



**A QUALITATIVE EXPLORATION OF EXPERIENCES OF OTHERS AND  
ACCOUNTS OF SELF IN THE NARRATIVES OF PERSONS WHO HAVE  
EXPERIENCED TRAUMATIC BRAIN INJURY**

By

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## ABSTRACT

Traumatic brain injury (TBI) affects thousands of people in South Africa. Our knowledge regarding this phenomenon has expanded rapidly and the problematic psychological wellbeing of persons who have been injured through TBI has been well documented. When reviewing the published literature regarding TBI it would appear that the majority originate from a positivist epistemology, quantitative methodology, and focus mainly on cognitive and/or motor ability changes of the injured individual. Furthermore, literature regarding interaction between the injured person and others tend to focus on uninjured family members' experience of and adaptation to the injured person – generally ignoring the injured person's experience of others. This study addressed this gap in the literature by making use of a qualitative research design to explore how injured persons' experience of others might contribute to the challenges, other than those related to cognitive and physical changes, persons face following TBI. Specifically, this study investigated whether themes that suggest a "loss of self" could be identified in the narratives of the participants' experiences of others. While not being able to support the idea of "loss of self" in the participants' narratives, there are indications that experiences of others may add to the challenges injured persons face following TBI.

### Key Terms

Traumatic brain injury, TBI, injured person's experiences of others, self-narratives, narrative psychology, identity construction, qualitative research, constant comparative method, grounded analysis



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## CHAPTER 1

### FIRST THINGS FIRST

#### *Introduction*

The online home of the South African National Lobby Group for People with Acquired Brain Injuries (BIG) refers to approximately 80 000 new cases of traumatic brain injury (TBI) in South Africa each year (BIG, 2005). The potential magnitude of human suffering from such a statistic should be clear. Our knowledge regarding brain injury is expanding rapidly but we appear to have a better understanding of what happens inside an injured head than we have about what happens between the person whom the head belongs to and other persons. This study aimed to start addressing this vacuum in our knowledge of TBI.

#### *A point of order*

For persons who are accustomed to, or prefer, a more formal style of presentation I ask you to bear with my, at times, less formal presentation style<sup>1</sup>. This is in keeping with the theory and philosophical position from which this study is conducted – this is more fully explained in chapter four. In line with the thinking underlying technologies such as the Internet – which make access to information much easier – the presentation style used in this thesis also aims to make the contents accessible to a wider audience. For persons not accustomed to academic writing, I also want to indicate that much of how this document is presented is based

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<sup>1</sup> This includes use of the first person “me”, “I”, “my” rather than the generally accepted third person form of “the researcher”.



on the writing guidelines of the American Psychiatric Association, which requires references when referring to the research or opinions of other people – this is why you will often find brackets containing someone's surname, and a date.

*What motivated this choice of topic?*

There are several reasons why I decided on this particular topic. One motivating factor is my fascination with the concepts of personhood, "self", brain-behaviour relationships and the field of neuropsychology in general. A further, and for the current project more relevant, motivating factor is part of my experience during my internship year.

During my internship, at a drug and alcohol rehabilitation centre, one of the people that I was involved with in my role as therapist was a woman who had, more than 12 months previously, experienced quite a severe brain injury following a motor vehicle accident. I was struck by the lasting and devastating effect the injury had on not only this woman's life but also her entire family. Her immediately apparent problems included, but were not limited to, concentration problems, memory problems, and physical difficulties that made walking cumbersome. The most notable problem from her family's perspective was challenging behaviour such as repeatedly attempting to drive a vehicle when medical opinion was that she shouldn't, because she was not able to do so safely. When prevented from driving she often responded with outbursts of impulsive and aggressive behaviour that included damaging the vehicle. Life for the family became largely unbearable.



With even limited knowledge of psychology and neuropsychology, the fact that a brain injury could have this effect should not be surprising. What I found especially frustrating though, was that it appeared that there was nothing that we could do to help this family. The institution where I completed my internship did not offer any form of neuropsychological rehabilitation and the woman was referred for neuropsychological assessment after which the family decided to place the woman in a long-term residential care facility. Considering the length of time since the injury, current conventional knowledge seems to offer little hope for *much* positive change or recovery for this woman and her family. This rather hopeless scenario begs the question whether this is the result of characteristics of the phenomenon. In other words, that many brain injuries and their related problems are not amenable to much recovery, or whether we should perhaps explore other avenues in our research?

Considering the number of persons who experience TBI annually the need for effective and potential new ways of assisting these people and their families is self-evident.

#### *What the research is about*

This research project is intended to explore how *people* are affected by, and respond to, traumatic brain injury. I am interested in exploring some of the possible challenges persons face while attempting to construct a coherent narrative of self and the world following traumatic brain injury, especially where these challenges originate in the relationships with other persons as opposed to cognitive and/or physical disability. Research by Nochi (1998) suggests that some persons may experience "a loss of self" following TBI and that one potential contributing aspect to



this "loss of self" could be related to their experiences with others, which is termed "loss of self in the eyes of others". The literature in this regard is reviewed in chapter three. The goals of this study are:

- Identifying themes in the narratives of a group of persons who experienced TBI that suggest experiences of others which could add to the challenges persons face following TBI.
- Exploring whether these types of experiences impact negatively on injured persons' self-narratives by leading to a "loss of self in the eyes of others".

The focus of this study is thus on experiences with others that could contribute to the challenges persons face following TBI. While the aim of this study is not to replicate the findings of Nochi (1998) it will shed light on the potential applicability, in the South African context, of the phenomenon of "loss of self in the eyes of others" as postulated by Nochi. In general, by beginning an enquiry along these lines it is hoped to contribute to our knowledge regarding TBI and to the eventual development of new or more effective rehabilitation practices.

*The theory that influenced the approach to the topic*

A large influence on my approach to this topic is my preferred approach to psychotherapy – namely narrative therapy. From a narrative psychology perspective, individuals in the process of living life, arrange experiences of events in sequence across time in such a way that they arrive at a coherent account of themselves and the world around them (White & Epston, 1994). When the stories people have about



themselves seem to be contradicted by experiences in their daily lives a narrative therapist would expect that the person would find this troubling. If someone were forced to live a story, which they do not agree with, or which does not make sense to them, it would also be expected to be problematic.

When considering the possible consequences of brain injury it appears that injured persons are faced with many experiences that may challenge their accounts of themselves and the world. Problems with memory and concentration, which are often part of the consequences of brain injury, would conceivably make it extremely difficult to make sense of the world. Turning back to the woman I saw during my internship I wondered afterwards whether many of the problems, especially the impulsive and aggressive behaviour could not be understood as resulting from frustrated efforts to maintain parts of her narrative that made herself and the world seem more coherent? For instance, in my conversations with her I got the impression that when her daughter would no longer ask her to help with her school work the woman would find it extremely upsetting – not because her cognitive skills did not any longer allow her to help (she seemed to be aware of her cognitive difficulties and appeared to understand that her cognitive problems made even basic arithmetic difficult) but because it contradicted her narrative of herself as a mother. It seems that when working with an individual or family, in this type of situation, an approach based on narrative practice may hold much promise.

#### *How the research was conducted*

Being influenced by ideas from narrative therapy has implications for any research project. These implications stem from technical issues that relate to the



philosophy of science, and include the ontological and epistemological assumptions that are the basis of a narrative perspective. A more detailed discussion of these issues and the research methods, including data collection and data analysis, applied in this study is presented in chapter four. The basic approach of the study was an exploratory qualitative research approach through which a number of persons who have experienced TBI were interviewed about their experiences. These interviews were then analysed to identify themes that relate to the questions mentioned earlier.

*What to expect from here on*

In the next chapter, I will provide an overview of the phenomenon of TBI paying particular attention to the consequences of brain injury. Chapter three will more closely motivate why the approach of this study seems to be required. Chapter four discusses philosophical and theoretical issues related to science and research in general, and details the methods and procedures employed to address the goals of the study. In chapter five the actual process of data analysis and the results thereof will be presented.



## CHAPTER 2

### TRAUMATIC BRAIN INJURY: AN OVERVIEW

#### *Introduction*

Damage to the human brain could result from a myriad of sources and have innumerable consequences. The Gauteng branch of Headway, a support organisation for the survivors of brain injury and their families, distinguishes between injuries to the brain which have an internal source and injuries which have an external source (Headway, 2005). Injuries related to an internal source include, but are not limited to, vascular accidents (stroke) and brain tumours; whereas external sources *usually* involve some form of impact to the head (Headway, 2005; Uomoto, 2000). The focus of this study is people who have experienced the second type of injury, which is more generally known as a traumatic brain injury (TBI). In this chapter I will provide an overview of and define the phenomenon of traumatic brain injury.

#### *Traumatic brain injury: What is it?*

Hannay, Howieson, Loring, Fischer and Lezak (2004) point out that the meaning of the term traumatic brain injury still appears unclear in the literature. This is reflected in the numerous systems used to classify and define traumatic brain injuries. The American College of Surgeons (2004) identify three broad classification systems for traumatic brain injury, namely mechanism of injury, severity of injury and morphology<sup>2</sup>.

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<sup>2</sup> The classification based on morphology, as used by the American College of Surgeons, will not be discussed as it shows a large degree of overlap with the more familiar discussion of pathophysiological processes which will be discussed.



### *Mechanism of injury*

Traumatic brain injuries are generally associated with motor vehicle accidents, falls, assault with a blunt object, as well as gunshot or stab wounds to the head (American College of Surgeons, 2004; Ponsford, 1995). The initial injury is classified as either being a blunt injury or a penetrating injury. In blunt head injuries, also referred to as closed head injuries, the skull remains intact and the brain unexposed – even though the skull might be fractured (Hannay et al., 2004). Penetrating head injuries, also referred to as open head injuries, involve injuries where the meninges and brain substance are penetrated by an object, which may include pieces of fractured skull (Kolb & Whishaw, 1996; Hannay et al., 2004). The two types of injuries appear to exhibit different pathophysiological processes as well as different neurological deficits (Kolb & Whishaw, 1996; Hannay et al., 2004; Ponsford, 1995). We shall return to the issues of pathophysiological processes and consequences of brain injury later.

### *Severity of injury*

TBI is not only classified on the basis of how the injury occurred but also on how severe the injury is judged to be. The severity of head injuries range on a continuum from mere bumps to the head that leave no lasting ill effects, to persons who are in prolonged comas or vegetative states (Hannay et al., 2004). The two main classification systems used to describe injury severity are Glasgow Coma Scale (GCS) scores and Posttraumatic Amnesia Duration (PTA).

*Glasgow Coma Scale.* The GCS score of a person is based on an evaluation of eye opening, motor response and verbal response. A person who opens his eyes





spontaneously, obeys commands, and whose verbal response indicate that he is oriented will have a score of 15 (the maximum possible score); whereas a flaccid person who does not open his eyes or talk will score the lowest possible score of 3 (American College of Surgeons, 2004). A person with a GCS score of eight or less is usually considered to be in a coma (Fischer, Hannay, Loring & Lezak, 2004). Generally head injuries are classified as either mild, moderate or severe, based on the GCS score (refer to Table 1).

Table 1. GCS scores and injury classification

GCS classification	Injury classification
$\geq 13$	Mild
9-12	Moderate
$\leq 8$	Severe

Adapted from Fischer et al. (2004)

One problem with the GCS classification system is that numerous GCS measurements can be recorded for the same person over time (Fischer et al., 2004) and there exists no standardised framework for reporting what GCS score to use when conducting research. This complicates matters especially when one attempts to relate reports of injury severity with outcomes. One should therefore, as pointed out by Fischer et al., (2004), take cognisance of the time/s that the GCS was measured and the circumstances surrounding the first hours and days following the injury, before deciding how much weight to place on a GCS score as a predictor of severity and potential outcome in individual cases.

*Posttraumatic amnesia.* Another estimate of injury severity is based on the period following the injury for which the person has amnesia (Kolb & Whishaw, 1996; Hannay et al., 2004). Refer to Table 2.



Table 2. PTA duration and Injury severity

PTA duration	Severity estimate
< 5 minutes	Very mild
5-60 minutes	Mild
1-24 hours	Moderate
1-7 days	Severe
1-4 weeks	Very severe
> 4 weeks	Extremely severe

Adapted from Hannay et al., 2004

This measure too does not allow for easy generalisation of associations between injury severity and outcome. This is again related to different approaches to and practical problems in judging PTA duration. It might be difficult, for instance, to judge PTA duration when a person is left with impaired communication abilities after the injury (Hannay et al., 2004).

Part of the complexity of traumatic brain injury as a phenomenon and as research topic should be evident when considering the different attempts that have been made to classify it. This complexity is further reflected when considering the numerous possible pathological processes that are associated with various forms of injury.

#### *Pathophysiological processes in TBI*

Most authors appear to be in agreement that closed head injuries involve two stages of injury to the brain, namely the primary injury and secondary injury (Kolb & Whishaw, 1996; Hannay et al., 2004; Uomoto, 2000). Primary injury is the damage that occurs at the time of the impact, whereas secondary injury is due to



physiological processes that are destructive of brain tissue; these processes are set in motion by the primary injury.

### *Primary injury*

Most of the damage during the primary injury is the result of acceleration and/or deceleration of the brain (Uomoto, 2000) that might result in cerebral contusion (bruising at the point of impact), diffuse axonal injury and haemorrhages (Ponsford, 1995; Uomoto, 2000).

*Contusions.* Cerebral contusions may occur when a blow to the skull causes an inward moulding of the skull that compacts the brain tissue – damage at this site is referred to as the *coup* (Kolb & Whishaw, 1996; Ponsford 1995). The initial impact on the brain may also force the brain against the opposite side of the skull causing an additional contusion known as the *countrecoup* (Hannay et al., 2004; Kolb & Whishaw, 1996). Contusions can also result *without* a direct impact to the skull when rapid deceleration slams the brain against the skull's bony ridges and protrusions located in the vicinity of the frontal and temporal lobes (Hannay et al., 2004; Uomoto, 2000). Contusions are not restricted to the surface of the brain but often involve deeper structures like the basal ganglia and hypothalamus (Hannay et al., 2004).

*Diffuse axonal injury.* Diffuse axonal injury takes place on a more microscopic level. Movement of the brain within the skull puts strain on nerve fibres and blood vessels, which can stretch and tear them (Kolb & Whishaw, 1996; Hannay et al., 2004; Ponsford 1995). On a neuronal level the actual axons of neurons may be stretched and torn leading to a myriad of axonal and neuronal disruptions effectively



disconnecting parts of the brain (Hannay et al., 2004; Uomoto, 2000). As with contusions, this type of injury can occur without a direct blow to the head and might therefore be seen in whiplash injuries.

*Haematoma.* The shearing forces already mentioned might also cause larger blood vessels in the brain to be torn which leads to the formation of haematomas<sup>3</sup> (a collection of blood in a confined space in the brain) within the skull (Hannay et al., 2004). Haematomas may form between the dura mater and skull (epidural haematoma), between the dura and the brain (subdural haematoma) as well as within the substance of the brain itself (intracerebral haematoma). A haematoma may exert pressure on the surrounding brain structures or presses the brain against the skull causing damage to the brain tissue (Kolb & Whishaw, 1996; Hannay et al., 2004).

### *Secondary injuries*

Following an injury to the brain an increase in the volume of the brain might occur. This may be due to increased cerebral blood volume (excess of blood in the brain) or cerebral oedema (swelling due to increased tissue water content). This swelling of the brain can be focal (limited to a specific area) or diffuse (spread through various parts of the brain) and might damage brain tissue by exerting pressure on surrounding brain structures or forcing the brain against the skull (Hannay et al., 2004; Ponsford, 1995; Uomoto, 2000). The swelling might also interfere with blood flow to areas of the brain (paradoxically even when the swelling is due to increased blood volume) leading to ischemia (insufficient blood flow which

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<sup>3</sup> Some authors regard haematomas as a secondary injury (Ponsford, 1995).



cannot support the metabolic needs of brain tissue) and/or hypoxia (inadequate oxygenation of tissue) that leads to cell death. An increased blood volume, cerebral oedema and elevated cerebrospinal fluid in the ventricles may also lead to increased intracranial pressure (ICP) which can result in decreased cerebral blood flow, leading to ischemia, and/or brain shift, which might culminate in different types of brain herniation which cause further brain damage (Hannay et al., 2004; Ponsford, 1995; Pang, 1985).

It should be noted that the discussion of damage to brain tissue was limited to closed head injuries and events that occur in the skull, so to speak. It should be kept in mind that events in the rest of the body might also contribute to brain tissue damage. For instance, a person's injuries during a motor vehicle accident might include both an injury to the head and chest injuries. This person could therefore experience the primary and secondary injuries, as described, related to the head injury while the chest injury may lead to reduced arterial blood passing to the brain causing or aggravating hypoxia (Ponsford, 1995).

With regard to brain damage that result from penetrating head injuries the tissue damage is associated with direct destruction of the brain tissue by the object or objects penetrating the brain as well as some of the injury mechanisms like contusions and haematomas, as discussed under closed head injuries. It appears that infection is a more problematic secondary injury with penetrating/open head injuries as opposed to closed head injuries (Hannay et al., 2004). A further difference between penetrating and closed head injuries regards the nature of the damage to



brain tissue, with penetrating injuries often causing a more circumscribed focal lesion (Kolb & Wishaw, 1996; Hannay et al., 2004).

At this stage it seems possible to offer a tentative definition of traumatic brain injury as an event involving some form of sudden acceleration and/or deceleration and/or impact and/or penetration of the brain which through various pathophysiological processes leads to anatomically specific and/or diffuse damage to brain matter. This type of definition would however miss what, to my mind, is one of the more crucial aspects of traumatic injury, namely the consequences thereof.

#### *Commonly reported consequences of TBI*

Damage to the brain, even if limited to a microscopic level, can have numerous consequences for a person. As previously indicated, damage to the brain might be limited to a relatively limited area or spread throughout the brain. Without considering these, and other lesion specific characteristics like anatomical location, size and depth of lesion, any number and combination of changed sensory, perceptual, cognitive, emotional and physical experiences, abilities and skills might result from brain injury (Kolb & Wishaw, 1996; Hannay et al., 2004).

In an attempt to provide a sensible integration of various authors I will divide the discussion into altered consciousness, motor and physical consequences, cognitive consequences as well as emotional and behavioural consequences. Many more possible consequences based on ever-finer classifications of neural and functional systems could be distinguished depending on one's conceptual framework. As pointed out by Lezak, Howieson and Loring (2004a) these



distinctions, though, often amount to “ticklish” theoretical distinctions "that are not material to most practical applications in neuropsychology" (p.23). The goal of this section, therefore, is not to provide an exhaustive list of all the possible consequences linked to specific lesions or injury severity, but to provide a broad overview of what has been reported to follow once a brain injury has occurred.

### *Altered consciousness*

One of the first, and probably most obvious, consequences of brain injury is an altered mental state, ranging from feeling dazed, disoriented or confused up to a loss of consciousness. In fact, closed head injuries are commonly, although not necessarily, associated with a loss of consciousness due to diffuse axonal injury, especially involving fibres in the brainstem reticular formation, while in penetrating head injuries there are often not a loss of consciousness (Kolb & Whishaw, 1996). Loss of consciousness could last a couple of minutes or could persist for days, weeks or months (Ponsford, 1995). When a loss of consciousness has occurred and the person regains consciousness, he or she usually remains confused and disoriented for a period ranging from hours to months after regaining consciousness (Ponsford, 1995) and is unable to register experience on a continuous basis (Hannay et al., 2004). This often leaves the person with amnesia for the period from when the injury occurred until continuous registration of experience returned. As indicated earlier this period of posttraumatic amnesia is often used as a measure of injury severity.

With or without an initial loss of consciousness other effects of the injury may be noticed – often only after the person has been discharged from hospital and has attempted to continue with their activities as before the injury.



### *Motor and physical problems*

Motor impairments in the form of weakness or paralysis on one or both sides of the body, incoordination of muscle movements (ataxia), loss of fine and gross motor dexterity, tremors, poor balance as well as reduced physical endurance often follow a brain injury (Kolb & Whishaw, 1996; Ponsford, 1995). Headache is another frequent feature following traumatic brain injury especially in the acute stage following brain injury but can also become a chronic problem (Hannay et al., 2004; Ponsford, 1995).

### *Problems with cognition*

Lezak et al. (2004a) distinguish four classes of cognitive functions that are analogous with computer operation, namely receptive (input), memory and learning (storage), thinking (data processing) and expressive (output) functions. In this regard the effects of brain injury might include

- Disturbance of sensory and perceptual function, including an impaired sense of smell, loss of visual acuity, double vision (diplopia), aversion to bright light (photophobia), ringing or buzzing in the ear (tinnitus) and intolerance of loud noises (hyperacusis).
- Disturbance of memory function in the form of the diminished ability to acquire new information, motor skills and cognitive skills or impaired recall of already learned information or personal history.
- Disturbance of abstraction, reasoning, judgement and problem solving.
- Disturbance of speaking, drawing, writing, physical gestures and facial expressions.





Another consequence of brain injury, although not exclusive to the domain of cognitive functioning, but that seem, at least at a conceptual level closely related, is impaired attention. This is usually exhibited as impaired ability to maintain focused attention – even in the absence of distractions; or being easily distracted by competing stimuli (Lezak et al., 2004a; Ponsford, 1995).

### *Emotional and behavioural changes*

Depression, anxiety, irritability, anger and sleep disturbances are common features following brain injury (Gouick & Gentleman, 2004; Hannay et al., 2004; Poggi et al., 2003; Starkstein & Lischinsky, 2002). Injured persons might also display a lack of initiative in thought and behaviour, difficulty in initiating or changing behaviour or thoughts, impulsivity, temper outbursts, poor social judgement, sexually inappropriate behaviour, self-centredness, lack of insight and lack of self-awareness (Greve et al., 2001; Ponsford, 1995; Uomoto, 2000). Changes of this nature might take the form of what are considered known psychiatric disorders such as major depressive disorder and/or syndromes that appear to be particularly associated with certain types of lesions like the disinhibited, egocentric behaviour linked to orbitofrontal damage (Eames, 2001; Hannay et al., 2004).

We should now expand the definition of traumatic brain injury offered earlier to include that the person so injured might exhibit one or a number of motor/physical and/or cognitive and/or emotional/behavioural impairments. This should suffice as a definition of what type of phenomenon will form part of this research project. Limiting this discussion only to a useable definition would however leave some very pertinent issues untouched. As such we also need to consider whether the mentioned



consequences of traumatic brain injury are permanent and we need to address the wider repercussions of these injuries.

### *Course and outcome of TBI*

#### *Improvement over time for some*

TBI and its effects are not static. Many of the initial consequences of the injury may improve over time to a level similar to before the injury, while others may show no improvement. Ponsford (1995) indicates that improvement is greatest in the first three to six months following the injury. In this regard Sadock and Sadock (2003) state “there is usually a 6- to 12-month period of recovery, after which the remaining symptoms are likely to be permanent” (p.362). There does however appear to be evidence that improvement can continue for years following the injury but generally improvements start levelling off during the second year following the injury (Hannay et al., 2004). The rate at which improvement occurs appears to hold for all levels of injury severity but more severe injuries tend to leave behind more impairments and more pervasive impairments. Novack, Alderson, Bush, Meythaler and Canup (2000) report – in a study that compared persons with mild/moderate TBI to persons with severe TBI – that both groups showed comparable rates of improvement. Specifically, in cognitive domains (especially memory) at both six and twelve months following the injury, but even after twelve months, those with severe injuries were classified as impaired when compared to an uninjured norm group. Hoofien, Gilboa, Vakil and Donovick (2001) reported, amongst other problems, continued psychiatric symptoms and impaired cognitive abilities as much as twenty years following a severe traumatic brain injury. Even in the case of less severe injuries persons might, after months or years following the injury, be left with what appears to be mild



cognitive deficits that often are most pronounced under conditions of stress (Hannay et al., 2004).

Hannay et al. (2004) state that survivors of severe traumatic brain injury remain almost inevitably affected in all areas of their daily living, and among areas of concern, work and family appear especially prominent.

#### *Unemployment or altered vocational status*

Keeping in mind the nature of the consequences of traumatic brain injury and their apparent long-term duration it is then probably also not surprising that loss of employment or returning to a lower level of employment is another outcome of traumatic brain injury. Estimates vary, but seem to indicate that 50-60% of persons who have suffered severe traumatic brain injury are unable to return to work (Hannay et al., 2004; Hoofien et al., 2001; Hellowell & Pentland, 2001). In one local study, Mokhosi and Grieve (2004) report that of 22 persons with severe TBI, who suffered their injury more than three years previously, 15 (68%) were unemployed and of the remaining seven, five were not coping with their work. A significant finding by Franulic, Carbonell, Pinto and Sepulveda (2004) is that persons who are employed tend to report greater life satisfaction and fewer negative consequences following TBI, leaving the said researchers to postulate that the ability to work might be therapeutic in itself – the possible direction of influence of variables must however also be acknowledged since it could be that persons who are less severely affected by an injury are more able/likely to resume work.



### *Impact on family and other relationships*

It is not only the injured individual who is affected by traumatic brain injury but other family members as well. Often family members, usually spouses or parents, are the ones that are responsible for the injured person's care after discharge from acute care (Knight, Devereux & Godfrey, 1998; Ponsford, 1995, Willer, Flaherty & Coallier, 2001). The experience of caring for or living with someone following traumatic brain injury is generally reported to be a stressful experience that often impacts negatively on family members. Gouick and Gentleman (2004) do point out though, that some families cope well with life following TBI – an observation supported by Mokhosi and Grieve (2004). Although not all outcomes are negative it would seem that apparent satisfaction with life is lower for persons living with a traumatically brain injured person than for the population in general (Harris, Godfrey, Partridge & Knight, 2001; Koskinen, 1998).

Especially coping with the emotional and/or behavioural consequences of TBI in the injured person seems to place considerable strain on others (Hannay et al., 2004; Hoofien et al., 2001; Willer et al., 2001) and is more strongly associated with depression and/or anxiety in carers than the other consequences of TBI like physical problems (Anderson, Parmenter & Mok, 2002; Douglas & Spellacy, 2000; Knight et al., 1998; J. Ponsford, Olver, M. Ponsford & Nelms, 2003; Watanabe & Taki, 2000). Although various contributing factors may play a role, social isolation becomes a frequent outcome for both injured persons and their families. Initially extended family and friends appear to support the injured person and family but over time the support wanes and many families are left with a very limited social and support network (Dell Orto & Power, 1994; Willer et al., 2001).



### *Conclusion*

In this chapter I have indicated that traumatic brain injury is a complex phenomenon with complex consequences. Although there exists a large degree of variability with regard to these consequences it would appear that very few people, even after suffering what might be considered mild brain injuries, return to their lives unaffected. The repercussions of brain injury also affect more than the injured person, often being associated with lower life satisfaction amongst family members who care for and live with the injured person. With all of this in mind, and in addressing the initial question of this chapter regarding how to define traumatic brain injury, it would seem insufficient to consider traumatic brain injury, and estimates of its severity only from a medical perspective that focus on the injury/damage to brain tissue. Although research and communication between medical personnel might be facilitated, it seems more apt that those so injured and their families be the ones to judge the severity of the injury based on how it affects them. Regardless of the perspective one adopts, the apparent consequences of traumatic brain injury raised in this chapter, in particular how persons appear to change from pre-injury to post-injury, do however, also raise questions about how we understand ourselves and our behaviour. It is to these issues that we turn next.



## CHAPTER 3

### PERSPECTIVE ON HUMAN BEHAVIOUR

#### *Introduction*

In the previous chapter I provided an overview of the consequences that might follow TBI, and concluded that some of these consequences, in particular challenging behaviour, raise some questions about how we understand human behaviour. It would appear that researchers and practitioners in the TBI field are yet to develop a fully integrated and comprehensive explanation that will allow us to make sense of these changes. Part of the difficulty appears to be that there are available to researchers and practitioners two main perspectives from which to attempt to make sense of human behaviour in general, but also when trying to explain behaviour changes following brain injury. In this chapter I will review these perspectives, I will show that these perspectives have a long historical tradition and their influence is so pervasive that it is reflected in our broader cultural context. Furthermore, I will indicate that even though both perspectives are employed in current theories regarding TBI, only one seems to enjoy research attention. I will lastly indicate what perspective will be adopted in this study.

#### *Opening salvo*

The debate between those holding differing opinions about how to account for changed behaviour following TBI can get quite heated as evidenced by an exchange in the journal *Archives of Clinical Neuropsychology*. In responding to an earlier article by Bigler (2001), who appears to favour a biological/neurological explanation of



symptoms following TBI, Lees-Haley, Green, Rohling, Fox and Allen (2003), who appear to favour a psychological explanation, laments that “. . . he [Bigler] even puts "psychological" in quotes as if psychological phenomena are somehow not recognized" (p.590) and "his article illustrates the danger of leaving the psychology out of neuropsychology" (p.591). Bigler (2003) responds “. . . we call behavior [sic] "psychological" because we do not have a better term to describe the behavior [sic] in question. As we gain biological understanding of the psychological event, we no longer have to view such phenomena within the context of psychological terminology" (p.606).

One of the major unresolved issues regarding human behaviour is how we understand what might be called human nature, in other words, the answer to the question "what am I?". As already alluded to, one contentious issue in the social/human sciences is whether human behaviour is solely the result of biological processes, which make us no different from monkeys or ants; or whether there is another dimension of human behaviour that is not solely reducible or attributable to biological processes. To adequately grasp the current context of the debate we need to make a quick historical detour – one admittedly with a Western historical bias.

#### *Answers from recent history*

Until about the 17<sup>th</sup> century it would appear that the predominant idea, albeit in various guises, about humans was that we consist of an immortal, non-material soul which is housed in a mortal body and that we are generally governed by external forces like spirits or gods (Hergenhahn, 1992; Macdonald, 2003).



Scholars trace this conceptualisation of humans to the early Greek Philosophers, usually Plato<sup>4</sup> (427-347 B.C.), and the incorporation of their ideas into Christianity, which predominated Western thought until the period of the Renaissance and Reformation (Brinich & Shelley, 2002; Hergenhahn, 1992; Levin, 1992). Macdonald (2003) identifies the first half of the seventeenth century as the period when an understanding of the natural world as being of a spiritual nature, was replaced by a view that nature, and hence humans, are subject to mechanical laws. This period is generally regarded as the beginning of modern science, including psychology (Hergenhahn, 1992), and also represents the period when the concept of "mind" replaced that of soul – a feat ascribed to René Descartes (1596-1650).

Descartes postulated a non-material mind, located in the pineal gland in the brain, that influences the machine-like body, and which in turn is influenced by the body (Hergenhahn, 1992; Macdonald, 2003; Maslin, 2001). As pointed out by Edwards (1964) Descartes's dualist position is still very much in the Platonic tradition but Descartes is generally singled out in the social sciences as laying the foundation for an understanding of humans as having a unified mind/self, transparent to itself, which is capable of reason and the exercise of free will but which is somehow contained in, as well as able to influence the body and in turn being influenced by the body (Spurrett, 2002). It might be said that during the Renaissance human agency – the ability to influence your own behaviour and life course as opposed to being left to the control of some external force came to prominence (Logan, 1987). Furthermore a division of attention between the human body and, what I will term the human

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<sup>4</sup> Maslin (2001) points out that although the foundation for the conceptualisation of an immortal soul housed in a mortal body probably has a much earlier beginning, Plato was amongst the first to present traceable, written arguments in it's favour.





"agentive entity"<sup>5</sup>, as explanatory factors of human behaviour and that which is the "thing" which is conscious of its experiences, became more commonplace. In the context of the developing fields of science in general; and medicine, psychiatry and psychology in particular, the years following the Renaissance mostly saw debate surrounding whether the "human agentive entity" is a proper subject for *scientific* investigation, and for those who assumed it was to debate its features, characteristics and workings. This has left us with contemporary perspectives in the social and human sciences that either mainly emphasise "humans as biological machines" or "humans as agentive entities". Terms that appear to have been, and still are being used, to refer to the "agentive entity" aspect of humans are spirit, soul, psyche, mind, personality, self, and identity. Next we shall review contemporary perspectives on behaviour in general and the changes that often accompany TBI.

### *The role of the brain*

In answering a hypothetical question "*What does the brain do?*" Eames (2001) states " . . . the most accurate answer is Everything. There is nothing that we sense, perceive, judge, do, think, recall, learn, feel, imagine, or create that is not done through the medium of brain mechanisms" (p.29). With recent advances in the neurosciences and the development of our knowledge regarding the brain and brain-behaviour relationships this statement should not be surprising and seems fairly accurate. This knowledge is actually also not new; in fact it would seem a similar view was held more than two thousand years ago – the following is attributed to Hippocrates (460-357 B.C.):

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<sup>5</sup> "Agentive entity" is taken to refer to an assumed aspect of human behaviour that is not solely reducible to, or indicative of, biological functioning. It implies the potential to be an active participant in life and being able to effect change in your environment and self.



Men ought to know that from the brain, and from the brain only, arise our pleasures, joys, laughter and jests, as well as our sorrows, pains, griefs and tears. Through it, in particular, we think, see, hear, and distinguish the ugly from the beautiful . . . It is the same thing which makes us mad or delirious, inspires us with dread and fear . . . brings sleeplessness, inopportune mistakes, aimless anxieties, absent-mindedness, and acts that are contrary to habit.

(In Edwards, 1964)

It would thus seem that for some the brain is the basis of what makes me behave the way I do, or simply that the brain is what makes me, me. The perspective that the brain is the basis of what makes me, me, is also not peculiar to highly trained neuroscientists or philosophers. In a study by Johnson (1990) it was found that children as young as six, generally associate the brain as being the location of the person, in other words, that if it was possible to transplant my brain into another body, even an animal body, that body would then be me. The brain appears to be so central to our understanding of ourselves that it has even influenced how we conceptualise death. In most countries throughout the world there exists the legislative identification of "brain death" which is regarded as the death of the person, even if metabolic processes continue in the rest of the body (Steineck, 2003). Kolb and Whishaw (1996) would therefore appear justified to state in the introductory chapter of their text on neuropsychology that "The deeper meaning of the riddle of human nature is still unanswered, and the object of this [Kolb and Whishaw's] book is to pursue the answer in the place it should logically be found: the brain" (p.3).



### *Altered personality and changed behaviour*

Seeing that the brain forms the basis of explanations for behaviour it is also, for many, the starting point to explain changes in behaviour. It would also seem that the concepts of "behaviour change" and "personality change" become somewhat synonymous in this context. The close association between the concepts of behaviour and personality is reflected in Allen's (2002) preference for using a hyphenated compound term "behavioural-personality sequelae" (p.63) when referring to some of the consequences of TBI. For our purposes here the concepts of behaviour and personality are used in the context of a person who, following TBI, might be experienced by themselves or others as being a different person to how they were previously – this might especially be reflected in behaviour that seems out of character for the person. This usage is consistent with Sadock and Sadock (2003) who define personality change as meaning that "the person's fundamental means of interacting and behaving have been altered" (p.355).

With regard to explaining personality change, and hence behaviour change, Taylor (1999) states, "Any relatively sudden or substantial personality change in a person over age 35 suggests brain dysfunction, disease, or damage until proven otherwise" (p.332). Sadock and Sadock (2003) reiterates this, "When a true personality change occurs in adulthood, the clinician should always suspect brain injury" (p.355), also "Structural damage to the brain is usually the cause of the personality change, and head trauma is probably the most common cause" (p.819). It is also noteworthy that both major diagnostic systems in use in the mental health field, the World Health Organisation's (WHO) tenth edition of the International Classification of Diseases (ICD-10) and the American Psychiatric Association's



(APA) revised fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR), make provision for diagnosing personality change following brain injury.

When reviewing the literature it seems that especially the frontal lobes of the brain are implicated in much of the personality change and challenging behaviour that are observed following TBI.

#### *Fronto-temporal structures and behaviour clusters following TBI*

Kolb and Whishaw (1996) state that brain injuries that damage the frontal and temporal lobes tend to have significant effects on people's personality and social adjustment. There have been various attempts to develop a nosology to be used when referring to these effects but there is not yet a universally standardised terminology or classification system in use. Terms that are often encountered in the literature when referring to personality change following TBI and which seem to imply a homogenous phenomenon, is that of *organic personality disorder* as well as *frontal lobe syndrome* (Franulic, Horta, Maturana, Scherpenise & Carbonell, 2000; Mathiesen & Weinryb, 2004; Taylor, 1999; Wood, 2001). Some authors, however caution against the use of these global terms as there appear to be different clusters of behaviour that appear together fairly consistently – and these behaviour clusters appear to correspond to different lesion characteristics (Hibbard, Bogdany, Uysal, Kepler, Silver, Gordon, & Haddad, 2000; Wood, 2001). This is also reflected in both the ICD-10 and DSM-IV-TR, which allow for the identification of different subtypes of personality change following brain injury. The DSM-IV-TR (APA, 2000) for instance makes provision for the identification of the following subtypes: labile, disinhibited,



aggressive, apathetic, paranoid, combined (any combination of the preceding subtypes) and "other" (if the presentation is not characterised by any of the preceding subtypes). Even amongst authors who appear to avoid global descriptive terms there is great variability in how changed behaviour is conceptualised and classified. Lezak et al. (2004b) for instance classify five general groups of behavioural disturbances following frontal lobe damage, namely:

*Problems of starting:* Appears as decreased spontaneity and/or productivity and/or initiative. Persons so affected might be described by relatives/friends as having become lazy/apathetic, or as never transforming plans into action. This cluster of behaviour seems associated with superior medial frontal lobe injury.

*Difficulties in making mental/behavioural shifts:* Appears as difficulty in suppressing ongoing activities or "moving" attention from a previous stimulus. A person might therefore continue to provide the same or similar response to various questions, tasks or situations. This cluster of behaviour seems to be particularly associated with dorsolateral lesions of the frontal lobes.

*Problems in stopping:* Usually appears as impulsivity, over reactivity, disinhibition, difficulties holding back a wrong/unwanted response, difficulty delaying gratification/reward. Lesions are generally located in the orbital aspects of the frontal lobes.

*Deficient self-awareness:* Appears as an inability to perceive own errors (defective self-criticism), recognise the impact one has on others, or have



empathy for others. Persons so affected might be described as euphoric/self-satisfied, to experience little or no anxiety, or to be impulsive and unconcerned with social conventions. Lesions are generally found in the orbital cortex and limbic areas.

*Concrete attitude*: This refers to an *attitude* where objects, experiences and behaviour are taken at their most obvious face value – it does not refer to the inability to use and understand abstract concepts. No particular lesion, other than frontal lobe involvement is specified.

It appears though that a dichotomous classification, which is not as broad as "frontal lobe syndrome" but combines some of the Lezak et al. (2004b) clusters into two, is possible. Wood (2001) distinguishes mainly between *disorders of drive, arousal, and motivation* as opposed to *disorders of inhibitory and regulatory control*. These two groupings appear to share much with the concepts of *pseudodepression* and *pseudopsychopathy*. Kolb and Whishaw (1996), based on the work of Blumer and Benson (1975) describe pseudodepression, associated with damage to the left frontal lobe, as characterised by outward apathy and indifference, loss of initiative, reduced sexual interest, emotional blunting, and little or no verbal output. Pseudopsychopathy, associated with damage to the right frontal lobe, is characterised by immature behaviour, lack of tact, use of coarse language, promiscuous sexual behaviour, increased motor activity, and a lack of social graces.

Whatever classification is used there appears to be some agreement that what appears as disinhibited, egocentric, immature, impulsive type behaviour is



associated with orbitofrontal lesions; while apparently apathetic, aspontaneous behaviour is associated with medial frontal lesions (Allen, 2002; Eames, 2001, Lezak et al., 2004b; McDonald, Flashman & Saykin, 2002; Stuss & Levine, 2002; Taylor, 1999; Wood, 2001).

#### *Other brain structures and behaviour changes following TBI*

Lezak et al. (2004b) state that behaviour change following brain injury is not solely restricted to lesions of the frontal structures. In this regard Wood (2001) states that injuries to other areas of the brain might also cause behavioural changes – he however maintains that lesions in other parts of the brain are assumed to damage areas that interact with the frontal structures. Personality changes have been reported following damage to such structures as the cerebellum, and thalamus (Lezak et al., 2004b).

In summary one might be tempted to agree with Sadock and Sadock (2003) that "the weight of opinion is leaning toward a biologically and neuroanatomically based association between the head trauma and the behavioral [sic] sequelae" (p.362). Before drawing this conclusion though, it might be noted that respected authors like Lezak et al. (2004a), in discussing behaviour problems after brain damage, endorse two different positions within the space of two paragraphs. In one paragraph, the authors state "Profound personality changes frequently follow brain injury . . . These seem to be not so much a direct product of the illness as *patients' reactions* to their experiences of loss, chronic frustration and radical changes in life style" (p.37, emphasis added), the next paragraph states "Few brain damaged patients experience personality changes that are simply either *direct consequences*



of the brain injury or secondary reactions to impairment and loss" (p.37, emphasis added). The authors then continue to state that behavioural changes following mild brain injury might be thought of as mostly "reactive" in nature whereas changes following more severe brain injury would have more of a direct "organic" contribution.

### *The role of the person*

Referring to the response of the *person* when discussing the consequences of TBI is not peculiar to Lezak et al. (2004a). It would in fact appear that most authors refer to the response of the person as a possible contributing factor in explaining changed behaviour after TBI. When discussing causative factors related to behaviour problems following TBI, Ponsford (1995) considers three factors namely, "brain injury", "person" and "context" – the latter appearing to be more the person's reaction to context, than features of the environment: "From the point of view of the *person* who has sustained TBI, the experience of being cared for . . . will almost certainly be unfamiliar and may be extremely threatening . . . such experiences undoubtedly contribute to the development of confusion, frustration, anger, depression, and lack of motivation" (p.169, emphasis added). Even Eames (2001), for whom the brain does everything, states that "Although many of the disturbances of affect and behaviour seen after acquired brain injury are generated specifically by direct effects of the injury itself, there certainly are many problems and emotional difficulties that result from the *individual's* reaction to increasing awareness of changes in both *person* and life situation" (p.43, emphasis added).

Researchers in the TBI field have however, especially judging by research output, been surprisingly disinterested in reporting the subjective experiences of the *person* to whom the injured brain belongs.





### *Contemporary TBI research focus*

If the content of journals that take an interest in TBI are anything to go by, it appears that researchers have not strayed from the solitary focus on the brain as advocated by Kolb and Whishaw (1996). In this regard searching the PSYCINFO literature database covering the period 1886 to 2005 and identifying English language literature that contains the term "traumatic brain injury", 4459 records were returned. Making use of the search terms "traumatic brain injury" and "lesion" returned 138 records. Reference to published literature that addresses the subjective experience of persons living with TBI presents a different picture. In this regard a literature search, in the same database, utilising the terms "traumatic brain injury" and "subjective experience" returned 11 records; while "traumatic brain injury" and "personal experience" returned 5 records. A similar pattern was found when repeating the search in the ScienceDirect literature database covering the records from 1995 onwards. The search term "traumatic brain injury" returned 1350 records; "traumatic brain injury" and "lesion" returned 94 records; while "traumatic brain injury" and "personal experience" returned 1 record. It is interesting to note that the search term "traumatic brain injury" and "malingering" produced 108 records in the PSYCINFO database. This seems to imply that although not interested in the personal experience of injured persons, researchers do acknowledge that persons, as "agentive entities" may actively/deliberately influence how they appear to others – this seems to be viewed as an act by a person, and not as a neurological anomaly. Although this methodology does not constitute a complete analysis of the entire TBI research database, and is open to criticism for not including other search terms, or not reviewing each record individually, it appears that a pattern of research interest that focuses on the brain is readily apparent. The lack of interest in the person has



also recently been commented on by others (Howes, Benton & Edwards, 2005; Judd & Wilson, 1999).

What appears as a lack of interest in the person is somewhat curious when considering the continued usage of "agentive entity"-like concepts (e.g. person, individual) in apparently biological/neurological-based explanations of human behaviour, *despite* the apparent two thousand year old knowledge regarding the brain, which is supported by a growing empirical research base. This unwillingness to discard a perspective of ourselves as "agentive entities" is also reflected in our broader context. It is for instance noteworthy that most religious and legislative systems throughout the world are based on the assumption that individual human beings can, and should, control their own behaviour and are held accountable when transgressing accepted norms and rules. Furthermore, Kitzinger (1992) points out that most Westerners, while being unable to define what it is, believe that they have a "self"<sup>6</sup> and use the term in a similar vein as earlier generations used "soul". Spurrett (2002) similarly states that most people's everyday behaviour suggests that they are committed to the existence of selves "whatever selves might be" (p.191).

With all the aforementioned in mind it seems an oversight not to turn attention to the "agentive entity" or "experiencing person" when researching brain injury. In light of the apparent gap in the TBI literature the focus of this research project is therefore not on the brain as such but on persons who have experienced an injury to the brain. A second motivation for the approach of this study stems from my

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<sup>6</sup> "Self", like "agentive entity", is taken to refer to an aspect of human behaviour that is not solely reducible to, or indicative of, biological functioning and which implies the potential to "have" agency.



preferred paradigm when approaching people and their behaviour in the context of psychotherapy – a paradigm grounded in narrative psychology.

### *A Narrative approach to persons*

Narrative psychology is an approach to psychotherapy that can be broadly identified as being a post-modern worldview (Freedman & Combs, 1996). It is largely associated with the writing of White and Epston (1990, 1995), but shares much with what has been termed social constructionism and discourse/discursive psychology, which is variably associated with, amongst others, authors like Gergen (1989, 1999), Shotter and Gergen (1989), as well as Potter and Wetherell (1987). The assumptions found in most post-modern thinking represent a very different epistemological and ontological position to that which has characterised the social and human sciences for the past two hundred years – these issues will be dealt with in the next chapter regarding research methodology. What is pertinent to the current discussion is to indicate how a narrative position makes sense of us as humans.

One of the major tenets of a narrative perspective is that we as humans are interpreting beings (Morgan, 2000). In other words, we try to make sense of, and explain the things that we experience in our daily lives. In the process of living life, we arrange/link experiences and events in sequence across time in such a way that we arrive at what forms, for us, a coherent narrative/account/story of the world and ourselves (Morgan, 2000; White & Epston, 1990). These latter, "self-narratives", seem to hold some potential to more fully understand some of the reported personality/behaviour changes following TBI.



### *Self-narratives*

We do not have only one narrative about ourselves but many. We might for instance have narratives about ourselves as being of a particular gender, being a good parent, being a person who likes to take risks, or even a narrative about myself as being a particularly bad cook. These narratives are not fixed immutable facts carved in stone, but may differ and even appear contradictory depending on the context (Burr, 1995; Morgan, 2000). What is especially significant to this project though is that even though we might have different self-narratives we all have *preferred narratives* about ourselves (Freedman & Combs, 1996). I might for instance place a very high value on the narrative of myself as a caring spouse or a skilled handyman.

Another aspect of self-narratives that is important is, as stated by Freedman and Combs (1996), that "We think of a self not as a thing inside an individual, but as a process or activity that occurs in the space between people" (p. 34). We are therefore, according to Burr, (1995), dependent on others in the construction of our narratives. If nothing else our narratives must be compatible with those of others who feature, or take part, in our narratives. A result of this is that in any given situation or relationship others can play a role in hindering our preferred self-narratives by denying our narratives outright, or suggesting/implying that other narratives might be more apt – in Gergen's (1989) view we might end up *competing* to have our preferred accounts prevail over others'. It should be noted that preferred and alternative narratives do not imply that one is accurate or true and others inaccurate or false. Our reasons for preferring certain narratives are complex and mostly bound up in larger cultural narratives that limit what narratives are desirable and how they



may be constructed. Therefore, as pointed out by Du Preez (2005), the relationship between individuals and society will also impact on what and how identities are constructed. When the narratives/accounts people have about themselves seem to be contradicted by experiences of *themselves*, a narrative therapist would expect this to be troubling to individuals. When someone is forced, by *others*, to live a story which they do not agree with, or which does not make sense to them, it would also be expected to be problematic.

*Self-narratives and TBI.* When considering the possible consequences of brain injury it appears that injured persons are faced with many experiences that may challenge their accounts of themselves and the world. In a qualitative study of the narratives of ten brain injury survivors, Nochi (1998) identified what he has labelled "loss of self". A phenomenon where persons following TBI might have difficulty in understanding their experience, themselves and their behaviour. A person might therefore be heard to make a statement to the effect of "This is not like me" (Nochi, 1998). This experience is reported as troubling for individuals and could require professional intervention (Nochi, 1998).

Three themes that relate to loss of self were identified in Nochi's research, namely "loss of clear self-knowledge", "loss of self by comparison" and "loss of self in the eyes of others". "Loss of clear self-knowledge" refers to the injured person's uncertainty about their history, due to memory loss, as well as uncertainty about their abilities and skills following TBI. "Loss of self by comparison" refers to the injured persons comparing their "post-injury self" to how they were before the injury and/or how they envisaged what their future would have looked like, and how they perceive



it now. The third theme, “loss of self in the eyes of others”, refers to injured persons’ accounts of themselves being denied validity by others, through being classified by other persons into pre-existing categories like "disabled", "crazy", or "stupid".

Especially the theme of "loss of self in the eyes of others", appears to provide support for the notion that experiences of others might actually make achieving or maintaining coherent narratives of self and the world more challenging. Nochi (1998) indicates that individuals are likely to resist a loss of self in their daily lives but the nature of this resistance remains unexplored – it seems an intriguing possibility that some of the challenging behaviour following brain injury could result from frustrated efforts to either re-construct pre-injury self-narratives, or construct new preferred self-narratives. In light of the current state of knowledge surrounding TBI and self-narratives this type of conclusion is somewhat premature. Research utilising ideas from narrative psychology in the study of any aspect of TBI is scarce and no such study has been conducted in South Africa. This study hopes to facilitate the further development of this line of enquiry. This then brings us to what the goals of this study are.

#### *Goals of the study*

With the aforementioned in mind, the development of a comprehensive theory about challenging behaviour following TBI that incorporates ideas from narrative psychology is not the aim of this study. This study is to begin the groundwork to aid in the eventual development of such a theory. As such this research is aimed at



- Identifying themes in the narratives of a group of persons who experienced TBI that suggest experiences of others which could add to the challenges persons face following TBI.

Stemming from this it is also hoped to explore

- Whether these types of experiences impact negatively on injured persons' self-narratives by leading to a "loss of self in the eyes of others".

### *Conclusion*

In this chapter I have indicated that there are a variety of ways to make sense of the behavioural changes that frequently occur following TBI. I have argued that the majority of TBI related research focuses on the brain as a causative factor of personality change but that most explanatory theories incorporate what I have termed the person as "agentive entity". I have shown that even though contemporary neuropsychology theory acknowledges the person as "agentive entity", the subjective experience of injured persons have however received little attention in the published research concerning TBI. I have followed this by indicating how this project will incorporate the person as "agentive entity", taking particular interest in injured persons' experiences of others and the potential impact thereof on narratives of self.

With the phenomenon of interest for the study more clearly identified the next issue that needs to be addressed is that of how the research was put into practice. The next issue is therefore that of research design and research methodology.



## CHAPTER 4

### RESEARCH DESIGN AND METHODOLOGY

#### *Introduction*

Many authors liken a research project to the building of a house, which requires extensive planning and numerous decisions to be made ahead of time to ensure a successful or at least effective result (Malan, Jacobs & le Roux, 1999; Mouton, 2001). There appears to be general consensus that research does not entail haphazardly stumbling around hoping to find something – it is a planned process. It is also customary in a research report to include a discussion of the research design and research methodology, which allow others to judge the adequacy of the methods used and therefore the merit of the research (Malan, et al., 1999; Mouton, 2001). As a novice researcher it seems that there are numerous generic plans to choose from that can then be adapted to suit an individual researcher's needs. It also seems that there exists much confusion between different approaches since terms like research design, research paradigm, research methodology, and research methods are used interchangeably, inconsistently, and confusingly by different authors.

Blaikie (2000) proposes that many of the conventional classifications of research designs result in recipe book solutions to research that might end up combining research elements in combinations that are technically not legitimate. The main purpose of research design is therefore to ensure, amongst other things, that decisions regarding data sources, data selection, data collection, and data analysis are made consistent with each other *and* the philosophical assumptions of the guiding theory (Blaikie, 2000).





To simplify matters Blaikie suggests what he terms "core elements" (p.42) that decisions need to be made about. Any researcher must make decisions about what phenomenon to study, why it should be studied and how it will be studied (Blaikie, 2000). The issues surrounding "what" and "why" have been dealt with in the preceding chapters. This chapter will address issues surrounding "how". Before addressing the specific methods and procedures of this project I deem it necessary to address how this project is related to scientific research practice in general as the approach adopted for this project departs in many ways from what readers might have become accustomed to in the neuropsychological and TBI literature. This should ultimately allow the reader greater scope to judge the actual methods that were used, the claims made from these methods, and ultimately the worth of this project as a whole.

#### *Research, science and knowledge/truth claims*

Theodorson and Theodorson (in Reber & Reber, 2001) define research as "Any honest attempt to study a problem systematically or to add to our knowledge of a problem" (p.626). Neuman (1997) likewise defines *research* as ". . . a collection of methods people use systematically to produce knowledge" (p.2) but also states that "*science* refers to both a system for producing knowledge and the knowledge produced from that system" (p.6, emphasis added). From this it is clear that research and science are related to gaining knowledge and that these terms are often considered to be synonymous. These terms are however not interchangeable – the difference between the two can be stated as *research* referring to an actual act or acts of attempting to gain knowledge and *science* on the other hand being a claim



about the status of the knowledge that one has gained. A brief overview of the history of science might make the difference clearer.

*A brief version of the history of science*

The existence and contribution of what is known as *science* is a relatively new development in the history of the search for knowledge. Most scholars identify the origin of what we now call science as a shift in thinking during the historical period known as the Enlightenment, which led to a preference amongst scholars for a combination of two methods of attaining knowledge, namely rationalism and empiricism (Hergenhahn, 1992; Neuman, 1997; Pine, 2003). In other words, knowledge that was based on the application of logical reasoning/argumentation *and* repeatable observations made by the sense organs came to be held in higher regard than knowledge stemming from church dogma, past authorities, superstition, or abstract thought processes alone (Hergenhahn, 1992; Trigg, 2002). This *combination* of reasoning and observations is also referred to as the hypothetical-deductive process (Pine, 2003) and can be summarised as follows:

- An observation is made using the senses.
- An idea (hypothesis) is generated about how, whatever was observed, works.
- A prediction, based on the hypothesis, is made that stipulates what one would observe if the hypothesis is correct.
- If what was predicted is observed to occur the hypothesis is confirmed and one can claim to have discovered a fact about a phenomenon.



Before knowledge derived from this process can be claimed to be truly scientific it must also be replicated by several other researchers to confirm the observations. Through the continual application of this method it was, and still is, thought that those who practice science would be able to discover everything about a phenomenon, including general causal laws that are universally valid for all time and all places. Discovery of these laws would make it possible to predict and control the phenomenon and thereby contribute to the improvement of human life (Neuman, 1997). The scientific/hypothetical-deductive process to attain knowledge became viewed by many as the superior way to acquire true knowledge and became synonymous with science (Neuman, 1997; Silverman, 2001, Trigg, 2002). This form of research is known by several labels including positivist science (Neuman, 1997; Trigg, 2002). Positivist science became the foundation for the physical sciences, like physics, as well as the social/human sciences, which include disciplines like psychology and sociology. Since this research project falls within the boundaries of social science we will turn our attention to it next.

### *Social science*

Humans have not only wondered about the natural world, but also about ourselves as beings in the natural world. According to Neuman (1997) until the early 1800s philosophers and religious scholars only engaged in “armchair speculation” (p.61) and writing about human behaviour. With the value placed on knowledge derived from science however, it became widely accepted that knowledge regarding human behaviour should be based on the same hypothetical-deductive process. From this developed a human/social science that emphasised the discovery of cause-effect relationships between human and social phenomena through a neutral,



detached, and objective researcher to ensure precise, objective measurement and/or observation, which could be replicated (Neuman, 1997; Struwig & Stead, 2001). This is still viewed by many as the traditional or dominant form of gaining knowledge about us as human beings (Maykut & Morehouse, 2000; Neuman, 1997; Silverman, 2001). This is probably also the form of social science that most people are familiar with.

It should be clear that research making use of the label "science" or "scientific" involves a belief that by conducting one's research in a particular way, one would be able to claim that the knowledge so discovered/produced is superior to, or more true, than other forms of knowledge. There are, however, today still numerous competing and contradicting views about exactly what form science/research should take – proponents of each claiming the other to be mistaken. This often boils down to a debate about which method of attaining knowledge actually has access to *the* truth.

#### *The nature of truth claims from science*

Henning, van Rensburg and Smit (2004) state that "Scientific methods can only give us an approximation of the truth" (p.20). Part of the explanation for this type of statement lies in the fact that claims about truth, in turn invoke arguments about certainty. However, no knowledge claim can be unequivocally claimed to be based on certainty. Even the hypothetical-deductive process claims a *belief* about the phenomena it investigates<sup>7</sup>.

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<sup>7</sup> The basis for this argument is found in formal logic, namely that the process of hypothesis testing rests on inductive logic and a conclusion based on inductive reasoning always goes beyond the evidence provided in the premises.



Another challenge to the nature of truth claims from science is found in post-modern thinking. As indicated in the previous chapter, this study is guided by a paradigm, which through its close association with social constructionism might be identified as post-modern and as such, departs in fundamental ways from more traditional social scientific paradigms. Guba and Lincoln (1998) regard a paradigm as a basic set of beliefs about the nature of the world, as well as how the individual "stands" in relation to the world and the different parts of the world. Furthermore, "The beliefs are basic in the sense that they must be accepted simply on faith (however well argued); there is no way to establish their ultimate truthfulness. If there were, the philosophical debates reflected in these pages [Guba and Lincoln's, as well as this text] would have been resolved millennia ago" (Guba & Lincoln, 1998, p.200). When a paradigm forms the basis for research, it becomes necessary to understand the ontological and epistemological assumptions of that paradigm or stated more simply, we need to understand our assumptions about reality and our assumptions about how we actually get to know anything about that reality.

*Ontological assumptions.* The position adopted in this study is an ontological assumption of reality being socially constructed. From this ontological position reality is not any one "thing" but rather consists of the interpretations people make of it. This project therefore falls within a branch of the social sciences that might be labelled as *interpretative* (Blaikie, 2000; Henning et al., 2004; Neuman, 1997). Especially relevant to the practice of research, a social constructionist position calls attention to the fact that the categories/labels we use in everyday life and the sciences, when apprehending the world, do not necessarily refer to "real" or "natural" divisions, but that the categories and labels we use are historically and culturally specific (Burr,



1995). This ontological position is closely linked with, and difficult to comprehend without considering, the accompanying epistemological position. It should be noted though, as pointed out by Guba and Lincoln (1998), that the distinction between ontology and epistemology becomes progressively less clear as paradigms depart from the positivist starting point.

*Epistemological assumptions.* The epistemological position, in other words, assumptions about the relationship between researcher and that being researched, held by a social constructionist stance, is one that views the investigator and objects of investigation as interactively linked (Creswell, 1998; Guba & Lincoln, 1998). In other words, knowledge is not discovered by an impartial observer but is a co-creation of the researcher and research participants. Guba and Lincoln (1998) make the point that it is this epistemological assumption that most differentiates the interpretative paradigm from other more traditional paradigms. This epistemological position also fits with a narrative approach in psychology where each person is considered to be an expert about his or her own life (Freedman & Combs, 1996; Morgan, 2000).

*Implications for research methodology.* Methodology in this context refers to what might be called the research endeavour – it does not refer to the actual procedures used in a particular research act. Henning et al. (2004) indicate that epistemology is similar to methodology in that both relate to “how we come to know”, but they consider methodology to have a more practical slant. Where epistemology involves the *philosophy* of how we come to know the world, methodology involves the *practice* of coming to know the world. In this regard Guba and Lincoln (1998)



consider a hermeneutical and dialectical methodology as appropriate based on the ontological and epistemological assumptions of a constructionist stance. The final aim of research is to reach a more informed and sophisticated construction about a phenomenon through dialectical interchange between what Guba and Lincoln (1998) term the investigator and respondents.

Based on the above it seems that the ontological, epistemological, and methodological assumptions compatible with a constructionist stance do not so much prescribe methods for data collection and analysis, as place a restriction on the type of knowledge claims that can be made. In other words, the emphasis remains on the position that knowledge is constructed, contextually specific, ever changing, and as such should be open to interpretation and re-interpretation. Search for objective ever-valid laws, at least in the social science endeavour, therefore is less important because “For one thing, people are not television sets. When they are approached as objects about which we know truths, their experience is often one of being dehumanized” (Freedman & Combs, 1996, p.21). The best we can strive for is better understanding of something. The judgement as to whether a particular knowledge claim constitutes an understanding, is not made by a panel of scientists or experts, it is made by each person as they interact with that claim.

Returning to the issues of how this project relates to scientific practice and the nature of truth claims from science, I maintain that in judging the scientific merit of this project, debates about certainty and who is ultimately right would be applying an incorrect standard. As Pine (2003) rightly points out the standard should not be whether a science endeavour can claim certainty about the phenomena it



investigates but whether some beliefs are better supported than others by the available evidence and therefore can be used as a *reliable basis for decision and action*. In this regard the hypothetical-deductive approach seems quite appropriate when investigating phenomena of the physical sciences like investigating earthquakes, gravity, and global warming. It is also appropriate when studying people and behaviour, it is however not *solely* appropriate, and might at times be wholly inappropriate when the object of investigation is human behaviour. Silverman (2001) states that "It is an increasingly accepted view that work becomes scientific by adopting methods of study *appropriate* to its subject matter" (p.224, emphasis in original). In judging this research project it should therefore be judged based on whether the claims that stem from it form a reliable basis for action or decision when considering the subject matter.

Having taken note of the philosophical foundation of this project it becomes necessary to address an important further issue that affects research planning and practice, namely research ethics.

#### *Ethical considerations*

Mouton (2001) states that because research is a form of human conduct it should take place according to generally accepted norms and values. There exist no one set of universal norms to guide research but certain general principles can be identified. These principles are also reflected in the *Ethical Code of Professional Conduct* of the Professional Board for Psychology of the Health Professions Council of South Africa (HPCSA). Mouton (2001) discusses ethics in terms of the researcher's relationship to the scientific community, society in general, the subjects





of science and the environment. As this project does not have any foreseeable impact on the environment this aspect of ethics will not be addressed. Based on the consideration that the order in which topics are discussed might be construed as indicating their relative importance and that the "subjects" of research in this case involve human beings it seems fitting to first address ethical issues regarding the research participants.

### *Research participants*

It is generally agreed that persons who participate in research have basic rights (Babie & Mouton, 2001; Mouton, 2001), namely:

- The right to privacy (including the right to refuse participation)
- The right to anonymity and confidentiality
- The right to informed consent
- The right not to be harmed

In this study, considering the aforementioned and in keeping with the HPCSA's code of conduct (2002), every effort was made to inform participants about the nature of the research, their right to decline to participate or to withdraw from the research – this was done in language that was thought to be reasonably understandable to participants. No form of deception was used during the project and no incentive or reward was offered for participation in the project. Participants were given the opportunity to inquire about aspects of the research that they might have felt unsure about. As the project involved recorded interviews, written consent was obtained



from participants and every effort made to safeguard these recordings. An example of the consent form as provided to the participants is included in Addendum A.

### *Society*

Mouton (2001) indicates that the relationship between researcher and the broader society rests on accountability. This amounts to a rejection of secret or clandestine research and the free and open dissemination of research results (Babie & Mouton, 2001; Mouton, 2001). Part of the commitment to free and open dissemination of research findings is reflected in this text in the use of a less formal writing style and the use of language that does not rely on jargon or where it is required to explain technical terms.

### *Scientific community*

In maintaining "professional ethics" (Mouton, 2001), special care is taken to avoid plagiarism, in other words where sources were consulted every effort is made to indicate this and credit the authors concerned. Efforts to maintain professional integrity are also reflected in the detailed nature of this text, which provides others with an overview of the process that was followed in reaching the conclusions of the study.

Having taken note of the philosophical assumptions of the study and the limits placed by considerations of ethical research the next issue that needs to be addressed is that based on this information, what procedures and methods will set the inquiry into motion (Guba & Lincoln, 1998). Methods that are associated with qualitative research appear the most appropriate for this.



### *Qualitative research*

Qualitative research has been conceptualised in numerous ways. For some it qualifies as a paradigm (Maykut & Morehouse, 2000), for some it is a research style (Neuman, 1997), for some it is a research strategy (Henning, et al., 2004), but most find it necessary to compare it to quantitative research (Babbie & Mouton, 2001; Guba & Lincoln, 1998; Henning, et al., 2004; Maykut & Morehouse, 2000; Neuman, 1997; Struwig and Stead, 2001). I adopt a position similar to Creswell (1998) that qualitative research is legitimate in its own right, it does not have to be continually compared to quantitative research to establish respectability. Denzin and Lincoln's (1998) statement should suffice as a definition of qualitative research, namely that "Qualitative research involves the studied use and collection of a variety of empirical materials – case study, personal experience, introspective, life story, interview, observational, historical, interactional, and visual texts – that describe routine and problematic moments and meanings in individuals' lives" (p.3).

Features of this type of research is that it is exploratory and descriptive, the outcome therefore is not generalisation of results, but a deeper understanding of experience from a rich description of the perspective of the participants (Babbie & Mouton, 2001; Maykut & Morehouse, 2000). Qualitative research also generally makes use of emergent research designs, which support inductive analysis of data collected in a natural – as opposed to laboratory – setting (Denzin & Lincoln, 1998; Henning, 2004; Maykut & Morehouse, 2000). Creswell (1998) indicates that qualitative research is especially well suited to encourage increased dialogue about an issue, to fill a void in the existing literature, establish a new line of thinking, or assess an issue with an understudied group or population (p.94).



Based on the above, qualitative research as strategy of inquiry was considered the most appropriate strategy for this project since:

1. A qualitative research strategy is consistent with the paradigm from which the research interest was stimulated.
2. Qualitative research is suited to the positioning of this research as exploratory. The positioning of the project as exploratory is based on:
  - 2.1. The current state of knowledge and research applying narrative ideas to the study of TBI.
  - 2.2. The opinion that *persons* who experienced TBI represent an understudied population – their injuries are well known, but *their* voices seems somewhat absent from the literature.

#### *Method of data collection*

The main method of data collection in qualitative research is that of interviews, which can be structured or unstructured, and involve individuals and/or groups (Babbie & Mouton, 2001; Maykut & Morehouse, 2000; Neuman, 1997). Other methods of data collection include unobtrusive and participant observation, as well as unobtrusive methods like examination of archival sources and personal documents (Babbie & Mouton, 2001; Blaikie, 2000; Struwig and Stead, 2001).

Although some authors regard true qualitative research as having to start out without a narrow focus of enquiry, Pidgeon and Henwood (2004) indicate that research with too loose an initial research design can leave a researcher with overwhelming and conceptually diffuse data. These authors suggest that data



gathering should be guided explicitly by what interests the researcher about the chosen topic. Charmaz (1995) also notes that practical considerations like the limited timeframe for the completion of academic qualification based research need to be considered when conducting research. Based on this and in keeping with qualitative research design that is emergent in nature, it was decided to make use of semi-structured interviews.

#### *Semi-structured interviewing.*

Material for the research was collected by making use of semi-structured interviews that were recorded. Semi-structured interviewing consists of having a set of interview questions contained in an interview schedule (list of questions), but the interview is guided by the schedule rather than dictated by it (Smith, 1995). This method of interviewing has advantages over structured interviewing, mainly as it is a more flexible approach to allow for the emergence, and follow up of interesting and unexpected avenues that develop during the interview. In other words, participants share more closely in the direction the interview takes and the interview therefore is more conversational in nature. This type of interview is consistent with a narrative position that views persons as the experts about the things that affect their lives. It also leaves space for the researcher to inquire about aspects that might be of particular interest based on theoretical insights. The interviewer's role remains one of facilitator during the interview (Smith, 1995). This type of interviewing also allows for some consistency between interviews with different participants, which could assist in making across case comparisons for patterns or common themes. This is a decided advantage of semi-structured interviews as opposed to unstructured interviews (Struwig & Stead, 2001).



The questions contained in the interview schedule were constructed based on the recommendations of Henning et al. (2004), and covered basic information about the participant as well as questions about persons, judged by the participant, to have played an important role in their lives since the injury. Questions also addressed how the participants would describe themselves prior to the injury and how they thought their significant other/s would describe them. Comparisons between current descriptions were also included. The "comparison questions" were aimed at identifying instances where there existed/exist competing descriptions of the person, which could indicate occasions where an implied self-narrative had to be resisted. Similar questions were also included to address experiences with strangers. A copy of the interview schedule is included in Addendum B.

In conducting the actual interview, Smith (1995) indicates that the interview should preferably proceed without interruption, in a setting that the participant is familiar with. To allow the interviewer to concentrate on the interview, rather than having to laboriously write down everything the participant says, it is advisable to record the interview. This was done with the consent of the participants.

### *Selecting participants*

The sampling procedures in qualitative research differs from quantitative research as generalisation of knowledge claims is not the main aim of the research; as such random selection of participants is not a primary concern for this type of research (Struwig & Stead, 2001). The main aim of sampling in qualitative research is to ensure information-rich participation (Struwig & Stead, 2001). Sampling is therefore not aimed at ensuring uniformity, but rather variability. Struwig and Stead



(2001) identify at least fourteen different types of sampling procedures that are generally used in qualitative research. The participants for this study were selected through convenience sampling. In other words, participants for this project were recruited from support groups for people who have experienced TBI but were not randomly selected.

With regard to the number of participants in this study, it was decided that interviews with at least five people would allow enough variability in the data, and allow time for the lengthy process of data reduction and analysis. The number of participants is also in keeping with South African trends for master's level qualitative research, which tends to include between five and twenty-five participants (Babbie & Mouton, 2001).

*Criteria for the selection of participants.* It should be appreciated that persons who have experienced TBI can generally not be considered to qualify as typical cases that make for easy identification of inclusionary/exclusionary criteria. At this stage, there exist little to indicate any specific criteria for selection to participate in a project of this nature, other than having experienced TBI, as well as the ability and willingness to participate in the project. By ability it is meant that a person's ability to communicate verbally should not have been overly compromised by the injury. It was also decided to include only persons who are aware of the injury and are able to reflect on their experience before and after the injury – consequently this precluded persons with severe anterograde amnesia from participating in the study. An attempt was made to include persons from a variety of backgrounds, including gender, culture and language. Representing a limitation of the researcher rather than



characteristics of injured persons, participants were limited to those who are at least comfortable to converse in either English or Afrikaans. This probably contributed to the final group of participants consisting only of white, English speaking participants. With regard to gender the final group of participants consisted of two females and three males.

Having detailed that data for the project was gathered by making use of semi-structured interviews, the next issue that needs to be addressed is that interviews in themselves do not lend them much to interpretation. For something meaningful to be made from the interviews the recorded material must be analysed.

#### *Method of data analysis*

Various methods exist that assist in the analysis of qualitative research material, and in fact Smith (1995) is of the opinion that "there is no one correct way to do qualitative analysis" (p.18). As a novice researcher this leaves one with a bewildering choice of how to approach analysis. After reviewing different analysis methods, and considering the aims and philosophical position of the guiding paradigm, a method of analysis was chosen that is closely related to what is known as the *constant comparative* method of analysis. This method of analysis is especially well suited to identify themes, and variations on themes across different personal narratives that ultimately allow the researcher to construct an integrated narrative that represents a new description and understanding of the human world. As pointed out by Maykut and Morehouse (2000), though, the "raw" data from interviews first need to be prepared to allow for analysis – this process will first be reviewed before returning to a discussion of the analysis method.





### *Transcribing the interviews*

The recorded interviews were transcribed verbatim to produce the empirical material that was analysed. In producing the transcripts the recommendations of O'Connell and Kowal (1995) as well as Henning et al. (2004) were followed, namely

- Only those components of spoken discourse that are to be analysed should be transcribed, and only what makes analysis intelligible should be presented in transcripts for the reader.
- Graphemes should be used only for the segmental representation of lexical items, and punctuation marks should be used only for their conventional purposes.
- The internal integrity of words should not be interrupted by any supernumerary symbols.
- Symbols used in the transcription should stand for only one feature of the spoken discourse, and no feature should be represented by more than one symbol.
- Descriptions, explanations, commentaries and interpretations should be clearly distinguishable from the transcription of phonological features of spoken discourse.

The researcher and not a third party, completed the process of transcription. This practice is in keeping with the position of Henning et al. (2004) as well as Charmaz (1995) that transcription by the researcher assists in later analysis. Transcribing the interviews allowed the researcher to become more familiar with the data and contributed to the confidentiality of the interview material. As pointed out by



Pidgeon and Henwood (2004), transcription is a highly labour-intensive and time consuming process – in the case of this project averaging between eight and ten hours of transcription time for every hour of recorded material. Each line of the transcripts was numbered, and following the recommendations of Maykut and Morehouse (2000) as well as Pidgeon and Henwood (2004), each individual page was identified with a code indicating the type of data, the source of the data and the page number of that page within the particular "data set". These transcripts formed the basis of the material that was then analysed using a version of the constant comparative method. A table presenting the notation symbols that were utilised in the transcriptions is presented in Addendum C.

#### *Constant comparative data analysis*

The constant comparative method has its origin in the grounded theory approach to qualitative research originally developed by Glaser and Strauss (1967) and Strauss and Corbin (1990, 1998). As pointed out by Pidgeon and Henwood (2004) the methods of grounded theory are not unique to grounded theory studies but represent "core strategies of qualitative inquiry" (p. 627). These authors regard the explicit techniques provided by methods derived from grounded theory as useful to beginning researchers – a position echoed by Charmaz, "Grounded theory methods allow novices and old hands alike to conduct qualitative research efficiently and effectively because these methods help in structuring and organising data-gathering and analysis" (p.28). Another benefit of grounded theory methods is that they provide rigorous procedures for researchers to check, refine and develop their ideas about the data (Charmaz, 1995). These methods therefore also contribute to the academic and scholarly merit of the research. A possible point of criticism that



may be levelled at the application of methods derived from grounded theory in this study, is that these methods originated in a positivistic epistemology where it was assumed that the researcher could *discover* the true meaning already inherent in the data. However, more recent approaches to grounded theory methods are consistent with post-modern paradigms (Pidgeon & Henwood, 2004; Charmaz, 1995) and call attention to the requirement that the *researcher* remains aware "that knowing always involves seeing or hearing from within particular individually, institutionally and other socio-culturally embedded perspectives" (Pidgeon & Henwood, 2004, p.628). It should also be borne in mind that the aim of this research project is not the development of a comprehensive theory and as such cannot be called a grounded theory study. By making use of methods originally associated with grounded theory, this project might be labelled a "grounded analysis" in Charmaz's (1995) terms or "qualitative content analysis" in Henning, et al.'s (2004) terms. The actual *process* that was followed during analysis is still most accurately described in the terms and procedures associated with what is known as the constant comparative method. In its most basic form this process consists of "breaking apart" the data through what is termed open coding and categorising, and then synthesising the different "chunks of data" into a new whole, indicating how the different parts relate to one another.

*Open coding.* Charmaz (1995) describes open coding as the process of defining what the data is about. This process consists of reading through all the transcripts to get a global impression of the content (Henning et al., 2004; Maykut & Morehouse, 2000). The next step is to start with an individual transcript and identifying units of meaning. Some authors (Charmaz, 1995) favour "unitising" each individual line of text, while others (Pidgeon & Henwood, 2004) prefer larger units



like individual turns in talk. Maykut and Morehouse (2000) state that each unit of meaning must be able to "stand" by itself, in other words, it must be understandable without additional information, except for knowledge of the researcher's focus of inquiry. I therefore concur with Henning et al. (2004) that meaning is not arbitrarily lodged in a line of text, and therefore sentences are considered to be the smallest possible unit of meaning – this is also compatible with the position of Pidgeon & Henwood (2004).

Each unit of meaning that appears relevant to the research problem is then labelled with a code (hence the name of this stage as coding). These codes are essentially made up by the researcher but should be an attempt to answer such questions as "what is going on in this unitised section?"; "what are people doing?"; "what is the person saying?". A code consists of a word, or more generally a phrase that defines the actions and events as the researcher sees it in a unitised section of data (Maykut & Morehouse, 2000). Charmaz (1995) suggests that codes should be as specific as possible and be written in the active tense. When a label/code is thought of it is recorded as the header of an index card, together with a summary of the data of interest, and a reference to the original transcript (Pidgeon & Henwood, 2004). Maykut and Morehouse (2000) suggest placing a copy of the part of the transcript that is of interest on the index card. The particular unitised section is then checked for other possible themes of interest and this process continues with all other unitised sections until the entire transcript has been coded. This process is followed with all the transcripts. Through this process recurring words, concepts, and themes might be identified – these recurring themes form the basis for categorising.



*Categorising.* This part of the analysis process involves comparing all coded unitised sections to one another and units that appear to "fit together" are combined into groups/categories and again given a name (Henning et al., 2004; Maykut & Morehouse, 2000). This is an iterative process, in other words, categories are continually refined, new categories are formed, previously identified categories are omitted and different relationships between categories might be contemplated – it should be clear why this process is referred to as the constant comparative method. Charmaz (1995) regards the significance of categorising, which she refers to as focused coding, as selecting codes that have overriding significance in explicating events or processes in the data and through this process the researcher moves beyond using codes as mere descriptive tools to a more sophisticated level of analysis.

The last part of the analysis process is to indicate what has been learned from the analysis – as Henning et al. (2004) states "the researcher is left with the all important task of *seeing the whole*" (p.106, emphasis in original). This involves formulating how the themes/categories that were developed appear to relate to one another, which forms a basic model that might be examined for correspondence with pre-existing common sense, theory, and professional assumptions (Pidgeon & Henwood, 2004). The result of this process is presented in the next chapter.

Before concluding this discussion it is important to note that while the process of analysis is presented as linear steps, which have clear boundaries, this is not the case in practice. Analysis continues in various stages and at different levels throughout the lifetime of the project. It is for this reason that it is also imperative to



make use of memo writing. Charmaz (1995) regards memo writing as an intermediate step between coding and the first draft of a completed analysis. It consists of exploring and reflecting about the data, concepts and categories (Henning et al., 2004; Charmaz, 1995). By keeping record of these written memo's one also forms what might be considered an audit-trail of the researcher's thinking and provides a record of how the analysis developed. The concept of an audit-trail calls attention to the requirement in research, that methods are employed which assist in maximising the credibility of research findings – this requirement is traditionally understood in terms of validity and reliability.

#### *Maximising credibility of the findings*

Traditional concepts of validity and reliability, as found in modern/positivistic science, are understood differently in qualitative research (Silverman, 2001). Post-modern qualitative research epistemology makes it practically impossible to present universalistic benchmarks for judging the credibility of research (Delamont & Atkinson, 2004; Struwig & Stead, 2001). In other words, there exist no globally accepted criteria that will allow one to *test* the validity of qualitative research. However, this does not mean that no guidelines exist. Delamont and Atkinson (2004) point out that the traditional notion of "internal validity" may fruitfully be replaced by the concept of "credibility". Maykut and Morehouse (2000) take a similar position but prefer the term "trustworthiness" about which they state that "the question of trustworthiness essentially asks: To what extent can we place confidence in the outcomes of the study? Do we believe what the researcher has reported?" (p. 145). The main procedures that are thought to contribute to credibility/trustworthiness are prolonged engagement, persistent observation, triangulation, referential adequacy,



peer debriefing and member checks (Babbie & Mouton, 2001). Considering the scope of this research project a number of these procedures are logistically impractical. The main procedures, which will be employed to contribute to credibility/trustworthiness of this project are triangulation, referential adequacy and member checks.

### *Triangulation*

Babbie and Mouton (2001) describe this as eliciting various and divergent constructions of reality by collecting information about different events and relationships from different points of view. This means asking different questions, seeking different sources, and using different methods. Struwig and Stead (2001) regard the use of multiple data sources as especially useful since it also allows for the discovery of conflicting findings, which can broaden the interpretation of the data. In this study triangulation is achieved mainly through making use of multiple participants and allowing space to add to the initial interview schedule based on previous interviews.

### *Referential adequacy*

Referential adequacy relates to the question of which materials are available to document research findings. Babbie and Mouton (2001) regard audio and video taping as useful methods to document one's findings. In this regard Silverman (2001) refers to the need for "low-inference descriptors" when making use of interviews in research and states that this can be achieved by



- tape-recording face-to-face interviews
- carefully transcribing the recordings according to the needs of analysis
- presenting long extracts of data in the research report – including the context which provoked a particular answer

Regarding the last point, Maykut and Morehouse (2000) consider a very detailed research report as an essential requirement of qualitative research.

### *Member checks*

Member checks involve returning to the participants with the findings, which allows them to check the factual accuracy of the information provided in the report, it allows participants to comment on how the data was interpreted and the conclusions drawn (Babbie & Mouton, 2001; Struwig & Stead, 2001). Member checks as procedure to contribute to credibility/trustworthiness is not without criticism. Bloor (1997) for instance points out that what he terms "member validation", is a social event and as such could be constrained by social dictates of polite conversation. In other words, participants may be hesitant to criticise a researcher's findings or to offer competing interpretations. Winter (in Struwig & Stead, 2001) also raises the question whether findings are only useful if participants concur with them.

### *Conclusion*

In this chapter I have presented the methodology whereby the project was approached. I have indicated how this project relates to the practice of science in general by arguing that science and research refer to attempts to gain knowledge, not truth. In claiming that this project is "scientific," I am stating that the research is





conducted according to a thorough thought out process, and the process through which the final knowledge claims are arrived at, are presented in detail for public and peer scrutiny. I have argued that when judging the scientific merit of this project it should be done on the basis of whether the practical methods and procedures utilised are appropriate and consistent with each other, the research interest, and philosophical assumptions of the guiding paradigm, and therefore form a reliable basis for decision and action. This project should also be evaluated in terms of the guidelines of ethical research practice. To assist readers in judging the credibility of the findings, I have also discussed the methods that are used in this project to help maximise credibility.



## CHAPTER 5

### **LEARNING ABOUT OTHERS AND ACCOUNTS OF SELF**

#### *Introduction*

In this chapter I will present what has been learnt from this research project. To allow adequate scope for others to judge the conclusions drawn from the research, or to draw conclusions of their own, the analysis is presented as completely as possible. In essence an attempt is made to have the reader present during the actual analysis process, rather than just present results that appear to have "magically" entered the mind of the researcher. By providing as much detail as possible to the reader, the study's credibility, which was discussed in the previous chapter, is enhanced by in effect presenting the audit-trail of the project to the reader. Presenting an audit-trail also requires being transparent about the *entire* process that was followed, which means also pointing out where errors were made.

Before presenting the results of the analysis, background information on the participants and other relevant information are presented to provide a greater understanding of the context of the data. Following this the reader is guided through the different stages of data analysis and interpretation. Next, the findings in relation to the questions posed in chapter three are discussed. Lastly the project is evaluated and recommendations for future research based on the findings from this study are made.



### *Participants in the study*

#### *Participant A*

Participant A is fifty years old, married, has three adult children, two of whom still reside in the house. He sustained a blow to the head in a freak sporting accident which resulted in him being hospitalised for a month – according to his recollection this included being in a coma for two weeks. Participant A completed his schooling to grade 10 level and prior to his injury was a successful self employed businessman. Even though he returned to work three months after the injury, he made a change in his career about a year prior to the research interview, but he indicates that he is struggling to cope at work. His main difficulties related to the injury are, according to him, problematic word finding, being at times slightly forgetful and fatigue. He does not report experiencing significant problems in his relationships with either his wife or children.

#### *Participant B*

Participant B is thirty-four years old, married, and mother to a three and half year old daughter. She sustained head injuries on two different occasions, separated by about three years. The first injury that resulted from falling from a horse, was according to her not very serious, because although she was hospitalised she did not undergo rehabilitation. The second injury, about three years prior to the research project, which was also sustained from a horse riding accident was to her mind much more serious – it included a loss of consciousness for an unknown length of time and she underwent intensive rehabilitation at an inpatient setting following discharge from hospital. Prior to her first injury she completed a B.Com degree and was employed; following her first injury she completed another qualification and made a change in



career. Since her second injury she has only been employed in "crappy jobs that do not require any brain power" and she admits that she is struggling with these jobs. Her main injury related problems appear to be fatigue, physical weakness, impaired sensation (paresthesia), problems with balance, forgetfulness, slowed writing and being "narrow minded" (referring to problematic problem solving, not an inflexible attitude). She reports experiencing considerable problems in her relationships with both her husband and daughter but also indicates that she and her husband were considering marital counselling prior to her injuries.

### *Participant C*

Participant C is in his early thirties, unmarried, has no children and is living with his parents. He is diagnosed with cerebral palsy and suffered a head injury in a motor vehicle accident about four years prior the research interview. He was hospitalised following the accident and was, according to his recollection, in a coma for about a week and underwent inpatient rehabilitation for about five months. Participant C completed his mainstream schooling to grade 10 level and completed his N5 level at college. He was employed in a banking group in an administrative capacity prior to his injury but has not been employed at all following his injury. His main injury related difficulties appear to be forgetfulness, aggressiveness and some physical weakness. He indicated that his relationship with his parents are at times very problematic due to his apparent aggressive outbursts and that his parents regard his current behaviour as being a very big change from his pre-injury behaviour.



### *Participant D*

Participant D is thirty years old, unmarried but in a serious relationship for about six months, has no children and lives alone. She was previously diagnosed with cancer but it is currently in remission. Participant D suffered a head injury in a motor vehicle accident five years prior to the research interview. She was in a coma for four days and underwent inpatient rehabilitation for two weeks and continued rehabilitation on an outpatient basis for an unknown length of time. She completed a bachelor's degree and was employed as a teacher prior to her injury and for some time following her injury. She has recently made a career change for reasons that are unrelated to the injury. Her main current difficulties related to the injury appear to be a slight name finding problem and fatigue. She did not report any problems in her current relationships.

### *Participant E*

Participant E is in his fifties, married, and has one adolescent daughter who lives with him and his wife. He was injured about five years prior to the research interview when he was knocked down by a motor vehicle while cycling. He suffered a loss of consciousness for an unknown time and underwent inpatient rehabilitation for about three months. Participant E completed his schooling to grade 12 level and worked in the financial industry his entire life prior to his injury, but has been unemployed since the injury and has no interest to return to work. His main injury related difficulties appear to be general slowing, "passiveness", unclear speech articulation (dysarthria), fatigue, and physical difficulties like right-sided weakness and tremor. He did not report any noteworthy problems in his relationships with either his wife or daughter.



### *Other relevant information*

The participants were contacted through the organisation Headway. After being provided with information on the nature of the study and being satisfied that the study met ethical research criteria, a therapist from Headway contacted participants who met the criteria for participation, to enquire about their willingness to take part in the research. Five individuals were identified in this manner and their contact details provided to the researcher. The researcher contacted the participants telephonically and all five agreed to take part in the research. The interviews were conducted at the homes of participants at a time convenient to them. The interviews lasted between one and two hours per participant. The interviews were recorded using a digital voice recorder and copies of the recordings were transferred to a personal computer. Once all the interviews were completed the recordings were transcribed – the completed transcripts were contained in 187 pages, containing 6383 lines of text. As a practical measure, physical copies of the transcripts were kept in a lever arch file in alphabetical order based on the participants' first names.

Being more familiar with the participants, it is now possible to present the analysis of the data. As indicated in the previous chapter, qualitative research involves what could be considered a taking apart of data and then integrating the different parts to learn something new. The process of "taking apart", or unitising as it is referred to, is presented first, followed by an interpretation, or "putting together" of the data.



### *Taking the data apart through coding*

During the process of transcription of the recorded interviews some parts of the conversation seemed to be especially relevant to the research and were labelled with codes. On completion of transcription of all the interviews the transcripts were read individually and the already constructed codes reviewed. On reflection it became apparent that the majority of these codes were extremely biased by theory and amounted to interpreting the data to fit a preconceived idea.

#### *The researcher's story: Initial bias and error*

The most striking example of this bias involved the identification of parts of the transcripts as indicating a relationship between reported behaviour, as recounted by a participant and a process assumed to represent an attempt to maintain a particular identity – this potential process is postulated in chapter three in the section on self-narratives and TBI. As an example, during transcription the following extract from participant C was labelled as "agreeing to unwanted identity - to keep the peace". The transcription notation system is presented in appendix C and in this, and all other extracts from transcripts, the capital letter M indicates the researcher and capital A, B, C, D or E indicate the respective participants. In all the transcripts the names of persons have been changed to protect the identity of the participants. This extract is part of a response to a question about how the injury has affected him, the participant indicated that he has some memory problems and then went on to describe what his mother would say.

90 C more. .sort of. .angry and aggressive. .she says "you were  
 91 never like this before". .my accident. . "you never did this"  
 92 . .let's just agree from there. .you know?. .will be better



On reflection – especially considering the context of the conversation, which was aided by re-listening to the recording of the conversation, this extract could not be considered to represent an "acceptance of identity" but rather appears to be a reported disagreement about factual events. Rather than search the data for particular preconceived themes, the techniques advocated by the authors mentioned in the previous chapter, like asking oneself "what seems to be happening in this section of the transcript?" and asking oneself *why* a particular code is chosen and not another, seemed to effectively reduce this type of bias. A deliberate effort had therefore to be made to maintain a critical stance during analysis by being reflexively aware of my own background and interests.

This bias might also have been reduced or even prevented by following the recommendations of the authors to unitise the interview transcripts by a process of literally cutting apart physical copies of the transcripts. During the initial attempts at coding, the researcher mistakenly assumed that the interview schedule already served the purpose of unitising the data to a large degree beforehand, which would allow themes to be simply noted on an *intact* transcript. This assumption does not hold true since using an interview schedule to effectively unitise the data would require knowing beforehand what *all* the relevant aspects are to be covered during an interview. This would make the research redundant in the first place and would also contradict the philosophical assumptions of the study. Another drawback of working *only* with intact transcripts is that analysis becomes tied to the particular context of that interview, which makes it difficult to recognise more generalised ideas.





### *A second attempt at unitising and coding*

The transcripts were again repeatedly read and re-read over a period of a number of weeks, often while listening to the recorded conversation and continually noting potential themes and important ideas. During this process it became clear that the order in which transcripts were read influenced the subsequent coding of the following transcripts. In other words, the researcher became sensitised to recognise only instances of a theme identified in earlier transcripts and the identification of new themes became hampered. During the reading of transcripts it was therefore deliberately decided to also read transcripts in reverse order – in hindsight it could also have been beneficial to use a method of repeatedly reading transcripts in a fairly random order.

Following this period of reading and re-reading the transcripts, the individual transcripts were unitised and coded by cutting relevant extracts from the transcripts and pasting these to index cards that were marked with what appeared to be the most appropriate label. The process of constant comparison was used to assess whether unitised sections were to be added to an already existing index card, or whether a new card and hence a new label had to be created.

Returning to the already mentioned extract from participant C's transcript, the above mentioned process lead to it being unitised on a data card labelled "Seeing self through other eyes". Two more extracts from the same participant were added to this data card that resulted in this data card containing the following extracts:



90 more. . sort of. .angry and aggressive. .she says "you were  
 91 never like this before". .my accident. . "you never did this"  
 92 . .let's just agree from there. .you know?. .will be better  
 93 ((chuckles))  
 94 M so. .so you sometimes. .you. .you almost kinda disagree  
 95 about that at times. .you feel "I::'m not sure about that"  
 96 C yah just. .start. .start. .start saying things "I didn't do that"  
 97 . ."you did that". .and that's when basically. .fighting starts  
 98 . .not good. .but things happen. .

198 M mm. .okay so. .you say. .now the getting angry. .uhm. .  
 199 after the injury. .is almost a bit worse than before the. .  
 200 the injury?  
 201 C yah cause. .I think it is yah. .a little bit worse but. .basically  
 202 my mom says. ."you were never. .you never got angry. .  
 203 now you're angry at me. .what's it like when you go out  
 204 with your friends?". .I say "I'm not angry at my friends"  
 205 ". .just unfortunately it's just that my. . my. .you and the  
 206 family. .you basically just". . "mom it's just [{specifically}]  
 207 because of you". .my dad sometimes. .but. .my. .friends  
 208 . .nothing. .you know?

727 C you can lose. .mom says uh. .I don't need to. ."I don't want  
 728 you to go to work in the mood that you are. .here. .cause  
 729 you could start causing fights at work" and that's where  
 730 you can easily lose you job. .so I said. . "I'm fine with  
 731 friends it won't happen at work she goes. ." ((shrugs  
 732 shoulders))



### *Further refinement of the data*

During this unitising and coding process, instances of "seeing self through other eyes" were noticed in other transcripts but there appeared to be a slight difference in these cases. Exploring these differences lead to the expanding of the initial data card code to "seeing self through other eyes – and disagreeing" and creating a separate data card "seeing self through other eyes – and agreeing". This second card contained extracts from four of the participants – it should be appreciated that the "agreement" aspect of the code is often less clear in the transcript than when simultaneously reading the transcript and listening to the conversation. Nonetheless, the absence of disagreement from the perspective of the participants when reporting how others might describe them is quite apparent even in the transcripts alone.

- 1032 M mm. .alright. .actually. .something. .I quickly wanna jump back  
 1033 to Mike ((her husband)). .how would he describe you?. .if I  
 1034 had him here and I asked him  
 1035 B you wanna phone him? ((smiles)). .how would he  
 1036 describe me?  
 1037 M mm  
 1038 B (. . .4) don't actually know (. . .) strong headed. .  
 1039 M and that's a euphemism for?  
 1040 B ((smiles)) euphemism for what?  
 1041 M if you're so strong headed it's kinda like. .it uh. .it's a nice  
 1042 word to choose but. .he might actually use something  
 1043 else  
 1044 B no, no. .he would. .he would use that one. .but he would  
 1045 mean. .stubborn ((smiles))  
 1046 M uh hu. .would you agree with him or disagree?  
 1047 B (. . .) uhm. .I wouldn't agree whole heartedly. .partly agree  
 1048 I do think I am stubborn



747 M mm . .and if I ask her ((D's mother)) describe your personality?

748 . . what would she say?

749 D my personality?

750 M mm

751 D she'll say I'm stubborn

752 M stubborn?

753 D yah . . no . .my mother will say that . . I don't know .

754 ((phone rings)) ((recording stopped and then resumed))

755 D yah . . my mom might . . uh . . I don't know she'll:: . . my

756 mom and I are very similar . . so I know she'll say I'm

757 very stubborn . . but I'm very loving

1074 M something I wanna get back to. .Moira ((his wife)) . .how would

1075 she describe you?

1076 A (. . .3) I've actually asked her (. . .3) she says (. . .) I'm

1077 a very loving. .helpful person but . .I still involve myself

1078 with too many things that are not my::... uhm. .what's

1079 the right word?

1080 M concern or. .

1081 A concern. .exactly. .so. ."something's happened. .leave

1082 it". ."it's got nothing to do with you". .

1083 ((points out example of wanting to fix-up minutely skew

1084 mirror, getting up to see if kids came home alright))

1085 so. .yah that's my main. . I get involved too much

539 M so if I were to ask . . her ((his wife)) to describe you . .what would

540 she say?

541 E uhm . . I'm very passive . .I nag a lot. . because . .if you say

542 "would you do this?" and you say "yes". .I want it done

543 now ((taps with finger on desk))



The above examples should be sufficient to illustrate the process whereby the data was coded and unitised – it is impractical in a text of this nature to describe in detail the creation of all the data cards. Overall, this process of repeatedly reading the transcripts, sometimes "revisiting" the recorded conversations, noting salient ideas, and only then unitising and coding transcripts by literally cutting them apart, contributed to the creation of codes that were more grounded in the data than in prior conceived theory and therefore lends more credibility to the analysis.

### *Integration of the data*

The data cards were further examined for relevance to the research topic and to explore how different themes might relate to one another or how multiple themes could be combined to form a single theme. Five of these grouped themes seemed to relate to "themes that suggest experiences of others which could add to the challenges persons face following TBI".

### *Themes relating to experience of others*

When addressing the first aim of the study, as identified in chapter three, the following emerged. *Significant others* featured much more prominently in the narratives of the participants with four of the five grouped themes *mainly* relating to experiences with significant others. Very few experiences with strangers seemed to be of significance for the participants. Experiences with persons from the medical/helping professions also featured in the narratives of the participants but were mainly part of recounting the details of their recovery.



*Significant others as caretakers and motivators.* Significant others like spouses, parents, children and close friends have a prominent role in the narratives of injured persons. These experiences are especially prominent in the recounting of recovery where significant others are recurrently encountered as caretakers and motivators. Participant A spontaneously recounted his experience of recovery.

62A first month I came home. .I was. . an invalid. .!::: .my wife  
63 had to put me in the bath. .fed me in bed it. .if it wasn't  
64 for my wife. .that's why I say get the caregivers there. .she  
65 helped me a hell of a lot. .she got me right. .she pushed  
66 me to come right she really did. .she worked. .

Based on the conversation with participant D it was clear that her mother played a significant role in her life since the injury.

661D oh:: very important role . . she's just . . I don't think I would  
662 have recovered . . as well if I didn't have . . the love and  
663 support that my mother . .  
664M mm  
665D gave me . . she made sure I never gave up, she made  
666 me fight (. . .) through the cancer, through this

The role of caretakers seem to go further than encouraging the injured person when things get tough, but in fact appears at times to influence the injured person's acceptance or rejection of their status as permanently injured.



881A the main thing that she's done. .was to get me to  
882 understand. .that. .I'm not. .injured. .I'm not. .permanently  
883 . .unable to do things. .she got me to believe that I could  
884 do things. .in the beginning. .I just thought "well that's  
885 it"  
886M mm  
887A "I can't do anything". .and she got me to believe that I  
888 can. .so she pushed me forward. .got me. .to believe  
889 in myself. .

Considering the length of time since the injuries of the participants, it also became clear that the role of significant others as caretakers and motivators is not limited to the early stages of recovery but continues into the present. In asking participant C who has played an important role in his life since the injury, he responds with an answer that describes what his parents are currently doing for him.

783C . .been my parents cause they. .I live with them now  
784 and they just uhm. .support me with uhm. where they  
785 can and they know what problems I got. .and they're  
786 always there for me. .to do the best they can. .basically  
787 congratulate me and. .just. .give me support and "well  
788 done" and. ."keep up the good work" "don't do this. .  
789 you're doing it wrong. .do it the correct way". .things like  
790 that. .very supportive of me. . yes



*Owing significant others a debt of gratitude.* Despite the very positive contribution of significant others as caretakers and motivators during recovery, there appears to be a potential downside to this. Injured persons appear to be at times disempowered, in their day-to-day relationships with their significant others, through a "debt of gratitude". This theme emerged spontaneously in the conversation with participant A when discussing the difficulty he often experiences with fatigue when he and his wife attend functions, which would make him prefer returning home earlier than his wife might want to.

488A she can extend for another hour ((laughs)). .but she  
 489 needs that break  
 490M mm  
 491A because. .she's changed her whole life. .for me. .her  
 492 work used to be:: .starting at ten o' clock in the morning  
 493 with the horse racing industry  
 494M mm  
 495A her brother's a bookmaker. .and she used to be there  
 496 at ten. .half past ten. .wake up. .make sure everything's  
 497 right at home. .go to gym for an hour. .bit of shopping. .  
 498 come home. .shower go to g. .work. .beautiful life. .  
 499 Mondays, Fridays off. .every second Sunday off. . her life  
 500 was brilliant. .now she works half past seven in the  
 501 morning here at her sister's house. .in the same  
 502 business I'm in. .building. .Monday to Friday. .no more  
 503 lifestyle. .squeezes in gym maybe once or twice a week  
 504 at. .after work  
 505M mm  
 506A she's tired. .works Saturday with the horses still. .and  
 507 gets every second Sunday off. .it's very heavy for her  
 508 . .so when we do get a chance to go out. .I say go





When specifically asking participants who have indicated that their significant others have at times done things that they have found unhelpful, whether they have ever mentioned it to the significant others, the general response is reflected by participants D and B – especially significant is the response of participant B.

688B and he's done everything in his power to be:: [mm] as  
 689 good as he can possibly be (. . .) but (. . .3) by trying too  
 690 hard he ends up . .taking a lot away from me. .[mm] as  
 691 well and like. .((sighs)) I sort of think . ."I can't sort of" . .  
 692 I can't . .sort of. . I can't. .put a spanner in the works by  
 693 saying something because he's being so good

727M alright . .have you ever told her that . . you know . . "calm  
 728 down" or "don't be so protective"? or . .  
 729D no:: like I don't . .I don't wanna hurt her feelings . .you  
 730 know she's just . . I know where she's coming from and  
 731 . . [mm] and she's almost lost me twice  
 732M mm  
 733D she . .she . . just didn't need to hear me say that and . .  
 734 I know she means well and she's done so much for me

It could therefore be difficult for injured persons to provide significant others with feedback that could be construed as criticism. This might even be reflected in participants generally appearing hesitant to respond with specifics to the question about "unhelpful things" their significant others have done, or still do – in other words participants might have felt guilty to, in effect, criticise their significant others during the conversation.



*Receiving special treatment.* This type of experience seems to be confined to others who are at least fairly well acquainted with the injured person and takes the form of the injured person being seen as someone who needs special treatment. Participant B described often having a sense of being accommodated at social gatherings.

1134B . .they're sort of not honest with  
 1135 you about. . how they feel about you. .maybe. . they don't  
 1136 want you around ((smiles)) and they're not honest with  
 1137 you and tell you that. .so. .would be nice if people did  
 1138 that  
 1139M is it. .is is ann. .annoying or what is it. .what happens. .  
 1140 is that people think you're not clever enough to notice  
 1141 it or. .why. .why is that bothersome?  
 1142B (. . .4) no it's just always like (. . .4) I think sometimes  
 1143 people want something but they don't want to fend you  
 1144 and sort of. .like often uhm (. . .7) maybe someone  
 1145 doesn't want you around because. .but they have to  
 1146 always accommodate you. .and make sure that you're  
 1147 alright and make sure there's enough seating and. .  
 1148 everything and that uhm. .to get there is not too difficult. .  
 1149 for you to get there and stuff like that so they have to  
 1150 always accommodate you. .so. .it would be nice if people  
 1151 say "no" uhm. ."don't come cause uhm. . we can't  
 1152 accommodate you". .that would be fine . .if they did that. .

Judging by lines 208-210 and line 577 from participant D, it would seem that getting treated as a victim who needs special treatment makes injured persons feel set apart from "normal" people.



204D . . if people knew about my  
 205 accident, people would feel sorry for me, "shame", [mm]  
 206 I didn't want their sympathy  
 207M mm  
 208D I wanted to be seen as . . seen as normal . .  
 209M mm  
 210D seen as. . equal . .

574M mm. .why is it. . why is it so important for you to. . to not  
 575 be a victim?  
 576D (. . .) well I just (. . .) you know (. . .2) ((sighs))( . . .) cause  
 577 I just want to be like everyone else . .

This sentiment is echoed by participant C, when he was asked what advice he has for people who are unfamiliar with TBI, about their interaction with others.

1058C just treat me as. .what I did before. .before my injury  
 1059 . .treat me as the way I. .nothing happened to me. .  
 1060 treat me as normal. .

The experience of receiving special treatment seems to add to the injured person's challenges by complicating relationships with others. Participant B added the following just as the interview was drawing to a close.

1190B my family has been so good. .and I think that's also. .  
 1191 where I always have bit of a problem cause I. .I sort of  
 1192 don't want to ask for something cause. .I know that  
 1193 they'll give it to me. .but I'm not always sure that they'll  
 1194 give it to me because they want to. .they'll do it  
 1195 because. . they. . feel that I need it



*Disputes about ability.* Based on the literature and my limited experience with persons who have been injured through TBI it was anticipated that participants would recount experiences with significant others where there existed a discrepancy between what the injured person regarded themselves as capable of doing and the opinion of others. This type of experience is not limited to significant others, or to a particular time of recovery. Participant D for instance recalls the experience of neuropsychological assessment early in her recovery.

67D . . and what I did was I remembered the test that he gave  
 68 me, I had to write down all the letters beginning with A, B,  
 69 C, so what I did when I went home I used to practice it,  
 70 so when I went back to him . . uhm I knew he was gonna  
 71 give it to me again ((clears throat)) so when I went back  
 72 there . . he said there's a VAST improvement [mm] uhm . .  
 73 I mean obviously there were a lot of other tests . . but he  
 74 said "I still don't think you're ready to go back to school"  
 75 cause being a school teacher [mm] . . and I told my  
 76 headmaster I'm coming back in term three  
 77M mm  
 78D . . and he said to me . . "I don't think you're ready to go  
 79 back" . . I said . . "that's going to be a problem because  
 80 I've told my headmaster [mm] I'm coming back" and he  
 81 says "well if you . . think you're ready for it, I'll support you".  
 82 So he did support me and I . . I just felt like if I'd stayed  
 83 at home I would have regressed

While this instance appears to have been resolved in a way that she preferred, these types of disputes can lead to significant conflict. It is not surprising that many of these types of disputes arise between injured persons and their significant others.



Participant E recounted some instances where he engaged in activities that were against the wishes of his wife and daughter, as well against medical advice.

- 634M alright. .uhm . .do you and your wife or . .mother in law  
 635 . .daughter at times. .disagree about what you can do:  
 636 or can not do?  
 637E oh yes . .oh yes!  
 638M so that's familiar ((smiling))  
 639E that is very familiar because . .I want to do things for . .  
 640 simple thing . . like climbing up a ladder  
 641M mm  
 642E now . .before they . . used to "no no no"  
 643M mm  
 644E I just (X X X X) and I do it by myself  
 645M mm  
 646E "why you up there?" . .I'm up here" . .they get used to  
 647 the idea. .and they leave me alone now. .so . .I have to  
 648 push myself. .because they don't want me to hurt myself  
 649M mm  
 650E so . . I understand their concerns. . because they don't  
 651 want me to hurt myself  
 652M mm  
 653E but . .I've got to push myself. .uh . .uh. .I . . I give you a  
 654 good example. .uhm. . I can't drive a car  
 655M mhm  
 656E now I drove the car . .round the crescent. . uhm . .by  
 657 myself [mm]. . and when I came back . .my wife and daughter  
 658 . . gave me uphill like you can't believe  
 659M mm  
 660E I don't blame them but . . I have to get that independence  
 661 . . and do it slowly but surely



These types of disputes, with the injured person wanting to do things which others regard him or her as incapable of doing, were the only “direction” that disagreements which could potentially imply disputed identity, were anticipated to take. It would however seem that injured persons judging themselves less capable compared to the opinion of others also should not be discounted. Participant B, when asked about her apparent “stubbornness” about generally refusing to write and her decision to want to stop working, both of which have led to conflict between herself and her husband, replied as follow.

- 866B (. . .5) I think it's. . knowing. .of what I can do. .and what. .  
 867 what I can't do  
 868M mm  
 869B I. .think I will listen to him. .and I will take it in and . .  
 870M mm  
 871B think about it. .but. .if I can't do it then I can't do it so. .  
 872 there's no changing that  
 873M mm  
 874B that's the way it is  
 875M mm  
 876B so I can't. .I can't go. .do his thing. .cause I just. .  
 877M alright=  
 878B I'm incapable of it. .

It is tempting to regard acts like participant E’s driving of a car, or participant B’s refusal to write or the decision to quit working as "defiant" acts, which resemble attempts to resist an implied identity of being disabled, or incompetent. It would however seem that these acts had very little to do with defiance. When asked about these acts participant E responded as follows:



743E uhm . .I wanted to see I could drive the car . .have . .  
 744 control of the car. .uhm. . that's why I did it. .slowly. .not  
 745 far . .now . .I came back. . "yes I can still drive". .I can still  
 746 drive the car. .my problem . .use my feet . .no problem  
 747 so . .it's fine

It would therefore seem that because he could *still* do some of the same things as before his injury, these acts allowed the participant the sense of not having changed all that much due to his injury. In the case of participant B it appears that due to her now deficient argumentation skills she is at times at an disadvantage when it comes to influencing decisions about herself and the family, it would seem that being stubborn is a way to compensate for lacking effective argumentation skills.

845M so would you say when. .when you guys kind of argue  
 846 . .or almost negotiate. .things like that who. .who's got  
 847 the most kinda. .negotiating power?  
 848B (. .4) I think Mike has but I'm strong headed so. .I  
 849 don't *bluff* him very much. .  
 850M alright so. .so it's actually kinda equal. .it.. it sounds like  
 851 it's. .he's. .he's got more negotiating power but you=  
 852B his arguing skills are better because he's more bo. .  
 853 broad minded  
 854M mm  
 855B than I am. .I'm quite narrow-minded. .but uhm. . I'm also  
 856 quite. .strong headed so I do what I want to do. .anyway



*Experiences with strangers.* None of the participants in this study identified any significant negative experiences with strangers where they felt they have been treated differently because of their injury. Participant D vaguely recalled an incident early in her recovery where she ran out of a shopping centre but this seems unrelated to how she experienced others.

870D RIGHT in the beginning . .right in the beginning my  
871 mother had to . . I ran out of a shopping centre . . I was  
872 uhm . .too many people [mm] but right in the beginning  
873M alright  
874D no I can't even really remember what happened

Participant E did however hint at more current instances where people at times seem to become impatient due to him being physically slower but he does not appear perturbed by this to any large degree.

824E . . but black people are a lot more  
825 compassionate. .and. .like if I go to the spar. .and I'm  
826 shaking. .putting my money in my wallet.  
827M mm  
828E they're quite relaxed and wait for me. .  
829M mm  
830E when I'm finished. .that's fine. .then I get out of the way  
831 . .with white people. ."move on . .get on. . do this. . do  
832 that" . .[as far as I'm feeling]} go to hell

The lack of negative experiences with strangers seems somewhat surprising considering the general lack of knowledge regarding TBI amongst the general public.





A number of reasons for the absence of these types of accounts are however found in the data. One possible explanation, for this group of participants, seems to be that negative experiences might be limited to when persons are in the early stages of recovery. Being in the early stages of recovery could mean having more noticeable deficits, with a higher likelihood of eliciting some kind of response from others than at present, and could also contribute to these events not being remembered at present. Another reason for the lack of negative experiences could be that these are prevented before they even happen. One way this is accomplished is by reducing direct interaction with strangers – usually by having a significant other present to do the talking or at least helping one "keep up" with a conversation.

1158B (. . .5) I think it often is the case and I think uhm. . I also  
 1159 take Mike with me. .to. .make sure that. .I'll be alright  
 1160 . .and. .that. .I'll be able to keep up with the conversation  
 1161 and be able to get there. .stuff like that. .so I suppose  
 1162 in some ways it's not actually relevant cause I've always  
 1163 got someone there to help me. .but if he's not around  
 1164 then. .I don't but then I wouldn't go anyway. .so. .

843E now I go to the shopping centres . .what ever. . I let my  
 844 wife talk. .but . .if I'm left alone . .I explain to the person  
 845 what . .what's my problem  
 846M mm  
 847E and they carry on. .with business. . that's fine



The extract from participant E also reveals another way of preventing negative experiences with strangers, namely to reveal their problem to others. Participant A also mentioned this strategy.

1206M so you've never had something where. .let's say you  
1207 struggle to. .to find a word that someone kinda look  
1208 at you strangely. ."is there something wrong with this  
1209 guy?". .or?  
1210A I open up straight. .that's why. .  
1211M mm  
1212A I. .like you. .I did the same to you  
1213M yah  
1214A "listen. .just what's that word now?"  
1215M mm. .so you actually prevent it then. .?  
1216A yah. .I'm=  
1217M by doing that  
1218A yah. .I believe it's right. .people tell me I'm stupid to  
1219 do that. ."leave it. .so what?"  
1220M mm  
1221A says "no. ." there's something wrong with me. .if I tell  
1222 you I've got a. .brain injury. .it doesn't mean I'm stupid

It would seem that having to reveals one's status as being injured can be quite daunting at times – especially when wanting to establish an intimate relationship.

956D when I had to . . when I met my boyfriend now . . I did  
957 it in stages . . the one dinner was the accident [mm] and  
958 ((chuckles)) and the next dinner was the cancer [mm] I  
959 didn't . . you know . .didn't tell him everything [mm] in one  
960 go cause I was like "ah shame you've got such baggage"



These five themes suggest that there exist some experiences of others that could add to the challenges persons face following TBI, however, the issue of “loss of self in the eyes of others” has yet to be addressed.

### *Loss of self in the eyes of others*

With regard to the second question posed in chapter three, namely whether themes that suggest a “loss of self in the eyes of others” are present in the narratives of the participants, the data from this study seems to suggest that there are not. None of the participants in this study appeared to be struggling to make sense of themselves or their post-injury experience *because of the experience of others*. Instances of having struggled to make sense of their experiences are mainly recounted as part of their narratives about the early stages of recovery. Participant A for instance recounted coming home for the first time after the injury.

- 159A when I came back. .and I walked into the house  
 160M mm  
 161A I didn't . .know what to see. .I didn't. .I didn't . .choose  
 162 the colour. .I don't remember choosing the colour  
 163M mm  
 164A cause the house was painted while I was in hospital  
 165 . .for that month  
 166M mm  
 167A uhm (. . .) I don't know. .I don't know (. . .) it was just a  
 168 wei::rd, weird time of. . thought of memory (. . .3)

Participant D recounted seeking medical advice to assist her in attempting to make sense of her experience while attending a computer software course following



her injury. Comparing lines 513 and 521, it is clear that she could not make sense of the experience of understanding new information yet not being able to apply it effectively.

505 then I mean I had a uhm . . I went for . . I think E.C.G.'s  
 506 hey?. .when they test your brain activity  
 507M uh . .E.E.G.=  
 508D E.E.G., E.EG. . . C is the heart . . E.E.G . .and I was . . I was . .  
 509 very upset . . my mom said "but no, this will answer more  
 510 questions" because like . . I've done the pastel course  
 511 . . the computer course  
 512M mm  
 513D and I couldn't understand why I battled with it  
 514 . . I mean I understood everything it's just I wrote the  
 515 exam. . and I just . . blanked out . . and I came out the  
 516 exam and I went to the examiner I said "my mark is no  
 517 reflection . . reflection of your. . of what . . of how you taught  
 518 us". . [mm] cause she was quite young and I just . . ah no I was  
 519 crying . . I just . . I could I just uh . . when it said save I  
 520 said save, when it said . .I just did everything the  
 521 computer said [mm] I . . but I understood everything [mm]

When instances of attempting to make sense of current experiences are encountered, these experiences are not related to experiences of others, but seem to focus on understanding changes between pre-injury and post-injury abilities, understanding physical problems like fatigue and the inability to convert intentions to action. Participant A for instance seemed troubled by the fact that at times he manages to clean the pool but fails to start physical exercise which he feels will benefit his continued recovery.



514A . .I don't know where. .I am . .I don't know whether  
 515 . .I'm (. . .4) lazy. .I am a lazy bastard ((smiles)). .I am  
 516 . .from before my accident I was also lazy. .I cleaned the  
 517 pool this morning. .am I lazy?. .I don't know. .is it because  
 518 it's something that's calming?

Even when there exists a clear difference in how participants viewed themselves and how they thought others would describe them, there was no evidence that this was experienced as being denied a preferred identity. In the case of participant C, who presented the only clear case of disputing the view others have of him, he struggles at times to make sense of his aggressive reactions and is more troubled by these reactions than his mother not validating his own perspective. When discussing the unpredictable nature of losing his temper he said the following:

737C and it's. .in the. .thinking about it. .you just. . do it and  
 738 . .cause. .one of those spur of the moment things. .just  
 739 like. ."come on. .just (. . .) go to shops for me". ."no I don't  
 740 want to go". ."why not?". ."do it yourself!"((mimics  
 741 getting short tempered)). .and I think "why did I do that?"  
 742 . .think afterwards. .one of those things that just. .if you're  
 743 not. .[suppose I could go down there for you]]. .it's just  
 744 don't want to go down but its just. .go yourself and do this  
 745 . .end up just getting angry and like you say. .aggressive  
 746 again. .don't really know if that's from. . the accident. .more  
 747 or less it will be. .but also from the. .epilepsy. .but I  
 748 (X X X) cause that's now under control  
 749M mm  
 750C so probably it's just. .probably was my accident. .my  
 751 brain injury now is. .cause of it all cause. .was it. .the  
 752 thing there was a. .uh. .frontal lobes. .that's it. .they say



753 that's uhm. .I don't understand properly. .but they say  
 754 that is actually. . a very bad area. .of the brain to get  
 755 injured. .so. . maybe that's what caused it and it's just  
 756 . .sort of them changed [{them}]. . from being this person  
 757 to that person and. .from being good or bad. .from bad  
 758 to good. .and I've gone. .and I've been . .  
 759M mm  
 760C so I've gone the. . other way  
 761M so you're still trying to. .kinda make sense of the  
 762 aggression and [yah] anger. .that sometimes happen. .  
 763 that to you. .it doesn't really make sense. .and. .you're not  
 764 sure whether it is actually. .the brain injury or whether it's  
 765 something else. .but it's not. .how you see yourself. .  
 766 you don't see yourself as being this aggressive person?  
 767C I'd say I wasn't like that. .it just uhm. .but. .one of those  
 768 spur of the moment things like. .before you know it. .  
 769 like something happened. .and. .(X X X X) and you sit  
 770 there . .in my room for a while . .and go "why did I do  
 771 what I just did?". .what for?"

*So what does this all mean?*

When planning this project it was hoped to identify instances of experiences of others that contribute to the challenges that injured persons face following TBI. It was anticipated that some of these experiences would also involve injured persons' accounts of themselves being denied validity by others, leading to what has been termed "loss of self in the eyes of others". When considering the data from this study it would appear that while some experiences with others may potentially add to the challenges injured persons have to contend with, there exists little in the data to suggest that these participants experienced self-narratives imposed by others or that



their self-narratives were denied validity by either significant others or strangers. In summary:

- None of the participants appeared to be struggling at present to make sense of their post-injury experiences because of their experiences with others.
- Four of the five participants agreed with how they thought their significant others would describe them, and therefore did not appear to feel that any unwanted identity is being imposed or implied by others.
- The one participant who did seem to dispute how others might describe him, appeared to be more distressed about the cause of his behaviour than the existence of the contradictory view held of him by others.
- None of the participants reported any negative experiences where they have been labelled by someone as for instance crazy.

The most notable finding from this study is that the context of the relationship itself between injured persons and their significant others may become a challenge to the injured person. It would seem that the caretaker role which significant others play may start to form the backdrop against which all other aspects of the relationship become framed, and can in effect leave the injured person in a debt of gratitude. This can make it difficult for injured persons to communicate their wishes freely to others, especially when this might constitute criticism of those others who played or still play a significant role in recovery. This type of situation will undoubtedly add to the frustration experienced by injured persons. The role of caretaker may also explain why others may feel it necessary to afford the injured person special treatment. This type of experience, when viewed from the perspective of self-



narratives, may not constitute an imposed narrative but runs the risk of invalidating the injured person's self-narrative by only acknowledging their status as injury victim and neglecting other parts of their identity.

While the potential negative impact of being a caretaker is recognised in the literature, as reflected in the numerous studies on the psychological health of carers (Anderson et al., 2003; Douglas & Spellacy, 2000; Hannay et al., 2004; McPherson, Pentland & McNaughton, 2000; Ponsford et al., 2003; Watanabe & Taki, 2000, Willer et al., 2001), the potential cost to injured persons has gone unrecognised. It should immediately be stressed that the role of significant others during recovery is invaluable – a position echoed by all the participants in this study. A relationship defined in terms of carer and patient roles, which often seems synonymous with parent-child roles, leave room for conflict when both parties are adults and even more so when dealing with couples. Once a relationship has been cast in these terms it may be difficult to move beyond these roles and this could conceivably be detrimental to both parties by, in effect, keeping their lives in limbo waiting for the "pre-injury" person to reappear. It would seem for some injured persons accepting their changed status and continuing with life can become more important than continuing waiting for changes which they feel will not occur. Participant B revealed that for the injured person this could be quite a conscious and rational decision but that it can be very hard for others to accept. In discussing an argument between herself and her husband about her wanting to quit working, she seems to regard his main intentions for preferring that she keeps on working as aiding her recovery – she however feels that it is time to give up on recovery.





804B it's like. .didn't make sense to me but that was one of  
 805 our big arguments this week. .is I wanted to give up . .  
 806 working for. .((mentions name)) and he said no I  
 807 mustn't do that and I think he's sort of thinking that. .  
 808 it's good for me. . for me to have that interaction  
 809 and he's also thinking that. .this is the thing. . at the  
 810 moment. . it's like. .((sighs)) I must start accepting that  
 811 . .this is the way it is. .and yes. .I'm gonna get little bit  
 812 better. .bit by bit. .but after the first two years you don't  
 813 improve much. .so. .I'm not gonna improve much so. .  
 814 there's no point in working. .everyday. .to try and make  
 815 myself better cause it's not gonna happen

The role of significant others as caretakers could therefore interfere with the identity construction of injured persons by being so focused on attempting to "reconstruct" the injured person's pre-injury self-narratives that it precludes the construction of a post-injury narrative that successfully incorporates changed aspects. Practitioners in the TBI field may therefore wish to take note of how the role of significant others as caretakers and motivators could impact on relationship dynamics. It would seem that there exists a need for practitioners to play an active role in assisting couples to re-evaluate when a relationship, based on carer/patient roles, is no longer beneficial and to assist them in making this transition. Further research on this topic is however required.

When assisting injured persons with integration back into society it appears that the strategy of informing others of their injury could contribute to lessening negative experiences with strangers – the use of this strategy should therefore be encouraged by practitioners in the TBI field.



### *Participant evaluation*

The participants who took part in the study were provided with a summary of the research findings and invited to comment on the findings. As indicated in chapter four this is one way to assist in judging the credibility of the study. Two of the participants have not, by the time of finalising this report, responded, to the invitation to comment on the findings. Overall, the participants who did respond did not disagree with any of the findings, which lend support to the credibility of the study. Participant C for instance re-iterated his lack of negative experiences with others and attributed this to their being aware of his injury. Participant A said in this regard that negative experiences of others only happen to injured persons who do not want others to know about their injuries. He also referred to a similar experience of strangers to that of participant E (refer to p.88 lines 824-832) – during the initial interview he was, however, adamant that he has had no negative experiences with strangers. In response to the theme of receiving special treatment from significant others he responded "that's exactly it, so I'm not hundred percent, treat me as normal". These responses point to two things, namely that experiences of others deserve further research attention and that future studies should make use of multiple interviews with the same person. The feedback from the participants therefore provides support for the credibility of the findings while calling attention to the limitations of the study.

### *Limitations of the study*

The findings from the study, in particular the apparent absence of "loss of self in the eyes of others", must be interpreted circumspectly, especially considering the limitations of the study.



- All the participants in this study have been injured more than three years ago – persons who are in the earlier stages after injury might present a different picture.
- While not disputing the seriousness of the participants' injuries, or diminishing the impact it has on their lives, persons with more severe or easily recognisable injuries might have different experiences with others.
- All the participants were white, English speaking persons and could be considered to fall in the middle, or higher, socio-economic group. Persons from a different demographic profile could have a different perspective.
- Participants were only interviewed once and could therefore have been more guarded in their response – especially when relating experiences with significant others are concerned.
- It is possible that the participants did not have an accurate perception of how others would describe them – collecting data from injured persons *and* their significant others might make it easier to judge the existence of conflicting accounts of the injured person.
- Relying only on interview data represents a methodological limitation – making use of participant observation or naturalistic observation might yield data not contained in interview material.

### *Recommendations*

Based on the findings and limitations from this project it is recommended to conduct further research on the topic of experiences of others and self-narratives of persons who have experienced TBI. Future research projects should however strive for:



- Purposeful selection of participants who appear to be having problems in making sense of themselves following injury – identifying such individuals may best be achieved by being familiar with participants for a longer period by for instance spending time at an organisation like Headway.
- Conducting more than one interview over an extended time period should allow for more information to be gathered and could also allow for changes across time to be noticed.
- Complementing interview data with other forms of data gathering, like participant or naturalistic observation.
- Ensuring greater variability between participants regarding such features as time since injury and socio-economic status.

### *Conclusion*

This project contributed to our knowledge regarding TBI by making use of a methodology that differs from more traditional approaches. While not being able to support the idea of “loss of self” in the participants' stories of their experiences of others, there are indications that experiences of others may add to the challenges injured persons face following TBI. This study, in keeping with its exploratory nature, did not only lay the groundwork for future research but also demonstrated the value of making use of different approaches in the study of TBI. In meeting the main aims of exploratory research, this study not only identified a number of topics that should be investigated in future research but also contributed in making recommendations about methodological issues. Lastly, this project produced findings that have relevance for practitioners in the TBI field.

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## **ADDENDUM A**

### **CONSENT FORM**

Title of project: A qualitative exploration of experiences of others and accounts of self in the narratives of persons who have experienced traumatic brain injury.

**This form tells you of the purpose of the study and indicates what your rights are and what you will be asked to do.**

#### **Purpose of the project:**

I am conducting this research project as part of my master's degree in counselling psychology and have chosen to learn more about the experiences that someone who has experienced a brain injury has with other people and how this affects them.

#### **What I will ask you to do:**

I will ask you to tell me about your experience with other people before and after your injury. There are no right or wrong answers to the question and I ask that you tell me as much as possible. To make sure that I understand what you are telling me I might ask you some questions about what you tell me. If you do not want to answer a particular question you do not have to.

With your permission I will tape-record our conversation. Only myself and my research supervisor (Dr. Elizabeth du Preez) will have access to the recording of our conversation. You may also ask to hear the recording of our conversation. When I have completed my research report at the end of this year I will destroy the recording of our conversation. In my research report I will not use your real name and will do my best that other people would not be able to identify you from the information in the report. You may ask for a copy of the research report and are welcome to give me feedback about what you think of the report.



You will not be paid, or rewarded in any other form, for taking part in this research.  
Just to make sure:

- No one may force you to take part in this research.
- You may decide at anytime, for any reason, that you no longer want to take part in this research by contacting me on 083 400 9413.
- You may ask to have a copy of your conversation with me.
- You may ask for a copy of the final research report.
- Please feel free to ask me if you feel unsure about the research.

**Do you give permission to take part in this research project?**

Yes \_\_\_\_\_ No \_\_\_\_\_

**Do you give permission that I record our conversation?**

Yes \_\_\_\_\_ No \_\_\_\_\_

Participant: \_\_\_\_\_ Date \_\_\_\_\_

Researcher: \_\_\_\_\_ Date \_\_\_\_\_





## ADDENDUM B

### INTERVIEW SCHEDULE

1. Your name? \_\_\_\_\_

2. Age? \_\_\_\_\_

3. Do you live alone or with someone? \_\_\_\_\_

3.1. If with someone, who/how related? \_\_\_\_\_

4. How long has it been since your injury? \_\_\_\_\_

5. How would you describe yourself before the injury?

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6. Please tell me how you would describe the person you are now.

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7. Who has played an important role in your life since the injury?

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7.1. How has he/she/they been helpful?

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7.2. How has he/she/they been less helpful?

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8. How would \_\_\_\_\_ (person named in question 5) describe you?

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9. What have you learned about people since the injury?

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10. Are there particular experiences with other people (other than person in q.5) since the injury that stick out in your mind? \_\_\_\_\_

10.1. How has this been positive/negative for you?

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11. If you can change something about your experiences with other people, what would it be?

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11.1. What kind of experiences would you want more of? (why?)

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11.2. What kind of experiences would you want less? (why?)

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12. Where/how do you see yourself in 2 or 5 years time?

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12.1. How would you compare the person you are now and the person you see yourself as then?

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12.2. What change will be noticeable for \_\_\_\_\_ (person in q.5), or other people who know you?

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12.3. What role do you see for other people in how you want to see yourself in 2 or 5 years time?

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13. What advice will you give to persons with TBI, and their relatives/friends, about relationships?

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14. What advice will you give to people who do not know much about TBI when they interact with people with TBI?

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15. Anything else you want to add or say more about, or any questions you want to ask me?

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## ADDENDUM C

### TRANSCRIPTION NOTATION SYSTEM

(...)	Denotes pauses. Three dots in parenthesis indicate silence of one and half seconds. Three dots and a number in parenthesis indicate silence and the length in seconds thereof.
(... 2)	
((laughing))	Double parenthesis contains author's descriptions.
(x x x x)	Words that cannot be clearly deciphered. Number of x's indicates approximate number of words.
[{word}]	Indicates possible hearing.
=	Denotes speech broken off at the point of interruption.
WORD	Entire word in capitals indicates speech louder than surrounding talk.
No:::	Sounds that are held.
<u>Go</u>	Underscoring indicates some form of stress via pitch or amplitude.
.,?	Punctuation indicates speaker's intonation.
A	Capital A following line number indicates participant A's talk.
B	Capital B following line number indicates participant B's talk.
C	Capital C following line number indicates participant C's talk.
D	Capital D following line number indicates participant D's talk.
E	Capital E following line number indicates participant E's talk.
M	Capital M following line number indicates researcher's talk.

(Adapted from Henning et al., 2004).