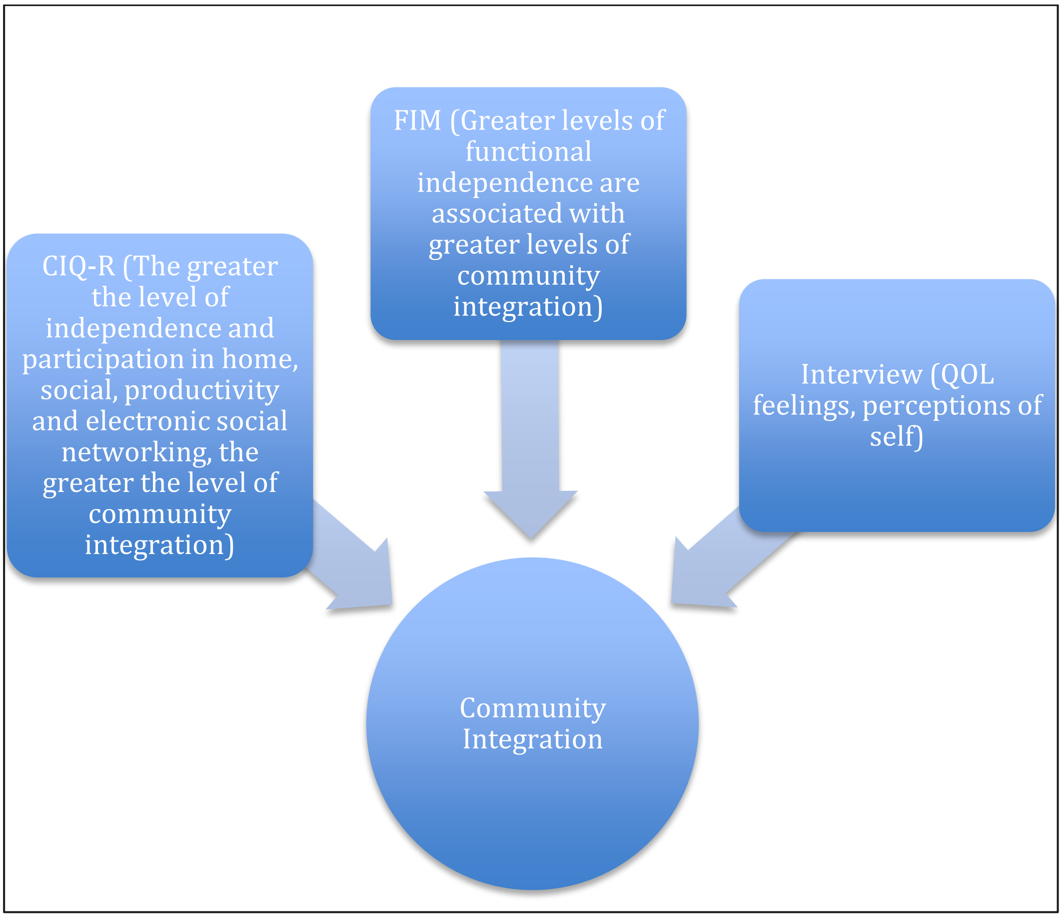


Figure 8. Various data collection avenues

2.9 Data Analysis

2.9.1 Descriptive Statistics

During the retrospective record review, demographic information obtained from the patient files was analysed in order to establish the age, race, employment status and marital status of each participant as well as to describe FIM and outcome levels at the time of discharge from outpatient rehabilitation services. The information obtained, described the sample by identifying participants who had shown change since discharge, as well as highlighted prominent areas in which change was/was not noted. These findings were further discussed whilst considering themes uncovered in the detailed analysis of the participant interviews.

The researcher administered the CIQ-R on each participant. Commonalities or differences in current feelings and beliefs between participants that pertained to the specific areas were highlighted using this tool. These were analysed and contrasted with themes emerging from the interviews.

2.9.2 Interpretative Phenomonological Analysis for Interview Analysis

The interviews conducted were utilised to inform themes pertaining to change and perceived factors that have contributed to this change or lack thereof post-discharge. The interviews were analysed in the following ways; once the data collection procedure had come to completion, the recorded interviews were transcribed and assembled to form raw data for analysis. The data was analysed using Interpretative Phenomenological Analysis (IPA) (Smith, Jarman & Osborn, 1999 as cited in Biggerstaff & Thompson, 2008). IPA can be understood best using the following descriptions; it is ideographic which entails a detailed exploration of a single interview/case until a particular degree of closure is obtained before moving on to examine further interviews/cases; it is inductive in that it allows researchers to unearth unanticipated themes during analysis; and lastly it is interrogative in that it attempts to probe or illuminate existing research (Smith, 2004).

The following discussion details the stages involved in detailed IPA:

- Initially, meticulous transcription of the interview occurred (Biggerstaff & Thompson, 2008). Herein the aim of the researcher was to become immersed in the data (Biggerstaff & Thompson, 2008).
- Once the transcripts of the interview were complete, IPA recommended re-listening to the interview and/or rereading of the text to identify preliminary themes (Bigerstaff & Thompson, 2008).
- At this stage, IPA proposed the inclusion of researcher notes that may have been accumulated during the interview or transcription process; such notes may reflect personal thoughts; observations and reflections that may have provided insight during comprehensive analysis of the data (Biggerstaff & Thompson, 2008). This stage was vital for the current research as it allowed for the amalgamation of transcriptions as well as researcher notes, wherein the participants' tone of voice, mood and body language gave richer meaning to what was captured by their words alone. In certain interviews the participants made sarcastic remarks, which couldn't be understood by examining the transcripts alone.
- Thereafter IPA proposed the grouping of found themes and the establishment of connections between these themes (Biggerstaff & Thompson, 2008). Themes or groups of themes were then tabulated. The tabulated themes from the first interview were then held as a reference point for the analysis of further interviews at which point similar emerging themes from the subsequent interviews could be recognised and additional themes could be added (Biggerstaff & Thompson, 2008). The process of IPA is cyclical. It allowed the researcher to proceed through iterative stages and thus build a detailed foundation of knowledge surrounding the data (Biggerstaff & Thompson, 2008).

IPA allowed for a more interventionist approach to interviewing (Smith, 2004). This was highly applicable when considering this research, as the researcher encountered patients with communication difficulties. As such, IPA proposed that the researcher, in this case a speech therapist, be allowed to draw on personal professional experience in order to assist participants with 'communication' difficulties through the interview process (Smith, 2004).

2.10 Ethical Considerations

It is essential, especially when working with human participants, to ensure that research is carried out in an ethical manner (Brink et al., 2012). In an attempt to uncover information which may highlight truths that aim to inform current practice in South Africa, the researcher conducted the research rigorously but never at the expense of the participants . The researcher endeavored to carry out the research competently and methodologically; resources were managed respectfully; contributions and guidance from others were acknowledged fairly, results were reported accurately and the consequences of the research for the society were carefully considered. This aligned with recommendations of Brink et al., (2012).

It was important for participants to be made aware of concepts such as autonomy, beneficence and confidentiality (Brink et al., 2012). For these reasons an information sheet was issued to each participant containing the details of the study as well as an invitation to participate (See Appendix E and G). It was made clear to each participant that to participate in the study did not come with any advantages, disadvantages or direct benefits.

With regard to the research findings, a short summary will be made available to the participants on request. In order to ensure confidentiality, patient and participant’s names did not appear on any forms. They were assigned codes. In addition, only the researcher and the supervisor had access to the raw data. The data will be stored at the Department of Speech-language Pathology and Audiology and the University of the Witwatersrand for a period of 5 years and destroyed thereafter should there be no publications.

2.11 Trustworthiness

Reliability and validity are vital in any study (Brink et al., 2012). Qualitative research places emphasis on ‘rigour’, which refers to the openness, relevance and methodological congruence of the study (Brink et al., 2012). In qualitative research it is important for the data collection and data analysis process to be thorough as well as the researcher’s self-understanding to be solid in order to ensure ‘trustworthiness’ of the findings (Brink et al., 2012). In order to ensure credibility in this study, the researcher aimed to ensure triangulation through the use of a variety of data collection techniques as mentioned above i.e. the description of FIM levels, the semi structured interviews and the CIQ-R. The findings from these various data collection methods were discussed and contrasted with one another to formulate a richer and more accurate pool of data.

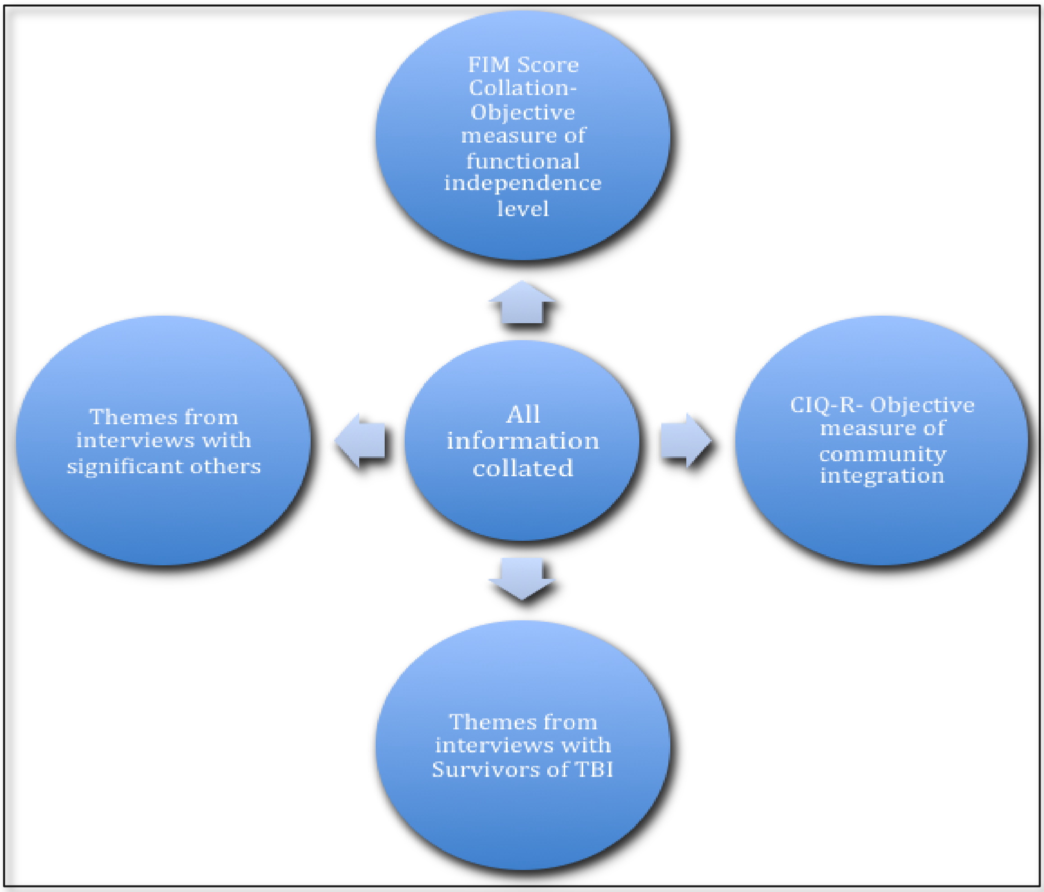


Figure 9: Description of data collection and collation

Peer Review: During the research process, the data also underwent a peer review. Peer review refers to the review of the data by another individual who is also familiar with the research (Creswell & Miller, 2000). During the peer review process another qualified SLP examined the data whilst constantly acting as a sounding board, challenging the researcher's assumptions and providing opinions and feedback regarding interpretation and analysis of the data (Creswell & Miller, 2000).

Inter-rater reliability: Inter-rater reliability refers to the process of comparing data obtained from various observers/raters from the same participant using the same instrument (Brink et al., 2012). In order to ensure inter-rater reliability of interviews, the researcher initially analysed the data and drew themes from it. Following this, another independent qualified SLP examined the data and analysed it to get themes. Thereafter, these results were compared to establish whether both raters drew similar themes. These similarities and differences can be observed in table 5 below. The higher the percentage of similar themes drawn, the greater the interrater reliability. After applying and interrater reliability formula, it was established that there was agreement in over ninety percent of the themes found.

Due to the variability which can arise amongst different human raters, it is essential to include procedures which measure agreement and reliability, as mentioned above, the extent of this agreement is referred to as interrater reliability (McHugh, 2012). A score of over ninety percent indicates that neither of the data collectors had an excessive number of disagreement in the named themes and as such the identification of the named themes is reliable (McHugh, 2012). The findings from the current study confirmed a good interrater reliability.

Pilot Study: As previously discussed, a pilot study was also conducted in order to enhance reliability of the research procedure. As mentioned, this was completed in order to identify unforeseen problems that may arise during the course of the project and also allowed the researcher to improve the study as necessary. This ensured that the study managed to investigate what it originally set out to.

Table 5: Inter-rater reliability across themes

Category	Emergent Theme Rater 1	Emergent Theme Rater 2	Agreement
Framing change positively or negatively	Less ego-driven	Less ego	Yes
	Considerate	Empathetic	Yes
	Lucky	Second Chance	Yes
	Uninhibited	More confident	Yes
	Religious	Religious	Yes
	Cautious	Self Doubt	No
Limited long-term resources and support. Helpful tips	External strategies	External aids	Yes
	Existing support groups not valuable	Need to relate with others	Yes
	Starting again	Steps and guidance for starting again	Yes
	Lack of information, poor medical support	Need for ongoing outpatient intervention	No
	Insight and acceptance	Insight	Yes
	Poor internal motivation	Poor internal motivation	Yes
The need for engagement in meaningful activities. Reconnecting with previous roles	Seeking meaning	Need for meaning and purpose in life	Yes
	Distracted	Restless	Yes
	Stuck on old self	Difficulty adapting to change	Yes
	Anger and changed sense of	Personality and identity	Yes

	self	difference	
	Support from parents/family	External support	Yes
	secondary complications from injury	Residual medical difficulties	Yes
Facilitators and barriers to community integration	Discomfort facing others in similar circumstances	Wounded healer	No
	Support by others in similar circumstances	Guidance for families lead by TBI survivors	Yes
	Awareness of impact on others	Insight and awareness	Yes
	Self motivation, routine and purpose	Routine and sense of purpose	Yes
	Poor community awareness	Poor insight from extended family and community	Yes
	Financial support	Financial/Family support	Yes
	Insight into impact of the family	Insight of family impact	Yes
	Reduced emotional and psychological support at the hospital	Reduced medical information and support	No
The transition into the home environment- a typical day	Need for a manager	Need for leadership role of family members	Yes
	Need for routine	Routine and structure	Yes
Caregiver burdens/changes	Taking on a parental role	Overprotective and stifling	Yes
	Guidance for families	Education for families lead by TBI survivors	Yes
	Family frustrations	Difficulty dealing with behavioural changes	Yes

	Family expectations of TBI survivor	Family providing support	Yes
Barriers in the workplace	Old self versus new self. Acceptance	Reduced motivation for new role	Yes
	Poor accommodations by employer	Poor support by employer	Yes
	Inability to manage behaviour in the work environment	Self awareness but inability to control	Yes
	Accommodations by employer	Supportive employers	Yes

3. Results and Discussion

This study investigated a small sample of TBI survivors who had access to private health care. The main aim was to examine perceptions of community integration for survivors of TBI as well as their SOs. It aimed to highlight perceptions of the participants regarding areas of strength and weakness in current practice, particularly post-rehabilitation support. It examined whether inpatient and outpatient rehabilitation services in private practice in South Africa leave individuals with TBI feeling adequately equipped to subjectively and objectively achieve levels of integration into community. The results of this study are outlined and discussed here.

3.1 Describing the Sample

(Refer to Table 1 Participant Demographic Information)

3.1.1 The sample of patients and caregivers

The patient and caregiver cohort obtained for the study confirmed that unlike in international studies where 45% of patients post-TBI and in some cases even 70% of patients who have suffered TBIs, return to work following their injuries (Shames, Treger, Ring & Giaquinto, 2007; van Velsen et al,. 2009). A reason contributing to less people returning to work post-TBI was found to be 'availability' of 'post acute' rehabilitation services in SA (Shames et al., 2007). Data from the interviews in this study, confirmed that availability of post-acute services were scarce. While international services would include post-acute brain injury rehabilitation (PABIR) (treatment that occurs in a variety of settings including that within different structures and programmes); residential neurobehavioural programmes (focuses on treating behavioural differences and disturbances post TBI); community reintegration programmes (accommodates patients with severe cognitive or behavioural difficulties) and various comprehensive day treatment programmes (CDTP) (to improve self-awareness, social skills and coping mechanisms for improved independence in daily living, vocational and social reintegration), such services are not available in SA (Shames et al., 2007). The availability of such resources in developed contexts highlights shortcomings of South Africa's public and private healthcare services. These shortcomings can be seen to contribute to the statistics seen in this study showing poor return to work outcomes.

Although the initial inclusion criteria, called for participants no longer attending therapies, this proved difficult as it appears participants with high resources (30% of the sample) tend to continue with outpatient therapy for as long as possible because of the ongoing support they feel it provides. As previously mentioned, socioeconomic status was determined based on how participants described themselves with regard to access to food, amenities and regular income. To explain this further, even though the injury may be over 2 years old, families apply for funding from medical aids on a yearly basis to be able to continue with some outpatient therapies.

CIQ-R and FIM Results

Table 6: Summary of CIQ-R and FIM Results

	CIQ-R results	**FIM results on Discharge (D/C)**	**FIM results Now**	**Relationship Positive/Negative**
P1	24	121	121	Positive
P2	26	126	126	Positive
P3	17	114	114	Positive
P4	12	120	116	Negative
P5	20	103	115	Positive
P6	18	118	118	Positive
P7	26	122	122	Positive
P8	15	73	93	Positive
P9	15	58	64	Positive
P10	22	124	124	Positive

Table 6 above details the scores that the participants achieved after the administration of the CIQ-R as well as once a FIM level had been determined. As previously mentioned the rehabilitation center of the current study utilises FIM scores and performance in rehabilitation to plot patients on a particular outcome level (those set out by Landrum et al., 1995). This is determined after examining whether or not the participant is able to fulfill premorbid activities and participate in previous life roles (based loosely on an ICF model). If the patient scores highly on the FIM and is able to perform some premorbid activities and life roles, they are deemed ‘community integrated’. Although the rehabilitation center of the current study does not typically use the CIQ-R as a measure of community integration, it is commonly used in research to gain an objective perspective (Seale et al., 2002). For the purpose of the current study, it was used to provide an additional score for discussion. Although the purpose of this study was not to compare CIQ-R and FIM score results, it is interesting to note how generally the participants who are more functionally independent (according to FIM score results) scored higher in the CIQ-R. These results, although correlating, are not directly comparable constructs and should not be viewed as such. In the studied rehabilitation center, often judgement on community integration levels are made based on such scores or achievements in therapy and therefore it is important to contrast these 'scores' against the feelings and perceptions of the participants and their significant others regarding community integration.

CIQ-R Results Explained

As mentioned previously, the CIQ-R is one of the most commonly used questionnaires designed to measure a person's integration into home, social and productive life following TBI (Seale et al., 2002). Table 6 shows that based on their higher scores, participants 1,2,5,7 and 10 were the most successful with regard to their integration into the community, which vary from between 20/35 to 26/35. In most cases the participants (1, 2, 7 and 10) with higher CIQ-R scores displayed higher FIM scores. Whilst conclusions cannot be drawn and comparisons cannot be made, for the purposes of this study the correlations in scores suggest that greater community integration is associated with higher functional independence levels. The FIM is a measure of functional independence, and whilst the topic of interest is community integration, a study by Fleming, Tooth, Hassell and Chan (1999), showed that functional independence measures have been successful in their ability to predict community integration 2-5 years after TBI.

It can be seen that none of the participants scored above 26 on the CIQ-R. This correlated with literature that individuals with brain injuries have lower CIQ-R scores across the domains of home, social and productive life when compared to non-TBI individuals (Sander et al., 1999). Participants living independently had higher community integration CIQ-R scores, than participants living in institutions or in communities with support (Sander et al., 1999). Findings from the CIQ-R in this study confirmed its potential as an indicator of outcome following TBI, correlating with other studies (Sanders et al., 1999).

FIM results explained

As described above, the FIM scores provided the researcher with clear indications of participant's functional ability during rehabilitation as well as following their discharge. FIM score results were calculated whilst reviewing participants' records to give an indication of scores during rehabilitation (just before discharge) as well as their current scores (1 year or more post discharge).

Results seen in Table 4 indicated that in most cases FIM results remained constant or improved following discharge from rehabilitation. This was positive and suggested that there was either continued recovery in functional independence on return home, or that patient's functional independence remained intact. Scores for participant 4 however decreased when assessed 1.5 years post discharge from rehab. This could be due to decreased responsibility or independence required from the TBI survivor on return home. Family members often take on significant responsibilities with regard to their loved ones with TBI (Lefebvre, Cloutier & Levert, 2008).

3.2 Themes Emerging from Interviews

With regard to the themes emerging from the interviews, seven key categories emerged from the data. The key categories are as follows; change, coping strategies based on experience, participation and redefinition of role, barriers and facilitators to community integration, home integration, repositioning of the caregiver and work place integration. Each of these categories and the associated themes will be discussed in the next section.

Table 7: Summary of Categories and Themes Emerging from Participant and Significant Other (SO) Interviews

Categories Arising from Interviews	**Themes that Emerged from Participant and Significant Other (SO) Interviews**
1. Change	Disinhibition
	Less Ego-Driven
	More sensitivity/ more cautious
	Turn to faith/religion Grateful for a

	second chance
2. Coping strategies based on experience	Feelings of starting again.
	Need for external strategies and support to use these
	Feelings that the wrong type of support is available
3. Participation and redefinition of role	Feelings of self-doubt when engaging in activities
	Lack of purpose. Poor internal motivation
	Loss of identity, difficulty accepting new self
	Residual medical difficulties impact on reconnecting with previous roles
4. Barriers and facilitators to community integration	Poor insight and awareness displayed by others.
	Lack of a structured environment
	Limited support available after rehabilitation
	Financial support
5. Home integration	**Need for routine**
	Need for self and external motivation
	Need for sense of purpose- wounded healer
6. Repositioning of the caregiver	**Take on a parental role becoming overprotective and stifling**
	Have expectations to motivate TBI survivor
	Frustrations in dealing with behavioral changes
7. Workplace integration	**Reduced identification with a new role**
	Poor accommodation of work

	environment
	Difficulty controlling behavior suitable for the work environment
	Poor support. Micro management

* The themes above that have been bolded, are themes that emerged across 5 or more interviews and as such will be discussed in more detail.

3.3.1 Change

A common element that arose in discussions with the survivors of TBI as well as their SOs within this study was the significant changes that occurred in the personalities of the survivors following their traumatic incidences. These changes varied, and were viewed both positively and negatively by both sets of participants. What is important to note is that although the changes may have differed, such changes were reported across every interview. The dominant changes mentioned, included disinhibition; altered egos; increased sensitivity as well as greater reliance or emphasis placed on religion and faith. The emergence of such a category (namely 'change'), is noteworthy because literature does indicate that often behavioural changes are what impact on successful community integration (Roozenbeek et al., 2013).

TBI can result in significant change to one's personal identity (Roozenbeek et al., 2013). It is common for TBI survivors to experience difficulty regulating their own behaviour, thus impacting on interpersonal relationships (Roozenbeek et al., 2013). Aggression, impulsivity and poor motivation are acknowledged difficulties impacting on the ability of survivors of TBI, to integrate successfully into community, social and vocational spaces (Roozenbeek et al., 2013).

> *P2: I'm more frustrated, I just snap easier*
>
> *P2: So now I'm probably less controlled*

In considering this impact, behavioural management; counselling and preparation for such changes could help to form a more integral part of the rehabilitation process in South Africa. SOs within this study reported feeling largely unprepared for the more difficult changes that occurred, often indicating that they would have preferred to know or have been better equipped to deal with the change. Such reports show a healthcare system in South Africa, which may be failing its members.

Positive outcomes or changes also transpired for some of the patients following the TBI. These were identified by the survivors of TBI themselves as well as their SOs:

> *P4*: *I was selfish. I have changed a lot, like before I used to do things on my own - I never used to ask my wife and family, but now I ask my wife about everything. I consult my family more than I used to.*

Findings from the study by McColl et al., (2000) also showed that individuals may feel closer to their families following a TBI. They tend to understand their particular role in the family more clearly than before as well as place importance on individual relationships within the family dynamic (McColl et al., 2000). This was identified among several of the patients in the current study and it was acknowledged to be a positive end-result.

Although correlations cannot be conclusively drawn between feelings of community integration and the scores of the CIQ-R and FIM, which predict levels of community integration and functional independence, links can be drawn between certain participants perceptions of community integration and their respective scores.
Analysis of data from the interview, suggested that post-injury, spirituality, comfort in religion and the act of positively linking the injury to something ‘meaningful’, positively impacted family and community integration. This could be seen with participants 1, 4 and 9. Spirituality and religion appeared to be sources of comfort for some of the participants. These same participants all scored higher on FIM NOW and CIQ-R results, displaying a match between objective measures and personal perceptions. While it may impact integration positively and could be encouraged, further research in this regard is necessary.

> *P4: Church I never used. After this accident I found the meaning of life – like before I would never go to church, but now I go to church as often as I can.*
>
> *P9: I am just grateful to have a second chance.*
> *P9SO: He says he's grateful to have a second chance to get his life in order. He often voices that and he's grateful to God for giving him a second chance.*

> *P1SO: The one thing – he often talks about the accident – and sometimes he gets emotional, but knowing him before and after the accident – I would say that the accident stripped him of his ego and I often say to him he's almost a better person now. He's a lot more in tune with his emotions, he's a lot more in tune with other people's emotions. He's an incredible people's person. He relates very differently to people now. Like really honestly.*

Spiritual growth, feelings of connectedness with God as well as closeness and depth of relationships following a traumatic injury, are highlighted in some of the literature on TBI and the changes that arise thereafter (McColl et al., 2000). This is true of some of the participants within this study. It was important during the acceptance process for participants within this study as well as those in the study performed by Lefebvre et al. (2008) to make sense of their head trauma and link it with 'something more' a deeper meaning and sense of purpose they were required to fulfill in life.

When considering whether spiritual connectedness and attribution of higher meaning to the TBI itself is linked with improved community integration, one should compare the FIM and CIQ-R results for the aforementioned participants. According to Table 4, P4 and P1 both scored higher on the FIM and CIQ-R respectively, linked to better integration within the community. It is not possible to link this improved integration to spirituality, however it is interesting to see that these participants who showed deeper insight and spiritual connectedness, were in fact, based on their scores, better integrated.

P9, whilst also having expressed feeling closer to God and his religion, on the other hand scored poorly on the CIQ-R and FIM. Again whilst conclusions cannot be drawn, his lack of community integration is better viewed as a function of his physical difficulties rather than lack of hope or spiritual connectedness.

Essentially, drawing links to spiritual notions and drawing a deeper meaning from the injury could have a positive influence on community integration and could be encouraged by family and health care providers for TBI survivors in their search for normalcy and understanding and in doing so, promoting better community integration

(Lefebvre et al., 2008). Such insights could be helpful in guiding rehabilitation aims. In each of the cases above, support from family and friends was paramount in drawing positive ‘meaning’ from the TBI or feeling more spiritually connected.

Introspection and ability to recognize change and behave accordingly are post-TBI challenges. This was confirmed in the current study. Participants 10 and 3 commented that they didn’t remember what they have forgotten about themselves or others i.e. had memory deficits and so were unable to identify that their behaviour was not always appropriate.

> *P5: Apparently people with brain injuries do change, but I haven't changed at all – which is good. I'm a good person and I'm still good now.*

The above comment by P5, who had changed significantly according to SO reports, is largely demonstrative of the lack of insight into their own behavior that many individuals with TBI display. Findings from the study by Lefebvre et al. (2008) looks closely at the lack of introspection many survivors of TBI experience as well as their constant need for the caregiving offered by relatives after they returned home. Such caregiving includes aspects such as exercises; cognitive and social stimulation as well as verbal reminders regarding rules of social behavior (Lefebvre et al., 2008). Similarly the current study showed the accepting, compromising and positive spin that SOs attached to otherwise negative behaviours from those for whom they were caring. Whilst the skill to do this may come naturally to some SOs, others may find it difficult. Such skills could be taught as part of a pre-discharge carer-training programme. Institutions may focus on physical carer-training but, as reported by SOs in the current study, the subtle behavioural aspects and skills to handle these are left untouched, to be figured out by SOs on their own.

> *P4SO: We have to be patient, because sometimes he gets angry about nothing, but we just have to accept that… If we don’t then he’s not going to accept himself.*

> *P5 SO talking about friends of P5: but they don't often come to visit. And when they do, it has been difficult for them. To deal with someone who's different. Not the same person they remembered. They’ve never taken her out, wanted to take her out.*

Later in the interview P5 identifies that there have been some changes.

> *P5: My confidence level has changed. Its really become better. I'm not afraid to just speak my mind, which is good. I've always been very shy and now I'm more confident. Before the accident I was very shy. Since the accident I'm more confident.*

While the above change would clinically be termed disinhibition and be an aspect that would require intervention, the family of P5 learned to frame their loved ones experience more positively. The family of P5 have helped her to frame her disinhibition as improved confidence and her sensitivity as intuition:

> *P5SO:… She's very brave. She's quite intuitive actually. She can pick up – she didn't before. That's been a change in her, but she can pick it up.*

When considering the CIQ-R and FIM results for P5, scores were found to be on the higher end of the spectrum, indicative of better community integration. This confirms the value of positive feedback from family and caregivers as described by Lefebvre et al. (2008) and the way it contributes to positive outcomes.

In some patients however, the TBI effects of self-doubt, insecurity and reduced levels of motivation were viewed by significant others less positively and they consequently were more vocally and openly negative in their labelling of these behaviours. The way that caregivers frame change in behaviour was also noted by Roozenbeek et al. (2013) as causing feelings of self–doubt and insecurity in survivors of TBI. These feelings ultimately affect confidence and social interactions.

> *P6SO: Yes – he needs more help because he's lazy, lazy, lazy, lazy. We have to push him in everything he does.*

When the CIQ-Rand FIM scores for P6 were interrogated (table 4), it revealed ‘poorer’ integration. It may therefore be deduced that the kind of support, reinforcement and general interactions between patients and caregivers is crucial to perceptions of integration by the patient with TBI. It is apparent that the support offered to survivors of TBI needs to be consistent. Whilst some SOs were proactive in trying to understand TBI and sought guidance as to the right ways to support their loved ones, others either lacked this insight, were unable to access this information or were not aware of the impact that their role could have on the outcome for the person with TBI. The essential role of the rehabilitation team in informing this decision by SOs could potentially impact both patient's perceptions and actual integration into different contexts.

3.3.2 Coping strategies based on experience

A number of themes emerged within this category, which highlighted the importance of support following a TBI as well as the significant need for conceptualisation of self. Douglas (2013) proposes that rehabilitation practice should be informed taking into consideration TBI survivors' concept of self as well as their experience of the recovery process, making attempts to improve and nurture these concepts in an attempt to improve community integration.

When referring to Table 4, P2 and P10 are seen to be the best integrated according to their FIM and CIQ-R scores. When evaluating their personal thoughts and perceptions of their perceived community integration against their scores some links can be drawn. P10 displays good insight into the process of his recovery and how he was forced to reestablish his self-concept. He achieved these insights by independently interrogating his feelings throughout his recovery. Such insights could provide support and guidance for other TBI survivors. These insights could be shared in the form of support groups prior to discharge or post-discharge from rehabilitation.

P10 reiterated feelings of starting again and the process he went through during his recovery.

> *P10: I went through these as a child, sleeping in the afternoon, not remembering, not focusing, not talking and I kind of see myself as growing up again and going through the stages of growing up. Obviously the problem would be you school and you'd have sports and things that you could then achieve. Then it came to the point of achievement. If I could achieve X, I would be moving to the next step and if I could get this right, and then with that I was able to identify what I needed to do and how I needed to do it, so I could put points down in my mind I needed to do this, and I needed to do that. I needed to get that done.*

> *P10: So it's going through the process of I'm broken – I'm not going to get this right. How do I stop myself from messing everything up. How do I make the damage not that bad and once you start to achieve little things, once you can identify what did happen – how I achieve little things, you get a basis of confidence and from that basis of confidence you can start on bigger things. It becomes a process and almost a habit and once you've got that in place then that a level to work through.*
>
> *P10: Every problem has an answer in this world and it's just to realise that you're going to fail, you're going to mess it up, but keep trying and those little achievements, you put them under your belt. Sure that's not an achievement I wasn't able to remember that I had to do this yesterday, but today I did and then tomorrow you would go "that's something I remember" and it becomes a bigger thing to you and it's something you've got to go through.*

Such insights and personal understanding are linked by Douglas (2013) to a process whereby the TBI survivor reconstructs his/her understanding of the 'self' and allows for the individual to accept the changes and move on with life. In the case of P10, understanding the process of the recovery and the difficulties and challenges faced may have contributed to a greater acceptance of self serving as a resource for more successful community integration.

Despite higher CIQ-R and FIM scores, P10 describes numerous areas where support structures were not in place to advise with coping strategies and tips that he could use in the home and community environments to improve his integration. Many of the participants and the SOs mentioned having to '*figure things out on their own*'. This may indicate that there are gaps in the dissemination of necessary and potentially helpful information, by healthcare professionals. Many professionals are involved in the overall rehabilitation of a particular patient, so everyone assumes that someone else has provided the information but in reality nobody does. Such information sharing should play a major role in preparing a patient and family for discharge from rehabilitation.

> *P10SO: I think if they could have extended the outpatient treatment that would have been hugely beneficial … There was a close bond formed between those therapists, especially when you're getting to the end of what they see as the treatment here. They start stepping it up and they operate on a professional level that's absolutely superb and then it cuts and then you've got un-experienced people like me, you've got people with a traumatic brain injury and we're all floundering around and it was unbelievably hard. The first eight months was unbelievable trauma. Where do you go – where do you turn to. (Name of post-acute support centre) were absolutely useless. There was some other brain association, they weren't much good either, and then (Name of medical aid) said "that's it, we're paying for nothing more – forget it". So financially that was difficult. I think being able to extend the outpatients, even if it could have been once a week or twice a week for the next six months, would have been helpful.*

> *P5SO: Think we need a project manager. I'll tell you what my biggest frustration has been, is that no one tells you the other things that can happen to people who have had traumatic brain injuries. No one mentioned hormones going wrong and that's been a huge thing for her because she's just ballooned. She still hasn't had her periods. No one sees that as an issue, and to me it's fundamental to her well being and her feelings. I had to approach people, I had to persuade the GP that this is something we need to look at, I had to find an endocrinologist that was prepared to deal with her. The same with her eyes – I had a huge fight with (Name of Optometrists), because I took her there, didn't get to see the person I had asked for, they never picked up the hemianopia and only picked it up a year later and I don't know what else is going on in her and no one is interested.*

Some of the participants in this study consequently developed their own external strategies and ways to use these. Data confirmed that survivors of TBI and SO's believed that this was the role of the professionals, and that it was necessary for professionals to adequately support and prepare survivors and caregivers for their new roles and responsibilities. This support, they believed, would facilitate improved community integration in the long term.

A major theme emerging from this research as well as in international studies is the need for adequate information sharing, education and support following a TBI (Jumisko, Lexell & Soderberg, 2007; Douglas, 2013). This research has highlighted the fact that our South African context is lacking in this regard, with reduced funding available for outpatient therapies, a lack of post discharge programmes and a general lack of education and information given to family members of TBI survivors upon discharge.

3.3.3 Participation and redefinition of role

A number of themes emerged within this category that highlight the challenges experienced by some participants with regard to engagement in meaningful activities as well as the importance of reconnecting with previous roles. This research uncovers how the subtle ‘feelings’ and ‘personal experiences’ of how survivors of TBI and their SOs perceive certain situations, may be difficult to measure using a general assessment tool and as such tend to go undetected and remain largely unreported.

Such subtle insights would help to guide a more personalized and specific rehabilitation programme or serve as a directive for post-discharge community integration programmes designed to target these particular areas of difficulty. Many reports by the participants of this study indicate that SA lacks post-rehabilitative support programmes and services. Participants of this study expressed a desire to want to participate or engage in meaningful activities however lack the space and support structures to enable them to do so. Some of the participants of this study mentioned existing post rehabilitation support centers in SA, however these programmes were deemed to cater for individuals who were more severely affected by their injuries. There was a broad feeling that services to assist with integration and participation for individuals that are functionally and physically at a level appropriate for community integration, were largely lacking.

Feelings of self-doubt when engaging in activities came up as a frequent determinant of active participation in previously enjoyed activities.

> *P10: Smaller things with wiring of the brain, memory – am I going to remember what my friends told me, am I going to remember what time we're meeting – things like that.*
> *A lot of it was my doubting myself – problems with my memory. Knowing that if things were done or things were said that I might not catch on or follow through and remembering specific things with specific people*

Moderate and severe TBI often result in loss of friendships or breakdown of certain relationships. This may be due to reduced interpersonal skills or poor self-control resulting from the brain injury (Dijkers, 2004). Such skills could be a useful component of a post-rehabilitation support programme designed to target the more subtle difficulties.

> *P7: I was playing soccer, and now even if sometime I may consider going to play, I worry maybe the ball hits me on the head and I fall down and all those kind of things, that's why I don't want to play soccer again.*

> *P10: "how was I going to do it" so I questioned and doubted myself a lot on everything. I'm an extremely skilled and an extremely experienced technician, but was I still good enough – I know the basics, they're in my head, but when a problem arose, was I able to put it down and make the client or customer happy. It was obviously a process that the memory and the reaction time of certain things needed to be worked out.*

Accounts by P10 and P7 demonstrate how self-doubt may result in reduced participation in certain activities as well as reduced formation or maintenance of certain relationships. These findings align with other studies, which indicate that TBI survivors often have shrinking social networks as well as declining recreational lives (Dijkers, 2004). Interestingly, both P10 and P7 scored higher on both the CIQ-R and FIM, indicating better community integration and good functional independence. This is not in line with their personal perceptions of their own community integration experience however. This demonstrates how scores alone do not always give a clear indication of personal feelings and factors that impact on participation and integration.

Another emergent theme within this category relates to the participants experiencing a lack of purpose as well as poor internal motivation.

> *P1SO: He talks about it a lot – he brings it up a lot. You know he's really got nothing to get up for in the mornings. I think it would be problematic on going if he doesn't find something to sink his teeth into or do.*
>
> *P1SO: ...and I really hope that he can find his sense of purpose, because he really does need that and I'm concerned that if it doesn't then the drinking may become a bit more – or he may do things that aren't good for himself, like not going to gym enough, and not cycle enough and I get a bit frustrated with that because there's no follow through with that.*
>
> *P1SO: ...it should definitely be something around helping people, because he's very good at doing that and I think he should go and motivate people and do talks and get involved in that kind of stuff, because he's really good at that. But it's something that he would want to do – so I plant the seeds and I try and suggest*
>
> *P10SO: The other thing that TBI's suffer with is they don't have a lack of motivation, they have a lack of self-motivation. So if you give him a list of things – I need these done today – he'll power through that and feel fantastic. He can't bring that self-direction in himself, yet. We are hoping that that is something that will happen. But he managed to move past the friends that he couldn't associate with any more. He couldn't go clubbing, he couldn't drink, he couldn't do this, he couldn't go dancing. So there was a mourning process – we got past that. He's now got a new set of friends, so he's changed direction.*

Interestingly this lack of internal motivation and reduced sense of purpose was articulated more by SOs of the TBI survivors as opposed to the survivors themselves. This could be linked to poor introspective abilities of survivors of TBI that was discussed previously. Building awareness and insight could be a post-rehabilitative goal, which looks at integrating individuals back into previous roles whilst targeting the specific unique difficulties that may be hindering their success.

SOs commented that it was necessary for them to actively assist and direct behavior of the survivors by compiling ‘lists’ or ‘suggestions’ of things to do, in order to assist the survivor of TBI with structuring of their day. Again, it is interesting to note that these external strategies were not provided by the professionals during rehab and that SOs “*figured this out*” by themselves.

Whilst P1 and P10 are among two of the ‘better’ integrated participants based on their FIM and CIQ-R scores, subtleties like the reminders provided by SOs are not featured as part of the measures and as such these measures are not consistently revealing the amount of support TBI survivors actually rely on. This confirms that tools such as the FIM and CIQ-R do have gaps and should not be used independently or relied on exclusively. The value of qualitative input and discussion with patients and caregivers is yet again confirmed (Wood, 2010).

Loss of identity

> *P10: The old* (Name of P10) *would have done it this way – old* (Name of P10) *would have fitted in. It would have been done. I sat there and I looked at my life and I thought I dealt with something and I wanted it to work that way, but it didn't - what would old* (Name of P10) *have done?*
>
> *P10: Those were one of the reasons why there was old* (Name of P10) *and new* (Name of P10)*). The old* (Name of P10) *fitted into everything and made everyone happy and the new* (Name of P10) *all of a sudden he would do the job and everything would be great, but he would forget this or he wouldn't focus on that.*
>
> *P8SO: I think we're trying to bring him back to doing the stuff he did. He wants to go back to cycling and he's doing spinning with me at night and we got him a tricycle to cycle on, but he wants to cycle on his own bike, he doesn't want to do it on the tricycle – he wants to do it on a normal bike like everyone else and when he can't do it that way – not that anyone else thinks badly or any different about him – I think it's a personal issue for him –Sometimes it's tiring and I try to explain - not now, just give it time. He sometimes doesn't understand that, but it's gotten us so far,*

A lack of self-awareness may impact an individual's perceptions of his or her own community integration and self-understanding (Djikers, 2004). This lack of self-awareness may impact on the outcomes achievable in rehabilitation, as well as on community integration following return home. This lack of self-awareness is clear in the case of P8 who scored in the lowest ranges on the FIM and CIQ-R measures with regard to community integration, but retained unrealistic perceptions of his own abilities and participation potential:

> *P8SO: He wanted to go back to flying, but the doctor showed him a very nicely, the rules of the SA Flying (I don't know what) Association, after any head injury and because he was in a coma for a week – he'd have to wait 5 years, so he's very fixated on flying again. He wanted to do his flying medicals until the doctor explained it nicely to him and then he was fine with that.*

Residual medical difficulties may impact on reconnection with previous roles for TBI survivors. This theme emerged for many of the participants in this study as a hindrance to active engagement in previous roles. Such issues are described in the literature as common factors, which may impact on individual's abilities to perform self-care, problem-solve or communicate effectively (Dijkers, 2004).

> *P3: No – because I can't walk or run like I used to. I can't lift heavy things, I can't lift certain things, so now I just stay at home or at a friend's house. That's the friend I told you about. He's the only friend and we watch movies or we sit and braai, something.*
>
> *I used to go to the gym a lot. And now? Now I can't because of my left arm, I can't lift anything. I can't lift heavy things. I used to pick up weights.*
>
> *P7: Well honestly I can say yes I've lost it because, there are a lot of other things that have also caused it, like I've got problems with my eyes.*
>
> *P6SO: Yes his behavior and a problem that he has is of headaches. Every morning he wakes up with a terrible headache. On Monday he didn't go to work because of a headache.*

> *He still loves his church very very much. He still plays football but not like before, because of the injury on his legs.*

> *P4SO: Except that he sometimes – his problem now is his eyes. When he comes from work, they're bad or sometimes they are red ……. I don't know what happened. It just comes*

When considering the FIM and CIQ-R scores for the aforementioned participants, one could attribute some of these medical concerns/difficulties to their slightly lower community integration. Research shows that TBI survivors report many more symptoms or health related problems than their unaffected counterparts (Dijkers, 2004). Such symptoms include fatigue, pain, sleep disturbances and depression none of which are assessed as factors in the CIQ-R or FIM but which may affect overall community integration. The data from the current study added that aside from the physical impediments adversely limiting integration, it also impacts their willingness to participate in certain activities. This identifies the emotional and psychological challenges resulting from a TBI.

3.3.4 Barriers and facilitators to community integration

Pertinent to this study was how community integration of persons with TBI and how the condition impacts on quality of life and participation in the long term was highlighted. By using interviews, the study hoped to interrogate the levels, factors and processes of transition and community integration for individuals with TBI, it sought to interrogate elements that would make the process more successful as well as outline the elements that survivors of TBI and their SOs found particularly challenging.

The feeling of being outside of a structured environment was associated with negative self-image and was perceived negatively by others.

> *P3SO: Now he's unfit, because he's lazing around.*
> *He's not interested in girls anymore.*

> *P3SO: Once he starts going back to the gym and he gets physio, I'm sure it's going to help him much better. He's no longer on any medication and he's picked up a lot of weight and not too fit.*

> *P1: I am currently busy with a couple of things at home, but often I sleep late and sometimes get up at midday, which is disgusting I think.*

> *P1: I just need to reset my body clock. I'll have a shave, shower and have a cup of coffee and then if I've got a project that I'm working on, I will start on that or if I'm in a slop mode, I'll just watch TV. I do feel that watching television is just turning off from the world and I do feel much better about myself if I do something a bit more purposeful - busy doing a project or going to gym, get on my bike, take the dogs for a walk*

The data supported documented literature; confirming that many TBI survivors along with their caregivers have explicit unmet needs post discharge from rehabilitation facilities (Kersel et al., 2001; Mellick et al., 2003; Eriksson et al., 2006 as cited in Evans & Brewis, 2008). This evidence as well as the findings and feedback of this research indicate the need for community services and support to assist in meeting these long-term rehabilitation needs of TBI survivors and their caregivers (Wade, 2003 as cited in Evans & Brewis, 2008). Having limited support available after rehabilitation emerged as a barrier to community integration in this research. Such community services would assist in providing the structure and routine that is listed as a serious need by the participants of this study and as a facilitator to successful community integration.

Financial support, was listed in a study by Winkler et al. (2006) as a potential facilitator for community integration. In re-examining the definition of community integration by McColl et al., (1998) as cited by Winkler et al., (2006), it looks at one's ability to fit in with and be accepted by other people, as well as knowing ones way around the environment. It refers to one's relationships with family, friends, and acquaintances. According to the definition, successful community integration requires an individual to have roles to fulfill each day as well as the ability to meaningfully participate in various activities and it looks at one's ability to be independent in daily tasks as well as having independence in decision/choice making. In accepting this definition and applying it whilst considering feedback from the participant interviews, it would appear that some participants perceived themselves to be successfully integrated into the community despite what formal measures may find..

> *P9SO: He spends a lot of time on the moto-med when he watches TV. He's on the moto-med all the time – that's one thing. Walking the dogs.*
>
> *P9SO: A 4x4 that you ride on and Abel goes with him. Abel takes the bike. What about going to the horses – checking up on the riding school – you do that every day. Farming. He goes to gym every day.*
>
> *P9SO: He does exercises, plinth exercises, similar to what you do here and he does muscle building exercises. He does leg presses. How many leg presses do you do? He presses 80 kg with his legs.*
>
> *P9SO: In summer it involves swimming. It's quite a bit of exercise, he works up a good sweat. You can see he's physically fit.*
>
> *P8SO: I must say his family and my family have been very supportive and especially friends. Friends that do come and visit and one friend, in the beginning came and picked him up and took him for coffee, I also try and take him out a bit. He goes and visits with his parents at the river house. Financially, his parents have their own company so they still give him his monthly salary so he'll go back to work when he's walking – that's his goal. We had great support, which made a big difference in the recovery and the emotional roller coaster we went on.*
>
> *P5SO: We have been very lucky with (Name of P5)'s carer. She was well trained, she was young – she had a real interest in seeing (Name of P5) get better. Right from the beginning she said tell me what I can do to get her better, and the therapists would give her homework to do and she would do it. So she actually had therapy 24 hours a day.*

The aforementioned participants, namely P9, P8 and P5 received the lowest scores from all the participants on the FIM and CIQ-R, indicative of poorer community integration as well as poorer functional independence. However, with the support of family and financial resources, their self-reported and family reported participation is perceivably higher than that of their higher scoring counterparts. The study by Winkler et al. (2006) in contrast confirmed that severity of injury and physical disability as opposed to financial support were the most significant predictors of community integration i.e. the more severe the injury or physical disability, the poorer the community integration.

In light of this, one would query if the financial costs of post-rehabilitation support should not be the responsibility of medical aid funders, given that these patients pay for medical insurance. The role of governments support in this process could also be raised. Interrogation of these issues is necessary as it is clear from this study that such initiatives may improve perceptions of successful community integration for all individuals regardless of financial standing, severity of injury or level of disability.

One of the challenges to integration that emerged was poor insight and awareness displayed by members of the family and the community.

> *P10SO: Simple things like taking a traumatic brain injury shopping – you can't do it - they can't cope with the external stimulus. He wanted to buy a belt – we went to Cresta and we got to the door and he said, "I can't do this". The brain injury can't cope with that. So yes, after a year – the first year we virtually lived in isolation.*

> *P10SO: The world out there does not really understand TBI. A man without a leg – his disability is in your face - you can see it. A traumatic brain injury you don't see - and I think you've been through it even if it was a long time ago, you don't understand the ramifications, the huge life changing things that come with a TBI – so no, they're not supportive.*

> *P3: Right now everyone is so cautious and careful of what they ask me to do and things like that, because they feel that because of the accident, I'm injured. To me it feels like they think I'm useless.*

> *P3: I feel that they feel I'm different because I don't do the things I used to do. I'm not that talkative, I'm not that active anymore.*

Education programmes with family members regarding behavioural changes of TBI survivors and how best to deal with these, resulted in reduced anxiety, reduced psychological distress and improved self-esteem (Sinnakaruppan, Downey & Morrison, 2005). In heeding the recommendations by Sinnakaruppan et al. (2005) rehabilitation services in SA may improve efficiency of services by breaking barriers and educating the greater community, social services, voluntary organisations and employment services in order to facilitate better community integration.

3.3.5 Home integration

Both positive and negative themes emerged regarding the return home. These pertained to the difficulties experienced as well as elements that were helpful in making the transition smooth. A prevalent theme was the need for routine and structure.

> *P10: That's quite nice that the family give me to do lists, so I need to do this, you see it but it doesn't process, as with everybody that's not a TBI problem, you kind of go a normal person would remember later, so the to do list gives me a point of contact that I can go back to.*
>
> *P5: On a Monday I go to (Name of post-acute support center) for the day – from 9:00 until 3:30. Monday at 18:00 I go to pilates. Tuesday I go to art – then I come to rehab, then I go to line-dancing form 19:00-20:00. Then on a Wednesday I do music therapy, then I have guitar lessons. Then on a Thursday it's basically a free day for now.*
> *P5SO: You are going to start eye therapy on a Thursday.*
> *P5: ...and then on Thursday night I have pilates. On a Friday, I have therapy and then I see my psychologist at 12:00. On Saturday, I do the park run – but I walk it – but I do do it.*

Structure and routine facilitates an active day for P5 and P10, however this appears largely dependent on external structuring and support from family and SOs. In contrast to this, in the absence of assistance and support, individuals who appear relatively well integrated and functionally independent according to their scores (P7 and P3), spend much of their time being unproductive. Whilst the CIQ-R evaluates items like going into the community and the frequency thereof, it does not evaluate whether this is meaningful for the individual relative to community integration. Individuals place emphasis and value on different things and as such, their own perspectives need to be considered with regard to how integrated they feel (Nalder et al, 2012).

> *P7: Nothing - if I don't have appointments or something to attend, then I would just stay at home. Watch TV, listen to music, just think…*
>
> *P3SO: He's mostly watching TV. When he comes home from work he would sit on the phone, basically all children are like that, so he's one of them, because I'm never at home when he comes from work. When we leave in the morning, then he will get up and go to work and some days he'll come back at about 2:00, then he would go to his room and maybe watch a movie or sleep because he can sleep and then he would sit on the phone, then he would go and see one of the twins' boyfriend – I never ask questions – like where have you been? Then he would come back and go to the garage and sit in his car on the phone. He's not the type of person who would take a broom and sweep. On Saturday mornings I make him tidy his room and sweep, but otherwise I don't know what his day is like. I can say that most of the time he sleeps or he's on the phone.*

This links to the theme the need for self and external motivation. Nalder et al. (2012) confirm in their research that 'perceptions' of successful community integration are largely dependent on active participation in meaningful activities. Such activities need to be meaningful for the TBI survivor as it contributes to a strong sense of integration (Nalder et al., 2012). This was noted with some of the participants.

Whilst P3 scored slightly lower on the CIQ-R and FIM, which seems to be in line with the negative self-reports of his integration, P7 on the other hand was one of the higher scorers on both measures. As mentioned previously a score of 26 out of 35 (highest scorer of the participants) should be linked with successful community integration. There was inconsistency however between how the participant was able to integrate based on his scores (higher), versus how he felt about or perceived the experience of community integration (more negative). This links very strongly to a predominant question of this research, that being, do individuals who are believed to be effectively 'community integrated' based on the rehabilitation outcome measure scores and other post-discharge community integration scores, feel as though they are successfully integrated? And in the case of P7, the answer is no. This again highlights that in order for community integration goals to be successful; focus should be placed on listening to the specific needs and perceptions of patients within a rehabilitation and post-rehabilitation setting. Such needs and perceptions have been expressed through this research, but could be brought to the forefront of rehabilitation programmes in order to align successful community integration scores with corresponding 'feelings/perceptions' of success by patients themselves. A study by Wood (2010) on stroke survivors and community integration, revealed that patients goals need to be constantly changing and that therapy and post rehabilitative programmes could be more specifically designed to cater for their continually developing needs and goals, based on their continually developing and changing self-perceptions (Wood, 2010).

Internationally much of the research indicates that the more severe the injury the more difficult it becomes to integrate into the community (Winkler et al., 2006; Nalder et al., 2012). In South Africa limited post rehabilitation support groups/centers exist, however those that do exist are believed to be geared toward integration and service of more severely injured individuals, those with greater residual difficulty. It is the individuals that are more functionally independent, those that score higher on the CIQ-R, who often struggle to integrate for a variety of reasons which will be interrogated further below. When asked about such services the following responses were obtained from a number of participants;

> ***In response to 'What could be supportive for others?'***
>
> *P1: …when you integrate with another group at (Name of post-acute support center), you find people who can't talk properly, physically they're disabled or in a wheelchair or maybe on crutches or something, it gives you a different perspective, it makes you aware of their scope of an accident that you can look*

> *at your own world without feeling victimized. Sometimes things happen and it's how you deal with it. (Name of post-acute support center) is a good ground for understanding that getting direction and you're doing it with people around you who are in therapy who are giving you therapy just with the discussions you have with them, just from a friendship perspective or just an interactive perspective and the same with the therapists there.*
>
> ***Going to (Name of post-acute support centre) do you feel like you relate with a lot of the people there – or not really?***
> *P1: No, I related to people who were maybe the caregivers, family or people who had come to what I'd been through or how I was functioning. I didn't like being included with people who were really disabled, it made me feel like I was a bit retarded. I didn't like that. I wanted to remove myself from the area of just being totally different from the rest of the world.*
>
> ***So if it was an environment where there were people who experienced a TBI and were at the same level as you, would it have been more beneficial?***
> *P1: I think so…*

The participants in the study who are more functionally independent (FIM), and scoring higher on the CIQ-R report finding integration harder. They are more aware of their difficulties and differences and feel self-conscious when being associated with disability.

Jung first coined the term wounded healer in 1951 as a way of explaining that in order for a physician to heal others, he needs to have been wounded himself as only then can he truly appreciate the perspective of the individual he is trying to help (Daneault, 2008). The concept of 'wounded healer' emerged in this research. Participants felt that current programmes/centers available in South Africa only serviced individuals with more severe injuries and difficulties. Such programmes/centers were associated by some as more of *'a creche for people with brain injuries – you can dump them there and come and fetch them later',* versus a community integration center. Many of the TBI survivors in this study as well as their SOs opted not to be associated with such services as the felt it hindered feelings of 'normalcy' as well as set them back with regard to their ability to integrate back into their communities. Other research by Nalder, Fleming, Cornwell, Shields & Foster (2013), confirms this desire for normality. Individuals in this study would rather be associated with a productive role of 'wounded healer' where they could be more involved in something productive such as volunteer work in helping others. Taking on the role of a wounded healer would allow them to share their experiences as well as gain a sense of purpose rather than attend a support center that services individuals who were more severely affected than they. Incorporating less physically affected survivors of TBI, who are cognitively able to share insights and experiences into such a role (wounded healer), may be an effective productive activity and goal for post-discharge community integration. From this research it was ascertained that this role may provide a sense of purpose and meaning for some survivors and thus may be a useful tool to incorporate into post-discharge programmes in SA.

3.3.6 Repositioning of the caregiver

Significant themes emerging from this research refer to perspectives of caregivers of survivors of TBI. SOs within this study mention having to adopt different roles and responsibilities as well as having to learn new ways of interacting or dealing with their family members with TBI. SO participants in this study often reported initially not knowing what to do or what to expect or how to handle certain situations that they faced.

Research supports, that often SOs feel as though they are completely alone with very few appropriate people to turn to for guidance (Rotondi, Sinkule, Balzer, Harris & Moldovan, 2007). Research completed by Lefebvre & Levert (2012) detail the overwhelming sense of under preparedness and lack of knowledge that family members and caregivers possess regarding how to adequately care for, manage and stimulate their loved ones who have experienced a TBI. Care providers express the distinct need for more information, and specifically the right kind of information at the right time (Lefebvre & Levert, 2012). This requires effort on the part of information providers i.e. rehabilitation specialists, healthcare providers, health funding organisations and other related institutions, to take the time and make the effort to understand the particular needs and frustrations of family members and caregivers of TBI survivors in order to be able to provide this appropriate and adequate service (Lefebvre & Levert, 2012).

In this research SOs expressed the distinct need to take on a parental role when caring for, stimulating and encouraging the TBI survivors. As described in the accounts below, often SOs are experienced as being overprotective and stifling by the TBI survivors.

> *P1: We were out for my birthday – a week back - my sister had just come out from the UK to visit and we were at a restaurant which is one of my favorite places and I had been thinking about having wine – I had been off alcohol for 18 months and I've slowly gone back into it – I do love my wine and whisky – and I had had a glass or two of wine then I ordered a whisky at the end of my lunch and my sister laid into me at the table saying that I have a drinking problem…*
>
> *P1: They would tell me that you can get a girl pregnant having sex and that girls can be just after money.*
>
> *P1SO: The one thing that really triggers him a lot is if I give like a motherly tone - he completely hates being mothered. I don't do it on purpose, but I would say "ok it's enough now" and then I use that tone on him if I get cross about something*
>
> *P6: More, because as I've told you, he's the last born – we treat him very very differently than the other kids because he was involved in an accident. Even his brothers also they treat him likewise. He loves food and he's always eating at home. We always tell him, even though he was hurt outside, when he comes to the family we support him 100%.*

In the current research, SOs described the substantial responsibilities they felt and the directive and supportive role they are required to play in the TBI survivor's life. Despite participants obtaining FIM or CIQ-R results that were indicative of 'measured' functional independence and community integration, these participants were still largely dependent on input and support from SOs. SOs in this study reported that they needed to have certain expectations in order to motivate the TBI survivor, often on a daily basis. Jumisko, Lexell & Soderberg (2007), mirror these experiences of family members living with TBI survivors in their research. Highlighted in the research by Jumisko et al. (2007) was the depth of SOs feelings and experiences and how poorly understood they felt. Family members described feelings that their worlds had collapsed as a result of the TBI, or that the TBI was the main thing directing their lives at that time (Jumisko et al., 2007).

> *P5SO: For now I'm trying to give her as many experiences as possible – I'm trying to challenge her in a particular way, we're keeping her really really busy, which is a huge challenge for us because she doesn't drive, so our calendars are kind of packed and I want her to do some short courses, whatever they are, because there are three areas where she's not quite competent yet – speed of work, abstract thinking and multi-tasking, so for me the best way I can get her to do those things is to give her things to do that will challenge her in that way in a safe and protected environment and that's what we've done.*
>
> *P5SO:I'm still trying to get her out there and integrated.*

The research by Jumisko et al. (2007) confirms that family members of TBI survivors require much energy. Interestingly, the well being of the TBI survivor directly impacts the well being of the SO or family in general, as was also noted in the current study.

Data confirmed that SOs feel a sense of responsibility to motivate their loved ones. This was confirmed in research from Lefebvre et al., (2008). Family caregivers play a vital role in long-term rehabilitation of TBI survivors with regard to their exercises; cognitive and social stimulation as well as assistance in relearning socially appropriate rules. Similar findings came out in the current research.

> *P5: **Talking about her parents**: They really push me when I can't do something like the right of my body, I couldn't move it and they kept pushing me to walk to paint to play guitar, things like that – they really push me - it's good because it makes me want to.*

> *P10SO: You talk, you encourage, you build, you up-lift, you hold, you care, you start all over again when they fall down and you just there and you support and you encourage and push.*

The research by Jumisko et al. (2007) aligns with the findings of the current research, where SOs experience frustrations in dealing with behavioral changes of their loved ones with TBI. SOs often report feeling like they are now dealing with 'raising' a child (Jumisko et al., 2007). SOs of the current research made similar comments, indicative of the difficulty in managing such behavioural changes and the potential need for ongoing support of SOs. Such insights should guide practice in South Africa, where very few resources and support structures are available for SOs.

> *P3SO: He doesn't want to mix with anybody – he doesn't want to speak – he would just say "morning" and that's it - he would go to work, come back and stay in his room and he's sort of moody. He can argue unnecessarily, but most of the time it's with me and he's got anger in him, then what he does if he upsets himself with one of us, then it's like that anger comes out. That's how I would describe it. He takes it out on us.*
>
> *We can't help him although we talk a lot and them maybe that anger I was telling you about, will come out. I reprimand him a lot with regard to that.*

> *P4SO: He forgets – he's very forgetful. When he wakes up I must wake up too and ask him. 'Have you done this? You haven't done this. You've forgotten this. Take this, until he finishes.' I have to make sure that I look after him and prepare for him, so that he will be on time.*

> *P8SO: I can say he doesn't have a filter so sometimes he will say stuff that's not appropriate, but not like in an ugly way – I think he might say wow that lady's fat. Also, I think when he struggles with something he does get cross, but not in a way that we can't manage it. In the beginning it was a struggle, but then the doctor gave him some medication, a sleeping pill that keeps him a bit calm, but he doesn't like to struggle, then he gets upset.*

This research clearly identifies areas of anxiety and uncertainty experienced by SOs of the survivors of TBI following the injury. Often SOs are seen to resume roles of earlier life stages such as that of a parent in order to cope with the changes that have occurred. These feelings of anxiety are mirrored in other international studies, which examine the challenges, and needs of caregivers of individuals with TBI (Rotondi et al., 2007). A strong sense of 'the need for further guidance and support' emerged from this research and could essentially be incorporated to guide service provision to carers of survivors of TBI in SA in order to allow for a better transition for all.

3.3.7 Barriers in the workplace

The current research highlights some of the challenges faced by TBI survivors in a South African context with regard to return to work issues following a TBI. Many of the participants were unable to return to their previous roles. Similarities can be seen in the study by Dijkers (2004), where TBI survivors returning to work often did so at a lower level or part time often impacting on financial income as well as perceptions of self. Research shows that TBI survivors who are employed display an improved sense of wellbeing, better health, greater community integration, less use of health services and generally better quality of life (van Velzen et al., 2009).

> *P3: Now I'm only in the office – they don't allow me to go out any more, working the over-time I used to work at the police station. I don't get to do that any more because the new superintendent decided I wasn't an asset to the high-speed unit any more. So now I'm at the station where you process the speeding fines, where it comes onto the computer you have to check the X on the camera, if it's on the car and no other cars interfering or people walking past in the photo, it's like when the person's skipper only touches the car, it an overlap – so you can't put it through. Then I have to check all that. You can go up to 40,000 cases, but I'm not the only one doing it. But that's what I do now.*

Whilst research shows that people who are employed following a TBI tend to show more positive outcomes (van Velzen et al., 2009), participants in the current research showed decreased motivation for new roles and therefore harbored negative feelings regarding return to work. Returning to work in a position that was less active and demanding for the survivor of TBI contributed to feelings of poor self-worth.

Many of the participants of the current research experienced poor accommodation of work environment. A large consideration for return to work is whether or not modifications to the job description or the context itself are required as well as whether individuals may require retraining or a reduction in working hours (Shames et al., 2007). Some of the experiences of the participants of the current research can be seen below;

> *P6: Last year in October, I had a problem with my knee and they said I must go to the doctor. When I went to the doctor they tell me I had a broken ligament inside so I must come and do an operation. When I go there and do the operation – since before I went they didn't pay me. So when I ask why they don't pay me because I'm still on duty, they say no work no pay so. They are very strict on me everything I do they're on my back.*
>
> *P6: I think they want to me to go, to resign from the job. (subsequently lost his job)*
>
> *P6: What I was doing before was a lot heavier than what I'm doing now, but now it's less than what I was doing before, but it's more difficult for me since the accident, which before it was easier.*
>
> *P6SO: The person that used to do that was an old man, so when he complains about the job being heavy for him, they mock him telling him that an old man used to do that job, so there's no way that he can say its heavy on him.*

Research has shown that whilst individuals with TBI may be able to perform jobs that they were routinely able to complete before, subtle difficulties with regard to learning of new skills, tasks requiring informational processing and those requiring more focused attention as well as managing behavior suitable for the particular work environment may prove more challenging (Shames et al., 2007). Reports from participants in the current study confirm these difficulties, especially those pertaining to controlling behavior suitable for the work environment.

> *P2: I still battle to control the anger like with that lady and it just goes and I know this, but I would just carry on. Even in the team meeting, for about 20 minutes me and the manager were going at each other ……… - probably*

> *about 6,7,8 months ago now and I just couldn't stop. I knew what I was doing and that but the anger was there and I just kept going and I wasn't able to stop it, but previously I would have known no, you can't do this. We might have argued, but then it would stop.*

According to Shames et al. (2007) services are available abroad designed specifically to reintegrate individuals slowly and successfully into the workplace. Such services in South Africa were identified as lacking. Both the TBI survivors and their SOs felt that there is poor support, micro management and a lack of employer education in this country.

> *P6: They're not supporting me.*
> *Yes, they're monitoring me more since the accident. Cutting off my hours, If I work they cut my hours*
>
> *P6SO: Maybe the hospital can help him to talk to his bosses at work so that because of the accident, so if they can maybe give him a light job and if he don't do that, they must call him and speak to him, not shout and do whatever, whatever. As if it was the end of the world. When they treat him badly at work - he comes from work and goes straight to his bedroom, so I can see that there is something wrong.*
>
> *P6SO: Yes, he was there in hospital for three months – they didn't phone, they didn't go, they didn't support us. We were on our own and we were not working*

Poor work accommodations and poor consideration of the necessary adaptations that may be required were displayed by some of the employers in the current study. These factors as well as the lack of handover from vocational rehabilitation services results in poorer feelings of self-worth as well as poorer feelings of community integration as can be seen for participant 6. Internationally TBI survivors may have the availability of supported employment as well as other services which have been previously mentioned such as structure neurobehavioural programmes, structured community integration programmes, comprehensive day treatment programmes and community re-entry programmes (Shames et al., 2007). Such programmes are nonexistent in SA and so unavailable to TBI survivors in South Africa.

4. Discussion

This research aimed to describe and compare the participants and their significant others' (SOs) or caregivers' experience of community integration and factors that have influenced the perceptions by each (i.e. the patient and the caregiver). This was achieved through the completion of personalised interviews designed to gain an understanding from each individual's unique perspective. Themes emerging from these interviews corresponded and overlapped well with existing research in the field, mainly research studies conducted internationally. This raised concern, in that although South Africa as a country is poorly resourced, with far fewer post rehabilitation support structures in place, many of the barriers faced by TBI survivors and their SOs internationally, parallel ones emerging within the South African context. The challenges that South Africa faces however, is that it is unable to meet these needs at various levels. Additionally it has emerged that although certain structures and facets of an ICF framework as well as outcome measure prediction procedures are being applied within a private rehabilitation facility, when patients are deemed 'community integrated' this is not always the case.

An exhaustive review of literature of what constitutes successful community integration was completed revealing various perspectives. Landrum et al., (1995) classifies community integration as the achievement of an appropriate level of function within the person's community, i.e. to be able to participate in social activities such as shopping, church and sport according to individual needs. McColl et al., (1998) proposed that being community integrated includes; being able to fit in with and be accepted by other people, as well as knowing your way around the environment; having relationships with family, friends and acquaintances; having roles to fulfill each day as well as the ability to meaningfully participate in various activities and being independent in daily tasks and decision/choice making. Common measures of community integration such as the CIQ-R provide insight into what individuals with TBI do in the home environment, socially, productively and using electronic social networks, however the subtleties of how they overcome everyday challenges like insecurities, memory difficulties or how much support they require from significant others is not revealed. This research interrogated these definitions and attempted to understand community integration, its challenges and the experiences of it, from the perspective of the survivor of TBI as well as his/her SO.

Research internationally reveals that QOL factors significantly impact on perceptions of community integration as well as perceptions of self (Dijkers, 2004). This research revealed significant themes relating to these issues. Participants experienced significant feelings of change- changed behaviour, changed personality traits, changed sense of self, which all resulted in changes in the way they coped with and approached new challenges especially those associated with the TBI. The participant interviews of this study revealed that whilst change is very real for the participants, very little is available during their rehabilitation as well as post-rehabilitation in South Africa to prepare them for it. In light of these findings, this research proposes the use of a multifaceted approach for assessing community integration. Figure 10. below illustrates the importance of taking into consideration the personal feedback of the survivors of TBI as well as their significant others prior to being able to accurately comment on their level of community integration.

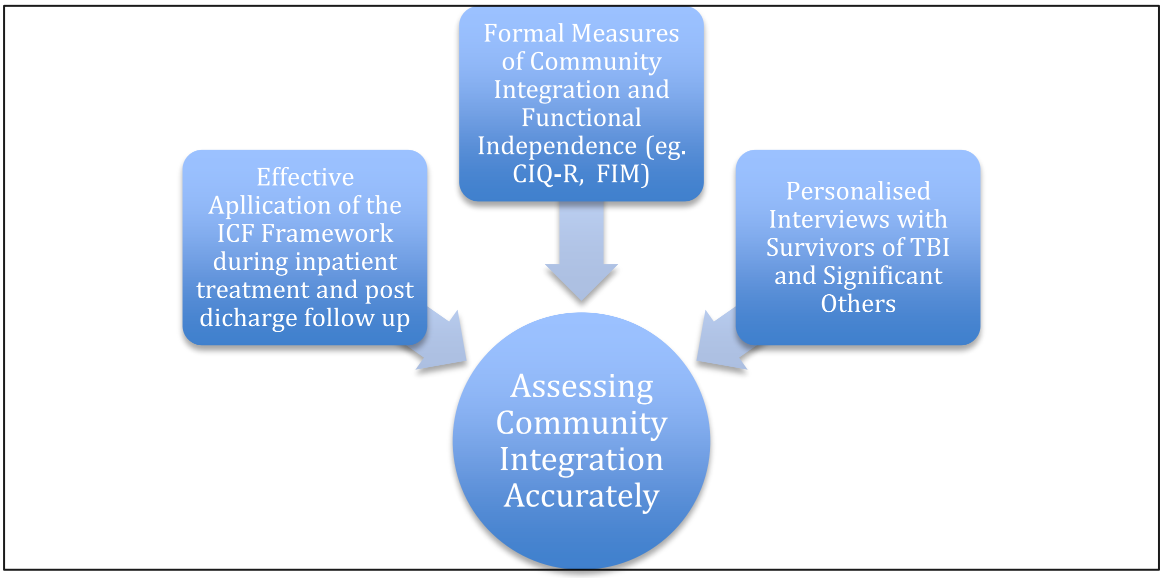


Figure 10. Proposed Model for Accurate Assessment of Community Integration

Whilst the rehabilitation center of this study utilises an ICF framework to a certain extent, greater inclusion and follow up with the patients themselves as well as their caregiver should be considered in order to deal with real life challenges and feelings they may be experiencing. The model described in figure 10 aligns well with Douglas

(2013) who proposes that rehabilitation practice should be informed taking into consideration TBI survivors' concept of self as well as their experience of the recovery process, making attempts to improve and nurture these concepts in an attempt to improve preparation for community integration.

The ICF is a tool designed to cater for the personal needs of the individual (Threats, 2006). Whilst it was loosely used to guide the treatment and goal setting processes for the studied sample, perhaps its application remains to be improved in the rehabilitation center of the study. The ICF, when accurately applied, incorporates patient involvement. The proposed model for ensuring successful community integration, which can be seen in figure 11 below, describes various elements that if included post-discharge, may ensure greater success with regard to community integration. The full application of an ICF framework could allow for the discussion of difficulties experienced and challenges faced by patients living in a community environment as well as those felt by their significant others. This process could play a major role in preparing a patient and family for discharge from rehabilitation. This being said, it should be noted here that the ICF is not an assessment measure and as such does not act to directly guide intervention (Threats & Worrall, 2004). In addition, in South Africa, a country lacking in adequate resources, limitations can be identified in various domains as outlined by the ICF framework, however the services needed to support the limitations in these domains are lacking.

One of the sub-aims of this study was to document barriers and facilitators to community integration within the familial, social and work contexts. This was achieved outlining significant barriers within all spheres. Families of the participants from this study were not provided the relevant information and so were under- and unprepared to deal with life as carers of survivors of TBI. They experienced very little support from healthcare institutions and their greater society. Many of the participants of the study (Survivors of TBI and SOs) experienced community members as having poor insight into TBI and the effects it holds for survivors. There are reduced support structures in place to encourage integration into the community as well as poor participatory opportunities for TBI survivors in order for them to gain a sense of normalcy in their previous contexts. Lastly some of the work environments described in the study were largely uninformed with regard to TBI and thus felt to be unsupportive. Whilst they could aid in the successful transition back into a previous work context, many of the survivors of TBI in this study found that return to work detracted from their personal feelings of success in community integration. Data confirmed that survivors of TBI and SO's believed that this was the role of the professionals, and that it was necessary for professionals to prepare survivors and caregivers for their new roles and responsibilities. This support, they believed, would facilitate improved community integration in the long term. Services such as behavioural management; counselling and preparation for such changes could help to form a more integral part of the rehabilitation process in South Africa.

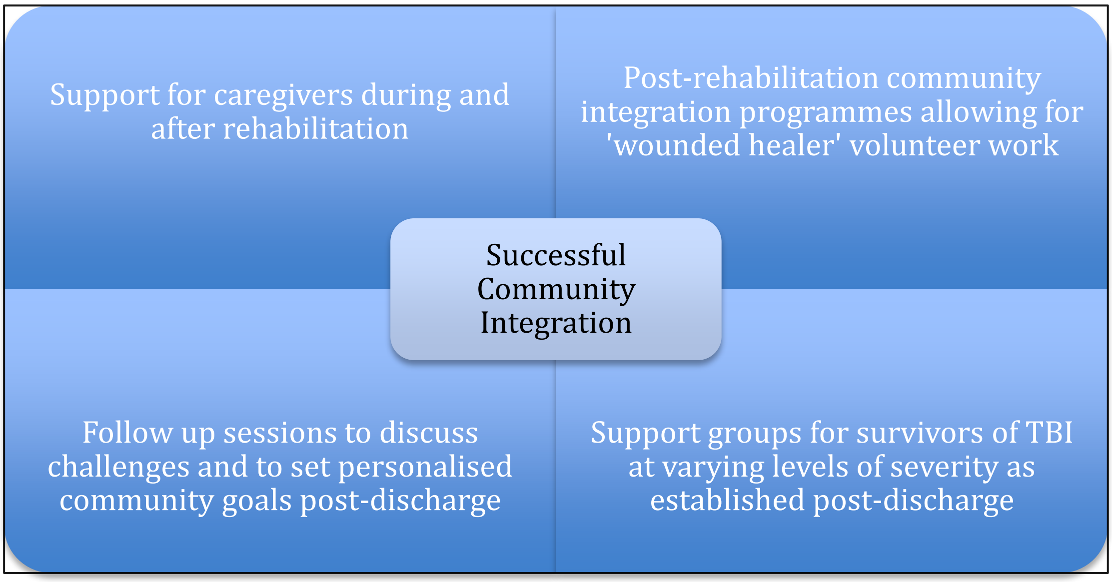


Figure 11. Proposed Model to Ensure Successful Community Integration Post-Discharge.

In addition to personalised interviews, a further sub-aim of this research was to monitor and describe the Functional Independence Measure (FIM) level at discharge and 1 year or more (no more than 2 years) post-discharge from rehabilitation in terms of associated outcome levels, and see how these relate to the results of the Community Integration Questionnaire- Revised (CIQ-R) scale for the TBI survivors. Across various areas of comparison, participants who scored higher in the CIQ-Rand FIM measures, often expressed more subtle difficulties or challenges that landed up going undetected and ultimately contributed to their personal feelings of poorer community integration. This reinforces the notion that scores alone do not paint an adequate picture of an individual who has suffered a TBI. A more personalised approach like that offered by the ICF appears more suitable as it considers the patient, who he/she is, what activities he/she used to participate in and what roles he/she fulfilled prior to the injury and establishes how the individual is now limited. This is proposed in figure 11, a model that highlights the prerequisites for successful community integration. The value of caregiver support upon termination of rehabilitation and attendance of support groups are vital. This together with personalized follow-up discussions post-discharge, and the use of community integration programmes can influence patient outcomes either positively or negatively. Results of this study revealed that this process and the listed components in Figure 11 are currently lacking. Evaluation appears to happen to a degree as an inpatient, to a lesser degree as an outpatient and not at all thereafter. Support seems to cease suddenly for TBI survivors and their caregivers as they enter residential and community environments.

Although the ICF was not utilised as a tool in this study, according to research the ICF model, if approached correctly, allows for the acknowledgement of limitations in function, activity and participation as well as areas where assistance is required (Threats & Worrall, 2004), it does not delve into the type of support or assistance needed for each particular individual. Whilst one person may respond well to support in the form of ‘to do lists’ another may find this type of support stifling. Another limitation of the ICF is that it does not provide information regarding the amount of assistance required. In addition, little attempts are made to prepare or counsel primary caregivers following discharge from rehabilitation. As previously discussed institutions may focus on physical carer-training but, as reported by SOs in the current study, the subtle behavioural aspects and skills to handle these are left untouched, to be figured out by SOs on their own. Caregiver education is paramount in order to ensure and reinforce better community integration exercises; cognitive and social stimulation as well as verbal reminders regarding rules of social behavior (Lefebvre et al., 2008).

Based on the findings of the study it can be said that a multi-faceted approach is currently lacking with regard to ensuring good community integration. For this reason the aforementioned models (figure 10 and 11) are proposed. These models take into consideration the efficacy of the ICF as a framework as well as the inclusion of personalised feedback from survivors of TBI and their significant others living with the effects of these injuries, in the community setting.

5. Conclusion

5.1 Implications

The research aimed to provide insights into the barriers and resources that exist in South Africa for people who have experienced a traumatic brain injury. It proposed to highlight how practice can improve with regard to their definition of community integration as well as with appropriate referrals at discharge from rehabilitation services. It also aimed to inform the need for further support programmes and long-term community integration centers to assist in the transition and continuous development and growth for individuals with TBI whom have exhausted all rehabilitation services and funding from medical aids. Considering this it has implications for the need for additional long term funding for such persons, to enable feelings of purpose, integration and participation despite having experienced such an injury.

This research highlights major inadequacies of the current system of TBI management post rehabilitation for private health care recipients in South Africa. If such challenges (lack of post-rehabilitation support centers, poor caregiver support, reduced preparation for return into the home, community and work settings) are felt within the private sector, it leaves one questioning how individuals with access to government health care facilities, where resources are less, fare. The implications therefore fall on rehabilitation providers and the larger health care institution as a whole.

The findings of this study imply the need for improved education and knowledge sharing within all spheres in South Africa including, the familial context, social/community contexts and very importantly within the workplace. Knowledge sharing should occur at various levels starting with healthcare professionals within both acute and rehabilitation settings. Following this, therapists; experienced caregivers and well-adjusted and well-integrated survivors of TBI can be incorporated to share knowledge from various perspectives. Not only will these initiatives contribute to a sense of purpose for survivors of TBI as well as SOs, but also it will allow for depth of understanding of the condition and implications thereof from a very personal stance to be passed on. This will assist to fill gaps that were reported by the participants of this study and perhaps felt by others within the greater South African context.

Whilst individuals are being discharged from outpatient therapy services under the premise that they are at a level of 'community integration', the reality indicated by their own self-reports and self-perceptions, is inconsistent with this. Survivors of TBI who are at functionally independent levels according to the FIM and who scored highly on the CIQ-R, articulate an 'experience' of their integration which is at odds with their scores. They are less likely to participate in premorbid activities, they feel socially isolated due to poor understanding by friends and members of the community, they are often unable to return to work or are dissatisfied by new roles they have to fulfill in the workplace, they experience long lasting medical symptoms, they feel isolated because they are unable to relate to others because they are different and they rely heavily on SOs to assist them with the subtleties of life. This therefore brings into question if the current means of interrogating integration is accurate and if these methods are suitable for the SA context, which is still largely illiterate and poorly educated. (According to Human Development Index, SA literacy level is 85.6% with an average of 6.9 years of schooling)

Whilst vocational services of the research site are aimed at providing early intervention for return to work, including a sensitisation programme for employers and colleagues, work visits, work hardening programmes, recommendations for reasonable workplace accommodations and the general identification of resources to accommodate clients that require re-skilling, many of the participants of this study felt a serious lacking in these services. As discovered from this study, often work environments of the participants were not accommodating of the changes that needed to occur or work environments were largely uneducated of the effects and repercussions of TBI resulting in a lack of support provided.

In addition, there is a significant lack of post rehabilitation support services available to TBI survivors and their SOs. Private medical aid funds do not take into account the ongoing difficulties that are experienced by individuals. There comes a point with private insurance where funds dry up or are no longer available, regardless of the need for continued support and rehabilitation. It is possible that insurers may be unaware of ensuing future medical complications for the person with TBI and their family. Conditions such as depression, stress, anxiety and other medical conditions are documented adverse outcomes (Dijkers, 2004).

5.2 Limitations of the study

The most significant limitation of this study is the small and specific sample size. The findings of the study however are rich and would be useful in guiding further research in this area.

In addition, this study focused primarily on individuals who received rehabilitation services in a private health-care facility in South Africa and as such conclusions or suggestions cannot be made to include individuals who received care in different settings to this.

The study made use of the FIM, which as a measure is not designed to predict outcomes of a ‘community integration’ nature, but rather one that focuses on improvement across an inpatient rehabilitation stay (Hall et al., 2001). This being said, as previously discussed, greater levels of functional independence can be linked to improved community integration (Fleming et al., 1999).

5.3 Recommendations and Conclusion

Spiritual connectedness, in line with the study by McColl et al. (2000), yielded feelings of integration for some of the participants of this study. In light of this emphasis could be placed on educating spiritual institutions as well as directing TBI survivors and their SOs toward such institutions in order to establish links to a healthy aspect of their community and a means of positively reframing what happened to them.

The support offered to TBI survivors by their SOs is a large contributing factor to feelings and perceptions of community integration held by TBI survivors (Lefebvre & Levert, 2012). Various studies, including the current study reveal that SOs have many unmet needs in terms of what they know and what they should expect with regard to handling their loved one with a TBI. There is a significant need for adequate information sharing, education and support following a TBI (Jumisko et al., 2007;

Douglas, 2013). As previously discussed, this research has highlighted the fact that our South African context is lacking in this regard, with reduced funding available for outpatient therapies, a lack of post discharge programmes and a general lack of education and information given to family members of TBI survivors upon discharge. As such this should be a major focus of health care providers in the future.

Whilst many of the studies highlighted in this research examine best assessment measures for predicting outcomes of TBI and community integration potential (Sander et al., 1999; Hall et al., 2001; Kaplan, 2001; Seale et al., 2002), future studies could perhaps focus more on personal feedback and accounts by TBI survivors and their caregivers in order to guide practice. This research revealed many subtleties that impact perceptions of community integration but go undetected by formal measure. Such subtleties could be used to direct specialised programmes, which should be made available to TBI survivors post discharge from rehabilitation services. Personal accounts of the return to work difficulties could also be used to guide future research as well as to educate workplace environments facing this challenge.

Lastly financial support, whilst not a main factor in determining successful community integration, plays a role in successful community integration (Winkler et al., 2006). This is true of this research wherein, some of the most poorly integrated (based on scores) participants, were the most actively participating with improved overall perceptions of their own community integration. This factor highlights the need for improved financial support from government as well as medical aids in South Africa in order to improve post rehabilitation support services thus making ‘community integration’ more accessible to all.

In conclusion, further research utilising a larger and more representative sample should be conducted in order to highlight and further pinpoint the specific post rehabilitative needs of TBI survivors and their SOs so as to allow for better service provision for these populations in the future.

Reference List

Arango-Lasprilla, J.C., Quijano, M.C., Aponte, M., Cuervo, M.T., Nicholls, E., Rogers, H.L. & Kreutzer, J. (2010). Family needs in caregivers of individuals with traumatic brain injury from Colombia, South America. *Brain Injury, 24* (7-8), 1017-1026.

Babbie, E. R., & Mouton, J. (2001). *The Practice of Social Research*. Cape Town: Oxford University Press.

Benson Yody. B., & Strauss, D. (1999). The effect of decreasing lengths of stay on long-term TBI patient outcomes. *Journal of Rehabilitation Outcomes Measurement*, *3*(3), 42-50.

Biggerstaff, D., & Thompson, A. R. (2008). Interpretative Phenomenological Analysis (IPA): A qualitative methodology of choice in healthcare research. *Qualitative Research in Psychology*, *5*(3), 214–224.

Brink, H., van der Walt, C., & van Rensburg, G. (2012). *Fundamentals of Research Methodology for Health-care Professionals* (3rd ed.). South Africa: Juta Academic.

Brown, D. S. O., & Nell, V. (1991). Epidemiology of traumatic brain injury in Johannesburg—I. Methodological issues in a developing country context. *Social Science & Medicine*, *33*(3), 283–287.

Bruns, J., & Hauser, A. W. (2003). The epidemiology of traumatic brain injury: A review. *Epilepsia*, *44*(10), 2–10.

Bryan-Hancock, C., & Harrison, J. (2010). The global burden of traumatic brain injury: Preliminary results from the Global Burden of Disease Project. *Injury Prevention*, *16*(A17).

Corrigan, J. D., Selassie, A. W., & Orman, J. A. L. (2010). The epidemiology of traumatic brain injury. *The Journal of Head Trauma Rehabilitation*, *25*(2), 72-80.

Cournan, M. (2011). Use of the functional independence measure for outcomes measurement in acute inpatient rehabilitation. *Rehabilitation Nursing*, *36*(3), 111–117.

Creswell, J.W., & Miller, D. L. (2000). Determining Validity in Qualitative Inquiry. *Theory Into Practice, 39*(3), 124-130.

Daneault, S. (2008). The wounded healer: Can this idea be of use to family physicians? *Canadian Family Physician*, *54*(9), 1218–1219.

Denzin, N.K., & Lincoln, Y.S. (Eds). (2008). Handbook of Critical and Indigenous Methodologies. Los Angeles, CA: Sage.

Dijkers, M. P. (2004). Quality of life after traumatic brain injury: A review of research approaches and findings. *Archives of Physical Medicine and Rehabilitation*, *85*(4), 21–35.

Douglas, J. M. (2013). Conceptualizing self and maintaining social connection following severe traumatic brain injury. *Brain Injury*, *27*(1), 60–74.

Evans, L., & Brewis, C. (2008). The efficacy of community-based rehabilitation programmes for adults with TBI. *International Journal of Therapy and Rehabilitation*, *15*(10), 446–458.

Fleming, J., Tooth, L., Hassell, M., & Chan, W. (1999). Prediction of community integration and vocational outcome 2-5 years after traumatic brain injury rehabilitation in Australia. *Brain Injury, 13*(6), 417-431.

Gage, M., Cook, J. V., & Fryday-Field, K. (1997). Understanding the transition to community living after discharge from an acute care hospital: An exploratory study. *American Journal of Occupational Therapy*, *51*(2), 96-103.

Hall, K.M., Bushnik, T., Lakisic-Kazazic, B., Wright, J. and Cantagallo, A. (2001). Assessing traumatic brain injury outcome measures for long-term follow-up of community-based individuals. *Archives of Physical Medicine and Rehabilitation*, 82(3), 367–374.

Hall, K.M., Mann, N., High, W.M., Wright, J., Kreutzer, J.S. and Wood, D. (1996). Functional measures after traumatic brain injury: Ceiling effects of FIM, FIM+FAM, DRS, and CIQ. *Journal of Head Trauma Rehabilitation*, 11(5), 27–39.

Harrison, S., Bhana, R., & Ntuli, A. (2007). *South African Health Review*. Durban: Health Systems Trust.

Hassan, S. A., Visagie, S., & Mji, G. (2012). The achievement of community integration and productive activity outcomes by CVA survivors in the Western Cape Metro Health District. *South African Journal of Occupational Therapy*, *42*(1), 11-16.

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.

Johnston, M. V., Shawaryn, M. A., Malec, J., Kreutzer, J., & Hammond, F. M. (2006). The structure of functional and community outcomes following traumatic brain injury. *Brain Injury*, *20*(4), 391–407.

Jumisko, E., Lexell, J. and Soderberg, S. (2007). Living with moderate or severe traumatic brain injury: The meaning of family members' experiences. *Journal of Family Nursing*, 13(3), 353–369.

Kreutzer, J. S., Serio, C.D., & Bergquist, S. (1994). Family needs after brain injury: A quantitative analysis. *Journal of Head Trauma Rehabilitation. 9*(3), 104-115.

Landrum, P. K., Schmidt, N. D., & McLean, A. (1995). *Outcome-oriented rehabilitation. Principles, Strategies and Tools for Effective Program Management.* First edition. Maryland: Aspen Publishers.

Lefebvre, H., Cloutier, G. & Josée Levert, M. (2008). Perspectives of survivors of traumatic brain injury and their caregivers on long-term social integration. *Brain Injury*, 22(7-8), 535–543.

Lefebvre, H. & Levert, M.-J. (2012). The close relatives of people who have had a traumatic brain injury and their special needs. *Brain Injury*, 26(9), 1084–1097.

Leith, K.H., Phillips, L., & Sample, P.L. Exploring the service needs and experiences of persons with TBI and their families: The South Carolina experience. *Brain Injury. 18*(12), 1191-1208.

Litchman, M. (2006). Qualitative Research in Education: A User's Guide. Thousand Oaks, CA: Sage.

Longlois, J. A., Rutland-Brown, W., & Wald, M. M. (2006). The epidemiology and impact of traumatic brain injury. *Journal of Head Trauma Rehabilitation*, *21*(5), 375-8.

McColl, M.A., Bickenbach, J., Johnston, J., Nishihama, S., Schumaker, M., Smith, K., Smith, M. & Yealland, B. (2000). Changes in spiritual beliefs after traumatic disability. *Archives of Physical Medicine and Rehabilitation*, 81(6), 817–823.

McColl, M. A., Carlson, P., Johnston, J., Minnes, P., Shue, K., Davies, D., & Karlovits, T. (1998). The definition of community integration: perspectives of people with brain injuries. *Brain Injury*, *12*(1), 15–30.

McHugh, M. L. (2012). Interrater reliability: the kappa statistic. *Biochemia Medica*, 22(3), 276-282.

McIntyre, D. (2010). *Private sector involvement in funding and providing health services in South Africa: Implications for equity and access to health care*. Regional network for equity in health in East and southern Africa (EQUINET). Cape Town: Health Economics Unit, University of Cape Town.

Mistiaen, P., Francke, A. L., & Poot, E. (2007). Interventions aimed at reducing problems in adult patients discharged from hospital to home: A systematic meta-review. *BMC Health Services Research*, *7*(1), 47.

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

Nalder, E., Fleming, J., Foster, M., Cornwell, P., Shields, C., & Khan, A. (2012). Identifying factors associated with perceived success in the transition from hospital to home after brain injury. *The Journal of Head Trauma Rehabilitation*, *27*(2), 143-153.

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

Netcare. (2015a). *Clinical Governance*. Retrieved 3 May 2015, from: https://www.netcare.co.za/live/content.php?Item_ID=249.

Netcare. (2015b). *Netcare Rehabilitation Hospital*. Retrieved 3 May 2015, from: https://www.netcare.co.za/live/content.php?Item_ID=5587

NHS Choices. (2013). *NHS Continuing Healthcare*. Retrieved 16 May 2015, from: http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/nhs-continuing-care.aspx#can

Padilla-Diaz. (2015). Phenomenology in educational qualitative research: philosophy as science or philosophical science. *International Journal of Educational Excellence, 1* (2), 101-110.

Paterson, B., Kieloch, B., & Gmiterek, J. (2001). ‘They never told us anything’: Postdischarge instruction for families of persons with brain injuries. *Rehabilitation Nursing*, *26*(2), 48-53.

Roozenbeek, B., Maas, A. I., & Menon, D. K. (2013). Changing patterns in the epidemiology of traumatic brain injury. *Nature Reviews Neurology*, *9*(4), 231-236.

Rotondi, A.J., Sinkule, J., Balzer, K., Harris, J. & Moldovan, R. (2007). A qualitative needs assessment of persons who have experienced traumatic brain injury and their primary family caregivers. *Journal of Head Trauma Rehabilitation*, 22(1), 14–25.

Rule, S., Lorenzo, T., Wolmarans, M., Watermeyer, B., Swartz, L., Lorenzo, T., & Schneider, M. (2006). Community-based rehabilitation: New challenges. In B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider & M. Priestley (Eds.), *Disability and social change: A South African agenda* (pp. 273-290). Cape Town: Human Sciences Research Council.

Sander,A.M., Caroselli, J.S., High, W.M., Becker, C.L., Neese, L.E. & Scheibel, R. (2002). Relationship of family functioning to progress in a post-acute rehabilitation programme following traumatic brain injury. *Brain Injury*.16(8), 649-657.

Sander, A.M., Fuchs, K.L., High, W.M., Hall, K.M., Kreutzer, J.S. & Rosenthal, M. (1999). The community integration questionnaire revisited: An assessment of factor structure and validity. *Archives of Physical Medicine and Rehabilitation*, 80(10), 1303–1308.

Seale, G.S., Caroselli, J.S., High, W.M., Becker, C.L., Neese, L.E. & Scheibel, R. (2002). Use of the community integration questionnaire (CIQ) to characterize changes in functioning for individuals with traumatic brain injury who participated in a post-acute rehabilitation programme. *Brain Injury*, 16(11), 955–967.

Shames, J., Treger, I., Ring, H. & Giaquinto, S. (2007). Return to work following traumatic brain injury: Trends and challenges. *Disability and Rehabilitation*, 29(17), 1387–1395.

Sinnakaruppan, I., Downey, B. & Morrison, S. (2005a). Head injury and family carers: A pilot study to investigate an innovative community-based educational programme for family carers and patients. *Brain Injury*, 19(4), 283–308.

Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, *1*(1), 39–54.

Threats, T.T. (2006). Towards an international framework for communication disorders: Use of the ICF. *Journal of Communication Disorders, 39* (4), 251-265.

Threats, T.T. & Worrall, L. (2004). Classifying communication disability using the ICF. *Advances in Speech-Language Pathology, 6*(1), 53-62.

Turner, B., Fleming, J., Cornwell, P., Worrall, L., Ownsworth, T., Haines, T., & 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.

Turner, B. J., Fleming, J. M., Ownsworth, T. L., & Cornwell, P. L. (2007). The transition from hospital to home for individuals with acquired brain injury: A literature review and research recommendations. *Disability & Rehabilitation*, *30*(16), 1153–1176.

van Velzen, J.M., van Bennekom, C.A.M., Edelaar, M.J.A., Sluiter, J.K. & Frings-Dresen, M.H.W. (2009). How many people return to work after acquired brain injury? A systematic review. *Brain Injury*, 23(6), 473–488.

Watt, N., & Penn, C. (2000). Predictors and indicators of return to work following traumatic brain injury in South Africa: Findings from a preliminary experimental database. *South African Journal of Psychology*, *30*(3), 27–37.

Wehman, P., Gentry, T., West, M., & Arango-Lasprilla, J. C. (2009). Community integration: Current issues in cognitive and vocational rehabilitation for individuals with ABI. *Journal of Rehabilitation Research and Development*, *46*(6), 909-918.

Willer B, Ottenbacher K. J., & Coad, M. L. (1994). The community integration questionnaire: A comparative examination. *American Journal of Physical Medicine*, *73*(2), 103-111.

Winkler, D., Unsworth, C., & Sloan, S. (2006). Factors that lead to successful community integration following severe traumatic brain injury. *Journal of Head Trauma Rehabilitation*, *21*(1), 8–21.

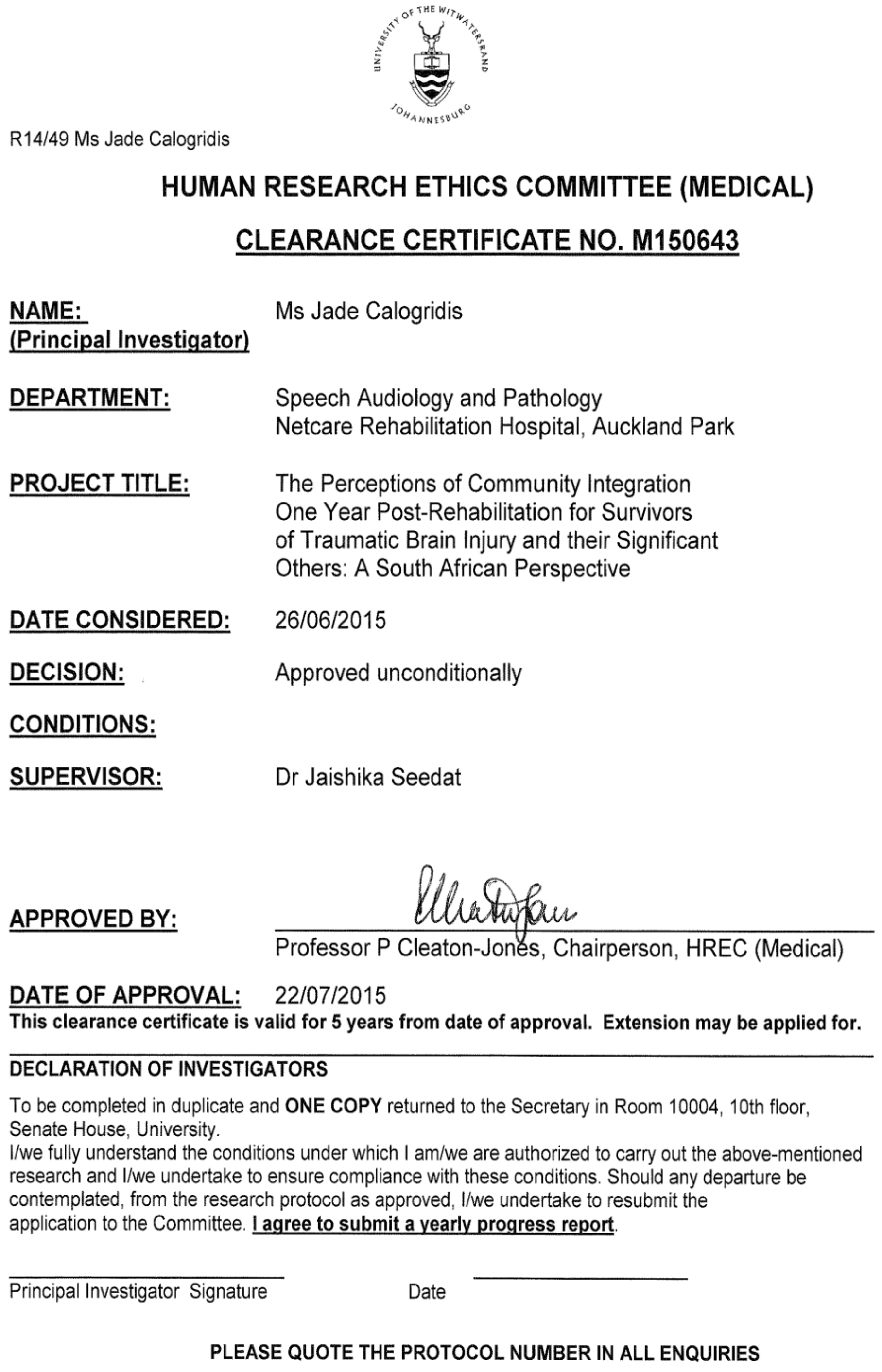
Wood, J. P., Connelly, D. M., & Maly, M. R. (2010). 'Getting back to real living': A qualitative study of the process of community reintegration after stroke. *Clinical Rehabilitation*, *24*(11), 1045–1056.

World Health Organisation. (2001). *International Classification of Functioning, Disability, and Health.* Geneva, Switzerland: World Health Organisation.

World Health Organisation (WHO). (2002). *Towards a Common Language for Functioning, Disability and Health. The International*

Classification of Functioning, Disability and Health. Geneva: World Health Organisation.

Appendix A: Human Research Ethics Certificate of Approval



UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

R14/49 Ms Jade Calogridis

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M150643

NAME: **(Principal Investigator)**	Ms Jade Calogridis
DEPARTMENT:	Speech Audiology and Pathology Netcare Rehabilitation Hospital, Auckland Park
PROJECT TITLE:	The Perceptions of Community Integration One Year Post-Rehabilitation for Survivors of Traumatic Brain Injury and their Significant Others: A South African Perspective
DATE CONSIDERED:	26/06/2015
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr Jaishika Seedat
APPROVED BY:	Professor P Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	22/07/2015

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

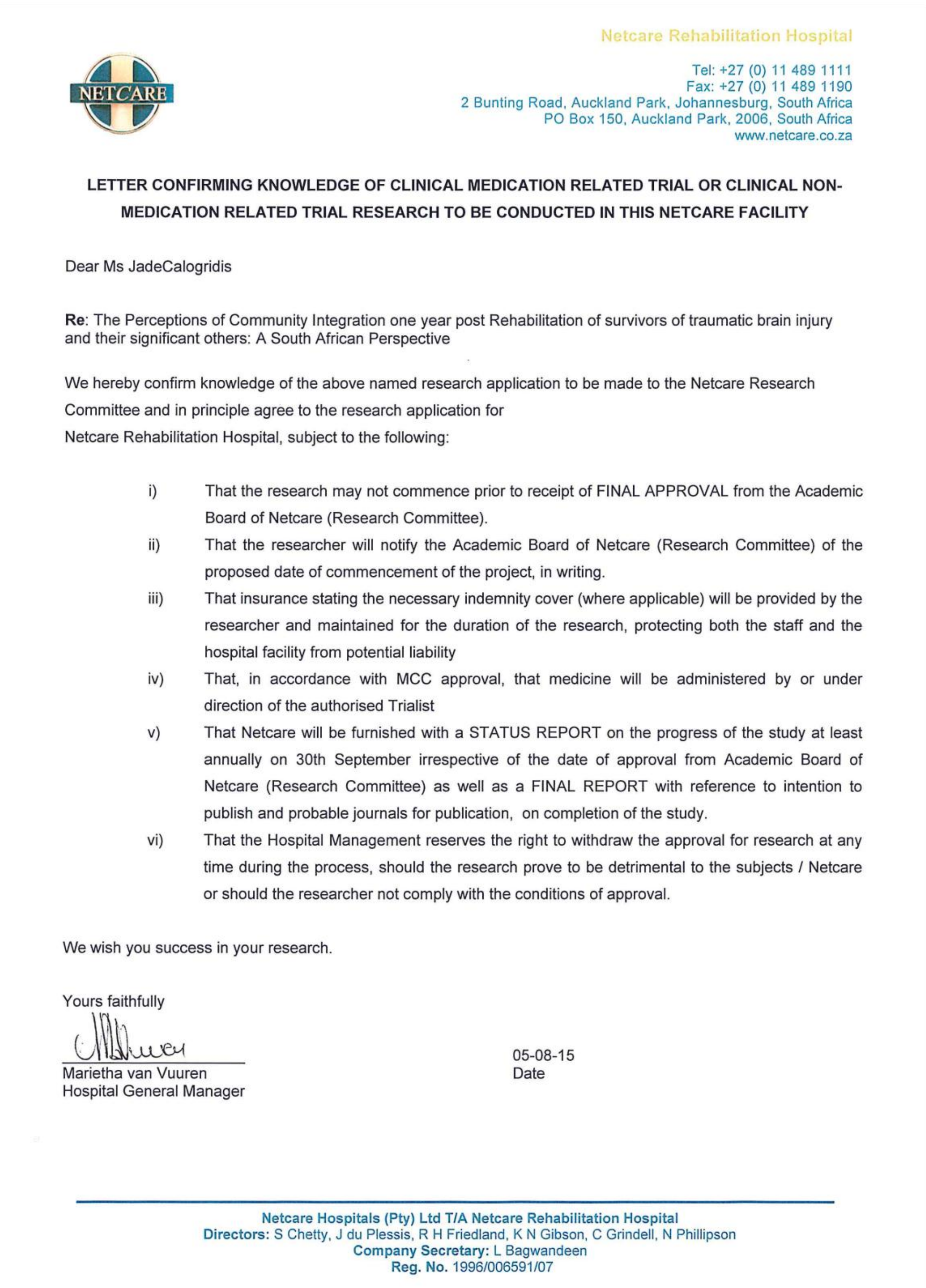
DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.
I/we fully understand the conditions under which I am/we are authorized 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 the application to the Committee. **I agree to submit a yearly progress report**.

Principal Investigator Signature ____________ Date ____________

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix B: Hospital Medical Advisory Ethics Committee (MAEC) Certificate of Approval



Netcare Rehabilitation Hospital
Tel: +27 (0) 11 489 1111
Fax: +27 (0) 11 489 1190
2 Bunting Road, Auckland Park, Johannesburg, South Africa
PO Box 150, Auckland Park, 2006, South Africa
www.netcare.co.za

LETTER CONFIRMING KNOWLEDGE OF CLINICAL MEDICATION RELATED TRIAL OR CLINICAL NON-MEDICATION RELATED TRIAL RESEARCH TO BE CONDUCTED IN THIS NETCARE FACILITY

Dear Ms JadeCalogridis

Re: The Perceptions of Community Integration one year post Rehabilitation of survivors of traumatic brain injury and their significant others: A South African Perspective

We hereby confirm knowledge of the above named research application to be made to the Netcare Research Committee and in principle agree to the research application for
Netcare Rehabilitation Hospital, subject to the following:

i) That the research may not commence prior to receipt of FINAL APPROVAL from the Academic Board of Netcare (Research Committee).
ii) That the researcher will notify the Academic Board of Netcare (Research Committee) of the proposed date of commencement of the project, in writing.
iii) That insurance stating the necessary indemnity cover (where applicable) will be provided by the researcher and maintained for the duration of the research, protecting both the staff and the hospital facility from potential liability
iv) That, in accordance with MCC approval, that medicine will be administered by or under direction of the authorised Trialist
v) That Netcare will be furnished with a STATUS REPORT on the progress of the study at least annually on 30th September irrespective of the date of approval from Academic Board of Netcare (Research Committee) as well as a FINAL REPORT with reference to intention to publish and probable journals for publication, on completion of the study.
vi) That the Hospital Management reserves the right to withdraw the approval for research at any time during the process, should the research prove to be detrimental to the subjects / Netcare or should the researcher not comply with the conditions of approval.

We wish you success in your research.

Yours faithfully

Marietha van Vuuren
Hospital General Manager

05-08-15
Date

Netcare Hospitals (Pty) Ltd T/A Netcare Rehabilitation Hospital
Directors: S Chetty, J du Plessis, R H Friedland, K N Gibson, C Grindell, N Phillipson
Company Secretary: L Bagwandeen
Reg. No. 1996/006591/07

Appendix C: Information sheet and Permission request to management of Netcare Rehabilitation/ Rita Henn & Partners

Code:

Speech-Language Pathology & Audiology
School of Human & Community Development
Private Bag 3, Wits 2050, South Africa. Telephone: +27 11-717-4500/2/3/4. Fax: +27-11-717-4559

Dear Madam/Sir,

Introduction

Dear Madam/Sir,

Hello. My name is Jade Calogridis, and I am conducting research for the purposes of obtaining a Master's Degree in the Discipline of Speech-Language Pathology at the University of the Witwatersrand. I am conducting a study titled 'The perceptions of community integration one year post-rehabilitation for survivors of traumatic brain injury and their significant others: a South African perspective' as part of my Masters Degree. The aim of my research is to investigate whether patients who have suffered a traumatic brain injury and undergone inpatient and outpatient rehabilitation at this facility, are integrating back into the community and participating actively in life activities, a year or more after returning home. The research is being conducted under the supervision of Dr Jaishika Seedat. The study will require that we have access to the files of patients whom have been discharged and whom fit the inclusion criteria for the study. We would like to seek your permission to conduct the study and access these files.

What is involved in the study?

If the participants decide to take part in this study it will mean that they agree have their hospital records reviewed as well as to be interviewed by myself, at a time and place that is convenient for them. The interview will last for approximately one to two hours. With their permission this interview will be recorded in order to make sure I can refer back to what they may have said and report on it accurately in the results section.

Risks

There will be no risks involved if they do decide to participate in the study.

Benefits

There will be no benefits to them participating in the study. However, with the information gained from the study, other people with TBI and their loved ones may find the transition back into the home environment and community more easy and findings may help them to cope better in their everyday lives.

Participation is voluntary

The decision to participate is voluntary, and they will not be advantaged or disadvantaged in any way for choosing to participate or not to participate in the study.

Reimbursements

If it is necessary for the participants to travel to the site of the interview, they will be compensated for transportation fees.

Confidentiality

All of their responses will be kept confidential, and no information that could identify them will be included in the research report. The interview material (tapes and transcripts) will only be seen and studied by myself and possibly the supervisor. All tape recordings will be kept in a secure place by the University of the Witwatersrand throughout the study and for five years after that. Following this will they will be destroyed.

The participants will be made aware of their rights, including that

- They may refuse to answer any questions they would prefer not to.
- They may choose to withdraw from the study at any point with no negative consequences.

- They have the right to withhold any of the recorded information from me.
- They have the right to contact me at any time with any queries or concerns
- If they have any concerns or complaints about the study or me as the researcher, they have the right to contact the Human Research Ethics Committee (Medical) chairperson, Professor Cleaton-Jones on 011 717 2301 or the Research Administration Office on 011 717 1234.

This research will contribute both to a larger body of knowledge on community integration for persons with TBI and may assist participants in understanding their own circumstances better. A one page summary of the research results will be made available on request.

For any further information I can be contacted telephonically on 083 669 0207 or via e-mail at jadecalogridis@gmail.com and my supervisor can be contacted at (011) 717 4576.

Sincerely, Jade Calogridis

Appendix D: Permission from Management of Netcare Rehabilitation/ Rita Henn & Partners

I___________________________________ hereby give permission for Jade Calogridis to conduct her study, on community integration of persons with Traumatic Brain Injury (TBI) after discharge from rehabilitation services.

I understand that the study will involve the following:

- A retrospective record review of the patient files.
- Patients who have been discharged from rehabilitation, and their significant others will be interviewed.
- The interviews will be recorded.
- All of the responses from the interviews will be kept confidential, and no information that could identify them will be included in the research report.
- The interview material (tapes and transcripts) will only be seen and studied by myself and possibly the supervisor.
- All tape recordings will be kept in a secure place by the University of the Witwatersrand throughout the study and for five years after that. Following this will they will be destroyed.
-

_________________________	_________________________
Hospital/Practice Manager Name (Print)	**Hospital/Practice Manager Signature**

____

Date

__________________________	__________________________
Witness Name (Print)	**Witness Signature**

____

Date

Appendix E: Participant (Person with TBI) Information Sheet

Code:

Speech-Language Pathology & Audiology
School of Human & Community Development
Private Bag 3, Wits 2050, South Africa. Telephone: +27 11-717-4500/2/3/4. Fax: +27-11-717-4559

Dear Madam/Sir,

Introduction

Hello. My name is Jade Calogridis, and I am a Speech Pathologist doing my Master's Degree at The University of the Witwatersrand. I am conducting a study titled 'The perceptions of community integration one year post-rehabilitation for survivors of traumatic brain injury and their significant others: a South African perspective' as part of my Masters Degree. The document you are reading is an information sheet. In it I will describe the reasons for why the study is being done, how it will be conducted and what will be required of the participants who are willing to volunteer. I will give you the document to read and will also attach a specially adapted form with pictures that will help to make sure the information is clear to you. If you require assistance I will read through the document with you, providing further clarification where needed. Once you have finished reading the document, I will ask you some questions to make sure you have fully understood everything. I will give you time to make a decision. If you agree, I will ask that you sign a form that shows that you consent to participating in the study. You will then be given a copy of the form you sign, to keep.

Research is the process to learn the answer to a question. The aim of my research is to investigate whether you, a person who has suffered a traumatic brain injury; and had both inpatient and outpatient therapy at Netcare Rehabilitation Hospital, are getting involved in your community and participating actively in life activities. With this research I also hope to understand what has helped you and what difficulties you have had with this process as well as what changes you believe have made getting back into the community easier or what could have made the process better. This will hopefully help to guide other people who have experienced a TBI to make these changes more easily and to cope better in their everyday lives

Invitation to participate

I will be doing this research under the guidance of a supervisor, Dr Jaishika Seedat. We would like to invite you to take part in this study.

What is involved in the study?

If you decide to take part in this study it will mean that you agree to be interviewed by myself, at Netcare Rehabilitation Hospital in Auckland Park. The interview will last for approximately one to two hours with breaks in between. With your permission this interview will be recorded in order to make sure I can refer back to what you may have said and report on it accurately in the results section. If necessary, it will be conducted over two sessions.

Risks

There will be no risks involved if you do decide to participate in the study.

Benefits

There will be no benefits to you participating in the study. However it may help other people with Traumatic Brain Injury(TBI) make the changes back into the community more easily and help them to cope better in their everyday lives.

Participation is voluntary

The decision to participate is voluntary, and you will not be advantaged or disadvantaged in any way for choosing to participate or not to participate in the study.

Reimbursements

If it is necessary for you to travel to the site of the interview, you will be compensated for transportation fees.

Confidentiality

All of your responses will be kept confidential, and no information that could identify you will be included in the research report. The interview material (tapes and transcripts) will only be seen and studied by myself and possibly the supervisor. All tape recordings will be kept in a secure place by the University of the Witwatersrand throughout the study and for five years after that. Following this will they will be destroyed.

What are my rights?

- You may refuse to answer any questions you would prefer not to.
- You may choose to withdraw from the study at any point with no negative consequences.
- You have the right to withhold any of the recorded information from me.
- You have the right to contact me at any time with any queries or concerns
- If you have any concerns or complaints about the study or me as the researcher, you have the right to contact the Human Research Ethics Committee (Medical) chairperson, Professor Cleaton-Jones on 011 717 2301 or the Research Administration Office on 011 717 1234.

If you choose to participate in the study please fill in your details on the form below. For any further information I can be contacted telephonically on 083 669 0207 or via e-mail at jadecalogridis@gmail.com and my supervisor can be contacted at (011) 717 4576.

This research will contribute both to a larger body of knowledge on community integration for persons with TBI and may assist you in understanding your own circumstances better. A one page summary of the research results will be made available on request.

Sincerely,

Jade Calogridis

Appendix F: Informed consent to participate and to be interviewed

I_______________________________ (NAME OF PARTICIPANT), the undersigned, agree to volunteer in this study in writing . I understand that I will be interviewed  by Jade Calogridis for her study on community integration  of persons with Traumatic Brain Injury (TBI)  after discharge from rehabilitation services  

I understand the following:

- The research is for a degree- Masters  at Wits University 

- I will allow Jade the researcher to go through my hospital medical file 

- Participation in this interview is voluntary 

-I may refuse to answer any questions I would prefer not to 

- The interview will be tape recorded for later use 

- I can hold back any tape-recorded material from the researcher. The recordings may be used in the future for research.

- I may withdraw from the study at any time.

-No information that may identify me will be included in the research report, and my responses will remain confidential

-Direct quotes from this interview may be used in the research report

-There are no direct risks or benefits involved in my participation.

- I can leave the study at any stage, for any reason and without negative consequences to myself.

- I can contact Jade at any time to ask about the study.

- I have read or spoken about this document and the information sheet. I recognize Jade Calogridis as the primary researcher for this project and agree to participate in her study.

______________________________ ______________________________

Participant Name (Print) **Participant Signature**

____

Date

______________________________ ______________________________

Witness Name (Print) **Witness Signature**

____

Date

Appendix G: Participant (Significant Other) Information Sheet

Code:

Speech-Language Pathology & Audiology
School of Human & Community Development
Private Bag 3, Wits 2050, South Africa. Telephone: +27 11-717-4500/2/3/4. Fax: +27-11-717-4559

Dear Madam/Sir,

Introduction

Hello. My name is Jade Calogridis, and I am a Speech Pathologist doing my Master's Degree at the University of the Witwatersrand. I am conducting a study titled 'The perceptions of community integration one year post-rehabilitation for survivors of traumatic brain injury and their significant others: a South African perspective' as part of my Masters Degree. The document you are reading is an information sheet. In it I will describe the reasons for why the study is being done, how it will be conducted and what will be required of the participants who are willing to volunteer. I will give you the document to read and if you require assistance I will read through the document with you, providing further clarification where needed. Once you have finished reading the document, I will ask you some key questions to make sure you have fully understood everything. I will give you time to make a decision. If you agree, I will ask that you sign a form that shows that you consent to participating in the study. You will then be given a copy of the form you sign to keep.

Research is just the process to learn the answer to a question. The aim of my research is to investigate whether you believe, your loved one, a person who has suffered a traumatic brain injury; and had both inpatient and outpatient therapy at Netcare Rehabilitation Hospital, is integrating in his/her community and participating actively in life activities. With this research I also hope to understand what you believe has helped your loved one and what difficulties they might have had with this process as well as what changes you believe have made integrating easier for them or what could have made the process better. Your contribution in this research is very important because you may help to provide information that is difficult for your loved one with TBI to share due to the cognitive or communication difficulties that he/she may have incurred. Also we are interested in the particular perspectives which you, as a significant other, may have that your loved one who has experienced a TBI may not fully understand and be able to inform us on.

Invitation to participate

I will be doing this research under the guidance of a supervisor; Dr Jaishika Seedat. We would like to invite you to take part in this study.

What is involved in the study?

If you decide to take part in this study it will mean that you agree to be interviewed by myself, at Netcare Rehabilitation Hospital in Auckland Park. The interview will last for approximately one to two hours and will be held after the interview with your loved one, the person who has suffered a traumatic brain injury. With your permission this interview will be recorded in order to make sure I can refer back to what you may have said and report on it accurately in the results section.

Risks

There will be no risks involved if you do decide to participate in the study.

Benefits

There will be no benefits to you participating in the study. However, with the information gained from the study, other people with TBI and their loved ones may find the transition back into the home environment and community more easy and help them to cope better in their everyday lives.

Participation is voluntary

The decision to participate is voluntary, and you will not be advantaged or disadvantaged in any way for choosing to participate or not to participate in the study.

Reimbursements

If it is necessary for you to travel to the site of the interview, you will be compensated for transportation fees.

Confidentiality

All of your responses will be kept confidential, and no information that could identify you will be included in the research report. The interview material (tapes and transcripts) will only be seen and studied by myself and possibly the supervisor. All tape recordings will be kept in a secure place by the University of the Witwatersrand throughout the study and for five years after that. Following this will they will be destroyed.

What are my rights?

- You may refuse to answer any questions you would prefer not to.
- You may choose to withdraw from the study at any point with no negative consequences.
- You have the right to withhold any of the recorded information from me.
- You have the right to contact me at any time with any queries or concerns
- If you have any concerns or complaints about the study or me as the researcher, you have the right to contact the Human Research Ethics Committee (Medical) chairperson, Professor Cleaton-Jones on 011 717 2301 or the Research Administration Office on 011 717 1234.

If you choose to participate in the study please fill in your details on the form below. For any further information I can be contacted telephonically on 083 669 0207 or via e-mail at jadecalogridis@gmail.com and my supervisor can be contacted at (011) 717 4576.

This research will contribute both to a larger body of knowledge on community integration for persons with TBI and may assist you in understanding your own circumstances better. A one page summary of the research results will be made available on request.

Sincerely, Jade Calogridis

Appendix H: Informed consent to participate and to be interviewed (SO)

I______________________________ (NAME OF PARTICIPANT), the undersigned, agree to volunteer in this study in writing. I understand that I will be interviewed by Jade Calogridis for her study on community integration of persons with Traumatic Brain Injury (TBI) after discharge from rehabilitation services

I understand the following:

- The research is for a degree- Masters at Wits University

- Participation in this interview is voluntary

- I may refuse to answer any questions I would prefer not to

- The interview will be tape recorded for later use

- I can hold back any tape-recorded material from the researcher. The recordings may be used in the future for research.

- I may withdraw from the study at any time.

-No information that may identify me will be included in the research report, and my responses will remain confidential

-Direct quotes from this interview may be used in the research report

-There are no direct risks or benefits involved in my participation.

- I can leave the study at any stage, for any reason and without negative consequences to myself.

- I can contact Jade at any time to ask about the study.

- I have read or spoken about this document and the information sheet. I recognize Jade Calogridis as the primary researcher for this project and agree to participate in her study.

____________________________	____________________________
Participant Name (Print)	**Participant Signature**

____

Date

____________________________	____________________________
Witness Name (Print)	**Witness Signature**

____

Date

Appendix I: Informed consent to be audio-recorded

I___________________________________ hereby consent to my interview with Jade Calogridis for her study, on community integration of persons with Traumatic Brain Injury (TBI) after discharge from rehabilitation services, being tape-recorded.

I understand that:

-The tapes and transcripts will not be seen or heard by any person in this organisation at any time, and will only be processed by the researcher.

-All tape recordings will be destroyed after the research is complete.

-No identifying information will be used in the transcripts or the research report.

-The transcriptions will be kept in a safe place throughout the research process.

-Direct quotes from the interview may be used in the research report.

____

Participant Name (Print)

____

Participant Signature

____

Date

____

Witness Name (Print)

____

Witness Signature

____

Date

Appendix J: Information sheet to Research Assistants, agreement to participate and maintain confidentiality

Code:

Speech-Language Pathology & Audiology
School of Human & Community Development
Private Bag 3, Wits 2050, South Africa. Telephone: +27 11-717-4500/2/3/4. Fax: +27-11-717-4559

Dear Madam/Sir,

Hello. My name is Jade Calogridis, and I am conducting research for the purposes of obtaining a Master's Degree in the Discipline of Speech-Language Pathology at the University of the Witwatersrand. The aim of my research is to investigate whether patients who have suffered a traumatic brain injury and undergone inpatient and outpatient rehabilitation at Netcare Rehabilitation Hospital, are integrating back into the community and participating actively in life activities, a year or more after returning home. The research is being conducted under the supervision of Dr Jaishika Seedat. The study will require that we have access to the files of patients whom have been discharged and whom fit the inclusion criteria for the study.

We would like to seek your participation and expertise in conducting a brief assessment of the potential participants in order to establish their FIM scores as well as their functional outcome level based on those outlined by Landrum, Schmidt & Mclean (1995). (Outline of levels will be available on request)

I will be doing this research under the guidance of a supervisor; Dr Jaishika Seedat. We would like to invite you to participate and assist in this study.

Yours Sincerely,
Jade Calogridis

Appendix K: Consent from Research Assistant to Participate

I___________________________________ hereby give consent to participate with Jade Calogridis in completing her study, on community integration of persons with Traumatic Brain Injury (TBI) after discharge from rehabilitation services.

I understand that the study will involve the following:

- A retrospective record review of the patient files.
- Patients who have been discharged from rehabilitation, and their significant others will be interviewed.
- My participation and expertise will be required in conducting a brief assessment of the participants (persons with TBI) in order to establish their FIM scores as well as their functional outcome level based on those outlined by Landrum, Schmidt & Mclean (1995).
- All information obtained will be kept confidential, and no information that could identify participants will be included in the research report.

___________________________ ___________________________

Research Assistant Name (Print) **Research Assistant Signature**

____

Date

___________________________ ___________________________

Witness Name (Print) **Witness Signature**

____

Date

Appendix L: Interview Questions

Semi-structured interview guideline (Participants)

(Adaptations from pilot study highlighted in red)

Areas to be covered during the interview:

- Please define what you understand by community integration/active participation in the community
- Describe your function within the family and community post-TBI
- What contributes to community integration/active participation?
- Describe your previous and current relationships with people at home, within the community, friends and at work
- Describe your typical day currently. (Based on this the interviewer will comment and probe further on changes that may or may not have occurred).
- What has helped/could help to contribute further to your community integration?
- The previous question will thus lead to this one – Describe how you feel after the TBI and being back home – (based on responses, sub questions will be asked)
- Is there anything you would like to add?

Semi-structured interview guideline (SOs)

- Describe your loved one's function within the family and community post-TBI
- Describe his/her previous and current relationships with people at home, within the community, friends and at work
- Describe his/her typical day currently. (Based on this, the interviewer will comment and probe further on changes that may or may not have occurred).
- The previous question will thus lead to this one – Describe how you think your loved one feels after the TBI and being back home – (based on responses, sub questions will be asked)

Appendix M: CIQ-R

The Community Integration Questionnaire-Revised (CIQ-R)

Name: ____ **Date:** ____________

1 Who usually does the shopping for groceries or other necessities in your household?

☐ Yourself alone ☐ Yourself and someone else ☐ Someone else

2 Who usually prepares meals in your household?

☐ Yourself alone ☐ Yourself and someone else ☐ Someone else

3 In your home who usually does normal everyday housework?

☐ Yourself alone ☐ Yourself and someone else ☐ Someone else

4 Who usually cares for the children in your home?

☐ Yourself alone ☐ Yourself and someone else ☐ Someone else

☐ Not applicable (no children under 17 yrs in the home)

5 Who usually plans social arrangements such as get-togethers with family and friends?

☐ Yourself alone ☐ Yourself and someone else ☐ Someone else

6 Who usually looks after your personal finances, such as banking or paying bills?

☐ Yourself alone ☐ Yourself and someone else ☐ Someone else

7 Approximately how many times a month do you usually participate in shopping outside your home?

☐ 5 or more ☐ 1-4 times ☐ Never

8 Approximately how many times a month do you usually participate in leisure activities such as movies, sports, restaurants, etc?

☐ 5 or more ☐ 1-4 times ☐ Never

9 Approximately how many times a month do you usually visit friends or relatives?

☐ 5 or more ☐ 1-4 times ☐ Never

10 When you participate in leisure activities do you usually do this alone or with others?

☐ Mostly alone ☐ Mostly with family members ☐ Mostly with friends who have a disability

☐ Mostly with friends who do not have a disability ☐ With a combination of family and friends

Permission to use the CIQ-R should be requested by contacting Libby Callaway via email at libby.callaway@summerfoundation.org.au or Barry Willer at bswiller@buffalo.edu

11 Do you have a best friend in whom you confide?

☐ Yes ☐ No

12 How often do you travel outside the home?

☐ Almost every day ☐ Almost every week ☐ Seldom / never (less than once per week)

13 Please check the answer that best corresponds to your current (during the past month) work situation:

☐ Full-time (more than 20 hours per week)
☐ Part-time (less than or equal to 20 hours per week)
☐ Not working, but actively looking for work
☐ Not working, not looking for work
☐ Not applicable, retired due to age

14 Please check the answer that best corresponds to your current (during the past month) school or training program situation:

☐ Full-time
☐ Part-time
☐ Not attending school or training program
☐ Not applicable, retired due to age

15 In the past month, how often did you engage in volunteer activities?

☐ 5 or more ☐ 1-4 times ☐ Never

16 How often do you write to people for social contact using the Internet (e.g., email, social networking sites such as Facebook)?

☐ Every day / most days ☐ Almost every week ☐ Seldom / never

17 How often do you talk to people for social contact using an online video link (e.g. Skype, FaceTime)?

☐ Every day / most days ☐ Almost every week ☐ Seldom / never

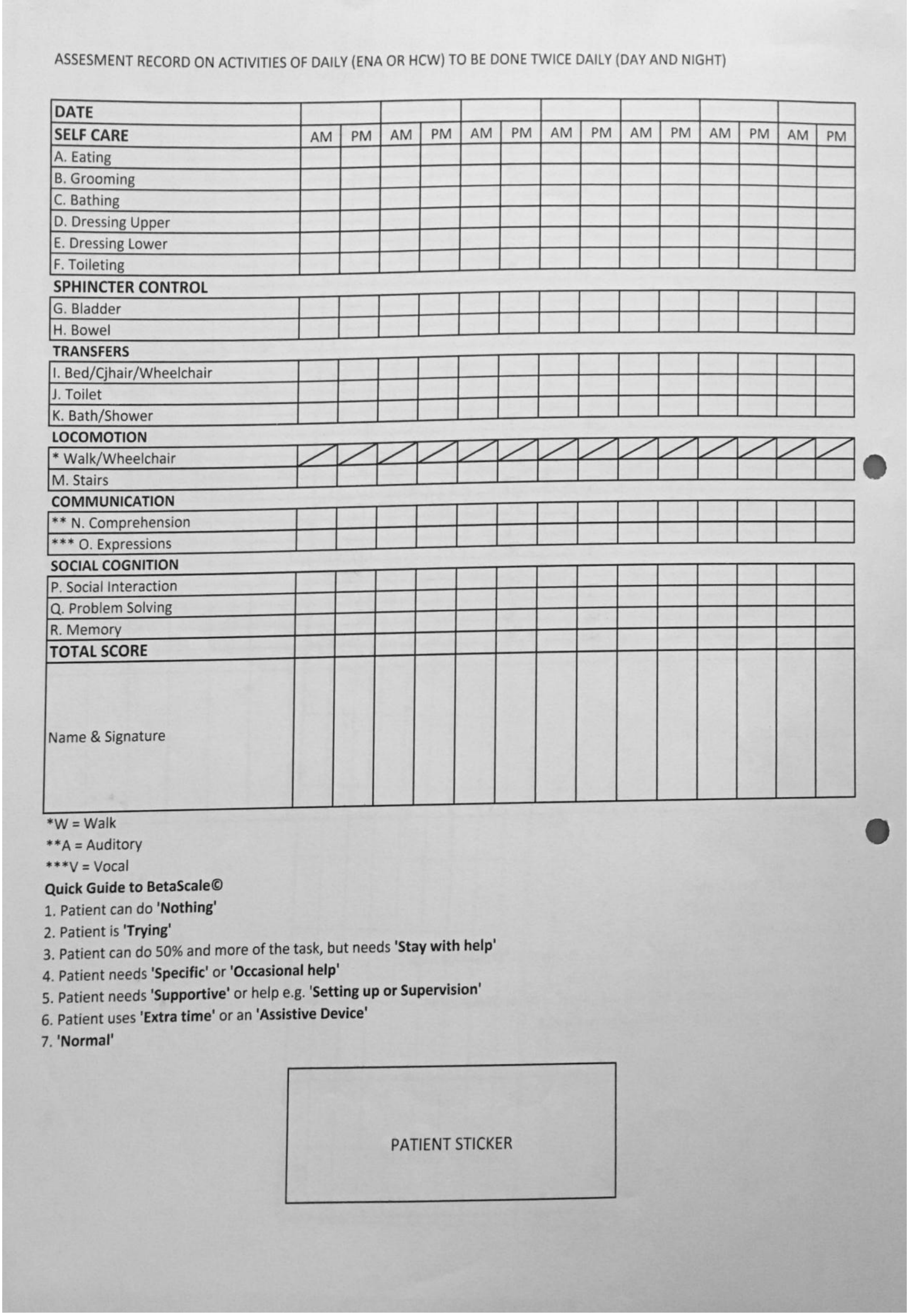
18 How often do you make social contact with people by talking or text messaging using your phone?

☐ Every day / most days ☐ Almost every week ☐ Seldom / never

Comments:

Permission to use the CIQ-R should be requested by contacting Libby Callaway via email at libby.callaway@summerfoundation.org.au or Barry Willer at bswiller@buffalo.edu

Appendix N: FIM



ASSESMENT RECORD ON ACTIVITIES OF DAILY (ENA OR HCW) TO BE DONE TWICE DAILY (DAY AND NIGHT)

DATE														
SELF CARE	AM	PM	AM	PM	AM	PM	AM	PM	AM	PM	AM	PM	AM	PM
A. Eating														
B. Grooming														
C. Bathing														
D. Dressing Upper														
E. Dressing Lower														
F. Toileting														
SPHINCTER CONTROL														
G. Bladder														
H. Bowel														
TRANSFERS														
I. Bed/Cjhair/Wheelchair														
J. Toilet														
K. Bath/Shower														
LOCOMOTION														
* Walk/Wheelchair														
M. Stairs														
COMMUNICATION														
** N. Comprehension														
*** O. Expressions														
SOCIAL COGNITION														
P. Social Interaction														
Q. Problem Solving														
R. Memory														
TOTAL SCORE														
Name & Signature														

*W = Walk
**A = Auditory
***V = Vocal

Quick Guide to BetaScale©

1. Patient can do **'Nothing'**
2. Patient is **'Trying'**
3. Patient can do 50% and more of the task, but needs **'Stay with help'**
4. Patient needs **'Specific'** or **'Occasional help'**
5. Patient needs **'Supportive'** or help e.g. **'Setting up or Supervision'**
6. Patient uses **'Extra time'** or an **'Assistive Device'**
7. **'Normal'**

PATIENT STICKER