

Examining the Nature of Resilience and Executive Functioning in People with Brain
Injury and People with Multiple Sclerosis

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ABSTRACT

This study describes, identifies, measures and nurtures traits of resilience and executive functioning in two groups of participants, (a) ten with traumatic brain injury; 6 males, 4 females, (Mean Age = 42 years, SD =6.23) and (b) ten with Multiple Sclerosis, 3 Males, 7 Females (M =44, SD = 10.80). Participants who fulfilled the selection criteria underwent a six month individualized psychosocial intervention. The intervention was based on principles of person centred and cognitive behaviour therapy. Skill building exercises, problem solving training, appropriate management of mood disorders and support for building social networks were fundamental components of the intervention. Outcome data were collected using the Resilience Scale (Wagnild & Young, 1993), the Dysexecutive Functioning Questionnaire (DEX) (Wilson, Alderman, Burgess, Emslie, & Evans, 1996), and Goal Attainment Scaling (GAS) (Kiresuk & Sherman,1968) on three occasions; (01) baseline, (02) post intervention and (03) at six months follow up. Supporting data were obtained through case studies, medical records, psychological reports, interviews and participant observation. Statistical analysis of scores (Spearman Correlation Coefficient) indicates that there was a significant correlation between executive functioning and resilient behaviours. As resilience improved for the MS group, so did executive functioning abilities. Significant improvements in resilience scores post intervention (Wilcoxon Signed Rank) were reported by both groups. However, due to the severity of cognitive impairments in participants with TBI, an increase in DEX scores post intervention was not obtained. Despite low scores, significant behavioural changes were identified. Amongst them was the ability to set and persist at tasks, set goals, demonstrate insight and the ability to problem solve. Successful achievement of personal goals was dependent on the availability of support. Only then, were resilient behaviours more perceptible in both groups. Resilient behaviour was also dependent on mood states. When experiencing sustained personal equilibrium,(ie an

optimistic and resilient state) participants were better able to respond to feedback, make decisions and plan activities. Given the right circumstances and support, even the most impaired participants (impaired because of serious frontal lobe damage for people with TBI or people with primary progressive MS experiencing considerable pain and loss of mobility) were capable of resilient behaviour which in turn, was motivating for them and inspiring for their family and friends.

SUPERVISOR'S CERTIFICATION

The researcher's supervisor confirms that he has approved all aspects of the research project detailed in this thesis, including the content of the literature review, the collection and analysis of data, reporting and the storage of data.

Supervisor:.....

Dr Brian Matthews

ETHICAL APPROVAL

The project titled: "Examining the nature and relationship of resilience and executive functioning in people with traumatic brain injury and multiple sclerosis has been granted ethical approval by the Social and Behavioural Ethics Committee of Flinders University, South Australia.

DECLARATION OF AUTHENTICITY

I certify that this thesis does not contain any material previously published or written by another person except where due reference is made in the text.

Signed:

Nivashinie Mohan

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IF.....

IF you can keep your head when all about you
Are losing theirs and blaming it on you,
If you can trust yourself when all men doubt you,
But make allowance for their doubting too;
If you can wait and not be tired by waiting,
Or being lied about, don't deal in lies,
Or being hated, don't give way to hating,
And yet don't look too good, nor talk too wise:

If you can dream – and not make dreams your master;
If you can think – and not make thoughts your aim;
If you can meet with Triumph and Disaster
And treat those two impostors just the same;
If you can bear to hear the truth you've spoken
Twisted by knaves to make a trap for fools,
Or watch the things you gave your life to, broken,
And stoop and build 'em up with worn-out tools:

If you can make one heap of all your winnings
And risk it on one turn of pitch-and-toss,
And lose, and start again at your beginnings
And never breathe a word about your loss;
If you can force your heart and nerve and sinew
To serve your turn long after they are gone,
And so hold on when there is nothing in you
Except the Will which says to them: 'Hold on!'

If you can talk with crowds and keep your virtue,
' Or walk with Kings – nor lose the common touch,
if neither foes nor loving friends can hurt you,
If all men count with you, but none too much;
If you can fill the unforgiving minute
With sixty seconds' worth of distance run,
Yours is the Earth and everything that's in it,
And – which is more – you'll be a Man, my son!

Rudyard Kipling

CHAPTER I

1 STATEMENT OF THE PROBLEM

1.1 Introduction

The repercussions of a diagnosis of Multiple Sclerosis and the experience of Traumatic Brain Injury burrow deep into the foundations of a person's being. The diagnosis and prognosis of MS is traumatic not only for the individual but also for their family. Likewise, the experience of TBI alters a person's life forever, such that former skills, relationships and professional life may no longer exist. The blueprints of lives post trauma are complex and participants have few norms to guide them.

Devoid of these norms or resilient models of behaviour, the person is often lost; at the mercy of their impulses, negative mood states, and self-destructive behaviour. TBI and MS effects participants' employment abilities, changes families, alters personalities and disrupts mood states (Mohr, et al., 1999; Rees, 2005; Sohlberg & Mateer, 2001). Participants lost spouses, lost their jobs, friends, lost homes, and even lost custody of their children. They were no longer the person they were pre trauma (Myles, 2004). Given the population of people who have TBI and the number of people with MS, interventions and support is in urgent need (Sohlberg, & Mateer, 2001; Stuss & Alexander, 2000).

Recent estimates of the incidence of brain injury suggest that there are approximately 390,000 people in Australia who have a traumatic brain injury (Fortune, 2006). From this figure, nearly two thirds of people reported that the injury occurred as a result of a motor vehicle accident (Fortune, 2006; Fortune & Wen, 1999; Khan, Baguley, & Cameron, 2003). A large percentage of people with TBI are males with the injury occurring between the ages of 15 to 25 (Fortune, 2006). However, even this figure probably underestimates the true incidence of brain injury due to classification and diagnostic errors (Khan, et al., 2003).

Multiple Sclerosis is said to affect over 15,000 people in Australia (Smith & Schapiro, 2000). The severity of MS can vary greatly within and among individuals. Many individuals exhibit steady and sometimes rapid deterioration (primary progressive MS), but others experience few symptoms and a relatively mild to moderate course characterized by relapses and remissions (relapse remitting MS). Studies of MS established that the incidence of the disease worldwide increased with the distance from the equator (Alonso & Hernan, 2008). For instance, the disease is more commonly seen in people from England, Scandinavia, Northern Germany, Canada and the northern part of the United States (Smith & Schapiro, 2000). This disparity (with higher numbers of people affected, further from the equator) is evident in Australia. In North Queensland, it is estimated that 12 per 100, 000 people have MS. In Tasmania, the furthest state from the equator, the incidence rises to 76 people per 100, 000 (Jelinek, 2000. p. 28).

TBI largely affects the frontal functions of the brain which results in the loss of abilities such as anticipating, planning, responding to feedback and having a flexible approach to life (Harris, Burns, & Rees, 1989; Rees, 2005). MS on the other hand is a chronic, progressive and degenerative neurological disease of the Central Nervous System (CNS) (Doraiswamy & Rao, 2004). Both these disorders induce significant lifestyle changes and disruptions as the diagnosed person confronts constant ambiguity of his/her health status, a sense of unfamiliarity as well as uncertainties for the future (Gold-Spink, Sher, & Theodos, 2000; VanderPlate, 1984).

MS also often follows a more unpredictable and uncertain path which is marked by periods of exacerbation and periods of remission (Mohr, et al., 1999). Some individuals experience a rapid progression of the illness, few have a “benign course”, and most experience a relapsing-remitting course (Mohr et al., 1999). The uncertain and sudden nature of MS, combined with physical disability often leaves the person vulnerable to emotional

distress (Rao, Huber, & Bornstein, 1992; Schubert & Foliart, 1993). When this occurs, effective everyday functioning is impaired (Beatty, 1993).

Both TBI and MS have lifelong consequences. Participants face challenges on a daily, if not hourly basis. They all experience significant psychological, social, vocational, and emotional difficulties. Yet despite these challenges, there are individuals who are able to adapt, to bounce back with minimal disruption to their lives. Others are eventually able to recover something approximating their pre trauma level of functioning, though this is rare (Curtis & Nelson 2003; Dyer & McGuinness, 1996; Wineman, 1990). Although their present functioning may not be exactly as it was pre trauma, a new baseline can be established. A baseline where participants learn new skills, and ways to cope with their disabilities. Garmezy (1997) describes this process of resilience as;

“(Resilience) lies in the power of recovery and in the ability to return once again to those patterns of adaptation and competence that characterized the individual prior to the pre-stress period....” (Garmezy as cited by Jacelon, 1997, p. 123).

1.2 Definitions of resilience and executive functioning

Luthar, Cicchetti and Becker (2000) describe resilience as “*A dynamic process encompassing positive adaptation within the context of significant adversity*”. Embedded within this notion are two critical circumstances: (a) exposure to significant threat or severe adversity; and (b) the achievement of positive adaptation despite major assaults on the life process of the individual (Luthar, Cicchetti, & Becker, 2000; 1983; Werner, 1993). Therefore resilience is viewed as a process which contributes to positive outcomes (Luthar, Cicchetti, & Becker, 2000).

However, unless resilient behaviour in participants with TBI or MS are nurtured by careful planning and sustained support, they face a greater risk of experiencing depression, anxiety, and isolation (Armstrong, 1991; Arnett, et al., 2001; Aroian & Norris, 2000; Goldney, Wilson, Dal-Grande, Fisher, & McFarlane, 2000; Hibbard, Ashman, & Spielman, 2004; Holsinger, Steffens, & Phillips, 2002; Kim, et al., 2007; Schubert & Foliart, 1993; Siegert & Abernethy, 2005).

To facilitate and nurture resilience, executive functioning skills such as planning, self regulation, responding to feedback and initiating can, given appropriate sensitivity to participants, be developed. Executive functioning is generally agreed to encompass the skills necessary for purposeful, goal-directed activity (Cummings & Bogousslavsky, 2000; Shallice, 1982; Stuss & Benson, 1986). Executive functions can be thought of as multiple processing modules collected together to direct cognitive activity (Stuss & Alexander, 2000, p. 291). These activities include mental functions associated with the ability to engage in purposeful, organized, strategic, self-regulated, goal-directed behaviour (Stuss & Alexander, 2000). These modules perform functions related to overseeing the use of other cognitive processes. For example, executive functions are not the cognitive processes which individuals use to think and act. Rather, they are the cognitive processes that direct the engagement of those processes that individuals use to think and act (Cicerone, Levin, Malec, Stuss, & Whyte, 2006; Stuss, 1992). This is pertinent for people who have to make significant life adjustments following trauma. Executive functions are hypothesised to exert an influence on participants' resilience and coping ability. Executive functioning skills reflect a diverse set of underlying cognitive processes, which are manifested behaviourally as adaptive functioning. It is predicted that participants who exhibit resilient behaviours also would generally have better executive functioning skills.

1.3 Rationale

Positive coping responses to adversity such as TBI or diagnosis of serious illness (MS) are facilitated by resilient behaviour (Masten & Coatsworth, 1995; Rutter, 1990). Can this trait of resilience be nurtured? Can resilient behaviour be demonstrated and modelled so that people who experience adversity can utilize resilient behaviours' to overcome, if not master their adversity? Identifying, measuring and utilizing resilience traits appears fundamental in post trauma rehabilitation interventions (Alvord & Grados, 2005; Bonanno, 2004). If resilience is an identified process, it appears crucial to tap resilient behaviours. These behaviours are considered to correlate with executive behaviours such as forward thinking, planning, and initiating action. Therefore, the research rationale is that nurturing appropriate executive functioning/cognitive skills in people with TBI and MS will lead to the development of resilient behaviours.

Research on resilience has shown that effective use of cognitive skills is associated with more positive outcomes (Masten & Garmezy 1985; Rutter, 2002; Sohlberg & Mateer, 2001; Werner, 1995). Some preliminary work has examined the contribution of specific facets of cognitive functioning to resilient outcomes (Curtis & Cicchetti, 2003). These studies have examined empirically derived aspects of cognition such as attention, problem solving and self regulation (Curtis & Cicchetti, 2003). Executive functions include similar aspects of cognition, such as problem solving, completing tasks and responding to feedback. That is why a relationship is thought to exist between resilience and executive functioning. A primary basis for this relationship is based on the notion that executive functions have strong links to higher cognitive functions of which resilience is a key characteristic.

Therefore the concepts of resilience (Block & Block, 1980; Garmezy 1985; Luthar, Cicchetti, & Becker 2000; Masten & Reed 2002) and executive functioning (Elliot, 2003; Eslinger & Geder, 2000; Khan et al., 2003; Pennington & Ozonoff, 1996) are examined

individually in order to gain an understanding of the nature of these concepts. A sample of people with frontal lobe injury and multiple sclerosis are observed, interviewed and assessed in order to understand how resilience operates. Although the adversity they each face is different, they all share the common experience of coping with continual major changes in their lives (Khan, Baguley, & Cameron, 2003; Sohlberg & Mateer, 2001). Therefore, it is crucial to be able to measure and understand the nature of resilience in order for it to be fostered in people with TBI (Conner & Davidson, 2003; Curtis & Cicchetti, 2003). The individual nature of participants' experiences and this influence on their resilient behaviours is acknowledged. The research commences by establishing a database of information on issues related to the development of resilient behaviour amongst individuals with either TBI or MS.

This database can be achieved through the use of ethnographic methods which aim to "give voice to people in their own local context, typically relying on verbatim quotations and a thick description of events" (Bickman & Rog, 2009). Measuring resilience and executive functions has proven to be difficult as it is hard to quantify these processes. In general, neuropsychological and psychological assessments of executive functions and resilience are often conducted in well-structured clinical settings, where the examiner devises and initiates the bulk of the evaluation. Lezak (1993) emphasizes that executive functioning difficulties are rarely reflected in test scores, as the majority of assessment tools are also highly structured and shape, if not determine responses (Eslinger & Geder, 2000; Stuss & Alexander, 2000). Similar complaints have been made for the measurement of resilience (Block & Block 1980). Therefore in order to effectively examine executive functioning and resilience, this study plans to integrate the use of structured tests as well as the use of qualitative, ethnographic, observation and unstructured interviews of the person with the brain injury or multiple sclerosis, in various contexts (Anderson, 1998). This enables 'the stories' of resilience to be told through the eyes of

participants as they pursue their activities in their own communities. The use of these mixed methods also enables the exploration of rich, untapped sources of data, which then informs the intervention and aids in answering the research questions.

Researchers of resilience have for years urged that the results from studies should be incorporated into interventions and used in clinical practice (Masten & Garmezy 1985; Rutter, 2002; Werner & Smith, 1992). However, information relevant to interventions on resilience is lacking and this problem is reflected in the limited number of studies which apply the development of resilience in intervention procedures (Waaktaar, Christie, Borge, & Torgersen, 2004). Therefore, this study aims to apply constructs of resilience derived from the literature, into supportive clinical interventions for people who have experienced trauma. It is proposed that irrespective of their TBI or MS, all participants can learn new skills and behaviors. This learning is facilitated through the provision of support, sustained rewarding activity, cues and structure throughout the intervention process.

Literature supports the belief that resilient behaviours can be learned and interwoven with contextual life experiences (Friborg et al 2003, Garmezy 1993; Luthar, Cicchetti, & Becker 2000; Masten & Reed 2002). Similarly, through improved understanding of the brain and its functions, it is known that executive functioning skills, which might be compromised as a result of frontal lobe injury, or MS, can be cued and re-learned (Schulz, Kopp, Kunkel, & Faiss, 2006; Sohlberg & Mateer, 2001; Stuss & Alexander, 2000). It is hypothesized that given the right structure, cues, context and support, individuals with brain injury and MS can learn to utilize their executive functioning skills more efficiently. In doing so, it is predicted that they develop foundations, which will help them, in turn, to be more resilient. Resilience is characterized by having 'a broader range of coping mechanisms'. The aim of the intervention is to nurture and enhance a person's 'coping mechanisms' as they cope with the adversity of TBI or MS.

1.4 Aims and Outcomes

This study examines the relationship between resilience and executive functioning in people with Traumatic Brain Injury (TBI) and people with Multiple Sclerosis (MS). There are two related aims in the study. Firstly, the nature of resilience and executive functioning such as the characteristics, individual presentation and variation of these constructs are examined in two population samples; (1) people with traumatic brain injury (TBI) and people with multiple sclerosis (MS). Secondly, the study examines the relationship that measured resilience has with measured executive functioning. In order to facilitate adjustment to severe trauma and effective coping behaviour, it is postulated that the presence of human resilience triggers the executive functioning behaviours and vice-versa.

A significant outcome of this study will be to improve the measured quality of life for people who experience MS (relapse remitting, primary progressive, secondary progressive) and those who experience TBI. Improved quality of life for these individuals would involve the ability, given appropriate support, to live as independently as possible. To maintain a positive outlook, irrespective of their disabilities. People with disabilities often face exclusion. However, characteristics of resilience such as (a) the use of protective mechanisms and (b) the capacity to have a positive outlook on life, together with the components of executive functioning such as self-monitoring and persisting at goal directed activities, are considered to promote meaningful inclusion in society. An outcome both short and long term of this study's intervention is to facilitate social inclusion for people disabled by TBI or MS.

1.5 Research and Documentation

This thesis has been divided into the following chapters;

- Chapter two is divided into 4 parts and begins with a review of the literature which outlines the definitions of (2.1) resilience and (2.2) executive functioning. Section 2.3 and 2.4 respectively discuss traumatic brain injury and multiple sclerosis. The relationship both people with TBI and MS have with resilient behaviour is also examined.
- Chapter three describes the aims and outcomes of the research methodology and goes on to explain the data collection and analysis procedures. Ethnographic methods are principally used; however quantitative data supports the qualitative data obtained through participant observation and interviews. This research design chapter presents significant research questions.
- Chapter four begins with outlining the procedure of the intervention, and the principles on which the intervention is based. This intervention description chapter highlights the form, structure and frequency of the meetings with participants during the intervention phase.
- Chapter five is the results section. Six case studies; three from participants with TBI and the other three from participants with MS begins this chapter. It is followed by participants' demographic data and analysis of scores on the Resilience Scale and the Dysexecutive Questionnaire. Data is presented in the form of tables and graphs.
- Chapter six answers the research questions with detailed description of the statistical findings.

- Chapter seven is a discussion of the results. It includes implications of the study's findings and is based on four major themes; resilience and its relationship to executive functioning, social support, mood states and relearning post trauma.
- Chapter eight highlights several limitations and presents guidelines for future studies. Recommendations for participants, their families, clinicians and policy makers are proposed.

Chapter II

2 LITERATURE REVIEW

2.1 Introduction

The literature review is divided into four sections. The constructs of resilience and executive functioning are reviewed in detail in sections 2.2 and 2.3. Section 2.2 of the review defines and describes the constructs of resilience and protective factors. A description of coping and how it differs from resilience follows. The impact of mood states on resilient behaviours and current advances in the literature are identified. The review then explores how resilience can be used in a clinical setting and to guide intervention practices. Executive Functioning is defined in section 2.3 and examples of executive functioning behaviours are presented. The importance of executive functioning, particularly for people with TBI, concludes this section.

TBI and MS are each reviewed separately in sections 2.4 and 2.5. This allows for a more in depth exploration of the behavioural and biological symptoms that affect these two groups of participants. Section 2.4 focuses on traumatic brain injury, providing the prevalence of TBI in Australia and ways in which a brain injury is diagnosed. Repercussions of an injury to participants in regards to psychosocial functioning, neurological difficulties and mood disorders are reviewed. Cognitive functions such as orientation, self awareness and memory difficulties are discussed along with rehabilitation strategies. These strategies include principles of cueing and errorless learning. The barriers to inclusion in community life for people with brain injury and how mentors can help the process are highlighted. This section concludes with a discussion of frontal lobe damage and the importance of resilience for this subgroup of people.

The final section of the literature review is on Multiple Sclerosis (2.5), its epidemiology, incidence and prevalence. Symptoms common to MS are discussed along with treatment options currently available. The psychosocial, mood and cognitive difficulties often reported by participants with MS follows. The literature review concludes with a discussion of the significance of resilience for people with MS.

2.2 Resilience

2.2.1 A definition

Resilience is the human ability to adapt when faced with tragedy, trauma, adversity, hardship, and continuous significant life stressors (Newman, 2005). Although every individual has to deal with major and minor stressors while adapting to life changes, some individuals are much more capable than others in effectively coping with hard times. This has provided a reason for theorists and researchers to investigate the nature of these individual differences (Block & Block, 1980; Tugade & Fredrickson, 2004; von Eye & Schuster, 2000). Garmezy in 1993 stated that:

“The study of resilience lies in the power of recovery and in the ability to return to those patterns of adaptation and competence that characterized the individual”.

(Garmezy, 1993, p. 129)

In order to investigate the nature of resilience, studies with children and adolescents defined to be at risk were conducted. It was found that some children developed without significant compromise to their well being despite the adversities with which they were confronted (Rutter, 1990; Werner, 1995). Researchers began to study this subgroup with interest, seeking to understand what differentiated them from others who developed social, psychological, medical and various other problems (Rutter, 2002). Interest in resilience grew, challenging risk focused models of development. This led to the growth of strength-based perspectives, which identified factors associated with adaptive development when coping with stressful life events (Fredrickson, 2001; Masten & Coatsworth, 1995; Tedeschi & Kilmer, 2005).

Certain characteristics of resilience were identified to be constant in people who seemed to “bounce back” in the face of adversity (Block & Kremen 1996). These agreed upon characteristics of resilient behaviours are described in Table 2.1.

Table 2.1 *Characteristics of resilient behaviour*

Characteristics of resilient behaviour
• Warmth and capacity for close relationships (Masten & Garmezy, 1985)
• Social poise and presence (Block & Kremen 1996)
• Productive; gets things done (Garmezy, 1993; Wolin & Wolin, 1993)
• Internal locus of control (Letzring, Greve, & Funder, 2005; Werner, 2000)
• Ability to elicit positive responses from others (Masten, Best, & Garmezy, 1990)
• Self regulate (Buckner, Mezzacappa, & Beardslee, 2003; Eisenberg et al., 2001, Werner, 1993).
• Socially perceptive of interpersonal cues; (Werner, 2000; Werner & Smith, 1982)
• Have positive future expectations (Wyman, Cowen, Work, & Kerley, 1993)
• Positive temperament (Letzring, et al., 2005; Werner, 2000)
• Internal locus of control (Garmezy 1993)
• High self-esteem and perceived self-efficacy (Bandura, Pastorelli, Barbaranelli, & Caprara, 1999; Watt, David, Ladd, & Shamos, 1995)
• Respond to humour; (Masten, 2001)
• Optimism (Seligman, 1995; Watt, David, Ladd, & Shamos, 1995)
• Value own independence and autonomy; (Blocker & Copeland, 1994)
• Tend to arouse liking and acceptance (Werner & Smith, 1982; Werner & Smith 1992)
• Insight into own motives and behaviour (Hawley, 2000)
• Hardiness (Bonanno, 2004; Kobasa, Maddi & Kahn, 1982)
• Are good at problem solving (Werner, 1995)
• Are internally motivated (Masten, 2001)
• Social Support (Fagot, Hagan, Leinbach, & Kronsberg, 1985; Watt, David, Ladd, & Shamos, 1995)
• Better cognitive abilities (Cicchetti & Rogosch, 1997; Luthar & Zigler, 1992)

Although researchers agree upon those characteristics which represent resilient behaviour, there is a lack of consensus as to an operational definition of the construct. Most definitions of

resilience consist of two main aspects: (a) specification of an identified risk or challenge that an individual is faced with followed by (b) some defined measure of positive outcome (Garmezy, 1993; Luthar, Cicchetti, & Becker, 2000; Masten & Coatsworth, 1995).

Given this notion, resilience may then be viewed either as an outcome that occurs at a definite point in time or as a trajectory that unfolds over a reasonably long period (Luthar, Cicchetti & Becker 2000; Rutter, 1987). Similarly, some researchers have suggested that a resilient person must show positive outcomes across a number of aspects of his/her life over different periods of time (Cicchetti & Rogosch, 1997). Having said this, it has been argued that resilience is not a one-dimensional, dichotomous attribute that people either have or do not have (Reivich & Shatte´, 2003). Rather, resilience entails the possession of multiple skills, in varying degrees, that help individuals to cope (Conner & Davidson, 2003a). Other significant findings from the resilience literature show that (a) the skills associated with resilience are ordinary in nature, not epic or phenomenal, and (b) the skills are adaptable and can be learned (Masten, 2001 ; Newman, 2005) . For that reason, it has been argued that resilience is not a trait that an individual either has or does not have, rather it involves behaviours, thoughts, and actions which can be learned and developed (White, Driver, & Warren, 2008).

2.2.2 Resilience: A Historical Background

Following from the definition of resilience, controversy exists as to what constitutes ‘resilience’. Early investigations of the construct emerged from research on the history and prognosis of patients with serious mental disorders. In particular, it focused on the pre morbid functioning of patients with schizophrenia (Garmezy & Rodnick, 1959). Garmezy found that some people with schizophrenia, irrespective of their disorder, adapted better and were more competent than others (Garmezy, 1970). It was found that this subgroup had pre morbid histories which included being competent at work,

having social relationships, stable families and the ability to fulfil responsibility (Garmezy, 1970). Similarly, there was growing interest in research on mothers with schizophrenia and their children, because these children had an elevated risk of developing the disorder (Garmezy, 1971; Masten & Garmezy, 1985). Whilst some of these children were not able to triumph over such adversity and continued to be underprivileged, a significant number of others were able to overcome their traumatic childhoods to lead healthy, productive lives (Masten, 1998). This then led to empirical efforts to understand individual variations in response to adversity (Garmezy, 1993; Masten & Coatsworth, 1995).

Subsequently, another influential study by Werner (1971) now spanning four decades, followed the development of children born on the Hawaiian Island of Kauai in 1955. In this study, the risk group (about 1/3 of the children) were defined as having four or more early risk factors that included poverty, prenatal stress, family conflict, and low parental education. About 1/3 of these high risk children developed well in terms of getting along with parents and peers, doing well in school, avoiding serious trouble, and having good mental health. It was found that those children who overcame adversities of childhood had one or more attributes (referred to as protective factors) such as temperament, role models, ability to seek help, and social skills which helped them to adapt to their environment (Lezak, 1995; Rutter, 1990; Werner, 1993, 1995). This in turn reinforced and sustained their active approach to life and rewarded their special competence and skills (Werner, 1993).

Following Werner's work, research on resilience grew to include various undesirable circumstances such as poverty and related risks (Garmezy, 1993; Masten & Coatsworth, 1995), mental illness (Beardslee & Podorefsky, 1988; Masten & Coatsworth, 1995), abuse (Cicchetti & Rogosch, 1997), attention deficit hyperactivity disorder (Hechtman, 1991), and traumatic life events (Al-Naser, 2000; Fredrickson, Tugade, Waugh, & Larkin, 2003; Laor, et al., 2006).

Early work on resilience mainly focused on the personal or trait characteristics inherent in children such as autonomy, and self esteem (Beardslee & Podorefsky, 1988; Garmezy, 1993; Rabkin, Remien, Katoff, & Williams, 1993). However, some authors argued that resilience is not a discrete quality children either have or do not have. Rutter (1990) stressed that:

“Resilience cannot be seen as a fixed attribute of the individual. If circumstances change, the risk alters” (Rutter, 1990, p. 184).

As research in the area grew, it became more common to think of resilience as a process which may be buffered by external factors such as the child’s environment and family (Luthar, et al., 2000; Masten & Garmezy, 1985; Rutter, 1987). It was found that protective factors such as the family, community and strengths within the individual interacted with risk factors and together they lead to a process of resilience (Masten & Garmezy, 1985; Werner & Smith, 1982). This resilience process is viewed as an underlying mechanism which contributes to positive outcomes (Luthar, et al., 2000). By viewing resilience as a process, it became apparent that resilience is not an absolute construct, but rather one which necessitates a developmental sequence (Luthar, et al., 2000; Werner 2000). New vulnerabilities and strengths often surface with varying life circumstances.

2.2.3 Protective factors

Resilience is built upon complex interactions between risk and protective factors which operate at individual, family and community levels. All of us exist in a dynamic environment and resilience involves ever-changing risk and protective factors (Hawley & DeHann 1996; Conger & Conger 2002). As a result, fostering resilience is not purely a matter of determining whether an individual is resilient, but how they are resilient (Simon et al. 2005). It is difficult to predict the relative importance of each protective factor. The interaction amid several risk factors may result in different outcomes. Similarly,

protective factors may be favourable at one point in time and detrimental at another (Hawley & DeHann 1996; Little et al. 2004). Thus, protective factors need to be assessed in context, as many influences may restrain or mediate their functioning.

It is now recognized that both external (contextual) and internal (psychological) processes influence an individual's capacity for resilience (Luthar, Cicchetti, & Becker, 2000; Masten et al., 1990; Werner & Smith, 1982). These factors, also referred to as 'protective factors', moderate the risks people face and also help them to achieve positive outcomes (Werner, 2000). Over the last three decades, common findings from international research suggest three main clusters of variables which appear to facilitate positive adaptation under conditions of adversity (Masten & Reed, 2002). Firstly, resilience consists of individual attributes or characteristics such as good cognitive abilities, high self esteem, self efficacy, ability to self regulate ability to form friendships and build a social network, and temperament (see resilience matrix Table 2.2 below).

Secondly, a positive family environment which is built upon warmth, quality parenting, realistic expectations, and which provides a structured, stable home with little conflict between parents, is viewed as essential in fostering resilience (Fredrickson, 2001; Rutter, 1990). Other protective factors relating to interpersonal relationships inside and outside the family would include close relationships with adults and social peers who abide by societal rules and norms.

Finally, broader contextual variables such as positive extra familial support sources such as effective schools, participation in extracurricular activities, neighbourhoods with high collective efficacy or those with high levels of social cohesion, a high level of public safety, effective emergency social services, good public health and links with extended family support networks (Luthar et al., 2000; Masten, 2001; Masten & Coatsworth, 1998; Werner & Smith, 1992). The concept of resilience and protective factors refers not only to psychological skills, but also to the possibilities for the

individual to take advantage of family, social and external support systems in order to cope better. Resilient people are more flexible than “vulnerable” people are, and they protect themselves against stress by making use of various protective resources. These protective factors which were adapted from the literature are summarized in Figure 2.1 below.

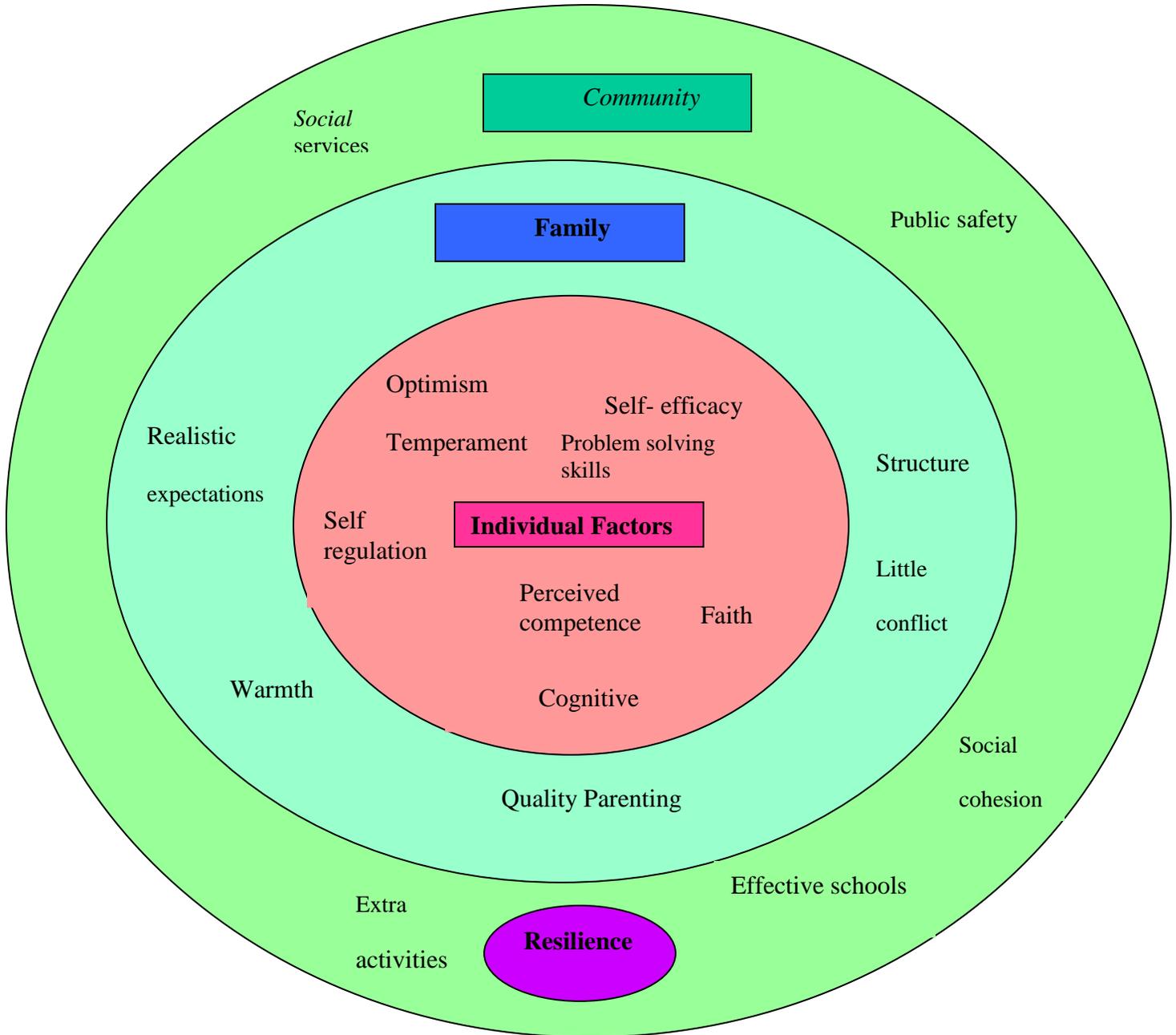


Figure 2.1 Protective factors which promote resilience

The diagram shows the dynamic nature of protective factors and the interplay between factors which contribute to the resilience process. In summary, resilience is most likely to be found when risk factors are minimized and protective factors are present (Rutter, 2002). A summary of

characteristics which act as protective factors and which promote resilience is presented in the literature review matrix below. An analysis of 45 articles from the literature was performed and 18 key factors were identified to guide the analysis.

Table 2.2 Literature review matrix of Characteristics of Resilience

Characteristics		
1= Warmth & capacity for close relationships	7 = Has positive future expectations	13= Setting goals
2= Social poise & presence	8 = High self esteem\ Positive self concept	14 = Good intellectual functioning
3= Productive & gets things done	9 = Responds to humour	15 = Positive Temperament\ emotion
4= Internal locus of control	10 = Good at problem solving	16= Self efficacy and independence
5= Optimistic	11 = Arouses liking and acceptance	17= Self regulation skills
6= Socially perceptive, social support	12 = Has insight into own behaviour	18 = experience positive affect

Number	Reference	Resilience Characteristics																		Total
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	
1	Newman, R (2005)	x				x	x		x				x							5
2	Tedeschi & Kilmer (2005)			x		x		x	x		x			x	x	x	x			9
3	Letzring, Greve & Funder (2005)				x				x									x	x	4
4	Werner (2000)		x	x	x	x			x	x	x	x		x	x	x	x	x	x	13
5	Garmezy (1993)				x		x							x		x				4
6	Block & Kreman (1996)		x													x	x	x		4
7	Masten, Best, & Garmezy, (1990)	x	x	x	x					x	x			x	x	x		x		10
8	Masten (2001)						x		x			x		x				x		5
9	Alvord & Grados (2005)	x				x	x	x	x		x	x		x	x	x	x	x	x	12
10	Hawley (2000)									X		x	x		x	x				5
11	Watt, David, Ladd, Shamos (1995)				x	x	x						x		x		x			6

Number	Reference	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	Total
12	Bonano (2004)				x				x							x		x		4
13	Curtis, Cicchetti (2003)									x			x		x	x		x	x	6
14	Connor & Davidson (2003)	x		x	x	x			x	x		x					x			8
15	Tugade, Fredrickson, Barrett (2004)					x					x	x				x			x	5
16	Masten (1994)	x	x								x		x		x			x		6
17	Fredrickson, Tugade, Waugh, Larkin, (2001)					x	x	x		x						x				6
18	Iwaniec, Larkin, Higgins (2006)						x		x		x	x			x		x	x		7
19	Connor, K (2006)	x		x		x	x				x	x		x		x	x			9
20	Karoly & Rhuelman (2006)				x	x		x			x				x	x	x	x	x	9
21	Campbell-Sills, Cohan, Stein, (2006)	x					x				x	x				x	x		x	7
22	Ong, Bergeman, Bisconti, Wallace (2006)															x		x	x	3
23	Tandon & Solomon, (2008)		x				x		x		x	x								5
24	Olssona, Bonda, Burns, Vella-Brodrick, Sawyer (2003)	x			x	x	x			x	x	x			x	x	x	x		11
25	Steinhardt, & Dolbier (2008)		x		x	x			x										x	5
26	Dumont, Widom, Czaja (2007)		x								x				x					3
27	Collishaw, Pickles, Messer, Rutter et al (2007)		x		x		x		x		x	x			x			x		8
28	Joyce, Yi-Frazier, Ronald, Peter et al (2009)				x	x			x		x						x			5
29	Edward, & Warelow (2005)	x	x	x		x	x		x	x	x			x	x		x			11
30	Brown, & Waite (2005)						x		x						x					3
31	Schweitzer, Jaimi & Kagee (2005)		x			x					x	x								4
32	Rajkumar, Premkumar, Tharyan, (2008)		x		x	x		x									x			5
33	Lansford, Malone, Stevens et al (2006)	x					x				x			x	x					5
34	Edward (2005)		x			x		x	x					x	x		x		x	8
35	Dowrick, Kokanovic, Hegarty (2008)		x		x	x	x		x	x	x						x	x	x	10

Number	Reference	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	Total
36	Benzies, & Mychasiuk, (2009)		x		x										x	x	x	x		6
37	Walsh (2003)		x			x		x			x							x	x	6
38	White,Driver, Warren, (2008)	x	x		x		x	x					x	x						7
39	Netuveli, Wiggins, Hildon, Blane (2008)		x																	1
40	Tinsley Li,Nussbaum, Richards (2007)		x				x		x											3
41	Riley,Valdez, Barrueco (2008)	x	x						x		x								x	5
42	Vanderbilt-Adriance, &Shaw (2008)				x						x				x	x		x	x	6
43	Donald, Dower, Correa-Velez, Jones,(2006)		x		x		x				x									4
44	Herrenkohl, Sousa,Tajima,et al (2008)				x				x						x					3
45	Armstrong, Birnie-Lefcovitch,Ungar,(2005)		x		x		x		x		x	x					x			7
Total		12	21	6	20	19	20	8	21	8	24	16	5	6	20	17	21	18	16	
<i>Percentages %</i>		27	47	13	44	42	44	18	47	18	53	36	11	13	44	38	47	40	36	

It was found that 53% of the articles identified good problem solving skills as being a significant factor in encouraging resilient behaviours, while 47% of the articles identified having positive self esteem, positive sense of self, self efficacy and independence. Other key factors were having an internal locus of control, good cognitive abilities and being able to elicit positive social responses in others. Self regulation skills, optimism and experiencing positive effect were also contributing factors.

Detailed descriptions of the protective factors identified are summarized in Table 2.3 below.

Table 2.3 *Description of Protective factors*

Warmth and capacity for close relationships	<p>Individuals who are secure in relation to attachment have high self-esteem (Bartholomew & Horowitz, 1991; Shaver, Belsky, & Brennan, 2000) and are considered well-adjusted, “more resilient”, nurturing, and warm by their peers (Bartholomew & Horowitz, 1991).</p> <p>Consequently, they are likely to explore the world self-confidently, initiate warm and sociable interactions with others, and are able to form lasting friendships (Campbell-Sills, Cohan, & Stein, 2006; Conner & Davidson, 2003; Masten & Garmezy 1985). Friendships provide support systems that can promote emotional, and social, adjustment (Rubin, et al., 2004).</p>
Loss of Control	<p>Loss of control refers to an individual’s awareness of where the causal responsibilities for life events reside (Benzies & Mychasiuk, 2009; Werner, 1993). Those with an internal locus of control believe that they: (1) control their own destiny; (2) have the power to change their situation; and (3) create their own circumstances (Benzies & Mychasiuk, 2009; Egeland, Carlson, & Sroufe, 1993; Juby & Rycraft, 2004). To effectively adapt to stressors, individuals needed to believe that they can exert influence and actively respond to adverse events (Juby & Rycraft, 2004). Internal locus of control is a fundamental feature of resilient individuals. When faced with a difficult situation, they are more likely to explore alternative strategies which will change the situation and make positive changes (Werner, 1995).</p>
Optimism	<p>Optimism reflects an individual’s expectation of a positive outcome in most situations (Scheier & Carver, 1985; Seligman, 1995). Being optimistic “enables the individual to set goals, make commitments, cope with adversity and pain, and to recover from trauma and/or stress” (Chang, Maydeu-Olivares, & D’Zurilla, 1997; Fischer & Leitenberg, 1986).</p> <p>Optimism allows individuals to take risks, try new things and accept the outcome irrespective of whether it is a success or failure.</p>
Has positive future expectations	<p>Individuals who have positive expectations of the future tend to adjust their behaviour, maintain positive emotions and generate opportunities for growth (Clausen, 1991; Wyman, Cowen, Work, & Kerley, 1993) On the contrary, those who have low expectations of the future are likely to engage in risk-taking behaviours such as alcoholism, drug use, criminal behaviour and at risk sexual activity (Nurmi, 1991; Robbins & Bryan, 2004).</p>

High self esteem\ Positive self concept	Self-esteem is typically regarded as the evaluation that people make about themselves that expresses a self-judgment of approval/disapproval, and personal worth (Demo & Savin-Williams, 1992; Rosenberg, 1965; Swann Jr, Chang-Schneider, & McClarty, 2007). The successful development of a positive sense of self worth and self concept may help enhance healthy outcomes or protect individuals from engaging in at risk behaviours.
Responds to humour	Resilient individuals have been found to use humour as a coping strategy when faced with stressful circumstances (Werner & Smith 1992; Wolin & Wolin, 1993). Humour has been defined as "a way of establishing connections, defusing conflict, coping with pain and anxiety, and bringing others fun and enjoyment" (Berg and Bockern, 1995). Coping by means of using humour is associated with the generation of positive emotions which help the individual to reduce stress, restore perspective and remain engaging to others (Masten , Best, & Garmezy, 1990). These attributes help people analyze life's misfortunes in different ways and in so doing, develop novel (and adaptive) ways to deal with adversity.
Good at problem solving	Problem solving skills enable an individual to be cognitively flexible through the generation of alternative strategies and solutions when faced with difficult situations (D'Zurilla & Nezu, 2000; Isen, Daubman, & Nowicki, 1987)
Arouses liking and acceptance	Having positive peer relationships is predictive of positive outcomes, including better social skills, better conflict-resolution skills (Newcomb & Bagwell, 1995; Strough, Swenson, & Cheng, 2001), more cooperative behaviour, (Hartup, 1996), and an overall positive self-concept (Vandell & Hembree, 1994). Moreover, there are many harmful outcomes linked to peer rejection, such as poor adjustment (Ladd, Kochenderfer, & Coleman, 1997) and aggression (Dodge, et al., 2003). Resilient individuals, therefore, are able to elicit liking and acceptance from their peers and those around them, which in turn helps build their repertoire of friendships and increases their social network.
Has insight into own behaviour	Resilient people possess insight and self-awareness. They are aware of their strengths and limitations. Insight includes intuitive awareness of environmental cues, especially of danger. It also helps in the realizations which transform one's perceived reality. This is achieved through "asking penetrating questions of oneself and providing honest answers" (Wolin & Wolin, 1993, p. 71). Insight allows individuals to interpret and perceive their adversity in a manner which allows them to move beyond victimhood and reconstruct their lives in new ways (O' Gorman, 1994).

<p>Good intellectual functioning</p>	<p>Research has found that better intellectual abilities have been related to more positive outcomes (Cicchetti & Rogosch, 1997; Garmezy 1993; Masten & Reed 2002). These cognitive abilities include processes such as planning, memory, attention, reasoning, behaviour regulation.</p>
<p>Positive and easy temperamental traits, which in turn shape a flexible personality</p>	<p>The construct of temperament is commonly viewed as the basic organization of personality, which is observable as early as infancy and becomes elaborated over the course of development as the individual's skills, abilities, cognitions, and motivations become more sophisticated (Berdan, Keane, & Calkins, 2008; Calkins & Degnan, 2006; Rothbart, Ahadi, & Evans, 2000). A person's temperament is relatively stable over the life course, but can be modified with environmental influence. Research done with children show that those who have an easy, happy temperament were more likely to elicit positive responses from their caregivers and less likely to be victims of maltreatment (Flores et al., 2005). Similarly, those with easy temperaments are more likely to display cognitive flexibility which entails the ability to see alternatives and try new strategies to overcome problems.</p>
<p>Self efficacy and independence</p>	<p>Linked to the concept of self-esteem, self-efficacy refers to an individual's judgement of their own ability to succeed in reaching a specific goal (Bandura, Pastorelli, Barbaranelli, & Caprara, 1999). Maddux (2002) describes self efficacy as "the simple, powerful truth that confidence, effort and persistence are more potent than innate ability" (p.285). Self efficacy beliefs regulate human functioning and emotional well-being through cognitive, motivational, affective and selective processes. When confronted with adverse events, those who maintain the belief that they will be able to exert control over their thoughts are more likely to persevere in their efforts. Those who are self-efficacious are also more likely to rebuff negative thoughts about themselves or their abilities (Ozer & Bandura, 1990).</p>
<p>Self regulation of emotions, and impulses</p>	<p>Throughout development, individuals learn to control their actions, behaviours and emotional responses (Eisenberg <i>et al.</i>, 2001). The ability to inhibit impulses enables individuals to delay gratification, have better interpersonal relationships and think clearly during stressful situations (Rubin, Coplan, Fox, & Calkins, 1995).</p>

2.2.4 Coping

Coping is behaviour aimed at managing internal and environmental demands, which strain or exceed a person's resources (Lazarus & Folkman, 1984). The idea of coping is a broadly used concept (Murphy, 1962) referring sometimes to mechanisms for adjusting anxiety in the face of challenge, frustration, or stress. In addition, with most coping definitions, there is a relationship with “stress,” that is, how individuals cope with stressful situations. For the purpose of this thesis, coping is used interchangeably with resilience.

Coping can be viewed in two forms (Lazarus & Golden, 1981):

- It may be an *emotionally focused method* of coping, which is an internal and physically oriented process. In emotion-focused coping, individuals try to directly moderate or reduce negative emotions (Edward & Warelow, 2005; Folkman & Moskowitz, 2000). Examples of emotion-focused coping include reframing the situation in a positive way, relaxation, denial, and wishful thinking. For instance when faced with a diagnosis of MS, a person with emotion focused coping might decide to ignore the problem, hoping it goes away, until the symptoms get worse (denial).
- A *problem focused* coping method that is active and externally focused (such as participating in a rehabilitation program). In problem-focused coping, individuals try to circumvent negative emotions by taking some action to modify, avoid, or minimize the threatening situation (Joyce, et al., 2009; Kohn, 1996; McCabe & Di Battista, 2004; Miller, 2003). They adjust their behaviour to deal with the stressful situation. (Examples include planning and seeking social support).

These two forms of coping strategies are not mutually exclusive, and an individual may use both types of coping. Although the literature suggests that individuals with chronic

disease use both problem-focused and emotion-focused coping behaviour to deal with stressors related to illness and disability, research has revealed that problem-focused behaviour is more often employed (Campbell-Sills, et al., 2006; Folkman & Moskowitz, 2000; Miller, 2003; Rutter 1983).

2.2.5 Mood states and resilient behavior

There is mounting evidence that positive mood states (displaying positive emotions) are related to better physical and psychological benefits (Fredrickson, 1998, 2001; Lefcourt, Davidson-Katz, & Kueneman, 1990; Ostir, Markides, Peek, & Goodwin, 2001). A comparison across several research methodologies showed that resilient individuals had optimistic, approaches to life, were open to new experiences, and were distinguished by high positive emotionality (Block & Kremen 1996; Feldman Barrett, Salovey, & Mayer, 2002). Positive emotions exhibit a buffering function and provide a useful remedy to the problems associated with negative emotions and ill health (Fredrickson, 2000). For instance, resilient people nurtured their positive mood states by intentionally inducing positive emotions. They also reported greater involvement in social activities (Burger & Caldwell, 2000; Watson, Clark, McIntyre, & Hamaker, 1992), more enjoyable social interactions (Berry & Hansen, 1996), and greater friendship contact. A reason why positive mood states lead to better social interactions could be that positive affect activates the dopaminergic system in brain areas responsible for executive control and flexible thinking (Isen, et al., 1987; Kumpher, 1999). In contexts such as social situations, flexible thinking leads to flexible perspective taking, which results in increased closeness.

Methods used by resilient individuals to nurture their positive mood states were (1) humour, (2) disclosing positive emotions, and (3) using coping strategies which promote

positive emotions (Tugade, Fredrickson, & Barret, 2004; Werner & Smith 1992). These three methods are described below.

2.2.6 Humour and resilience

Humour can be defined as "a way of establishing connections, defusing conflict, coping with pain and anxiety, and bringing others fun and enjoyment" (Berg & Bockern, 1995). Based on the above definition, there appears to be a relationship between humour and resilience. Humour helps to transform anger and sadness into laughter. It helps people distance themselves from pain and adversity (McBroom, 2002). In doing so, humour acts as an avenue through which people can analyze life's misfortune in a positive way (Higgins, 1994; Vaillant, 2000). This in turn enables them to develop different, novel ways to solve problems and deal with adversity (Vande Berg & Van Bockern, 1995). Consequently, people who use humour to cope report higher levels of positive mood (Lefcourt, et al., 1990).

2.2.7 Disclosing positive emotions

Emotional disclosure has been shown to increase the experiencing of positive mood (Emmons & McCullough, 2003; Pennebaker & Seagal, 1999). For instance, when asked to write about experiences of trauma, participants who were identified as resilient disclosed a greater proportion of positive-emotion (vs. negative-emotion) words, showed increased positive mood, and were less depressed (Hughes, Uhlmann, & Pennebaker, 1994; Pennebaker & Francis, 1996).

Disclosing emotions through writing and talking involves executive functioning processes such as organizing, integrating, and analyzing one's problems (Lyubomirsky, Sousa, & Dickerhoof, 2006). This in turn helps the individual to better understand, and make meaning of the adversity (Singer, 2004). When the meaning of an experience is understood,

the individual is better able to manage and control their emotional experiences (Pennebaker & Seagal, 1999).

2.2.7.1 Coping strategies which promote growth post trauma

Research examining reactions to life-threatening illness and other traumatic events has typically focused on the coping process. Successful coping strategies are described as keeping the traumatized person from experiencing excessive psychological distress and helping him or her to adjust to life in the wake of a stressful encounter. These strategies represent positive changes in an individual's life which occur in response to trauma, including shifts in perception of the self, relationships with others, and worldview in general.

Coping strategies which promote positive growth post trauma such as, (1) positive reappraisal, (2) problem focused coping and (3) finding positive meaning, help buffer against adversity and depression (Davis, Nolen-Hoeksema, & Larson, 1998; Folkman & Moskowitz, 2000).

(1) Positive reappraisal - Positive reappraisal refers to the process of discovering the 'bright side' of events in a stressful situation (Tugade & Fredrickson, 2004). The core of positive reappraisal is to reframe a traumatic situation by recognizing potential positive outcomes (Pressman & Cohen, 2005). For example, in qualitative studies, caregivers commented on how their care giving activities demonstrated their love and support for their ill partners (Folkman, Chesney, & Christopher-Richards, 1994). Consequently, the painful, exhausting, and stressful experience of being a caregiver was reappraised as being worthwhile. Being aware of the value of care giving activities in this study had a motivational effect on subsequent care giving. Focusing on the value of their care giving effort and positively appraising this effort may be important in helping people sustain efforts, over long periods of time.

(2) Problem focused coping- Problem focused coping refers to efforts which are directed at directly solving or managing problems (Folkman & Moskowitz, 2000). Strategies such as gathering information, making decisions, goal setting and planning are often employed to solve the problem (Lazarus & Folkman, 1984). This can be contrasted with emotional focused coping where emotional responses are regulated in response to stress. Strategies such as distancing, accepting the problem, and escaping are often used (Kohn, 1996). It may seem contradictory to use strategies such as problem solving and goal setting under conditions which are extremely stressful, such as coping with TBI or MS. This is largely because the nature of TBI and MS are uncontrollable, and unpredictable. However, it may be possible to return a sense of control to individuals through the relinquishment of old goals, and forming new ones. For instance, individuals often feel a sense of helplessness when coping with a diagnosis of MS because of the unpredictable and uncontrollable nature of the disease. Rather than being passive, individuals were pro active and pursued realistic, attainable goals by focusing on specific, achievable tasks. These included adhering to their medication, although it made them really sick, or maintaining an exercise routine daily.

(3) Finding positive meaning - Finding positive meaning can be achieved through finding benefits in adversity. For instance, positives can be found in traumatic situations by focusing on strengths or the lessons learnt through the process (Fredrickson, Tugade, Waugh, & Larkin, 2003b). Individuals with TBI may find positive meaning in preparing a special meal for themselves, or by attending a pre arranged meeting with friends. Pleasure and positive emotions may also be derived from enjoying a walk in the park, receiving a compliment for achieving a task or even for some, by just making an effort to get out of bed each morning.

Tedeschi and Calhoun (1995) state that in response to a traumatic situation, personality characteristics contribute to how an individual attempts to cope with stress. However, in the

case of an unusually stressful event, the coping strategies, upon which the individual usually relies, may prove unsatisfactory. The consequential emotional distress presents a challenge to existing schemas. This can lead the individual to engage in a period of constructive reflection during which these schemas are revised. A range of different coping strategies may then be employed, including positive reappraisal, problem-focused coping and finding positive meaning. Post trauma growth occurs in response to the development of new schemas and the helpfulness of coping strategies. Positive emotions then, came into view as an important building block of psychological resilience post trauma.

2.2.8 Fredrickson's broaden and build theory of positive emotions

Fredrickson's (1998) broaden-and-build theory of positive emotions hold that the broadening activated by positive emotions constructed a variety of personal resources, including physical resources (e.g., health), social resources (e.g., friendships), intellectual resources (e.g. intellectual complexity), and psychological resources (e.g., resilience). Consequently, by experiencing positive emotions, people grow to be more imaginative, educated, socially included, healthy, and resilient individuals. This perspective on positive emotions might help explain why those who experience positive emotions in the midst of stress are able to benefit from their broadened mindsets and successfully regulate their negative emotional experiences. The ability to recover quickly from negative affect is more than likely mediated by a multifaceted neural network. This network includes perception, contextual evaluation, and expression of emotion. It is also linked to the amygdala, several regions of the prefrontal cortex, brain stem structures, the hippocampus, and aspects of the cingulate cortex (Davidson, 2000; LeDoux, 1996). Similarly, these might be the same regions of the brain which are responsible for eliciting resilient coping behaviours.

2.2.9 *Recent advances*

Recent advances in resilience research show that resilience is not determined by static protective factors but by dynamic ones through which multiple or accumulated risks may be moderated (Rutter, 2002; Tugade & Fredrickson, 2004). Due to the dynamic nature of resilience, it is now acknowledged that people deemed resilient in one domain may not be so in another. Similarly, people can demonstrate resilience in one area of functioning and not others (Gilgun, 2005).

Having said that, current research is focusing on ways in which people can learn to become more resilient, and how their resilience can be fostered and nurtured (Alvord & Grados, 2005; Flores, Cicchetti, & Rogosch, 2005). The next section deals with ways in which resilience can be nurtured and the implications this has on clinical practice.

2.2.10 *The relevance and clinical implications of resilience to practitioners*

Clinicians and researchers in a similar way agree about the relevance of resilience; however, not many strategies exist in research which suggests ways for clinicians to apply and build resilience in their clients. Nevertheless, the literature can be used to provide valuable information to practitioners regarding strategies which inform assessment and guide clinical intervention. Almost all definitions of resilience assume that individuals demonstrate a capacity to overcome adverse circumstances through the use of inherent or attained resources and strengths (Rutter, 2002; Tedeschi & Kilmer, 2005; Werner, 2000). A resilience framework which emphasizes existing strengths and assets would be useful for positive growth and change, despite the development of problems (Luthar & Cicchetti, 2000). Focusing on strengths then directs the practitioner's attention to positives and allows for a balanced assessment, from which intervention goals can then be formulated (Hawley, 2000). These goals could include building resources and facilitating protective processes, regulating

themselves in times of stress, managing emotions and behaviour, in addition to reducing other presenting problems (Tedeschi & Kilmer, 2005).

Nonetheless, it is important to remember that an individual's strengths and potential protective influences arise from various levels of the client's environment, that is, individual, family, and community (see Figure 2.1). Accordingly, rather than viewing a goal of assessment as measuring resilience by itself, it may be more appropriate to assess factors related to positive adjustment, ability to cope in a variety of domains, and healthy outcomes under adversity (Tedeschi & Kilmer, 2005).

2.2.11 Assess resilience as a developmental process

Resilience is often assessed as a static characteristic in individuals which is assessed at one given point in time, arguably at the time the client comes in for therapy (Hawley, 2000). For example, most commonly during a clinic session, a diagnosis is given to the client based mostly on the current or recent presenting problem with little consideration to the development of the problem (Lezak 1995). Therapy is then focused on changing the current problem through therapeutic goals aimed at the situation at hand.

Whilst there is nothing wrong with this, resilience based therapy for clients with psychiatric, psychological and disability related problems would benefit from viewing resilience as a dynamic process through which, over time, the individual learns to respond to significant stressors (Hawley, 2000). This is also consistent with the notion that individual's resilience is built over time and that she/he constantly learns new ways to respond to significant stressors (Rutter, 1983). Consequently, when trying to understand the underlying strengths and risks faced by the patient, clinicians should not only focus on the problem at hand but seek to identify the developmental processes of resilience that the person currently uses and those he/she previously had (Hawley, 2000; Tedeschi & Kilmer, 2005).

For this purpose it is crucial to evaluate the journey the participant pursues before and in response to an adverse situation. Therapy can then focus on anticipating and planning strategies which will help the individual to adapt to problem situations (Harris, Burns, & Rees, 1989; Khan, Baguley, & Cameron, 2003). For example, following a traumatic brain injury, a person may come into therapy experiencing major losses in his/her life and may appear to have little or no resilience. They may be experiencing depression, confusion, grief, trauma, as well as other problems from their injury. Given their circumstances, resilient behaviours may not be easily anticipated as the person is confronted with the immediate effects and consequences of his/her accident or injury (Rees, 2005; Thomsen, 1992). This is in no way indicative of the individuals' resilience or ability to be resilient (Rutter, 1990; Werner, 1995). A complete history, taking into consideration the person's pre and post trauma functioning, may provide a more comprehensive understanding of individuals and the problems they currently experience (Garmezy, 1993; Tedeschi & Kilmer, 2005). This ability will not be seen if the person had been assessed solely based on their resilience at one given point in time (Hawley, 2000).

2.2.12 Developing healthy perceptions of stressors

The way in which an individual views a particular stressor or crisis situation is crucial to the development of not only his/her resilience but also, perhaps more importantly, to his/her response and reaction (Alvord & Grados, 2005). How an individual copes with or adapts to an adverse situation can be viewed in relation to their internal working model or perception about themselves, others and the world around them (Cicchetti, 2002; Cicchetti & Rogosch, 1997). These working models are often referred to as mental representations, scripts or schema's (Gilgun, 2005). These mental interpretations arise from the individual's

previous experiences, and are influenced by his/her gender, age, social class, ethnicity, and historical development at that time (Hawley, 2000).

Schema theories are linked with Piaget's theories of cognitive development, attachment theory, and cognitive science. These mental representations are believed to occur involuntarily in reaction to individual's perceptions of ecological cues and are external to conscious awareness (Bargh & Chartrand, 1999 in; Gilgun, 2005). Schemas can however change as new experiences become entwined into existing schemas and old schemas are replaced by differently perceived experiences, better known as the process of 'accommodation' (Young, Klosko, & Weishaar, 2003).

In relation to applying the schema theory in practice, clinicians can aim to understand a person's mental representations to get a picture of how he/ she see and perceive the world, his/ her belief systems and what he/ she expects from themselves and others (Gilgun, 2005). Questions clinicians can use to obtain this information are taken from Gilgun (2005) and summarized in Table 2.4 below.

Table 2.4 *Questions which can be used when assessing a client's schemas*

Questions which can be used when assessing a client's schema's
➤ How automatic are the client's behaviours, and the emotions and cognitions associated with the behaviours?
➤ What are his/her belief systems and when are they mainly apparent?
➤ How rigid are these beliefs?
➤ What triggers in the environment set off the client's schemas which lead to both negative and positive behaviours?
➤ Who in the client's environment supports the activation of positive schemas?
➤ Who supports negative schemas?
➤ How can these automatic schemas be modified to avoid negative outcomes?

Using schema theory to inform clinical intervention is based on the principle that responses to adversity can be automatic, often bypassing conscious thought (Young, Klosko, & Weishaar, 2003). This idea can then be used to help practitioners identify the triggers of strengths and negative automatic responses for the client. Strategies and plans for alternative ways of dealing with stress can then be thought, practiced, and modified over the intervention (Gilgun, 2005; Young, et al., 2003).

2.2.13 *Conclusion: Research on resilience*

In summary, resilience research has taken important steps in delineating the characteristics that differentiate individuals who achieve positive outcomes in the face of stress from those who meet with more negative outcomes. Building on these findings, researchers have increasingly advocated understanding the processes through which such characteristics impact on coping efforts (Aspinwall & Taylor, 1997; Blonna, 2007; Miller, 2003).

Also the field would be less fragmented if researchers could come to a consensus about how to study resilience. Specifically, the field needs to address issues such as: How do we create an operational definition of resilience as (one hopes) a process? How do we study the process? How do we foster the process? How do we evaluate the process? At this point, adequate research exists on the many correlates of resilience. To design effective interventions, however, more needs to be known and studied about causal processes.

Perhaps the most relevant question for clinicians would be how resilience can be fostered or built? To start with, resilience is multi dimensional and not a single concept. As mentioned, there appears to be no one trait or characteristic that defines resilience. In addition, one person's strategy for building resilience will probably not be the same as

another's. Choosing a strategy that works best for the individual to build resilience is a personalized process dependent upon his/her strengths, skills and experiences.

Therefore, building resilience is assumed to be something which can be done by everyone; however, it is not so easily accomplished by people who have specific disabilities and psychological disorders. For instance a person with brain injury can definitely benefit from building resilience. However, it appears unlikely that the person can achieve this without appropriate intervention strategies and support as part of their rehabilitation process. The current study focuses on highlighting ways in which resilience can be nurtured.

In the current researcher's view, there is a great need for the design and evaluation of complex, resilience based multi-faceted programs which target youth, families, schools, and communities. Not only should existing, successful, evidence-based research be replicated in different areas but also with different populations and cultures.

With this in mind, it can be said that people with brain injury are a logical sample to study because their disability (adversity) is not short lived, but a life-long condition often with no medical cure. Similarly, participants with MS cope with a disease which is unpredictable. They live in constant fear of another relapse, often not knowing for how long their symptoms may persist. Both groups of participants face disabilities that will not disappear, and have to employ new ways to manage their struggles (executive function) as well as to overcome and achieve positive adaptation (resilience). There has been little research on resilience behaviour and higher cognitive functions of the brain (Curtis & Cicchetti, 2003; Curtis & Nelson 2003). This study seeks to contribute in understanding the cognitive and social interactions of resilience.

2.3 Executive functions

The “executive functions” broadly encompass a set of cognitive skills that are responsible for the planning, initiation, sequencing, and monitoring of complex goal directed behaviour (Anderson, 1998; Lezak, 1993; Pennington & Ozonoff, 1996). Executive functions have been traditionally defined as

“integrative cognitive processes that determine goal-directed and purposeful behavior and are superordinate in the orderly execution of daily life functions including: the ability to formulate goals; to initiate behavior; to anticipate the consequences of actions; to plan and organize behavior according to the spatial, temporal, topical or logical sequences; and to monitor and adapt behavior to fit a particular task or context” (Cicerone et al., 2000, p. 1605).

Executive functions have been associated with specific higher cognitive functions such as insight, will, abstraction, reasoning and judgment, which are mostly dependent on the frontal lobes (Cicerone, Levin, Malec, Stuss, & Whyte, 2006b; Tranel, Anderson, & Benton, 1994). This means that, like memory or language, the executive *cognitive* functions are acquired skills that can be directly measured. Disruptions and impairments to the frontal lobes may result in the diminishment or loss of these capacities (McCloskey, 2003; Pennington & Ozonoff, 1996; Stuss, 1992).

Examples of a sophisticated level of executive functioning might include a woman talking to a friend on a mobile phone, whilst keeping an eye on her children as they play, planning what to cook for dinner and deciding that she needs to run to the store to get meat. In this example, the person is alternating between concentrating on a conversation and making sure her children are safe, thinking about dinner and what time it should be ready, and also reminding herself to run to the store before it closes. Each of these tasks is not particularly difficult, but the combination of them together is complex. Failure to attend adequately to each of the task demands can have catastrophic outcomes. This coordination of various processes and thoughts required in multitasking reveals the high load on one’s

executive functioning processes even while engaged in the relatively basic aspects of life (Logan, 2003).

Getting multifarious systems to perform various tasks close in time often requires some type of coordinating process in the brain. Over the years, it has been hypothesized that the brain contains an “executive” system or process which directs and controls the activities of lower level systems. The executive functions, therefore, consist of those capacities which enable a person to engage successfully in independent, purposive, self serving behaviour (Lezak, Howieson, & Loring, 2004).

Over time, there has been a gradual conceptual shift regarding the definition of executive functions. Early notions described it as a homogenous set of processes, and did not differentiate among individual sub-skills which might be integrated by such a label (Anderson, 1998). Presently, most authors agree that executive functions may be best understood as an umbrella term, which encompasses a number of consistent sub-skills, necessary for purposeful, goal-directed activity (Lezak 1993; McCloskey, 2003; Stuss & Benson, 1986).

The following aspects of human behaviour have been identified as part of the definition of executive functions (see Table 2.5).

Table 2.5 *Executive functioning behaviours*

Executive functioning behaviours
• Self-regulation,
• Setting and managing goals,
• Planning and organizing,
• Initiating and inhibiting actions and behaviour,
• Self-monitoring and evaluating,
• Thinking and acting strategically,
• Solving problems,
• Flexibly shifting among cognitive and affective sets,
• Consciously controlling cognitive functions (e.g., attention, memory),
• Managing information for effective processing (i.e., working memory),
• Perceiving social cues and interpreting others' social behaviour,
• Deliberately controlling emotional responses and interaction with others,
• Learning from consequences and adjusting behaviour accordingly, possessing reasonable self-awareness and sense of personal identity (Sohlberg & Mateer, 2001).

The neural substrates of these competencies are considered to lie in the prefrontal cortex. Successful performance on tests of executive function are critically dependent on the function of the frontal cortex and this is why the terms executive function and frontal lobe function are often used interchangeably. Similarities between ongoing maturation of the frontal lobes and the emergence of executive capacities have been reported in a number of studies (Anderson, 1998). Also, another reason why the two terms are often used in parallel is due to observations in people with frontal lobe damage who exhibit executive dysfunction. However it should be stressed that, while the frontal regions play a vital role in the mediation of executive functions, the employment of the entire brain is necessary for intact executive

function (Stuss & Benson, 1986). Figure 2.2 shows the coordination umbrella like functions of the frontal lobe (Rees, 1999; 2005, pg 170).

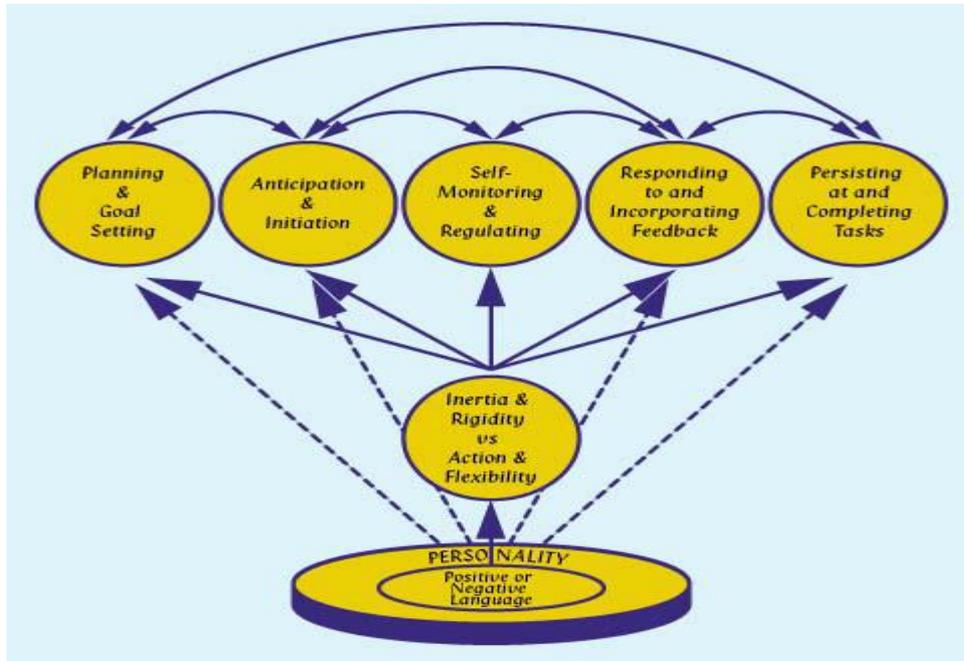


Figure 2.2 Frontal lobe umbrella: Executive functions and the relationship to personality.

The prefrontal lobes' associations to cortical and sub-cortical regions help to organize behaviour by activating, inhibiting and integrating ideomotor and sensorimotor activity in the brain (Sohlberg & Mateer, 2001). What this means is that the frontal lobes act as an executive branch of the brain that controls the functions of the neural systems which are involved in goal-directed behaviours. The frontal lobes also have strong connections with the limbic structures such as the hippocampus and amygdala, which are involved in processes such as learning, memory, emotional processing and regulation (Elliot, 2003). Lezak (1993) makes a distinction between cognitive abilities, which could be seen as being specific to a particular domain, and executive functioning skills, which act more globally and impact upon all

aspects of behaviour. She also states that in order to achieve socially appropriate conduct, the reliability of these functions are necessary.

Shallice (1990), modified the concept of executive functions by arguing that executive functions are not predominantly used for the execution of routine, well-learned behaviours, but are more specifically stimulated in novel or unfamiliar circumstances, where no previously established routines for responding exist (Anderson, 1998). This is where the concept of 'resilience' would seem to be important. When people are faced with newly emerging adversities, they have no previously established ways to respond, and therefore are forced to employ new methods of overcoming their hardships.

There are numerous ways of assessing executive functioning skills and a few of them are provided in Table 2.6 below.

Table 2.6 *Methods which can be used to assess executive functions*

Direct Observation	Norm-referenced scores	Process Variable Descriptions (quantitative and qualitative)	Qualitative observation of cognitive processes during task performance
Standardized, individually administered task performance	Delis-Kaplan Executive Function System (D-KEFS) (Delis, Kaplan, & Kramer, 2001).	Delis-Kaplan Executive Function System (D-KEFS) (Delis, Kaplan, & Kramer, 2001).	WISC-IV Block Design, Coding, Symbol Search, Cancellation (Wechsler, 2003).
	NEPSY, A Developmental Neuropsychological (Korkman, Korkman, Kirk, & Kemp, 1998)	WISC-IV Integrated Process Observations (Wechsler, 2003).	NEPSY Verbal Fluency (Phonemic contrasted with Semantic Fluency) (Korkman, Korkman, Kirk, & Kemp, 1998)
	WISC-IV Integrated (formerly the WISC-III PI) subtest scores and Process scores. (Wechsler, 2003).	California Verbal Learning Test-Children's Edition (CVLT-C) variables (Delis, Kramer, Ober, & Kaplan, 1994).	Behaviour Ratings
	Rey Complex Figure Test (RCFT) (Meyers & Meyers, 1994)	Children's Memory Scale Sequences Subtest (Cohen, 1997).	Behaviour Rating Inventory of Executive Function (BRIEF) (Gioia, Isquith, Guy, & Kenworthy, 2000)
	Wisconsin Card Sorting Test (WCST) (Kongs, Thompson, Iverson, & Heaton, 2000)	NEPSY Verbal Fluency Subtest (Korkman, Korkman, Kirk, & Kemp, 1998)	Adolescent and Adult Self-Rating Scales (McCloskey, 2003)

2.3.1 *Importance of executive functions*

If executive functions are those required to succeed with tasks that pose new challenges, then it follows that people with brain injury, typically frontal lobe damage, require specific attention to the development of strategies that will facilitate dealing with problem solving about how to deal with these challenges (Sohlberg & Mateer, 2001). The frontal areas of the brain are particularly vulnerable when there is trauma to the head which explains why executive control deficits are pervasive in brain injury (McCloskey, 2003; Sohlberg & Mateer, 2001). However, as mentioned above, reliable executive control makes use of all cognitive processes and therefore virtually any injury to the brain, regardless of its location in the brain, may result in some degree of executive dysfunction (Elliot, 2003; Lezak 1993; Stuss, 1992).

Executive dysfunction is normally connected to frontal lobe damage and simply put, is an organically based inability to plan, put into action, and carry through with an appropriate course of action (Benedict, et al., 2004; Cummings & Bogousslavsky, 2000; Eslinger & Geder, 2000; Lezak, 1993). Additional behaviours related to executive dysfunction include difficulty sequencing events, loss of self-monitoring ability, and inability to analyze social situations and self-adjust to changes in the environment (Eslinger & Geder, 2000; Fish, et al., 2007). When people demonstrate such behaviours, they may have difficulty interacting with others and may be identified as cognitively impaired, unmotivated, and disinterested (Armstrong, 1991; Khan, et al., 2003). Such effects of diminished executive functioning create pervasive social and vocational problems (Elliot, 2003; Isen, 1987).

Table 2.7 below presents a few common problems with executive functioning, which people with frontal lobe injury often experience.

Table 2.7 *Executive functioning processes commonly difficult for people with frontal lobe injury*

Executive functioning processes
• Inhibiting reflexive, impulsive responding
• Interrupting, and returning to, ongoing activity.
• Interacting with and selectively directing attentional processes, screening out interference and sustaining attention
• Cueing the initiation of effort, judgments about the amount of effort required to complete a task and sustaining a sufficient amount of effort to effectively complete the task
• Demonstrating flexibility when shifting cognitive resources to focus on new demands or respond to new conditions or information
• Directing the efficient use of, and alternation between, pattern and detail processing.
• Monitoring and regulating speed of information processing.
• Monitoring task performance for accuracy and efficiency
• Directing motor output, altering performance based on feedback
• Directing the use of working memory resources
• Directing the efficient placement of information in long-term storage
• Directing the retrieval of information from long-term storage
• Regulating social behaviour
• Regulating emotional control
• Enabling self-observation and self-analysis
• Enabling the capacity to “take the perspective of the other” in order to infer how someone is thinking or feeling at a given point in time

(Cicerone, et al., 2006; Elliot, 2003; Foong, et al., 1997; McCloskey, 2003; Stuss, 1992).

2.4 Traumatic brain injury

“Success is not final, failure is not fatal; it is the courage to continue that counts”

Winston Churchill

2.4.1 Introduction

Recent estimates of the incidences of brain injury, suggest that there are approximately 30, 000 people per annum in Australia, who are admitted to hospital with Traumatic Brain Injury (Khan et al., 2003). This figure underestimates the true incidences of TBI due to classification and diagnostic errors (Khan et al., 2003). Most Traumatic Brain Injuries in Australia are a result of motor-vehicle-related trauma (Khan et al., 2003).

Brain injury displays an extremely diverse spectrum of probable lesions and consequential disabilities (Fortune & Wen, 1999). The range of severity of TBI is also extensive, from injuries which result in concussion through to persistent vegetative states (Fortune & Wen, 1999). One of the most common injuries which occur, as a result of an external force to the brain, is damage to the frontal lobe (Eslinger & Geder, 2000). TBI largely affects the frontal functions of the brain which results in the loss of abilities such as anticipating, planning, responding to feedback, and having a flexible approach to life (Cicerone, Levin, Malec, Stuss, & Whyte, 2006; Eslinger & Geder, 2000; Stuss & Alexander, 2000).

Devoid of proper interventions, people with Traumatic Brian Injury become more at risk for depression, isolation, and withdrawal behaviours (Burns, 1989; McKinlay, 1999; Taylor & Jung, 1998; Thomsen, 1992; Wood & Yurdakul, 1997). This is why research on resilience is important as it allows individuals to equip themselves with skills which enable them to cope when faced with adversity (Rutter, 1990).

2.4.2 *Neuropathology and causes of TBI*

Most TBIs occur under conditions of rapid deceleration resulting in injuries to fronto-temporal structures. However, the primary neuropathology of TBI is diffuse axonal injury (Povlishock et al., 1986). Diffuse axonal injury (DAI) occurs as a result of counter coup injuries and rotational shearing as the brain glides or rotates within the cranial cavity due to impact forces. Dura mater protrusions restrict the brain's movement and enhance these shearing stresses (Meythaler, Peduzzi, Eleftherious, & Novack, 2001). DAI is presumed by some to have occurred whenever there is any loss of consciousness (Meythaler, Peduzzi, Eleftherious & Novak, 2001), so the outcome of TBI is dependent primarily on the amount and distribution of axonal damage. This notion came from a large primate study conducted by Gennarelli et al. (1982) which showed that the presence and extent of DAI correlated highly with four variables: lateral direction of acceleration, duration of coma, degree of neurological impairment and outcome from injury. The primary distribution of DAI injury seems to be in parasagittal deep white matter spreading from cortex to brainstem (Gennarelli et al., 1982). This localization may account for deficits in memory, attention and executive functions that are common in even mildly impaired TBIs (Alexander, 1995).

Other causes of TBI include primary damage to brain tissue at the impact site from mechanical forces, and secondary effects from other mechanisms. The latter include a release of neurotoxins, brain ischemia, delayed subdural hemorrhage, and cerebral edema. Guberman (1994) reported that early pathophysiological features of TBI include altered blood flow, altered brain metabolism, and neurochemical excitotoxicity. Excitotoxicity includes apoptotic cell death; that is, active suicide that cascades through the tissue resulting in a diffuse loss of cells extending beyond the site of injury (Rink et al., 1995). Neurons also die as a result of necrosis, which is characterized by passive swelling, and leads to membrane lysis and release of intracellular constituents that evoke an inflammatory reaction (Majno & Joris, 1995).

2.4.3 *Diagnostic criteria for Traumatic Brain Injury*

2.4.3.1 *Loss of consciousness*

In most research studies and often in clinical care, TBI severity is classified according to single indicators such as the Glasgow Coma Scale (GCS), duration of post-traumatic amnesia (PTA), and duration of loss of consciousness (LOC) (Brown, et al., 2005; Klonoff, Snow, & Costa, 1986; Levin, Grossman, Rose, & Teasdale, 1979; Sherer, et al., 2002).

In cases of mild TBI, loss of consciousness is a less accurate predictor of severity or indication of outcome as even ‘mild TBI’ without LOC can result in cognitive and/or functional impairment (Lovell, Iverson, Collins, McKeag, & Maroon, 1999). Research has shown that even in cases of a brief LOC in TBI, there appears to be some degree of diffuse axonal injury (DAI) which is likely to be permanent (Guberman, 1994).

2.4.4 *Physical changes following TBI*

The physical, behavioural, and psychological changes in TBI depend on the areas of the brain that are injured (Jorge, Egan, & Wolf, 2000; Khan, et al., 2003; Myburgh, et al., 2008; Rees, 2005). The severity of the injury is not necessarily associated with the extent of the person’s functional impairments (Binder, 1997; Sterr, Herron, Hayward, & Montaldi, 2006) and post-TBI functioning is multifactorial.

Physical symptoms might consist of: fatigue, clumsiness, decreased sensory functioning (i.e., changes in hearing, vision, smell and taste), dizziness, changes in appetite, seizures, and difficulties with sleep and temperature regulation (Brown & Gordon, 1999; Brown, Gordon & Spielman, 2003; Gordon, Brown, Hibbard & Sliwinski, 2001). Sensory loss has been described to develop or occur as long as ten years after TBI (O’Connor, Colantonio, & Polatajko, 2005), with impairments of smell and hearing being most frequently

reported (Callahan & Hinkebein, 1999; O'Connor, et al., 2005). Fatigue, expressed as exhaustion after simple and routine physical or mental tasks (Borgaro, Baker, Wethe, & 2005; Ouellet, Savard, & Morin, 2004) is one of the most widespread physical symptoms reported after TBI. This difficulty is often complicated by interference in the sleep cycle. Lack of sleep and feeling sleepy during the day further impairs cognition, behaviour and mood, and can challenge treatment. Moreover, chronic pain (Nicholson & Martelli, 2004) and headaches normally follow even mild brain injury (Borgaro, et al., 2005; Mahmood, Rapport, Hanks, & Fichtenberg, 2004) and can interfere with cognitive functioning.

2.4.5 Cognitive functions

Cognitive problems following TBI include impaired attention and concentration, reduced processing speed, word finding difficulties, and decreased academic abilities. Other difficulties include decreased memory and learning abilities, and impaired executive functioning (i.e., reduced ability to plan, sequence, prioritize, think flexibly, abstract or problem solve) (Lezak, Howieson, & Loring 2004; Sohlberg & Mateer, 2001). Although a broad range of cognitive deficits may occur following TBI, deficits in specific aspects of attention, orientation, language, self awareness and memory seem to prevail (Fleming, Chiaravalloti, & Deluca, 2003; Levin, Grossman, Rose & Teasdale, 1979; Jennet, 1996). This is either due to direct effects on memory systems or secondary to interrupted attention and concentration (McAllister & Arciniegas, 2002; Potter, Bassett, Jory, & Barrett 2001).

2.4.5.1.1 Attention

Attentional problems that frequently follow TBI include impairment of arousal, focused attention and divided attention (Levitt & Johnstone, 2001). Arousal refers to level of alertness, whilst focused attention refers to a person's ability to focus attention on a stimulus

and ignore irrelevant material. Divided attention refers to the ability to pay attention to more than one thing at a time. Attentional problems may be obvious and more pronounced when a person is operating in unstructured settings (Leclecq, Deloche & Rousseaux, 2002; O'Shanick & O'Schanick, 1994). Attentional problems are also more apparent in higher order tasks such as executive functioning which involves working memory and cognitive flexibility (Hanks et al., 2004). These deficits may present as a reduced capacity to maintain conversation in a noise setting, an impaired ability to read complex instructions, and as difficulties interpreting simultaneous sensory events. Strategies which promote attention (Rees, 2005) in people with TBI are presented in Table 2.8 below.

Table 2.8 *Strategies which facilitate attending behaviours*

Strategies which facilitate attending behaviors
<ul style="list-style-type: none"> • Availability of cuing to facilitate attention- for instance, mentors cuing participants to attend to instructions being read out on how to operate the computer.
<ul style="list-style-type: none"> • Sustained feedback during attending behaviour
<ul style="list-style-type: none"> • Previous experience of successful attending to objects and people (remind participants about their previous experiences when they get frustrated)
<ul style="list-style-type: none"> • Plan breaks so that fatigue does not reduce attending
<ul style="list-style-type: none"> • Give the person with TBI opportunities to verbalize and direct their attention
<ul style="list-style-type: none"> • Provide cues, which are visual, auditory, somatosensory or a combination of these sense
<ul style="list-style-type: none"> • Practice attending behaviors such as shifting from one task to another

2.4.5.1.2 *Orientation*

Orientation refers to the awareness of self and of one's surroundings (Karol, 2003, p. 34; Rees, 2005). This definition includes motor, emotional, cognitive and language orientation. People, who are oriented, know where they are, what day it is, to whom they are speaking and how they are feeling at the present moment. When they are disoriented, they experience irritability, anxiety and confusion, particularly if they are unable to locate themselves in place and time (Karol, 2003).

Importance is placed on orientation particularly in people with brain injury because of the distinct difficulties they face in becoming aware and getting started on tasks. If a person is not oriented to a task or process, "the process of reception, analysis and storage of information which provides people with their knowledge of the external world is denied" (Rees, 2005, p. 34). However, there are certain factors which hinder a person's ability to effectively orientate. These factors include experiencing negative emotions such as depression, anxiety and irritability. This disorientation is often a result of diffuse cerebral injury, particularly those involving the limbic structures (Ashley, 2004). Similarly, being presented with too many competing stimuli and lack of clear direction also makes orienting him/ herself more challenging for a person with TBI (Frensch & Funke, 1995). For people with brain injury, strategies to reduce confusion and facilitate orientation are summarized in Table 2.9 below.

Table 2.9 *Strategies to reduce orienting difficulties*

Strategies to reduce orienting difficulties
• Ensure that surrounding and environment is familiar
• Establish routine and predictability
• Avoid uncertainty by presenting unnecessary choices
• Provide clear and direct guidance
• Use positive future oriented statements

Adapted from (Rees, 2005, p. 72)

2.4.5.2 *Language*

Impairments of language function, which include problems of fluency, understanding, and naming objects, have been repeatedly demonstrated following TBI (McCullagh & Feinstein, 2005). Aphasic symptoms with a loss or decline in receptive or expressive language skills can emerge following damage to the left or dominant hemisphere (Priganto et al., 1986). Verbal language deficits in expression and comprehension may be paralleled by deficits in writing and reading abilities (Holland & Larimore, 2001). Non-aphasic language disturbances are also commonly seen post TBI. These impact the individual's social adaptation, and include problems such as talkativeness or verbal expansiveness, tangential thought patterns in conversations, and the use of peculiar words or phrases (Priganto et al., 1986). Strategies to facilitate language impairments are summarized in Table 2.10 below.

Table 2.10 *Strategies which facilitate language difficulties*

Strategies which facilitate language difficulties
<ul style="list-style-type: none"> • Identifying the role of routine domestic, recreational and social activities in generating language and communication (there is an established pattern of language associated with known and pre planned activities).
<ul style="list-style-type: none"> • Reading aloud to friends, which facilitates speech production, and subsequent discussion
<ul style="list-style-type: none"> • Participating in discussion groups

2.4.5.3 *Self - awareness*

Self-awareness can be defined as ‘the capacity to perceive the self in relatively objective terms whilst maintaining a sense of subjectivity’ (Prigatano & Schacter, 1991, p. 13). Impaired self-awareness and self-regulation skills are common aspects of brain injury (Fleming, Chiaravalloti, & Deluca, 2003).

Common characteristics of impaired self-awareness in clients, who have a TBI or MS, include a diminished understanding of impairments resulting from the disability, and their functional consequences (Fleming, Strong, & Ashton, 1996). These functional impairments often include executive functioning difficulties such as setting realistic goals for the future (Fleming & Strong, 1995), recognizing limitations, and actively participating in rehabilitation (Berquist & Jacket, 1993; Prigatano & Schacter, 1991). Strategies which promote self-awareness (Cicerone, Levin, Malec, Stuss, & Whyte, 2006) are presented in Table 2.11 below.

Table 2.11 *Strategies which promote self-awareness*

Strategies which promote self- awareness
<ul style="list-style-type: none"> • Setting and accomplishing realistic goals
<ul style="list-style-type: none"> • Developing compensatory strategies when unable to perform a task independently
<ul style="list-style-type: none"> • Practise new behaviours/skills with mentors
<ul style="list-style-type: none"> • Cueing the participants to anticipate obstacles to task performance and their consequences, and to select strategies for compensating for difficulties prior to task performance
<ul style="list-style-type: none"> • Selecting tasks that participants recognise they have difficulty performing and can make corrections to, without feeling too overwhelmed
<ul style="list-style-type: none"> • Role-reversal where the participant observes the mentor perform the task and points out errors that the therapist makes

2.4.5.4 *Memory*

What people remember, and how they remember it, has an impact on every facet of life. Consequently, amnesia or memory loss due to traumatic brain injury makes life extremely difficult. Memory, as summarized by Rees (2005), is seen as being personal in its establishment and retrieval. It is involved in every feature of how people contribute and think, what activities they perform, how they develop skills and also how people behave (Rees, 2005).

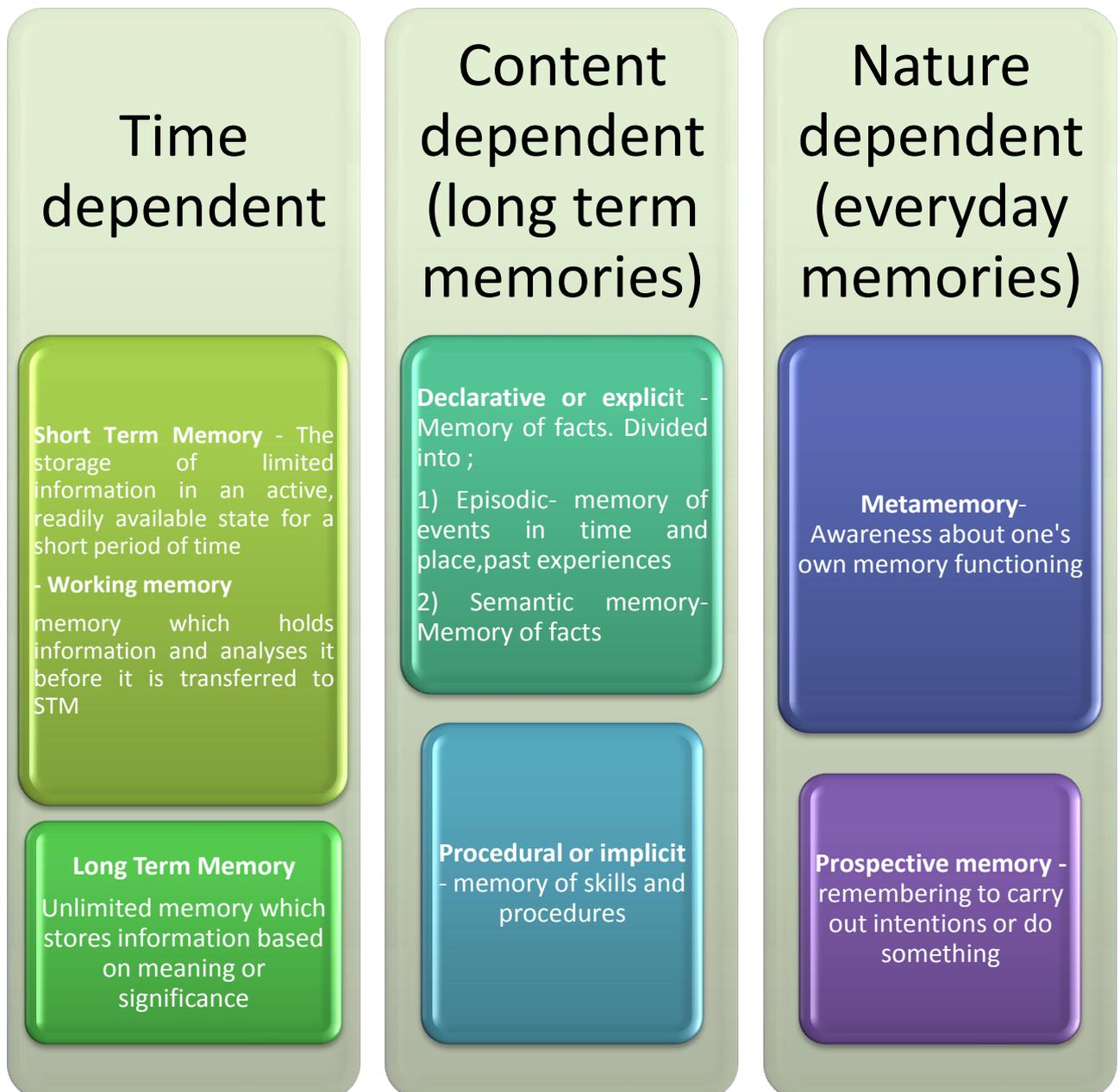
The formation of a memory happens in stages and is broken down into the stages of encoding, retrieval and storage (Baddeley, 1992; Zola-Morgan & Squire, 1993).

Encoding – The processes where information is registered into memory (examples include extracting meaning, categorizing information into chunks such as “animals”, “tools”, “colours”).

Storage – The retention of encoded information over time (for example, performing previously learnt actions like driving, or speaking)

Retrieval – Accessing information which was previously stored through recognition and recall (for example, remembering a previously learnt task such as driving).

Once memories are formed, they can be further classified according to whether these are (1) time dependent, (2) content dependent and (3) nature dependent. They are summarized in Table 2.12 below.

Table 2.12 *Types of memory*

(Baddeley, 1992; Gold & McGaugh, 1975; Jonides, et al., 2008; Kane & Engle, 2002;

Sohlberg & Mateer, 2001; Squire, 1992; Tulving, 2002; Zola-Morgan & Squire, 1993).

Memory rehabilitation strategies which are commonly used are presented in Table 2.13 below.

Table 2.13 *Memory Rehabilitation Strategies*

External memory aids	Useful guidelines in the rehabilitation of memory
Diary Use	Simplify information – instructions should be clear and concise
Notepads	Reduce the amount of information to be memorized
Camera's	Check that the person has understood the task
Mobile phones	Set up various practices sessions which occur at different times (learning something a few times a day as opposed to several hours at a time)
Phone calls or cues such as text messages	Help individuals organize information that needs to be remembered (chunk information into categories)
Notes around the house	Train individuals to use communication techniques which encourage the processing of meaning (asking questions, rephrasing and rehearsal)

Table adapted from Wilson and Moffat (1992)

Other approaches which can be used in the rehabilitation of memory are cueing and errorless learning.

2.4.6 *Impairments in Psychosocial Functioning following Frontal Lobe Injury*

Traumatic brain injury (TBI) often affects physical, cognitive, emotional, behavioural, and social functioning (Grimm, 1986; Marsh, 1999; McKinlay, 1999; Thomsen, 1992).

Current research has led to a more accurate understanding of the impact of TBI on cognitive functioning (Dikmen, 1995). However, despite the existence of continuing physical and cognitive impairment, it is the psychosocial changes that are said to cause the utmost amount of

distress for the person with TBI and their family (Cummings & Bogousslavsky, 2000; McKinlay, 1999).

Psychosocial functioning refers to the emotional, behavioural, and social aspects of a person's functioning (Cummings & Bogousslavsky, 2000; Marsh, 1999; McClelland, 1988; McKinlay, 1999; Rosenthal, 1998; Taylor & Jung, 1998). The current flow of research has focused on providing accurate information in terms of the broad nature of these psychosocial difficulties experienced by people with TBI. There is a reasonable uniformity in the TBI literature concerning a person's post trauma psycho-social difficulties (Brooks & McKinlay, 1983; Cummings & Bogousslavsky, 2000; Hellowell et al., 1999; Van Zomeren & Van Den Burg, 1985). These difficulties are presented in Table 2.14.

Table 2.14 *Psychosocial difficulties in people with frontal lobe damage*

Psychosocial functioning	Difficulties	
Emotional	Depression	Fatigue
	Anxiety	Continuing mood changes
	Irritability	Frequent and erratic mood swings
	Anger	Over expression of emotion Loss of ability to react to emotion
Behavioural	Verbally intimidating behaviour	Inappropriate or rash social behaviour
	Aggressive behaviour	Lack of spontaneity
	Disinhibition	Agitation
	Childishness	Emotional lability
	Impulsivity	Irritation Over sensitivity
		Sexually inappropriate behaviour

(Ashley, 2004; Cicerone, et al., 2006a; Crowe, 2008; Hellowell, Taylor, &

Pentland, 1999; Lezak, 1989; Marsh, 1999; McClelland, 1988; Thomsen, 1992).

Despite the fact that some of these problems might be a reaction to one's newly acquired disability (e.g., depression, anxiety), many have been found to have a neurological bases. Prefrontal lobe damage often generates disinhibition, euphoria, lack of tact, and childishness, a cluster of symptoms commonly referred to as "frontal lobe syndrome." Irritability and increased aggressiveness are normally observed after temporal lobe damage (Cummings & Bogousslavsky, 2000; Eslinger & Geder, 2000; Kolb, 2001). Injuries to the central and basal frontal areas are typically related to aspontaneity, decreased energy and enthusiasm (McClelland, 1988, Sohlberg & Mateer, 2001; Winston, 2003).

Personality change and impaired psychosocial function have been reported in survivors at all stages of TBI severity (Spatt, Zebenhoizer & Oder, 1994; Hoofien, Gilboa, Vakil & Donovan, 2001) including mild TBI (Kay et al., 1993; Levin et al., 1979).

2.4.7 Mood disorders following a Traumatic Brain Injury

In addition to physical, cognitive and behavioural changes that occur following TBI, a majority of individuals are also diagnosed with one or more mood disorders (Ashman, Spielman, & Hibbard, 2004; McGuire, Burright, Williams, & Donovan, 1998). Alterations in mood can arise as the individual with TBI becomes depressed, withdrawn and anxious as a reaction to the disruption caused in their lives. This can be seen as a profound reaction to their losses, and to the chronic frustration associated with their cognitive and physical disabilities (Rosenthal & Bond, 1990). Mood disorders are also complicated with the loss of skills necessary for the individual to regain their pre-trauma abilities. These skills include difficulties with planning, initiating, persisting at tasks, anticipating and responding to feedback (Elliot, 2003; Lezak 1993; McCloskey, 2003; Stuss, 1992). Individuals with frontal lobe injury may have minute or no insight into their difficulties, hold unrealistic beliefs about their future and also show a lack of concern in relation to their own difficulties (Fleminger & Powell, 1999, p. 428). Individuals with TBI may also display little motivation to engage in activities which are not immediately or intrinsically rewarding. They also may express explosive anger, often disproportionate to the trigger.

Emotional processing and mood regulation involves the multifaceted interaction between the prefrontal regions (anterior cingulate gyrus, orbitofrontal cortex) and limbic structures (amygdala, hippocampus, and ventral striatum) (Campbell & MacQueen, 2006; Drevets, Price, & Furey, 2008). Different areas of traumatic lesions such as diffuse axonal injury and cerebral contusions may affect these neural circuits and, consequently, result in

affective disturbance (Evans, et al., 2005). Mood disorders often disrupt a person's ability to maintain equilibrium, and the result is the individual displaying irregular and unpredictable behaviours (Tetlock, 2002). For example, being hysterical, crying, anger outbursts and prone to violent tempers.

2.4.7.1.1 Depression

Major depressive disorder (MDD) is the most prevalent psychiatric disorder after traumatic brain injury. It is estimated that rates range from 14 – 77% (Ashman, et al., 2004; Holsinger, Steffens, & Phillips, 2002; Jorge, Robinson, & Moser, 2004), with about 60% of clients meeting a diagnosis of depression at some point after injury (Hibbard, Uysal, Sliwinski, & Gordon, 1998). A further 20% of clients develop depression at any given time after TBI (Ashman, et al., 2004). The increased risk of depression is not limited to those with moderate to severe TBI; it is also present among those with mild TBI (Fann et al., 2004; Hoge et al., 2008). There is also an increased risk of suicide subsequent to TBI, with one study noting that 10% reported suicidal ideation at 1 year post-TBI, and 15% attempted suicide by 5 years post-injury (Brooks et al., 1986).

It has been put forth that there are two major types of affective disorders; (1) unipolar affective disorder or depression without mania and (2) bipolar affective disorder which is an alternation between depression and mania. Unipolar depression features a continuous and unremitting episode, whilst bipolar disorder features mania which lasts for a few days to several weeks (Drevets, et al., 2008; Jorge, et al., 2004; Rosenthal, 1998).

A major depressive episode is characterised by at least 2 weeks where there is depressed mood or loss of interest or pleasure in most activities. Other features include a loss of interest or enjoyment, reduced self-esteem, feelings of guilt or worthlessness, a pessimistic world view, ideas or acts of self harm, disturbed sleep, increased or reduced

appetite, reduced energy and concentration and decreased libido (Crowe, 2008; Publication Manual of the American Psychiatric Association: DSM IV- TR, 2000).

In bipolar disorder, mania is defined by the presence of a persistently abnormal elevated, expansive or irritable mood which persists for at least one week. For people with TBI this mania is usually accompanied by at least three additional symptoms such as inflated self esteem, grandiosity, decreased need for sleep, pressure of speech, flight of ideas, distractibility, increased interest in goal directed activities or psychomotor agitation, and excessive involvement in pleasurable activities with a high potential for painful consequences. In order to be classified as bipolar disorder, the impairments' must also be sufficiently severe to cause marked impairment of social or occupational functioning (Barlow, 2007; DSM IV- TR, 2000; Rosenthal, 1998).

2.4.7.1.1.1 Treatment of depression post Traumatic Brain Injury

A recent study by Fann, Hart and Schomer (2009) found that the most effective treatments for depression post TBI were the use of serotonergic antidepressants (SSRI) and cognitive behavioural interventions (CBT). Due to their favourable side effect profile, an SSRI is recommended as a good first line antidepressant for TBI patients (Ashman et al., 2009). The main SSRI's recommended are sertraline and citalopram (Fann et al 2000; Turner- Stokes et al 2002). Among the SSRIs, sertraline has the most dopaminergic effect, thus potentially having a positive impact on cognition (Lee et al, 2005).

CBT-based treatments are an option for individuals with TBI as three of the four CBT-based studies reported positive effects of treatment on mood (Fann, Hart, Schomer, 2009). When these CBT based treatments were closely studied, it was found that they comprised of cognitive components such as examination and correction of distorted thinking and behavioural components such as engaging in more reinforcing activities. It was also

found that the behavioural methods tended to be more successful (Dimidjian et al., 2006). Cuijpers et al., (2007), found that therapies focusing on behavioural activation, such as scheduling activities, or participating in regular activities were an effective method of treatment, comparable to cognitive behaviour therapy. Therefore, having regular activities scheduled, and an increase in positive interaction appears to be a recommended treatment for depression post TBI.

Both biomedical and psychosocial factors contribute to depression in people with TBI. Generally, after TBI, depression may be more biologically determined, by pre-injury susceptibility and/or lesion location (Jorge et al., 1993). On the other hand, psychosocial factors, such as impaired close personal relationships and an unstable job situation, can be stronger determinants of depression predominantly, as time since injury increases (Gomez-Hernandez et al., 1997). Therefore, pharmacotherapy and psychotherapy approaches can be combined and balanced for individual circumstances, risk factors, and time post-injury (Fann et al, 2009).

2.4.7.1.2 Anxiety following Traumatic Brain Injury

Anxiety disorders occur in a considerable percentage of patients with a TBI and often coexist with depressive disorders (Hiott & Labbate, 2002; Koponen, Taiminen, & Portin, 2002). There appears to be a significant degree of co morbidity between mood and anxiety disorders amid clients with a TBI. Approximately two-thirds of clients who had major depression also met diagnostic criteria for generalized anxiety disorder (Jorge, et al., 2004). Anxiety or ‘anxious apprehension’ has been defined as a cognitive affective structure that is composed primarily of high negative affect, a sense of uncontrollability, and an inward, self focus shift in attention (Barlow, Chorpita & Turovsky, 1996). Naturally individuals with TBI

are anxious and depressed about their diagnosis and condition. The core psychological feature of anxiety is a sense of lack of control or helplessness.

Anxiety may have cognitive, behavioural and somatic presentations which become disabling and hinder the client's recovery and adaptation to life with a TBI. For instance, the content of unrelenting worrying thoughts may consist of personal and emotional threats to self, physical health, competence at work, or general world problems. These thoughts are mentally practised repeatedly and are hard to dismiss (Mathews, 1990). Physical symptoms are also commonly present, such as pounding heartbeat, sweating, dizziness, feeling of choking, and shortness of breath (Nitschke, Heller, Palmieri, & Miller, 1999). Clients also, at times, experience anxious apprehension, which includes restlessness, fatigue, and muscle tension (Nitschke, Heller, Palmieri, & Miller, 1999).

Anxiety explicitly affects cognition. It has been significantly related with an attentional bias toward threatening stimuli (Compton, Heller, Banich, Palmieri, & Miller, 2000; McNally, 1998; Nitschke & Heller, 2002). Attention is usually captured by confusing, emotional, or threatening information, which typically produces anxious thoughts. Anxiety also impairs performance on tasks that are complicated or stressful, because worrying thoughts interfere with a person's ability to attend to task relevant information (McNally, 1998). These attentional effects have been recognized in trait and state anxiety (Egloff & Hock, 2001) and in every DSM-IV-TR anxiety disorder (Heller, Koven, & Miller, 2003; Nitschke & Heller, 2002). This suggests that, when someone is anxious, their attention is at constant risk of distraction from the task at hand, which in turn slows or impairs performance (Moore, Terryberry-Spohr, & Hope, 2006).

2.4.7.1.3 Aggression and Irritability

Difficulties with expressing anger and irritability are common behavioural disturbance that can occur following TBI (Crowe, 2008; Jorge, et al., 2000; McGlynn, 1990). These difficulties may persist far longer than the physical effects of the brain injury (Alderman, 2003; Miller, 1990). According to the DSM IV-TR, there are several subtypes to classify behaviour changes associated with aggression (DSM IV-TR, 2000). The aggressive type is characterized by predominantly aggressive behaviour, which may be directed to self, others or inanimate objects. The second type is the disinhibition form which is marked by disinhibition and sexual indiscretions. Clients with the third type known as the labile type demonstrate affective lability, which may include verbal outbursts with little or no provocation and subsequent threatening and violent behaviour (Kim, et al., 2007).

It has been postulated that aggression is often a result of frontal system impairment (Miller, 1990). The frontal lobes are identified to be involved in the self-regulation of behavioural and emotional responses (Eslinger & Geder, 2000; Stuss & Alexander, 2000). Therefore, damage to these areas result in the patient having little or no control over sudden changes in mood and consequently behaviour (Alderman, 2003; Cummings & Bogousslavsky, 2000). Such changes in behaviour, especially in physical aggression, contribute to poor community and vocational reintegration (Medd & Tate, 2000). It may also be an important stimulus for long-term institutional placement, and poses a serious challenge to rehabilitation.

2.4.8 Substance abuse and disability

Having a disability such as traumatic brain injury or multiple sclerosis is often further complicated by substance abuse. Research has shown that the incidence of substance abuse among people with disability is much higher than that in the general population (Watson,

Franklin, Ingram, & Eilenberg, 1998). This study found that more than 50% of people with traumatic injuries or those with mental illness, may abuse alcohol and other substances. Living with a disability greatly increases the likelihood of substance abuse (Chandras, Chandras, & DeLambo, 2007; Vash & Crewe, 2003). Individuals with a disability and a coexisting disability of substance addiction (i.e., dual-diagnosis) tend to have higher relapse and symptom exacerbation rates, and thus poor treatment outcomes (Donnell, Lustig, & Strauser, 2004; Mueser, Bellack, & Blanchard, 1992). They also have limited social relationships, increased family stress, and have a higher risk of suicide (Ziedonis & Stern, 2001).

For some people, TBI will occur in the context of a pre-existing substance abuse. A study by Kelly et al (1997), found that participants who were admitted to the trauma unit with a positive toxicology screen performed worst on neuropsychological assessment post injury then those without substance abuse issues. These data suggest the existence of an additive effect of substance abuse on neuropsychological outcome in TBI.

Most people with disabilities have to face significant life changes such as unemployment, marital problems, loss of income, loss of social life and loss of meaning in life (Garske, 1999; Hilburger, 2000). A substance related disorder affects every aspect of the individual's daily life. As they become more addicted, individuals lose interest in self care, may show decreased appetite, and have sleep disturbances which result in sleep deprivation. Their daily activities become focused solely on obtaining more of the substance (Coyne & Downey, 1991). Activities they previously enjoyed are no longer joyful and do not stimulate their interest anymore. These individuals may no longer function within their social network, social and family relationships become strained and are often destroyed (Barrett & Turner, 2006). Individuals with a substance abuse disorder often become violent and abusive or engage in socially unacceptable or even criminal behaviour while under the influence of the

substance (Corrigan & Watson, 2005; Fazel, Bains, & Doll, 2006). This behaviour further alienates them from others, and results in social isolation. As individuals become more isolated, they also feel more guilt, self loathing, and shame (Boles & Miottoa, 2003). They feel rejected by their friends and family and thus tend to interact with other substance abusers like themselves (Boles & Miottoa, 2003).

Sexual dysfunction is another common characteristic of individuals with substance abuse (Meade & Weiss, 2007). Women may experience a decrease in libido, or may become promiscuous (Johnson, Phelps, & Cottler, 2004; YÃ¡nez, Castelo-Branco, Hidalgo, & Chedraui, 2006). Men may experience sexual impotence, erectile dysfunction, decreased sexual desire, and increased ejaculation latency (Jiann, 2009).

Subsequently, they may turn to alcohol or drugs to lessen their emotional pain. Similarly, people with disabilities sometimes resort to alcohol and substances to numb their physical pain (Fishbain, Rosomoff, & Rosomoff, 1992). They may use substances such as alcohol, street drugs and even prescription drugs such as opiates, to self medicate (Compton & Athanasos, 2003).

2.4.9 Identification and management of dual diagnosis

When working with individuals with a dual-diagnosis, for example those with TBI and a history of substance abuse, it is crucial to be able to discriminate between the symptoms of these concomitant disabilities (Benshoff & Janikowski, 2000). For example, a participant with bipolar disorder may present depressive symptoms arising mainly from the use of methamphetamine and reduction of neurotransmitters, rather than from the psychiatric disorder. Devoid of identifying the methamphetamine use, successful outcomes such as employment, symptom reduction, and independence, are unlikely to be achieved (Doweiko, 2006). Some common characteristics of substance abuse include marginal living

arrangements, drug-user social networks, depression, bingeing or heavy drug use, difficulty with abstinence, symptom exacerbation (e.g., psychosis), relapse, self-medication, and poor work history (Brady, Killeen, Saladln, Dansky, & Becker, 1994; Gearon, Bellack, Rachbeisel, & Dixon, 2001). The rehabilitation professional must be aware of these characteristics and address them in identifying appropriate interventions and when planning effective services.

While any of the problems discussed above can be momentous problems in themselves, their full impact is seen when observed in a social or interpersonal context, in which a person must relate with others to meet his or her own needs, to meet the needs of others, and to achieve common goals (Cabness, 2003). In general, almost every individual who sustains a brain injury will face some type of psychosocial disruption because psychosocial functioning is predisposed by cognition, behaviour, emotions, and personality, and interrelates with nearly all aspects of a person's life (Rutter, 2002).

2.4.10 Aspects of rehabilitation used in the intervention

A few principles of brain injury rehabilitation were utilized as part of the intervention. These principles were cueing, errorless learning and the use of mentors or significant other's (key actors).

2.4.10.1 Cueing

The Mosby's Medical Dictionary defines cues as a stimulus that determines or may prompt the nature of a person's response (Anderson, Anderson, & Glanze, 2009). It has been observed that throughout a person's rehabilitation, cueing is vital in ensuring personal success (Parker & Crawford, 1992). Cues support the effort required for the person to be oriented, vigilant and to attend (Rees, 2005, p. 79). For instance, when working with a client

who has short term memory problems, a cue in the form of a phone call prior to a meeting reminds the client and ensures attendance.

Cues could be statements that contradict an incorrect assumption, or 'reinforced' a correct inference, identified a specific fact, or modelled correct behaviour (Merbitz, Miller, & Hansen, 2000). Examples include:

- Modelling desired behaviour such as how to pick up food with a spoon and place it in mouth
- Reminding client to write in his to do list or notebook
- Providing statements of encouragement to complete a writing task

2.4.10.2 Errorless learning

Errorless learning is one of the most effective ways to teach any content such as information, rules, procedures, and habits to individuals with Traumatic Brain Injury or those who have significant cognitive impairments and problems with memory (Kessels & Haan, 2003; Ylvisaker & Feeney, 1998). The basic assumption of the errorless learning approach is that errors that are produced during learning obstruct or hinder correct responses (Baddeley, 1992). There is evidence that these errors are stored in memory through intact implicit learning (memory which does not require retrieval of the past such as memory for skills, and habits) (Kessels, Boekhorst, & Postma 2005; Ylvisaker & Feeney, 1998). These errors are usually corrected by explicit memory (memory for facts, words, and names). However, given that explicit memory is often impaired in clients with brain injury and amnesia, these errors are consolidated into implicit memory (Baddeley & Wilson, 1994). Similarly, errors may be consolidated and remembered because they are associated with strong emotions such as embarrassment, shame, or anger. This makes the incorrect response more likely to be repeated the next time (Tailby & Haslam, 2003).

2.4.10.2.1 Structure and strategies which promote errorless learning

Learning post traumatic brain injury is often a tiring and emotional process. It is therefore necessary to provide sufficient structure in order to facilitate the relearning process (Rees, 2005). Errorless learning helps to structure information, and also prevents the occurrence of errors (Kessels & Haan, 2003). Examples of structure which promotes errorless learning are described in Table 2.15 below.

Table 2.15 Structure which promotes errorless learning

Structure which promotes errorless learning
<ul style="list-style-type: none"> • Adjust tasks into manageable levels -Reduce tasks to manageable levels to ensure successful completion. For instance break down a reading task into reading a few words, then sentences before attempting to read the whole paragraph. • Ensuring that clients are clear about what is expected of them - For instance modelling correct responses, ensuring instructions are simple and clear. • Perform the task with the client, gradually withdrawing support – Saying, “Let’s do this together, instead of “I’d like to see if you can complete this task”. • Anticipate errors and pre- correct – For example, if a client has difficulty walking uphill, then say something like “I know its hard walking up hill, let me know if you need help” before approaching the hill. • Provide positive reinforcement – Encouraging and celebrating small achievements with praise, or rewards • Creating tasks which are close to real life difficulties – Performing learning in the clients own home where they are challenged daily. • Enhance retrieval – Provide sufficient cues to ensure that the client can retrieve information, for instance, practice a task without errors so that client can perform it successfully utilizing their own skills and habits. <p>(Rees, 2005; Ylvisaker & Feeney, 1998; Ylvisaker, Jacobs, & Feeney, 2003)</p>

2.4.10.3 Mentors

A mentor is a more experienced person who serves as a role model, educates, supports, encourages and counsels an individual (Bellon, Gardner, & Riley, 2008). Mentors provide direction and feedback concerning future plans and personal development (Hunt & Michael, 1983; Lee, Theoharis, Kyeong-Hwa, Liss, Nix-Williams, Griswold & Walther-Thomas, 2006). A mentoring relationship is based on reciprocated respect and agreed expectations that seeks to benefit all involved (Heartfield, Gibson & Nasel, 2005). In the management of people with traumatic brain injury, mentors are often useful as they help cue and trigger action oriented responses in participants. They are often students or volunteers who dedicate their time to help a person with a brain injury. Therefore, mentors are not expected to 'know all the answers', but rather, they assist in providing direction and guidance with problem solving (Duffy & Forgan, 2005).

The function of a mentor in this context is to support the individual with TBI to achieve personal goals, reduce isolation, and develop social networks for (Rees, 2005). A key goal for interventions is to help individuals with TBI to identify people in their lives who can act as mentors and to strengthen this relationship. The mentor is then able to facilitate and help in the executive functioning of the person with brain injury by; (a) facilitating forward planning, (b) initiating positive behaviour, (c) developing reality-based ideas in relation to activity, (d) providing constructive language about the self and realistic language/ideas about others, (e) listening and reinforcing the positive behaviours, and (f) setting goals (Bellon, Gardner, Riley, 2008; Rees, 2005).

2.5 Multiple Sclerosis

2.5.1 Epidemiology, Incidence and Prevalence of Multiple Sclerosis

Multiple sclerosis (MS) is neurological disorder in which the insulating myelin of the central nervous system is attacked, causing disruption of nerve impulses in the brain and spinal cord. It has been estimated that about 10,000 individuals worldwide per year receive a diagnosis of MS (Smith & Schapiro, 2000). At present there are more than 15 000 Australians with MS. The onset of the illness most commonly occurs between the ages of 20 to 40 and appears to be more prominent among women, affecting women twice as often as men (Mohr, Dick, Russo, Pinn, Boudewyn, Likosky, & Goodkin, 1999; Smith & Schapiro, 2000). The illness is also more apparent in Caucasian individuals and those of Scandinavian descent (Sadovnick, Dyment, & Ebers, 1997). It is less frequently seen in Hispanics or African Americans, and rarely seen among Asians and Black Africans (Poser, 1994; Smith & Schapiro, 2000).

The incidence and prevalence of MS has also been noted to be related to the distance the individual is from the equator, with more cases occurring further away from the equator (Alonso & Hernan, 2008; Ford, Gerry, & Johnson, 2002). In Australia, the incidence rate is higher in North Queensland (12 per 100,000 people) whilst in Tasmania the furthest Australian state from the equator, the incidence rises to 76 people per 100,000 (Jelinek, 2000).

The data from migration studies shows that if the exposure to a higher risk environment occurs during adolescence (before 15 years of age the migrant assumes the higher risk of the original environment (Acheson, 1977; Compston, McAlpine, Confavreux, Lassmann, & McDonald, 2006; Kurtzke & 2000; Kurtzke, Delasnerie-Lauprêtre, & Wallin, 1998). These data give rise to the hypothesis that there is a critical age of exposure to

unknown causal or triggering factors, and suggests that there is a long period of latency between exposure and disease onset (Garnieri et al, 1993).

2.5.2 *Etiology*

Although the cause of MS remains unknown, it is believed to be an autoimmune reaction in which the myelin sheath is attacked by the body's defence system (Berg, et al., 2000; Gold-Spink, Sher, & Theodos, 2000; Wingerchuk & Weinshenker, 2000). This causes scar tissue build up (lesions) that ultimately interfere with the passage of nerve impulses (Berg, et al., 2000; Pujol, Bello, Deus, Marti-Vilalta, & Capdevila, 1997). However, it is not known what triggers the immune system to attack the myelin. As yet, no virus has been identified, although the measles, rubella, Epstein- Barr and herpes viruses have been implicated as possible triggers (Haahr & Höllsberg, 2006). Depending on the site of demyelination, MS presents different symptoms which may include deterioration of cognitive, emotional and/or physical functioning (Devin's & Shnek, 2000).

2.5.3 *Symptoms of Multiple Sclerosis*

All persons with MS experience different degrees and combinations of symptoms (Van der Westhuizen, 2001). Symptoms of MS differ greatly from individual to individual and are typified by periodic remissions and exacerbations. These periods of exacerbations can vary between a few months to even years (Fraser, Clemmons, & Bennet, 2002). Symptoms usually become more severe with time (Pakenham & Stewart, 1997) and with the progression of the illness (Trojano et al., 2003). A summary of common symptoms of MS is presented in Table 2.16

Table 2.16 *Symptoms of Multiple Sclerosis*

Symptoms	Symptoms
<p>Visual disturbances</p> <ul style="list-style-type: none"> Blurring of vision Double vision (diplopia) Optic neuritis Involuntary rapid eye movement 	<p>Abnormal Speech</p> <ul style="list-style-type: none"> Slowing of speech Slurring of words Changes in rhythm of speech Difficulty in swallowing Pain
<p>Balance and co ordination problems</p> <ul style="list-style-type: none"> Loss of balance Tremor Ataxia (unstable walking) Vertigo Clumsiness of a limb Lack of co-ordination Weakness (affecting mainly the legs) 	<p>Abnormal Sensations</p> <ul style="list-style-type: none"> Pins and needles Tingling Numbness Burning sensations Pain
<p>Spasticity</p> <ul style="list-style-type: none"> Altered muscle tone/stiffness Spasms 	<p>Cognitive difficulties</p> <ul style="list-style-type: none"> Short term memory loss Loss of concentration
<p>Sexual difficulties</p> <ul style="list-style-type: none"> Loss of sensation Diminished arousal Impotence 	<p>Bladder and bowel problems</p> <ul style="list-style-type: none"> Frequency incomplete micturition Urgency to void Constipation Loss of bowel/bladder control

(Gold-Spink, et al., 2000; Gottberg, et al., 2007; Mohr & Cox, 2001; Mohr, et al., 1999; Rao, Huber, & Bornstein, 1992; Schulz, Kopp, Kunkel, & Faiss, 2006; VanderPlate, 1984; Wingerchuk & Weinshenker, 2000).

2.5.4 *Fatigue*

Fatigue is the most common symptom experienced by people with MS. Recent studies indicate that approximately 77% of people with MS experience fatigue (Schwartz, Coulthard-Morris, & Zeng, 1996). Fatigue can have a major impact on the individual's social and vocational functioning and on his or her ability to carry out activities of daily living. Four types of fatigue which can be experienced in varying degrees or simultaneously by people with MS have been identified (Schapiro, 1994). They are (a) general tiredness or a persistent weariness similar to that experienced at the end of a long day at work; (b) 'worn out' fatigue, which is a more intrusive form characterized by lethargy, indifference, and reduced self-esteem; (c) 'short circuiting' fatigue resulting from the hardening and scarring of the myelin sheath reducing the transmission of electrical impulses to the extremities; and (d) MS fatigue which is marked by an overwhelming sense of exhaustion affecting the individual abruptly, without warning, and persisting from a few hours to several days (Schapiro, 1994).

MS fatigue can be differentiated from that associated with depression (Kroencke, Lynch, Denney, 2000). Fatigue in depression is often present earlier during the day and remains constant, whilst MS fatigue increases during the course of the day (Schapiro, 1994; Sibley, 1996). Stress, exercise, depression, and increase in body temperature can cause an exacerbation of fatigue (Rumrill, 1996). Fatigue experienced by those with MS is often out of proportion with the activity in which the person is engaged. For example, a few minutes of walking may result in extreme fatigue.

Fatigue is considered as one of the most difficult symptoms to treat because it is often invisible (Sibley, 1996). Fatigue is often misunderstood by family and friends, who misinterpret this symptom as laziness and, thus, minimize its importance (Schapiro, 1994).

2.5.5 Pain and Multiple Sclerosis

Pain is one of the innumerable symptoms that may be engendered by MS. Pain and MS have been linked since the initial identification of the disease by Charcot in 1872 (Charcot, 1872). Approximations of the prevalence of pain in MS have ranged from 29% to 86 % (O'Connor, Schwid, Herrmann, Markman, & Dworkin, 2008; Stenager, Knudsen, & Jensen, 1995).

The incidence of pain in MS is both related to an inflammatory, demyelinating process as well as ascribed to the very nature of the chronic disease (Moulin, 1989; Osterberg, Boivie, & Thuomas, 2005). In particular, the presence of a demyelinated lesion on the spinal cord directly injures nerves of the brain and spinal cord in persons with MS (Ehde, et al., 2003). In addition, pain may also be due to the inflammatory process that occurs with relapses. Regardless of the cause, it is critical that pain be identified and effectively managed.

Some common first line treatments for Dysesthetic pain typically seen in people with MS are low doses of tricyclic antidepressants such as amitriptyline (Elavil), imipramine (Tofranil), or desipramine (Norpramin) (Gass, et al., 1997; O'Connor, et al., 2008).

2.5.6 Types of Multiple Sclerosis

The progression of the disease is uncertain in that the individual can never anticipate its course. However, it has been noted that there are two patterns which are (1) the relapsing remitting pattern and (2) the gradual deterioration or progressive pattern (Mohr et al., 1999). While most MS patients will not experience all of the symptoms discussed previously, they will experience some combination of them at different levels of severity and duration.

Secondary symptoms of MS are complications caused by the underlying impairments. Examples include falling down, reduced activity of daily living, urinary tract infection,

pneumonia, depression, and physical barriers in the environment such as difficulty walking, climbing stairs and limited access to public places (Smeltzer & Bare, 2000).

Based on the severity and progression of the symptoms, MS can be categorised as follows:

1. *Relapsing-Remitting*: This is characterized by defined acute attacks where symptoms grow more severe for a few days or weeks, and then partially or completely disappear for a random amount of time. This pattern continues, alternating between attack and remission. The illness does not progress between relapses or during remissions.

2. *Primary Progressive*: This is characterized by the progression of the disease and gradual decline from the initial onset. There may be only temporary minor improvements.

3. *Secondary Progressive*: In this pattern, the disease begins with a relapsing-remitting course, followed by progression that may include occasional relapses and minor remissions. Generally the remissions cease and the patient enters a steady, gradual decline.

4. *Progressive-Relapsing*: This type presents a clear progression in the level of disability from the onset of the illness. The person experiences a gradual decline, yet also suffers attacks of more severe symptoms. There are clear acute relapses. The individual may or may not recover from relapse-related symptoms.

The most common form of MS is the relapse remitting type which affects up to 65 to 70 percent of people with MS (Devins & Shnek, 2000; Jelinek, 2000). In relapsing-remitting MS (RRMS), there are repeated occurrences of acute illness, producing a moderate level of disability (Minden, 1992). The individual experiences “periodic attacks or exacerbations that

remit partially or fully.” (Mohr et al., 1999, p. 376). The disease goes into remission and symptoms improve or disappear, usually for about four to eight weeks. Relapses are also described as attacks, exacerbation, or flare-ups. They can be mild or severe and may last days, weeks, or even months. Based on the damage to the myelin, the person experiences a number of the symptoms previously discussed. After a relapse, the person may experience a period of remission and symptoms may partially improve (Calabresi, 2007).

An estimated 40 percent of people with MS experience the secondary progressive form. Some people with Secondary MS are initially diagnosed with relapse remitting MS but the course of the disease changes with progressive disability (Lubin & Reingold, 1996). Primary progressive MS is characterized by a lack of attacks, unlike the relapse remitting form (Trojano, Paolicelli, Bellacosa, & Cataldo, 2003). Primary Progressive MS has a slow onset with increasing worsening of symptoms. The disability may stop deteriorating after a few months or years. Approximately 15% of people with MS have this type (Jelinek, 2000).

2.5.7 Diagnosis of MS

Diagnosing MS can be a difficult task due to the clinical presentation of the disease and particular diagnostic challenges (Thomson, 2002). The main challenge lies in the fact that there is no single diagnostic test available (McDonald et al., 2001). Also, MS is hard to diagnose because clients often present with confusing and transient symptoms. Early symptoms of MS are often vague and could be attributed to other disorders such as stroke and brain tumours (Rao, Huber & Bornstein, 1992). Therefore, in order to diagnose MS, one has to exclude all other possible disorders (McDonald et al, 2001). Normally, blood tests are used in persons with suspected MS to rule out other conditions (Coyle & Harper 2001). Analysis of the cerebrospinal fluid (CSF) can be useful to support a diagnosis of MS. Similarly, recent advances in magnetic resonance imaging (MRI) have improved the efficacy of the diagnosing

MS (Thompson, 2002). Lesions can now be detected by MRI and provide evidence of the disease process (McDonald et al, 2001).

2.5.8 *Treatment*

There is no cure yet for Multiple Sclerosis. However, there are a number of methods of treating the adverse symptoms of the disease. Current medical treatments focus on symptomatic relief such as managing inflammation with corticosteroids. Corticosteroids shorten the duration of the relapse and accelerate recovery; however, there is no convincing evidence that the overall degree of recovery or the long term course of the disease is affected. (Polman, & Uitdehaag, 2000).

The purpose of treatment in patients with relapsing remitting multiple sclerosis is to diminish the frequency and severity of relapses (and in so doing prevent exacerbations) as well as to avert or delay the onset of the progressive phase of the disease. Previously, immunosuppressive drugs have been used, but they have never achieved widespread acceptance due to limited efficiency and significant toxicity.

Currently, interferon beta 1a, interferon beta-1b, and glatiramer acetate are being used (Clerico, Rivoiro, Contessa, Viglietti, & Durelli, 2008; Rudick, Lee, Simon, Ransohoff, & Fisher, 2004). These substances are viewed as immune modulators rather than immune suppressors. These drugs are marketed under the names of Avonex, Biogen, USA; Betaferon, Schering, Betaseron, Berlex, USA; Copaxone, TEVA, Israel; Rebif, and Serono, Switzerland (Jacobs, 1996; Polman, 2000). However, these disease-modifying therapies for multiple sclerosis (interferon beta and glatiramer acetate) are only partially effective (Jacobs, 1996; Johnson, Brooks, & Cohen, 1995) and most patients with multiple sclerosis have breakthrough disease activity despite therapy with these drugs. Therefore, there is a need for the development of additional treatment options in multiple sclerosis.

Natalizumab (Tysabri) is an attractive new therapy, which is being trialled for use with current disease-modifying therapies in patients with breakthrough disease (Polman, et al., 2006; Rudick, et al., 2006). However, to date, no long term outcome studies have been published regarding its efficacy and success in treating MS symptomology.

Another recommended treatment to help lessen some of the symptoms of MS is exercise.

2.5.9 Exercise and Multiple Sclerosis

During the last decade, it was common to recommend physical exercise for MS patients, because of its recently proven beneficial effects in these patients (Petajan & White, 1999; Romberg et al., 2004). Sedentary people have an increased risk of developing various other health problems, like obesity and cardiovascular disease. Conversely, very low activity levels observed in people with MS (Ng & Kent-Braun, 1997) often coincide with a loss of leisure activities, social contacts, or regular activities of daily life, which are important for self-esteem and psychological well-being.

Impairments which are a direct result of the disease in most cases may not be reversible following exercise. However, impairments arising as a consequence of inactivity probably are reversible with exercise (Karpatkin, 2006). Recent studies have shown noticeable improvements in almost all aspects of the physiological profile of MS patients after exercise (Karpatkin, 2006; Romberg et al., 2004; Smith et al., 2006; Sutherland & Andersen, 2001). Therefore, it appears likely that a considerable part of the impairments associated with MS are a result of inactivity, rather than a result of non-reversible tissue injury. These postulations along with the fact that exercise is a non-pharmacological intervention, makes exercise a very significant factor in MS rehabilitation (Kent-Braun, Sharma, Weiner, & Miller, 1994).

2.5.10 *Psychosocial Correlates of MS*

Developing MS is a highly stressful life event which raises major challenges and obstacles to everyday functioning. Adjusting to MS requires not only an initial adjustment to the diagnosis of the condition, but also continuous readjustment due to the inconsistent nature of the symptoms (Matson & Brooks, 1977). People with MS may have to endure not only the psychological aspects, but the social challenges imposed by the illness, such as, school disruption, unemployment, problems with family functioning (Pakenham & Stewart, 1997), concerns with parenting, pregnancy, sexual problems, difficulty maintaining their independence and severe financial strain (Minden, 1992). Individuals with MS have reported higher levels of emotional disturbance, a lack of interest in meaningful activities, loss of enjoyment in relationships, hopelessness, despair, suicidal ideations, changes in sleeping and eating patterns as common reactions to the illness (Mullins, Cote, Fuemmeler, Jean, Beatty, & Paul, 2001; Whitlock & Siskind, 1980). Depression and anxiety are the most reported psychological effects of the disorder (Mohr & Cox, 2001).

2.5.10.1 *Depression and Multiple Sclerosis*

Depressive Disorders are the most common psychiatric co morbidity in patients with Multiple Sclerosis (MS), with a prevalence rate of 20-50% (Sollom & Kneebone, 2007; Wingerchuk & Weinshenker, 2000). The occurrence of depression in people with multiple sclerosis (MS) is also significantly greater than found in individuals suffering from other chronic, progressive, neurological illnesses (Mohr & Cox, 2001; Schubert & Foliart, 1993) Depressive symptoms have also been identified in approximately 80% of all patients with MS (Gottberg et al., 2007; Siegert & Abernethy, 2005). However, certain symptoms of MS have also been identified as depressive symptoms which may lead to some diagnostic confusion

(Huber, Rammohan, Bornstein, & Christy, 1993; Mohr, 1997). Examples include fatigue, concentration difficulties and lack of interest.

A reason for the high rates of depression among MS patients is that there is a wide range of potential etiologies. Patients with MS experience more losses than the general population, including loss of physical and cognitive functioning, loss of interpersonal relationships, and loss of social roles including employment (Mohr & Dick, 1999). Certain medication used in the treatment of MS, such as interferon P-1b, may also produce depression as an adverse side effect (Neilley, Goodin, Goodkin, & Hauser, 1996; Schiffer & Wineman, 1990).

There is also evidence that depression in multiple sclerosis is not only due to the social and psychological impact of MS but to the disease process itself (Kroencke, Lynch, & Denney, 2000). Multiple Sclerosis damages the myelin and nerve fibers deep within the brain. Consequently, if the disease damages areas of the brain which are involved in emotional expression and control, such as the basal limbic structures, depression may result (Berg et al., 2000).

2.5.10.1.1 Treatment of depression in people with MS

Given that depression in MS could be related to the ongoing structural damage in the central nervous system (CNS) (Siegart, 2005), it is uncertain whether depression in patients with MS should be treated as in the general population, or whether it requires a different approach. The current literature on pharmacological intervention suggests that the treatment of depression in MS with desipramine or paroxetine may be effective in the short term, although adverse effects are common (Koch, Glazenborg, Uyttenboogaart, Mostert, & De Keyser, 2011). Anticholinergic side effects, however, were reported in a significant majority of desipramine-treated patients. In an open-labeled trial of 11 depressed patients with MS,

Scott et al. demonstrated that sertraline was both effective and well tolerated (Scott, Nussbaum, McConnell, & Brill, 1995). Similarly, Mohr et al. demonstrated that a 16-week trial of sertraline significantly reduced depression scores in patients with MS and major depressive disorder (Mohr, Boudewyn, Goodkin, Bostrom, & Epstein, 2001).

Cognitive behavioural therapy (CBT) is the most frequently used psychological approach in the treatment of depression in MS (Thomas, Thomas, Hillier, Galvin, & Baker, 2006). CBT in MS focuses on behavioural activation for increasing pleasant activity and social interaction and on cognitive restructuring for identifying and challenging maladaptive thoughts and beliefs associated with depression.

CBT interventions that centre on specific coping skills and MS symptom management are generally more successful than interventions that emphasize emotional expression, gaining insight or knowledge. Moreover, CBT is as effective as antidepressant medication (Wallin, Wilken, Turner, Williams, & Kane, 2006).

2.5.10.2 Anxiety

Coping with an illness which has a highly uncertain progression causes great anxiety to those who are diagnosed with MS (Korostil & Feistein, 2007; Mohr & Cox, 2001). The occurrence of reported anxiety amongst MS patients has ranged from 14% to 41% (Janssens et al., 2003; Korostil & Feistein, 2007). Anxiety has been reported to increase the level of depression, and has been associated with increased rates of suicidal ideation, compared to depressed MS patients with little or no anxiety (Feinstein et al., 1999).

Certain MS related physical symptoms have been related to the level of anxiety experienced. Chronic pain for instance has been associated with higher levels of anxiety (Kalia & Connor 2005), whilst the association with level of disability status is only moderate (Tsivgoulis, Triantafyllou, & Papageorgiou, 2007).

2.5.11 *Impairment of Cognitive and Executive functions in Multiple Sclerosis*

Most patients with MS experience a decline in cognitive function, even in the early stages of the disease when there is little to no apparent physical disability (Rao, Leo, Bernardin, & Unverzagt, 1991). Neuropsychological studies have suggested a prevalence rate of up to 65%. (Rao et al, 1991). Cognitive dysfunction in MS is often difficult to detect on routine examination, because language skills and intellectual functions are usually preserved (Rao *et al.*, 1989; Schulz, Kopp, Kunkel, & Faiss, 2006). In addition, these impairments can range from mild, to global and severe (Ryan, Clark, & Klonoff, 1996) and appear to be irrespective of the type of MS, disease duration, depression, or physical disability.

The cognitive domains most often impaired in MS are prior knowledge, memory, learning, conceptual reasoning, speed of information processing, attention, concentration, and executive functioning (Brassington & Marsh, 1998; Rao, 1995). Executive functioning capabilities such as working memory, initiation and inhibition of responses, utilization of feedback, problem solving, strategic planning and conceptual ability have frequently been shown to be reduced in people with MS (Arnett, et al 1994; 1997; Beatty, Goodkin, et al, 1990).

Decline in cognitive functions can severely impact the quality of life for people with MS. In spite of the degree of physical disability, illness length, disease course, and demographic variables, people with MS-related cognitive deficits experience a decrease in daily living activities. These people are reported, in comparison to cognitively intact controls, to be less likely to be working, not as occupied in social and vocational activities, report more sexual dysfunction, experience more difficulty in carrying out household tasks, and to exhibit more psychopathology (Rao, Leo, Ellington et al. 1991).

Regardless of the evident challenges faced by persons with MS, successful adjustments to the disease are possible and likely (Eklund, & MacDonald, 1991). Some people have been found to adjust or “bounce back” through using different problem solving approaches, regulating emotions and behaviour in order to maintain some sense of control, experiencing positive emotions and having an objective and optimistic outlook. These aspects and other contributing factors of their resilience will be studied in the current project in order to understand what resilience means to a person with MS and how resilience relates to executive functioning.

2.5.12 *Resilience for People with Multiple Sclerosis*

People with MS may have to endure not only the psychological aspects, but the social challenges imposed by the illness. For the majority, disruptions include unemployment, tense family relationships, parenting difficulties, financial strain, sexual problems and decreased independence (Pakenham, Stewart, Rogers, & 1997).

As Holland, Murray, Reingold (1996) describe,

“The person receiving the diagnosis usually experiences a profound feeling of sadness as he or she has been forced to confront the frailty and vulnerability of the human condition in a personal and immediate way”(Holland et al, 1996, p. 52).

Consequently, resilience for people with MS would involve the ability of the individual to maintain a sense of stability. They have to find a way to incorporate their adversity into their lives (Wagnild & Young, 1990). This is crucial given the uncertain nature of MS and also provides a way of developing effective coping strategies to accommodate their ever changing lifestyles.

Maintaining a strong sense of self, participating in activities both social and recreational, determination, humour and having a positive perception of life are

characteristics which have been previously identified as features of highly resilient individuals (Wagnild & Young, 1990). The characteristics of resilience appear to buffer the individual not only in the day to day situations they face but also enables them to better anticipate, plan and deal with future adversity (Bonanno, 2004; Davidson, 2000; Dyer & McGuinness, 1996; Foster, 1997; Garmezy 1971).

2.5.13 *Summary and conclusion*

Multiple sclerosis is an inflammatory, demyelinating disorder of the Central Nervous System (CNS). It is the most common neurological condition which affects young adults in Australia. The course of the disorder is unpredictable and presents a wide array of fluctuating and confusing physical symptoms. There is no known cure. Certain symptoms such as fatigue are debilitating and often invisible to others. Other symptoms such as motor weakness are highly visible symptoms and most often are a source of depression and anxiety for the individual. The unpredictable nature of the disorder affects many aspects of life for not only the individual but also their families. The individual is in constant anxiety over when an attack might occur and what symptoms it may present.

Despite these factors, there are individuals who rise above their adversities, and demonstrate common characteristics associated with what is termed “resilience”. Based on anecdotal observations these individuals display similar characteristics to those with brain injury who are described as resilient, such as initiating social contact, displaying appropriate problem solving skills, and having an optimistic outlook on life. However, most studies investigating multiple sclerosis have focused on maladjustment and emotional problems rather than on resilience. The current project aims to study and observe individuals with multiple sclerosis to understand how resilience is demonstrated in this group of people. The role of executive functioning and how these skills relate to resilience will also be considered.

CHAPTER III

3 RESEARCH METHODOLOGY

3.1 Introduction

This study used a predominantly ethnographic, mixed methods research design, combining both qualitative and quantitative data and methodology. Mixed methods has been defined as “entities that are associated with or linked to each other but retain their essential character; metaphorically, apple juice and orange juice are both used, but they are never mixed together to produce a new kind of fruit juice” (Sandelowski, 2003 p.326). The combination of both quantitative and qualitative methods provided the opportunity for detailed description of human behaviour and experiences that were not otherwise obtained from using either method alone (Casebeer & Verhoef, 1997).

Due to the nature of the research questions, which require an in depth understanding and familiarity with the lives of participants with TBI or MS, the use of ethnographic methods, influenced the greater part of the research methodology. Ethnography has been defined as “the art and science of describing a group or culture” (Fetterman, 1998). The ethnographic methodology “begins with a panoramic view of the community, closes in to a microscopic focus on details, and then pans out to the larger picture again, but this time with new insight into the minute details. Only by both penetrating the depth and skimming the surface can the researcher portray the landscape in detail rich enough for others to comprehend and appreciate” (Fetterman, 1998, p 37). This involved participant observation on a weekly basis over 12 months.

In more detail, the ethnographic methods employed (Hammersley & Atkinson, 2007) to answer the research questions in this study included:

- Studying participants' actions and behaviour in everyday contexts, rather than under conditions created by the researcher.
- Gathering data from a range of sources, including documentary evidence such as medical and psychological records. However, participant observation, field work and unstructured interviews are the main source of data.
- Immersing in the culture of the participants with TBI and MS. This consists of close, long term contact with the participants, interaction with their families or significant others, and contact with their carers, social workers and rehabilitation professionals.
- Interpreting participants' language and behaviour in an unstructured random fashion. This information is recorded and used to exemplify and analyse individual case studies.
- Unstructured interviews are conducted. They range from spontaneous, informal conversations in the course of other activities, to formally arranged meetings in participants' homes. Positive advantages are obtained when participants are observed and interviewed in different contexts as this provides insight into how they would behave when the setting or circumstances change.
- The focus of the results is on six case studies along with answers to the research questions generated. This facilitates an in depth study into the ebb and flow of everyday life for participants with TBI and those with MS.
- Participating with recording and reviewing the behaviours of all 20 participants (10 with TBI and 10 with MS) to obtain an overall and more general picture of their lives.
- Analysis of data involving the interpretation of the meanings, functions, and consequences of participant's resilient and executive functioning behaviours. This data

is presented through verbal descriptions, explanations and observations made in the case studies, answered research questions and use of quantitative measures.

- Triangulation or the cross-checking of the accuracy of collected data and analytic statements is used. Through analyzing data from multiple sources, which are collected by diverse methods, and are supported by a range of theories, comparisons of concepts from participant observation, interviewing and other documents are made.
- Statistical analysis of the quantitative data will be used to support the data obtained through qualitative methods. This is another form of data triangulation, also known as parallel mixed analysis (Bickman & Rog, 2009). Whilst the quantitative data will be analysed using non parametric statistics, data from participant observation and interviews will be analysed throughout the case studies and answers given to the researcher's questions (Hammersley & Atkinson, 2007).

3.2 Quantitative Methods

Quantitative data were used to supplement the qualitative data obtained. Quantitative research involves data represented by numbers and analyzed by descriptive or inferential statistics, in a precise and unambiguous manner (Pelham & Blanton, 2003). For the purpose of this study four assessment instruments were used: (1) the Resilience Scale (Wagnild & Young, 1993) (2) the Dysexecutive Questionnaire (DEX) (Wilson, Alderman, Burgess, Emslie, & Evans, 1996) (3) the Goal Attainment Scale (GAS) (Kiresuk & Sherman, 1968) and (4) the Outcome Rating Scale (Miller & Duncan, 2000). These instruments were chosen after a comprehensive evaluation of the available assessment tools measuring resilience and executive functions was performed. Two key factors influenced the selection of an instrument

for this study, (1) psychometric properties such as good reliability and validity, and (2) appropriateness for use in people with TBI and MS (Groth-Marnat, 2003).

3.3 Resilience Scale

Resilience was measured using the Resilience Scale (RS) (Wagnild & Young, 1993), a 25-item scale which measures the degree of individual resilience (see Appendix 5). The Resilience Scale was initially developed from a qualitative study with a sample of elderly women (M age= 78.1 years) (Wagnild & Young, 1990). Although originally tested with adult subjects, numerous studies have validated that the scale has worked well with samples of all ages (Ahern, 2006; Monteith & Ford-Gilboe, 2002) and ethnic groups (Heilemann, Lee, & Kury, 2003; Nygren, Randstrom, Lejonklou, & Lundman, 2004).

Participants were asked to rate on a 7-point scale the extent to which they “disagree” (1) or “agree” (7) with a list of positive personal statements regarding how they view themselves. The possible scores ranged from 25–175, and the higher the score, the higher the demonstration of resilience suggested by the scale. Resilience scores were categorized as scores between 25-121 were classified as ‘low resilience’, 121-145 as ‘medium resilience’ and 145-175 as ‘high resilience’.

The Resilience Scale has demonstrated internal consistency within a range of $\alpha = .76$ to .91 (Cooley, 1990; Wagnild & Young, 1990, 1993; cited in Aroian et al., 1997). Test-retest correlations have ranged from .67 to .84 ($p < .01$), which suggest that resilience is a construct which is stable over time (Humphreys, 2003). Concurrent validity has also been demonstrated in other studies by attaining significant correlations between the resilience scale and measures of other constructs which are theoretically linked with resilience. These include morale ($r = .28$), life satisfaction ($r = .30$), stress ($r = -.24$), self-esteem ($r = .57$), depression ($r = -.37$) and health ($r = .50$) (Aroian & Norris, 2000; Humphreys, 2003; O’Neill, 1999).

3.4 Assessing Executive Functioning

The Dysexecutive Questionnaire (DEX) (Wilson, Alderman, Burgess, Emslie, & Evans, 1996) is a standardized self-report measure of behavioural difficulties associated with executive functioning. It is one of the few assessments which measure behavioural difficulties in people with executive dysfunction. The DEX was designed to evaluate the severity of dysexecutive symptoms shown by patients with frontal lobe damage (Wilson et al., 1996). It is one of six subtests included in the Behavioural Assessment of Dysexecutive Syndrome (Wilson et al., 1996).

The DEX is a 20 item questionnaire that is rated on a five point likert scale (0 = “never” to 4 = “very often”). The DEX is inversely scored with higher scores indicating a greater degree of symptoms or greater executive functioning difficulties. Participants are requested to rate their subjective experience of definite behavioural difficulties which are frequently related with executive functioning difficulties (e.g., abstract thinking, impulsivity, confabulation and planning problems). The items on the scale are divided into four categories: (a) emotional or personality problems, (b) motivational problems, (c) behavioural problems, and (d) cognitive problems (Stuss & Benson, 1986). Example questions consist of “I act without thinking, doing the first thing that comes to mind” and “I have difficulty thinking ahead or planning for the future.”

The DEX has two versions: (a) the self-rating version (DEX-S), which is completed by the participant, and (b) the rater version (DEX-R), which is completed by a relative or caregiver who has frequent contact with the participant. The two questionnaires are identical, with the exception of the way the questions are phrased, taking the first- or third-person frame of reference. For the purpose of this study, the DEX self- rater questionnaire was used where participants completed the questionnaires themselves.

Although initially the DEX was designed to be a qualitative instrument, several studies on its application as a quantitative test instrument have appeared (Bennett, Ong, & Ponsford 2005; Chan, 2001). The DEX has been shown to be an efficient instrument in diagnosing executive functioning difficulties. Bennett et al. (2005) even argue as to whether it is a promising “gold standard”. The DEX on its own has a good reliability of $r = 0.85$ (Bodenburg, 2008). Bennet et al (2005) have previously used the DEX in an Australian sample of people with Traumatic Brain Injury and have found it to be a reliable scale of measuring executive functioning. Inter- rater reliability is also high ($>.90$) (Bennett, Ong, & Ponsford, 2005). Table 3.1 below displays questions from the DEX questionnaire and the corresponding characteristics of executive functioning difficulty they measure.

Table 3.1 *Characteristics of the Dysexecutive Syndrome measured by the DEX Questionnaire**(in question order)*

Questions on the DEX	Behavioural Characteristics
1. I have a problem understanding what other people mean unless they keep things simple and straightforward	Abstract thinking problems
2. I act without thinking, doing the first thing that comes to mind	Impulsivity
3. I sometimes talk about events and details that never actually happened, but I believe did happen	Confabulation
4. I have difficulty thinking ahead or planning for the future	Planning problems
5. I sometimes get over excited about things and can be a bit over the top at these times	Euphoria
6. I get events mixed up with each other and get confused about the correct order of events	Temporal sequencing deficits
7. I have difficulty realizing the extent of my problems and am unrealistic of the future	Lack of insight and social awareness
8. I seem lethargic, or unenthusiastic about things	Apathy and lack of drive
9. I do or say embarrassing things when in the company of others	Disinhibition
10. I really wants to do something one minute, but couldn't care less about it the next	Variable motivation
11. I have difficulty showing emotion	Shallowing of affective responses
12. I lose my temper at the slightest thing	Aggression
13. I am unconcerned about how I should behave in social situations	Lack of concern
14. I find it hard to stop repeating doing or saying things once started	Perseveration
15. I tend to be very restless and can't sit still for any length of time	Restlessness–hyperkinesis
16. I find it difficult to stop doing something even if I know I shouldn't	Inability to inhibit responses
17. I will say one thing but do something different	Knowing–doing dissociation
18. I find it difficult to keep my mind on something and am easily distracted	Distractibility
19. I have trouble making decisions and deciding what I want to do	Poor decision-making ability
20. I am unaware or unconcerned about how others feel about my behaviour	No concern for social rules

3.5 Goal Attainment scaling

Goal Attainment Scaling is a method for measuring progress towards the type of highly individualized goals that are used in rehabilitation (Kiresuk & Sherman 1968; Malec, 1994). It is a method of goal definition and goal measurement that allows the quantification of specific outcomes, as well as the evaluation of the overall intervention program (Malec, 1994). Goal Attainment Scaling has been found useful for monitoring progress in a time-limited setting, planning and making decisions about ongoing rehabilitation, providing succinct and relevant communication to the client, encouraging more accurate self-awareness, and redeveloping the capacity for goal setting (Malec, 1994). The goals used in the intervention were identified in collaboration by the participants and the researcher. The long term goals identified were written by the researcher and examples are presented in the case studies. The long term goals then helped define and form the short term objectives and participant goals.

The GAS was applied to participant's short term goals and was rated together by the participant and researcher at the end of the intervention period. Whilst all participants were involved in the goal setting process, they were not included in the development of the five point scales by which the goals were measured. Writing of the goals by the researcher was identified in the literature as being less time consuming and less confusing for participants (Malec, 1999). Some goals were measurable through physical achievements or measurable or meeting timeframes. Other goals relied on participants' self report, observations, and recordings during the intervention to establish that they were achieved. Table 3.2 below details the steps used when selecting goals.

Table 3.2 *Steps used for Goal selection*

Goal selection
<ul style="list-style-type: none"> • Weighting goals • Designation of follow up time period • Articulation of the “expected” level of outcome in objective behavioural terms • Articulation of other outcome levels • Assessment of GAS level on admission and at follow up (Malec, 1994)

Example of Goal Scaling

Goal: I feel comfortable in expressing my personal opinions and feelings (even when they differ from others) and am able to accept feedback.

+2 I am able to express opinions and feelings more than two times per week using effective social skills 90–100% of the time.

+1 I am able to express opinions and feelings two times or more per week using effective social skills 75–89% of the time.

0 I am able to express opinions and feelings two times or more per week using effective social skills 50–74% of the time.

–1 I am able to express opinions and feelings two times or more per week using effective social skills less than 50% of the time.

–2 I am able to express opinions and feelings less than twice per week.

3.6 The Outcome Rating Scale

The Outcome Rating Scale (ORS) is an “ultra brief outcome measure” developed by Miller and Duncan, (2000). It was developed as a shorter alternative to the Outcome Questionnaire 45.2 (Lambert, Hansen, et al., 1996). The ORS is recognised as a method to operationalise practice-based evidence through the collection and communication of patient feedback (Campbell & Hemsley, 2009). The ORS utilises standardised measures that correspond to ongoing outcomes, thus allowing practitioners to predict “with a high degree of

certainty” the significance of therapy and the continuity of interventions (Campbell & Hemsley, 2009). The ORS is a 4 item visual analogue scale. Participants are requested to put a mark on a line of each item nearest to the pole that most accurately describes their experiences. The ORS is scored based on each 10-cm line using a ruler. This yields four separate scores between 0 and 100 using a millimetre for scale measurement. As no scaling is provided, for the purpose of this study, scores of 0- 30 were considered low, 30-70 were considered moderate and 70-100 were considered high.

Items on the ORS were adapted from three areas of client functioning, specifically, individual (personal well being), interpersonal (family close relationships), and social (work, school) and global (general sense of well being). Improvements in these three areas are recognized as valid indicators of successful treatment outcome (Kazdin, 1994; Lambert, Burlingame, et al., 1996; Lambert & Hill, 1994).

The ORS possess high internal validity. The Cronbach’s coefficient alpha ranged from .87 at the first administration to .96 at the third and fourth administration. Coefficient alpha for all administrations ($N = 336$) was .93. The high degree of internal validity reveals that the four items on the scale correlate quite highly with one another. This shows that the measure may be a global measure of distress rather than being subscales for separate dimensions. The scale also possesses concurrent validity, correlating with the Outcome Questionnaire 45, $r = .59$ (Lambert et al, 1996), and the Symptom Checklist 90 Revised, $r = .57$ (Derogatis, 1994). The ORS also has a test retest reliability of .66 (Miller et al, 2003).

The ORS attempts to balance the reliability and validity of longer outcome measure, with the practicability required for everyday use (Anker, Duncan & Sparks, 2009; Miller et al, 2003).

3.7 Participant Selection

The use of a purposive sample was employed in this study. Purposeful selection is a type of non probability sampling whereby particular settings and participants are selected deliberately to provide data which often may not be obtained using other methods (Shaughnessy, Zechmeister, & Zechmeister, 2005). These samples of people are selected because they are “people who are uniquely able to be informative because they are expert in an area or were witness to an event” (Weiss, 1994 p. 17). A sample of twenty participants (n = 10 with TBI, n = 10 with MS) were used as this enabled personal examination of resilience through the building of a narrative with the participants. Demographic data on participants is presented in Table 5.1 (chapter 5). Taking into account the target population size and criteria for subject selection, a sample of twenty participants was considered representative and manageable (Maxwell, 2005). Criteria for selection of participants in this study required that they:

1. Had a diagnosed traumatic brain injury or diagnosed multiple sclerosis.
2. Were over 18 years old at commencement of study.
3. Had functional expressive and receptive language.
4. Agreed to allow the researcher full access to all medical and psychological records.
5. Were clients of a particular rehabilitation consultant with access to the Community Re- entry Program or were members of the Multiple Sclerosis Society.
6. Were accessible for a minimum period of 12 months.
7. Were living in the community in metropolitan Adelaide.

Potential participants were identified through contact with a rehabilitation consultant specialising in working with people who have TBI as well as through the Multiple Sclerosis Society. The consultant and the MS society were identified as sources for recruiting participants as they were the “gatekeepers into the community” of people with TBI or MS (Fetterman, 1998). A gatekeeper is someone who is in a position of authority to introduce the researcher to other members of the community, whilst sharing their own insider information about the participants (Reeves, 2010). In order to gain entry to the private lives of people living with TBI or MS, it was pertinent to go through someone who acted as an intermediary who “opened doors otherwise locked to outsiders” (Fetterman, 1998). The gatekeepers chosen had good rapport with the participants, and initially this rapport made it easier for the researcher to access participants. Strong recommendations and introductions from the gatekeepers strengthened the researcher’s capacity to form meaningful relationships with participants, with their carers, family and allied health professionals where appropriate.

An in-person interview explaining the purpose of the research was arranged with participants who met the criteria and who chose to participate. Informed consent was obtained from each participant prior to the beginning of the study.

Participant demographic and diagnostic data was gathered from medical records, as well as interviews with participants, and these data are later presented in case studies. All 10 participants with TBI had post trauma IQ scores (Weschler, 1997), as they were assessed formally as part of a previous study (Rees, 1997).

3.8 Participant Demographic and Diagnostic Data

Table 3.3 below presents demographic and social information for each of the 20 participants. The participants included 10 individuals with Multiple Sclerosis (MS) and 10 with Traumatic Brain Injury (TBI).

Table 3.3 *Participants' demographic and social data*

Participant	Group	Age	Gender	Education	Pre trauma/illness occupation	Current Employment	Type of MS	TBI location	Time Since Diagnosed	Married	Children
1.	TBI	39	F	High School	Dancer	No		Frontal	10 yrs	Divorced	1
2.	TBI	51	M	High School	Metalworker	No		Frontal	15 yrs	No	None
3.	TBI	35	F	Degree	Musician	No		Frontal	2yrs	No	None
4.	TBI	40	M	Degree	Uni student	No		Diffused	16yrs	No	None
5.	TBI	35	M	Degree	Manager	Yes		Diffused	9yrs	No	None
6.	TBI	44	F	Degree	Teacher	No		Diffused	12yrs	No	None
7.	TBI	48	M	Post Grad	Scientist	No		Diffused	12yrs	No	None
8.	TBI	35	F	High School	Student	No		Diffused	23yrs	Divorced	1
9.	TBI	44	M	Degree	Teacher	No		Diffused	19yrs	Divorced	2
10.	TBI	50	M	High School	Uni student	No		Diffused	24yrs	No	None
Mean		42.10									
11.	MS	60	M	Technical School	Electrician	No	PP		1yr	Divorced	None
12.	MS	53	F	Diploma	Bio medic	Yes	RR		15yrs	Yes	3
13.	MS	32	F	Degree	Social worker	Yes	RR		10yrs	No	None
14.	MS	35	F	Degree	Social worker	No	RR		2yrs	Yes	2
15.	MS	43	F	Degree	Public liaison	No	SP		7yrs	Divorced	4
16.	MS	48	M	Technical School	Electrician	No	RR		22yrs	No	None
17.	MS	45	F	Degree	Teacher	No	PP		10yrs	Divorced	3
18.	MS	26	F	High School	cleaner	No	RR		2yrs	Yes	2
19.	MS	56	F	Degree	Social worker	No	RR		25yrs	Yes	2
20.	MS	45	M	Post Grad	Engineer	No	RR		8yrs	Divorced	None
Mean		44.3									

Key : PR – Primary progressive RR- Relapse Remitting SP- Secondary Progressive

3.8.1 *Mean age*

The mean age for participants with TBI was 42 years (SD 6.23) and 44 years (SD 10.80) for participants with MS. There is a slight mean age difference of 2 years between the two groups. Participants' ages ranged from 26 years to 60 years. The mean age of both groups is much higher than the "at risk" population of people who sustain a TBI or are first diagnosed with MS. This at risk group for TBI is identified as individuals in the 15- 25 years old age group (Fortune, 2006). Similarly MS is usually first diagnosed in individuals who are in the 20-30 years age group (Smith & Schapiro, 2000). This is the time when MS symptoms usually become first apparent and formal diagnosis is made. However, if the current age of all participants is deducted from the time since their accident or time when they were first diagnosed, then the current sample fits the at risk group of people with TBI or MS (see Table 3.3 above). A detailed description of each participant's age and his/her ability to be resilient is presented under the research questions section of this chapter.

3.8.2 *Gender*

The TBI group consisted of 60 percent males. This higher percentage of males than females is consistent with statistics which show that 75 percent of individuals with a brain injury are males (Myburgh, et al., 2008). Within the MS group, 70 percent of participants were female. Again this is consistent with statistics which show that the ratio of females to males with MS is 2.3:1 (Hammond, English, & McLeod, 2000).

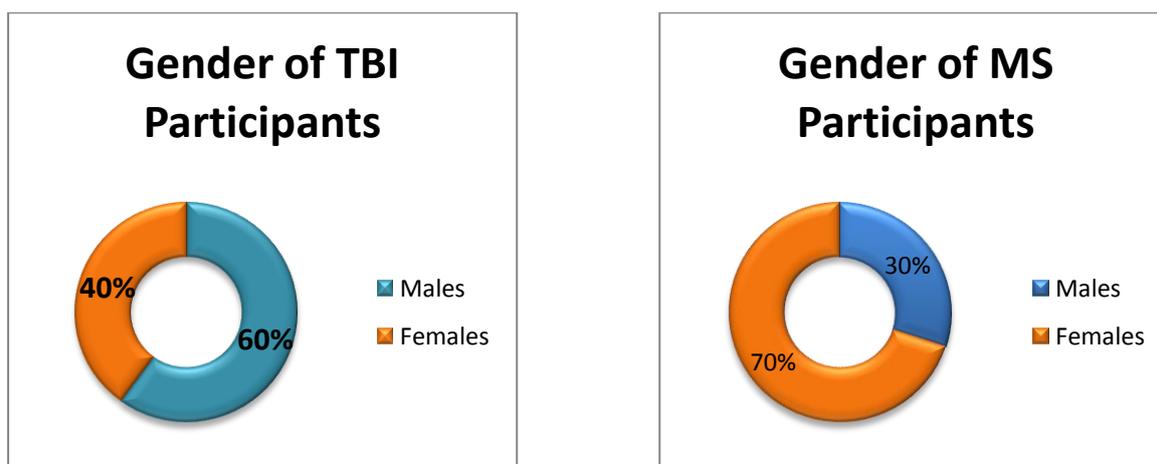


Figure 3.1 Gender of both groups of participants

3.8.3 Education

The MS participants were only slightly more educated when compared with the TBI group. Of the MS participants, 60 percent had a degree and 10 percent had post graduate qualifications. The TBI group had 50 percent of participants with a degree, 10 percent with post graduate qualifications, and no technical school or diploma graduates. Two participants with MS had qualifications in technical skills. One plausible reason for this could be that participants with TBI had their accidents at a young age (between 20-30years) and this affected their abilities to pursue higher education.

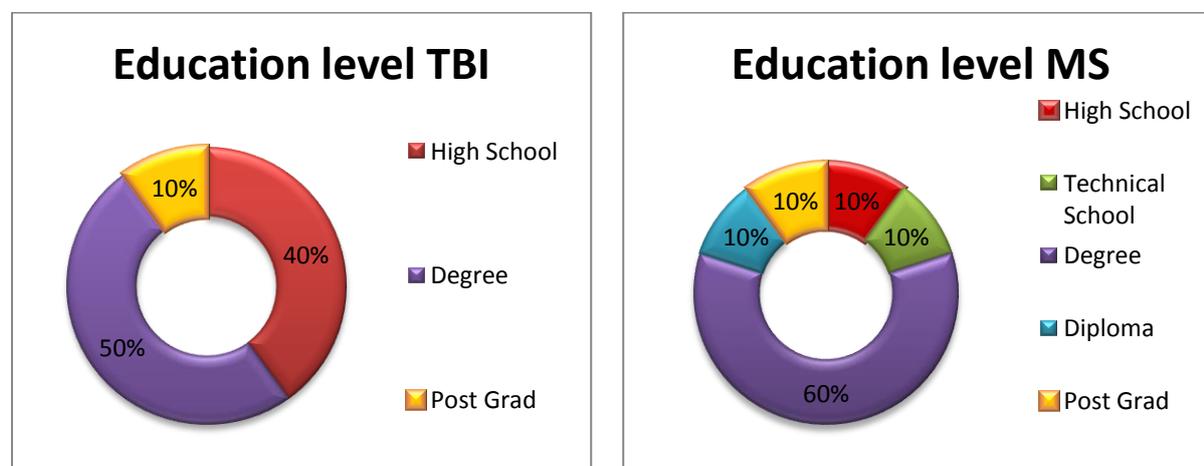


Figure 3.2 Levels of education for both groups of participants

3.8.4 Employment

Only one participant from the brain injury group was employed (part time) at the time of the study. Two participants with MS had casual jobs whilst the rest were unemployed and had not returned to work due to their disabilities. TBI and MS can leave an individual with a number of persistent impairments that interfere with finding and keeping a job (Machamer, Temkin, Fraser, Jason, & Dikmen, 2005). These problems may be (a) cognitive (for example, difficulties with attention, memory, communication, reasoning, and problem-solving), (b) physical (such as weakness or lack of coordination in arms or legs, impaired vision, fatigue, sleep problems), (c) emotional problems (for example, vulnerability to depression, difficulty controlling anger or anxiety), or (d) behavioural (for instance, being impulsive, and having difficulty initiating or sustaining behaviour) (Malec & Scanlan, 2004). These problems present barriers to employment for people with a disability (Rees, 1997). Some participants had severe disabilities which prevented them from returning to work. For others, volunteering, education, or other unpaid activities have been rewarding options.

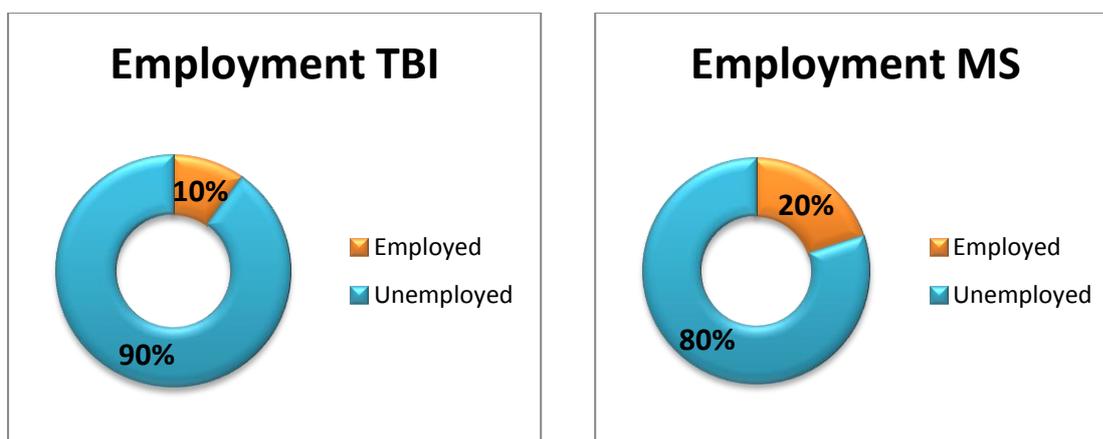


Figure 3.3 Employment for both groups

3.8.5 Types of Multiple Sclerosis

There are essentially two patterns of Multiple Sclerosis (MS) which are represented in this study. These are the relapse remitting pattern, which affects up to 70 percent of people with MS, and the other which is a gradual deterioration, also known as progressive MS (Mohr & Cox, 2001). Progressive MS is further divided into the categories primary progressive (15 percent) and secondary progressive (40 percent) (Wingerchuk & Weinshenker, 2000). In this study, 70 percent of participants had relapse remitting MS, whilst 20 percent had primary progressive, and 10 percent had secondary progressive MS.

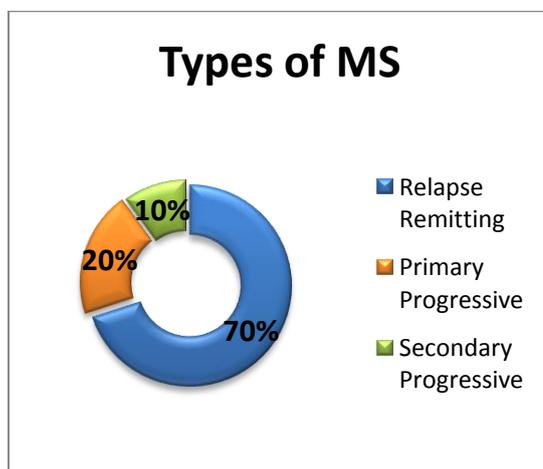


Figure 3.4 Types of Multiple Sclerosis

3.8.6 Location of Brain Injury

In traumatic brain injury the brain may be injured in a specific location or the injury may be diffuse, affecting different parts of the brain (Meythaler, Peduzzi, Eleftherious, & Novack, 2001). All participants in the study had a focal frontal lobe brain injury. Focal injuries are typically associated with specific deficits, depending on the location of injury (Gualtieri, 2002). TBI is most commonly associated with focal damage particularly to the frontal lobes (Eslinger & Geder, 2000). Some participants also had diffuse injuries with

damage to the brainstem and sub cortical white matter in addition to areas of focal pathology.

Of the participants in this study, 70 percent had injuries in multiple locations (diffuse).

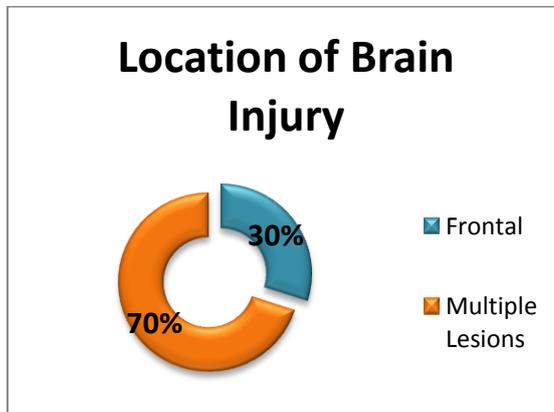


Figure 3.5 Location of brain injury for TBI participants

3.8.7 Time since diagnosis

Participants with TBI had been living with their disabilities for a mean of 14 years, while for participants with MS the mean was 10 years. These data show that participants have been coping with their disabilities between one and 25 years and during this period have received treatment and intervention for their respective disabilities. Most of the participants with brain injury had been attending a community rehabilitation program or visiting their rehabilitation consultant on a regular basis. Similarly the participants with MS were receiving support through the Multiple Sclerosis Society of South Australia.

3.8.8 Marital status

70 percent of the TBI participants and 20 percent of participants with MS are not married nor in a relationship. 30 percent of the TBI group and 40 percent of the MS group have been married and are currently divorced. Another 40 percent of those with MS are currently married whilst none of the TBI group is married at present. This difference in both

groups shows that whilst both disabilities pose significant disruptions to marriage and relationships, TBI appears to be linked with greater relationship disruptions. Role changes, social isolation, increased dependency and psychological changes in personality are commonly experienced, particularly as time since injury increases (Dupont, 1995; Wood & Yurdakul, 1997). All participants were of the opinion that having a partner to support and share responsibilities would enable them to cope and be more resilient (Conger & Conger, 2002).

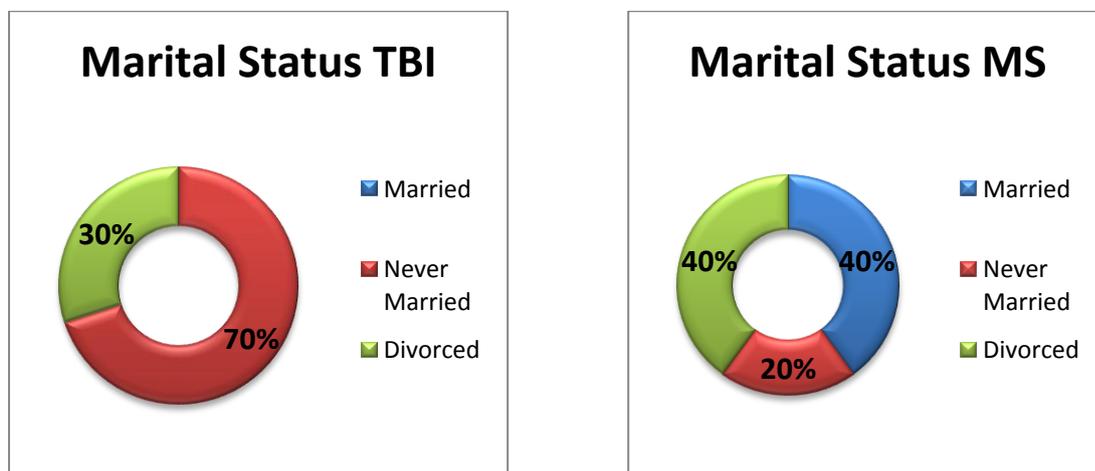


Figure 3.6 Marital status for both groups of participants

3.8.9 Children

30 percent of participants with TBI had children, whilst the figure for participants with MS was 60 percent. Also, out of the participants with TBI, only one had custody of her child whilst the others had lost custody of their children. However, all of the participants with MS were living with their children at the time of the study. The results (see chapter 5) show that those with children reported that their children were their main protective factors, which enabled them to be resilient (Ducharme, 2003). Their children provided them with a sense of purpose and meaning in life, which enabled them to cope better when faced with adversity.

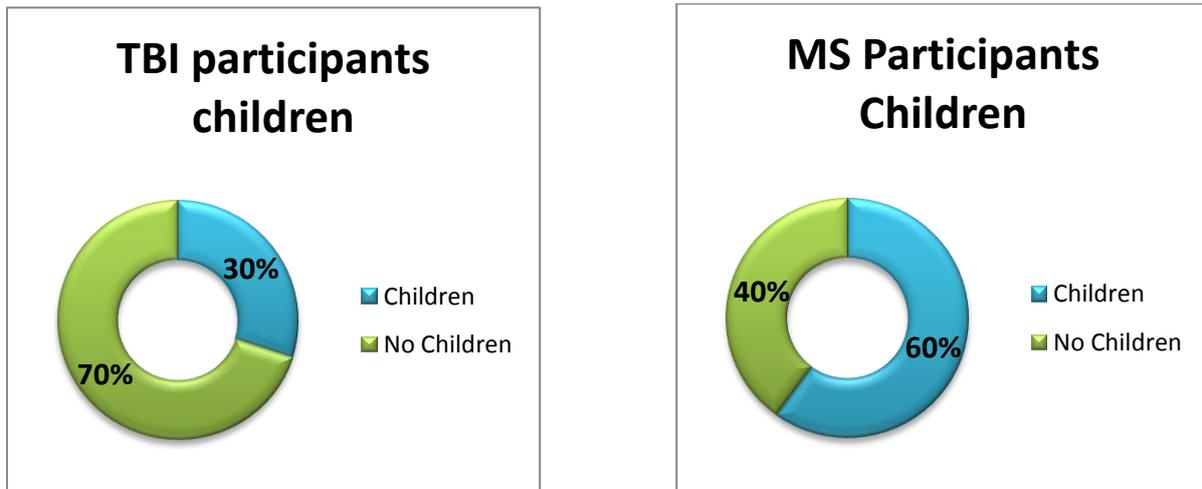


Figure 3.7 Children for both groups of participants

3.8.10 *Community Re- Entry Program*

Most participants with TBI were either (a) currently active participants of the Community Re- entry Program or (b) used to be members of the CRP. CRP is a community rehabilitation program for people with brain injury based at the Flinders University. The CRP is a program which organizes and supports daily physical, social, communication and recreational activities for people with a brain injury. The program aims to reintegrate people with brain injury into their local community through organised, sustained and monitored participation and learning.

3.8.11 *The Multiple Sclerosis Society*

The MS Society enhances the quality of life of people with MS and aims to reduce the impact of MS on the families and carers of those with Multiple Sclerosis. The MS society offers professional support through their social workers, psychologists, occupational therapists, physiotherapists and peer support groups. The society organizes regular talks on

topics of relevance to those with MS such as managing depression, stress and anxiety.

Members can also join local MS support groups held by their peers, in their neighbourhood.

3.9 Ethical Considerations

The following is a list of the measures taken to preserve the anonymity and integrity of participants. Consent for participation was gained from each participant. Each participant was fully informed of the details of the study, including: (a) aims, (b) purpose, (c) what was involved for the participant, (d) how the data would be used, and (e) their right to withdraw at any time. All information was treated in the strictest confidentiality, with the identity of all participants concealed. Notes taken did not reveal any names, and the participants were identified only by anonymous letters. Information obtained was not discussed with people, other than with the researcher's supervisors. The method and use of the data generated did not threaten or harm the participants' physical and psychological well being or dignity in any way. In addition, all participant information and data were stored in a locked filing cabinet and participants were given the opportunity to read and comment on the data and conclusions made.

3.10 Data collection points

The researcher met with each participant prior to commencement of the study; at 01 (see Figure 3.8 below). The participants who desired to be involved in the study were informed of the aims and purpose of the research, the nature of their involvement, how the data would be used, and of their right to withdraw from the study at any time. If they agreed to participate, an informed consent form was signed.

At that time, the participant completed the Resilience Scale (RS) and the Dysexecutive Questionnaire (DEX). The researcher demonstrated how to use and complete

both instruments, and answered any questions which were raised. The questionnaires were required to be completed by the participant independently to ensure reliability, however a researcher/mentor was present and, where required, assisted in completing the questionnaire in cases where items were not clearly understood, as well as to debrief the participants and ensure issues raised did not upset or concern participants in any way. Scores on both the instruments were recorded at baseline (01) at the end of the 6 month intervention (02) and again at follow up after 6 months (03) (see Figure 3.8 below). Goals were set together with the participant at the initial interview and were reviewed every 2 months. Progress was recorded and new goals were set if necessary. The Outcome Rating Scale was administered after every session.

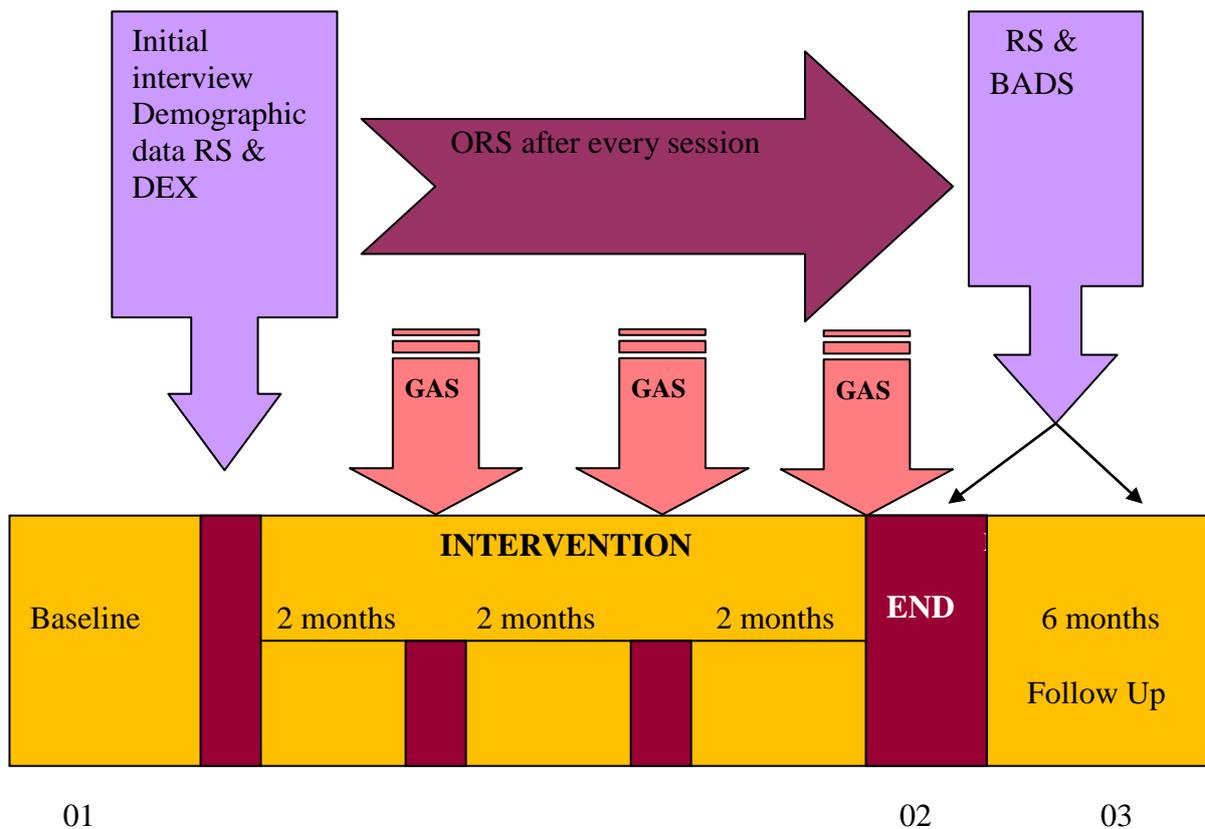


Figure 3.8 Time line of data collection

3.11 Analysis of Data

Quantitative data analysis in this study comprised of non parametric statistics due to the small sample size. Given the mixed method nature of the study a combination of statistical methods were employed. The Wilcoxon signed rank test (Keppel & Zedeck, 2002; Wilcoxon, 1945) was used to analyze intervention effectiveness and the Mann Whitney U test (Mann & Whitney, 1947) was used to measure group differences in the demonstration of resilience and executive functioning between the two groups. The Spearman correlation coefficient (Spearman, 1904) was used to determine if there was a relationship between resilience and executive functioning. The qualitative research questions were answered using triangulation and case studies.

3.11.1 *Wilcoxon Signed Rank Test*

The Wilcoxon signed rank test (Wilcoxon, 1945) is an alternative to a within-subjects t test when numbers are small. This test assumes that there is information in the magnitudes of the differences between paired observations, as well as the direction (signs) of the differences (Keppel & Zedeck, 2002). Paired data means that the values in the two groups being compared are naturally linked, and usually arise from individuals being measured more than once. In this case data from participant's scores pre intervention and post intervention were compared. A significance level of $\alpha = 0.05$ was assumed.

3.11.2 *Mann -Whitney U Test*

This test is a non-parametric test that can be used in place of a between-subjects t-test. It is used to test the null hypothesis that two samples come from the same population (i.e., have the same median) or, alternatively, whether observations in one sample tend to be larger than observations in the other (Mann & Whitney, 1947). Participant's scores on the tests will illustrate group differences (TBI & MS) or similarities in resilience and executive functioning.

3.11.3 *Spearman Correlation Coefficient*

The Spearman Correlation is used to measure the relationships between two variables (Spearman, 1904). Spearman's rank correlation coefficient has a value between -1 and +1. A positive correlation is one in which both the variables increase together. A negative correlation is one in which the ranks of one variable increase as the ranks of the other variable decrease. Cohen (1988) defined the standard for assessing the size of correlations. The size of the effect of one variable on another variable is known as effect size. A correlation of 0.5 is considered a large effect size, 0.3 a medium effect size, and 0.1 a small

effect size. The Spearman correlation was used to assess the relationship measured resilience has with executive functioning. Namely it assessed if resilience increased with greater executive functioning or vice versa.

The SPSS (Statistical Package for the Social Sciences) version 16.00 (Norusis, 1990) was used for all statistical computations and presentation of data. The SPSS program performed all statistical analysis. The program also documented data such as recording participants' demographic information and computing results of scores on assessments.

3.12 Triangulation

Triangulation in research refers to the mixture of two or more theories, data sources, methods, or investigators in one study of a single phenomenon targeting a single construct (Deacon, Bryman, & Fenton, 1998). In this study, for instance, interview data were triangulated against data obtained from participant observation and quantitative instruments, therefore allowing the examination of one result against another, and increasing the reliability of the result (Alvesson, & Skoldberg, 2000).

The following list further reflects the types of triangulation used in this project:

- Data triangulation: multiple data sources such as formal interviews, self reports, data from family and friends with similar foci are used to obtain diverse views through a range of data about the participants.
- Time: The data is collected at different points in time along a period of 1 year.
- Space: The data is also collected at different sites such as through participant observations, ethnography and formal interviews.
- Theory triangulation: The linking of neuropsychological (executive functioning) theory with resilience theory.

Triangulating is used to provide verification and completeness (Morse, 1991). Using triangulation the researcher can capture a more total, holistic and contextual portrayal and make known the varied dimensions of a given experience (Deacon et al., 1998). The researcher's bias can also be minimized and the validity of the findings improved (Alvesson, & Skoldberg, 2000).

3.13 Reliability

Reliability refers to the consistency or repeatability of a measure or observation (Pelham & Blanton, 2003). Kirk and Miller (1986) identify three types of reliability which are: (1) the degree to which a measurement, given repeatedly, remains the same (2) the stability of a measurement over time; and (3) the similarity of measurements within a given time period (pp. 41-42). Lack of internal consistency as well as instability of measures can limit the generalizability of research findings (Cronbach, Gleser, Nanda & Rajaratnam, 1972).

Therefore the reliability measures used in this study were;

1. The use of instruments which have been widely researched for their reliability and stability.
2. The Cronbach's alpha was also used as a measure of reliability. According to Kerlinger (1973), a reliability coefficient of .60 or better would be needed to meet a moderate standard of reliability and this was achieved by both the DEX and the RS.
3. Consensus between observations and participants' scores on instruments
4. Observations of the participants over a long period of time in various contexts
5. Triangulation

3.14 Validity

In quantitative research, validity is concerned with whether the means of measurement are accurate and whether they are actually measuring what they are intended to measure (Joppe, 2000). When qualitative researchers address research validity, they are usually referring to qualitative research that is plausible, credible, trustworthy, and, therefore, defensible (Davies & Dodd, 2002; Mishler, 2000). Therefore the three types of validity often used are (1) descriptive, (2) interpretive and (3) theoretical. Descriptive validity refers to accuracy in reporting the facts whilst interpretive validity refers to accurately describing the meaning attached by participants to what is being studied (Johnson, 1997; Maxwell, 1992). Theoretical validity refers to a theoretical rationalization which fits the data and, as a result, is credible and justifiable (Johnson, 1997). A key aim of this study is to understand the inner worlds of participants, to “look through the participants' eyes, and see and feel what they see and feel” (Johnson, 1997). Therefore validity, in this instance, refers to the degree to which the participants' views, thoughts, feelings, meanings, and experiences are precisely understood and portrayed in the research (Maxwell, 1992).

The steps taken to ensure validity in this study are:

- Extended Field Work – The researcher spent an extended amount of time with participants over a period of 12 months.
- Low inference descriptors – Where appropriate, the researcher used direct quotations and exact phrases used by the participants as descriptions of their experiences
- Participant feedback – The discussion on the results, case studies and conclusions were fed back to participants to ensure accuracy and to verify content.

- Peer review – Continual discussions between the researcher and an external supervisor not directly involved in the research was carried out with the consent of the participants.
- Reflexivity - Ongoing self reflection and critical examination of the researcher's biases was done in order to identify potential inclinations and interpretive tendencies
- Small sample- The use of a small sample might confound the study but in this particular study it added to the validity because it allowed for an in-depth exploration of issues and it added breadth to the research (Crouch & Mckenzie, 2006).

3.15 Research Questions

The research questions were generated from the statement of the problem and also by initial examination of the scales which were used to measure resilience and executive functioning in this study. The research questions included:

- 1) What is the relationship between measured resilience and executive functioning for all participants?
- 2) Is there an improvement in resilience and executive functions after the intervention?
- 3) Are there any group similarities or differences in the demonstration of resilient and executive functioning behaviours?
- 4) What is the evidence of resilient behaviours in the sample in this study?
- 5) What factors contribute to the resilience and effective executive functioning of participants?
- 6) How does having family/ spousal support influence resilience?
- 7) Does unemployment compound the difficulties of TBI & MS and if so how?
- 8) What part does level of education play in coping with these conditions?
- 9) What is the nature of social networks for all participants?
- 10) To what extent is denial a factor in coping with either condition?

- 11) To what extent is age a factor in coping with either MS or TBI?
- 12) Since people with frontal brain damage generally have impaired executive functioning to what extent does a) training and/or b) mentoring compensate for executive functioning difficulties?
- 13) To what extent do mood swings for either sample affect measures of executive functioning and resilience?

Chapter IV

INTERVENTION

4 INTRODUCTION

The intervention was based on psychological and educational principles, identified in the literature, which were considered to nurture a person's resilience. Examples of these principles included having regular meetings to build and maintain the therapeutic relationship, writing down participants' strengths and personal resources, working on problems of daily living, and aiding in the building of social networks.

The main theories which the intervention was comprised of were (a) Person Centred Therapy (Kirschenbaum & Jourdan, 2005; Rogers, 1961), (b) Cognitive Behaviour Therapy (Beck, 1995), (c) the strengths based model (Smith, 2006), (d) strengthening protective factors (Alvord & Grados, 2005) and (e) the solution focused approach (Lightsey, 2006). Items from each approach were incorporated and used to develop the intervention.

4.1 Intervention Procedure

The researcher met with all participants individually, for approximately 1- 1.5 hours every two weeks, over a period of 12 months to maintain continued contact (Rees, 2005; Vlasek, 2010). These meeting took place in participants' 'natural settings'. Sometimes this meant visiting participants in their homes or at a cafe. Where weekly meetings were not possible, contact was maintained over the phone or through SMS.

The items of the intervention are outlined in Table 4.1 below. It should be noted that the items contained in the intervention did not necessarily have to be carried out in a particular sequence, but were used as a basis for developing personalized intervention programs for each participant. Goals were determined upon discussion with the participants

and both short term and long term goals were identified at the start of the intervention. Every two months goals were assessed using the Goal Attainment Scaling process (GAS) (Kiresuk & Sherman, 1968). The participant and researcher reviewed and evaluated the progress and new goals were set where necessary.

Table 4.1 *Items contained in the intervention*

Intervention process
1. Creating the therapeutic relationship
2. Listening and taking case histories (validating client's story)
3. Identifying strengths/ protective factors
4. Assessing presenting problems
5. Empowering and instilling hope
6. Reframing behaviour using optimistic thinking, positive language constructs and perspective taking
7. Facilitating problem solving
8. Building networks, as and when needed, to help develop competence and resilience
9. Identifying, planning and working on goals
10. Skills training as necessary (relaxation, self control, thought stopping, etc)
11. Evaluating and terminating

These items are described individually below. Due to the nature and design of the study, the intervention was developed to accommodate individual differences and was designed to be implemented on a needs basis. For instance, a goal for one participant might have been to learn how to take public transport and, therefore, he/she might have required support with this, whilst another participant might have required assistance in developing his/her social network. Therefore, the strategies and skills needed to be incorporated into the intervention would need to be different for the two individuals.

The intervention process was aimed at not only aiding the development of resilient behaviours, but also strengthening executive functioning through the use of modelling appropriate behaviours, and maximizing learning using principles of contextualized errorless learning (Gordon, Cantor, Ashman, & Brown, 2006; Rees, 2005).

4.2 Items of the intervention

Item 1 – *Creating the therapeutic relationship*

In creating the therapeutic relationship, principles of person centred therapy (Rogers, 1959, 1986) were often used. Rogers (1969) stresses that the therapist's primary effectiveness is through the formation of this therapeutic relationship. The foundational theory in person-centred therapy is the actualizing tendency, which is an intrinsic directional tendency for the human beings to grow, to develop, and to realize their full potential (Rogers, 1986; Rogers & Holdstock, 1977). He says that

“ ...the individual has within himself or herself vast resources for self-understanding, for altering his or her self-concept, attitudes, and self-directed behaviour -- and that these resources can be tapped if only a definable climate of facilitative psychological attitudes can be provided.” (Rogers, 1986, p. 135)

Consequently, creating the therapeutic relationship requires the therapist to promote the actualizing tendency by creating an interpersonal climate through the attitudes of congruence, unconditional positive regard and empathic understanding (Bozarth & Brodley, 1991; Rogers, 1959). For instance, not making any negative judgements when they reveal personal, intimate details of which they are ashamed. These three conditions are necessary in order for the relationship to become the "definable climate" of which he speaks:

1) *Congruence* – Congruence is the therapist’s genuineness or realness within the helping relationship. Rogers discussed the crucial importance of the clinician to “freely and deeply” be himself. The clinician has to be a “real” human being. Not an all knowing, all powerful, strict, and controlling figure (Rogers, 1957).

2) *Unconditional positive regard* - This facet of the relationship involves experiencing a warm acceptance of each aspect of the client’s experience as being a part of the client. There are no conditions or restrictions made when accepting the client as who they are. The clinician needs to accept the client as who they are and view them as a unique individual (Rogers, 1957).

3) *Empathic understanding* – According to Rogers (1961, p.284) this is “To sense the client’s private world as if it were your own, but without ever losing the ‘as if’ quality”. An accurate empathetic perception of the client’s awareness of his own experience is central to the therapeutic relationship. It is important to have the ability to enter the client’s private world and understand their thoughts and feelings without making judgment (Rogers, 1957).

Item 2 - Listening and taking case histories (validating client’s story)

Telling one’s life story, making sense of one’s life, and viewing oneself as a survivor rather than a victim has a powerful effect. Through listening and validating the individual's story, the therapist starts establishing rapport with the client, understanding the client's world view, and starts the process of examining the client’s resilience. Case histories permit the therapist to get a more holistic perception of the client and a better understanding of their domestic, personal, vocational and recreational environment. For example, a 34 year old woman with four young children was diagnosed with MS following disorientation and a collapse in a lift. In the early stages of the disease, she perceived this to be terminal condition

a life sentence and responded with much anger and reckless behaviour. Recklessness involved a range of disinhibited sexual behaviour (becoming a temporary sex worker). Behaviours she would not have entertained pre diagnosis. Through listening to her story, and helping her create a new story, this participant was able to view herself as a survivor of MS and not as a victim of circumstance. Yet there were moments when her reckless behaviour still emerged. However, she was able to display awareness and insight into what triggered these behaviours.

Item 3 - *Identifying strengths/ protective factors*

Discovery of a client's strengths may not be easy because strengths may be buried by symptoms or repressive circumstances (Bretton, 1993). The therapist helps the client uncover strengths at the biological, psychological, social, cultural, environmental, economic, material, and political levels (De Jong & Miller, 1995). The clients were presented with the protective factors diagram to help them identify which factors were most applicable to them (see Figure 2.1 protective factors diagram for an illustration).

The therapist also helps identify client strengths by asking clients to express what positives they would like to continue in their relationships (Durrant & Kowalski, 1992; Saleebey, 1992). To help elucidate a client's strengths, the therapist might ask such questions as the following: How have you managed to survive? What do you do well? What do other people look to you for? What are your outstanding qualities? How and with whom do you build alliances? How have you been able to adapt to change? What special characteristics or talents distinguish you from others? (Smith, 2006).

Item 4 - *Assessing presenting problems*

The therapist asks the clients to express what they perceive their problems to be, why they believe the problems exist, what behaviours/situations cause them the most problems, and the consequences of the problems (Selekman, 1997). Correspondingly, the therapist might start reviewing previous client records (e.g., counselling, education, police, medical, rehabilitation) to help identify important patterns which the client may be unaware of or reluctant to discuss readily (e.g., problems with authority figures, self-injurious behaviours, depression). These records are a fundamental source of information. Also the therapist will get an idea of what previous rehabilitation treatment efforts have been attempted. This can consequently rule out previous ineffective treatment regimes and those which were found helpful can be re-implemented. Concurrently, past records tie the client's history to the presenting problem. A therapist can gain increased clarity of the pressing concern based upon a better understanding of previous stressors or transitions which contribute to the client's current situation.

Item 5 - *Encouraging, empowering and instilling hope**Encouraging and empowering*

Persons experiencing traumatic events such as TBI and MS often may experience discouragement or demoralization. They frequently, “lack hope” and a key task as therapists is to assist in “restoring patterns of hope” (Littrell, 1998, p. 63). From an Adlerian perspective, this “restoring patterns of hope” is an essential aspect of the encouragement process. Encouragement is based on the behavioural principle of positive reinforcement and

has been defined as feedback that emphasizes individuals' effort or improvement rather than the outcomes of their efforts (Smith, 2006).

Encouragement helps to create an optimistic, empowering, and growth-enhancing environment for clients; a place where they feel "enabled rather than disabled" (Carlson, Watts, & Maniaci, 2006). From this point of view, encouragement is both an attitude and a way of interacting with clients in therapy. Dreikurs (1967, in Watts & Pietrzak, 2000) noted that presenting problems are based on discouragement and devoid of encouragement, "without having faith in himself restored, the client cannot see the possibility of doing or functioning better" (p.62). Therefore part of the intervention process would involve increasing skill, knowledge, positive behaviours, and the use of compensatory strategies that will improve the client's independent functioning (Sohlberg & Mateer, 2001).

The ways a therapist can communicate encouragement during the session is conveying to the client that this/her participation, contribution, thoughts and feelings are valued (Smith, 2006). Similarly, a therapist can also provide encouragement by positively reinforcing behaviours, sincerely complimenting the client or by making statements that contribute to the client's sense of self-worth and sense of belonging (Evans, 1996). These behaviours will help move clients toward change and hope in a situation that previously appeared unchangeable (Wall, Kleckner, Amendt, & Bryant, 1989). The therapist's hope, respect, and optimism start to be transferred to the client and to serve as foundation for building a trusting relationship and empowering the client to change (Cowger, 1992). Accentuating the client's strengths not only provides a sense of safety and security in the relationship, but conveys that the client will be respected and not judged negatively (De Jong & Berg, 2002).

Hope

Hope is a positive psychological capacity comprising two components: goal-directed determination, and pathways, or planning ways to meet goals (Snyder et al., 1991). Research has shown that clients who have higher hope have goals and means to obtain their goals (Snyder & Lopez, 2002). Characteristically, people who have hope are more resilient and motivated for change (Seligman et al., 1995; Snyder et al., 2000). These people are able to initiate and maintain the pathways to attain their goals. For instance when faced with a challenge, people with higher hope and resilience not only have one possible option to overcome their challenge, but rather they have the capacity to generate multiple alternative pathways to achieve and accomplish their goals (Irving, Telfer, & Blake, 1997).

Many studies have shown that cognitive strategies such as positive self-talk, reading motivational books, imagining hopeful images, listening to inspiring music, and humour are used by hopeful persons when suffering some adverse life event (Farran, Herth, & Popovich, 1995). Suggestions for developing hope include clarification of goals, breaking down goals into smaller steps, developing alternative plans, and being optimistic in overcoming obstacles (Luthans & Jensen, 2002).

Item 6 - *Reframing of cognitive distortions*

Clients often experience distorted thinking patterns which are known as cognitive distortions. These distortions have been referred to as errors in thinking, dysfunctional thoughts or irrational beliefs and can be seen as categories of automatic thoughts which have a common bias (Beck, 1995; Lam & Cheng, 2001; Lam & Gale, 2004). Beck (1995) proposes that often emotions and negative behaviour arise not because of events but from how they are appraised or interpreted (Beck, 1995). What this means is that it is not an event or situation

per se which causes us to react, but rather it is the thoughts which we appraise or attribute to the event which causes an emotional response in us. Cognitive distortions have been characterized as occurring rapidly, often without awareness of the person experiencing these thoughts, and often go unchallenged (Beck, 1995; Lam & Cheng, 2001; Lam & Gale, 2004). These thoughts appear real and patients are often able to justify their dysfunctional thinking with evidence due to their discriminatory and routine nature of thinking (Hobbis & Sutton, 2005; Lam, 1997; Lam & Cheng, 1998).

In order to dispute or challenge a person's routine nature of thinking, cognitive reframing is used. Reframing examines a situation or circumstance which was previously viewed as negative and describes the experience as positive, functional, or constructive (Watzlawick et al., 1974). Often, cognitive distortions have a tendency to be global and idiosyncratic in nature (Beck, 1976; Beck, 1995). Therefore interventions, aim to bring the dysfunctional thoughts to a specific, quantifiable level, and to help the patient to think objectively, and to develop a higher level of cognition so that they can dispute their dysfunctional thoughts (Lam, 1997; Overholser, 1993). A review of literature (Beck, 1991; Beck, 1995; Grazebrook & Garland, 2005; Hawton, Salkovskis, Kirk, & Clark, 1990; Lam & Gale, 2000, 2004; Najavits, Gotthardt, & Weiss, 2004) shows that effective strategies for disputing dysfunctional thoughts involve three stages:

- (1) Empirically evaluating the client's dysfunctional thinking and identifying underlying irrational beliefs
- (2) Identifying the consequences of holding on to these dysfunctional thoughts and the potential benefits of changing; and
- (3) Developing resilient and objective thinking that the client could relate to their personal problem.

Similarly, Smith (2006) proposes that reframing also involves (a) teaching the client that there is a choice for how to view adversity, (b) changing the meaning attributed to an

event, and (c) redefining situations around the client's strengths and protective factors.

Research has also shown that individuals who view adversity and negative life events as temporary rather than permanent have been observed to be more resilient (Seligman, 2002). Hence helping clients to reframe negative experiences gives them skills which they can then utilize the next time they are faced with adversity. Clients have greater control over what has happened to them by actively changing the meaning of the event.

Item 7- *Facilitating problem solving*

A problem exists “when a person wants something and does not know how to get it” (Bedell & Lennox, 1996). This means that a problem is essentially an unmet want which at the moment does not have a way of being fulfilled (Bedell & Lennox, 1996). In order to solve the problem, goal directed cognitive activity is required (Luria & Tsvetkova, 1990). The individual must use cognitive skills to go past the information given in order to find a solution to the problem at hand (Bruner, Goodnow, & Austin, 1956; D'Zurilla, & Nezu, 2000).

Deficits in problem solving are said to arise when there is a lack in purposeful, logical, analytical thought which is often a result of some form of brain injury (von Cramon, Matthes-von Cramon, & Mai, 1991). These deficits can be thought of as part of a disturbance in executive function. Due to the various roles the frontal lobe plays in organizing problem solving, it is not hard to understand the frequency of these impairments in people with brain injury or multiple sclerosis (Ylvisaker et al., 2005). By nature, TBI and MS pose many problems in everyday functioning for individuals and therefore places increasing demands on their problem solving abilities.

Bedell and Lennox explain that “since problems are a natural and inevitable part of life, it is in everyone’s best interest to learn better ways of solving them” (1996, p. 163). Effective problem solving skills reinforce self efficacy, help develop personal awareness, improve language and communication, and allow for the individual to attain greater independence (Bedell & Lennox, 1996; Rees, 2005). As a result, focusing on facilitating problem solving, and helping people develop new skills in this area is crucial as part of their ongoing rehabilitation program (Sohlberg & Mateer, 2001; Ylvisaker et al., 2005).

For the purpose of this intervention a social problem solving model, which provides a set of procedures aimed at problem orientation by Bedell and Lennox (1996) was used. It consists of two parts: (1) the seven guiding principles of problem solving and (2) the problem solving process. They are shown in table 4.2 below.

Table 4.2 *Seven principles of problem solving*

Seven Guiding Principles (Bedell and Lennox, 1996)
1. Problems are natural – Not all problems are bad nor does their presence imply weakness
2. Think before jumping to a solution – Emphasize self regulatory behaviour to reduce impulsivity
3. Most problems can be solved – Providing hope and showing that positive change is possible
4. Take responsibility for problems – Focus not on blaming or criticizing but rather on recognizing our contribution to the problem and that we are capable of change
5. State what you can do not what you can’t do – Learn positive alternatives and actions instead of stopping or avoiding the problem
6. Behaviour must be legal and socially acceptable - Use solutions which are socially accepted and legal
7. Solutions must be within our power and ability – Learn that you can control your own behaviour and not that of others. Set yourself up for success by having attainable goals.

The steps taken in the problem solving process which is part two of the problem solving equation is presented below.

Table 4.3 *Problem solving process*

Problem solving process (Bedell and Lennox, 1996)
1. Problem Recognition
2. Problem Definition
3. Generation of alternative solution
4. Evaluation of alternative solutions
5. Making a decision
6. Implementation of the solutions
7. Verification of the solution's effect

Item 8- *Building networks as and when needed to help develop competence and resilience*

A person's social network is often viewed as a structured representation of an individual's social world. It consists of an individual's social relationships and provides a framework for the provision of social support (Rauch & Ferry, 2001). These social relationships or networks reduce the probability of any one person being burdened with the responsibility of caring, planning and supporting the individual with a disability (Rees, 2005). The social network is divided into a primary and secondary network. The primary network mainly carries out most of the social support functions and comprises of the individual's partner, family members and close friends (Evert, Harvey, Trauer, & Herrman, 2003; Hardiman & Segal, 2003). The secondary network on the other hand is built of more formal and less personal relationships (Henderson, Duncan-Jones, McAuley, & Ritchie, 1978).

Research has shown that a majority of people with a chronic illness and traumatic brain injury report a decline in their social networks following their injury (Rauch & Ferry,

2001; Wineman, 1990). Similarly, the composition of the social networks is also different between people with TBI or MS than with non injured people. The networks of people with a disability tend to consist mainly of family members and service providers and appear to have a reduced number of friends, acquaintances or co- workers (Kozloff, 1987; Zencius & Wesolowski, 1999). The reduction of social networks and support has a direct effect on the individual's health outcomes, and ability to buffer against the effects of stress on the person's wellbeing (Dean & Lin, 1977; Finset et al., 1995). Consequently, the lack of social support and the poor use of leisure time often results in depression, low self esteem and the gradual decline in personal skills (Rees, 2005). If a broad social network is not established, the individual and their primary social network experiences excessive stress and emotional overload, which erodes their resilience (Achat, et al., 1998; Hardiman & Segal, 2003).

However, resilience can be nurtured and promoted, with the right social support and skills. Social skills and support for people with TBI and MS involve utilizing communication skills which enable them to participate with others, and to effectively solve problems (Marsh, 1999; Rees, 2005). Therefore it is crucial to help the individual rebuild their social networks and establish new relationships which will assist them in receiving the social support they require. Consistent participation and interaction is also another important aspect in building social networks and skills as this provides the individual with something to anticipate and plan for (Elliot, 2003; Stuss & Alexander, 2000).

Biegel, Tracy and Corvo, (1994) propose increasing a person's social network through (a) building new network ties, (b) maintaining and strengthening existing ties and (c) enhancing family ties. Individual members and more groups of people can be added to the network to create new ties. The maintenance and strengthening of existing ties can be accomplished, by organizing support group meetings, and by providing the individual with opportunities to practice their social and communication skills (Zencius & Wesolowski,

1999). Family ties may be improved by the development of family support programs which may include family meetings, promoting communication within the family, and providing options for external support when the family can't cope on their own (Raunch & Ferry, 2001). Opportunities for self directed participation in social, leisure and prevocational activities are also another significant aspect of building social networks and are the most effective strategy for enabling the individual to cope with emotional difficulties, effectively problem solve and be independent (Rees, 2005).

Item 9- Goal Planning

Goal planning is a central process in any neuropsychological rehabilitation program, and has been used in various client groups with positive outcomes (Barnes & Ward, 2000; McClellan, 1997; Wade & de Jong, 2000). A central theme of the approach is that goals affect performance by “focusing attention, directing effort, increasing motivation and enabling the development of strategies to achieve one's objectives” (Hurn, Kneebone, & Cropley, 2006; Locke, 1968). Similarly, Wade (1980) defines goal planning as:

“The process of agreeing on goals, this agreement usually being between the patient and all other interested parties. The process might include setting goals at various levels and in various time frames” (p. 273)

This definition highlights the most crucial aspect of goal planning which is developing goals in collaboration with the client, and identifying needs which are unique to each individual at a given time period.

Rehabilitation practitioners are faced everyday with the overwhelming task of helping individuals whose physical and psychological selves have been severely altered by trauma or disease such as TBI and MS (Barnes & Ward, 2000; McClellan, 1997). Consequently, there

is a need in such situations for immediate and practical solutions which can be measured and used to track the progress of clients both in a hospital and community setting (Hurn et al., 2006; Levack, Taylor, Siegert, & Dean, 2006). One such system for goal planning that has become particularly popular is goal attainment scaling (GAS) (Hart & Evans, 2006; Malec, 1999). It was developed by Kiresuk and Sherman (1968) within a mental health service for use as an outcome measure that provided autonomy to the client and also allowed for the evaluation of the effectiveness of the process. A more detailed explanation of the procedure is discussed in section 3.5 research methodology.

Item 10 - *Psychological Skills Training*

There are a number of other skills and strategies that are used in conjunction with the intervention principles outlined above. These strategies come from Cognitive Behaviour Therapy (Beck, 1995) and have been found useful in the cognitive restructuring process and also increases effective outcomes for people with TBI and MS. The skills used are outlined below.

Social Skills Training

Ylvisaker defines social skills as those necessary for both general and specific goal directed, appropriate verbal and nonverbal behaviour (Ylvisaker et al., 2005). Individuals use such skills on a daily basis in relating to others, in gaining acceptance by peers and family members, to establish friendships, and to cope with school, work, and community living (Rees, 2005; Rosenthal, 1998; Sohlberg & Mateer, 2001). Appropriate social skills increase the likelihood of mutual friendships and a rewarding social life. Similarly, people who act awkwardly in social situations are likely to be rejected by peers and, as a result often show

signs of depression, loneliness, have a negative self view, and are more anxious which further reduces their social competence (Ylvisaker et al., 2005). For instance if an isolated client is able to initiate contact and arrange to meet friends at the mall, then these skills enable her to sustain a relationship which in turn reduces her isolation and loneliness.

Relaxation skills

Progressive muscle relaxation

Progressive muscle relaxation [PMR] is a relaxation technique often used to manage stress which was developed by Edmund Jacobson in 1934 (Conrad & Roth, 2006; Jacobson, 1934). The PMR technique focuses on tensing and releasing tension in the 16 different muscle groups. Muscle tension is an automatic response by the sympathetic nervous system when reacting to perceived stress. It mobilizes adrenaline, increases blood sugar and heart rate, dilates heart, leg and arm muscles and produces other physical and mental changes which, enable the stressor to be dealt with more efficiently (Palmer & Dryden, 1996).

Relaxation training teaches people how to lessen the level of stress in the body and, through regular practice, to be able to relax consciously and at will in the face of a stress situation. Jacobson argues that since muscular tension is a common side effect of stress, one can lower and reduce stress by understanding and learning how to relax those muscles (Mccallie, Blum, & Hood, 2006). The rationale behind this process is that the relaxation response is initiated by taking control of the voluntary muscles through creation of tension in them. This is then followed by forcing the muscles into a state of relaxation (Mccallie et al., 2006). When the body is aware of the presence of the tension, it will react by activating the muscles to relax. The participant will be given instructions to sit comfortably and then begin by tensing and relaxing each muscle group one at a time. For instance hands – “Clench the

fists tightly to tense it and then relax. Next, the fingers are extended fully to create tension and relaxed”.

Item 11 - *Evaluation and Terminating the Intervention*

Terminating is the final phase of the intervention and is often seen as an important step in the therapeutic process (Beck, 2000; Kirschenbaum & Henderson, 1990). It has been conceptualized as an intentional process which occurs over time when the participant has achieved most of the agreed upon goals and aims of their treatment or when the intervention must end for other reasons in this case the given time frame of six months. The process of termination in general allows participants to evaluate their goals, express the changes they have integrated, and to work through feelings in ending the intervention process (Beck, 2000; Vasquez, Bingham, & Barnett, 2008). Appropriate termination helps avoid feelings of betrayal of trust and expresses genuine concern and respect for the participant (Pope & Vasquez, 2007; Rogers, 1957).

A key goal of termination is to develop the participant’s ability to maintain gains and generalize positive outcomes after termination. For instance, using positive language to describe the participants’ progress and achievements of goals is a way in which their strengths and resilience can be nurtured and maintained (Lightsey, 2006). Discussing and problem solving potential future challenges and how the participants plans to deal with them is another example of appropriate terminating and this also empowers the participant to be able to handle challenging situations on their own (Leahy, 2004; Nelson- Jones, 2007; Noonan, 2002; Pope & Vasquez, 2007).

Similarly, teaching participants relapse prevention skills is a crucial aspect in ensuring the maintenance of outcomes from the intervention. Relapse Prevention (RP) is a cognitive-

behavioural approach to the management of behaviours that specifically addresses the nature of the relapse process and suggest coping strategies useful in maintaining change (Parks, Marlatt, & Anderson, 2001). Some strategies used to minimize relapse are by identification of a participant's individual profile of high-risk situations for relapse. The participant's ability to cope with these high risk situations without having a relapse is evaluated (Wanigaratne, Wallace, Pullin, Keaney, & Farmer, 1995). If coping difficulties are apparent, it is then evaluated to establish if this is due to a lack of knowledge and skill or if there are other factors. These factors include low motivation, cognitive difficulties, and mood disorders such as anxiety and depression (Marlatt, Parks, & Witkiewitz, 2002). Steps are then taken to support the individual with TBI or MS in order to prevent relapse. Closer supervision and mentoring can help cue the participant and watch out for possible relapse. Similarly, teaching the participant to identify and be aware of possible negative thoughts and situations in which relapse is likely is also a key factor in reducing relapse.

Another useful practice in terminating is by explaining to participants at the onset of the intervention the time frame of the process and when the intervention will end. This can also be gently brought into conversations throughout the intervention especially in the months nearing the termination stage (Hill, 2005; Nelson- Jones, 2007; Vasquez et al., 2008). For instance, when discussing future goals and challenges the researcher asked the participants about how they would feel once the intervention was over and what might help them cope better when they are anxious or worried. Also participants were reassured that they could contact the researcher if any problems arose that they may need help with and if they required further assistance, they could contact their social worker or rehabilitation consultant.

4.3 Structure of the bi weekly intervention sessions

Certain key features were identified to be crucial at every meeting with participants. These elements are outlined below.

1. Be where the client is at, be present, pick up on person's language, mood
2. Get to know and respect each participant's history, strengths, needs, accomplishments, vulnerabilities and potential (Levack et al., 2006; McMillan & Sparkes, 1999; Noonan, 2002; Rees, 2005).
3. Discuss and set personal goals that are mutual, individualized, behavioural in nature, unambiguous and achievable (Houts & Scott, 1975; Hurn et al., 2006; Levack et al., 2006; McMillan & Sparkes, 1999).
4. Discuss the availability and participation in social, recreation and prevocational activities within the community (Marsh, 1999; Rees, 2005; Wineman, 1990). Find out what their plans are for today, tomorrow, next week, who they are seeing, what time, what activities they have planned.
5. Plan activities in conjunction with significant people in the participants' social network .To ensure that there is always some activity available to participate in.
6. Enquire about their network and if necessary try to stimulate this by making contact with significant persons (Rauch & Ferry, 2001; Rees, 2005; Zencius & Wesolowski, 1999).
7. Manage personal distressing issues such as finances, interpersonal relationships, and health concerns (Beck, 2005; Leahy, 2004; Smith, 2006). Present them with an issue that needs to be solved which is related to them and problem solve this together.
8. Use principles of errorless learning and positive reinforcement to encourage and instil hope in participants.
9. Work on inappropriate behaviour and provide mutually acceptable alternatives

Examples of how this is carried out are presented in Table 4.4 below.

Table 4.4 *Examples of the principles used in the intervention*

Principles used in the intervention	Examples
1. Be where the client is at	Be present and pick up on person's language, mood, and appearance.
2. Getting to know and respect each participant's history, strengths, needs, accomplishments, vulnerabilities and potential (Levack et al., 2006; McMillan & Sparkes, 1999; Noonan, 2002; Rees, 2005).	Spend time getting to know the person, what they like, dislike, what they are good at, what they feel comfortable doing, what's going on in their lives at the moment.
3. Discuss and set personal goals that are mutual, individualized, behavioural in nature, unambiguous and achievable (Houts & Scott, 1975; Hurn et al., 2006; Levack et al., 2006; McMillan & Sparkes, 1999)	Set both long term and short term goals with participants and modify these according to changes in circumstances. For instance, a long term goal would be to widen social network. Short term goals would be, initiate a phone call to friends, make a list of activities you enjoy doing.
4. Discuss the availability and participation in social, recreation and prevocational activities within the community (Marsh, 1999; Rees, 2005; Wineman, 1990).	Find out what their plans are for today, tomorrow, next week, who they are seeing, what time, what activities they have planned.
5. Planning of activities in conjunction with significant people in the participants social network .	Make sure there is something going on in terms of activities, and helping to identify key people in participant's network.
6. Enquire about their network and if necessary try to stimulate this by making contact with significant persons (Rauch & Ferry, 2001; Rees, 2005; Zencius & Wesolowski, 1999).	Help contact friends and family identified by participant during session to arrange outings, to ensure successful participation
7. Management of personal distressing issues such as such as finances, interpersonal relationships, health concerns (Beck, 2005; Leahy, 2004; Smith, 2006).	Present them with an issue that needs to be solved which is related to them and together problem solve
8. Using principles of errorless learning and positive reinforcement encourage and instil hope in participants.	Remind participants of achievements and use positive language to motivate further practice of skills such as walking without an aid, or using a wheelchair. Provide opportunities for errorless learning to take place in a safe environment.
9. Working on inappropriate behaviour and providing mutually acceptable alternatives.	Swearing profoundly during group sessions can be limited through the use of subtle cues by carer to remind participants of inappropriateness.

CHAPTER V

RESULTS

5 INTRODUCTION

This chapter includes six case studies, featuring the experiences and results of participants. The case studies also present and analyse participants Goal Attainment Scaling scores. The use of ethnographic and mixed methodology allows for multiple interpretations of each participant's reality and alternative interpretations of data collected. These data are presented throughout the case studies. These results provide an understanding into the lives of participants through an emic, or insider's perspective (Fetterman, 1998). A description of participants' demographic information, and an analysis of their Resilience and Dysexecutive Questionnaire scale scores follows. The demographic results are then followed by answers to the research questions. These answers are based on the statistical analysis of the observations of behaviour and data collected. Elaboration and the implications of the results will be outlined in the discussion chapter (Chapter 8).

5.1 Case studies

Six case studies are presented. Names of participants have been changed to maintain confidentiality. Similarly, any identifying information has been replaced. A representative sample of 3 people with Multiple Sclerosis and 3 people with Traumatic Brain Injury were selected as they;

(1) Represent people whose assessment scores display both the high and the low end of the resilience and executive functioning scales spectra.

- (2) Highlight various themes and characteristics of resilient and executive functioning behaviours as depicted in the literature review (see Table 2.2 Literature review matrix).
- (3) Are key actors, who weave personal stories which highlight the fabric of living with TBI or MS. The individuals selected for the case studies may not represent the whole group participants, or even generalize to the population of people with TBI or MS. Yet their personal descriptions provide an integrated picture of the target population (Bickman & Rog, 2009).

In all the case studies, it is difficult to make a distinction between emotional stress and cognitive difficulties brought on by TBI or MS. Some behaviours are more cognitive in nature, whilst others are more emotional. Discussions throughout the case studies centre around the intricate and interwoven nature of these difficulties.

5.1.1 *Tina*

Tina is a 39 year old woman who was injured ten years ago in a pedestrian accident. Whilst walking outside late one night she was hit by a passing car. She was rushed to hospital where she was in a coma for 6 hours. Tina sustained severe frontal lobe injury. Her Glasgow Coma Scale Score on initial observation was 5, indicating severe loss of consciousness (Teasdale & Jennett, 1974). Tina also had retrograde amnesia and her short term memory was impaired.

Tina had a lucrative career as a performer and led an active social life. She was able to support herself financially and led a fast paced life filled with partying and socializing. Medical records indicate that post trauma, Tina had an average to high intelligence with an assessed IQ score of 112 (Wechsler, 1997). At present, Tina reports feeling depressed and isolates herself from contact with others. Her Beck Depression Inventory II Score of 54 at the start of the intervention indicated severe depression (Beck, Steer & Brown, 1996). Observations revealed a typical episode of depression for Tina as persisting for two to four weeks and portrayed by:

- persistent sadness,
- loss of interest in life,
- loneliness, feelings of worthlessness,
- anxiety about the future,
- fatigue,
- problems with inattention and memory,
- Suicidal thoughts.

During these depressive episodes, Tina often finds herself isolated and alone for days. Her activities are limited to lying on the couch and watching television. She would sleep for hours, only to wake and scan the day for rewarding activities. When she finds that she has nothing planned, she gets even more disappointed and depressed. Studies on depression in

people with traumatic brain injury suggest that a dysfunction of the limbic prefrontal cortical structures impairs the modulation of the amygdala (Cummings & Bogousslavsky, 2000; Drevets & 1999). This then contributes to the unregulated processing of emotional stimuli; which in the case of Tina is displayed through prolonged periods of depression and withdrawal. She finds it difficult to rise above her depression as loneliness and inactivity engulf her.

Pre -Trauma, Tina lived in a world surrounded by people. Parties, raves and nightclubs were a routine for her. She engaged in at-risk behaviours from an early age used recreational drugs, and abused alcohol. Her childhood was one of rebellion; she often had arguments with her parents, and was in trouble with the law. Post-trauma, these behaviours only magnified in nature and coupled with depression. Tina's life of experimenting with drugs and alcohol became her way of escaping the reality of her injuries. Impaired judgment, impulsivity and despair led her to putting herself further at risk by engaging in unprotected sex, having multiple partners and she often found herself waking up next to strangers who took advantage of her disabilities. Tina was starving for companionship, to have someone to love and accept her for who she had become. Unfortunately, she looked for solace in the wrong places.

At times, she would get so frustrated and angry that she would lash out at her carers who were the only contact she had with the outside world. Studies have found that often when people are depressed, or experience intense emotions such as anger, they engage in maladaptive behaviour. This is seen as an emotional regulation strategy, where the at-risk behaviour is a way of coping with intense emotions such as depression (Whiteside & Lynam, 2001). For Tina, acting in a self destructive and aggressive manner was her way of coping with her intense pain, loneliness and depression. Often her behaviour was rationalized by thinking "what the hell do I have to lose". Her carers would have great difficulty persuading her to do her chores or leave the

home for a walk as most of the time Tina would be intoxicated. They would arrive in the late afternoon only to find her looking back at them with stone cold eyes and a hollow look on her face. Empty bottles of alcohol would be found strewn over the coffee table, and next to them ashtrays full of cigarettes butts. Her house would have a musky stench from lack of ventilation as Tina would not have opened her blinds, doors or turned on the fan for weeks. This together with cigarette smoke made her house almost unbearable for people to inhabit. However, Tina appears unaware of the effect of this environment on others.

Her difficulties are also exaggerated by other factors, such as having limited psychosocial support (Jorge, 2005). Tina lives alone in a five bedroom home. It is estimated that she spends up to 10 hours at a time on her sofa watching television. During these times her activity is limited to changing the channel and feeding herself. She does not leave her house nor have any physical activity (although physically she is able to). Tina is capable of getting around independently on her electric scooter. She can also walk around her home using a walking stick. However, her only contact with the outside world is when her carers arrive or if her rehabilitation consultant visits.

Part of Tina's difficulty could be due to impaired orientation. Orientation in her case refers to the inability to adjust to surroundings, people or objects (Rees, 2005, p. 70). This occurs particularly in novel or unknown situations where greater demand is placed on her executive functioning (Stuss & Alexander, 2000). For instance, because Tina is not appropriately prepared, she would experience frustration and anger in a crowded shopping mall where many events occur at once. The opposite of orientation is disorientation or unawareness (Rees, 2005; Sohlberg, Mateer, Penkman, Glang, & Todis, 1998). Tina is often at the mercy of whatever is going on at the current moment. Arrangements would have been made for her to go for a walk to

the beachfront on her electric scooter. Even though she previously agreed to go, she is so engrossed watching television that she refuses to leave the couch. It takes a lot of persuasion to get her to reorientate, and attend to a new task. Future orientated statements such as “now we shall go to beach” are effective ways of getting Tina appropriately oriented to the task at hand. Similarly, by providing clear physical guidance such as getting her electric scooter ready, Tina is required to switch her orienting and attending to taking a walk on the beach. Her resistance to stop watching television also demonstrates rigidity in shifting sets which is characteristic of people with brain injury (Stuss & Alexander, 2000).

Tina also finds it difficult to maintain and develop relationships. She was married and had a child. Her husband obtained custody of the child and left. The reasons for her marriage breakdown are many, however her brain injury and the lack of understanding of this by her husband and family members was significant. Case evidence indicates that her husband could not cope with her disability, her change in personality and her depressed mood state. Apparently, she used to throw alcohol bottles at him during arguments. She became a ‘wanderer’ and could go missing for days. Another destructive behaviour is her capacity to steal. She would steal jewellery, money and anything of value from her parents and husband. Once Tina stole her parent’s credit card and went on a shopping spree, purchasing items for which she had little or no use.

Since her accident, Tina has not been employed and lives on a disability pension. Tina tries to return to work as an actor/entertainer, but post trauma this is no longer possible. The decisions she makes in her domestic, personal and social life often bear little resemblance to her resources. However, when she is physically and psychologically well, there are glimpses of her ability to make plans, regulate her behaviour and respond to feedback. She is able to plan her

trip to attend a local camp held by the community re-entry program, or her visit to the doctors and keeps the appointment. It is against this backdrop that one observes her resilience allied to her ability on ideal occasions, to plan, persist with tasks and respond to others in a rewarding fashion.

Protective Factors and Strengths

Tina faces challenges constantly in her personal life. Her severe depression and her inactivity place her in a vulnerable state. Subsequently, she is very isolated and lonely. This frustration and sometimes deep resentment of her injury is often acted out through hostile and aggressive behaviour. However, she does have certain factors which protect her from her destructive behaviour and they are summarized in Figure 5.1.

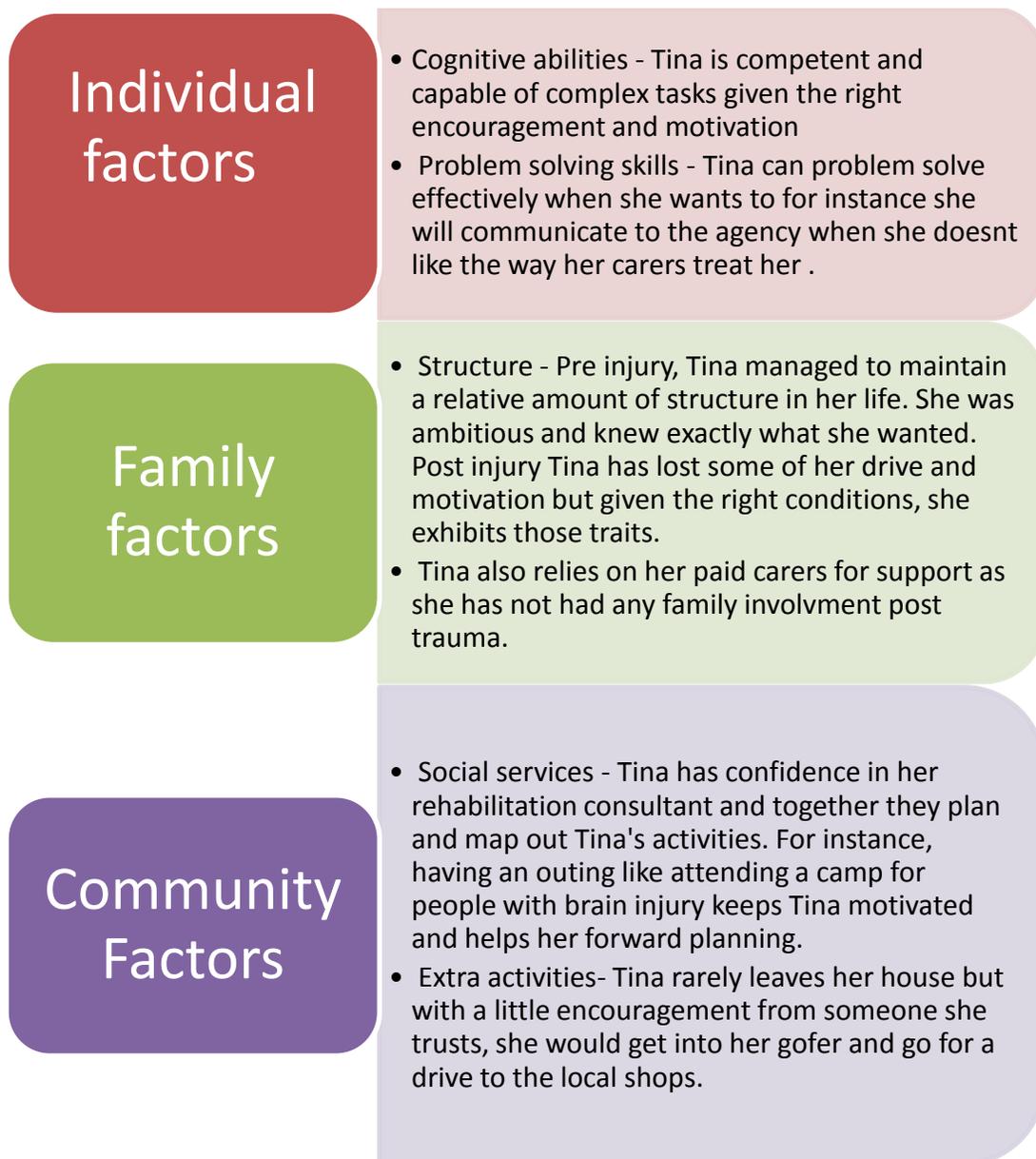


Figure 5.1 Tina's strengths and protective factors

Nature of the Intervention

The intervention with Tina consisted of fortnightly visits to her home. With much persuasion and encouragement usually from her rehabilitation consultant, Tina would get into her scooter and go for a walk. This became an activity which was encouraged throughout the intervention as it improved her depressed mood, and allowed her to engage in mild exercise. Research has shown that often depression and exercise influence each other. An inactive lifestyle increases the risk of depression and subsequently depression increased the likelihood of a sedentary lifestyle (Scully, Kremer, Meade, Graham, & Dudgeon, 1998). For Tina, getting out of the home and going for a walk was therapeutic because it was (a) a social event, (b) physical activity which reduces stress chemicals such as adrenaline which promotes a more relaxed mental state and (c) is distracting and breaks the cycle of pessimistic thinking (Rosenthal, 1998).

On most sessions, Tina would score herself on the extreme lower end of the Outcome Rating Scale indicating dissatisfaction with her own well being, and reflective of her feeling of being depressed. The clusters of low scores were sustained (scores lower than 30). This indicates that her depressive behaviours are chronic, and the intervention which was over a period of six months did not affect a sustained change in Tina. However, immediately post-intervention, she scored only slightly higher on areas of interpersonal relationships, social relationships and an overall general sense of wellbeing. Her scoring on four occasions during the intervention is presented below in Figure 5.2.

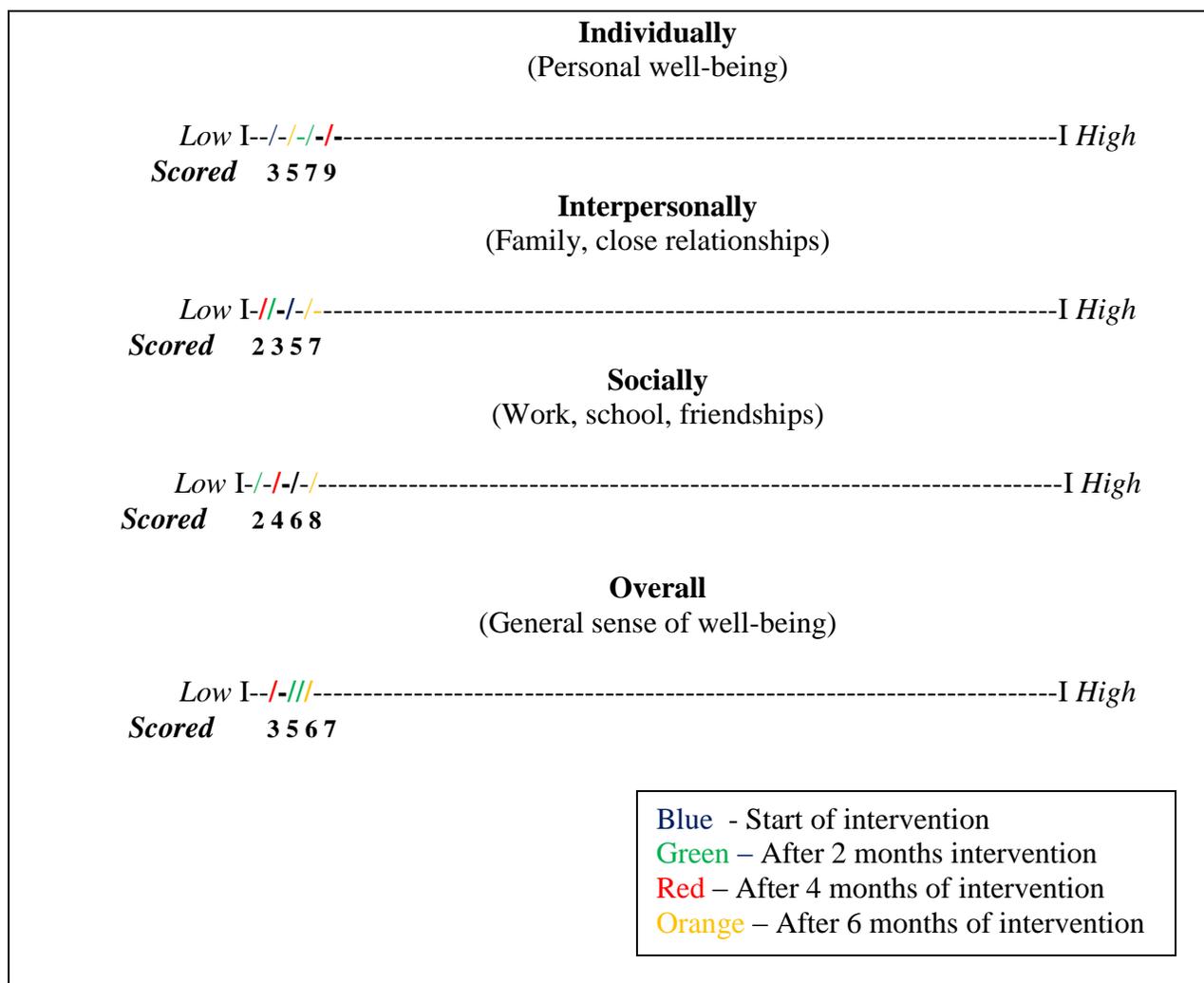


Figure 5.2 Tina's Outcome Rating Scale Scoring at 0, 2, 4 and 6 months of the intervention

Tina scored consistently low on all four measures of her ORS . Her scores corresponded with periods of seriously depressed behaviour. However, once Tina's mood states were regulated with a balanced mix of her anti-depressant medication, exercise in the company of friends and healthier eating then there was increased likelihood that Tina would participate in social and recreational activities. Her scores on the ORS improved only slightly (see orange lines) as she perceived herself to be happier and more in control of her circumstances, although this particular claim on her part was questionable. Yet when this occurred she was more receptive to talking

about her current and past experiences with ‘seriously depressed behaviour’. In this state she was willing to look for possible triggers for her depressed feelings and was more aware of the influence of her negative self-talk. One often recurring thought, most clearly expressed was that of “I don’t care what happens to me”. This often precipitated episodes of withdrawal and binge drinking. She became marooned then; sitting in her curtained lounge with television blaring, staring, chain smoking, unable to let her cat far from her, mumbling to her visitor as she sank down into her sofa. She struggled then to make sense of what was happening. It was natural in these circumstances that her ORS scores were so low.

Tina’s behaviour is highly unpredictable. It is difficult to know what to expect when visiting her home. Sometimes, she is able to open the door, ask who is outside and then she might say “I don’t want you coming in” or “I don’t want to see anyone today” and slam the door shut. A bit of persuasion and encouragement would eventually get her to open the door and she would then be able to carry on the rest of the session, behaving quite well. Often she would rage at her carers, who had little or no training in working with someone with injuries such as hers.

Creating the therapeutic relationship was crucial when working with Tina. For this to be achieved, an environment of trust, openness and unconditional positive regard was necessary (Rogers, 1986). A relationship where the researcher was honest and sincere was significant as it promoted Tina’s “self actualizing tendency” or her ability to work at her full potential. She needed someone who was “real” who operated at her level and did not appear to be all knowing or in a position of power (Rogers & Holdstock, 1977). During one session with her rehabilitation consultant, she was reluctant to open the door because he brought a student mentor along. However, as Tina became more familiar with the student, she engaged in conversation, initiated questions and even made jokes. Establishing this sense of familiarity and openness was

imperative when working with Tina. She constantly needed reassurance that the researcher could be trusted and building that trust took time. Gradually over each session, Tina would become more comfortable and at ease with the presence of the researcher. Once trust was established, Tina was more agreeable to suggestions by the researcher. She would look forward to the sessions and even write in her journal whenever she experienced feelings of depression.

Her carers would often have great difficulty in getting Tina to engage in positive behaviours such as reducing her alcohol consumption. Tina reported that this was “bloody annoying because they think they know me but they don’t”. She resented being told what to do in an authoritarian manner. Instead, an approach which displayed more unconditional positive regard was more effective (Corsini & Wedding, 2005). It involved not condoning her drinking, but accepting it as part of her, and viewing it as her coping mechanism. She would normally resort to drinking when she had no future planned activity, or when she had nothing to anticipate and to which she could look forward. By providing her with activity and engaging her in goal directed activity, Tina would often reduce her dependence on alcohol independently. Discussions on her goals are provided in more detail below (see Table 5.1 below). Tina’s long term goals were identified in consultation with the researcher and are written in the form of therapist goals. These goals are broken down into short term objectives and participant goals.

Long term goals

- Recognize, and manage feelings of depression.
- Participate in role reversal strategies which provide clear guidelines for acceptable behaviour, for instance, the researcher plays Tina and Tina is the researcher. Together we act out a scenario whereby Tina has to remain calm, and polite when meeting new carers.

- Develop healthy cognitive patterns and beliefs about self and the world that help prevent the relapse of depression symptoms. For instance, practicing saying and thinking “I do not need alcohol to feel good about myself”
- Reduce triggers or situations which precede impulsive behaviours and increase self talk that controls behaviour. For instance, depression and loneliness often promote drinking for Tina. In order to reduce this, she has to have activities planned. Activities such as attending her Community Re- Entry Program weekly workshops, going to the mall with her carers, and taking regular walks outside her home.
- Learn problem solving strategies such as discussing a problem with her rehabilitation consultant instead of getting frustrated and binge drinking.
- Management of personal care such as eating, sleeping and taking medication as prescribed
- Making links with community social and recreational organizations so that community participation is increased. For instance, maintaining good relationships with her carers and the manager of a community re entry program for people with brain injury.

Table 5.1 *Tina's short term objectives, therapeutic intervention and goals*

Short-Term Objectives	Therapeutic Interventions	Tina's Goal Attainment Scaling Goals
Describe current and past experiences with depression complete with its impact on function and attempts to resolve it.	Assess current and past mood episodes including their features, frequency, intensity, and duration	-1 I will write in my journal when I get depressed 30- 40 % of the time
Take prescribed anti depressant medications responsibly at times ordered by physician.	Monitor and evaluate the client's medication compliance, effectiveness, and side effects; communicate with prescribing physician.	-1 I will remember to take my medication and use cues to remind me every day 30 % of the time
Identify and replace negative self-talk	Keep a daily journal of automatic thoughts associated with depressive feelings	-1 I will record my automatic thoughts when they occur 30% of the time
Learn and implement problem-solving and/or conflict resolution skills to resolve interpersonal problems.	In conjoint sessions, help the client resolve interpersonal conflicts.	0 I will take my medication as prescribed 30% of the time

Goal Attainment Scaling

Tina had difficulty achieving most of her goals. Her short term memory problems and lack of motivation often interfered with her progress. For instance she would start writing in her journal and then get distracted by the phone. However, she was encouraged to keep trying and small achievements were rewarded with praise. When she wrote in her journal once a week, she was congratulated and cued to write in her journal more often the next week. Structure and routines were set in place which enabled her to be more resilient. She knew the researcher would visit once every fortnight on the same day and at the same time. She was also reminded and cued to complete her journal entries before the researcher arrived. This was done through a phone call

asking how she was doing and if she had anything prepared to share during the session. An example of how her goal was stated is presented below.

Example 1

+2 I will write in my journal when I get depressed 80-90% of the time

+1 I will write in my journal when I get depressed 60-70% of the time

0 I will write in my journal when I get depressed 40-60% of the time

-1 I will write in my journal when I get depressed 30-40% of the time

Assessment Scores

Tina scored in the low range of resilience with a post intervention score of (111) which increased slightly after intervention (120). Her frontal lobe injury reflected her scores on the Dysexecutive Questionnaire (DEX) with a baseline score of (77) and post intervention score of (70).

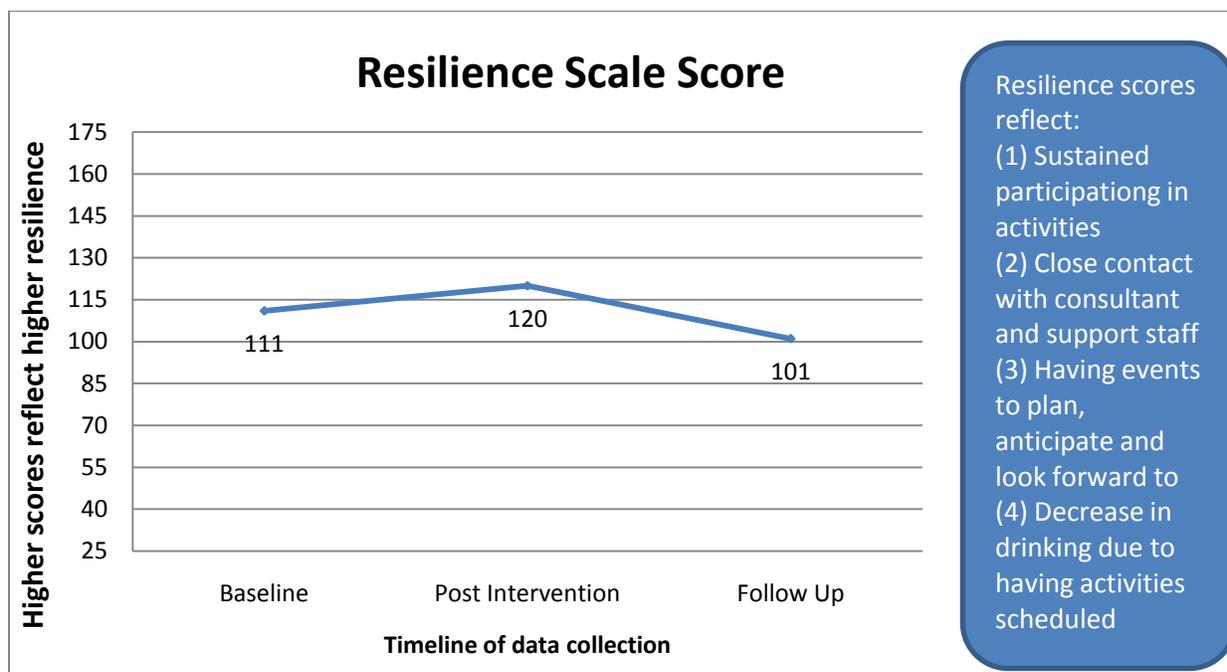


Figure 5.3 Tina's Resilience Scale Score

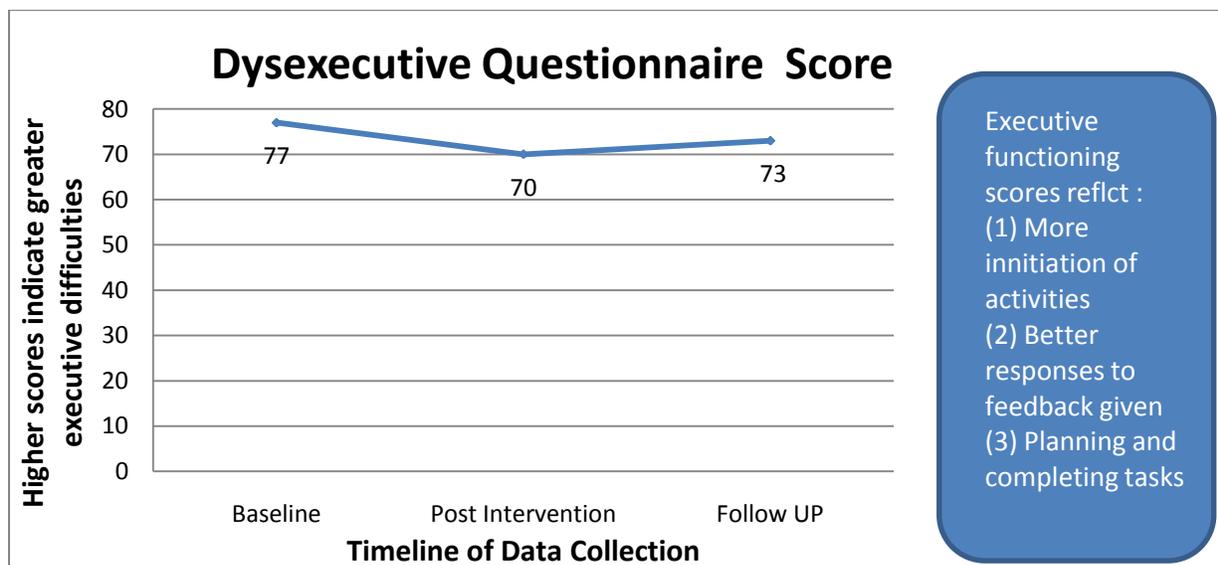


Figure 5.4 Tina's Dysexecutive Questionnaire scores

Resilience

Pre trauma evidence showed that Tina was often pessimistic, especially when at work where the load of stress became too great. A key difficulty for Tina was initiating support or “asking for help” when she needed it. This was almost impossible post trauma. Therefore sustained support which becomes expected and therefore habitual influenced her behaviour. Tina often was trapped in her cycle of negative self talk. She often felt lonely and alone, and would turn to alcohol to fill this void. In order to help her better problem solve, using alternative strategies to cope were enlisted. Tina’s drinking was almost an unconscious automatic response to her negative thoughts. It was a way to waste the years away, a means to occupy herself so that time passed quickly. In order to attempt to break this cycle, habituation was used. Other positive behaviours such as taking a walk or writing in her journal were suggested. Once Tina got into the habit of substituting drinking with other activities, these behaviours then became habitual (Rees, 2005). She no longer has to produce the orienting reaction or think about something else to do instead of drinking.

She needs structure, in order to be able to plan, organize and effectively complete tasks. Devoid of structure, Tina would sleep all day and be awake at night, or she would not eat regularly and can’t recall if she has eaten or taken her medication. Her resilience surfaces in contexts which provide her these structures such as:

- Asking for support when required
- Making links with community social and recreational organizations in order to increase activity
- Opportunities to participate in activities which promote errorless learning such as working on goals which are manageable and ensure success

Devoid of active intervention in the form of community participation and sustained individual support, Tina finds herself excluded from the social network (Hardiman & Segal, 2003). Her housing arrangements also increase her sense of isolation and depression. Tina would benefit from living in a small unit where she would be presented with opportunities for social contact with other residents, which would increase the likelihood of her having community contact. She is fiercely resistant to the idea of moving and refuses to even consider this. Her home provides her with a sense of luxury, yet reinforces her lack of activity and increases her hours of solitude. She spends most of her day alone.

She finds her loneliness extremely hard to cope with. She describes it by saying “I hate being alone, I have nobody”. Her social network is limited and she is exasperated by the fact that the only contact she has with others is via health professionals (Granerud & Severinsson, 2006). Ways in which Tina overcame some of her loneliness was through encouraging and supporting her participation in a community brain injury program. This promoted her social integration through providing her with a platform for developing friendships and increasing activity (Marsh, 1999). She attends workshops and goes along to camps. There she is introduced to others, initiates conversations and participates in activities such as writing, going to movies and walks outdoors.

Tina’s behaviour is often unpredictable especially if she is devoid of the structure she needs. She also has low motivation which is attributed to her injury and her negative experiences growing up. Tina often perceives herself as a failure and this negative attribution, along with negative emotions is visible in her aggressive behaviour.

Tina is controlled by her negative experiences and this leads to her being depressed. Her mood states control her present thoughts and actions. For instance she experiences difficulty in

making new friends and finds it hard building significant relationships. She finds it difficult to plan, organize or initiate activities for herself and as a result becomes deeply reliant on those around her.

Resilience for Tina requires that she finds meaningful activity to occupy her time. This would provide her an opportunity to have something rewarding to look forward to. Participating in activities also encourages social interaction and helps develop social networks. For instance Tina likes being around people and in order for her to be with people she has to first leave her home. Therefore sustained contact with her carers and rehabilitation professional ensure that Tina has some contact with people, and together they encourage and support her in efforts to leave her home. Devoid of this activity, Tina resorts to destructive behaviour. Once her carers had to let themselves in to her house as there was no response from Tina and they knew she was home. They walked in to find her home in utter chaos, broken glass all over the floor, furniture torn and thrown across the room. Tina was lying on a heap on the floor, out cold presumably from overdosing herself on alcohol and prescription pain killers.

Tina does enjoy trying new food, along with doing new and different things. This can be seen in her ability to successfully demonstrate the use of the Alexander Technique (a method for reducing tension in the body) during a camp for people with brain injury. Tina was the first to raise her hand when the instructor asked for a volunteer and she quickly learnt how to do the exercise, which she later proudly showed off to other participants. She has an average resilience score but can't sustain her positive behaviours. Consequently, she is quite impulsive and she puts herself at the risk of her own disinhibitions. For instance she would engage in at risk sexual activity, and binge drinking. Without much thought Tina would allow herself to be talked into excessive drinking at a pub and be taken advantage of by strangers.

Depending on her mood state, she fluctuates from one end of the resilience scale to the other. Sometimes she can be extremely resilient, where she maintains a positive outlook, assumes responsibility for her own care and initiates social contact (Dyer & McGuinness, 1996). Sometimes, she lets her resilience go and is perceived to “give in” to her impulsive, depressive behaviours.

Executive Functions

Executive functions, when intact, allow sophisticated, organized and appropriate behaviour (Anderson, 1998; Lezak, Howieson, & Loring 2004). When damaged in certain cases such as Tina’s, the person reverts to dysfunctional, uninhibited behaviour in which the person is at the mercy of the disinhibition (Sohlberg & Mateer, 2001). She would sometimes swear loudly while at a restaurant, completely unaware of the inappropriateness of her language. This behaviour is also reflected on her high scores on question 7 and 16 on the DEX (“I have difficulty realizing the extent of my problems and am unrealistic about the future; I find it difficult to stop doing something even if I know I shouldn’t”) which measures lack of insight and social awareness and inability to inhibit responses. This may also be attributed to having difficulty orienting to the situation. In order for Tina to successfully orientate, she needs to be cued to anticipate other’s actions, anticipate the meaning of others actions and control over her own actions (Goody, 1995). Some strategies which were used to help Tina orientate better and strengthen her executive functioning were:

- To ensure surroundings and activities were familiar (i.e.; going to the same restaurant)
- Break down tasks and goals into manageable sequences (i.e.; practice getting in and out of her gofer before attempting to leave the house)

- Provide time to respond (i.e.; allow Tina time to think about appropriate responses during conversations)
- Use positive future oriented statements (i.e.; Tina, we will go to the shops tomorrow when we meet).

(Rees, 2005; Shallice, Burgess, & 1991; Sohlberg & Mateer, 2001)

Unless she is cued, Tina has difficulty in evaluating, creating goals and implementing plans. Tasks such as getting up in the morning or having a shower are inherently difficult for her because they require desire and motivation for action (Rees, 2005a, p. 180). Tina's motivations and desires are heavily dependent on her mood state (Sohlberg & Mateer, 2001, p. 276). To facilitate goal setting, Tina has to be first orientated, and motivated. For motivation to be generated the goal had to have a sense of purpose (Levack, Taylor, Siegert, & Dean, 2006). For instance walking to the shops with the intention to buy groceries or have coffee.

Motivated behaviours, such as eating, drinking, sleeping, and sexuality, are dependent on learning (Rao et al., 2007). However, these normal behaviours can become a "disorder" when they are performed excessively or too frequently. Tina's risky sexual behaviour and excessive drinking are characteristic examples of an "abnormal" goal-directed behaviour (Sohlberg & Mateer, 2001; Stuss & Alexander, 2000). Although injury to the frontal lobes may have resulted in her impulsivity and disinhibition, making her vulnerable, this behaviour is probably shaped and maintained through positive overt reinforcements (Bezeau, Bogod, & Mateer, 2004).

For Tina, this reinforcement is in the form of drinking and impulsive attention seeking behaviour such as risky sexual acts. When inappropriate behaviour occurs, Tina is aware that the behaviours are risky. However, because her ability to self regulate emotions is impaired, aggressive behaviour follows. She scored highly on question 2 and 20 of the DEX which were

(“I act without thinking, doing the first thing that comes to mind”; and “I am unaware or unconcerned about how others feel about my behaviour”) which measure impulsivity and no concern for social rules. To facilitate improved monitoring and control of these behaviours, the initiation and planning of various domestic and social activities were conducted. The rehearsal of these activities was done during the session and lists of activities were written down for Tina.

In order for Tina to effectively plan, initiate, persist at tasks and achieve goals, structure is needed. This is provided in the form of external cues, visualizing and sequencing tasks (Grafton, Hazeltine, & Ivry, 1995). During a session, Tina was asked to visualize the route she would take to the local shops. She had to describe in detail the landmarks she would pass, and the potential difficulties she might face. Once this was done, Tina was encouraged to get into her gofer and together, the researcher and Tina walked to the shops. This exercise helped Tina orientate to her environment and prepared her for possible difficulties such as missing a turn, and getting lost. Initiating activities for Tina, and guiding her in breaking down the task, and persisting at it till completion are other examples. If Tina could not visualize the route to the shops, she was taken on a walk and was encouraged to write down significant landmarks.

Once taken outside her routine, Tina gets panicked, is easily stressed and sometimes has explosive outbursts of anger. She gets depressed and would often use strong, negative language to express her feelings. Her most common expression would be “I don’t want to” or “I don’t give a ****”. In order to encourage Tina’s participation the following strategies were identified:

- Individual planning activities which are carried out on a bi weekly basis
- Shaping and reinforcing participation in social, recreational activities
- Sustained feedback and rewards for effective goal completion
- Provision of certainty and routine in activities and contact

Tina also has limited self awareness, which is perhaps due to the right frontal injury (Prigatano & Schacter, 1991; Stuss, 1992). Participation in the brain injury group, discussing inappropriate behaviour and role playing helped improve her awareness which results in improvement in her behaviour. For instance, the researcher would assume the role of a carer and Tina would rehearse displaying anger without swearing through the monitoring of her language. During a session of role rehearsal, Tina would be the researcher, asking questions which were pre written down such as “Tina would you like to go to your writing workshop today?” The researcher would then respond politely, saying “I don’t feel like it today maybe next week”, this is then contrasted with Tina’s previous response of “Get lost, I’m not ****ing in the mood to go”.

At the 6 month follow up, Tina’s unpredictable and risky behaviours were still apparent. Unless she had support and activities planned on a weekly basis, Tina still resorted to alcohol and withdrawal behaviour.

Conclusion

In order for Tina’s resilience to emerge, she needs constant support and those working with her need to nurture her by making contact, listening to her needs and building her trust. For instance she would respond to suggestions and activities when they come from her rehabilitation consultant who she trusts and with whom she has a good relationship, but not from her carers, many of whom she makes angry statements about. Tina also responds to feedback and is able to plan and anticipate when opportunities are created for her to do so. For instance when she is asked to participate in a brain injury camp, Tina would often refuse but once she is given the opportunity to contribute in some way towards the camp such as by helping a new person fit in,

Tina is motivated and eager to attend. She also constantly needs routine and structure for her resilience and executive functioning to develop such as scheduling weekly meetings with friends or careers. Her resilience scale scores were (111) at baseline, (120) post intervention and (101) at follow up. Her executive functioning scores were (77) at baseline, (70) post intervention and (73) at follow up. Tina's case demonstrates that a person regardless of circumstances, and injury, is capable of displaying resilient behaviours. This can occur through strengthening and supporting her executive functions such as being able to initiate, plan and anticipate. When this occurs, her resilient behaviours are observed more frequently.

5.1.2 *Leslie*

Leslie is a man in his late forties with successful university entrance scores. He has traumatic brain injury as a result of a farming accident. Leslie spent most of his childhood growing up on a farm in the outskirts of Adelaide and up till his accident was described as a happy but reserved young man. He loved the outdoors and would often spend hours in a day on the farm or going for walks regularly. He did well in school and was a university student at the time of the accident.

At present, Leslie is unable to pursue his studies or work at a level commensurable with his measured intelligence. Post injury, Leslie had a measured Weschler Intelligence Score (IQ) (Wechsler, 1997) score of 120 with strengths in mathematics and accounting.

The accident resulted in mild right-sided hemiplegia, frontal lobe damage, short-term memory problems and posttraumatic epilepsy. His epilepsy is controlled by therapeutic use of anti convulsive medication. He often experiences flattened affect, depression and other such negative mood and emotional states. His mood often fluctuates and he is known to have severe anger and temper outbursts. When faced with difficult situations, such as not being able to communicate clearly what he needs to his carer, Leslie would get frustrated with himself. He would become agitated, and sometimes start yelling, cursing or throwing things. This behaviour seems to be consistent with that of people with traumatic brain injury, in particular those with frontal lobe injury (Tateno, Jorge, & Robinson, 2003). Leslie would act on his frustration, in risky, impulsive behaviour. He visited nightclubs and strip joints and would only return in the early hours of the morning. He would spend the rest of the day sleeping, only to return to the clubs the next day. This pattern would persist for weeks, unless someone (usually his rehabilitation consultant) recognizes his destructive behaviour and stops him. He finds it difficult

to accept frustration and his aggressive behaviour is often disproportionate to the trigger. For instance he might start yelling and shouting at his carer for moving his mug. He would start shouting and pacing back and forth, unable to regulate his emotions. His outbursts last for a few minutes and then subside.

Leslie is a man plagued by loneliness. He is uncomfortable being alone, and yet is unable to initiate activity or maintain sustained contact with anyone. This is a key factor in his depression, as he often feels “down, and “cut out of life”. He watches those around him, smiling children, happy couples and wishes he was one of them. He yearns for companionship, and would love to have a partner, although a part of him knows that this dream will never come true. He imagines what it would be like having someone next to him, to share with, to do things with and is happy for a while. However, he lives a harsh reality, and making friends is not easy for him. In his case, depressive symptoms such as withdrawal, anxiety, lack of motivation and sadness imitate and mask the symptoms of loneliness (Cacioppo, Hawkley, & Berntson, 2003). For Leslie, the thought of not being able to control his life circumstances is often a trigger for depressive thoughts and behaviour. He is treated for depression with medication. However considering the possibility that loneliness may be a contributing and sustaining factor in his condition, the underlying loneliness is overlooked. Therefore his depressive symptoms continue and he falls into a cycle of depression and manic episodes.

He also has problems switching between mental tasks also known as dual task interference, which is consistently seen in people with brain injury (Cummings & Bogousslavsky, 2000). Once engaged in a task such as watching television, or delivering newspapers, Leslie finds it very difficult to establish a new mental set. As such his behaviour is rigid. Similarly, Leslie often feels people make fun of him as he does not respond to humour.

During workshops when participants joke light heartedly, Leslie often does not laugh. Rather he feels hurt that people are laughing at him. In reality his concreteness and rigid thinking prevent him from understanding the joke. Therefore he appears cold, aloof and unreasonable to others. This results in further alienation of him from his peers.

Leslie also has had major problems in regards to regulating the dosage and type of his medication. He has been subject to the mismanagement of his medication and this has had catastrophic effects on his behaviour. He would lash out at those around him, be obsessive with whatever he was doing and would not stop doing an activity once he started. For example, during a hyper manic episode, Leslie was found carving into the doors of his house for days with a screwdriver. He had little awareness of what he was doing. When asked why he did this; he replied that it was his job as a “door sandwich maker” to do so. During these manic episodes, Leslie would display enhanced talkativeness, increased psychomotor activities, and decreased need for sleep. During that particular episode, he worked through the night for three days straight, barely eating. He also becomes irritable when hindered. When friends came to visit, he snapped at them and sent them away. Six days later, his rehabilitation consultant, who noticed that Leslie had an overdose of medication, had to ring for an ambulance. He was taken to a locked ward for care, as he became hostile and aggressive, hitting, screaming and kicking at staff, refusing to go to hospital.

With proper management and close supervision from his mentor, Leslie is able to live independently. Proper management for Leslie is the regulation of his sleep patterns, monitoring his medication, sufficient exercise, and proper eating habits. When Leslie doesn't watch his diet or get sufficient food, his medications have little or no effect and he becomes manic and irrational. He is compulsive and would for instance take one week's medication all at once, or

sleep for days in a row. When his sleep patterns are uneven, it takes a toll on his behaviour and he becomes either depressed or manic. However, once these core functions are monitored and regulated, Leslie is able to care for himself and keeps a very neat and tidy home.

He still has problems with his short term memory but over the years has learnt ways to work around them. For instance, he uses a diary to keep track of his appointments and has a notebook where he records the tasks he needs to do. This strategy has not always been useful because in times of depression or low mood states, Leslie often forgets to write in his diary and therefore misses appointments on a regular basis.

Leslie also often has periods of depression. He has a Beck Depression Inventory Score of 45 indicating severe depression (Beck, Steer, & Brown, 1996). Depression for Leslie is characterized by: inactivity and lack of motivation to do daily chores. He sleeps for extended periods during the day. He experiences periods of self loathing and self injurious behaviour such as neglect for personal care and safety. He would not take his medication or would take medication on an empty stomach which is hazardous to his health. His negative thoughts consist of him thinking he is not good enough, people don't like him, and that he is worthless and incapable of anything. During these depressive episodes, Leslie lacks concentration, and tasks which he could perform previously such as showering or even brushing his teeth seem difficult.

Protective Factors and Strengths

Leslie loves watching sports and occasionally attends a support group for people with brain injury. There he participates in various activities such as writing workshops, computer workshops, drama and structured group outings.

Leslie's strengths and protective factors are described in the table below. These are identified following observation and in consultation with Leslie. Likewise they are also based on the findings in the literature review (Gordon, Cantor, Ashman, & Brown, 2006; Lightsey, 2006; Rutter 2002). These examples include support from his community, his ability to learn and retain information, and his supported living arrangement which provide opportunities for social contact for Leslie.

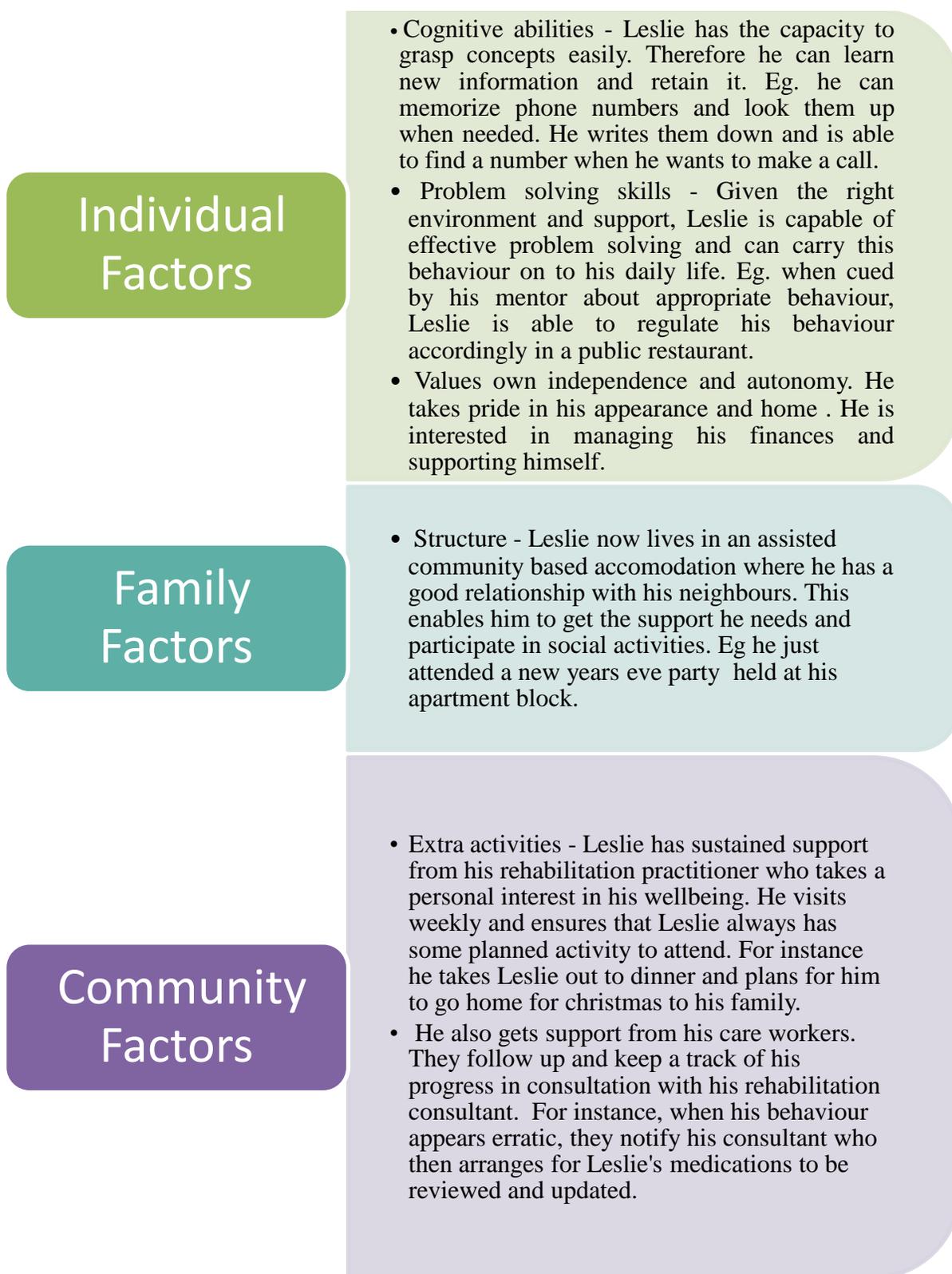


Figure 5.5 Leslie's protective factors and strengths

Nature of the Intervention

The intervention consisted of fortnightly visits to Leslie's home. During the intervention period, Leslie and the researcher would either choose to remain in his home or do outdoor activities such as going for walks or going to the coffee shop. Leslie's mood was also highly unpredictable. Sometimes during the sessions he would experience mania, where he would become frantic, talking at high speed, sometimes not making any sense. At other times, Leslie would appear uninterested, withdrawn and would remain quiet for the entire session, reluctant to participate.

Leslie's scores on the Outcome Rating Scale were moderate (scored between 30-70) on some meetings and scored moderate to high (scores between 70-100) on others. Depending on his mood state, Leslie could evaluate his environment and wellbeing. He often experiences mood swings. For instance he experienced a period of extremely low mood approximately two months after the commencement of the intervention. When his mood states are balanced, he scores in the high range of the ORS. Leslie's ORS scoring on four occasions throughout the intervention is presented in Figure 5.6 below.

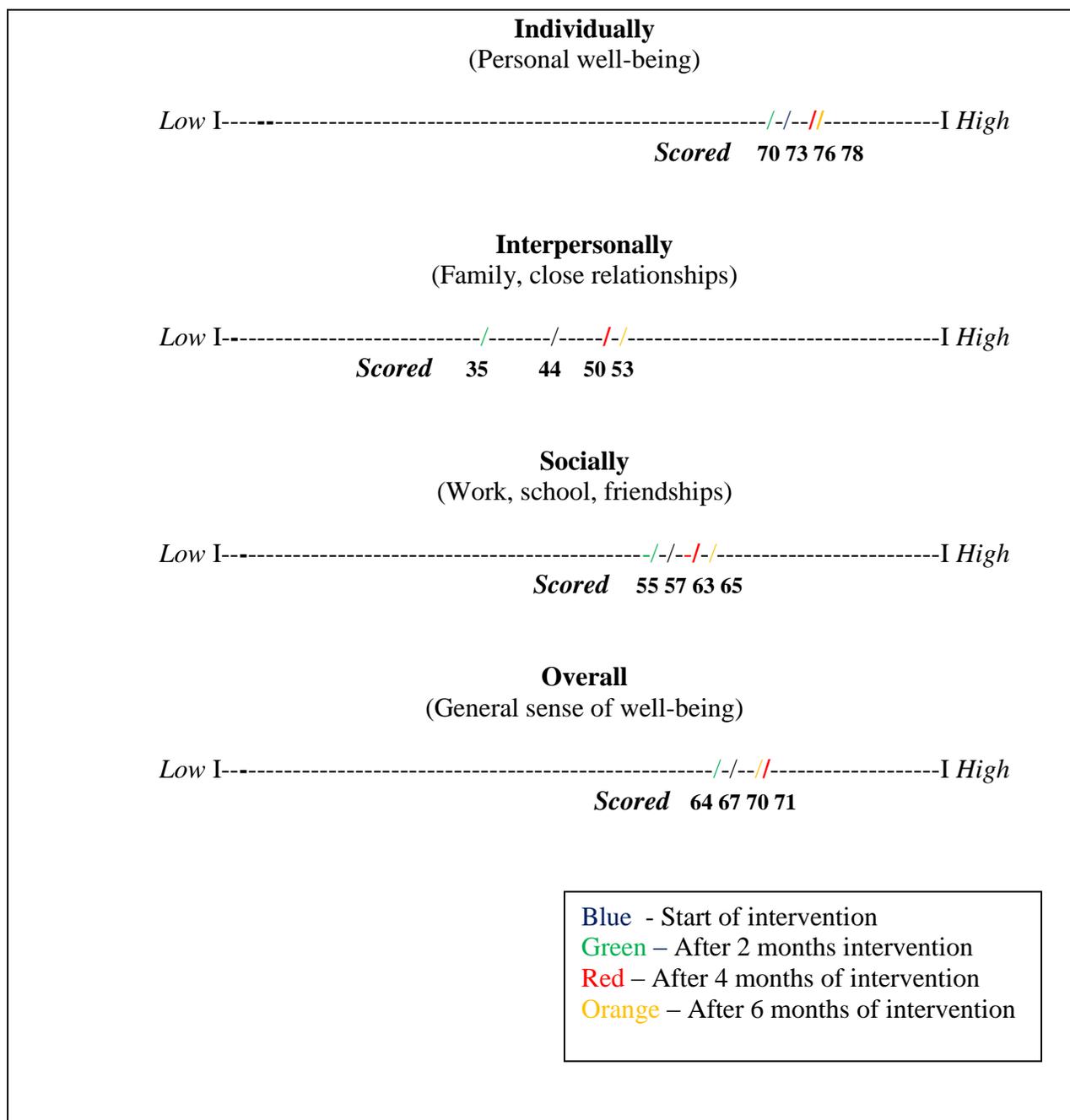


Figure 5.6 Leslie's Outcome Rating Scale scoring at 0, 2, 4, and 6 months of the intervention

Leslie's self scoring of the ORS, rated relatively low scores of 35- 53 on interpersonal relationships. These scores represent the lack of close family relationships. His family live quite far away from where he is, and he only visits them occasionally. Apart from his sporadic visits,

he has limited contact with his family. He is prepared to isolate himself from them, often rejecting their invitations for him to be included in family events. Leslie scored medium (55-65) on the social item of the scale. These scores indicate his loneliness and lack of social interaction. Leslie was extremely lonely during the intervention, and this was in part due to his living arrangements. At the start of the intervention, Leslie lived alone. Loneliness with no one to share his time would creep up on Leslie so he was rarely if ever nurtured by a friend's company. Therefore with no one to share laughter, discuss problems, 'rev' him up, he slipped back without purpose into an often morose and depressed state. As a result he was strongly encouraged to move into assisted community living by his rehabilitation consultant. He was in the process of moving during the end phase of the intervention. This move is expected to help break the cycle of depression and loneliness faced by Leslie. All his scores on the ORS are fragile, because he can withdraw suddenly and his scores could easily slip to the much lower end of the scale, than they actually are.

Leslie reported that his major areas of concern were his depressed mood and his memory difficulties. Together, the researcher and Leslie developed both long term and short term goals for Leslie to work on during the intervention session. Leslie's long term goals were identified in consultation with the researcher and are written in the form of therapist goals. These goals are broken down into short term objectives and participant goals (see Table 5.2 below).

Long-term Goals

- Alleviate depressed mood and return to previous post trauma level of effective functioning (for instance, create opportunities for sustained social and recreational activities).

- Recognize, and cope with feelings of depression (emphasize the role of self talk; that negative thoughts lead to negative emotions).
- Develop healthy cognitive patterns and beliefs about self and the world that leads to alleviation and help prevent the relapse of depression symptoms (reinforce positive self talk; have positive experiences).
- Maintain and develop healthy interpersonal relationships that lead to reduction and prevention of relapses of depression symptoms (encourage participation in group outings, make forward plans which he can anticipate and plan).

Table 5.2 *Leslie's short term objectives, therapeutic intervention and goals*

Short-Term Objectives	Therapeutic Interventions	Leslie's Goal attainment Scaling Goals and Score
Describe current and past experiences with depression, complete with its impact on function and attempts to resolve it.	Assess current and past mood episodes including their features, frequency, intensity, and duration (e.g. Ask Leslie on a scale of 1-10 to rate his depressive mood state for the past week).	+2 Rate depressive mood state every week 80% of the time
Verbally identify, if possible, the source of depressed mood. Check for any history of suicide attempts and any suicidal urges. Focus on automatic thoughts	Assist the client in developing an awareness of his/her automatic thoughts that reflect depressive schemata. Do "behavioural experiments" in which depressive automatic thoughts are treated as a prediction and actual predictions are generated. Both are tested against the client's past, present, and/or future experiences. (e.g. an automatic thought of "I am useless" can be tested with giving Leslie the opportunity to participate in a rewarding activity such as assembling a do it yourself bookcase).	+1 Able to identify and recognize negative thoughts 30 % of the time +2 Participating in behavioural experiments and successfully completing them 60 % of the time
Learn and implement problem-solving and/or conflict resolution skills to resolve interpersonal problems.	Assist the client in developing coping strategies (e.g., more physical exercise, less internal focus, increased social involvement). Help Leslie in "behavioural activation" by arranging activities that have a high likelihood for pleasure and mastery (using principles of errorless learning); Use rehearsal, role-playing, role reversal, as needed, to assist implementation in the client's daily life; For instance, Leslie is not sure how he can make friends as he tends to be shy and introverted, part of the intervention process is working together with him in role playing conversation scripts he can use when in social situations. Appropriate language is reinforced.	+1 I use my copings skills always and feel depressed and angry 10–30% of the time. +2 Participating in behavioural experiments and successfully completing them 60 % of the time + 2 Participate and complete role reversal during sessions with therapist 70 % of the time

<p>Implement a regular exercise regimen as a depression reduction technique</p>	<p>Identify what activities Leslie enjoys doing which give him exercise and help him get out of the house</p>	<p>0 Play golf or go for a walk at least twice a week</p>
<p>Learn and implement relapse prevention skills.</p>	<p>Utilize self-reliance training in which Leslie assumes increased responsibility for routine activities (e.g., cleaning, cooking, and shopping) Encourage the client to share his/her feelings of depression in order to clarify them and gain insight as to causes (e.g. getting Leslie to identify what triggers a depressive episode and what thoughts maintain this behaviour).</p>	<p>0. I take care of myself by doing my own cooking, cleaning, bathing and grooming over 50–74% of the time 0 Identify triggers of depressive behaviour and the consequence of these thoughts 30 % of the time.</p>

Goal Attainment Scaling

Leslie was able to achieve all of his goals given sustained support and energy. He continues to work on improving the skills he learnt on a weekly basis with his support team.

Table 5.1 above provides his scores according to each short term objective. Two examples of detailed goal scaling are provided below.

Example 1

- +2 I use my coping skills constantly and feel depressed and angry less than 10% of the time.
- +1 I use my copings skills always and feel depressed and angry 10–30% of the time.
- 0 I use some of my coping skills and feel depressed and angry 35–50% of the time.
- 1 I use some of my coping skills and feel depressed and angry more than 60% of the time.
- 2 I rarely use coping skills, and generally feel depressed and angry.

Leslie scored +1 for this goal and reported using his coping skills such as ensuring he gets physical exercise daily, focusing on his strengths not weaknesses and increased participation in social activities. His main problem was remembering the skills and subsequently writing them down in his diary which he is then cued to read every day and discuss with his mentor.

Example goal 2

- +2 I take care of myself by doing my own cooking, cleaning, bathing and grooming over 90% of the time
- +1 I take care of myself by doing my own cooking, cleaning, bathing and grooming over 75–89% of the time
- 0 I take care of myself by doing my own cooking, cleaning, bathing and grooming over 50–74% of the time

- 1 I take care of myself by doing my own cooking, cleaning, bathing and grooming over 25–49% of the time
- 2 I take care of myself by doing my own cooking, cleaning, bathing and grooming over 25% of the time

Leslie scored a 0 for this goal but this reflected an improvement for him because he was more aware of what he needed to do. This meant he would do his own cooking and self grooming 50 % of the time. Given appropriate support and cueing from his carer network, Leslie could perform these tasks independently. For instance, his care workers would cue him to go shopping when they notice his pantry was low on food supplies and this would ensure that Leslie has food over the weekend.

Assessment Scores

Leslie recorded low resilience scores on the Resilience Scale at baseline (80) and his scores improved post intervention (103) and (101) at follow up. His DEX scores however were (77) at baseline and this went down to (71) post intervention and (75) at follow up. A complete discussion on his resilience and Executive Functioning follows below.

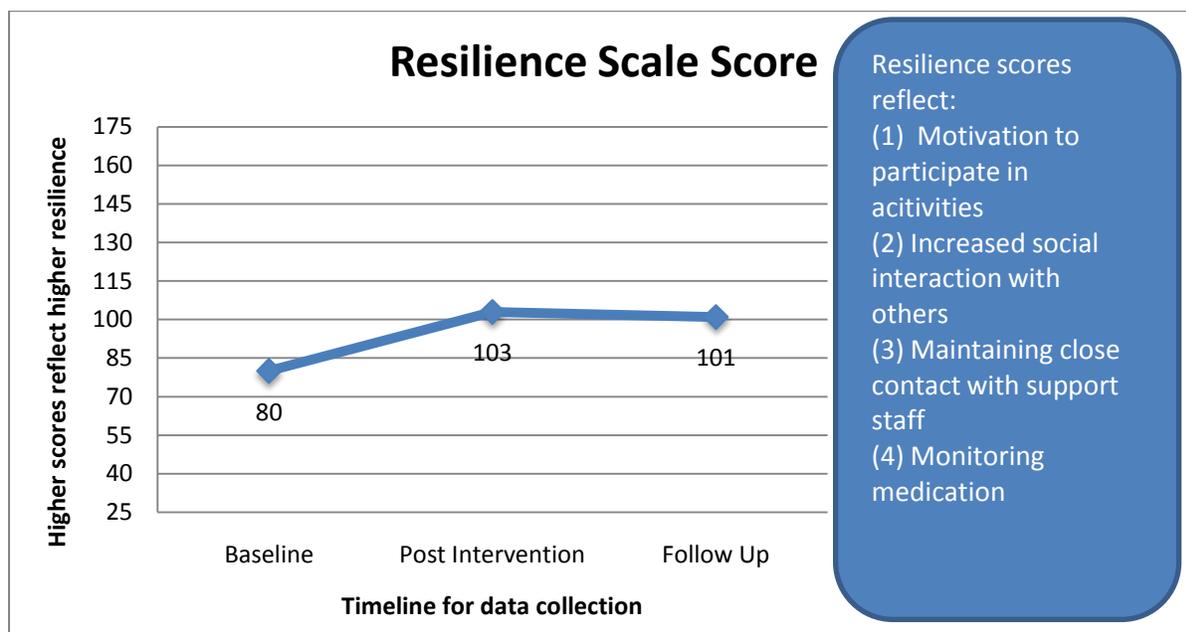


Figure 5.7 Leslie's Resilience Scores

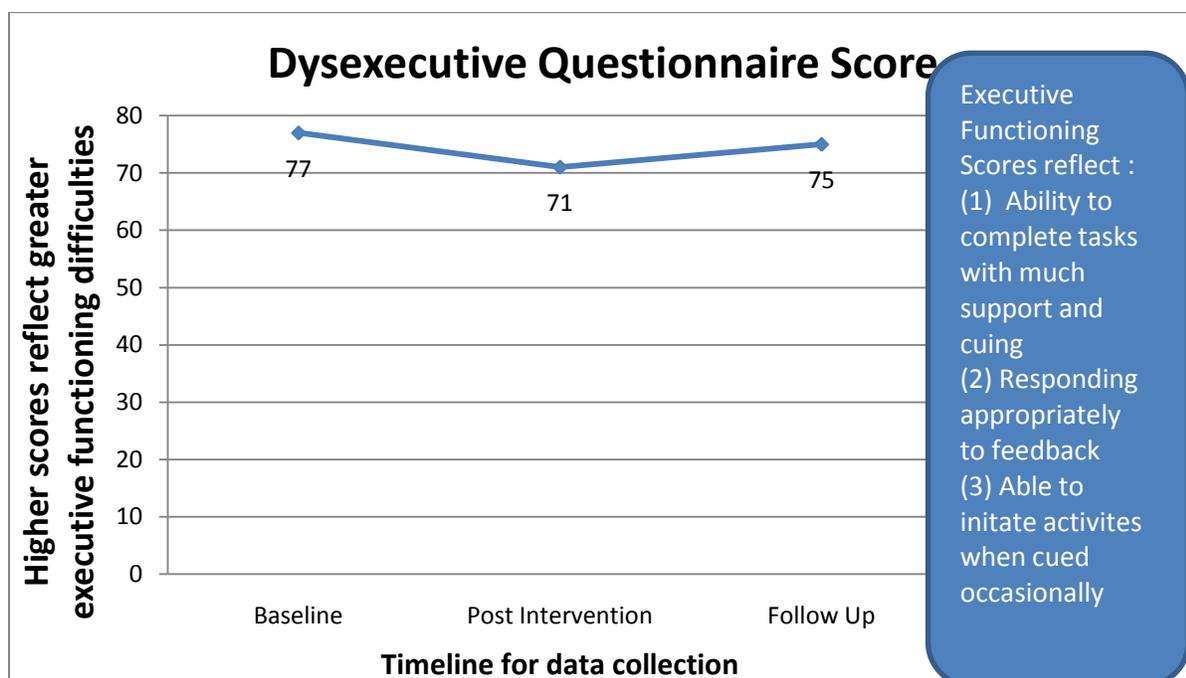


Figure 5.8 Leslie's Dysexecutive Questionnaire Scores

Leslie's resilience

When his mood state is at equilibrium, Leslie's short term memory is appropriate and his language is clear. When he is involved in structured activities that he likes, Leslie feels needed and is happy. The availability of structured activities and people to carry them out with him is difficult to attain and carry out on a sustained daily basis. Leslie has season tickets to the football. He refuses to go unless someone goes with him.

Those who know him would describe Leslie as a kind, gentle and soft spoken man. He is caring and when secure, appears interested in others. He has a particular liking and fondness towards animals and feels strongly about the need to protect them. He is often shy and would not participate willingly in activities unless he is persuaded by someone he knows to do so.

He does not like new things or new people very much, but given the right cues and encouragement he slowly adapts his behaviour. For instance, if his mentor brought along a student to one of his coffee outings with Leslie, it would take a lot of persuasion from the mentor before Leslie would engage in conversation with the student. His rigid behaviour and shy personality results in a limited number of friends and people who can help him in times of need.

Leslie likes routine. He has a few interests, and dislikes interruption to that routine or the introduction of new activities. Once involved in an activity such as watching sports on television, he finds it difficult to choose different channels or change to a new activity such as making lunch unless he is cued to do so. His apprehension hinders him from liking new people. He is constantly suspicious and anxious. However, he doesn't necessarily hold grudges against people and is capable of getting over his anger reasonably quickly. For instance, he was suspicious of new members in his brain injury group, and would not speak to them. However, once he has had

the opportunity to be introduced, has a conversation, and spends time with them he overcomes his suspicions.

Most of Leslie's resilience is determined by the mood he is in at the given moment. When he is depressed he often doesn't seem to be able to "see the bigger picture" and can't see what the point of it all is. He will respond to people in a very flattened and negative manner, with pessimistic statements like "I don't know why any of us do what we do really", or "what's the point it's not like anything's going to change". He moves between periods of being depressed and periods of hyper mania.

Leslie rarely enjoys life because he is trapped in his rigid thinking patterns which prevent him from leaving the comfort and safety of home. Leslie lives a life where he is unheard and invisible, often on the fringe of society, never quite making it in. He does not risk leaving the safety of his comfort zone for the possibility of greater happiness or self-fulfilment. His comfort zone is his home and the few carers he has contact with regularly. He has been offered a job that he can undertake given his level of skill, and competence, but yet he doesn't want the job because he is afraid he will fail. He participated in self reliance training successfully, but this was not generalized to his personal domestic life. Leslie responded to the training, and with cues was able to sustain his daily activities such as brushing his teeth every morning, showering before leaving home daily, and wearing clean clothes. The training had to be repeated and more support given to Leslie on a daily basis by his carers such as checking up on him and phoning him regularly to make sure he had his shower, brushed his teeth and wore clean clothes.

Leslie is lonely, and his difficulties interacting with others and his rigid thinking result in him being isolated most of the time. For instance, when someone asks him out for coffee, Leslie would immediately be suspicious of the person's motives, and would decline without even

considering the idea. This self-imposed isolation means that Leslie would either sleep or watch TV, and often this behaviour lasts for days at a time. Despite his interest in sport, he often has motivational difficulties, which hinder him from taking part in any games or recreational activities. When in a social group, he often retreats and secludes himself especially if he is in a negative mood state. This is observed when at a party during a social camp; he hid in his room and refused to come out.

Observations of Leslie indicate that personal stability can be sustained for weeks on end where he can maintain a positive mood and display resilient behaviours. This is usually linked to continuous participation in social and prevocational activities, along with the effective management of his medication. An example of this is Leslie taking his anti convulsion medication night and day as prescribed without requiring external cueing. However, there appears to be a cyclical nature to his mood states. His positive mood state can last anywhere between six weeks to two months, but it eventually (irrespective of intervention), gives way to withdrawal, reactive depression and non-functioning behaviour. These non-functioning behaviours place him at risk, particularly with regards to the effective management of his epilepsy.

In this flattened mood and personal low, he becomes inflexible, resistant and for the most part negative, almost to the point of self-destruction. Special intervention is required to support him at this time and to help him begin the climb out of his depression. Observation of his behaviour, over many years by his rehabilitation consultant, demonstrates that he is unable to resurrect a positive mood state unaided. He appears to have a fragile hold on positive behaviour and mood state.

This seems to contribute to his “brittle” resilience. Leslie can be classed as being a survivor more than being described as “resilient”. In these measures, he rarely overcomes the present circumstance, and therefore can become a prisoner of his poor executive functions.

Executive functioning

Leslie experiences severe difficulty planning and organizing tasks. He rarely initiates positive action unless he is cued, and he cannot develop plans much beyond 24 or 48 hours. He also experiences much difficulty executing his plans once he made them. This often results in him being confused and consequently, he is resistant to change, and appears rigid in his thinking and actions. These observations also reflected on his scores on the DEX in particular to questions 1, 6, 8 and 18 (“I have a problem understanding what other people mean unless they keep things simple and straightforward”; “I get events mixed up with each other and get confused about the correct order of events”; “I seem lethargic, or unenthusiastic about things”; “I find it difficult to keep my mind on something and am easily distracted”). These questions measure abstract thinking problems, temporal sequencing deficits, apathy and lack of drive and distractibility.

For Leslie to participate in conversations with people with whom he is unfamiliar, he often needs them to repeat what they are saying and to keep things direct. When cued, Leslie would ask someone to clarify what they mean. At other times he would not respond to questions which he did not understand. Similarly, his difficulties with temporal sequencing of tasks are evident in his inability to follow complex instructions such as directions to the bus stop which require higher order sequencing of events. For example, he can follow the instructions, “turn left at the traffic light” but gets confused with instructions such as “turn left at the traffic lights, then right at the post office”. Often, although he understands and writes down what he has to do (i.e.

turn right at the post office), he would get distracted by something which caught his attention such as a display of lights in a store window.

In relation to his executive functioning difficulties, certain tasks were set up for Leslie which enabled him to learn and practice his skills in a safe environment which promoted errorless learning. Leslie likes walks, and during a walk, he is encouraged to notice the birds in the trees, the colour of the sky, and the running water in the stream. Later, he is asked to recall what he saw with cues such as “running...” or “the sky was....” This promotes behaviour activation by getting Leslie involved in activities which are pleasurable and which he can master.

Summary and Conclusion

Leslie’s residual physical impairments from his accident are only one aspect of the disability he faces. He is prone to emotional disturbances, outbursts and attacks of a myriad of emotions ranging from depression to frustration to extreme rage. He often has difficulty remembering appointments and relies heavily on his diary. Through years of intensive rehabilitation, Leslie now is able to live independently, given regular support. His resilience emerges in contexts where there is structure. This structure in the form of community support, routine and predictability is key in nurturing his resilience. He can anticipate and plan, when he knows that there would not be disruption in his daily routine. Community participation and integration is possible for Leslie given these support systems are in place.

5.1.3 *Betty*

Betty is a 34 year old woman, who is outgoing, lively and has a warm personality. She sustained injuries in a road accident when she was 12, which resulted in frontal lobe damage and severe right sided hemiplegia. Betty was riding her bicycle on her way to attend a Red Cross meeting when she was hit by a car. Only days before her accident her parents had ordered a helmet, which until then was not a legal requirement for cyclists in South Australia. She was in coma for a period of 27 days with a Glasgow coma scale score of 5.

Her post trauma measured intelligence using the Weschler Intelligence Scale (WAIS- III) (Wechsler, 1997) is in the average range with a score of 107. Looking through the window into a cafe, one would easily assume Betty is a happy young woman, full of vibrancy, life and energy. She has an easy laugh and humour is never far around the corner. She jokes and teases, drawing in people around her. At times, there are glimpses of “over the top” behaviour, a loud laugh or a lewd comment. Betty is relatively unaware and unconcerned about the effect of her behaviour on others.

Looking into her past, Betty as a young girl grew up dreaming of being a princess, a model, and an actress. She was determined, driven and was encouraged to pursue her dreams. Fortunately for Betty, the accident did not scar her face and she was able to take up modelling in her teens. She spends hours focusing on the way she looks, shopping with her mother and preparing for the next photo shoot. Meanwhile, in school, Betty’s academic performance was declining and she had trouble concentrating and completing tasks. She would start writing her homework, only to be distracted by her friends.

She became withdrawn, often sitting alone, whilst her friends were playing netball, or going to the movies. She watched as her friends went on dates and parties while she was left out.

Unable to maintain friendships, Betty clung on to those few friends who remained. Her social network grew smaller, and Betty became more dependent on her parents. Together, they tried to engage Betty in activities where she would meet friends, others with the same difficulties as her. However, Betty refused to attend workshops or support groups, saying “I’m not like them, I’m a normal teenager”. Once Betty left high school, she tried to gain employment. However, this was not possible as she faced difficulties initiating and starting tasks, and persisting at them till completion. She would be excited and motivated to go to work one day and be completely indifferent and refuse to go the next. She was employed at irregular intervals in the past and did some volunteer jobs but feels that her memory is not good enough to maintain long term employment. She experiences difficulty with short term memory, and unless cued, forgets appointments and meetings. Likewise she experiences both physical and cognitive fatigue, which prevents her from working for long hours.

Betty dreams of finding her soul mate, someone who understands her, cares for her, and who would pamper her. She was married for a short time, but her marriage did not work out and she got divorced. According to Betty, her husband was unable to cope with her depression, and constantly “picked on her” for not getting chores done. Betty has a young son (David) and currently lives alone. Her parents and brother maintain close contact. Her parents live nearby and help her with shopping, personal care and looking after David. She and her ex- husband share custody of their son and she has David for two weeks at a time.

Over the years, Betty yearned to be like other girls. She watched people around her get married, have children and she desperately wanted to be like them. Often depressed, Betty turned to food for comfort. She would have episodes of binge eating and meets the DSM IV-TR criteria for binge eating disorder (BED). She has ‘two or more weekly episodes of eating a large amount

of food in a short period of time”. This episode is usually accompanied by a sense of loss of control. For Betty the binge eating episodes consist of her eating more rapidly than normal; eating until uncomfortably full; and eating when not physically hungry. These behaviours usually occurred when she was; (1) bored (2) stressed or depressed (3) when watching television and (4) when she sees food that she likes and is unable to resist temptation.

After her episode, she would feel very disgusted with herself, which often leads to her having negative thoughts such as “I am fat and ugly, who would want to spend time with me”, “I should not be allowed to go out looking like I do”. These thoughts would trigger her to eat more as she uses food to numb her feelings of inadequacy and depression. During an outing to the local markets, Betty spent approximately 200 dollars on food items. When questioned, she replied she was buying chocolates for David as it was Easter. In reality, she ate most of the food herself and felt sick the next day. The trigger for her binge eating was that she was all alone and had no one to spend the holidays with. Her extreme loneliness pushed her to turn to food as solace. It is possible that Betty eats as a way of coping with stress and challenges in her daily life. She gets sensory rewards such as feeling satisfied, happy, and calm when she eats and therefore eats according to her mood state. She also has associated eating with family connectedness, positive emotions and as a means of socialization. When asked to describe the times where she does not binge eat, Betty replied “I don’t eat when I have something to do, something to take my mind of things”. It is apparent also that Betty eats as a means of escaping boredom.

Betty also constantly worried about her weight. She is medically obese and her obesity has impacted her mobility as she often has pain in her legs. This is further complicated with

cellulites, endometriosis and the resetting of her bones in her arms and leg. She often experiences swelling and her pain sometimes prevents her from walking and getting the exercise she needs.

Through manipulation of her surroundings, Betty was encouraged to change the likelihood of her binge eating. Strategies recommended for her included:

- (a) Limiting the purchase of high fat, or high sugar food. If these foods are not around her, she can't snack on them.
- (b) Increasing the purchase of vegetable and fruits. When these were visible and easily available Betty was more likely to eat them.
- (c) Designating a place in her house such as the dining table where Betty will eat. She is to make sure that she does not eat anywhere else such as in the bedroom or in front of the television.

Consequently, Betty's mood state and binge eating episodes often impact on her ability to display resilient behaviour. For instance, when she is not depressed, she engages in activities and is socially connected with her friends and family. During these times, she displays resilient behaviours' such as;

- responding to humour,
- initiating contact with others,
- being open to new experiences and
- is confident in herself and her abilities to cope

However, her mobility and health problems, add to Betty's depression and isolation. She used to be able to drive and this gave her a sense of autonomy and independence as she did not have to rely on others to go shopping or to do chores. Because her legs are weak, she experiences pain walking and driving. Her judgment is also impaired and Betty's driving became reckless.

She would often knock into trash cans or make swift sharp turns without looking for approaching cars.

Betty often experiences loneliness and despises being alone. She has a few friends but these friendships do not last as Betty often becomes dependent on them. She relies on the few friends that she has to provide her with activities. As a result, her friends feel overwhelmed, and cannot cope with the demands placed on them. She would repeatedly text them or ring them till they pick up the phone. Or she would send depressing messages when lonely, often saying “I have no one, you don’t care about me, everyone is happy except for me”.

When she has activities planned, usually social activities involving people she likes, Betty’s behaviour changes drastically. She is receptive to new ideas, and responds well to feedback. She is able to plan and organize events and even looks forward to them. During this time, her short term memory appears to improve and she remembers to meet her friends, or attend a social gathering. She would plan every detail of her outing such as what she will wear, how she will get to the meeting and where they will eat. Betty’s depression at present is dependent on the level of activity and the frequency of social contact she gets.

Protective Factors and Strengths

Certain factors in the diagram below aid in Betty's ability to display resilient behaviours.



Figure 5.9 Betty's protective factors and strengths

Nature of the Intervention

Betty met the researcher every fortnight for sessions which lasted 1-2 hours. The context and environment which the meetings were held affected Betty's mood and she often choose to meet in cafés. A quiet table, and a cup of coffee normally was the setting for the sessions and this also provided Betty with an outing to plan, and anticipate. She looked forward to the meetings. The researcher initiated the sessions and then later would leave the planning and follow up to Betty. For instance, the researcher would suggest they meet again next week, and Betty would decide where they met and how the session progressed. She wrote down things she wanted to discuss and was reminded to bring her list along to the meeting. Betty was also hospitalized for the period of a month during the intervention when her left knee was being reset. This affected her mood state drastically as she was depressed when she perceived that no one cared and therefore did not visit her. Her loneliness and depression intensified during this period as yet again she experienced rejection. Her friends did visit her but not frequently and Betty wanted someone there with her every day. Therefore she felt that everyone had forgotten about her and that she was all alone. Her operation also affected her ability to drive and she was immobile for a period of three months. During her hospitalization the sessions were carried out in her hospital room.

Betty relied on her parents to provide much of the care for David and they were also her sole carers. Therefore her family was also included in the intervention. The days that Betty met the researcher, her parents were able to take some time off for themselves.

Betty scored low (scores between 0-30) on most occasions on the Outcome Rating Scale. She would focus on her negative emotions and thoughts and as a result, evaluate her general wellbeing in a depressed manner. She rarely remembered positive moments or interaction with

others as she allowed her negative thoughts to cloud her objective appraisal of her circumstances. Her ORS scoring on four occasions throughout the intervention is presented in the table below.

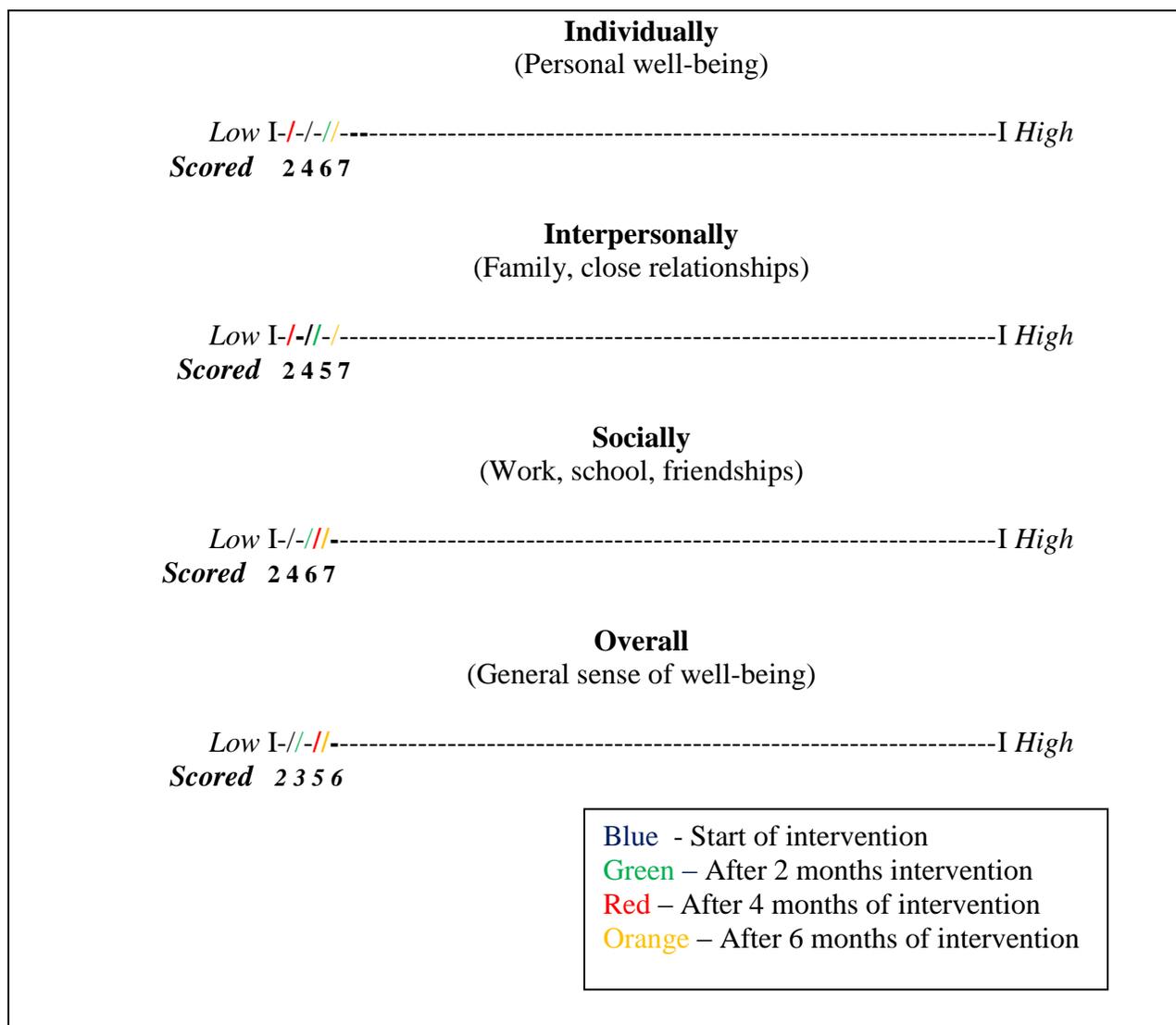


Figure 5.10 Betty's Outcome Rating Scale scoring at 0, 2, 4, and 6 months of intervention

Betty scored low on all occasions of her ORS scores. She often reported that she had little or no social interaction. This was not always the case as she did go out with her mentors occasionally, and she did have social activities. These activities were not as often as Betty would have liked them to be. These feelings of loneliness and lack of social interaction showed on her

self scoring of the ORS. She often reported her sense of general well being according to her mood states. Her mood states subsequently, depended on the amount of social interaction she had.

Together goals for Betty to work on were developed and are described below. Betty's long term goals were identified in consultation with the researcher and are written in the form of therapist goals. These goals are broken down into short term objectives and participant goals

Long term goals

- Develop confidence that she is capable of meeting own needs and of tolerating being alone (e.g. challenge her negative thought that she needs a partner in order to be happy with “I can be happy on my own if I have to”).
- Achieve a healthy balance between independence and dependence (e.g. practice daily chores independently and ask for help only when necessary).
- Decrease dependence on relationships. Betty is encouraged to be independent and practices doing rewarding activities alone (e.g. find activities which can be done alone, such as using the exercise bicycle at home).
- Develop consistent and positive self-esteem (e.g. engage in activities which promotes self confidence such as exercise and beauty workshops).
- Recognize, and manage feelings of depression (e.g. identify negative thoughts which are depressive in nature such as “I am not good enough, I have no one in life”).

Table 5.3 *Betty's short term objectives, therapeutic intervention and goals*

Short-Term Objectives	Therapeutic Intervention	Betty's Goal Attainment Scaling Goals and Scores
Identify positive traits and talents about self	Encourage Betty to keep a growing list of positive traits and have her read the list at the beginning and end of each session.	+ 2 I will write in my journal all the positive things in my life every night before bed
Decrease statements of being a victim while increasing statements that reflect personal empowerment.	Encourage and reinforce the client's statements that show progress away from viewing self as a victim and toward personal empowerment as a survivor. "I can do this because I have done it before".	+1 When I am confronted with a problem I will remember positive ways to cope which have worked before 80% of the time
Identify and replace distorted automatic thoughts associated with assertiveness, being alone, or keeping personal responsibility boundaries	Explore and identify the client's distorted, negative automatic thoughts associated with being alone, or not being in a relationship.	0 I will remember that I do not need a man to be happy and be proud of my own achievements 50 % of the time

Goal Attainment Scaling

Betty achieved 2 out of 3 goals during the intervention but still struggles with her depression. She found challenging her negative thoughts very difficult. With practice and support from her friends and family, she is getting more accustomed to challenge negative thoughts. An example of how her goal was stated is described below

Example 1

+2 When I start doubting myself and get depressed, I will stop and check my thoughts
80% of the time

+1 When I start doubting myself and get depressed, I will stop and check my thoughts
60-70 % of the time

0 When I start doubting myself and get depressed, I will stop and check my thoughts
50% of the time

-1 When I start doubting myself and get depressed, I will stop and check my thoughts 30
– 40% of the time

Assessment Scores

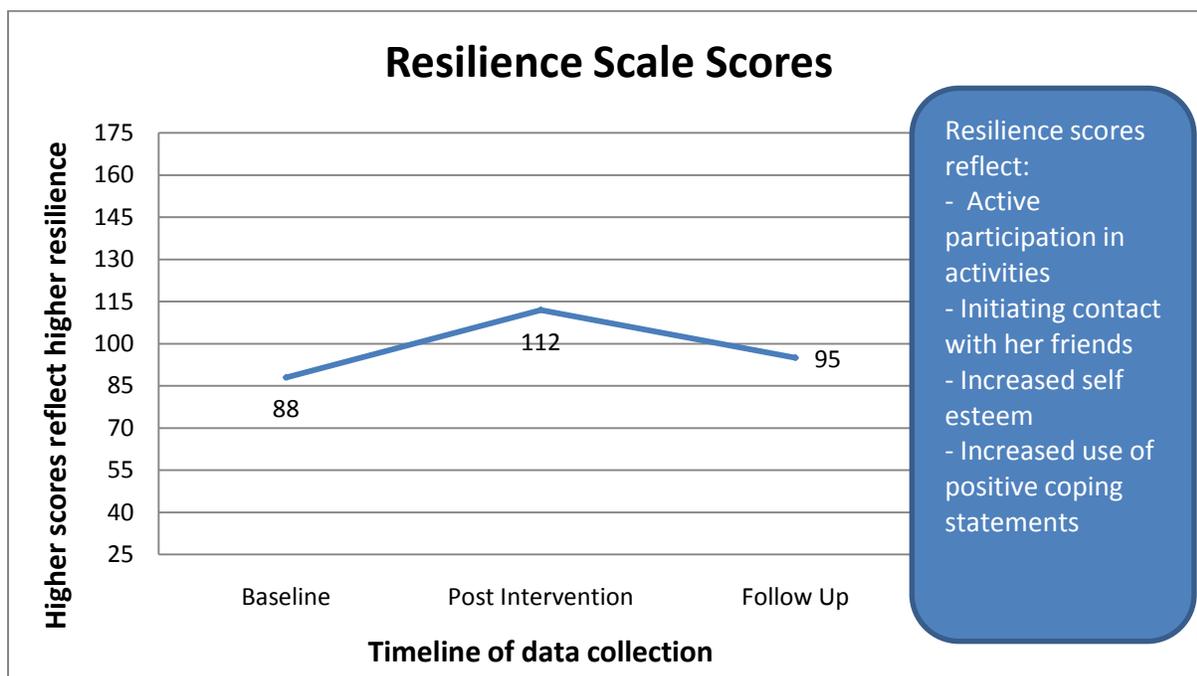


Figure 5.11 Betty's resilience scale scores

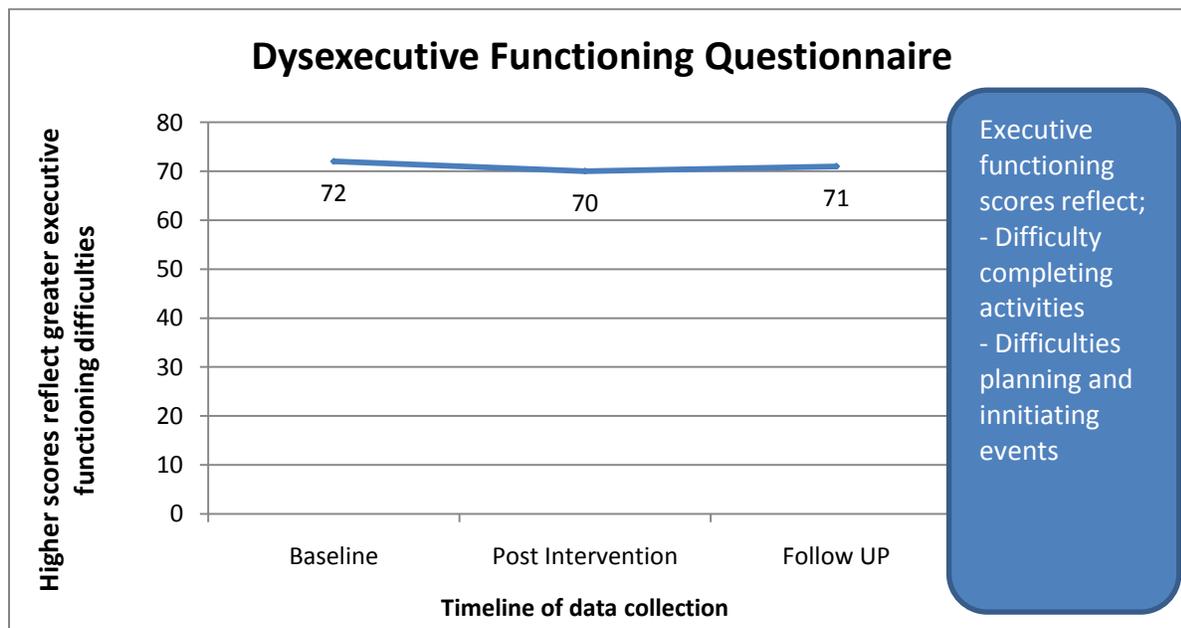


Figure 5.12 Betty's Dysexecutive Questionnaire scores

Betty's assessment scores reflect her resilience as in the low range (88) baseline, (112) post intervention and (95) at follow up. Her executive functioning scores on the DEX are also on the average range (72) baseline, (70) post intervention and (71) at follow up.

Her scores at follow up reflect fluctuation in her ability to display resilient behaviour. Betty needs support on a continual basis from friends and family. Devoid of this, she is often left at the mercy of her mood states. She feels depressed when she is alone, or when she has a lack of pre planned activities to which she can look forward. Her executive functioning scores show that she continues to have difficulty with sustaining activities and completing plans which she has made.

Resilience

Betty demonstrates the capacity to socialise and to maintain positive interactions with other people. For example, when attending a party, Betty maintained conversation with ease and interacted with people, most of whom she had never met before. Given the right context and support, she is motivated to undertake and complete tasks. When she is not depressed, she is open to change. She would try new things and finds activities in which to participate. She enrolled in a beading workshop, where she learnt how to make jewellery. However, Betty finds it difficult to sustain her positive mood state and as a result experiences fluctuating emotional states. She would be happy, optimistic and cheerful one day, or sad, depressed and poorly motivated the next. She relies on others to help her carry out her plans. Therefore often, she does not participate because she can't find anyone to accompany her.

Her resilience is also demonstrated in her use of humour and creativity. She is described by her friends as being "lively, bubbly and funny". Betty likes being around people and is

capable of forming deep friendships. With her friends, she can also be generous and shows a genuine interest helping others by using her skills. For example, she would volunteer to help a friend with writing. Maintaining and forming friendships is crucial in building resilience. Research has shown that those who have supportive and intimate friendships tend to be more resilient than those who do not have friends (Hartup & Stevens, 1999).

Betty is most often emotionally unstable. She often experiences dramatic mood swings. For instance, she might display uncontrolled aggressive behaviours one second, and be sincerely remorseful and apologetic the next. As a result of Betty's emotional difficulties, she often has a difficult time adapting to new situations and displays blunted social sensitivity (Cummings & Bogousslavsky, 2000; Eslinger & Geder, 2000). As an example, Betty has difficulty in suppressing out of context responses and as she would use flowery and grossly exaggerated language (i.e.; "How do you do" and "Oh dear me") unaware of the inappropriateness of her language in the context. This feature of her language is seen to heighten according to the context or situation (McKinlay, 1999; Rees, 2005a). In particular she would resort to using exaggerated language when she was anxious, nervous, depressed or in the company of people whom she did not know.

When anxious or depressed, Betty also frequently displays impulsive behaviour. She has a difficulty controlling her emotions, and has problems self monitoring and regulating her responses (Khan, Baguley, & Cameron, 2003). This interferes with her learning of new skills, or with the performance of tasks which require delayed responses. For instance she can be withdrawn and not do anything because she is depressed one day, and the next day she would frenetically start various projects only to leave them unfinished.

Devoid of appropriate support and cueing, Betty would withdraw, isolate herself and binge eat. Her bingeing episodes are normally triggered by depressive automatic negative thoughts such as “everyone has someone but me, why am I always alone?” During these times, Betty solely focuses on negative events and experiences. She resorts to rigidity in her thinking such that she does not see the positives. She would say “no one visits me in hospital ever”, not realizing that only yesterday her carers and mentor paid her a visit. Or she would say she has no friends, when in reality she does have people around her who care for her and want to be her friend. During the intervention, Betty was encouraged to write a list of her strengths and these included items such as “I have friends, Suzie, Jamie, Bryan are my friends,” or “people do care about me, mum and dad are always there when I need them”. When she was depressed, or knew she would slip into her destructive bingeing pattern, Betty would reach for her list and her negative thoughts would be challenged by her own written evidence.

Executive functions

Betty often wishes to carry out plans quickly and effectively, but is poorly organized and devoid of structure she cannot carry out the simplest plan. For example, she might have to buy milk but would not write it down on her shopping list. She would then run out to the shop straight away only to return and realize she is missing another ingredient. Observation reveals that Betty is often poorly motivated, largely because she is often depressed. On the DEX Betty scored highly on item 10 which was (“I really want to do something one minute, but couldn't care less about it the next “). This item measures variable motivation which is a difficulty Betty faces. For instance, she became really excited and started planning a dinner party, inviting 10 of her friends. When people replied they could not make it, or Betty could not find a recipe for

something she wants to cook, she became disinterested in the whole event. She would then respond by cancelling the party and sending out depressed messages such as “I can’t be bothered with the whole thing; no one seems to care about it but me”.

However, with the right cues, and when planned activities are presented to her, Betty’s motivation is enhanced. This motivation difficulty might be in part due to Betty’s problem with working memory. Effective working memory is seen as part of extended consciousness (remembering the past and anticipating the future) which makes the planning of events possible (Damasio, 2000, p 112). Due to consistent cueing and rewarding interaction, Betty learns to anticipate events and as a result, she demonstrates an improvement in her planning and task completion skills. This difficulty was also apparent on her scores on question 4 of the DEX (“I have difficulty thinking ahead or planning for the future”) which measured planning problems. For instance, she is often reminded of her wish to write poetry and is motivated verbally with comments such as “you really have a flair for writing” or “that’s a beautiful poem Betty”. This would then encourage Betty to persist at finishing her poem or help her plan writing another one. In addition, teaching and guidance on a one to one basis, governed by the principles of errorless learning which is structured and organized to nurture confidence, is required in order for Betty to be successful at planning and completing tasks (Kessels & Haan, 2003; Rees, 2005a).

Conclusion and Summary

Betty has a vivacious, bold and charismatic personality. She is capable of displaying resilient behaviour, and using her strengths. For instance she would use her personality to help her make new friends. However, she constantly has to struggle to manage her depression and mood states. She has bouts of productivity devoid of negative moods where she would engage in

social activities such as going out with friends and attending her brain injury rehabilitation workshops. Her life would be organized around her son and her socializing which are two crucial aspects of her motivation. She would find interesting things for her and David to do together and this would help reinforce her positive mood. However, this would not last long and a small trigger, normally the lack of having anything rewarding planned such as meetings with friends, would send her back into depression. Her resilience is heavily dependent on her mood and when she is not depressed then she sees herself as being resilient. Her executive functioning difficulties along with her short term memory problems also hinder her from achieving all that she wants to do. Her resilience is “brittle” and needs support, cueing and frequent encouragement before she displays persistent signs of resilient behaviour.

5.1.4 Peter

“To have this illness and not feel anything, that’s not living”

Peter was only 19 years old when he first experienced symptoms of MS. He had diplopia or double vision which lasted for about a week. Seven years after the first attack Peter once again experienced vision problems and was diagnosed as having scotoma (a blind spot in his left eye). Soon after, he experienced extreme pain and weakness in his legs. At the time of these symptoms Peter was employed as an aircraft engineer working in a highly competitive and challenging environment. His symptoms lasted for a few weeks and went into remission for another couple of years. His career was soaring and he was achieving positive results at work. For instance he was given more and more challenging tasks which required technical and leadership skills. This changed one morning when Peter woke up and his eyesight problems returned. He also had trouble walking and his balance was off which meant Peter kept tripping and falling over. It was at this point that he was diagnosed as having Relapse Remitting Multiple Sclerosis.

At the time of diagnosis, Peter lived in the Northern Territory which had high humidity and much sun exposure. To manage his MS symptoms, Peter decided to move to Adelaide where the humidity is lower. He also modified his diet to include more vegetables, less animal fat and fish oil (Schwarz & Leweling, 2005). Although research has yet to find a correlation between diet and MS, Peter decided to change his eating habits to become more healthy and has found his energy levels increase when he does this. He also spoke to his managers at work and they decided together that the best thing for Peter to do would be to work in the office and not out in the field anymore. Peter used to be in charge of servicing and maintenance of aircrafts as they came in the hanger. However, he was allowed to do paper work and organize aircraft

maintenance on the computer instead. This worked for him until a few years ago when his eyesight deteriorated and Peter decided to leave work before he hurt himself or those around him (Kornblith, LaRocca, & Baum, 1986; LaRocca, 1995).

Peter is 45 years old and has also lost his mobility and ability to walk. His legs became weak especially his left leg and he has problems standing and getting in and out of the bath. He has to rely on a gofer to get around and for him the loss of his job and his ability to walk and drive were the “worst thing about having MS” (McReynolds, Koch, & Rumrill, 1999).

McReynolds, Koch and Rumrill have found that people with MS often experience a devastating loss, in particular when they compare their pre- and post-illness functional levels. In the case of Peter, there is a greater feeling of loss, as he experienced high levels of success and productivity at work prior to the onset of MS.

Peter was married in 2005 after going out with Rena for 4 years. Rena met Peter seven years ago around the time he was diagnosed with MS. She was very supportive of his illness. She took over the role as provider, worked overtime to sustain their lifestyle and would help him with his self care such as bathing, when he couldn't do it himself. However, since his early retirement and his deteriorating health, Peter and Rena's marriage is “on the rocks”. They fight constantly and this is a major area of concern for Peter.

Having MS and dealing with unemployment is a traumatizing time in his life. Peter lost his independence and in his words his “sense of manhood.” His role as a provider was suddenly reversed and Rena had to work overtime to support them financially. Peter resented the fact that Rena had to undergo so much stress at work only to return home to a “needy man”. Peter would do all he could to contribute as an equal partner in the relationship. For instance he would ensure the house is neat, pay the bills, attend his medical checkups and monitor his medication.

These increased responsibilities on both Peter and Rena imposed a strain on their relationship. For individuals like Peter who were able to “function at highly independent levels” prior to his diagnosis, the increased need to rely on others is a major cause of distress (McReynolds et al., 1999). Similarly for Rena, managing her husband’s disability along with being able to cope with her own personal issues was difficult and she was experiencing extreme stress and frustration. These significant changes in the dynamics of their relationship triggered a variety of emotional and behavioural responses. For instance they were both angry, depressed, faced considerable anxiety and guilt and more importantly resented the other for causing these problems (Livneh & Antonak, 1997).

Peter also suffers from reactive depression and has suicidal thoughts. He has a score of 24 on the Beck Depression Inventory II indicating moderate depression (Beck, 1996). Depression for Peter is characterized by:

- Depressed mood most of the day, nearly every day
- Diminished interest or pleasure in activities
- Fatigue
- Diminished ability to think or concentrate
- Feelings of worthlessness or guilt
- Suicidal ideation or recurrent thoughts of death (DSM- IV-TR criteria for major depressive episode)

During periods of depression, Peter would not get out of bed and would rarely leave the comfort of his home. He would not interact with anyone, would not answer phone calls, and would isolate himself from family and friends. He would get extremely irritable and fatigued.

This fatigue is worst when he is depressed as opposed to fatigue due to MS (Mohr & Cox, 2001). Peter would feel drained, and extremely exhausted. Along with thoughts such as, “I am not man enough”, “I can’t do this anymore”, Peter would sometimes think that killing himself is a way to escape his life and to “make everyone else’s life easier”.

He finds it hard to control his temper especially when he is with Rena and regrets his behaviour after the outbursts. He would shout and react to the slightest provocation and then be extremely regretful and apologetic. Research has shown that anger is an appropriate response to an exasperating illness (Mohr & Cox, 2001). However, in Peter’s case his anger was not only directed at himself but at Rena and this fuelled his anxiety and depression as well as his apprehension. The triggers of his anxiety, anger and depression appeared to be his perception that he could not control the stressor. It was a sense of uncontrollability which often led to Peter feeling anxious or depressed. For instance when Rena comes home and finds him struggling to cook dinner because he can’t stand long enough to complete cooking, her efforts to help him are met by a temper outburst. Peter is not really angry at her, rather he is angry at himself and the fact that he cannot control the nature of his MS. He reports that some days just the thought of not knowing what is next in terms of the progression of his illness gets him so down, that killing himself seems to be his only solution.

At the other end of the continuum, when Peter is able to evaluate his options, to plan his course of action ahead of time and to make sure he has sufficient resources to accomplish his tasks, resilient behaviours emerge. He is able to write down his shopping list and buy the groceries he needs to prepare dinner. He cooks some dishes ahead of time to avoid fatigue and is then able to successfully cook dinner in time Rena comes home. The level of conflict between them is lessened, and Peter does not get so angry with himself or with Rena.

Peter also reported slight memory problems and wanted to make sure that his memory was not affected by MS. Peter was referred to a neuropsychologist with the MS society and was found to have normal memory. A review of his neuropsychological assessment showed that he scored average on the Weschler Memory Scale (Wechsler, 1997).

During the intervention period, Peter was experiencing difficulty with his bladder and needed to self catheterize. Self catheterization was painful for him and he had to try many times before he was successful. The whole experience of going to the doctor and being in hospital to learn how to catheterize was embarrassing and shameful. Although he didn't discuss it directly, he did hint that his sexual relationship was affected and that both he and Rena were dissatisfied and unfulfilled with their marriage. Lack of fulfilment and less satisfaction with their social relationships, marital relationships, and their sex lives is observed to occur frequently in people with MS (McCabe & Di Battista, 2004). As a result, they were both frustrated, and unable to communicate effectively with one another.

For Peter this only added to his sense of loss and produced immense anxiety. He didn't want to burden Rena with his problems as he felt that she had enough to deal with. For this reason, Rena was not included in the meetings or intervention session. He also constantly worried about how his illness is affecting Rena and had constant negative thoughts which fuelled his depression and suicidal ideation (Nortvedt et al., 2001). He felt embarrassed and ashamed and often felt that he "failed as man".

However, Peter was highly committed to working on his marriage, and managing his MS in any way possible. He sought the support of a counsellor and social worker from the MS society. He also maintained a close relationship with his neurologist and this was a crucial factor

for him in managing his illness. Peter explained that having a neurologist who understood what he was going through and who empathized gave him confidence and helped him remain hopeful.

Protective Factors and Strengths

Despite the struggles and hardship Peter faces on a daily basis, he is incredibly resilient and has a warm and open disposition. He scored highly on the Resilience Scale with a score of 148 pre intervention. His strengths are shown in the diagram below.



Figure 5.13 Peter's protective factors and strengths

Peter was often worried about his relationship with Rena as they appeared to be having a lot of arguments lately. He was also concerned about his memory and thought that he was “losing it”.

Nature of the Intervention

The intervention took place in Peter’s home and lasted between 1 to 2 hours per visit. During this time, Peter wanted to talk through his emotional difficulties, particularly those relating to Rena. He also wanted to learn how to do relaxation exercises and this was something which was practiced regularly during sessions. Peter was always ready and prepared for his sessions. He regularly wrote down issues which were worrying him throughout the week and any ideas or thoughts he wanted to share. For instance, he wrote down wanting to talk about having someone accompany him to a meeting with his doctor as he didn’t want Rena going with him.

There was a period where he experienced depression and this persisted for approximately three months. It was triggered by constant fights with Rena and Peter was overwhelmed, worried that his marriage was coming to an end. The sessions were then focused on talking through doubts, fears and concerns Peter had. A significant level of trust, and genuine openness was achieved between Peter and the researcher (Rogers, 1995).

Peter did not require much help with his executive functioning and most of the sessions were spent on working out ways he could improve his relationship with Rena. Through the course of the intervention, Peter and Rena separated and did not continue living together. He was upset and disappointed but the separation was mutually agreed upon and Peter was convinced that it was the best outcome for both of them at that time. He was determined to move on and poured his energy into how he could re build his life with MS as a part of this.

During this time, Peter rated his general wellbeing as moderate (scores between 30-70) to high (scores between 70-100). This was measured on the Outcome Rating Scale. The figure shows ratings taken during a time when Peter was not depressed and reported generally good wellbeing. He says “I’m okay, could be better but I’m happy with where I’m at now”. Peter’s ORS scoring on four occasions throughout the intervention is presented in Figure 5.14 below.

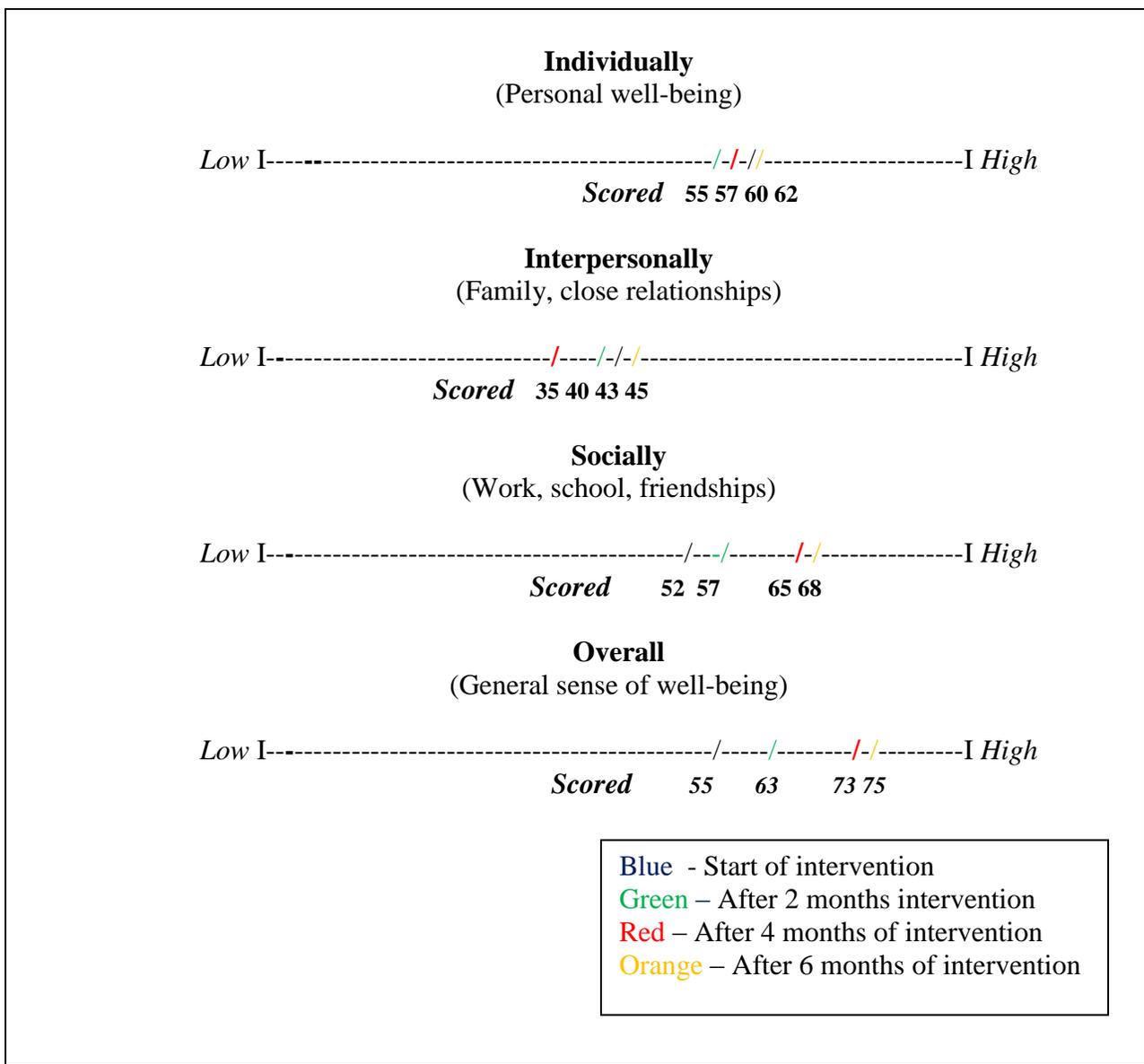


Figure 5.14 Peter’s Outcome Rating Scale scoring at 0, 2, 4 and 6 months of the intervention

Peter scored low on the interpersonal item on the ORS. This reflected the break up in his marriage to Rena. He was extremely hurt and was going through a rough period of separation from Rena. He was also adjusting to living alone, and coping by himself. Previously he had relied heavily on Rena. Immobilized in his wheelchair, Peter spends endless hours trying to complete the household chores and cooking. Tasks which previously took him a couple of hours now take days. His companion, his dog, witnesses his struggles. Struggles which he desperate tries to hide from Rena. He fights with the demons within himself daily, trying to regain independence. He loathes the idea of having to rely on or “burden” Rena with his care. He is a man with a great sense of pride. Pride he experiences from accomplishing his daily care and chores without help from other. Despite this, he knew the importance of seeking help and support when needed. He still maintained close relationships with his ex-working colleagues and made efforts to see them when he could. He also had regular visits from his social worker. These social interactions aided in his sense of maintaining his general wellbeing. His overall scores on the ORS were in the medium to high range (see orange lines in the figure above).

Goals which Peter and the researcher worked on are outlined below. Peter’s long term goals were identified in consultation with the researcher and are written in the form of therapist goals. These goals are broken down into short term objectives and participant goals

Long Term Goals

- Recognize, acknowledge, and manage feelings of depression (for instance, be aware of negative thoughts and emotions).

- Develop healthy cognitive patterns and beliefs about self that lead to easing and help prevent the relapse of depression symptoms (replace negative thoughts such as “I am not good enough”, with “I am good enough”).
- Develop strong interpersonal relationships that lead to alleviation and help prevent the relapse of depressive symptoms (build and maintain friendships with people in his social network).
- Learn and implement problem solving skills (together problem solving issues he has in his relationship with his wife).

Table 5.4 *Peter's short term objectives, therapeutic intervention and goals*

Short term objectives	Therapeutic Intervention	Peter's Goal Attainment Scaling Goals and Scores
Verbally identify, if possible, the causes of depressed mood.	Suggest the client make a list of what he/she is depressed about; go through list together.	+ 2 I write in my list and record negative thoughts when they occur daily
Verbalize any history of suicide attempts and any current suicidal urges.	Encourage the client to share his/her feelings of depression in order to elucidate them and gain insight as to cause. Investigate the client's history and current state of suicidal urges and behaviour	+2 I am able to express opinions and feelings more than two times per week 90–100% of the time
Identify important people in your life, past and present, and describe the quality, good and bad, of those relationships.	Keep a journal and record of thoughts especially those related to relationship with Rena.	+1 I write in my journal every other day most of my negative thoughts and fights I have had 60 % of the time
Learn and implement problem-solving and/or conflict resolution skills to resolve interpersonal problems.	Aid the client in developing coping strategies (e.g., more physical exercise, less self focus, increased social participation, more assertiveness) reinforce success. Help the client manage depression related to relationship problems through the use of reassurance and support, explanation of cognitive and affective triggers that start conflicts, and active problem-solving	+2 I will use my coping strategies and feel depressed less than 10 % of the time

Goal Attainment Scaling

Peter achieved all the goals he set for himself during the intervention. His complaints regarding his memory problems were not part of the intervention because he felt that he was “overly paranoid” and that his claims were not founded. A neuropsychological assessment confirmed that Peter did not have memory problems. Peter’s goals were realistic and he felt that he achieved them successfully which in turned reinforced his positive believes about himself and his abilities. An example of how one of his goals was stated is as follows.

Example 1

- + 2 I write in my list and record negative thoughts when they occur daily
- + 1 I write in my list and record negative thoughts when they every other day
- 0 I write in my list and record negative thoughts when I remember every week
- 1 I seldom write in my list and record negative thoughts
- 2 I rarely write in my list and record my negative thoughts

Assessment Scores

Peter scored very highly on the Resilience Scale at baseline (148) and these scores improved post intervention (159) and (150) at follow up. His DEX scores were low indicating high executive function and did not vary significantly. They were (29) at baseline and (28) post intervention and (31) at follow up. A complete discussion of his resilience and Executive Functioning are given below.

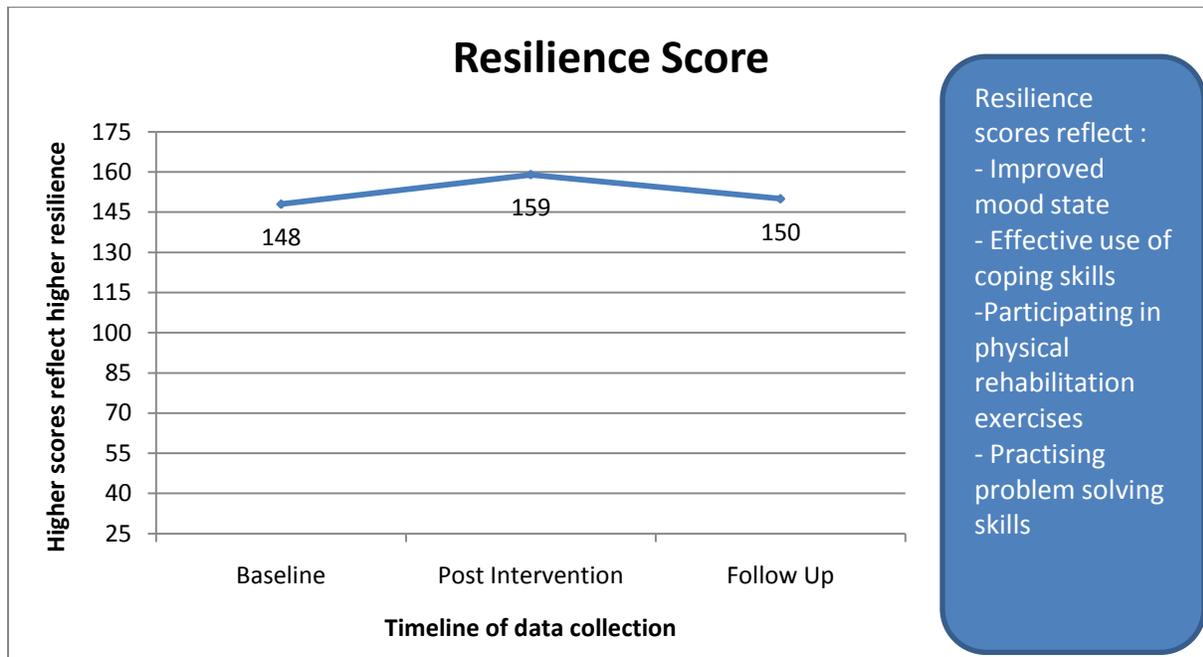


Figure 5.15 Peter's Resilience Scale Scores

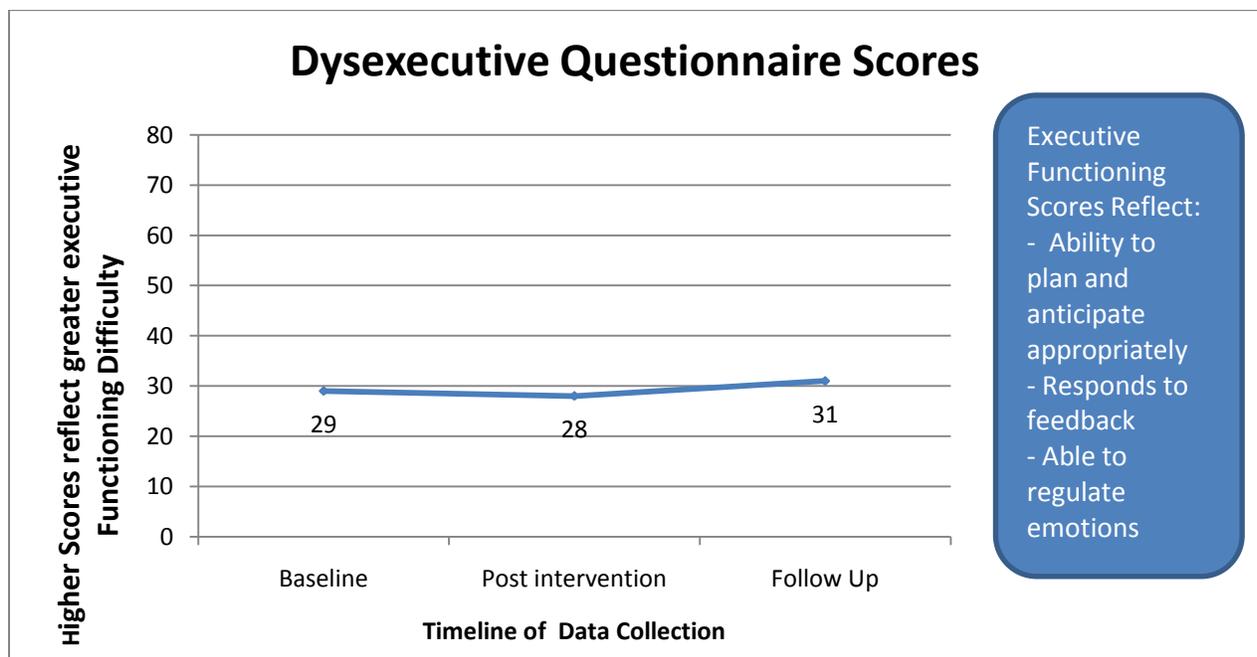


Figure 5.16 Peter's Dysexecutive Questionnaire Scores

Resilience

Peter has an easy going temperament and is well liked by those around him. He makes friends easily and has a good social network. He forms close relationships with friends and his care workers. However, despite his easy going nature, Peter has in recent years found it difficult to make new friends. As a person experiences personal decline following diagnosis of MS, it is especially difficult for him to make new friends (Hakim et al., 2000). Consequently, he has been prone to episodes of depression and has isolated himself with the exception of allowing a few people to see him on a regular basis. His mood state has been unstable and he has had suicidal ideations on more than one occasion.

His relationship with Rena has been affected as a result and throughout the intervention his main concern was how he could be a better partner for her. For instance, he had to go to the hospital to self catheterize and this was not only embarrassing but a little intimidating for him. Upon suggesting he gets someone to accompany him, Peter refused saying he didn't want to burden Rena anymore than he already has. He explained that she had troubles of her own and he could not bear to see her suffer any more than necessary because of his illness. He decided to get a volunteer from the MS society to go with him to the medical appointment showing his ability to be independent without relying on Rena.

In order for Rena to be able to cope better with Peter's disability and increased demand on her, she was provided with emotional and psychological support from a psychologist and friends. Peter was frequently given positive encouragement in relation to working on his goals, for example "you did well Peter sorting out your bills". He was also provided with help from the MS society to address issues relating to transport, physiotherapy equipment to ease mobility problems and access to the MS society healthcare team. These supports enabled both Rena and

Peter to have more time individually to deal with their marriage issues, and also allowed them relief from some of their daily burdens (McReynolds et al., 1999).

Peter is a very determined man and although at times gets depressed, he is determined not to let his MS defeat his spirit. He is happy on his own during the day and finds activities such as yoga, reading, paying the bills and doing housework to keep him occupied. He takes things in stride often saying “to have this illness and not feel anything is not living”. He accepts that MS is going to be an ongoing part of his life and that he will continue to struggle with his health and “failing body”. His courage and strength are an inspiration to all who know him and he plans to keep fighting MS one day at a time.

Executive Functioning

Peter’s DEX scores showed that he had high executive functioning and he attributed this to his background as an engineer. He is a very meticulous and logical person with an incredible memory for numbers and digits. He excels in mathematical problems and loves to do anything in relation to numbers. He is orderly in his daily living, keeping lists of things to do and reminders of events and occasions. He plans ahead and thinks through his decisions thoroughly before acting. For example, when things with Rena were not going to well, Peter decided it was better for them to take a break and he had come up with a living arrangement that suited them both. They decided together that it would be best if Rena moved out for a few months whilst they worked on their problems. He thought of not only himself but of Rena as well and suitable arrangements were made accordingly.

Peter is also able to plan and anticipate future events in relation to his present circumstances. For instance he now knows that he has to plan for uncertainties and although this

concept seemed discouraging at first, Peter soon realized it was crucial to his wellbeing. This is reflected in his low score on the DEX question 7 indicating little or no difficulties in planning. “I have difficulty realizing the extent of my problems and am unrealistic about the future”. This question measures lack of insight and social awareness. For example, Peter knows that his eyesight is getting worse and instead of waiting until he completely loses his sight, he has sought help and has obtained equipment to help him see such as a big screen monitor and magnifying glasses.

When he is not depressed, Peter is able to self analyze and regulate his thoughts and behaviour appropriately. For instance, he is insightful and knows when to ask for help. He is self aware and learns from consequences. If he can't bathe himself anymore, he asks for a male carer who can assist him in a respectable manner. He is self critical but also responds to feedback and incorporates positive suggestions which he thinks are useful. Examples include being able to see how his illness is affecting Rena but also accepting that there are some things such as changing the way she deals with stress which are out of his control.

Peter's motivation enabled him to successfully accomplish tasks he set. He was able to initiate, put into action and carry through on most plans he made. He would call up a friend to help him put in a new ramp, or have someone come over just to be with him when he saw himself falling into depression. His wider social network also proved to be a great source of support for him when his relationship with Rena could no longer sustain him. This showed that he was capable of maintaining friendships (perceiving social cues) and also that he could regulate social and emotional behaviour in various settings.

Conclusion and Summary

In summation, Peter is a highly resilient individual who is facing considerable stress and challenges. His diagnosis of MS shocked him and as a result affects every aspect of his personal, social, domestic and vocational life. He overcomes most challenges with triumph and maintains a positive disposition. He is insightful and optimistic about the future and given the nature of his disability, has found ways to compensate and deal with his adversities. He has high resilience with scores of (148) at baseline, (159) post intervention and (150) at follow up. Similarly, his executive functioning also did not show much fluctuation with low scores of (29), (28) and (31) respectively.

He maintains strong relationships with his friends and family, and this in turn reinforces and strengthens his social networks, networks which are crucial in the building of resilience and the strengthening of executive functioning for Peter. He continues to have a respectable relationship with Rena. They talk over the phone and have plans to attend joint counselling sessions if needed. His ability to anticipate, plan for the future and remain self aware is what he is relying on to get him through difficult times and it has proved successful for him in the past. His courage, realistic expectations and determination to “not let MS rob him of his life” have put him on the path of accepting and managing his illness the best he can.

5.1.5 Rob

“Stuck in the shadows of the past”

Rob is a man in his late forties with diagnosed relapse remitting Multiple Sclerosis. He was originally from a small mining town in Northern Australia and moved to Adelaide 30 years ago, when he was 19. As a young man Rob worked in the mines and recalled “earning a lot of money at an early age”. He was a risk taker and loved taking on shifts which were termed “risky” in the mines. He has a big motorcycle which he practiced and did stunts with. Once he climbed a 15 foot billboard to declare his love for his girlfriend at that time. He loved the thrill and adrenaline rush he got from his risk taking behaviour and as a result was well known in his community as a dare devil.

Rob came from a family of women, where he was raised by his mother and has two older sisters. His mother worked hard to raise her three children alone. His father left them when he was three years old. Rob’s mother struggled raising a son and often told Rob that she didn’t know how to raise a son. For instance, Rob used to be dressed in his sister’s hand me down clothes and constantly sought his mother’s approval.

At 17 Rob had a girlfriend whom he was going to propose to and he would lavish her with expensive gifts. However, Rob had a secret he wanted to share with her before they got married and what he told her affects every aspect of his life. Rob has a fascination with women’s under garments and would sometimes put them on for fun. During the intervention, he admitted that this behaviour had little to do with his sexuality and more to do with unresolved issues with his mother not knowing how to relate to him as a man.

Rob's girlfriend left him and he moved to Adelaide as a depressed and confused young man. He was employed as an electrician and would drown his pain in alcohol and promiscuous behaviour with multiple women.

It was during this time that Rob noticed pain and muscle spasms in his left leg. The pain lasted for a few weeks and Rob dismissed it as muscular aggravation. When the pain returned, it was more severe, this time lasting for 3 months and causing him mild paralysis. He went to the Doctor, tests were performed and he was diagnosed as having relapse remitting multiple sclerosis. Rob didn't know what that meant and he says "he didn't care". His grief over losing his girlfriend really affected him emotionally and he still talks about it as if it happened to him only yesterday.

Rob's grief along with his deteriorating health made it hard for him to sustain a job and he just "gave up on life". With help from his MS society social worker, Rob managed to buy a flat with his compensation money and lived there till about a year ago. He decided to sell the flat because he could not walk up the stairs and instead of using the money from the sale (which was minimal) to secure other housing, Rob spent it on alcohol, cigarettes and women. He currently lives alone in government housing.

Rob's personal appearance is messy, dirty and he doesn't bathe himself because he is now in a wheelchair and has minimal use of his hands. He cannot support himself long enough to shower without falling over and refuses to get help from paid support workers and carers. He feels ashamed and embarrassed about the way he looks and smells but is stubborn about not getting help.

He is constantly bullied in the community where teenagers throw eggs and rotten food at him and call him names. People take advantage of his vulnerability and break into his home. For

instance drunken girls broke into his room and Rob thought there were there to talk to him and be his friend. He only suspected something was amiss when the girls' boyfriends who were outside decided to come in. Lucky for him they were just having fun and didn't harm him or steal from him.

Rob lives from social security cheque to cheque. He is often found hungry, without much food for days until his next cheque arrives. He lives on tea and bread. He uses what money he has to buy alcohol and cigarettes. This behaviour correlates with periods of depression. When he is in a depressed mood state, his inability to buy food for himself is apparent. He becomes accustomed to relying on cigarettes and alcohol, whilst neglecting to buy food. Over time, this becomes a habit. Similarly, these behaviours of self neglect are also apparent when Rob is lonely. He has no other social interaction, apart from the occasional visits by his social worker. She to him is a lifeline, offering him help and support. Rob would benefit from a change in his current living arrangements. He would be better supported in a community housing facility, where someone other than his social worker monitors his daily activities, medication and routine. For instance, having pre planned activities in the home, where he is provided opportunities to interact with others will help break his cycle of loneliness.

Despite the "risks" he faces on a daily basis, there are certain factors which help "protect" Rob. These include his individual traits, members of his family and support from his community.

Protective Factors and Strengths

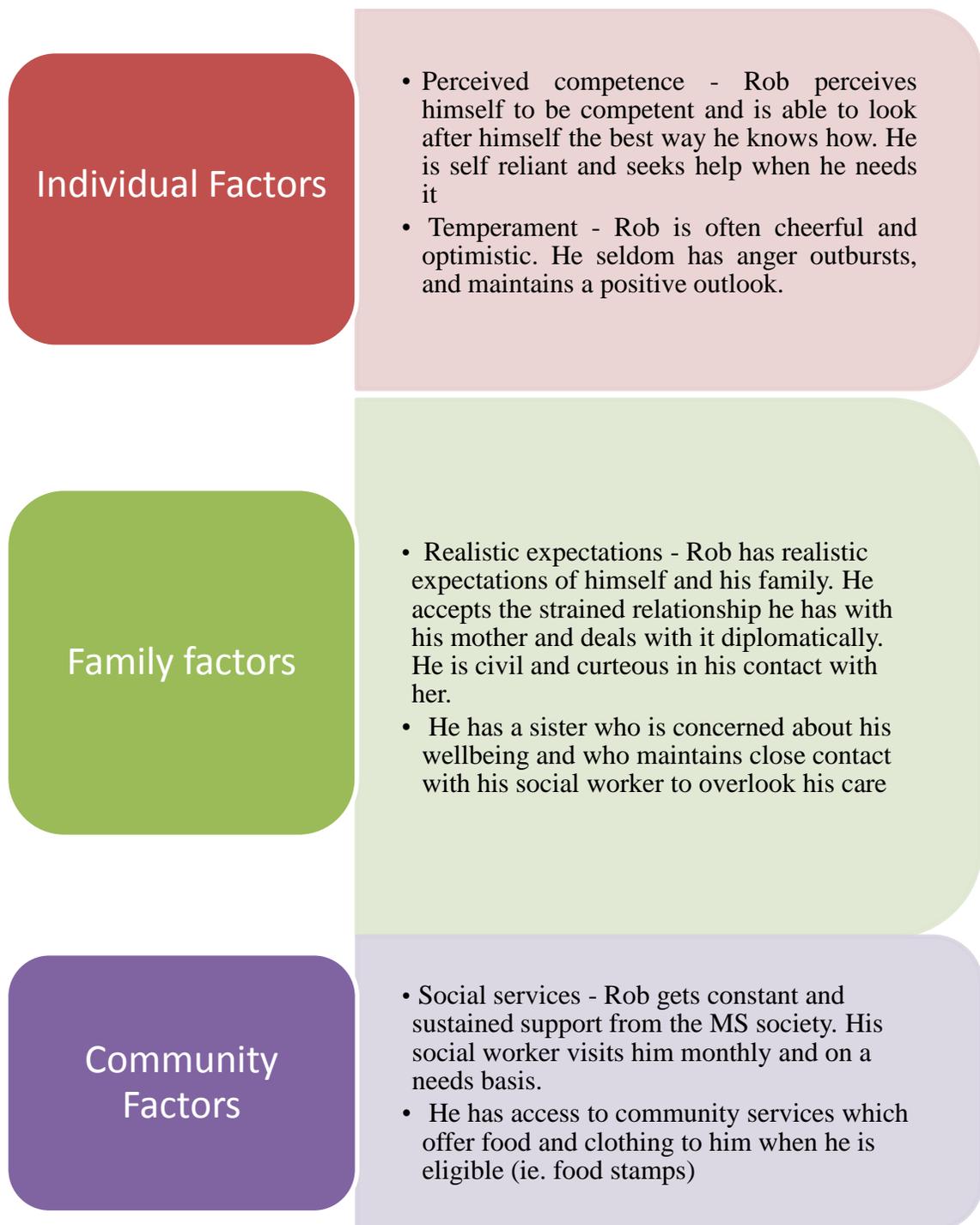


Figure 5.17 Rob's protective factors and strengths

Nature of the Intervention

The intervention took place in Rob's home. For most of the sessions, a social worker from the MS society accompanied the researcher. This was because Rob's home was a good distance away from the city, and Rob trusted and wanted his social worker present during the sessions. Once he developed a relationship of openness and trust, Rob was more comfortable sharing his personal history and present concerns (Kirschenbaum & Jourdan, 2005). He looked forward to the sessions and was always happy and eager to participate.

Rob scored himself highly every time on the Outcome Rating Scale. He perceived his life to be going well and rarely reported any problems or difficulties. This is due in part to him being "frozen in the past". He perceived his past to be a "tragic story of lost love", and based on this tragedy, his present circumstances 'didn't seem so bad'. He therefore scored high on almost all sessions. Rob's ORS scoring on four occasions throughout the intervention is presented in Figure 5.18 below.

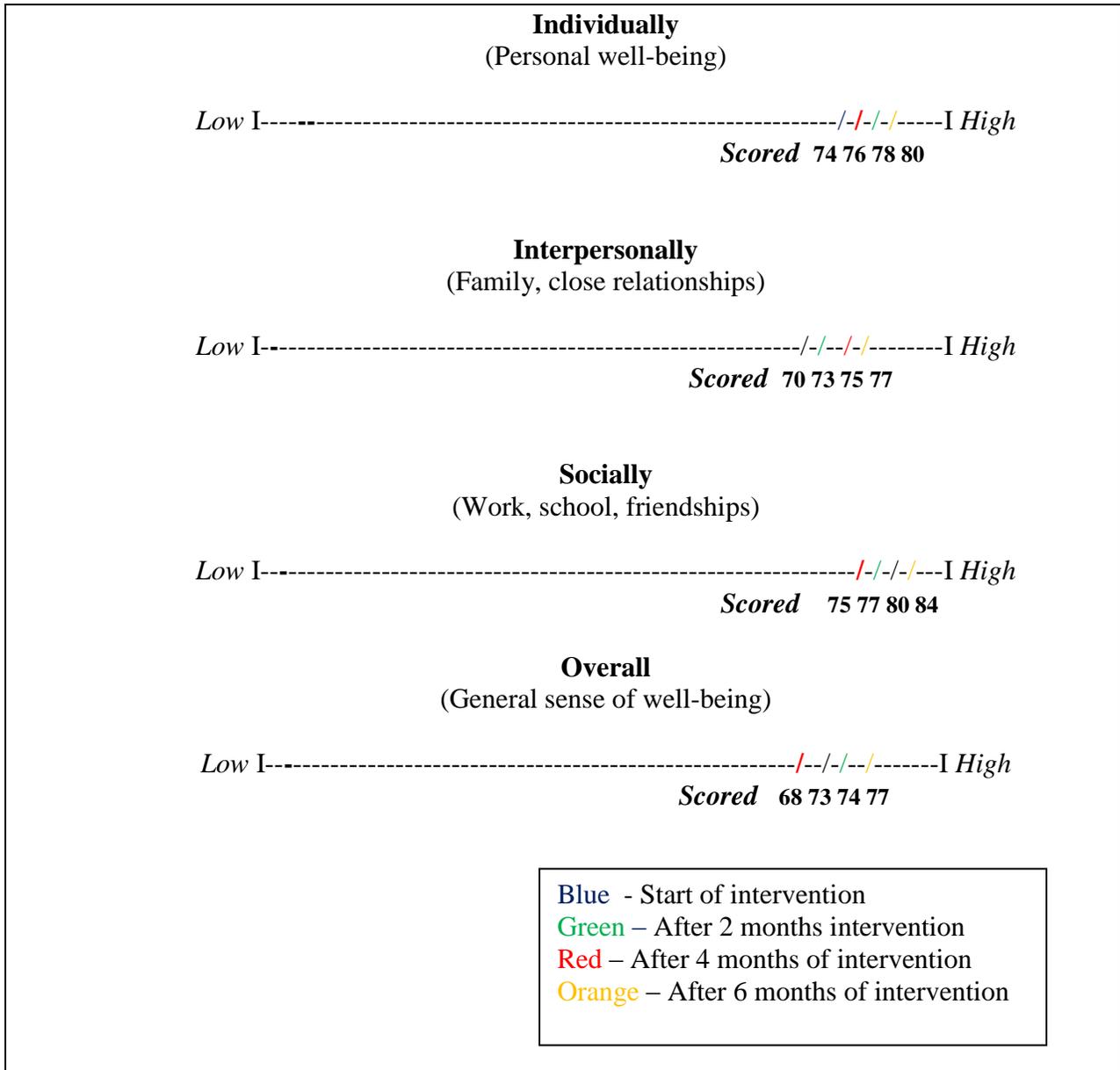


Figure 5.18 Rob’s Outcome Rating Scale scoring on 0, 2, 4 and 6 months of the intervention

Rob scored high (scores between 70-100) on all occasions of the ORS scoring for all items, except on one (score = 68). He reported generally being happy and of stable mood. He also scored high on an overall sense of well being. Rob was often ‘stuck in the past’, unable to break

away from the memories which still haunt him. These memories which have been briefly described earlier are related to a broken relationship he had with his girlfriend almost twenty years previously. He relives daily, memories of a time when he was happy and in a well paying job . Often vividly describing events as if they occurred only yesterday. His perceptions of his current reality are perhaps slightly inaccurate. He appears uninterested in his hygiene, self care and nutrition. To him, the present consists of merely existing so that he can fantasize about memories of a more pleasant time. This may account for his high scores on the ORS.

Together, the researcher and Rob developed long term goals for him to work on. Rob's long term goals were identified in consultation with the researcher and are written in the form of therapist goals. These goals are broken down into short term objectives and participant goals

Long-term Goals

- Develop an awareness of how childhood issues have affected and continue to affect his life.
(Discuss issues in an open and safe environment with the researcher).
- Encourage and promote healthy behaviour such as bathing daily, and improve self care.
(Develop skills needed to ensure he is capable of meeting own needs. For instance, help him develop a budget and allocate certain funds to food, and personal grooming items).

Table 5.5 Rob's short term objectives, therapeutic intervention and goals.

Short-Term Objectives	Therapeutic Interventions	Rob's Goal Attainment Scaling Goals and Scores
Identify and replace unrealistic expectations of the past relationship	Identify irrational beliefs and unrealistic expectations regarding relationships. Assist in adopting more realistic beliefs and expectations of others and of the relationship.	0 I will write down my negative thoughts when they occur 50 % of the time.
Narrate in detail the story of the current loss that is triggering symptoms.	Using empathy and compassion to encourage the client to retell in detail the story of his/her recent loss. Actively build the level of trust with the client in individual sessions through consistent eye contact, active listening, unconditional positive regard, and warm acceptance to help increase his ability to identify and express thoughts and feelings.	+1 I will describe my story with accuracy and honesty willingly during every meeting 60% of the time
Identify how the use of substances has aided the avoidance of feelings associated with the loss.	Assess the role that substance abuse has played as an escape for the client from the pain or guilt of loss.	-2 I will stop to think how alcohol is affecting my life before every drink 20 % of the time
Decrease statements and feelings of being responsible for the loss.	Confront the client's statements of responsibility for the loss and compare them to factual reality-based statements.	-1 I will write in my book when I start doubting myself or thinking about the past 20 % of the time
Attempt to follow through to completion simple sequential tasks.	Assign appropriate sequential tasks for the client to perform and redirect when needed so as to assess his cognitive abilities. For instance, get him to read the papers and then switch to make a cup of tea.	0 I will participate in the tasks set out for me and complete them 20% of the time

Goal Attainment Scaling

Although Rob was motivated to participate in the intervention, he lacked insight and was not aware of the poor conditions in which he was living. He knew he had Multiple Sclerosis and that he was on government social welfare to support himself. Apart from that Rob did not find his living arrangements untidy. He also seemed unconcerned by the fact that he was starving himself and using his money on alcohol. These behaviours were taking a toll on his health. Due to these factors, getting Rob to understand his behaviour was difficult and most of the sessions were spent on resolving grief he had from the past. An example of one of his goal is below.

Example 1

- + 2 I will stop to think how alcohol is affecting my life before every drink 75- 80 % of the time
- +1 I will stop to think how alcohol is affecting my life before every drink 65-70 % of the time
- 0 I will stop to think how alcohol is affecting my life before every drink 50-60 % of the time
- 1 I will stop to think how alcohol is affecting my life before every drink 30-40 % of the time
- 2 I will stop to think how alcohol is affecting my life before every drink 20 % of the time

Assessment scores

Rob, surprisingly, scored moderate in his assessments of resilience (134) and this score remained consistent post intervention (139). His executive functioning was in the average range (50) but improved post intervention (37). The figures below depict his assessment scores.

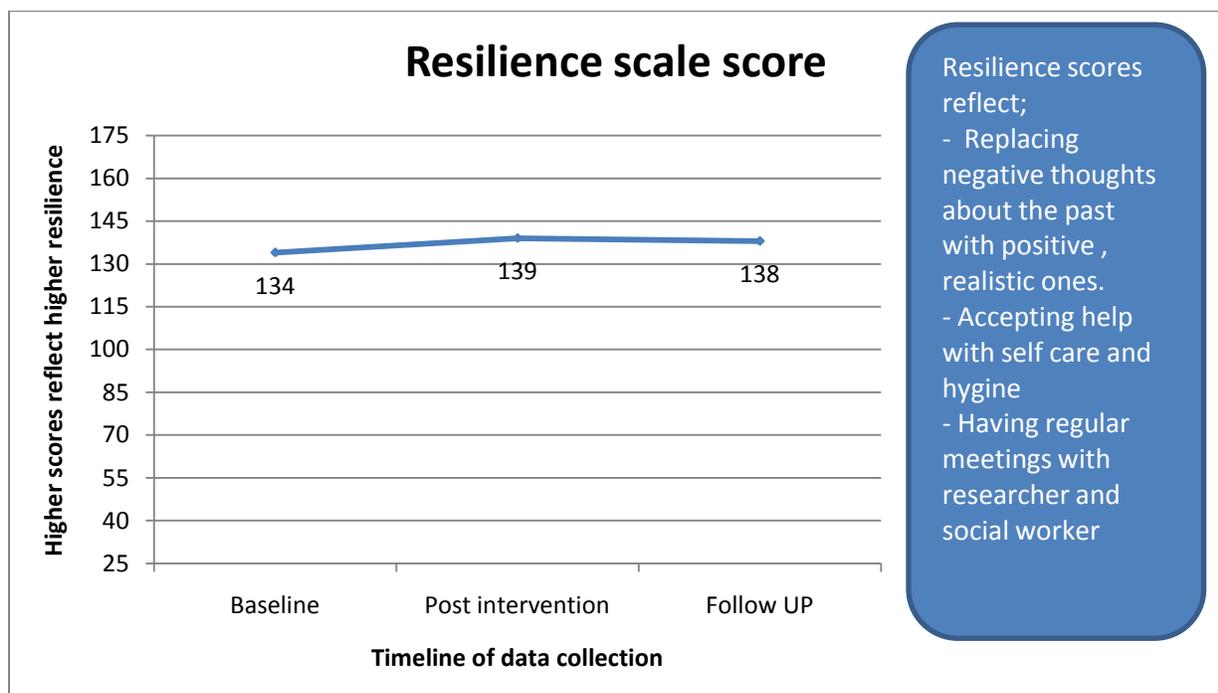


Figure 5.19 Rob's Resilience Scale scores

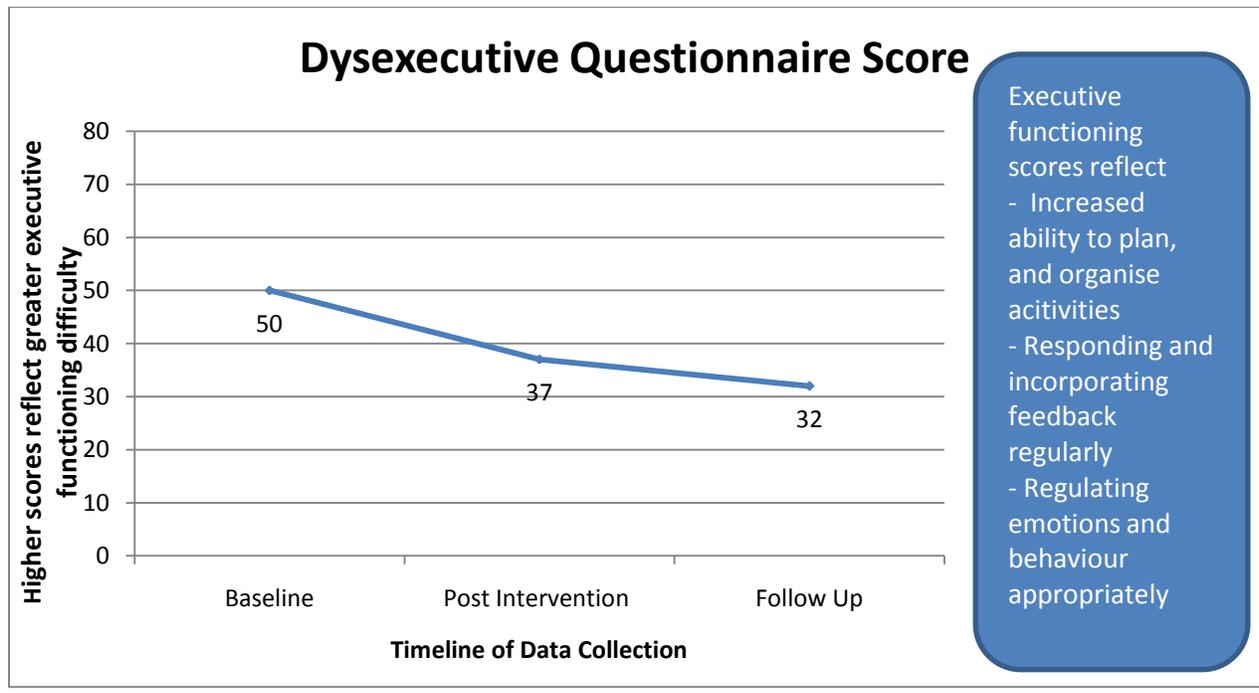


Figure 5.20 Rob's DEX scale scores

Resilience

Rob's resilience is highly fascinating and somewhat surprising. To the outside world, he appears dishevelled, messy and typically one would assume he is not generally resilient. He appears to be coping and struggling to keep afloat in his personal and daily life. However, Rob is fixated on his past. This prevents him from moving forward and he appears contented with his current situation. Given his circumstances and lack of willpower to move ahead, Rob is resilient in his own unique way. He is happy with his life and if questioned will say there is nothing wrong with the way he lives. He views himself as being resilient and observation over a prolonged period of time support this view. Resilience has been defined as "the ability to bounce back in the face of adversity" and Rob managed to bounce back every time he is faced with difficulty (Conner & Davidson, 2003). For instance, he has learnt to ignore people who bully him, and not react to their comments. In the past, he has resorted to violence and this resulted in him being taken into police custody. He learnt from his actions.

He manages one way or the other and is able to depend on himself in times of need. He is resourceful and is able to satisfy his basic needs. For instance he would buy a loaf of bread and eat that with tea for a whole week. When his finances permit, he would buy some meat in cans so that it would last him longer. He is determined to live the way he wants and does not let anyone tell him otherwise. He keeps interested in things by fixing old electrical appliances and watching television. He is banned from the local supermarket because he is not very good at using his gofer and would crash into aisles. However he manages to persuade people to buy him groceries when he needs them.

He smokes heavily and has used cigarettes and sometimes alcohol as a means of escaping his emotional pain. This has become habitual to Rob and he turns to substance abuse when he

can't cope or when he is bullied or feels ashamed (Passik, Kirsh, Donaghy, & Portenoy, 2006). He is especially vulnerable around women and can't seem to regulate his behaviour around them. Instead he is either overly courteous or suggestive and inappropriate. During the intervention, he expressed how relieved he was that he found someone who didn't judge him for his fetish but who could see the person he really was. That meant a lot to Rob and it improved his self esteem and appeared to alter slightly the way he looked at women.

He takes each day in stride and seldom wonders what the point of it all is. Denial is a strong feature of his behaviour and, for him, this seems to be adaptive. From his perspective he is resilient and therefore scores highly on his assessments. Observations from both the researcher and his social worker were in agreement that he is capable of resilient behaviour. For instance, he has warmth and he displayed it throughout the intervention. He has a good sense of humour and is able to laugh at himself and see the absurdity in most situations. He also is disciplined in that, if he decides upon something, he follows through with what is planned. For instance, when he needs to go to the doctor, he rings up to organise his appointment and then rings his social worker to arrange for him to be picked up and taken to the doctor's.

Rob's resilience was also heavily dependent on his emotional state (Tugade & Fredrickson, 2004). He is angry and depressed about his past and keeps reliving those good and bad moments again and again. He has not had a significant relationship since he broke up with his girlfriend, and continues to struggle relating to people especially women. These issues were worked upon in the intervention to a certain extent and Rob's motivation and outlook improved through the sessions. He experienced a cathartic effect just by sharing the burden he had carried along with him and the level of trust and openness demonstrated by the researcher and social

worker enabled him to feel valued. He did not experience any judgment, just unconditional positive regard and empathy (Kirschenbaum & Jourdan, 2005).

Executive Functioning

Rob scored within the average range on his executive functioning at baseline and he has problems with planning. He scored high on item 4 on the DEX which reports problems in planning, which was sensitive to his difficulties in planning and thinking ahead. As a result Rob gets easily fatigued and lethargic. For instance, he would attempt to go out to the shops in the middle of the afternoon, when his energy levels are low and he knows that he will get fatigued. Once he had to sit down and fell asleep on the bench outside the shop because he was too tired to go home.

Rob would also start doing something, only to get distracted and forget what he was doing. He scored high on item 18 of the DEX which measures distractibility. He would go for a walk on the beach, and get distracted by the traffic passing by. Sometimes he would stand on the side of the road wondering what he was doing there and unable to resume his task of going for a walk.

He has good mathematical skills and was always prompt at paying bills. When he wants to, he would plan his finances, allocate enough money to pay his gas, electricity and cable bills and still have some left over for food. He is proud of his intelligence especially in his ability to calculate finances and bills. This strength was reinforced throughout the intervention and thus enhanced his motivation to apply himself to other tasks. Role playing with Rob as an observer and the researcher performing offensive social behaviour such as swearing in public, or simply leaving the house dirty proved successful and Rob soon understood the impact his behaviour had

on those around him. He knew social rules and what he should do but just “couldn’t care less sometimes.” Consequently he scored himself highly on question 12 of the DEX which relates to having no concern for social rules.

With appropriate monitoring and cueing, Rob is aware of his hygiene and makes plans to go to the dentist, doctor and physiotherapist. He follows through on these plans and once motivated, his self care improved and he even now allows carers to come into his home.

Conclusion and Summary

Rob’s case demonstrates that resilience is a construct which can be nurtured and taught. For instance Rob learnt how to cope with stress, particularly that of his past relationship, through the intervention. He sought help when he needed it, and was never ashamed to ask for assistance. He would frequently seek assistance when he was finding it difficult to manage his daily needs such as ringing his MS social worker and requesting her to plan a visit. He has good executive functioning skills such that he is able to plan his activities, and manage his finances well enough to pay his bills on time. He ensures that he always has basic amenities such as water and electricity. He looks forward to and anticipates his visits to the local shops and this aids his forward planning abilities. Rob also responds well to feedback and would practice suggestions. For instance, he would practice budgeting and buying food on a weekly basis. He is a ‘survivor’ and despite his living conditions, he appears resilient and copes to the best of his abilities.

5.1.6 Sarah

“Know that it's your decisions, and not your conditions, that determine your destiny”

Sarah is a 32 year old, energetic, fun loving and a very outgoing young woman. Fifteen years ago she was participating in a triathlon when she realized that her performance was not as good as normal and that something was not right. She had just hiked up a mountain and thought that it was fatigue due to muscle strain so she dismissed it. The next morning, she woke up and realized that she couldn't stand and kept falling over. She hiked back down still falling and was sent to the hospital. Five days later, she was diagnosed with Relapse Remitting Multiple Sclerosis. Sarah had never heard of MS and it was a traumatic time in her life. Her legs were weak but apart from that she had none of the symptoms of MS. Looking back she realized she had experienced a period where her vision was blurred but this had only lasted a few days and never reoccurred. She read up about the illness and found out that she might eventually lose mobility in her legs (Olney, 2005). She decided that, instead of living in denial and crying over her losses, she would instead make the most use of her strengths and abilities while she could. She was determined to not let MS control her life and she managed to complete her university degree, and to travel to exotic countries which were the two main passions in her life at the time.

She returned to Australia after spending time abroad and started working as a health care professional. However after five years, the quality of her work was declining and she took twice as long to complete reports and assessments. She had to put in more hours at work to finish her daily tasks and this was increasingly taxing on her health. She decided to stop work as she believed that her clients deserved someone more capable and in retrospect she

feels that she was too hard on herself. However her decision to stop work didn't stop her from doing the things she loves. She took up art and joined many support groups and community projects. Her days are filled with activity and she leads a rich and meaningful life. Meaning in life for Sarah is found in her illness. She uses her experiences with MS to help others going through the same things as she is. Her negative experiences are transformed into personal development and satisfaction (Wagnild & Young, 1990). One way in which she achieved this perspective was through acquiring knowledge of her illness. This is seen as a method which increases self awareness and has been defined as the "knowledge of one's illness" (Toglia & Kirk, 2000, p. 57). Therefore an important aspect of Sarah's reaction to her circumstances is her level of self-awareness regarding her difficulties in everyday life. She recognizes and appreciates her limitations, sets realistic goals, and actively participates in rehabilitation (Ownsworth, McFarland, & Young, 2000).

Sarah learnt early on that isolation and depression were significant themes in people's lives and made conscious efforts to avoid falling into those traps (Mohr et al., 1999). She ensured that she surrounded herself with positive and supportive people. Forward thinking and planning ahead were crucial aspects of Sarah's life. For instance when her walking abilities deteriorated, and Sarah would constantly lose balance she acknowledged that in a few months, she wouldn't be able to get up the stairs in her home. She knew that the wait to get a ramp fixed was about six months and therefore started the process of getting a ramp fitted for her home as soon as possible. She says planning ahead saves her the trauma of realizing she can't do things and not having a solution at hand.

Sarah used to advocate for other people with disability and a big change for her was to advocate for herself. She now spends time writing letters to service providers and finding

ways to cope with her increasing disability. She has an amazingly positive outlook on life which permeates through everything that she does. For instance, being in a wheelchair is seen as a major loss of independence for most. Sarah however chooses to see it as a benefit because it allows her greater mobility. She can move around easily in a gopher or cabs as opposed to not being able to walk or be bed ridden. She jokes that this way she can drink and not worry about driving and that she can actually look out the window and enjoy the scenery.

It has only been the past three years that Sarah has been using a wheelchair and she is now finding mobility a big issue. She has problems getting in and out of her wheelchair and thinks she can do things but physically cannot. For example she often stands up without realizing the extent of the weakness in her legs. She, like many other MS clients suffers from occasional bouts of depression as the reality of her MS hits. It is during these times that she isolates herself and does not have the energy to do the things she likes doing, or keep in touch with friends. She also reports finding it difficult to have relationships with men. However this characteristic was present even before she had MS symptoms. She feels inadequate in romantic relationships although she has no problems relating and forming friendships. She sometimes feels like she missed out on getting married and especially feels sad when she realizes that she may never have children of her own.

Protective Factors and Strengths

Sarah's strengths and protective factors are described below. These were identified in consultation with Sarah.

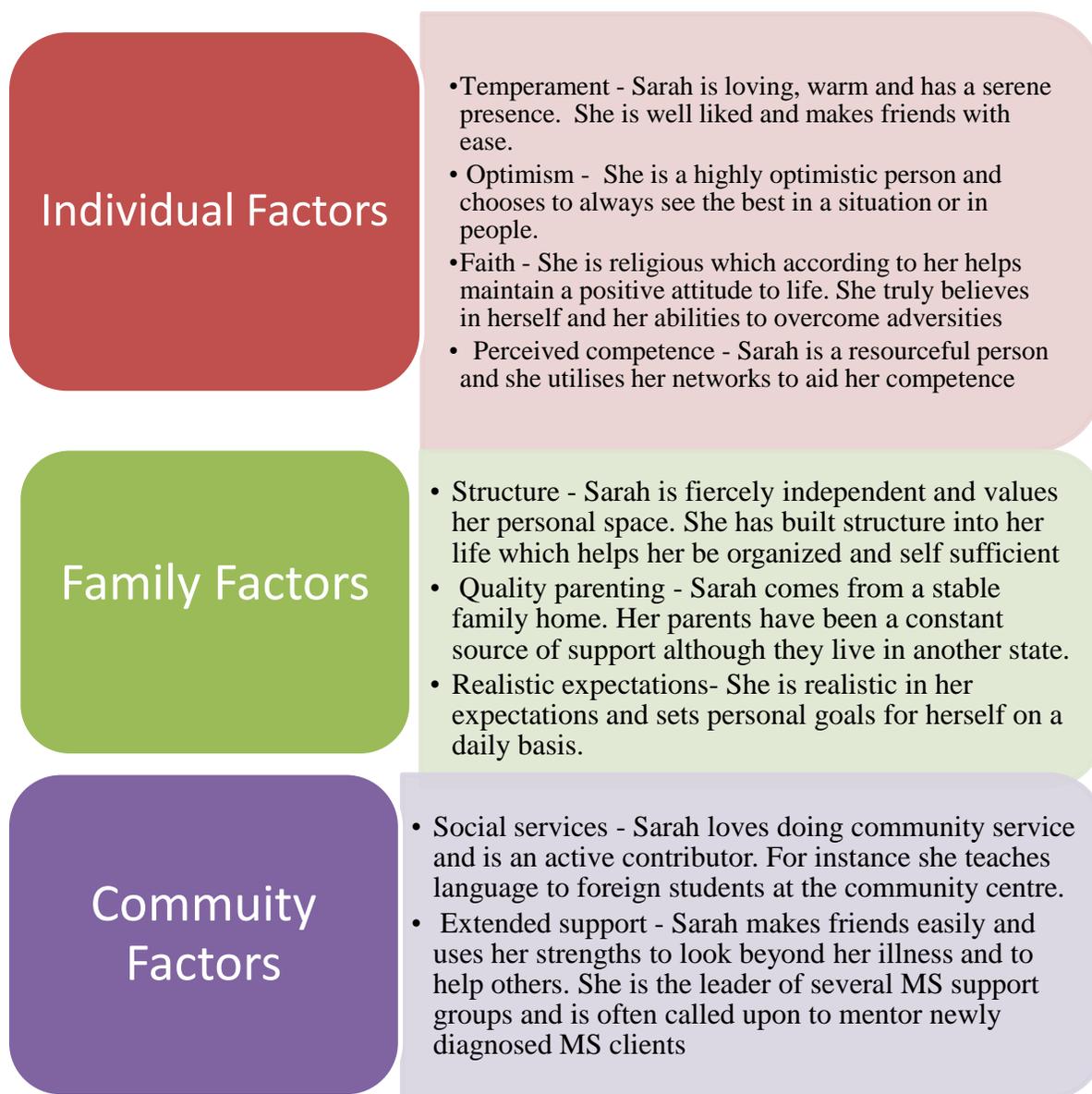


Figure 5.21 Sarah's protective factors and strengths

Like many other people with MS Sarah has her period of occasional depression. She worries about her future when she won't be able to support herself and she makes plans to anticipate future difficulties. She maintains a positive outlook but sometimes it just gets too hard for her and during those periods she gives in to her depressed mood. During these states she does not bother getting out of bed, does not eat well and does not exercise. This adds to her depression as she knows she is not helping herself in any way but yet "just doesn't give a damn". She puts on weight and the vicious cycle of self loathing begins. Her mobility is also deteriorating and she is having increasing difficulty using her legs. She has almost lost all sensation in her legs and is having problems getting in and out of her wheelchair. However, these periods don't last long and Sarah forces herself out of bed and throws herself into her daily routine of teaching at the local language school, hosting a support group for people with MS and attending church events.

Nature of the intervention

The intervention sessions were held in Sarah's home during the mornings. This was when Sarah had the most energy and could concentrate better. She was less likely to be fatigued. Likewise in summer the weather would not be so hot. She rarely missed sessions and was always well organized with what she wanted to cover during sessions. For instance she would write down questions she had and goals on which she wanted to work. She experienced mild depression for a period of three weeks during the intervention but still remained insightful and aware of her condition. For instance she rang the researcher and arranged a meeting to demonstrate that although she was a resilient person, she sometimes

broke down and gave in to her negative emotions. This resulted in her refusing to leave her room, not attending work, inactivity and limited social contact with others.

Sarah was optimistic during most sessions and rated her general well being as high on almost every session, on the Outcome Rating Scale. She perceived herself in a positive manner, and believed that she was doing the best she could, given her circumstances. She tried her best to overcome obstacles, taking them ‘one day at a time’. During the sessions, Sarah did not dwell on negative thoughts or emotions. She had insight into her disability and said she had found the resources necessary to help her cope. Her ORS scoring on four occasions throughout the intervention is presented in Figure 5.22 below. She reported a high score on the overall general wellbeing as she felt she was “doing alright” in coping with MS.

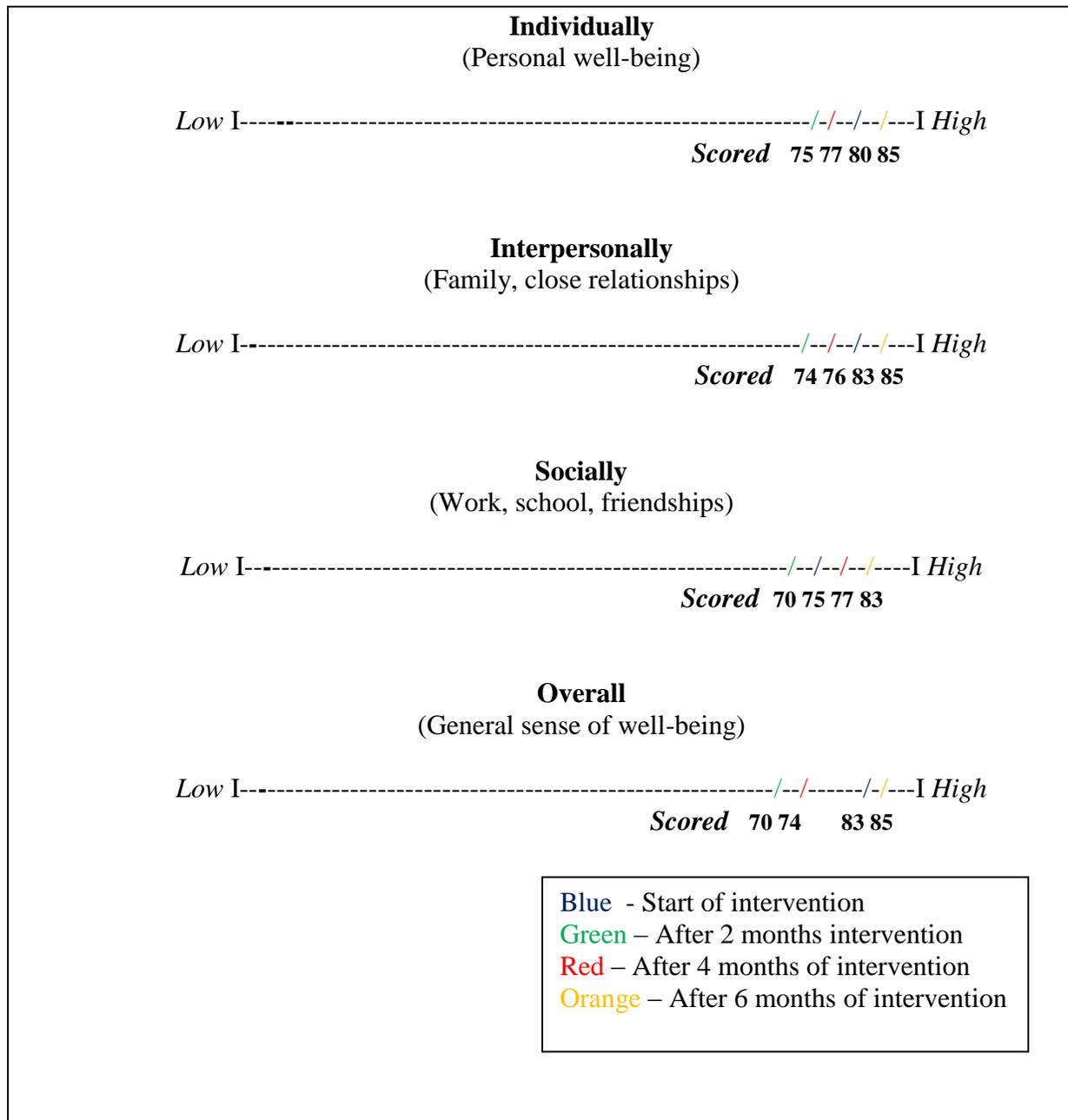


Figure 5.22 Sarah's Outcome Rating Scale score at 0,2,4 and 6 months of the intervention

The figure shows that Sarah scored herself highly (scores between 70-100) on all occasions during the intervention. She scored high on the ORS overall, with her scores dropping slightly half way during the intervention. This could have been due to a period of low mood. Even Sarah, with her positive and optimistic disposition, experienced periods

when the “hellish nature of her condition” was too much for her to cope with. During these times, Sarah yearns to be like her friends - married, having children and who have her ‘ideal life’. A life which has become nothing but a distant dream since she was diagnosed with MS.

Together, Sarah and the researcher developed and worked on long term goals. Sarah’s long term goals were identified in consultation with the researcher and are written in the form of therapist goals. These goals are broken down into short term objectives and participant goals

Long-term Goals

- Alleviate depressed mood and return to effective functioning.
- Recognize, and cope with feelings of depression.
- Develop healthy cognitive patterns and beliefs about self and the world that lead to alleviation and help prevent the relapse of depression symptoms.

Table 5.6 Sarah's short term objectives, therapeutic intervention and goals

Short Term Objectives	Therapeutic Intervention	Sarah's Goal Attainment Scaling Goals and Scores
Verbally identify, if possible, the source of depressed mood.	<p>Assist the client in developing an awareness of her automatic thoughts that reflect a depressive schema.</p> <p>Reinforce the client's positive, reality-based cognitive messages that enhance self-confidence and increase adaptive action</p>	<p>+ 2 I will keep a journal of my negative thoughts when they occur daily</p> <p>+1 I will focus on my strengths, when I feel depressed 70% of the time</p>
Learn and implement problem-solving and/or conflict resolution skills to resolve interpersonal problems.	<p>Engage the client in "behavioural activation" by scheduling activities that have a high likelihood for pleasure and mastery; use rehearsal, role-playing, role reversal, as needed, to assist adoption in the client's daily life; reinforce success.</p> <p>In conjoint sessions, help the client resolve interpersonal conflicts.</p>	+ 2 I will participate and complete behavioural experiments 80% of the time
Identify and replace negative self-talk that is engaged in and which maintains depression	'Assist the client in developing coping strategies (e.g., more physical exercise, less internal focus, increased social involvement, more assertiveness, more anger expression) for feelings of depression; reinforce success.	+2 I use my coping skills constantly and feel depressed and angry less than 10% of the time.
Implement a regular exercise regimen as a depression reduction technique.	Help the client identify pleasurable activities to participate in regularly	+1 I will stick to my exercise regime and perform my physio regularly 80 %of the time

Goal attainment scaling

Sarah achieved all the goals she set for herself successfully. She was positive and optimistic about her goals and this encouraged her to continue working of future goals. Some examples of how her goals were stated are as below.

Example 1

- +2 I will focus on my strengths when I feel depressed 80-85 % of the time
- +1 I will focus on my strengths when I feel depressed 70% of the time
- 0 I will focus on my strengths when I feel depressed some of the time 50%
- 1 I will focus on my strengths when I feel depressed 40- 45 % of the time
- 2 I rarely focus on my strengths when I feel depressed 20-30% of the time

Example 2

- +2 I will stick to my exercise regime and perform my physio daily
- +1 I will stick to my exercise regime and perform my physio regularly 80 % of the time
- 0 I will stick to my exercise regime and perform my physio often 60 -70% of the time
- 1 I seldom stick to my exercise regime and perform my physio 50-40% of the time
- 2 I rarely do my exercise regime and perform my physio 20- 30 % of the time

Assessment Scores

Sarah reported moderate resilience scores (138) at baseline and (140) post intervention and (141) at follow up. She has high executive functioning which on the DEX was a score of (37) at baseline, (31) post intervention and (34) at follow up.

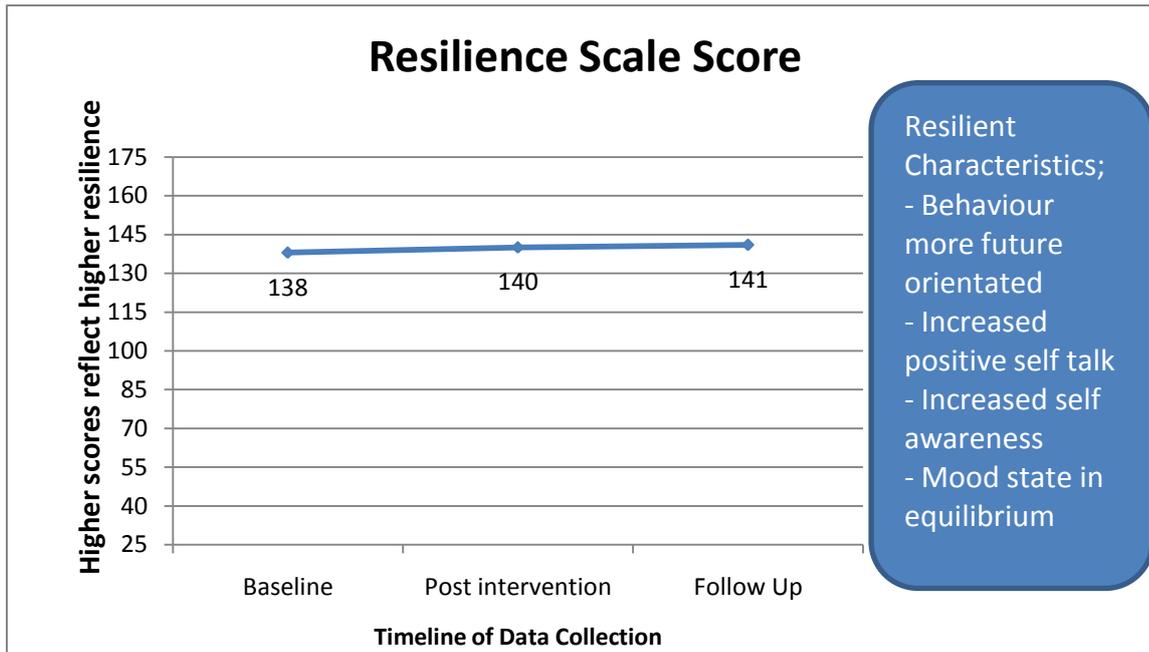


Figure 5.23 Sarah's Resilience Scale Scores

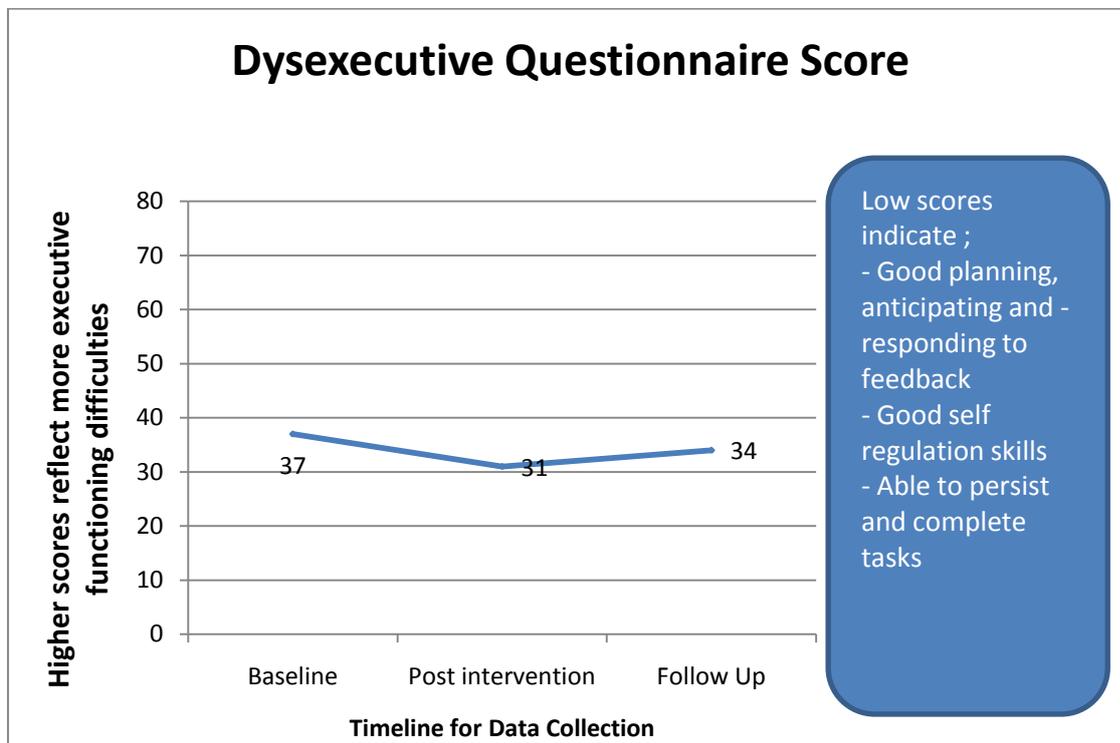


Figure 5.24 Sarah's Dysexecutive Questionnaire score

Resilience

Sarah is an extremely resilient woman with a determined personality. She is also realistic in her expectations. Being realistic despite having advanced MS is a prime characteristic of resilience.

She makes friends easily and is a 'people person'; magnetically drawing those around her into her world. She is someone who engages in contact with others because this is self enhancing. Participation in social activities also gives her something to anticipate and for which she can plan. This enables effective inclusion into society which provides Sarah with a sense of belonging. She likes socializing and organizes activities for her to be with her friends. She has made the most of what she has and is thankful for this. Her faith and spirituality help her cope when things get tough and she has come to depend on Jesus for encouragement and sustenance. Her beliefs also help in restoring hope, and this leads to a greater sense of control (Tedeschi & Calhoun, 1996). For instance, she is often hopeful about her future and therefore is better able to deal with everyday challenges. Greater spiritual beliefs also help her develop meaning in life which is seen to underlie purposive behaviour (Connor, Davidson, & Lee, 2005). For Sarah, her beliefs enable her to cope with her illness, and to do something constructive about her circumstances.

She likes trying new things and is open to new experiences. For instance when invited to dinner at a Japanese restaurant, Sarah immediately agreed although she has never eaten Japanese food before. She tried everything at least once. Her openness to experience is also demonstrated in her accurate perception of her feelings (Rogers, 1961). This occurs for instance when she realizes that she is depressed and seeks help to overcome this.

Being optimistic and positive is also another characteristic which Sarah displays in her behaviour. She chose to focus on her strengths such as socializing with others and sharing her knowledge. Her ability to remain positive is linked with her self- talk. Self talk is shown

to shape one's thoughts, feelings and behaviour. For instance self talk enables effective self regulation, problem solving and planning (Morin, 1993). It guides the person in breaking down the task, and strategies to complete the task (Duncan & Cheyne, 1999; Kim, 2002). This in return provides feedback to the person regarding their behaviour and how to adjust accordingly. Self talk is also found to be used more often in novel situations where tasks place a greater demand on the person's executive functioning (Duncan & Cheyne, 1999). For instance, when given a difficult problem to solve such as managing her finances, she has to develop strategies and break down the problem in order to get to a solution.

Executive Functioning

When Sarah's moods are at equilibrium, she easily gets through the day because of careful planning. In these situations she anticipates and uses forward thinking. For instance, she writes down her appointments and reminds herself of the things she needs to do. However, when depressed, she displays bad habits such as inactivity, not exercising, binge eating and negative thinking. Developing good habits however, assists in Sarah's rehabilitation and helps her manage her MS symptoms. These habits include;

- Maintaining ongoing physical therapy exercises such as stretching and light strength training with dumbbells. This improves motor skills and helps Sarah be independent.
- Having a good healthy diet which supplies the body nutrients which it needs to keep healthy. It also prevents excessive weight gain which impacts on her mobility as she is in a wheelchair.
- Maintaining social contact in order to increase social network. This provides her with support in times of need.

- Effective planning to ensure that she has enough energy to complete tasks. Ways this can be done is through scheduling her most important activities for the times when she has the most energy.

Sarah is proactive in her behaviour and, often, she plans ahead and anticipates her needs. For example, Sarah is well acquainted with the disability support system in South Australia. She knows that it takes a few months before items she requested will arrive such as ramps, wheel chairs and other aids. Taking this into account, Sarah orders items she knows with certainty she is going to need in advance so that she won't be left stranded without them when the time comes. She consults her doctors and therapists before making these decisions and together they realistically assess her circumstances and condition. She then assimilates the feedback which she receives. Assimilation occurs when she adds new skills and knowledge to what she already knows (Rees, 2005).

Her forward thinking and planning abilities are impressive and she often plans month's ahead anticipating glitches and problems long before they arise. She is rarely pessimistic and her planning is rational. She is persistent and completes tasks she has set out for herself like cleaning the house or reminding herself to meet the newly diagnosed clients at the society.

Conclusion and Summary

Sarah is a young woman who had to deal with her failing health at an early age. She chooses to be optimistic, positive and has a cheerful outlook. She doesn't give in to her illness and instead uses it to help give meaning to her life. For instance she helps others who are going through the same thing to be positive. She is a pillar of strength to other members of the MS society and an invaluable contributor to the support groups she runs. She is always occupied with something interesting and motivating to do and ensures she keeps busy. She plans ahead and anticipates future events realistically. She is extremely insightful and is

aware of her own personal strengths and weaknesses. Her belief in her abilities and her faith in God help her bounce back from most adversity with determination. She is seen as a fighter and not a victim of her illness. She has high resilience scale scores of (138) at baseline, (140) post intervention and (141) at follow up. Her resilience is also seen to be stable across time. Although she has occasional bouts of depressive mood, she is able to pick herself up and resume the routine of her daily life. Her executive functioning scores as scored on the DEX are also low indicating good executive functioning. They were (37) at baseline, (31) post intervention and, (34) at follow up. Upon observation, there appears to be a strong correlation between her executive functioning skills and her ability to be resilient. She utilizes her planning, anticipating and forward thinking skills to help her cope and manage her MS.

5.2 Resilience Assessment Scores

All twenty participants completed the Resilience Scale (Wagnild & Young, 1993) on three occasions:

- i. Baseline
- ii. Post intervention (9 months after baseline) and
- iii Follow up (6 months after intervention).

Their scores are presented in Table 5.7 below.

Table 5.7 *Total Resilience Scale Scores*

Participants	Baseline	Post Intervention	Follow Up
Traumatic Brain Injury			
1.	111	120	101
2.	119	147	143
3.	117	137	132
4.	106	121	117
5.	121	129	123
6.	128	124	121
7.	91	104	121
8.	80	103	101
9.	127	134	117
10.	88	112	95
<i>Mean Scores</i>	<i>108.8</i>	<i>123.1</i>	<i>117.1</i>
Multiple Sclerosis			
11.	141	144	147
12.	124	131	132
13.	138	140	141
14.	97	110	115
15.	138	137	142
16.	134	139	138
17.	131	138	141
18.	148	152	150
19.	119	130	125
20.	148	159	149
<i>Mean Scores</i>	<i>131.8</i>	<i>138.0</i>	<i>138.0</i>

Resilience scores between 25-121 are classified as low resilience, 121-145 as medium resilience and 145-175 as high resilience. A summary of participants' scores according to the categorization are presented in Table 5.8 and 5.9 below.

Table 5.8 *Resilience Scale categories for TBI participants*

Resilience Scale Scores	Low Resilience (25-121)	Medium Resilience (121-145)	High Resilience (130-175)
Baseline	70 %	30 %	0%
Post Intervention	40%	50%	10%
Follow Up	50%	50%	0%

Table 5.9 *Resilience Scale categories for MS participants*

Resilience Scale Scores	Low Resilience (25-121)	Medium Resilience (121-145)	High Resilience (145-175)
Baseline	20%	60%	20%
Post Intervention	10%	70%	20%
Follow Up	10%	70%	20%

The results show that on all three data collection points, the TBI participants mainly fell into the low or medium resilience categories, whilst the MS group were in the medium to high resilience categories. The MS participants reported the highest self reported increase in resilience scores post intervention (20 percent with high resilience). The TBI participants (10 percent) reported high resilience scores post intervention. The resilience scores remained constant at follow up for the MS group but dropped significantly for the participants with TBI. Analysis of both group's resilience scores are presented below.

5.3 Analysis of scores on the Resilience Scale

Total scores for both groups were analyzed. The results show that;

- Wilcoxon signed rank analysis on participants' resilience baseline scores ($z = 6.0, p < 0.01$) shows that scores were significantly higher for the Multiple Sclerosis participants than those with Traumatic Brain Injury (see Appendix 6).
- Following a six month customized intervention, both groups of participants reported increased resilience as shown on the resilience scale (TBI $z = 2.70, p < .05$, MS $z = 2.70, p < .05$).

This effect was maintained for the Multiple Sclerosis participants at 6 months follow up, but not for the TBI group (TBI $z = 1.99, p > .05$, MS scores $z = .35, p > .05$). Intervention effects for the TBI group were slightly reduced at follow up indicating the greater need for continued and sustained support. See Figure 5.25 below.

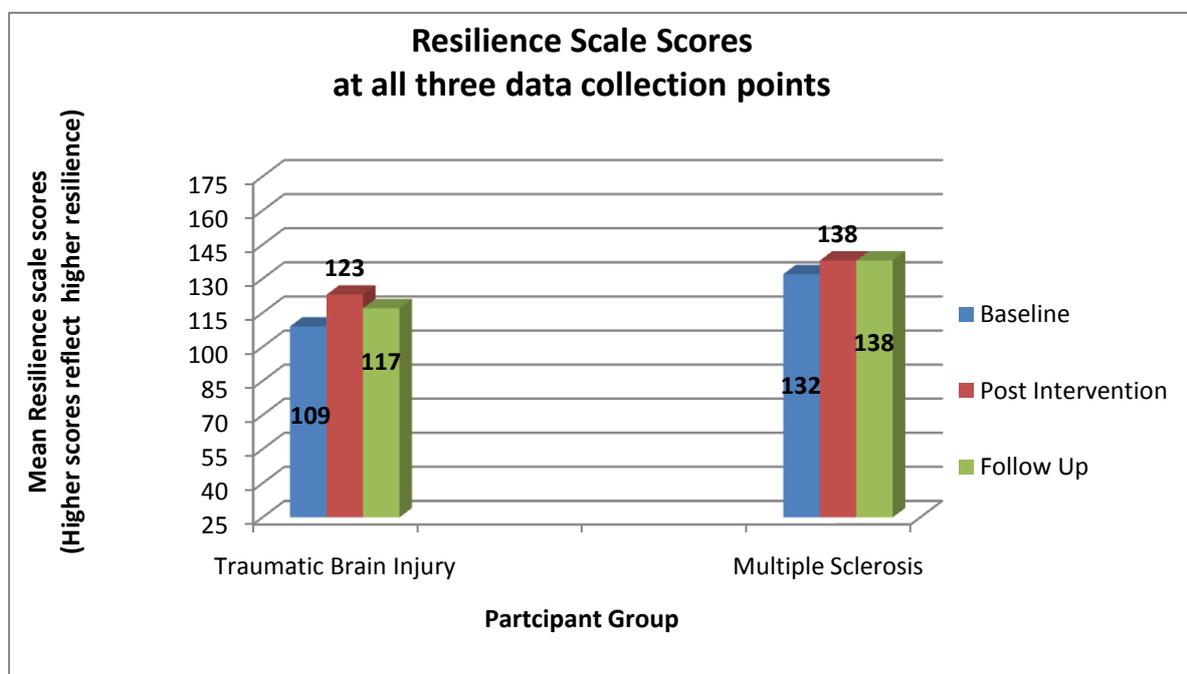


Figure 5.25 Mean resilience scale scores for both groups

5.4 Executive Functioning Assessment Scores

All participants also completed The Dysexecutive Questionnaire (DEX) (Wilson, Alderman, Burgess, Emslie, & Evans, 1996) at baseline, post intervention and follow up. The DEX is a 20 item questionnaire examining the behavioural characteristics of executive functioning. Items on the DEX assess aspects of executive functioning such as initiation, planning and functional problem solving. Higher scores reflect greater executive functioning difficulties. Results are presented in Table 5.10 below.

Table 5.10 *DEX scores for all participants*

Participants	Baseline	Post Intervention	Follow Up
TRAUMATIC BRAIN INJURY			
1.	77	70	73
2.	45	46	54
3.	55	53	56
4.	57	61	66
5.	57	62	64
6.	72	71	61
7.	67	63	75
8.	77	71	75
9.	51	52	67
10.	72	70	71
<i>Mean Scores</i>	63.0	61.9	66.2
MULTIPLE SCLEROSIS			
11.	48	31	30
12.	40	35	31
13.	37	31	34
14.	44	35	30
15.	42	32	33
16.	50	37	32
17.	55	34	32
18.	38	36	32
19.	32	27	27
20.	29	28	31
<i>Mean Scores</i>	41.5	32.6	31.2

* Higher scores reflect greater executive functioning difficulties

Similar to the scores on the Resilience Scale, participant scores on the Dysexecutive Questionnaire were categorised into three categories. Scores from 80-50 were classified as severe executive functioning difficulties, 50-30 moderate executive functioning difficulties and 30- 0 mild executive functioning difficulties. Scores on the DEX are inverse meaning higher scores reflect greater executive functioning difficulties. Scores according to these three categories are presented in Table 5.11 and 5.12 below.

Table 5.11 *Dysexecutive Questionnaire scores for participants with TBI*

Dysexecutive Questionnaire Scores	Severe Executive Functioning difficulties (80-50)	Moderate executive functioning difficulties (50-30)	Mild executive functioning difficulties (30-0)
Baseline	90%	10%	0%
Post Intervention	90%	10%	0%
Follow Up	100%	0%	0%

Table 5.12 *Dysexecutive Questionnaire scores for participants with MS*

Dysexecutive Questionnaire Scores	Severe Executive Functioning difficulties (80-50)	Moderate executive functioning difficulties (50-30)	Mild executive functioning difficulties (30-0)
Baseline	10%	80%	10%
Post Intervention	0%	80%	20%
Follow Up	0%	90%	10%

As predicted, the TBI group had greater executive functioning difficulties. On all three data collection points, the TBI participants reported “severe executive functioning difficulties”, whilst the MS participants reported “moderate executive functioning difficulties”. Scores are described below (see Figure 5.26). A detailed discussion of the interpretation of these scores is presented in the discussion of research questions.

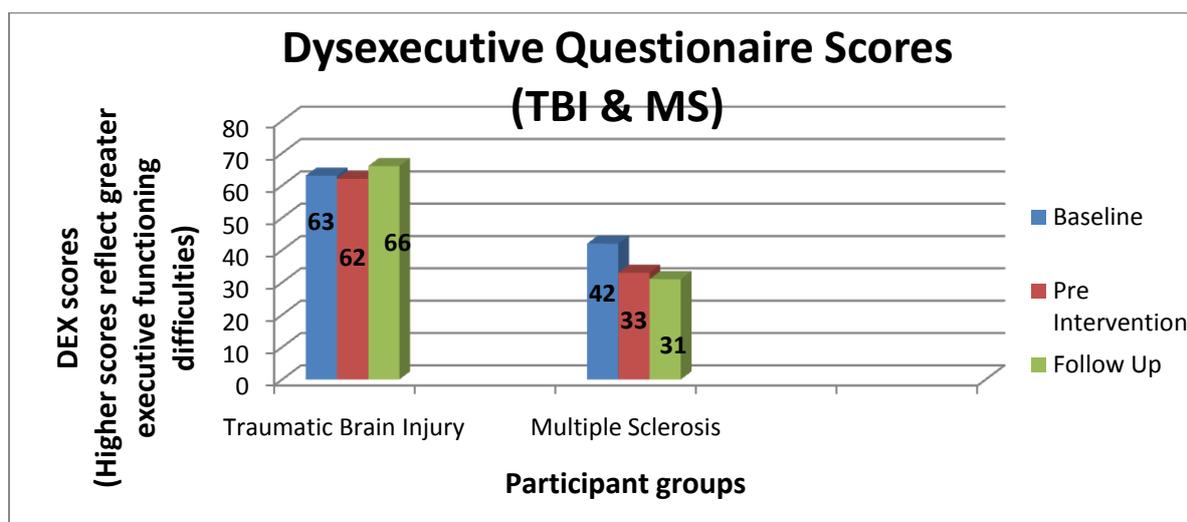


Figure 5.26 Scores on the Dysexecutive Questionnaire (DEX) for all participants

5.5 Analysis of scores on the Dysexecutive Questionnaire

Mean scores on the Dysexecutive questionnaire show;

- Overall, the participants with traumatic brain injury have higher mean DEX scores on all three data collection points.
- TBI participants' DEX scores showed a slight decrease between baseline and post intervention testing, however, this was not significant ($z = 0.92, p > 0.01$). For the MS group, a similar pattern emerged ($z = 2.8, p > 0.01$) which was also not significant.
- At follow up, gains made during the intervention were not maintained for the TBI group ($z = 1.99, p > 0.01$), which could be due to the removal of routine and structure. The MS group showed a decline in DEX scores showing greater improvements in executive functioning ($z = 1.42, p < 0.01$). The MS group was able to sustain gains made without much support. It could be interpreted that devoid of severe executive functioning difficulties, the participants with MS were able to respond and retain skills learnt throughout the intervention. The participants with TBI found this difficult without support.

CHAPTER VI

6 RESEARCH QUESTIONS ANSWERED

6.1 What is the relationship between measured resilience and executive functioning for all participants?

The correlations between total resilience scores and total executive functions scores for both groups show a significant result. The spearman correlation coefficient shows if two variables are related in a positive or negative manner. A negative relationship was expected showing that resilience scores improve as executive functioning scores decrease. This is because the DEX is inversely rated. A decrease in executive functioning scores reflects improvement behaviourally in executive functioning skills. The results are presented in Table 6.1 below.

Table 6.1 *Participants' correlation significance scores on the DEX and RS*

Data collection points	Correlation scores	Significance
Baseline	$r(18) = -.721$	$p < 0.05$
Post Intervention	$r(18) = -.653$	$p < 0.05$
Follow Up	$r(18) = -.612$	$p < 0.05$

A significant negative correlation between measured resilience and executive functioning was found on all three data collection points. However, because the DEX is inversely rated, (higher scores reflect greater executive functioning difficulty), a negative relationship in this instance indicates that as resilience increases, executive functioning difficulties decrease. In other words, as executive functioning scores drop in value,

participants are in fact reporting an improvement in their functioning. Therefore the results show that participants who have higher measured executive functioning skills also exhibit higher resilience.

There also appears to be an effect of condition (TBI or MS) which appears to mediate the relationship between executive functioning and resilient behaviours in the sample. The TBI group have higher DEX scores and lower RS scores whilst the opposite was found for the participants with MS. This finding could be due to some other variable that is related to having TBI or MS. It could be hypothesized that cognitive difficulties which were present in all participants in the TBI group could have a potential impact on their executive functioning and subsequent resilient behaviours. Measures of executive functioning and resilience are taken to reflect a heterogeneous set of underlying cognitive processes that are manifested behaviourally as adaptive functioning. Therefore, participants who were resilient also demonstrated better executive functioning skills. They were better at planning, responding to feedback, setting and achieving goals, used positive language, reasoning, and behavioural inhibition. For instance, a participant with TBI (see participant 2, Table 3.3) who had high resilience scale scores and low DEX scores was able to cope with the breakup of his family, the loss of his children and deal with losing his job. It was not easy for him, and although he experienced occasional bouts of depression, he was able to motivate himself again. At the time of writing he lived alone, but instead of seeing himself as a victim, he chose to remain optimistic. He says “I have a life for myself now. It may not be the same life I had pre trauma but I am contented and happy with what I have. I made new friends through the community re- entry program and also received support from “Peter” (his rehabilitation consultant)”. He plans and initiates participation in activities such as nature walk, outings with friends and goes to the movies. His story can be compared to participant 8, a woman with TBI. She is prone to mood swings and her resilience is fragile. Her ability to be resilient heavily depends

on what mood she is in at the time of assessment. When depressed, she is unable to care for herself. She isolates herself and spends all her time in bed, refusing to get up to shower, eat or go out. She is unable to resume her usual activities and unless cued or supported by her health care workers, she would remain in this state for months. She does not plan ahead, and has difficulty maintaining a positive mood for long. Her language becomes pessimistic often saying “I can’t, I don’t care, I’m not good enough, and No one likes me”.

Each of the executive functions referred to above, represent cognitive processes which help a person manage and cope with his/her daily challenges. They enhance the person’s behavioural flexibility by providing them with alternative problem solving and coping strategies. For instance, when dealing with change, those who were resilient had proactive coping mechanisms. In order to deal with change, they had to plan strategies and set goals, anticipate, regulate their thought processes, and incorporate the change into their lives. Successful completion of these processes enabled them to overcome their daily challenges. With the aid of cues and constant practice, a person learns to use and apply these skills, in times of adversity. This is how resilience was observed to be fostered (see Case Studies).

Consequently, participants who had difficulties with executive functioning were observed to be resistant to change, and of new and unusual circumstances. For instance, a man with MS was so set with his routine physiotherapy exercises such as weights and using the treadmill, that he resisted suggestions to try swimming, or other exercises. Once he was encouraged and motivated to try swimming he enjoyed himself and refused to return to the treadmill.

The people who seemed to cope best and were characterized as resilient appeared to be those who had particular qualities. They demonstrated the ability to be flexible, and were not rigidly tied to perceptions of how situations or circumstances should be. For instance, they took one obstacle at a time and responded to it accordingly. A woman with MS had a relapse,

her child's 21st birthday party to organize, and her mother in law coming to visit, all in the same week. Instead of being overwhelmed and breaking down, she planned her week according to her abilities at that time. She organized for her son's party to be held in a club instead of at home, and for family members to bring a dish each. That way she did not get fatigued and could still manage to have the party. Observed characteristics of people who are to be regarded as flexible are illustrated in Table 6.2 below.

Table 6.2 *Characteristics of people who are regarded to be flexible*

Flexibility characteristics observed in resilient participants
• Copes with alterations to plans and schedule (e.g., does not resist trying new activities)
• Shares (e.g., readily shares learnt skills and knowledge, shares food with other participants when they forget to bring their lunch)
• Initiates contact with others (e.g., makes appointments to see the MS social worker who can provide contacts to other service providers).
• Reads and responds appropriately to interpersonal cues (e.g., is sympathetic with a friend when they are crying or upset)
• Is able to have a broad view of life (sees the bigger picture)
• Responds to social reinforcement (e.g., accepts praise when successfully take the bus home)
• Responds to challenges (e.g., always tried new activities even when thinks they can't complete these).

Likewise, they demonstrated the ability to develop skills and attitudes which they used when faced with the challenge of adjusting their behaviour to different circumstances. For example, instead of viewing their disability as an obstacle, they viewed it as being given the opportunity to learn and experience things they would not have been able to otherwise. This in return helped them achieve positive adaptation. Secondly, they exhibited the ability to communicate openly. For instance, they were able to ask and obtain help when they felt they

could not cope. They were also able to directly express emotions both positive and negative such as being able to identify and tell their mentor when they were feeling sad. People with higher resilience were also able to not only recognize their own needs, but also to identify the needs of those around them. They were also observed to be effective at tasks which required executive functioning such as planning, organizing and achieving the goals they had set for themselves. A few cognitive activities which required these skills are illustrated in Table 6.3 below, along with strategies which were used by participants to compensate for these difficulties.

Table 6.3 *Cognitive activities involved in executive functioning and compensating strategies*

Executive Functioning Skills	Compensating Strategies
Anticipating events	Keeping a diary
Retrieving information	Using verbal and written cues
Motivation and persisting at tasks	Focusing attention and concentration
Self Monitoring	Responding to feedback and adjusting behaviour

6.2 Is there an improvement in resilience and executive functions after the intervention?

Observable changes were noted in participant scores after the intervention. This shows that participation in the intervention resulted in significant changes in participant's ability to be resilient and to have better executive functioning skills. In order to test this, the Wilcoxon signed rank test was used. This test measured if there was a statistically significant difference in the direction of participants' scores from baseline to post intervention and from

post intervention to follow up. This measures changes in scores to establish the success of the intervention on participant's resilience and executive functioning. The results show that;

On the resilience scale;

- The TBI group, had a statistically significant score immediately post intervention ($z = 2.70, p < .05$) showing that the intervention had an effect on participants' reported scores.
- These effects however were not maintained post intervention as there was no significant result found ($z = 1.99, p = 0.46$) (see Figure 6.1 below).

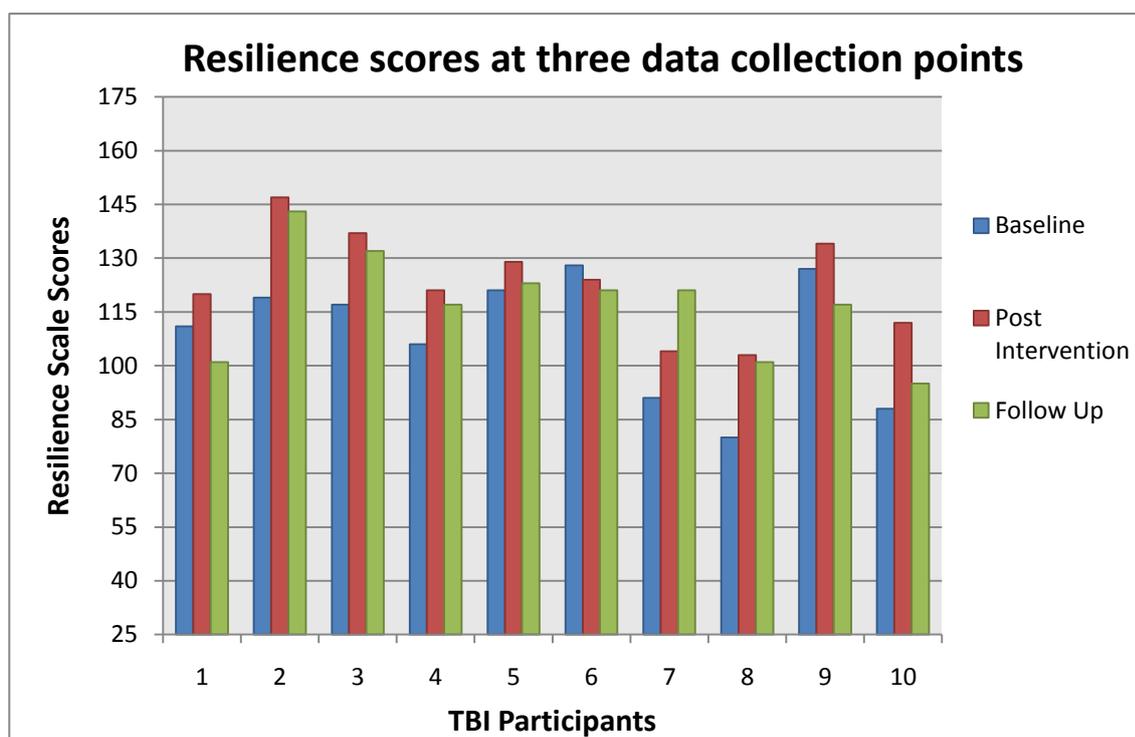


Figure 6.1 TBI participant's resilience total scores at the three data collection points

A similar trend was observed in the MS group where a significant result was found post intervention ($z = 2.70, p < .05$), showing an improvement in resilience scores post

intervention. At follow up however there was no significant difference in scores ($z = .35, p = .359$).

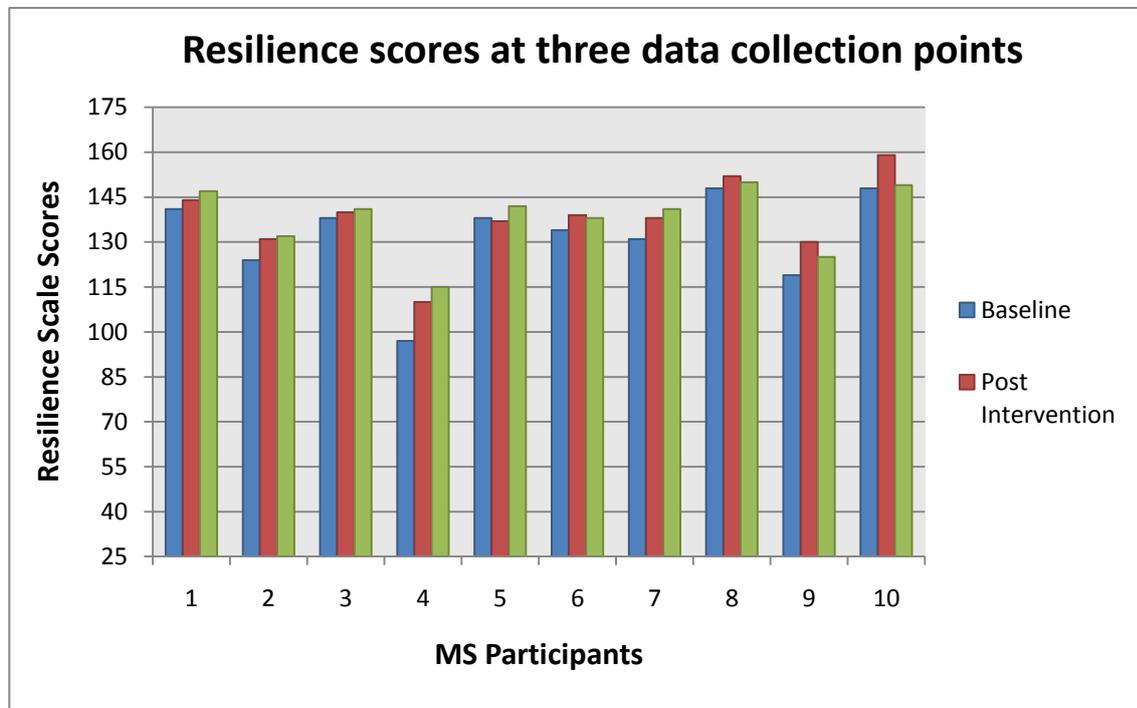


Figure 6.2 MS participant's resilience total scores are three data collection points

For the DEX;

- The TBI group had no significance changes in scores on the DEX. Post intervention, participants reported having about the same level of executive functioning difficulties as they did at baseline ($z = .92, p = .357$) (see data in Appendix 6). At follow up, participants' DEX scores again showed no significant increase or decrease ($z = 1.98, p = .05$).

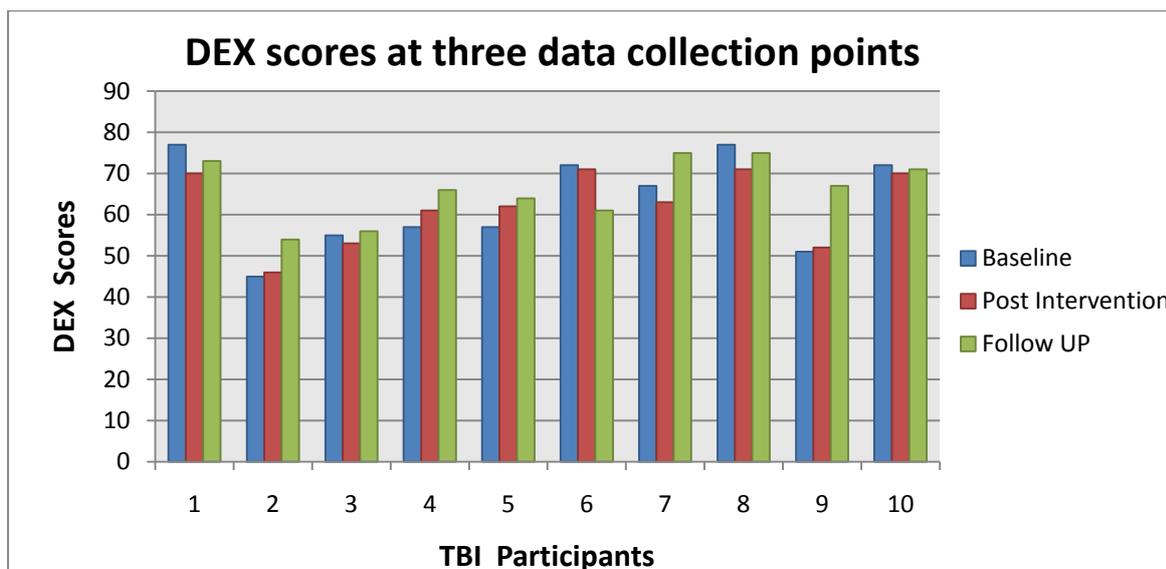


Figure 6.3 TBI participants' Dysexecutive Questionnaire scale scores at three data collection points.

- The MS group reported a statistically significant difference in DEX scores post intervention ($z = 2.80, p < .05$). These gains were maintained at follow up ($z = 1.42, p < .05$.)

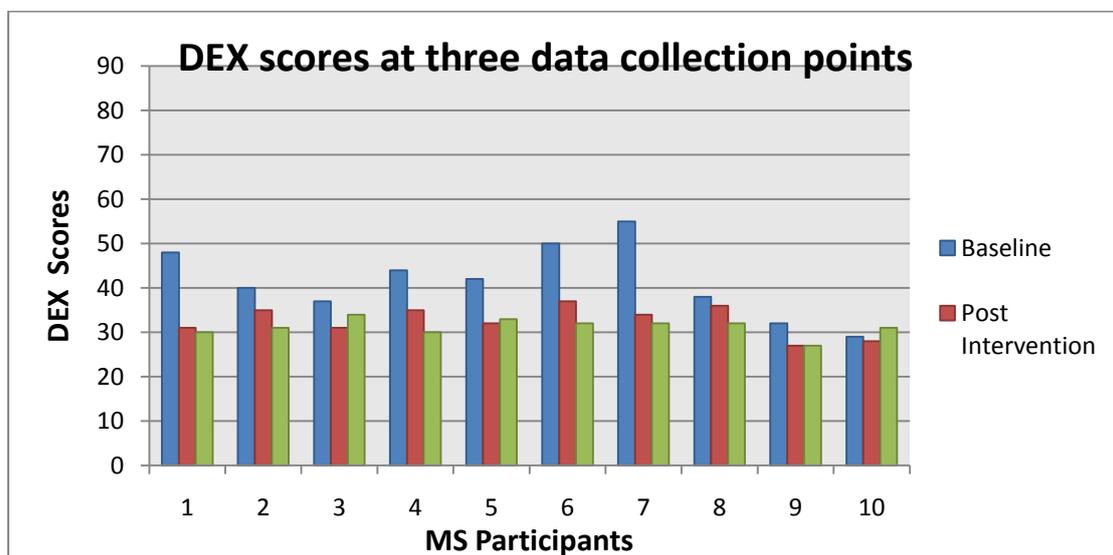


Figure 6.4 MS participant's Dysexecutive Questionnaire scale scores at three data collection points.

As can be seen, both groups demonstrated a significant increase in scores of resilience post intervention. They also experienced improved executive functioning skills. Although the TBI group did not have significant improvements on the DEX scores, significant behavioural changes were noted. Through bi weekly individual sessions, participants appeared to be better able to develop alternative coping strategies, plan ahead, anticipate future relapses, and participate in social activities. For instance, a participant with TBI learnt problem solving skills which enabled him to better manage his finances, pay his bills and save money for future uncertainties. He used a diary to write down his budget together with the researcher and was cued to remind him to update this. Another example can be seen in a woman with MS who was better able to plan for future relapse by recording symptoms which might suggest another attack. She took more breaks during the day, by planning a schedule where she specifically identified times to rest. This ensured that she had enough energy to get through the day without getting tired and overwhelmed.

Table 6.4 below shows the benefit reported by participants after the intervention.

Table 6.4 *Benefits of participation in the intervention program*

Benefits gained through the intervention	Useful Principles of the intervention	Examples from the participants
Feeling heard, understood, able to establish trust- participants reported being able to honestly express themselves during the intervention.	This was established using principles of person centred therapy which emphasizes unconditional positive regard, empathy and congruence.	A participant with MS felt comfortable and able to share his intimate experiences with sexuality. He was not judged, rather was accepted and appreciated for his honesty.
Able to make sense of trauma	Listening, validating participants' stories	A mother with MS felt valued, respected and was able to make sense of her diagnosis. She spoke openly to the researcher of her struggles with the illness such as suicidal thoughts, substance abuse and through it was able to see the pattern of her self-destructive behaviour.
Identify individual protective factors	Writing down a list of protective factors such as family, individual and community factors.	A participant with TBI when cued to write down significant people in his social network was surprised to find more people than he initially thought he knew. This provided him with opportunities to widen his network and make more contacts as he realized the importance of having significant people around him in times of adversity.
Helping manage daily problems	Assessing presenting problems and working together to solve them	Helping participants keep journals of their mood to identify possible triggers of depressive symptoms. Or helping participants plan their weekly activities such as shopping, meeting friends and keeping doctor's appointments.
Feeling encouraged and motivated	Encouragement, remaining optimistic and positively reinforcing participants	TBI participants are verbally praised for accomplishments such as memorizing a phone number, or taking the bus without cues from mentor.
Regaining hope	Positive encouragement and motivation from researcher	When performing a difficult task such as walking a child to school, the participant who has mobility problems, can take breaks, walk slower and plan the journey to avoid disappointment and failure. They then are hopeful that they can do it again the next day.

Establishing routine and predictability	Arranging sessions at the same time each week, consistent with weekly visits	A man with TBI knew exactly when the researcher would arrive because a routine had been established. It enabled him to remember the session, plan for it and anticipate the arrival of the researcher.
Effectively solve problems	Provide alternative solutions together with the participant	A participant with MS didn't want to burden his wife with having to take him to the doctor's office. Instead he decided to get the help of his social worker who arranged for someone to take him to and from the doctor's appointment.
Building social network	Identify key people who can help widen social network	A Woman with MS lived alone and her only contact with others was through her weekly visits by her social worker. Together, she decided that she could widen her network by attending a support group in her neighbourhood for people with MS.
Achieving goals	Completing the Goal attainment scaling process	Improving memory was a goal for a participant with MS. During the sessions he practiced memory exercises, memorizing numbers, names, playing memory games and reported an improvement at the end of the intervention. He was able to remember where he left his keys as he practiced leaving them in the same place each day.
Learning to implement relaxation techniques to manage stress	Using visualization and guided imagery to relax	A mother of two with MS complained that she slept too much during the day because she was fatigued and could not sleep well at night. To help her relax without sleeping, she was given a recording or progressive muscle relaxation which helped her rest during the day. She sometimes slept through the recording but with practice was able to stay awake yet relax her mind and body.

At follow up however, gains made during the intervention were not reported to be maintained. Participant's scores decreased or remained the same on measures of resilience, in particular for the participants with TBI. This could be due to the removal of structure and routine once the intervention was terminated. Having a set routine, where participants meet the researcher provided them with a sense of structure and routine to which participants responded well. Participants knew what to expect the next week and also had something to which they could look forward.

Similarly, regular meetings also provided participants with social interaction. During the intervention, participants sometimes met the researcher in a cafe, or outside their home environment, which for most was their only social recreational activity for the day. For instance one participant with TBI would not leave her home unless cued, encouraged and persuaded to do so. Throughout the intervention, she came to expect the researcher to come to her home every week and to take her out for coffee. She even initiated the outings once she was comfortable knowing what to expect each week. Research has shown that the setting is often the most important aspect of an intervention program (Diller & Ben- Yishay, 2003). Participant observation shows that when participants feel safe, and can predict the outcomes of meetings, they are more likely to be open and accept difficulties, and behave in a non defensive manner. Through the creation of a supportive and open environment, the setting can provide opportunities for participants to better manage complex issues. For instance, during meetings with the researcher, a participant revealed that she had been having panic attacks. Through challenging her negative thoughts and honest discussion, she came to understand the cause of her attacks and was not as disturbed by the attacks. It turned out that her home was a trigger for the attacks as she was afraid the clutter would prevent her from leaving the house in times of emergency. She learnt to clean up after herself and was helped to organize her belongings so that they did not block her entrance or doorways.

The MS group had a significant decrease in scores post intervention showing improved executive functioning. At follow up their scores remained constant and did not decrease further. These effects show that participation in the six month intervention program changed the way participants viewed themselves and also their ability to face novel situations with improved resilience. For instance, participants with initial executive functioning difficulties learnt to monitor and self regulate their emotions. Self -regulation and self-monitoring are abilities which are potentially important characteristics of resilience.

According to Karoly (1993, p. 25):

Self-regulation refers to those processes that enable an individual to in guide his/her goal-directed activities over time and across changing circumstances (contexts). Regulation implies modulation of thought, affect, behaviour, or attention via deliberate or automated use of specific mechanisms and supportive metaskills.

For instance a man with MS was bullied and often called names by children when he left his home. Apparent reasons for the bullying included his unkempt looks and odd behaviour such as scratching himself and walking while swaying. During the intervention, it was discovered that the reason for his untidy looks was that he was unable to bathe himself due to his limited mobility and weakness in his arms. His social worker was approached and she arranged for carers to come in regularly to aid him in bathing and self care. He also started to use a ‘gopher’ (an electric scooter with seat) for mobility in the community as it enabled him to stay out longer without getting tired and lowered the risk of children bullying him. He was then also able to regulate his behaviour and emotions appropriately given the social context and was not prompted to swear or call out obscenities to the children who had previously teased him.

Similarly, participants also learnt through the intervention that there is more than one way to view a situation. Flexibility in thinking, by those who were “more resilient” , was demonstrated as they had the ability to create alternative problem-solving strategies, were

able to direct their efforts towards the most relevant aspects of an issue, and were considered to be strategic in their approach to new and unusual situations. This can be contrasted with a person with frontal lobe injury. Most participants with frontal lobe injury often had difficulty with problem solving. This explains why they are sometimes afraid of new and unusual situations (Rees, 1999; Sohlberg & Mateer, 2001). However, participants were observed to relieve some of their problem solving difficulties by:

- Stating and writing out the objectives they want to achieve,
- Sharing problems with their mentor,
- Developing strategies to cope with change,
- Learning one problem solving strategy at a time, and
- Practicing the strategy and using it when required.

Although the scores show that participants with TBI were not able to maintain gains from the intervention, the intervention still had an effect in helping them build their resilience repertoire. With appropriate support and cueing, these gains can be brought to the fore and used in future contexts when faced with similar adversity. For instance, a person can be reminded about the way they dealt with their depression in the past, which strategies were useful in helping them and what strengths they used previously.

6.3 Are there any group similarities or differences in the demonstration of resilient and executive functioning behaviours?

The two groups of participants were chosen in particular because they have both experienced trauma. Both TBI and MS pose significant psychological, social, vocational, and emotional challenges to the participants. Yet despite these challenges, there are individuals

who are able to adapt, to bounce back with minimal disruption to their lives and others are eventually able to recover their baseline level of functioning. Although baseline functioning for these individuals may not be exactly as it was pre trauma, a new baseline can be established where the person learns new skills, and ways to cope with their disabilities. A quote by Ernest Hemmingway summarizes this beautifully;

"The world breaks everyone and afterward some are strong at the broken places."

(Hemmingway, 1929)

How individuals deal with their adversity (broken places) is what distinguished those who were resilient from those who had “brittle” or low resilience. Those who demonstrated higher resilience were able to bounce back and carry on with their daily tasks and routines faster than those with “brittle” resilience (Ahern , Kiehl, Lou Sole, & Byers, 2006). It was hypothesized in this study that irrespective of their disability, life adversities and psychological problems, participants would be able to demonstrate resilient behaviours (Friborg, Hjemdal, Rosenvinge, & Martinussen, 2003). Similarly, although participants with TBI have more executive functioning difficulties, it was hypothesized that they would be able to learn, and improve their functioning skills. In order to establish group similarities in the experiencing of resilience and executive functioning, the Mann Whitney U test was conducted. The results show;

- That there is a significant difference in the experience of resilience for both groups on all three data collection points. Baseline ($U= 6.0, p < 0.05$), post intervention ($U = 19.5, p < 0.05$) and at follow up ($U= 14.5, p < 0.05$) (see Appendix 7). What this means is that, contrary to what was predicted, there were group differences found in the experience of resilient behaviours in this sample. Figure 6.5 below shows that, on average, participants with MS had higher resilience scale scores at all three data collection points.

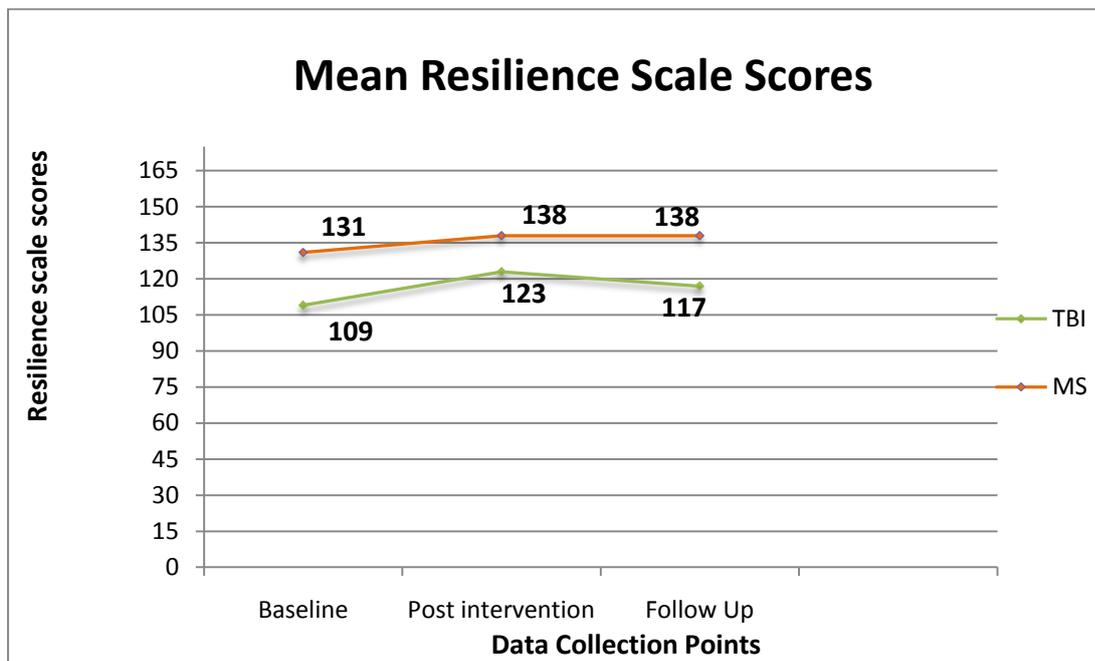


Figure 6.5 Mean total resilience scores for both groups at baseline, post intervention and follow up.

- Similarly, scores on the DEX show that both groups experience executive functioning difficulties differently with significantly different scores at baseline ($U = 4.5, p < 0.001$), post intervention ($U = 0.00, p < 0.001$) and at follow up ($U = 0.00, p < 0.001$) (see Appendix 7). Figure 6.5 below shows that participants with TBI had more executive functioning difficulties than those with MS, as predicted, and this is shown by the higher DEX scores.

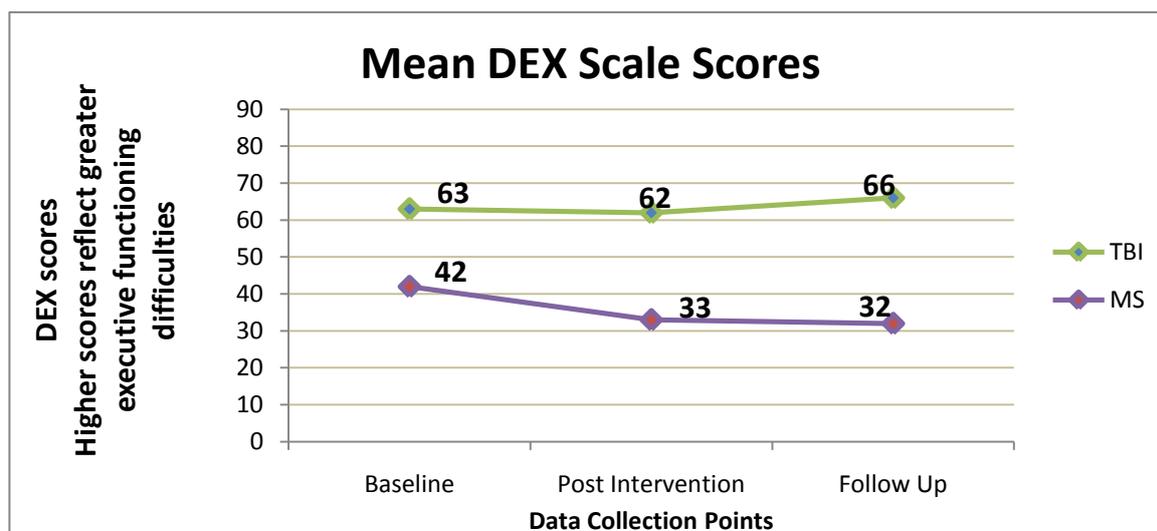


Figure 6.6 Mean scores on the DEX at baseline, post intervention and follow up

This pattern is consistent with the nature of TBI, as most participants have frontal lobe damage. The MS participants reported fewer and less executive functioning problems. When a person experiences brain injury, his or her life is dramatically changed. Depending on the extent of the damage to the brain, people with frontal lobe damage have to live with a variety of long term disabilities. Adapting to their lives post trauma, and dealing with the changes their disability brings is a battle these people face on a daily basis (Werner, 1993; Werner & Smith, 1982; White, Driver, & Warren, 2008; Wolin & Wolin, 1993; Wood & Yurdakul, 1997). How they deal with their adversity is what distinguished those who were resilient from those who had “brittle” resilience (Masten 2001; Rutter, 2002; Tugade & Fredrickson, 2004).

Additionally, an individual's adjustment to stressful events occurs in the context of specific family and community settings. Therefore it can be argued that whilst most of the participants with MS were living with their family, almost all the TBI participants had family break ups. It is important to consider how structures at the family and community levels can help or deter an individual's responses to stressors. Factors such as stability, organization, and

cohesion in families (Garmezy, 1987) and strong social networks in communities (Wandersman & Nation, 1998) can provide protective effects for individuals. Devoid of these structures, individuals become isolated, withdraw and are more likely to be depressed (Granerud & Severinsson, 2006; Hellowell, Taylor, & Pentland, 1999; Marsh, 1999; Rutter, 2002). For instance, most TBI participants live alone, have limited contact with others apart from their health care providers and rarely participate in any social activities. They also have little or no contact with their families and, as a result, have a restricted range of social networks to rely on in times of adversity.

Two aspects of social support are critical to managing stress and enabling a person to be resilient. Caring and supportive relationships can provide emotional support that may buffer the impact of extremely stressful situations and permit the expression of difficult emotions.

Secondly, large social networks can provide help and information relevant to managing stressors (Eide & Roysamb, 2002; Evert, Harvey, Trauer, & Herrman, 2003). From the results, it was observed that MS participants, although not as socially active as they were pre diagnosis, appeared to have a wider social network than TBI participants. They were able to maintain friendships with colleagues, friends, ex-partners and also to form new friendships, for instance, through the MS society. They initiated contact, anticipated future events such as birthday parties, Christmas celebrations and were able to plan ahead for them. One example of this was a woman who knew Christmas was going to be hard on her family as she depended on a disability pension for income. She started saving money, putting away every spare dollar she had into a little jar so that come Christmas, she had some money to spend.

In conclusion, there is a significant difference in the experience of resilience and executive functioning behaviour between the MS and TBI groups. As can be seen in Figure

6.5 and Figure 6.6 above, the MS group had higher mean resilience on all three occasions and lower DEX scores. The TBI group had lower mean resilience and consequently higher DEX scores. The results highlight the fact that scores come from two, separate and distinct populations of participants.

6.4 What is the evidence of resilient behaviours in the sample in this study?

The intervention was designed to observe and measure participant's resilient behaviours:

- 1) Over a period of 15 months from baseline to follow up
- 2) On different occasions and across various settings such as at home, interacting with peers and in social contexts such as at the cafe or on a camp.

A summary of behaviours of individuals with high resilience scores (130-175) and low resilience scores (25-90) is presented in Table 6.5 below. These characteristics were observed by the researcher and also obtained through the interviews with participants and their rehabilitation professionals.

Table 6.5 Characteristics of high and low *resilient behaviours*

Characteristics of high resilience	Characteristics of low resilience
<ul style="list-style-type: none"> • Has warmth; capacity for close relationships (e.g., is able to draw others into his/her social network. Makes and maintains friendships) • Has social self-confidence and presence (e.g., is a likeable and warm person whom others want to be around). • Is productive; gets things done (e.g., completes tasks such as shopping and house work when they are due instead of putting them off for another day). • Calm, relaxed in manner (e.g., does not get easily stressed and can remain composed in stressful situations. For instance, reaching for the fire extinguisher when food on the stove starts smoking). • Socially sensitive of interpersonal cues (e.g., is able to respond to social cues such as noticing when a friend is upset and wants to talk, or keeping quiet in the library) • Able to see to the heart of important problems (e.g., realizing that they are fatigued and that it is due to MS, not a personal failure). • Is a genuinely dependable and responsible person (e.g., able to care for self and children independently with support from others) • Responds to humour (e.g., able to laugh at a joke or funny story) • Values own independence and autonomy (.e.g. uses a wheelchair to be able to go out and be mobile.) • Tends to arouse liking and acceptance (e.g., Is helpful and supportive of others in the same situation) 	<ul style="list-style-type: none"> • Does not respond well under stress (e.g., gets overwhelmed and panics when there is a minor fire in the kitchen). • Is self-defeating (e.g., constantly feels sorry for himself, asking why me?) • Is uncomfortable with uncertainty and complexities (e.g., overly worries when things don't go as planned) • Over-reactive to minor frustrations, irritable (e.g., gets annoyed when a friend asks a question during a writing workshop). • Denies unpleasant thoughts and experiences (e.g., does not acknowledge feelings of depression and thoughts of harming self). • Does not vary roles; relates to all in same way (e.g., makes jokes during a serious consultation with the doctor). • Is basically anxious (e.g., worries constantly about what will happen tomorrow). • Gives up and withdraws from frustration, (e.g., when making a cup of coffee, would give up when spills water on the ground). • Is unable to regulate emotions (e.g., responds with anger outburst when carers are late). • Is vulnerable to real or fancied threat; fearful (e.g., lives alone and is the victim of local bullies). • Tends to ruminate and have pre-occupying thoughts (e.g., constantly lives in the past, thinking of the accident and the person they were before the injury). • Feels a lack of personal meaning in life (e.g., thinks life is over and there is no happiness to look forward to).

Irrespective of which group the participants were from (MS or TBI), those who were resilient appeared to share similar traits and characteristics. They often demonstrated an optimistic, zestful, and energetic approach to life. For example, these participants were curious and open to new experiences. In addition, they were people who were described as having positive emotionality (Fredrickson, 1998). Friends and other participants would refer to them as “He is always happy and smiling, or “she can do it, she’s always so positive”. They are willing to participate in a range of activities to which they have never been exposed or with which they are not familiar. For instance, in a writing skills workshop where participants are normally required to work on computers, participants are suddenly asked to stop working with the computer and to start writing a poem depicting what they see in a photograph. Most participants were reluctant to try writing poetry because they have never done so before, and it is a change in their routine. One participant who was identified as being resilient talked the others into trying to write poems by saying “come on, it will be fun”.

Resilient participants were also able to see the core issues in their difficulties. They had the ability to “see the bigger picture”. For instance a participant said

“Today I realized how much the accident has changed me. I have lost everything that has ever meant something to me. I lost the world I used to know. I can win it all back if I allow and encourage my affections to develop and enjoy simple activities. I will create a “New life story”, I will make every effort to put misery behind me and form a new role for myself. I refuse to accept any other role/status assigned to me”.

When faced with major changes after a brain injury, most people have similar types of feelings. Fear, anxiety, helplessness, despair and loss of control are some of the emotions experienced. However, what differentiates a resilient person from a person with “brittle” resilience is how they react to that change. Participants were observed to act in a reactive or proactive manner. By being reactive, people let change happen and then they respond or

adapt to this. For example, some participants with low resilience scores view change as loss or a threat in most situations. In contrast, those who were proactive were able to plan and anticipate change. They were open to new or multiple ways of doing things and saw change as an opportunity. Even if they did not plan or anticipate changes in their lives, they are at least open to reframing how they view change.

The results demonstrated that those who were “more resilient” used alternative personally developed coping strategies, which were associated with their positive emotions. For instance, these participants were found to use humour, creative exploration, relaxation, and optimistic thinking as ways of overcoming adverse situations. This diverse set of coping strategies has, in general, the ability to nurture positive emotions, such as happiness, interest, satisfaction, anticipation, hope, and appreciation (Folkman & Moskowitz, 2000; Kohn, 1996; Lazarus & Folkman, 1984; Tugade, Fredrickson, & Barret, 2004). It is also evident that participants who were identified as being more resilient not only cultivated positive emotions in themselves but were also capable of drawing out positive emotions in others with whom they had a close relationship. Consequently, this ability then helped the person to form a supportive social context which facilitated their coping.

6.5 What factors contribute to the resilience and effective executive functioning of participants?

The characteristics of both resilience and executive functioning were measures which required very careful interpretation. They appeared to be dependent on the context in which the individual was required to use these skills. The data from the Resilience Scale (RS) and the Dysexecutive Questionnaire (DEX) were used to measure stable characteristics of resilience and executive functioning. These instruments were used because they represent a

degree of reliability. For participants with TBI or MS, their scores on the RS and DEX provided factors, and guidance to support the ethnographic observations. For example, factors such as social support networks and mood disorder (see sections 6.5.2 and 6.5.3 below) can be measured at a specific time using quantitative instruments. However, over time, these constructs change and therefore quantitative measures may become unreliable.

These factors also change according to context or physical space in which the participants find themselves. The study found that some people were resilient in certain situations and their ability to problem solve, respond to feedback, use positive language and self regulate also improved with support. This context underpinned resilient and executive functioning behaviours for participants. For instance, executive functioning difficulties for a participant (Leslie) with TBI were observed to improve when changes were made in his domestic domain. He moved into community assisted living where he received regular meals, monitoring of his medications and had social interaction with others. There is a defined structure, a routine for Leslie to rely on. With this foundation, Leslie was observed to be less disoriented, better able to plan and attend meetings. Previously, he would forget meetings, or be too withdrawn to want to attend. For a participant with MS, when on a holiday or attending a yoga retreat, she reported experiencing less fatigue and less cognitive difficulties.

People with TBI and MS often report being two people (Rees, 2005). The person they remember being before the injury or illness and the person they are now. In the current study, this might have been because most of the participants had problems with short term and working memory (Khan, Baguley, & Cameron, 2003). They were observed to use their long term memories to facilitate their present thoughts and behaviour (Elliot, 2003; Eslinger & Geder, 2000). The further an event was from the accident or onset of illness, the better the recall they had of it (Sohlberg & Mateer, 2001). As a result of this, they often live more in the

past than in the present because the past is all they can remember (Cicchetti & Tucker, 1994; Khan, et al., 2003; Laughlin, McManus, & Aquili, 1990). This is how their early experiences seemed to influence their present resilience. New information and experiences can only be fully integrated if a structure of past experience exists (Tulving, 2002). For instance, a participant remembered how his father “made friends easily and liked doing new things, he was always involved in activities like fishing, he loved life”. This participant also said that “I am exactly like him (father). I see it as it is, dad wouldn’t get frustrated and that’s basically what I do”. Another participant with MS, who used to be a musician, is able to appreciate going to the opera or music recitals because of her past experience. When she plans and goes to these events with her social worker, she is able to integrate the experience with her previously acquired knowledge of music.

For professionals or people working with participants with TBI or MS, this means that they have to get a grasp of the participants, and to observe the extent to which a new post trauma life can be constructed. All participants have a “structure of past experiences” based on their friendships, jobs, religion, social networks and hobbies. Therefore, it is crucial to spend significant time with participants in order to establish the basis of their long term memories, which aid in shaping their present resilient behaviours. Long term memory can be used for either group of participants to build new experiences (Johansen, 2002).

6.5.1 *Problem solving difficulties*

Also evident in the particular sample was the use of effective problem solving strategies. Both groups of participants showed that those who were resilient often faced and reflected on their problems instead of avoiding them. By learning to problem solve effectively, participants reported feeling more empowered. They learnt to trust their capabilities when faced with future challenges. They learnt to anticipate possible obstacles to

their daily problems. They were also able to creatively generate alternative solutions and plan future strategies to deal with similar situations.

When participants did not possess good problem solving skills, they were more likely to act impulsively, to make decisions which did not resolve problems, and engage in self defeating behaviours. For instance, a participant with MS who had problems walking refused to use a walking stick because she was embarrassed and ashamed to be seen as being disabled. One day when walking her 3 year old child to school, her legs felt extremely weak, and she collapsed on the street with no way of getting up. Since it was early in the morning she had to lie on the street till someone walked past and helped her up. Her inability to accurately judge and accept her difficulties with walking impacted not only her, but affected her child as well.

6.5.2 *Social support*

Social support was another major theme which was common between both groups. Resilient individuals demonstrated the ability to reach out to others for help, were better able to maintain healthy social relationships and were able to reciprocate. (A detailed discussion on social support is presented in section 6.6 below). As a result they had a wider social network and were less isolated (Hardiman & Segal, 2003). They participated in community activities such as being involved in community rehabilitation programs, and recreational outings which also helped them to overcome their isolation and loneliness.

6.5.3 *Mood disorders*

Another factor which drastically influenced all participants' ability to display resilient behaviours was the occurrence of a mood disorder. In this sample of participants, depression was present in all participants at some point of the intervention process. Although those

participants who had higher resilience scores were less likely to experience depression, they also reported periods of low mood and experienced intense negative emotions. This finding is consistent with other studies which found that resilient behaviours do provide some protection to the individual from experiencing depression (Judd et al., 2003; Komiti et al., 2003; Ryden, Karlsson, Sullivan, Torgerson, & Taft, 2003). However, resilient behaviour and subsequent protective factors such as optimism, hope, positive language and support did not totally prevent participants from being depressed. Resilient behaviour does not “protect” individuals from risks such as depression. Rather, it stems from exposure to depression and the consequent successful adaptation to the challenges this entails (Luthar, Cicchetti, & Becker, 2000). For instance, some participants used their social network to help them overcome depression. They rang their social workers or rehabilitation professionals and actively sought help when this was required.

The incidence of depressive behaviours for people with TBI and MS in this study was such that sustained and effective management for the future is required. Certain conditions contributed to depression in the participants of this study. These conditions, which were often triggers of depression, are summarised in the matrix below. See Table 6.6 below.

From the table above, it can be seen that participants with MS and TBI experienced all 15 conditions which contribute to depression. These conditions consisted of everyday events and circumstances which predisposed participants to experiencing depressed mood, isolation and loneliness. It is clear that the MS and TBI groups are at higher risk of depression than the general population as they regularly experience more risk factors and the results of the current study are consistent with the literature (Jorge, Robinson, & Moser, 2004; Rosenthal, 1998; Schubert & Foliart, 1993; Siegert & Abernethy, 2005). A detailed analysis of each participant's response to conditions which contributed to his/her depression is presented in Table 6.7 below.

Table 6.7 Individual conditions which contribute to depression in subjects with MS or TBI.

Conditions which contribute to depression		
1= Physical Tiredness/ Fatigue	7= Relationship Breakdown	13 = Rejection/ Low self esteem
2= Cognitive Tiredness/Fatigue	8= Mobility Issues	14= Negative language/expectations
3= Inactivity	9= Financial Problems	15= Sleep deprivation
4= Pain	10= Unemployment	
5= Progressing of condition	11= Loneliness	
6= Fragmented Support	12= Body Image	

Participants	Factors which contribute to depression															Total	
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15		
TBI																	
1	x	x	x	x	x	x	x	x		x	x	X	x	x	x		14
2		x	x			x				x	x		x	x			7
3		x	x	x	x	x	x	x	x	x	x	X	x	x			13
4	x	x	x	x	x	x	x	x	x	x	x		x				12
5	x	x	x		x	x	x	x	x	x	x		x	x	x		13
6	x	x	x	x	x	x	x			x	x	X	x	x			12
7	x	x	x	x		x	x	x	x	x	x		x	x	x		13
8	x	x	x	x	x	x	x	x	x	x	x	X	x	x	x		15
9		x	x	x		x	x		x	x	x		x	x	x		11
10	x	x	x	x	x	x	x	x	x	x	x	X	x	x	x		15
Total	7	10	10	8	7	10	9	7	7	10	10	5	10	9	6		
MS																	
11	x		x	x	x	x	x	x	x	X	x		x	x	x		13
12	x		x	x	x	x						x	x			x	8
13	x	x	x	x	x	x	x	x	x	X	x	x	x				13
14	x	x	x	x	x	x	x	x	x	X	x	x	x	x		x	15
15	x	x	x	x	x	x	x	x	x	X	x	x	x	x	x		15
16	x	x	x	x	x		x	x	x	X	x		x				11
17	x	x	x	x	x	x	x	x			x	x	x	x			13
18	x	x	x	x	x	x	x	x			x	x	x	x		x	13
19	x	x	x	x	x	x	x	x		X	x	x	x	x			13
20	x	x	x	x	x	x	x	x	x	X	x	x	x	x			14
Total	10	8	10	10	10	9	9	9	7	7	9	8	10	7	5		

It is clear that participants with MS and TBI rated physical and cognitive fatigue as a major contributor to their depression. All participants reported that inactivity was a significant factor in depression (100 %, 100 %). Another key factor was the availability of social support. People with MS and TBI appeared to have more trigger factors which may be attributed to their disability. These factors included physical and cognitive fatigue, progression of disease, mobility issues, loss of employment, breakdown in social support, and relationship breakdown. Detailed discussion of these factors and how they contributed to participants' ability to display resilient behaviours are presented in the answers to the research questions below.

6.6 How does having family/ spousal support influence resilience?

Family/ spousal support has been long studied as a protective factor which contributes to a person's ability to be resilient in the face of adversity (Wills, Vaccaro & Mcnamara, 1992). Similarly, having a partner to support and share responsibilities was found as the most important form of support which enables participants to cope better in times of stress (Conger & Conger, 2002). Family/spousal factors which contribute to participant's resilience in this study are described below.

6.6.1 *Emotional support*

Emotional support has been defined as resources and assistance exchanged through social relationships and interpersonal interactions (Helgeson, 2003). Close personal relationships are typically viewed as the place of intimacy and source of care, as well as the place where people share emotions and secrets. For this reason, people often seek emotional support from friends, family members, and romantic partners during times of stress, difficulty, or frustration (Helgeson, 2003; Izaute, et al., 2008). Participants with MS and TBI cope with difficult situations frequently and therefore would appear to require greater levels of emotional support from those around them. Most participants have family break ups and consequently do not receive support from partners, or their spouse. They have to rely on family members or the community to support them. For example a woman with TBI in the current study had to move in with her parents as she was unable to care for her son by herself. Her parents had to care for her post TBI as she was going through a divorce. Although she did not always get along well with her mother, she had no other option but to move in with them.

Emotional support has been often associated with a reduced risk of mental and physical illness, as well as mortality (Achat, et al., 1998; Gielen, McDonnell, Wu, O'Campo, & Faden, 2001; Seeman, 2000). It has also been suggested that emotional support may buffer a person from cardiovascular, endocrine, and immune functioning diseases (Seeman, 1996). It can also affect the way in which people cope with stress (Moriarty, Zack, & Kobau, 2003; Seeman, 2000). For instance, participants in the current study who received emotional support reported benefits such as;

1) Adhering to rehabilitation and treatment efforts – They received constant cues and encouragement from family and friends and were motivated to seek treatment and participate in rehabilitation efforts. For instance, two MS participants decided to band together and watch their diets, whilst attending regular physiotherapy. The presence of a friend made the process a lot easier and they relied on each other when they were less motivated or not feeling well.

2) Elevated mood – Participants reported being in a better mood and were more optimistic when they had someone supporting them emotionally. They were then more likely to accomplish their goals, felt less anxious and were less lonely or depressed. For instance, a man with MS would regularly meet his ex work mates to catch up on what was happening in the work place. Although he didn't work there anymore, he didn't want to lose his friends due to his MS. He made a point of meeting his friends regardless of how bad he was feeling. His friends in turn encouraged his progress, and were a form of contact to the outside world.

Emotional support is only one type of support that people with TBI and MS require from their spouse/ partner. Another form of emotional support is through acceptance. For instance, accepting incontinence in a partner with MS. The individual may feel disgusted

and ashamed of him/herself. However, with support from a loving partner or family, the individual then can better cope and find ways to address his/her incontinence. A participant with MS recalls her experience;

“oh, it's just humiliating! It really feels demeaning. It's hard sometimes to maintain a positive self-image when you're constantly running to the toilet or wetting yourself. My family has supported me and my husband has been a real gem. He is so loving and says he stills finds me attractive despite it. I couldn't have coped without him.”

Helpful ways in which participants reported receiving acceptance was through the expression of desire to offer support (Barbee, Derlega, Sherburne, & Grimshaw, 1998). An example of this is when the partner or spouse explains (“I really want to help you with this problem”) or (“we can work on this together”). Another way is through the expression of positive regard (Kirschenbaum & Jourdan, 2005). (“I understand what you are going through,” you are not alone; there are others with the same problem”). Similarly, acceptance can be conveyed through the provision of routine or stability (Caplan & Samter, 1999). Particularly for people with an illness such as MS or an injury such as TBI, routine and stability is vital in their rehabilitation process. Knowing what to expect, and knowing that their partner will not walk out on them because of their disability is a significant factor in relationships for participants. For instance, from the example above, knowing that her husband loves her despite her incontinence was a huge relief and a form of acceptance for that participant. Not all participants had positive stories of acceptance. The majority of them reported being stigmatized, embarrassed and put down by health care providers, friends and family. One man reported that just because he was in a wheelchair, people assumed he was “stupid”, “dumb” and “retarded”. They would speak to his carer and never directly to him. Rogers describes acceptance beautifully when he says

“In my relationships with persons, I have found that it does not help, in the long run to act as though I were something that I am not. It does not help to be understanding when I do not understand him. It does not help to act as though I know the answers

when I do not. It does not help to act as though I were acceptant of another person when underneath that exterior I feel rejection of him". (Rogers, 1995).

Partners/families can also provide emotional support through enhancing self esteem. In accordance with humanistic theory, a person's self esteem can be enhanced through the provision of positive (affirming) feedback about themselves and their behaviour (Bednar & Peterson, 1995). For instance, words of encouragement such as "you did that well, keep going" and "you were amazing on the camp, everyone was proud of the way you mixed with other participants". Self esteem can also be enhanced through helping the individual develop appropriate problem solving skills. Resilience and coping mean that a person is able to manage or deal with their problems with a degree of competence. Therefore, by helping participants to effectively problem solve, they gain more self confidence. For instance, during the intervention sessions, skills were broken down into manageable steps such as helping a person with short term memory problems by making labels for items. Labels were done for the kitchen during one session, for the bedroom the next and later for the living room. This made it easier for the participant to manage finding items and get used to using the labels as cues to where things were kept. These steps helped the participants to recognize the problem (finding items), identify possible responses (use the cues or open every cupboard till they find what they are looking for), and their likely outcomes (find the item faster). Other executive functioning skills are also practiced in these activities such as knowing how to select the best alternative given the situation, being able to develop a realistic plan and accomplishing their goal (D'Zurilla & Nezu, 2000).

6.6.2 *Practical support*

Practical support consists of items such as money, physical intervention and material aid (Cutrona & Russell, 1990). Most participants did not have family or spouses to provide

them with the amount of support they required. Therefore the availability of community programs such as the Multiple Sclerosis society and the Community Re Entry Program (CRP) were key support agents for all participants. Participants relied heavily on the services provided by these agencies as they provided much needed practical support. For instance, for participants who could not get to workshops, the CRP would arrange for transport and in most cases, over the weeks teach the person with TBI how to catch the bus. A mentor would normally accompany the individual until they are comfortable taking the bus alone. Money was another area of concern for all participants. All of them lived on a disability pension and were struggling to manage their daily finances. Some participants with TBI were impulsive and would make big purchases often finishing their pension the day it was received. Others with MS had families depending on them for income and had to make their money stretch for the whole month. Practical support for them was in the form of helping with their budgeting, notifying them of resources available in the community such as food stamps, subsidies on disability equipment such as wheelchairs, rails and ramps.

6.6.3 Strength of the family unit

Internal strength of the family unit (e.g., problem solving and communicating difficulties together as a family). Communicating openly about issues was also a vital aspect of support for participants. Being able to honestly express emotions and discuss problems enables the individual to work through emotional reactions to stressful events. It also promotes the reassessment of a situation more effectively (Walen & Lachman, 2000). When people are aware of social support from their family, they may worry less about their problems and perceive them as being more manageable. For example, a participant with TBI

was able to care for her son independently, knowing that her parents lived just across the street and were there to support her when she needed them. Similarly, families of participants also helped support the individual with TBI and MS when they were fully aware of the condition and receive updated information. The MS society and Community Re Entry Program for instance regularly provided participants with leaflets, informational handouts and maintained close contact with families.

6.6.4 Religious and spiritual support

In addition to family and spousal factors, social support can also take the form of organised community involvement (Greeff & Human, 2004). Religious ties are important aspects of support for individuals as they provide spiritual and fellowship opportunities. For instance, some churches visit their sick members in hospitals, provide transportation to services and provide recreational and social activities to members to participate (Taylor, Ellison, Chatters, Levin & Lincoln, 2000). One participant with MS reported that her only friends and support were from the local church. Her family lived too far away to provide assistance and her church group had been extremely helpful to her.

Aspects of religion, such as religious beliefs, practices, and relationships, were used to assist participants in coping with their physical and psychosocial stress (Hathaway & Pargament, 1991). It has been observed that stronger religious beliefs can lead to greater sense of control, meaning, and deeper intimacy (Pargament et al., 1990; Tedeschi & Calhoun, 1996). Observations in the current study reveal that participants who were more religious and spiritual reported feeling less depressed, were more contented with what they had and had wider social networks.

Pargament (1990) proposed different ways that religious coping efforts potentially assist those coping with stressful experiences. First, religion may be a factor of coping

through one's understanding (e.g., the accident is part of God's plan). Second, religion may influence coping by shaping the coping process (e.g., religious background may help an individual to cope with illness by remaining positive). Third, religion may be shaped by the coping process (e.g., a near-death experience may lead an individual to seek out God). When faced with the trauma of an automobile accident, participants have to come to terms with the fact that the world can be unsafe, unjust and unpredictable. For instance, they often struggle to find explanations as to why the accident happened? Or have unanswered questions such as why me? A spiritual approach may be helpful in restoring hope, and acquiring a more optimistic view about justice and injustice, safety and danger, good and evil (Drescher & Foy, 1995).

6.7 Does unemployment compound the difficulties of TBI & MS and if so how?

TBI and MS are extensively connected with economic burden and unemployment (Julian, Vella, Vollmer, Hadjimichae, & Mohr, 2008). Unemployment is considerably higher after TBI and an illness such as MS. (Doctor, et al., 2005; Julian, et al., 2008). TBI and MS often rob the individual of the ability to participate in meaningful activities, such as through employment and other social involvement (Ashley, 2004; Yasuda, Wehman, Targett, Cifu, & West, 2001). Participants reported that being unemployed was one of the main reasons they were often isolated and excluded from the community (Machamer, et al., 2005; Mohr, et al., 1999). In situations such as this, their self esteem and confidence erodes, they experience financial stress, and are likely to lose vital social and vocational skills (Machamer, et al., 2005; Rao, Leo, & Bernardin, 1991; Rees, 2005b). In turn, they become pessimistic, use negative language and lose hope for the future. This stress, coupled with their existing disabilities takes a toll on their physical and mental health (Granerud & Severinsson, 2006).

As a result, returning to work post injury or illness is not easily accomplished and may not be accomplished at all by some individuals. In this study, 90% of participants with TBI and 80% with MS were unemployed. Those who were employed participated in casual or volunteer work and were given supported work options. For example, a woman with MS who returned to work was employed three times a week for half a day each time. She was unable to sustain a full day of work due to feelings of fatigue and she would subsequently become overwhelmed. She reported sometimes being bed ridden for a whole day in order to recover her strength from working. At work, she performed administration related tasks on a computer. She reported taking longer than usual to type out e mails as her thoughts wandered and she could not remember what she was typing a moment ago. She was easily distracted and would find herself unable to resume work when interrupted by a phone call or a colleague dropping in to chat. The tasks that she was required to perform placed less stress and demand on her executive functioning.

Figure 6.7 below, adapted from Rees (2005), shows the implications of persistent unemployment. As can be seen in the diagram, the implications of unemployment not only affect individuals, but have impacts on their family, and the community. For instance a participant with TBI was approached by a local newspaper to write weekly articles. He had been unemployed for 10 years post injury and this was his first employment opportunity. As a result, his mood changed dramatically. He was no longer depressed or angry. He was now able to laugh and joke during social outings where previously he would have sat alone in a corner not interacting with others. However, for most participants, returning to work has been a difficult and frustrating process. Some participants, particularly those with MS, reported trying to return to work without disclosing the nature of the difficulties they encountered as a result of their illness. The main areas of difficulties reported by both groups of participants were maintaining interpersonal relationships (Ashley, 2004, p. 511). For instance,

participants with TBI might get extremely angry with themselves for not being able to complete a given task and take their anger out on a co- worker. Or they would get teased at work by colleagues when they took time to respond to a question. Their delayed response time was assumed, by others, to be related to incompetence. Participants with MS also cited depression as a major reason they were unable to maintain employment. When depressed, they would miss going to work for weeks and when they did return, they were less motivated and unable to concentrate on work related issues.

Other problems reported by participants included job demands which exceeded their physical abilities such as standing for long hours or jobs which require lots of walking. Task related aspects of the job were another issue for participants for instance writing, slurred speech and working under stressful conditions (Gordon, Feldman, Shipley, & Weiss, 1997).

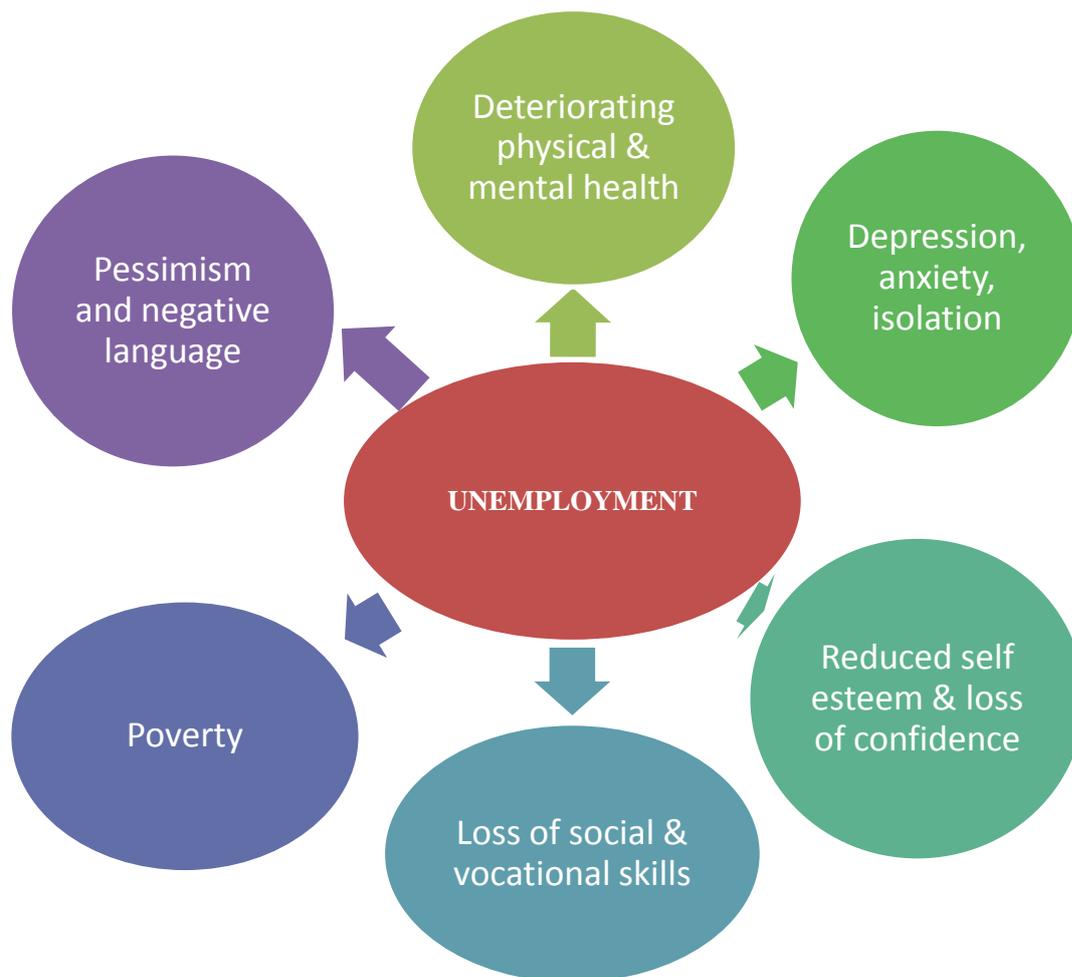


Figure 6.7 Implications of persistent unemployment.

For most participants, work was a part of their definition of self. When they lost employment, they often blamed themselves; felt doubtful, worthless, angry, frustrated and sad. For instance Peter, a participant with MS ,who recently had to stop work due to his increasing vision problems and mobility issues (see case study) described being unemployed as ;

“I lost my life that day. I don’t know who I am anymore, I have been working for so long and it was something I was good at. Now I have nothing. To me that’s the worst aspect of having MS”.

In order for people with TBI and MS to regain skills, participation in work experience activities is required. For this to be achieved, the person with TBI or MS needs the creation of opportunities to participate in work (e.g., having a realistic appreciation of current abilities and skills and finding work which suits the current not the previous level of functioning.)

Support at the worksite can also help the person to adjust better to their current level of functioning. This support can range from an occasional reminder from a co-worker to having a job coach present to help the person with TBI learn job skills and routines (Malec & Scanlan, 2004). These skills include help planning, anticipating, setting goals and completing tasks effectively. Such services are often critical for people with TBI to find and maintain employment. Once the person is able to learn the skills they need to be effective at their job, then the expensive supports such as the job coach can be faded out. Other cues such as written instructions can then be used to help the person.

Employer understanding is also a crucial factor in returning to employment. This includes educating the employer about the nature of the person's disabilities and their cognitive functioning. In the case of Peter, his employers were informed about his MS, and together they decided that a less physically demanding job was required in order for him to remain employed.

6.8 What part does level of education play in coping with these conditions?

Level of education has been found to be linked with resilience (Brewin, Andrews, & Valentine, 2000). Those with higher levels of education have increased likelihood of resilient outcomes (Bonanno, 2004). This finding also mirrors that of participants in the study with those in the MS group (who have slightly higher levels of education) displaying more resilient behaviours. However, research has not yet identified why this relationship occurs

(Bonanno, Galea, Bucciarelli, & Vlahov, 2007). A plausible explanation could be that those who are educated have an increased understanding of their injury/illness. This then enables them to get the support and services required from the appropriate agencies.

Similarly, cognitive capacity, which includes intelligence, has been found to be associated with better resilience (Glicksen, 2006, p. 123). For instance, those with higher intelligence as measured by standard IQ tests, have been found to have better communication, reasoning and problem solving skills (Mandleco & Peery, 2000). Intelligence may also include the ability to control impulses. Observations reveal that participants who were resilient thought carefully about problems before responding. They did not react impulsively. For instance, when angry with a carer, a male participant wrote a letter of complaint and thought out what he would say before writing.

6.9 What is the nature of social networks for all participants?

Social networks consist of the participant's friends, family, social support workers, colleagues and health care professionals. The presence of support has been found to promote adjustment from trauma over time (Koenen, Stellman, Stellman, & Sommer, 2003).

Perceived social support is generally associated with health and well-being (Izaute, et al., 2008).

Post trauma, participants and those around them often reported personality and behaviour changes which placed tremendous stress on their social networks. This in turn affected relationships and networks often broke down. It seems likely that the participants in this study had social networks which were fragile and in most cases, nonexistent post trauma (Eide & Roysamb, 2002; Helgeson, 2003; Rees, 2005, p. 12). Most participants had considerably small social networks which were mainly comprised of social workers, health

care professionals and rehabilitation groups such as the MS society or the Community Re Entry Program. In most instances one person is overloaded with the task of caring for the person with TBI or MS (e.g. mother, spouse). For instance, a participant with MS had little or no family living in Australia. Her husband left her, and she had three teenage children to care for. She supports them on her disability pension. Finances are always tight and to make matters worse, she cannot return to employment because of her mobility and bladder problems. Her social network consists of her children and her mother. She relies on her teenage children for support, both emotional and physical. Her family does not understand the nature of her illness and often place unrealistic demands on her. They ignore her MS and expect her to go on functioning like she used to. They rely on her for support and aid when they can't cope. Although she is happy to provide this support, she finds it takes a toll on her health and she once again has to depend on her children to take care of her. She feels extremely guilty to place the burden of care on her teenagers, who are too young to have to carry such heavy responsibilities.

In order to reduce the load, it is important to widen the range of significant social contacts. Devoid of active interventions in the form of community participation and individual support, people with disabilities often find themselves excluded from any social network (Hardiman & Segal 2003). In order to be an active participant in social situations (for example, in a club or at work), opportunities to participate in rewarding activities need to be created by mentors, social workers and rehabilitation professionals (Evert, et al., 2003; Rees, 2005). For example, people with TBI often have executive functioning difficulties which make it hard for them to initiate contact, follow up and plan social activities (Elliot, 2003; McCloskey, 2003). Mentors, friends and relatives can help by organizing recreational activities such as meeting up for coffee regularly, or going to the movies with the participant. They can then slowly fade out initiating activities, whilst encouraging the participant to plan,

organize and monitor future outings. Cues in the form of a phone call reminder, or sending a text message to remind them of the meeting can be used in order to help the participant successfully initiate social interaction.

A wider social network leads to a sense of belonging and promotes group unity, the opportunity to participate in new groups and to experience reciprocated support where everyone helps one another (Eide & Roysamb, 2002). This in turn often leads to more positive behaviours, and promotes resilience (Bengtsson-Tops 2001). For instance, all TBI participants reported finding companionship and friendships through attending the community re- entry rehabilitation program. They looked forward to their weekly workshops as it provided an avenue for social activity and participation.

6.9.1 Breaking of the social network

During the early stages following TBI, or a diagnosis of MS, the individual is typically focused on physical recovery. However, several years post injury, individuals become more conscious of reduced community integration, social isolation and boredom. These issues are of major concern to the individual and may worsen over time (Burleigh *et al.*, 1998; Ponsford, Sloan & Snow, 1995). Having a disability frequently results in isolation from social contacts (Olver *et al.*, 1996). Five years post injury, 50% of a follow-up group of people with TBI said they had lost friends (Olver *et al.*, 1996). Eames *et al.* (1996) reported that 71% of their participants had “no social life except that arranged by family” (p. 645). An additional 15% reported a noticeable reduction in social activity. For example, figure 6.8 and Figure 6.9 below describe the social networks of two participants in the study.

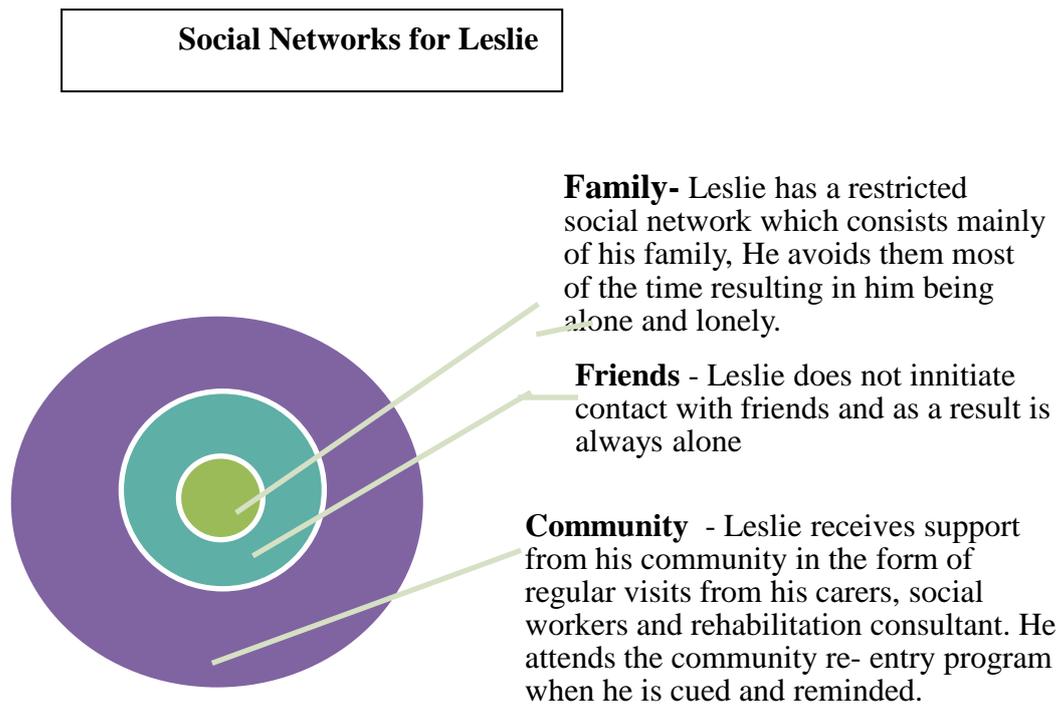


Figure 6.8 Social networks for Leslie a participant with TBI

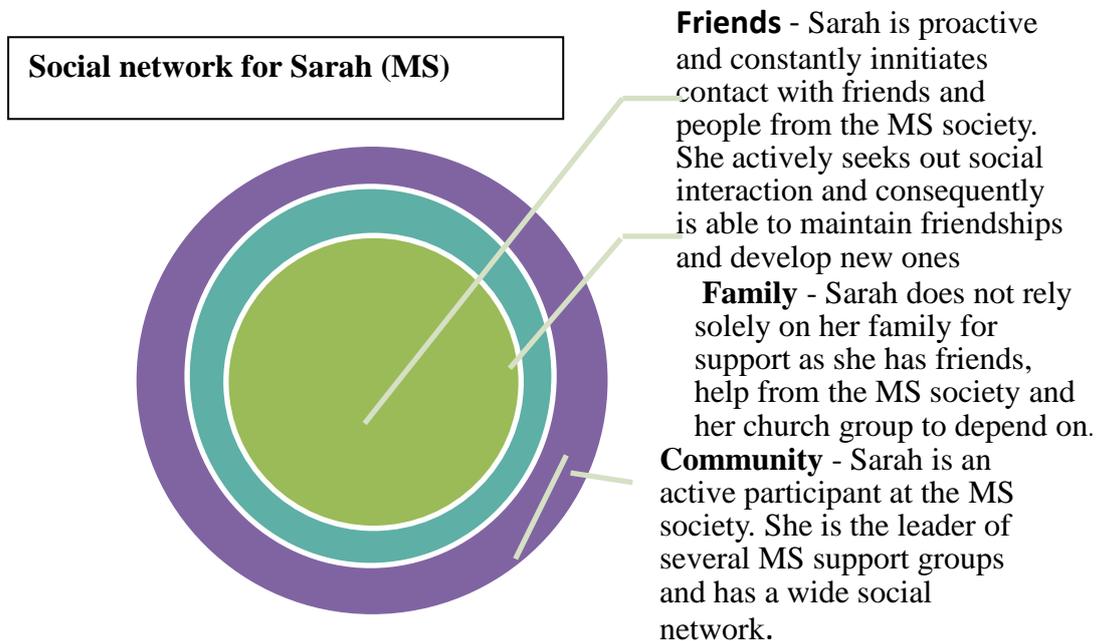


Figure 6.9 Social networks for Sarah a participant with MS

From the diagrams above it can be seen that these two people have very different social networks. Leslie relies heavily on his community for support and spends 80% of his time alone at home. This is consistent with most TBI participants in the study as social withdrawal, lack of initiation and inability to sustain friendships were often found. In addition to losing friends, participants with TBI experience significant cognitive-behavioural, difficulties (Ponsford *et al.*, 1995), which impact on their ability to develop new friendships. For Leslie, mood swings were an example of behavioural difficulties, which often confused people who did not know him. This added to his problems making friends. For instance Leslie would appear cheerful, talkative and proactive one day, and sad, pessimistic and withdrawn the next. He also influences his social setting by exhibiting a lack of self-esteem, becoming more sensitive to the opinions of others, and more importantly by becoming less physically active (Lewinsohn, Gotlib, & Seeley, 1997). For Leslie this meant not wanting to go out, and not wanting to exert himself. For instance, he would not attend the Community Re Entry Program, and when coerced and encouraged he would grudgingly attend. However when there, he did not participate in any of the group activities, because he was depressed, As a result, he performed poorly, and his group mates expressed disapproval at him for his poor performance. As a depressed person, Leslie then became overly sensitive to his group mates comments and his self-esteem tumbled even more. He then dropped out of the group, began to withdraw and argued with everybody he knew.

Sarah on the other hand, was able to better regulate her moods. She also became depressed sometimes and during these times withdrew from contact with others and isolated herself. However, she was able to resume contact and form new friendships once her mood was regulated and she was feeling better. Her friends know when she is absent from social gatherings or misses her MS support group meetings, that she is probably depressed. They then make the effort to contact her, to visit her at home and to persuade her to go out with

them. This support network is extremely helpful for Sarah as although she does not want to go out or see anyone; her friends give her no choice. They know that once she has participated in activities with them, her mood state improves and she enjoys herself. Most of her friends in her MS support group understand what she is going through because they have also experienced depression. Slowly Sarah inches her way back into her social network, and with support from her network, is able to reintegrate and be supportive to others. She initiates contact, makes phone calls, hosts support group meetings and makes new friends. Sarah reported that these networks ensure that Sarah is surrounded by dependable, resourceful people in times of need.

6.10 To what extent is denial a factor in coping with either condition?

The diagnosis of disability and the related implications can be devastating and anxiety provoking. Denial is a coping strategy some participants used to reverse the ‘reality’ of a situation (Lazarus & Folkman, 1984; Vos & de Haes, 2006). A young mother with MS, denied having primary progressive MS as she says it enables her “carry on living without the nightmare” of her condition. She would on some occasions refer to her MS being in remission, and on other days deny even having MS. For this participant, denial protected her from being helpless. She denied having a disability therefore resuming her pre diagnosis identity. Another participant with TBI did not want to associate with other who had a brain injury. He denies having an injury and often got very angry when asked to attend a brain injury program. For these participants denial allows them to temporarily be protected from the consequences of their illness. Consequences such as requiring a catheter, when bladder problems arise, or not being able to carry their children because they are fatigued. These

participants use denial to protect themselves, to retreat to a 'secluded inner world'. An inner world which allows them to go on living, despite the harsh realities of TBI or MS.

Research has viewed denial as a primitive defence that may be problematic (Derstine & Hargrove, 2001; Lazarus & Golden, 1981). Yet denial is also deemed as a method of healthy coping (Lazarus & Golden, 1981; Martz, Livneh, & Wright, 2007). For instance, in early stages of adjustment to a diagnosis of MS or coping with TBI, denial may have been beneficial in that it enabled participants to adjust to the painful reality of their situation at their own pace, preventing excessive anxiety. When denial continues, however, it can prevent participants from following medical recommendations or from learning new skills. A woman with MS refused taking breaks when fatigued. She instinctively performed the same amount of work as she did pre diagnosis, and as a result, collapsed a couple of times in public. Despite this, she kept her pace and to her, "keeping busy" was a protective mechanism as she did not think about her illness during these times.

Denial can also be maladaptive when it interferes with the accurate interpretation of reality. For instance, a participant with MS in the study denies having the illness as her symptoms are currently in remission. She refused to seek treatment and coped through denying her condition. However, because of this, she was able to live independently, have employment and go on with her life as it was pre diagnosis. That was until she experienced another bout of MS symptoms and had to be on leave for a long period of time to manage her symptoms such as blurred vision, bladder problems and fatigue. Denial enabled her to "make sense of the world" which in turn gave her confidence. It allowed her to achieve tasks which she could not master otherwise.

Denial of the chronic illness or disability can also have far reaching effects on others if, by denying the condition, individuals place others at risk (Falvo, 2005, p. 5). For instance, some participants put others at risk by denying their limitations such as driving recklessly due

to impaired judgment and poor decision making skills, or driving with vision problems or post traumatic epilepsy. A participant with TBI was involved in a series of car accidents, yet insists on driving herself. Her cognitive difficulties impaired her judgement on the road and she was often oblivious to other cars around her. Denial in the case of TBI can result in not taking essential medication. For instance, not taking antiepileptic medication may precipitate a seizure. Most participants with TBI had to be constantly cued and reminded to take their medications as they either forgot, or refused to take them when depressed.

Participants with TBI, who experienced denial often clung to a rigid mode of behaviour because this had become predictable and manageable. For instance, a man with TBI, relied heavily on a pre established routine of getting up at the same time each day, and performing the same activities daily. With the support of his carers and mentors, he was able to sustain this routine, which gave him the structure he needed to perform his domestic routines effectively. He would do laundry on a certain day, clean his home on another, and prepare meals when needed. Without this structure, he was observed to become, disoriented, would neglect his self care and would experience depressive or withdrawal behaviours.

Other participants experiencing depressive or withdrawal behaviours use denial as a way to cling on to the memories of the past self. For instance, the case study of Rob shows how he lived entirely in the past and neglected his self-care, hygiene and eating habits. Denial of condition and subsequent problems occurred because these difficulties were perceived as psychologically threatening. In doing so he sometimes prevented the development of a realistic self-concept. When this happens, the participant almost becomes incapable of taking advantage of new experiences, and as such “fails to develop” (Rees, 2005). For instance, a participant with TBI often took on a stereotypical perspective of saying no to anything his mentors or friends from the brain injury program proposed. When asked if he wanted to

attend a movie with the group he would say no, when asked if he wanted to write a poem he would say no. This was characteristic of his rigid and defensive behaviours.

There is empirical evidence that early denial plays a positive role in long term adjustment but that its persistence inhibits the rehabilitation process (Armstrong, 1991; Lazarus & Folkman, 1984; Lazarus & Golden, 1981). For instance, a participant recalled her reaction to being newly diagnosed with MS. She was in her early thirties, a young mother of two children below the ages of 5. She had never heard of MS, and her only problem with her health was that she had weakness in her right leg. Her doctor ran some tests and she was expecting to hear that it was some muscular problem which would go away in a few days. The reality was she was told she had MS. For months she never told anyone, not even herself that she had MS. She ignored it, hoped it would go away and thought the Doctor must be mistaken. Since she had no other symptoms, this reinforced her beliefs. She said

“At that time denial was all I had. It helped me set aside my anguish for a while because it was too much for me to face. At the same time it allowed me little glimpses into reality. I was able to begin to see MS clearer and make changes. It took me two years to come to terms with it. I’m still not used to telling anyone, least not myself that I have it”.

However, for some individuals a degree of denial is necessary as it represents hope. For instance, a participant with MS was hopeful of a total cure after her symptoms went into remission. Her hope for a cure motivated her to attend physiotherapy to strengthen her muscles, go swimming to improve fitness and eat large quantities of vegetables to improve her health. It is this hope which enabled some participants to respond to the challenges of their illness and to master them. From denial, participants are able to embrace tragedy, as well as triumph. It is therefore crucial to identify if denial facilitates or interferes with the learning of new skills and seeking help when needed. Only then is denial seen as maladaptive. However for most participants, aspects of denial were often their only source of hope. Hope for a life without the pain, suffering and challenges, which come hand in hand

when dealing with TBI or MS. The issue of denial although explored, was not really measured quantitatively in this study. Future studies could look into the relationship between measured denial and measured resilience.

6.11 To what extent is age a factor in coping with either MS or TBI?

The age of the participants at the time of a post traumatic event such as TBI or MS has shown a mixed pattern of findings in earlier research (Bonanno et al., 2007). Some studies have found that younger children have the ability to cope better with stressors such as trauma, and consequently are able to be resilient (Brewin et al., 2000, Bonanno & Kaltman, 1999). Others have shown that older adults have better coping skills, and have developed tried and tested coping mechanisms and problem solving techniques (Montross, Depp, & Daly, 2006; Wagnild, 2003). Thus, they have a well established repertoire of skills to use when dealing with novel and adverse situations. Similarly, Bonano et al (2007) found that participants over 65 years of age were least likely to have Post Traumatic Stress Disorder and more than 3 times as likely to be resilient when compared with younger participants. A possible explanation for this could be that older participants have developed effective coping strategies which they have used with success in the past.

The participants in this study did not show an age effect in their ability to be resilient. There was a small age difference between the mean age of both groups (TBI = 42, SD 6.23 and MS = 44, SD 10.80). No significant correlations were found for age and its relationship to total Resilience Scale Scores. Correlations at baseline were ($r(19) = .107, p > 0.05$), post intervention ($r(19) = .111, p > 0.05$) and at follow up ($r(19) = .129, p > 0.05$). These results show that participants in their 30's scored as high if not higher than older participants on the

resilience scale. (See table 5.1 in chapter 5). In particular, see participants 2, 9, 11, and 18 whose age range varies between 26 to 60 years (Table 3.3 and Table 5.1). Regardless of their age, there were older participants who displayed resilient behaviours and similarly, there were younger participants who responded and bounced back after trauma. Resilient behaviours included having a positive outlook, a sense of a personal mastery, actively engaging in activities and finding meaning and purpose in events (Bonanno, 2004; Foster, 1997; Fredrickson, Tugade, Waugh, & Larkin, 2003). These participants, regardless of age were able to display greater resilience in response to difficult or challenging life experiences such as having TBI and MS. They were able to maintain a positive emotional state under stress and generally reported less distress following a stressful event.

For instance the youngest participant in the present study, a 26 year old woman with MS, displayed resilient behaviours such as seeking support when needed, acknowledging difficulties in walking, exercising to lessen stiffness in her muscles and accepting help. All these behaviours are seen as active coping strategies on her part to deal with her diagnosis of MS. Similar behaviours were observed in an older participant with MS (aged 60). Therefore based on observations in the given study, age appears to have no effect on participant's ability to be resilient (Netuveli et al., 2008).

6.12 Since people with frontal brain damage generally have impaired executive functioning to what extent does a) training and/or b) mentoring compensate for executive functioning difficulties?

When executive functions are impaired, the motivation to participate in rehabilitation and the ability to compensate strategically for continuing disability, including executive functioning difficulties, are compromised (Stuss & Alexander, 2000; Ylvisaker & Feeney, 1998).

However, given appropriate training and intervention, executive functioning difficulties can be minimized or compensated for. Examples of some strategies used in intervention programs are;

- Building of trust as participants know the researcher will visit and a routine is established.
- The practice of repetition to improve behaviour (for instance practice writing lists daily)
- Making use of preserved skills or functions to compensate for impaired ones. For instance one participant used a tape recorder to record ‘to do lists’ because she had memory problems.
- Modifying the environment, social or work role, or personal resources such as physical stamina, so as to reduce the likelihood of executive functioning difficulties (for instance participants with TBI organize their kitchen to reduce distractors, or participants with MS taking frequent breaks to avoid feeling fatigued).
- Following and sticking to a routine in order to facilitate anticipation and predictability For instance, participants went shopping at 3 pm every Wednesday. This was a routine that was established by the participant and their carers.

Routine and predictability was crucial in the intervention, especially for participants with TBI. They needed a set routine such as meeting with the researcher every week at the same place and same time. This gave them something to anticipate, reduced confusion and enabled them to plan for the meeting. Participants would often write in their diary, and receive a cue in the form of a phone call reminding them of the meeting. (Johnstone & Stonnington, 2009; Ylvisaker & Feeney, 1998).

6.13 To what extent do mood swings for either sample affect measures of executive functioning and resilience?

Research has found that being in a positive mood state can improve performance on some types of cognitive tasks (Phillips, Bull, Adams, & Fraser, 2002). For instance, positive mood states can improve creativity (Hirt, Melton, McDonald, & Harackiewicz, 1996; Isen, 1999) and improve recall of pleasant memories (Nandrino, Dodin, Martin, & Hennisiaux 2004; Teasdale & Fogarty, 1979). It has been argued that having a positive mood state allows increased cognitive flexibility. Being in a positive mood is also said to enhance the ability to switch between different cognitive sets which is the ability to shift attention between different tasks (Isen, 1999). For example, a woman with MS reported that singing makes her happy, helps her be in a better mood and relaxes her. She bought a karaoke machine so that she can sing and practices singing daily. Since then she reports being less depressed, finds her health has improved (falls sick less often) and is able to focus her attention on tasks for longer. She can now bake a cake and clean her kitchen without getting fatigued or making mistakes. Similarly, a woman with TBI reported that going on a family holiday to the beach was the highlight of her year. She uses her memories of that time when she does relaxation imagery.

She remembers her emotions such as “feeling light as a feather”, “joyful”, “carefree” and “childlike”. She says that whilst on holidays, she never once forgot to take her medication (she was afraid she would fall sick otherwise and not be able to go to the beach). Her ability to make plans, follow through and complete them improved as she made plans to go fishing, rented the equipment and carried out the task with help from her father. She tried new things such as eating different types of seafood and going snorkelling.

Consequently, positive mood states have also been found to increase frontal lobe activity, predominantly in the left hemisphere (Davidson, Ekman, Saron, Senekis, & Friesen, 1990). An induced happy mood has been found to increase cerebral blood flow in various regions within the frontal lobes (Baker, Frith, & Dolan, 1997). This results in improved mood, increased self esteem and more positive behaviour. This effect has also been described by Fredrickson (1998), who cited evidence that positive emotions broaden the scope of attention, cognition, and action, and help build physical, intellectual, and social resources. For example, when out for a walk along the beach, a participant with TBI expressed feeling happy, his speech was more audible, he was able to effectively problem solve, and he used more humour. His positive mood helped him count sufficient change to buy coffee, strike a conversation with the waitress and find his way home without cueing.

Another similar mechanism participants who were more resilient used to regulate and manage their moods was that of producing a positive psychological break. This was done through infusing ordinary events with positive meaning (Folkman, Moskowitz, Ozer, & Park, 1997). For instance, they noticed the sunset whilst on a walk, or remembered a happy event while looking at old photographs. Such breaks provided them with a reprieve from their ongoing daily stress. The occurrences of these events were not accidental. To a certain extent they were usually created through planning positive events ahead in time, being aware of positive events when they occurred by chance, or by infusing neutral events with positive

meaning. These were ways participants could have a few moments of relief from their immense stress and trauma. For example, a participant with TBI noticed birds singing, the dew on the grass, and water trickling down the stream whilst on a nature walk. For these few moments, he reported feeling “one with nature”, he forgot his disabilities and his cares and he enjoyed these precious events as they occurred naturally. Similarly, participants with MS reported that sometimes they just sat quietly watching their children play, or attending football matches in which their children participated.

For most participants, planning ahead, anticipating these mood altering events and accomplishing them were carried out successfully when there was support from a friend or carer (Armstrong, 1991; Eide & Roysamb, 2002; White, Driver, & Warren, 2008). TBI participants needed cues and help arranging outings whilst MS participants relied on friends and carers more for companionship on these activities. However, the benefits to improving their mood states and maintaining a positive mood were reaped by both groups of participants irrespective of their disabilities.

CHAPTER VII

7 DISCUSSION

7.1 Introduction

In the months of the intervention, a range of issues surrounding human behaviour, personal tragedy and loss have been exposed. Despite crippling disabilities, certain individuals appear to ‘thrive’ whilst others merely ‘survive’. What made these individuals different? What nurtured their will to go on, when giving up was easier? It was their everyday resilience (Garmezy 1993; Jacelon 1997; Bonanno, Papa et al. 2001; Bonanno 2004). Resilient participants are observed to continue fulfilling personal and social responsibilities despite the trauma they experience. They are able to maintain a capacity for generative experiences and positive emotions (Bonanno & Keltner, 1997; Bonanno, Wortman, & Nesse, 2004; Folkman & Moskowitz, 2000; Tugade & Fredrickson, 2004). However, they often are not able to do this alone. Without long term support, or adequate management of mood disorders, even the most resilient participants are observed to break down. How then can their resilience be nurtured? Whilst avoiding adversity may not be possible, nurturing resilience helps participants to “bounce back” and reconstruct their lives post trauma.

The emergent principal theme in nurturing resilient behaviour is executive functioning. Quantitative data and participant observations reveal that resilient behaviours and executive functioning skills are interdependent. As participants’ resilience scores increased (Resilience Scale), so did their executive functioning abilities (Dysexecutive Questionnaire) (see Table 6.1). Executive functioning is crucial because it appears to underpin resilient behaviour. Through the effective use of executive functioning skills, participants are more equipped to face change and deal with adversity. This in turn fostered their resilience.

In the demonstration of resilient and executive functioning behaviours, the two groups of participants (TBI or MS), are noticeably different. The TBI group have severe cognitive difficulties which are readily apparent. The participants with MS have less marked, and more disguised cognitive difficulties. The nature of emotional difficulties faced by participants with TBI is varied according to the nature of their injury, extent of their physical disabilities, and type of medication they take. Some participants experience long periods of depression whilst others have equilibrium mood states. For participants with MS, their emotional difficulties often depend on the stage or type of MS, and coping or anticipating relapses. Differences in emotions between the two groups are subtle and change according to circumstances. Circumstances such as being immobilized by depression, or being imprisoned by anxiety. Coping with the loss of the person they once were, and the loathing of whom they have become often permeates their way of life. This description applies both to people with TBI and those with MS, although some of the participants with TBI have severe retrograde amnesia and cannot remember the person they once were. Measuring the relationship between resilient behaviours and executive functioning provides an understanding of their mood states. The relationship between these two factors provides significant implications and opportunities for psychological, social and educational interventions.

Evaluations indicate three central themes in the nurturing of post trauma resilient behaviours. The significant themes identified are (a) the effective use of executive functioning skills, (b) strong social support and networks, and (c) having equilibrium mood states. The literature review matrix (table 2.2) shows that similar factors were highlighted by previous research (Alvord & Grados 2005; Dowrick, Kokanovic et al. 2008; Masten 2001; Rutter 2002; Newman 2005; Werner 2000). There are parallels in the individual and group results in this study which are comparable with the notion of resilience in the context of chronic illness such as cancer, AIDS and mental illness (Antoni & Goodkin ,1988; Rabkin,

Remien, Katoff, & Williams, 1993). These studies identify personal characteristics associated with resilience to be optimism, an adaptable or proactive coping style, and the ability to elicit social support (Antoni & Goodkin, 1988; Rabkin, Remien, Katoff, & Williams, 1993).

In addition, similar to the findings of this study, Rabkin et al. (1993) suggest having wide-ranging interests, and an ability to articulate future goals as attributes of resilient individuals. This evidence demonstrates the importance of executive functioning skills for people with traumatic brain injury (TBI) and for people with multiple sclerosis (MS).

7.2 Executive functions and resilience

Among significant executive functioning skills, it is each person's intent which gives their lives focus and regulates their behaviour (Elliot 2003; Bennett et al. 2005; Cicerone et al. 2006; Fish, Evans et al. 2007; McCloskey 2003). This intent is apparent when individuals are purposeful, and have made conscious choices to behave in a certain manner. This is of course difficult if not impossible when participants experience anxiety and depressed mood. Two years after being diagnosed with relapse remitting MS a participant describes making a committed decision to not let MS rob her of all the things she wants to do. She said "*I refuse to let it get to me. I am stronger than it (MS), I may have MS but MS does not and will not have me*". Her will and intent to take positive action enables her to achieve her goals of being as independent as possible and to carry on working part time. Her history of proactive behaviour creates the likelihood that she can deal more effectively with the changes to her lifestyle post MS. These included changes such as struggling with inserting a catheter, managing the severe nausea and dizziness from her steroid treatment, and coping with her physical loss of muscle mass. However, she copes and remains positive. She goes back for more treatment, although the side effects were being "sick for a few days". She has become less mobile and learned to use a walking stick. She adapted to this.

Her actions can be contrasted with another young participant with primary progressive MS. She was diagnosed 4 years ago and to date is struggling with her diagnosis. She lives with her husband and three children. Yet, she isolates herself, and is often a prisoner of her depression. Prior to the diagnosis she had not experienced depression. On various occasions she has reported attempting to end her own life because of the unrelenting pain, both physical and psychological. Her physical and psychological health deteriorates. She experiences multiple infections which frequently reoccur. Life for her, as she says, is “hell on earth”. Engulfed by depression, she often finds no way out of her circumstances.

Increasing and sustaining planned constructive social interaction is an essential intervention. This planned constructive interaction (often between the social worker, mentor or family) is a basis for solving everyday difficulties. The interaction needs to be ‘congruent’ to the participant. A level of trust needs to be fostered between the mentor and the participant. Consensual knowledge has to be achieved by the mentor and the participant, for effective social interaction to occur (Rees, 2005). For instance, the mentor needs to be aware of the presence of depression, and how it may affect participants’ normal motivated social behaviour. Most thinking, planning, decision making and judgement materialize through communication with others (Zajonc & Adelman, 1987; Rees, 2005, pg 175). Interventions should facilitate this interaction.

Although resilient behaviour and executive functioning skills are seen to be inter related, there are instances when these two constructs occur independent from one another. This is especially the case for participants with TBI who have difficulties with executive functioning skills unless they are cued and supported. Only then can they manage essential tasks such as planning, sequencing tasks, anticipating future events and regulating their own behaviour (Cicerone, et al. 2006; Fish, et al. 2007). Support on a regular basis by mentors who know them well often helps compensate for executive functioning impairments (Barbee,

et al. 1998; Mohr, et al. 2001; Izaute, et al. 2008). This raises the issues as to whether sustained external support can or will compensate for executive functioning impairments. External support and structure is observed to be necessary, particularly for participants with TBI to cope. For example, a participant with TBI receives a phone call reminding her that her carer will arrive at 3 pm to take her to her drama workshop. These cues (phone call) become predictable and enable the participant to plan /anticipate an outing she would have otherwise missed.

Effective use of executive functioning skills enables individuals to make choices. When intact, effective executive functioning regulates a person's behaviour which then matches their intent. A young mother with MS has the intention of getting her children ready for school on time. She wakes up an hour earlier so that she has ample time to get herself ready before waking her children. She also plans the things she had to do ahead of time, like preparing lunches, and sorting her clothes out the night before. These actions occurred irrespective of her MS. Devoid of this planning and self regulation, the same woman, with the same intent, would often break down in the mornings. She feels overwhelmed by the many tasks she has to perform. Her children's occasional tantrums and refusal to go to school are responded to with shouting and yelling. This leaves her exhausted. Mornings can easily become a nightmare for the young mother without proper planning. The need for service providers to be sensitive to the needs of their clients is fundamental. It is often the understanding of these micro issues within the home, allied with deep respect for the client which makes interventions effective. To ignore these issues often renders interventions non functional and irrelevant.

With the aid of cues and constant practice, participants learned to use and apply executive functioning skills in times of adversity. A participant with MS plans to work part time during the mornings when her energy levels are high. She writes down her chores and

work related tasks in a notepad and cuts out the tasks she can't fit into her day. She prioritizes. She completes the tasks at the top of her list. She plans her day, organizes her clothes for the next day, and prepares breakfast the night before, so that she would have fewer things to do in the morning. She is less stressed and is able to better focus. The language she uses about herself and others is much more constructive. The young mother is not so angry with herself.

Similarly, a participant with TBI uses his diary to remind him to attend his brain injury rehabilitation program. He was cued by his mentors to regularly write in his diary and to check his diary entries in preparation for the week ahead. Nevertheless the adversity of family breakdown and the loss of regular access to his children are often too much to bear. It makes him bitter, and often angry. He despairs over never again experiencing family life. Nothing compensates him for this loss. His bitter language, often justifiable, impairs judgement and ipso facto, executive functioning. The fact that participants' language is impaired post TBI, often means that they are isolated from the community (Brown, Gordon, & Spielman, 2003; Curtiss, Vanderploeg, Spencer, & Salazar, 2001; Pennebaker & Francis, 1996; Ylvisaker & Feeney, 1998). Prolonged isolation results in atrophy of language, and diminishes the development of thinking and problem solving. Alternatively, sustained interaction and participating in rewarding social, cognitive, recreational and prevocational activities facilitates thinking.

Spending time in a variety of settings, on a regular basis was observed to help all participants generalize their executive functioning skills. Generalization of these skills needs to be planned, so that participants are provided with opportunities to use them in different settings (Fish, 2007; Wilson, 1992). For those with TBI, generalization of skills often did not occur when participants faced novel situations. Participants, particularly those with TBI are often rigid, and depend heavily on their predictable routines. Away from this routine, they do

not have pre-established norms to guide their behaviour. For instance a participant with TBI has frozen meals bought for him each week. He would reheat three meals a day. When these meals are not available, he is unable to make a meal for himself, although there is food around him.

Generalization is observed to be achieved when principles of errorless learning are used (see Table 2.15). Through the use of errorless learning principles, participants ultimately build a repertoire of skills which help them learn more complex skills. For people with TBI, this is often achieved in the presence of a mentor. In particular, when there are limited and specific goals. The mentor adapts these goals to the particular need, motivation and ability of the participant. For instance, a participant is given the task of turning on and off the computers before a writing workshop. He is shown how to do this by the program coordinator. Then he is asked to turn on the computer with cues provided. Eventually he is able to turn the computers on without the presence of his mentor. This process is not carried out to belittle the participant. Rather, it is designed to take into account participants' current abilities.

Successful completion of this task is covertly reinforcing (Cautela, 1973; Sohlberg & Mateer, 2001). This reinforcement is powerful because of its immediate consequences in promoting self directed behaviours. Mastery of the goal, with or without support is the definitive aim of intervention. In order for executive functioning skills to be generalized, there needs to be awareness of the importance of these skills. Unless the significance of executive functioning behaviour is understood, it often becomes a secondary focus of rehabilitation. Whilst professional literature uses the term executive functioning, there appears to be little or no awareness of the meaning of the term within families and those who provide services. It is therefore crucial for the success of any intervention, that knowledge about executive functioning becomes more "commonplace" and functional, rather than

academic or medical. For instance, families and service providers can be offered educational materials or attend small group discussions. Attending groups like the Community Re Entry Program for people with TBI or workshops at the MS society provide services which on the surface appear to be purely recreational. However these activities such as nature outings, computer and writing workshops or seminars on managing depression/anxiety offer opportunities for participants to practise their executive functioning skills.

Within the rehabilitation process for people with TBI or MS, there are many issues which trigger executive functioning such as responding to the feedback of service providers, or adhering to a diet and medicine regime. Yet, it is often isolation and withdrawal behaviours which makes resilient behaviour more difficult. Social networking appears crucial provided adequate medical interventions are operative. For instance the use of the drug Tysabri in the management of primary progressive MS or the use of anti convulsion medication for the management of epilepsy. Appropriate management of participants' anxiety and depression which may require anti depressants or in some cases anti psychotic medication is fundamental. Even the strongest networks can easily break down when the person with MS is in severe pain due to the rapid demyelisation which can occur in primary progressive MS. Under these circumstances, no amount of support or social contact can persuade the individual to leave their bed. Therefore unless the symptoms of MS can be managed, other interventions appear inferior.

Throughout this study, it was apparent that information about medication, cognitive difficulties and resilient behaviour needs to be shared amongst significant people in participants' lives. For instance, a participant with TBI attending a brain injury camp needs to inform the organizers about his anti convulsion medication, when he needs to take it and the exact dosage. Insurance companies often need information on the extent of a person's cognitive difficulties to fund compensation plans. Families need information and education

about the personality changes as a result of TBI, or the behavioural changes as a result of depression for participants with MS. At present, it appears that only a limited number of medical professionals have this knowledge, and in order for interventions to be successful, this information needs to be shared. In some cases, there is a concern that information of this sort may have reverse effects, where the participants are labelled as “psychotic”, or seen as being “helpless”. Through improved understanding of TBI and MS, it is hoped that these misconceptions are clarified.

7.3 Social support and networks

A key goal of the intervention is to help participants maintain and develop social networks. Attempts to increase or create social networks following TBI and MS are based on the principle that such efforts will lead to an improvement in the availability of people whom participants can rely on in times of need. The increase of available support and a wider social network has been related to better health outcomes (Gielen, McDonnell, Wu, O’Campo, & Faden, 2001; Hardiman & Segal, 2003; Helgeson, 2003; Sollom & Kneebone, 2007). An example of this can be found in the case studies of Leslie and Sarah (see Figure 6.8 and Figure 6.9). Sarah’s network was wider and included more key supporters. Leslie’s on the other hand was more limited to community supports such as his rehabilitation consultant and carers. The effect of this is that Leslie has fewer friends and people to rely on whilst Sarah has people she could call when she experiences another relapse. Social interactions within participants’ networks facilitate the inclusion process. It allows participants to experience belonging and ownership. The social isolation of people with TBI or MS often means that significant associations with local communities seldom occur, thus further depriving participants.

For people with TBI and those with MS, social networks “don’t just happen”. They need to be created. Eames et al. (1996) found that 71 percent of their sample of people with TBI, had ‘no social life except that arranged by family’, and a further 15 percent reported a marked reduction in social activity. All participants’ report that their relationship with friends have changed substantially, and the range of interests they share are restricted. In addition to losing friends, people with TBI experience significant cognitive-behavioural impairments (McDonald, 2003; Ponsford *et al.*, 1995), which impact on their ability to develop new friendships. Participants with TBI often have difficulty initiating behaviours which are required in sustaining relationship (e.g., inviting a friend to lunch, conversing with others without cues). Stable relationships with close family members and peers for those with TBI, are often based on reciprocal exchange (Berry, 2000; Hartup, 1999; Hartup, 1996; Strough, 2001; Vandell, 1994). Reciprocal exchange such as making the effort to return a phone call, inviting a friend for a meal or ensuring attendance at planned activities was part of the social mechanism of network building. Despite this, there is considerable significance in increasing participants’ social contacts and the number of community locations in which they are valued and accepted.

The friendship bond is fragile because unlike marital, family or work relationships, there are no formal ties (Wiseman, 1986). Friendships are maintained through mutual interests, and these change over the lifespan and therefore are vulnerable to termination following a major life change, such as TBI or MS. Participants need sustained support to reciprocate the gestures of others (Achat, 1998; Cabness, 2003; Coyne, 1991; Eide, 2002; Helgeson, 2003). Devoid of active interventions in the form of community participation and individual support, people with TBI often find themselves on the edge of social networks. Too often they are excluded (Hardiman & Segal 2003). To facilitate participation in social situations, opportunities for rewarding activities need to be created (Evert, Harvey, Trauer, &

Herrman, 2003; Rees, 2005). Mentors, families and rehabilitation professionals can help create these opportunities. For example by making forward plans in conjunction with the participants that involve social, recreational and prevocational experiences such as going to the cafe or a walk along the beach.

The development of social supports and networks is imperative. These networks when in place offer much needed solace and respite for not only the participants but also for their carers (Helgeson, 2003; Rauch, 2001; Seeman, 1996; Tomberg, 2007). The intervention addressed participants' social network problems through (a) building new network ties, (b) maintaining and strengthening existing ties and (c) enhancing family and carer ties (Biegel, Tracy, & Corvo, 1994; Hardiman & Segal, 2003). New network ties are built by adding more individual members and more groups of people (clusters) to the network. For participants with TBI, this included making friends in the Community Re Entry Program. Participants with MS are encouraged to maintain contact with their ex colleagues, and friends. A participant with MS slowly lost contact with friends. She felt that she had nothing in common with them anymore.

Unfortunately "not having anything in common", was characteristic for all 20 participants. When the participant with MS did invite her friends over for coffee, she realised that they were concerned for her and missed having her around. There is a willingness of the community to support people with TBI and MS. However, participants' misconception of the availability of support often prevents them from initiating contact (Haefffel, 2007; Sarason, Sarason, & Gurung, 2001). Perceptions of support from significant family members/friends reassure participants that in the event of a stressful situation, there will be available support. This often reduces the extent to which participants feel threatened. Thus the social network appears to directly influence threat or risk appraisals. Reassuring participants that they have the intrinsic (coping skills) or external resources (family support) to cope with problems gave

them confidence in their abilities. For instance, a man with MS knows that he can talk to his parents or wife about the horrific side effects of medication. A participant with TBI feels more confident to initiate contact with others when a mentor is present. The perception of support appears almost as crucial as the availability of support.

It is the regularity and predictability of social interaction which alters the perception of support for people with TBI and MS. Regularity and predictability in social interaction increases the likelihood of the person with TBI or MS subsequently initiating contact with others.

Participants are observed to rely heavily on asymmetrical relationships such as those with a mentor, or rehabilitation professional. Asymmetrical ties are often more typical of formal relationships and these are more difficult to sustain in the long term. These ties are also harder to depend on for emotional support. Participants, especially those with TBI, are often divorced, have problems developing friendships, and consequently live alone with limited social contact from the outside world. Those with MS often experience a heavy strain on most of their personal networks. Johnson (1991) says "*individuals free of negative psychological symptoms are more likely to attract and maintain positive social relationships than individuals who exhibit such symptoms*" (p. 408). As a result, it is often peer and family relationships which are damaged by the psychological stress of participants with TBI or MS. All participants' families/spouses/carers report that the behaviours which constitute a load or a problem for them are often the psychosocial sequelae and changes in the personality of the person with TBI that persist over time. These findings are similar to previous studies which have found consistent family emotions such as depression, denial, anger, grief and disturbances in social and family functions (Florian et al., 1989; Lezak, 1988; Livingstone & Brooks, 1988). These emotional responses may contribute to a strong sense of "burden", which may lower the level of family functioning.

Network members, in close relationships with participants, are more likely to be “burdened” by demands of support, which is often ‘one-way’ rather than reciprocal. Participants reported frequently experiencing breaking of their networks where friends and family find their disabilities too challenging and, reportedly, “could not cope” or “tolerate them anymore” (Armstrong, Birnie-Lefcovitch, & Ungar, 2005; Hays, Steffens, Flint, Bosworth, & George, 2001). Families and friends no longer have norms to guide their interactions with the participants. As a consequence, friends soon “disappear” and families are often at a loss as to how they can cope with the breakdown of social networks. An option for people with TBI or MS is to have someone live in. This person acts not only as a means of support, but also provides valuable companionship. Independent living arrangements have proved successful and can be an important intervention for families of persons with TBI. This can take the form of two or three persons sharing an apartment with full-time or part-time supervision. This type of living arrangement can be beneficial both to the person and the family (Friss, Whitlatch, & Yale, 1990). For instance, when a participant with TBI could not live alone, he was encouraged to move into a care facility for people with disabilities. He now shares an apartment with another gentleman with an intellectual disability. He reports that “*I don’t have to wake up alone anymore. Sometimes when I am in a bad mood, I don’t even talk to him but it’s nice knowing he is there*”. Although this may not be possible for all participants, live-in companions can provide an alternative avenue of support.

Social isolation is often a characteristic of participants with TBI or MS. Pre trauma/pre diagnosis, participants report that their social networks were rich. Carers and mentors are instrumental in creating opportunities for interaction and ensuring the availability of socially rewarding activities for participants. For instance, working with participants to increase interests in regular community-based activities may offer increased opportunities for social contact and the potential for development of new friendships. For example, a participant with

TBI developed his interest in sailing by joining a sailing program for people with a disability (Sailability). His interest in the sport may lead to the development of skills in sailing and, with appropriate support, participation at a local sailing tournament. Routine participation in this activity will offer regular contact with other club members. Often being present in the community is the first step towards integration. However, presence in the community may not necessarily lead to inclusion or expansion of social networks. At times, although participants are actively involved in community-based groups, friendships do not occur naturally and may need to be fostered. Acquaintances, who have common interests with participants, may be encouraged to develop their friendship through active social planning by the participant with TBI, supported by their mentors. Mentors can cue the participant to plan and attend meetings with friends. Devoid of external intervention, this opportunity for constructive social interaction is denied.

The behaviours of self induced social isolation act “both as a measure for protecting one’s vulnerable self and as an attempt to minimize further hurt that might be caused by failed attempts to associate with others” (Rokach & Brock, 1998, p. 113). Without the availability of structure and support from their rehabilitation carers, participants face significant challenges. These challenges involve breaking the cycle of loneliness through relating to and initiating contact with others. Yet, by staying home, participants attempt to protect themselves from future rejection and pain. The participant with TBI or MS oscillates between volition, perceived rejection and a maelstrom of organised activity.

Some participants rejected the idea of interactions with others who also had TBI or MS. For instance a participant with TBI refuses to attend a brain injury program because “she is not like them” (others with TBI). There are negative consequences when peers with TBI are included in her support network. She doesn’t want to be seen as disabled (often a characteristic of people with an acquired disability). She rejects the social contacts her peers

offer. This behaviour may in fact have the effect of perpetuating or increasing loneliness, including the pain of loneliness resulting in further need to protect oneself (Cacioppo & Hawkley, 2003; Rokach, 1998).

While similarity may induce social comparison and negative consequences, it is not necessarily true that similar others threaten the self esteem of participants. For instance, participants in support groups for people with disabilities often report that others with similar conditions are better able to understand their problems. This is where support groups play a significant role in promoting relationships. These relationships can often be the foundations of vital support.

But all too often, service providers and care workers are overwhelmed and recognise that resources are inadequate. They know that the pre determined path of the injury/illness can break down even the most resilient participants. The resources and manpower needed to support people with TBI and MS in the community is scarce. Often the individual is at the mercy of whatever help they can get. When support is limited, individuals are often pushed to 'extreme behaviour'. Behaviours, such as contemplating suicide. All participants in this study reported battling with the idea of ending their own lives. A woman with MS said "*I remember just wanting to end this life that imprisons me. I would have killed myself a long time ago, but each time I even think about it, a jolt brings me back to here and now. My children need me, I cannot leave them. I wake up each morning because of them*". A young woman with TBI reported that she often weighed the idea of suicide as it would mean her parents no longer have to be burdened with looking after her. She says, "*My mind kept playing games with me, one minute I wanted to live the next I just wanted to disappear and the only way I know how is to die*".

There appears little or no "connoisseurship" of the stress that participants with TBI and MS experience within the community. Rees (2005, p. 5) describes connoisseurship as

people who develop a comprehensive understanding of the effects of brain injury/ MS for persons known to them. Connoisseurs, in this context, are people who have an “intimate familiarity” with the phenomena of TBI or MS. From participants’ reports and observations, connoisseurship appears to be limited to rehabilitation professionals and a limited number of service providers. In order to better support participants with TBI or MS, there needs to be an advancement of information within the community regarding the difficulties and factors influencing rehabilitation. Ways this can be done for example are to include participants’ friends or carers (with participants’ consent) in the rehabilitation process. People within the participants’ social network can then develop an understanding of the cognitive-behavioural, physical and communication sequelae of TBI or MS. They can help to identify strategies to facilitate engagement in activities and relationships. In the early stages of rehabilitation, particularly post TBI, actively engaging friends in the rehabilitation process may not seem important, given the other demands on the consultant’s time. However, the provision of education and support to help prevent the loss of friends at this stage appears likely to be more effective and efficient than attempting to re-engage friends or help participants develop new friendships several years post injury (Callaway, Sloan, & Winkler, 2005). Often, the lack of sustained support of such nature can leave participants overwhelmed. It is during these times that people may “snap”.

Recently in South Australia, a mother of two children with intellectual disabilities was alleged to have murdered her son and she took his body to the local police station. She admitted murdering her severely disabled son. She could not cope with being his sole carer. She “just had enough” and “snapped” (Schriever, 2010). Comparable stress was often reported by participants in this study. This is an extreme example of how, under conditions of tremendous stress and the breaking of social networks, people can act in a manner that may seem inconceivable to others.

The psychological trauma participants all deal with is unrelenting. The intolerable aspect of dealing with the trauma of having a brain injury or being diagnosed with MS lies in the foreknowledge that no remedy will come; not in a minute, an hour, a day, or a month. There appear periods of mild relief, when support is available, where someone (a carer or family member) is there to lessen the burden. But this is only temporary. The emotion and pain too often and too easily returns. Observations reveal that emotional pain renders decision making inoperative. It appears that, wherever they go or whatever they do, it is impossible for participants to forget the acquired disability. Their disability is attached to them, part of who they have become. These participants live for the brief moments where they are stirred to experience joy, to have hope for another day and to know they will receive support. But they report that it slips away just as soon as it arrives.

In order to strengthen existing social networks, families are often a part of the intervention. Although participants received individual sessions, their families also often require support. Family ties are enhanced by the development of family support programs. These support programs included family meetings and education, respite breaks and the linking of families to external sources of support (Greeff, 2006; Conger, 2002; Rutter, 1999 Monteith, 2002). For instance, families are provided with information about the nature of MS and TBI to better help them understand and cope. Families are also provided with respite services through the MS society. For example, participants are scheduled to have carers come in regularly to ease the burden of care on the families. Rob has carers who came in regularly to clean his house, Peter has someone come in to help him shower and cook, whilst Sarah has carers come and take her to her job at the community centre. Families also help create a symmetrical relationship. For example including the wife of a participant with MS as part of his intervention. The participant's wife feels like she belongs and her expert "connoisseur"

knowledge of the participant can help the mentors/ rehabilitation professionals understand her husband's personal experiences.

Devoid of support, participants are often alone, with little or no opportunities for social activity. Leslie, Rob, Betty and Tina all rely solely on their carers, mentors and rehabilitation professionals to create participation and future activities. Mentors and carers provide hope, by giving participants something to which they can look forward. This is light at the end of a dark tunnel. Support of this nature needs to be sustained over long periods of time (Coyne, 1991; Fredrickson, 2001; Ownsworth, 2000; Rauch, 2001; Rutter, 2002; Ylvisaker, 2003). The problem is that often there is a severe lack of professional and government action required to generate viable support networks in every domain (Barbee, 1998; Hays, 2001; Schulz, 2004; Wineman, 1990). Without support networks, Leslie wouldn't have been able to go on a nature trail walk, Betty would not have gone to watch the latest movie and Tina would most likely never leave her home.

7.4 Mood states and positive emotions

Depression was apparent in all participants at some point during the intervention process. Participants who have higher measured resilience score are less likely however to experience depression. Yet, they too reported periods of low mood and often experienced 'intense negative emotions'. The case study of Sarah describes how she is mostly optimistic, keeps herself occupied and plans activities in which to participate. She attends supports groups, works part time and is an active member of her local church. However, despite her best efforts, the influence of her MS sometimes becomes too much to bear. During these times, she does not watch her diet; she eats to satisfy her emotional vacuum and does not want to leave her bed. She puts on weight which makes it harder for her to get in and out of her wheelchair. She says; *"I give myself time to be depressed, to cry. I cry every morning in*

bed for five minutes. Then I make myself stop. I drag myself out of bed and some days all I can do is shower and get dressed. On these days, getting dressed is my achievement. I do not let myself get upset about the things I cannot do”.

Even when depressed, Sarah has a level of awareness and displays significant personal insight. She knows when she is depressed and although she is not “immune” to getting depressed, she knows when and how to pick herself up again. She resumes her daily routine after a short period and does not let her negative mood state persist.

Depression often persists when participants are not able to display personal insight. The longer depressive behaviour persists, the greater is the likelihood of social and cognitive deterioration. Personal insight/awareness is necessary for the effective functioning of higher order cognitive functions (Abreu, et al., 2001; Crosson, et al., 1989; Newman, Garmoe, Beatty, & Ziccardi, 2000; Tandon & Solomon, 2008). Reduced insight is often linked with withdrawal and non participatory behaviours. When this occurs, any form of rational thought disappears and participant’s thinking is replaced by distress (Rees, 2005). Participatory behaviours shaped and supported by mentors/carers are crucial to overcome flattened mood and reduced insight. For instance, participants gain insight through sharing and being upfront about their difficulties with others. This is especially successful when there is a pre established relationship between the participant and the person they choose to share with. Building a positive therapeutic alliance with participants is recommended in order to assist them to become more aware of their abilities (Ownsworth, McFarland, & Young, 2000; Sohlberg, Mateer, Penkman, Glang, & Todis, 1998). This therapeutic alliance enables participants to be open rather than defensive. Participants also reported that having previous successful experiences such as being able to problem solve with little or no cueing contributed to the raising of their awareness. They are confident in their abilities knowing

that any new activity can be accommodated. When this occurred, participants displayed more resilient behaviours and experienced less negative mood states.

The findings in this study that participants who have higher measured resilience are less prone to depression, is consistent with other studies which find that resilient behaviours can protect the individual from experiencing and/or coping with depression (Judd et al., 2003; Komiti et al., 2003; Ryden, Karlsson, Sullivan, Torgerson, & Taft, 2003). However, resilient behaviour and subsequent protective factors such as optimism, hope, positive language and support do not prevent participants from being depressed. Resilience does not result from avoidance of risk (behaviours or symptoms of depression and anxiety). Rather, it stems from exposure to risks. The consequent successful adaptation depends on how well these risks are managed (Luthar, Cicchetti, & Becker, 2000). For instance, some participants used their social network to help them overcome depression. They ring their social workers or rehabilitation professionals and actively seek help when needed.

Table 6.6 summarises participants' response as to what conditions contribute to their depression. Both groups rated physical and cognitive fatigue as a major contributor to their stress and depressed mood and this contributes to their social isolation. Not having rewarding activity planned, nor having any social or recreational event to look forward to was often reported to result in depressed mood.

One participant with TBI, who used to be a musician, is depressed as she cannot play a musical instrument as she could in the past. She was encouraged to try relearning, but gives up in frustration as she clearly remembers how well she used to play. She lives alone and her only companion "is her cat", contrasting significantly with the comprehensive network of friends she had pre trauma. She doesn't want to go out or see anyone as she doesn't want them to see 'who she has become'. She allows her rehabilitation consultant to visit but few others are invited when she becomes withdrawn and depressed. She used to have regular

visitors but she could end up crying over “sheer exhaustion, humiliation and frustration”. Eventually friends stopped visiting. The loneliness of being isolated in her own home is ‘even worse’ according to her than her disability.

7.4.1 *High risk*

Participants’ with MS and TBI have more trigger factors which can be attributed to their disability. These factors include physical and cognitive fatigue, progression of disease, mobility issues, loss of employment, breakdown in social support, and relationship breakdown. The interaction between these risks factors and participants’ current environment act together to influence their ability to display resilient behaviours. For instance a young mother with MS having difficulty with her mobility will definitely have more challenges parenting compared to another individual without MS. She has to cope with her physical disability, along with the pain and medical complications associated with MS such as bladder weakness, loss of vision and numbness. Her psychological health is also affected as she has to manage her depressed mood. This places added strain on her ability to cope.

During periods of anger, depression or anxiety, a person’s emotions may take control (Campbell & MacQueen, 2006; Nitschke, et al., 2009). When mood states are dominant, then resilient behaviours related to reasoning and judgement are reduced. Low levels of executive functioning in turn lead to poor control over impulsive behaviour and emotions (Nitschke, et al., 2009). This was apparent in almost all participants with TBI in this study. They tended to be impetuous. Most had difficulty reasoning and inhibiting behaviour. As an example, one participant with TBI who was anxious went on a shopping spree, spending hundreds of dollars, only to be left penniless for food and bills the next week. Similarly the case study of Rob shows that when anxious or depressed, he resorted to alcohol and heavy smoking. He might spend all of his weekly allowance on tobacco and alcohol, with little or no money left

for food. His social worker visits, only to find that he has not had a proper meal in days.

Rob's experience of anxiety and depression disrupts effective executive functioning. There is an absence of resilient proactive behaviour. The absence of "proper meals" is a sign of Rob's depression which indicates the need for domestic structure and supportive intervention.

Mentors, families and significant care workers need to appreciate that there are resilient behaviours in people with TBI or MS. However, when mood states take control, it makes it difficult for these resilient behaviours to emerge.

Resilient behaviour generally occurs when participants living with mood disorders discover, or relearn, their ability for pursuing personal goals. Goals which allow them to be independent again. In order for this to occur, there appears a need to first develop a sense of self which allows them to grow beyond the symptoms of their mood disorder (Repper & Perkins, 2003; Warner, 2003). To see themselves as fighters, not just surviving the adversity they each face. This process can take many years, requiring skilled and sustained support.

7.4.2 Coping and Resilience

Resilience and coping are related constructs, but coping refers to the set of cognitive and behavioural strategies used by an individual to manage the demands of stressful situations (Folkman & Moskowitz, 2004), whereas resilience refers to adaptive outcomes in the face of adversity. However, most researchers use resilience and coping interchangeably (Folkman & Moskowitz, 2000; Fredrickson, Tugade, Waugh, & Larkin, 2003; Jacelon, 1997; Tugade, Fredrickson, & Barret, 2004).

It appears that a general tendency to respond to adversity with an active, problem solving approach promoted resilience in participants (Aspinwall & Taylor, 1997; Blonna, 2007; Folkman & Moskowitz, 2000; Kohn, 1996; Schweitzer, Jaimi, & Kagee, 2007). The active, problem-solving approach of coping has been shown to promote effective recovery

from many types of stressful situations (Penley et al., 2002; Zeidner & Saklofske, 1996). This proactive style of coping allowed participants to move away from stressors effectively and experience a consequential sense of self-efficacy (Campbell-Sills, et al., 2006). Participants identified as being resilient used coping strategies effectively in times of adversity (Aspinwall & Taylor, 1997; Fredrickson et al., 2003b; Garnezy 1993; Rutter 1983). For instance some behaviours displayed by resilient and less resilient participants are described in Table 7.1 below.

Table 7.1 *Observed adaptive and maladaptive coping behaviours*

Adaptive coping behaviours	Maladaptive coping behaviours
<ul style="list-style-type: none"> • Talking to parents or friends • Exercise / sports • Yoga / meditation • Problem-solving • Thinking positive / being optimistic • Using humour • Listening to music • Hobbies / recreation • Praying / religious activities • Social support / asking for help • Having regular meals • Proper sleep pattern • Activities to look forward to 	<ul style="list-style-type: none"> • Isolation / social withdrawal • Eating comfort foods (Often this is instead of eating a healthy diet or perhaps taking in excessive calories) • Aggressive behaviour/ Physical fights • Using drugs • Thrill-seeking (Putting yourself at risk or in danger to get a "high" or thrill) • Binging/ eating disorders • Excessive alcohol consumption

Ethnographic Research, especially in relation to identifying and explaining coping behaviours as per table 7.1 above, can also be regarded as observing strategies which help keep a person's thoughts in alignment with specified goals. The coping behaviours and activities or goals help the participants to think about how they intend to behave. It was observed that when they are focused, their intentions regarding painting, meditating, reading, relaxing and sharing with friends come to life. If the person has a strong intent to hold activities in their mind then these activities can be regarded as 'coping behaviours'.

When a person is very focused on a task or activity then, in effect, the frontal lobe can make the conscious thoughts in relation to the activities so important that, at that moment, nothing else exists. According to Dispenza (2007, p 365) a person's internal picture takes up so much of their conscious attention that negative aspects of their experience, in this case Tina's or Leslie's loneliness and state of anxiety and depression, disappears.

Listening to relaxing music, such as some selections of classical music, results in the listener experiencing positive emotions and increases in parasympathetic nervous system arousal (Knobloch & Zillman, 2002). This increase in parasympathetic arousal is considered to play a crucial role in reducing participants' levels of anxiety and stress. For instance, a participant with MS would always have soft, relaxing music playing in the background whilst she does her daily chores. She said it "calms her down" when she experiences difficulties doing the chores that previously she had no problems completing. Music can cause intense emotional arousal followed by feelings of relaxation and satisfaction. When listening to relaxing music, the participants described "being taken over". Music has the power to temporarily uplift people, minimizing their anxieties and enabling them to "escape entirely from all afflictions" (Schopenhauer; in Storr, 1997). Like other arts, music can provide temporary retreat from the 'pains of existence' (Storr, 1997, p. 98). For participants, music was a way of retreating from the pains of their disability, a way to escape reality, even if it was for the briefest moments. In order for listening to music to be a coping strategy for participants, it had to become a positive habit. A habit which participants performed regularly. A man with MS reported turning on the radio when alone to avoid feeling lonely. The radio often was his only companion, filling the silence which was his post diagnosis life. Music he said "raised his spirits", or at least it relieved the sterility of being unable to care about anything or anyone, which was characteristic of his depressive behaviours.

Buddhists have long viewed coping and problem solving to be achieved in meditation (Doidge, 2007, p. 171). Meditation has proved most effective in lowering stress and so is likely to help preserve a person's memory (Newberg, Wintering, Khalsa, Roggenkamp, & Waldman, 2010). Research has also found that during meditation, the orientation association area of the brain (the superior parietal lobe), goes silent, whilst the frontal lobe lights up with activity (Dispenza, 2007). This activity in the brain allows individuals meditating to perceive the self as endless and "intimately interwoven with everyone and everything" (Newberg, D'Aquili, & Rause, 2002). Meditation for participants entails focusing their awareness on what is happening in the present. In a state of meditation, they are not thinking or doing, they are simply being. "If you are truly living in the present moment, you can let go of the past and the future; they no longer have a hold on you. That can be incredibly freeing," (Williams, Teasdale, Segal, & Kabat-Zinn, 2007). Participants recognised the value of meditation and were willing to participate when classes were organised through the MS society or Community Re-Entry Program. A participant with MS reported that within a few weeks of practising meditation, she was once again "an active character in my life. It was as if a fog had started to lift". She also said. "Those around me noticed the changes, I didn't withdraw as much, and I was less confused and could deal with more noise around me". Other participants who practised in classes also reported that their sense of isolation decreased, as their time alone "doesn't seem so bad". However, these cases were the exception not the rule. Helping people with TBI or MS to make meditation a habit was much more complex. In their circumstances, naturally they needed much support to develop and sustain the habit of meditating regularly.

Anthony Storr, (1997) observed that, "urban civilization cuts us off from our inner lives. We easily lose touch with the wellsprings of creative phantasy which make life worth living" (p. 121). Tapping into the "wellsprings of creative phantasy" can be achieved through

meditation. The notion of 'inner calm' and 'creative phantasy' which Storr is referring to can be 'mere vapour' for people who are severely traumatised. These notions did not exist unless participants had support. For example a participant with TBI struggled with finding inner calm, when coping with losing custody of his children. He met regularly with his rehabilitation consultant, and together he managed to find a way of achieving stillness. In that stillness, they usually solved problems in regards to regular access to his children. For a participant with MS, 'inner calm' meant that she could begin to talk about being denied the opportunity to become an opera singer. Yet she enjoyed the great singers and being taken to concerts. It is only in this state of 'inner calm' that she can begin to come to terms with her great sense of loss. Once this inner calm is achieved, then achieving more stillness can be contemplated. All participants wanted to have employment, or to have their own families. When some approximation to either took place, then a greater sense of inner stillness was observed.

Another coping strategy used by participants was physical activity. A man with TBI enjoyed sports and was encouraged to practise golf, to improve his swing. Practising golf not only provided this participant with a hobby, but it also allowed him an opportunity to exercise. Practising his swing was the motivation but a habit had to be established. This participant had regular access to the golf course. He had a volunteer at the course who helped him establish a habit and practise with him. The participant did not do this alone or in isolation. The habit is established in conjunction with others. Increasing physical activity has been found to lower levels of depression (Dunn et al., 2005). Physical activity is also helpful as it raises the levels of oxygen in the brain, which stimulates the sensory and motor cortices.

According to Doidge (2007), nothing speeds brain atrophy more than being immobilized in the same environment; the monotony undermines any attentional systems irrespective of is the extent of the person's disability. Physical activity such as playing golf or

learning a new dance not only had physical benefits to participants, in some cases, it also promoted social behaviour. Long term benefits to participants who exercised regularly were noted in the improvement of their mood state on the days they exercised. Carers and family describe them to be less 'moody' and 'more optimistic'. These participants were able to use an adaptive coping strategy (exercise) which helped them in the management of their depressive mood state. In turn, exercise as a coping behaviour had a positive effect on their physical and psychological health. Establishing regularity of physical activity was crucial; whether it meant going to the gym for one participant, walking on the beach for another or practising golf. Participants, particularly those with TBI, needed support to establish regularity. For instance, both the MS society and the Community Re-Entry Program have movement workshops each week. There are networks of people present who can support participants on a weekly basis. Over time, attending these workshops becomes a habit.

It appears that isolation and loneliness which result in a person feeling sad underpin most of the maladaptive coping strategies. Sadness is an emotion experienced in the face of events described as unpleasant; characteristically sadness is regarded as a response to a goal lost or not attained (Camras & Allison, 1989; Hackenbracht & Tamir, 2010). For instance, Tina would often resort to excessive consumption of alcohol when she felt extremely sad and lonely. This state generally occurred when she had not participated in any activities for a period of time. She would isolate herself, refusing contact with anyone. Tina was often unable to break the vicious cycle of drinking excessive amounts of alcohol. Her alcohol consumption is considered to be closely linked to loneliness and to her 'feeling sad'. A participant with MS often locked herself in her room for days, without allowing anyone near her. This behaviour was extremely distressing on her family as she had three young children under the age of 5 witnessing her withdrawal. During these periods, her husband reported that they could often hear her crying, or sometimes getting aggressive and punching the walls.

The participant reported feeling lonely and isolated despite the presence of her family. She said that “they had no idea what I was going through, and I felt more alone than ever before”.

Reducing loneliness is a central issue when working with people with TBI or MS. While social interaction with others is important, it may not always be feasible. Having hobbies, and other recreational activities which participants felt were meaningful, reduces reliance on others. Encouraging active coping strategies which participants can engage in alone is beneficial. It can be a source of comfort for people who find themselves alone, without wanting to be so (Storr, 1997, p 111). For instance, a participant with MS was encouraged to take up painting, as she recalled she used to enjoy it when she was younger. Art or painting in this instance engages many aspects of mental life simultaneously; filling the senses whilst at the same time making demands on intelligence and emotions (Matrevers, 2001). For instance, painting for participants can elicit a range of emotions from amusement, delight and sadness, or that of hope and fear. The artist draws upon emotions to create art. Similar experiences occurred for participants. Freud explains that through art, people suffer, they face mortal danger, they fall in love, they encounter infidelity, and they strive for difficult goals. In expressing these emotions, the painter arrives at a clearer understanding of his/her own emotions (Freud, 1904, Oatley, Keltner, Jenkins, 2006). The act of painting then becomes a vehicle for the participants to express emotions and experience ‘catharsis’ (the act of expressing or experiencing strong emotions). Catharsis achieved through art can help alleviate feelings of anxiety and depression by inducing the physiological response of relaxation. It is known that self soothing qualities of painting, drawing or working with art, increases levels of serotonin, the chemical linked to depression (Matrevers, 2001). For example, participants reported feeling a sense of relief or “a huge weight lifted” after attending an art session. Others were observed to be more calm and still, when painting. Their ‘whole being’ immersed in the act of painting.

Talking to friends, writing in journals and reading were ways of building narrative for participants. This was another way in which participants coped with TBI or MS. Johansen, (2002) argues that narratives involve building a new story. A new life story post trauma. By talking or reading out loud, participants were able to build a new story of their lives post trauma, a bridge between their former lives and the 'unknown that was still to evolve'. For instance, Sarah had regular meetings with a support group for people with MS. This group became her beacon of support, an avenue for hopes, dreams, fears and problems to be shared. Another participant with TBI used writing in his diary as a way in which he built his narrative. He wrote about the happenings of each day, his thoughts, and sometimes short verses. Over time, his writings were a way in which he would express his desires, and aspirations for himself.

These were ways in which active coping behaviours helped in building and sustaining resilient behaviours in participants. However, it is considered that these behaviours are only possible when participants experience an equilibrium mood state (Phillips, Bull, Adams, & Fraser, 2002). During periods of depression, it was often difficult to engage the participants in any hobbies or recreational activities. A strong relationship and good rapport between the rehabilitation professionals and participants is crucial in helping participants break the cycle of isolation and therefore initiating coping behaviours. For instance, a woman with MS often did not want to see anyone when she was depressed. However, during the intervention, she requested the researcher to visit her despite her low mood. This meeting was only possible because of the rapport that was built gradually over time. Rapport involved creating an interpersonal climate through the attitudes of congruence; unconditional positive regard and empathic understanding (Bozarth & Brodley, 1991; Rogers, 1959) (see 4.2, item 1 creating the therapeutic relationship). To sense the participant's 'private world', not judging the participant,

accepting her for who she is, and being ‘real’ was crucial in creating a therapeutic environment. An environment centred on trust, helping the participant through the ‘rapids of life’.

7.5 Resilience the norm?

Recent research has suggested that the tendency of individuals to be resilient in the face of a tragic or life-altering event may be “the norm” for the majority of individuals (White et al., 2008). According to Mancini and Bonnano (2006), an escalating amount of evidence proposes that even following an extremely traumatic event, such as the loss of a partner, physical assault, terrorist attacks, and rape, the majority of people “*maintain relatively stable, healthy levels of psychological and physical functioning*” (p. 972). While the important work done by Mancini and Bonanno provides added insight into human resilience, it is possible that individuals who experience a life-threatening event (e.g., motor vehicle accident) that results in chronic disability (e.g., traumatic brain injury) might not have the same capacity to return to previous levels of cognitive functioning. For example, injury to the frontal lobes, commonly seen in traumatic brain injury, poses significant changes to their executive functioning skills. They become different people and family members have difficulty comprehending the change.

A participant with TBI could not comprehend the extent of his change in personality post injury. His family described him as a “*totally different person, as being angry all the time and appearing self absorbed*”. This behaviour is uncharacteristic and appears as a complete reversal of his pre injury personality. He however appears almost unaware of this significant change. A year post injury, his mood, sleep, appetite, interest in self-care, and participation in day-to-day activities declined. At the time of the intervention, his mood and behavioural symptoms have stabilized, with medication. However, he remained mildly

irritable, disinhibited, endlessly flirtatious, and impulsive. All characteristics which were the opposite of his pre trauma behaviour.

There are possibly two distinct problems that a person who has sustained a traumatic injury or illness such as MS must face. The first is dealing with the trauma created by the injury such as loss of employment, depression, family break up, and changes in personality. Secondly they must also cope with the physical, social and emotional changes of having an injury or disability (Eide & Roysamb, 2002; Johnstone & Stonnington, 2009; Marsh, 1999). Based on the findings of this study, participants with TBI reported having lower levels of resilience and more executive functioning difficulties than the participants with MS. There is a possibility that resilience is not the same for an individual who experiences a traumatic event (e.g., motor vehicle accident) coupled with subsequent physical disability (e.g., traumatic injury) compared with individuals who do not have comparable cognitive disabilities. Cognition is significant in human resilience (Curtis & Cicchetti, 2003). When cognitive impairment occurs, resilience can break down. Those with TBI and MS need support, in the form of carers, mentors, and rehabilitation professionals who help nurture and facilitate their resilience.

7.6 Relearning and reconstructing shattered selves

Resilience does not mean bouncing back untouched, but rather struggling well, and effectively working through adversity. While it is a tall order, resilience involves learning from adversity. Attempting to integrate resilient behaviour into the fabric of one's life is an ongoing process (Bonanno, 2004; Connor, 2006; Higgins, 1994; Luthar, Cicchetti, & Becker 2000; Rutter, 1990). The case studies of Sarah, Rob, Peter and Leslie reveal that resilient functioning emerges from the interaction between inherited factors, individual characteristics

and experiential factors over time. All participants experienced setbacks, but have learned to adjust and cope. Rutter (1987, p 313) states that,

“It also follows that “resilience” involves an inference based on findings concerning individual differences in response to stress or adversity. It is not, and cannot be, an observed trait. People may be resilient in relation to some kinds of environmental hazards but not others. Equally, they may be resilient with respect to some outcomes, but not all.”

Resilience is situation specific. Some individuals endure one type of adversity and overcome the associated hardships, whereas these same individuals may disintegrate under the load of different adversities. There appears to be a breaking point. A point when the load they carry is too great, when even the most resilient individual breaks down. Then they reach their coping limit, and become vulnerable. It can be hypothesized that people with higher resilience can bear a greater load. It does not mean that these people are unaffected or untouched by circumstances and adversity (Masten, 2002; Rajkumar, 2008; Rutter, 2007; von Eye, 2000; Watt, 1995; Werner, 1995). ‘Load’ in this sense is defined as the various forms of stress, difficulties and problems people with frontal lobe injury and MS experience. The different loads people carry are known to contain social, personal, environmental, physical, financial, relational, and biological aspects (Buckner, et al., 2003; Luthar, Cicchetti, & Becker, 2000; Masten & Garmezy, 1985; Rutter, 2002).

Through improved understanding of the brain and its functions, it is known that executive functioning skills, which might be compromised as a result of frontal lobe injury, can be re-learned or at least cued (Schulz, Kopp, Kunkel, & Faiss, 2006; Sohlberg & Mateer, 2001; Stuss & Alexander, 2000). Given the right structure, cues, context and support, individuals with brain injury and MS (although not all of the latter participants had executive functioning difficulties) can learn to utilize executive functioning skills more efficiently (Abreu, 2001; Cicerone, 2006; Crosson, 1989; Ducharme, 2003; Eslinger, 1995; Johnstone, 2009). A participant with MS said *“Some days I craved to be in charge of my life again in*

the way I once was. Driving my car, running, walking along the park. I miss moving my body effortlessly through space. Mainly, I plan activities to fill my days. There are times I am grumpy all day. Sometimes I'm sad. But mostly I keep busy and am content". Through effective planning, and having something to look forward to each day, this participant effectively triggers her executive functioning which in turn promotes her resilient behaviours. She is optimistic and positive when she is "busy".

To avoid breakdown, and to keep a person's intent and resilience alive, effective executive functioning skills are necessary. In the current study, even the most resilient participant fell apart under extreme demands. For example Sarah, who reported high resilience scores. Yet, she like others, suffered from depression, mood swings and periods of stress. She overcame these periods with support and contact with people in her social network. She was observed to "come out" of her depression faster than other participants who were not as resilient. Nonetheless, given the nature of her MS, she often required help from those around her (e.g., family, friends, social workers) to try and lighten the load (Curtis & Nelson, 2003; Rees, 1999; Sohlberg & Mateer, 2001). A participant with MS reported that sometimes for weeks her children had to live off takeaway and other fast food because she did not have the energy to cook or even make a sandwich. She jokingly said the "*people at Hungry Jacks know us by name now*". She learned from her experience that there was no point in trying to over work herself, and inevitably be sick with fatigue the next day.

Although all participants are adjusting to their lives with a disability, their experiences are unique. They varied according to the nature and severity of disability. Irrespective of TBI or MS, there are moments where participants are optimistic, and have hope. They then display resilient behaviours. With the support of carers and rehabilitation professionals, even the most 'damaged' participants are buoyant. In taking action to improve or to find new ways of performing previously simple tasks, participants develop foundations, which help them

become more resilient. Being resilient generally indicates that they have a better chance of coping with future adversity (Alvord, 2005; Bonanno, 2004; Connor, 2006; Jacelon, 1997; Luthar, 2000).

7.6.1 *Everyday Heroes*

Participants who are observed to be resilient view themselves in relation to their strengths, instead of as victims of MS or TBI. They identify protective factors, which when accepted, enhanced their self esteem (Harpham, 2006; Synder, 2000; Tedeschi & Kilmer, 2005). A participant with MS learned to value having her spouse and children to support her, rather than perceiving she was going through her illness alone. Another participant with TBI learned that living in a community residence for people with disability was not a negative twist of fate. Rather it offered him the support system and friendships he desperately needed. Joseph Campbell summarizes this precisely in *The Hero Has a Thousand Faces* (Campbell, 1968, p. 23).

“A hero ventures forth from the world of common day into a region of supernatural wonder: fabulous forces are there encountered and a decisive victory is won: the hero comes back from this mysterious adventure with the power to bestow boons on his fellow man.”

Participants are everyday heroes, facing trials and tribulations on their journey. They overcome many of their adversities and in return became motivated due to their new found self knowledge and skills. The participant with MS who learned that using a walking stick gave her independence to walk without having to rely on someone to support her physically is an example. So is a participant with TBI who learnt to use a computer so that she can send and receive e mails from her sister who lives far away. Similarly, a participant with TBI lived alone for 15 years post injury. He now chooses to live in a residential facility for people with intellectual disability. He says it reduces his loneliness. This is a heroic decision. How

participants use these skills and go on fighting, resisting and being resilient, is their own Heroes' journey.

CHAPTER VIII

8 RECOMMENDATIONS AND CONCLUSION

Chapter eight concludes this work by considering the limitations of the study, possible directions for further study, and makes specific recommendations about the services provided to people with TBI and MS.

8.1 Limitations

The criteria used to operationally measure resilience, both qualitatively and quantitatively, are not absolutes. They are appropriate given the present context and sample, but the generalizability of these measures to other populations cannot be assumed. However, following a view advocated by Cicchetti and Garmezy (1993), the use of multiple measures, across a variety of contexts, to distinguish people with high or low resilience, reduced the misclassifying of participants. For instance participants might appear resilient on a couple of measures, in certain contexts, but might not be classified so in other situations. Much care is required in the interpretation of resilience scores.

One participant, a woman with MS, was observed to display resilient behaviours such as initiating contact with others, making an effort to look her best and participate in physiotherapy. Yet she was passive and unmotivated the next week. It can be expected that resilience, as well as vulnerability, changes over time, often from week to week (Masten, Best, & Garmezy, 1990). Therefore participants were assessed across a time period of a year. This allowed the researcher to develop a richer understanding of participants and their circumstances.

Executive functioning and resilience was measured using self report measures. People with traumatic brain injury are a population known to have little insight into their difficulties.

Measures taken to compensate for this included using direct observation and obtaining data from other sources such as past medical and psychological reports. However, these data were not formally compared with data obtained from significant others. This could potentially limit the reliability of findings. The reason reports from significant others was not obtained was that a majority of participants with one of the conditions being studied (TBI) lived alone and their families were not easily accessible.

Although participants (particularly those with TBI) scored highly on the DEX (the DEX scores are inversely scored), they did display significant behavioural changes in regards to the executive functioning behaviours (See discussion of research question 6.2). The behavioural changes which were observed and recorded during the intervention does identify a potential limitation of the DEX in assessing a broad range of executive functioning skills in participants with TBI. A recent study by Simblett and Bateman (2011) found that the DEX did not perform as a one-dimensional, interval-level scale of executive functioning. They suggest that the DEX measures more than one psychological construct. The DEX measures executive functioning per se, but in this study it did not indicate the factors which contribute to effective executive functioning. For instance, it was found that mood, support and social structure were strong determinants of participants' ability to demonstrate effective executive functioning. A way to overcome this issue according to Simblett and Bateman (2011) is by using several new subscales which address the theoretical conceptualisations of the different dimensions of executive functioning.

Another constraint of the study was that participants' pre injury or pre diagnosis resilience and executive functioning behaviours were not quantitatively measured. Although detailed case histories were obtained from all participants, there was insufficient data to make any correlations between how participants responded to challenges or adversity in the past, and their coping behaviours at present. Future studies could attempt to obtain this information

through interviewing significant family members or friends who knew the individual pre injury/diagnosis.

In addition, the use of a purposeful sample (participants with TBI and MS) and the controlled geographical area from which the data were collected may limit the generalizability of the findings. Participants in this study were members of the Multiple Sclerosis Society of a particular state, whilst the TBI participants were clients of a particular rehabilitation consultant with access to a weekly community organised rehabilitation program. Thus, the sample consisted of individuals who obtained social, financial and emotional support from their respective health care workers. These participants also had greater access to resources. Therefore, it is unlikely that these findings reflect those individuals with MS or TBI whom do not have access to these services and support networks.

Similarly, the number of participants in this study was limited to ten in each group. This limitation was in part due to time constraints. Restricting the number of participants to a manageable size was also done to enable the collection of rich personal information which may not have been possible for a larger sample. However, future studies, with greater resources in relation to time and researchers, could use a larger sample. This could also be extended over a longer period of time to further generalise the findings of the current study.

The intervention process was individualized and occurred every two weeks for all participants. Due to time constraints and the number of participants in the study, it was not feasible for weekly meetings with all participants. However, Vlasek (2010) recommend that contact with participants should ideally be made on a weekly basis. Individual contact on a weekly basis is significant because, only sustained weekly contact can help a person at risk and in need (Vlasek, 2010). “*The person who provides weekly contact ... became a constant in my life* (Vlasek, 2010 p 18). “*She still is, and she still regularly takes my phone calls and provides support to me in any way I need*”. This weekly contact enables participants to feel

supported and nurtured. Future studies could look into sustained weekly contact perhaps through the use of another researcher.

8.2 Directions for future research

Despite limitations, significant issues were addressed. These issues generated useful implications for future research. A key finding reported, was support for the relationship between resilience and executive functioning skills. Resilience appears to be linearly correlated with executive functioning (i.e. as measured resilience increases, so does measured executive functioning ability). To better understand this relationship, future research, employing larger samples would be useful. Larger samples would allow more powerful statistical analysis of the data obtained.

Participants in the present study were recruited and divided into two groups (i.e. TBI and MS). No further grouping was carried out based on the type of MS they had or the location of brain injury. Future research could look at these variables to see if they have an impact on participants' ability to display resilient behaviour. For instance, participants can be recruited and grouped based on the type of MS (primary progressive vs. relapse remitting). Group comparisons can then be carried out to ascertain differences or similarities.

It would also be useful to compare the data obtained from participants with TBI or MS with those from a normal sample. A normal sample which consists of people who are matched demographically to participants, and who do not have TBI or MS. This would allow comparisons to be made regarding the influence of social support, mood states, disability as well as any other factors contributing to participants' resilience.

Further research can also examine the validity of this type of approach and what is necessary in follow up sessions after the intervention program. In the current research, at follow up, gains made during the intervention were not sustained, particularly by the TBI

participants. It is likely that this was due to removal of sustained support which was present during the intervention. Other studies could explore ways in which intervention gains could be maintained even after the removal of formal support. For instance, evaluation of the bi-weekly sessions can be carried out to ascertain the sustainability of lifestyle changes.

Research on resilience and its cognitive underpinnings has extensive potential to guide the advancement of understanding human behaviour (Cicchetti & Tucker, 1994; Curtis & Cicchetti, 2003). The present study attempts to bridge the gap in research through integrating psychological, cognitive, and social contributors of resilience. Future studies can re examine this interaction. For example, studies looking at the role of cognitive processes such as memory difficulties and/ or the enhancement of memory would be useful in understanding how resilience operates in a subgroup of individuals with severe memory difficulties.

Understanding the nature of resilience has global implications for populations of people with TBI and MS. To date resilience research has mainly focused on “at risk children” and adults post trauma (Higgins, 1994; Rutter 1983; Wagnild & Young, 1990). There are currently no other studies measuring resilience and executive functioning in people with TBI or MS. Therefore, it will be important to undertake studies of a longitudinal nature to elucidate examples of resilient behaviour. Observing how resilient behaviour is promoted across the life course of people with debilitating disabilities such as MS, and TBI will contribute to the understanding of how support and management for these populations can be improved.

Another area in need of further research is how rehabilitation professionals working with people with TBI, or Multiple Sclerosis can help them ‘lessen the load they carry’. For participants with MS, personal overload occurs when they are fatigued (Deatrick, Brennan, & Cameron, 1998; Kroenke, Lynch, & Denney, 2000; Schwartz, Coultland-Morris, & Zeng,

1996). For participants with TBI it is often mood disorders such as depression which causes personal overload. When fatigued or depressed, it is observed that participants are in most cases not able to be functionally effective. For instance, participants have no energy or motivation to perform their usual day to day tasks such as getting out of bed and showering. Unless these underlying issues of fatigue and mood disorders are addressed, research and clinical interventions related to higher order problem solving will have limited success.

Community Reintegration Programs are a facet of post acute brain injury rehabilitation. Programs such as the Community Re Entry Program for people with Brain Injury (CRP) generally include a number of approaches that allow individuals with TBI to benefit from further rehabilitation. These programs focus on treatment of mood, behaviour, and executive functioning difficulties in a supervised environment. However, there has been little research done on the effectiveness of these community reintegration programs. This has been attributed to the lack of standardized intervention strategies (Turner-Stokes, 2004; Turner-Stokes, Disler, Nair, & Wade, 2005). Therefore there is a need for further research in this area. By identifying effective approaches to the rehabilitation of people with brain injury and executive functioning difficulties, it is anticipated that cost effective and standardized programs can be delineated. Through assessing the effectiveness of community re entry programs, rehabilitation professionals are better able to assist individuals with TBI to be meaningfully integrated into the community. Such programs are critical to meet the ever-escalating needs of the population of people with TBI.

8.3 Recommendations

It may not be possible to prevent road or industrial accidents in which people acquire brain injuries, nor is it yet possible to prevent people from developing MS. Therefore, more research which helps to elucidate how people with TBI and MS can be supported in order to nurture their resilience appears essential. For this to be possible there is a huge need for more resources to fund community programs such as the Community Re Entry Program, and the programs offered by the MS society. Money is required to hire more staff, carers and support workers who lessen the burden of care placed on family members. Resources to educate and train people working with individuals with a disability appear a priority. Most importantly, resources which enable the sustained and long term provision of support in the form of more carers, respite for family members, access to community rehabilitation programs and recreational activities is urgently needed. It does not suffice to just provide rehabilitation immediately post trauma or post diagnosis. There needs to be continued and sustained support in order for community integration and participation to be achieved.

When a person experiences TBI or diagnosis of an illness such as MS, their families are also affected in a significant manner (Allen, 1994; Jumisko, 2005). Although some public expenditure supports the needs of people with TBI and MS, families provide most of the care (Allen, Linn, Gutierrez, & Willer, 1994; Knight, Devereux, & Godfrey, 1998), often without adequate professional support and intervention. This study found that families were often faced issues such as (a) dependency, where they experience stress associated directly with caring for the individual, and (b) personal burden or feeling that all the responsibility of care falls on one person. In most families, particularly those with ageing parents, there is an ongoing worry about what will happen to their son/ daughter when the parents are no longer physically able to care for them. Or who will take over the responsibility of care-giving decisions when the parents are no longer around? Therefore, more resources to lessen the

burden of care on parents, especially ageing parents, are required. Supported residential facilities which provide support, care, and professional treatment for people with TBI and MS is a viable option. However these facilities are scarce and participants are often on long waiting lists to gain admission.

The system of community-based services and supports for people with TBI and MS is largely fragmented, inaccessible, and in short supply (Armstrong, 2005; Hays, 2001; Helgeson, 2003; Izaute, 2008). Areas which are in great need of services for participants in this study were (a) assisted living arrangements for those with TBI, (b) respite for carers and parents, (c) the availability of social, financial and physical support, and (c) carer training and education. Similar findings were found in a study by Kreutzer, Gervasio and Camplair, (1994) which highlighted the lack of counselling services for people with TBI and the lack of availability of respite services for care givers (Kreutzer, 1994; McCabe, 2007). These are areas in which government funding can aid in lessening the load people carried by people with disabilities and their families.

For people with TBI and MS, integration in a social network is considered a significant indicator of community involvement (Tomberg, 2007; Willer, 1993). The social network can be viewed as a planned representation of an individual's social world. In the present study, each participant's social network was comprised of their social relationships and provided a framework for the provision of social support (see Figure 5.18 and 5.19). People with TBI and MS have considerable social network deficits. Therefore their support needs are substantial. Despite frequent claims in the literature regarding the likely benefits of addressing social network and support needs of people following TBI and MS, there have been very few reports of intervention work using the development of these networks as a focus (Rauch, 2001).

Society often excludes people with TBI or MS. Special conditions are required to facilitate inclusion. Modelling and role playing techniques used in the intervention can be included in community rehabilitation to improve social skills. This would help to minimize isolation. For participants in this study, the creation of opportunities to participate in rewarding social activities such as support groups, writing workshops, and personal awareness workshops were beneficial. This contributed to the maintenance of their social networks. Being given the opportunity to interact with a variety of other people in a secure setting creates opportunities for learning. These skills can be rehearsed in different contexts to generalise learning. In order for this to be effective in the long term, there is a great need for well known and trusted mentors to be present. These mentors cue and encourage participation. For all participants in the study, particularly those with TBI, there was a significant need for mentors to model social competence and to facilitate social support. Further studies can look at ways in which mentors can be recruited and provided sufficient training to help support people with TBI or MS.

People who experience difficulties initiating behaviour, such as those with TBI, may face particular challenges in establishing and maintaining long term social relationships. Johnson and Davis (1998) point to the need to develop strategies aimed at maintaining relationships long-term. The issue of long-term maintenance of relationships was also raised in an intervention study by Glang et al (1997). To address this issue, a model for social interaction was proposed. The intervention consisted of asking participants to meet with matched counterparts (mentors) to engage in leisure activities once per week for a month. Four volunteer counterparts were matched to each participant and received a short training session on TBI, detailed suggestions on interacting with their matched participant, and weekly telephone calls from the researcher. Johnson and Davis propose that this is an

example of a social network intervention which can enhance social integration whilst requiring only limited staff resources.

Future research could also examine means by which viable social networks can be constructed to support people with disabilities who are at risk. These networks would have the provision of friendships and professional links which optimise a person's health (Schulz & Martire, 2004). These include addressing issues such as (a) what factors aid in increasing a person's network size? Or (b) how do the frequency of contacts aid in developing a person's resilient behaviours, and (c) how does the client's perception of support influence their subsequent resilient behaviours (Rauch, 2001)?

Other studies have suggested that social contacts and social support improve physical recovery after TBI and MS (Achat, 1998; Berkman & Glass, 2000; Biegel, 1994; Hardiman, 2003). There has also been research done to see if social contacts have an effect on individuals' cognitive functioning (Fratiglioni, 2004). Observations from this study show that participants with more social support had better psychosocial outcomes. They experienced more positive emotions which resulted in an increase in their resilient behaviours. The executive functioning demands of social interactions, such as receptive and expressive communication, recall of shared experiences and problem solving, appear to have direct benefits for neurological functioning. For instance, members of close social networks may encourage patients to engage in health preserving behaviours (such as medication adherence for people with post traumatic epilepsy or people experiencing depression).

Social interactions and social support was also observed to compensate for harm to physical and cognitive function arising from highly stressful events. For example when participants with MS were part of a support group, they received emotional and practical support. They had a platform to voice their thoughts and share their feelings. This produced a cathartic effect and encouraged them to keep facing the challenges they were experiencing.

Future research can study the relationship between social networks and cognitive change and resilience in greater depth. In particular, looking at how having a larger social network may affect cognitive change in participants with TBI and MS. Observations from this study indicate that those who have a wider social network, consisting of more key people, generally encourages resilient behaviours. A wider social network also provides more opportunities for the practice of executive functioning skills.

In order to address the limitations in service provision and lack of resources, there needs to be advocacy at the local, state and national levels. Through such advocacy, social policymakers and rehabilitation program planners can better understand the needs and challenges faced by individuals and families coping with the challenges of TBI and MS.

Another key recommendation would be to use different or complimentary methodology to study the relationship between resilience and executive functioning. For instance, using Interpretive Phenomenological Analysis (IPA), which is a qualitative method aimed at trying to understand the experiences an individual has in life, how they made sense of events and what meanings those experiences hold (Smith, 2009). IPA uses semi-structured interviews which are taped and transcribed verbatim. These transcripts are then subjected to detailed qualitative analysis, which attempts to elicit key themes in the participant's language. This means that the researcher generates codes from the data, rather than using a pre-existing theory to identify codes that might be applied to the data.

8.4 Conclusion

Participants continue to struggle with their respective disabilities. Social networks and resilient mood states can and do break down. But even in the most difficult of situations, some participants in the current study demonstrated resilient behaviours. They planned and acted according to the demands of their circumstance. Others whose resilience was more brittle, however, often found their support fragmented. Under these circumstances, their will to plan and act in a positive manner was often greatly reduced. Behaviours of resilience and effective executive functioning may not be publicly displayed, but rest within the individuals. This 'will' underpins the ability to maintain friendships on the one hand, whilst absence of will leads to isolation and depression on the other. Positive thinking about the self and a buoyant mood can be contrasted with negative language and depressive behaviour. In all this, whether the person displays resilience or is somewhat brittle or broken, the evidence from this study suggests that most are still hopeful to better themselves and cope with their disabilities. The individual struggles demonstrated by case evidence and quantitative data in this study provide a working base for further research into this crucial aspect of human behaviour; how individuals do "bounce back" from the consequences of long term, severe disability.

REFERENCES

- Abreu, B. C., Seale, G., Scheibel, R. S., Huddleston, N., Zhang, L., Ottenbacher, K. J. A. P. M., et al. (2001). Levels of self-awareness after acute brain injury: How patients' and rehabilitation specialists' perceptions compare. *Archives of Physical Medicine and Rehabilitation*, 82, 49-55.
- Achat, H., Kawachi, I., Levine, S., Berkey, C., Coakley, E., & Colditz, G. (1998). Social networks, stress and health-related quality of life. *Quality of Life Research*, 7(8), 735-750.
- Acheson, E. D. (1977). Epidemiology of Multiple Sclerosis. *British Medical Bulletin*, 33(1), 9-14.
- Ahern, N. (2006). Adolescent Resilience: An Evolutionary Concept Analysis. *Journal of Pediatric Nursing*, 21(3), 175-185.
- Ahern , N., Kiehl, E., Lou Sole, M., & Byers, J. (2006). A Review of Instruments Measuring Resilience. *Issues in Comprehensive Pediatric Nursing*, 29(2), 103-125.
- Alderman, N. (2003). Contemporary Approaches to the Management of Irritability and Aggression Following Traumatic Brain Injury. *Neuropsychological Rehabilitation*, 13, 211-240.
- Alexander, M. P. (1995). Mild traumatic brain injury: Pathophysiology, natural history, and management. *Neurology*, 45(7), 1253-1260.
- Allen, K., Linn, R. T., Gutierrez, H., & Willer, B. S. (1994). Family burden following traumatic brain injury. *Rehabilitation Psychology* 39, 29-48.
- Al-Naser , & Sandman. (2000). Evaluating resilience factors in the face of traumatic events in Kuwait. *Journal of Medical Sciences Sultan Qaboos University* (2), 111-116.

- Alonso, A., & Hernan, M. A. (2008). Temporal trends in the incidence of multiple sclerosis: A systematic review. *71*(2), 129-135.
- Alvesson, M., & Skoldberg, K. (2000). *Reflexive Methodology, New Vistas for Qualitative Research*. London: Sage.
- Alvord, M., & Grados, J. (2005). Enhancing Resilience in Children: A Proactive Approach. *Professional Psychology: Research and Practice*, *36*(3), 238-245.
- American Psychiatric Association: *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition, Text Revision. Washington, DC, American Psychiatric Association, 2000.
- Anderson, K., Anderson, L., & Glanze, W. (2009). Mosby's Medical Dictionary (9th ed.).
- Anderson, V. (1998). Assessing executive functions in children: biological, psychological, and developmental considerations. *Neuropsychological Rehabilitation*, *8*(3), 319-349.
- Anker, M., Duncan, B., & Sparks, J. (2009). Using Client Feedback to Improve Couple Therapy Outcomes: A Randomized Clinical Trial in a Naturalistic Setting. *Journal of Consulting and Clinical Psychology*, *77*, 693-704.
- Antoni, M. H., & Goodkin, K. (1988). Host moderator variables in the promotion of cervical neoplasia—I. Personality facets. *Journal of Psychosomatic Research*, *32*, 327-328.
- Arco, L., Cohen, L., & Geddes, K. (2004). Verbal self-regulation of impulsive behaviour of persons with frontal lobe brain injury. *Behaviour Therapy*, *35*(3), 605-619.
- Armstrong, C. (1991). Emotional Changes Following Brain Injury: Psychological and Neurological Components of Depression, Denial and Anxiety. *The Journal of Rehabilitation*, *57*.
- Armstrong, M., Birnie-Lefcovitch, S., & Ungar, M. (2005). Pathways Between Social Support, Family Well Being, Quality of Parenting, and Child Resilience: What We Know. *Journal of Child and Family Studies*, *14*(2), 269-281.

- Arnett, P. A., Higginson, C. I., & Randolph, J. J. (2001). Depression in multiple sclerosis: Relationship to planning ability. *Journal of the International Neuropsychological Society, 7*(06), 665-674.
- Arnett, P. A., Rao, S. M., Bernardin, L., Grafman, J., Yetkin, F. Z., & Lobeck, L. (1994). Relationship between frontal lobe lesions and Wisconsin Card Sorting Test performance in patients with multiple sclerosis. *Neurology, 44*, 420-425.
- Aroian, K., & Norris, A. (2000). Resilience, stress, and depression among Russian immigrants to Israel. *Western Journal of Nursing Research, 22*(1), 54-67.
- Ashley, M. (2004). *Traumatic Brain Injury: Rehabilitative Treatment and Case Management* CRC Press.
- Ashman, T. A., Cantor, J. B., Gordon, W. A., Spielman, L., Flanagan, S., Ginsberg, A., et al. (2009). A randomized controlled trial of sertraline for the treatment of depression in persons with traumatic brain injury. *Archives of Physical and Medical Rehabilitation, 90*, 733-740.
- Ashman, T. A., Spielman, L. A., & Hibbard, M. R. (2004). Psychiatric challenges in the first 6 years after traumatic brain injury: cross sequential analyses of axis I disorders. *Archives of Physical and Medical Rehabilitation, 85*(4), s36-42.
- Aspinwall, L. G., & Taylor, S. E. (1997). A stitch in time: Self-regulation and proactive coping. *Psychological Bulletin, 121*, 417-436.
- Axelrod, B. N., & Ryan, J. J. (2000). Prorating Wechsler Adult Intelligence Scale-III summary scores. *Journal of Clinical Psychology, 56*(6), 807-811.
- Baddeley, A. (1992). Working memory. *Science, 255*(5044), 556-559.
- Baddeley, A. (2003). Working memory: looking back and looking forward. *Nature Review Neuroscience, 4*(10), 829-839.

- Baddeley, A., & Hitch, G. (1974). Working memory. In G. H. Bower (Ed.), *The psychology of learning and motivation: Advances in research and theory* (Vol. 8, pp. 47-89). New York: Academic Press.
- Baddeley, A., & Wilson, B. (1994). When implicit learning fails: amnesia and the problem of error elimination. *Neuropsychologica*, 32(1), 53-68.
- Baker, S. C., Frith, C. D., & Dolan, R. J. (1997). The interaction between mood and cognitive function studied with PET. *Psychological Medicine*, 27, 565-578.
- Bandura, A. (1986). *Social Foundations of Thought and Action*. New Jersey: Prentice Hall.
- Bandura, A. (1994). Self-efficacy. In R. J. Corsini (Ed.), *Encyclopedia of psychology*. New York: Wiley.
- Bandura, A., Pastorelli, C., Barbaranelli, C., & Caprara, G. V. (1999). Self-efficacy pathways for childhood depression. *Journal of Personality and Social Psychology*, 76, 258-269.
- Barbee, A. P., Derlega, V. J., Sherburne, S. P., & Grimshaw, A. (1998). Helpful and unhelpful forms of social support for HIV-positive individuals *HIV and social interaction* (pp. 83-105). Thousand Oaks, CA: Sage.
- Bargh, J., & Chartrand, T. (1999). The Unbearable Automaticity of Being. *American Psychologist*, 54(7), 462-479.
- Barkley, R. (1997). Behavioral Inhibition, Sustained Attention, and Executive Functions" Constructing a Unifying Theory of ADHD. *Psychological Bulletin*, 121(1), 65-94.
- Barlow, D. (2007). *Clinical Handbook of Psychological Disorders: A Step-by-Step Treatment Manual*. New York: Guilford Press.
- Barlow, D., Chorpita, B. F., & Turovsky, J. (1996). Fear, panic, anxiety, and disorders of emotion. In D. A. Hope (Ed.), *Nebraska Symposium on Motivation: Perspectives on anxiety panic and fear* (Vol. 43, pp. 251-328). Lincoln: University of Nebraska Press.

- Barnes, M. D., & Ward, A. B. (2000). *Textbook of rehabilitation medicine*. Oxford, England: Oxford University Press.
- Barrett, A., & Turner, R. (2006). Family structure and substance use problems in adolescence and early adulthood: examining explanations for the relationship. *Addiction, 101*(1), 109-120.
- Bartholomew, K., & Horowitz, L. M. (1991). Attachment styles among young adults: A test of a four-category model. *Journal of Personality and Social Psychology, 61*, 226-244.
- Batty, D. (2008). Euthanasia: Woman wins right to review of law on assisted suicide. *The guardian*
- Bavelier, D., & Neville, H. J. (2002). Cross-modal plasticity: Where and how? *Nature Reviews:Neuroscience, 3*(443–452).
- Beardslee, W., & Podorefsky, D. (1988). Resilient adolescents whose parents have serious affective and other psychiatric disorders: Importance of self- understanding and relationships. *American Journal of Psychiatry, 1*(145), 63-69.
- Beatty, W. (1993). Cognitive and emotional disturbances in Multiple Sclerosis. *Behavioural Neurology, 189-202*.
- Beatty, W., Goodkin, D., Monson, N., & Beatty, P. (1990). Implicit learning in patients with chronic progressive multiple sclerosis. *International Journal of Clinical Neuropsychology, 12*, 397-100.
- Beck, A. T. (1976). *Cognitive therapy and emotional disorders*. New York: International Universities Press.
- Beck, A. T. (1991). Cognitive therapy: A 30-year retrospective. *American Psychologist, 46*, 368-375.

- Beck, A. T., Steer, R. A., & Brown, G. K. (1996). *Manual for the Beck Depression Inventory-II*. Unpublished manuscript, San Antonio.
- Beck, J. (1995). *Cognitive therapy: Basics and beyond*. New York: Guilford Press.
- Beck, J. G. (2000). *Treatment Encyclopaedia of psychology*. Washington, DC: American Psychological Association & Oxford University Press.
- Beck, J. S. (2005). *Cognitive therapy for challenging problems: What to do when the basics don't work*. New York: Guilford Press.
- Bedell, J. R., & Lennox, S. (1997). *Handbook for communication and problem-solving skills training: a cognitive behavioural approach*. New York: Wiley & Sons.
- Bedell, J. R., & Lennox, S. S. (1996). *Handbook for Communication and Problem-Solving Skills Training: A Cognitive-Behavioural Approach*. John Wiley and Sons.
- Bednar, R., & Peterson, S. (1995). *Self-esteem: Paradoxes and innovations in clinical theory and practice*. Washington, DC: American Psychological Association.
- Bellon, M., Gardner, J., & Riley, R. (2008). *Strengthening Communities: A mentoring program for adults with acquired brain injury. Community Re-entry Program Research Report*. South Australia: Flinders University South Australia.
- Benedict, R. H. B., Weinstock-Guttman, B., Fishman, I., Sharma, J., Tjoa, C. W., & Bakshi, R. (2004). Prediction of Neuropsychological Impairment in Multiple Sclerosis: Comparison of Conventional Magnetic Resonance Imaging Measures of Atrophy and Lesion Burden. *Archives of Neurology*; 61: 226-230.
- Bengtsson-Tops, A., & Hansson, L. (2001). Quantitative and qualitative aspects of the social network in schizophrenic patients living in the community. *International Journal of Social Psychiatry* 47, 67-77.

- Bennett, P. C., Ong, B., & Ponsford, J. (2005). Measuring executive dysfunction in an acute rehabilitation setting: Using the Dysexecutive Questionnaire. *Journal of the International Neuropsychological Society, 11*, 376-385.
- Bennett, P. C., Ong, B., & Ponsford, J. (2005). Assessment of executive dysfunction following traumatic brain injury: Comparison of the BADS with other clinical neuropsychological measures. *Journal of the International Neuropsychological Society, 11*(05), 606-613.
- Benshoff, J. J., & Janikowski, T. P. (2000). *The rehabilitation model of substance abuse counseling*. Belmont, CA: Brooks/Cole.
- Benzies, K., & Mychasiuk, R. (2009). Fostering family resiliency: a review of the key protective factors. *Child and Family Social Work, 14*, 103-114.
- Berdan, L., Keane, S. P., & Calkins, S. D. (2008). Temperament and externalizing behaviour: Peer acceptance as a protective factor. *Developmental Psychology, 44*, 957-968.
- Berg, D., Supprian, T., Thomae, J., Warmuth-Metz, M., Horowski, A., Zeiler, B., et al. (2000). Lesion pattern in patients with multiple sclerosis and depression. *Multiple Sclerosis, 6*(3), 156-162.
- Berg, D. V., & Von Brockern, S. (1995). "Building resilience through humour". Reclaiming children and youth. *Journal of Emotional and Behavioural Problems, 4*, 26-29.
- Bergquist, T. F., & Jacket, M. P. (1993). Awareness and goal setting with the traumatically brain injured. *Brain Injury, 7*, 275-282.
- Berkman, L. F., Glass, T., & (2000). Social integration, social networks, social support, and health. In B. Kawachi (Ed.), *Social Epidemiology* (pp. 137-173). Oxford: Oxford University Press.
- Berquist, T. F., & Jacket, M. P. (1993). Awareness and goal setting with the traumatically brain injured. *Brain Injury, 7*, 275-282.

- Berry, D. S., & Hansen, J. S. (1996). Positive affect, negative affect, and social interaction. *Journal of Personality and Social Psychology, 71*, 796-809.
- Berry, D. S., Willingham, J. K., & Thayer, C. A. (2000). Affect and personality as predictors of conflict and closeness in young adults' friendships. *Journal of Research in Personality, 34*, 84-107.
- Bezeau, S. C., Bogod, N. M., & Mateer, C. A. (2004). Sexually intrusive behaviour following brain injury: approaches to assessment and rehabilitation. *Brain Injury, 18*, 299-313.
- Bickman, L., & Rog, D. J. (2009). *The SAGE Handbook of Applied Social Research Methods* (2nd ed.). Thousand Oaks, Ca: Sage Publications.
- Biegel, D., Tracy, E., & Corvo, K. (1994). Strengthening social networks: intervention strategies for mental health case managers. *Health and Social Work 19*, 206-216.
- Binder, L. M. (1997). A review of mild head trauma. Part II: Clinical implications. *Journal of Clinical and Experimental Neuropsychology, 19*(3), 432-457.
- Blakemore, S. J., & Choudhury, S. (2006). Development of the adolescent brain: implications for executive function and social cognition. *Journal of Child Psychology and Psychiatry, 47*(3), 296-312.
- Block, & Kremen , A. (1996). IQ and Ego-Resiliency: Conceptual and Empirical Connections and Separateness. *Journal of Personality & Social Psychology February 1996;70(2):349-361.*
- Block , J., & Block , J. (1980). The role of ego-control and ego-resiliency in the organization of behavior. In W. A. Collins (Ed.), *Minnesota symposia on child psychology (Vol. 13, pp. 39-101)*. Hillsdale,N J: Erlbaum.
- Block , J., & Kremen , A. (1996). IQ and Ego-Resiliency: Conceptual and Empirical Connections and Separateness. *Journal of Personality & Social Psychology 70(2), 349-361.*

- Blocker, S., & Coperland, S. (1994). Determinants of resilience in high stressed youths. *High School Journal*, 77, 286-293.
- Blonna, R. (2007). *Coping with Stress in a Changing World* (4th ed.): McGraw- Hill.
- Bodenburg, S. (2008). The Dysexecutive Questionnaire Advanced: Item and Test Score Characteristics, 4-Factor Solution, and Severity Classification. *The Journal of Nervous and Mental Disease*, 196(1), 75-78.
- Bogar, C., & Hulse-Killacky, D. (2006). Resiliency Determinants and Resiliency Processes among Female Adult Survivors of Childhood Sexual Abuse. *Journal of Counselling & Development*, 84, 318-327.
- Boles, S., & Miottoa, K. (2003). Substance abuse and violence: A review of the literature *Aggression and Violent Behaviour*. 8(2), 155-174.
- Bonanno, G. (2004). Loss, Trauma, and Human Resilience Have We Underestimated the Human Capacity to Thrive After Extremely Aversive Events? *American Psychologist*, 59(1), 20-28.
- Bonanno, G., Galea, S., Bucciarelli, A., & Vlahov, D. (2007). What predicts psychological resilience after disaster? The role of demographics, resources, and life stress. *Journal of Consulting and Clinical Psychology*, 75(671-682).
- Bonanno, G. A. (2004). Loss, Trauma, and Human Resilience Have We Underestimated the Human Capacity to Thrive After Extremely Aversive Events? *American Psychologist*, 59(1), 20-28.
- Bonanno, G. A., Galea, S., Bucciarelli, A., & Vlahov, D. (2007). What predicts psychological resilience after disaster? The role of demographics, resources, and life stress. *Journal of Consulting and Clinical Psychology*, 75(671-682).
- Bonanno, G. A., Papa, A., & O'Neill, K. (2001). Loss and human resilience. *Applied and Preventive Psychology*, 10, 193-206.

- Bonanno, G. A., Wortman, C. B., & Nesse, R. M. (2004). Prospective patterns of resilience and maladjustment during widowhood. *Psychology and Aging, 19*(2), 260-271.
- Borgaro, S. R., Baker, J., Wethe, J. V., & (2005). Subjective reports of fatigue during early recovery from traumatic brain injury. *Journal of Head Trauma Rehabilitation, 20*, 416-425.
- Bozarth, J., & Brodley, B. (1991). Actualization: A functional concept in client-centred psychotherapy. *Journal of Social Behaviour and Personality, 6*, 45-59.
- Brady, K. T., Killeen, T., Saladln, M. E., Dansky, B., & Becker, S. (1994). Co morbid Substance Abuse and Posttraumatic Stress Disorder: Characteristics of Women in Treatment, *Inforna Healthcare, 3*, 160 - 164.
- Brassington, J., & Marsh, N. V. (1998). Neuropsychological aspects of multiple sclerosis. *Neuropsychological Review, 8*, 43-77.
- Bretton, M. (1993). Relating competence-promotion and empowerment. *Journal of Progressive Human Services, 5*, 27-44.
- Brewin, C. R., Andrews, B., & Valentine, J. D. (2000). Meta-analysis of risk factors for posttraumatic stress disorder in trauma-exposed adults. *Journal of Consulting and Clinical Psychology, 68*, 748-766.
- Brooks, D. N., & McKinlay, W. (1983). Personality and behavioural change after severe blunt head injury - a relative's view. *Journal of Neurology, Neurosurgery, and Psychiatry, 46*, 336-344.
- Brooks, N., Campsie, L., Symington, C., Beattie, A., & McKinlay, W. W. (1986). The five year outcome of severe blunt head injury: A relative's view. *Journal of Neurology, Neurosurgery, and Psychiatry, 49*, 764-770.
- Brown, A. W., Malec, J. F., McClelland, R. L., Diehl, N. N., Englander, J., & Cifu, D. X. (2005). Clinical elements that predict outcome after traumatic brain injury: a

- prospective multicenter recursive partitioning (decision-tree) analysis. *Journal of Neurotrauma*, 22, 1040-1051.
- Brown, E. J., & Waite, C. D. (2005). Perceptions of Risk and Resiliency Factors Associated With Rural African American Adolescents' Substance Abuse and HIV Behaviours, *Journal of the American Psychiatric Nurses Association*, 11, 88-100.
- Brown, M., & Gordon, W. A. (1999). Quality of life as a construct in health and disability research. *Mount Sinai Journal Of Medicine*, 66(3), 160-169.
- Brown, M., Gordon, W. A., & Spielman, L. (2003). Participation in social and recreational activity in the community by individuals with traumatic brain injury. *Rehabilitation Psychology*, 48(4), 266-274.
- Bruner, J., Goodnow, J., & Austin, A. (1956). *A Study of Thinking*. New York: Wiley.
- Buckner, J. C., Mezzacappa, E., & Beardslee, W. R. (2003). Characteristics of resilient youths living in poverty: The role of self regulatory processes. *Developmental Psychopathology* (15), 139-162.
- Burger, J. M., & Caldwell, D. F. (2000). Personality, social activities, job-search behaviour and interview success: Distinguishing between PANAS trait positive affect and NEO extraversion. *Motivation and Emotion*, 24, 51-62.
- Burleigh, S. A., Farber, R. S., & Gillard, M. (1998). Community integration and life satisfaction after traumatic brain injury: Long-term findings. *American Journal of Occupational Therapy*, 52, 45-52.
- Burns, R. (Ed.). (1989). *Traumatic brain injury: a neurologic perspective*. Adelaide: Institute for the Study of learning Difficulties.
- Cabness, J. L. (2003). Psychosocial resilience, depression, and subjective well-being in long-term care. *Dissertation Abstracts International*, 63(12-A), 4473, US: University Microfilms International.

- Cacioppo, J. T., & Hawkley, L. C. (2003). Social isolation and health, with an emphasis on underlying mechanisms. *Perspectives in Biology and Medicine*, 46, S39-S52.
- Cacioppo, J. T., Hawkley, L. C., & Berntson, G. G. (2003). The anatomy of loneliness. *Current Directions in Psychological Science*, 12, 71-74.
- Calabresi, P. (2007). Multiple sclerosis and demyelinating conditions of the central nervous system. In Goldman L & A. D (Eds.), *Cecil Medicine* (Vol. 436). Philadelphia, Pa: Saunders Elsevier.
- Calkins, S. D., & Degnan, K. A. (2006). Temperament in early development. In R. Ammerman (Ed.), *Comprehensive handbook of personality and psychopathology*. Hoboken, NJ: Wiley.
- Callahan, C. D., & Hinkebein, J. H. (1999). Neuropsychological significance of anosmia following traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 14(6), 581-587.
- Callaway, L., Sloan, S., & Winkler, D. (2005). Maintaining and developing friendships following severe traumatic brain injury: Principles of occupational therapy practice. *Australian Occupational Therapy Journal*, 52(3), 262-263.
- Campbell, A., & Hemsley, S. (2009). Outcome Rating Scale and Session Rating Scale in psychological practice: Clinical utility of ultra-brief measures. *Clinical Psychologist*, 13(1), 1-9.
- Campbell, A. G., & Hemsley, S. (2009). The Validity of the Outcome Rating Scale and Session Rating Scale in Psychological Practice. *The Clinical Psychologist*, 13(1), 1-10.
- Campbell, J. (1968). *The Hero with a Thousand Faces*. Princeton. Novato, California: Princeton University Press.

- Campbell, S., & MacQueen, G. (2006). An update on regional brain volume differences associated with mood disorders, *Current Opinions in Psychiatry*, *19*, 25-33.
- Campbell-Sills, L., Cohan, S., & Stein, M. (2006). Relationship of resilience to personality, coping, and psychiatric symptoms in young adults. *Behaviour Research and Therapy*, *44*(4), 585-599.
- Camras, L. A., & Allison, K. (1989). Children's and adults' beliefs about emotion elicitation. *Motivation and Emotion*, *13*(10), 53-70.
- Caplan, S. E., & Samter, W. (1999). The role of facework in younger and older adults' evaluations of social support messages. *Communication Quarterly*, *47*, 245-265.
- Caracelli, V., & Greene, J. (1997). Crafting mixed-method evaluation designs. In J. Greene & V. Caracelli (Eds.), *Advances in mixed-method evaluation: The challenges and benefits of integrating diverse paradigms* (pp. 19-32). San Francisco: Jossey-Bass.
- Carlson, J., Watts, R., & Maniaci, M. (2006). *Adlerian therapy: Theory and practice*. Washington, DC: American Psychological Association.
- Casebeer, A., & Verhoef, M. (1997) Combining Qualitative and Quantitative Research Methods: Considering the Possibilities for Enhancing the Study of Chronic Diseases. *Chronic Diseases in Canada*, *18* (3).
- Cautela, J. R. (1973). Covert processes and behaviour modification. *Journal of Nervous Menial Diseases*, *157*, 27-36.
- Chan, R. C. (2001). Dysexecutive symptoms among a non-clinical sample: A study with the use of the dysexecutive questionnaire. *British Journal of Psychology*, *92*(3), 551-565.
- Chandras, K. V., Chandras, S. V., & DeLambo, D. A. (2007). Dual diagnosis and substance abuse: Implications for the counselling arena.

- Chang, E. C., Maydeu-Olivares, A., & D’Zurilla, T. J. (1997). Optimism and pessimism as partially independent constructs: Relationship to positive and negative affectivity and psychological well-being, *Personality and Individual Differences*, 23, 433-440.
- Charcot, J. M. (1872). *Lecons sur les maladies du systeme nerveux faites a la Salpetriere*. Paris: Delahaye.
- Cheour, M., Ceponiene, R., Lehtokoski, A., Luuk, A., Allik, J., Alho, K., & Naatanen, R. (1998). Development of language-specific phoneme representations in the infant brain. *Nature Neuroscience*, 1, 351-353.
- Cicchetti, D. (2002). *How a child builds a brain: Insights from normality and psychopathology*, 32: Child psychology in retrospect and prospect. Mahwah, NJ: Erlbaum.
- Cicchetti, D., & Rogosch, F. A. (1997). The role of self-organization in the promotion of resilience in maltreated children. *Development and Psychopathology*, 9, 797-815.
- Cicchetti, D., & Tucker, D. (1994). Development and self-regulatory structures of the mind. *Development and Psychopathology*, 6, 533–549.
- Cicerone, K., Levin, H., Malec, J., Stuss, D., & Whyte, J. (2006). Cognitive Rehabilitation Interventions for Executive Function: Moving from Bench to Bedside in Patients with Traumatic Brain Injury. *Journal of Cognitive Neuroscience*, 18(7), 1212-1222.
- Clausen, J. S. (1991). Adolescent competence and the shaping of the life course. *American Journal of Sociology*, 96, 805-842.
- Clerico, M., Rivoiro, C., Contessa, G., Viglietti, D., & Durelli, L. (2008). The therapy of multiple sclerosis with immune-modulating or immunosuppressive drug: a critical evaluation based upon evidence based parameters and published systematic reviews. *Clinical Neurology and Neurosurgery*, 110(9), 878-885.

- Cohen, J. (1988). *Statistical power analysis for the behavioural sciences*. New Jersey: Lawrence Erlbaum.
- Cohen, J. (1997). Children's memory scale: Psychological Corporation.
- Cohler, B. J. (1987). *Adversity, Resilience, and the Study of Lives*. New York: Guildford Press.
- Collishaw, S., Pickles, A., Messer, J., Rutter, M., Shearer, C., & Maughan, B. (2007). Resilience to adult psychopathology following childhood maltreatment: Evidence from a community sample. *Child Abuse & Neglect*, *31*(3), 211-229.
- Compston, A., McAlpine, D., Confavreux, C., Lassmann, H., & McDonald, I. (2006). *McAlpine's multiple sclerosis*. Philadelphia: Churchill Livingstone.
- Compton, P., & Athanasos, P. (2003). Chronic pain, substance abuse and addiction, *Nursing Clinics of North America*, *38*(3), 525-537.
- Compton, R. J., Heller, W., Banich, M. T., Palmieri, P. A., & Miller, G. A. (2000). Responding to threat: Hemispheric asymmetries and interhemispheric division of input. *Neuropsychology*, *14*(2), 254-264.
- Condly, S. J. (2006). Resilience in Children: A Review of Literature with Implications for Education, *Urban Education*, *41*, 211-236.
- Conger, R. D., & Conger, K. J. (2002). Resilience in Midwestern families: selected findings from the first decade of a prospective, longitudinal study. *Journal of Marriage and Family*, *64*, 361-374.
- Conner, K., & Davidson, R. (2003). Developemtn of a new resilience scale: The Connor-Davidson Resilience Scale (CD- RISC), *Depression and Anxiety*, *18*, 76-82.
- Connor, K. (2006). Assessment of resilience in the aftermath of trauma. *Journal of Clinical Psychiatry*, *67*(Sup 2), 46-49.

- Connor, K., Davidson, R., & Lee, L. (2005). Spirituality, resilience, and anger in survivors of violent trauma: A community survey. *Journal of Traumatic Stress, 16*(5), 487-494.
- Conrad, A., & Roth, W. T. (2006). Muscle relaxation therapy for anxiety disorders: It works but how? *Journal of Anxiety Disorders 21*, 243-264.
- Cooley, L. L. (1990). *Exercise, hardiness and the stress-illness relationship*. University of Washington, Seattle, WA.
- Corkin, S. (2002). What's new with the amnesic patient H.M.? *Nature Reviews Neuroscience, 3*(2), 153-160.
- Corrigan, P., & Watson, A. (2005). Findings from the National Co morbidity Survey on the frequency of violent behaviour in individuals with psychiatric disorders *Psychiatry Research, 136*(2), 153-162.
- Corsini, R. J., & Wedding, D. (2005). *Current psychotherapies* (7 ed.). Belmont, Calif: Thomson/Brooks/Cole.
- Cowger, C. (1992). Assessment of client strengths: Clinical assessment for empowerment. *Social Work, 39*, 262-268.
- Coyle, P. K., Halper, J., & (2001). *Meeting the Challenge of Progressive Multiple Sclerosis*. New York: Demos Medical Publishing.
- Coyne, J. C., & Downey, G. (1991). Social Factors and Psychopathology: Stress, Social Support, and Coping Processes, *Annual Review of Psychology, 42*, 401-425.
- Cronbach, L. J., Gleser, G. C., Nanda, H., & Rajaratnam, N. (1972). *The dependability of behavioural measures*. New York: Wiley.
- Crosson, B. C., Barco, P. P., Velozo, C. A., Bolseta, M. M., Werts, D., & Brobeck, T. (1989). Awareness and compensation in post-acute head injury rehabilitation. . *Journal of Head Trauma Rehabilitation, 4*, 46-54.

- Crouch, M., & McKenzie, H. (2006). The logic of small samples in interview-based qualitative research. *Social Science Information*, 45(4), 483-499.
- Crowe, S. F. (2008). *The Behavioural and Emotional Complications of Traumatic Brain Injury*. USA: Psychology Press.
- Cuijpers, P., van Straten, A., & Wamerdam, L. (2007). Behavioural activation treatments of depression: A meta-analysis. *Clinical Psychology Review*, 27, 318-326.
- Cummings, J. L., & Bogousslavsky, J. (2000). *Behaviour and mood disorders in focal brain lesions*: Cambridge University press.
- Curtis, J., & Cicchetti, D. (2003). Moving research on resilience into the 21st century: Theoretical and methodological considerations in examining the biological contributors to resilience. *Development and Psychopathology* (15), 773–810.
- Curtis, W. J., & Nelson, C. A. (2003). Toward building a better brain: Neurobehavioral outcomes, mechanisms, and processes of environmental enrichment. In S. Luthar (Ed.), *Resilience and vulnerability: Adaptation in the context of childhood adversities* (pp. 463–488). New York: Cambridge University Press.
- Curtiss, G., Vanderploeg, R. D., Spencer, J., & Salazar, A. (2001). Patterns of verbal learning and memory in traumatic brain injury. *Journal of International Neuropsychological Society*, 7, 574-585.
- Cutrona, C. E., & Russell, D. (1990). Type of social support and specific stress: Toward a theory of optimal matching. In I.G. Sarason, B.R. Sarason & G. R. Pierce (Eds.), *Social support: An interactional view*. New York: Wiley.
- Damasio, A. R. (2000). *The feeling of what happens: Body and emotion in the making of consciousness*. New York: Harcourt Brace.
- Davidson, R. J. (2000). Affective style, psychopathology, and resilience: Brain mechanisms and plasticity. *American Psychologist*, 55, 1196–1214.

- Davidson, R. J. (2002). Neural and behavioural substrates of mood and mood regulation. *Biological Psychiatry, 52*, 478-502.
- Davidson, R. J., Ekman, P., Saron, C. D., Senekis, J. A., & Friesen, W. V. (1990). Approach-withdrawal and cerebral asymmetry: Emotional expression and brain physiology. *Journal of Personality and Social Psychology, 58*, 330-341.
- Davies, C. (2009, 23.9.2009). Assisted suicide guidelines will ease fears, says DPP. *Guardian*.
- Davies, D., & Dodd, J. (2002). Qualitative research and the question of rigor. *Qualitative Health research, 12*(2), 279-289.
- Davis, C. G., Nolen-Hoeksema, S., & Larson, J. (1998). Making sense of loss and benefiting from the experience: Two construal's of meaning. *Journal of Personality & Social Psychology, 75*, 561-574.
- Dayton, T. (2007). *Emotional sobriety: from relationship trauma to resilience and balance*. Florida: Health Communications, Inc.
- De Jong, P., & Miller, S. (1995). Interviewing for client strengths. *Social Work, 40*, 729-736.
- De Ruiter, C. J., Jongen, P. J., van der Woude, L. H., & de Haan, A. (2001). Contractile speed and fatigue of adductor pollicis muscle in multiple sclerosis. *Muscle Nerve, 24*, 1173-1180.
- Deacon, D., Bryman, A., & Fenton, N. (1998). Collision or collusion? A discussion and case study of the unplanned triangulation of quantitative and qualitative research methods. *International Journal of Social Research Methodology, 1*(1), 47-63.
- Dean, A., & Lin, N. (1977). The stress-buffering role of social support: problems and prospects for systematic investigation. *The Journal of Nervous and Mental Disease, 165*, 403-417.

- Deatrick, J. A., Brennan, D., & Cameron, M. E. (1998). Mothers with multiple sclerosis and their children: Effects of fatigue and exacerbations on maternal support. *Nursing Research, 47*, 205-210.
- Dejong, G. (1999). *Access to brain injury rehabilitation and other post-acute services*. Bethesda, MD: U.S. Department of Health and Human Services.
- DeJong, P., & Berg, I. (2002). *Interviewing for solutions* (2nd ed.). Belmont, CA: Brooks/Cole.
- Delis, C., Kaplan, E., & Kramer, J. (2001). *The Delis-Kaplan Executive Function System: Examiner's Manual*. San Antonio, TX.
- Delis, D., Kramer, J., Ober, B., & Kaplan, E. (1994). *The California Verbal Learning Test: Administration and interpretation*. San Antonio, TX: Psychological Corporation.
- Demo, D. H., & Savin-Williams, R. C. (1992). Self-concept stability and change during adolescence. In R. P. Lipka & T. M. Brinthaupt (Eds.), *Self-perspective across the life span* Albany, NY: State University of New York Press.
- Derogatis, L. R. (1994). *Symptom Checklist 90-R: Administration, scoring, and procedures manual*. Minneapolis, MN.
- Derstine, J., & Hargrove, S. (2000). *Comprehensive rehabilitation nursing*, Elsevier Health Sciences.
- Derstine, J. B., & Hargrove, S. D. (2001). *Comprehensive rehabilitation nursing*. Philadelphia, PA: W. B. Saunders.
- Devins, G. M., & Shnek, Z. M. (2000). Multiple sclerosis. In Frank RG & E. TR (Eds.), *Handbook of Rehabilitation Psychology* (pp. 163-184). Washington, DC: American Psychological Association.

- Devins, G. M., & Shnek, Z. M. (2000). Multiple sclerosis. In R. G. Frank & T. R. Elliott (Eds.), *Handbook of rehabilitation psychology* (pp. 163-184). Washington, DC: American Psychological Association.
- Dikmen, S., Machamer, J., Winn, H. et al. (1995). Neuropsychological outcome at 1-year post head injury. *Neuropsychology*, 9, 80-90.
- Dikmen, S., & Reitan, R. M. (1977). Emotional sequelae of head injury. *Annals of Neurology*(2), 492-494.
- Diller, L., & Ben-Yishay, Y. (2003). The clinical utility and costeffectiveness of comprehensive (holistic) brain injury daytreatment programs. In G. P. Prigatano & N. H. Pliskin (Eds.), *Clinical neuropsychology and cost outcome research*. (pp. 293–312). New York: Psychology Press.
- Dimidjian, S., Hollon, S. D., Dobson, K. S., Schmaling, K. B., Kohlenberg, R. J., Addis, M. E., et al. (2006). Randomized trial of behavioural activation, cognitive therapy, and antidepressant medication in the acute treatment of adults with major depression. *Journal of Consultant Clinical Psychology*, 74, 658-670.
- Dispenza, J. (2007). *Evolve Your Brain: The Science of Changing Your Mind*: Health Communications.
- Doctor, J. N., Castro, J., Temkin, N. R., Fraser, R. T., Machamer, J. E., & Dikmen, S. S. (2005). Workers' risk of unemployment after traumatic brain injury: a normed comparison. *Journal of the International Neuropsychological Society*, 1(6), 747-752.
- Dodge, K. A., Lansford, J. E., Burks, V. S., Bates, J. E., Pettit, G. S., & Fontaine, R. (2003). Peer rejection and social information-processing factors in the development of aggressive behavior problems in children. *Child Development*, 74(2), 374-393.
- Doidge, N. (2007). *The Brain That Changes Itself: Stories of Personal Triumph from the Frontiers of Brain Science*: Scribe Publications.

- Donald, M., Dower, J., Correa-Velez, I., & Jones, M. (2006). Risk and protective factors for medically serious suicide attempts: a comparison of hospital-based with population-based samples of young adults'. *Australian and New Zealand Journal of Psychiatry*, *40*(1), 87-96.
- Donnell, C. M., Lustig, D. C., & Strauser, D. R. (2004). The working alliance: Rehabilitation outcomes for persons with severe mental illness. . *Journal of Rehabilitation*, *70*, 12-18.
- Doraiswamy, M., & Rao, S. (2004). Treating cognitive deficits in multiple sclerosis: Are we there yet? *Neurology*, *63*, 1552-1553.
- Doweiko, H. E. (2006). *Concepts of chemical dependency* (6th ed.). Belmont, CA: Wadsworth.
- Dowrick, C., Kokanovic, R., Hegarty, K., Griffiths, F., & Gunn, J. (2008). Resilience and depression: perspectives from primary care. *Health*, *12*, 439.
- Drescher, K. D., & Foy, D. W. (1995). Spirituality and Trauma Treatment: Suggestions for Including Spirituality as a Coping Resource. *National Center for PTSD Clinical Quarterly*, *5*(1).
- Drevets, W. C., & (1999). Prefrontal cortical-amygdalar metabolism in major depression. *Annals of the New York Academy of Sciences*, *877*, 614-637.
- Drevets, W. C., Price, J. L., & Furey, M. L. (2008). Brain structural and functional abnormalities in mood disorders: implications for neurocircuitry models of depression. *Brain Structure and Function*, *213*(1-2), 93-118.
- Ducharme, J. (2003). "Errorless" Rehabilitation: Strategies of Proactive Intervention for Individuals with Brain Injury and Their Children *The Journal of Head Trauma Rehabilitation.*, *18*(1), 88-104.

- Duffy, M. L., & Forgan, J. (2005). *Mentoring new special education teachers: A guide for mentors and program developers*. : Thousand Oaks CA: Corwin Press
- DuMont, K. A., Widom, C. S., & Czaja, S. J. (2007). Predictors of resilience in abused and neglected children grown-up: The role of individual and neighbourhood characteristics. *Child Abuse & Neglect*, *31*(3), 255-274.
- Duncan, R. M., & Cheyne, J. A. (1999). Incidence and functions of self-reported private speech in young adults: A self-verbalization questionnaire. *Canadian Journal of Behavioural Science*, *31*, 133-136.
- Dunn, A. L., Trivedi, M. H., Kampert, J. B., Clark, C. G., & Chambliss, H. O. (2005). Exercise treatment for depression: efficacy and dose response. *American Journal of Preventative Medicine*, *28*, 1-8.
- Dupont, S. (1995). Multiple sclerosis and sexual functioning - a review. *Clinical rehabilitation*, *9*, 135-141.
- Durrant, M., & Kowalski, K. (1992). Enhancing views of competence. In S. Friedman (Ed.), *The new language of change* (pp. 107-137). New York: Guilford.
- Dyer, C. (1995). *Begining research in psychology*. Oxford: Blackwell Publishers Inc.
- Dyer, J. G., & McGuinness, T. M. (1996). Resilience: Analysis of the concept. *Archives of Psychiatric Nursing*, *10*(5), 276-282.
- Dyment, D. A., Ebers, G. C., & Sadovnick, A. D. (2004). Genetics of multiple sclerosis. *The Lancet Neurology*, *3*, 1-5.
- D'Zurilla, T. J., & Nezu, A. M. (2000). Problem-solving therapies. In K. S. Dobson (Ed.), *Handbook of cognitive-behavioural therapies* (Vol. 2). New York: Guilford.
- Eames, P., Cotterill, G., Kneale, T. A., Storrar, A. L., & Yeomans, P. (1996). Outcome of intensive rehabilitation after severe brain injury: A long-term follow-up study. *Brain Injury*, *10*, 631-650.

- Ebers, G. C., & Sadovnick, A. D. (1994). The role of genetic factors in multiple sclerosis susceptibility. . *Journal of Neuroimmunology*, *54*, 1-17.
- Edward, K., & Warelow, P. (2005). Resilience: When coping is emotionally intelligent. *Journal of American Psychiatric Nurses Association.*, *11*(2), 101-102.
- Edward, K.-l. (2005). Resilience: A Protector from Depression. *Journal of the American Nurses Association*, *11*(4), 241-243.
- Edward, K.-l., & Warelow, P. (2005). Resilience: When Coping Is Emotionally Intelligent (Vol. 11, pp. 101-102).
- Egeland, B., Carlson, E., & Sroufe, A. (1993). Resilience as process. *Development and Psychopathology*, *5*, 517-528.
- Egloff, B., & Hock, M. (2001). Interactive effects of state anxiety and trait anxiety on emotional Stroop interference. *Personality and Individual Differences*, *31*, 875-882.
- Ehde, D. M., Gibbons, L. E., Chwastiak, L., Bombardier, C. H., Sullivan, M. D., & Kraft, G. H. (2003). Chronic pain in a large community sample of persons with multiple sclerosis. *Multiple Sclerosis*, *9*(6), 605-611.
- Ehde, D. M., Osborne, T. L., Hanley, M. A., Jensen, M. P., & Kraft, G. H. (2006). The scope and nature of pain in persons with multiple sclerosis. *Multiple Sclerosis*, *12*, 629-638.
- Eide, A., & Roysamb, E. (2002). The relationship between level of disability, psychological problems, social activity, and social networks. *Rehabilitation Psychology*, *47*, 165-183.
- Eisenberg, N., Cumberland, A., Spinrad, T. L., Fabes, R. A., Shepard, S. A., Reiser, M., et al. (2001). The relations of regulation and emotionality to children's externalizing and internalizing problem behavior. . *Child Development*, *72*, 1112-1134.

- Eklund, V. A., & MacDonald, M. L. (1991). Descriptions of persons with multiple sclerosis, with an emphasis on what is needed from psychologists. *Professional Psychology: Research and Practice, 22*, 277-284.
- Elliot, R. (2003). Executive functions and their disorders. *British Medical Bulletin, 65*(1), 49.
- Emmons, R. A., & McCullough, M. E. (2003). Counting blessings versus burdens: An experimental investigation of gratitude and subjective well-being in daily life. *Journal of Personality and Social Psychology, 84*, 377-389.
- Ertmer, P. (1997). Common qualitative research designs. In P. Leedy (Ed.), *Practical research: Planning and design* (Vol. 6, pp. 155-172). New Jersey: Prentice Hall.
- Eslinger, P., & Geder, L. (2000). Frontal lobes. In J. L. Cummings & J. Bogousslavsky (Eds.), *Behaviour and mood disorders in focal brain lesions*: Cambridge University Press.
- Eslinger, P., Grattan, L. M., & Geder, L. (1995). Impact of frontal lobe lesions on rehabilitation and recovery from acute brain injury. *Neurorehabilitation, 5*, 161-185.
- Evans, D., Charney, D., Lewis, L., Golden, R., Gorman, J., Krishnan, K., et al. (2005). Mood Disorders in the Medically Ill: Scientific Review and Recommendations. *Biological Psychiatry, 58*(3).
- Evans, T. (1996). Encouragement: the key to reforming classrooms. *Educational Leadership, 54*, 81-85.
- Evert, H., Harvey, C., Trauer, T., & Herrman, H. (2003). The relationship between social networks and occupational and selfcare functioning in people with psychosis. *Social Psychiatry and Psychiatric Epidemiology, 38*, 180-188.
- Fagot, B. I., Hagan, R., Leinbach, M. D., & Kronsberg, S. (1985). Differential reactions to assertive and communicative acts of toddler boys and girls, *Child Development, 56*, 1499-1505.

- Farran, C. J., Herth, K. A., & Popovich, J. M. (1995). *Hope and hopelessness: Critical clinical constructs*. Thousand Oaks, CA: Sage Publications.
- Fann, J., Hart, T., & Schomer, K. J. o. N. A. (2009). Treatment for Depression Following Traumatic Brain Injury: A Systematic Review. *Journal of Neurotrauma*, *Epub ahead of print*.
- Fann, J. R., Burington, B., Leonetti, A., Jaffe, K., Katon, W. J., & Thompson, R. S. (2004). Psychiatric illness following traumatic brain injury in an adult health maintenance organization population. *Archives of General Psychiatry*, *61*, 53-61.
- Fann, J. R., Uomoto, J. M., & Katon, W. J. (2000). Sertraline in the treatment of major depression following mild traumatic brain injury. *Journal of Neuropsychiatry and Clinical Neurosciences*, *12*, 226-232.
- Falvo, D. (2005). *Medical and psychosocial aspects of chronic illness and disability* (3 ed.). Sudbury, MA: Jones & Bartlett Publishers.
- Fazel, S., Bains, P., & Doll, H. (2006). Substance abuse and dependence in prisoners: a systematic review. *Addiction*, *101*(2), 181-191.
- Feinstein, A. (1999). *The Clinical Neuropsychiatry of Multiple Sclerosis*. Cambridge: Cambridge University Press.
- Feinstein, A. (2002). An examination of suicidal intent in patients with multiple sclerosis. . *Neurology*, *59*, 674-678.
- Feldman Barrett, L., Salovey, P., & Mayer, J. D. (2002). *The Wisdom in Feeling: Psychological Processes in Emotional Intelligence*, New York: Guilford Press.
- Ferguson, B., Matyszak, M. K., Esiri, M. M., & Perry, V. H. (1997). Axonal damage in acute multiple sclerosis lesions. *Brain*, *120*, 393-399.
- Fetterman, D. M. (1989). *Ethnography: Step by Step*. Newbury Park, CA: Sage Publications.
- Fetterman, D. M. (1998). *Ethnography: Step by Step* (2nd ed.). Thousand Oaks, CA: Sage.

- Finset, A., Dyrnes, S., Krogstad, J., & Berstad, J. (1995). Selfreported social networks and interpersonal support 2 years after severe traumatic brain injury. *Brain Injury*, 9, 141-150.
- Fischer, J., & Mathieson, C. (2001). The history of the Glasgow Coma Scale: implications for practice. *Critical Care Nursing Quarterly*, 23(4), 52-57.
- Fischer, M., & Leitenberg, H. (1986). Optimism and pessimism in elementary school-aged children. *Child Development*, 57, 241-248.
- Fish, J., Evans, J., Nimmo, M., Martin, E., Kersel, D., Bateman, A., et al. (2007). Rehabilitation of executive dysfunction following brain injury: "Content-free" cueing improves everyday prospective memory performance. *Neuropsychologia*, 45(6), 1318-1330.
- Fish, J., Evans, J. J., Nimmo, M., Martin, E., Kersel, D., Bateman, A., et al. (2007). Rehabilitation of executive dysfunction following brain injury: "Content-free" cueing improves everyday prospective memory performance. *Neuropsychologia*, 45(6), 1318-1330.
- Fishbain, D. A., Rosomoff, H. L., & Rosomoff, R. S. (1992). Drug abuse, dependence, and addiction in chronic pain patients. *The Clinical journal of pain* 8(2), 77-85.
- Fleming, J. M., Chiaravalloti, N. D., & Deluca, J. (2003). Assessing the behavioral consequences of multiple sclerosis: An application of the Frontal Systems Behavior Scale (FrSBe). *Journal of Cognitive Behavioural Neurology*, 16, 54-67.
- Fleming, J. M., & Strong, J. (1995). Self-awareness of deficits following brain injury: Considerations for rehabilitation. *British Journal of Occupational Therapy*, 58, 55-60.

- Fleming, J. M., & Strong, J. (1999). A longitudinal study of self-awareness: Functional deficits underestimated by persons with brain injury. *The Occupational Therapy Journal of Research, 19*(1), 3-17.
- Fleming, J. M., Strong, J., & Ashton, R. (1996). Self-awareness of deficits in adults with traumatic brain injury: How best to measure? *Brain Injury, 10*, 1-15.
- Fleminger, S., & Powell, J. (1999). *Evaluation of outcomes in brain injury rehabilitation*. United Kingdom: Taylor & Francis Group.
- Flores, E., Cicchetti, D., & Rogosch, F. (2005). Predictors of Resilience in Maltreated and Nonmaltreated Latino Children. *Developmental psychology, 41*(2), 338-351.
- Florian, V., & Katz, S. (1991). The other victims of traumatic brain injury: consequences for family members. *Neuropsychology 5*(21).
- Florian, V., Katz, S., & Lahav, V. (1989). Impact of traumatic brain damage on family dynamics and functioning: A review. *Brain Injury, 3*, 219-233.
- Folkman, S., Chesney, M. A., & Christopher-Richards, A. (1994). Stress and coping in partners of men with AIDS. *Psychiatric Clinics of North America, 17*, 35-55.
- Folkman, S., & Moskowitz, J. T. (2000). Positive affect and the other side of coping. *American Psychologist, 55*, 647-654.
- Folkman, S., & Moskowitz, J. T. (2004). Coping: pitfalls and promise. *Annual Review of Psychology, 55*, 745-774.
- Folkman, S., Moskowitz, J. T., Ozer, E. M., & Park, C. L. (1997). Positive meaningful events and coping in the context of HIV/AIDS. In B. H. Gottlieb (Ed.), *Coping with chronic stress*. New York: Plenum.
- Foong, J., Rozewicz, L., Quaghebeur, G., Davie, C. A., Kartsounis, L. D., Thompson, A. J., et al. (1997). Executive function in multiple sclerosis. The role of frontal lobe pathology. *Brain and, 120*, 15-26.

- Ford, H. L., Gerry, E., & Johnson, M. (2002). A prospective study of the incidence, prevalence and mortality of multiple sclerosis in Leeds. *Journal of Neurology*, 249, 260-265.
- Fortune, N. (2006). *Australian Statistics on Acquired Brain Injury*. Paper presented at the Brain Injury Australia National Conference.
- Fortune, N. (2006). *Australian Statistics on Acquired Brain Injury*. Paper presented at the Brain Injury Australia National Conference.
- Fortune, N., & Wen, X. T. (1999). The definition, incidence and prevalence of brain injury in Australia. *Australian Institute of Health and Welfare*.
- Foster, J. R. (1997). Successful coping, adaptation and resilience in the elderly: An interpretation of epidemiologic data. *Psychiatric Quarterly*, 68(3), 189-219.
- Fraser, R. T., Clemmons, D., & Bennet, F. (2002). *Multiple Sclerosis. Psychosocial and Vocational Interventions*. New York: Demos.
- Fratiglioni, L., Paillard-Borg, S., & Winblad, B. (2004). An active and socially integrated lifestyle in late life might protect against dementia, *The Lancet Neurology*, 3(6), 343-353.
- Fredrickson, B. L. (1998). What Good Are Positive Emotions?. *Review of General Psychology*, 2(3), 300-319.
- Fredrickson, B. L. (2001). The Role of Positive Emotions in Positive Psychology: The Broaden-and-Build Theory of Positive Emotions. *American Psychologist*, 56(3), 218-226.
- Fredrickson, B. L., Tugade, M. M., Waugh, C. E., & Larkin, G. R. (2003). What Good Are Positive Emotions in Crises? A Prospective Study of Resilience and Emotions Following the Terrorist Attacks on the United States on September 11th, 2001. *Journal of Personality and Social Psychology*, 84(2), 365-376.

- Fredrickson, B. L., Tugade, M. M., Waugh, C. E., & Larkin, G. R. (2003). What Good Are Positive Emotions in Crises? A Prospective Study of Resilience and Emotions Following the Terrorist Attacks on the United States on September 11th, 2001.
- Frensch, P., & Funke, J. (1995). *Complex problem solving: The European perspective*: Lawrence Erlbaum Associates.
- Freud, S. (1904). Psychopathic Characters on the Stage. *Psychoanalytic Quarterly*, *11*(4), 459-464.
- Friborg, O., Hjemdal, O., Rosenvinge, J., Martinussen, M., Aslaksen, P., & Flaten, M. (2006). Resilience as a moderator of pain and stress, *Journal of Psychosomatic Research*, *6*(3), 213-219.
- Friedemann, M., & Tubergen, P. (1987). Multiple sclerosis and the family. *Archives of Psychiatric Nursing*, *1*(47-54).
- Friss, L. R., Whitlatch, C. J., & Yale, R. (1990). *Who's taking care? A profile of California's family caregivers of brain impaired adults*. San Francisco, CA: Family Survival Project.
- Frydenberg, E. (1997). *Adolescent Coping: Theoretical and Research Perspectives*. New York: Routledge.
- Gall, M., Borg, W., & Gall, J. (1996). *Educational research: An introduction* (6 ed.). New York: Longman Publishers.
- Garnezy, I., & Rodnick, A. (1959). Pre-morbid adjustment and performance in schizophrenia: Implications for interpreting heterogeneity in schizophrenia. *Journal of Nervous and Mental Diseases*, *129*, 450-466.
- Garnezy, N. (1970). Process and reactive schizophrenia: Some conceptions and issues. *Schizophrenia bulletin*, *2*, 30-74.

- Garmezy, N. (1971). Vulnerability research and the issue of primary prevention. *American Journal of Orthopsychiatry*, 41, 101-116.
- Garmezy, N. (Ed.). (1985). *Stress-resistant children: The search for protective factors*. In J.E. Stevenson (Ed.), *Recent research in developmental psychopathology* (Vol. 4): Oxford: Pergamon.
- Garmezy, N. (1987). Stress, competence and development: Continuities in the study of schizophrenic adults, children vulnerable to psychopathology, and the search for stress-resistant children. *American Journal of Orthopsychiatry*, 57, 159-174.
- Garmezy, N. (1993). Children in poverty: Resilience despite risk. *Psychiatry*, 56(1), 127-136.
- Garmezy, N. (1993). Children in poverty: Resilience despite risk. *Psychiatry*, 56(1), 127-136.
- Garnieri, E., Casetta, I., & Tola, M., et al. (1993). . (1993). Multiple sclerosis: does epidemiology contribute to providing etiological clues? *Journal of the Neurological Sciences*, 115(Supl), 16-23.
- Garske, G. (1999). The challenge of rehabilitation counsellors: Working with people with psychiatric disabilities, *Journal of Rehabilitation Medicine*, 33(2), 21-24.
- Gass, A., Kitchen, N., MacManus, D. G., Moseley, I. F., Hennerici, M. G., & Miller, D. H. (1997). Trigeminal neuralgia in patients with multiple sclerosis: lesion localization with magnetic resonance imaging. *neurology*, 49, 1142-1144.
- Gearon, J., Bellack, A., Rachbeisel, J., & Dixon, L. (2001). Drug-use behaviour and correlates in people with schizophrenia. *Addictive Behaviours*, 26, 51-61.
- Gennarelli, T. A., Thibault, L. E., Adams, J. H., Graham, D. I., Thompson, C. J., & Marcincin, R. P. (1982). Diffuse axonal injury and traumatic coma in the primate. *Annals of Neurology*, 12, 564-574.

- Gielen, A., McDonnell, K. A., Wu, A. W., O'Campo, P., & Faden, R. (2001). Quality of life among women living with HIV: the importance violence, social support, and self care behaviours. *Social Science Medicine*, 52(2), 315-322.
- Gilgun, J. (2005). Evidence based practice, descriptive research and the Resilience- Schema- Gender- Brain Functioning (RSGB) assessment. *British Journal of Social Work*, 35(843-862).
- Gilligan, R. (2000). Adversity, resilience and young people: the protective value of positive school and spare time experiences. *Children and Society*, 14, 37-47.
- Gioia, G. A., Isquith, P. K., Guy, S. C., & Kenworthy, L. (2000). Behaviour Rating Inventory of Executive Function: Professional Manual. Lutz, FL: Psychological Assessment.
- Glang, A., Todis, B., Cooley, E., Wells, J., & Voss, J. (1997). Building social networks for children and adolescents with traumatic brain injury: a school-based intervention. *Journal of Head Trauma Rehabilitation*, 12, 32-47.
- Glicklen, M. (2006). *Learning from Resilient People: Lessons We Can Apply to Counseling and Psychotherapy*. Phoenix, USA: Sage Publications.
- Gold, P. E., & McGaugh, J. L. (1975). A single-trace, two-process view of memory storage processes. In D. Deutsch & J. A. Deutsch (Eds.), *Short-term Memory* (Vol. New York, pp. 355-378): Academic Press.
- Goldney, R. D., Wilson, D., Dal- Grande, E., Fisher, L. J., & McFarlane, A. C. (2000). Suicidal ideation in a random community sample: attributable risk due to depression and psychosocial and traumatic events. *Australian and New Zealand Journal of Psychiatry*, 34, 98-106.
- Gold-Spink, E., Sher, T., & Theodos, V. (2000). Uncertainty in Illness and Optimism in Couples with Multiple Sclerosis. *International Journal of Rehabilitation and Health*, 5(3).

- Goody, E. (1995). *Social Intelligence and Interaction Expressions and implications of the social bias in human intelligence*, Cambridge.
- Gordon, P., Feldman, D., Shipley, B., & Weiss, L. (1997). Employment issues and knowledge regarding ADA of persons with multiple sclerosis. *Journal of Rehabilitation*, 63(4), 52-58.
- Gordon, W., Cantor, J., Ashman, T., & Brown, M. (2006). Treatment of Post-TBI Executive Dysfunction Application of Theory to Clinical Practice. *Journal of Head Trauma Rehabilitation*, 21(156-167).
- Gordon, W., L, H., Brown, M., Hibbard, M., & Sliwinski, M. (2001). The sensitivity and specificity of self-reported symptoms in individuals with traumatic brain injury *Brain Injury*, 14(1), 21-33.
- Gottberg, K., Einarsson, U., Fredrikson, S., von Koch, L., Holmqvist, L. W., & (2007). Neurology Neurosurgery and Psychiatry. *A population-based study of depressive symptoms in multiple sclerosis in Stockholm county: association with functioning and sense of coherence*, 78(1), 60-65.
- Grafton, S. T., Hazeltine, E., & Ivry, R. B. (1995). Functional mapping of sequence learning in normal humans. *Journal of Cognitive Neuroscience*, 7, 497-510.
- Granerud, A., & Severinsson, E. (2006). The struggle for social integration in the community – the experiences of people with mental health problems. *Journal of Psychiatric and Mental Health Nursing*, 13, 288-293.
- Grant, I., & Alves, W. (1987). Psychiatric and psychosocial disturbances in head injury. In H. S. Levin, J. Grafman, H. M. Eisenberg (Eds.) *Neurobehavioral Recovery from Head Injury* (pp. 232-261). New York: Oxford University Press.

- Gray, J. A., & McNaughton, N. (1996). The neuropsychology of anxiety: Reprise. In D. A. HOPE (Ed.), *Perspectives on anxiety, panic, & fear* (pp. 61-134). Lincoln, NE: University of Nebraska Press.
- Grazebrook, K., & Garland, A. (2005). *What are Cognitive and/or Behavioural Psychotherapies*, Unpublished manuscript.
- Greeff, A. P., & Human, B. (2004). Resilience in families in which a parent has died. *The American Journal of Family Therapy*, 32, 27-42.
- Greeff, A. P., Vansteenwegen, A., & Ide, M. (2006). Resiliency in Families with a Member with a Psychological Disorder. *The American Journal of Family Therapy*, 34, 285-300.
- Greve, K. W., Sherwin, E., Stanford, M.S., M., C., Love, J., & Ramzinski, P. (2001). Personality and neurocognitive correlates of impulsive aggression in long-term survivors of severe traumatic brain injury. *Brain Injury*, 15(3), 255-262.
- Grimm, B. H. a. B., J. (1986). Psychological rehabilitation in traumatic brain injury *In: S. B. Filskov and T. J. Bell (editors) Handbook of Clinical Neuropsychology* (Vol. 2, pp. 495-560). New York: Wiley.
- Groth-Marnat, G. (2003). *Handbook of Psychological Assessment* (4th ed.). New Jersey: John Wiley and Sons
- Gualtieri, C. T. (2002). *Brain Injury and Mental Retardation: Psychopharmacology and Neuropsychiatry*. Philadelphia, PA: Lippincott William & Wilkins
- Guberman, A. (1994). *An Introduction to Clinical Neurology*. Boston: Little, Brown and Company.
- Haahr, S., & Höllsberg, P. (2006). Multiple sclerosis is linked to Epstein-Barr virus infection. *Reviews in Medical Virology*, 16, 297-310.

- Hackenbracht, J., & Tamir, M. (2010). Preferences for sadness when eliciting help: Instrumental motives in sadness regulation. *Motivation and Emotion, 34*(3), 306-315.
- Haefffel, G. J., Voelz, Z. R., & Joiner, T. E. (2007). Vulnerability to depressive symptoms: Clarifying the role of excessive reassurance seeking and perceived social support in an interpersonal model of depression. *Cognition & Emotion, 21*(3), 681 - 688.
- Haggard, P. (2000). Interference between gait and cognitive tasks in a rehabilitating neurological population *Journal of Neurology, Neurosurgery, and Psychiatry, 69*, 479-486.
- Hakim, E. A., Bakheit, A., Bryant, T. N., Roberts, M., McIntosh-Michaelis, S., Spackman, A. J., et al. (2000). The social impact of multiple sclerosis – A study of 305 patients and their relatives. *Disability and Rehabilitation Medicine, 22*, 288-293.
- Hammersley, M., & Atkinson, P. (1995). *Ethnography : principles in practice*. London Routledge.
- Hammond, S. R., English, D. R., & McLeod, J. G. (2000). The age-range of risk of developing multiple sclerosis: Evidence from a migrant population in Australia. *Brain, 123*, 968-974.
- Hammond, S. R., English, D. R., & McLeod, J. G. (2000). The age-range of risk of developing multiple sclerosis: Evidence from a migrant population in Australia (Vol. 123, pp. 968-974).
- Hanks, R. A., Ricker, J. H., & Millis, S. R. (2004). Empirical evidence regarding the neuropsychological assessment of moderate and severe traumatic brain injury In J. H. Ricker (Ed.), *Differential Diagnosis in Adult Neuropsychological Assessment*. New York: Springer Publishing.
- Hardiman, E. R., & Segal, S. P. (2003). Community membership and social networks in mental health self-help agencies. *Psychiatric Rehabilitation Journal, 27*, 25-33.

- Harpham, W. (2006). *Happiness in a Storm: Facing Illness and Embracing Life as a Healthy Survivor* Texas: Norton.
- Harris, E. C., & Barraclough, B. (1997). Suicide as an outcome for mental disorders. A meta-analysis. *British Journal of Psychiatry*, *170*, 205-228.
- Harris, R., Burns, R., & Rees, R. (Eds.). (1989). *Recovery from brain injury: Expectations and processes*. South Australia: Institute for the Study of Learning Difficulties Adelaide.
- Hart, T., & Evans, J. (2006). Self-regulation and Goal Theories in Brain Injury Rehabilitation. *The Journal of head trauma rehabilitation*, *21*(2), 142-155.
- Hart, T., Giovannetti, T., Montgomery, M. W., & Schwartz, M. F. (1998). Awareness of errors in naturalistic action after traumatic brain injury. *The Journal of head trauma rehabilitation* *13*(5), 16-28.
- Hartup, W., & Stevens, N. (1999). Friendships and Adaptation across the Life Span. *Current directions in psychological science*, *8*(3).
- Hartup, W. W. (1996). Cooperation, close relationships, and cognitive development. In W.M. Bukowski, A.F. Newcomb & W. W. Hartup (Eds.), *The company they keep: Friendship in childhood and adolescence*. (pp. 213-237). New York: Cambridge University Press.
- Hathaway, W. L., & Pargament, K. I. (1991). The religious dimensions of coping: implications for prevention and promotion. *Religion and Prevention in Mental Health*, *64*, 65-92.
- Hawley, D. R., & DeHaan, L. (1996). Toward a definition of family resilience: Integrating life-span and family perspectives. *Family Process*, *35*, 283-298.
- Hawley, D. (2000). Clinical implications for family resilience. *The American Journal of Family Therapy*, *28*, 101-116.

- Hawton, K., Salkovskis, P. M., Kirk, J., & Clark, D. M. (1990). *Cognitive Behaviour Therapy for Psychiatric problems: A Practical Guide*. Oxford: Oxford University Press.
- Hays, J. C., Steffens, D. C., Flint, E. P., Bosworth, H. B., & George, L. K. (2001). Does social support buffer functional decline in elderly patients with unipolar depression? *American Journal of Psychiatry*, *158*, 1850-1855.
- Heartfield, M., Gibson, T., & Nasel, D. (2005). *Mentoring Fact Sheets for Nursing in General Practice*. Adelaide: University of South Australia.
- Heather, N. R., Carsten, W., Michael, F. S., & Charles, S. C. (2006). Self-Regulation Processes and Health: The Importance of Optimism and Goal Adjustment (Vol. 74, pp. 1721-1748).
- Hechtman, L. (1991). Resilience and vulnerability in long term outcome of attention deficit hyperactivity disorder. *Canadian journal of psychiatry*(36), 415-421.
- Heilemann, M., Lee, K., & Kury, F. (2003). Psychometric properties of the Spanish version of the Resilience Scale. *Journal of Nursing Measurement*, *11*(1), 61-72.
- Helgeson, V. S. (2003). Social support and quality of life. *Quality of Life Research*, *12*(1), 25-31.
- Hellawell, D. J., Taylor, R., & Pentland, B. (1999). Cognitive and psychosocial outcome following moderate or severe traumatic brain injury. *Brain Injury* (13), 489-504.
- Heller, W., Koven, N. S., & Miller, G. A. (2003). Regional brain activity in anxiety and depression, cognition/emotion interaction, and emotion regulation,. In K. Hugdahl & R. J. Davidson (Eds.), *The Asymmetrical Brain* (pp. 533-564). Cambridge, MA: MIT Press.
- Hemmingway, E. (1929). *A farewell to arms*.
- Henderson, S., Duncan-Jones, P., McAuley, H., & Ritchie, K. (1978). The patient's primary group. *British Journal of Psychiatry*, *132*, 74-86.

- Herman, R. M., D'Luzansky, S. C., & Ippolito, R. (1992). Intrathecal baclofen suppresses central pain in patients with spinal lesions: a pilot study. . *Clinical Journal of Pain*, 8, 338-345.
- Herrenkohl, T. I., Sousa, C., Tajima, E. A., Herrenkohl, R. C., & Moylan, C. A. (2008). Intersection of Child Abuse and Children's Exposure to Domestic Violence. *Trauma Violence and Abuse*, 9(2), 84-99.
- Hesse-Biber, S., & Leavy, P. (2006). *The Practice of Qualitative Research*. Thousand Oaks Sage.
- Hibbard, M. R., Ashman, T. A., & Spielman, L. A. (2004). Relationship between depression and psychosocial functioning after traumatic brain injury. . *Archives of Physical and Medical Rehabilitation*, 85(4), s43-53.
- Hibbard, M. R., Uysal, S., Sliwinski, M., & Gordon, W. A. (1998). Undiagnosed health issues in individuals with traumatic brain injury living in the community. *Journal of Head Trauma Rehabilitation*, 13(4), 47-57.
- Higgins, G. (1994). *Resilient adults: Overcoming a cruel past*. San Francisco: Jossey-Bass.
- Hilburger, J. (2000). A rehabilitation counsellor education program with a specialization in vocational rehabilitation of people with severe mental illness. . *Journal of Applied Rehabilitation Counselling*, 31(4), 15-17.
- Hill, C. E. (2005). Therapist techniques, client involvement, and the therapeutic relationship: Inextricably intertwined in the therapy process. *Psychotherapy*, 42, 431-442.
- Hiott, D. W., & Labbate, L. (2002). Anxiety disorders associated with traumatic brain injuries. *NeuroRehabilitation*, 17, 345-355.
- Hirt, E., Melton, R. J., McDonald, H. E., & Harackiewicz, J. M. (1996). Processing goals, task interest, and the mood-performance relationship: A mediational analysis. *Journal of Personality and Social Psychology*, 71, 245-261.

- Hobbis , I., & Sutton, S. (2005). Are Techniques Used in Cognitive Behaviour Therapy Applicable to Behaviour Change Interventions Based on the Theory of Planned Behaviour? *Journal of Health Psychology, 10* (1), 7-18.
- Hoge, C. W., McGurk, D., Thomas, J. L., Cox, A. L., Engel, C. C., & Castro, C. A. (2008). Mild traumatic brain injury in U.S. soldiers returning from Iraq. *New England Journal of Medicine, 358*, 453-463.
- Holland, N. J., Murray, T. J., & Reingold, S. C. (2002). *Multiple Sclerosis: A Guide for the Newly Diagnosed*. New York: Demos.
- Holsinger, T., Steffens, D. C., & Phillips, C. (2002). Head injury in early adulthood and the lifetime risk of depression. *Archives of General Psychiatry, 59*(1), 17-22.
- Hoofien, D., Gilboa, A., Vakil, E., & Donovanick, P. J. (2001). Traumatic brain injury (TBI) 10-20 years later: a comprehensive outcome study of psychiatric symptomatology, cognitive abilities and psychosocial functioning. *Brain Injury, 15*(3), 189-209.
- Houts, P. S., & Scott, R. A. (1975). Goal planning in mental health rehabilitation. *Goal Attainment Review, 2*(33-51).
- Howard, S., Dryden, J., & Johnson, B. (1999). Childhood resilience: Review and critique of literature. *Oxford review of education, 25*(3), 307.
- Howell, D. (2004). *Fundamental Statistics for the Behavioural Sciences* (Fifth Edition ed.). London: Duxberry Press.
- Huber, S., Rammohan, K., Bornstein, R., & Christy, J. (1993). Depressive symptoms are not influenced by severity of multiple sclerosis. *Neuropsychiatry Neuropsychology and Behavioural Neurology, 6*, 177-180.
- Hughes, C. F., Uhlmann, C., & Pennebaker, J. W. (1994). The body's response to processing emotional trauma: Linking verbal text with autonomic activity. *Journal of Personality, 62*, 565-585.

- Humphreys, J. (2003). Resilience in Sheltered Battered Women. *Issues in Mental Health Nursing* 24(2), 137-152.
- Hunt, D., & Micheal, C. (1983). Mentorship: A Career Training and Development Tool. *Academy of Management Review*, 8(3), 475-485.
- Hurn, J., Kneebone, I., & Cropley, M. (2006). Goal setting as an outcome measure: a systematic review. *Clinical Rehabilitation*, 20, 756-772.
- Indaco, A., Iachetta, C., Nappi, C., Socci, L., & Carrieri, P. B. (1994). Chronic and acute pain syndromes in patients with multiple sclerosis. *Acta Neurologica*, 16, 97-102.
- Irving, L., Telfer, L., & Blake, D. (1997). Hope, Coping, and Social Support in Combat-Related Posttraumatic Stress Disorder. *Journal of Traumatic Stress*, 10(3).
- Isen, A. M. (1987). Positive affect, cognitive processes, and social behaviour. *Advances in Experimental Social Psychology*(20), 203-253.
- Isen, A. M. (1999). Positive affect. In T. D. M. Powers (Ed.). *The handbook of cognition and emotion* (pp. 75-94). Hillsdale, NJ: Erlbaum.
- Isen, A. M., Daubman, K. A., & Nowicki, G. P. (1987). Positive affect facilitates creative problem solving. *Journal of Personality and Social Psychology*, 52, 1122-1131.
- Iwaniec, D., Larkin, E., & Higgins, S. (2006). Research Review: Risk and resilience in cases of emotional abuse. *Child and Family Social Work*, 11 (1), 73-82.
- Izate, M., Durozard, C., Aldigier, E., Teissedre, F., Perreve, A., & Gerbaud, L. (2008). Perceived social support and locus of control after a traumatic brain injury (TBI). *Brain Injury*, 22(10), 758-764.
- Izquierdo, I., Medina, J., Vianna, M., Izquierdo, L., A., & Barros, D. (1999). Separate mechanisms for short- and long-term memory. *Behavioural Brain Research*, 103(1), 1-11.

- Jacelon, C. (1997). The trait and process of resilience. *Journal of Advanced Nursing*, 25, 123-129.
- Jacobs, L. D. (1996). The Multiple Sclerosis Collaborative Research Group Intramuscular interferon beta-1a for disease progression in relapsing Multiple sclerosis. *Annals of Neurology*, 3, 285-294.
- Jacobson, E. (1934). *You Must Relax*. Chicago,: University of Chicago Press.
- Janoff-Bulman, R., & Timko, C. (1987). Coping with traumatic life events: The role of denial in light of people's assumptive worlds. In C. R. Snyder & C. Ford (Eds.), *Coping with Negative Life Events: Clinical and Social Psychological Perspectives*. New York: Plenum.
- Janssens, A., van Doorn, P. A., de Boer, J. B., van der Meche, F., Passchier, J., & Hintzen, R. Q. (2003). Impact of recently diagnosed multiple sclerosis on quality of life, anxiety, depression and distress of patients and partners. *Acta Neurologica Scandinavica*, 108, 389-395.
- Jelinek, G. A. (2000). *Taking control of Multiple Sclerosis*. Melbourne: Hyland House.
- Jennet, B. (1996). Epidemiology of head injury. *Journal of Neurology Neurosurgery and Psychiatry*, 60, 362-369.
- Jiann, B.-P. (2009). Sexual Dysfunction in Men Who Abuse Illicit Drugs: A preliminary report. *Journal of Sexual Medicine*. 6,1072-1080.
- Johansen, R. K. (2002). *Listening in the Silence, Seeing in the Dark; Reconstructing Life after Brain Injury*, Berkeley, LA: University of California Press.
- Johnson, K., Davis, P. K., & (1998). A supported relationships intervention to increase the social integration of persons with traumatic brain injuries. *Behaviour Modification*, 22, 502-528.

- Johnson, K. P., Brooks, B. R., & Cohen, J. A. (1995). Copolymer 1 reduces relapse rate and improves disability in relapsing-remitting multiple sclerosis: results of a phase III multicenter, double-blind placebo-controlled trial. *Neurology*, *45*, 1268-1276.
- Johnson, R. (1997). Examining the Validity Structure of Qualitative Research. *Education*, *2*, 282-290.
- Johnson, S., Phelps, D., & Cottler, L. (2004). The Association of Sexual Dysfunction and Substance Use among a Community Epidemiological Sample. *Archives of Sexual Behaviour*, *33*(1), 55-63.
- Johnson, T. P. (1991). Mental health, social relations, and social selection: A longitudinal analysis. *Journal of Health and Social Behaviour*, *32*, 408-423.
- Johnstone, B., & Stonnington, H. (2009). *Rehabilitation of Neuropsychological Disorders: A Practical Guide for Rehabilitation Professionals*. Philadelphia: PA: Psychology Press.
- Jonides, J., Lewis, R. L., Nee, D. E., Lustig, C. A., Berman, M. G., & Moore, K. S. (2008). The mind and brain of short-term memory. *Annual Review of Psychology*, *59*, 193-224.
- Joppe, M. (2000). The Research Process. Retrieved from <http://www.ryerson.ca/~mjoppe/rp.htm>
- Jorge, R., Acion, L., Starkstein, S. E., & Magnotta, V. (2007). Hippocampal volume and mood disorders after traumatic brain injury. *Biology and Psychology*, *62*, 332-338.
- Jorge, R., Egan, J., & Wolf, S. (2000). *Neuropsychiatric aspects of traumatic brain injury*, in *Comprehensive Textbook of Psychiatry* (7 ed.).
- Jorge, R., Robinson, R. G., & Moser, D. (2004). Major depression following traumatic brain injury. *Archives of General Psychiatry*, *61*, 42-50.
- Joyce, P. Y.F., Ronald, E. S., Peter, P. V., Jean, C. Y., Scarlett, M., Matthew, H., et

- al.(2009). A person-focused analysis of resilience resources and coping in patients with diabetes. *Stress and Health*, 25 (3).
- Juby, C., & Rycraft, J. R. (2004). Family preservation strategies for families in poverty. *Families in Society*, 85, 581-587.
- Judd, F., Cockram, A., Davis, J., Fahey, A., Hodgins, G., Jackson, H., et al. (2003). First year of practice visits for the rural depression anxiety research and treatment general practice program. *Australian Journal of Rural Health*, 11, 175-180.
- Julian, L. J., Vella, L., Vollmer, T., Hadjimichae, I. O., & Mohr, D. (2008). Employment in multiple sclerosis. Exiting and re-entering the work force. *Journal of Neurology*, 255(9), 1354-1360.
- Julian, L. J., Vella, L., Vollmer, T., Hadjimichae, I. O., & Mohr, D. C. (2008). Employment in multiple sclerosis. Exiting and re-entering the work force. *Journal of Neurology*, 255(9), 1354-1360.
- Jumisko, E., Lexell, J., & Söderberg, S. (2005). The Meaning of Living with Traumatic Brain Injury in People with Moderate or Severe Traumatic Brain Injury. *Journal of Neuroscience Nursing*, 37(1), 42-50.
- Jung, C. G. (1936). *The concept of the collective unconscious*. In *The archetypes and the collective unconscious*.
- Kahana, E., Leibowitz, U., & Alter, M. (1971). Cerebral multiple sclerosis. *Neurology*, 21, 1179-1185.
- Kalb, R. (2005). *Multiple sclerosis: a guide for families*. New York: Demos Medical Publishing.
- Kalia, L. V., & Connor, P. W. (2005). Severity of chronic pain and its relationship to quality of life in multiple sclerosis. *Multiple Sclerosis*, 11, 322-327.

- Kalia, L. V., & O'Connor, P. W. (2005). Severity of chronic pain and its relationship to quality of life in multiple sclerosis. *Multiple Sclerosis, 11*, 322-327.
- Kane, M. J., & Engle, R. W. (2002). The role of prefrontal cortex in working-memory capacity, executive attention, and general fluid intelligence: An individual-differences perspective. *Psychonomic Bulletin and Review, 9*, 637-671.
- Kapur, N. (1999). Syndromes of retrograde amnesia: A conceptual and empirical synthesis. *Psychological Bulletin, 125*(6), 800-825.
- Karol, R. L. (2003). *Neuropsychosocial Intervention; The practical treatment of Severe Behavioural Dyscontrol after acquired brain injury*. Florida: CRC Press.
- Karoly, P., & Rhuelman, L. (2006). Psychological “resilience” and its correlates in chronic pain: Findings from a national community sample. *Pain, 123*, 90-99.
- Karpatkin, H. (2006). Multiple sclerosis and exercise – a review of the evidence. *International Journal of Multiple Sclerosis Care, 7*, 36-41.
- Kay, T., Adams, R., Anderson, T., Berrol, S., Cicerone, K., & Dahlberg, C. (1993). Definition of mild traumatic brain injury. *Journal of Head Trauma Rehabilitation, 8*, 86-87.
- Kazdin, A. E. (1994). Methodology, design, and evaluation in psychotherapy research. In A. E. Bergin & S. L. Garfield (Eds.), *Handbook of psychotherapy and behavior change*. New York: John Wiley.
- Kelly, M. P., Johnson, C. T., Knoller, N., Drubach, D. A., & Winslow, M. M. (1997). Substance abuse, traumatic brain injury and neuropsychological outcome. *Brain Injury, 11*(6), 391-402.
- Keltner, D., & Bonanno, G. A. (1997). A study of laughter and dissociation: The distinct correlates of laughter and smiling during bereavement. *Journal of Personality and Social Psychology, 73*, 687-702.

- Kendall, E., Shum, D., Halso, D., Bunning, S., & Teh, M. (1997). The assessment of social problem solving ability following traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 12(3), 68-78.
- Kent-Braun, J. A., Sharma, K. R., Weiner, M. W., & Miller, R. G. (1994). Effects of exercise on muscle activation and metabolism in multiple sclerosis. *Muscle Nerve*, 17(1162-1169).
- Keppel, G., & Zedeck, S. (2002). *Data analysis for research designs: Analysis of variance and multiple regression/correlation approaches*. New York: Freeman.
- Kerlinger, F. N. (1973). *Foundations of behavioural research*. New York: Holt, Rinehart, & Winston.
- Kessels, R., Boekhorst, S., & Postma, A. (2005). The contribution of implicit and explicit memory to the effects of errorless learning: A comparison between young and older adults. *Journal of the International Neuropsychological Society*, 11(2), 144-151.
- Kessels, R. P. C., & Haan, E. H. F. (2003). Implicit Learning in Memory Rehabilitation: A Meta-Analysis on Errorless Learning and Vanishing Cues Methods (Vol. 25, pp. 805 - 814): Psychology Press.
- Kessler, R. C., Borges, G., & Walters, E. E. (1999). Prevalence of and risk factors for lifetime suicide attempts in the National Comorbidity Survey. *Archives of General Psychiatry*, 56, 617-626.
- Khan, F., Baguley, J., & Cameron, I. (2003). Rehabilitation after traumatic brain injury. *Rehabilitation Medicine*, 178, 290-295.
- Kim, E., Lauterbach, E. C., Reeve, A., Arciniegas, D. B., Coburn, K. L., Mendez, M. F., et al. (2007). Neuropsychiatric Complications of Traumatic Brain Injury: A Critical Review of the Literature (A Report by the ANPA Committee on Research) (Vol. 19, pp. 106-127).

- Kim, H. S. (2002). We talk, therefore we think? A cultural analysis of the effect of talking on thinking. *Journal of Personality and Social Psychology*, 83, 824-842.
- Kiresuk, T., & Sherman, R. (1968). Goal attainment scaling: A general method for evaluating comprehensive community mental health programs. *Community Mental Health Journal*, 4(6), 443-453.
- Kiresuk, T., & Sherman, R. (1968). Goal attainment scaling: A general method for evaluating comprehensive mental health programs. *Community Mental Health Journal*, 4, 443-453.
- Kiresuk, T. J., & Sherman, R. E. (1968). Goal attainment scaling: A general method for evaluating comprehensive community mental health programs. *Community Mental Health Journal*, 4(6), 443-453.
- Kirk, J., & Miller, M. (1986). *Reliability and Validity in Qualitative Research*. Newbury Park, CA: Sage.
- Kirschenbaum, H., & Henderson, V. L. (1990). *The Carl Rogers Reader*. London: Constable.
- Kirschenbaum, H., & Jourdan, A. (2005). The current status of Carl Rogers and the person-centred approach. *Psychotherapy: Theory, Research, Practice, Training*, 42(1), 37-51.
- Klonoff, P. S., Snow, W. G., & Costa, L. D. (1986). Quality of life in patients two to four years after closed head injury. *Neurosurgery*, 19, 735-743.
- Knight, R. G., Devereux, R., & Godfrey, H. P. D. (1998). Caring for a member with a traumatic brain injury. *Brain Injury*, 12, 467-481.
- Knobloch, S., & Zillman, D. (2002). Mood management via the digital jukebox. *Journal of Communication*, June, (351-366).
- Kobasa, S., Maddi, S., & Kahn, S. (1982). Hardiness and health: A prospective study. *Journal of Personality and Social Psychology*, 42(1), 168-177.

- Koch, M. W., Glazenborg, A., Uyttenboogaart, M., Mostert, J., & De Keyser, J. (2011). Pharmacologic treatment of depression in multiple sclerosis. *Cochrane Database of Systematic Reviews*, 2.
- Koenen, K. C., Stellman, J. M., Stellman, S. D., & Sommer, J. F. J. (2003). Risk factors for course of PTSD among Vietnam veterans: A 14-year follow-up of American Legionnaires. *Journal of Consulting & Clinical Psychology*, 71, 980-986.
- Kohn, P. M. (1996). On coping adaptively with daily hassles. In M. Zeidner & N. S. Endler (Eds.), *Handbook of coping: Theory, research, applications* (pp. 181-201). New York: Wiley.
- Kolb, B., & Gibb, R. (2001). Early brain injury, plasticity, and behaviour. In C. A. Nelson & M. Luciana (Eds.), *Handbook of developmental cognitive neuroscience* (pp. 175–190). Cambridge: MA: MIT Press.
- Komiti, A., Judd, F., Grech, P., Mijch, A., Hoy, J., & Williams, B. (2003). Depression in people living with HIV/AIDS attending primary care and outpatient clinics. *Australian and New Zealand Journal of Psychiatry*, 37, 70-77.
- Kongs, S. K., Thompson, L. L., Iverson, G. L., & Heaton, R. K. (2000). Wisconsin Card Sorting Test—64 card computerized version. Odessa, FL: Psychological Assessment Resources
- Koponen, S., Taiminen, T., & Portin, R. (2002). Axis I and II psychiatric disorders after traumatic brain injury: a 30-year follow-up study. *American Journal of Psychiatry*, 159(8), 1315-1321.
- Korkman, M., Kirk, U., & Kemp, S. (1998). NEPSY: A Developmental Neuropsychological Assessment. San Antonio, TX.

- Kornblith, A. B., LaRocca, N. G., & Baum, H. M., 9 (1986), 1555–1165. (1986).
Employment in individuals with multiple sclerosis, *International Journal of Rehabilitation Research*, 9, 1555-1165.
- Korostil, M., & Feinstein, A. (2007). Anxiety disorders and their clinical correlates in multiple sclerosis patients. *Multiple Sclerosis*, 13(67-72).
- Kozloff, R. (1987). Networks of social support and the outcome of severe head injury. *Journal of Head Trauma Rehabilitation*, 14-23.
- Kreutzer, J. S., Gervasio, A. H., & Camplair, P. S. (1994). Patient correlates of caregivers' distress and family functioning after traumatic brain injury. *Brain Injury*, 8, 211-230.
- Kroencke, D. C., Lynch, S. G., & Denney, D. R. (2000). Fatigue in multiple sclerosis: relationship to depression, disability, and disease pattern. 6(2), 131-136.
- Kumpher, K. L. (1999). Factors and processes contributing to resilience: The resilience framework. In G. M.D & J. J.L (Eds.), *Resilience and development: Positive life adaptations* (pp. 179 -224). New York: Plenum.
- Kurtzke, J. F., & (2000). Epidemiology of multiple sclerosis. Does this really point toward an etiology? *Neurological Science*, 21, 388-403.
- Kurtzke, J. F., Delasnerie-Lauprêtre, N., & Wallin, M. T. (1998). Multiple sclerosis in North African migrants to France. *Acta Neurologica Scandinavica*, 98, 302-309.
- Ladd, G. W., Kochenderfer, B. J., & Coleman, C. C. (1997). Classroom peer acceptance, friendship, and victimization: Distinct relational systems that contribute uniquely to children's school adjustment. *Child Development*, 68(6), 1181-1197.
- Lam, D. (1997). Cognitive behaviour therapy territory model: effective disputing approach. *Journal of Advanced Nursing*, 25, 1205-1209.
- Lam, D., & Cheng, L. (1998). Cognitive behaviour therapy approach to disputing automatic thoughts: a two-stage model. *Journal of Advanced Nursing*, 27(6), 1143-1150.

- Lam, D., & Cheng, L. (2001). Cognitive behaviour therapy approach to assessing dysfunctional thoughts. *Counselling psychology quarterly*, 14(3), 255-265.
- Lam, D., & Gale, J. (2000). Cognitive behaviour therapy approach: teaching a client the ABC model-the first step towards the process of change. *Journal of Advanced Nursing*, 31, 444-451.
- Lam, D., & Gale, J. (2004). Cognitive behaviour therapy: an evidence-based clinical framework for working with dysfunctional thoughts. *Counselling psychology quarterly*, 17(1), 53-67.
- Lambert, M. J., Hansen, N. B., Umphress, V., Lunnen, K., Okiishi, J., & Burlingame. (1996). Administration and scoring manual for the OQ-45.2. American Professional Credentialing Services.
- Lambert, M. J., & Hills, C. E. (1994). Assessing psychotherapy outcomes and processes. In A. E. Bergin & S. L. Garfield (Eds.), *Handbook of psychotherapy and behaviour change*. New York: John Wiley.
- Langer, K., & Padrone, F. (1992). Psychotherapeutic treatment of awareness in acute rehabilitation of traumatic brain injury. *Neuropsychological rehabilitation*, 2(1), 59-70.
- Lansford, J. E., Malone, P. S., Stevens, K. I., Dodge, K. A., Bates, J. E., & Pettit, G. S. (2006). Developmental trajectories of externalizing and internalizing behaviours: Factors underlying resilience in physically abused children. *Cambridge Journals Online*, 18, 35-55.
- Laor, N., Wolmer, L., Alon, M., Siev, J., Samuel, E., & Toren, P. (2006). Risk and Protective Factors Mediating Psychological Symptoms and Ideological Commitment of Adolescents Facing Continuous Terrorism. *The Journal of Nervous and Mental Disease*, 194(4).

- Laor, N., Wolmer, L., Alon, M., Siev, J., Samuel, E., & Toren, P. (2006). Risk and Protective Factors Mediating Psychological Symptoms and Ideological Commitment of Adolescents Facing Continuous Terrorism. *The Journal of Nervous and Mental Disease*, 194(4).
- LaRocca, N. G. (1995). *Employment and multiple sclerosis*. Unpublished manuscript, New York.
- Laughlin, C., McManus, J., D., & Aquili, E. (1990). *Brain, Symbol, & Experience: Towards a Neurophenomenology of Human Consciousness*. New York: Columbia University Press.
- Laureys, S., Majerus, S., & Moonen, G. (2002). Assessing consciousness in critically ill patients. In J. L. Vincent. (Ed.), *Yearbook of Intensive Care and Emergency Medicine* (pp. 715-727): Heidelberg, Springer-Verlag.
- Lazarus, R. (1993). Coping theory and research: past, present, and future (Vol. 55, pp. 234-247).
- Lazarus, R., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Lazarus, R., & Golden, G. Y. (1981). The function of denial in stress, coping, and aging. In J. L. McGaugh & S. B. Kiesler (Eds.), *Aging. Biology and behaviour* (pp. 283-307). New York: Academic Press.
- Leahy, R. L. (2004). *Contemporary cognitive therapy*. New York: Guilford Press.
- Leclercq, M., Deloche, G., & Rousseaux, M. (2002). Attentional complaints evoked by traumatic brain injured and stroke patients; frequency and importance. In M. Leclercq & P. Zimmermann (Eds.), *Applied Neuropsychology of Attention: Theory, Diagnosis, and Rehabilitation*. London: Psychology Press.
- LeCompte, M. (2002). The transformation of ethnographic practice: Past and current challenges. *Qualitative Research*, 2(3).

- LeDoux, J. (1996). *The Emotional Brain*. New York: Simon and Schuster.
- Lee, H., Kim, S. W., Kim, J. M., Shin, I. S., Yang, S. J., & Yoon, J. S. (2005). Comparing effects of methylphenidate, sertraline and placebo on neuropsychiatric sequelae in patients with traumatic brain injury. *Human Psychopharmacology*, *20*, 97-104.
- Lee, S.-H., Theoharis, R., Fitzpatrick, M., Kim, K.-H., Liss, J. M., Nix-Williams, T., et al. (2006). Create effective mentoring relationships: strategies for mentor and mentee success. *Intervention in School and Clinic*.
- Lefcourt, H. M., Davidson-Katz, K., & Kueneman, K. (1990). Humor and immune-system functioning. *Humor: International Journal of Humor Research*, *3*, 305-321.
- Lehmann, E., & D'Abrera, H. (1998). *Nonparametrics: Statistical Methods Based on Ranks*. NJ: Prentice-Hall.
- Letzring, T. D., Greve, L. A., & Funder, D. C. (2005). Ego-control and ego-resiliency: Generalization of self-report scales based on personality descriptions from acquaintances, clinicians, and the self. *Journal of Research in Personality*, *39*, 395-422.
- Levack, W. M., Taylor, K., Siegert, R. J., Dean, S. G., McPherson, K. M., & Weatherall, M. (2006). Is goal planning in rehabilitation effective? A systematic review. *Clinical Rehabilitation* *20*, 739-755.
- Levin, H. S., Benton, A.L, Grossman, R.G. (1982). *Neurobehavioral Consequences of Closed Head Injury*. New York: Oxford University Press.
- Levin, H. S., Grossman, R. G., Rose, J. E., & Teasdale, G. (1979). Long-term neuropsychological outcome of closed head injury. *Journal of Neurosurgery*, *50*, 412-422.
- Levitt, T., & Johnstone, B. (2001). The assessment and rehabilitation of attention disorders. In B. Johnstone & H. Stonnington (Eds.), *Rehabilitation of Neuropsychological*

Disorders; a practical guide for rehabilitation professionals. Philadelphia: Psychology Press.

- Lewinsohn, P. M., Gotlib, I. H., & Seeley, J. R. (1997). Depression-related psychosocial variables in adolescence: Are they specific to depression? . *Journal of Abnormal Psychology, 106*, 365-375.
- Lezak , M. (1989). Assessment of psychosocial dysfunctions resulting from head trauma. *In Lezak (Ed.), Assessment of the Behavioural Consequences of Head Trauma* (pp. 113-144). New York: Alan R. Liss.
- Lezak , M. (1993). Newer contributions to the neuropsychological assessment of executive functions. *Journal of Head Trauma Rehabilitation, 8*, 24-31.
- Lezak , M. (1995). *Neuropsychological Assessment* (3rd edition ed.). New York: Oxford University Press.
- Lezak , M., Howieson , D., & Loring , D. (2004). *Neuropsychological assessment* (4th ed.). New York: Oxford University Press.
- Lezak, M. D. (1988). Brain damage is a family affair. *Journal of Clinical and Experimental Neuropsychology, 10*, 111-123.
- Lezak, M. D. (1993). Newer contributions to the neuropsychological assessment of executive functions. *Journal of Head Trauma Rehabilitation, 8*, 24-31.
- Lightsey, O. R., Jr. (2006). Resilience, meaning, and well-being. *The Counselling Psychologist, 34*, 96-107.
- Littrell, J. (1998). *Brief counselling in action*. New York: Norton.
- Livingston, M. G., & Brooks, D. N. (1988). The burden on families of the brain injured: A review. *Journal of Head Trauma Rehabilitation, 2*(4), 6-15.

- Livneh, H., & Antonak, R. (1997). *Psychosocial adaptation to chronic illness and disability*. Gaithersburg, Maryland: Aspen Publishers.
- Locke, E. A. (1968). Toward a theory of task motivation and incentives. *Organisational Behaviour and Human Performance*, 3, 157-189.
- Logan, G. (2003). Executive control of thought and action: In search of the wild homunculus. *Current directions in psychological science*, 12(2), 45-48.
- Lovell, M. R., Iverson, G. L., Collins, M. W., McKeag, D., & Maroon, J. C. (1999). Does loss of consciousness predict neuropsychological decrements after concussion? *Clinical Journal of Sport Medicine*, 9, 193-198.
- Lublin, F. D., & Reingold, S. C. (1996). Defining the clinical course of multiple sclerosis: Results of an international survey. *Neurology*, 46(2), 907-911.
- Luria, A. (1961). *The role of speech in the regulation of normal and abnormal behaviour*. New York: Liveright.
- Luria, A. R., & Tsvetkova, L. S. (1990). *The Neuropsychological Analysis of Problem Solving*. Orlando: Paul M. Deutsch Press.
- Luthans, F., & Jensen, S. M. (2002). Hope: A new positive strength for human resource development. *Human Resource Development Review*, 1, 304-322.
- Luthans, F., & Stajkovic. (1998). *Social Cognitive Theory and Self-Efficacy: Going Beyond Traditional Motivational and Behavioural Approaches*.
- Luthar, S., Cicchetti, D., & Becker, B. (2000). The Construct of Resilience: A Critical Evaluation and Guidelines for Future Work. *Child Development*, 71(3), 543-562.
- Luthar, S., Cicchetti, D., & Becker, B. (2000). Research on Resilience: Response to Commentaries. *Child Development*, 71(3), 573-575.
- Luthar, S., & Zigler, E. (1992). Intelligence and social competence among high-risk adolescents. *Development and Psychopathology*, 4, 287-299.

- Luthar, S. S., Cicchetti, D., & Becker, B. (2000). The Construct of Resilience: A Critical Evaluation and Guidelines for Future Work. *Child Development, 71*(3), 543-562.
- Lyubomirsky, S., Sousa, L., & Dickerhoof, R. (2006). The Costs and Benefits of Writing, Talking, and Thinking about Life's Triumphs and Defeats. *Journal of Personality and Social Psychology, 90*(4), 692-670.
- Machamer, J., Temkin, N., Fraser, R., Jason, N., & Dikmen, S. (2005). Stability of employment after traumatic brain injury. *Journal of the International Neuropsychological Society, 11*(7), 807-816.
- Maddux, J. E. (2002). Self-efficacy: The power of believing you can. In C. R. Snyder & S. J. Lopez (Eds.), *Handbook of positive psychology* (pp. 829). London: Oxford University Press.
- Mahmood, O., Rapport, J. L., Hanks, R. A., & Fichtenberg, N. L. (2004). Neuropsychological performance and sleep disturbance following traumatic brain injury. *Journal of Head Trauma Rehabilitation, 19*, 378-390.
- Majno, G., & Joris, I. (1995). Apoptosis, oncosis, and necrosis. An overview of cell death. *American Journal of Pathology, 146*, 3-15.
- Malec, J. (1994). Goal Attainment Scaling in Rehabilitation. *Neuropsychological Rehabilitation, 9*(3/4), 253-275.
- Malec, J. (1999). Goal Attainment Scaling in rehabilitation. . *Neuropsychological Rehabilitation 9*, 253-275.
- Malec, J., Brown, A., Leibson, C., Flaada, J., Mandrekar, J., Diehl, N., et al. (2007). The Mayo Classification System for Traumatic Brain Injury Severity. *Journal of Neurotrauma, 24*(9), 1417-1424.
- Malec, J., & Scanlan, R. (2004). Employment after Brain Injury. *Brain Injury Association of America, 1-20*

- Malec, J. F., & Scanlan, R. A. (2004). *Employment after Traumatic Brain Injury*. Washington, D.C.
- Mancini, A. D., & Bonanno, G. A. (2006). Resilience in the face of potential trauma: clinical practices and illustrations. *Journal of Clinical Psychology, 62*(8), 971.
- Mandleco, B. L., & Peery, J. C. (2000). An organizational framework for conceptualizing resilience in children. *Journal of Child and Adolescent Psychiatric Nursing, 13*, 99-111.
- Mann, H. B., & Whitney, D. R. (1947). On a test of whether one of two random variables is stochastically larger than the other. *Annals of Mathematical Statistics, 18*, 50-60.
- Mann, J. J., Waterneux, C., Haas, G. L., & Malone, K. M. (1999). Toward a clinical model of suicidal behavior in psychiatric patients. *American Journal of Psychiatry, 156*, 181-189.
- Marlatt, G. A., Parks, G. A., & Witkiewitz, K. (2002). *Clinical Guidelines for Implementing Relapse Prevention Therapy A Guideline Developed for the Behavioural Health Recovery Management Project*. Seattle, Washington.
- Marsh, N. V. (1999). Social skill deficits following traumatic brain injury: assessment and treatment. In: S. McDonald, L. Togher and C. Code (editors) *Communication Disorders Following Traumatic Brain Injury* (pp. 174-210). Hove, UK: Psychology Press.
- Martin, R., & Lefcourt, H. (1983). Sense of humour as a moderator of the relation between stressors and mood. *Journal of Personality and Social Psychology, 45*, 1313-1324.
- Martz, E., Livneh, H., & Wright, B. (2007). *Coping with Chronic Illness and Disability Theoretical, Empirical, and Clinical Aspects* Tennessee, USA: Springer.
- Masten, A. (2001). Ordinary Magic: Resilience Processes in Development. *American Psychologist, 56*(3), 227-238.

- Masten , A., Best, K. M., & Garmezy, N. (1990). Resilience and development: Contributions from the study of children who overcome adversity. *Development and Psychopathology*, 2, 425-444.
- Masten , A., & Coatsworth, J. (1995). Competence, resilience and psychopathology. *Developmental Psychopathology*, 2, 715-752.
- Masten , A., & Coatsworth , J. (1998). The Development of Competence in Favorable and Unfavorable Environments: Lessons From Research on Successful Children. *American Psychologist*, 53(205-220).
- Masten, A., & Garmezy, N. (1985). Risk, vulnerability and protective factors in developmental psychopathology. *Advances in clinical child psychology*, 8, 1-52.
- Masten , A., & Garmezy , N. (1985). Risk, vulnerability and protective factors in developmental psychopathology. *Advances in clinical child psychology*, 8, 1-52.
- Masten , A., & Reed , M. (2002). Resilience in Development. In C. R. Snyder & S. J. Lopez (Eds.), *Handbook of Positive Psychology*. New York: Oxford University Press.
- Mathews, A. (1990). Why worry? The cognitive function of anxiety. *Behaviour Research and Therapy*, 28, 455-468.
- Matrevers, D. (2001). *Art and Emotion*. Oxford, London: Oxford University Press.
- Matson, R. R., & Brooks, N. A. (1977). Adjusting to multiple sclerosis: an exploratory study. *Social Science and Medicine*, 11, 245-250.
- Mauss, I., Bunge, S., & Gros, J. (2007). Automatic Emotion Regulation. *Social and Personality Psychology Compass* 1(1), 146-167.
- Maxwell, J. (1992). Understanding and validity in qualitative research. *Harvard Educational Review*, 62(3), 279-300.
- Maxwell, J. (2005). *Qualitative Research Design: An Interactive Approach*. (2nd ed.): Sage Publications.

- McAllister, T. W., & Arciniegas, D. (2002). Evaluation and treatment of postconcussive symptoms. *Neurorehabilitation* 17, 265-283.
- McBroom, P. (2002). Positive emotions, including laughter are important paths out of trauma, according to UC Berkeley psychologist. *Campus News*.
- McCabe, M. P., & Di Battista, J. (2004). Role of health, relationships, work and coping on adjustment among people with multiple sclerosis: A longitudinal investigation. *Psychology, Health and Medicine*, 9, 431-439.
- McCabe, P., Lippert, C., Weiser, M., Hilditch, M., Hartridge, C., & Villamere, J. (2007). Community reintegration following acquired brain injury. *Brain Injury*, 21(2), 231-257.
- McCallie, S., Blum, M., & Hood, C. J. (2006). Progressive Muscle Relaxation. *Journal of Human Behaviour in the Social Environment*, 13(3), 51-66.
- McClellan, D. L. (1997). Introduction to rehabilitation. In B. A. Wilson & D. L. McLellan (Eds.), *Rehabilitation Studies Handbook*. Cambridge: Cambridge University Press.
- McClelland, R. J. (1988). Psychosocial sequelae of head injury - anatomy of a relationship. *British Journal of Psychiatry*, 153, 141-146.
- McCloskey, G. (2003). Executive functions overview. Paper presented at the Eighteenth Learning and the Brain Conference, Boston, MA. Retrieved June, 2004.
- McDonald, W., Compston, A., Edan, G., & al., e. (2001). Recommended diagnostic criteria for multiple sclerosis: guidelines from the International Panel on the diagnosis of multiple sclerosis. *Annals of Neurology*, 50, 121-127.
- McGlynn, S. M. (1990). Behavioural approaches to neuropsychological rehabilitation. . *Psychological Bulletin*, 108, 420-441.

- McGuire, L. M., Burright, R. G., Williams, R., & Donovick, P. J. (1998). Prevalence of traumatic brain injury in psychiatric and non-psychiatric patients. *Brain Injury, 12*(3), 207-214.
- McKee-Ryan, F., Song, Z., Wanberg, C., Kinicki, A., & (2005). Psychological and physical well-being during unemployment: a meta-analytic study. *The Journal of applied psychology, 90*(1), 53-76.
- McKinlay, W. W., & Watkiss, A. J. (1999). Cognitive and behavioral effects of brain injury. In M. Rosenthal, E. R. Griffith & J. S. Kreutzer (Eds.), *Rehabilitation of the Adult and Child with Traumatic Brain Injury* (3rd edn ed., pp. 74-86). Philadelphia: Davis.
- McMillan, T. M., & Sparkes, C. (1999). Goal planning and neurorehabilitation: The Wolfson Neurorehabilitation Centre approach. *Neuropsychological Rehabilitation, 9*, 241-251.
- McNally, R. J. (1998). Experimental approaches to cognitive abnormality in posttraumatic stress disorder. *Clinical Psychology Review, 18*, 971-982.
- McReynolds, C., Koch, L., & Rumrill, P. D. (1999). Psychosocial adjustment to multiple sclerosis: implications for rehabilitation professionals. *Journal of Vocational Rehabilitation, 12*, 83-91.
- Meade, C., & Weiss, R. (2007). Substance Abuse as a Risk Factor for HIV Sexual Risk Behaviour Among Persons With Severe Mental Illness: Review of Evidence and Exploration of Mechanisms. *Clinical Psychology: Science and Practice, 14*(1), 23-33.
- Medd, J., & Tate, R. L. (2000). Evaluation of an anger management therapy programme following ABI: A preliminary study. *Neuropsychological Rehabilitation, 10*, 185-201.
- Merbitz, C., Miller, T., & Hansen, N. (2000). Cueing and logical problem solving in brain trauma rehabilitation: frequency patterns in clinician and patient behaviours. *Behavioural Interventions, 15*(3), 169-187.

- Meyers, J. E., & Meyers, K. R. (1994). *Rey Complex Figure Test; Professional Manual: Psychological Assessment Resource*.
- Meythaler, J. M., Peduzzi, J. D., Eleftherious, E., & Novack, T. A. (2001). Current Concepts: Diffuse axonal injury associated traumatic brain injury. *Archives of Physical Medicine and Rehabilitation, 82*, 1461-1471.
- Miller, E. (2003). Reconceptualising the role of resiliency in coping and therapy. *Journal of Loss and Trauma, 8*, 239-246.
- Miller, L. (1990). Major syndromes of aggressive behaviour following head injury: An introduction to evaluation and treatment. *Cognitive Rehabilitation, Nov/ Dec*, 14-19.
- Miller, L. (1993). *Psychotherapy of the Brain-Injured Patient: Reclaiming the Shattered Self*. New York: Norton,.
- Miller, S. D., & Duncan, B. L. (2000). *The Outcome Rating Scale*. Chicago.
- Miller, S. D., Duncan, B. L., Brown, J., Sparks, J., & Claud, D. (2003). The Outcome Rating Scale: A preliminary study of the reliability, validity, and feasibility of a brief visual analog measure. . *Journal of Brief Therapy, 2(2)*, 91-100.
- Minden, S. L. (1992). Psychotherapy for people with Multiple Sclerosis. *Journal of Neuropsychology and Clinical Neuroscience, 4*, 198-213.
- Mishler, E. G. (2000). Validation in inquiry-guided research: The role of exemplars in narrative studies. In B. M. Brizuela, J. P. Stewart, R. G. Carrillo & J. G. Berger (Eds.), *Acts of inquiry in qualitative research*. Cambridge, MA: Harvard Educational Review.
- Mohr, D. (1997). Identification of Beck Depression Inventory items related to multiple sclerosis. *Journal of Behavioural Medicine, 20*, 407-414.
- Mohr, D., Boudewyn, A. C., Goodkin, D. E., Bostrom, A., Siskin, L., Epstein, L., et al. (2001). Comparative outcomes for individual cognitive-behaviour therapy,

- supportive-expressive group psychotherapy, and sertraline for the treatment of depression in multiple sclerosis. *Journal of Consulting and Clinical Psychology*, 69, 942-949.
- Mohr, D., & Cox, D. (2001). Multiple Sclerosis: Empirical literature for the clinical health psychologist. *Journal of Clinical Psychology*, 57(4), 479-499.
- Mohr, D., Dick, L., Russo, D., Pinn, J., Boudewyn, A., Likosky, W., et al. (1999). The psychosocial impact of Multiple Sclerosis: Exploring the patient's perspective. *Health Psychology*, 18(4), 372-376.
- Mohr, D. C., Boudewyn, A. C., Goodkin, D. E., Bostrom, A., & Epstein, L. (2001). Comparative outcomes for individual cognitive- behavior therapy, supportive-expressive group psychotherapy, and sertraline for the treatment of depression in multiple sclerosis. *Journal of Consultant Clinical Psychology*, 69(6), 942-949.
- Monk, C. S., Nelson, E. E., McClure, E. B., Mogg, K., Bradley, B. P., Leibenluft, E., et al. (2006). Ventrolateral Prefrontal Cortex Activation and Attentional Bias in Response to Angry Faces in Adolescents with Generalized Anxiety Disorder. *American Journal of Psychiatry*. 163, 1091-1097.
- Monteith, B., & Ford-Gilboe, M. (2002). The relationships among mother's resilience, family health work, and mother's health-promoting lifestyle practices in families with preschool children. *Journal-of-Family-Nursing*, 8(4), 383-407.
- Montross, L., Depp, C., & Daly, J., et al. . (2006). Correlates of self-rated successful aging among community-dwelling older adults. *American Journal of Geriatric Psychiatry*, 14, 43-51.
- Moore, E. L., Terryberry-Spohr, L., & Hope, D. A. (2006). Mild traumatic brain injury and anxiety sequelae: A review of the literature. *Brain Injury*, 20(2), 117-132.

- Moriarty, D. G., Zack, M. M., & Kobau, R. (2003). The centres for disease control and prevention's healthy days measures—population tracking of perceived physical and mental health over time. *Health and Quality of Life Outcomes, 1*(1), 37.
- Morin, A. (1993). Self-talk and self-awareness: On the nature of the relation. *The Journal of Mind and Behaviour, 14*(3), 223-234.
- Morse, J. (1991). Approaches to qualitative-quantitative methodological triangulation. *Nursing Research, 40*(1), 120-123.
- Mostert, S., & Kesselring, J. (2002). Effects of a short-term exercise training program on aerobic fitness, fatigue, health perception and activity level of subjects with multiple sclerosis. *Multiple sclerosis 8*(2), 161-168.
- Moulin, D. (1989). Pain in multiple sclerosis. *Neurology Clinic, 7*(2), 321-330.
- Mueser, K., Bellack, A., & Blanchard, J. (1992). Comorbidity of schizophrenia and substance abuse: Implications for treatment. *Journal of Consulting and Clinical Psychology, 60*, 845-856.
- Mullins, L. L., Cote, M. P., Fuemmeler, B. F., Jean, V. M., Beatty, W. W., & Paul, R. H. (2001). Illness intrusiveness, uncertainty, and distress in individuals with multiple sclerosis. *Rehabilitation Psychology, 46*(2), 139-153.
- Murphy, L. (1962). *The widening world of childhood: Paths toward mastery*. New York: Basic Books.
- Myburgh, J., Cooper, D., Finfer, S., Venkatesh, B., Jones, D., Higgins, A., et al. (2008). Epidemiology and 12-Month Outcomes from Traumatic Brain Injury in Australia and New Zealand. *The Journal of trauma, injury, infection, and critical care, 64*(4), 854-862.

- Myles, S. (2004). Understanding and Treating Loss of Sense of Self Following Brain Injury: A Behavior Analytic Approach. *International Journal of Psychology and Psychological Therapy*, 4(3), 487-504.
- Nadel, L., & Moscovitch, M. (2002). Memory consolidation, retrograde amnesia and the hippocampal complex. *Current opinion in neurobiology*, 7(2), 217-227.
- Najavits, L., Gotthardt, S., & Weiss, R. (2004). Cognitive Distortions in the Dual Diagnosis of PTSD and Substance Use Disorder. *Cognitive therapy and research*, 28(2), 159-172.
- Nandrino, J., Dodin, V., Martin, P., & Henniaux, M. (2004). Emotional information processing in first and recurrent major depressive episodes *Journal of Psychiatric Research*, 38(5), 475-484.
- Neilley, L. K., Goodin, D. S., Goodkin, D. E., & Hauser, S. L. (1996). Side effect profile of interferon beta-1b in MS: results of an open label trial. *Neurology*, 46, 552-554.
- Nelson, C. A. (1999). Neural plasticity and human development. *Current Directions in Psychological Science*, 8(42-45).
- Nelson- Jones, R. (2007). *Basic Counselling Skills :A Helper's Manual* Sage Publications Ltd.
- Netuveli, G., Wiggins, R. D., Hildon, Z., & Blane, D. (2008). Mental health and resilience at older ages: bouncing back after adversity in the British Household Panel Survey *Journal of Epidemiology and Community Health*, 62, 987-991.
- Newberg, A., Wintering, N., Khalsa, D., Roggenkamp, H., & Waldman, M. (2010). Meditation Effects on Cognitive Function and Cerebral Blood Flow in Subjects with Memory Loss: A Preliminary Study *Journal of Alzheimer's Disease*, 20(2).
- Newberg, A. M., D'Aquili, E. G., & Rause, V. (2002). *Why God Won't Go Away: Brain science and the biology of belief*: Ballantine Books.

- Newcomb, A. F., & Bagwell, C. L. (1995). Children's friendship relations: A meta-analytic review. *Psychological Bulletin, 117*, 306-347.
- Newman, A. C., Garmoe, W., Beatty, P., & Ziccardi, M. (2000). Self-awareness of traumatically brain injured patients in the acute inpatient rehabilitation setting. *Brain Injury, 14*(4).
- Newman, R. (2005). APA's Resilience Initiative. *Professional Psychology: Research and Practice, 36*(3), 227-229.
- Ng, A. V., & Kent-Braun, J. A., (1997). Quantitation of lower physical activity in persons with multiple sclerosis. *Medicine and Science in Sports and Exercise, 29*(4), 517-523.
- Nicholson, K., & Martelli, M. F. (2004). The problem of pain. *Journal of Head Trauma Rehabilitation, 19*(2), 2-9.
- Nitschke, J. B., & Heller, W. (2002). The neuropsychology of anxiety disorders: Affect, cognition, and neural circuitry. In H. D'Haenen, J. A. den Boer & P. Willner (Eds.), *Biological Psychiatry*. Chichester, UK: John Wiley & Sons.
- Nitschke, J. B., Heller, W., Palmieri, P. A., & Miller, G. A. (1999). Contrasting patterns of brain activity in anxious apprehension and anxious arousal. *Psychophysiology, 36*(5), 628-637.
- Nitschke, J. B., Sarinopoulos, I., Oathes, D. J., Johnstone, T., Whalen, P. J., Davidson, R. J., et al. (2009). Anticipatory Activation in the Amygdala and Anterior Cingulate in Generalized Anxiety Disorder and Prediction of Treatment Response (Vol. 166, pp. 302-310).
- Nock, M. K., Borges, G., Bromet, E. J., Cha, C. B., Kessler, R. C., & Lee, S. (2008). Suicide and Suicidal Behaviour. *Epidemiology Review, 30*: 133-154.
- Noonan, D. (2002). Developing a best practices psychosocial rehabilitation principles template

International Journal of Health Care Quality Assurance, 15(4), 168-172.

Nordstrom, M., Skarsater, I., Bjorkman, T., & Wijk, H. (2009). The life circumstances of persons with a psychiatric disability: a survey in a region in southern Sweden. *Journal of Psychiatric & Mental Health Nursing*, 16, 738-748.

Nortvedt, M., Riise, T., Myhr, K., Landtblom, A., Bakker, A., & Nyland, H. (2001). Reduced quality of life among multiple sclerosis patients with sexual disturbance and bladder dysfunction. *Multiple Sclerosis*, 7, 231-235.

Norusis, M. J. (1990). *SPSS/PC+ (TM) 4.0: for the IBM PC/XT/AT and PS/2*. Chicago: SPSS, Inc.

Nurmi, J. (1991). How do adolescents see their future? A review of the development of future orientation and planning. *Developmental Review*, 11, 1-59.

Nygren, B., Randstrom, K., Lejonklou, A., & Lundman, B. (2004). Reliability and validity of a Swedish language version of the Resilience Scale. *Journal of Nursing Measurement*, 12(3), 169-178.

O' Shanick, G., & O' Shanick, A. (1994). Personality and intellectual changes. In J. M. Silver, S. C. Yudofsky & R. E. Hales (Eds.), *Neuropsychiatry of Traumatic Brain Injury*. Washington, DC: American Psychiatric Press.

O'Connor, A., Schwid, S., Herrmann, D., Markman, J., & Dworkin, R. (2008). Pain associated with multiple sclerosis: Systematic review and proposed classification. *Pain*, 137, 96-111.

O'Connor, C., Colantonio, A., & Polatajko, H. (2005). Long term symptoms and limitations of activity of people with traumatic brain injury: a ten-year follow-up. *Psychological Report*, 97(1), 169-179.

O'Neill, M. (1999). *Measuring Resilience*. Paper presented at the Annual Meeting of the Mid South Educational Research Association.

- Oatley, K., Keltner, D., & Jenkins, J. M. (2006). *Understanding emotions*. Oxford: Blackwell Publishing.
- O'Gorman, P. (1994). *Dancing backwards in high heels: How women master the art of resilience*. Center City, MN: Hazelden Educational Materials.
- O'Leary, V. E., & Ickovics, J. R. (1995). Resilience and thriving in response to challenge: An opportunity for a paradigm shift in women's health. *Women's Health: Research on Gender, Behavior, and Policy*, 1(2), 121-142.
- Olney, R. K. (2005). Weakness, Disorders of Movement, and Imbalance. In D. L. Kasper, E. Braunwald, S. Anthony & A. S. Fauci (Eds.), *Harrison's Internal Medicine* (16 ed.). New York: McGraw- Hill.
- Olsson, C., Bonda, L., Burns, J., Vella-Brodick, D., & Sawyer, S. (2003). Adolescent resilience: a concept analysis. *Journal of Adolescence*, 26, 1-11.
- Olver, J. H., Ponsford, J. L., & Curran, C. A. (1996). Outcome following traumatic brain injury: a comparison between 2 years and 5 years after injury. *Brain Injury*, 10(11), 841-848.
- Ong, A., Bergeman, C., Bisconti, T., & Wallace, K. (2006). Psychological Resilience, Positive Emotions, and Successful Adaptation to Stress in Later Life. *Journal of Personality and Social Psychology*, 91(4), 730-749.
- Oquendo, M. A., Friedman, J. H., Grunebaum, M. F., Burke, A., Silver, J. M., & Mann, J. J. (2004). Suicidal Behavior and Mild Traumatic Brain Injury in Major Depression. *Journal of Nervous and Mental Disease*, 192, 430-434.
- Osterberg, A., Boivie, J., & Thuomas, K. (2005). Central pain in multiple sclerosis: prevalence and clinical characteristics. *European Journal of Pain*, 9, 531-542.

- Ostir, G. V., Markides, K. S., Peek, M. K., & Goodwin, J. S. (2001). The association between emotional well-being and the incidence of stroke in older adults. *Psychosomatic Medicine*, *63*, 210-215.
- Ouellet, M. C., Savard, J., & Morin, C. M. (2004). Insomnia following traumatic brain injury: a review. *Neurorehabilitation Neural Repair*, *18*(4), 187-198.
- Overholser, J. (1993). Elements of the Socratic method: I. Systematic questioning. *Psychotherapy*, *30*(1), 68-74.
- Owensworth, T., McFarland, K., & Young, R. (2000). Self-awareness and psychosocial functioning following acquired brain injury: An evaluation of a group support programme. *Neuropsychological Rehabilitation* *10*(5), 465-484.
- Owensworth, T. L., McFarland, K., & Young, R. M. (2000). Self-awareness and psychosocial functioning following acquired brain injury: An evaluation of a group support programme. *Neuropsychological Rehabilitation*, *10*, 465-484.
- Owensworth, T. L., & Oei, T. P. S. (1998). Expression after traumatic brain injury: Conceptualization and treatment considerations. *Brain Injury*, *12*, 735-751.
- Ozer, E., & Bandura, A. (1990). Mechanisms governing empowerment effects: A self-efficacy analysis. *Journal of Personality and Social Psychology*, *91*, 328-246.
- Ozer, E. M., Bandura, A., & (1990). Mechanisms governing empowerment effects: a self-efficacy analysis. *Journal of personality and social psychology* *58*(3), 472-486.
- Pakenham, K. I., Stewart, C. A., & Rogers, A. (1997). The role of coping in adjustment to multiple sclerosis-related adaptive demands. . *Psychological Health and Medicine*, *2*, 197-211.
- Palmer, S., & Dryden, W. (1996). *Counselling for Stress Problems*. London: Sage.
- Palmer, S., & Dryden, W. (1996). *Stress Management and Counselling: theory, practice, research and methodology*. London: Cassell.

- Pargament, K. (1990). God help me. Toward a theoretical framework of coping for psychology of religion. . *Research in the Social Scientific Study of Religion*, 26, 182-200.
- Parker, D. M., & Crawford, J. R. (1992). Assessment of frontal lobe dysfunction. In J. R. Crawford, D. M. Parker & W. W. McKinlay (Eds.), *A Handbook of Neuropsychological Assessment* (pp. 267-294). Hove: Erlbaum
- Passik, S. D., Kirsh, K. L., Donaghy, K. B., & Portenoy, R. K. (2006). Pain and Aberrant Drug-Related Behaviors in Medically Ill Patients with and Without Histories of Substance Abuse (Vol. 22, pp. 173-181).
- Passingham, R. (1982). *The Human Primate*. Oxford: Freeman.
- Pelham, B., & Blanton, H. (2003). *Conducting research in psychology: Measuring the weight of smoke*: Wadsworth, Thomson.
- Penley, J. A., Tomaka, J., & Wiebe, J. S. (2002). The association of coping with physical and mental health outcome: A meta-analytic review. *Journal of Behavioural Medicine*, 25, 551-603.
- Pennebaker, J. W., & Francis, M. E. (1996). Cognitive, emotional, and language processes in disclosure. *Cognition & Emotion*, 10, 691-626.
- Pennebaker, J. W., & Seagal, J. (1999). Forming a story: The health benefits of narrative. *Journal of Clinical Psychology*, 55, 1243-1254.
- Pennington, B. F., & Ozonoff, S. (1996). Executive functions and developmental psychopathology. *Journal of Child Psychology and Psychiatry*, 37, 51-87.
- Petajan, J. H., & White, A. T. (1999). Recommendations for physical activity in patients with multiple sclerosis. *Sports Medicine*, 27, 179-191.
- Phillips, L., Bull, R., Adams, E., & Fraser, L. (2002). Positive Mood and Executive Function: Evidence from Stroop and Fluency Tasks. *Emotion*, 2(1), 12-22.

- Pine, D. S. (1995). Patients with MS presenting to psychiatric hospitals. *Journal of Clinical Psychology, 56*(7), 297.
- Plum, F., & Posner, J. B. (1972). *The Diagnosis of Stupor and Coma*. Philadelphia: F. A. Davis.
- Polman, C. H. (2000). Drug treatment of Multiple Sclerosis. *British Medical Journal, 321*, 490-494.
- Polman, C. H., O'Connor, P. W., Havrdova, E., Hutchinson, M., Kappos, L., Miller, D. H., et al. (2006). A Randomized, Placebo-Controlled Trial of Natalizumab for Relapsing Multiple Sclerosis. *New England Journal of Medicine, 354*, 899-910.
- Polman, C. H., & Uitdehaag, B. (2000). Regular review: Drug treatment of multiple sclerosis. *British Medical Journal, 321*, 490-494.
- Ponsford, J. L., Sloan S., & P., S. (1995). *Traumatic Brain Injury: Rehabilitation for Everyday Adaptive Living*. London: Lawrence Erlbaum and Associates.
- Pope, K. S., & Vasquez, M. (2007). *Ethics in Psychotherapy and Counselling: A Practical Guide*: Jossey-Bass.
- Poser, C. (1994). Multiple sclerosis. Epidemiology and genetics. *Annals of Neurology, 36*(2).
- Posner, M. I., & Rothbart, M. K. (2000). Developing mechanisms of self-regulation. *Development and Psychopathology, 12*, 427-441.
- Potter, D. D., Bassett, M. R. A., Jory, S. H., & Barrett, K. (2001). Changes in event related potentials in a three-stimulus auditory oddball task after mild head injury. *Neuropsychologia, 39*, 1464-1472.
- Povlishock, J. T., Becker, D. P., Cheng, C. L. Y., Vaughan, G. W., Liang, Z. Z., & Nearly, J. T. (1986). Axonal change in minor head injury. *Journal of Neuropathology and Experimental Neurology, 42*, 225-242.

- Pressman, S. D., & Cohen, S. (2005). Does positive affect influence health? *Psychological Bulletin*, *131*, 925-971.
- Prigatano, G. P. (1987). Psychiatric aspects of head injury: Problem areas and suggested guidelines for research. In H.S. Levin, J. Grafman, & H. M. Eisenberg (Eds.), *Neurobehavioral Recovery from Head Injury* (pp. 215-231). New York: Oxford University Press.
- Prigatano, G. P., & Schacter, D. L. (1991). *Awareness of deficit after traumatic brain injury. Clinical and theoretical issues*. New York: Oxford University Press.
- Pujol, J., Bello, J., Deus, J., Marti-Vilalta, J. L., & Capdevila, A. (1997). Lesions in the left arcuate fasciculus region and depressive symptoms in multiple sclerosis. *Neurology*, *49*, 1105-1110.
- Pyszczynski, T., Greenberg, J., Sheldon, S., Arndt, J., & Schimel, J. (2004). Why Do People Need Self-Esteem? A Theoretical and Empirical Review. *Psychological Bulletin*, *130*(3), 435-468.
- Rabkin, J., Remien, R., Katoff, L., & Williams, J. (1993). Resilience in adversity among long term survivors of AIDS. *Hospital and community psychiatry*, *2*(44), 162-167.
- Rajkumar, A. P., Premkumar, T. S., & Tharyan, P. (2008). Coping with the Asian tsunami: Perspectives from Tamil Nadu, India on the determinants of resilience in the face of adversity. *Social Science & Medicine*, *67*(5), 844-853.
- Ramachandran, V. S., & Blakeslee, S. (1998). *Phantoms in the Brain: Probing the Mysteries of the Human Mind*. New York: William Morrow & Co.
- Rao, S., Huber, S., & Bornstein, R. (1992). Emotional changes with Multiple Sclerosis and Parkinson's Disease. *Journal of consulting clinical psychology*, *60*, 369-378.
- Rao, S., Leo, G., & Bernardin, L. (1991). Cognitive dysfunction in MS. II. Impact on employment and social functioning. *Neurology*, *41*, 692-696.

- Rao, S. M. (1995). Neuropsychology of Multiple Sclerosis. *Current Opinions in Neurology*, 8(3), 216-220.
- Rao, S. M., Huber, S. J., & Bornstein, R. A. (1992). Emotional changes with multiple sclerosis and Parkinson's disease. *Journal of Consultant Clinical Psychology*, 60, 369-378.
- Rao, S. M., Leo, G. J., Ellington, L., Nauertz, T., Bernardin, L., & Unveragt, F. (1991). Cognitive dysfunction in multiple sclerosis. II. Impact on employment and social functioning. *Neurology*, 41, 692-696.
- Rao, V., Handel, S., Vaishnavi, S., Keach, S., Robbins, B., Spiro, J., et al. (2007). Psychiatric Sequelae of Traumatic Brain Injury: A Case Report (Vol. 164, pp. 728-735).
- Rauch, R., & Ferry, S. (2001). Social networks as support interventions following traumatic brain injury *NeuroRehabilitation*, 16(1), 11-16.
- Reed, J. M., & Squire, L. R. (1998). Retrograde amnesia for facts and events: findings from four new cases. *Journal of Neuroscience*, 18(10), 3943-3954.
- Rees, R. (1997). *Plateaus and Summits: transition to supported open employment for people with acquired brain injury*. Flinders University, Adelaide.
- Rees, R. (1999). *Re- writing the script: demonstration of skills and talents of people with brain injury*: Adelaide ISLD (Institute for the study of learning difficulties).
- Rees, R. (2005). *Interrupted lives; Rehabilitation and learning following brain injury*. Melbourne: IP Communications.
- Rees, R., & Hannaford, M. (1996). Effects on the primary caregiver when a family member experiences acquired brain injury. *Australian Journal of Social Issues*, 31(4), 392-409.
- Reeves, C. L. (2010). A difficult negotiation: fieldwork relations with gatekeepers. *Qualitative Research*, 10(3), 315-331.

- Reivich, K., & Shatte', A. (2002). *The resilience factor*. New York: Broadway Books.
- Repper, J., & Perkins, R. (2003). *Social Inclusion and Recovery: A Model for Mental Health Practice*: Balliere Tindall.
- Riley, A., Valdez, C., Barrueco, S., Mills, C., Beardslee, W., Sandler, I., et al. (2008). Development of a Family-based Program to Reduce Risk and Promote Resilience among Families Affected by Maternal Depression: Theoretical Basis and Program Description. *Clinical Child and Family Psychological Review* 11(1-2), 12-29.
- Rink, A., Fung, K. M., Trojanowski, J. Q., Lee, V. M., Neugebauer, E., & McIntosh, T. K. (1995). Evidence of apoptotic cell death after experimental traumatic brain injury in the rat. *American Journal of Pathology*, 147, 1575-1583.
- Robbins, R. N., & Bryan, A. (2004). Relationships between future orientation, impulsive sensation seeking, and risk behaviour among adjudicated adolescents. *Journal of Adolescence Research*, 19, 428-445.
- Robinson, J. (2000). Are There Implications for Prevention Research from Studies of Resilience? *Child Development*, 71(3), 570-572.
- Rogers, C. (1957). The necessary and sufficient conditions of therapeutic personality change *Journal of Consulting Psychology*, 95-103.
- Rogers, C. (1959). A theory of therapy, personality, and interpersonal relationships as developed in the client-centred framework. In S. Koch (Ed.), *Psychology: A study of science. Formulation of the person and the social context* (Vol. 3, pp. 184-256). New York: McGraw Hill.
- Rogers, C. (1961). *On becoming a person: A therapist's view of psychotherapy*. Boston: Houghton Mifflin.
- Rogers, C. (1986). A personal perspective on similarities and differences. *Person-Centered Review*, 1(2), 125-140.

- Rogers, C. (1995). What Understanding and Acceptance Mean to Me. *Journal of Humanistic Psychology, 35*, 7-22.
- Rogers, C., & Holdstock, T. (1977). Person-centred theory. In R. Corsini (Ed.), *Current personality theories* (pp. 125-151). Itasca: F. E. Peacock.
- Rokach, A., & Brock, H. (1998). Coping with loneliness. *Journal of Psychology, 132*, 107-128.
- Romberg, A., Virtanen, A., Aunola, S., Karppi, S. L., Karanko, H., & Ruutiainen, J. (2004). Exercise capacity, disability and leisure physical activity of subjects with multiple sclerosis. *Multiple Sclerosis, 10*, 212-218.
- Romberg, A., Virtanen, A., Ruutiainen, J., Aunola, S., Karppi, S. L., Vaara, M., et al. (2004). Effects of a 6-month exercise program on patients with multiple sclerosis: a randomized study. *Neurology, 63*(11), 2034-2038.
- Rosenberg, E. L., & Fredrickson, B. L. (1998). Overview to Special Issue: Understanding Emotions Means Crossing Boundaries Within Psychology.
- Rosenberg, M. (1965). *Society and the adolescent self-image*. Princeton, NJ: Princeton University Press. .
- Rosenthal, M., Christensen, B. K. and Ross, T. P. (1998). Depression following traumatic brain injury. *Archives of Physical Medicine and Rehabilitation, 79*, 90-103.
- Rosenthal, M., & Bond, M. R. (1990). Behavioural and psychiatric sequelae. In M. Rosenthal, M. Bond, E. R. Griffith & J. D. Miller (Eds.), *Rehabilitation of the Adult and Child with Traumatic Brain Injury*. Philadelphia: FA Davies.
- Rothbart, M. K., Ahadi, S. A., & Evans, D. E. (2000). Temperament and personality: Origins and outcomes. *Journal of Personality and Social Psychology, 78*, 122-135.

- Rubin, K. H., Coplan, R. J., Fox, N. A., & Calkins, S. D. (1995). Emotionality, emotion regulation, and preschoolers' social adaptation. *Development and Psychopathology*, 7, 49-62.
- Rubin, K. H., Dwyer, K. M., Booth-LaForce, C., Kim, A. H., Burgess, K. B., & Rose-Krasnor, L. (2004). Attachment, Friendship, and Psychosocial Functioning in Early Adolescence. *Journal of Early Adolescence*, 24, 326-356.
- Rudick, R. A., Lee, J. C., Simon, J., Ransohoff, R. M., & Fisher, E. (2004). Defining interferon response status in multiple sclerosis patients. *Annals of Neurology*, 56(4), 548-555.
- Rudick, R. A., Stuart, W. H., Calabresi, P. A., Confavreux, C., Galetta, S. L., Radue, E.-W., et al. (2006). Natalizumab plus Interferon Beta-1a for Relapsing Multiple Sclerosis (Vol. 354, pp. 911-923).
- Rumrill, P. D. (1996). *Employment issues and multiple sclerosis*. New York: Demos Vermande.
- Rutter, M. (1983). *Stress, coping and development: Some issues and some questions*. New York: McGraw-Hill Book Company.
- Rutter, M. (1987). Psychosocial resilience and protective mechanisms. *American Journal of Orthopsychiatry*, 57(3).
- Rutter, M. (1990). Psychosocial resilience and protective mechanisms. In: J. Rolf, A. S. Masten, D. Chichetti, K. H. Nuechterlin & S. Weintraub (Eds), *Risk and protective factors in the development of psychopathology* (pp. 181-214). New York: Cambridge University Press
- Rutter, M. (1991). *Resilience: Some Conceptual Considerations*. Paper delivered at the Institute of Mental Health Initiatives Conference on "Fostering Resilience." Washington, DC.
- Rutter, M. (1999). Resilience concepts and findings: Implications for family therapy. *Journal of Family Therapy*(21), 119-144.

- Rutter, M. (2002). Psychosocial resilience and protective mechanisms. *American Journal of Orthopsychiatry*, 57(3), 316-331.
- Rutter, M. (2007). Resilience, competence, and coping. *Child Abuse & Neglect*, 31(3), 205-209.
- Ryan, L., Clark, C. M., Klonoff, H., & Paty, D. (1996). Models of cognitive deficit impairment in relapse-remitting multiple sclerosis and their relationship to neuropathology on MRI images. *Journal of clinical Experimental Neuropsychology*, 15, 563-577.
- Rydén, A., Karlsson, J., Sullivan, M., Torgerson, J. S., & Taft, C. (2003). Coping and distress: What happens after intervention? A 2-year follow-up from the Swedish Obese Subjects (SOS) study. *Psychosomatic Medicine*, 65, 435-442.
- Sacks, O. W. (1985). *The man who mistook his wife for a hat*. New York: Perennial Library.
- Sadovnick, A., Dyment, D., & Ebers, G. C. (1997). Genetic Epidemiology of Multiple Sclerosis. *Epidemiologic Reviews*, 19(1), 99-106.
- Sadovnik, A. D., Eisen, R. N., Ebers, G. C., & Paty, D. W. (1991). Cause of death in patients attending multiple sclerosis clinics. *Neurology*, 41, 1193-1196.
- Saleebey, D. (1992). *The strengths perspective in social work practice*. New York.
- Salovey, P., Bedell, B. T., Detweiler, J. B., & Mayer, J. D. (2002). Current directions in emotional intelligence research. New York: Guilford Press.
- Sandelowski, M. (2003). Tables or tableaux? Writing and reading mixed methods studies. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of Mixed Methods in Social and Behavioral Research* (pp. pp. 321–350). Thousand Oaks, CA: Sage.
- Sarason, B. R., Sarason, I. G., & Gurung, R. A. R. (2001). *Close personal relationships and health outcomes: A key to the role of social support*. Chichester: Wiley.

- Sawchyn, J., Mateer, C. A., & Suffield, J. B. (2005). Awareness, Emotional Adjustment, and Injury Severity in Post acute Brain Injury *Journal of Head Trauma Rehabilitation*, 20(4), 301-314.
- Schacter, D. L. (1995). Implicit memory: A new frontier for cognitive neuroscience. In M. Gazzaniga (Ed.), *The Cognitive Neurosciences* (pp. 815-824). Cambridge: MIT Press.
- Schapiro, R. T. (1994). *Symptom management in multiple sclerosis* (2nd ed.). New York: Demos.
- Scheier, M. F., & Carver, C. S. (1985). Optimism, coping, and health: Assessment and implications of generalized outcome expectancies. *Health Psychology*, 4, 219-247.
- Schiffer, R. B., & Wineman, N. M. (1990). Antidepressant pharmacotherapy of depression associated with multiple sclerosis. *American Journal of Psychiatry*, 147, 1493.
- Schriever, J. (2010). Smiling mum Beverly Eitzen denies murdering disabled son. *The Advertiser*.
- Schubert, D., & Foliart, R. (1993). Increased depression in Multiple Sclerosis: A meta-analysis. *Psychosomatics*, 34, 124-130.
- Schubert, D. S. P., & Foliart, R. H. (1993). Increased depression in multiple sclerosis: a meta-analysis. *Psychosomatics*, 34(124), 30.
- Schulz, D., Kopp, B., Kunkel, A., & Faiss, J. (2006). Cognition in the early stage of multiple sclerosis. *Journal of Neurology*, 253, 1002-1010.
- Schulz, R., & Martire, L. M. (2004). Family Care giving of Persons with Dementia: Prevalence, Health Effects, and Support Strategies. *American Journal of Geriatric Psych*, 12(3), 240-249.
- Schwartz, C, Coultland-Morris, L., & Zeng, Q. (1996). Psychosocial correlates of fatigue in multiple sclerosis. *Archives of Physical Medicine and Rehabilitation*, 77, 165-170.

- Schwarz, N., & Bless, H. (1991). Happy and mindless, but sad and smart? The impact of affective states on analytic reasoning. In J. E. Forgas (Ed.), *Emotion and social judgment* (pp. 55-71). Oxford, England: Pergamon Press.
- Schwarz, S., & Leweling, H. (2005). Multiple sclerosis and nutrition. *Multiple Sclerosis*, *11*(24).
- Schweitzer, R., Jaimi, H., & Kagee, A. (2007). Coping and resilience in refugees from the Sudan: a narrative account. *Australian and New Zealand Journal of Psychiatry*, *41*(4), 282-288.
- Scott, T. F., Nussbaum, P., McConnell, H., & Brill, P. (1995). Measurement of treatment response to sertraline in depressed multiple sclerosis patients using the Carroll scale. *Neurological Research*, *1995*(16), 6.
- Scoville, W. B., & Milner, B. (1957). Loss of recent memory after bilateral hippocampal lesions. *Journal of Neurology, Neurosurgery and Psychiatry* *20*(11-21).
- Scully, D., Kremer, J., Meade, M. M., Graham, R., & Dudgeon, K. (1998). Physical exercise and psychological well being: a critical review. *British Journal of Sports Medicine*, *32*, 111-120.
- Seeman, T. E. (1996). Social ties and health: the benefits of social integration. *Annals of Epidemiology*, *6*(5), 442-451.
- Seeman, T. E. (2000). Health promoting effects of friends and family on health outcomes in older adults. *American Journal of Health Promotion*, *14*(6), 362-370.
- Selekman, M. (1997). *Solution-focused therapy with children: Harnessing family strengths for systemic change*. New York: Guilford.
- Seligman, M. (1995). *The Optimistic Child*. Boston: Houghton Mifflin.
- Seligman, M. (2002). *Authentic Happiness: Using the New Positive Psychology to Realize Your Potential for Lasting Fulfillment*. New York: Free Press.

- Shallice, T. (1982). Specific impairments of planning. *Philosophical Transactions of the Royal Society of London*, 298, 199–209.
- Shallice, T., Burgess, P., & (1991). Deficits in strategy application following frontal lobe damage in man. *Brain*, 114, 727-741.
- Shannon, K. E., Beauchaine, T. P., Brenner, S. L., Neuhaus, E., & Gatzke-Kopp, L. (2007). Familial and temperamental predictors of resilience in children at risk for conduct disorder and depression (Vol. 19, pp. 701-727): Cambridge Journals Online.
- Shaughnessy, J., Zechmeister, E., & Zechmeister, J. (2005). *Research Methods in Psychology* (7 ed.). Boston: McGraw-Hill.
- Shaver, P. R., Belsky, J., & Brennan, K. A. (2000). The adult attachment interview and self-reports of romantic attachment: Associations across domains and methods. . *Personal Relationships*, 7(25-43).
- Sherer, M., Sander, A. M., Nick, T. G., High, W. M., Malec, J. F., & Rosenthal, M. (2002). Early cognitive status and productivity outcome following traumatic brain injury: findings from the TBI Model Systems. *Archives of Physical and Medical Rehabilitation*, 8, 183-192.
- Sibley, W. A. (1996). *Therapeutic Claims in Multiple Sclerosis*. (4th ed.). New York: Demos.
- Siegert, R., & Abernethy, D. A. (2005). Depression in multiple sclerosis: a review. *Journal of Neurology, Neurosurgery and Psychiatry* 76(469-475).
- Siegert, R. J., & Abernethy, D. A. (2005). Depression in multiple sclerosis: A review, *Journal of Neurology Neurosurgery and Psychiatry*, 76, 469-475.
- Simblett, S. K., & Bateman, A. (2011). Dimensions of the Dysexecutive Questionnaire (DEX) examined using Rasch analysis. *Neuropsychological Rehabilitation: An International Journal*, 21(1), 1 - 25.

- Simon, J. B., Murphy, J. J., & Smith, S. M. (2005). Understanding and Fostering Family Resilience. *The Family Journal*, 13(4), 427-436.
- Simpson, G. K., & Tate, R. L. (2002). Suicidality after traumatic brain injury: demographic, injury and clinical correlates. *Psychological Medicine*, 32, 687-697.
- Singer, J. A. (2004). Narrative identity and meaning making across the adult lifespan: An introduction. *Journal of Personality*, 72, 437-459.
- Smeltzer, S., & Bare, B. G. (2000). *Textbook of medical surgical nursing*. Philadelphia: Lippincot.
- Smith, C. R., & Schapiro, R. T. (2000). Neurology. In R. Kalb (Ed.), *Multiple Sclerosis: The Questions You Have — The Answers You Need*. New York: Demos.
- Smith, J. (2006). The Strength-Based Counselling Model. *The counselling psychologist*, 34(13), 13-79.
- Smith, J.A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory Method and Research*. London: Sage
- Smith, R. M., ey-Steel, M., Fulcher, G., & Longley, W. A. (2006). Symptom change with exercise is a temporary phenomenon for people with multiple sclerosis. . *Archives of Physical Medicine* 87, 723-727.
- Snyder, C. R., Feldman, D. B., Taylor, J. D., Schroeder, L. L., & Adams III, V. (2000). The roles of hopeful thinking in preventing problems and promoting strengths. *Applied & Preventive Psychology: Current Scientific Perspectives*, 15, 262-295.
- Snyder, C. R., Harris, C., Anderson, J., Holleran, S., Irving, L., Sigmon, S., et al. (1991). The will and the ways: Development and validation of an individual-differences measure of hope. *Journal of Personality and Social Psychology*, 60, 570-585.
- Snyder, C. R., & Lopez, S. J. (2002). *The Handbook of Positive Psychology*. New York: Oxford University Press.

- Sohlberg, M., Mateer, C., Penkman, L., Glang, A., & Todis, B. (1998). Awareness intervention: Who needs it? . *Journal of Head Trauma Rehabilitation, 13*(5), 62-78.
- Sohlberg, M., & Mateer, C. A. (2001). *Cognitive Rehabilitation: an integrative neuropsychological approach*. New York: Guilford Press.
- Solaro, C., Bricchetto, G., Amato, M. P., Cocco, E., Colombo, B., & D'Aleo, A. (2004). The prevalence of pain in multiple sclerosis: a multicenter cross-sectional study. *Neurology, 63*, 919-921.
- Sollom, A. C., & Kneebone, I. I. (2007). Treatment of depression in people who have multiple sclerosis. *Multiple Sclerosis, 13*, 632-635).
- Spatt, J., Zebenholzer, K., & Oder, W. (1994). Psychosocial long-term outcome of severe head injury as perceived by patients, relatives, and professionals. *Acta Neurologica Scandinavica, 95*(3), 173-179.
- Spearman, C. (1904). General intelligence" objectively determined and measured. *American Journal of Psychology, 15*, 201-293.
- Spren, O., Risser, A. H., & Edgell, D. (1985). *Developmental Neuropsychology*. New York: Oxford University Press.
- Squire, L. R. (1992). Memory and the hippocampus: a synthesis of findings with rats, monkeys and humans. *Psychological Review, 99*, 195-221.
- Startup, M., Jackson, M. C., & Startup, S. (2006). Insight and Recovery from Acute Psychotic Episodes: The Effects of Cognitive Behaviour Therapy and Premature Termination of Treatment. *The Journal of Nervous And Mental Disease, 194*(10):740-745
- Steinhardt, M., & Dolbier, C. (2007). Evaluation of a Resilience Intervention to Enhance Coping Strategies and Protective Factors and Decrease Symptomatology. *Journal of American college health, 56*(4), 445-453.

- Stenager, E., Knudsen, L., & Jensen, K. (1995). Acute and chronic pain syndromes in multiple sclerosis: a 5-year follow-up study. *Italian Journal of Neurological Science*, *16*, 629-632.
- Stenager, E. N., Stenager, E., Koch-Henrikson, N., & al., e. (1992). Suicide and multiple sclerosis: an epidemiological investigation. *Journal of Neurosurgery and Psychiatry*, *55*, 542-545.
- Sterr, A., Herron, K., Hayward, C., & Montaldi, D. (2006). Are mild head injuries as mild as we think? Neurobehavioral concomitants of chronic post-concussion syndrome. *BMC Neurology*, *6*(1), 7.
- Stewart, M., A., & Tilden, V. (1995). The contributions of nursing science to social support. *International journal of Nursing Studies*, *32*(6), 535-544.
- Storr, A. (1997). *Music and the mind*: London, Harper Collins.
- Strough, J., Swenson, L. M., & Cheng, S. (2001). Friendship, gender, and preadolescents' representations of peer collaboration. *Merrill-Palmer Quarterly*, *47*(4).
- Stuifbergen, A. K. (1997). Physical activity and perceived health status in persons with multiple sclerosis. *Journal of Neuroscience Nursing* *29*(4), 238-243.
- Stuss, D., & Alexander, M. (2000). Executive functions and the frontal lobes: A conceptual review. *Psychological Research*, *63*, 289-298.
- Stuss, D. T. (1992). Biological and psychological development of executive functions. *Brain and Cognition*, *20*, 8-23.
- Stuss, D. T., & Alexander. (2000). *Principles of frontal lobe function*: Oxford University Press.
- Stuss, D. T., & Alexander, M. (2000). Executive functions and the frontal lobes: A conceptual review. *Psychological Research*, *63*, 289-298.
- Stuss, D. T., & Benson, D. F. (1986). *The frontal lobes*. New York: Raven Press.

- Sutherland, G., & Andersen, M. B. (2001). Exercise and multiple sclerosis: physiological, psychological, and quality of life issues. *Journal of Sports Medicine and Physical Fitness, 41*, 421-432.
- Svendsen, K., Jensen, T. S., Overvad, K., Hansen, H. J., Koch-Hendricksen, N., & Bach, F. W. (2003). Pain in patients with multiple sclerosis: a population-based study. *Archives of Neurology, 60*, 1089-1094.
- Swann Jr, W., Chang-Schneider, C., & McClarty, K. (2007). Do People's Self-Views Matter? Self-Concept and Self-Esteem in Everyday Life. *American Psychological Association, 62*(2), 84-94.
- Snyder, C. R. (2000). *Handbook of Hope*. San Diego: Academic Press.
- Tailby, R., & Haslam, C. (2003). An investigation of errorless learning in memory-impaired patients: improving the technique and clarifying theory. *Neuropsychologia, 41*(9), 1230-1240.
- Tandon, D. S., & Solomon, B. S. (2008). Risk and Protective Factors for Depressive Symptoms in Urban African American Adolescents (pp. 0044118X08327520).
- Tantucci, C., Massucci, M., Piperno, R., Grassi, V., & Sorbini, C. A. (1996). Energy cost of exercise in multiple sclerosis patients with low degree of disability. *Multiple Sclerosis, 2*, 161-167.
- Tateno, A., Jorge, R., & Robinson, R. G. (2003). Clinical correlates of aggressive behaviour after traumatic brain injury. *Journal of Neuropsychiatry and Clinical Neurosciences, 15*, 155-160.
- Taylor, C. A., & Jung, H. Y. (1998). Disorders of mood after traumatic brain injury. *Seminars in Clinical Neuropsychiatry*(3), 224-231.
- Taylor, M., In Bannister, P., Burman, E., Parker, I., & C., T. (1994). *Qualitative Methods in Psychology, A Research Guide*. Philadelphia: Open University Press.

- Taylor, R. J., Ellison, C. G., Chatters, L. M., Levin, J. S., & Lincoln, K. D. (2000). Mental health services in faith communities. The role of the clergy in Black Churches. *Social work* 45(1), 73-87.
- Teasdale, G., & Jennett, B. (1974). Assessment of coma and impaired consciousness. A practical scale. *Lancet*, 2(7872), 81-84.
- Teasdale, J. D., & Fogarty, S. J. (1979). Differential effects of induced mood on retrieval of pleasant and unpleasant events from episodic memory. *Journal of Abnormal Psychology*, 88, 248-257.
- Teasdale, T. W., & Engberg, A. (2001). Suicide after traumatic brain injury: a population study
Journal of Neurology, Neurosurgery, and Psychiatry, 71(4), 436-330.
- Tedeschi, R. G., & Calhoun, L. G. (1996). The Posttraumatic Growth Inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress*, 9, 455-472.
- Tedeschi, R. G., & Kilmer, R. P. (2005). Assessing Strengths, Resilience, and Growth to Guide Clinical Interventions. *Professional Psychology: Research and Practice*, 36(3), 230-237.
- Tetlock, P. E. (2002). Social-functionalist metaphors for judgment and choice: The intuitive politician, theologian, and prosecutor. *Psychological Review*, 109, 451-472.
- Thomas, P. W., Thomas, S., Hillier, C., Galvin, K., & Baker, R. (2006). Psychological interventions for multiple sclerosis. *Cochrane Database of Systematic Reviews*, 1.
- Thompson, A. J. (2002). Developing Clinical Outcomes in Multiple Sclerosis; An Evolving Process. *Multiple Sclerosis*, 8, 357-358.
- Thomsen, I. V. (1992). Late psychosocial outcome in severe traumatic brain injury. Preliminary results of a third follow-up after 20 years. *Scandinavian Journal of Rehabilitation Medicine* (26), 142-152.

- Tinsley Li, S., Nussbaum, K., & Richards, M. (2007). Risk and protective factors for urban African-American youth. *American Journal of Community Psychology, 39*, 21-35.
- Toglia, J. P., & Kirk, U. (2000). Understanding awareness deficits following brain injury. *NeuroRehabilitation 15*(57).
- Tomberg, T., Toomela, A., Ennok, M., & Tikk, A. (2007). Changes in coping strategies, social support, optimism and health-related quality of life following traumatic brain injury: A longitudinal study. *Brain Injury, 21*(5), 479-488.
- Tranel, D., Anderson, S. W., & Benton, A. (1994). Development of the concept of “executive function” and its relationship to the frontal lobes,. In F. Boller & J. Grafman (Eds.), *Handbook of Neuropsychology* (Vol. 9, pp. 125-148). Amsterdam: Elsevier Science.
- Trojano, M., Paolicelli, D., Bellacosa, A., & Cataldo, S. (2003). The transition from relapsing-remitting MS to irreversible disability: clinical evaluation. *Neurological Sciences, 24*, S268-S270.
- Trojano, M., Paolicelli, D., Bellacosa, A., & Cataldo, S. (2003). The transition from relapsing-remitting MS to irreversible disability: clinical evaluation. *Neurological Sciences, 24* Suppl 5:S268-270.
- Tsivgoulis, G., Triantafyllou, N., & Papageorgiou, C. (2007). Associations of the Expanded Disability Status Scale with anxiety and depression in multiple sclerosis outpatients. *Acta Neurologica Scandinavica 115*, 67-72.
- Tugade, M. M., & Fredrickson, B. L. (2004). Resilient Individuals Use Positive Emotions to Bounce Back From Negative Emotional Experiences. *Journal of Personality and Social Psychology, 86*(2), 320-333.

- Tugade, M. M., Fredrickson, B. L., & Barret, L. F. (2004). Psychological Resilience and Positive Emotional Granularity: Examining the Benefits of Positive Emotions on Coping and Health. *Journal of personality, 72*(6).
- Tulving, E. (2002). Episodic memory: from mind to brain. *Annual Review of Psychology, 53*, 1-25.
- Tulving, E., & Schacter, D. L. (1990). Priming and human memory systems. *Science, 247*, 301-306.
- Turner-Stokes, L. (2004). The evidence for the cost-effectiveness of rehabilitation following acquired brain injury. *Journal of Clinical Medicine, 4*(1), 10-12.
- Turner-Stokes, L., Disler, P. B., Nair, A., & Wade, D. T. (2005). Multidisciplinary rehabilitation for acquired brain injury in adults of working age. *Cochrane Database System Review, 3*.
- Turner-Stokes, L., Hassan, N., Pierce, K., & Clegg, F. (2002). Managing depression in brain injury rehabilitation: The use of an integrated care pathway and preliminary report of response to sertraline. *Clinical Rehabilitation, 16*, 261-268.
- Vaillant, G. (2000). Adaptive mental mechanisms: Their role in a positive psychology. *American Psychologist, 55*, 89-98.
- Van der Westhuizen, N. (2001). Coping with Multiple Sclerosis. *Nursing Update, 25*(6), 14-15.
- Van Zomeren, A. H., & Van Den Burg, W. (1985). Residual complaints of patients two years after severe head injury. *Journal of Neurology, Neurosurgery, and Psychiatry*(48), 21-28.
- Vande Berg, D., & Van Bockern, S. (1995). Building resilience through humor. *Journal of Emotional and Behavioural Problems, 4*(3), 26-29.

- Vandell, D. L., & Hembree, S. E. (1994). Peer social status and friendship: Independent contributors to children's social and academic adjustment. *Merrill-Palmer Quarterly*, 40, 461-477.
- Vanderbilt-Adriance, E., & Shaw, D. (2008). Conceptualizing and Re-Evaluating Resilience Across Levels of Risk, Time, and Domains of Competence. *Clinical Child and Family Psychological Review*, 11, 30-58.
- VanderPlate, C. (1984). Psychosocial aspects of Multiple Sclerosis and its treatment: Toward a biopsychosocial perspective. *Health Psychology*, 3, 253-272.
- Vash, C., & Crewe, N. (2003). *Psychology of disability* (2nd ed.). New York: Springer.
- Vasquez, M. J., Bingham, R. P., & Barnett, J. E. (2008). Psychotherapy termination: clinical and ethical responsibilities. *Journal of Clinical Psychology*, 64(5), 653-655.
- Vlasek, L. (2010). The secret history of me. *The Australian Weekend Magazine*, pp. 26-27.
- von Cramon, D., Matthes-von Cramon, G., & Mai, N. (1991). Problem-solving deficits in brain-injured patients: A therapeutic approach. *Neuropsychological Rehabilitation*, 1(1), 45-46.
- von Eye, A., & Schuster, C. (2000). The Odds of Resilience. *Child Development*, 71(3), 563-566.
- Vos, M., & de Haes, J. (2006). Denial in cancer patients, an explorative review. *Psycho-oncology*, 16(1), 12-25.
- Voydanoff, P. (2005). The effects of community demands, resources, and strategies on the nature and consequences of the work-family interface: an agenda for future research. *Family Relations*, 54, 583-595.
- Waaktaar, T., Christie, H., Borge, A., & Torgersen, S. (2004). How can young peoples' resilience be enhanced? Experiences from a clinical intervention project. *Clinical Child Psychology and Psychiatry*, 9(2), 167-183.

- Wade, D. T., & de Jong, B. (2000). Recent advances in rehabilitation. *British Medical Journal*, 320(14), 1385-1358.
- Wagnild, G. (2003). Resilience and successful aging: comparison among low and high income older adults. *Journal of Gerontology Nursing*, 29, 42-49.
- Wagnild, G., & Young, H. (1993). Development and psychometric evaluation of the Resilience Scale. *Journal of Nursing Measurement*, 1(2), 165-178.
- Wagnild, G., & Young, H., (1990). Resilience among older women. *Journal of Nursing Scholarship*, 22, 252-255.
- Walen, H., & Lachman, M. E. (2000). Social support and strain from partner, family and friends: Costs and benefits for men and women. *Journal of Social and Personal Relationships*, 17, 5-30.
- Wall, M., Kleckner, T., Amendt, J., & Bryant, R. (1989). Therapeutic compliments: Setting the stage for successful therapy. *Journal of Marriage and Family Therapy*, 15, 159-167.
- Wallin, M., T., Wilken, J., A., Turner, A. P., Williams, R. M., & Kane, R. (2006). Depression and multiple sclerosis: Review of a lethal combination. *Journal of Rehabilitation Research and Development*, 43(1), 45-62.
- Walsh, F. (2003). Family Resilience: A Framework for Clinical Practice. *Family Process*, 42(1), 1-18.
- Wandersman, A., & Nation, M. (1998). Urban neighborhoods and mental health: Psychological contributions to understanding toxicity, resilience, and interventions. *American Psychologist*, 43(6), 647-656.
- Wanigaratne, S., Wallace, W., Pullin, J., Keaney, F., & Farmer, R. (1995). Relapse prevention for addictive behaviours: A manual for therapists. Cambridge, MA: Blackwell Science Ltd.

- Warner, R. (2003). *Recovery from Schizophrenia: Psychiatry and Political Economy* (3rd ed.). London: Brunner-Routledge.
- Watson, A., Franklin, M., Ingram, M., & Eilenberg, L. (1998). Alcohol and other drug abuse among persons with disabilities. *Journal of Applied Rehabilitation Counselling, 29*(2), 22-29.
- Watson, D., Clark, L. A., McIntyre, C. W., & Hamaker, S. (1992). Affect, personality, and social activity. *Journal of Personality and Social Psychology, 63*, 1011-1025.
- Watt, N. F., David, J. P., Ladd, K. L., & Shamos, S. (1995). The Life Course of Psychological Resilience: A Phenomenological Perspective on Deflecting Life's Slings and Arrows. *The Journal of Primary Prevention, 15*(3).
- Watts, R., & Pietrzak, D. (2000). Adlerian “encouragement” and the therapeutic process of solution focused brief therapy. *Journal of Counselling and Development, 78*, 442-447.
- Watzlawick, P., Weakland, J. H., & Fisch, R. (1974). *Change: principles of problem formation and problem solution*. New York: Norton.
- Wechsler, D. (1997). Wechsler Adult Intelligence Scale—3rd Edition , WAIS-3®. San Antonio, Texas: Harcourt Assessment.
- Wechsler, D. (2003). The Wechsler Intelligence Scale for Children fourth edition (WISC-IV). San Antonio, TX: Psychological Corporation.
- Weiner, I., Freedheim, D., Stricker, G., Schinka, J., Widiger, T., & Velicer, W. (2003). *Handbook of Psychology; Clinical Psychology* (Vol. 8): Wiley.
- Weiss, R. S. (1994). *Learning from strangers: The art and method of qualitative interviewing*. New York: Free Press.
- Weissman, M. M., Bland, R. C., & Canino, G. J. (1999). Prevalence of suicide ideation and attempts in nine countries. *Psychological Medicine, 29*, 9-17.

- Werner, E. (1971). *The children of Kauai : a longitudinal study from the prenatal period to age ten*. Honolulu: University of Hawaii Press.
- Werner, E. (1993). Risk, resilience, and recovery: Perspectives from the Kauai Longitudinal Study. *Development and Psychopathology*, 5, 503-515.
- Werner, E. (1995). Resilience in development. *Current directions in psychological science*, 81-85.
- Werner, E. (2000). Protective factors and individual resilience. In P. Shonkoff & S. Meisels (Eds.), *Handbook of early childhood intervention* (2nd ed., pp. 115-132). Cambridge: Cambridge University Press.
- Werner, E., & Smith, R. (1982). *Vulnerable but invincible: A Longitudinal Study of Resilient Children and Youth*. New York: McGraw-Hill.
- Werner, E., & Smith, R. (1992). *Overcoming the odds: High risk children from birth to adulthood*. Ithaca: Cornell University Press.
- White, A. T., Wilson, T. E., Davis, S. L., & Petajan, J. H. (2000). Effect of precooling on physical performance in multiple sclerosis. *Multiple Sclerosis*, 6(176-180).
- White, B., Driver, S., & Warren, A. (2008). Considering Resilience in the Rehabilitation of People With Traumatic Disabilities. *Rehabilitation Psychology*, 53(1), 9-17.
- Whiteside, S. P., & Lynam, D. R. (2001). The five-factor model and impulsivity: Using a structural model of personality to understand impulsivity. *Personality and Individual Differences*, 30, 669-689.
- Whitlock, F. A., & Siskind, M. M. (1980). Depression as a major symptom of multiple sclerosis. *Journal of Neurology, Neurosurgery, and Psychiatry*, 43, 861-865.
- Wilcoxon, F. (1945). Individual Comparisons by Ranking Methods. *Biometrics Bulletin*, 1, 80-83.

- Willer, B., Rosenthal, M., Kreutzer, J., Gordon, W. A., Rempel, R., & (1993). Assessment of community integration following rehabilitation for traumatic brain injury. *Journal of Head Trauma Rehabilitation, 8*, 75-87.
- Williams, M., Teasdale, J., Segal, Z., & Kabat-Zinn, J. (2007). *The Mindful Way Through Depression*. New York: Guilford Press.
- Williams, R. (2009). Landmark ruling that gives couple freedom to get on with their lives. *The Guardian*.
- Wills, T. A., Vaccaro, D., & McNamara, G. (1992). The role of life events, family support, and competence in adolescent substance abuse: A test of vulnerability and protective factors. *American Journal of Community Psychology, 20*(3), 349-374.
- Wilson, B., Alderman, N., Burgess, P., Emslie, H., & Evans, J. (1996). *Behavioural Assessment of the Dysexecutive Syndrome (BADS)*. London.
- Wilson, B., & Moffat, N. (1992). *Clinical Management of Memory Problems*. London: Chapman and Hall.
- Wineman, N. (1990). Adaptation to multiple sclerosis: the role of social support, functional disability, and perceived uncertainty. *Nursing research, 39*(5), 294-299.
- Wingerchuk, D. M., & Weinshenker, B. G. (2000). Multiple sclerosis: Epidemiology, genetics, classification, natural history, and clinical outcome measures. *Neuroimaging Clinics of North America, 10*(4), 611-624.
- Winston, R. (2003). *The human mind: And how to make the most of it*. London, United Kingdom: Bantam press.
- Wiseman, J. P. (1986). Friendship: Bonds and binds in a voluntary relationship. *Journal of Social and Personal Relationships, 3*, 191-211.
- Wolin, S. J., & Wolin, S. (1993). *The resilient self: How survivors of troubled families rise above adversity*. New York: Villard.

- Wood, R. L., & Yurdakul, L. K. (1997). Change in relationship status following traumatic brain injury. *Brain Injury, 11*(7), 491-501.
- Worden, W. (1991). *Grief Counselling and Grief Therapy*. London: Routledge.
- Wyman, P. A., Cowen, E. L., Work, W. C., & Kerley, J. H. (1993). The role of children's future expectations in self-system functioning and adjustment to life stress: A prospective study of urban at-risk children. *Development and Psychopathology, 5*, 649-661.
- Yáñez, D., Castelo-Branco, C., Hidalgo, L. A., & Chedraui, P. A. (2006). Sexual dysfunction and related risk factors in a cohort of middle-aged Ecuadorian women. *Informa Healthcare, 26*, 682 - 686.
- Yasuda, S., Wehman, P., Targett, P., Cifu, D., & West, M. (2001). Return to work for persons with traumatic brain injury. *American Journal of Physical Medicine and Rehabilitation Medicine, 80*(11), 853-864.
- Yeager, K. R., & Roberts, A. R. (2003). Differentiating Among Stress, Acute Stress Disorder, Crisis Episodes, Trauma, and PTSD: Paradigm and Treatment Goals. *Brief Treatment and Crisis Intervention, 3*, 3-26.
- Ylvisaker, M., & Feeney, T. (1998). *Collaborative brain injury intervention: Positive everyday routines*. Clifton Park, New York.
- Ylvisaker, M., Jacobs, H., & Feeney, T. (2003). Positive supports for people who experience disability following brain injury: A review. *Journal of Head Trauma Rehabilitation, 18*(1), 7-32.
- Ylvisaker, M., Turkstra, L., & Coelho, C. (2005). Behavioral and social interventions for individuals with traumatic brain injury: a summary of the research with clinical implications. *Seminars in Speech & Language, 26*(4), 256-267.

- Young, J., Klosko, J., & Weishaar, M. (2003). *Schema Therapy: A Practitioner's Guide*. New York: Guilford Publications.
- Zajonc, R. B., & Adelman, P. K. (1987). Cognition and communication: A story of missed opportunities. *Social Science Information*, 26, 3-30.
- Zeidner, M., & Saklofske, D. H. (1996). Adaptive and maladaptive coping. In M. Zeidner & N. S. Endler (Eds.), *Handbook of Coping: Theory, Research and Applications* (pp. 505-531). New York: John Wiley.
- Zencius, A. H., Wesolowski, M., (1999). Is the social network analysis necessary in the rehabilitation of individuals with head injury? *Brain Injury*, 13, 723-724.
- Zerubavel, E. (2006). *The elephant in the room: silence and denial in everyday life*. US: Oxford University Press.
- Ziedonis, D. M., & Stern, R. (2001). Dual recovery therapy for schizophrenia and substance abuse. *Psychiatric Annals*, 31(4), 255-264.
- Zola-Morgan, S., & Squire, L. R. (1993). Neuroanatomy of Memory. *Annual Review of Neuroscience*, 16(1), 547-563.

Appendix 1

CONSENT FORM FOR PARTICIPATION IN RESEARCH

(By interview, observation and filling out questionnaires)

I being over the age of 16 years hereby consent to participate as requested in the Letter of Introduction for the research project on Resilience and executive functioning in people who have experienced brain injury or who have diagnosed multiple sclerosis.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I am aware that I should retain a copy of the Consent Form for future reference.
4. I understand that:
 - I may not directly benefit from taking part in this research.
 - I am free to withdraw from the project at any time and am free to decline to answer particular questions.
 - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
 - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
 - I may ask that the observation be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.
5. I have had the opportunity to discuss taking part in this research with a family member or friend.

Participant's signature.....**Date**.....

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name.....

Researcher's signature.....**Date**.....

NB. Two signed copies should be obtained. The copy retained by the researcher may then be used for authorisation of Items 8 and 9, as appropriate.

8. I, the participant whose signature appears below, have read a transcript of my participation and agree to its use by the researcher as explained.

Participant's signature.....**Date**.....

9.I, the participant whose signature appears below, have read the researchers report and agree to the publication of my information as reported.

Participant's signature.....**Date**.....

Social and Behavioural Research

Ethics Committee

Room 105, Registry Building

GPO Box 2100

Adelaide SA 5001

Tel: 08 8201 5962

Fax: 08 8201 2035

Appendix 2

Ethics Approval Letter

SBRE 4005

6 December 2007

Ms Nivashinie Mohan

37A Stuart Road

DULWICH SA 5065

Dear Ms Mohan

Project 4005 Examining the nature and relationship of resilience and executive functioning in people with traumatic brain injury and multiple sclerosis

Further to my letter dated 16 November 2007, I am pleased to inform you that approval of the above project has been confirmed following receipt of the additional information you submitted on 8 October 2007. Approval is given on the basis of information provided in the application, its attachments and the information subsequently provided and is valid until **30 November 2009**.

In accordance with the undertaking you provided in the application, please inform the Social and Behavioural Research Ethics Committee, giving reasons, if the research project is discontinued before the expected date of completion and report anything which might warrant review of ethical approval of the protocol. Such matters include:

- serious or unexpected adverse effects on participants;
- proposed changes in the protocol; and
- unforeseen events that might affect continued ethical acceptability of the project.

I draw to your attention the requirement of the *National Statement on Ethical Conduct in Human Research* that you submit an annual progress and/or final report to SBREC. If a report is not received beforehand, a reminder notice will be issued in twelve months' time. A copy of the report pro forma is available from the SBREC website <http://www.flinders.edu.au/research/info-for-researchers/ethics/committees/social-behavioural.cfm>.

Yours sincerely

Sandy Huxtable

Secretary

Social and Behavioural Research Ethics Committee

inspiring
achievement

Appendix 3

Letter of Introduction

Dear Sir/Madam,

This letter is to introduce Nivashinie Mohan who is a PhD student in the Department of Disability Studies at Flinders University. She will produce her student card, which carries a photograph, as proof of identity.

She is undertaking research leading to the production of a thesis or other publications on the subject of resilience and how people's resilience can be nurtured. It also examines executive functioning which is the use of the frontal part of the brain in everyday activities such as planning, anticipating, responding to feedback and self regulating behaviours. The research is titled "*Examining the nature and relationship of resilience and executive functioning in people with Traumatic Brain Injury and Multiple Sclerosis*".

She would be most grateful if you would volunteer to spare the time to assist in this project, by (a) completing two assessment instruments at three points in time, and (b) participating in the intervention program over a period of 6 months. The questionnaires will take no more than 50 minutes to complete. The intervention is individually designed to nurture and foster resilience as well as to promote effective executive functioning. She will meet with you for approximately 1-2 hours every 2 weeks during this six month period to work on goals which are set by you. Every two months these goals will be evaluated and new goals will be formed.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Since she intends to make a recording of the interview, she will seek your consent, on the attached form, to record the interview, to use the recording or a transcription in preparing the thesis, report or other publications, on condition that your name or identity is not revealed, and to make the recording available to other researchers on the same conditions (or that the recording will not be made available to any other person).

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on (8201 3645), fax (8201 3646) or e-mail (Michelle.Bellon@flinders.edu.au)

Thank you for your attention and assistance.

Yours sincerely,

Dr Michelle Bellon

Lecturer

Department of Disability Studie

School of Medicine



Appendix 4

PARTICIPANT INFORMATION SHEET

Title of Study: Examining the nature and relationship of resilience and executive functioning in people with traumatic brain injury and multiple sclerosis

Principal Researcher: *Nivashinie Mohan* (Flinders University Department of Disability Studies)

You are being invited to participate in a research study conducted by me Niva Mohan and PhD student at the Flinders University. “This is a student research project conducted under the supervision of Dr Brian Matthews and Dr Michelle Bellon. The study will help me learn more about the topic area and develop skills in research design, collection and analysis of data, and writing a research thesis.

In order to decide whether or not you want to be a part of this research study, you should understand what is involved and the potential risks and benefits. This form gives detailed information about the research study, which will be discussed with you. Once you understand the study, you will be asked to sign a consent form if you wish to participate. Please take your time to make your decision. Feel free to discuss it with your friends and family, or your family physician.

WHY IS THIS RESEARCH BEING DONE?

This research is being done to understand what resilience is for people with a Traumatic Brain Injury (TBI) and Multiple Sclerosis (MS). It also assesses how a person ability to be resilient correlates with their executive functioning. Executive functioning refers to the abilities of the frontal part of the brain and usually involves planning, initiating, responding to feedback and monitoring emotions and behaviour. There is a lack of research into how resilience can be nurtured and enhanced in a clinical setting and this research aims to fill that gap in the literature.

WHAT WILL MY RESPONSIBILITIES BE IF I TAKE PART IN THE STUDY?

If you volunteer to participate in this study, we will ask you to do the following things:

- (1) Fill in a resilience questionnaire and complete the Behaviour Assessment of Dysexecutive Syndrome which is a pencil and paper assessment instrument measuring executive functioning. You will be required to fill them in at the start of the study, at the end of the intervention period (6 months in duration) and again after a 6 month follow up period.
- (2) Be involved in an intervention procedure which involves a 1 hour session every two weeks with me working on goals and strategies to help you in strengthening resilience and executive functioning. The intervention will go on for 6 months and can be done in an informal setting (i.e. your home, café)
- (3) Allow me access to your medical and psychological reports which are relevant to the study.
- (4) Continued contact with me over a 12 month period including follow up which consists of phone calls, e mails and sms.

If you choose to take part in this study, you will be told about any new information which might affect your willingness to continue to participate in this research.

HOW MANY PEOPLE WILL BE IN THIS STUDY?

There are a total of 20 people involved in this study. 10 with TBI and 10 with MS.

WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR FOR SOCIETY?

The potential benefits from the study will be to improve resilience and coping with a traumatic condition. The intervention aims to teach strategies which will help you nurture resilience, facilitate community integration and strengthen social support networks.



If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published without your specific consent to the disclosure.

CAN PARTICIPATION IN THE STUDY END EARLY?

If you volunteer to be in this study, you may withdraw at any time and this will in no way affect the quality of care you are currently receiving from the Community Re Entry Program or the Multiple Sclerosis Society. You have the option of removing your data from the study. You may also refuse to answer any questions you don't want to answer and still remain in the study.

IF I HAVE ANY QUESTIONS OR PROBLEMS, WHOM CAN I CALL?

If you have any questions about the research now or later, or if you think you have any potential problems relating to participating in the study please contact :

Dr Brian Matthews

Department of Disability Studies,
Flinders University, GPO Box 2100,
Adelaide, South Australia 5001

Brian.matthews@flinders.edu.au

08- 82013448

Dr Michelle Bellon

Department of Disability Studies,
Flinders University, GPO Box 2100,
Adelaide, South Australia 5001

Michelle.bellon@flinders.edu.au

08-8201 3645

If you have any questions regarding your rights as a research participant, you may contact *Social and Behavioral Research Ethics Committee Secretary*: Sandy Huxtable, Office of Research, phone (08) 8201 5962.

You will also be given the opportunity to review, read and understand all research documentation related to your participation such as the case studies, final reporting of results and the discussion of the results.

Appendix 5
Resilience Scale

Appendix 6

Wilcoxon signed rank test

Resilience scores for TBI and MS groups

Ranks

			N	Mean Rank	Sum of Ranks
TOTALRTBI2 - TOTALRTBI1	Ranks	Negative	1 ^a	1.00	1.00
	Ranks	Positive	9 ^b	6.00	54.00
		Ties	0 ^c		
		Total	10		
TOTALRTBI3 - TOTALRTBI2	Ranks	Negative	9 ^d	5.22	47.00
	Ranks	Positive	1 ^e	8.00	8.00
		Ties	0 ^f		
		Total	10		

a. TOTALRTBI2 < TOTALRTBI1

b. TOTALRTBI2 > TOTALRTBI1

c. TOTALRTBI2 = TOTALRTBI1

d. TOTALRTBI3 < TOTALRTBI2

e. TOTALRTBI3 > TOTALRTBI2

f. TOTALRTBI3 = TOTALRTBI2

Test Statistics^c

	TOTALRT BI2 - TOTALRTBI1	TOTALRT BI3 - TOTALRTBI2
Z	-2.701 ^a	-1.994 ^b
Asymp. Sig. (2-tailed)	.007	.046

a. Based on negative ranks.

b. Based on positive ranks.

c. Wilcoxon Signed Ranks Test

Ranks					
			N	Mean Rank	Sum of Ranks
TOTALRMS2 - TOTALRMS1	Ranks	Negative	1 ^a	1.00	1.00
	Ranks	Positive	9 ^b	6.00	54.00
		Ties	0 ^c		
		Total	10		
TOTALRMS3 - TOTALRMS2	Ranks	Negative	4 ^d	6.00	24.00
	Ranks	Positive	6 ^e	5.17	31.00
		Ties	0 ^f		
		Total	10		
a. TOTALRMS2 < TOTALRMS1 b. TOTALRMS2 > TOTALRMS1 c. TOTALRMS2 = TOTALRMS1 d. TOTALRMS3 < TOTALRMS2 e. TOTALRMS3 > TOTALRMS2 f. TOTALRMS3 = TOTALRMS2					

Test Statistics^a

	TOTALRMS2 - TOTALRMS1	TOTALRMS3 - TOTALRMS2
Z	-2.705 ^a	-.359 ^a
Asymp. Sig. (2-tailed)	.007	.720

a. Based on negative ranks.

b. Wilcoxon Signed Ranks Test

Appendix 6 continued

Wilcoxon signed rank test

Total DEX scores for TBI and MS groups

Ranks

			N	Mean Rank	Sum of Ranks
DEXTB2 - DEXTBI1	Ranks	Negative	6 ^a	6.08	36.50
	Ranks	Positive	4 ^b	4.63	18.50
		Ties	0 ^c		
		Total	10		
DEXTBI3 - DEXTB2	Ranks	Negative	1 ^d	8.00	8.00
	Ranks	Positive	9 ^e	5.22	47.00
		Ties	0 ^f		
		Total	10		
TOTALDEXMS2 - TOTALDEXMS1	Ranks	Negative	10 ^g	5.50	55.00
	Ranks	Positive	0 ^h	.00	.00
		Ties	0 ⁱ		
		Total	10		
TOTALDECXMS3 - TOTALDEXMS2	Ranks	Negative	6 ^j	5.75	34.50
	Ranks	Positive	3 ^k	3.50	10.50
		Ties	1 ^l		
		Total	10		

a. DEXTB2 < DEXTBI1

b. DEXTB2 > DEXTBI1

c. DEXTB2 = DEXTBI1

d. DEXTBI3 < DEXTB2

e. DEXTBI3 > DEXTB2

f. DEXTBI3 = DEXTB2

g. TOTALDEXMS2 < TOTALDEXMS1

h. TOTALDEXMS2 > TOTALDEXMS1

i. TOTALDEXMS2 = TOTALDEXMS1

j. TOTALDECXMS3 < TOTALDEXMS2

k. TOTALDECXMS3 > TOTALDEXMS2

l. TOTALDECXMS3 = TOTALDEXMS2

Test Statistics^c

	DEXTB2 - DEXTBI1	DEXTBI3 - DEXTB2	TOTALDEXMS2 - TOTALDEXMS1	TOTALDECXMS3 - TOTALDEXMS2
Z	-.921 ^a	-1.989 ^b	-2.805 ^a	-1.427 ^a
Asymp. Sig. (2-tailed)	.357	.047	.005	.154

Appendix 7
Mann Whitney U Test

Ranks

Participants		N	Mean Rank	Sum of Ranks
TOTALR1	Tbi	10	6.10	61.00
	Ms	10	14.90	149.00
	Total	20		
TOTALR2	Tbi	10	7.45	74.50
	Ms	10	13.55	135.50
	Total	20		
TOTALR3	Tbi	10	6.95	69.50
	Ms	10	14.05	140.50
	Total	20		

Test Statistics^a

	TOTALR1	TOTALR2	TOTALR3
Mann-Whitney U	6.000	19.50	14.50
		0	0
Wilcoxon W	61.00	74.50	69.50
	0	0	0
Z	-	-	-
	3.326	2.306	2.689
Asymp. Sig. (2-tailed)	.001	.021	.007
Exact Sig. [2*(1-tailed Sig.)]	.000 ^a	.019 ^a	.005 ^a

a. Not corrected for ties.

b. Grouping Variable: Participants

Ranks

Participants		N	Mean Rank	Sum of Ranks
DEX1	tbi	10	15.05	150.50
	ms	10	5.95	59.50
	Total	20		

DEX2 tbi	10	15.50	155.00
ms	10	5.50	55.00
Total	20		
DEX3 tbi	10	15.50	155.00
ms	10	5.50	55.00
Total	20		

Test Statistics^b

	DEX 1	DEX 2	DEX 3
Mann-Whitney U	4.50 0	.000	.000
Asymp. Sig. (2-tailed)	.001	.000	.000
Exact Sig. [2*(1-tailed Sig.)]	.000 a	.000 a	.000 a