

An autoethnographic account of married life after traumatic brain injury:
A couple's co-construction of their journey

by

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STATEMENT

I declare that **An autoethnographic account of married life after traumatic brain injury: A couple's co-construction of their journey** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

SIGNATURE :

DATE:

(Mrs Jennifer Graham)

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ABSTRACT

This autoethnography explores the phenomenon of marriage after traumatic brain injury (TBI). Capturing as its data, through a series of audio-recorded conversations and journal entries, the first-hand, co-constructed experiences of a married couple, it provides an 'insider' and as such, intimate perspective on life together following such an unexpected, disruptive and life-altering event. Situated within 'a systemic constructionist' epistemology, it spotlights, in particular, the relational aspects of the post-TBI marriage unfolding over time, rather than just the individual perspectives of each spouse at a single point in time - as most existing studies on the topic do. As a qualitative study, it made allowance for the collection and use of rich, nuanced data so as to do some justice to the complex nature of the topic being studied. David Reiss' explanatory theory on 'crisis and the development of the family paradigm' was applied deductively during the carrying out of a thematic analysis of the data, with the intention of bringing new insights to the understanding of the phenomenon of the post-TBI marriage. Data were also analysed inductively, in that themes emerging from the data itself were also used. A discussion based on the findings of the data analysis was proffered. Based on these findings, recommendations on what issues therapists working from within a family-systems orientation might focus their attention on were made. A recommendation for TBI couples to receive support from early intervention and follow-up services was also made, along with identifying the consequent need for research first to be done on developing and implementing such a service.

Key terms: Autoethnography, co-constructed narratives, dyad, family paradigms, post-TBI marriage, systemic constructionist perspective, traumatic brain injury, TBI

Chapter 1

Introduction

1.1 Beginning on a personal note

September 4th, 2006: One tragic accident portends another

I have just dropped my two daughters off at school and have stopped at a local grocery store to buy a few items. Pausing between produce laden shelves, a breaking news broadcast from the in-store radio catches my attention. The intrepid television personality and wildlife expert, Steve Irwin, better known to his many viewers as 'The Crocodile Hunter' has died. Snorkelling somewhere off the coast of Queensland, Australia, during the filming of a documentary, he inadvertently cornered a stingray in the reef. Lashing out defensively, the creature had pierced Steve's chest with a poisoned barb from its tail, fatally wounding him. I am momentarily stunned. His larger than life presence and daredevil antics, beamed into our home on a weekly basis, had kept our two daughters riveted to the screen for many an hour, securing him a regular and much anticipated spot in their television viewing timetable. "His poor family", I think to myself, reaching for my phone to share the news with my husband, Matthew.

Although I would see Matthew again briefly in the day for lunch, this will be the last phone call I make to him for some time to come and despite losing all memory of the few days leading up to the accident - the result of a phenomenon we will later come to know as retrograde amnesia (Lezak, Howieson, & Loring, 2004), he will remember the content of this call. Returning home a little later in the day we will share a quick meal together. I leave him sitting at the kitchen counter making tea for himself and his employee, EM (initials used for the purpose of confidentiality), whom I greet on my way out to the car. It will be the last time I see EM. He is squatting comfortably on his haunches beneath the giant Tipuana tree growing in the front yard. The first rains of the year have not yet come and despite the recent arrival of spring, it is still dry and dusty and he is drawing in the sand with a fallen twig. It is a sharply poignant image permanently etched into my memory, one which I will revisit frequently in the wake of the accident and even now. I smile and wave at him. He returns the gesture. I fleetingly think to ask him about his recent trip home for his son's 10th birthday but I am running late and do not stop.

Driving to a job that afternoon, the vehicle in which Matthew and EM are travelling is struck head on by a mini-bus taxi transporting school children. A burst front tyre causes the mini-bus driver to lose control of the speeding taxi and veering sharply into oncoming traffic it collides with Matthew's vehicle. The mini-bus driver and one of his passengers die on impact and most of the children are seriously hurt. Both Matthew and EM sustain life-threatening injuries. The most critical of these injuries are caused by the rapid acceleration-deceleration motion of their heads on impact as well as the focal injuries – bruising or damage to a particular area – to the front of their brains (Banich, 2004), the result of their heads striking either the dashboard or the crumpled roof of the vehicle.

Tragically, seven days later, EM succumbs to his injuries in hospital without ever having regained consciousness. For some days, Matthew's life hangs tentatively in the balance. Lying in the intensive care unit (ICU) of a hospital in an induced coma, medical staff treat and monitor the secondary physiological processes triggered by the traumatic brain injury (TBI) that he has sustained. Swelling to his head – a common and dangerous secondary consequence of traumatic brain injury, caused by the build-up of intercranial fluids (Lezak et al., 2004) – and crushed facial bones render him unrecognisable even to us, his closest family members.

Approximately three weeks from the accident and after having endured multiple surgeries including a tracheotomy, a craniotomy, maxilla-facial and orthopaedic surgery, Matthew is discharged from hospital and returns home to us. He is thirty one years old and we have been married for ten years at the time of the accident.

1.2 Introducing this autoethnographic study

“We do not choose our topics accidentally”, declares Richards (2008), “and our motive for researching them is often personal” (p. 1718). Having experienced first-hand what is like to live with a spouse who has sustained a traumatic brain injury (TBI), this is certainly true of my motive for choosing to make the phenomenon of the post-TBI marriage the focus of this study. Fortunately, as this is an autoethnographic study, I am not required to hide this fact. Whilst still deciding on an appropriate method for this study, and after having perused through a substantial chunk of the existing literature on the topic of marriage after TBI, I came to agree with Richards (2008), who argues that when it comes to studies, especially those in which illness or

disability features, participants tend to be “squashed into a medicalised narrative”, or similarly, into a problem narrative, in which they are robbed of their agency in being rendered the objects of study (p. 1719). There seems to be, suggests Richards (2008), “an underlying assumption that such people should be talked about, but should themselves remain silent” (p. 1719). As an alternative research method, autoethnography challenges these assumptions by providing traditionally silenced people with an opportunity to be the ‘tellers’ of their own experiences. It therefore signals not only a change in form but also a change in purpose, suggests Bochner (2000), in that the one doing the research is able to “extract meaning” from their own personal experience rather than attempting to depict the experience of others from some objective vantage point (p. 270).

The autoethnographic data from which meaning is extracted for this study, come from a co-constructed account told by my husband Matthew and I - during a series of conversations between us - of our post-TBI experience as a married couple. It is a retrospective account in that it spans a period of eight years, beginning on the fateful day Matthew sustained a traumatic brain injury in a car accident, up until recently, that being the end of 2014. We have shared this personal account in the hope that because we are privy to an ‘insider’, and as such, intimate view of living with a TBI as a married couple, we would impart something of the experience that otherwise might not be accessible to a researcher positioned on the ‘outside’ of the TBI marital experience.

1.3 Problem statement

Deaths and disabilities resulting from TBI have reached epidemic proportions worldwide (Bryan-Hancock & Harrison, 2010). This is the case even more so for South Africa where TBI rates are estimated to be as much as 3.5 times higher than that of the global rate (Bryan-Hancock & Harrison, 2010). Importantly, a chronic condition such as TBI, occurs within the context of family, marriage, friendship and workplace relationships, affecting them significantly (Jumisko, Lexell, & Söderberg, 2007). The changes it brings to these relationships are sudden and dramatic, as often the family member who has sustained a TBI goes from being healthy and able in one moment, to requiring acute care in the next, and then again to a chronic state of disability in the next (Jumisko et al., 2007). Coming to terms with a family member

as they are after the injury, can be a lengthy and challenging process, and is frequently characterised by a period of grief as family members find themselves mourning the loss of the person as they once were (Smith & Smith, 2000). Although close family members often display a tremendous willingness to adjust their lives to accommodate the needs of the injured person, emotional and behavioural changes as a result of the TBI, can still place pronounced strain on relationships (Kneafsey & Gawthorpe, 2004). This is particularly so for marital relationships, given that the injured spouse is often no longer able, either temporarily or permanently, to fulfil his or her former roles (Kosciulek, 1995).

Although many studies have focused their attention on the post-TBI marriage, a number of shortcomings in this existing body of literature have been identified. In a review carried out by Godwin, Kreutzer, Arango-lasprilla, and Lehan (2011) for example, it was found that most existing research on the marital relationship after TBI is based on perspective of either one or the other spouse “with little or no assessment of the relationship” between them (p. 43). Findings from these studies, although related to marital relationships, are essentially approached from an individualistic perspective and are therefore biased toward the perceptions of a single spouse. In their review of the post-TBI marriage literature, Sanders and Struchen (2011) argue that by primarily making use of questionnaires that pull for relationship distress and/or negative changes after TBI, studies of relationship changes may have “failed to provide a more comprehensive picture of the reality faced by a couple following a TBI” (p. 2). They also assert that as relationships evolve over time, attempting to understand the relationship by assessing it at a single point in time, which they found a majority of these studies do, is problematic.

1.4 Aims and significance of study

Following on from the problem statement and the shortcomings discussed therein, an aim of this study was to explore a post-TBI marital relationship from a systemic constructionist perspective (discussed in detail in chapter three). In shifting the focus from the individual onto the relationship, a systemic constructionist perspective (Yerby, 1995) made it possible for the couple dyad to take centre stage as the unit of analysis in this study. As such it enabled a more comprehensive understanding of the shared constructions between a married couple of their TBI experience, which

the majority of previous studies on the topic - rooted in traditionally individualistic perspectives, have not been able to do (Godwin et al., 2011).

As a qualitative study, another aim of this study was to produce a more nuanced account of the post-TBI marriage journey, one which was better able to reflect the complexities such a profoundly life-changing event brings about - not only the negative or difficult aspects of the experience, which has been the predominant focus of most studies on the topic (Sanders & Struchen 2011), but also the more positive ones. Furthermore, as a retrospective study spanning a period time following a spouses TBI, yet another aim of this study was to attempt to capture the changes or evolutionary trajectory that a marital relationship undergoes following an upheaval or crisis of such a magnitude, which existing studies assessing the post-TBI-marriage at a single point in time, have failed to do (Sander & Struchen, 2011)

Finally, being an autoethnography, an additional aim of this study was closely aligned to the overall aim of autoethnography as a method which, according to Bochner and Ellis (2006), is first and foremost to tell a story, one that “depicts people struggling to overcome adversity” and shows “people figuring out what to do, how to live, and the meaning of their struggles” (p. 11). As an autoethnography then, this study was able to acknowledge and accommodate that which is deemed worthwhile by the philosophical underpinnings of this method, namely subjectivity, emotionality, relational dynamics, and existential struggle amongst other things (Ellis, Adams, & Bochner, 2011). In short then, it allowed for an understanding of the multi-layered nature of a chronic illness or injury, particularly as it was experienced within the context of a marital relationship (Ettorre, 2010).

1.5 Research question

Incorporating the above aims of this study into a broad, over-arching question, the research question of this study is:

What are the dyadic experiences of a married couple following a TBI over a period of time?

1.6 Where to from here

Chapter two of this study comprises of the literature review I undertook for this study and is divided into three parts. The first part of this review looks at the facts surrounding the phenomenon of traumatic brain injury itself, the purpose of which was to better acquaint myself and the reader with the nature and long-term consequences of this type of brain injury, as well as its potential impact on family relationships. I then move on to explore the existing body of literature specifically focusing on the phenomenon of the post-TBI marriage, the purpose of which was to identify the shortcomings which informed a number of the research decisions I made in regards to this study. In the third part of the literature review, I briefly touch on the developing field of autoethnography, before moving on to explore particular autoethnographies relating to or informing this study in some way.

Chapter three of this study makes up the theoretical framework of this study and is divided into two parts. The first part of this chapter deals with the metatheory or epistemology of this study, namely 'a systemic constructionist perspective'. As such, it delineates where the broad focus of the data analysis for this study lies. The second part of this study introduces the explanatory theory I selected to use also for the purpose of analysing the data. This theory provided me with a more narrowed down focus when analysing the data for this study in that I used it as a 'lens' of sorts to zoom in on the particular phenomenon of chronic illness and injury within the context of family relationships.

Chapter four of this study is the methodology section of this study and as such contains a discussion on the type of study this is, namely a qualitative study, the paradigm in which this study is located, namely the constructivist paradigm, and the method utilised for this study, namely the method of autoethnography. Also contained within this chapter are discussions on the pragmatics of undertaking this study, namely the way in which data was collected, and analysed, as well as the way in which ethical issues were broached.

Chapter five, the heart of this study, contains the findings of the autoethnographic data that was analysed and the discussion thereon. Chapter six concludes this study with an overview of the storyline based on the findings and discussion in chapter five. It also contains a discussion on the potential benefits this study makes,

as well as the limitations of it. Recommendations are also made in this chapter, based on what was revealed by this study.

Chapter 2

Literature review

2.1 Overview of chapter

This literature review is comprised of three parts. I begin by situating myself and this study in the facts surrounding the phenomenon of traumatic brain injury (TBI) in general, and then move on to explore the existing literature on post-TBI marriages in particular, in the second part of this chapter. Included in this second part of the chapter is a summation of the shortcomings and recommendations I discovered during my review of the literature. In the third part of this chapter I situate myself and the study in the “newly developing field” of autoethnography (Taber, 2010, p. 13) - a qualitative method challenging “ideas about what research is and how research should be done” (Ellis, Adams, & Bochner, 2011, p. 2) - whilst at the same time exploring autoethnographies relating to or informing this study in some way.

Although I discuss autoethnography in more detail towards the end of this chapter, and in even greater detail in the methodology chapter, there is a literary device commonly used by autoethnographers which I will introduce from the outset, as I have utilised this device in this chapter and throughout this study. Ellis et al. (2011) refer to this technique or device as that of alternating between “authorial points of view” (p. 5). This means that autoethnographers may alternate between the use of first person, to tell a story of something they have personally observed or lived through for example, and the use of third person, in order to establish the context for these observations or experiences.

The first two parts of this review are discussed in third person, whilst the last section is written in such a way as to combine both first and third person. My intentions for doing this are threefold. Firstly, by starting with a discussion of the empirical data on TBI in third person, I have, as Anderson (2006) points out, gained “insight into some broader set of social phenomena” (p. 387). Secondly, by reviewing the existing literature on post-TBI marriages, also in third person, I have set out to establish “an argument and an empirical basis” for this study. By doing so, I hope to avoid, as Taber (2010, p. 14) puts it, simply producing a story - which although in and of itself can make an important contribution to understanding our world, does not

necessarily constitute research. Thirdly, in the final part of this chapter, I discuss my discovery of autoethnography as a method and my subsequent exploration of various autoethnographies in both first and third person, in order to move away from the more orthodox manner of doing research. By allowing myself to speak and by acknowledging and accommodating my subjectivity in such a way as to “blend the personal and the scholarly” as Burnier (2006, p. 413) puts it, I have aimed to reflect the method of autoethnography not just in content, but also in form.

2.2 PART I. Situating myself in the facts: An overview of TBI

2.2.1 Epidemiology

Traumatic brain injury (TBI) is a leading cause of disability worldwide (Bryan-Hancock & Harrison, 2010) with over 10 million people either dying from or being hospitalised with a TBI annually (Hyder, Wunderlich, Puvanachandra, Gururaj, & Kobusingye, 2007). Although global incident rates for TBI are estimated at about 200 per 100 000 people per year (Bryan-Hancock & Harrison, 2010), the prevalence of TBI is probably much higher, as many of those sustaining a milder TBI fail to seek treatment for their injury or, because of its silent nature, go undiagnosed if they do (Lezak, Howieson, Bigler, & Tranel, 2012).

TBI rates are under-reported in many parts of the world, largely due to the absence of injury surveillance or reporting systems (Hyder et al., 2007). Incident rates also vary across regions, with significantly higher rates occurring in developing countries. South Africa’s TBI incident rate, for example, is estimated to be 1.5 to 3.5 times that of the estimated global rate (Bryan-Hancock & Harrison, 2010). International epidemiological studies also show that about twice as many males sustain a TBI than females (e.g., Langlois, Rutland-Brown, & Wald, 2006; Tagliaferri, Compagnone, Korsic, Servadei, & Kraus, 2006).

Most TBI’s are the result of road traffic injuries, with falls, violence, and workplace or sports-related injuries accounting for the rest (Hyder et al., 2007). Ironically though, aside from these more obvious causes, the rise in the prevalence of TBI is most likely due to improvements in modern medicine

(Barnes, 1999). Rapidly responding roadside assistance as well as advances in medical techniques and treatment have helped to dramatically increase the survival rates of many accident victims who would have more than likely succumbed to their injuries as little as two decades ago (Lezak et al., 2012). This ever-increasing number of TBI survivors is familiarising us with the fairly recent and often heartrending phenomena of mostly young, still physically fit, but significantly brain damaged individuals (Lezak et al., 2012), as well as revealing to us “something of the inconsistency between the ability of modernity to rescue life heroically, and its capacity (or willingness) to provide ‘mundane’ or routine long-term care” (Webb, 1998, p. 543).

2.2.2 Towards the conceptualisation of TBI

TBI refers to an acquired injury to the brain most often caused by an impact to the head (Lezak et al., 2012), such as when the head strikes against or is struck by an object, or is penetrated by a foreign object (Menon, Schwab, Wright, & Maas, 2010). The majority of TBI's are closed though, meaning that the skull remains intact and the brain unexposed (Lezak et al., 2012). A fractured skull does not necessarily rule out a diagnosis for a closed head injury however, as long as the brain or brain covering has not been penetrated by or through the skull (Lezak et al., 2012).

A penetrating head injury (PHI), also known as an open head injury, on the other hand, includes all injuries in which the brain covering and/or brain has been penetrated by a foreign object (Banich, 2004). Firearms are the predominant cause of this open head injury (Griffin & Hickey, 2012). Whilst closed and open head injuries share some similarities, both the nature of and the pathophysiological processes triggered by the damage sustained differ somewhat in these two types of injuries (Lezak et al., 2012).

The primary mechanism of damage in a closed head injury (CHI) is the rapid acceleration-deceleration motion of the head which causes the brain to move violently within the skull (Banich, 2004). The movement of the brain in this manner often results in the widespread “twisting and shearing of neurons”, typically leading to diffuse damage across the brain (Banich, 2004, p. 480).

The subsequent breakdown in functioning that occurs is therefore not restricted to a single cognitive domain.

Damage to a certain area of the brain - commonly referred to as a focal injury - may also occur in closed head injuries, usually the result of the brain impacting with the inner wall of the skull (Banich, 2004). The direct point of impact to the brain is known as a coup injury, whilst the area opposite the point of impact is known as the contrecoup injury (Lezak et al., 2012). A closed head injury may therefore result in extensive damage across various regions of the brain, as well as to more localised damage to certain areas of the brain (Hammeke & Gennarelli, 2003) .

As a penetrating head injury results in a more localised injury - in that damage is largely confined to the path of the projectile - it is easier to predict the nature of the neurobehavioural features likely to present in such a case (Hammeke & Gennarelli, 2003). In this respect a PHI is similar to a stroke, as the manifesting cognitive and behavioural syndromes are unique to the area of damage (Hammeke & Gennarelli, 2003).

Secondary damage or delayed injury to the brain can be as devastating, if not more so, than the initial primary injury (Lezak et al., 2012). Secondary damage is usually caused by cerebral bleeds (haemorrhaging), insufficient blood flow (ischemia) and oxygen supply (hypoxia) to the brain, as well as by pathophysiological processes set in motion moments, hours or days following the initial injury (Lezak et al., 2012; Maas, Stocchetti, & Bullock, 2008). These pathophysiological processes include the massive release of neurotransmitters into the brain resulting in the phenomenon of excitotoxicity - potentially leading to the structural and functional damage of neurons (neurodegeneration) or cell death (necrosis) - and a build up of intracranial pressure due to the brain swelling (edema) (Maas et al., 2008). A better understanding of these processes has led to improvements in monitoring techniques, pharmacological treatments and other interventions (Lezak et al., 2012).

2.2.3 Assessment and classification of TBI

TBI severity is broad, ranging from mild concussion on the one end of the continuum to prolonged coma or persistent vegetative states on the other (Khan, Baguley, & Cameron, 2003). Injury severity generally relates to outcome prediction which helps to guide treatment and future rehabilitation plans (Foreman, Caesar, Parks, Madden, Gentilello, Shafi, ... Diaz-Arrastia, 2007), however it is important to note, warns Lezak et al.(2012), that “exceptions occur at all points along the severity continuum” (p. 183). Those with injuries deemed as mild by accepted standards of measure may have relatively poor outcomes both cognitively and socially, whilst some classified as moderately to severely injured have experienced surprisingly good outcomes (Foreman et al., 2007).

TBI is usually classified on the basis of mechanism (closed vs. penetrating), on clinical severity (using the Glasgow coma scale [GCS]) - as either mild, moderate or severe - and by assessing structural damage through neuroimaging, such as magnetic resonance imaging (Maas et al., 2008). The GCS has grown to be universally utilised as a classification system for the severity of TBI, consisting of a sum score ranging from three to 15, of three components (eye, motor, and verbal scales) (Teasdale & Jennett, 1976).

The measurement of TBI severity using the GCS relies upon an evaluation of “both the depth and duration of altered consciousness” (Lezak et al., 2012, p. 183), and although it is considered to be a good predictor of outcome for more severe injuries (Kraus & Chu, 2005), as a measure on its own, it is a poor predictor of outcome in many TBI survivors who have experienced a loss of consciousness for only short periods of time (Wrightson & Gronwall, 1999). Furthermore, classification of TBI by clinical severity has become increasingly limited due to the fairly recent practice of early aggressive treatment of brain injured patients involving sedation and intubation (Balestreri, Czosnyka, Chatfield, Steiner, Schmidt, Smielewski, ... Pickard, 2004).

The duration of posttraumatic amnesia (PTA) is also used as an assessment measure for the severity of TBI, where brief or no PTA is associated with mild

injury and longer periods of PTA with more severe injury (Lezak et al., 2012). PTA is defined as the period of time during which the brain is unable to lay down continuous day-to-day memory (Khan et al., 2003). According to Khan et al. (2003), duration of PTA is the best indicator of the extent of cognitive and functional to be expected following a TBI.

2.2.4 Long-term sequelae of TBI

A distinguishing characteristic of TBI is the wide spectrum of disabilities and dysfunctions that can result (Kosciulek, 1995). These may include marked deficits in physical, cognitive, behavioural and emotional functioning (Arango-lasprilla, Dezfulian, Kreutzer, Neil-Pirozzi, Hammon & Jha, 2008). Many TBI sufferers make a full physical or outward recovery though, which is why a TBI is notoriously known as a 'hidden disability' (Gouick & Gentleman, 2004). "Little may seem wrong to a casual observer once a few weeks or months have passed, but the reality can be very different", note Gouick and Gentleman (2004, p. 285).

The implications of the many potential deficits arising from a TBI are often profound and long-lasting, impacting upon the injured individuals interpersonal and vocational functioning and thus upon families and wider society (Kosciulek, 1995). According to Rosenthal (1999), it is those that are psychosocial in nature which prove to be the most disruptive though. Similarly, Lezak et al. (2012), assert that the most "far-reaching effects of TBI involve personal and social competence", more so than the cognitive impairments experienced (p. 182).

Whereas cognitive impairments may be challenging to the individual with a TBI, changes in personality and social behaviour, for example, impact upon the brain injured individual's ability to stay employed, maintain or establish social relationships and fulfil many other social roles (Kosciulek, 1995). Psychosocial deficits include depression and anxiety, which are especially common in TBI survivors (Silver, Mcallister, & Arciniegas, 2009; Vaishnavi, Rao, & Fann, 2009), aggressive behaviour, sexual disinhibition or sexual disinterest, childishness, impulsivity (Banich, 2004; Lezak et al., 2012), and a

lack of self-awareness and /or diminished appreciation of one's deficits most often associated with frontal lobe injury (Prigatano, 2009).

2.2.5 TBI within the context of family

A chronic condition, such as TBI, occurs within the relational context of family, marriages, friendships and workplace, affecting these relationships in many ways (Jumisko, Lexell, & Söderberg, 2007). Typically, close family members experience sudden and dramatic life changes without any forewarning. The injured member who has sustained a moderate to severe TBI “moves abruptly from a healthy state through to a life threatening episode requiring acute care”, to a state of chronic disability (Jumisko et al., 2007, p. 354). These events occur so quickly that family members initially struggle to grasp the shift in the injured person's condition - from being critically injured to being chronically disabled (Duff, 2002).

Reconciling themselves to these changes is a process that takes family members time and many find themselves mourning the loss of the pre-injured person who has now, in a sense, become a stranger to them (Smith & Smith, 2000). Boss (2004) terms this type of loss, “ambiguous loss”, which arises from a situation in which a loved one is perceived as being “physically present but psychologically absent” (p. 554). It is further described by Boss (2004) as being a particularly stressful type of loss in that closure eludes those who grieve. Whereas the death of a family member is validated through sociocultural processes that permit the family to work through their loss and grief, with ambiguous loss, such processes do not exist.

Although intimate partners and family members often display a tremendous willingness to adjust their lives to accommodate the needs of the injured person, emotional and behavioural changes can still place a great deal of strain on relationships (Kneafsey & Gawthorpe, 2004). Webb (1998), poignantly describes the aftermath of a TBI as bringing with it “the liminality of being neither here nor there”, of the injured adult becoming child-like again, the repercussions of which can be both “distinctive and profound” on marital roles and relationships (p. 541). The injured person, explain Landau and Hissett (2008), often attempts to hide his or her deficits while the family “walk

on eggshells” around them, making them the “predominant presence in every conversation and major decision” (p. 71). Similarly, Kneafsey and Gawthorpe (2004) highlight the prolonged sense of uncertainty and upheaval commonly experienced by affected family members.

2.3 PART II. Situating myself in the existing literature on the post-TBI marriage

Having situated this TBI study in the context of marriage, in the second part of this review, I now pay particular attention to the studies that have been done on post-TBI marital relationships. Historically, literature in the field of traumatic brain injury (TBI), has primarily considered marriage within the context of marital stability and marital quality (Kreutzer, Marwitz, Hsu, Williams, & Riddick, 2007). I have therefore divided the following discussion into two sections using these two distinctions as the framework under which I have sorted and arranged the various studies. I then conclude this second part of the chapter with a discussion on the shortcomings and recommendations which came to light whilst I was reviewing the literature hereunder.

2.3.1 Post-TBI marital stability studies

With regard to post-TBI marital stability studies, by investigating the likelihood that couples will stay together following a TBI and by contrasting these assessments with other populations, researchers hoped to gain a better understanding of the post-TBI marital relationship. Wood and Yurdakel (1997), for example, published the first study investigating marriage status outcome after TBI. Out of a sample of 131 individuals comprised of all levels of brain injury severity, the researchers found the breakdown rate five to eight years post-injury to be 49%. Kreuter, Dahllof, Gudjonsson, Sullivan, and Siosteen (1998) included marital status as a variable in a study done with patients recovering from spinal cord injury (SCI) and TBI. Out of the 92 patients with all levels of TBI severity, 58% were separated or divorced from their spouses. These findings did not differ statistically from either the SCI group or the general population.

A comparison of divorce rates reported within the TBI literature reveals widely disparate findings however, with studies reporting breakdown percentages

ranging from 15% (Wood & Rutterford, 2006) to 78% (Thomsen, 1984). Within the last decade, three research teams: Arango-lasprilla et al. (2008); Vanderploeg, Curtiss, and Duchnick (2003); and Kreutzer et al. (2007), have conducted studies aimed at clarifying the widely varying findings of previous studies investigating marital stability in terms of marital breakdown rates. Vanderploeg et al. (2003) examined demographic, medical, and psychiatric variables correlated with marital status following mild TBI for a sample of 626 veterans. Findings suggested that 33.8% of the TBI group were divorced or separated at an average time of eight years post-injury. Pre-injury characteristics, as well as length of coma, were found to moderate stability outcomes. Kreutzer et al. (2007) assessed the marital status of 120 patients across all levels of TBI severity an average of four years post-injury and found that 75% remained married. Arango-lasprilla et al. (2008) also found low rates of marital breakdown. Within a sample of 977 patients moderately or severely brain injured, 82% remained married. Their findings further suggest that age, gender, cause of injury, and injury severity were predictive of marital breakdown.

Godwin, Kreutzer, Arango-lasprilla, and Lehan (2011) argue that although understanding marital breakdown rates is an important part of designing effective interventions for support systems, a comprehensive understanding of post-TBI marriages cannot however, be solely achieved from these findings.

2.3.2 Post-TBI marital quality studies

Godwin et al. (2011) identify three frameworks within which literature investigating post-TBI marital quality has evolved: the comparison of couples after TBI with control groups on various components of marital quality (e.g., Bracy & Douglas, 2005; Rosenbaum & Najenson, 1976) the exploration of either sexual or marital satisfaction after TBI (e.g., Blais & Boisvert, 2007; Ponsford, 2003), and the identification of predictive personal and familial variables as they relate to marital quality following a TBI (e.g., Moore, Stambrook, & Peters, 1993; Wood, Liossi, & Wood, 2005). Several studies have also documented the ambivalence and distress experienced by the uninjured spouse as a result of role changes occurring within marriage after

TBI (e.g., Brooks, 1991; Gosling & Oddy, 1999). Studies pertaining to each of these four broad groups of marital quality studies are discussed in more detail below.

2.3.2.1 Studies comparing TBI couples with control groups

Research on marital quality was introduced to brain injury literature over 30 years ago with the foundational study of Rosenbaum and Najenson (1976) which explored the impact of wives' perceived changes to family life after the Yom Kippur War in 1973. The research team compared three groups of wives: women married to Israeli soldiers who had sustained a TBI in the war, women married to soldiers who had sustained a spinal cord injury in the war, and women married to soldiers who had not been injured in the war. Various components of the marital relationship were assessed. The wives in the TBI group differed significantly from those in the other two groups on all variables, their responses persistently reflecting more negatively perceived changes to their family life and marital relationship since the injury than the other wives. Godwin et al. (2011) argue that although this seminal work introduced relational assessment to the field of TBI, it was rooted in an individualistic model in that spousal perceptions were examined, not the post-TBI marriage.

Two, more recent, studies also making direct comparisons of TBI groups with control groups are those of Peters et al. (1992) and Bracey and Douglas (2005). Peters et al. (1992) selected two groups of married couples, a TBI group and a spinal cord injury group, for their study. Only the uninjured spouse was requested to complete assessments of relational quality. Spouses in the spinal cord injury group expressed higher levels of satisfaction than spouses in the TBI group, supporting the much earlier findings of Rosenbaum and Najenson (1976).

Bracey and Douglas' (2005) study differed significantly from most studies focusing on the marital quality of TBI couples in that it included

input from both the injured and the uninjured spouse in the study. Couples with mild, moderate and severe TBI were compared with couples following an orthopaedic injury in an assessment of dyadic consensus, a variable related to interpersonal communication skills. Although couples in the TBI group reported more communication challenges than the orthopaedic group, they did show a significant level of dyadic consensus within their marriages, whereas the orthopaedic group did not. The study's findings thus revealed that dyadic consensus may be a strong point in TBI marriages. Godwin et al. (2011) assert that these findings highlight the value of assessing spouses shared perceptions of the TBI marriage.

2.3.2.2 Studies exploring marital and/or sexual satisfaction after TBI

In their review of TBI literature, Perlesz, Kinsella, and Crowe (1999) count Lezak (1978, 1986, 1988) as being amongst the first researchers to bring the impact of a brain injury on the spouse and the marriage relationship to the attention of the field of brain injury rehabilitation. In her findings, Lezak (1986) eloquently describes the state of social limbo that the uninjured inhabits, mourning, in a sense, their still-living but characterologically changed partner. Camplair, Kreutzer, and Doherty (1990) point out that Lezak's (1978, 1986, 1988) information was sourced primarily from people attending support groups though, which may have biased her findings to a more distressed sample group.

A qualitative study carried out by Willer, Allen, Liss, and Zicht (1991) confirmed many of the difficulties experienced by spouses of a brain injured partner already raised by Lezak (1978, 1986, 1988). Out of a sample of 31 participants (20 wives and 11 husbands), the wives identified several main areas of concern regarding their husbands, including: changes in personality; changes in cognitive abilities; lack of insight and acceptance of disabilities; reduction in financial resources; loss of emotional support, sharing and companionship; and an inability

to meet their children's needs. The husbands were predominantly concerned with their wives' loss of autonomy, mood swings, insecurities and overprotectiveness, reluctance to leave home, and a general change in lifestyle following the injury. Perlesz et al. (1999) revealed a selection bias in the sample of this study though, similar to that of Lezak's (1978, 1986, 1988), in that all the respondents were recruited from support groups.

Ponsford's (2003) study of sexuality following TBI, aimed to identify changes in sexual behaviour, affect, self-esteem, and relationship quality, and their inter-relationships. Comparing post-injury survivors, one to five years following a moderate to severe brain injury, with a control group, Ponsford (2003) found that reports of negative changes to sexual functioning and overall marital quality were significantly higher for the TBI group than for that of the control group. More than half of the TBI participants also reported decreased self-confidence and sex appeal, higher levels of depression, and decreased communication levels with their sexual partner.

Studies incorporating marital sexual satisfaction and/or sexual adjustment as a component also include Garden, Bontke, and Hoffman (1990), Gosling and Oddy (1999), and Kreuter et al (1998). Garden et al. (1990) assessed couples post-TBI, through measures of sexual interest, frequency, and functioning and TBI spouse-only measures of sexual adjustment. Findings indicated that a majority of the brain injured spouses reported overall marital sexual satisfaction, whereas a minority believed that their partners were also satisfied. Kreuter et al. (1998) also assessed marital sexual satisfaction from the perspective of the brain injured spouse. Again, a majority reported marital sexual satisfaction with fewer believing their partner to be sexually satisfied. Comparing these two studies, Godwin et al (2011) surmised that "both partners in a couple may be relatively satisfied with their sexual relationship but may be uncertain of their partner's level of satisfaction" (p. 49).

Gosling and Oddy (1999) examined spouses' marital and sexual satisfaction pre- and post-injury. Results indicated that both marital and sexual satisfaction were significantly higher pre-injury. The reports of the injured spouses were also compared with those of the uninjured spouses. Findings showed that the uninjured spouses were significantly less satisfied with their marriage than the injured spouses. Godwin et al. (2011) distinguish this study from other studies also investigating marital sexual satisfaction in that both spouses' perspectives were included and compared.

2.3.2.3 Studies correlating patient and family variables with TBI marital quality

Peters, Stambrook, Moore, and Esses (1990) study was one of the earliest to investigate the relationship between patient injury severity and marital satisfaction. The marital relationships of male head injury patients were assessed based on their spouse's self-report obtained through an interview and questionnaires. Findings showed that wives of patients who had sustained a severe TBI experienced significantly less marital cohesion than both the wives of patients in the moderate and mild group.

Another two studies were carried out by the same group of researchers investigating the relationship between family coping strategies and marital adjustment (Moore, Stambrook, Peters, & Lubusko, 1991), and the effect of family life cycle factors on marital adjustment (Moore et al., 1993) respectively. In the former study, the coping strategies (CS) used by families of severe, moderate and mild head-injured male patients and the relationship of these strategies to marital adjustment were investigated. Three CS groups were identified: a high and medium CS use group that was older than a low CS use group. Injury severity, time post-accident, and patients' psychosocial functioning were not associated with CS use. However, high-use families reported higher dyadic adjustment, while low-use families reported higher sexual intimacy. Findings indicated that the amount and pattern of CS use as

well as age seem to be important factors in accounting for the relationship between CS and marital adjustment. In the latter study, using the family life cycle model, Moore et al. (1993) investigated the effect family life cycle factors have on marital adjustment following a TBI. According to this model, centripetal forces bring members together while centrifugal forces loosen ties between family members. This study examined the association of normative, developmental and centripetal family forces with patient outcome on families of married male TBI patients. Centripetal variables included measures of family coping, marital adjustment, and number of years married. Centrifugal variables included number of children, age of oldest child, and amount of perceived financial strain. The findings suggest that families dealing with the developmental stage of the family with young children may face unique challenges when a husband sustains a TBI, especially when financial strain exists.

More recently, two groups of researchers conducted studies investigating the relationship between variables related to TBI patient functioning and overall marital satisfaction. Both studies included a more or less equivalent number of TBI patients in mild, moderate and severe injury categories and compared couples post-TBI with control groups. Blais and Boisvert's (2007) study examined the relationships between the personal characteristics of individuals with TBI and their spouses and their level of psychological and marital adjustment. Findings showed that characteristics most strongly related to marital adjustment were an effective attitude towards problems, infrequent use of avoidance coping strategies, and a positive perception of one's spouse's communication skills. Individuals with TBI and their spouses reported significantly lower scores on some of these personal characteristics, compared to those of a control group of couples from the general population.

Burridge, Huw Williams, Yates, Harris, and Ward (2007) examined spousal relationship satisfaction following an acquired brain injury (ABI) to one partner. Two other groups were used for comparison and control

purposes: couples affected by chronic pain and a group of healthy couples. Compared to the healthy control group current satisfaction was poorer in the ABI group, and satisfaction with the relationship had dropped pre to post-injury. Furthermore, patients in the ABI group had less insight into their empathic skill than those with the chronic pain group, tending to overestimate their abilities. BurrIDGE et al. (2007) concluded that low relationship satisfaction in partners of the brain injury group was associated with poorer socio-emotional functioning and insight into overall socio-emotional skill, and empathic skill in particular.

2.3.2.4 Studies investigating marital role changes after TBI

Maitz and Sachs (1995), define roles as being a set of integrated and socially determined beliefs, values and expectations guiding behaviour. Society upholds certain familial roles, especially those relating to parental and spousal obligations, which drive married couple's expectations concerning domestic responsibilities such as housekeeping, financial management, child-rearing and income earning (LarØi, 2003). A TBI often disrupts and necessitates a change in such roles and as a result, a number have studies have focused their attention on this aspect of the post-TBI marriage.

Spouses make up a large percentage of those having to adopt the role of caregiver following a TBI, for example, with some studies indicating that they experience significantly greater burden when compared with other caregivers such as parents (e.g., Kreutzer, Gervasio, & Camplair, 1994). The findings of Bailey (1989) and Ben Azri, Solomon and Dekel (2000), similarly suggest that parents seem to cope better than spouses when it comes to the role of caregiving, as do Kreutzer et al. (1994), who found that post-TBI role changes are more distressing for spouses because they may have lost, either temporarily or permanently, a peer-based, reciprocal relationship whilst caregiving parents are continuing in a role to which they are already used to. As Perlesz et al. (1999) explain, "it is actually more difficult and stressful to

care for and 'parent' a spouse than it is to parent a brain-injured child" (p. 21).

2.3.3 Identifying the shortcomings and acknowledging the recommendations within the extant body of post-TBI marriage literature

Although post-TBI marital quality studies and post-TBI marital stability studies have provided some insight into the post-TBI marriage, they have not necessarily presented a comprehensive picture of these marriages. In my review of the literature, four key reasons for this lack of comprehensiveness have come to light.

Firstly, as Sanders and Struchen (2011) point out, researchers have predominantly made use of questionnaires that pull for relationship distress and/or negative changes after TBI and have failed to capture the many positive relationship changes that do occur in addition to the more difficult ones. Secondly, researchers have attempted to explain marital quality by eliciting responses from only one spouse or each spouse individually, on marital assessment instruments (e.g., Ponsford, 2003; Rosenbaum & Najenson, 1976; Wood, Liossi, & Wood, 2005). Godwin, Kreutzer, Arango-lasprilla, and Lehan (2011) argue that without assessing the marital system, individual perceptions of marital change rather than holistic changes to the marriage are revealed. Sanders and Struchen (2011) agree that findings from such studies, although related to marital relationships, are biased toward the perceptions of a single spouse or significant other. Similarly, an earlier review conducted by Duff (2006) identifies the tendency of TBI relationship research to use the views of a single individual as being representative of the views of the whole family.

The third reason is linked to the second reason in that most of the TBI relationship studies eliciting responses from a single spouses or partner, have been quantitative studies by design (Duff, 2006; Godwin et al., 2011). Whilst these studies have provided some insight into TBI marital relationships, they have however tended to oversimplify the complexity inherent in such relationships (Duff, 2006), or as Malterud (2001) points out, such studies are

forced to confine their knowledge production “to questions and phenomena that can be controlled, measured, counted and analysed by statistical methods” (p. 397). In response to the knowledge gaps linked to the limitations specifically inherent in quantitative studies, Arango-lasprilla et al.(2008) recommend that more qualitative studies, specifically focusing on the TBI marital relationship, be undertaken. Likewise, Duff (2006) identifies and promotes qualitative research design as being the vehicle sufficient for exploring and capturing richer accounts, context and processes within the TBI relationship as they unfold over time.

Godwin et al. (2011) also argue that a better understanding of the dyadic impact of TBI calls for qualitative studies rather than quantitative studies, but further recommend that such studies should be situated within social constructionism, using family systems theory as a guiding theory, to better understand the shared constructions and dialogical processes of married couples from a subjective perspective.

Social constructionism explains relationships as the development of reality within the social interchanges between people (Gergen & Gergen, 2000). From this perspective, both partners make up the marital dyad, and thus create and define one another’s experiences through continuous, interpersonal interaction. It is on this basis, assert Godwin et al. (2011), that the investigation of any relationship requires input from both individuals involved in the relationship, not just one partner’s perspectives on that relationship. Research findings based on the singular perspective of either partner, render most research findings not just incomplete, suggest Godwin et al. (2011), but illusionary representations of the marriage as a whole.

Lastly, as relationships evolve over time, attempting to understand the relationship by assessing it at a single point in time - which the majority of these studies have done - is a further limitation of such studies. Both Sander and Struchen (2011) and Duff (2006), call attention to this shortcoming evident in the existing research on post-TBI relationships, noting that researchers have generally failed to utilise methods capable of capturing

complex changes to relationships over time, resulting in a limited understanding of the essentially evolving nature of such relationships.

The motives underlying my choice of research design (discussed in chapters three and four respectively) for this study have been informed and directed, in part, by these limitations and recommendations discussed above. For example, although my research questions already presupposed a qualitative design, Duff (2006) and Angelo-lasprilla et al.'s (2008) calls for more qualitative studies on post-TBI marriages served to confirm and underscore the need for the type of study I have embarked upon. My decision to situate the study within social constructionism utilising the works of family system theorists (also situating themselves within social constructionism) for my theoretical framework, was also influenced by the recommendations of Godwin et al. (2011). Likewise, the method I have selected, namely autoethnography, aims to address a number of the shortcomings I have discussed. In the next section of this review, I discuss, amongst other things, how this method addresses these shortcomings.

2.4 PART III. Situating myself in the stories

My reasons for having chosen to do an autoethnographic study have been varied, ranging from more personal reasons on the one hand to more research-related reasons on the other. Although I discuss the method of autoethnography in greater detail in chapter four, I explore and discuss these various reasons hereunder, along with examples of autoethnographies primarily focusing on illness, disability and/ or trauma. I have also sought to include autoethnographies that have been co-constructed. My intended outcome for this part of the literature review was, as Ellis et al (2011) direct, "to find and fill a gap in existing, related storylines" and to use this knowledge to "illustrate new perspectives on personal experience" (p. 5).

2.4.1 Mining a method, a motive and many meaningful stories: An autoethnographic account

"We do not choose our topics accidentally and our motive for researching them is often personal", states Richards (2008), in her autoethnographic account of

kidney failure (p. 1718). This was certainly true for me. With my husband having sustained a TBI, not only had our life together been disrupted; irrevocably, the experience changed us, as individuals and as a couple. Spurred on by a desire to better understand and reflect upon our experiences surrounding TBI and a curiosity about other married couples TBI experiences, I chose to make marriage after TBI the focus of my study.

Having made this choice, I was faced with a dilemma though, much like the one Smith (2005) describes when she decided to explore her experiences of life after an acquired brain injury: Given my “unusual closeness to the subject I was researching, I knew that I was more than just the researcher” and as such, my contributions would be as valid as those of participants (p. 70). I was plagued by numerous questions as I sought to situate myself optimally as a researcher. Would my experiences, for example, taint my interpretations of the participant’s experiences? Was there a research method that might legitimise my own voice in the study? It was with these and many other such questions in mind that I finally stumbled upon the method of autoethnography.

Ellis (2004) defines autoethnography as both a research approach and a way of writing which strives to describe and analyse personal experience, with the intention of also describing and understanding a broader cultural experience in the process. It is “an emerging qualitative method”, elaborates Wall (2006), which allows a researcher to write in a “highly personalised style, drawing on his or her experience to extend understanding about a social phenomenon” (p. 146). As a method therefore, autoethnography combines characteristics of both autobiography and ethnography (Ellis, Adams, & Bochner, 2011).

In Smith’s (2005) autoethnographic account of life after an acquired brain injury (ABI) for instance, she describes how during her study, it became clear to her that, not only was she describing and interpreting her own experiences with ABI, but inadvertently, also those of a particular cultural group, namely people who had sustained ABIs. The culture of ABI, Smith (2005) explains, “has distinguishing qualities, as does any culture”, some of which “make aspects of reintegration into society difficult after an ABI, for example, when

survivors try to fit into old social roles” (p. 70). In a way then, Smith’s (2005) personal account of a particular experience is a token of a broader type, or as Bruner (1991) articulately puts it, the particularity of her account achieves “emblematic status by its embeddedness in a story that is in some sense generic” (p. 7).

Autoethnography as a research method thus provided me with the freedom as a researcher “to speak as a player” in my research without fear of contaminating the data and in fact promoted the sharing of a researcher’s experiences as “precisely what is needed to move inquiry and knowledge further on” (Wall 2006, p. 148). Not only did this method release me from having to lay aside my subjectivity though, it also presented me with an opportunity, as Ellis et al. (2011) point out, to make use of “facets of storytelling”, such as plot and character development as well as chronological progression, whilst doing research (p. 6).

This creative way of doing research appealed to me on a personal level but importantly, it also provided me with the means to address some of the shortcomings I had encountered whilst reviewing current TBI marriage literature. As a method that allows for an account of events occurring over time for instance, I quickly realised that it was a method capable of capturing complex changes to relationships over time, and the more autoethnographies I read, the more apparent the “irreducibly durative” nature of these accounts became (Bruner, 1991, p. 6). Jago, (2002) for example, chronicles her ‘academic depression’ spanning many months. Ettorre (2006) draws on her diary entries covering a two year struggle with hyperthyroidism and her subsequent journey towards health. Feder-Alford (2006) reflects on an eight-day hospital stay, during which time she experiences a constant tension between the loss of her sense of self and the struggle to reclaim it. Adamson (1997) confronts existential and clinical uncertainty over a medical diagnosis and shares how this twofold uncertainty shaped the course of his illness experience. Typically, these stories captured events occurring over time, in what Bruner (1991) calls a “meaning-preserving sequence”, a device he deems essential to narrative and storytelling (p. 6).

Whilst delving into the craft of autoethnography and devouring a variety of riveting and evocative autoethnographies, it also became apparent to me that by comparison, the existing body of TBI research, most of it quantitative by design (Duff, 2006; Godwin et al., 2011) and therefore restricted to questions and phenomena that can be controlled, measured and counted, represented “confined access” to knowledge and understanding of post-TBI marital relationships (Malterud, 2001, p. 397). And while we have, as Bruner (1991) compellingly put it, “learned a great deal indeed about how we come eventually to construct and explain a world...in terms of causes, probabilities...,and so on, we know altogether too little about how we go about constructing and representing the rich and messy domain of human interaction” (p. 4).

It was this “rich and messy domain”, to which Bruner (1991, p.4) alluded some time ago, that I encountered in one autoethnography after another. Personal accounts ranging from ordinary and everyday experiences and observations, such as growing up in Northern Ireland (Wright, 2008), remembering a grandmother (Rambo, 2005), and interviewing an elderly woman (Evans, 2007); to issues usually shrouded in secrecy, such as struggling with bulimia (Tillmann, 2009); to expositions on race, gender and sexuality, such as representations of Black women on TV (Boylorn, 2008) and same-sex attraction (Adams, 2011); to stories of trauma, suffering, and loss, such as a smash-and-grab incident (Borawski, 2007) , making sense of the September 11th attacks and its aftermath (Ellis, 2002), and coming to terms with the sudden death of a sibling (Ellis, 1993), kept me riveted for many an hour, experiencing vicariously the experiences of others.

It was however predominantly autoethnographies dealing with illness, disability, trauma and loss which piqued and held my interest and to which I paid particular attention: because of how they related to and informed my own study on the one hand, and because of how much they resonated with me personally on the other. I began to understand how, through reading and engaging with these stories, the process could be deemed, as Ellis et al. (2011) suggest, a therapeutic one. Furthermore, I soon noticed that a major

theme repeatedly surfaced in many of the illness and disability accounts I was reading. One which spoke to both my personal convictions on the matter and to the shortcomings identified in the existing body of TBI literature. That being the problem of the dominant, even “pernicious” voice, as Richards (2008) goes as far to call it, of the “distant expert”, almost always silencing the voice of the patient - aptly called a “structured silence” by Zola (1991, p. 2) - through research in general, and clinical research in particular (p. 1717).

Casting a backward glance over the past few decades, it was Foucault (1963/1973) who was amongst one of the first to alert us to the dehumanising practice of what he termed the ‘medical gaze’ of the ‘expert’, which taken to be the only true source of knowledge, “has consistently been privileged over the voice of the patient” (Malterud, Candib, & Code, 2004, p. 8). The disability movement has also been central, asserts Richards (2008), “in reminding us that there is a long history of people living with illness or disability – already othered by society – being othered further through the writings and research of outsiders...” (p.1717). Elaborating on the meaning of “othering”, Richards (2008) describes this term as referring to “turning a person into an object of some sort, such as a stereotype or even an object of study” (p. 1717). Reflecting along similar lines, Frank (2002) explains how being ill or disabled can be “a profoundly...disenchanted business” (p. 358). Calling the process by which many become disenchanted, “the ride”, Frank (2002) describes an aspect of the ride as being the tendency of society to reduce the world to mere “sign values” (p. 359, 360). In the field of research, interpretations of these sign values by experts are then presented as the truth of who we are (Frank, 2002).

The ride is not hegemonic though. Personal stories are the means by which we can go about “remoralising” the often demoralising experience of being ill or disabled, advocates Frank (2002, p. 358), of incorporating the “missing voice” of the patient into medical sociology for example, advises Rier (2000, p. 68), and of representing “illness and disability from the inside”, suggests Richards (2008, p. 1717). Whilst reading though numerous illness and disability autoethnographies I began to understand how stories “establish new

terms of common sense and new relations of reciprocity within a community that affords recognition” for “those whose disrupted lives fall outside others’...knowledge” (Frank, 2002, p. 366). Ettorre's (2006) autoethnography documenting her struggle with hyperthyroidism for example, reveals that medical practices are often outdated and “based on gendered stereotypes of ageing, sick bodies” (p. 153). Neville-Jan's (2004) autoethnography on living with unrelenting neurogenic pain as a person with spina bifida, poignantly tells of the trade-off she experiences when the treatment she is prescribed finally controls her pain, but also results in sexual dysfunction in the form of anorgasmia. An entry in Neville-Jan's (2004) husband's journal movingly captures the conundrum the couple experience: “It seems to me like selling your soul to the devil, trading relief of pain for loss of pleasure” (p. 113). It is insider accounts such as these, declare Ellis and Bochner (1999), which provide an intimate view of experience not accessible to the researcher on the outside.

With this knowledge in mind, I began wondering how I could go about incorporating the voice of my husband into this autoethnography without making the “auto” suspect, as Averett and Soper (2011) put it. Although I was privy to an insider view of the TBI experience being the spouse of a TBI survivor, my story represented only half of the story after all, and I did not want to perpetuate research that was biased towards the views of a single spouse in the post-TBI marriage. Also, not wanting to contribute to the further silencing or “othering” of my husband as the TBI survivor, I questioned how, rather than making him an object of this study, I might make him an agent of it, albeit a part-agent. Whilst trawling through autoethnographic studies for ways in which I could go about this, I became increasingly aware that different forms of and approaches to the method autoethnography exist. Ellis et al. (2011) attribute these differences to the varying degrees of emphasis placed on: the study of others; the researcher's self; interaction with others; and traditional analysis.

It was when I came across Ellis and Bochner's (1992) co-constructed autoethnography, relating the story of their painful decision to terminate a

pregnancy and the profound impact this would have on their relationship and personal lives, that I realised this particular form of autoethnography, which Ellis et al. (2011) call the co-constructed narrative, was an ideal way in which relational experiences might be captured or, particularly in the light of this study, how a couple collaboratively copes with the aftermath of a TBI. This form of autoethnography allows for the telling of story in a way that shows “dyads engaged in the specific, concrete, and unique details of daily living” resplendent with “the untidy ambiguities, ambivalences, and contradictions of relationship life” as “they try to make sense of their local situations” (Ellis & Berger, 2003, p. 477). Simply put, I had found a form of autoethnography which placed an emphasis on relational interactions and the complexities thereof rather than on individual perspectives.

Chapter 3

Theoretical framework

3.1 Committing to an analytic agenda

Using existing theory to analyse autoethnographic texts or data is somewhat of a contentious issue within the genre of autoethnography as a qualitative research method (e.g., Anderson, 2006; Denzin, 2006; Ellis & Bochner, 2006). Whilst Anderson (2006) argues for an analytic approach to autoethnography, distinguishing it from what he calls an evocative approach, Ellis and Bochner (2006), who have served a critical role in defining autoethnography, shy away from making categorical distinctions and from placing analytic impositions on the method.

Although this study is aligned with the broader intention of autoethnography, that being to provide an insider's perspective on a personal experience and to evoke emotional resonance with the reader, I have also decided to adopt, what Anderson (2006) describes as being, a "data-transcending goal" for the study (p. 387). This means that I have made use of existing theory to "gain insight into some broader set of social phenomena than those provided by the data themselves", and to illuminate particular aspects of the data over and above others (p. 387).

3.2 Overview of chapter

As both Anfara and Mertz (2006) and Ravitch and Riggan (2012) point out, the term 'theory' is often the source of confusion for many, particularly as it relates to the theoretical framework of a study. This is most likely because the word theory has been defined in a variety of ways, and to complicate matters further, attest Ravitch and Riggan (2012), theory is also described at multiple levels. It is for the sake of clarity therefore, that I have distinguished between two levels of theory making up the theoretical framework of this study. I have also used Anfara and Mertz's (2006) definition of a theoretical framework as a guide in constructing the framework for this study which is "any empirical or quasi-empirical theory of social and/or psychological processes, at a variety of levels (e.g., grand, mid-range, and explanatory), that can be applied to the understanding of a phenomena" (p. xxvii).

The first part of this theoretical framework encompasses the metatheoretical perspective from which I have approached this study, that being a constructionist

family systems perspective (Yerby, 1995). Drawing from Botella's (1995) definition, by metatheory I mean "a theory that deals with the nature of theories", or in other words, a theory which deals with "the nature of epistemic assumptions" embedded in theories, and as such, is superordinate to any particular theory (p. 2). The metatheoretical aspect of this framework therefore reveals the epistemological underpinnings of this study. Sleeter (2001) describes epistemology as referring to "how people know what they know, including assumptions about the nature of knowledge and reality" (p. 213).

As Becvar and Becvar (2009) argue though, a metatheory is also descriptive, telling us where to focus our attention in a broad sense. It provides the researcher with the "philosophical scaffolding" necessary for making sense of the research enterprise so to speak, states Maydell (2010, p. 10). A metatheory is limited in its practical utility though, explain Becvar and Becvar (2009), when it comes down to understanding and analysing a particular phenomenon, that being the TBI marriage in the case of this study. They therefore suggest fleshing out the bones of one's metatheory with theories from a variety of other sources (p. 11).

With this in mind, I have also opted to make use of what Anfara and Mertz (2006, p. xxvii) call an explanatory theory, the likes of which can be applied as a 'lens' to the study of a particular phenomenon like the post TBI relationship. This theory is discussed in the second part of this chapter. Theories of this nature are defined by Kerlinger (1986) as being "a set of interrelated constructs, definitions, and propositions that presents a systematic view of phenomena by specifying relations among variables, with the purpose of explaining or predicting phenomenon" (p. 9). As Anfara and Mertz (2006) point out though, any theoretical framework or theory allows the researcher to 'see' and understand only certain aspects of the phenomena being studied on the one hand, whilst concealing other aspects of that phenomena on the other.

It is also important for the reader to note that, as Becvar and Becvar (2009) point out, the use of the term '*family*' as in 'family systems theory' and 'family therapy' is something of a misnomer (p. 12). Although the family is the context in which most of us live and derive meaning, family systems theory and family therapy is not limited to a family unit consisting of two parents and their children, but includes work at

multiple levels of relationships; including that of the couple level, the extended family level, the neighbourhood level, or the societal level. Family systems theory also guides us in describing relationships at all of these various levels rather than just at the family level. The significance of this issue to this study is that, although I often refer to the family - in order to hold true to the literature I've consulted and for the purpose of expediency - the focus of this study is at the couple level and the discussion which follows remains nonetheless pertinent to and inclusive of this unit of focus.

3.3 PART I. Metatheory: Establishing the epistemology and wide-lens focus of study

3.3.1 Towards an understanding of a systemic constructionist perspective

With Godwin et al's. (2011) call for studies that might provide a better understanding of the dyadic impact of TBI on marital relationships from a systemic, constructionist perspective in mind (see chapter two), I set out to find how family systems theory could incorporate a constructionist perspective - if indeed it even could - so that I might answer this call. I soon came across the works of Hoffman (1990), Yerby (1995) and others, who as family systems theorists have adopted a systemic constructionist view. In order to better understand how this systemic constructionist perspective evolved into what it is now though, I first look back at what family systems theory initially started out as.

3.3.1.1 Cybernetics and family systems theory: A loop-de-loop down memory lane

Family systems theory has, for several decades now, dominated the scene in terms of how family therapists and theorists describe and analyse family communication. The family systems, or cybernetic model, caught the attention of family theorists and communication scholars, reflects Yerby (1995), because of its apparent ability to raise our consciousness on how family life is conceptualised. Becvar and Becvar (1988/2009) describe this growing awareness and acceptance

of systemic thinking as being a “gestalt switch from a linear to a recursive worldview” (p. 32). Rogers, Millar, and Bavelas (1985) similarly described the growing interest in and focus on the family, as being a paradigmatic shift, the nature of which could be likened to a figure-ground reversal. “Previously, the relationship was ‘background’, with the individual as ‘figure’; in a systemic approach, individuals recede into the background as the relationship becomes figure”, explain Rogers, Millar, and Bavelas (1985, p. 175).

As an alternative worldview, family systems theory challenged psychoanalytic theory and humanistic psychology with its shift in focus, as Yerby (1995) points out, “from the internal psychological processes of the individual to interaction patterns within whole families” (p. 339). Emphasising this shift in focus, Yerby (1995) explains that:

“Systems theory has taught us to see our own and other family members’ behaviour as interrelated, to locate predictable patterns of interaction that seem to exert more power over the family than do any individual family members themselves, to see problems in terms of relationship struggles rather than the ‘fault’ of one person who is ‘scapegoated’ and ‘blamed’ for others’ pain and to explore the intergenerational legacy of family experience. Most of all, systems theory has helped us pay attention to our interdependence” (p. 339-340).

Becvar and Becvar’s (2009) historical overview of the birth and subsequent development of the family therapy movement stretches as far back as the 1930s reaching a high point in the 1970s, the seeds of which were sown by a “disparate groups of researchers and theorists from a variety of disciplines who were early explorers in the field of cybernetics” (p. 16).

Interestingly, research leading to the science of cybernetic systems was connected to guided missile experiments during World War II (1939), enlightens Hoffman (1990), following which a series of cross-disciplinary meetings called Macy Conferences took place, attended by

researchers from both the physical and social sciences. These researchers were, according to Hoffman (1990), intent on exploring the possible application to various fields, “this new and fascinating idea that both living and nonliving entities may be governed by error-activated feedback loops” (p. 3).

Norbert Wiener (1948), a mathematician, is usually accredited with having come up with the name ‘cybernetics’, which was used to describe the activity of feedback cycles not only in machines but also in human affairs, and which came to represent a central tenet of general systems theory (von Bertalanffy, 1950). The word cybernetics, explained Weiner (1948), taken from the Greek *kybernetes*, meaning steersman, is a basic concept meant to describe “a feedback mechanism, which is especially well represented by the steering engine of a ship” (p. 14). It was during the 1950s, as an adaptation of general systems theory, that family therapy put down roots as a distinct practice (Becvar & Becvar, 2009).

Bateson’s cybernetic model (1972) and Minuchin’s structural therapy model (1968) provided the main points of departure for most family theorists and family therapists up until the 1980s (Boston, 2000). The Milan model (Selvini Palazzoli, Boscoli, Cecchin, & Prata, 1978) and De Shazer’s (1985) brief therapy model were, for example, both based on the cybernetics model. The cybernetic model, explains Boston (2000), viewed the family as being a “homeostatic mechanism with communication patterns analogous to those in mechanical information processing systems”, whilst the structural therapy model focused predominantly on “the issue of optimal organisation of the family and clarity of boundaries” (p. 450). These were first-order models, indicates Boston (2000), characterised by the modernist assumption that reality is ‘knowable’, and by the therapists observation of the family system “from the outside” (p. 450).

It was towards the end of the 1970s that the field of cybernetics “underwent a schism”, explains Hoffman (1990), when von Foerster

(1979) in opposition to the first-order cybernetics of “the ‘hard’ scientist”, proposed a second-order cybernetics (p. 3). At the level of second-order cybernetics “the observer is understood to be part of that which is observed” indicate Becvar and Becvar (2009, p. 87), which meant for family therapists, that their personal or theoretical biases were now to be acknowledged and included as part of their observations. Shifting from what Becvar and Becvar (2009, p. 89) describe as being a “belief in facts to an awareness of perspectives” and from a modernist to a postmodernist worldview, second-order cybernetics was marked by the inclusion of constructivism, a body of thought encompassing perspectives that “in one form or another, see the person as actively engaged in the creation of their own phenomenal world” (Burr, 2003, p. 19).

3.3.1.2 Criticisms of the circular systemic paradigm

Confronted by revisionist ideas and critique, family systems theory has continued to evolve and change. Hoffman (1998) argues that two movements in particular, namely feminism and postmodernism, caused many family therapists to question “the objectivist belief systems on which the early approaches to family therapy had been based” (p. 145). Concerns shared by both these movements included the failure of family systems theory to take into consideration the wider social context.

In what Becvar and Becvar (2009, p. 46) deem a “groundbreaking article”, feminist psychologist Rachel Hare-Mustin (1978) for example, criticised systems theory and its proponents for maintaining a sexist status quo. It was feminist critiques such as this one, point out Becvar and Becvar (2009), which revealed to family therapists how their use of mechanistic metaphors had blinded them to the ways in which social, political, and economic conditions contributed to family dysfunction, and additionally how the rejection of the idea of unilateral control had resulted in their failure, inadvertently or otherwise, “to acknowledge the

realities of the power relationships that characterise our patriarchal society” (p. 46).

The challenge posed to family systems theory from the postmodern movement gained momentum within a much larger postpositivist critique of ‘ways of knowing’. At the heart of the postmodern critique of family systems theory though “is a sense of skepticism about or uneasiness with dogmatism, authoritarianism, and the assumption that one person (e.g., an observer) can discover the ‘objective truth’ about another person’s (e.g., a subjects) reality”, surmises Yerby (1995, p. 342).

Directing a somewhat scathing attack on the family systems approach, Erickson (1988) for example, honed in on the problematic issue of the so-called ‘objective’ observer, pointing out that “family members and their subjective intentions, their individual and shared sense of a past, their creation of meaning, all vanish and are replaced by a particular understanding of a set of relations as called forth by a therapist” (p. 226). As a result, suggests Erickson (1988), one could view a ‘systems analysis’ as being either a “creative act” on the one hand or “an act of mystification and sophistry wearing a mask of science” on the other (p. 226). Critiques such as Erickson’s (1988) contributed to a growing awareness of the postmodern view that reality is a social construction and to the recognition, as Guba (1990) argues, “that what I am about to say is my own construction, not necessarily an objective (whatever that may be) analysis” (p. 17).

3.3.1.3 Family systems theory reconsidered: Integrating social constructionist theory

In an article exploring the influence of postmodernism on family systems therapy Boston (2000) asserts that a profoundly different, and postmodern view of considering reality came from the body of work known as social constructionism. It has been three decades since Gergen (1985) introduced social constructionism “to a wider audience within the discipline of psychology”, attests Liebrucks (2001, p. 363),

prompting what Edley (2001) calls a large scale “turn to language” (p. 434).

Suggesting that ‘reality’ is constructed through language in an ongoing interactional relational process, social constructionism challenges the idea that our words or discourses about the world are a ‘true’ reflection or map of the world (Gergen, 1985). Language, according to a social constructionist view, is productive rather than reflective or, as Edley (2001) puts it, “‘reality’ isn’t so much mirrored in talk and texts as actually constituted by it” (p. 435). This is consistent with a postmodern view which understands language to be “the means by which individuals come to know their world and in their knowing simultaneously to construct it” (Becvar & Becvar, 2009, p. 91).

A social constructionist inquiry, explains Gergen (1985, p. 266), is one which “is principally concerned with explicating the processes by which people come to describe, explain, or otherwise account for the world”, placing knowledge between people rather than within individual minds or outside of them, clarifies Botella (1995). Ours is a storied reality according to the social constructionists view, and thus calls on family therapists, asserts Becvar and Becvar (2009), “to place greater emphasis on context, on the social constructions of individuals and problems, and on the creation of narratives” (p. 90).

Boston’s (2000) description of two postmodern models of family systems therapy, namely Anderson and Goolishian’s (1988) postmodern systemic therapy model and White and Epston’s (1990) narrative therapy model, helpfully contributed to my understanding of family systems models based on or influenced by social constructionism. In their efforts to create new options for ways of thinking about human systems for instance, Anderson and Goolishian (1988) drew from social constructionism the idea that it is the communication processes between family members which construct for that family their own particular ‘reality’.

From the social constructionist premise that the family system is a “language-generating and, simultaneously, meaning-generating system”, Anderson and Goolishian (1988) derived the term ‘linguistic systems’, using it to refer to human systems in general and family systems in particular (p. 371). Tracing the development of systemic thinking from cybernetic to social constructionist models of understanding relationships, Cecchin (1992) also touches on the idea of family systems being linguistically co-constructed, noting that families began to be seen as people “involved in staying together, not to control one another or to control their relationships, but to make sense with one another” (p. 89). This ran contrary to the cybernetic model which holds that the family developed predictable patterns of relating and of maintaining control over one another in order to maintain stability.

Also contributing significantly to the understanding of systemic thinking through a social constructionist’s lens as she puts it, was an article by family therapist Lynn Hoffman (1990) describing her own move away from a “cybernetic-biological analogy” for family systems therapy. Hoffman (1990) largely attributes this move to her discovery of social constructionism theory. Encountering the ideas of Berger and Luckman (1966) in their book, *‘The social construction of reality’*, and those of Gergen (1985) in his overview of the social constructionist position for example, as well as being influenced by family therapists like the Galveston group (Anderson & Goolishian, 1988) with their focus on narrative and linguistics, Hoffman (1990, 1998) was persuaded to set aside the cybernetic model in favour of a social constructionist one.

Juxtaposing the cybernetics metaphor, which compares a family to an organism or a machine, with a metaphor of flow, fluctuation and evolution for social constructionism, Hoffman (1990) likens the latter, also metaphorically speaking, to “rivers through time” and the former to “timeless circles” (p. 2). Although Hoffman (1990) concedes that we cannot say that one metaphor is more ‘true’ than another, she does

however argue that the metaphor attributed to social constructionism provides “a better analogue for describing the shifting trajectories of human groups than do the more static cycles of cybernetic theory” (p. 2).

Initially adopting a constructivist position, which she later abandoned because she “did not like the idea that people were stuck in biological isolation booths”, Hoffman (1990) turned to social constructionism as it allowed her and other family therapists, she attests, to “bypass the fixity” of the constructivist model (p. 2). A constructivist stance implies that all interaction takes place between what Maturana called ‘informationally closed’ nervous systems that can only influence each other in indirect ways (Maturana & Varela, 1980). In contrast, social constructionism offers “an evolving set of meanings that emerge unendingly from the interactions between people”, explains Hoffman (1990), going on to elaborate that these meanings are not “skull-bound” as is the case with constructivism, but are rather “part of a general flow of constantly changing narratives” (p. 2).

3.3.2 Settling on a particular systemic constructionist perspective for this study

Having scoured through a substantial amount of literature on the various family systems approaches which have incorporated a constructionist view, it was family systems theorist Janet Yerby’s (1995) clear delineation of what she terms ‘a constructionist family systems perspective’ on which, because of its comprehensiveness, clarity, and fit with the method of autoethnography, I finally settled for the metatheory of this study. To reiterate what I have already pointed out at the start of this chapter, my rationale for wanting to select a metatheory for this study was so that, when it came to the analysis of the data, I would have a clear idea of where to focus my attention in a broad sense. Furthermore, as I have also previously mentioned, it would also allow this study to speak to the gap in the existing post-TBI marriage literature which I identified in chapter two of this study.

3.3.2.1 Yerby's 'constructionist family systems perspective'

By incorporating social constructionist theory and a dialectical approach to interpersonal relationships in a conceptual framework for understanding the family, Yerby's (1995) constructionist family systems perspective, conceives of relational processes between family members as being continually evolving or unfolding rather than circular. Consequently, therapists and researchers operating from within this perspective can focus the "emergent nature of conversation and the influence of the unpredictable on how family members relate to one another" which had been ignored by previous systems approaches (Yerby, 1995, p. 343). Furthermore, working from within this perspective, one can also explore the dialectical tensions inherent in personal relationships.

The social constructionist idea that individual, family, and cultural stories are constantly unfolding and that meanings are constantly changing is compatible with the dialectical approach, indicates Yerby (1995), because - as a number of researchers interested in dialectical processes have suggested (e.g., Baxter, 1988; Bochner, 1984; Montgomery, 1992; Rawlins, 1992), "meanings emerge from apparently opposite forces and alternative perspectives" (p. 351). Baxter and Montgomery (1996) give credence to Yerby's (1995) assertion that social constructionism and a dialectical approach are compatible as they posit that dialectical contradictions are located in the interpersonal relationship rather than the individual.

According to Wilmot (1987), dialectical process describes the relationship between "opposites that are bound together" (p. 107). Family communication literature (e.g., Bochner & Eisenberg, 1987; Montgomery, 1992) has identified two significant dialectical tensions in the family, namely the tension between integration and differentiation and that between stability and change, both of which have been explored by numerous family theorists, including Hoffman (1981), Kerr and Bowen (1988), and Weeks (1986).

The works of these and other family theorists highlight for example, the family's struggle to maintain a balance between separateness and connectedness, and also argue for example, that family stability is related to the family's adaptability to change. Montgomery (1992) reminds us that a dialectical tension also exists between the family and the wider culture, as although families construct their own culture through their shared experiences and the stories they tell of these, they simultaneously function within a culture which prescribes to them the way they are supposed to be.

Whilst exploring the dialectical perspective, I soon realised that it supported my chosen research method of autoethnography, which positions me as both the researcher and the researched. This is because, as Yerby (1995) points out, the concept of dialectical process allows one to view apparent opposites as emerging from a construct that is inclusive of both ends of a polarity, and in this way then, the researcher and subject can be viewed as inhabiting the same system. Also consistent with a social constructionist view, it allows one to explore alternative and opposing perspectives within the same system, such as a marriage, and listen to different experiences of a shared event, such as a TBI. This was particularly important to note for this study, I realised, because it allowed for the co-construction of the story I hoped to tell together with my husband.

Again I was struck by how this integrated perspective complemented the method of autoethnography in general, and a co-constructed autoethnography specifically, when I read Yerby's (1995) explanation of how it allows us to view the family:

"We can come to understand a social system that includes individual, family, and cultural narratives by noticing how the three are simultaneously bound together in opposition to one another and in mutual reinforcement of one another. Family communication is manifested and realities are constructed in the dialogue, conversation, and multiple narratives of family

members. The identification of apparent opposites that are bound together – the individual and the family, the family and the larger culture, marginalised voices and dominant voices in the culture, researcher and subject – create the possibility for new constructions as alternative perspectives and realities are explored” (p. 351-352).

Also confirming this compatibility, between the method of autoethnography and a dialectical view, Bochner, Ellis, and Tillmann-Healy (1998) profess to using dialectic as a tool for writing about personal experiences and relational struggles. Adopting Rorty's (1989) belief that contradictions are not issues to be resolved, but rather circumstances to be understood and lived with, Bochner et al. (1998) make it their goal to engage with their readers in such a way as to invoke “in their minds and feel in their bodies the complexities of concrete moments of lived relationship life” (p. 51). Emphasising their intention for telling stories of personal relationships infused with dialectic, Bochner et al. (1998) insightfully explain that it is:

“to show how people breach canonical conventions and expectations; how they cope with exceptional, difficult, and transformative crises in their relationships; how they invent new ways of speaking when old ways fail them; how they make the absurd sensible and the disastrous manageable; and how they turn calamities of fate into the gifts of humanity” (p. 53).

3.3.3.2 The characteristics of a constructionist family systems perspective unpacked

In proposing a model that integrates social construction theory and dialectical process into a systems view of the family, Yerby (1995) identifies the following characteristics: a constructionist family systems perspective would be one which (1) views family process as continually evolving or unfolding rather than circular; (2) explores the dialectic between the individual and the family, and the dialectic between the family and culture; (3) suggests that meaning in family systems is

linguistically co-constructed through conversation, and; (4) conceptualises knowledge of systems as a reflexive process that includes both researcher and subject (p. 352). Each of these characteristics are discussed in more detail below. Such a model, asserts Yerby (1995), would provide an interpretive rather than a causal framework for analysing family process, whilst retaining the insight and understanding that has been provided by “historical family systems theory” (p. 352).

3.3.3.2.1 Family processes as continually evolving: The dialectic of stability and change

Describing the family as being “a collection of individuals who create a history and a set of memories from which family experience is continually reconstructed”, Yerby (1995), suggests that these shared memories help to create for that family a world which is both stable and predictable. There exists a dialectic “between memory and the flow of life as time moves forward” though (p. 353). Although families seek for and create some sense of permanence and predictability through conversations patterns Parry (1991, p. 52) calls “myths”, the likes of which, he suggests, embody or encode a family’s particular beliefs about the way things are, family members nonetheless encounter experiences outside of the family unit, are faced with unexpected events, and also grow and develop biologically. As Yerby (1995) puts it, life within and around the family is continually in motion. Montgomery (1993) similarly asserts that the natural state of relationships, according to a dialectical view, is one of change, fluctuation, evolution and movement - and stability for the family is “but a momentary transition in a stream of continuous change” (p. 208).

A constructionist family systems perspective would shift the focus from attending to stable patterns in the family to attending to the family’s capacity for change, proposes Yerby (1995),

potentially leading researchers to investigate family member's accounts of past experiences and how they cope with difficulties over time.

3.3.3.2.2 The self and the system as interdependent: The individual systems dialectic

The dualism reflected in debates between psychoanalytic theory and family systems theory is reconciled, argues Yerby (1995), by the dialectic of the self in the system. This means that focusing on the family is no longer viewed as being antithetical to attending to the individual. A constructionist systems approach integrates "the conceptual schism between the individual and the family", explains Yerby (1995), focusing instead on how individual, family, and cultural narratives are interrelated, rather than on just one or the other in isolation (p. 354).

3.3.3.2.3 The family system as culturally constructed: The dialectic of family and culture

As Montgomery (2012) points out, the individual systems dialectic is broader than just the interpersonal context. Couples are challenged by the need to be apart from and, at the same time, a part of the larger social community, explains Montgomery (2012), one which does not just encourage connection, but demands it. This connection with the wider culture, within which the couple and the family is embedded, provides a shared sense of how relationships work and reduces uncertainty about how couples should act, explains Montgomery (2012). Yerby (1995) similarly highlights how relationships are played out "within the context of legitimised worldviews or ways of knowing" (p. 356).

In explaining how normalising values of a culture are given 'truth' status, Foucault (1980) alerted our attention to how

legitimised communities of knowledge inadvertently serve to control us. Research practices, because they are inherently related to social practices and knowledge systems, can exert this kind of control, in that they often label and negatively evaluate individuals and families. They do this, explains Yerby (1995), by negatively generalising for example, about divorced families, single-parent families, alcoholic families, homosexual families, and as I have indicated in my literature review, about TBI couples, etcetera, in such a way that “differentiates ‘them’ from ‘us’” (p. 355).

One way to pay more attention to this dialectic between the family and culture and the political nature thereof, using a constructionist systems approach, would be to include more family narratives reflecting the diversity of family life in our research, advises Yerby (1995). For as families share their stories - of divorce and desertion, of trauma and injury, of conflict and struggle, a space is created for them to be heard rather than labelled and stigmatised.

3.3.3.2.4 Family systems as linguistically co-constructed: Meaning as dialectically derived

Yerby's (1995) assertion that families are linguistically co-constructed and defined by their conversation as such, reflects the social constructionist view which holds that meaning is generated through conversation between individuals in a social system. From a social constructionist perspective therefore, meanings are seen as being intersubjectively constructed. According to Anderson and Goolishian (1988), intersubjectivity refers to an “evolving state of affairs” in which two or more people come to understand or agree that they are experiencing the same event in a similar way (p 371). This agreement is a fragile one however; open to dispute and continual renegotiation.

From a constructionist family systems approach then, we come to understand a family through participation in the conversations that they share about their lives together, explains Yerby (1995). Constructions of a TBI couples experiences may emerge, for example, in the language they use to describe the dialectic between being 'part of' and yet 'apart from' normative life.

3.3.3.2.5 Knowledge of systems as a reflexive process: The dialectic of knower and participant

By including the dialectic between knower and participant in an integrative approach such as the constructionist family systems approach, one addresses the epistemological assumptions of systems theory, asserts Yerby (1995). The researcher is positioned "within the frame of that which is being studied" rather than outside of it, "legitimising the contribution of the subjective experience of the researcher" (p. 358). This epistemological stance recognises what Guba (1990) describes as being "the absurdity of assuming that it is possible for a human inquirer to step outside the pale of humanness while conducting inquiry" (p. 20). It also supports the argument reiterated by Steier (1991) that researchers actually construct that which they claim to find.

3.4 PART II. Explanatory theory: Zooming in on the phenomenon of the post-TBI marriage

Hoping to bring new insights to the understanding of the phenomenon of the post-TBI marriage, I chose to apply the explanatory theory of psychiatrist, psychoanalyst, and pioneering family systems therapy researcher, David Reiss (1981) to the analysis of the data for this study. Reiss' (1981) seminal book, '*The family's construction of reality*' contains empirical and theoretical work undertaken by him over a seventeen year period, relating to broad processes of family life. It is specifically his theory on 'family paradigms and crisis' (Reiss, 1981) therein, and his subsequent work on 'the family's organisation around chronic illness' (Reiss,

Steinglass, & Howe, 1993) though that I have selected to utilise for this study in light of its applicability to the post-TBI marriage.

3.4.1 Reiss' theory on family paradigms and crisis

According to Reiss (1981), the family develops a shared system “to which each contributes and in which each believes” (p. 163). Reiss (1981) attributes this line of theorising to the ideas of sociologists, Berger and Luckman (1966) whose seminal work, *‘The social construction of reality’* is considered to have made a major contribution to our understanding of social constructionism (Burr, 2003; Gergen, 1995). This shared system, which develops between couples and family members, plays a crucial role, asserts Reiss (1991), in defining boundaries, clarifying objectives and roles, and establishing norms for interaction. Reiss (1981) likens a family’s shared system of ‘framing assumptions’ to Kuhn’s (1962) concept of paradigm, in that the term ‘family paradigm’ presents the family as having “a distinct and uniform way of thinking about and dealing with life” (Boss, Doherty, & La Rossa, 2009, p. 259). Similar to Kuhn (1962), Reiss also argues that “a group cleaves to a particular mode of explaining its world because the essential elements of that mode of explanation were dramatically successful attempts to deal with a severe crisis” (p. 175).

Reiss (1981) describes the ‘framing assumptions’, which make up the family paradigm, as being implicit, “specifying – with great generality – certain fundamental properties of the perceptual world” (p. 174). This does not mean that consensus or agreement between couples or family members is a given though, explains Reiss (1981). In terms of family consensus, these implicit assumptions function more as meta-rules determining such things as, for example: how is disagreement between family members recognisable; is disagreement between family members even permissible; and on what grounds is agreement established. Although paradigms are implicit, they do however manifest themselves in what Reiss (1981) calls the family’s ‘*organising patterns of daily living*’. These patterns, elaborates Reiss (1981), “shape the family’s relationship with its social environment, synchronize each

member's action and planning with others in the family, and maintain the family continuity with its own past" (p. 174).

The concept 'family paradigm', as a set of underlying framing assumptions and interaction patterns has, according to Reiss (1981), limited explanatory power in terms of how they "arise and why they persist" though, which is why he introduced the concepts of stress, crisis and family disorganisation into his explanatory model of the family paradigm (p. 175). Reiss (1981) distinguishes family stress from family crisis and disorganisation in that stress lies outside of the family's borders and is something that happens to a family, whilst crisis and disorganisation are processes that happen within the family. According to Reiss (1981), "an event is stressful by virtue of a common social construction that it will produce a substantial change or alteration" in the life of an average family (p. 177). As a result of this stress, a crisis arises when a married couples or family's "previous modes of construing the environment" fails, and why a new paradigm, once it has been established in response to the crisis, is adhered to (p. 175).

Reiss (1981) posits that new paradigms are constructed and "make their first appearance during grave family disorganisation" (p. 175). Family disorganisation is poignantly described in the following way:

"Each member feels as if the centre of his life is loosening, that his unseen ties to others and to his past have become highly visible, vulnerable, and finally torn. The family, as a group, loses its most precious possession: an extended and dependable repertoire of background understandings, shared assumptions, traditions, rituals, and meaningful secrets which made it possible for them to function implicitly" (p. 177, 178).

Paradigms begin as shared constructs, which emerge, explains Reis (1981), as an "active response to extreme stress" and as an effort to "restore integrity in the wake of disorganisation" (p. 175). Constructs used to successfully deal with a severe crisis tend to stand out as extraordinary achievements to the couple or family members and will therefore continue to be applied to more ordinary problematic events of daily life.

3.4.2 Reiss on family disorganisation in the face of crisis

According to Reiss (1981) family disorganisation occurs in three phases: the emergence of rules; the emergence of an explicit family as a tyrannical social construction and; the rebellion of individual members. Elaborating on each stage, Reiss (1981) describes the family's first response to stress as being characterised by the emergence of explicit rules. These rules are usually verbally articulated, often in an attempt to deal with the uncertainty arising from unexpected events. This is a frequently experienced stage in the life of the family and is, argues Reiss (1981), an essential one for the family to experience before they can once again return to an implicit level of functioning. It can also signify the start of a "deeper slide" into disorganisation though (p. 179).

The explicit family emerges when articulated rules multiply and coalesce, into what Reiss (1981) describes as being, "more rigid systems" of control (p. 179). These unyielding systems, attests Reiss (1981), represent "desperate attempts by the family to forestall further decay", or serve as "temporary supports against a passing stress" (p. 179). This new set of interlocking rules has the potential to transform a family, whose life was previously distinguished by "a fine texture of implicitly understood gestures and codes" before the crisis, into "an encroaching, all-too-explicit family" thereafter (p. 179,182).

Rebellion and action characterise the third stage of family disorganisation, probably because the family or someone in it, is perceived to be "a tyrant or a malevolent source of enduring difficulty for most members" (Reiss 1981, p. 179). In the case of families and marriages where an individual has a chronic illness or injury, such as alcoholism or traumatic brain injury for example, the chronic illness or injury itself can become the central organising principle for family and married life. The source of difficulty; be it the family, an individual, or a chronic condition, comes "to dictate the pace" of family or married life, superseding all else (Reiss et al., 1993, p. 176). Individual family members may therefore begin to view the family as being the enemy, and could become embroiled in a struggle to escape from or destroy it.

This stage of rebellion and action is most easily recognisable in marital dyads, asserts Reiss (1981). Using a hypothetical example of a married couple in distress, Reiss (1981) further illustrates this stage:

“Soon more rules were suggested. Explicit schedules were aimed at getting Ann to take more responsibility and others were aimed at forestalling the potentially murderous effects of Fred’s anger. Each one came to feel trapped and overwhelmed by an engulfing, unproviding marriage for which each blamed the other. Neither individual could recognise his [or her] own contribution to the edifice. Each sought to escape it, or – more dangerously – to destroy it. The explicit, opaque, and constraining rules – that last vestige of family order and cohesiveness – were defied, circumvented, unilaterally enforced, or capriciously modified (p. 183).

It is at this phase, indicates Reiss (1981), that the family, in a desperate bid to repair itself, paradoxically lives out its own destruction.

As the family moves through these stages, from implicit functioning, to explicit constraints and then to rebellion, other important parallel shifts also occur, proposes Reiss (1981). The first of these is a reduction in the family’s capacity to pay attention to its social world. As the family’s social processes become more explicit, each member experiences what Reiss (1981) calls a decentering. Attention shifts away from how each family member experiences him or herself in their wider social world, to a preoccupation with the now obvious processes occurring within the family. The ‘process oriented’ family – as a group – thus “withdraws its investment in managing identifiable tasks and instead struggles with itself” (Reiss 1981, p. 184). It is however, within a family’s preoccupation with itself, albeit somewhat maladaptive, that the seeds for its healing and return to implicit functioning are contained, suggests Reiss (1981).

The other shift which occurs within the family as the crisis deepens and disorganisation becomes more severe, is that of outsiders taking on a more significant role in the life of the family. Reiss (1981) conceives of the concept of outsider broadly, making use of the term in two senses. In the first sense,

outsiders may include family, friends, or total strangers not previously engaged in the inner life of the family. In the second sense, the term is used to denote certain attributes of family members themselves. An aspect of a family member's personality, for example – which had, for whatever reason, been suppressed or excluded from the everyday life of the family when it functioned at an implicit level – may now emerge.

3.4.3 Reiss' crisis construct

Although increasing disorganisation can lead to the dissolution of the family, it can also be the basis for its redemption, argues Reiss (1981). The path to recovery begins with a new form of construct which Reiss (1981) calls the crisis construct. Recognising that it is in crisis, the family starts to develop some shared concept of the crisis unlike any other shared construct it has developed in the past. Whereas most constructs have as their central focus some aspect of life outside of the family and are concerned with the family's position in its social world, asserts Reiss (1981), the crisis construct focuses more on the family itself and includes some percept of its disorganisation. It is also independent from previous systems of explanations and meaning because these have been shattered through the family's crisis.

In conclusion, because the crisis construct is separate from the family's prior system of explanations and understandings and is subject to outside influences, it is different in many essential attributes from other constructs the family have previously shaped. It is for these reasons, argues Reiss (1981), that the crisis construct constitutes a basis for family change, and because it is the one that initiates redemption, holds a special place among the family system of constructs.

Chapter 4

Methodology

4.1 Overview of chapter

Having already made my reasons, both personal and research related, for choosing to do a qualitative study explicit in chapter two of this study - as is common practice in a qualitative inquiry (Creswell, 2012), in this chapter I address the question: “Why conduct qualitative research?” in more general terms. I also briefly touch on some core characteristics of this research approach before locating my chosen method of autoethnography in the overall genre of qualitative research. I then move onto discussing the method of autoethnography itself in more detail, particularly as to how I applied it to this study. Finally, I conclude this chapter off with the pragmatic issues that were involved in carrying out this study, namely the collecting of data, the analysing of data, the efforts made to establish trustworthiness, and the ethical issues arising when doing an autoethnography.

4.2 Qualitative research

Qualitative research is defined by Denzin and Lincoln (2011) as being:

“ ... a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meaning people bring to them” (p. 3).

A qualitative inquiry, such as this one, “represents a legitimate mode of social and human science exploration, asserts Creswell (2012), without apology or comparisons to quantitative research” (p. 6). I deliberately raise this issue here because, as Ellingson and Ellis, (2008) point out, “dichotomous thinking remains the default mode of the academy” the likes of which is particularly evident in the “quantitative-

qualitative divide” (p. 445). Binaries (mutually exclusive, paired opposites) such as objective/subjective, hard/soft, science/art, for example, regularly crop up in the literature describing and differentiating between quantitative and qualitative approaches, and as Denzin and Lincoln (2011) point out, “under such a framework, qualitative research becomes suspect” (p. 7). In light of this, and what Maxwell (2004) calls a re-emergent scientism, “qualitative researchers must resist conservative attempts to discredit qualitative inquiry...” advise Denzin and Lincoln (2011, p.7).

Advocating what they believe to be a more productive approach to research in general, Ellingson and Ellis (2008) prefer to locate qualitative research somewhere along the “vast and varied middle ground of a continuum, with artistic interpretivists anchoring the one end and scientific positivists the other” (p. 445). It is however Maxwell’s (2004) postmodern perspective on research which resonates with me most strongly, and makes way for the more contemporary qualitative methods such as autoethnography. Maxwell (2004) asserts that in the field of research, “diversity is fundamental and irreducible” and like Lather (2004), he experiences a sense of disbelief towards meta-narratives that claim “a unified, totalizing understanding of some phenomenon” (p. 35). A statement made by the philosopher Richard Bernstein (1992) on his analysis of Habermas and Derrida is used by Maxwell (2004) for the purpose of drawing a comparison to and elucidating his stance in the quantitative/qualitative debate:

“I do not think there is a theoretical position from which we can reconcile their differences, their otherness to each other – nor do I think we should smooth out their “aversions and attractions.” The nasty questions they raise about each other’s “project” need to be relentlessly pursued. One of the primary lessons of “modernity/postmodernity” is a radical skepticism about the possibility of a reconciliation – an *aufhebung*, without gaps, fissures, and ruptures. However, together, Habermas/Derrida provide us with a force-field that constitutes the “dynamic, transmutational structure of a complex phenomenon” – the phenomenon I have labelled “modernity/postmodernity” (p. 225).

Despite efforts to discount them, in part because of their ‘otherness’, qualitative research methods have continued to grow in credibility, confirms Morrow (2007) . This may be due to a number of reasons. Gergen (2001), for example, asserts that by broadening our intellectual and philosophical perspectives and research methodologies, psychology as a discipline has and will continue to grow, both in terms of professional knowledge and societal impact. Also, whereas quantitative methods are limited to providing a broad understanding of a phenomenon, qualitative approaches allow researchers to “delve into complex processes and illustrate the multifaceted nature of human phenomena” (Morrow 2007, p. 211). Furthermore, in revealing to us the meanings people make of their experiences in a more accessible and convincing way, qualitative approaches, especially narrative ones, may have a wider appeal in terms of audience, suggests Creswell (2012).

Exploring the extensive literature available on qualitative research itself, one quickly realises that it is by no means a unified field of theory or practice either though. As a result of having roots in numerous disciplines, such as anthropology, sociology, history, and literature, explains Ponterotto (2005), a plethora of different types of qualitative approaches have arisen. Another challenge facing qualitative researchers, is that qualitative research can emanate from multiple paradigms, “each valid in its own right, and each with its own criteria for conducting and evaluating research” (Ponterotto, 2005, p. 132). It is therefore important, advises Ponterotto (2005), that researchers “understand and clearly explicate” the paradigms from within which they are operating from (p. 132). I have endeavoured to do so further on in this chapter.

4.2.1 Core assumptions of qualitative research

Although qualitative research is, as Denzin and Lincoln (2011, p. 8) put it, “many things to many people”, it is nonetheless grounded in a number of core assumptions and values. As Morrow (2007) indicates, these assumptions and values span disciplines and paradigms. Some aspects are emphasised more and others less however, depending on the paradigm and method used in the study.

To begin with, qualitative research is both emic and idiographic. The term ‘emic’ was originally used by Pike (1967) to indicate an approach to

understanding phenomenon from within a particular cultural setting (Terre Blanche, Durrheim, & Painter, 2006). Qualitative research is also idiographic in that it views research participants as being unique and complex entities (Ponterotto, 2005) and produces “knowledge claims about one or very few individuals” (Morrow & Smith, 2000, p. 200). This stands in sharp contrast to quantitative research which being nomothetic, focuses on a large number of individuals (Morrow, 2007).

Another common thread running through all qualitative research is that it is iterative and therefore flexible in nature. As Morrow (2007) elaborates, a qualitative inquiry starts with research questions rather than hypotheses, and it is these questions which guide the data gathering process. As the data accrues and the researcher seeks to understand the meanings of the participants, inductive analyses of the data is carried out. Themes and categories emerging from the data are then “tested deductively by comparing and contrasting with existing and new data” (p. 215). Alternating between data collection and analysis displays a sensitivity to emerging findings that is desirable in qualitative research, explains Morrow (2007), and is why qualitative inquiry is often described as having an emergent design.

Also ubiquitous to qualitative research is the rejection of the notion that a researcher can maintain a stance of true objectivity. Instead, qualitative researchers acknowledge and accommodate their subjectivity, explains Morrow (2007), recognising “both the promise and limitations” of doing so (p. 216). Subjectivity in a qualitative inquiry, she further explains, is usually addressed on a number of levels. At the level of the participant, subjective experiences, usually told retrospectively in the form of self-reports, are considered to be an integral part of the information collected by the qualitative researcher, whilst the relationship between the researcher and participant is said to be characterised by intersubjectivity (shared meaning). At the level of the researcher, the degree to which his or her subjectivity is managed is paradigm-dependent and, as is especially evident in an autoethnographic study such as this one, also largely determined by the method.

As with the issue of subjectivity, a number of other core assumptions and values underpinning qualitative research are similarly affected by or dependant on the paradigm within which the researcher has positioned the inquiry as well as by the method selected. This includes but is not limited to: the criteria by which participants are selected, the social location of the researcher in relation to the participants in the study, and knowing when one has achieved sufficiency of data, for example. In light of this specificity, and in order to avoid unnecessary explanations and repetition, I will discuss these issues as they relate to the interpretivist-constructivist paradigm and more particularly to the method of autoethnography under each respective discussion below.

4.3 The paradigm in which this study is situated

Although numerous taxonomies for describing qualitative research paradigms exist, I have drawn predominantly from those proposed by Guba (1990) some time ago, and from Denzin and Lincoln (2011) who have, over the last 20 years, articulated and re-articulated the philosophical assumptions underpinning qualitative research in successive editions of the *Sage Handbook of Qualitative Research* (Denzin & Lincoln 1994, 2000, 2005, 2011). More specifically, I have drawn from the paradigm Denzin and Lincoln (2011) call the constructivist paradigm, as it is the one in which this study is located. I have also drawn from Creswell's (2012), Morrow's (2007), and Ponterotto's (2005) work, all of whom refer extensively to the aforementioned authors.

A paradigm, explains Guba (1990), is “ a basic set of beliefs that guides actions, whether of the everyday garden variety or action taken in connection with a disciplined inquiry” (p. 17). Describing a paradigm more in terms of the latter aspect, namely a disciplined inquiry, Morrow (2007) suggests that a paradigm may be seen as a ‘net’ which holds the researcher’s beliefs about ontology (the nature of reality), epistemology (which constitutes knowledge as well as the relationship between the knower and the known or investigator and participants), axiology (the role of values in one’s research), and methodology. The methodology emerges from and is guided by the researcher’s ontological, epistemological, and axiological assumptions and

focuses on the means by which the researcher can best go about gaining knowledge about the world in light of these assumptions (Denzin & Lincoln, 2011).

Albeit useful to separate qualitative research paradigms into three overarching paradigms, namely postpositivism, constructivism, and critical theory as Denzin and Lincoln (2011) have done, Morrow (2007) reminds us that these categories “oversimplify the variety and complexity contained within each paradigm” (p. 213). Denzin and Lincoln (2011) point out that this oversimplification is understandable though as paradigms represent sets of beliefs based on “first principles” or “ultimate’s” (p. 91).

The constructivist paradigm, or constructivist-interpretivist paradigm as Ponterotto (2005) calls it, has a relativist ontology (Denzin & Lincoln, 2011) which, as described by Schwandt (1994) sometime earlier, assumes multiple, apprehendable, and equally valid realities. This view marks a significant departure from the naive realism of positivism which assumes a single external reality. Furthermore, as meaning is viewed as being something which is co-constructed between participants and researchers, a transactional and subjective epistemology is implied (Denzin & Lincoln, 2011). Creswell (2012) similarly describes the epistemological stance of constructivist research as being one which allows for participants to construct the meaning of a situation which is “typically forged in discussions or interactions with other persons” (p. 25).

Constructivist methodologies are hermeneutical and dialectical (Denzin and Lincoln, 2011). A hermeneutical approach proposes that meaning lies buried within the text and can only be apprehended through deep reflection, the likes of which is stimulated through dialogue, elaborates Ponterotto (2005). Constructivist methodologies are also dialectical, explains Schwandt (1994), because they foster a comparison between or contrasting of constructions, either in an attempt to reach consensus, or failing that, to promote an agenda for negotiation, regarding the “issues and concerns that define the nature of the inquiry” (p. 128).

4.3.1 You say constructivism, I say constructionism...Let's call the whole thing off?: An autoethnographic interjection

Trying to determine where and how social constructionism fitted into the constructivist paradigm, if indeed it even did, became an important endeavour to me for two reasons. Firstly, the epistemology of the metatheory I have used in delineating where the focus of my data analysis will lie, is predominantly a social constructionist one, and secondly, the method I have used, namely autoethnography, is described by Ellingson and Ellis (2008) as being a constructionist project.

The search to understand these two constructs often left me confused though. I was relieved to discover that, as Burr (2003) assures, a lack of clarity over this issue is not uncommon amongst researchers. Confusion over constructivism and social constructionism exists because, for example, some position social constructionism as a sub-paradigm within constructivism (e.g., Godwin, Kreutzer, Arango-lasprilla, & Lehan, 2011), others synthesise them (e.g., Botella, 1995), and still others emphasise the distinction between the two (e.g., Cecchin, 1992).

Taking my cue from Schwandt (1994) and Botella (1995), I eventually settled on positioning social constructionism as an approach within constructivism - as there are points on which the two converge (Burr, 2003). I do so knowing and acknowledging that an important epistemological difference between constructivism, especially as it relates back to Glasersfeld's (1984) radical constructivism, and social constructionism does exist though. This difference has already been briefly raised in chapter 3, in which I discuss Hoffman's (1990) motives for shifting from a constructivist view of the world to a social constructionist view of the world, however I will elaborate on this issue here as it has important implications for where the focus of this study lies.

Social constructionism focuses explicitly on the role of social processes, asserts Gergen (1985), rejecting both exogenic and endogenic epistemologies. Endogenic epistemologies emphasise the role of the individual mind in the construction of meaning, as in constructivist approaches in general and radical constructivism in particular, whilst exogenic

epistemologies emphasise “the role of external reality”, as in the positivistic stance, explains Botella, (1995, p. 4). Social constructionism, continues Botella (1995), “places knowledge neither within individual minds nor outside them, but between people” (p. 4). According to social constructionism, in other words, “knowledge is generated by people interacting and collectively negotiating a set of shared meanings” (Botella, 1995, p. 4).

Describing the constructivist epistemology as being one that is both subjectivist and transactional, Denzin and Lincoln (2011) seem to accommodate social constructionism within their constructivist paradigm. My assumption is supported by Schwandt (1994), who described earlier versions of Denzin and Lincoln's (2011) constructivist paradigm as being “a wide-ranging and eclectic framework” (p. 129).

4.4 Situating autoethnography in qualitative research

Qualitative research, proposes Gergen and Gergen (2000), offers us some of the richest and most rewarding research opportunities and methods available in social science today. The diversity currently found within this research domain is the result of a number of historical convergences, the likes of which Denzin and Lincoln (2011) have broken down into eight moments of qualitative research. Whilst a detailed discussion on the historical development of qualitative research falls beyond the scope of this study, what is however pertinent to mention here is that autoethnography is positioned within Denzin and Lincoln's (2011) fifth historical moment.

The fifth moment of qualitative research is described by Denzin and Lincoln (2011, p. 20) as being “the postmodern period of experimental ethnographic writing”, a time during which, according to Ellis and Bochner (1996), new ways of composing ethnographies were explored. This period also saw the tenability of the so-called aloof observer challenged, assert Denzin and Lincoln (2011), along with the search for grand narratives. In place of the universal story, more local and small-scale narratives, specific to problems and situations, began appearing.

Contemporary qualitative methods like autoethnography, reflect Gergen and Gergen (2000), have provided an outlet for those wanting to express perspectives that were

frowned upon in the past, especially within the confines of traditionally narrow and inhibited disciplines. They have made way for the expression of diverse interests and activities such as social critique and political activism for example, as well as for literary, artistic and dramatic expression (Gergen & Gergen, 2000). These new and innovative methods, elaborates Gergen (2001), have liberated researchers from the task of trying to present the 'world as it is', challenging them instead to "articulate new and potentially transformative..." ways of doing research (p.14).

Further evidence of more creative impulses at work in research can also be found in recent attempts to "reformulate psychological processes in relational terms" (Gergen, 2011). This relational turn has set in motion what Gergen (2001) calls a "more collaborative view of human life" (p. 14). A focus on how reality is social constructed between people necessitated the proliferation of methods suited for uncovering patterns of discourse and their interpersonal implications (Gergen, 2001). Gergen (2001) acknowledges autoethnography as being one of these methods – in which the investigator uses his or her personal life experiences to provide insight into human functioning (Ellis & Bochner, 1996).

4.5 Autoethnography as method

An autoethnography, explains well-known autoethnographer Carolyn Ellis (2004), describes and analyses (graphy) the researcher's personal experience (auto) with the intention of understanding a wider cultural, political and/or social experience (ethno) whilst doing so. Along similar lines, Muncey (2010) describes an autoethnography as juxtapositioning the researcher's "own experience and outside influences, and the interaction between the two" (p. 10). In her influential book, *Auto/ethnography: Rewriting the self and the social*, Reed-Danahay (1997) also affirms the importance of linking the self with the social when doing autoethnography.

As is the case with this study, autoethnographies are usually about epiphanies – "remembered moments perceived to have significantly impacted the trajectory of a person's life", periods of existential crises demanding one's attention, and life changing events (Ellis, Adams, & Bochner, 2011, p. 4). These experiences are selectively and retrospectively written about by the researcher, who also possesses

a particular cultural identity. In this sense, states Ellis (2004), autoethnographers utilise tenets of both autobiography and ethnography. It also differs significantly from both of these approaches though.

What sets autoethnography apart from simply telling a story though, is the ‘analysis’ aspect of it, asserts Chang (2008). By looking at their experiences analytically, an autoethnographer’s personal account transcends mere autobiographical writing. Moreover, when it comes to what differentiates autoethnography from ethnography, although both types of inquiry search for understanding of others (culture/society), autoethnographers use their personal experiences, rather than the experience of others, as their primary data (Chang, 2008). As Muncey (2005) puts it, “autoethnography celebrates rather than demonizes the individual story” (p. 2).

Autoethnographers endeavour to produce aesthetic and evocative texts in which they capture thick descriptions of their personal and interpersonal experiences, state Ellis et al. (2011). This is usually achieved through “discerning patterns” of wider social or cultural experiences first though (p. 6). By producing texts which are both meaningful and culturally engaging, a wider and more diverse audience – one which was previously ignored by more traditional research, is accessed, and as a result, greater personal and social change is made possible, propose Ellis et al. (2011).

Whilst autoethnography is an exploration of the self and the social, autoethnographic studies differ according to the emphasis placed on one of these two aspects (Taber, 2010). Where the emphasis of an autoethnography lies, whether it is more on the researcher’s self, on the researcher’s interaction with others, on the interview context, or on power relationships, elaborates Ellis et al. (2011), will determine the form of or the approach to the autoethnography being done. Although Ellis et al. (2011) go on to identify a number of different forms of or approaches to autoethnography, I will limit this discussion to the type of autoethnography I have undertaken which Ellis and Berger (2003) call the *co-constructed narrative* (p. 477). They identify this particular form of autoethnography as being one of a number of variations falling within the broader category of *collaborative interviewing* (p. 471).

With collaborative interviews, explain Ellis and Berger (2003):

“The interview process becomes less a conduit of information from informants researchers that represents how things are, and rather a sea swell of meaning making in which researchers connect their own experiences to those of others and provide stories that open up conversations about how we live and cope” (p. 471).

On a more practical note, these interviews are collaborative endeavours in which researcher and participant/s - who are recognised as being one and the same - probe issues that come up over conversing about a particular topic. Unlike conventional one-on-one interviews between strangers, they take place over numerous interview sessions within the context of developing and well-established relationships (Ellis et al., 2011).

It is through the collaborative interview process that *co-constructed narratives* are jointly constructed by relational partners. Ellis and Berger (2003) differentiate between a mediated and an unmediated approach to co-constructed narratives. In the case of the mediated approach, the conversation is monitored by a researcher. With an unmediated approach, a researcher may study his or her own relationship with a partner or two researchers may study their relationship with each other. As the focus of this study is on the relationship between me, the researcher, and Matthew, my husband, it therefore qualifies as being, according to Ellis and Berger’s (2003) definition, an *unmediated co-constructed narrative*.

4.6 Getting down and dirty: The pragmatics of producing this study

4.6.1 Data collection

Numerous conversations between Matthew and I constituted the primary source of data for this study. These unmediated conversations that were had between the two of us, were audio-recorded and transcribed for the purposes of analysis and to contribute to the trustworthiness of the study. Our conversations followed a similar protocol to that of an unstructured interview, in that there was a great deal of flexibility when it came to the questioning and responding aspects of the process.

Taking my cue from Spradley's (1979) guidelines for conducting ethnographic interviews, the questions I asked during the conversations between Matthew and me alternated between, what Spradley (1979) calls the more research directed, but general "grand-tour" questions of an interview, and the more spontaneous, but detailed "mini-tour" one's once the interview, or as in this instance, our conversations, were in progress (p. 86). In other words, to kick start the conversations between Matthew and me, my initial questions were planned using the research focus of the study as a general guide. Follow-up questions were more spontaneously derived however, arising in response to where the conversations took us, as it were. Ultimately though, our conversations were guided by the implicit knowledge that we were attempting to provide data that was rich and complex, and able to do some justice to our shared TBI experience within the context of our marital relationship.

In addition to these audio-recorded and transcribed conversations between Matthew and I, data for this study was also derived from two other sources. These other sources included my personal journal entries captured around the time of the car accident in which Matthew sustained his traumatic brain injury, as well as a journal kept specifically for the purposes of this study - capturing my personal reflections for the duration of putting this study together. The journal I was keeping around the time of Matthew's accident proved to be invaluable to this study, as it provided me with personally produced data in which my thoughts, emotions, and perspectives had been preserved in a form that, as Chang (2008) puts it, was "untainted by my research agenda" (p.107). The journal I kept during the compilation of this study also proved extremely helpful though, as it served as a useful means of recording my more recent recollections stirred up during this period of intense reflection over Matthew and my TBI relational experience. As such, these recollections were intentionally and purposely generated for the purpose of this study.

4.6.2 Data analysis

The data for this study was analysed thematically, utilising Braun and Clarke's (2006) guidelines for doing so. Braun and Clarke (2006) differentiate between

two camps of analytical methods, namely those that tied to or stem from a particular theoretical or epistemological position and those that are not. The thematic analysis I employed for this study falls into the second camp of analytical methods, and is as such, essentially independent of any theory or epistemology. Braun and Clarke (2006) do however confirm that this more generic form of thematic analysis is compatible with the constructivist paradigm within which this study is situated.

Loosely following Braun and Clarke (2006) six-step guide for thematically analysing data, I started off the analysis process with reading through and re-familiarising myself with the various data sources making up my data set. In the field of qualitative research, this initial phase of the coding process is commonly referred to as 'immersing' oneself in the data. Whilst doing this, I began jotting down notes and actively searching for meanings and patterns contained within data in preparation for the more formal coding process. Moving into the more intentional coding phase of the analysis, I sought out and coded aspects of the raw data that I felt could be assessed, at a later stage, in a meaningful way, regarding the phenomenon of the post-TBI marital relationship under study. This process was both 'data-driven' – in that I derived codes inductively from the data itself, and 'theory-driven' – in that I coded deductively with the theoretical framework of the study (discussed in detail in chapter three) in mind.

I decided to err on the side of caution when it came to selecting extracts of data to be coded and to this end coded fairly large chunks of data rather than smaller ones, so as to retain context, narrative flow, and because the emphasis of the study lies in the fact that it is a co-constructed endeavour, to also retain the conversational aspect of the data. Braun and Clarke (2006) also recommend coding more inclusively so as not to lose context.

Once all of the data was coded, I began to collate the coded data extracts by sorting them into meaningful groups and under potential themes. During this process, I contemplated the relationship between codes, between potential themes, and began differentiating between levels of themes, deciding on what would be a sub-theme and what would be an overarching theme. So as to

maintain order during this process, I created a 'coding report' in a table format (see addendum D), in which I entered ideas for overarching themes in one column, their possible respective sub-themes in another column, and then began populating each sub-theme with coded data extracts in a third column.

Having devised a set of what Braun and Clarke (2006, p. 20) call "candidate" themes and sub-themes, I began the process of refining them. This process included collapsing some into each other, whilst breaking others up into separate themes or sub-themes. It also entailed a reshuffling of themes, as the order in which the themes were placed was also an important consideration for me during this phase of the process - especially in light of one of the aims of the study, which was to present a TBI-marital relationship over a period of time. To this end I wanted the themes and sub-themes to flow into each other in such a way as to achieve this aim.

Moving on to the writing up of my analysis, I began by defining and refining each individual theme, and sub-theme. During this phase of the analysis process, I set out to identify and articulate what Braun and Clarke (2006) describe as being the "essence" of each theme (p. 22). I achieved this by returning to my coding report - specifically to the coded extracts of data contained under each theme - and selecting and organising certain of these extracts into what I discerned to be coherent and internally consistent account, accompanied by a descriptive analytic narrative. The purpose of these selected data extracts, together with their accompanying analytic narratives, was to tell the 'story' of each theme, in relation to the research questions of the study. In generating the accompanying analytic narratives to their respective data extracts, I drew from other literature, particularly TBI literature - in order to compare our TBI experience with other reported TBI experiences, and from my chosen theory with which I intended to analyse my data with, namely Reiss' (1981) theory (see chapter three of study for a detailed discussion of this theory).

The final phase of the process, mostly entailed checking through and refining the analysis (the write-up of it, including data extracts) in order to ensure that, as Braun and Clarke (2006) advise, I had embedded the data extracts within

an analytic narrative that told the story of the data in a – hopefully - compelling way, and in a way that addressed the research questions of the study.

Although I've laid out this process in step-by-step form above, in reality, the process was a far more organic and iterative one. Ideas for themes arose, for instance, whilst I was still transcribing the data, and before I had officially started with the coding process. Refinement and naming of themes continued up until the end of the analysis process and I continued tweaking the end product long after I had finished with the final write-up of the data analysis.

4.6.3 Measures to enhance trustworthiness

The criteria for judging autoethnographies is another contentious issue within this still relatively new field of research. Some argue against the use of an objective set of criteria in judging personally generated data, whilst others argue for it. Falling into the former camp on the issue, Sparkes (2000), for example, argues that because different epistemological and ontological assumptions inform autoethnographic inquiry, it does not make sense to impose traditional criteria in judging the value of personal texts. Also falling into the former camp, Adams and Holman Jones (2008) further argue that attempting to make use of such criteria in producing an autoethnography gives the false impression of 'truth' - in that it deceptively promises to bring certainty, stability, and legitimacy to one's project. Frank (2000) also notes that those trying to criticise the rigour of personal texts when using objective criteria are perhaps missing the point - the point being, according to Frank (2000), that texts of this nature are not to be engaged with systematically, but personally. To this end, suggests Richardson (2000) - of engaging with the text personally instead of systematically that is - we should rather "seek to meet literary criteria of coherence, verisimilitude, and interest", when judging personal narratives (p. 11).

Falling into the latter camp of arguing for the use of objective criteria in judging autoethnographies, Duncan (2000) is critical of personal narratives that rely solely on evoking an emotional response from its readers, advocating for a more conservative type of autoethnography which utilises analysis, is

grounded in theory, and displays methodological rigour - a view shared by Anderson (2006). Because I have opted to align this autoethnography with this more conservative approach - as discussed in detail in chapter three of this study – I have also chosen to adhere to more stringent measures in ensuring, as much as possible given the type of study this is, the trustworthiness of the co-constructed account Matthew and I have rendered herein, which makes up the bulk of the data used for this study. This does not mean that I have forgone one of the most important aims of the autoethnographic method, which is, by and large, to produce an evocative and believable account of an experience, but rather that I have sought to take steps to legitimise the process whilst attempting to do so, so as to maintain some level of rigour in this study.

Qualitative researchers have conceptualised the idea of rigour in numerous ways. For the purposes of this study however, I have made use of Lincoln and Guba's (1985) criteria of trustworthiness, consisting of credibility, transferability, dependability, and confirmability, as a guiding framework in my pursuit of establishing rigour. I have also consulted with Shenton's (2004) article in which he suggests ways in which qualitative researchers can go about meeting Lincoln and Guba's (1985) four criteria. Additionally, because it is a co-constructed autoethnography and therefore similar to this study, I have drawn from Hoelson and Burton's (2012) article in which they have adapted and utilised these same four criteria for the purposes of establishing trustworthiness when utilising this unorthodox method of qualitative research.

The credibility of this study, was addressed by utilising a well-established - albeit somewhat controversial and more recent - research method, the likes of which has been clearly and comprehensively discussed in this study (see chapter's two and four). The specific procedures employed, such as the way in which the data was gathered and analysed, have been meticulously detailed and derived from those that have been successfully utilised in previous comparable projects (e.g., Ellis & Bochner, 1992; Hoelson & Burton, 2012). Utilising more than one source of data, a practice commonly referred to as data triangulation (Shenton, 2004), namely the audio-recorded and

transcribed conversations had between Matthew and myself for the purposes of this study, entries from my journal made during the days immediately following Matthew's accident and as such untainted by any research agenda, and more recent journal entries containing my retrospective reflections on the our TBI experiences, also contribute to the credibility of the study. Member checks, a practice Lincoln and Guba (1985) propose to further bolster a study's credibility, were carried out in that both Matthew and I read through the conversations we had had once they had been transcribed, to ensure that our articulated experiences reflected therein satisfactorily captured: firstly, what is was we had intended to convey, and secondly, how we remembered them. Also adding to the credibility of this study, as proposed by Shenton (2004), was the provision of thick and lengthy descriptions of the phenomena under study, namely our TBI experience as a married couple, across the data set, as well as a thorough examination of previous research findings on TBI and post-TBI marital relationships, which was both reported on in the literature review of this study (see chapter two), and related to the findings of this study (see chapter five).

The transferability of this study i.e. the extent to which its findings can be applied to other similar situations, as with all qualitative studies in general, and even more so with autoethnographic studies in particular, is limited. However, as Denscombe (1998) notes, although each case in a qualitative study is unique, it is also potentially an example within a broader group, and as such the prospect of its transferability should not be completely ruled out. By striving for verisimilitude, i.e. whether "...the experience described is lifelike, believable, and possible..." (Ellis & Bochner, 2000, p. 751), in retelling our TBI experience for the purpose of this study, we have also inadvertently contributed to the potential transferability of the study. This is because the more lifelike, believable, and possible the account of our TBI marital experience is, the more likely the findings of this study will relate to other married couples going through a similar TBI experience. Furthermore, by providing a comprehensive description of what Guba (1981) calls the contextual factors impinging on the inquiry (see chapters: one, five, and six), the potential transferability of the study has also been further enhanced.

The criteria of dependability, argue Lincoln and Guba (19985) are closely tied to the criteria of credibility, therefore, in practice, a demonstration of a study's credibility goes a long way in ensuring its dependability as well. In addition to the measures taken to enhance the credibility of this study which have simultaneously contributed to the dependability of it then, a number of additional factors have also contributed towards meeting some of the criteria for the dependability of this study. These additional factors are primarily to do with peer review processes. Firstly, in the capacity of peer reviewer, or "objective other"(Anthony 2005, p. 39), during the conception phases of the study, Dr Retha Visage, a published and experienced qualitative researcher and research consultant, critically read through my proposal and provided me with advice on going forward with the study. The conception phase of this study was also subject to a further, more stringent, peer review process connected to the one year on-campus part of the Masters degree in Psychological Research Consultation at Unisa. As part of this on-campus course, intermittent 'proposal development sessions' were scheduled throughout the year, during each of which I had to present on the 'developing' proposal for this study. It was then evaluated and critiqued by fellow students also doing the same course, as well as by Prof. Vasi van Deventer who facilitated these sessions. Adjustments and improvements were then made to this study in light of the invaluable feedback received during these sessions. Last but not least, also contributing significantly to the dependability of this study, was the regular advice, guidance and critical feedback received from my two research supervisors at the various phases of its construction.

Finally, the confirmability of this study was sought through providing transparent and detailed descriptions of my preferred and chosen research approach, epistemology, and method. I also made provisions for an 'audit trail' - an important aspect of a study's confirmability according to Shenton (2004) - by transcribing the audio recordings of the conversations between Matthew and I (the primary data source for this study). One of the transcribed conversations has been made available in the addenda (see addendum B). The journal which I kept at the time of Matthew's accident in 2006 is also still in existence and I have selected a copy of an entry which has also been

included in the addenda of this study (see addendum C). The data coding and analysis process for this study was also captured and presented as a 'coding report', a printed hardcopy of which has also been included in the appendix of this study (see addendum D).

4.6.4 Ethical considerations in doing this autoethnography

Given that this is an autoethnography, some of the ethical issues usually present in qualitative studies, were not as salient. As Ellis (2007, p. 20) explains of a co-constructed autoethnography she collaborated in, "we did not confront the ethical tensions inherent in most research", which asks of people to participate in or submit to something which they did not seek out or ask for, and which will be of no benefit to them directly. Matthew, keen from the outset to contribute to this study, felt that not only could he personally benefit from it, but that others might also benefit from him sharing his TBI experience somehow. I shared this sentiment. Consequently both of us felt invested in and committed to the study, shared the goals of the research, felt we had something to gain, as well as to impart, in doing it, and were in control of how it went.

Nevertheless, given the personal and emotional nature of this study and having to make it available for public consumption, meant that some ethical issues did still need to be considered. To begin with, in line with the procedural ethics of research as mandated by Unisa, I initiated the process of getting Matthew's informed consent as a co-participant in the study (see addendum A). The issue of consent did not end with the signing of a document though. Based on Ellis' (2007) recommendations stemming from what she identifies as being the 'relational ethics' involved in doing research, I engaged in the practice of 'process consent' (p. 4). This meant that I actively sought Matthew's informed consent throughout the construction of this study rather than just at the beginning of it. I did this by regularly consulting with him during most of the research process, but particularly during the phase of selecting and analysing our conversational data, in order to ensure that he was comfortable with how the data was being used and how he was being

portrayed in it. In the event that he wanted something changed and/or omitted, I did so.

As self-revelations always involve revelations about others (Freadman, 2004), Matthew and I also had to be mindful of how others might be implicated in or affected by this study. Consulting Tolich's (2010) ethical guidelines for including peripheral but unknowing participants in the construction of an autoethnography, this concern was addressed through ensuring as far as possible the anonymity of others, along with careful constructionist framing and non-accusatory wording, where others were spoken of as part of our experience.

Finally, as Chatham-Carpenter (2010) aptly points out and grapples with in her article on protecting the self when doing an autoethnography, Matthew and I also had to be mindful of how the study was affecting us, especially given that we continue to live with some of the challenges the TBI initially brought into our lives. Issues that we had 'lived past' so to speak, had to be resurrected for the purposes of the study, and as such, we were sometimes painfully reminded of all we had been through. In order to minimise the sometimes weighty and potentially negative effect of having to recollect the earlier and more intense aspects of our TBI journey on both Matthew and I, we recorded most of our conversations over the course of one day, and a few follow-up conversations only when we both felt emotionally equipped to do so. The intention of this was to limit as much as possible our exposure to some of the more painful memories that came back and the emotions they stirred up.

Chapter 5

Findings and discussion

5.1 Introduction

My analysis of the data resulted in five major themes, each of which was constructed from a number of sub-themes. Although I have analysed the data inductively, using Braun and Clarke's (2006) six-step guide to doing a thematic analysis of qualitative data, certain of my analytic decisions were also deductively made, such as the selection and refinement of my themes and sub-themes, and the order in which I have placed them. By this I mean that my analysis of the data was directed not only by the data, but by my research questions and theoretical framework as well.

5.2 Themes and sub-themes

Before delving in to discuss each theme and their respective sub-themes individually, I will begin by drawing the reader's attention to the order in which I have placed the themes and sub-themes (see table 5.2 below). Rather than construct stand-alone or static themes and sub-themes, I have tried instead to construct themes and sub-themes which when viewed in relation to each other, capture or illustrate life in motion. Although these themes and sub-themes do not necessarily flow into each other chronologically, they do merge in a way I hope, that reflects change, fluctuation, evolution, and movement - as well as another important goal of this study, which is to capture a TBI-relational experience unfolding over time. In doing so, I do feel that I have been able to remain true to the data so to speak, as well as fulfil the epistemological and methodological commitments of this study which are discussed in chapter 3 and in chapter 4 respectively.

Furthermore, lining up the focus of the themes and sub-themes with the epistemological commitments of this study – as outlined in the discussion of Yerby's (1995) '*Constructionist family systems perspective*' in chapter 3 - was also an important consideration in their construction. To this end, the five themes and their sub-themes incorporate in their focus, both Matthew and my experiences as individuals, as well our shared experiences as a couple, and show how the two are interrelated. This combined focus on both the individual and the system - in this case the system being our marital relationship, fulfils the 'individual systems dialectic'

aspect of Yerby's (1995) perspective which advocates a focus on both. A number of the themes and their sub-themes also reflect Matthew and my connection with and embeddedness in a larger social community and wider culture (see for example theme 5.2), further fulfilling another aspect of Yerby's (1995) perspective, that being the dialectic of system and culture which positions a couple as being both apart from and yet also a part of a broader social system.

Table 5.1 Themes and sub-themes

Themes	Sub-themes
5.2.1 We've come undone	<p>5.2.1.1 Life disrupted: A fracture in the storyline</p> <p>5.2.1.2 From hospital to home: The bathos of survival</p> <p>5.2.1.3 Nomic rupture: Experiencing the past as myth and misconception</p> <p>5.2.1.4 Feeling betrayed: When reality fails to meet and one's own sense of truth</p> <p>5.2.1.5 Beyond words: Trauma's legacy of incomprehensibility</p> <p>5.2.1.6 Despondent intoxication: When existential musings dominate the narrative</p>
5.2.2 Stranger in the mirror, stranger in the mix	<p>5.2.2.1 Ties that bind: Self-loss, other loss</p> <p>5.2.2.2 Far from the madding crowd: Self-imposed exile</p>

	<p>5.2.2.3 Keeping morbid company: Depression as TBI's faithful companion</p> <p>5.2.2.4 Walking on eggshells: When impulse reigns</p> <p>5.2.2.5 Uncomfortably numb: On tablets and trade-off's</p>
5.2.3 A cosmology of three: You, me, and the brain injury	<p>5.2.3.1 The 'new' we: Rethinking happily ever after</p> <p>5.2.3.2 Retrogenesis: On relationship regression and parenting a partner</p> <p>5.2.3.3 Contagion: Just who is the injured party anyway?</p>
5.2.4 Felix culpa: Fortunate misfortune	<p>5.2.4.1 Angels in the architecture: Reconstruction and growth through adversity</p> <p>5.2.4.2 On second thoughts: Taking stock, then and now</p> <p>5.2.4.3 Us intensified: Co-struggle as locus of intimacy</p>
5.2.5 The show must go on	<p>5.2.5.1 Now you see me, now you don't: The</p>

	<p>ever-present yet elusive nature of TBI</p> <p>5.2.5.2 By the sweat of one's brow: Back to the grindstone</p> <p>5.2.5.3 What time has told: Finding the phoenix amidst the ashes</p>
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5.2.1 We've come undone

This theme was constructed from the six sub-themes listed in table 5.2 below. Together these sub-themes encapsulate the sudden and unexpected way in which Matthew's TBI came about as well as the initial repercussions it had on both Matthew and I both as individuals and as a married couple. Central to this theme is the fact that the TBI and the irrevocable and life-changing consequences thereof, challenged Matthew and my understanding of our world, and also our place in it. Each of the individual sub-themes making up this theme attest to the fact that, and as Reiss' (1981) affirms, in the face of a major crisis and grave family disorganisation, many of our previously established and familiar conceptions of our environment i.e. pre-TBI family paradigms, were shattered or lost.

Table 5.2 Theme 1: We've come undone

5.2.1 We've come undone	<p>5.2.1.1 Life disrupted: A fracture in the storyline</p> <p>5.2.1.2 From hospital to home: The bathos of survival</p> <p>5.2.1.3 Nomic rupture: Experiencing the past as myth and misconception</p> <p>5.2.1.4 Feeling betrayed: When reality fails to meet and one's own sense of</p>
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	<p>truth</p> <p>5.2.1.5 Beyond words: Trauma's legacy of incomprehensibility</p> <p>5.2.1.6 Despondent intoxication: When existential musings dominate the narrative</p>
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5.2.1.1 Life disrupted: A fracture in the storyline

It is almost impossible to comprehend that in one moment all is well with your spouse and in the next they are lying critically injured in hospital. On receiving the phone call notifying me of Matthew's accident, I was instantly thrown into a state of emotional turmoil, my only thought to get to him immediately. Once at the hospital and on being told of the extent of his injuries, my initial reaction was one of disbelief and shock. Later, I would also experience feelings of anguish at having to witness his pain and suffering, anger that this could have happened to him, and fear over the possibility of losing him. Mathis (1984) found a similar combination of responses in family members of critically injured patients on first learning about the injury, as did Uomoto and Uomoto (2005) in their study on the impact of TBI on the family and spouse.

J: "You struggle to wrap your mind around the suddenness of it all. It was as if I'd taken a quantum leap into a parallel dimension. In an instant life as I'd known it, as we'd known it, up to that point, came to a standstill - and was forever changed" (PR's: 13 July 2013).

Without any forewarning, day-to-day life for Matthew and I was radically altered. Matthew's construction business which he had built up over a period of ten years had to be shut down and the employees retrenched. Vehicles and stock had to be sold off to pay suppliers. Our means of making a living had come crashing down around us in a single moment. Plans of a personal

nature, like celebrating our daughter's birthday, were also shelved. The way in which his brain injury suddenly upended our lives is aptly captured by Bury's (1982) concept of 'biographical disruption'. Similar to the way in which a chronic illness does, which is the focus of Bury's (1982) work, Matthew's TBI disrupted the biographical flow of our lives.

J: "Rachel's 7th birthday party was planned for the Saturday after the accident happened. I had to cancel it of course. Matthew was scheduled to undergo the first of a series of operations on that day. It was to have been a beading party. Hundreds of brightly coloured plastic beads lay discarded on the kitchen countertop, garish reminders of life interrupted" (PR's: 13 July 2013)

Our desire to engage in ordinary daily tasks that were not essential to our survival waned. Coming to terms with Matthew's head injury and the consequences thereof become an all-consuming priority to us. According to Reiss' (1981) theory, we'd become process-orientated, meaning that as a family we'd withdrawn our investment in managing everyday tasks, and were instead struggling with ourselves as a unit.

J: "I did not put the Christmas tree up that year. The cheer and excess of the Christmas season juxtaposed against the doom and gloom that permeated our home at that point in time, seemed particularly out of place, ridiculous really. I could just not muster up the energy to try to ward off, or at least to counteract to some degree, the tangible heaviness that had descended upon us. All of my energies, and indeed all of Matthew's energies, were being expended on the simple yet enormous task of surviving each day - and if truth be told, of surviving each other at times. Other things, like gardening and home improvement tasks, also stopped. And it is only in retrospect that you come to realise how important these seemingly unimportant menial and mundane little acts of domesticity are. They hold within them an unspoken message of sorts, one of hope, of investing in your life together, an assurance that you'll be around for another day to enjoy the fruits of your combined labour, albeit on this small and intimate scale. It was this proverbial rug, of unspoken meanings so to speak, which was so suddenly pulled out from beneath us" (PR's: 17 July 2013).

As we soon discovered though, Matthew's TBI and the magnitude of the consequences thereof, did not only affect our 'here-and-now'. Continuity with our past was also lost (see sub-theme 5.2.1.3). Picking up on this sense of historical displacement amongst family members of TBI survivors, Jumisko, Lexell, and Söderberg (2007) describe their participants as feeling as if "they've entered a vacuum in which everything they considered important earlier" has lost its value (p. 358). Furthermore, not only was our connection to our past affected, but expectations and plans for the future were also derailed.

M: "...it had required a lot of effort to get to where I was and I thought that I was climbing, progressing, but now... [pause] ...suddenly being disabled..." (Conv 5: 8 Sept 2013)

M: "...my understanding of the course of life, the sequence of events of life...well previously I had thought, I had believed, in more of a neat construction, an orderly progression...almost like a musical progression - that there is harmony and that your life would, if you implemented certain principles, if you undertook it in this manner, with this attitude, you would have a very steady [pause] ...you would experience a progression of things in the right direction" (Conv 2: 11 Aug 2013)

5.2.1.2 From hospital to home: The bathos of survival

Whilst keeping vigil at Matthew's hospital bed, I hovered between hope and despair as his condition fluctuated. As Jumisko et al. (2007) aptly found, the initial experience of uncertainty with regard to the survival of the injured family member, or in this case, partner, is a stressful and anxiety ridden time. My attention was split between managing household and financial responsibilities, trying to keep Matthew's business running, while simultaneously attempting to manage my feelings and fears. With a great deal of energy being expended on surviving the crisis on a number of fronts, Uomoto and Uomoto's (2005) findings also attest to the fact that the uninjured spouse is often exhausted and emotionally depleted as a result.

J: "Life was temporarily suspended after the accident. It really felt as if time stood still, as if I was holding my breath, submerged in some strange new world. Torn

between caring for our two girls and wanting to spend as much time as possible with Matthew, I was constantly on the run, rushing between hospital and home.

Desperately trying to keep the business afloat, also meant that I was fielding a myriad of calls from clients, and trying to coordinate work for our staff. Once at the hospital though, all of my attention zeroed in on Matthew as he lay comatose, poised as it were between life and death. Arriving each morning at the trauma ICU ward, long before official visiting hours started, walking in a fighting-off-the-urge-to-run fashion down the corridors of the hospital, I'd compulsively douse my hands with sanitiser from just about every wall-mounted bottle en-route. And once in the ward, I'd attentively listen to his heart beat translated into a rhythm of steady and reassuring beeps, diligently noting any temperature fluctuations, and readjusting tubes carrying fluids to and from his body. All the while offering up prayers and whispering words of encouragement, declarations of love, and desperate pleas into an ear I'd only later find out was now completely deaf, and in-between all of this, wooing nurses in a bid to win allies in this life-and-death fight. It was these acts, all be they seemingly small and impotent in retrospect - this bedside vigil and the quickly established routine of it, that provided me with a much needed modicum of control amidst the uncertainty of it all. Existing for a time, in such close proximity to death and often despairing, when he did finally regain consciousness, the elation and euphoria I felt was overwhelming. He was to me Lazarus rising from the dead." (PR's: 2 Aug 2013)

Still made buoyant by feelings of euphoria and elation over Matthew having survived a number of risky surgeries, and for having regained consciousness, I was initially very optimistic over the prospect of him making a full recovery. After bringing him home from the hospital and in trying to resume everyday life with him though, these feelings were soon quelled as the reality of the situation seeped in. In their study on the impact of traumatic brain injury on a family member or spouse, Uomoto and Uomoto's (2005) similarly picked up in their participants a diminishing sense of optimism once they leave the hospital with the injured person and return home. They attribute this to the fact that the survival of the brain injured family member or spouse raises the understandable expectation that they will recover in the same way as one would recover from other types of injuries. The growing realisation that their struggles do not end with the head injured person's survival though is a

difficult one, note Uomoto and Uomoto (2005), and spouses and family members are then faced with the challenging and protracted process of coming to terms with and adjusting to the long-term deficits that TBI imposes on the survivor.

J: "Almost six months since the accident and I am still realising that this trial is far from over. Although I am so thankful for Matthew's survival, I am slowly realising that recovering from a traumatic brain injury is a very slow process!" (JE: 19 Feb 2007)

Dealing with dismissive and evasive medical specialists, I did not initially fully comprehend the nature and extent of Matthew's TBI. This exacerbated for me, the difficulty of the coming-to-terms-with-it process. Uomoto and Uomoto's (2005) study also touches on what their participants experienced as being an alien world of doctors and hospitals, in which family members crave answers and reassurance but are often met with the unwillingness or inability of physicians to give a prognosis.

J: The complexities of a traumatic brain injury are numerous. Those around us are ignorant to the profound impact such an injury has on a human being! No one warned me! Not even the doctors - who must have known! Why? Why did the doctors not bother to pull me aside and explain to me what to expect? Having done my own research on the subject his behaviour is not uncommon for someone with a brain injury. On the contrary, Matthew displays many of the classic symptoms described. (JE: 5 June 2007)

5.2.1.3 Nomic rupture: Experiencing the past as myth and misconception

It was only years later, with the benefit of hindsight, that Matthew and I began to grasp the profound extent to which his TBI and the major crisis it introduced into our lives, challenged our understanding of the world as we had construed it up until that point in time. Almost everything we knew, or thought we knew, no longer seemed to make sense. Reiss' (1981) theory supports our life-altering experience, arguing that a family's previous modes of construing their environment i.e. their family paradigms, do indeed fail them in the wake of a

disaster. To borrow from Reiss' (1981) eloquent way of putting it, it felt for Matthew and I as if the very centre of our lives was "loosening" (p. 177). Berger and Kelner (1964), in their seminal essay on "*Marriage and the Construction of Reality*", fittingly call this sudden and dramatic change in how a married couple defines their reality and themselves as being a nomic rupture.

J: "So to reiterate, it's like the physical injury or the shattering of your skull and damage to your brain, it's almost analogous of your..."

M: [interrupts] "... yes I've often thought that. There was a simultaneous shattering of my mindsets, my ideas, my makeup, my thinking ..." (Conv 5: 8 Sept 2013)

M: "...in retrospect, I did think I was a good guy and that good would just flow with me, it would...surely goodness and mercy will follow me all the days of my life...and I'm thinking back on who I was then and I realise now that there's darkness and there's negativity and there's resentment towards self and resentment of misconceptions about this reality, an anger of misconceptions about God..." (Conv 3: 11 Aug 2013)

5.2.1.4 Feeling betrayed: When 'reality' fails to meet one's own sense of 'truth'

Having experienced such a disruptive event, one which not only disconnected him from his past, and derailed his future plans, but robbed him of his sense of purpose and identity, Matthew in particular, struggled with feelings of having been betrayed by his previously held conceptions of 'reality', particularly, as was evident in his frequent referencing of scripture and God, in a spiritual sense.

M: "I was angry at my misconceptions of God , my misconceptions of reality, I felt fooled. I felt like..." [Long pause]

J: "Betrayed?"

M: "Yes, betrayed because I felt like I had delivered what should have produced a return."

J: “So you felt like the principle of sowing and reaping, that somehow that whole principle had come to nothing?”

M: “ ...that it had been defied somehow...but to a point. I didn’t deem myself that perfect. I was aware of the ebbs and flows, the vicissitudes, the inconsistent nature of the course of life, but I felt that there were many unfair things that were happening. The order and the frequency of adversities were too closely staggered. They were just more frequent than the positive and they...those adversities contributed to the dissonant sounds of the voices I was hearing and the spirit they were coming in. The so-called voices of authority were so redundant and yet they were speaking with such gusto and I despised them.”

M: “And then I started to get angry at the God, who is real and say, “How can you allow this?”...and then I’d say’ “well you’re not in this programme then...” (Conv 2: 11 Aug 2013)

Also connected to Matthew’s feelings of betrayal, were his attempts to impose meaning on the seemingly arbitrary event of the accident. In particular was the belief that somehow - especially in light of the protracted financial struggles we experienced after the accident and his inability to work as he had before - he must have deserved the TBI, that it was his comeuppance for being a bad person, a punishment of sorts. As Bury (1882) similarly found with his chronically ill participants, cause and meaning frequently coincide.

M: “But worst of all were the financial implications of this. The financial shortfall at the end of every month impacted on my self-esteem and I felt punished. I felt as if there was disfavour on me. And looking around, comparing myself to others who seemed to be doing so well, started me thinking that well I must have done something wrong. I must have deserved this somehow. There must be something fundamentally wrong with me that I’m not aware of, because my intentions were always to try to do good.” (Conv 9: 1 Nov 2014)

5.2.1.5 Beyond words: Trauma's legacy of incomprehensibility

Sustaining a life-threatening and life-altering injury so suddenly, propelled both Matthew and I into unintended and unarticulated territory. Trauma leaves a legacy of incomprehensibility, confirms Caruth (1995), threatening a “collapse of witness” (p. 7). The impact of a trauma, she claims, “lies precisely in its belatedness, in its refusal to be simply located...” (p. 9). In other words, the traumatised are possessed by an experience that only later they can begin to grasp and attempt to put into words.

M: “Initially, your emotions, your person is raw, your inner person is raw from the trauma, so your receptivity capacity is low. I’m trying to think of the right terminology to use. It has no meaning for you... What had meaning to me and what I knew or understood at the time, what I had an intuitive knowing of, frustrated me because of my inability to express it and because of the trauma I’d undergone. I knew that it was a futile exercise even trying to express it. So my expressing was frustrated, it was immature...Alienated, was the way I felt, because I couldn’t explain...I knew I didn’t have the ability to express what I was going through. And the social structure that we had was inept, unable to even...there was nobody qualified to listen, to hear...” (Conv 4: 11 Aug 2013)

J: It seemed to me that Matthew had in a sense lost his ability to articulate himself to himself, and therefore to articulate himself to others. He had stopped making sense to himself, and therefore the world had stopped making sense to him. There descended upon him a deep despair, a sullenness which set over into depression and a rage that was all too easily provoked. His loss and grief were in a sense incommunicable for a long time after the accident. (PR’s: 26 July 2013)

Although the inability to articulate what he was going through for a length of time after sustaining his brain injury was particularly felt by Matthew – being the one who had *lived past death*, as Zornberg (2009) calls the survivor of a near-death experience, I also experienced to some degree an inability and a lack of desire to communicate what we were going through at the time. After diligently trying to capture the details of the accident in my journal, I abruptly gave up on this endeavour, as indicated by this entry:

J: Am not able to do this at this time (JE: 19 Feb 2007)

My personal reflections, written years later, further reveal evidence of this initial silent period invoked by trauma.

J: I remember well enough what it was like to be on the 'giving end' of things. Back when life made sense. When you think you have all the answers. The luxury of it, the myopia of it. I remember what it felt like to be smug in solutions, to take comfort in your 'knowing', to be seated in the seat of the scoffer. And then your world comes crumbling down around you - and you are silenced (PR's: 11 Aug 2013).

5.2.5.6 Despondent intoxication: When disillusionment and despair dominate the narrative

Exploring trauma survivors narratives of “rupture and reconnection”, Zornberg (2009) found that communication after trauma is both impossible and essential. Reiss’ (1981) findings substantiate this “unfathomable, yet fathomable” aspect of living through a trauma (p. 192). Struggling with this paradox that both Reiss (1981) and Zornberg (2009) identify as being inherent in the survival experience, Matthew and I found the gap between the polarities of rupture and reconnection a difficult one to bridge at first. And for a considerable length of time after the accident and his injury, our narrative tended more toward the rupture end of this continuum. The predominantly existential nature of our conversations reflected the disillusionment and despair we were feeling for some time. A singular narrative can come to dominate in this way, acknowledges Weingarten (2013). In effect, a dominant narrative colonises the self-narrative, “crowding out” all other versions (Roos & Neimeyer, 2007, p. 91-92). This single track narrative, which came to dominate for a time, was also likely influenced and exacerbated by the severe depression Matthew was suffering with which lasted for many months after sustaining his injury - a common consequence of TBI (see sub-theme 5.2.2.3).

M: “... you start despairing about the world because your thinking expounds on existence...you realise how arbitrary life is ...you read in the newspaper or you hear on the radio about someone whose faced a terrible tragedy, young people... and you

start to congratulate the dead...because the turmoil within yourself is such that you don't want to carry on...why?...because you have [pause] no faith..." (Conv 2: 11 Aug 2013)

M: "...before the accident there was always hope: ... "we can do this, we can break through, ...we can bring change to people's lives", and then when I...after the accident I just looked at things through a very bleak lens." (Conv 1: 11 Aug 2013)

Reading through Broyard's (1993) moving collection of essays documenting his struggle with terminal cancer, I was struck by how eloquently he expresses a dilemma that lies at the heart of this sub-theme; that while illness, or in this case brain injury - and all the related trauma that goes along with it, is indeed an awful experience, it is also one which "stinks with revelation" (p. 7). Hence the intoxicating aspect of it. Revelation, as Matthew and I discovered, can be isolating though. As Broyard (1983) explains, one is isolated from others by this grand notion that as the person going through the ordeal, you are the healthy one and others are the 'sick ones'. "Like an existential hero", writes Broyard (1993), you are the one who has been "cured by the truth, while they still suffer the nausea of the uninitiated" (p. 5). This existential distance, felt by Matthew in particular – and not just from others, but also from me, revealed itself in one of the conversations we had.

J: "So it becomes more important that you get to air or voice yourself than it is to consider others..."

M: [interrupts] "...yes, but you think you're not voicing yourself...you think you're voicing a reality. You think everyone sees in the parameters that you see but they don't, they don't. People have...people are still working through...humbly going through what it is they're seeing and assimilating their little worlds, they haven't expounded, they haven't taken a step back, or read these things..."

J: "...or experienced these things?"

M: "...or considered other people's lives..., because their experiences have been limited to what they've had in their lives, what their life has delivered them, they're not able to empathise with someone whose been through some trauma...you on the other hand have more of a capacity, your faculties have been stretched almost, your

mental faculties, your inner faculties...I don't know what they are, are can't describe, I cannot articulate what terms to use for those...for the capacity to empathise...what it is...the mechanism, but they've been stretched..."

J: "So you felt in a sense that you wanted to force it on them...?"

M: "Almost...yes, you do, you do... But not uhhh ...force it on them, how can I..."

J: "You want them to see the way you see?"

M: "You do...but they can't, they can't see the way you see, because life hasn't delivered that to them..." (Conv 2: 11 Aug 2013)

5.2.2 Stranger in the mirror, stranger in the mix

This theme was constructed from the five sub-themes listed in table 5.3 below. Central to this theme are Matthew and my experiences with self-alienation, alienation as a couple, loss and social withdrawal in the months following the accident and TBI. Obviously our reasons for experiencing self-alienation and loss differed significantly, with Matthew's reasons having both a strong physiological and psychological basis, and mine a more relational basis. The various sub-themes making up this theme capture these differences in our individual experiences as well as the interrelatedness between them. Social withdrawal is positioned within this theme as being an outcome of our shared sense of self-alienation and loss. Two of the sub-themes deal specifically with what Lezak (1988) identifies as being either the direct or indirect emotional and behavioural consequence of a TBI, namely depression (see sub-theme 5.2.2.3), and impulsivity (sub-theme 5.2.2.4), whilst a third sub-theme deals with the combined effects an antidepressant and TBI had on Matthew. These three sub-themes are situated within this particular theme because of their combined contribution to and exacerbation of Matthew and my experiences with self-alienation, loss and social withdrawal.

Also inherent in this theme, when viewing it through the lens of Reiss' (1981) theory, is that because of the chronic nature of Matthew's TBI and our protracted struggle with it, we were sliding into an ever deeper state of family disorganisation. Having had our previous systems of explanations and meaning so badly shattered (see sub-theme 5.2.1.3), along with Matthew's ability to earn a living having been so seriously

compromised, we were no longer afforded the luxury of inhabiting a mostly stable and predictable environment, as it had once been prior to the accident and TBI. This meant for us that - given the volatile and unfamiliar set of circumstances we were facing - we were also no longer able to operate at what Reiss (1981) calls an implicit-level functioning. We had instead, by all intents and purposes, become a family preoccupied with its own survival and as such were functioning at an explicit level.

Table 5.3 Theme 2: Stranger in the mirror, stranger in the mix

<p>5.2.2 Stranger in the mirror, stranger in the mix</p>	<p>5.2.2.1 Ties that bind: Self-loss, other loss</p> <p>5.2.2.2 Far from the madding crowd: Self-imposed exile</p> <p>5.2.2.3 Keeping morbid company: Depression as TBI's faithful companion</p> <p>5.2.2.4 Walking on eggshells: When impulse reigns</p> <p>5.2.2.5 Uncomfortably numb: On tablets and trade-offs</p>
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5.2.2.1 The ties that bind: Self-loss, other-loss

Matthew, inhabiting a mind which now seemed so different from his own, expressed the changes brought on by the brain injury as feeling like a diminishment of self, and as a loss of his identity. As Weingarten's (2012) work shows, people with chronic conditions and disabilities live with a painful gap - between who they were before and who they are now, of how they would like to be and how they can be. As Boss and Couden (2002) put it, "they are here, but no longer as they once were" (p. 1352). Roos (2012) calls

this loss of self, related to having acquired a chronic condition or disability, “self-loss” (p. 55). In addition to this, as was evident in our conversations, Matthew also experienced what Landau and Hissett (2008) found to be an important aspect of self-loss after TBI, that being the loss of self in the eyes of others.

M: “...but God help me I don’t want to be like this, THIS IS NOT WHO I AM! Your identity is totally shattered! And you think of what that person there must think about you and you hear about this that comes back to you, and you hear this one:

“No...He’s angry, he’s angry with God”, or no “He’s angry because of the accident”, or “He’s angry but he doesn’t know it”, or “He’s ungrateful.” (Conv 2: 11 Aug 2013)

M: “It was like I was trying to grab at straws, I had nothing, no sense of credibility as such, because they all knew I was injured, they all saw me as a victim.” (Conv 5: 8 Sept 2013)

I also felt as if I had lost myself somewhere in the midst of our ongoing struggles. In her work focusing on couple’s experience of self- and other-loss in the context of chronic illness, Weingarten (2013) found that it not unusual for one partner’s experience to flow into and inform the other’s. For couples, asserts Weingarten (2013), “who am I?” is always also “who are you?” (p. 83). This is why, as Roos (2012) points out, self-loss can and frequently does result in other-loss, especially when it comes to couples – they being a particularly intense and intimate arena of social negotiation. In other words, it is common for the partner of a person with an illness, or as in our case a brain injury, to have corresponding feelings of self-loss.

J: “So in a sense we hid ourselves from others...”

M: “...and that worsened it...”

J: “...yes and no. But also you must remember I was experiencing you as a different person, you were different. You were making rash decisions...”

M: “...I’m not justifying myself...”

J: "I understand, I'm just trying to explain how I experienced things, why I battled to understand things, because there was this fear of, "Who are you now? Who am I now? Who are we now?" - of not recognising you or me or us anymore..."

M: "...that's right I became an alien to myself" (Conv 4: 11 Aug 2013)

Experiencing a profound sense of self-loss and confusion over his 'new' identity – a phenomenon experienced by TBI survivor's that Landau and Hissett (2008) call 'identity ambiguity', the way in which Matthew related to himself and to me changed dramatically after the accident. Experiencing my own sense of self-loss - a ripple-effect of Matthew's self-loss, I realise now in retrospect that I was also grieving the loss of Matthew as he was before the accident. In their study focusing on couples and family members dealing with chronic conditions, Boss and Couden (2002) recognise this type of loss, and call it "ambiguous loss" - describing it as a situation where a loved one is perceived as physically present while psychologically absent or altered (p. 1352).

J: "I was incredibly sad for a long time. I was mourning the loss of a husband as I'd known him before the TBI, of our relationship as it was, of the people we'd been. And yet I was so grateful that he's survived. You feel tremendously conflicted at times" (PR's: 14 Sept, 2013).

5.2.2.2 Far from the madding crowd: Self-imposed exile

Rendered a stranger to himself and to others, Matthew began to withdraw himself from the people we knew. Fulfilling the role of elder in our church, the church congregants' expectations - based on who he had been and what he was able to do before the accident, now weighed heavily on him.

M: "...you see implicit in them - implicit or unwitting, because they're not aware of it - an expectation... And I felt expended, like I just don't have the capacity to...[pause]... to deliver what it is that I get the sense that you want, that you need." (Conv 1: 11 Aug 2013)

I too began withdrawing myself from others. With the growing realisation that Matthew's return to daily life heralded only the beginning of our struggles

rather than the end of them, I retracted into myself, trying to make sense of and come to terms with the now uncertain and seemingly hostile future that stretched out before us. Also struggling to reconcile our situation with the relentless positivity of the health and prosperity message coming from the church pulpit, I could not help but feel a sense of failure - that we were just not measuring up somehow.

J: Although over time, the need to keep up appearances lessens, for a long time after the accident we hid from the others the full impact of the injury...the changes it wrought on Matthew, on our relationship, on our home life. Perhaps it was out of fear of being misunderstood, of being deemed a failure somehow, or simply –on my part anyway – a case of good manners. I did not want to put anybody out. This led to a pronounced duality in our existence. A kind of Jekyll and Hyde situation in terms of our private and public lives. (PR's: 26 July 2013)

Social withdrawal also served a protective function for both Matthew and I. Managing the invisibility aspect of having a TBI (see sub-theme 5.2.5.1) we soon found, was not easy. As Webb (1998) points out, 'passing for normal' does not necessarily work to the benefit of the person with a TBI. Those around us; friends, family members, and business clients alike, seeing the rapid physical recovery Matthew made, frequently made the faulty assumption that this recovery represented an overall recovery of both his body and his mind. This meant for Matthew that, although there was an initial scaling down of expectations from others towards him, this wore off as his physical condition improved. Privy to his continual struggles which persisted long after he began to look well, my withdrawal from others was also partly due to wanting to shield him from people and their expectations.

J: The thing about a traumatic brain injury is that you do not know what you are dealing with immediately. The nature and extent of the injury reveals itself to you in daily increments - for a long time afterwards. And as the spouse of the injured person, you are not only having to endure your own kind of struggle, but are also witnessing the momentous struggle your partner is having to endure, and so you become protective of them. There is a sacredness to it all. And part of that protectiveness

involves withdrawing yourself from others, removing yourself, and your partner from harm's way...(PR's: 28 July 2013)

Another reason for our shrinking social circle was the converse of our withdrawal from others, that being the withdrawal of others from us. When people did pick up on the changes in Matthew as a result of the brain injury, some were deterred by them. Webb (1998) offers an interesting explanation for people's uneasiness around brain injury which confirmed our own experience with it. Whereas most people can cope with impairments and illness considered to be the result of natural causes and are as such legitimised through secular commonsensical explanations, head injury is somehow considered to be a consequence of something 'you' have done, a divine punishment of sorts (p 549). Even Matthew himself intermittently viewed his injury as such (see sub-theme 5.2.1.4).

J: ... And at the same time, others begin withdrawing themselves from you. It's a two-way street if truth be told. A brain injury is not like cancer for instance. Whereas a person battling cancer is well-received in the general public, has been normalised, even heroised in our collective consciousness, a brain injury is a different story all together. There is strangeness to it, and people just don't quite know how to respond it. And so initially, there is a tremendous amount of support - but this starts to wane as people began to pick up on the changes. This falling away, I would think, also had a lot to do with Matthew having played a particular role in many people's lives, a strong and supportive role, which he was no longer able to play. And not being able to fulfil this role anymore, many of the people in our social circle, especially from the church, drifted off. Which is understandable really. (PR's: 28 July 2013)

Finally, our social withdrawal may also be attributed to both Matthew and I feeling, for quite some time, that we could not share with others what we were going through. Matthew in particular, felt that when he did try to divulge to others what he was experiencing as a result of the injury, he was frequently misunderstood. As Weingarten (2013) notes, it is common for a person struggling with illness, or in this case a brain injury, to see reflected back at themselves in the eyes of others, a person they do not wish to be, whether

this version of themselves “is projected through compassionate or hostile eyes” (p. 94).

M: “... and you feel like this and no one understands” (Conv 2: 11 Aug 2013)

M: “And the social structure that we had was inept, unable to even...there was nobody qualified to listen, to hear...” (Conv 4: 11 Aug 2013).

J: There is also this element of knowing that you are being summed up in certain people’s heads, short changed, boxed in by some or other parochial mindset, which is extremely disconcerting. And so you think to yourself that it is better to disappear, to escape from the prying eyes, to avoid even the well-intentioned efforts to help (PR’s: 28 July 2013)

5.2.2.3 Keeping morbid company: Depression as TBI’s faithful companion

Although I have included depression as its own sub-theme, it feeds into and imbues many of the other themes and their sub-themes. Depression, for example, acted as both a cause and a consequence of Matthew experiencing a sense of self-loss (see sub-theme 5.2.2.1). Depression skewed our narrative towards that of rupture, despair and despondency (sub-theme 5.2.1.6). Depression also affected our relational intimacy and fed Matthew’s anger (see sub-theme 5.2.2.4).

Matthew’s depression has since his brain injury, maintained its pervasive presence in our lives, varying only in its intensity. Confirming that ongoing bouts of depression are not uncommon after TBI, Silver, Mcallister, and Arciniegas (2009) explain that although depression occurs most frequently during the first year after the TBI, the risk of developing depression remains elevated for decades thereafter. Lezak (1988) attributes the development of chronic depression in most TBI survivors to having an organic basis such as brain tissue damage. She also notes that, and as we have personally found over the years, it feeds on and exacerbates difficulties of an emotional and social nature.

M: “...I was seeing through that bleak lens...” (Conv1: 11 Aug 2013)

M: “And my disillusionment just compounded ...” (Conv 3: 11 Aug 2013)

J: Matthew’s depression was severe. It was a heavy, tangible thing that would come over him. You could see it in his eyes, read it in his movements. It brought with it a dark sense of hopelessness that pervaded the household and settled on all of us to some degree. This went on for years after he sustained the injury - and still shows up every now and then. (PR’s: 19 Aug 2013)

M: There’s no doubt that reading Ecclesiastes, reading about the meaningless of man’s pursuits, spoke to me during this time. I was just living, going through the motions, hoping that something would be sparked in me again. Because I was just going through the motions without hope, without intention. And that was what I’d lost, an intentional way of living (Conv 7: 31 Aug 2014)

Despite my attempts to encourage him and ease his transition back into daily life, Matthew’s depression, especially in the early days after his TBI, rubbed off on me (see sub-theme 5.2.3.3). I struggled, unsuccessfully at times, not to take his dark moods personally. Similar to what Lezak (1988) found in the spouses of TBI survivors, Matthew’s depression eroded my self-esteem, often leaving me feeling inadequate as a result of my inability to relieve it.

5.2.2.4 Walking on eggshells: When impulse reigns

Also linked to Matthew’s depression, was his self-expressed “*loss of impulse control*”. Although anger outbursts were the more obvious manifestation of his impulsivity, Matthew also struggled for a long time with setting boundaries in both social and business relationships. When it came to work especially, the more pressure he was under, the more impulsively he would act. Rash decisions made at work resulting in dire financial consequences then amplified what Webb (1998) calls “secondary reactions” of frustration, loss of confidence, and depression (p. 543).

M: “But the loss of impulse control is the worst of all of it. The inner voice, no longer hearing it, knowing there is an inner voice but not ever giving it time...” (Conv 3: 11 Aug 2013)

Wary of and distressed by Matthew's frequent and aggressive outbursts, I became anxious and fearful around him. This did not help the situation, as my fear and anxiety also triggered his anger. And although he never became physically abusive, his virulent tirades, usually directed against himself, often left me feeling devastated. Lezak's (1988) findings similarly show how anger outbursts, being the most commonly reported form of impulsivity in TBI survivors, are experienced as being distinctively burdensome and distressing by their spouses and family members.

J: There was an aspect to Matthew that had become - well frightening, to say the least. His anger, or rage actually, when it manifested, had a hint of madness to it. It was like a never-quite-sleeping dragon that could be roused as quickly as 1, 2, 3! As if someone had flipped an invisible switch! There was no reasoning with him in this state. And when he was upbeat, his optimism had a rash and unstable quality to it, a capriciousness that - although less intimidating than his anger, was unsettling nonetheless (PR's: 19 Aug 2013).

5.2.2.5 Uncomfortably numb: On tablets and trade-offs

Realising that his depression and anger were creating an untenable environment for us at home, Matthew decided to try taking an antidepressant in the hope that it would alleviate the emotional distress as well as the physiological discomfort he was experiencing as a result of the TBI. As a journal entry of mine written in early 2007 reveals, I must have also been encouraging Matthew to go the antidepressant route.

J: "Almost 6 months after the accident and I still realise this trial is far from over...Matthew struggling profoundly. He has finally agreed to antidepressants." (JE: 19 Feb 2007)

Although Matthew reported experiencing an improvement in his overall cognitive functioning and felt more in control of his impulsivity while on the antidepressant, he did experience these improvements as a trade-off of sorts, in that he also felt emotionally numbed and detached from others.

M: "...because of the antidepressants...you have more capacity to think and to rationalise and to remember things, but with not much life, and you don't really care

because you know its expedient for the time being - to be that way, and obviously you take advantage of it” (Conv 3: 11 Aug 2013)

M: “...the conscience is not, is not engaging, the conscience is dormant for the time being...And so when you see people struggling with emotional issues, with experiences, it’s like you think to yourself, “well, just get over it now”...I lost sensitivity to how I made people feel” (Conv 2: 11 Aug 2013).

Although Matthew’s depression seemed to be marginally alleviated and his anger flare-ups somewhat curbed, the emotional numbness and loss of sensitivity he felt, brought with it a different but equally challenging set of dynamics into our relationship. Most notable amongst these changes was his inability to empathise with me and with others.

J: I remember one particular incident quite vividly still. It would have occurred in the May of 2007, a few days after me and our eldest daughter had been hijacked at gunpoint, and what would have been about 8 months after Matthew’s accident. We were standing in the kitchen, leaned up against the cupboards. We’d had an argument and I was crying, trying to convey to him how I felt – knee-deep in post-traumatic stress no doubt. Trying to justify to him the reasons behind my burgeoning paranoia, rationalising my irrationality in a sense. I looked across at him, expecting some kind of response and...nothing. It was as if he was flat-lining emotionally. His eyes were strangely devoid of compassion. There was an aspect of him missing it seemed, or unreachable. The combination of an antidepressant and a traumatic brain injury, although necessary for a time perhaps, cauterised something in him (PR’s: 19 Aug 2013).

After having taken an antidepressant for a few months, in light of what he considered to be the adverse effects it was having on him and his relationships with others, Matthew decided to stop taking it.

5.2.3 A cosmology of three: You, me, and the brain injury

This theme was constructed from the three sub-themes listed in table 5.4 below. As the two preceding themes show, the TBI brought with it such dramatic and distinctive changes: in Matthew, in me, and to our relationship with each other and with others, that it came to be like a third presence in our marriage and as such, we had to reorganise our thinking and our lives in a way that would accommodate it. Central to this theme are the difficulties we experienced in trying to do just that. The first sub-theme touches on having had to rethink our ideas about marriage in general, with the second theme picking up on the challenges we experienced with regards to temporarily changed marital roles in particular. The third sub-theme deals with what I experienced as being the ‘contagious’ nature of a TBI in the context of our relationship.

Also implicit in this theme, through the lens of Reiss’ (1981) theory, is that because our previously held family paradigms were no longer sufficient to contain our new experiences, the struggles we became explicitly engaged in - reflected in the sub-themes making up this theme, also represent our attempts at reconstructing around the TBI, new family paradigms which would.

Table 5.4 Theme 3: A cosmology of three: You, me, and the brain injury

5.2.3 A cosmology of three: You, me, and the brain injury	5.2.3.1 The ‘new’ we: Rethinking happily ever after 5.2.3.2 Retrogenesis: On relationship regression and parenting a partner 5.2.3.3 Contagion: Just who is the injured party anyway?
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5.2.3.1 The new ‘we’: Rethinking happily ever after

Undergoing a dramatic transformation in how we perceived reality and ourselves as a result of Matthew’s TBI also meant that our perceptions about

marriage in general and our marriage in particular underwent change. We experienced what Webb (1998) fittingly describes as being “a dislocation in a whole range of assumptions about reciprocity and exchange” that we had previously held about marriage (p. 545). Having entered into and participated in a marriage that up until the injury, conformed more closely to the prevailing idea of marriage, we now had to actively collaborate in constructing a new union, one that could accommodate the disruptions that a chronic condition like TBI brings with it.

J: “...there was initially your forced dependence on me and then there was a backlash against that...”

M: “...there was, there was a backlash against, “Okay, I’ve accepted this, but hell I didn’t bargain for that” ... I was prepared to accept that we could dig down deeper and that we could be credible in the eyes of...you know...the authorities of marriage...the great spiritual authorities of marriage...”

J: [Laughs]

M: “I’m just taking this on a peculiar course of thinking. I’m trying to articulate something that I’ve never really thought to articulate.”

J: “Just as you’re speaking I have to reflect on how I saw marriage. A person comes into this thing, very immature and I suppose with a whole lot of ideas from external sources...and then you’re in this thing and you’re trying to...and I suppose as a female, for whatever reason, we’re more prone to attempting to create this ideal. And so the accident for me also led to the shattering of many of these ideas, but also...well I suppose it brought into question: “Are we supposed to be together really?” or “Can we still be together?” given the changes we’d both undergone because of your injury” (Conv 5: 8 Sept 2013)

5.2.3.2 Retrogenesis: On relationship regression and mothering a partner

A particularly salient and significant example of how we came to be disembedded from our pre-TBI assumptions, was the disruption of the marital roles we had come to fulfil up to that point. In need of my constant care and

attention, and not being able to drive, Matthew's temporary dependence on me for a number of months after the TBI, necessitated a change in my role from that of spouse, to one more befitting of a mother. This led to a scenario in our marriage - which in their review of the literature on the post-TBI marriage, Perlesz, Kinsella, and Crowe (1999) found to be a common one - where one spouse was 'parenting' another.

J: "...I mean I became like a mother to you..." (Conv 4: 11 Aug 2013)

My sense of having to mother Matthew was further magnified by his erratic mood swings and impulsivity (see sub-theme 5.2.2.4). As a result of his frequent displays of emotional instability, it felt at times as if there was an adolescent in the home. Issues reminiscent of a time much earlier in our relationship also seemed to resurface.

J: "I didn't see you so much as changed ... as having regressed into an adolescent phase at times. It was you, but you the adolescent. You, but magnified somehow. Not an adolescence caused by hormones but an adolescence caused by the injury rather. But it was almost a replay of our earlier years, wasn't it?"

M: "Yes, a lot of our confrontations were definitely a result of that..." (Conv 5: 8 Sept 2013)

Matthew's adolescent-like behaviour can further be attributed to him experiencing a great deal of frustration over his sudden loss of autonomy. Matthew's loss of autonomy, when viewed in light of Reiss's (1981) theory, can also be linked to the sudden emergence of 'explicit rules' in our relationship. Initially, finding ourselves in strange and as yet undefined territory, newly established, usually verbally articulated rules were being laid down – by myself in particular - in a bid to cope with the uncertainty and unfamiliarity of it all. These explicit rules were on my part, and as Reiss' (1981) theory validates, "desperate attempts to forestall further decay" in our marriage, as well as temporary supports against what I hoped would be a passing stress (p. 181).

In trying to protect Matthew from further harm, and our family as a whole, from further losses, I was also inadvertently reinforcing the mothering role that I

had adopted in our relationship. One such explicit rule for instance, was that Matthew was not allowed to drive for six months after his injury. Following instructions from his doctor, I enforced this rule vigorously, despite Matthew feeling that he was ready to drive before this allotted time was up.

As Reiss' (1981) theory predicts, Matthew began to experience this rule and others like it, as a rigid system of control, and me as being over-controlling. Also, with many of these newly instituted rules coming from a place of fear (see sub-theme 5.2.3.2 and sub-theme 5.2.3.3) his rejection of, or rebellion against my attempts to constrain him were further exacerbated.

J: ...and for a long time afterwards, my thoughts and actions were these pre-emptive strikes against some future disaster – the potential for which was ever-present in my mind – well-intended but destructive in their own way (PR's: 8 Sept 2013).

M: "...and then after ...you had to take responsibility for everything, the running of the household, the business, and you were very cautious, wary of everything, and obviously to a degree you were paranoid ... because now your ...sense of security was no longer... it was shaken rather. And so naturally your method of handling things was sort of an anxious jolt which didn't bode well with me. I felt claustrophobic. But in the past where I may have been able to detach myself from it, perhaps be more in control, at that point I found myself, just reacting to you, flying into you, criticising you..."(Conv 5: 8 Sept 2013)

As Reiss' (1981) theory further predicts, functioning now as an 'explicit' rule-driven family, and as such becoming aware of ourselves as being this struggling and combative unit, both Matthew and I perceived our marriage and each other as being a source of enduring difficulty at times. As Weingarten (2013) aptly explains it, we frequently found ourselves "locked into duelling ineffective self- and other-protective strategies", both of which compromised our relationship (p. 88). In my 'other-protective' role as rule-maker/mother-figure, it is easy to see how Matthew adopted the 'self-protective' role of being like a rebellious adolescent in response to me.

J: "...there was initially your forced dependence on me and then there was a backlash against that..."

M: "...there was, there was a backlash against, "Okay, I've accepted this, but hell I didn't bargain for that"

J: "You seemed to be rebelling...maybe against the constraints of our marriage, or from the weight of responsibility?"

M: "There was a rebellion. You're right..." (Conv 5: 8 Sept 2013)

5.2.3.3 Contagion: Just who is the injured party anyway?

Investing most of my time and energy into caring for Matthew, his injury became for us as Reiss, Steinglass, and Howe's (1993) theory predicts, the central organising factor in our relationship for some time. Occupying such a large space in my consciousness, I struggled to get distance from and as such define myself outside of it. In a strange sense I have often felt injured right along with Matthew. Weingarten (2013), I believe, manages to shed some light on my experience of injury contagion. Because self-experience is derived from socially constructed processes she explains, the fact that most people with a chronic condition "negotiate their views of self with fewer and fewer people", and the spouse's view of the injured person and themselves similarly retracts, creates in that relationship the potential for "a distorting hall of mirrors" (p. 87).

J: I had become so fearful in the months following the accident, and my fear triggered Matthew's anger, and his anger aggravated my fear. It was an awful feedback loop that was set in motion by the accident and by a series of events following it. At least anger is active. Fear on the other hand is paralysing. And only later, I became aware that to live in fear is a type of death, worse than death even. It is death by retraction and subtraction. It shrinks you, diminishes you, until all you are left with is a Lilliputian soul, cowering and pathetic. You become someone, something, you do not recognise, and certainly do not like - a limping and wounded shadow of your former self. (PR: 8 Sept 013)

On a less existential level, my experience with feeling somehow wounded myself, can also be attributed to a phenomenon Solomon, Levy, Fried, Benbenishty, and Bleich (1992) identify as being "secondary traumatisation" (p. 289). According to their findings, the psychic trauma Matthew experienced

as a result of his TBI, can be likened to a stone being thrown into a pool of water. It created ripples that affected not only him, but also those close to him. They also confirm that as the spouse of the injured person, and as such being intimately involved in Matthew's life, made me particularly vulnerable to experiencing this indirect form of trauma.

5.2.4. Felix Culpa: Fortunate misfortune

“Positive transformations are achieved when initial disequilibrium, which is traumatic and brief, gives way to psychic reorganisation, which is gradual and enduring. It would appear to be true that what doesn't kill you makes you stronger” (Solomon, 2013, p. 42).

This theme was constructed from the three sub-themes listed in table 5.5 below. Implicit in the sub-themes of this theme is the paradox that out of loss there is gain, loss in this instance being the catalyst for a 'new', albeit violently, conceived life. Central to the concept 'gain' as I use it here, is the idea that despite everything, Matthew and I have ultimately benefitted from our difficult experiences arising from his TBI, both personally and relationally. As Tedeschi and Calhou (2004) put it though, “...appreciating a disability, giving it value, need not require that it be preferred in and of itself; just that its ramifying value is appreciated” (p. 5).

Furthermore, this theme is indicative of us as a couple - having survived the dissolution of our old paradigms (previous modes of construing our lives together) as well as the tumultuous phase of 'explicit' functioning - arriving at a place where we could once again function implicitly according to our newly constructed paradigms. Reiss (1981) describes these new or post-stressful-event paradigms as being comprised of a family or couple's shared constructions of the stressor event, their initial response to it, and the solutions required to live past the event. These paradigms were - and continue to be - constructed over a protracted period, during which time Matthew and I have had to reorganise our lives around his TBI and come to terms with the long-term consequences thereof. Referring to this process of reorganisation that takes place following a stressful event, Reiss' (1981, p. 191) theory also points to the “growth through experience” aspect of it - which is either directly addressed or alluded to throughout the sub-themes making up this theme.

Table 5.5 Theme 4: Felix culpa: Fortunate misfortune

5.2.4 Felix culpa: Fortunate misfortune	<p>5.2.4.1 Angels in the architecture: Reconstruction and growth through adversity</p> <p>5.2.4.2 On second thoughts: Taking stock, then and now</p> <p>5.2.4.3 Us intensified: Co-struggle as locus of intimacy</p>
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5.2.4.1 Angels in the architecture: Reconstruction and growth through adversity

Although we did not consciously set out to make meaning out of, or benefit from our experience with Matthew's TBI, the growth that both of us perceive to have undergone because of it, is likely the consequence of having gone through and survived the initial aftermath of the injury, as well as having to coexist with the residual effects it continues to have on us daily. Surmising from Joseph and Linley's (2005, p. 268) premise that "growth is by definition about new worldviews", the subsequent reconstruction of our assumptions about the world in general and our world in particular, now so different from those we held prior to the TBI, is also indicative of us having grown because of it.

M: "And what I realised, because of the changes in my own personality, my ability now to appreciate things in a completely different way, what I realised is that almost like a kaleidoscope, my own lens had shifted, my own perspective on life shifted and with that - not willingly but unwittingly - I had given up on a way of thinking."

J: "In light of what you are saying, would you view your injury, the accident, as having been something that ultimately benefitted you then?"

M: "Yes, it set in motion this process of letting go of flawed ideas I'd been holding on to. There was a dissolving of an immature way of thinking, a fragmentation of ideas that seemed to keep it all together. It was recognising that the old wine skins were no longer useful, no longer able to hold the new wine, the new ideas." (Conv 6: 17 Oct 2013)

While it is obviously not possible to distinguish between the growth we may have undergone simply as a result of normative developmental processes, and the growth which can be attributed to our experiences related the TBI, research by Tedeschi and Calhoun (2004) comparing persons who had experienced a severe trauma with those who had not, shows that positive changes were reported at a reliably higher rate among the trauma survivors.

M: "Is it because of the natural process of maturing, or is it part of a head injury, or is it part of just a change in perspective because of having faced certain challenges? I don't know what to attribute to what. But on the other hand when I see people who have lived a long life who have still not graduated past a way of thinking so there must be something that's happened to me because of what I've been through."

J: "Yes, and in terms of our relationship I mean for me it's been quite remarkable, the change that it's brought about. I mean initially it was obviously very difficult but now I feel like if I reflect back on who we were before the accident, I don't know, I just don't feel like we were completely real with each other, that we were connected like we are now."

M: "No, we weren't. My realisation of how you showed so much care to me through it all, that was tremendous, to see your capacity and to see our family's capacity to love me, I didn't know that was possible. And so coming to know...learning of how you are loved, it's an amazing thing. It's rewarding, it's...I don't even know how to describe that. There's always the idea that you're loved but the manifestation of it...the working out of it, and the demonstration of it...actually seeing the capacity that you had to love me through this thing, that was what blew me away..." (Conv 8: 31 Aug 2014)

As the above conversational extract reveals, both Matthew and I experienced the changes to our relationship - some more than likely due to the process of relational maturing, but some evidently due to having endured the struggles brought on by the TBI together - as having benefitted us somehow. We both felt that there was a 'realness', and as such an intimacy to our relationship which had not existed to the same degree prior to our TBI experience. Matthew also expressed feeling a deep sense of gratitude over coming to know *how* he was loved through his TBI ordeal. As Prager (1995) proposes – and in support of what our TBI experience has revealed to us - relational intimacy deepens when there is a clearly perceived adjustment of one partner's behaviour to the needs of another.

5.2.4.2 On second thoughts: Taking stock, then and now

As already mentioned above (sub-theme 5.2.4.1), growth for us did not come as a direct result of the trauma, but as an outcome of our struggle in the aftermath of the trauma. This struggle included for us in particular, a significant amount of reflecting on our past, on who we had been before the TBI and who we were after it. Matthew especially felt as if his thinking had been naive - deluded even - prior to his injury, and that subsequent to it and because of it, he now possessed a more measured and realistic outlook on life. Writing about his experience with cancer and ensuing paralysis as a result of it, Price (1994) shares similar sentiments on feeling like a distinctly different, more matter-of-fact person in light of his struggles. "Trauma forces a person to be somebody else", reveals Price (1994), "the next viable you- a stripped-down whole other clear-eyed person, realistic as a sawed off shotgun..." (p. 103). Matthew's perception of himself as having unrealistic beliefs before his TBI is also closely linked to the 'zealous' religious convictions he professed to hold at that time.

M: "...and then I started to reflect... and now I became cognisant of a real dysfunctionality... a faculty within myself that hadn't even been activated, an inability to be a good father, an inability to be a real husband, because that hadn't been trained...into existence, it hadn't been exemplified ... and I realised... "what the hell was I thinking?", that's not even there, that's non-existent... how did I think that it

would just suddenly come into motion? I was in cuckooland or something to think that. ...and I realised also that my impression of you as my wife was also that you were a work in progress that you were at an undeveloped stage and that somehow everything would just fall into place if we just aimed with an immeasurable amount of zeal... “seek first the kingdom of God and all else will be added unto you”...that kind of mentality, and everything else would just fall into place...boom! Simple as that!”

J: “And post-accident, now?”

M: “Now I’m thinking back and seeing that there is ... a need for a systematic working through, a reflecting on things, reading and building, understanding that... it’s not something that is innate, you don’t just have an inner ability to grasp these things, there’s not a knack for these things, so you actually need to seriously consider this and you to take heed of that...” (Conv 3: 11 Aug 2013)

M: “...and there’s a deep gratitude for this realisation. Why, because I have friends today who I value so deeply, I love them so much, I love sitting with them, talking with them, exchanging substance with them. And I love that. And that’s only been made possible by what I’ve been through.” (Conv 7: 31 Aug 2014)

Despite having experienced a profound sense of loss (see sub-theme 5.2.2.1) because of his TBI - of being aware that he is now living a life that is fundamentally not the life he could have lived had his brain not been injured, Matthew expressed feeling a strong sense of relief that he is no longer the person he was before the TBI, even deriding this ‘pre-TBI self’ in conversations between himself and me at times.

M: “But that’s the idiot I used to be. Those things used to impress me. I was disgusted at the person that I used to be.” (Conv 8: 31 Aug 2014)

A sense of not only being different a different person because of the TBI, but of having lived life in two parts, of feeling as if he inhabited two distinct realities somehow, was also expressed by Matthew.

M: “...after the accident, what I realised was... that with time to think, you do get that...you think on a different level, you think in terms of a frame of reference: Before and after.” (Conv 3: 11 Aug 2013)

5.2.4.3 Us intensified: Co-struggle as locus of intimacy

Magnifying the usual vicissitudes inherent in marital relationships, the TBI posed numerous challenges to our relationship, some of which seemed to be insurmountable at times (see themes 5.2.1 and 5.2.2). Having been married for ten years already at the time of Matthew's injury, and therefore being well-versed in adjusting to, and reconciling with, what Montgomery (1993) calls the "oppositional, relational forces" present at various stages of a couple's life together, served us well in weathering the TBI and ensuing crisis though. According to Montgomery and Baxter's (1998) dialectical understanding of relationships, intimacy and growth in a marriage can only come by way of struggle. This supports Matthew and my perception that the intimacy we now enjoy in our marriage, albeit hard-won through struggle, is deeper now than it has ever been before.

M: "...but now I realised that I was digging ...mining....I was thrown into a place where I had no choice but to dig down deep, to be...I had seriously examine our position as a union, our development and our course as a married couple... Now there was a new sense of learning loyalty toward a partner which I never knew prior to that" (Conv 5: 8 Sept 2013)

J: The relationship we have now – the depth of it, the richness of it, I wouldn't trade it for the world. A young, untried marriage has an unyielding, selfish quality to it. Wrapped up in all kinds of ideas, terms and conditions, there is an unreasonableness to it, a tempestuousness about it. The maturity we developed, accelerated by the trauma and the difficulties thereof, tempered things considerably over time, eventually bringing with it a sanity to the union; A kindness, an easiness, and a closeness that although tinged with sadness, has made for something far more pleasant than its brash predecessor. It certainly made for a more sustainable set-up for us personally in the long run (PR's: 8 Sept 2013)

5.2.5 The show must go on

This theme was constructed from the three sub-themes listed in table 5.6 below. The first two sub-themes making up this final theme deal with the residual deficits of Matthew's TBI and the consequences of these deficits in the light of having to get

back into everyday life and work. The third sub-theme also touches on the notion, as proposed by Reiss' (1981) theory, that new family paradigms constructed around a stressful event, are more resilient than their predecessors.

Table 5.6 Theme 5: The show must go on

<p>5.2.5 The show must go on</p>	<p>5.2.5.1 Now you see me, now you don't: The ever-present yet elusive nature of TBI</p> <p>5.2.5.2 By the sweat of one's brow: Back to the grindstone</p> <p>5.2.5.3 What time has told: Finding the phoenix amidst the ashes</p>
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5.2.5.1 Now you see me, now you don't: The ever-present yet elusive nature of TBI

Making a full physical recovery so remarkably quickly after sustaining a TBI, ironically only added to the nature of Matthew's struggles with his condition. The impact of the brain injury was - and continues to be - difficult to gauge, because Matthew's outward appearance does not reflect his inner reality - that being the residual emotional and cognitive difficulties he experiences on a daily basis. Although some do pick up the changes in Matthew, in a "there is something different about him, but we're not quite sure what" kind of way, many people do not. The invisible nature of his injury has therefore meant that he has had to forgo the compassion and understanding that a more visible injury might have earned him. Consequently, he has often felt profoundly alone in his struggle with an injury which because of its nature lacks external validation of its existence.

M: "What I struggle with, it's difficult for people to perceive, they think that because everything looks good that I'm fine, but they have no idea. And you get tired of trying

to explain yourself, and you can't explain yourself to everybody. You can't explain your experience anyway, because then it just sounds glib..."

J: "It doesn't do it justice?"

M: "Exactly, it doesn't do it justice and you also run the risk of sounding like you're trying to make excuses" (Conv 8: 31 Aug 2014).

In addition to the elusive or unseen nature of the TBI, the ever-present aspect of it has contributed significantly to what may be looked at as Matthew's new identity. Many types of lifelong and distinctive conditions, become both illness and identity, confirms Solomon (2013).

5.2.5.2 By the sweat of one's brow: Back to the grindstone

Having Matthew return to work six months after his injury, posed numerous challenges for us initially. Receiving little mitigation from work and personal acquaintances alike for the unseen residual deficits of the TBI, Matthew frequently felt overwhelmed by the expectations that were placed on him (see sub-theme 5.2.2.2). Perceiving his new reality to be a harsh and unforgiving one, he turned this perceived hostility in on himself. Consequently, personal and work-related failures were deemed by him to be a failure of self.

M: "...I turned autoimmune against myself..." (Conv 2: 11 Aug 2013)

Experiencing a sense of helplessness at my inability to make things easier for Matthew on the work front has turned out to be one of my greatest struggles with the TBI. Life, in the face of our myriad responsibilities goes on, and relentlessly so. I have learnt through trial-and-error that attempts on my part to alleviate things for Matthew will not necessarily ease things for him though (see sub-theme 5.2.3.2). Instead, my interventions - all be they well-intentioned - can potentially add to his already existing feelings of self-diminishment.

5.2.5.3 What time has told: Finding the phoenix amidst the ashes

Living in an age which, as Webb (1981) points out, has become increasingly future-orientated, the taken-for-granted notion – even if it is never realised in

reality – that some promise of success is always yet to be fulfilled, was an especially alienating one for us in the weeks and months after the TBI. Attending a church which emphasised this way of thinking, with a ‘breakthrough’ supposedly waiting around every corner, only served to reinforce the idea, for Matthew in particular, that because of the permanent implications of his injury he’d been disqualified from the ‘race’ somehow, or that he was no longer able to be a fully productive member of society.

M: “Everything in my life just seemed to be atrophying...my ability to do things had been made so much more difficult...like for example my fine motor skills, balance, concentration, ability to think...it just didn’t seem like I had what I’d had before. And in light of this ontological fallacy of the light awaiting us at the end of the tunnel while still here on earth, this sales pitch coming from the pulpit - your experiences in life have brought you to a point where nothing is easy, and you realise that your experiences are not reconcilable with what this preacher, this salesman really, is putting across. And it becomes very antagonistic because...the sales pitch is just such a segmented take on life. Here you’ve had this experience which you are trying to reconcile with but it’s just totally irreconcilable with this platitudinal approach. And it was so alienating...you feel alienated and excluded by a system which ultimately should be all about reconciling with your fellowman and with your creator...but instead the views and the philosophies that were being put across were puerile...and irreconcilable with the experience I’d had ” (Conv 9: 30 Nov 2014).

Over time however, we have come to perceive our disillusionment with this type of contemporary thinking as a positive thing, because in its place we have constructed an understanding of reality that is more robust, resilient and enduring. Our experience with feeling as if we have ultimately benefitted from our disillusionment is supported Tedeschi and Calhoun's (2004) assertion that the cognitive rebuilding which takes place in the aftermath of a devastating trauma, because it takes into account the changed reality of one's life afterwards, is stronger and consequently more resistant to being shattered again. Between Matthew and I, there is the shared perception that the extent of our growth as individuals and as a couple, because of the TBI, has surpassed what growth may have occurred in the absence it.

Chapter 6

Conclusion

6.1 Overview of chapter

In this final chapter of the study, I begin with an overview of the central storyline as reflected more comprehensively in the findings of chapter five. I also introduce photographs into this overview, so as to enhance the narrative with a visual and personal touch. I then discuss the potential contributions this study makes to the existing body of knowledge on the post-TBI marriage, and the limitations of the study, make some recommendations in light of its findings, and briefly conclude with a discussion on how the aims of the study were, for the most part, successfully achieved.

6.2 Wrapping-up: An overview of the central storyline

A traumatic brain injury, as Matthew and I discovered first-hand, happens with a suddenness that is difficult to comprehend. The biographical flow of our life together as a married couple was, in the brief space of a moment, profoundly disrupted and indelibly altered. The full repercussions of the TBI were not initially grasped however, and proceeded to unfold themselves to us over time, within the context of our relationship and wider social network.



Image 6.1 A twisted wreck:
Matthew's barely recognisable vehicle bears morbid testament to the awfulness of the accident he and Elvis were in.



Image 6.2 Crown of steel: A CT scan Matthew had following a craniotomy to decompress the brain, cauterise the bleeding, and remove shards of skull which had penetrated the frontal lobe. The white specks towards the top and at the outer periphery of Matthew's head, show the staples used to close up the wound.



Image 6.3 Bionic arm: In an attempt to brace himself on impact, Matthew's shoulder was also fractured.

Continuity with our past, our place in the present, and our plans for the future were all affected. Previously held assumptions of our world and our place in it were

shattered and crisis ensued in the wake of this devastation. Complex feelings of loss, resulting in a sense of alienation from self and others, were experienced by us both, as individuals and – being two individuals whose experiences were and still are inextricably intertwined in a marital relationship – as a couple as well. Matthew, struggling to come to terms with and adjust to the cognitive and emotional deficits of his brain injury, felt as if the person he had been before the TBI was lost to him, along with his bearings in a world which now seemed hostile and unfamiliar to him. He had become a stranger to himself, inhabiting a strange land.



Image 6.4 Bearing a burden:

Unaware that I was observing him from afar, Matthew walks alone along a deserted stretch of beach taken some time after the accident.



Image 6.5 An unguarded moment: *Matthew home from work, weary and meditative.*

As the uninjured spouse I too grappled with confusing feelings of loss: over a partner who, although not gone, was considerably different to the person he had been before the TBI, over my own corresponding feelings of self-loss and fearful diminishment, and over a life differently imagined. Essentially, we had both lost an implicit epistemology: of self, of how to be together, and of a taken-for-granted way of being.



Image 6.6 Blissfully naive: *Our wedding day on the 6th of January, 1996.*

With everything we knew or thought we knew in tatters and as such no longer afforded the ease of functioning implicitly (according to a tried and trusted repertoire of background understandings and shared assumptions) as before the TBI, we entered into a pronounced phase of explicit functioning – acutely aware of the processes going on between us. Preoccupied with our struggles, we withdrew our investment in many things outside of simply surviving each day.

Particularly prominent during this time of explicit functioning was the temporary disruption to our pre-TBI marital roles that occurred. Fulfilling the role of Matthew's caregiver during the early days of his recovery, saw me adopting a role more befitting of a parent than that of a spouse towards him and as such a structural skew developed in our relationship resulting - for a time - in a dysfunctional 'spouse-as-controlling parent' vs. 'spouse-as-rebellious adolescent' scenario in the relationship. This setup not only impinged on our relational intimacy but contributed to Matthew's already floundering sense of autonomy.

Returning to the comfort of being able to function implicitly again as a couple took a considerable length of time and required our adaption to and acceptance of the enduring nature of the TBI. This acceptance has not been a once-and-for-always type of acceptance though, but rather an ongoing-work-in-progress type of acceptance, especially for Matthew, who must coexist daily with the residual effects of his brain injury. This is made all the more challenging given the invisible nature of a TBI and the low cultural resonance of a brain injury.



Image 6.7 Now you see me, now you don't: *The picture on the left was taken at approximately eight weeks after the accident. The picture on the right was taken just after a year from the accident. Matthew's rapid and remarkable physical recovery masked the cognitive and emotional difficulties he was still experiencing as a result of the TBI.*

Not all of the changes we have experienced subsequent to the TBI have been negative or the cause of relationship distress though. On the contrary, having made it through the more challenging times of the TBI journey - particularly the initial phases shortly after the TBI, both Matthew and I feel as if we've benefitted positively from the experience, as individuals and as a couple. As our conversations reveal, Matthew has wrestled through this experience on an intensely spiritual level, and feels as if the experience has "*stretched*" him so to speak. A strong revelation-through-struggle aspect imbues his contemplative thoughts on the whole experience. I too have experienced disillusionment as something positive. Matthew's TBI forced us to confront issues like mortality and the inevitability of our physical demise – issues usually relegated to later in life – sooner than we otherwise might have. Our relationship has undergone a revision in order to accommodate this broader 'reality'

and has deepened our relational intimacy as a result. This growth-through-struggle aspect of our experience has been what has offset what may be considered to be the dark side of the TBI relational experience.



Image 6.8 Before and after: The photograph on the left of Matthew and I before the TBI - a couple with the world at their feet. The photograph on the right, taken some years after the TBI - a more grounded couple.

6.3 Contributions of study

The contributions which this study makes to the existing body of knowledge on the post-TBI marriage, and what potentially sets it apart from others on this topic, are inextricably linked to the contributions that autoethnography as a method makes to the overall field of research in general. Given the interconnectedness between the two, I discuss the potential contributions this study makes in light of it being an autoethnography and then how, having made use of this particular method, the gaps in the existing literature on TBI marriages - which were identified in chapter two of this study – have been addressed because of it.

6.3.1 First-hand sharing is caring: Contributing to an intimate understanding of the post-TBI marriage

In keeping with the method of autoethnography, this study provides a subjective, 'insider' account of the complex issues arising within a marriage after TBI. This 'insider' view may benefit the particular area of research on the post-TBI marriage in that, as Chang (2008) puts it, Matthew and I, having

lived through the actual TBI experience as a couple, are as such “privileged with a holistic and intimate perspective” on it (p. 52). Sharing this perspective first-hand - which up until this point in time has remained concealed deep within our personal lives - as we have done here, is viewed by advocates of autoethnography as being potentially beneficial for a number of reasons.

Firstly, the level of authenticity a first-hand account holds is likely to surpass that of a more distanced, second-hand account. Ettorre (2010) attributes this to the fact that a first-hand account of an experience usually has an emotional reliability about it that may be lost in its retelling by another. Or as Wall (2006) simply argues, the person best able to describe his or her experience most accurately, is that person him or herself. Given then that this co-constructed autoethnography is a first-hand account, and as such may achieve greater authenticity over some of the other studies on the topic, it is likely to resonate more with other couples who have been through a similar TBI experience to the one we have shared here, as well as with a wider audience who have not necessarily experienced something of this nature but are nonetheless still able to relate.

Secondly, sharing a personal account of a challenging life experience first-hand, as Matthew and I have done, can as Ellis, Adams, and Bochner (2011) affirm, be a therapeutic exercise - for the one's telling it as well as for the one's reading it. As this study reveals, a TBI relational experience is by its nature an isolating one, and is usually endured and contended with behind closed doors so to speak. Having to expose our personal experiences for the sake of this study has inadvertently allowed us to better make sense of ourselves and of our experience, as well as to better understand our relationship in the process. As Ellis et al. (2011) further attest, the one reading our personal first-hand account also benefits from it though, in that it makes ‘witnessing’ possible for them. By ‘witnessing’ Ellis et al. (2011) means that the reader, after having encountered this study for example, should be better able to ‘testify’ on behalf of a TBI-relational experience which they themselves have not necessarily experienced. This study therefore

contributes to the raising of self- and other-consciousness and understanding of the post-TBI marital relationship.

Thirdly, this study may contribute to a growing body of work which aims to bring the personal and the particular into medical and psychological social science research. As Ellis and Bochner (1999) explain, the dominant methodological orientation of medical social science depends primarily on clinical observations, surveys and/or interviews which may produce useful information, but usually glosses over or ignores aspects of an illness or injury experience that cannot be reduced to concepts or abstract knowledge. This study and others like it, in which those going through the actual experience personally attest to the ambiguity, pain, and suffering associated with what Ellis and Bochner (1999) refer to as being the “sense-making challenges” of illness and injury crises, offer a valuable alternative to those constrained by more orthodox methods.

6.3.2 The best of both worlds: Contributing to a theoretical understanding of the post-TBI marriage

As an *analytical* autoethnography, this study is more than just a subjective, first-hand account of a married couples experience with TBI though. By blending our personal data with existing TBI and other literature, my intention for this study was that it would extend beyond what Anderson (2006, p. 379) calls the “idiographic particularity” of a personal account. Having used Reiss’ (1981) theory with which to interpret our personal data for instance, has put a unique spin on it so to speak, and has also grounded the study within the discipline of psychology. Viewing our personal data through the lens of Reiss’ (1981) theory has also allowed me to access and report on far deeper and more complex issues arising within a TBI marriage than most of the available literature on the topic reveals. Additionally by linking our data to current knowledge on the phenomenon of TBI and post-TBI marriages, has meant then that this study is potentially also able to contribute “to a spiralling refinement, elaboration, extension, and theoretical understanding” of marriage after TBI (Anderson, 2006, p. 388).

6.3.3 Minding the gap: Contributing by way of addressing the existing shortcomings in post-TBI literature

As a co-constructed autoethnography, this study represents the views of both spouses, those being both Matthew and my views. This study therefore contributes to a dyadic understanding of the post-TBI marriage in contrast to the majority of the existing studies on the topic which represent the individual perspective of one or the other spouse and as such have oversimplified the complexity inherent in the TBI-relational experience.

Furthermore, being a retrospective account of a TBI-relational experience - spanning a period of eight years - this study also stands in contrast to the majority of the existing studies on the topic which present a static understanding of a post-TBI marriage by assessing it at a single point in time. This study therefore potentially contributes to a more comprehensive understanding of a TBI relationship, as it attempts to capture the ambiguities and changes that occur in such a relationship as they unfold over time. Also, being an account which makes a more extensive sweep of the TBI-relational experience so to speak, has meant that both the negative as well as the positive aspects inherent in the TBI relational experience have been represented. Again this stands in contrast to the majority of the existing studies on the topic which predominantly focus on and highlight the negative aspects and relationship distress experienced within the TBI relationship.

6.4 Limitations of study

As with the possible contributions this study makes to the body of work on the post-TBI marriage, the limitations of this study are largely attributable to the limitations of autoethnography as a method of research. In view of the personal and particular nature of this study for instance, the findings of it cannot be widely generalised to other post-TBI marriages.

Given that Matthew and I had been married for ten years at the time of him sustaining a TBI, and the fact that we already had two children by then, for example, means that our experiences are not necessarily representative of less well-established TBI relationships prior to the TBI. Moreover, because Matthew's TBI

falls somewhere on the continuum between moderate to severe, the findings of the study may not reflect the experience of couple's relationships in which one of the spouses has a mild or more severe TBI. Also, when considering the wider array of structurally differentiated positions one may hold in a society like the South African one, as a middle-class couple, our experiences may differ substantially from those married couples belonging to a different socio-economic group from ours.

Nonetheless, these factors mentioned here – and others like them - which limit the degree to which this study can be generalised to others on the same or similar topic, do not necessarily detract from the objective of this study. For the objective of this study, nor indeed of most autoethnographic studies, is not to hold up our experience as an exemplar of a generalised pattern, but rather to explore and describe our personal and particular experience first-hand from the perspective of 'insiders' and in so doing, reveal aspects of the topic of the post-TBI marriage which may not be available to an 'outsider' so to speak. However, by having made this an analytical autoethnography rather than just an evocative one, and by drawing on and comparing our particular TBI relational experience with those in existing TBI and post-TBI marriage literature, means that the limits to this study's generalisability to others like it have been somewhat curbed.

In view of the retrospective nature of the study, Matthew and my account of our TBI-relational experience may be affected by recall bias - remembering only those things we wish to or are able to remember, in other words. This recall bias may, for example, be attributed to the passage of time or that other experiences in the intervening years may have altered our original perception of things. This may be an issue of greater concern for studies seeking to describe perceptions surrounding an event at a single point in time, but given that this study aimed, among other things, to capture the evolution of perceptions about an event over time, it does not pose as much as a concern for this study. Also, this study is not so much about capturing the 'truth' of an experience, as it is about capturing a co-construction of an experience. However, Matthew and I did still evaluate our recollection of things by referring back to our past journal entries and through numerous discussions in which we were able to compare, contrast, and check our memories of things relating back to when he sustained the TBI and there onwards.

6.5 Recommendations

As the findings of this study shows, the experience of one spouse in a TBI marriage flows into and feeds off of the experience of the other spouse. As such then, their experiences are inextricably intertwined. The practical implication of this provides support for recommending a family-systems orientation when considering treatment interventions for individuals who are married at the time of having sustained a TBI. Any treatment that focuses exclusively on the individual in the TBI marriage and ignores the interpersonal context would have significantly reduced chances of success. This assertion is borne out by Solomon et al's. (1992) findings in a study focusing on the secondary traumatisation which wives of traumatised war veterans returning home from the frontline experience. Whereas the troubled veteran is the focus of concern for most treatment agencies, Solomon et al. (1992) found that the wife, who suffers considerable emotional and social distress, is often ignored. They argue that if the wife's suffering is ignored she is unlikely to respond in ways that will foster the recovery of her traumatised husband. On the contrary, she will in all likelihood reinforce or even exacerbate her spouse's own distress. Krantz and Moos (1987) reached similar conclusions about spouses of depressed patients.

Going on by what this study's findings revealed about a particular TBI-relational experience, issues that could be addressed by therapists working from within a family-systems orientation might include: identifying and normalising difficult and ambiguous feelings arising between the couple, particularly those related to loss; establishing clear injury boundaries so that the TBI does not come to eclipse everything in the couple's life; preventing relationship skews from developing, particularly those brought on by the uninjured spouse having to fulfil a caregiving role, or alternately, how to cope with such skews given that in some instances there development may be unavoidable. Beliefs about whom or what caused the TBI and what can affect its course could also be broached.

As the findings of this study also shows, the way in which Matthew and I related to ourselves and to each other, before his TBI, was significantly disrupted and such we were thrown into a state of confusion which persisted for some time after the TBI. As such, our ability to cope with and adapt to the changes that the TBI brought into our

lives was more than likely hampered. Boss and Couden's (2002) study confirms that the uncertainty of predicting the course of a chronic illness, forestalls a families adaptation to it. Therefore, early intervention programmes aimed at facilitating a married couples understanding of a TBI, and its practical and psychosocial demands over time, may help ease and accelerate this adaptation process.

A recommendation for early intervention of some kind is further supported by the fact that, as was our personal experience also reflected in the findings of this study, Matthew was discharged from the hospital without either of us receiving any information from his attending doctors or hospital staff, on what we might expect from, or how to cope with a TBI. We were left in the lurch as it were. Findings from Dhawan, Rose, Krassioukov, and Miller's (2006) article focusing on the benefits of an early intervention plan for mild TBI sufferers, underscore the importance of and effectiveness of such a plan. Hospitals and doctors in South Africa, who are not doing so, could similarly benefit their TBI patients by implementing an early intervention model something like the one Dhawan et al. (2006) refer to (currently in operation in Vancouver, Canada) in their article. According to this model, referrals are made from hospital emergency wards and neurological or trauma units, and by family physicians to a centrally established early intervention and follow-up service. Once contacted, an appointed intervention coordinator provides the following service:

- Makes contact with the patient and/or the patient's family.
- Provides verbal and written information and reassurance about recovery from traumatic brain injury to the patient and family.
- Identifies risk factors that may contribute to symptom prolongation and delay return to work or school.
- Provides suggestions and strategies on how to cope with symptoms.
- Meets with the patient who is experiencing significant post-injury symptoms that affect daily life or at risk for symptom prolongation or delayed return to work or school.
- Guides the patient in resuming activities at home, school, or work in a graduated way.
- Makes follow-up calls to track patient's progress.

- Evaluates rehabilitation needs and facilitates referrals to community resources.
- Contacts and collaborates with family doctors and other service providers.
- Conducts a neuropsychological assessment of cognitive deficits and abilities if cognitive symptoms persist after six months and there are issues related to driving, school, or employment.

Obviously a substantial amount of research would also need to go into developing and implementing an early intervention model or models such as this one, specifically suited for diverse South African contexts, and is therefore also recommended.

6.6 Conclusion

This study was conducted with a twofold objective in mind. Firstly, to produce an autoethnographic account of a married couple's relational TBI experience, and secondly, in so doing, to simultaneously address the shortcomings identified in the existing post-TBI marriage literature as discussed in detail in chapter two. In brief, given these shortcomings, the aim of this study was to produce a more comprehensive picture of the post-TBI relational experience which would: incorporate both the negative as well as the positive changes that occur in the wake of the injury; provide an account of the post-TBI experience reflecting not just the perspective of one of the spouses in the marriage, but both; provide an alternative qualitative study to the existing, primarily quantitative studies on the topic, which would be better able to reflect the complexity inherent in the post-TBI relational experience; and lastly, to capture a post-TBI relationship evolving over time, rather than presenting it at a single point in time as most have done.

For the most part, this study was successful in achieving these aims. Matthew and my first-hand account of our TBI-relational experience aims to be an intimate and detailed one and as such, fairly comprehensive and complex. As a co-constructed account it represents a dyadic understanding of a TBI marital relationship and as a retrospective account, spanning a period of eight years, it captures some of the changes this relationships underwent over time.

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ADDENDUM A

Consent Form

**CONSENT FORM
FOR PERSONS CO-PARTICIPATING IN AN
AUTOETHNOGRAPHIC STUDY**

Study Title: An autoethnographic account of married life after traumatic brain injury: A couple's co-construction of the journey

Researcher: Jennifer Ann Graham

Supervisor: Gcina Kheswa (Dept. of Psychology, UNISA)

Co-Supervisor: Christine Laidlaw (Dept. of Psychology, UNISA)

13th, November, 2012

Dear Co-Participant,

This consent form, a copy of which has been given to you, is part of the formal process of consent. It should give you an idea of what the research project is about and what your participation will involve. If you would like more information about something mentioned here, or information not included here, you should feel free to ask me. Please take the time to read this carefully and to understand any accompanying information.

Purpose of study: To explore the impact of TBI on a marital relationship

What is an autoethnography? An autoethnography is an analytical narrative of one's own experiences, helping one to better understand the ways in which a culture, social environment or event impacts on oneself and others.

Your participation in the study: I would like to write an autoethnographic reflection on our past experiences spanning the six year period following your accident in which you sustained a traumatic brain injury, specifically related to the effects it had on our marital relationship in terms of how our dyadic constructions of reality (paradigms) were altered as a result. I will be my primary research participant and you will be my co-participant in the co-construction of our story.

Risk to you: There is a minimal risk to you of feeling discomfort about the information being shared. You will however be giving the opportunity to review the transcriptions and/or summaries of our conversations and opt to omit information you no longer feel comfortable with having shared. I will then remove this information at your behest. You will also be given the opportunity to review my interpretations of the data and respond to it.

Storage of materials: Data will be stored in confidential and secure locations (i.e. password protected electronic folders).

Publication of results: I will report data from my autoethnography in my dissertation and may also use it for the purpose of public presentations and/or publication.

Informed consent: Your signature below indicates that you have understood to your satisfaction the information regarding your co-participation in this research project and agree to co- participate as a subject. Your co-participation in this research is however voluntary and you have the right to withdraw at any point of the study, for any reason, and without any prejudice, and the information collected and recorded will be destroyed. Your continued co-participation remains as informed as your initial consent, so you should feel free to ask for clarification or new information throughout the construction of this study.

A copy of this form with both our signatures will be left with you as well.

Co-participant's name _____

Signature _____ Date _____

Researcher's name _____

Signature _____ Date _____

ADDENDUM B

Transcribed Conversation

Conversation 2: 11-08-2013 (27m: 36s)

M: My reality was...my understanding of the course of life, the sequence of events of life that, well previously I had thought...I had believed in more of a neat construction, progress, a progression, almost like a musical progression, that there's harmony and that your life would, if you implemented these principles, if you undertook it in this manner, with this attitude you would have a very steady, you would experience a progress of things in the right direction and you would build a wonderful life and everyone around you would respect you and love you and you would [Hhh]. But now...everything now is out of sync, everything is off kilter... is out of order and you're battling to synchronise things... because whatever you think about seems to be a priority. It's strange you, ...there's a sense of urgency about e-v-e-r-y-thing so that you can't prioritise, you can't say this is more important than that, then you see that and you "Ooh gee whiz" and there's just a rushing, a tyranny of urgency! So everything is...everything is...

J: Do you think that before the accident you were more able to focus?...because before the accident you also seemed to tend towards being overcommitted...

M: [interrupts]...of course, yes, funny enough, the funny thing is the accident probably gave me time where I never had before, to think about who I was before and to think. Not that... there was obviously chemical differences now...but now I looked with a discriminatory...an element of discrimination, a, a, against who I was before and almost disgusted at the, at the habits and the manner in which I approached life. It's funny, it felt like I was disgusted at that person, at who I was.

J: You felt a sense of alienation to this previous self?

M: Exactly and I almost blamed, I blamed the system, I blamed myself and the system and I turned autoimmune against myself. I called it a spiritual autoimmunity. Second guessing every thought I had and thinking...

J: Do you think that had something to do with the fact that because you felt like because of that expectation, because you could no longer meet that expectation and so there was an element of resentment towards people now? And then you saw that, "hold on, if I can't perform in a certain way I don't fit here and ..."

M: That's exactly it, exactly. I knew that I could no longer fit and I realised that I have to start looking, I had to find something, some other form of outlet, some form of therapeutic outlet... and music became that therapy. And I would read and study hard but use it in a way that was...that was undermining the system that I'd come from, and seeing faults and pointing them out and talking and almost..., and then I totally eroded my..., I systematically eroded my past persona by vocalising...

J: You mean...

M: By speaking, speaking against [REDACTED], telling them... [pause]. I shouldn't have done that, I shouldn't have...I systematically...

J: But wasn't it almost an explicit remaking of yourself...?

M: Yes, it was, it was. It was a deconstructing and reconstructing of a persona. Perhaps it was selfish...I don't know, perhaps there was some good intent, but when I heard people using the catch phrases, when I heard people speaking...what do you call it?...uhh...their superstitions, their charismatic superstitions...

J: Platitudes?

M: Ja (yes), their religious platitudes, I was repulsed by it all, I just found it...ja (yes) it was it...it represented my obligation, incarceration of obligation and yet in fairness to them, ...some of them were new in it and some of them were just trying to find their feet in this new found sense of hope. And when I look back, when I reflect on it, I do have a lot of regrets. Why could I have not just been silent? Or just say let's go, let's leave this place, let's be somewhere else, let's go find...somehow reconstruct in silence. Leave them unto themselves, let them deal with themselves. Let them come to their own realisations...but somehow it was a compulsion from within...to speak it out, to tell people...and they don't want to know it, they don't want to hear it. All they do is quietly... marvel outwardly, but then you get the sense that the go away and say that "look that way is not sustainable, not sustainable for me. At least this unreality, if you want to call it that, is something that gives me handles and principles and props that I can hold on to...uhhh....what do you call it?...mantra's that I can... catch phrases that I can just speak out and comfort me", you know and ...

J: So a form of escapism?

M: Perhaps that, or perhaps just a ... yardsticks for them to feel like they're making progress. But is this is part of...? The thing that happened to me was that on the antidepressants I became acutely cerebral, and I saw that same thing in [REDACTED], acutely cerebral.

J: When you say cerebral, what do you mean?

M: Whereas before there were ebbs and flows, emotions... I could feel things, I could feel the music, I could feel a sense of...I don't know how to describe the ...

J: In terms of our relationship you became quite cold and removed. I remember you looking at me when I expressed emotion, especially after my hijacking, and cried, you almost looked at me with ...

M: Disgust...

J: What was that about?

M: Numb...numbness...

J: But was there also a sense of expectation from me that you felt you couldn't meet?

M: There's a sense of expectation from everything. On a feeling level you just can't...you cannot feel and that stuff, the antidepressant, they remove from you a capacity to feel, but you feel that it's...almost expedient. There's an expedience in not feeling and you know it. It's a peculiar...I suppose what the chemistry does, the dynamic of that chemistry you can't explain but you... within yourself you feel, your thinking is so...its not feeling... its thinking, purely thinking. Because you're able to...you shut off a faculty of your humanness and your emotion.... your capacity to read, to learn, to reason, to rationalise becomes more acute and so there's an inner pride in a sense. And so when you see people struggling with emotional issues, with experiences, it's like you think to yourself, "well just get over it now"

J: So there's a sense of superiority?

M: There is, and you saw it in [REDACTED] [REDACTED] had that sense of superiority and you can just imagine why and you don't...because you've shut a faculty off, you've offset the inner energies, the inner person, the inner being has more capacity to think and to rationalise and to remember things but with not much life and you don't really care for that because you know its expedient for the time to be that way and obviously you take advantage of it.

J: But do you think, obviously there was the aspect of your head injury in that as well, I mean a frontal lobe injury also numbing your emotions?

M: Of course, it made it even more acute, even more and that's why it became autoimmune and that whole death wish came over me, because you know it's wrong, this way of being is not right, you know it's not right so you become...your conscience is seared, well that's how I felt that my conscience was seared and I never had, I lost sensitivity to how I made people feel and then I became hateful towards myself. I just turned inwards and I had a death wish.

J: Bringing it back to family again, how did you see that playing out here in the home? Reflecting back?

M: Outbursts of anger, of emotion were shown, so there was an aspect of emotion obviously with the outbursts of anger just, almost a measured sense of anger. "I know I can stop myself from doing this but I'm going to do it anyway because the conscience is not...is not engaging, the conscience is dormant for the time being".

J: But in terms of the marriage and the kids, what I picked up was a sense of, you can't get it right so you'll just pursue your cold, angry path?

M: Exactly, you know that you don't have the capacity to feel and you've got no...you don't have a desire, it kills the desire to ...I'm saying it, it, but that's a nameless entity. What is it? Is it the chemical combination of the injury with the antidepressant, is it the ..., this is the inner dialogue [I have with myself], I'm saying is it an inner bent, a sin? Is it the antidepressants affecting me like this, or is it just a chemical compound, a combination of the three and now they're just in absolute turmoil, or is it just the removal...the affect that the antidepressant has... where it a... periodically numbs the emotion... takes out that, and now there's this inner war because the being, the person... so there's almost a differentiating between the entities within you as a person... and you feel like this and no one understands, and you don't care, you don't care and you're sick and tired...

J: Well you did care in a way because you were angry?

M: Ja (yes), sorry you do care, but you go through ebbs and flows of caring and not caring, you go through...it's a turmoil, an inner turmoil and then you think ...you then you start looking at... the type of person I am... and you start seeing other people who've suffered and you think "yours is not that bad, look at you, you're functional, you can do things that a lot of

people can't do". I was even swimming everyday, I was going through the motions of...autopilot, thinking...and then you start despairing about the world because your thinking expounds on existence and you're looking at other people, other peoples examples, other peoples experiences and you're saying to yourself, and you ask yourself...

J: So it becomes an existential crisis?

M: It is, that's it, an existential crisis, and epistemic rupture. Everything you've known, all your systems of knowledge, your matrix of understanding, the props that you've held onto, the support structures that you've...you're safety net that you've fallen back on – is no longer there. There's nothing there, there's a nothingness. Your safety net was, "well there's redemption for man", and then you question that, "hey have I now rejected that", and you start questioning your salvation, "have I...", because you've spoken so impulsively, the impulse ... I've left out one of the most crucial things. The impulse control...with all of this and in the midst of it all, in your dialogue with people because there's a conscience defect, you no longer feel that prompting, that sense of inner...that inner voice that says to you, "be sensitive to these people". You're just speaking, and you say things...

J: So it becomes more important that you get to air or voice yourself than it is to consider others...

M: [interrupts] ...yes, but you think you're not voicing yourself...you think you're voicing a reality. You think everyone sees in the parameters that you see but they don't, they don't. People have...people are still working through their systematic...humbly going through what it is they're seeing and assimilating their little worlds, they haven't expounded, they haven't taken a step back, or read these things...

J: ...or experienced these things?

M: ...or considered other people's lives so ably, vividly, because their experiences have been limited to what they've had in their lives, what their life has delivered them, they're not able to empathise with someone whose been through some trauma, whose been through ...

J: Right...

M: ...you on the other hand have more of a capacity, your faculties have been stretched almost, you're mental faculties, you're inner faculties...I don't know what they are, are can't

describe, I cannot articulate what terms to use for those...for the capacity to empathise...what it is...the mechanism, but they've been stretched...

J: So you felt in a sense that you wanted to force it on them...?

M: Almost...yes, you do, you do...you force it, you do, you force it on people. But not, uhhh ...force it on them, how can I...

J: You want them to see the way you see?

M: You do...but they can't, they can't see the way you see, because life hasn't delivered that to them ...and then you start to look up and you're thinking because now there's constant progress and then a reverting back, a muddling, a pastiche of ideas, and then an ebb and a flow, and a peak and trough and you can't describe, you can't ... and the sequence of it, you realise how arbitrary life is ...you read in the newspaper or you hear on the radio about someone whose faced a terrible tragedy, a young people...I remember a story of a young guy not even 30 who was in a car accident, who got out his car and didn't know his neck was broken and died there and you start to congratulate the dead...because the turmoil within yourself is such that you don't want to carry on...why?...because you have no, no faith in structure, no faith in ...

J: So it all becomes seemingly arbitrary? But would you say there's a healing of that over time?

M: Yes, there is, there is...because you almost feel like you pay for that, you do, you pay for those ideas, you pay for them severely because they come back at you, they reward you...

J: So it becomes a self-fulfilling prophecy?

M: They do. And you feel the pain and you get worn out because up to that point in time you've still got a lot of energy and zeal and you're trying to direct it and trying to focus it but its constantly misguided, misdirected and offending and hurting and you start to regret and you start to say things... but God help me I don't want to be like this, this is not who I AM! Your identity is totally shattered! And you think of what that person there must think about you and you hear about this that comes back to you, and you hear this one: "No...He's angry, he's angry with God", or no "He's angry because of the accident", or "He's angry but he doesn't know it", or "He's ungrateful".

J: But in a sense, maybe hearing that, was the resentment maybe because you felt there was elements of truth in what was being said? Or did you feel that they completely misunderstood you?

M: I think I told you, I was angry at my misconceptions of God, my misconceptions of reality, I felt fooled. I felt like... [Long pause]

J: Betrayed?

M: Yes, betrayed because I felt like I had delivered what should have produced a return

J: So you felt like that principle of sewing and reaping, that somehow that whole principle had come to nothing?

M: ...that it had been defied somehow...but to a point. I didn't deem myself that perfect. I was aware of the ebbs and flows, the vicissitudes, the inconsistent nature of the course of life, but I felt that there were many unfair things that were happening. The order and the frequency of adversities were too closely staggered. They were just more frequent than the positive and they...those adversities contributed to the dissonant sounds of the voices I was hearing and the spirit they were coming in, the so-called voices of authority were so redundant and yet they were speaking with such gusto and I despised them

J: And so in a sense was it that you could not reconcile what they were saying with what was going on in your life and around you?

M: Yes, and then I became angry at the forces...I called them "the forces that be". Why? Because why are their lives so happy-go-lucky if we were all experiencing things in a fairly, not arbitrary, but fairly random order?" But this person is on such a different wave length that I can't stomach this, I just cannot. And so I would read more and I would read things that would concur with my convictions and then I would talk them out and some people would marvel and others would, "whoa, stay away from that..."

ADDENDUM C

Copy of Journal Entry

19-FEB-2007

THINGS TO DEAL WITH :

BUSINESS CLOSING DOWN

DEBT TO COVER

MATTHEWS DEPRESSION + ANGER

EXHAUST + NEW JOB

7/1-16 JAN

MOM MURDERED AT GUNPOINT 31-JAN

NEW JOB

FINANCIAL YEAR END TO BE SORTED OUT.

OLLIE RIDDEN OVER + DIES IN MY ARMS

THESE THINGS AND MORE HAVE NEARLY

DROWNED ME.

HAVE REACTED IRRATIONALLY, IN

ANGER. THIS RAGE WELLS UP

ESPECIALLY ON THE ROADS.

HAVE FELT :

SHELL-SHOCKED

ANGRY

SAD

HOPELESS

AFRAID

OVER-WHELMED

DESPONDENT

ALMOST 6 MONTHS AFTER ACCIDENT

How many are your works, O Lord! In wisdom you made them all; the earth is full of your creatures.

- Psalm 104:24

AND I STILL BELIEVE THAT THIS

TRIAL IS FAR FROM OVER.

ALTHOUGH I AM SO THANKFUL

FOR MATTHEWS RECOVERY IT

AM SLOWLY REALISING THAT A

T. BEHAVIOUR IS A VERY SLOW

PROCESS OF RECOVERY.

MATTHEW STRUGGLING PROFOUNDLY.

HE HAS FINALLY AGREED TO ANTI-

DEPRESSANTS.

The fear of the Lord is the beginning of wisdom; all who follow his precepts have good understanding.

- Psalm 111:10

ADDENDUM D

Coding Report

Coding report for

Jennifer Graham

for the study aimed at:

Exploring and describing the
co-constructed experiences of a couple following a
traumatic brain injury

CODING WAS GUIDED BY THE FOLLOWING BROAD RESEARCH QUESTION:

What are the experiences of a married couple after one spouse sustains a traumatic brain injury?

Table 1: Overview of themes, sub-themes, and evidence of sub-themes, reflecting the co-constructed experiences of a married couple following a traumatic brain injury.

Coding framework

Overview:

1. Theme one:

We've come undone

Derived from sub-themes:

- 1.1 Life disrupted: A fracture in the storyline**
- 1.2 From hospital to home: The bathos of survival**
- 1.3 Nomic rupture: Experiencing the past as myth and misconception**
- 1.4 Feeling betrayed: When reality fails to meet one's own sense of truth**
- 1.5 Beyond words: Trauma's legacy of incomprehensibility**
- 1.6 Despondent intoxication: When disillusionment and despair dominate the narrative**

2. Theme two:

Stranger in the mirror, stranger in the mix

Derived from sub-themes:

2.1 The ties that bind: Self-loss, other-loss

2.2 Far from the madding crowd: Self-imposed exile

2.3 Keeping morbid company: Depression as TBI's faithful companionship

2.4 Walking on egg shells: When impulse reigns

2.5 Uncomfortably numb: On tablets and trade-off's

3. Theme three:

A cosmology of three: You, me, and the brain injury

Derived from sub-themes:

3.1 The 'new' we: Renegotiating the marriage relationship after TBI

3.2 Retrogenesis: On relationship regression and mothering a partner

3.3 Contagion: Just who is the injured party after all?

4. Theme four:

Felix culpa: Fortunate misfortune

Derived from sub-themes:

4.1 Angels in the architecture: Reconstruction and growth through adversity

4.2 On second thoughts: Taking stock, then and now

4.3 Us intensified: Co-struggle as locus of intimacy

5. Theme five:

The show must go on

Derived from sub-themes:

<p>5.1 Now you see me, now you don't: The ever-present yet elusive nature of TBI</p> <p>5.1 By the sweat of one's brow: Back to the grindstone</p> <p>5.3 What time has told: Finding the phoenix amidst the ashes</p>		
Main Themes	Sub-themes	Evidence of sub-themes
<p>1. We've come undone</p> <p>(The sudden and irrevocable nature of a TBI catastrophe)</p>	<p>1.1 Biographical disruption: A fracture in the storyline</p>	<p><i>J: "You struggle to wrap your mind around the suddenness of it all. It was as if I'd taken a quantum leap into a parallel dimension. In an instant life as I'd known it, as we'd known it, up to that point, came to a standstill - and was forever changed." (PR's: 13 July 2013)</i></p> <p><i>M: "...it had required a lot of effort to get to where I was and I thought that I was climbing, progressing, but now [pause], being disabled..." (Conv5: 8 Sept 2013)</i></p> <p><i>J: I did not put the Christmas tree up that year. The cheer and excess of the Christmas season juxtaposed against the doom and gloom that permeated our home at that point in time, seemed particularly out of place, ridiculous really. I could just not muster up the energy to try to ward off, or at least to counteract to some degree, the tangible heaviness that had descended upon our home. All of my energies, and indeed all of Matthew's energies, were being expended on the simple yet enormous task of surviving each day - and if truth be told, of surviving each other at times. Other things like gardening, and home improvement tasks also stopped. And it is only in retrospect that you come to realize how important these seemingly unimportant menial and mundane little acts of domesticity are. They convey within them an unspoken message of sorts, one of hope, of an investment in your life together, an assurance that you'll indeed be around for another day to reap the fruits of your combined labour, albeit on this small and intimate scale. It was this proverbial rug, of unspoken meanings so to speak, that was so suddenly pulled out from beneath us." (PR's: 17</i></p>

		<p>July 2013)</p> <p><i>J: Rachel's 7th birthday party was planned for the Saturday after the accident happened. I had to cancel it of course. Matthew was scheduled to undergo the first of a series of operations on that day. It was to have been a beading party. Hundreds of brightly coloured plastic beads lay discarded on the kitchen countertop , garish reminders of life interrupted. (PR's: 13 July 2013)</i></p> <p><i>J: Initially, I was afraid to sleep. This was because when sleep would finally come, I was hit afresh with the whole thing on waking up. It was like someone kept sucker punching me in the stomach each time I surfaced, leaving me unable to breath, stunned. I'd have to digest it anew each time, wrap my mind around the whole thing again and again – like a repeat of some awful show on television - those first few days after the accident happened. (PR's 13 July 2013)</i></p>
	<p>1.2 From hospital to home: The bathos of survival</p>	<p><i>J: Life was temporarily suspended after the accident. It really felt as if time stood still, as if I was holding my breath, submerged in some strange new world. Torn between caring for our two girls and wanting to spend as much time as possible with Matthew, I was constantly on the run, rushing between hospital and home. Desperately trying to keep the business afloat, also meant that I was fielding myriad calls from clients, and trying to coordinate work for our staff. Once at the hospital though, all of my attention zeroed in on Matthew as he lay comatose, poised as it were between life and death. Arriving each morning at the trauma ICU ward, long before official visiting hours started, walking in a fighting-off-the-urge-to-run fashion down the corridors of the hospital, I'd compulsively douse my hands with sanitizer from just about every wall-mounted bottle en-route. And once in the ward, I'd attentively listen to his</i></p>

		<p><i>heart beat translated into a rhythm of steady and reassuring beeps, diligently noting any temperature fluctuations, and readjusting tubes carrying fluids to and from his body. All the while offering up prayers and whispering words of encouragement, declarations of love, and desperate pleas into an ear I'd only later find out was now completely deaf, in-between wooing nurses in a bid to win allies in this life-and-death fight. It was these acts, all be they seemingly small and impotent in retrospect - this bedside vigil and the quickly established routine of it, that provided me with a much needed modicum of control amidst the uncertainty of it all. Existing for a time, in such close proximity to death and often despairing, when he did finally regain consciousness, the elation and euphoria I felt was overwhelming. He was to me Lazarus rising from the dead. (PR's: 2 Aug 2013)</i></p> <p><i>J: Almost six months since the accident and I am still realising that this trial is far from over. Although I am so thankful for Matthew's survival, I am slowly realising that recovering from a traumatic brain injury is a very slow process! (JE: 19 Feb 2007)</i></p> <p><i>J: The complexities of a traumatic brain injury are numerous. Those around us are ignorant to the profound impact such an injury has on a human being! No one warned me! Not even the doctors - who must have known! Why? Why did the doctors not bother to pull me aside and explain to me what to expect? Having done my own research on the subject his behaviour is not uncommon for someone with a brain injury. On the contrary, Matthew displays many of the classic symptoms described. (JE: 5 June 2007)</i></p>
	<p>1.3 Nomic rupture: Experiencing the past as myth and misconception</p> <p>Notes: A pervasive sense that life</p>	<p><i>M: "Everything you've known, all your systems of knowledge, your matrix of understanding, the props that you've held onto, the support structures that you've...you're safety net that you've fallen back on – is no longer there.</i></p>

	<p>was illusory before the accident. Feeling alienated from pre-injured self/couple. Linked to sub-themes: 'Feeling Betrayed'</p>	<p><i>There's nothing there, there's a nothingness" (Conv 2: 11 Aug 2013)</i></p> <p><i>J: "So to reiterate, it's like the physical injury or the shattering of your skull and damage to your brain, it's almost analogous of your..."</i></p> <p><i>M: [interrupts] "... yes I've often thought that. There was a simultaneous shattering of my mindsets, my ideas, my makeup, my thinking ..." (Conv 5: 8 Sept 2013)</i></p> <p><i>J: "...you were saying something about breaking out of a mould... that your actions were an exaggerated retort of some kind..." (Conv 1: 11 Aug 2013)</i></p> <p><i>M: "Then that becomes my frame of reference, the disaster that has happened to me. The resultant reconstruction of life, trying to reconstruct a framework of belief. Everything that you've been hearing, everything, through this church megaphone, this voice of church, there's just no substance there anymore. No meaning. There's nothing there that has any relevance to your situation and you just want to break the hell out of it! And that's what I wanted. I just wanted to exit!" (Conv 1: 11 Aug 2013)</i></p> <p><i>J: "You seemed to be rebelling...maybe against the constraints of marriage, or from the weight of responsibility?"</i></p> <p><i>M: There was a rebellion. You're right. You know what it was. It was a retort against who I'd been before ..." (Conv 5: 8 Sept 2013)</i></p> <p><i>M: "...my understanding of the course of life, the sequence of events of life...well previously I had thought, I had believed, in more of a neat construction, an orderly progression...almost like a musical progression - that there is harmony and that your life would, if you implemented certain principles, if you undertook it in this manner, with this attitude, you would have a very steady [pause]...you would experience a progression of things in the right</i></p>
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		<p><i>direction” (Conv 2: 11 Aug 2013)</i></p> <p><i>M: “When I looked at myself, when I had a moments of introspection I felt disgusted” (Conv 1: 11 Aug 2013)</i></p> <p><i>M: “...in retrospect, I did think I was a good guy and that good would just flow with me, it would...surely goodness and mercy will follow me all the days of my life...and I’m thinking back on who I was then and I realise now that there’s darkness and there’s negativity and there’s resentment towards self and resentment of misconceptions about this reality, an anger of misconceptions about God...” (Conv 3: 11 Aug 2013)</i></p> <p><i>M: “...there were obviously chemical differences now...but now I looked with...an element of discrimination at who I was before and was almost disgusted at the, at the habits and the manner in which I approached life. It’s funny, it felt like I was disgusted at that person, at who I was.” (Conv 2: 11 Aug 2013)</i></p> <p><i>M: “And what I realised, because of the changes in my own personality, my ability now to appreciate things in a completely different way, what I realised is that almost like a kaleidoscope, my own lens had shifted, my own perspective on life shifted and with that - not willingly but unwittingly - I had given up on a way of thinking.”</i></p>
	<p>1.4 Feeling betrayed: When reality fails to meet one’s own sense of truth</p>	<p><i>M: “I was angry at my misconceptions of God , my misconceptions of reality, I felt fooled. I felt like...”[Long pause]</i></p> <p><i>J: “Betrayed?”</i></p> <p><i>M: “Yes, betrayed because I felt like I had delivered what should have produced a return.”</i></p> <p><i>J: “So you felt like the principle of sewing and reaping, that</i></p>

		<p><i>somehow that whole principle had come to nothing?"</i></p> <p><i>M: "...that it had been defied somehow...but to a point. I didn't deem myself that perfect. I was aware of the ebbs and flows, the vicissitudes, the inconsistent nature of the course of life, but I felt that there were many unfair things that were happening. The order and the frequency of adversities were too closely staggered. They were just more frequent than the positive and they...those adversities contributed to the dissonant sounds of the voices I was hearing and the spirit they were coming in. The so-called voices of authority were so redundant and yet they were speaking with such gusto and I despised them.. And then I started to get angry at the God who is real and say, "How can you allow this?"...and then I'd say' "well you're not in this programme then..." (Conv 2: 11 Aug 2013)</i></p> <p><i>M: "I'm looking at God, essentially angry at how he has put this world together" (Conv 3: 11 Aug 2013)</i></p>
	<p>1.5. Beyond words: Trauma's legacy of incomprehensibility</p>	<p><i>J: I remember well enough what it was like to be on this 'giving end' of things. When life all made sense. When you think you have all the answers. The luxury of it. The myopia of it. I remember what it feels like to be smug in solutions, to take comfort in your 'knowing', to be seated in the seat of the scoffer. And then your world comes crumbling down around you - and you are silenced (PR's: 11 Aug 2013)</i></p> <p><i>M: "I was so tired of always feeling guilty about things. I was tired of always second guessing... I'd been second-guessing myself, third-guessing, fourth-guessing myself. I'd taken second-guessing to a new level..." (Conv 3: 11 Aug 2013)</i></p> <p><i>M: "Everything that you've been hearing, everything... there's just no substance there. No meaning. There's nothing there that has any relevance to your situation..." (Conv 5: 8 Sept)</i></p>

		<p><i>J: It seemed to me that Matthew had in a sense lost his ability to articulate himself to himself, and therefore to articulate himself to others. He had stopped making sense to himself, and therefore the world had stopped making sense to him. There descended upon him a deep despair, a sullenness which set over into depression and a rage that was all too easily provoked. His loss and grief were in a sense incommunicable for a long time after the accident. (PR's: 26 July 2013)</i></p> <p><i>M: "Initially, your emotions, your person is raw, your inner person is raw from the trauma, so your receptivity capacity is low. I'm trying to think of the right terminology to use. It has no meaning for you... What had meaning to me and what I knew or understood at the time, what I had an intuitive knowing of, frustrated me because of my inability to express it and because of the trauma I'd undergone. I knew that it was a futile exercise even trying to express it. So my expressing was frustrated, it was immature...Alienated, was the way I felt, because I couldn't explain...I knew I didn't have the ability to express what I was going through. And the social structure that we had was inept, unable to even...there was nobody qualified to listen, to hear..." (Conv 4: 11 Aug 2013)</i></p> <p><i>J: It all makes sense one day and none the next. So much of how I initially thought about the accident, about Matthew's injury, was caught up in the way that I thought I was supposed to think about it. It's like there are two streams flowing in your mind. One noisy stream filled with myriad voices you've accumulated over the lifespan and another much quieter one. Your own voice maybe, the voice of God perhaps. It takes time and courage to hear and acknowledge the latter. In the meantime, you scramble about, doing mental gymnastics, trying to understand everything, trying to make sense of it all, coming up with superfluous explanations for it all – as if these explanations might contain the catastrophe somehow - and then finally coming to the conclusion that some things just don't make</i></p>
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		<p>sense. And then you go quiet. (PR's: 14 Aug 2013)</p> <p>M: "And then I lost my ability to get up and talk, and share, because I knew that there would be people – and I could hear their voices in my head – who would be dissing what I wanted to put across and so I could no longer try to persuade people of things. Of anything. Of a belief system, of a philosophy, or the worthiness of something because I knew that everybody is different. It's all just so subjective. Life is just so subjective." (Conv 6: 17 Oct 2013)</p>
	<p>1.6 Despondent intoxication: When disillusionment and despair dominate the narrative</p>	<p>M: "... you start despairing about the world because your thinking expounds on existence...you realise how arbitrary life is ...you read in the newspaper or you hear on the radio about someone whose faced a terrible tragedy, young people... and you start to congratulate the dead...because the turmoil within yourself is such that you don't want to carry on...why?...because you have [pause] no faith..." (Conv 2: 11 Aug 2013)</p> <p>M: "...before the accident there was always hope: ... "we can do this, we can break through, ...we can bring change to people's lives", and then when I...after the accident I just looked at things through a very bleak lens." (Conv 1: 11 Aug 2013)</p> <p>J: "So it becomes more important that you get to air or voice yourself than it is to consider others..."</p> <p>M: [interrupts] "...yes, but you think you're not voicing yourself...you think you're voicing a reality. You think everyone sees in the parameters that you see but they don't, they don't. People have...people are still working through...humbly going through what it is they're seeing and assimilating their little worlds, they haven't expounded, they haven't taken a step back, or read these things..."</p> <p>J: "...or experienced these things?"</p> <p>M: "...or considered other people's lives..., because their</p>

		<p><i>experiences have been limited to what they've had in their lives, what their life has delivered them, they're not able to empathise with someone whose been through some trauma...you on the other hand have more of a capacity, your faculties have been stretched almost, your mental faculties, your inner faculties...I don't know what they are, are can't describe, I cannot articulate what terms to use for those...for the capacity to empathise...what it is...the mechanism, but they've been stretched..."</i></p> <p><i>J: "So you felt in a sense that you wanted to force it on them...?"</i></p> <p><i>M: "Almost...yes, you do, you do... But not uh...force it on them, how can I..."</i></p> <p><i>J: "You want them to see the way you see?"</i></p> <p><i>M: "You do...but they can't, they can't see the way you see, because life hasn't delivered that to them..." (Conv 2: 11 Aug 2013</i></p>
<p>2. Stranger in the mirror, stranger in the mix [Experiencing self-alienation and social disapprobation]</p>	<p>2.1. The ties that bind: Self-loss, other-loss</p>	<p><i>M: "...but God help me I don't want to be like this, THIS IS NOT WHO I AM! Your identity is totally shattered! And you think of what that person there must think about you and you hear about this that comes back to you, and you hear this one: "No...He's angry, he's angry with God", or no "He's angry because of the accident", or "He's angry but he doesn't know it", or "He's ungrateful." (Conv 2: 11 Aug 2013)</i></p> <p><i>M: "It was like I was trying to grab at straws, I had nothing, no sense of credibility as such, because they all knew I was injured, they all saw me as a victim" (Conv 5: 8 Sept 2013)</i></p> <p><i>M: "I turned autoimmune against myself. I called it a spiritual autoimmunity. Second guessing every thought I had..." (Conv2: 8 Sept 2013)</i></p> <p><i>M: "The sequence of tasks which I'd become skilled at, and executed without thought...it had become second nature for me to climb up step ladders, to move geysers, cut pipes, troubleshoot problems... and now my flow of thinking, my</i></p>

		<p><i>abilities had been messed up. I was unable to think in a straight line. So tasks took longer, even my balance was gone, I'd struggle to balance on a step ladder, and the simplest task would take a long time and people would see that I was deficient, and they would caution me, and this compounded my feelings of inadequacy. It highlighted my shortcomings." (Conv 9: 1 Nov 2014)</i></p> <p><i>J: I was incredibly sad for a long time. I was mourning the loss of a husband as I'd known him before the TBI, of our relationship as it was, of the people we'd been. And yet I was so grateful that he's survived. You feel tremendously conflicted at times. (PR's: 14 Sept 2013)</i></p>
	<p>2.2. Far from the madding crowd: Self-imposed exile</p>	<p><i>J: "So in a sense we hid ourselves from others..."</i></p> <p><i>M: "...and that worsened it..."</i></p> <p><i>J: "...yes and no. But also you must remember I was experiencing you as a different person, you were different. You were making rash decisions..."</i></p> <p><i>M: "...I'm not justifying myself ..."</i></p> <p><i>J: "I understand, I'm just trying to explain how I experienced things, why I battled to understand things, because there was this fear of: "Who are you now? Who am I now? Who are we now?- of not recognising you or me or us anymore ..."</i></p> <p><i>M: "...that's right I became an alien to myself "(Conv 4: 11 Aug 2013)</i></p> <p><i>J: "Do you think that had something to do with the fact that because you felt like because of that expectation, because you could no longer meet that expectation and so there was an element of resentment towards people now? And then you saw that, "hold on, if I can't perform in a certain way I don't fit here and ..."</i></p> <p><i>M: That's exactly it. ... I knew that I could no longer fit and I</i></p>

		<p><i>realised that I have to start looking, I had to find something else..." (Conv 2: 11 Aug 2013)</i></p> <p><i>M: "But now...everything is out of sync...everything is off kilter... is out of order, and you're battling to synchronise things - because whatever you think about seems to be a priority. It's strange ...there's a sense of urgency about e-v-e-r-y-thing so that you just cannot prioritise!" (Conv 3: 11 Aug 2013)</i></p> <p><i>J: Although over time, the need to keep up appearances lessens, for a long time after the accident we hid from the others the full impact of the injury...the changes it wrought on Matthew, on our relationship, on our home life. Perhaps it was out of fear of being misunderstood, of being deemed a failure somehow, or simply –on my part anyway – a case of good manners. I did not want to put anybody out. This led to a pronounced duality in our existence. A kind of Jekyll and Hyde situation in terms of our private and public lives. (PR's: 26 July 2013)</i></p> <p><i>M: "...you see implicit in them - implicit or unwitting, because they're not aware of it - an expectation... And I felt expended, like I just don't have the capacity to, to deliver what it is that I get the sense that you want, that you need." (Conv1: 11 Aug 2013)</i></p> <p><i>J: The thing about a traumatic brain injury is that you do not know what you are dealing with immediately. The nature and extent of the injury reveals itself to you in daily increments - for a long time afterwards. And as the spouse of the injured person, you are not only having to endure your own kind of struggle, but are also witnessing the momentous struggle your partner is having to endure, and so you become protective. There is a sacredness to it all. And part of that protectiveness involves withdrawing yourself from others. And at the same time, others begin withdrawing themselves from you. It's a two way street if truth be told. A brain injury is not like cancer for instance. Whereas cancer is well-received in the general public, has</i></p>
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		<p><i>been normalized, even heroised in our collective consciousness, a brain injury is a different story all together. There is strangeness to it, and people just don't quite know how to respond it. And so initially, there is a tremendous amount of support - but this starts to wane as people began to pick up on the changes. This falling away, I would think, also had a lot to do with Matthew having played a particular role in many people's lives, a strong and supportive role, which he was no longer able to play. And not being able to fulfill this role anymore, many of the people in our social circle, especially from the church, drifted off. Which is understandable really. (PR's: 28 July 2013)</i></p> <p><i>M: And the social structure that we had was inept, unable to even...there was nobody qualified to listen, to hear..."(Conv4: 11 Aug 2013)</i></p> <p><i>J: There is also this element of knowing that you are being summed up in certain people's heads, short changed, boxed-in by some or other parochial mindset, which is extremely disconcerting. And so you think to yourself that it is better to disappear, to escape from the prying eyes, to avoid even the well-intentioned efforts to help (PR's: 28 July 2013)</i></p>
	<p>2.3. Keeping morbid company: Depression as TBI's faithful companionship</p>	<p><i>M: "...and perhaps I was seeing through that bleak lens..." (Conv 1: 11 Aug 2013)</i></p> <p><i>M: "And my disillusionment just compounded ..." (Conv 3: 11 Aug 2013)</i></p> <p><i>J: Matthew's depression was severe. It was a heavy, tangible thing that would come over him. You could see it in his eyes, read it in his movements. It brought with it a dark sense of hopelessness that pervaded the household and settled on all of us to some degree. This went on in varying intensities for about five years after he sustained the injury - and still shows up now and then until today. (PR's: 19 Aug 2013)</i></p>

	<p>2.4. Walking on egg shells: When impulse reigns</p> <p>[linked to the sub-themes 'Uncomfortably numb' and 'Keeping morbid company']</p>	<p><i>M: "But the loss of impulse control is the worst of all of it. The inner voice, no longer hearing it, knowing there is an inner voice but not ever giving it time..." (Conv 3: 11 Aug 2013)</i></p> <p><i>J: There was an aspect to Matthew that had become - well frightening, to say the least. His anger, or rage actually, when it manifested, had a hint of madness to it. It was like a never-quite-sleeping dragon that could be roused as quickly as 1, 2, 3! As if someone had flipped an invisible switch! There was no reasoning with him in this state. And when he was upbeat, his optimism had a rash and unstable quality to it, a capriciousness that - although less intimidating than his anger, was unsettling nonetheless. (PR's 19 Aug 2013)</i></p> <p><i>M: "...what I meant is any impulse would just control me... so I would not give great thought to things, I would be in the moment." (Conv 3: 11 Aug 2013)</i></p> <p><i>M: "...and then I went on absolute autopilot then." (Conv 3: 11 Aug 2013)</i></p>
	<p>2.5. Uncomfortably numb: On tablets and trade-off's</p> <p>[Combining an antidepressant with traumatic brain injury]</p> <p>Note: Expressed as/manifesting as being "on autopilot", dulled emotions, disengaged conscience, loss of sensitivity towards others. Linked to sub-theme "Keeping morbid company"</p>	<p><i>M: "...because of the antidepressants...you have more capacity to think and to rationalise and to remember things, but with not much life, and you don't really care because you know its expedient for the time being - to be that way, and obviously you take advantage of it" (Conv 3: 11 Aug 2013)</i></p> <p><i>M: "...the conscience is not...is not engaging, the conscience is dormant for the time being"(Conv 2: 11 Aug 2013)</i></p> <p><i>J: I remember one particular incident quite vividly still. It would have occurred in the May of 2007, a few days after me and our eldest daughter had been hijacked at gunpoint,</i></p>

		<p><i>and what would have been about 8 months after Matthew's accident. We were standing in the kitchen, leaned up against the cupboards. We'd had an argument and I was crying, trying to convey to him how I felt – knee-deep in post-traumatic stress no doubt. Trying to justify to him the reasons behind my burgeoning paranoia I suppose. Rationalising my irrationality in a sense. I looked across at him, expecting some kind of response and...nothing. His eyes were strangely devoid of compassion. There was an aspect of him missing it seemed, or unreachable. And two things struck me. The combination of an antidepressant and a traumatic brain injury, although expedient for a time perhaps, cauterized something in him. (PR's: 19 Aug 2013)</i></p> <p><i>M: "And so when you see people struggling with emotional issues, with experiences, it's like you think to yourself, "well just get over it now" (Conv 2: 11 Aug 2013)</i></p> <p><i>M: "I lost sensitivity to how I made people feel and then I became hateful towards myself. I just turned inwards and I had a death wish." (Conv 2: 11 Aug 2013)</i></p> <p><i>M: "I know I can stop myself from doing this but I'm going to do it anyway because the conscience is not...is not engaging, the conscience is dormant for the time being." (Conv 2: 11 Aug 2013)</i></p>
<p>3. A cosmology of three: You, me, and the brain injury</p>	<p>3.1. The new we: Rethinking happily ever after</p>	<p><i>J: "...there were so many events between all of that, it was initially the forced dependence and then there was a backlash against that..."</i></p> <p><i>M: "...there was, there was a backlash against, "Okay, I've accepted this, but hell I didn't bargain for that...I'm not taking it that far". I want my cake and I want to eat it sort of thing. I was prepared to accept that we could dig down deeper and that we could be credible in the eyes of...you</i></p>

		<p><i>know...the authorities of marriage...the great spiritual authorities of marriage..."</i></p> <p><i>J: [Laughs]</i></p> <p><i>M: "I'm just taking this on a peculiar course of thinking. I'm trying to articulate something that I've never really thought to articulate."</i></p> <p><i>J: "Just as you're speaking I have to reflect on how I saw marriage. A person comes into this thing, very immature and I suppose with a whole lot of ideas from external sources...and then you're in this thing and you're trying to...and I suppose as a female, for whatever reason, we're more prone to attempting to create this ideal. And so the accident for me also led to the shattering of many of these ideas, but also...well I suppose it brought into question: "Are we supposed to be together really?" or "Can we still be together?" given the changes we'd both undergone because of your injury." (Conv 5: 8 Sept 2013)</i></p>
	<p>3.2. Retrogenesis: On relationship regression and mothering a partner</p> <p>Notes: [Role change of wife to mother, breadwinner to dependent, replaying the early years of marriage]</p>	<p><i>J: "...I mean I became like a mother to you..."(Conv 4: 11 Aug 2013)</i></p> <p><i>J: "I didn't see you so much as changed ... as having regressed into an adolescent phase at times. It was you, but you the adolescent. You, but magnified somehow. Not an adolescence caused by hormones but an adolescence caused by the injury rather. But it was almost a replay of our earlier years, wasn't it?"</i></p> <p><i>M: Yes, a lot of our confrontations were definitely a result of that...</i></p> <p><i>J: You seemed to be rebelling...maybe against the constraints of marriage, or from the weight of responsibility?</i></p> <p><i>M: There was a rebellion. You're right. You know what it was. It was a retort against who I'd been before ..." (Conv 5:</i></p>

		<p>8 Sept 2013)</p> <p><i>J: "...there was initially your forced dependence on me and then there was a backlash against that..."</i></p> <p><i>M: "...there was, there was a backlash against, "Okay, I've accepted this, but hell I didn't bargain for that"</i></p> <p><i>J: "You seemed to be rebelling...maybe against the constraints of our marriage, or from the weight of responsibility?"</i></p> <p><i>M: "There was a rebellion. You're right..." (Conv 5: 8 Sept 2013)</i></p>
	<p>3.3 Contagion: Just who is the injured party anyway</p>	<p><i>J: ...and for a long time afterwards, my thoughts and actions were these pre-emptive strikes against some future disaster – the potential for which was ever-present in my mind – well-intended but destructive in their own way. (PR's: 8 Sept 2013)</i></p> <p><i>M: "...and then after ...you had to take responsibility for everything, the running of the household, the business, and you were very cautious, wary of everything, and obviously to a degree you were paranoid ... because now your ...sense of security was no longer... it was shaken rather. And so naturally your method of handling things was sort of an anxious jolt which didn't bode well with me. I felt claustrophobic. But in the past where I may have been able to detach myself from it, perhaps be more in control, at that point I found myself, just reacting to you, flying into you, criticising you..."(Conv 5: 8 Sept 2013)</i></p> <p><i>J: I had become so fearful in the months following the accident, and my fear triggered Matthew's anger, and his anger aggravated my fear. It was an awful feedback loop that was set in motion by the accident and by a series of events following it. At least anger is active. Fear on the other hand is paralysing. And only later, I became aware that to live in fear is a type of death, worse than death even. It is death by retraction and subtraction. It shrinks you,</i></p>

		<p><i>diminishes you, until all you are left with is a Lilliputian soul, cowering and pathetic. You become someone, something, you do not recognise, and certainly do not like - a limping and wounded shadow of your former self. (PR: 8 Sept 013)</i></p>
<p>4. Felix Culpa: Fortunate misfortune</p> <p>Notes:</p> <p>[The dialectic of loss and gain - loss being the catalyst for a new - albeit violently conceived, life]</p>	<p>4.1. Angels in the architecture: Reconstruction and growth through struggle</p>	<p><i>M: "And what I realised, because of the changes in my own personality, my ability now to appreciate things in a completely different way, what I realised is that almost like a kaleidoscope, my own lens had shifted, my own perspective on life shifted and with that - not willingly but unwittingly - I had given up on a way of thinking." (Conv 6: 17 Oct 2013)</i></p> <p><i>J: "So it all becomes seemingly arbitrary? But would you say there's a healing of that over time?"</i></p> <p><i>M: "Yes, there is, there is...because you almost feel like you pay for that, you do, you pay for those ideas, you pay for them severely because they come back at you, they reward you..."</i></p> <p><i>J: "So they become like self-fulfilling prophecies?"</i></p> <p><i>M: "They do." (Conv 2: 11 Aug 2013)</i></p> <p><i>J: "A're you saying that you've developed a respect for the individual journey of everyone..."</i></p> <p><i>M: [interrupts] "That is what I gained, was a respect for each person's own journey, however..."</i></p> <p><i>J: "...that everybody arrives at a certain point at a different time, and at their own point for that matter..."</i></p> <p><i>M: "Correct, exactly that, nicely put. Everyone arrives at their own point, in their own time. Don't try to push people into believing this or try to force people into liking that, not that I was trying to force anyone, but don't waste your energy on promoting this idea or that idea."</i></p> <p><i>J: "But then wouldn't you say that your idea of trying to force everybody into like a unified belief system almost</i></p>

		<p><i>childish, it's like a phase in your life..."</i></p> <p><i>M: "Its bigotist ..."</i></p> <p><i>J: "...It's a phase in your life, an immature phase..."</i></p> <p><i>M: "...where you feel like you've got the answers..."</i></p> <p><i>J: "...and obviously some people never grow out of it, but when you go through a trauma and you have a TBI, or your partner has a TBI, it almost forces you to grow, you cannot remain as you were, you cannot think like you did before."</i></p> <p><i>(Conv 6: 17 Oct 2013)</i></p> <p><i>J: "In light of what you are saying, would you view your injury, the accident, as having been something that ultimately benefitted you then?"</i></p> <p><i>M: "Yes, it set in motion this process of letting go of flawed ideas I'd been holding on to. There was a dissolving of an immature way of thinking, a fragmentation of ideas that seemed to keep it all together. It was recognising that the old wine skins were no longer useful, no longer able to hold the new wine, the new ideas." (Conv 6: 17 Oct 2013)</i></p>
	<p>4.2. On second thoughts: Reflecting, reprioritising and reorganising</p>	<p><i>M: "...and then I started to reflect... and now I became cognisant of a real dysfunctionality... a faculty within myself that hadn't even been activated, an inability to be a good father, an inability to be a real husband, because that hadn't been trained...into existence, it hadn't been exemplified ... and I realised... "what the hell was I thinking", that's not even there, that's a non-existent... how did I think that it would just suddenly come into motion? I was in cuckoo land or something to think that. ...and I realised also that my impression of you as my wife was also that you were a work in progress that you were at an undeveloped stage and that somehow everything would just fall into place if we just aimed with an immeasurable amount of zeal... "seek first the kingdom of God and all else will be added unto you"...that kind of mentality, and</i></p>

		<p><i>everything else would just fall into place...boom! Simple as that!"</i></p> <p><i>J: " And post-accident, now?"</i></p> <p><i>M: "Post-accident I'm thinking back and seeing that there is ... a need for a systematic working through, a reflecting on things, reading and building, understanding...that...it's not something that is innate, you don't just have an inner ability to grasp these things, there's not a knack for these things, so you actually need to seriously consider this and you to take heed of this..." (Conv 3: 11 Aug 2013)</i></p> <p><i>M: "...and there's a deep gratitude for this realisation. Why, because I have friends today who I value so deeply, I love them so much, I love sitting with them, talking with them, exchanging substance with them. And I love that. And that's only been made possible by what I've been through." (Conv 7: 31 Aug 2014)</i></p> <p><i>M: "...because I had time to think. I tell you what it does. It takes you to a place, when you're in recovery, you take the time to reflect upon your life as a whole ...reflecting on your life and your past and where you've gotten to and what you've actually achieved. And you take cognisance of ...I did an inventory of my past." (Conv 5: 8 Sept 2013)</i></p>
	<p>4.3. Us intensified: Co-struggle as locus of intimacy</p> <p>Notes:</p> <p>(intimacy born from struggle)</p>	<p><i>M: "...after the accident, what I realised was... that with time to think, you do get that...you think on a different level, you think in terms of a frame of reference: Before and after." (Conv 3: 11 Aug 2013)</i></p> <p><i>M: "...but now I realised that I was digging ...mining....I was thrown into a place where I had no choice but to dig down deep, to be...I had seriously examine our position as a union, our development and our course as a married couple... Now there was a new sense of learning loyalty toward a partner which I never knew prior to that" (Conv 5: 8 Sept 2013)</i></p>

		<p><i>J: The relationship we have now – the depth of it, the richness of it, I wouldn't trade it for the world. A young, untried marriage, has an unyielding, selfish quality to it. Wrapped up in all kinds of ideas, terms and conditions, there is an unreasonableness to it, a tempestuousness about it. The maturity we developed, accelerated by the trauma and the difficulties thereof, tempered things considerably over time, eventually bringing with it a sanity to the union; A kindness and an easiness, that although tinged with sadness, has made for something far more pleasant than its brash predecessor. It certainly made for a more sustainable setup for us personally in the long run.</i></p> <p><i>(PR's 8 Sept 2013)</i></p>
<p>5. The show must go on</p>	<p>5.1. Now you see me, now you don't: The ever-present yet elusive nature of TBI</p>	<p><i>M: "What I struggle with, it's difficult for people to perceive, they think that because everything looks good that I'm fine, but they have no idea. And you get tired of trying to explain yourself, and you can't explain yourself to everybody. You can't explain your experience anyway, because then it just sounds glib..."</i></p> <p><i>J: "It doesn't do it justice?"</i></p> <p><i>M: "Exactly, it doesn't do it justice and you also run the risk of sounding like you're trying to make excuses" (Conv 8: 31 Aug 2014).</i></p>
	<p>5.2. By the sweat of one's brow: Back to the grindstone</p>	<p><i>M: "But the hardships of the financial circumstances contributed to that. I just thought, "hell, I have to try, I've got to make a living somehow". So the pressures of our financial situation, of the world, compounded everything."</i></p> <p><i>(Conv 3: 11 Aug 2013)</i></p>
	<p>5.3. What time has told: Finding the phoenix amidst the ashes</p>	<p><i>M: "Everything in my life just seemed to be atrophying...my ability to do things had been made so much more difficult...like for example my fine motor skills, balance, concentration, ability to think...it just didn't seem like I had</i></p>

		<p><i>what I'd had before. And in light of this ontological fallacy of the light awaiting us at the end of the tunnel while still here on earth, this sales pitch coming from the pulpit - your experiences in life have brought you to a point where nothing is easy, and you realise that your experiences are not reconcilable with what this preacher, this salesman really, is putting across. And it becomes very antagonistic because...the sales pitch is just such a segmented take on life. Here you've had this experience which you are trying to reconcile with but it's just totally irreconcilable with this platitudinal approach. And it was so alienating...you feel alienated and excluded by a system which ultimately should be all about reconciling with your fellowman and with your creator...but instead the views and the philosophies that were being put across were puerile...and irreconcilable with the experience I'd had "</i> (Conv 9: 30 Nov 2014).</p>
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