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A STRESS MANAGEMENT PROGRAMME FOR MOTHERS OF CHILDREN WITH SENSORY MODULATION DISORDER: A SENSORY MODULATION-BASED APPROACH

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A dissertation submitted to the Faculty of Health Sciences, School of Therapeutic Sciences, University of the Witwatersrand, Johannesburg, in fulfilment of the requirements for the degree of Master of Science in Occupational Therapy

Johannesburg, 2017

DECLARATION

I, Carryn Martin, hereby declare that this thesis is my own work. It is being submitted for the degree of Master of Science in Occupational Therapy of the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.

Signature 

Date 6 June 2017

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ABSTRACT

Parents of children who have sensory modulation disorder (SMD) and who have sensory over-responsiveness (SOR) themselves may display mal-adaptive self-regulatory strategies, contributing to elevated stress levels. The purpose of the study is to determine the perceived stress levels and sensory self-regulatory strategies of mothers of children with SMD, who presented with SOR themselves.

A twelve-week stress management programme using a sensory modulation-based approach was developed and implemented with a sample of five mothers with SOR. The quasi-experimental pre-test post-test design required the participants to complete the Parenting Stress Index-4 Short Form and a sensory self-regulatory questionnaire. The effectiveness of the programme was assessed by determining change in perceived stress and self-regulatory behaviours immediately after and three months following the programme.

Although no statistically significant change was found, clinically relevant change with large effect sizes was evident in the scores for parental distress, difficult child, total stress, and self-regulatory behaviour after the intervention period. Further clinical change was found for parental distress, difficult child and parent child dysfunctional interaction with moderate effect sizes after the follow up period. The results of this study indicate the importance of addressing the mother's stress levels, in addition to treating their child with SMD.

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DEFINITION OF TERMS

Autonomic nervous system: One of the components that plays a role in the physiological role of homeostasis and is referred to as the balance system (Champagne, 2011; Porges, 2003).

Clinically relevant change: When the 95% confidence intervals (CI) of effect sizes do not contain a zero and both have the same sign clinical change, then it can be considered significant. When the CI contains a zero but remains relatively large, particularly in the positive range with a moderate to large effect size, the intervention might be beneficial, especially if a high percentage of the participants achieved a meaningful outcome (Page, 2014).

Difficult child: The behavioural characteristics of the child that impacts on the level of difficulty to manage their child. These difficulties are often temperament related, but may also be characterised by uncooperative or demanding behaviour (Abidin, 1995).

Disattention: Lack of attention to relevant feedback given by the body and mind that are required for harmonious functioning of both (Kabat-Zinn, 2013).

Hyperarousal: Arousal is characterised by one's level of alertness or consciousness. If an individual is alert, then they can perceive their internal and external environment (Bundy, Lane, & Murray, 2002). Hyperarousal is "characterized by a great deal of muscle tension and the activation of strong emotions, which may vary from terror, fright, or anxiety, shame, or embarrassment to rage and anger"[p312] (Kabat-Zinn, 2013) Bundy, Lane, and Murray (2002) further elaborate that hyperarousal can lead to behavioural organisation and negative responses.

Low neurological threshold: The individual requires very little sensory stimuli to meet the threshold. They tend to react to one or multiple sensory inputs quicker, with greater intensity or for a longer period of time than people with typical sensory responsivity (Brown & Dunn, 2002; Miller, Anzalone, Lane, Cermak, & Osten, 2007).

Neurological thresholds: The level of stimuli required for a neuron or nervous system to respond (Brown & Dunn, 2002).

Parasympathetic nervous system: Component of the autonomic nervous system. It helps an individual recover from a stressor, which has an inhibitory effect on the SNS (Champagne, 2011; Nance & Hoy, 1996).

Parental distress: The parent's level of distress which includes their sense of parenting competence, stressors associated with other life roles, parental conflict, social support and depression (Abidin, 1995).

Parent-child dysfunctional interaction: The parent-child interactions and expectations (Abidin, 1995).

Self-regulation: The ability to "modulate mood, self-calm, delay gratification and tolerate change or transitions in activities"[p18] (DeGangi, 2012)

Sensory diet: An individualised daily plan of meaningful sensory activities to help improve their ability to function more optimally (Wilbarger, 1984).

Sensory ergonomics: An act whereby one changes the individuals surrounding environment through the addition or removal of sensory stimuli in order to meet their sensory needs (Lombard, 2016 [accessed 3 February 2017]).

Sensory modulation: The regulatory aspect of sensory processing (Champagne, 2011) and "is a dynamic central nervous system process"[p103] (Bundy, Lane, & Murray, 2002). It is the ability "to regulate and organise the degree, intensity and nature of responses to sensory input in a graded and adaptive manner"[p2] (Lane & Miller, 2000). Optimal sensory modulation is important for one's ability to participate in everyday occupations, with adequate attention and engagement (Bundy, Lane, & Murray, 2002).

Sensory over-responsiveness: A fight-or-flight reaction or an array of aversive reactions to harmless sensory stimuli across one or more sensory systems (Bundy, Lane, & Murray, 2002; Wilbarger & Wilbarger, 2012). Sensory over-responsiveness is brainstem based, referring to the intensive reactions that one has to various sensory sensations (Heller, 2002).

Sensory processing: The nervous systems' ability to receive and organise incoming sensory information for effective daily functioning (Dunn, 1997).

Sensory under-responsiveness: An individual will under-respond or fail to react in an expected manner to a sensory experience (Bundy, Lane, & Murray, 2002). According to Dunn's model, individuals who have sensory under-responsiveness have

a high neurological threshold to sensory input, and therefore require a lot of sensory input to produce a response, can take longer to respond to sensory input and can appear lethargic (Brown & Dunn, 2002).

Stress: A physiological and psychological reaction (Selye, 1980), which is characterised as being a resource imbalance between the stressor and the individuals resources or coping skills (Perry, 2004). Bundy, Lane, and Murray (2002) states that stress is a "behavioural response to environmental input that is variable in both its intensity and its triggers" [p115].

Sympathetic nervous system: Component of the autonomic nervous system. It is the activating system for when the individual is under stress or threat (Champagne, 2011).

Total stress: The parents' overall stress that they are experiencing (Abidin, 1995).

ABBREVIATIONS

ADD	Attention Deficit Disorder
ANS	Autonomic Nervous System
CVI	Content Validity Index
DC	Difficult child
EHP	Ecology of Human Performance
HREC	Human Research Ethics Committee
OT	Occupational Therapy
PCD-I	Parent Child Dysfunctional Interaction
PNS	Parasympathetic Nervous System
PS	Parental Stress
PSI-4-SF	Parenting Stress Index-4-Short Form
PTSD	Post Traumatic Stress Disorder
SI	Sensory Integration
SMD	Sensory Modulation Disorder
SME	Subject matter experts
SNS	Sympathetic Nervous System
SOC	Sense of Coherence
SOR	Sensory over-responsiveness
TS	Total Stress

CHAPTER 1 INTRODUCTION

1.1 INTRODUCTION

Research indicates that there is increased stress in parents who have children with disabilities (Baker, McIntyre, Blancher, Crnic, Edelbrock, & Low, 2003; Gupta, 2007; Neece, Green, & Baker, 2012), particularly in mothers (Oelofsen & Richardson, 2006). This is also true for parents who have children with sensory modulation disorder (SMD) (Gourley, Wind, Henninger, & Chinitz, 2013). Research has found that providing a structured intervention programme for parents can have a positive effect on parental stress when comparing to those parents with no support or parents receiving standard child-orientated services (Hastings & Beck, 2004). Numerous studies have recommended the implementation and evaluation of specific stress reduction intervention programmes for parents (Hastings & Beck, 2004; Kinnealey, Koenig, & Smith, 2011; Neece, Green, & Baker, 2012; Oelofsen & Richardson, 2006).

An additional compounding factor to mother's stress levels, is that they may be presenting with SMD themselves, due to the moderate genetic link evident in sensory over-responsiveness (Goldsmith, Van Hulle, Arneson, Schreiber, & Gemsbacher, 2006). A person with sensory modulation disorder (SMD), specifically sensory over-responsiveness (SOR), may display poor self-regulatory strategies, which are important for managing one's stress levels and coping with everyday life (Bundy, Lane, & Murray, 2002; Kinnealey, Oliver, & Wilbarger, 1995). Dunn (2001) and Kinnealey, Oliver, and Wilbarger (1995), believe that increasing an individual's knowledge of their own sensory profile and their self-regulatory coping mechanisms, as well as preforming a daily structured sensory diet; can help an individual with SOR function and manage their life more productively. These strategies could help the mothers manage their existing and future stress levels.

The purpose of this study is to investigate the effectiveness of a stress management programme that is focused on empowering mothers to take responsibility in managing their stress levels, through the use of education and various sensory

modulation principles. It will explore whether such a programme will have an effect on the stress levels of mothers with children who have SMD and who may have SMD (specifically SOR) themselves.

1.2 STATEMENT OF THE PROBLEM

Numerous research studies have found that parents of children with disabilities have higher levels of stress than those parents with children without disabilities (Baker et al., 2003; Emerson, 2003; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001). In particular, mothers of children with developmental disabilities were found to have significantly decreased health and higher parenting stress than their spouses (Gourley et al., 2013; Oelofsen & Richardson, 2006). Children with SMD can display difficulties with family interactions, relationships (Dunn, 1997) and social skills, as well as decreased participation in play; difficulties with their self-confidence and self-esteem, regulation of their emotions and anxiousness (Case-Smith, 2005). They also can experience problems with daily life skills, scholastic skills, and poor progression of other developmental skills (Case-Smith, 2005). These difficulties can result in heightened levels of parental stress (Gourley et al., 2013). Coupled with these factors is a genetic predisposition to SOR which may play a role in parents' stress levels. Wilbarger and Wilbarger (1991) found that fifty percent of children with SOR are estimated to have a family member presenting with similar problems. Therefore, the challenges of having a child with SMD may be compounded by the mothers' own neurological thresholds and lack of self-regulatory strategies. These factors could add to the mothers' stress levels which can further impact on their ability to optimally self-regulate.

From an occupational therapy perspective, the implementation of sensory diets and evaluating the child's sensory needs plays a vital role in treating children with SMD. It is important to perform various sensory strategies at home, in order to promote change and improve the child's symptoms related to SMD. From my experience as an occupational therapist in private practice, the family's busy lifestyles and increased parental stress have a negative impact on consistent implementation of home programmes. Gourley et al. (2013), believed that parental education, and early identification and treatment of children with SMD, will most likely improve the child's symptoms and thus reduce parental stress. Currently, this is standard OT

practice in the treatment of children with SMD. However, a reciprocal relationship was found by Neece, Green, and Baker (2012) between parental stress and children with challenging behaviour, which highlights the importance of focusing on both the parents and the children.

Few research studies explore the well-being of mothers who have children with difficulties, with less studies focusing on parents of children with SMD. Through a selective review conducted by Hastings and Beck (2004), they found that stress interventions for parents of children with intellectual disabilities revealed clinically significant improvements. There is no study evaluating a stress reduction treatment model for parents in relation to SMD. However, various studies have recommended that the implementation and evaluation of specific stress reduction intervention programmes for parents in a variety of contexts are needed (Hastings & Beck, 2004; Kinnealey, Koenig, & Smith, 2011; Neece, Green, & Baker, 2012; Oelofsen & Richardson, 2006). Through reviewing various research studies, the need to develop a stress management programme for mothers, who have children with SMD was identified.

1.3 PURPOSE OF THE STUDY

The purpose of this study was to determine the stress levels, sensory profile and sensory self-regulatory strategies of mothers with children being treated for SMD in occupational therapy. A stress management programme using a sensory modulation-based approach was developed and implemented with those mothers who present with SOR. This aimed to assist the mothers to create lifestyles consistent with their sensory preferences and incorporate positive self-regulatory strategies in order to improve their current and future stress levels. The change in the mothers' stress levels was assessed following a twelve -week stress management intervention and at a three month follow up after the intervention was complete.

1.4 RESEARCH QUESTION

Is a structured twelve-week stress management programme that is based on sensory modulation principles, effective in reducing the stress levels of mothers who have SOR and children with SMD?

1.5 AIM OF THE RESEARCH

The aim of the study is to investigate the relationship of the mothers' perceived stress levels and their sensory self-regulatory strategies; as well as to implement and evaluate the effectiveness of a structured twelve-week sensory modulation-based stress management programme for mothers, who present with SOR and have children with SMD.

1.6 RESEARCH OBJECTIVES

- To determine the sensory profiles (using the Adult Sensory Profile) and self-regulatory behaviours (using a sensory self-regulation questionnaire) of mothers of children with SMD.
- To determine the perceived stress levels of mothers who present with SOR using the Parenting Stress Index-4 (Short form).
- To determine the relationship of the perceived stress levels of mothers who present with SOR and their sensory self-regulatory behaviours.
- To develop and implement a structured twelve-week sensory modulation-based stress management programme for mothers who present with SOR and have children with SMD.
- To evaluate the effectiveness of a twelve-week sensory modulation-based stress management programme on the mothers' perceived stress levels.

1.7 NULL HYPOTHESIS

A twelve-week stress management programme, based on sensory modulation principles will have no effect on the perceived stress levels of mothers of children with SMD and who have SOR themselves.

1.8 JUSTIFICATION OF THE STUDY

Comparisons have been made between stress, self-regulation and SOR (Engel-Yeger & Dunn, 2011; Kinnealey & Fuiek, 1999; Kinnealey, Koenig, & Smith, 2011; Liss, Timmel, Baxley, & Killingsworth, 2005). However, the reduction of mother's perceived stress levels following a stress management programme that is sensory modulation-based, has not been explored. Understanding the relationship between the mother's sensory self-regulatory strategies and their stress levels, will allow for

the consideration and implementation of an intervention programme for mothers when treating children with SMD. The study will provide evidence as to whether a sensory modulation-based stress management programme will effectively improve mothers' stress levels. This will reinforce the importance of providing more direct support to the mothers and the need to further crystallise and broaden the scope of a family-centred approach, as well as to display the influence that sensory-based strategies have on one's perceived levels of stress.

1.9 OVERVIEW OF DISSERTATION

Chapter 1

Chapter 1 introduced the study by exploring research that has been completed and not yet completed in the field of stress, SOR, intervention for parents with disabilities and self-regulation. It reinforces the problem identified and reasons why stress intervention with mothers who have children with SMD and SOR themselves, should be investigated. The purpose of the study, as well as the study's aims and objectives, are laid out. Justification for the study is also discussed.

Chapter 2

Chapter 2 explores various literature that is related to the different components of the study, namely, sensory processing, sensory over-responsiveness and stress, particularly parental stress when parenting a child with a disability. In addition, self-regulation and the role of self-regulation in adults with SOR, as well as intervention addressing self-regulation are reviewed. This chapter aims to explain these various components, as well as to provide the reader with knowledge as to what research has been completed in this field.

Chapter 3

This chapter presents the pre-test-post-test methodology used for the research and the procedures used, as well as discussing the development of the twelve-week stress management programme. The chapter is divided up into two parts, where part 1 describes the steps taken to develop the stress management programme and part 2 describes the steps taken to execute and analyse the stress management programme.

Chapter 4

Chapter 4 presents the results from the study, which include the results received from the following questionnaires: the demographic questionnaire, Sensory Profile, Parenting Stress Index (Short Form), sensory self-regulatory questionnaire and the stress management programme evaluation questionnaire. The Sensory Profile was used to confirm the participants SOR and inclusion in the study, as well as providing a base for individual programme implementation. Change in the scores on the Parenting Stress Index (Short Form) and sensory self-regulatory questionnaire was analysed to determine the effectiveness of the programme.

Chapter 5

This chapter presents the discussion of the findings of the study in relation to the objectives and the perceived stress levels of mothers of children with SMD, as well as their patterns of sensory processing and their self-regulatory behaviours. The change found in the study is depicted in a framework, presented in the development of the programme, which is used to explain the relationship between the participants perceived stress levels and their self-regulatory strategies. The effectiveness of the structured twelve-week sensory modulation-based stress management programme, as well as the study's strengths and limitations of the study are also included.

Chapter 6

This chapter concludes the research by summarizing important findings from the study. in addition to providing conclusions made from these findings, clinical implications of the findings and various research recommendations are also shared.

CHAPTER 2 LITERATURE REVIEW

2.1 INTRODUCTION

This literature review considers sensory processing, sensory over-responsiveness, and stress - particularly, parental stress when raising a child with a disability. Self-regulation, the role of self-regulation in adults with sensory over-responsiveness, and interventions addressing self-regulation are reviewed.

The literature was sourced from EBSCO Host, Science Direct, ProQuest, Ovid, ClinicalKey, Sage Journals, PubMed, Springer and Wiley databases from 1990, to cover original research and models for stress and sensory processing to date.

2.2 SENSORY PROCESSING AND SENSORY OVER-RESPONSIVENESS

Our daily experiences are characterized by sensory events that we encounter on a moment to moment basis. The way an individual processes or perceives sensation makes each of us unique and guides our preferences and choices (Dunn, 2001). Dunn (1997) described sensory processing as the nervous systems' ability to receive and organise incoming sensory information for effective daily functioning.

Sensory modulation is the regulatory aspect of sensory processing (Champagne, 2011) and it is described as the ability "to regulate and organise the degree, intensity and nature of responses to sensory input in a graded and adaptive manner"[p2] (Lane & Miller, 2000). Ayres (1979), a pioneer in the field, defined modulation as "the process of increasing or reducing activity to keep the activity in harmony with all functions of the nervous system" [p182]. Intact sensory modulation helps the individual respond appropriately to a given situation by responding to some sensory stimuli and ignoring other sensory stimuli (Brown & Dunn, 2002). A resilient and versatile nervous system allows one to participate in socially and meaningful activities throughout the day, to occupy roles efficiently, and to cope with stressors of daily life (Champagne, 2011). Sensory Modulation Disorder (SMD) is a diagnostic pattern of dysfunction relating to sensory processing, which is multidimensional in nature (Bundy, Lane, & Murray, 2002).

2.2.1 Classification of Sensory Modulation Disorder

Hanft, Miller, and Luce (2000) described SMD as a dysfunctional pattern of sensory integration, whereby an individual will either under-respond or over-respond to sensory input from their body or the environment. An individual with SMD may struggle to reach and maintain an optimal range of arousal, display inconsistent responses to their sensory environment, and may have difficulty in adapting to sensory challenges encountered in everyday life (Lane & Miller, 2000; Miller et al., 2007). Furthermore, individuals with SMD display a "mismatch between the external contextual demands of a person's world (e.g. culture, environment, tasks, and relationships) and a person's internal characteristics"[p1] (Hanft, Miller, & Luce, 2000).

The individualised responses to sensory input were initially represented as a continuum, with sensory over-responsiveness on one end and sensory under-responsiveness on the other end (Royeen & Lane, 1991). Royeen and Lane (1991) further hypothesised that this continuum was circular, which allowed for fluctuations between over-responsiveness and under-responsiveness. Through clinical experience, various authors believed that sensory modulation is in fact multidimensional and cannot be represented in a continuum (Dunn, 1997; Parham & Mailloux, 1995; Wilbarger & Wilbarger, 1991). Following these insights, Dunn (1997) developed a model for sensory processing that displays the interaction between neurological thresholds and behavioural responses (Figure 2.1 below).

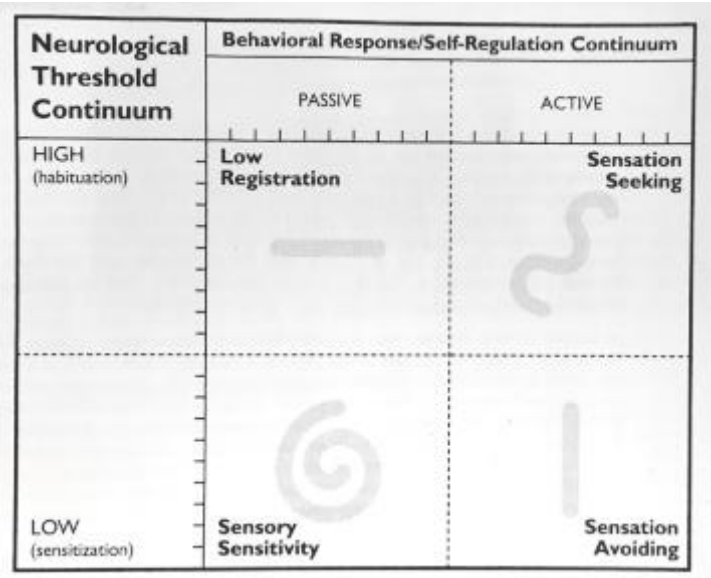


Figure 2.1: Adapted representation of Dunn's Model of Sensory Processing Brown, C. and Dunn, W. (2002)

Dunn's model shows that these two categories are presented as continua, which interact with each other. This model explains how people process sensory information and provides guidance for intervention. An individual's response to sensory input or their sensory processing presentation could be positioned anywhere on Dunn's model (Dunn, 1997). Neurological thresholds will be explained later in this section and the behavioural responses will be explained in further detail in the self-regulation section.

Brown and Dunn (2002) make use of a classification system which is used to analyse and interpret each quadrant of the model. It demonstrates where the individual is placed on the continua, in comparison to other individuals their age for each particular quadrant (Brown & Dunn, 2002). The classification system represents the frequency distribution of scores. It is divided up into the following categories:

- "Much less than most people" indicates that the individual has "moderate differences in sensory processing patterns when comparing to others in the same age category". It shows that "the individual's performance is less than the 2nd percentile".
- "Less than most people" indicates that the individual has "mild differences in sensory processing patterns when comparing to others in the same age category". It shows that "the individual's performance is at the 2nd to less than the 16th percentile".
- "Similar to most people" indicates that the individual has "typical sensory processing patterns when comparing to others in the same age category". It shows that "the individual's performance is between the 16th and 84th percentile".
- "More than most people" indicates that the individual has "mild differences in sensory processing patterns when comparing to others in the same age category". It shows that "the individual's performance is at greater than the 84th and up to the 98th percentile".

- "Much more than most people" indicates that the individual has "moderate differences in sensory processing patterns when comparing to others in the same age category". It shows that "the individual's performance is greater than the 98th percentile."[p32] (Brown & Dunn, 2002).

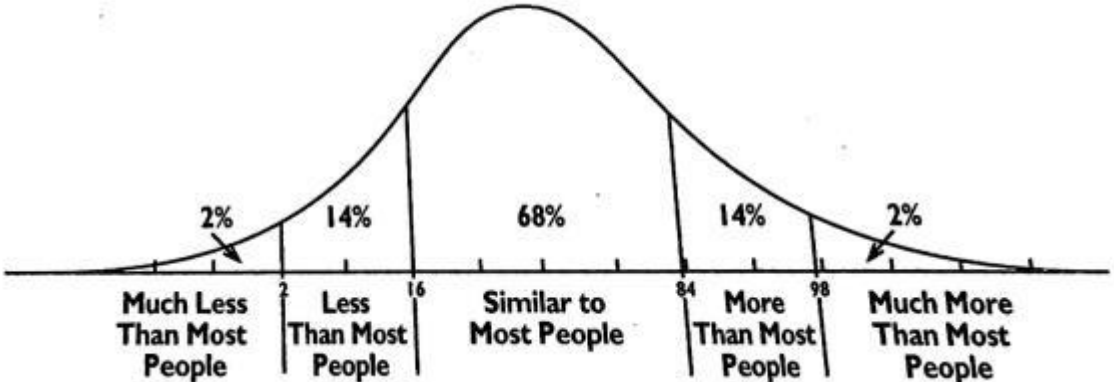


Figure 2.2: The classification system used for Dunn's conceptual model of quadrants (behavioural responses and neurological thresholds) (Brown & Dunn, 2002)

This classification is explained in the Figure 2.2 above. When interpreting an individual's scores on the quadrants, it is important to look at the individuals unique combination of scores across all quadrants, in order to fully understand their sensory processing preferences and how this impacts on their current performance (Brown & Dunn, 2002).

An individual with SMD can either under-respond (due to a high threshold) or over-respond (due to a low threshold) to sensory input (Bundy, Lane, & Murray, 2002). This is related to the individual's threshold towards each sensory input (Dunn, 2001). Neurological thresholds refer to the level of stimuli required for a neuron or nervous system to respond (Brown & Dunn, 2002). An individual with a high neurological threshold requires more sensory input to respond, in comparison to an individual with a low neurological threshold. Individuals with low neurological thresholds will be the focus of this study, as a noteworthy relationship was found between a this subtype and stress (Engel-Yeger & Dunn, 2011).

2.2.2 Sensory over-responsiveness

An individual with a low neurological threshold means that they require very little sensory stimuli to meet the threshold. They tend to react to one or multiple sensory inputs quicker, with greater intensity, or for a longer period of time than people with typical sensory responsivity (Brown & Dunn, 2002; Miller et al., 2007). Since they readily register sensory stimuli more than others, they can become easily distracted by sensory inputs and are more bothered and uncomfortable with sensations - such as bothered by the sounds in a movie theatre, or uncomfortable with clothing tags (Bundy, Lane, & Murray, 2002; Dunn, 2001). DeGangi (2012) further explains that these individuals can become highly disorganised and overwhelmed when placed in environments with too much stimulation or too many activities occurring in a short time span. As a result, they may avoid engaging with others or partaking in certain situations (especially those that are very stimulating).

Two quadrants in Dunn's model correlate to low neurological thresholds, namely: sensory sensitivity and sensation avoiding. Individuals who present in the sensation sensitivity quadrant, display passive responding strategies (whereby they let things happen). Sensory avoiders on the other hand, will display more active behaviours to limit their sensory input throughout the day (Brown & Dunn, 2002; Dunn, 2001). Individuals with sensory over-responsiveness (SOR) display various coping strategies to assist them in managing their sensory defensiveness, and to help regulate or reduce the negative impact of the non-noxious sensory input. These could include the following: avoidance behaviours (such as avoiding sensory input, occasions or environments); controlling behaviours (such as relying on rigid routines); cognitive strategies (such as self-talk and accepting aversive sensations for short periods of time); and lastly, sensory seeking behaviours (such as seeking intense sensory stimulation to self-regulate, or partaking in various repetitive motor behaviours including jaw clenching and biting on objects) (Wilbarger & Wilbarger, 2012). Each individual would display a different representation in Dunn's quadrants (Dunn, 2001). For example, an individual may display SOR to one or more sensory systems (visual, auditory, or vestibular) with varying degrees of severity (Oliver, 1990).

According to Bundy and colleagues, SOR is a fight-or-flight reaction or an array of aversive reactions to harmless sensory stimuli across one or more sensory systems (Bundy, Lane, & Murray, 2002; Wilbarger & Wilbarger, 2012). These reactions are related to an individual with sensory processing difficulties who is having problems with hyperarousal, and which could result in negative responses, anxiousness and behavioural disorganisation (Bundy, Lane, & Murray, 2002; Miller, 2006).Therefore, depending on the degree of their over-responsiveness, even a mild sensory stimulus may result in the individual feeling overwhelmed, or having feelings of annoyance. In some cases, the sensory stimulus may even be considered to be painful (Champagne, 2011). Modulation, on the other hand, occurs when the

> "nervous system balances the person's level of arousal with the intensity of stimulation being experienced. It's the body's internal thermostat that cues one when to rouse or to calm oneself"[p335] (DeGangi, 2012).

An individual with SOR will display a disorganised response to sensory input, as a result from an imbalance evident between the inhibition and excitation of the central nervous system (Knickerbocker, 1980). They then display avoidance or withdrawal behaviours, as well as distractibility and distress from strong sensory stimuli (Brown & Dunn, 2002; Bundy, Lane, & Murray, 2002).

2.2.3 Sensory over-responsiveness in adults

Sensory over-responsiveness results in sympathetic nervous system activation (Lane & Miller, 2000; Mangeot, Miller, McIntosh, McGrath-Clarke, Simon, Hagerman, & Goldson, 2001). As a result, an individual will present with a range of symptoms including increased tension, anxiety, avoidance, anger, violence and stress (Heller, 2002; Kinnealey, Koenig, & Smith, 2011). In addition, Kinnealey, Koenig, and Smith (2011) found that individuals presenting with SOR displayed

> "decreased vitality, poorer social functioning, decreased general health and increased bodily pain" [p. 325].

Oliver (1990) believes most adults with SOR had these difficulties as a child because they were left untreated. DeGangi (2012) reinforces this, by stating that sensory processing difficulties can extend throughout an individual's lifetime, especially if the individual has not received treatment for their presenting sensory difficulties. Furthermore, there is a possibility that adults with SOR may be

misdiagnosed as a result of the lack of knowledge surrounding SOR, and due to the similar presentations of SOR and mental health problems (Oliver, 1990). Abernethy (2010) reports that if an adult with SOR did not receive intervention, their problems relating to SOR could increase due to the psychological consequences of having to cope with their daily life. However, when mental health issues are accompanied with SOR, DeGangi (2012) believes that the individual will often react in maladaptive ways, they may also misinterpret soothing sensory experiences as being aversive and will associate anxiety with certain types of sensory stimuli.

Numerous studies have explored the relationship between SMD (particularly SOR) and various mental health issues, such as anxiety and depression (Abernethy, 2010; DeGangi, 2012; Kinnealey & Fuiek, 1999; Kinnealey, Koenig, & Smith, 2011; Liss et al., 2005). Adults with learning and emotional difficulties often display difficulties related to sensory processing. Although mental health problems and SOR can coexist, it is important to identify SOR as a separate condition to ensure appropriate and effective intervention (Abernethy, 2010). Wilbarger and Wilbarger (1991) found that fifty percent of children with SOR are estimated to have a family member presenting with similar problems. Therefore, the challenges of having a child with SMD may be compounded by the mother's own neurological thresholds and lack of self-regulatory strategies. These factors could add to mothers' stress levels which can further impact on their ability to optimally self-regulate. In addition, clinicians have hypothesised that anxiety resulting from stress can intensify ones SOR (Bundy, Lane, & Murray, 2002).

2.3 STRESS

Stress is a physiological and psychological reaction (Selye, 1980), which is characterised as being a resource imbalance between the stressor and the individual's resources or coping skills (Perry, 2004). Bundy, Lane, and Murray (2002) further states that stress is a

> "behavioural response to environmental input that is variable in both its intensity and its triggers" [p115].

Individuals experience stress differently which may both harm and or help them (Champagne, 2011). Stress can originate from many different sources, such as internal stressors (an individual's thoughts and feelings), chronic stressors (such as taking care of a family member with a chronic disability), or acute stressors (such as work deadlines, traffic etc.). These stressors may not be isolated and can all occur at once (Kabat-Zinn, 2013).

2.3.1 Parental stress

Numerous research studies have found that parents of children with disabilities have higher levels of stress than those parents with children without disabilities (Baker et al., 2003; Emerson, 2003; Hauser-Cram et al., 2001). Mothers are specifically vulnerable to stress which could influence the way they respond to their children (Griffith, Hastings, Nash, & Hill, 2010). This is significant as they play a pivotal role in their child's life, with regards to their child's social skills, emotional regulation and interpersonal relationships (Fuvish & Sales, 2006). Research has found that mothers of children with developmental disabilities were found to have significantly decreased health and higher parenting stress than their spouses (Gourley et al., 2013; Oelofsen & Richardson, 2006).

However, despite numerous research finding correlations in parental stress in parents who have children with disabilities, there have been some research studies that have not found a bidirectional relationship, but have instead found varying responses to coping with disabilities in some families (Jones & Passey, 2004; Perry, 2004). For example, some research has found that although some families are at risk, some families cope and display healthy adaptation to stress (Konstantarcas, 1991). This indicates that there are many factors that can influence the parents' ability to cope.

2.3.2 Assessment of parental stress

Stress in parents is usually assessed using self-report questionnaires, which typically explore various stress influencing factors by requesting some information in relation to both the parent and child's behaviour. The assessment developed by Abidin (1995), namely, the Parenting Stress Index-4 Short Form (PSI-4-SF), particularly looks at these dynamics.

Scores are provided within each of the following categories:

- A defensive responding scale is provided in the PSI-SF, which evaluates the individual's response bias to presenting as a more favourable impression of themselves. Should the individual have a raw score of 10 or below for defensive responding, then further interpretation into possible reasons is recommended.
- Total stress provides insight into the parents' overall stress that they are experiencing. The parent is displaying clinical significant levels of stress if they score in the 91st percentile or higher. It is recommended that these individuals be referred for more specific professional support.
- Parental distress displays the parent's level of distress which includes their sense of parenting competence, stressors associated with other life roles, parental conflict, social support and depression. If the parent scores above the 90th percentile for parental distress and below the 75th percentile for difficult child, then the parent is likely to be experiencing personal adjustment difficulties. They would then therefore require support to assist with this area, in order to strengthen the parent-child relationship.
- Parent-child dysfunctional interaction looks at the parent-child interactions and expectations. A child is at risk of abuse (such as neglect or rejection), should the parent score on the 96th percentile or higher for this category. This would then require further interpretation of the scores for the other categories.
- The difficult child subscale looks at the characteristics of the child that impacts on the level of difficulty to manage their child. Scores from 96th percentile and higher for this category would require further diagnostic exploration to assess for more significant psychopathology. If the difficult child score is on the 90th percentile or higher and two other categories are on the 75th percentile or lower, then parental education would be of benefit. However, a high difficult child score coupled with a low parental distress score (75th percentile or lower) and higher scores for the remaining categories (91st percentile or higher), would indicate that more intensive intervention for the child is needed (Abidin, 1995).

In understanding and further evaluating parental stress, there are various models that explore all these different factors, and the relationship between them. This will be discussed in the following sections, specifically when it is applied to parenting a child with a disability.

2.3.3 Stress related to parenting child with a disability

Although parents perceived locus of control has an influence on their coping (Miller, Gordan, & Daniele, 1992), the severity and nature of the child's disability also has an influential factor on parental stress (Jones & Passey, 2004; Minnes, 1998). This can be characterised by the daily frustrations that are associated with the child's disability. Mash and Johnston (1990) created a simplistic model (Figure 2.3) which includes three variables, namely: child characteristics, parent characteristics and environmental characteristics. The interaction of these three factors then impact on the parent-child interactive stress (Mash & Johnston, 1990).

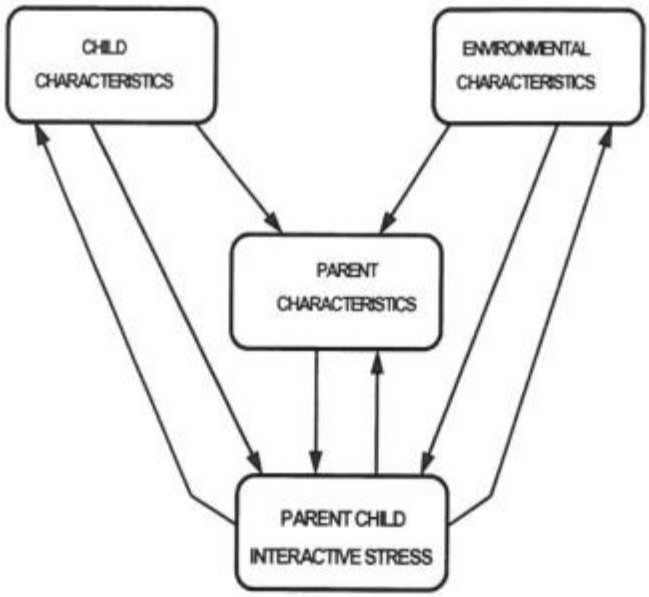


Figure 2.3: Mash and Johnston's Model representing parental stress (Mash and Johnston, 1990)

In addition, other models of parental stress reinforce the same concepts. The parent stress model developed by Abidin (1995) takes some of these characteristics into account, by considering the child's characteristics and measures the extent to which parents find these factors stressful (Perry, 2004). Abidin's theoretical model (Figure 2.4) demonstrates and reinforces how the child and parent characteristics influence the interaction between the child and the parent. This has a knock on effect as it then influences parenting behaviours and ultimately, the child's outcomes.

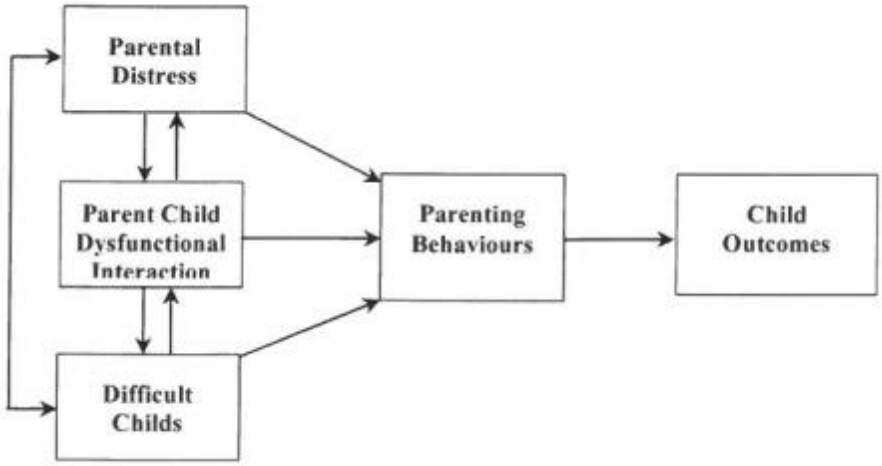


Figure 2.4: Abidin's theoretical model for the Parenting Stress Index-4-Short Form (Abidin, 1995)

Perry (2004) formed an extended model (Figure 2.5) that includes: stressors, resources, supports, and outcomes. This model provides a practical visual representation that considers stressors relating to the child and other life stressors; resources (including the individual's resources, as well as the family's resources) and supports (including the support provided from immediate family to more informal support networks).

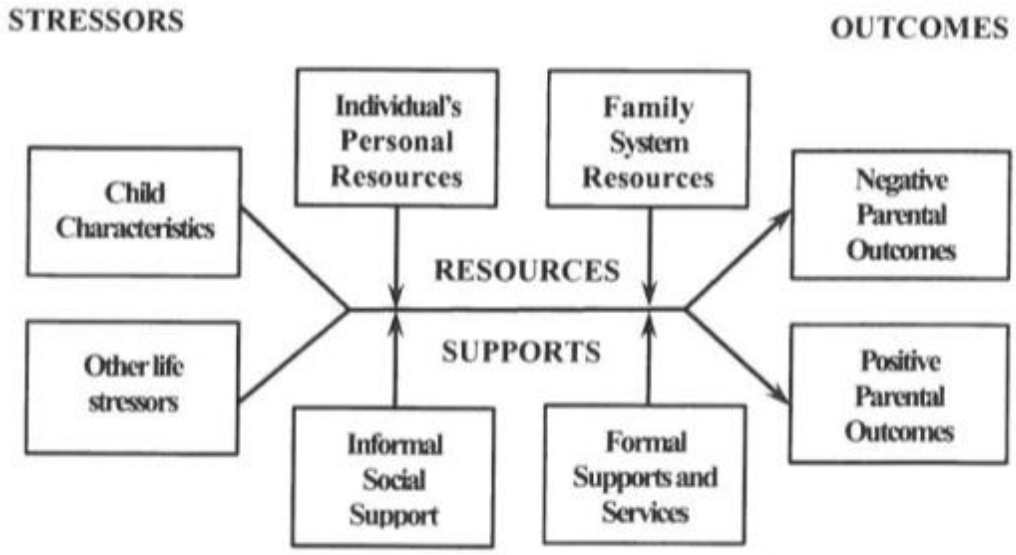


Figure 2.5: Perry's Model of stress for families of children with developmental disabilities (Perry, 2004)

Depending on the balance between the resources and the supports provided, the parental outcomes can vary between positive or negative. The residual outcome consists of the emotional states and cognitive appraisals of the individual, as a result of all the factors (Perry, 2004).

All of the abovementioned models show that parent characteristics play an integral role in parental stress. Is this why some research has revealed that some families who have a child with disabilities, displayed healthy adaptation and coping to stress (Jones & Passey, 2004), while others have not?

Gourley et al. (2013) investigated the impact of sensory processing on parental stress. Although a smaller sample size (59 participants), Gourley and colleagues found that parental stress increased as the child's sensory modulation difficulties increased. They specifically scored higher in the difficult child category for the PSI-SF and the research suggested that the characteristics relating to the child's sensory processing difficulties impacted on parental stress (Gourley et al., 2013).

2.3.4 Stress and coping as a parent

Antonovsky (1979 and 1987) derived a model called the Salutogenic model, which proposed that individuals can be located on a continuum between 'health-ease' and 'health dis-ease'. Any means that promotes the movement of the individual to the 'health-ease' side of the continuum, is called the generalised resistance resource. This could include money, ego strength, or social support.

> "Generalised resistance resources foster an individual's ability to make sense of what is happening (comprehensibility), enhance confidence that the resources available are adequate (manageability), and increase motivation to engage with the challenges faced (meaningfulness)"[p2] (Oelofsen & Richardson, 2006)

Antonovsky then developed the term 'sense of coherence' (SOC), which encapsulates these factors and describes them as resources that facilitate greater health (Antonovsky, 1979, 1987; Oelofsen & Richardson, 2006). An individual with a strong SOC displays more adaptive coping strategies and thus will present with more effective maintenance of personal health and stability, despite the presence of stressors (Geyer, 1997). There is minimal published research on parents' SOC, who have children with disabilities. However, some studies have revealed that parents who

have children with disabilities have lower SOC than parents who do not have children with disabilities (Oelofsen & Richardson, 2006). Oelofsen and Richardson (2006) found that mothers of children with developmental disabilities displayed weaker SOC than their partners, coupled with higher parenting stress. These weaker SOC scores for mothers, implies that their ability to cope effectively is hampered - not only relating to caring for a child with a disability, but also other stressful life events in general. They are thus more vulnerable to stress (Oelofsen & Richardson, 2006).

McCubbin and Patterson (1983) acknowledge the parents' personal characteristics and formulated the Double ABC-X model of stress and coping (Figure 2.6). This model demonstrates that the parents' ability to cope with stressful circumstances is determined by the following factors: the interaction between the stressor and subsequent life stressors, family resources, as well as the parents' perceptions and coping strategies.

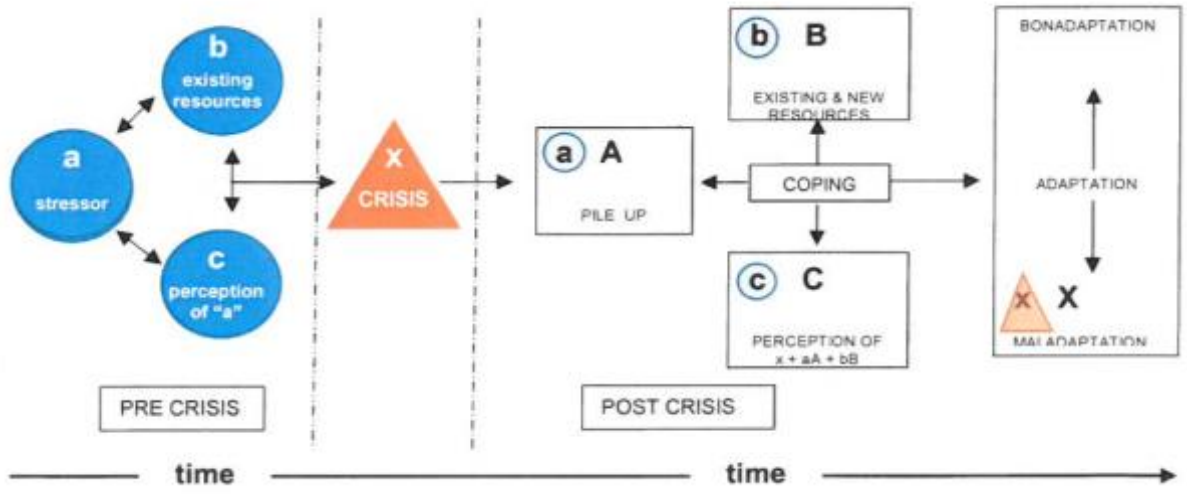


Figure 2.6: Double ABC-X model of stress and coping (McCubbin and Patterson, 1983)

A parent of a child who has developmental disability has increased physical, financial and emotional demands placed on them (Oelofsen & Richardson, 2006). While demanding child characteristics can increase stress in parent (Abidin, 1995), the aforementioned models display that child characteristics are only one influential factor to parental stress. The parental characteristics, resources and SOC also play a major role in parental stress. Numerous studies highlight coping strategies used by individuals to manage stress levels. For example, social support (Frey, Greenberg, &

Fewell, 1989; Friedrich, Wilturner, & Cohen, 1985; Krauss, 1993) or various cognitive processes (Bugental & Johnston, 2000; Coleman & Karraker, 1997; Grusec & Mammone, 1995; Johnston, 1996)

A reduction in stress and better coping has been related to the ability to self-regulate (Brock, 2016). However, there is no research that investigates the effects of using sensory self-regulatory strategies in order to cope and minimise stress, particularly in parents who have children with disabilities.

2.4 SELF-REGULATION

Zimmerman (2000) considers one's ability to self-regulate as the most important quality that an individual can have. Self-regulation is the ability to "modulate mood, self-calm, delay gratification and tolerate change or transitions in activities"[p18] (DeGangi, 2012). It provides an individual with the ability to maintain an inner-balance and adaptability to new circumstances (Kabat-Zinn, 2013). Self-regulation is made possible by the complex interplay between one's psychological experience and their internal physiological state (Porges, 2009). The autonomic nervous system (ANS) is one of the components that plays a part in the physiological role of homeostasis and is referred to as the balance system (Champagne, 2011; Porges, 2003).

The polyvagal theory provides explanations as to how the ANS responds to social interactions, environmental demands and sensory stimulation, providing feedback on how the body should respond to external environmental demands (DeGangi, 2012).

> "Dynamic bidirectional communication occurs between the peripheral nervous system and the brain, providing a feedback loop between the vagal system and the brain"[p3] (DeGangi, 2012).

The vagus nerve serves as the main component of the ANS, which helps with breath and heart control, and physiological relaxation. Not only does it promote overall calmness, it can also help prepare the body for a flight or fight reaction in response to a threat (DeGangi, 2012).

2.4.1 The role of the autonomic nervous system in stress according to the Polyvagal theory

The autonomic nervous system or the balancing system, regulates visceral functions of the body, such as cardiovascular activity, digestion, metabolism and thermoregulation (Champagne, 2011; Porges, 2003). Not only does it regulate the

internal environment, but it also helps regulate the external environment, such as helping the individual to adapt to sensory and motor environmental changes that the individual is exposed to (Nance & Hoy, 1996). The hypothalamus is the principal controller of the ANS (Kabat-Zinn, 2013), which consists of the sympathetic nervous system (SNS) and the parasympathetic nervous system (PNS). The SNS is involved in activating the body when the individual is under stress or threat. Changes in the body would include: increase in heart rate and respiration, pupil dilation, secretion of catecholamine's from the adrenal gland, as well as an inhibition of smooth muscle activity in the digestive system. This is often referred to as the fight or fight mode (Champagne, 2011). In contrast, the PNS has an inhibitory effect on the SNS (Champagne, 2011). The PNS helps an individual recover from a stressor (Nance & Hoy, 1996), and influences their flexibility and ability to cope with a variety of stimuli (Degangi, Dipietro, Greenspan, & Porges, 1991; DiPietro & Porges, 1991).

Porges (2004) developed the Polyvagal theory, which demonstrates that there is a hierarchy of nervous system responses based on the evolution of the nervous system. Earlier views suggested that the SNS directed all changes in the ANS, and that the SNS and PNS had a bipolar-type balancing function (Champagne, 2011; Porges, 2004). However, according to the Polyvagal theory, there are three hierarchical organised ANS subsystems that have an effect on the body's heart rate, level of alertness, the ability to communicate functionally and relate to others, as well as the ability to respond to perceived threats (Champagne, 2011; Porges, 2009).

The vagus nerves form an important component to the ANS, and relay bidirectional communication between the viscera and the brain (Porges, 2003). Each branch provides a different behavioural approach (Porges, 2003). The phylogenetically newest and myelinated PNS branch, named the ventral vagal PNS, responds first. If this response does not deal with threat, then the SNS responds. Thereafter, the dorsal vagal PNS, the oldest and most primitive, unmyelinated PNS branch, is activated(See Table 2.1) (Champagne, 2011).

Table 2.1: The three phylogenetic stages of the autonomic nervous system according the Polyvagal Theory (Porges, 2003; Champagne, 2011)

Phylogenetic stage	ANS component	Structure	Function
III	Ventral Parasympathetic branch of the vagal nerve	Myelinated vagus nerve	Social communication, self-soothing and calming. Has an inhibitory effect on the sympathetic adrenal influences.
II	Sympathetic branch	Sympathetic adrenal	Mobilisation (Fight, flight response)
I	Dorsal Parasympathetic branch of the vagal nerve	Unmyelinated vagus nerve	Immobilisation (Fright response). Survival, protection, energy conservation function.

The following example helps to clarify the Polyvagal theory. Communicating to a colleague about an incident that occurred at work, the firing of the ventral vagal PNS may portray the individual's relaxed manner when they initiate the conversation. But should they feel wrongfully accused for the incident, it may be enough to trigger the SNS response, as this is the next phylogenetic progression. The more flexible and cohesive the individual's nervous system is, the better control the individual may have in not allowing the incident to trigger the SNS, and the increased likelihood that the ventral vagal PNS branch may be activated (Champagne, 2011).

Siegal (1999) refers to the flexibility of the nervous system as the window of tolerance, which describes the degree to which individuals can modulate the PNS and SNS systems before the next hierarchical level is activated. This can be closely related to the flexibility of an individual with SOR, as all these variables are interconnected and interdependent (Champagne, 2011). According to Siegel, one's window of tolerance is narrowed in individuals who are chronically stressed, have mental health issues, experienced trauma or have sensory processing difficulties (Siegal, 1999). In these cases, the other systems, other than the ventral vagal system response take preference (Champagne, 2011).

2.4.2 Deficits in self-regulation

Homeostasis and an individual's ability to adaptively cope with vastly changing sensory stimuli is linked to high parasympathetic activity. Conversely, low or disorganised parasympathetic activity has been linked to more of a "narrow range of behavioural adaptation to changing stimuli and predicts stress" [p444] (Degangi et al., 1991; DiPietro & Porges, 1991; Porges, 1995; Porges & Byrne, 1992; Schaaf, Miller, Seawell, & O'Keefe, 2003). Schaaf et al. (2003) reinforce that a compromised parasympathetic nervous system can influence the individual's ability to

> "achieve and maintain a calm, focused state in face of the sensations encountered in daily life and, by inference, affect activity participation" [p447]. (Schaaf et al., 2003).

During stress, an individual will respond to either reduce or eliminate a stressor (Bundy, Lane, & Murray, 2002). When stressed, vagal tone decreases, which means that the nerve is less activated and is, therefore, displaying a more inefficient PNS (Kabat-Zinn, 2013; Schaaf et al., 2003). Since one's ventral vagal system, or PNS, does not take preference when chronically stressed, the ventral vagal system is not the leading force that drives the balance between all the other subsystems. Signs of chronic SNS or dorsal vagal PNS responses result.

Functioning with an inflexible ANS for long periods of time can have severe implications on one's overall health and wellness (Champagne, 2011). During times of stress, cortisol (the stress hormone), elevates and causes hyperarousal, that can be highly deregulating to an individual (DeGangi, 2012). Hyperarousal is

> "characterized by a great deal of muscle tension and the activation of strong emotions, which may vary from terror, fright, or anxiety, shame, or embarrassment to rage and anger"[p312](Kabat-Zinn, 2013).

One of the major causes of dysregulation, is a term used by Kabat-Zinn (2013) as *disattention*, which he describes as a lack of attention to relevant feedback given by the body and mind that is required for harmonious functioning of both. DeGangi (2012) also believes that self-awareness plays an important role in self-regulation. Self-awareness entails reading, differentiating and interpreting the physiological responses and body rhythms. A person with poor self-monitoring, will display "poor self-control, poor self-awareness, restlessness and usually cannot delay gratification".[p10] Poor self-awareness is seen in individuals who are chronically stressed and have poor

modulation (DeGangi, 2012). Kabat-Zinn (2013) reports that *disattention* could lead to disconnection, which in turn leads to dysregulation, disorder and then to disease.

2.4.3 Self-regulation and sensory processing

Difficulties relating to self-regulation could be termed as dysregulation, which is a result of the imbalance or disruption with the body's feedback loops. The dysregulated system does not have dynamic stability and tends to be more disordered (Kabat-Zinn, 2013). DeGangi (2012) reports that problems relating to poor self-regulation include difficulties with self-calming, sleep, eating, concentration, SOR and poor mood regulation. These problems in turn influence an individual's daily functioning and social relationships.

DeGangi (2012) explains that one's self-regulation can influence the individual's ability to tolerate sensory exposure. Therefore individuals with SOR display socially inappropriate self-regulatory mechanisms (Kinnealey, Oliver, & Wilbarger, 1995), and do not have the internal capacity to regulate or modulate their level of arousal (DeGangi, 2012). Individuals with sensory processing difficulties display problems with self-regulation, and they may tend to rely on others to assist with their self-regulation (DeGangi, 2012). Although there is minimal research on self-regulation in adults, very often, self-regulatory difficulties stem from childhood. An individual starts learning self-soothing behaviour during infancy, which is important for one's successful adaptation to one's changing environment (DeGangi, 2012).

Brown and Dunn (2002) describe behaviour strategies individuals use in relation to their thresholds (See Figure 2.1). When relating self-regulatory strategies to SOR, Dunn (1999) believes that due to the dynamic nature of individuals' behavioural responses, an individual may actively avoid aversive stimuli, they may not act to avoid the stimuli (and thus, remain passive), or they may be a combination of both. Individuals using passive strategies, on one end of the continuum, respond in accordance with their neurological threshold; while individuals on the opposite end of the continuum, using active strategies, act to counteract their thresholds in order to achieve homeostasis (Brown & Dunn, 2002).

Brown and Dunn (2002) explain that if a person receives overall high scores in the passive column, then he or she will tend to accept the environment as it is, and respond to external sensory stimuli in accordance with their neurological threshold.

Individuals who solely use passive self-regulatory strategies, benefit from adopting methods which help them take more control of their environment. These individuals may present with unpredictable behaviour, since they are easily influenced by the constantly changing environment. Conversely, if an individual receives higher scores for active strategies, then they are more likely to change their environment, so that their threshold needs are met. Individuals who solely use active strategies, may present with more rigid behaviour, and may find certain environments challenging to accept (Brown & Dunn, 2002).

Champagne (2011) developed a visual representation (Figure 2.7) to explain the relationship between the dynamic nature of ANS responses, sensory processing patterns, and potential effects of trauma and sensory processing-related experiences. Champagne's representation includes the Wilbarger model of ANS arousal levels, Dunn's quadrant model of neurological thresholds, Porge's Polyvagal theory, and Siegel's window of tolerance. This representation in a visual model displays relationships between these concepts, but does not represent the entire complexity of the nervous system (Champagne, 2011).

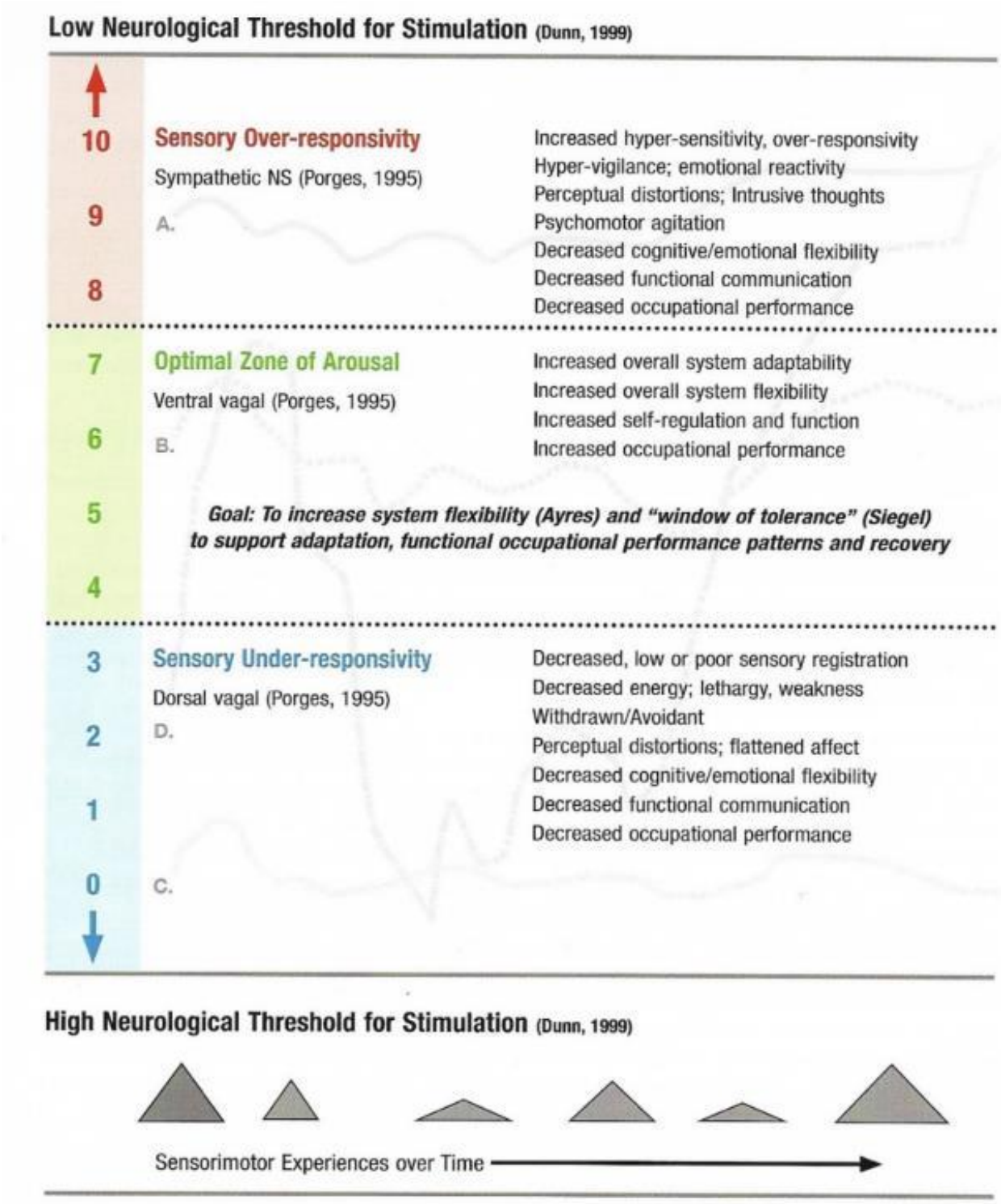


Figure 2.7: Autonomic Nervous System arousal patterns and correlations to sensory modulation, and the Window of Tolerance Scales (Champagne, 2011)

2.5 INTERVENTION

2.5.1 Intervention in treating children with SPD

In line with occupational therapy philosophy, Dunn, Brown, and McGuigan (1994) reinforce the importance of considering *context* when looking at human performance during evaluation and intervention. It is essential to understand that an individual does not function in a vacuum, and that their physical environment, social, cultural and temporal factors all influence their behaviour, in combination with the individual's experiences, and sensorimotor, cognitive and psychosocial skills and abilities.

The Ecology of Human Performance (EHP) framework was developed to consider these important aspects. The EHP model shows how the interplay between the individual and the environment can influence one's behaviour and performance; and that performance cannot be understood without looking at the context (Dunn, Brown, & McGuigan, 1994). When treating children with SPD, it is thus important to look at the child's whole context, as outlined in the EHP framework. Atypical processing of sensory information can have a significant impact on the quality of life of children and for the families, due to their limited participation in various activities, thus influencing school, home and community based activities (Cohn, Miller, & Tickle-Degnen, 2000; Dunn, 2001; Parham & Mailloux, 1995). Gallimore, Weisner, Kaufman, and Bernheimer (1989) reinforce the equal importance of the functioning of the whole family system and each individual family member in ensuring the wellbeing of the family. Therefore, one of the factors included in the child's context, is their interpersonal relationships, primarily with their parents.

Perry's model of stress for families with children with developmental disabilities (Figure 2.5), highlights that treating the child's characteristics associated with their disability alone will not necessarily reduce parental stress, since many other factors also play a role in their stress levels (Perry, 2004). Taking care of children with disabilities requires a high level of "focused attention, cognitive flexibility, and emotional regulation"[p1476](Benn, Akiva, Arel, & Roeser, 2012). Parental stress can also have a negative influence on the child's outcomes (Lee, Lopata, Volker, Nida, Toomey, & al, 2009). Neece, Green, and Baker (2012) believe that addressing parental stress can ultimately reduce behaviour problems in children. Parental stress is particularly prevalent with the population of children with SMP targeted in this research. Children

with SMP have difficulties with self-regulation and have numerous needs that can be complex in nature (Cohn, Miller, & Tickle-Degnen, 2000).

2.5.2 Increased focus on parents

There are numerous approaches that investigate interventions to reduce stress in parents. Hastings and Beck (2004) conducted a selective review of interventions that are designed to reduce stress in parents who have children with intellectual disabilities. Firstly, they came to the conclusion that the implementation of providing a structured intervention programme seemed to have a positive effect on parental stress when comparing those parents with no support, or parents receiving standard services. Secondly, support groups run by parents who are experiencing similar circumstances, could also effectively reduce parental stress (Hastings & Beck, 2004). Case-Smith (2005) found that increased social support programmes for parents, which included supportive community and everyday coping strategies, can lower levels of stress and improve the family's well-being. Lastly, Hastings and Beck (2004) also found that group interventions that focused solely on cognitive behavioural techniques, or that include a number of cognitive behavioural techniques, effectively decreased parental stress and improve mental well-being. They report very few studies investigating other approaches, although numerous researchers have recommended the implementation and evaluation of specific stress reduction intervention programmes for parents (Hastings & Beck, 2004; Kinnealey, Koenig, & Smith, 2011; Neece, Green, & Baker, 2012; Oelofsen & Richardson, 2006). No studies could be found that focused on the intervention model when addressing stress in parents with a sensory modulation focus.

2.5.3 Stress management and sensory modulation-based intervention

There are varying approaches which have been studied that focus on stress reduction. Benson (2000), Chopra (1993) and Kabat-Zinn (2005) have focused on the mind-body connection, meditation and mindfulness when reducing stress with individuals and promoting wellness (Champagne, 2011). Champagne (2011) believes that awareness of the source of stress and assisting an individual change to a more dynamic state of well-being, should be the objective for therapy.

> The "decreased fragmentation and ultimately the increasing flexibility and restoration of the coordination between the spirit-mind-body-world" allows one

> to experience more “feelings of coherence and well-being”[p19] (Champagne, 2011).

In attempting to reduce an individual’s stress levels and to help restore a greater balance of well-being, both sensory modulation and utilisation of the EHP framework can be considered. Sensory modulation interventions are different from standard stress reduction interventions, since they understand and consider the wide range of stress reduction techniques available according to the individual’s sensory needs and preferences. These options range from those activities that are considered to be relaxing to the individual, to those activities that are considered as being alerting, or a combination of the two (Champagne, 2011). These individualised options are reinforced by Dunn, who states that

> “individuals have preferences for certain sensory stimuli, and the same sensory input can be supportive or disruptive to different people, depending on their place along this continuum.”[p10] (Brown & Dunn, 2002).

Sensory processing information provided from each individual will allow professionals to design individualised and effective learning and coping strategies for that individual (Brown & Dunn, 2002).

The EHP framework can also be applied when helping parents manage their stress. The EHP framework utilizes five concepts when applying intervention strategies to an individual: alter, adapt, prevent, create and establish/restore. Firstly, *alter* refers to altering the individuals’ context to which they are functioning, so that they can perform their current skills and abilities. Secondly, *adaptation* involves adapting the individual’s environment or context, as well as the task demands, so performance of the task is supported in the context. Thirdly, *prevent* involves the prevention of a maladaptive behaviour or performance from occurring. Fourthly, *create* refers to the creation of situations that can promote more adaptive or complex participation. And lastly, *establish and restore* refers to the process involved whereby one would establish or remediate an individual’s skills and abilities. This would involve focusing on the parents’ self-regulatory or coping strategies in order to help restore their role as a parent (Dunn, Brown, & McGuigan, 1994).

DeGangi believes that when adults find themselves to be highly stressed, they have no time for self-regulatory activities (DeGangi, 2012). Case-Smith (2005) also indicates that parents often do not have the time and resources to participate in

calming or activating self-regulatory activities. However, insufficient participation in self-regulatory activities could increase parental stress levels, which can then influence their capacity to deal with their child's behaviours and needs (Donenberg & Baker, 1993). Neece, Green, and Baker (2012) believe that stressed parents do not model good self-regulation for their children, which could also lead to more behavioural problems. The lack of performing daily self-regulating activities can result in a dysregulated adult, who would display "high irritability, impulsive actions, withdrawal, explosive or angry reactions, and high stress to overwhelming feelings"[p5] (DeGangi, 2012).

Kinnealey, Oliver, and Wilbarger (1995), found that adults with SOR benefited from self-regulatory strategies in order to cope with their daily stresses. However, these self-regulatory strategies can be demanding from a time, physical and emotional point of view. These demands then impact on the quality, amount, type and choice of the adults' activities performed throughout their day (Kinnealey, Oliver, & Wilbarger, 1995). While there are negative connotations to self-regulatory strategies, Kinnealey, Koenig, and Smith (2011) stressed the importance of developing a lifestyle that promotes self-regulation, which will contribute to forming foundations to one's quality of life. DeGangi (2012) believes that an individual with poor self-regulation needs to learn how to develop their internal control so that they are able to tolerate change, modulate their distress, and understand the impact that their irritability has on relationships with others.

Young and Ensing (1999) acknowledged that there are five stages of recovery, namely:

> overcoming "stuckness, discovering and fostering self-empowerment, learning and self-re-definition, returning to basic functioning and improving quality of life"[p222] (Young & Ensing, 1999).

Empowerment is when the individual takes control and responsibility for their own life. An individual can feel empowered by providing them with knowledge of their own sensory processing, and identifying and implementing individualised self-regulatory coping mechanisms. With self-knowledge about one's sensory processing, they are better able to utilise strategies to form environments or situations that support their sensory preferences (Brown, 2002).

2.6 SUMMARY

Considering all the literature reviewed, it is evident that SOR can have an influence on one's self-regulatory strategies or coping mechanisms, their flexibility of the ANS, and in turn, their stress levels. The EHP framework, the Abidin's PSI-SF model, Perry's model, and Mash and Johnston's Model have stressed the importance of addressing the parent's needs or challenges when treating a child with a disability (or in this study's case, SPD). In addition, it has provided avenues of focus when trying to ultimately achieve more homeostasis within the parents' ANS, in order to help them become less stressed. Due to the bidirectional influence that sensory processing has on one's self-regulation, it is vital to address both realms. Focusing on an individual's skills and abilities, such as their sensory self-regulatory strategies, provides a more individualised focus in stress management. The sensory self-regulatory strategies remain unexplored in current research, especially when focusing on parents who have children with disabilities.

"*Life involves a constant encounter with the sensory world. Increasing awareness of particular responses to that encounter is empowering. It gives the means by which people can seek out or adapt environments that are more supportive of their own particular needs. In doing so, people move from being dominated by their environments and to a position of mastery*"[p125] (Brown, 2002).

CHAPTER 3 METHODOLOGY

3.1 INTRODUCTION

The methodology for this study was completed in two parts based on the three steps described by Fraser and Galinsky (2010), in their development of an intervention programme: (Table 3.1).

Part 1 considered the first two steps in which the programme was developed. The research design incorporated a description of the theory underlying the programme, constructs on which the programme was based and the development of the essential elements of the programme to be implemented.

In Part 2, the third step of implementation and evaluation of the programme was addressed, including the quasi-experimental pre-test post-test research design used, as well as the sampling techniques and sample size. Research procedure in terms of the assessment instruments used, as well as the data collection, and data analysis are presented.

Table 3.1: Steps in programme development by Fraser and Galinsky (2010)

PART 1
Step 1 Problem and programme theories
• Define theory for stress and sensory self-regulation problems in target group - mothers with SOR who have children with SMD
• Identify intervention level, setting, and constructs on which the programme will be based and outcomes
• Develop or confirm assessment of change for stress and sensory self-regulation
Step 2 Specify program structures & processes
• Design an intervention strategy
• Specify essential program elements
PART 2
Step 3 Confirm in efficacy tests
• Implementation with target group
• Assess changes in stress and sensory self-regulation at baseline and after intervention, as well at three month follow up
• Estimate effect sizes and perceptions of efficacy
• Suggest adaptation based on findings, group member values and needs, other issues

PART 1: DEVELOPMENT OF THE STRESS MANAGEMENT PROGRAMME

"Sensory modulation is part of the human condition and is an ongoing process to which we often pay little attention. As we become more aware of the repertoire of activities, habits and rituals we use to self-organise and participate in meaningful life activities, we become much more aware of our unique system tendencies and preferences…. sensory modulation interventions are used for prevention, health and wellness purposes." [p98] *(Champagne, 2011, p. 98)*

3.2 STEP 1: PROBLEM & PROGRAM THEORIES

3.2.1 Theory for stress and sensory self-regulation problems in parents of children with SMD

Research has shown that parents of children with disabilities have higher levels of stress than those parents with children without disabilities (Baker et al., 2003; Emerson, 2003; Hauser-Cram et al., 2001). Lee et al. (2009) also found that maternal stress can pose risk to the mother-child relationship and ultimately the child's outcomes. A highly stressed parent does not have the capacity to model optimal self-regulatory strategies to their children, which could further impact on their child's behaviour (Neece, Green, & Baker, 2012). Modelling good self-regulation is particularly important for children with SMD (Voss, 2014 [accessed 5 January 2017]). Cohn and Cermak (1998) believe that by educating parents about their child's SMD, they can display improved understanding of their child's behaviours. This then results in improved response to their needs and enhancement of more adaptive responses due to better structuring of their environment. Lombard (2007) further elaborated and is of the view that by gaining knowledge on one's own sensory needs, as well as one's child's sensory needs, mothers can become better equipped to optimise their child's learning environment without under- or over- stimulating them. These extremes are considered to have a negative impact on the child's sensory, motor and social development. Although numerous researchers have recommended the implementation and evaluation of specific stress reduction intervention programmes for parents (Hastings & Beck, 2004; Kinnealey, Koenig, & Smith, 2011; Neece, Green, & Baker, 2012; Oelofsen & Richardson, 2006), no studies could be found that focused on the intervention model when addressing stress in parents who present with SMD

themselves. The programme developed for this study had a sensory modulation focus and was aimed at a target group of mothers who have children with SMD.

Based on the literature reviewed, it appears that parent's stress may pose great risk to the child's outcomes, and is therefore a very important component that needs to be considered in the holistic intervention of children with SMD. Due to the lack of published and evaluated stress management programmes for parents who have children with SMD, a sensory modulation-based programme was developed to address parental stress for mothers in this population. The theory on sensory modulation, self-regulation and stress presented in Chapter 2 formed the crux of this programme.

These theoretical concepts were integrated into a framework which was designed to explain the relationship between the parents perceived stress levels and their sensory self-regulatory strategies, and which includes other factors that previous models and frameworks have not considered (Figure 3.1 below). The framework provides a visual representation of the dynamic nature of a family system, when considering the effects of the autonomic nervous system, sensory processing, stress and self-regulatory strategies.

The conceptualisation used in this framework incorporates various neuroscience, psychology and occupational therapy perspectives. Although it is difficult to show the complexity and dynamic presentation that such a system truly exhibits, the framework is intended to represent the relationship between various components within a family system. The framework takes into consideration Porge's Polyvagal Theory (Porges, 2003, 2004), Abidin's parental stress short form questionnaire (Abidin, 1995), the EHP framework (Dunn, Brown, & McGuigan, 1994) and sensory modulation concepts explored by Champagne (2011).

The framework presents the interplay between two people in a family system – namely, the parent and child, which is a dynamic system that is multi-factorial and complex in nature. When treating a child with SMD, the occupational therapist needs to focus on the whole family system or context in which the child is functioning in order to ensure effective intervention (Cohn & Cermak, 1998; Dunn, Brown, & McGuigan, 1994). Both the parent and the child have their own characteristics, namely their sensorimotor, cognitive and psychosocial abilities (Dunn, Brown, & McGuigan, 1994). As the parent's characteristics are more developed than the child's characteristics, the

size of the square allocated to the parent in the framework is larger. This signifies the parent's responsibility to the child which includes protection, teaching and self-regulation. Both the parent and the child have their own context or environment in which they function. It is important to consider an individual's environment separately, as well as together. Due to the unique differences in their sensory processing, they perceive and react to their context and environment differently (Dunn, 2001).

Lane and Miller (2000) have found that one's reactivity to sensory experiences have a direct influence on one's autonomic nervous system. The triangles in the framework represent the ANS, or more specifically, the individual's vagal tone. When vagal tone is low, the sympathetic or dorsal vagal system is in dominance, and when the vagal tone is high, the parasympathetic nervous system is in dominance (Champagne, 2011; Schaaf et al., 2003). One wants to achieve or maintain high vagal tone, as this indicates greater flexibility, adaptability, self-regulation and increased occupational performance (Champagne, 2011).

There is a continuum on the right-hand side of the diagram that represents the parent's level of stress - from a stressed, over-aroused state, to a more regulated state. This can be assessed by, and correlates with, the Total Stress (TS) subscale in the PSI-4-SF. This continuum is represented in the form of a balancing scale. To achieve homeostasis, one needs to have optimal balance between one's stressors and regulators. This correlates with the ANS triangle shown to the right of the balancing scale.

The framework also demonstrates the continuous stressors that are placed on both the parent and the child, in addition to their experience and perception within their own context and environment in which they are functioning. These stressors can remain constant, but are also dynamic. One's perception and experiences of the stressors can change according to the level at which their ANS is functioning. A more resilient and versatile nervous system allows one to efficiently occupy roles and cope with daily life stressors (Champagne, 2011).

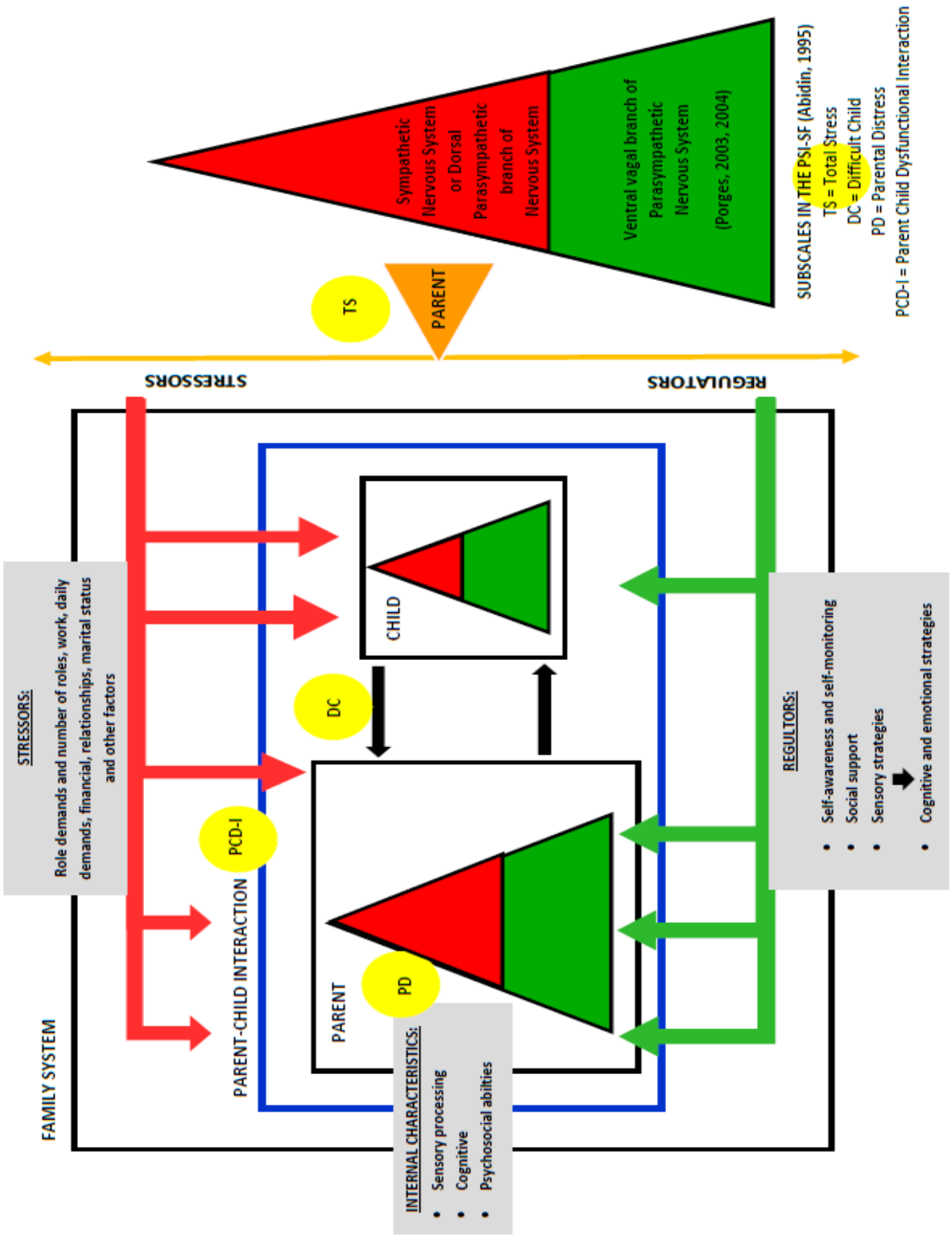


Figure 3.1: Conceptual framework illustrating the relationship between the parents' perceived stress levels, their sensory self-regulatory strategies and the interaction with their child

For the parent, the stressors can include the following: role demands and number of roles, daily demands, work, relationships, financial, marital status and other factors. The parent has a direct effect on the child, and the child has a direct effect on the parent. The effects are demonstrated with the arrows and are dynamic in nature. The effect could either be positive or negative in either direction. A stressed parent could have a negative effect on a child (Lee et al., 2009), due to their limited capacity to attend to and read their child's sensory needs. The effect that the child has on the parent can be assessed by, and correlates to, the Difficult Child (DC) subscale in the PSI-4-SF. The parent's ANS triangle can be assessed by and correlates to the Parental Distress (PD) subscale in the PSI-4-SF. The Parent Child Dysfunctional Interaction (PCD-I) subscale in the PSI-4-SF is indicated in the box that surrounds both the child and the parent which indicates the perceptions and experiences related to the interaction between the parent and the child.

The most important component of the framework are the regulators, which are represented as green arrows pointing upwards, displaying the support that it provides to an individual. The forces of these regulators are also dynamic and change depending on the individual's ANS functioning or stress levels. For example, an individual functioning in a more parasympathetic state will display improved self-regulatory strategies (Champagne, 2011). Key regulators in the framework include the following: social support, self-awareness and self-monitoring, sensory strategies, as well as cognitive and emotional strategies. An important aspect of the regulatory strategies, is that one needs to make use of sensory strategies first, before one can utilise emotional or cognitive strategies in an effort to self-regulate.

All self-regulatory coping strategies that have been reviewed in literature revolve around cognitive or emotional focused strategies. However, the very crux and foundation to one's cognitive and emotional thinking is one's sensory processing. Each individual displays a different neurological threshold to various sensations, which influence their mood, temperament, organisation and cognitive mechanisms (such as attention, memory and problem solving) (Dunn, 2001). For an individual who is stressed and is functioning in a sympathetic state, their cognitive and emotional functioning will be compromised (Champagne, 2011). In order to reach a more regulated state, it thus seems apt to focus on their sensory processing first, before one can look at various cognitive and emotional self-regulatory strategies. This is

reinforced by Dunn (2001), who states that interventions can become more effective with insight into one's sensory processing.

The various principles of the EHP model could be applied to different sections of the framework. The barriers to the mothers' performance are their heightened stress levels and ineffective self-regulatory strategies. Intervention thus needs to be designed to improve on these two areas.

The first principle, *establish and restore*, would be used to focus more on the regulator aspect of the model, in order to help regain improved homeostasis within the individuals' overall system. This is done through healthy habit formation, breathing exercises and performing sensory activities in their sensory diet.

Secondly, *adapt*, would be used in the way one can adapt the context to which the mothers' function in, in order to promote better participation and utilization of their skills and abilities. This can be done by creating more congruent sensory spaces within a particular environment (such as their home or workspace), in order to promote improved self-regulation and decrease stress. For example, sensory ergonomics could be considered in their work environment, whereby a mother could change the placement of their desk so that it's facing a window versus facing their co-workers in the office, taking into consideration their visual sensitivities. Sensory ergonomics is an act whereby one changes the individuals surrounding environment through the addition or removal of sensory stimuli in order to meet their sensory needs (Lombard, 2016 [accessed 3 February 2017]).

Thirdly, *alter* was also considered whereby the intervention promoted social interaction through the use of the group session. Adding a social context to which the mothers function in, helps promote a feeling of community. *Alter and adapt* were also used when analysing the mothers level of arousal graphs throughout their day. When their level of arousal increased, the researcher and mother would investigate ways in which activities prior to the increase in level of arousal can be adapted or altered in such a way to minimize such an increase. Adapting the way a mother manages their child's difficult behaviour was also another way to decrease their stress.

Lastly, *prevent* was also considered in the EHP model, whereby the mothers performed sensory self-regulatory activities throughout their day in order to prevent high increases in their level of arousal. Anticipation before a particular stressful event was considered, whereby the mothers would anticipate an increase in level of arousal

and thus perform regulatory activities prior to the event in order to minimize the effects of the stressful event to their bodies (Dunn, Brown, & McGuigan, 1994).

3.2.2 Intervention level and setting

The long term outcome of the programme was aimed at the parents of children receiving therapy in the private sector for SMD, becoming more regulated themselves. Thus they may become more attuned to their child's reactions, so they will be able to model good self-regulation to their child. The programme was therefore developed with the principal aim of addressing stress reduction on a secondary level with parents who already demonstrated high stress levels, as well as SOR on their sensory profiles.

The secondary aim was to ultimately improve the outcomes for the children of the parents who receive the intervention. The intervention was designed to provide parents with greater insight into their own sensory profiles and self-regulatory strategies, and to provide them with greater understanding of their child's sensory needs.

The short term outcome for the programme was for the parents to have reduced stress and develop the ability to react more skilfully to situations; and to respond with greater skill and calmness when confronted with challenging situations.

3.2.3 Constructs on which the programme was based

3.2.3.1 Sensory self-regulation

A person with SMD, specifically SOR, may display poor self-regulatory strategies (Bundy, Lane, & Murray, 2002; Kinnealey, Oliver, & Wilbarger, 1995). The stress management intervention programme developed for this study, therefore focused on sensory self-regulatory strategies as this appeared to be a more logical and better first-step in helping the individual reach a more regulated and parasympathetic state of functioning. Kinnealey, Oliver, and Wilbarger (1995) and Dunn (2001) believe that when people understood their sensory profiles, they could monitor their exposure to stress-provoking sensory inputs and thus display an improved ability to manage their life and function productively. Champagne (2011) further reinforces this by stating that improving an individual's awareness of their sensory preferences can result in them learning more about the sources of their frustrations, promoting different avenues to function and change these preferences. She believes that this will ultimately lead to

improved functional performance (Champagne, 2011, p. 47). Dunn (2001) reinforces Champagne's notions by stating that knowledge about their sensory systems can provide the individual with ways to manage their daily lives, in that it enables individuals to either decrease or increase their exposure to various sensory inputs so that they can live a more satisfying life. This is particularly prevalent in individuals who have SOR.

Sensory over-responsiveness is "brainstem based", referring to the intensive reactions that one has to various sensory sensations (Heller, 2002). Therefore, an individual with SOR would more than likely not benefit from cognitive behaviour therapy. The SOR needs to be treated first, so that higher cognitive functioning can occur (Abernethy, 2010). The importance of sensory self-regulation highlights the critical role that occupational therapists play in the treatment of SOR, due to the development of the SI theory in the profession and thus their understanding of sensory processing and the influence that senses have on the body and the role on everyday activities, and visa versa. In addition, occupational therapists have a unique understanding of occupational performance and the effects that this has on one's overall function. Through activity analysis, occupational therapists can optimise activity participation, in order to support the individuals motor, sensory an behavioural needs. In addition, they can provide adaptive strategies to facilitate full participation in daily activities.

3.2.3.2 Breathwork

Over many years, great healers have found the impact of breathing on people, when looking at their physical, mental and spiritual well-being (Brown & Gerbarg, 2012). Various studies have shown:

> "that by changing patterns of breathing it is possible to restore balance to stress response systems, calm an agitated mind, relieve symptoms relating to anxiety and post-traumatic stress disorder (PTSD), improve physical health and endurance, elevate performance, and enhance relationships" [p. 2] (Brown & Gerbarg, 2012, p. 2).

The vagus nerve (relating to the parasympathetic nervous system) plays a very important role in how an individual copes with stress. When a person is stressed, they display a decrease in vagal tone. When an individual is displaying greater resiliency and calmness, greater recovery from stress and more positive emotions, their vagal tone is high (Kabat-Zinn, 2013). Stress can threaten one's homeostasis, which triggers

the sympathetic system (Kabat-Zinn, 2013, p. 313; Varvogli & Darviri, 2011). Various research has revealed that slow deep breathing helps balance the autonomic nervous system by reducing sympathetic activity in the body and increasing parasympathetic activity or increasing vagal tone (Bhargava, Gogate, & Mascarenhas, 1988; Jerath, Edry, Barnes, & Jerath, 2006; Pal, Velkumary, & Madanmohan, 2004; Varvogli & Darviri, 2011).

3.2.3.3 Social Support

Case-Smith (2005) found that increased social support programmes for parents can lower levels of stress. Thus, inclusion of social support in the form of a group session was considered vital in helping reduce the parents stress levels. Social support is particularly relevant in this programme as people with SOR display less use of community resources and poorer social skills (Pfeiffer, Kinnealey, Reed, & Herzberg, 2005). Kinnealey, Koenig, and Smith (2011) believes that perceived social support can have an important influence for a person with SOR, and thus effective intervention should focus on the development and maintenance of social support networks.

Numerous sociologists believe that social support can reduce the negative effects of stressful events or life situations. By mobilising various coping resources through the use of social support, one can better cope with one's stressful situation (Brownell & Shumaker, 1984). The social engagement system has powerful effects on one's health and happiness and can be inherently self-calming. It acts as protection when one's body is dominated by the sympathetic nervous system (Levine, 2010, p. 94). Schwerdtfeger and Friedrich-Mai (2009) found evidence that social engagement is associated with elevated vagal tone, protecting their depressive participants from parasympathetic withdrawal. As evidence has demonstrated that social engagement and social support is important for improving coping mechanisms, it is important to bring this into consideration when developing the programme, particularly for people with SOR.

3.2.4 Assessment of change for stress and sensory self-regulation

In order to optimise the mother's benefit from the programme, various assessment methodologies were utilised. Please refer to Chapter 4 for scoring, validity and reliability studies for the assessments and questionnaires used.

3.2.4.1 Stress

Stress in parents is usually assessed using self-report questionnaires, with a Likert scale used to indicate the level of stress. The scales usually request some information in relation both the parent and child's behaviour. The assessment developed by Abidin (1995), the Parenting Stress Index 4 Short Form (PSI-SF) was found to be suitable for assessing stress for this intervention as it identifies both parent and family characteristics that affect normal functioning in children who present with possible behavioural and emotional problems. The PSI-4-SF also identifies dysfunctional parenting and behaviour problems and can be used to assess the effects of stress management intervention.

3.2.4.2 Sensory over-responsiveness

Sensory modulation is assessed by self-report scales. In the case of Dunn's Sensory profile, the adults are asked to rate their sensory tolerances according to various sensory systems, using a Likert scale. The participants reported on their response to various sensory experiences by the frequency of their response, such as almost never (approximately 5% or less of the time), seldom (approximately 25% of the time), occasionally (approximately 50% of the time), frequently (approximately 75% of the time) and almost always (approximately 95% or more of the time).

Dunn's Adolescent/Adult Sensory Profile is particularly suitable since the items in the questionnaire are relevant to everyday life events, which makes it understandable and familiar to the individual who is completing the questionnaire. This questionnaire was particularly relevant for assessment purposes, since it provides its results according to Dunn's model of sensory processing (the quadrants). It thus provides the researcher with an understanding of the mother's sensory processing according to their neurological thresholds (over-responsive, under-responsive or typical) and behavioural responses continua, which provides a framework for the intervention (Brown & Dunn, 2002).

3.2.4.3 Sensory self-regulation

There were no questionnaires found that could assess sensory self-regulatory strategies. A questionnaire was consequently developed to evaluate the mother's sensory self-regulatory strategies pre and post intervention, acknowledging that each individual makes use of their own unique set of sensory self-regulatory strategies, in

addition to one's cognitive and emotional strategies, in order to self-regulate. The questionnaire is a self-report measure that provides subjective views on the mother's current self-awareness and connectedness to their bodies, their ability to monitor their stress levels and to react accordingly, their knowledge of their self-regulatory strategies, their current use and execution of sensory self-regulatory activities, the effectiveness of their strategies, as well as their willingness to improve on their strategies in order to achieve greater equilibrium.

3.3 STEP 2: SPECIFY PROGRAM STRUCTURES & PROCESSES

3.3.1 Target Audience

At this stage the programme was designed to include mothers only, with the aim of empowering them to perform more optimal self-regulatory strategies during their day to calm themselves and to allow them to provide opportunities for themselves to implement these strategies.

3.3.2 Facilitator

The intervention agent (or person administering the programme) should be a person who is an occupational therapist and is sensory integration certified. The therapist must have an in-depth understanding of sensory processing and the effects that this has on one's occupations and overall well-being.

3.3.3 Intervention strategy

The stress management programme used in this research was mainly based on the guidelines outlined by the Sensory Modulation Programme (SMP) constructed by an occupational therapist, Champagne (2011).

Champagne's SMP provides various approaches or tools to help improve or maintain one's participation in meaningful life roles and activities. Her programme focuses on healthy habit formation through the implementation of a variety of sensory modulation activities and to help achieve more meaningful participation in various life roles and activities. These include the formation and use of a "sensory diet", creation of "personalised sensory kits" and the establishment of "meaningful spaces" in one's environment, such as the home (Champagne, 2011). Champagne (2011) identified numerous potential benefits when using these sensory modulation strategies,

including: firstly, an improved ability to nurture oneself, rest and sleep; secondly, increased self-awareness, resilience, self-esteem and body image; thirdly increased ability to partake in various activities of daily living (such as self-care, social and other meaningful life roles and social activities), and lastly, an improved ability to deal with triggers. (Champagne, 2011, p. 99). In addition to using Champagne's various strategies, other principles were also used based on Lombard's ideas on Sensory Intelligence (2007). Lombard's concepts include the following: sensory profiling; plotting one's Sensory Tree™; goodness of fit; coping with sensory overload, stress and shutdown; and self-regulation (Lombard, 2007).

3.3.4 Essential programme elements

3.3.4.1 The sensory modulation-based approach

The sensory modulation-based approach was used in the stress management programme, based on the above-mentioned constructs. The programme was designed to include the principles of insight or self-awareness and sensory-based activities. Research has demonstrated the positive effects that these two sensory modulation principles can have on reducing symptoms relating to SOR (Kinnealey, Oliver, & Wilbarger, 1995).

The implementation of these principles took the participants' individual sensory profiles into account, since sensory processing is so individualistic and contributes to our unique preferences and choices (Dunn, 2001). Due to these differences, the programme was largely based on individual sessions to accommodate the individual's sensory profile. A Sensory Matrix (developed by Lombard) was used to gain information with regards to each sensory system, that the adult sensory profile could not provide (Lombard, 2015). This provided information on each sensory system according to their neurological threshold, so that each individual's intervention was unique to their sensory processing.

In addition to self-awareness and sensory-based activities, based on stress research, the programme also required exploration of the effects that various stress interventions had on the body or autonomic nervous system. This includes the value of breathwork strategies to activate the parasympathetic nervous system. Lastly; the benefit of social support to further develop a sense of belonging was considered.

3.3.4.2 Insight or self-awareness

The process of self-awareness and insight makes use of a client-centred approach, where the individual plays an active role in realising and identifying various factors that impact on their ability to function more optimally, to ultimately reduce their stress levels. To help promote self-awareness, the researcher utilised Lombard's concept of Sensory Intelligence©, which involves understanding how one perceives sensory information from the environment.

Promoting self-awareness involved the following activities: firstly, understanding the sensory systems through sensory profiling; secondly, gaining insight into arousal levels in a typical day; and lastly, exploring various self-regulatory strategies. The PSI-SF, Sensory Profile, Sensory Matrix and Self-regulatory questionnaires were used at the beginning of the programme in order to identify sensory preferences, tendencies and patterns, as well as current self-regulatory strategies and stress levels. This provided the researcher with background information to facilitate the participants' self-awareness. Sensory profiling and analysis using the Sensory Tree™ was used to promote understanding. The Sensory Tree™ was designed to provide an easy understanding of their sensory profile and how this impacts on behaviours, relationships and everyday activities (Lombard, 2015).

Figure 3.2 provides an example of a sensory tree that was explored in the programme. Once the Sensory Tree™ was explored, arousal levels in a typical day were plotted. This assisted in further reading the body's arousal levels and in increasing self-awareness. This also provided an opportunity to reflect on the fluctuations of arousal levels throughout the day. Problem identification was also completed in conjunction with this, whereby the sensory events in the day that resulted in a sympathetic nervous system response or an increase in arousal levels were identified. This was correlated to the sensory profiles, which assisted in identifying various sensory situations which trigger increase in stress levels.

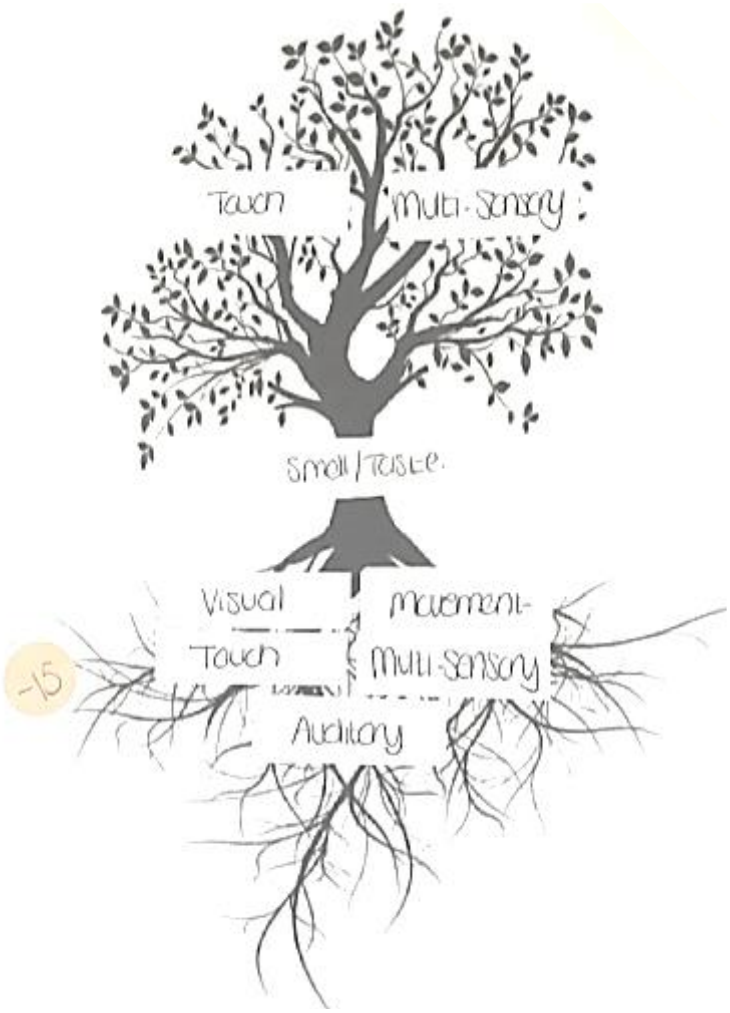


Figure 3.2: A participants' Sensory Tree ™, which was used to enhance self-awareness

Following the plotting of the arousal levels and identifying sensory events which result in increased stress, brainstorming and problem solving was planned to guide the reduction or alleviation in the effects of the sensory events where possible. Various self-regulatory strategies were established through the process of problem solving and through the exploration of the Sensory Tree™ and this was used to help facilitate exploring what changes or additions can be made with regards to self-regulatory strategies. The Sensory Tree™ assisted in focusing on the important self-regulatory strategies that would have the most profound impact in helping manage stress levels. This was coupled with applying Lombard's principle of anticipation, planning and preparation which assist with exploration of sensory strategies.

3.3.4.3 Sensory-Based Activities

Sensory-based activities were used as part of the stress management programme to assist in helping reduce and manage stress levels. According to Champagne (2011), sensory modulation intervention is very different from other forms of stress relaxation activities. Sensory modulation considers and understands individual preferences, in order to select appropriate activities that will optimally relax the individual.

Engel-Yeger and Dunn (2011) believe that

> "by using sensory-based strategies as part of management and coping, professionals can enhance the client's positive experiences and positive affective reactions, leading to better participation in life experiences, elevated heath status and wellbeing" [p 463].

The various types of sensory activities that were calming and alerting were explored. Pertinent sensory activities were collaboratively identified that would be the most efficient sensory calming or self-regulating activities. A *sensory diet* was then created over a few sessions, to implement sensory strategies. Wilbarger (1984) developed the term *sensory diet*, to describe an individualised daily plan of meaningful sensory activities to help improve their ability to function more optimally. The *sensory diet* was carefully designed to comply with the participant's lifestyle and daily routine, ensuring that the activities were meaningful and purposeful, and to promote compliance. Regular feedbacks and reanalysis was done over several sessions to ensure the effectiveness of these *sensory diet* activities.

Lombard (2015) states that "sensory defensive individuals cope best when they can anticipate and plan their day and activities", which will help the individual cope and manage their day and transitions better. When exploring various sensory events that could trigger a sympathetic response in the participants, Lombard's principle of anticipation, planning and preparation were utilised by plotting a typical day arousal graph and exploring associations to various sensory events. When focusing on an arousal stimulating sensory event, three stages were considered: the time before the event, the actual event itself and then the time afterwards. Various sensory strategies were explored during each of these stages to help reduce the stimulating effects of the sensory event.

3.3.4.4 Breathwork

Various breathing techniques (specifically diaphragmatic breathing) were explored and practiced during the sessions. Regular breathing practice was recommended and included in the *sensory diet*. Once the *sensory diets* had been practiced and implemented at home, a group session was provided to demonstrated the use of this technique and to provide an opportunity for social support.

3.3.4.5 Social support

The participants attended one group session, enabling them to share their experiences or stressors, and provide feedback on what had worked with regards to their self-regulatory mechanisms since the initiation of the programme. A therapeutic activity was used in the group session to help stimulate conversation and provide the participants with a calming experience. This involved creating a mandala. The creation of a mandala was inspired by Buchalter (2013), who is a clinical therapist and certified art therapist, licensed professional counsellor and certified group psychotherapist.

Guidance for the activity was gleaned from the various therapeutic techniques and methods outlined in her book, *Mandala symbolism and techniques*. In creating a mandala, one's individuality is emphasised and the fact that there are no limitations and no right or wrong mandala. Mandala's help encourage more mindfulness, which ultimately improves one's self-esteem, self-awareness and self-acceptance (Buchalter, 2013). Oil pastels, watercolour pencils and koki pens were used to create their mandala, as these provided an element of resistance when drawing, which also has a calming effect.

3.3.5 Stress management programme outline

The outline of the stress management programme using the principles of self-awareness, sensory-based activities, breathwork and social support is presented in Appendix A. The stress management programme extended over a period of 12 weeks, and consisted of five individual sessions and one group session. All sessions were approximately 90 minutes long and were held in private therapy rooms in Lonehill.

PART 2: IMPLEMENTATION AND EVALUATION OF THE STRESS MANAGEMENT PROGRAMME

3.4 RESEARCH DESIGN

This study made use of a quasi-experimental pre-test/post-test design, in order to evaluate the effectiveness of a stress management programme (Harris, McGregor, Perencevich, Furuno, Zhu, Peterson, & Finkelstein, 2006; Trochim, 2006). The main independent variable is the stress levels of mothers who have children with sensory processing difficulties. This design was quasi-experimental as the main independent variable used in this study (mother stress) was manipulated through the implementation of the stress management programme. This was manipulated in the absence of a control group. Since no control group was used, the design used was a one-group pre-test post-test design (Harris et al., 2006). Self-reported research instruments were used prior to the programme, immediately after the programme and three months after the programme was completed, in order to analyse the effectiveness of the stress management programme. In these type of designs, the pre-test research instrument acts as the "control", since it provides the researcher with information on the participants with no intervention received (Harris et al., 2006).

Quasi-experimental designs are also commonly used in circumstances when it is not logically or ethically possible to make use of a randomised control, such as the case in this study (Harris et al., 2006), due to the small sample size. While randomisation can benefit a study since it creates a balance between all variables from the intervention and control group, it does not optimally achieve this balance with smaller sample sizes. Therefore, in order to optimally evaluate an intervention, other designs and other methods of analyses would need to be explored and used (Harris et al., 2006).

3.5 SAMPLE POPULATION

The population for this study were mothers of children receiving occupational therapy for sensory processing deficits. The mothers selected for the study were those who presented with sensory over-responsiveness (SOR) themselves, as well as high stress levels. Mothers with SOR was only considered for this study (and mothers with sensory under-responsiveness were excluded), in order to restrict the study to a homogeneous sample population and to control variables investigated. The

researcher established patterns or trends when analysing the relationship between stress and self-regulation to one type of responsivity to sensory input. This enabled the researcher to gain a view of the findings and conclusions for one type of sensory dysfunction and added rigor to the study.

The sample for the study were selected by convenience from mothers whose children attend various established paediatric private practices in the northern and southern suburbs of Gauteng. Permission was requested from these practices for the recruitment of participants (Appendix B). The practices were provided with the following inclusion and exclusion criteria in order to guide the selection of suitable participants.

3.5.1 Inclusion criteria:

- Mothers who have a child or children presenting with SMD. Their children will have to be attending occupational therapy with a Sensory Integration (SI) certified therapist.
- The mothers who agree to attend the full 12-week stress management programme, and agree to comply with the various sensory diets and activities recommended during the programme.
- Mothers who are displaying SOR in one of their sensory systems, and “more than most people” or “much more than most people” for the sensory sensitivity or sensation avoiding quadrants on the Adult Sensory Profile.

3.5.2 Exclusion criteria:

- Mothers who have been formally diagnosed as having post-traumatic stress disorder or have recently (within the last year), been involved in a traumatic event.
- Mothers who are participating in another psychological or stress-based programme.
- Mothers who display typical functioning with all sensory systems and all quadrants on the Adult Sensory Profile.

3.5.3 Sample size

The sample size was established through power analysis based on the results of a study on group intervention for children with dyslexia by Multhauf, Buschmann, and Soellner (2016). A change of 10 points (SD 12.37) on the Parenting Stress Index (PSI) (parent

distress scale), a sample size of 15 mothers were required, providing an 80% power to detect a difference in the mother's perceived levels of stress with alpha set at 0.05. Eleven mothers were initially interested and willing to partake in the study. However, five mothers completed the programme as the remaining number of mothers were unable to meet the inclusion criteria and were not able to fully commit to the programme.

3.6 RESEARCH INSTRUMENTS

3.6.1 Assessment of sensory over-responsiveness to confirm inclusion into study

3.6.1.1 Adolescent/Adult Sensory Profile

The adolescent/adult sensory profile (see Appendix C) is a 40 itemed self-report questionnaire that describes the individual's responses to daily sensory experiences. The adolescent/adult sensory profile provides evidence of the impact of an individual's sensory processing on their functional performance (Brown & Dunn, 2002). The results from this questionnaire provided the researcher with information on the individual's sensory processing patterns, which was then used for intervention planning.

Studies performed by Brown, Tollefson, Dunn, Cromwell, and Filion (2000) and by Brown and Dunn (2002), found evidence to support the reliability and validity of the Adult Sensory Profile. According to Brown and Dunn (2002), the alpha coefficient ranged from 0.639 to 0.699 and the standard error of measurement ranged from 3.58 to 4.47 for the sensory processing quadrants (such as low registration, sensory sensitivity, sensory seeking and sensory avoiding). The age group classifications are as follows: adolescent (11:0-17:11 years old), adult (18:0- 64:11 years old) and older adult (65:0 years and older).

The classification system and Dunn's quadrants model are used to interpret data received from the sensory profile. Dunn's model displays the interaction between neurological thresholds and behavioural responses. An individual with SMD can either under-respond (due to a high threshold) or over-respond (due to a low threshold) to sensory input (Bundy, Lane, & Murray, 2002). In addition, an individual can display passive to active regulatory strategies, as represented on the continua (Brown & Dunn, 2002). An individual's response to sensory input or their sensory processing presentation could be positioned anywhere on Dunn's model (Dunn, 1997). This is further described in chapter 2.

3.6.2 Use of Assessments used pre- and post- intervention to evaluate effectiveness of the stress management programme

The assessments used at baseline and post-intervention included the PSI-4-SF and a sensory self-regulatory questionnaire. The PSI-4-SF was also used for the three month follow up assessment. This allowed the researcher to evaluate changes in the mothers perceived stress levels and self-regulatory strategies following the programme and three months after the intervention.

3.6.2.1 Parenting Stress Index (Short Form) (4th edition)

The short form of the PSI (4th edition) was used to evaluate the parent's perceived stress levels. The PSI-SF (see Appendix D) is a scaled subjective 36-itemed questionnaire, which looks at the parents' opinions on various statements, such as strongly agree, agree, not unsure, disagree or strongly disagree.

The PSI-SF yields a total stress score of the overall level of parenting stress, as well as other scores including: parental distress, parent-child dysfunctional interaction and difficult child. T-scores and percentiles are used to interpret the PSI-SF. Scores ranging between 16th and 84th percentile is considered as the normal range. Scores between the 85th and 89th percentile is considered to be high, and scores in the 90th percentile and above are considered to be clinically significant.

The reliability and validity of the PSI-SF is detailed in the PSI manual, which indicates a 0.91 alpha coefficient for the total stress score and a 0.84 test-retest reliability (Abidin, 1995).

3.6.2.2 Sensory self-regulatory questionnaire

The sensory self-regulatory questionnaire (Appendix E) is 27-itemed self-report questionnaire that was developed by the researcher for the purpose of this study. This was developed to assist with intervention planning and to assess changes made in the mothers' self-regulatory strategies. The questionnaire is divided into two sections.

The first section (10 Likert-scale items) looks at the mothers' opinions on various statements, such as strongly agree, agree, not unsure, disagree or strongly disagree. This section looked at the mothers' self-awareness when relating this to their self-regulatory mechanisms (for example, how often they perform self-regulatory activities). It also includes their opinions on their current self-calming strategies, if they

have self-calming mechanisms, and if they perform various self-calming activities in reaction to how they are feeling.

The second section contains specific questions that the parents are required to answer. These questions included the type of activities they use to self-regulate and the frequency of these activities. Also included are various questions exploring their habits, such as smoking, alcohol consumption, caffeine intake and their eating habits. The questionnaire concluded with a few yes/no questions and three sliding rating scales that looked at the mothers' feelings of connectedness to their body, rating of their self-calming strategies as a whole and their motivation level to learn new strategies. The information obtained from the sensory self-regulatory questionnaire was analysed descriptively.

3.6.2.2.1 Pilot study for content analysis of the sensory self-regulatory questionnaire

The sensory self-regulatory questionnaire was piloted to confirm content validity. The purpose of this pilot study was to measure the relevance, accuracy, comprehensibility and representativeness of the content in the questionnaire, related to the assessment of sensory self-regulation.

The content validity index (CVI), developed by Waltz and Bausell (1983) was used to determine the content validity of the Sensory self-regulatory questionnaire. The CVI used four criteria to measure the content validity - namely relevance, clarity, simplicity and ambiguity. For each of these four categories, a 4-point scale was used (Table 3.2) (Yaghmale, 2003).

Table 3.2: Content Validity Index categories and scale

Relevance	Clarity	Simplicity	Ambiguity
1= Not relevant	1= Not clear	1= Not simple	1= Doubtful
2 = Item needs some revision	2 = Item needs some revision	2 = Item needs some revision	2 = Item needs some revision
3= Relevant but needs minor revision	3= Relevant but needs minor revision	3= Relevant but needs minor revision	3= Relevant but needs minor revision
4= Very relevant	4= Very clear	4= Very simple	4= Meaning is clear

The questionnaire was sent via e-mail to three subject matter experts (SME), who were chosen on the basis of their sound understanding of sensory self-regulation, which the questionnaire was intended to evaluate.

Inclusion criteria for subject matter experts are as follows:

- experienced occupational therapists who have practiced for least 5 years (Schell & Schell, 2008) and,
- qualified sensory integration certified occupational therapists.

The subject matter experts were asked to score each item according to the CVI criteria and comment on the content. On return of the questionnaires, the CVI scores were collated. Items that had a CVI over 0.75 were retained in the questionnaire although some were modified on the basis of the therapists' opinions.

It was found that all the items received a score over 0.75, but the SMEs recommended that some be discarded as they were too similar to other questions in the questionnaire. In total, 20 items were amended, based on the CVI the opinions of the SMEs. The initial version of the Sensory self-regulatory questionnaire, the details of the changes and scoring relating to the content of the questionnaire are presented in Appendix F. See Appendix E for the final version of the sensory self-regulatory questionnaire

3.7 RESEARCH PROCEDURE

Once ethical clearance had been obtained from the Human Research Ethics Committee (HREC) at the University of the Witwatersrand (M150852) (Appendix G), occupational therapy practices were approached to recruit participants for the study. Although it was originally intended that an alternate group design would be used with one group of mothers acting as a control while the other group received the intervention, the small number of participants made this research design unrealistic. The research was consequently changed to a pre-test post-test design.

The researcher compiled a presentation detailing all the aspects of the study and arranged to present this to various occupational therapists at their practices. Where this was not possible, an email was sent to the occupational therapists detailing all the relevant information regarding the study. It was then the occupational therapists' responsibility to approach mothers who they felt met the inclusion criteria and who they thought would benefit from the stress management programme. Once the

therapists identified a potentially participant, they provided the identified mothers with the study's information sheet in order to invite them to take part in the study (see Appendix H). The mothers were required to contact the researcher directly should they be interested.

There were 11 mothers who were initially interested in participating in the study, but only seven of these consented to participate in the programme. On contact with the interested mothers, the researcher explained the purpose of the study, as well as the inclusion and exclusion criteria. The consenting mothers were then requested to complete the consent form and sensory profile, which was sent to them via email. All questionnaires were loaded onto RedCap so that all questionnaires could be completed electronically. RedCap also provided a platform for data to be captured and analysed.

The specific research measures used according to allocated times in the research timespan is presented in Table 3.3. The participants completed pre-test baseline questionnaires prior to the intervention, following which they received the 12-week intervention. Following the intervention, the participants completed the post-test questionnaires, including an evaluation questionnaire (see Appendix I). The evaluation questionnaire was also completed on RedCap. The mothers then received no intervention for a period of 3 months, until they completed the PSI-4-SF at follow up.

Table 3.3: Design of non- experimental study using pre-test/post-test design

	Pre-test Baseline	**Intervention**	**Post- test After intervention**	**No Intervention**	**Follow up / post-test**
All participants	• PSI-4-SF • Sensory Profile • Self-regulatory Questionnaire • Demographic Questionnaire (See Appendix J)	12-week Stress management programme	• PSI-4-SF • Self-regulatory Questionnaire • Evaluation Questionnaire	3 months	PSI-4-SF

Once the researcher received the completed consent forms and sensory profile, the results were analysed in order to determine if they met the inclusion criteria. If the mother was a suitable prospective participant, the researcher arranged to meet with the mother for their first session. The mothers all started the programme in the same week. The stress management programme extended over a period of 12 weeks and

consisted of six sessions in total - five individual sessions and one group session. Five mothers attended the whole programme and met the inclusion criteria.

3.7.1 Individual sessions

Although the programme was individualised towards the mothers' sensory needs, all the mothers received the same amount of sessions, which followed the same basic structure, as shown in Appendix A.

The first session with all the mothers followed the same structure, whereby the researcher shared more details about the programme and discussed the researcher's goals and expectations. The mothers were required to establish their own goals and to share their main concerns and stress triggers. They were also provided with time to complete the remainder of the questionnaires, namely the Sensory Matrix, the PSI-4-SF and the sensory self-regulatory questionnaire. The programme was then individualised based on the results from the Sensory Matrix, Sensory Profile and sensory self-regulatory questionnaire. Following the first session, the mothers met for three more individual sessions (scattered over a period of six weeks) before the group session, which focused on breathwork, their sensory profiles, sensory diets and increasing their self-awareness, as well as aspects involving their arousal graphs (for example, anticipating stressful events or triggers). Thereafter, the mothers met for their group session, which is detailed below. Following the group session, the mothers had a three week break, which provided them with time to implement their sensory diet and apply various sensory principles and sensory self-regulatory strategies. At week twelve, the mothers attended their final individual session, which entailed the following: relooking at their goals, reflection of the programme and completion of the questionnaires (the PSI-4-SF and sensory self-regulatory questionnaire).

3.7.2 Group session

The mothers all attended the group session in week eight. This date was established by the researcher and was set on a date that suited all mothers.

A "WhatsApp" social media support group was formed after the group session, to create a platform for communication between the participants and to further reinforce social support between participants. The purpose was to increase the emotional support and to create feelings of belonging. Since the group members were

experiencing similar circumstances, they used this group as a means to express their frustrations, offer support to each other and share positive words of encouragement.

Figure 3.3 display participation in the group setting and the remaining figures (Figure 3.4) display the Mandalas completed in the group. At the end of the group session, the participants were required to identify the top five things that they were going to do over the next month in order to self-regulate. A bracelet was given to each of the mothers to act as this reminder (see Figure 3.5 below).



Figure 3.3: Participating in the group session



Figure 3.4: Participants Mandalas



Figure 3.5: Bracelet given to act as a visual reminder

3.8 ETHICAL CONSIDERATIONS

General ethical considerations were considered throughout the research study, which included the mother's autonomy, justice and that they received maximum benefit from the study. Due to the participants significantly high levels of stress, careful consideration was given to the requirements made of their time and energy, so as not to exacerbate existing stress levels. The amount of contact time needed by the researcher was minimised as far as possible within the context of the mother's time and availability constraints, whilst maximising their potential benefit which they could derive from the programme and to ensure its effectiveness in reducing their overall stress levels. A significant component of the design of the research study revolved around ensuring that all participants benefited from the research, and that they all took part in the stress management programme. Counselling was also made available to the mothers on request.

Ethical clearance for the study was obtained from HREC at the University of the Witwatersrand (M150852) (Appendix G). Permission was requested from various occupational therapy practices for the recruitment of participants (Appendix B). Participants were invited and provided with the opportunity to voluntarily commit to participating in the stress management programme. Information sheets and informed consent forms were provided (Appendix H). This reminded the mothers that they were allowed to withdraw from the study at any time, that there were no risks involved in the study and that confidentiality was ensured throughout the study. The researchers' goals and a detailed overview of the programme was also explained to the participants.

Confidentiality could not be ensured throughout the study due to the nature of the group work involved but the names of the participants on all questionnaires used for analysis were omitted. The participants were allocated a code, which was used as their form of identification throughout the study. Any forms of treatment notes made during the study were identified using the participant's code. A list of codes and names was used to link the mothers' names to the questionnaires used, which was locked in a secure place.

In order to help eliminate bias, the researcher made use of RedCap to score the self-report measures. Since the evaluative measures used in the study are self-report, the investigator was not able to manipulate or control the data recorded. The participants

of the study completed the self-report measures independently and thus the researcher had no influence over the results of the questionnaire or evaluative measures. Feedback on the results of the study has been made available to the participants on request.

3.9 DATA ANALYSIS

RedCap and Statistica v 12 were used for capturing and analysing the data received from the questionnaires. For demographic data, descriptive analysis was done using frequency distribution, medians and percentiles.

The scores from the PSI-4-SF, sensory profile and the information obtained from the sensory self-regulatory questionnaire were also analysed descriptively.

Quantitative analysis was used to analyse the effectiveness of the stress management programme, using both descriptive and inferential statistics. Due to the small sample size and convenience sampling method, non-parametric statistics was used to analyse data. Data obtained from the various outcome measures made use of ordinal data scales of measurement. Median scores and quartile ranges were used to analyse the results from the PSI-4-SF and sensory self-regulatory questionnaire. In order to determine the change from pre-test to post-test, the Wilcoxon rank sign tests were used to compare the participants scores for significance set at 0.05. Effect sizes (using Cohen's r) were used on the median scores to determine clinical implications of the change, as the small sample was not conducive to statistically significant change (Algina, Keselman, & Penfield, 2005). Correlations were used to analyse the results to determine the association of the data between the PSI-4-SF and the sensory profile. The correlations were interpreted according to the following criteria (Tomita, 2006):

0 - 0.29	no correlation
0.30 – 0.39	a weak correlation
0.40 – 0.59	a moderate correlation
0.60 – 0.79	a strong correlation
0.80 – 1.00	excellent

CHAPTER 4 RESULTS

4.1 INTRODUCTION

The sample for this study consisted of five mothers. There were initially seven mothers, who gave consent to participate in the programme. One mother discontinued the programme after the first session, as she was unable to commit to the time requirements. The other mother discontinued the programme as she did not meet all the inclusion criteria. This resulted in a dropout rate of 14.2%, which is below the accepted 20% dropout rate (Thiese, 2014).

4.2 DEMOGRAPHICS

4.2.1 Personal demographics

The personal demographics of the participants indicated that one was below 30 years, two were between 30 to 40 years, and two participants were older than 40 years. Only one participant was not married (Table 4.1).

Table 4.1: Personal demographics (n=5)

	n (%)		
Age years	<30	30-40	>40
	1 (20%)	2(40%)	2 (40%)
Marital status	Married	Single	
	4(80%)	1(20%)	

4.2.2 Education and employment

The participants had varying levels of education with one finishing high school as her highest level of education. One participant had a university degree and 60% (3) participants had a postgraduate degree.

Sixty percent of the participants work full time, whilst 20% work part time or have no formal employment. Figure 4.1 demonstrates the amount of hours worked per week for the participants. Forty percent of the participants work more than 40 hours per week.

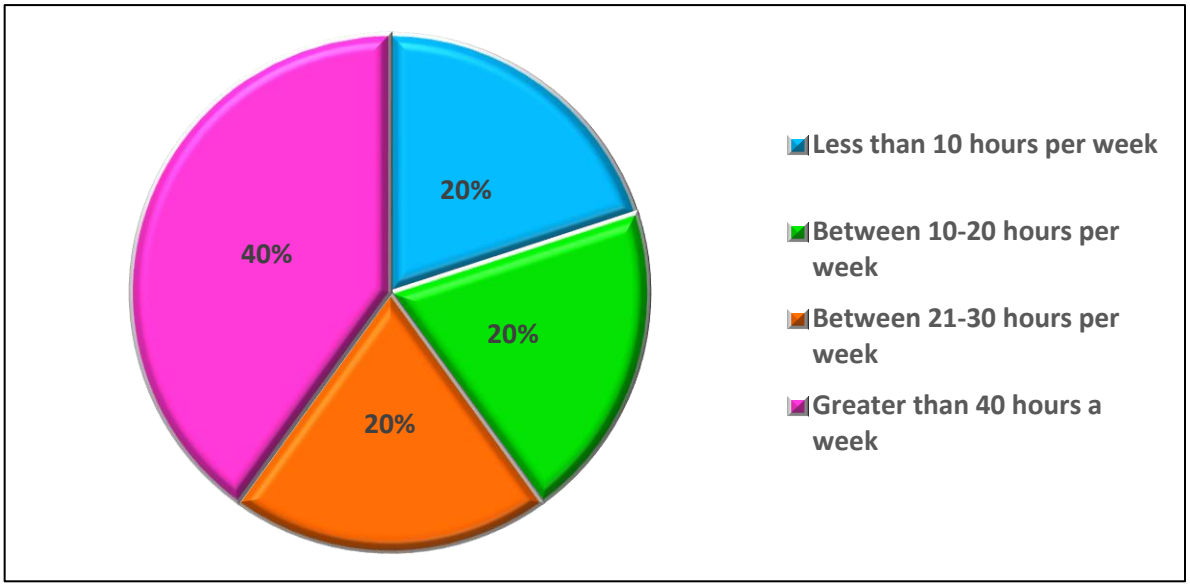


Figure 4.1: Working hours of participants (n=5)

4.2.3 Medical conditions

The following medical conditions were reported by the participants: hypertension, high cholesterol, diabetes, irritable bowel syndrome, depression, anxiety disorder, ADD and hyperthyroidism. There were two participants who reported depression, with one additional participant suspecting depression. One participant reported an anxiety disorder, and another reported experiencing irritable bowel syndrome. Two of the participants reported they frequently suffer from colds or flu. The majority of the participants (80%) were on medication for a variety of reasons, namely: depression, anaemia, thyroidism, and concentration.

4.2.4 Sleeping deficits and major life events

The majority of the participants (80%) have sleeping difficulties. However, despite this, all of the participants sleep in total 6-8 hours a night. The sleeping deficits reported include waking up three or more times a night then battling to fall back to sleep (60%), taking more than 30 minutes to fall asleep at night, and having nightmares or sleep terrors (40%). All the participants reported not feeling well rested when they woke up in the morning, and always feeling tired.

Two participants (40%) had experienced a major life event in the recent past.

4.2.5 Children receiving therapy

Two (40%) of the participants have one child, and two participants have three children, while 20% of the participants have 2 children.

All the participants in the study have at least one child attending therapy with the majority of the children in occupational therapy (80%). Three of the participants have a second child in therapy and one participant had all three children in therapy. (Table 4.2)

Table 4.2: Children in order of birth receiving therapy (n=)

	First child (n=5)	Second Child (n=3)	Third Child (n=1)
	n (%)		
Percentage Receiving Occupational Therapy	4 (80%)	1 (33%)	1 (50%)
Percentage Receiving Speech Therapy	2 (40%)	1 (33%)	1 (50%)
Percentage Receiving Physiotherapy	0%	3 (100%)	1 (50%)
Percentage Receiving Play Therapy	1 (20%)	0%	0%

4.3 SENSORY PROFILE RESULTS

4.3.1 Neurological threshold results from Sensory Profile

The following outlines the sensory profiles of the participants on four of Dunn's quadrants: sensation avoiding, low registration, sensory sensitive and sensory seeking.

Three (60%) of participants presented with sensation avoiding behaviour, and scored *much more than most people* or greater than 98th percentile. One participant presented with sensory avoiding behaviour between the 84th and 98th percentile, and the other participant presented with behaviour *similar to most people*. (Figure 4. 2)

Three (60%) of participants also presented in the low registration quadrant which scored at *more than most people* or between the 84th and 98th percentile. The other two participants presented with low registration *similar to most people* and *much more than most people*.

Two (40%) of participants displayed sensory sensitive behaviour which was scored *more than most people*, and two (40%) participants scored within the *much more than most people* or greater than 98th percentile. The remainder (20%) of participants scored within the mid-range or *similar to most people* (Figure 4.2).

Two participants (40%) present with sensory seeking behaviour *much less than most people* (between 2nd and 16th percentile). The remaining three participants presented with sensory seeking behaviour *less than most people*, *similar to most people* and *more than most people* respectively.

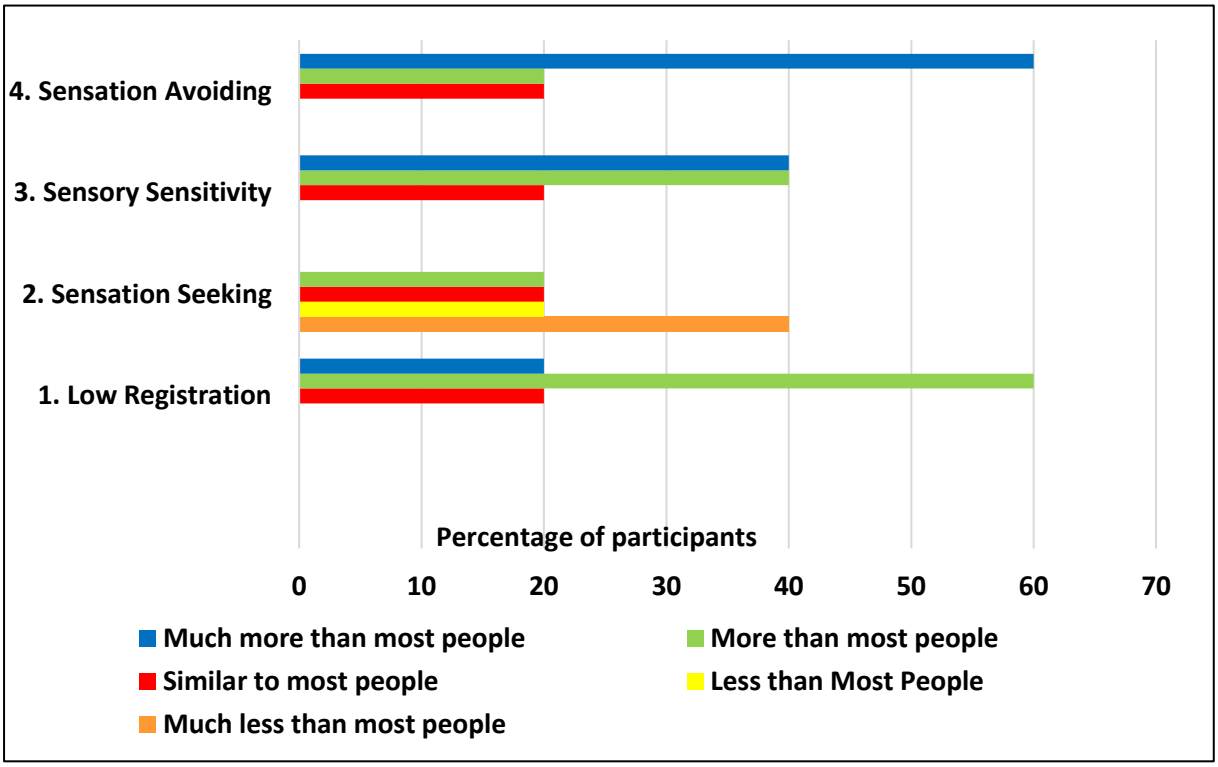


Figure 4.2: Sensory profile quadrant results (n=5)

Figure 4.3 below displays the scores for the participants across Dunn's quadrant model. It indicates that the overall participants presented in the low threshold continua (sensory sensitivity and sensation avoiding), which correlates with the inclusion criteria of the study, that is, individuals scoring within the low threshold section, displaying SOR. For the high threshold section, the participants scored *more than most people* for low registration, but *less than most people* for sensation seeking.



Figure 4.3: Quadrant with dysfunction for participants' sensory profiles – median scores (n=5)

4.3.2 Behavioural responses or self-regulation results from Sensory Profile

4.3.2.1 Active strategies

Since four participants (80%) displayed *much more than most* and *more than most* sensation avoiding behaviour, this indicates that most of the participants display active strategies in order to avoid sensory input. In addition, three participants (60%) displayed *much less than most* or *less than most* for sensation seeking behaviour. This indicates that these participants display less sensation seeking behaviour than other people compared to their age.

4.3.2.2 Passive strategies

Four participants (80%) scored *much more than most* or *more than most* for sensory sensitive behaviour and for low registration behaviour. This demonstrates that the majority (80%) of participants display passive strategies in an attempt to self-regulate.

No participants made use of passive strategies exclusively, however the majority of the participants made use of a combination of passive strategies and sensation avoiding active strategies.

4.4 PARENTING STRESS INDEX RESULTS

The Parenting Stress Index (PSI-4-SF) was analysed using the four subscales in the assessment: parental distress (PD), parent-child dysfunctional interaction (P-CDI), and difficult child (DC), as well as total stress (TS) score. The following table displays changes made for all of the abovementioned categories. It depicts changes made at baseline, post-intervention, and three months follow up (Table 4.3).

Table 4.3: Change in percentile scores on the Parenting Stress Index (PSI-4-SF) from baseline to post-intervention and at three month follow up

	Baseline	Post intervention	P value	Effect size Cohen's r	95% Confidence intervals	Follow up	P value	Effect size Cohen's r	95% Confidence intervals
	Median (lower and upper quartiles)					Median (lower and upper quartiles)			
Parental Distress	85 (82-99)	71 (64-99)	0.10	0.71 Large	-0.27 to 1.69	62 (59-73)	0.46	0.32 Moderate	-0.66 to 1.30
Parent Child Dysfunctional Interaction	76 (67-83)	73 (67-76)	0.71	0.16 Low	-0.82 to 1.14	70 (63-73)	0.46	0.32 Moderate	-0.66 to 1.30
Difficult Child	96 (93-98)	93 (88-95)	0.10	0.72 Large	-0.26 to 1.70	83 (81-91)	0.34	0.42 Moderate	-0.56 to 1.40
Total Stress	88 (87-93)	79 (75-97)	0.34	0.42 Moderate	-0.56 to 1.40	74 (72-93)	0.71	0.16 Low	-0.82 to 1.14

Significance p ≤0.05*
Significance p ≤0.01**

Small effect size 0.1
Medium effect size 0.3*
Large effect size 0.5**

No statistically significant differences were found for the change in stress over the three times it was assessed. However, large and moderate clinical change, equivalent to half a standard deviation or more, was found for most aspects of stress assessed by the PSI-SF 4. The difference assessed using effect sizes was not clinically significant as the 95% confidence intervals (CI) did contain 0 and stretched from a negative to a positive score. The larger positive CI values indicate positive clinically relevant change.

4.4.1 Total Stress

Total stress is the overall parental stress that the parent is experiencing (Abidin, 1995). The median overall total parental stress decreased (Figure 4.4) from a median of 88th percentile (high) to 79th percentile (normal) between baseline and after intervention. A marginal difference was found in the median scores between the percentiles from post intervention to the three month follow up test (79th percentile to 74th percentile), remaining both in the normal range. Overall the decrease in the participants' stress was not statistically significant, although there was a clinically relevant reduction in stress for this group of participants after the intervention as the effect size was moderate.

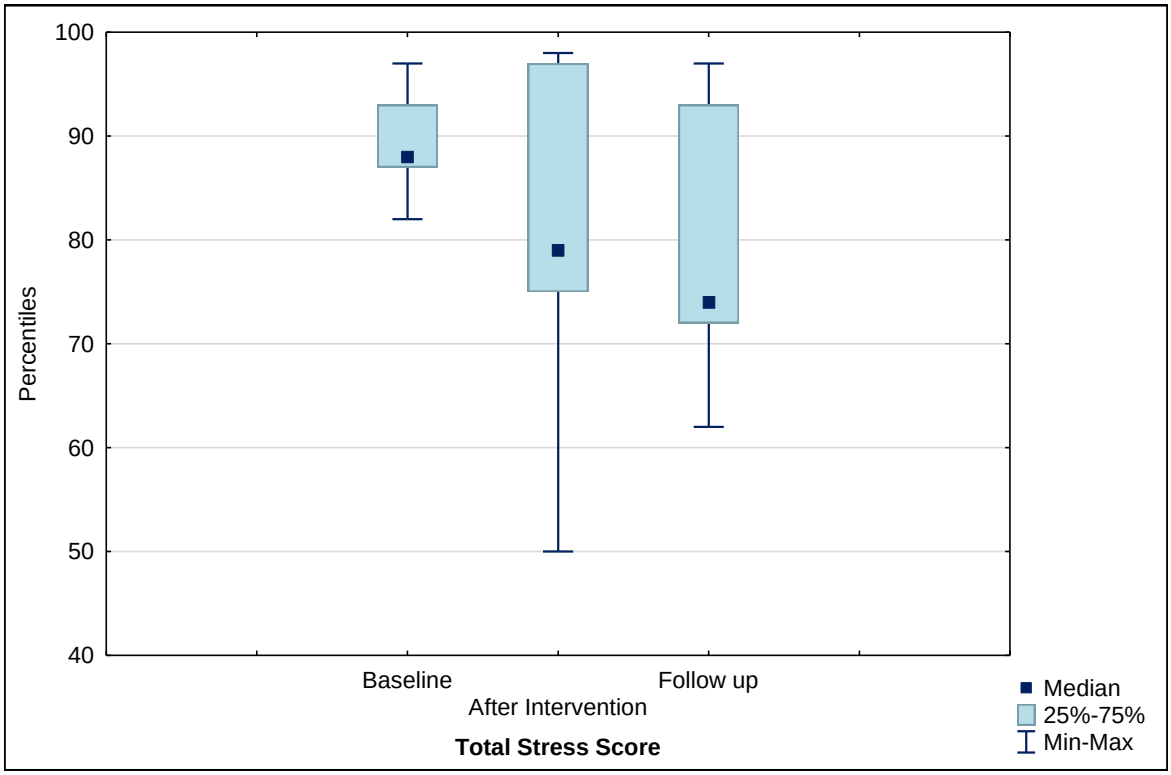


Figure 4.4: Median change in total stress score at baseline, post intervention and at three months follow up

Two participants (40%) scored above the 91st percentile for total stress indicating clinically significant high levels of stress. The stress levels of these two participants remained above the 91st percentile after the intervention and for the three month follow up test, showing only a marginal difference.

The change in the participant's stress continued to decrease slightly in the follow up three months after intervention, but was also not statistically significant with no clinically relevant difference as the effect size was low. (Table 4.3 and Figure 4.4)

4.4.2 Parental Distress

Parental distress examines the level of stress that a parent is experiencing based on their role as a parent (Abidin, 1995). For 40% of participants, no change in parental distress scores from baseline to after intervention was made. However, the group median scores for parental distress decreased from the high range (85th percentile) down to the normal range (71st percentile) and then decreased to the 62nd percentile for three months follow up (Figure 4.5). The parental distress change seen after intervention and at follow up was not statistically significant, but clinical change measured by the effect size was large post intervention.

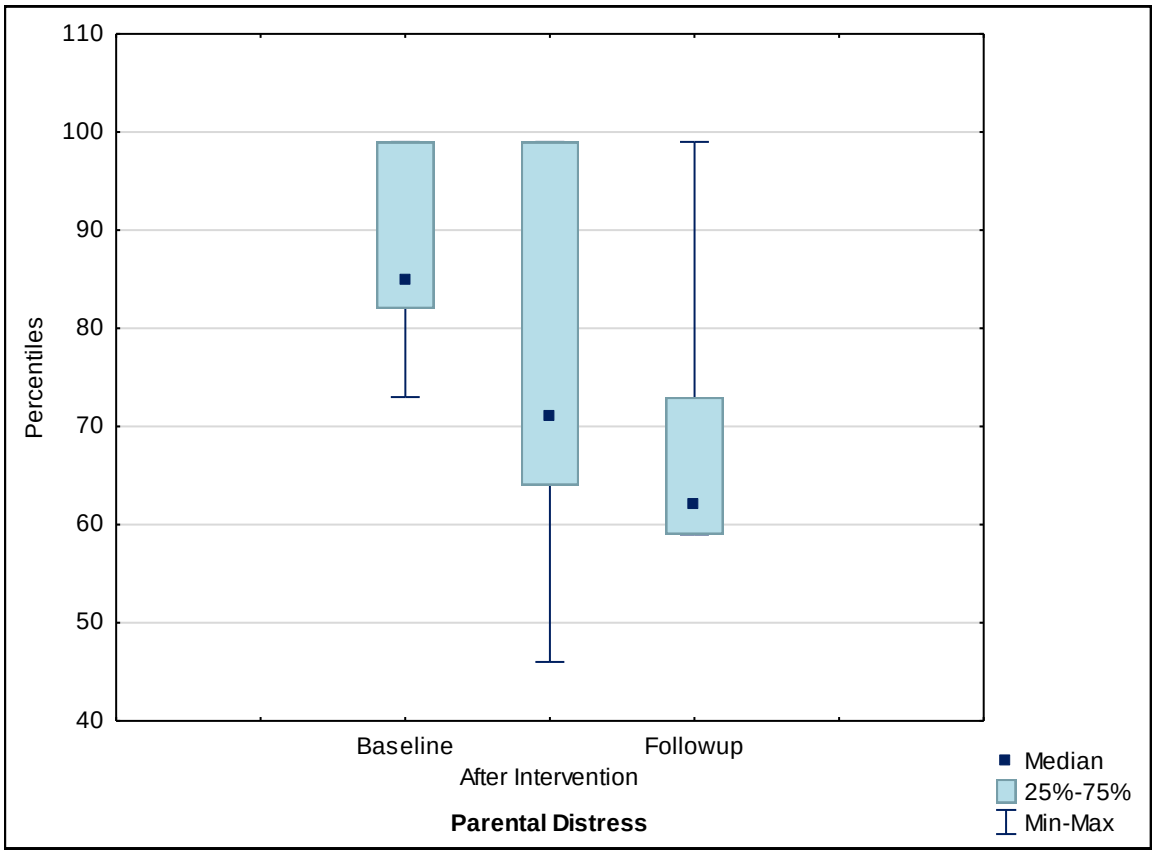


Figure 4.5: Median change in parental distress at baseline, post intervention and at three month follow up

The reduction in stress was sustained with participants reporting continued decrease in stress over this three-month period. Effect size was moderate indicating further clinical reduction in parental distress. The upper quartile range in Figure 4.5 indicates that for one participant, the stress did not decrease for parental distress at all.

4.4.3 Difficult Child

The difficult child subscale looks at the characteristics of the child that impacts on the level of parents' difficulty to manage their child (Abidin, 1995). Difficult child scores displayed the highest stress scores out of all the categories. Baseline median scores were at the 96th percentile, which indicated clinically significant stress for this aspect. These scores decreased to the 93rd percentile, which still indicated significant stress after intervention. The scores decreased further three months' post intervention, to 83rd percentile, which fell within the normal range (Figure 4.6). The change in the scores for difficult child was not statistically significant. However, it displayed a large effect size after intervention and a moderate effect size at three months follow up, indicating clinically relevant change in the participants' stress.

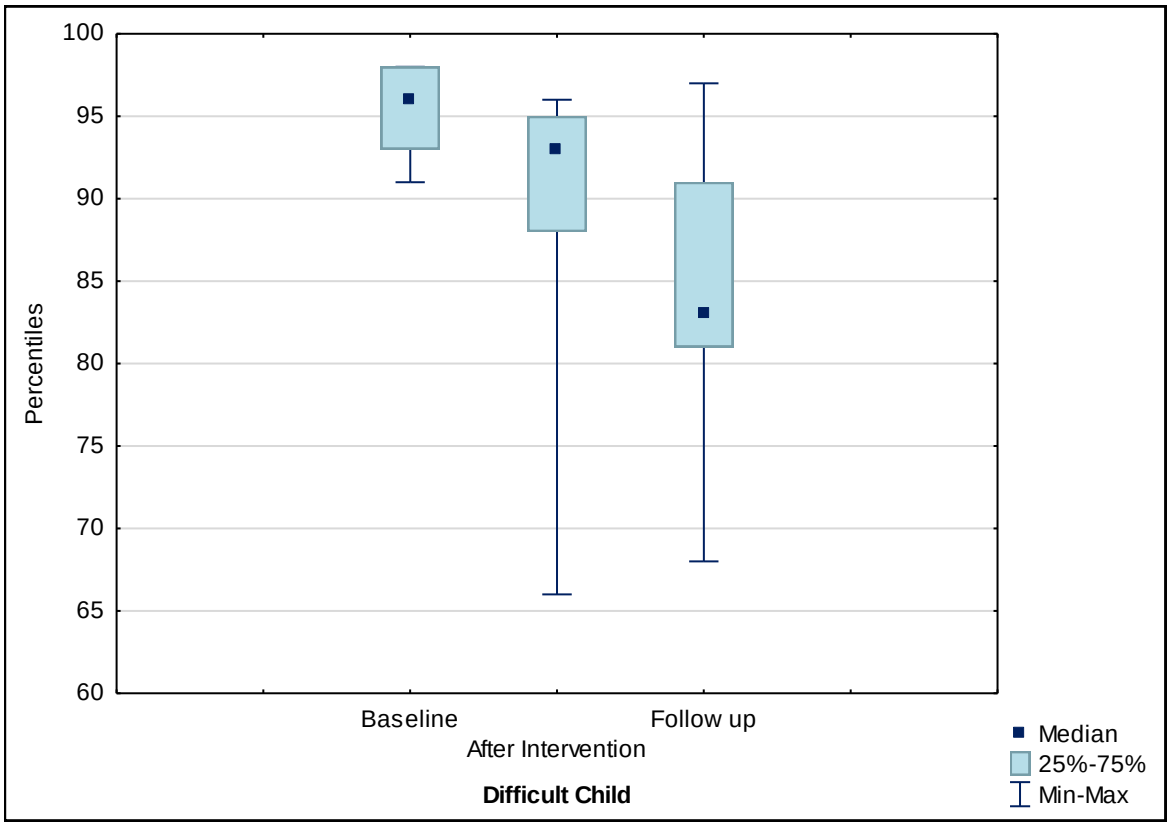


Figure 4.6: Median change for difficult child at baseline, post intervention and at three months follow up

4.4.4 Parent-Child Dysfunctional Interaction

Parent-child dysfunctional interaction looks at the parent-child interactions and expectations (Abidin, 1995). The group median scores decreased from the 76th percentile to the 73rd percentile, after intervention, which are both within the normal range. The group scores median decreased marginally to 70th percentile three months' post intervention. The lowest stress levels were assessed for the parent-child dysfunctional interaction, and these levels showed the least change over the course of the study. The change for the parent-child dysfunctional interaction subscale was not statistical significant or clinically significant - with low effect size between baseline and after intervention. Clinical change increased at three months' post intervention, indicating a moderate effect size. Despite this decrease seen at three months' after intervention, two participants (40%) displayed increased scores and a high level of stress as indicated by the upper quartile in Figure 4.7.

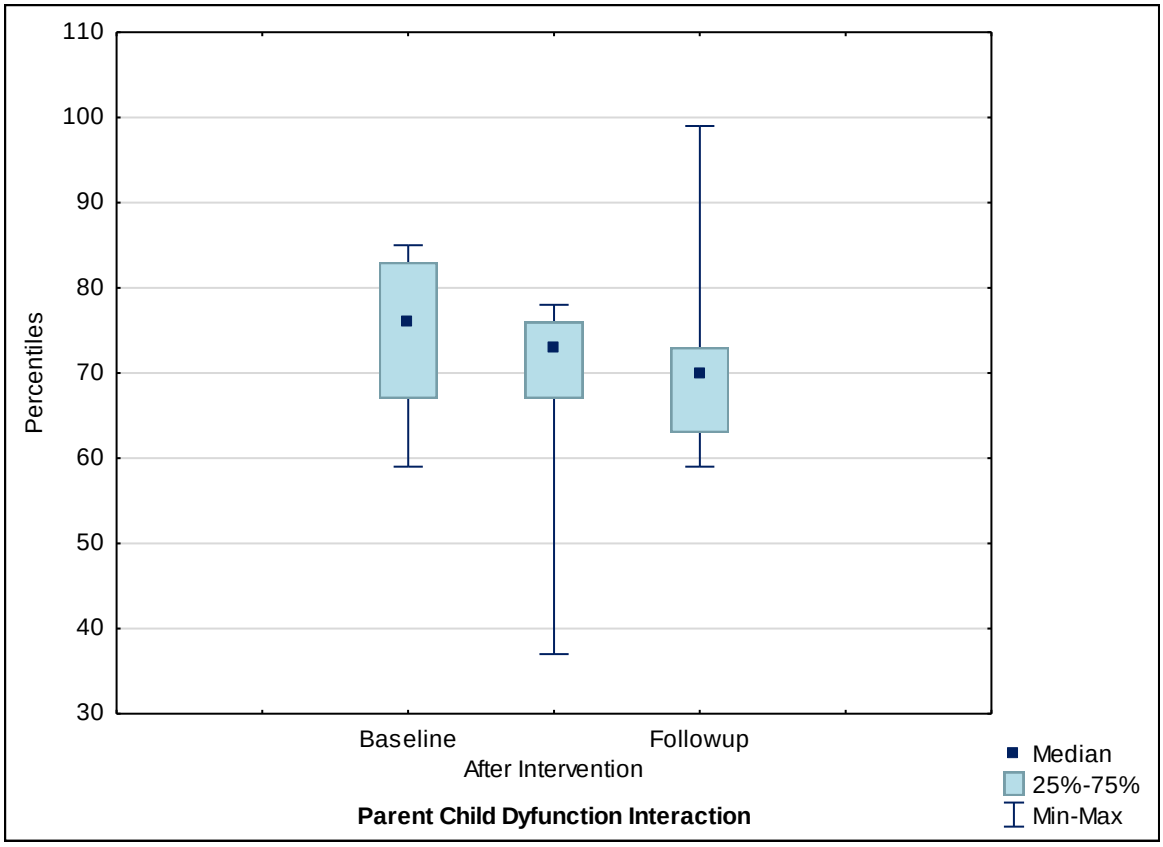


Figure 4.7: Median change in parent child dysfunctional interaction at baseline, post intervention and at three months follow up

4.4.5 Individual items of the Parenting Stress Index with decreased scores after intervention

In the analysis of the individual items from the PSI-4 SF, the following displayed a decrease in scores indicating a decrease in stress for the participants post intervention:

Table 4.4: Items which showed decrease in scores indicating decreased stress post intervention.

Median score change	Parental Distress category	Parent-Child Dysfunctional Interaction category	Difficult Child category
DECREASE BY 1 POINT	• "I often have the feeling that I cannot handle things very well" • "Since having a child, I feel that I am almost never able to do the things that I like to do" • "There are quite a few things that bother me about my life" • "I feel alone and without friends" • When I go to a party, I usually expect to not enjoy myself"	• "When playing, my child doesn't often giggle or laugh" • "My child doesn't seem to smile as much as most children" • "It takes a long time and it is very hard for my child to get used to new things"	• "My child seems to cry or fuss more often than most children" • "My child's sleeping or eating schedule was much harder to establish that I expected" • "Think carefully and count the number of things which your child does that bother you. for example: dawdles, refuses to listen, overactive, cries, interrupts, fights, whines etc."
DECREASE BY 2 POINTS	• "I am unhappy with the last purchase of clothing I made for myself" • "Having a child has caused more problems than expected in my relationship with my spouse (or male/female friend)" • "I don't enjoy the things as I used to"		• "My child turned out to be more of a problem than I had expected"

4.4.6 Correlation between the Sensory Profile and Parenting Stress Index

A significant positive moderate correlation was found between the passive quadrants in Dunns' model (namely, the low registration and sensory sensitivity in the sensory profile) and the parent-child dysfunctional interaction domain on the initial assessment. The results from correlations between other subtests of the PSI-4-SF and the sensory profile quadrants were inconclusive due to the small sample size. Table 4.5 displays the positive correlations that showed an association between these variables, namely, low registration and sensory sensitivity.

Table 4.5: Correlation between the quadrant scores on the Sensory Profile and the baseline percentile scores on the Parenting Stress Index-4- Short Form

Percentiles	Low Registration	Sensory Sensitivity
	r	r
Parent-child dysfunctional interaction	0.67	0.70

4.5 SELF REGULATORY QUESTIONNAIRE RESULTS

4.5.1 Change in self-regulation

Positive changes were noted in 80% of the rating scale items on the self-regulatory questionnaire.

Table 4.6: Clinical change in self-regulation between baseline and post intervention

Self-regulatory Questionnaire items	Baseline	After Intervention	p-value	Effect Size Cohen's r	95% Confidence intervals
	Median (Lower and upper quartile)				
"I know what to do to calm myself down"	3 (3-3)	2 (2-2)	0.06	0.81 Large	-0.17 to 1.79
"I tend to perform regulatory or self-calming activities to prevent feelings of overwhelm, stress or anxiety"	4 (4-4)	3 (2-3)	0.10	0.71 Large	-0.27 to 1.69
"I plan and actively perform regulatory or self-calming activities in the day"	4 (3-5)	2 (2-2)	0.10	0.71 Large	-0.27 to 1.69

Significance p ≤0.05*
Significance p ≤0.01**

Small effect size 0.1
Medium effect size 0.3*
Large effect size 0.5**

Although no significant change was seen between baseline and post intervention for self-regulation, Table 4.6 depicts the items with a large effect size. Although this indicates a clinical change, the change was not significant as the confidence intervals range from negative to positive.

4.5.2 Factors preventing participants from performing calming activities

Participants were required to indicate which statements were most relevant to them that prevented them from performing calming activities in their week. All participants felt that after the intervention, the following factors hindered their ability to perform calming activities: that they feel too stressed and overwhelmed, feels like they have minimal access to resources and that they don't know what activities to do (Table 4.7). All participants (100%) reported that they did not have enough time for themselves during both assessments.

Table 4.7: Clinical change in factors preventing participants from performing calming activities between baseline and post intervention

Self-regulatory Questionnaire items	Baseline	After Intervention	p-value	Effect Size Cohen's r	95% Confidence intervals
	Median (Lower and upper quartile)				
"I feel too stressed and overwhelmed"	1 (0-1)	0 (0-0)	0.10	0.71 Large	-0.27 to 1.69
"I feel like I have minimal access to resources"	1 (1-1)	0 (0-0)	0.06	0.81 Large	-0.17 to1.79
"I feel like I don't know what activities to do"	1 (1-1)	0 (0-0)	0.06	0.81 Large	-0.17 to 1.79

Significance p ≤0.05*
Significance p ≤0.01**

Small effect size 0.1
Medium effect size 0.3*
Large effect size 0.5**

4.5.3 Self-calming activities and frequencies

The participants were required to list their top three choices of activities that calm them down the most. Table 4.8 displays the participants top three activities that they chose at baseline and post intervention, and the frequency of their performance for each activity choice:

Table 4.8: Self-calming activity choices and frequency for all participants (pre-test versus post-test)

	Activity choice 1		Activity choice 2		Activity choice 3	
BASELINE	• Scrapbooking • Smoking, glass of wine • Cleaning • Talking to people • Sitting on my veranda with a cup of tea		• Movies • Crafts • Reading • Breastfeeding • Sleeping in a dark room		• Massage • Crosswords, reading • Watching TV • Playing with my children • Colouring in	
	Frequency of Performance					
	• Daily • 2-6 times a week • Twice a month	60% 20% 20%	• Daily • 2-6 times a week • Once a month	20% 20% 60%	• Daily • 2-6 times a week • Twice a month • Less than once a month	20% 20% 20% 40%
AFTER INTERVENTION	• Breathing, • Deep breathing • Chewing gum • Having coffee with a friend • Having a nap		• Eating crunchy foods • Stretching • Listening to gospel music • Playing with the kids • Walking		• Deep massage cream on my arms and hands • Reading • Being in a dark space alone • TV • Reading	
	Frequency of Performance					
	• Daily • Once a week	60% 40%	• Daily • Once a week	80% 20%	• Daily • Once a week	60% 40%

The following increases in frequencies were indicated in participants' calming activity choices: 80% of the participants increased the frequency of performing activity choice two from performing the activities 2-6 times a week or less, to performing them daily. In addition, 60% of the participants increased the frequency of activity choice three from performing the activities 2-6 times a week or less to performing them daily.

A large and moderate clinically relevant change was shown in the frequency of the participants' performance in two of the calming activities (Table 4.9).

Table 4.9: Change in frequency of performance of calming activity for each activity choice between baseline and post intervention

Self-regulatory Questionnaire items	Baseline	After Intervention	p-value	Effect Size Cohen's r	95% Confidence intervals
	Median (Lower and upper quartile)				
Calming Activity Choice 1	1 (1-2)	1 (1-3)	1.00	0.0 None	0
Calming Activity Choice 2	3 (2-5)	1 (1-1)	0.108	0.71 Large	-0.27 to 1.69
Calming Activity Choice 3	4 (2-6)	1 (1-3)	0.201	0.51 Moderate	-0.47 to 1.49

Significance p ≤0.05*
Significance p ≤0.01**

Small effect size 0.1
Medium effect size 0.3*
Large effect size 0.5**

4.5.4 Use of foods and caffeine to self-regulate

After the intervention, findings indicate that participants consumed less sweet foods and decreased their caffeine intake. A moderate effect size indicating clinically relevant change was found (Table 4.10).

Table 4.10: Change in the use of foods and caffeine in order to self-regulate between baseline and post intervention

Self-regulatory Questionnaire items	Baseline	After Intervention	p-value	Effect Size Cohen's r	95% Confidence intervals
	Median (Lower and upper quartile)				
"What types of foods do you tend to enjoy eating?" - Sweet Foods	1 (1-1)	0 (0-1)	0.17	0.59 Moderate	-0.39 to 1.57
"How many times per day do you typically consume caffeine"	1 (2-3)	2 (2-2)	0.17	0.59 Moderate	-0.39 to 1.57

Significance p ≤0.05*
Significance p ≤0.01**

Small effect size 0.1
Medium effect size 0.3*
Large effect size 0.5**

4.5.5 Visual analogue scale items on the self-regulatory questionnaire

For the visual analogue scale (VAS) in the questionnaire, two out of the three scales noted a positive difference. The scales rating was out of 100. The first scale evaluated how connected the individual felt to her body, and showed a 10-point improvement. After the intervention, the scale rating self-calming mechanisms improved by 20 points. A moderate clinically relevant change was found for these two VAS scales (Table 4.11).

Table 4.11: Change on the visual analogue scales in the self-regulatory questionnaire from baseline and post intervention

Self-regulatory Questionnaire visual analogue scale items	Baseline	After Intervention	p-value	Effect Size Cohen's r	95% Confidence intervals
	Median (Lower and upper quartile)				
"Currently, how connected do you feel to your body? Rate this by selecting the number that best describes how you are feeling now."	50 (35-50)	60 (51-71)	0.22	0.54 Moderate	-0.44 to 1.52
"How would you rate your self-calming strategies as a whole? In other words, how effective do you find your self-calming mechanisms?"	40 (22-70)	60 (55-78)	0.22	0.54 Moderate	-0.44 to 1.52

Significance p ≤0.05*
Significance p ≤0.01**

Small effect size 0.1
Medium effect size 0.3*
Large effect size 0.5**

4.6 STRESS MANAGEMENT PROGRAMME EVALUATION

4.6.1 Frequency of positive ratings of the stress management programme

All the participants either strongly agreed or agreed to the following statements about the stress management programme (Table 4.12).

Table 4.12: Ratings for the evaluation of the stress management programme

Linkert scale statements	Strongly Agree	Agree
I feel that the programme met my overall needs	40%	60%
Expectations of me as a programme participant were reasonable for the purpose and the time frame	60%	40%
I would recommend this programme to other parents	100%	
Useful strategies were provided to help me manage my stress levels	80%	20%
I understand all the concepts shared on the programme	80%	20%
I was able to implement strategies learnt and apply them to my life	60%	40%
Strategies provided were relevant to my life and situation	80%	20%

4.6.2 Useful aspects of the programme

The participants found the following aspects of the programme useful:

- “The self-awareness that this programme has facilitated has been most valuable. I feel the burden of having to CHANGE who I am has been lifted, and it's rather about better MANAGING who I am, which is doable and very liberating. Learning sensory strategies that work for me has been very helpful, along with learning how to apply them throughout any given day.”
- “Understanding my sensory triggers.”
- “Understanding myself and in turn how to manage and understand my family better and in turn manage to reduce global stress”
- “Being aware of and understanding my sensory profile and also how to self-regulate and implement”
- “Realising the importance of self-regulation”

Most of the trends depicted in the above statements are related to the concept of self-awareness (Table 4.13).

Table 4.13: Aspects of what aspects the stress management programme helped the participants with

Statements indicating what the stress management programme helped the participants with:	Percentage
Gain greater insight into my body's sensory needs	100%
Manage my child's sensory needs better	80%
Gain greater insight into my stress levels	80%
Gain greater insight into the effect of the stress levels on my well-being and life in general	80%
Recover from a stressful situation quicker or better	80%
Manage my child's challenging behaviour better	60%
Cope with everyday stress better	60%
Manage my overall daily stress	60%
Gain different perspective on life	40%

Greater self-awareness relates to findings in the table below, where *all* the participants believed that the programme helped them to gain greater insight into their body's' sensory needs. The programme also helped with other aspects relating to stress and their child's needs, as detailed in the table above.

4.6.3 Stress management programme changes

Three participants recommended the following changes to the programme:

- "A second group session to meet with the other participants again. The first group session was very helpful, and the resultant WhatsApp group has kept us connected and able to support each other."
- "Larger focus on coping mechanisms for moms, e.g. how to deal with tantrums."
- "A few more sessions would be beneficial."

4.7 SUMMARY OF RESULTS

Five mothers participated in the study. Their ages ranged between 20 to 50 years old and all had at least one child attending therapy. There was one single mother in the study. The participants had varying levels of education. 60% of the mothers worked full time, and 40% of the mothers worked more than 40 hours per week. The following medical conditions were reported by participants: hypertension, high cholesterol, diabetes, irritable bowel syndrome, depression, anxiety disorder, ADD and hyperthyroidism. The majority of the participants (80%) were on medication for a variety of reasons, namely: depression, anaemia, thyroidism, and concentration. The majority of the participants had sleeping difficulties.

According to Dunn's quadrant model, the overall scores presented in the low threshold continua (sensory sensitivity and sensation avoiding). This finding coincides with the inclusion criteria of the study as individuals scoring within the low threshold section display SOR. The participants also scored *more than most people* for low registration (a high threshold section), but *less than most people* for sensation seeking. The majority of the participants made use of passive strategies and sensation avoiding active strategies in order to self-regulate.

No statistically significant differences were found for the change in stress at baseline, after intervention, and then three months' post intervention. However, large and moderate clinically relevant change, equivalent to half a standard deviation or more, was found for most aspects of stress assessed by the PSI-SF 4. A large clinically relevant change was noted for parental distress and difficult child, after intervention. A moderate clinically relevant change was noted for parental distress and difficult child three months' post intervention. A moderate clinically relevant change was noted for total stress post intervention and for parent child dysfunctional intervention three months' post intervention. A significant moderate positive correlation was found between the passive quadrants in Dunn's model (namely the low registration and sensory sensitivity) and the parent-child dysfunctional interaction domain.

Two participants (40%) scored above the 91st percentile for total stress indicating clinically significant high levels of stress. The stress levels of these two participants remained above the 91st percentile after the intervention and for the three month follow up test, showing only a marginal difference.

Positive changes were noted in 80% of the rating scale items on the self-regulatory questionnaire. Although no significant change was seen between baseline and after intervention for self-regulation, there were large effect sizes for a number of items in the self-regulatory questionnaire. These included the following: knowing what activities calmed the participants down; that they tend to perform self-regulatory activities to prevent feelings of stress, overwhelm and anxiety; that they plan to perform self-regulatory activities during their day; the choice and frequency at which they perform these self-calming activities; changes in the factors that prevent them from performing self-regulatory activities; as well as their intake of sweet foods and caffeine. Positive changes (moderate effect size) were also noted with their rating of how connected they feel to their body, and the rating of their self-calming mechanisms as a whole.

All the participants either strongly agreed or agreed to the various statements about the stress management programme in the evaluation questionnaire. The majority of the trends depicted in the evaluation of the stress management programme were related to the concept of self-awareness, where all the participants believed that the programme helped them gain greater insight into their body's' sensory needs.

CHAPTER 5 DISCUSSION

5.1 INTRODUCTION

This chapter presents the discussion of the findings of the study in relation to the objectives and the perceived stress levels of mothers of children with SMD, as well as their patterns of sensory processing and their self-regulatory behaviours. A framework is also presented, which explains the relationship between the participants perceived stress levels and their self-regulatory strategies, with family factors taken into account. The effectiveness of a structured twelve-week sensory modulation-based stress management programme for mothers is considered both after the intervention and three months later. Strengths and limitations of the study are also included.

5.2 DEMOGRAPHICS

The participants in this study were a group of mothers from a middle class background, with education levels of matric and above. Research that indicates a moderate genetic link evident in sensory over-responsiveness was confirmed (Goldsmith et al., 2006) as there was a familial incidence of SMD in the mothers recruited into this study. They all presented with SOR themselves and at least one of their children presented with SMD. They could afford private therapy for their children and between one to three of their children were attending therapy.

There was no correlation found between heightened stress and the number of children or the number of children receiving therapy. All participants displayed heightened levels of total stress, despite the variations in these details pertaining to their children. Based on the high difficult child score in the PSI-SF, it is apparent in the study that's its more the characteristics of the child that is contributing to the participants' total stress, rather than the number of children. The effects of other demographic factors on stress, including employment marital status, medical conditions and sleep will be explored in greater detail below, in relation to perceived stress levels.

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5.3 SENSORY PROFILES, SELF-REGULATORY BEHAVIOURS AND PERCEIVED STRESS LEVELS

The first objective of the study was to determine the sensory profiles and self-regulatory behaviours of the participants, who were mothers of children with SMD presenting with SOR on their own sensory profiles.

5.3.1 Sensory profiles and self-regulatory behaviours

The participants displayed a typical presentation of SOR, with overall scores presented in the low threshold continua of Dunn's quadrant model, namely, sensation avoiding and sensory sensitivity. This presentation indicates that the participants displayed low neurological thresholds to sensory input. The participants also displayed much less sensory seeking behaviour than others, which could strengthen the fact that they are avoiding sensory input, because of their low neurological thresholds. Interestingly, they also presented in the low registration quadrant. Although they tend to over-react to sensory input, they also display an element of a lack of engagement or passivity. Their presentation in the low registration quadrant could be because they are functioning in a sympathetic state, due to their low threshold sensory profile, and thus did not notice some sensory stimuli. Engel-Yeger and Dunn (2011) also found a similar presentation in their study, when evaluating the relationship between affect and sensory processing patterns. Although different characteristics were found between low neurological threshold patterns and low registration, they found a correlation between a negative affect and sensation avoiding, sensory sensitivity, as well as low registration (Engel-Yeger & Dunn, 2011).

Participants in this study used a combination of passive strategies and sensation avoiding strategies to self-regulate, with fewer sensory seeking behaviour strategies. Initially, the majority of the participants rated their self-regulatory mechanisms as being average (40 out of 100), and they reported that they did not feel that the activities they performed in the day was sufficiently calming. They also reported that they did not perform self-regulatory activities to prevent feeling overwhelm or to reduce stress. This correlates to their behavioural strategies on the sensory profile, as they did not display enough active strategies in the form of sensation seeking behaviours to self-regulate. Instead, they displayed strategies where they tended to accept the environment as it was and respond to external sensory stimuli in accordance with their low neurological threshold. They used these strategies rather than using strategies to change their

environment so that their threshold needs are met, thus allowing them to cope with their low neurological threshold (Brown & Dunn, 2002).

Individuals with SOR displaying problems with self-regulation, tend to rely on others to assist with their self-regulation (DeGangi, 2012). Problems with self-regulation were particularly evident in the participants of this study, which appeared to be related to the high baseline score for their initial parental distress score and total stress score on the PSI-4-SF. Their self-regulatory strategies were not efficient, which did not assist in reducing their overall stress. Their inefficient self-regulatory strategies were evident in the participants' report in the sensory self-regulatory questionnaire. They felt stressed and overwhelmed, they had minimal access to resources, did not have time for themselves, and felt unsure of activities to self-regulate and calm themselves. This inefficiency could be related to the participants being "robbed" by their sympathetic nervous system, a state, when the body is hijacked by all reasoning and logical thinking, due to being in a state of constant fright and flight. As a result of their SNS being in dominance, they were not able to self-initiate the process of self-regulation, even though they reported in the self-regulatory questionnaire that they knew they needed to self-regulate and were motivated to do so. It was clear that they did not know how to start the process or what strategies to use. In addition, as a result of being stressed for so long, they could no longer access previous strategies to self-calm and they appeared fixed in their mal-adaptive habits (Champagne, 2011).

It is evident in the findings from the sensory profile and self-regulatory questionnaires, that the combination of the participants' SOR and their mal-adaptive self-regulatory strategies, appeared to both play a role in their ability to efficiently manage their stress levels. Therefore, their total stress was not only exacerbated by difficulties relating to their child, but also due to their own personal characteristics. The next objective was to determine perceived stress levels of mothers of children with SMD, followed by the third objective to determine the correlation between the participants' sensory profile and self-regulatory behaviour with their perceived stressed levels.

5.3.2 Perceived stress levels of mothers

Overall, the participants in the study displayed high levels of total stress in the PSI-4-SF (in other words, between the 85th and 89th percentile), with two mothers displaying clinically significant levels of stress (above the 90th percentile). This concurs with numerous research studies that have found that parents of children with disabilities,

particularly mothers, have higher levels of stress than those parents with children without disabilities (Baker et al., 2003; Emerson, 2003; Hauser-Cram et al., 2001). According to the PSI-4-SF scores for the group, the largest contributors to the participants' stress was their own parental distress, as well as the difficulties relating to their child, which scored within the high and clinically significant range, respectively.

In closer consideration of parental distress, it suggests that the participants in the study may present with a poor sense of coherence (SOC). Their lowered SOC is associated with mal-adaptive coping strategies, due to their high parental distress scores, which is characterised by their inability to use their resources effectively in order to manage their stress levels. Although there is little published research on the SOC of parents who have children with disabilities, a study by Oelofsen and Richardson (2006) supported the findings of this study. They revealed that parents who have children with disabilities have lower SOC than parents who don't have children with disabilities (Oelofsen & Richardson, 2006). In particular, the mothers of children with developmental disabilities displayed lower SOC than their partners, coupled with higher parenting stress (Oelofsen & Richardson, 2006). These lower SOC scores for mothers implied that their ability to cope effectively is hampered, not only in caring for the child with a disability, but also for other stressful life events in general, thus being more vulnerable to stress (Oelofsen & Richardson, 2006).

It was noted that the working hours, marital status and the medical conditions most influenced their stress, especially with having to juggle roles of being a working mother and a parent of a child with SMD. Participants in this study were formally employed between 10 to over 40 hours a week. This affected one particular participant in the study and contributed to her parental stress. This participant worked more than 40 hours per week, was a single mother and reported the most comorbid medical conditions, including hypertension, cholesterol, irritable bowel syndrome and depression. This participant scored the highest level of stress in the PSI-4-SF at baseline and remained within the clinical significance range after intervention.

The participants who remained in the 90th percentile for parental distress and total stress post-intervention were interestingly the only two participants who worked more than 40 hours per week. The participant who showed the most significant decrease in total stress post-intervention was the only one who worked less than 10 hours per week. Although there could be other factors influencing these participants' perceived stress levels, it appears that the demands related to working greater than 40 hours per

week had a significant impact on their stress levels, and possibly the time to implement more self-regulatory strategies. Research has found both positive and negative effects of employment in mothers (Tingey, Kiger, & Riley, 1996). Findings in this study show that it is not necessarily the role of being a working mother that creates stress, but the increased working hours that could amplify one's stress levels. Recent research indicates that stress is greatest among mothers where demands are high both at work and home, especially when there is increased responsibility in household tasks and child care, characterized as role overload (Ross & Mirowsky, 1992; Tingey, Kiger, & Riley, 1996; Williams, Suls, Alliger, Learner, & Wan, 1991).

Role overload seemed to affect the participant who was a single mother as she remained in the clinically significant range for total stress and parental distress not only after intervention, but also in the follow up period. These two scores remained in the clinically significant range even though her parental-child dysfunction interaction and difficult child stress deceased after intervention, indicating in her case that her demographic factors played a marked role in her stress levels. The effect of being a single parent on stress is further reinforced by Crnic, Greenberg, Ragozin, Robinson, and Basham (1983) who indicated that parental support, particularly emotional support from a partner or spouse, can lower the negative effects of stress experienced by mothers, as well as stress related to mother-child interaction. Webster-Stratton (1989) found that single mothers display higher perceived parental stress. In addition, they were observed to display more deviant and noncompliant behaviours when managing their child (Webster-Stratton, 1989, 1990).

In addition to the impact that one's roles can have on stress, is the effect that sleep can have on one's stress levels, and visa versa. Despite sleeping 6-8 hours per night, the majority of the participants had sleeping difficulties. The following difficulties were noted: waking up three or more times a night and difficulty falling back to sleep, taking more than 30 minutes to fall asleep at night, and having nightmares or sleep terrors. Sleep promotes health and helps restore one's physical and psychological resources (Kabat-Zinn, 2013). It was interesting to find that the participants in the study had sleeping difficulties, in addition to their high stress levels and poor self-regulatory strategies. Their sleeping difficulties appear to be negatively influencing their ability to restore the inner resources needed to perform efficient regulatory activities during the day, and thus affecting their parental distress. DeGangi (2012) found that individuals with sleeping difficulties display hyperarousal and difficulties in inhibiting their alert

state in order to progress to a sleep state. As a result of their lack of rest or sleep, an individual can become stuck in a vicious cycle, spending their day in hyperarousal, and therefore struggling to calm their bodies down to a parasympathetic state at the end of the day, in order to fall asleep. This in turn perpetuates and exacerbates one's level of stress.

A relationship between the participants' health status and stress levels could also be apparent. The following medical conditions were reported by various participants: hypertension, high cholesterol, diabetes, irritable bowel syndrome, depression, anxiety disorder, ADD and hyperthyroidism. In addition, the majority of the participants (80%) were on medication for a variety of reasons, namely: depression, anaemia, thyroidism, and concentration. Kabat-Zinn (2013) believes that a bidirectional relationship exists between chronic stimulation of the sympathetic nervous system (associated from stress) and health-related difficulties. He states that sympathetic dominance can result in "long-term physiological dysregulation, resulting in problems such as increased blood pressure, cardiac arrhythmias, digestive problems, chronic headaches, backaches, and sleep disorders, as well as psychological distress in the form of chronic anxiety, depression, or both." [p323] (Kabat-Zinn, 2013). These correlations were evident for the participants in this study.

Depression was the most common medical condition amongst the participants in the study. This correlates to links found in research between SOR and depression (Kinnealey, Koenig, & Smith, 2011; Pfeiffer & Kinnealey, 2003). Champagne (2011) found that SOR can contribute to mental health problems and that individual's with SOR may have other diagnostic presentations. Another correlation found in literature and the participants in this study was the link between parental stress and depression. This is strongly related to the perception of their competence in parenting and from being socially isolated and without support (Silver, Heneghan, Bauman, & Stein, 2006).

The difficult child subscale had the highest stress scores out of all the subscales within the PSI-SF at baseline. This high score indicates the severity of the characteristics that the children of the participants are experiencing, which contributes to the level of difficulty when managing their behaviour. Such behaviours could include, managing their child's temper tantrums, difficulty tolerating changes in routine, or defiant or manipulative behaviour. The severity and nature of the child's disability can have an influential factor on parental stress (Jones & Passey, 2004; Minnes, 1998). However,

it was interesting to find that the child-parent interaction stress subscale scored within the normal range for this group of participants. It thus shows that although these participants were stressed, were struggling with their own personal distress and were having to deal and manage challenging behaviour from their child, they still perceived their relationship with their child to be normal.

5.3.3 Relationship between the participants' stress and the sensory profile

The third objective of the study was to determine the relationship of the perceived stress levels of mothers who present SOR and their sensory self-regulatory behaviours. In addition to the findings that the participants displayed mal-adaptive self-regulatory strategies, which appear to contribute to the participants' overall perceived stress, the relationship between the participants' sensory profiles and perceived stress was explored. Since the correlations exploring this relationship were performed on a very small sample and due to the variation in the participants' sensory profiles, minimal correlations were found.

The only significant positive moderate correlation was found between the passive quadrants in Dunn's model (namely low registration and sensory sensitivity) and the parent-child dysfunctional interaction domain. Although the participants' perceive their relationship with their child to be normal, the way they manage their child's behaviour or respond to their child's sensory needs, may be hampered. Since the participants displayed passive regulatory behaviours, they may display similar co-regulatory strategies towards their child. They thus may not attend to their child's sensory needs, which could impact on the parent-child interaction and ability to manage their child's difficult behaviour.

For the link between low registration and PCD-I, the participants may not easily register and respond appropriately to their child's needs. For example, they may not assist in removing their child from an overwhelming sensory environment, which could lead to their child having an emotional outburst and in turn, influence the parent-child interaction. With regards to the sensory sensitive quadrant, the participants may over-respond to their child's behaviours. For example, they could over-react to their child's crying by responding in an emotional manner, rather than responding in a calm manner. Conversely, the participants could be functioning in a state of shutdown, and thus present more passively to their child. These instances could impact on the interaction with their child. It is hypothesized that if a mother has a low threshold for

sensory input, then they could experience high anxiety or stress in relation to their child a lot quicker than a mother with a higher threshold for sensory input. Poor self-regulation can result in difficulties relating to social relationships, in this case, the parent-child relationship (DeGangi, 2012). In addition, insufficient participation in self-regulatory activities could increase parental stress levels, which can then influence their capacity to deal with their child's behaviours and needs (Donenberg & Baker, 1993)

The correlation between the passive quadrants of Dunn's model and the PCD-I subscale, may account for the scores the participants reported in the PCD-I domain, indicating a lack of awareness of issues related to their interaction with their child, interpreting the problems in relation to their stress as having a difficult child initially. In other words, they initially perceived difficulties pertaining to their difficult child, and not within them or in their interaction with their child. Although there was no clinically relevant change found, there was a positive change found with PCD-I post-intervention, which could be as a result of the mothers improved self-regulation and self-awareness. These improvements appear to result in an improved awareness of their child's needs and ability to deal with their child's needs, which in turn improves the interaction between the mother and child.

5.4 EFFECTIVENESS OF A TWELVE-WEEK SENSORY MODULATION-BASED STRESS MANAGEMENT PROGRAMME FOR MOTHERS

The fourth objective of the study was to develop and implement a structured twelve-week sensory modulation-based stress management programme for mothers who present with SOR and have children with SMD. The development of the stress management programme was discussed in chapter 3. Strengths, limitations and recommendations relevant to the programme will be discussed in section 5.5 and 5.6 and chapter 6.

The fifth objective was to evaluate the effectiveness of a twelve-week sensory modulation-based stress management programme on the mothers' perceived stress levels.

5.4.1 Change in relationship between perceived stress and self-regulation of participants

The sensory self-regulatory questionnaire and the PSI-4-SF scores were analysed and interpreted in order to evaluate the effectiveness of the stress management programme. Although no statistical significance was found in the subscale scores in the PSI-SF, clinical change was found using effect sizes in the scores for parental distress, difficult child and total stress scores.

A framework was developed to assist in analysing the effects of the stress management programme and to assist in evaluating the parent-child context in greater detail. This framework explains the relationship between two factors, namely perceived stress and self-regulation. The change in the relationship of the participants' perceived stress levels and their self-regulatory strategies at baseline and after intervention based on this framework is discussed. (Figure 5.1 and Figure 5.2)

At baseline, the participants displayed high scores for stress and inefficient sensory regulation. This made it difficult for them to withstand the various stressors in their life, such as managing the high demands at work, or coping with getting the children ready for school in the morning. As a result of their high stress scores, the participants evidently had trouble with self-calming, sleeping and showed signs of mood dysregulation (such as depression or anxiety). Without participating in self-regulatory activities, an individual can quickly become dysregulated, leading to impulsivity, withdrawal, emotional outbursts, feelings of overwhelm and high stress (DeGangi, 2012). The participants' difficulties resulting from their high stress levels, portrays the fact that their bodies are not in equilibrium, because of their sympathetic nervous system being in dominance. This is demonstrated by the unbalanced orange scale on the right hand side of Figure 5.1 and the larger red triangle for the parent. The smaller red triangle for the child shows that their body is also dominated by the sympathetic nervous system, as a result of their SMD.

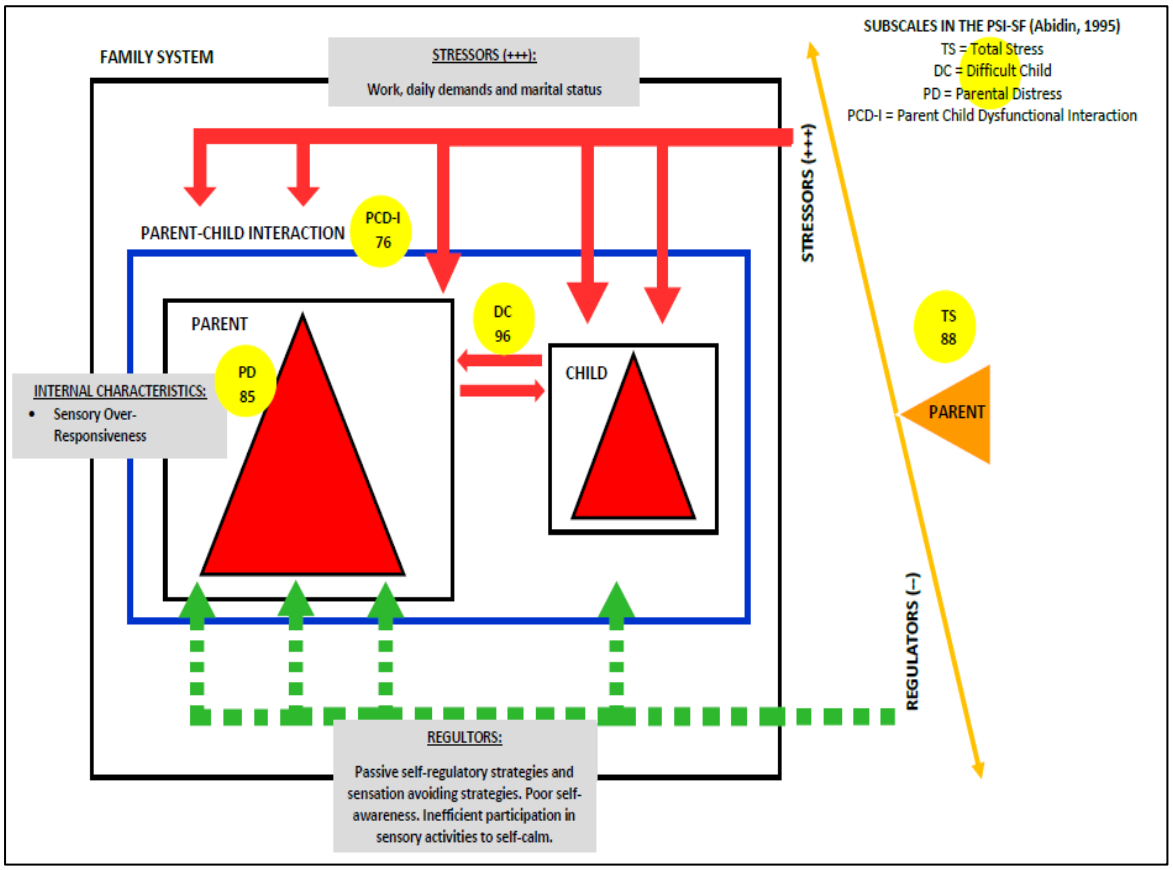


Figure 5.1: Framework displaying comparison between regulatory strategies and stress at baseline

The three contributors to the participants' stress were their own parental distress (the downward red arrows in Figure 5.1, labelled stressors), stressors relating to the challenging behaviour of their child (the red arrow pointing from the child to the parent in Figure 5.1) and the difficulties related to their SOR (in other words, the internal characteristics for the parent).

DeGangi (2012) found that adults who have difficulties with self-regulation, tended to rely on others to help achieve greater calm. This difficulty in self-initiation of self-calming activities was evident in this study, as the participants initially stated that they did not know what activities best calmed them down. As a result, the effectiveness and participation of self-regulatory activities was deficient, as shown in the broken green arrow lines in Figure 5.1.

The participants therefore required guidance on what activities were the most efficient, in order to achieve greater regulation. During the programme, the participants gained greater insight into the sensory activities that were most effective to assist with their self-regulation. The participants initially executed various activities that they

considered to be calming, but these activities were not efficient or effective enough to optimally self-regulate them and reduce their stress levels. The choice, amount and type of activities that an individual with SOR may typically engage in, usually has a negative impact on their quality of life (Abernethy, 2010) and may be more demanding to one's time and energy (Kinnealey, Oliver, & Wilbarger, 1995), which in turn influences one's bodily resources and ability to cope. Due to the participants lack of efficient and effective active self-regulatory strategies, they were initially functioning in a sympathetic stress state (as demonstrated by the red triangle in Figure 5.1). After the intervention, a shift was noted in the choice of activities that the participants took part in and the frequency at which they performed these activities. A change was also seen in their intake of sweet foods and caffeine. In addition, they performed regulatory activities to *prevent* feeling overwhelmed, stress and anxiety; and planned and actively performed these activities during the day to self-regulate.

A critical skill in self-regulation, is the individuals' ability to adjust their actions, thoughts and feelings in reaction to their situational demands, as well as developing good self-awareness (DeGangi, 2012). The positive change in the participants' participation in self-regulatory activities was reflected in the decrease in their total stress and parental distress. Following the programme, they felt more connected to their bodies, implying that they achieved greater self-awareness, which is an important component of self-regulation and management of stress. DeGangi (2012) highlights that an individual with poor self-awareness may not recognise that he or she is exhausted, which can result in fatigue and failure at tasks. The participants also felt that their self-regulatory strategies were more optimal post intervention. A bidirectional relationship is shown between stress, self-awareness and self-regulation. As the participants felt less stressed and gained greater self-awareness, they had a greater capacity to perform more optimal self-regulatory activities, which appeared to further decrease their stress levels.

After the intervention (Figure 5.2), the participants displayed an improved homeostatic state, which was reflected in the positive change in their total stress scores. They reached a more normal range for their total stress post-intervention. Although the difficulties relating to their child were still within the high range (as shown in the red arrow pointing from the child to the parent in Figure 5.2), they displayed an improved ability to tolerate the demands relating to their child (as shown in the green arrow pointing from the parent to the child in Figure 5.2). The positive change in their total stress score was largely due to the decrease in their parental distress score, which decreased from a high range to a more normal range. This normal range score is illustrated by the green parent triangle in Figure 5.2. The participants displayed an improved autonomic nervous system state, due to their improved self-regulatory strategies.

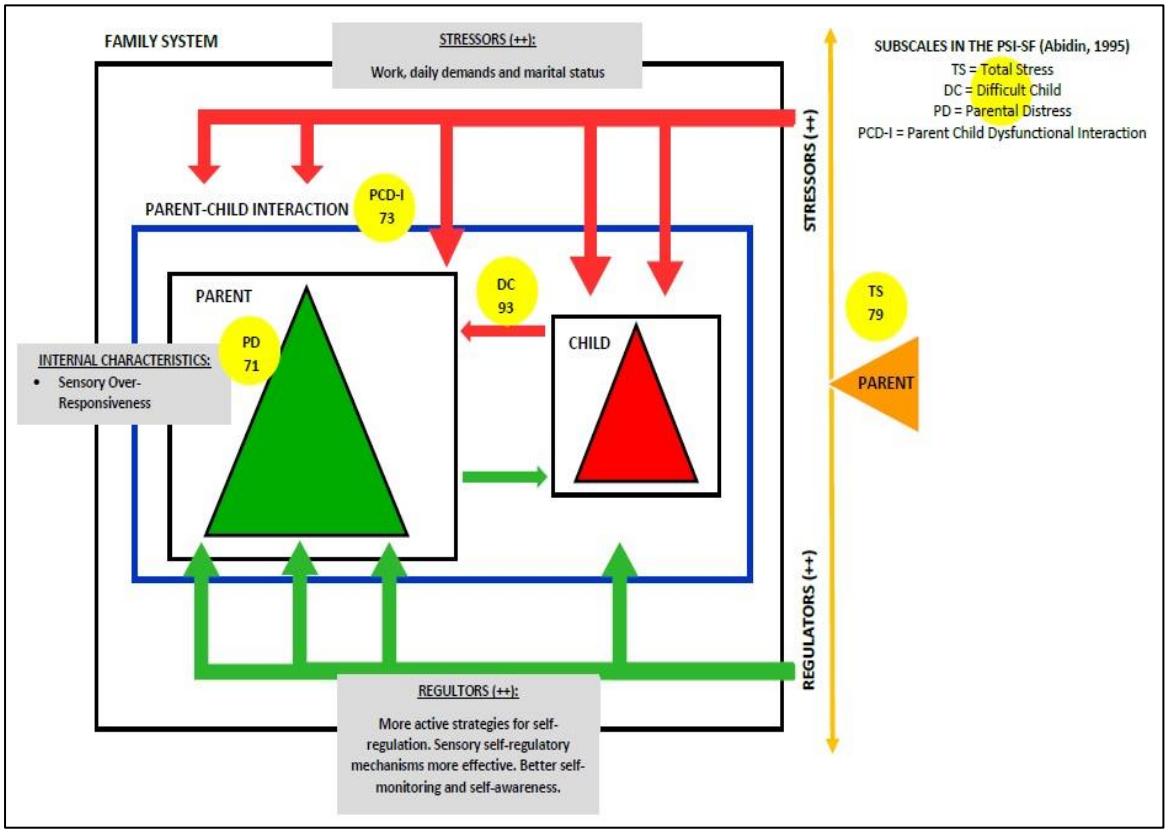


Figure 5.2: Framework displaying comparison between regulatory strategies and stress after intervention

When evaluating the effectiveness of the stress management programme, each component of the PSI-SF was considered, including total stress in particular.

5.4.2 Parental Distress

Parental distress displays the parent's level of distress, which includes their sense of parenting competence, stressors associated with other life roles, parental conflict, social support and depression (Abidin, 1995).

The parental distress score decreased post-intervention with a large effect size indicating clinically relevant change and then decreased further with a moderate clinically relevant change three months following the programme. The participants' scores started in the high range for parental distress, and by the end of the programme and three months follow up, they reached a more normal range for the parental distress scale on the PSI-SF, as a group.

This positive clinically relevant change may be attributed to the self-regulatory strategies that were explored and implemented over the course of the programme. Based on the programme evaluation, the participants found the programme to be helpful, reporting that it helped them gain greater insight into their body's sensory needs, their stress levels, on how to manage their stress and recover from stressful situations quicker than previously. This confirms the programme was meaningful to the participants, which is one of the criteria for judging relevant change in conjunction with statistical analysis. Effect sizes has confirmed the positive changes, particularly in the participants' parental distress scores, due to the insight and implementation of more efficient self-regulatory strategies learnt during the stress management programme.

5.4.3 Parent-Child Dysfunctional Interaction

The PCD-I subscale looks at "the parents perception that the child does not meet his or her expectations, and that his or her interactions with the child are not reinforcing" to them as a parent (Abidin, 1995). In the programme, this subscale showed the least change. It could be due to the fact that the participants remained within the normal range for this subscale, and initially did not perceive to have significant negative feelings to their child or display concerns related to the bonding they have with their child. However, the passive behaviour presentation in the Sensory Profile (namely, low registration and sensory sensitivity) confirms that they may struggle to manage their child's needs and behaviours, but did not perceive this to be a problem. It appears that any difficulties experienced were seen to be routed in the child (as seen in the DC score), and not the way they respond to their child.

5.4.4 Difficult Child

The characteristics of the child impacts on the level of difficulty to manage their child (Abidin, 1995). Although the difficult child scores started in the clinical significant range pre-intervention and post-intervention; at three months follow up, the DC score fell within the normal range. Although these changes could be attributed to the therapy that the child was also receiving during the time of the intervention, it is possible that addressing the participants stress levels further decreased the child's difficult child score.

A highly stressed parent does not have the capacity to model optimal self-regulatory strategies to their children, which could further impact on their child's behaviour (Neece, Green, & Baker, 2012). Thus, one could infer that a less stressed parent could model better self-regulatory strategies and thus positively influence their child's behaviour. This is reinforced by Abidin's (1995) model, which shows the bidirectional relationship between parental distress and difficult child. This bidirectional relationship is shown by the two arrows pointing between the parent and child in Figure 5.1 and 5.2. The bidirectional relationship is also highlighted by Sbarra and Hazan (2008), who report that the most potent regulator is from the individual who the child is most closely attached to, and that bonding behaviours can increase parasympathetic nervous system activity. This supports with findings from the evaluation questionnaire, as the majority of the participants found that they were able to manage their child's behaviour and sensory needs better. Gaining knowledge on one's own sensory needs, as well as one's child's sensory needs, the participants become "better equipped to optimise their learning environment without under- or over- stimulating them, both of which extremes may be detrimental to children's development on a sensory, motor and social level" [p94-95] (Lombard, 2007).

5.4.5 Total Stress

The two largest contributors to an overall decrease in the participants' total stress score were their parental distress and difficult child score. Three months' follow-up from the programme, the participants maintained the downward trend of decreasing their stress scores, but to a lesser degree. This indicates firstly that it does take time to implement strategies and effect change, and secondly, that the strategies learnt in the programme were maintainable. The question remains whether the downward trend in their stress scores would continue to decrease beyond three months, or would

further intervention be required to assist with the sustainability of managing the participants stress.

There was one particular participant who displayed the most severe SOR presentation on her sensory profile: *much more than most* for sensation sensitive, sensation avoiding and low registration. She also displayed *much less than most* for sensation seeking behaviour. This presentation indicates that she makes use of passive strategies to self-regulate and uses sensation avoidance as her active strategy. This participant displayed the greatest benefit from the programme, showing the most significant change in her total stress score, post-intervention. The significant change indicates and reinforces that individuals with SOR may benefit the most from a sensory modulation-based stress management programme.

Upon evaluation, the participants indicated a wish to attend more group sessions, but nevertheless felt that the programme addressed their needs, they gained useful strategies to manage their stress levels, they understood the concepts learnt in the programme, they were able to implement the strategies, and that the strategies were relevant to their life and situation. I, as the researcher found that the participants particularly benefited from the social interaction and support that the group session provided. The participants felt like they were part of a community, as they realised that they were not the only ones experiencing the difficulties relating to their child and to their SOR. Upon completion of the programme, it was evident that the participants gained insight into their body's' sensory needs and felt more empowered to manage their stress levels. These positive reports reinforce the positive changes found in the total stress scores of the PSI-SF post-intervention.

5.5 LIMITATIONS OF THE STUDY

The following limitations must be noted for the study. Firstly, the PSI-SF, sensory profile and sensory self-regulatory questionnaire are self-report measures, which may not accurately portray the individual's true presentations. The reliance on self-report measures can be influenced by factors including error and method variance, which includes aspects like social desirability, memory and mood at the time of completion of the questionnaires. It is thus recommended that an additional form of outcome measure be included, in order to correlate with the data received in the self-report measures. The data collected was only by the mother, which could indicate further single source measurement bias. Thus it would also be beneficial to have an additional

source to note changes made. For example, an outcome measure that is completed by the child's teacher or therapist to assess the child's characteristics or by a family member, noting changes in the mother. In addition, it would be useful to utilise other outcome measures to correlate with the participants' reported parental stress, such as other biomarkers to evaluate stress that assess parasympathetic function.

Secondly, a small non-randomised sample size was used. Therefore, the results received from this study cannot be generalised to the population and thus caution needs to be taken in interpreting the results. It could also influence the meaningful analyses of the group of mothers and possible differences. In addition, mothers from the Gauteng region whose children are receiving private therapeutic services was used in the sample. A larger sample and greater target population would be of greater benefit in order to optimally evaluate the effectiveness of the intervention for the target population. Extending the target population to various socioeconomic areas, as well as including fathers, would provide more diverse results.

Although it was originally intended that an alternate group design would be used with one group of mothers acting as a control while the other group received the intervention, the small number of participants made this research design unrealistic. The research was changed to a pre-test post-test design and no control group was used. It is therefore difficult to conclude that the intervention itself directly influenced to the mother's parental stress. The difficulty of including a control group, is the ethics of excluding the control group participants from receiving intervention, especially since no known intervention is offered to mothers of this target population. Although there was no control group used in this study, findings did show the feasibility of a sensory modulation-based stress management programme for mothers with children with SMD.

5.6 STRENGTHS OF THE STUDY

The following strengths were identified in the intervention provided in the study, which aided in the positive clinical changes made in the PSI-SF.

The mothers received an individualized treatment programme, which ensured that their individual sensory needs were taken into consideration. Individualisation enhances the effectiveness of stress reduction. In addition, the self-regulatory activities performed were sensory based, which focuses on a bottom-up approach in

terms of stress reduction, thus enhancing more sustainability of the changes made. The mothers were also provided with time to implement the sensory strategies within their various environments.

The programme was administered by one person, to ensure consistency in the delivery and administration of the programme. Although the programme was individualized and applied to the mother's needs, the procedure and manner employed, was the same for each mother.

5.7 SUMMARY

The participants displayed a typical SOR presentation, with overall scores presenting within the low threshold continua of Dunn's quadrant model, namely sensory sensitivity and sensation avoiding. They also presented in the low registration quadrant. When further analysing the participants' sensory profiles, it became evident that they used a combination of passive self-regulatory strategies and sensation avoiding strategies to self-calm, with fewer sensory seeking behaviour strategies. This presentation was reflected in the results of the sensory self-regulatory questionnaire, which revealed that the participants had weak and inefficient self-regulatory strategies as a whole. It became evident in the findings, that the combination of the participants SOR and mal-adaptive self-regulatory strategies, reduced their ability to efficiently manage their stress levels. As a result of their SNS being in dominance, they were not able to self-initiate the process of self-regulation and display optimal self-awareness, which is the crux to self-regulation. They thus displayed high levels and clinically significant levels of stress in the PSI-4-SF. The results also revealed that working hours, marital status and medical conditions most influenced their stress. As a result of the participants increased stress, they struggled to cope with juggling multiple roles, deal with their daily demands, sleep optimally at night, and manage their child's behaviour.

A framework was developed to assist in analysing the effects of the stress management programme implemented in this study. Although no statistical significance was found in the change in subscale scores in the PSI-SF, clinically relevant change was found using effect sizes in the scores for parental distress, difficult child and total stress score. The choice, frequency and type of activities that the participants performed throughout their day post-intervention shifted. This resulted in the participants displaying a greater homeostatic state, a greater ability to cope with their stressors and thus overall decrease in their total stress.

The parental distress score started in the high range, but by the end of the programme and three months follow up, the group reached a more normal range for the parental distress scale on the PSI-SF. This positive clinical change may be attributed to the self-regulatory strategies that were explored and implemented over the course of the programme. Although PCD-I was the subscale with the least change, a positive correlation was found between the low registration and sensory sensitive quadrant of Dunn's model. This positive correlation shows that although the participants perceived their relationship with their child to be normal, the way they managed their child's behaviour and responded to their child's needs, may be hampered. Encapsulating the parent-child relationship are the characteristics of the parent and child. A bidirectional relationship was evident between parental distress and difficult child, which were the two largest contributors to the parents' total stress. Although the difficult child scores started in the clinical significant range pre-intervention, by the end of the study, the DC score fell within the normal range. Although these changes could be attributed to the therapy that the child was also receiving during the time of the intervention, it is possible that addressing the participants' stress levels further decreased the child's difficult child score. This bidirectional relationship highlights the importance of co-regulation. It also shows that the co-regulator needs to be have adequate knowledge and understanding of their own sensory needs, their child's sensory needs, as well as their need to be in an optimum state to efficiently attend to the needs of their child, particularly a child with SMD.

A few limitations were identified in the study, which included the small sample size, lack of control group and that the study solely made use of self-report measures. However, a few strengths of the study suggest that promoted changes found were as a result of the stress management programme. Although individualisation was ensured to enhance the effects of the stress reduction intervention, the programme followed a set structure and consistency in the administration of the programme was ensured. The programme primarily made use of a bottom-up approach whereby sensory strategies were the main focus in decreasing the participants stress. These factors aided in the promotion of changes made post-intervention. Although the participants would have liked to have attended more group sessions, they felt that the programme addressed their needs, they gained useful strategies to manage their stress levels, they understood the concepts learnt in the programme, they were able to implement the strategies and that the strategies were relevant to their life and situation.

CHAPTER 6 CONCLUSION

6.1 INTRODUCTION

The purpose of the study was to investigate the stress levels, sensory profile and sensory self-regulatory strategies of mothers who have children with SMD, and who have SOR themselves. In addition, it aimed to investigate the effectiveness of a twelve-week stress management programme using a sensory modulation-based approach. Results from the study indicated that the participants were not able to optimally manage their high stress levels, as a result of a combination of the their SOR and mal-adaptive self-regulatory strategies. It is questionable as to what the implications of high parental stress would have on a child and on the management of the child's behaviour, especially when having a child with SMD. Findings from other studies has found that negative, intrusive and less sensitive parenting behaviour has been linked to parenting stress. In addition, this type of parenting behaviour has been linked to more child behavioural difficulties (Abidin, 1992). This study suggests a bidirectional relationship between the participants' total stress, parental distress and difficulties relating to their child. Therefore, by reducing parental stress through the use of a stress reduction programme, it is proposed that the parents' sensitivity and responsiveness to their child could improve their child's behaviour.

Parents who have children with SMD reported that their children struggle with self-regulation (Cohn, Miller, & Tickle-Degnen, 2000), and that their child's sensory behaviours can limit their family activities and routines (Schaaf et al., 2003). From an occupational therapy perspective, the parent plays a vital co-regulatory role when treating a child with SMD, by implementing sensory diets at home and constantly evaluating the child's sensory needs. Cohn and Cermak (1998) believe that by educating parents about their child's SMD, they can better understand their child's behaviours and thus structure the environment more optimally. Greater understanding promotes more adaptive responses and therefore an improved response to their child's behaviours (Cohn & Cermak, 1998). However, if parents do not have the capacity to self-regulate themselves, and if their bodies are functioning in a sympathetic state, then they will not be able to apply these principles learnt and

efficiently co-regulate their child. This would be especially prevalent with mothers who are displaying SOR.

Research findings support the fact that more focus needs to be provided to parents who have children with disabilities, due to the parental stress associated with this (Baker et al., 2003; Gupta, 2007; Neece, Green, & Baker, 2012). However, there was no research that explored interventions for parents who have children with SMD. While research findings support the importance that a family needs to be incorporated into the treatment of children with SMD (Cohn & Cermak, 1998), this was limited. This study aims to highlight the importance of addressing the parents' needs when treating children with SMD. In addition, two other parental characteristics were viewed as important when treating parental stress, namely, sensory processing and sensory self-regulatory strategies. The findings from this study suggest that by addressing the mother's sensory needs and empowering them with sensory strategies to manage and reduce their stress levels, they were better able to manage the difficulties relating to their child. Following intervention, the participants' in this study presented with clinical reductions in their scores for total stress, parental distress, and in their perceived difficulties relating to their child.

This study contributes to the limited literature on SOR in adults, and how to effectively treat them. In addition, it includes a more holistic approach to the effective treatment of children with SMD, by including mothers in the treatment plan. Occupational therapists can play a unique role in stress management due to their knowledge of sensory processing, and the effects that sensory experiences can have on one's nervous system (Dunn, 2001). They are therefore better equipped to empower individuals with self-regulatory activities that are specific to that individual's sensory preferences, therefore making the intervention as effective as possible. In addition, occupational therapists value the importance of occupation, and can therefore employ a holistic view when treating individuals with SMD or individuals who are stressed. Paediatric occupational therapists have neglected the true role that they can play when treating children with SMD. Although research provides evidence of the importance of including family context when using sensory integration therapy (Cohn & Cermak, 1998), occupational therapists neglect to prioritise the importance of family context in their treatment plans. Evidence provided in this research highlights the finding that focusing on the parents does not only decrease their overall distress, but also decrease the perceived level of difficulty of their child. Their change in perception can

then enable more positive outcomes for the child. Results from the research confirm the importance of examining the family context and the dynamic interplay between each component in the family system. This is important in an attempt to try decrease the vulnerability of the family system. The model conceptualised for this study can provide an intervention framework for other therapists to use when treating a child more holistically in their practice. This model allows for a more comprehensive and integrated view of the family system.

In conclusion, this study contributes to the body of research available that, firstly investigates stress in parents with children with disabilities, and secondly adds to the treatment of adults with SMD. Additionally, this study contributes to the understanding of the effectiveness of a stress management programme for mothers as an intervention tool in therapeutic contexts.

6.2 CLINICAL IMPLICATIONS OF FINDINGS

Children with SMD have complex and multiple needs (Cohn, Miller, & Tickle-Degnen, 2000). Since parent's mental health and well-being can have a significant impact on the child's overall development, it is important to address both the child's and the parent's needs. This study highlights a more holistic intervention to enhance therapeutic outcomes for children, without neglecting to address the inherent vulnerability of the family system.

Findings in this study suggest that interventions with children become more multi-dimensional. When treating a child with SMD, this study has shown the importance of addressing the mother's stress levels, in addition to treatment of the child. Including a parental stress outcome measure in occupational therapy evaluations, such that of the PSI-SF, would provide valuable information pre-intervention. It would provide insight into the parents' stress levels and would assist in identifying the needs of the family system, as well as that of the child. The information received from the PSI-SF and the insights gained from the model could inform the intervention plan required for the child and his or her family.

An evaluation of the stress management programme includes the participants' recommendations. Firstly, that another group session would be of benefit. Secondly, that other coping strategies be included in the sessions, such as the management of their child's challenging behaviour. And lastly, the mothers requested more sessions.

Therefore, the follow up amendments to the sensory modulation-based stress management programme is advised: more social support, more intervention time, and the addition of other cognitive coping strategies which addresses parent-child relationships. In addition, to fully address parental stress, initiating the programme with sensory modulation-based principles, and then transitioning to more emotional and cognitive focused coping strategies, would be of greatest benefit.

When treating adults with SOR, it is vital to assess the context of their functioning and to apply sensory strategies that are relevant to their lifestyle, roles and needs. The sensory self-regulatory questionnaire provided some useful insights into the mothers' current coping mechanisms, and areas that need to be addressed to optimise their coping strategies. There are questionnaires available that assess an individual's emotional and cognitive self-regulation, but there are no self-regulatory questionnaires that look at an individual's sensory self-regulation. The sensory self-regulatory questionnaire, designed for this study, offers an additional measure that can be used when evaluating parental stress.

6.3 RECOMMENDATIONS FOR FURTHER RESEARCH

Three recommendations for further research are suggested.

Firstly, including participants with sensory over-responsiveness and sensory under-responsiveness in such a study would provide a more representative view of SMD as a whole.

Secondly, further investigation into the realms of stress intervention for parents who have children with SMD is recommended.

Thirdly, continued research that investigates the effectiveness of a sensory modulation-based stress management programme with a larger sample and a control group, would be of benefit. Ensuring a larger sample and control group would assist in establishing if the stress management programme has true benefits to parental stress. Therefore, a more longitudinal research design, characterised by alternating treatment groups should be used. This is to ensure that the participants who are placed in the control group receive intervention at a later stage.

And lastly, although the sensory self-regulatory questionnaire has obtained validity on its content, it would require further research to establish both its validity and reliability, in order to use this for assessment and treatment purposes.

Further research that explores the realms of parental stress in relation to the child's therapeutic journey is recommended, specifically in providing more holistic treatment plans when treating a child with SMD.

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APPENDIX A

Stress management programme outline

The following table provides a description of the topics used in each session in the stress management programme.

Week number	Session Number	Main Topic	Description
1	1	Individual session: Initial contact	• Introduction to programme • Researchers goals and expectations explained • Mothers goals established (choose 1-2) • Mothers main concerns and triggers of stress. • What kind of sensory situation do you encounter on a regular basis that bothers you the most? Just choose 1 sensory experience. Rate from 1-10 • Complete questionnaires
2	2	Individual session: Sensory Profile	• Explain thresholds and significance of senses to our functioning • Plotting and exploring the mother's sensory profile on the Sensory Tree ™. • Insights of sensory tree into personal life and habits • Goodness of fit – relationship of mom and child (done if deemed necessary). • Plot arousal graph • Identify what sensory activities can be done in a day to reduce increases in arousal levels. • Start on formation of sensory diet.
3	One week break to execute daily sensory diet and apply sensory principles and self-regulatory strategies.		

4	3	Individual session: Stress, sensory diet and sensory exploration.	• Feedback on PSI-SF. • Sensory overload and stress…how this relates to ANS. • Sensory exploration • Reflection on sensory diet and making amendments. • Continuation of formation of sensory diet. • Breathwork
5-6	Two week break to execute daily sensory diet and apply sensory principles and self-regulatory strategies.		
7	4	Individual session: Sensory diet, functional application and sensory experience.	• Breathwork • Reflection of sensory diet and making amendments. • Questions or clarification • Functional application of scenario. Anticipation, planning and preparation.
8	5	Group session: Mandala	• Breathwork • Mandala • Sharing of sensory diet and experience thus far.
9-11	Three week break to execute daily sensory diet and apply sensory principles and self-regulatory strategies.		
12	6	Individual session: Closing session	• Relook at goals • Breathwork • Completion of questionnaires • Reflection of programme

APPENDIX B

Occupational Therapy
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LETTER OF PERMISSION

31 May 2015

Ms K Bailey and Ms N Katzenellenbogen
Block G Rochester Place
173 Rivonia Road
Morningside
Johannesburg
South Africa

Dear Kate and Nicole

This letter serves to obtain your permission in offering the mothers at your practice an opportunity to take part in my research study. My research is looking at the effectiveness of a stress management programme for mothers who have children with sensory modulation difficulties and who have sensory over-responsiveness themselves.

Research studies have found that parents of children with sensory modulation difficulties have higher levels of stress. In addition, mothers of children with varying developmental difficulties were found to have significantly poorer wellbeing and higher parenting stress than their spouses. Furthermore, due to the genetic predisposition, the mothers of these children may have sensory processing difficulties themselves. The challenges of having a child with sensory processing difficulties may be compounded by the mothers own neurological thresholds and their limited coping mechanisms. This further adds to their stress levels. Research has found that in order to significantly reduce the parents stress levels, more specific focus needs to be made on the parents (specifically mothers) well-being and stress management. This therefore has led me to my research study. The aim of my research is to: Firstly,

investigate the relationship of the mothers perceived stress levels and how they self-regulate; and secondly, to evaluate the effectiveness of a 12-week sensory modulation-based stress management programme for mothers with sensory over-responsiveness.

The stress management programme will be conducted over a period of 12 weeks. This includes 5 individual sessions with myself at a practice in Lonehill and 2 group sessions at a practice at Wilgeheuwel Hospital. Various activities will need to be done at home that will help reduce the mothers stress levels. On initiation and at the end of the programme, they will also be required to complete 4 different questionnaires. This will help individualise the stress management programme, so that it caters for the mother's needs, as well as provide me with information in order to analyse the effectiveness of the stress management programme and investigate the relationship between one's stress levels and coping mechanisms.

Once I have received the mothers consent and willingness to take part in the research, they will firstly be required to complete 2 questionnaires. These questionnaires will help me establish their perceived stress level and sensory profile, as well as assess as to whether they meet the inclusion criteria for the research. They will need to display clinically significant levels of stress in the stress questionnaire, sensory over-responsiveness in one of their sensory systems, as well as display a "sensory sensitive" or "sensory avoiding" sensory profile. In addition to these aforementioned inclusion criteria, they also need to meet the following criteria in order to patriciate in the research.

- They need to agree to attend the full Stress Management programme, as well as agree to comply with the various activities recommended during the programme.
- They are currently not on any medication for a mental health condition.
- They have not been formally diagnosed as having post-traumatic stress disorder or have recently been involved in a traumatic event (within the last year).
- They are not participating in another psychological or stress-based programme.

Should the mothers meet the inclusion criteria and agree to participate in the research, they will randomly be assigned to either group A or group B. Group A will take part in the stress management programme first and group B will take part in the second round of the stress management programme, in about 4-5 months' time. I will need to gather a certain number of participants in order to start with the stress management programme.

During my time together with the mothers during the programme, I will help the mothers understand why they respond to sensory input the way they do and the effects of their coping mechanisms on their stress levels. We will also establish various mechanisms that can help them function more effectively within their environment and cope with their stressors. My aim is to empower the mothers and provide them with various skills, so that they are able to cope and manage their current and future stress levels. There are no risks involved in partaking in the research.

The programme is designed to help the mothers benefit as much from the programme as possible. This is a unique stress management programme that will help create a different perspective on their stress levels and how to manage them. It will empower them and create spaces for self-healing. It is important to note that the information shared to me throughout the research or programme will be kept strictly confidential and that the programme is completely voluntary.

I will be requiring a total number of 30 mothers to take part in my research study and thus would greatly appreciate it, if you would allow me to invite the appropriate mothers at your practice, of whom their children are being treated by one of your therapists at your practice for sensory modulation difficulties. This will not interrupt with your therapeutic process in any way. The results of my research will be made available to you once the research has been finalised.

If you have any queries or require more information, please do not hesitate to contact me on 072 858 8083. If you agree to grant me permission to invite the mothers at your practice, please sign the attached permission form.

If you have any ethical concerns please contact the chairperson of the Wits Human Research Ethics Committee, Prof P Cleaton-Jones on 011 7171234 or at zanele.ndlovu@wits.ac.za

Your assistance would be greatly appreciated.

Thank you,

Kind regards,



Carryn Martin

PERMISSION FORM

I, KATE BAILEY grant Carryn Martin permission to invite the relevant and appropriate mothers at our practice in MORNINGSIDE to partake in her research study.

Signature: 

Date: 4th August 2015

APPENDIX C



ADOLESCENT/ADULT SENSORY PROFILE™

Catana Brown, Ph.D., OTR, FAOTA
Winnie Dunn, Ph.D., OTR, FAOTA

Self Questionnaire

Subject code _____ Age: _____ Date: _____

Birthdate: _____ Gender: ☐ Male ☐ Female

Are there aspects of daily life that are not satisfying to you? If yes, please explain. _____

_____

_____

_____

INSTRUCTIONS

Please check the box that **best** describes the frequency with which you perform the following behaviors. If you are unable to comment because you have not experienced a particular situation, please draw an X through that item's number. Write any comments at the end of each section.

Please answer all of the statements. Use the following key to mark your responses:

ALMOST NEVER	When presented with the opportunity, you **almost never** respond in this manner (about 5% or less of the time).
SELDOM	When presented with the opportunity, you **seldom** respond in this manner (about 25% of the time).
OCCASIONALLY	When presented with the opportunity, you **occasionally** respond in this manner (about 50% of the time).
FREQUENTLY	When presented with the opportunity, you **frequently** respond in this manner (about 75% of the time).
ALMOST ALWAYS	When presented with the opportunity, you **almost always** respond in this manner (about 95% or more of the time).

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Item		A. Taste/Smell Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
	1	I leave or move to another section when I smell a strong odor in a store (for example, bath products, candles, perfumes).					
	2	I add spice to my food.					
	3	I don't smell things that other people say they smell.					
	4	I enjoy being close to people who wear perfume or cologne.					
	5	I only eat familiar foods.					
	6	Many foods taste bland to me (in other words, food tastes plain or does not have a lot of flavor).					
	7	I don't like strong tasting mints or candies (for example, hot/cinnamon or sour candy).					
	8	I go over to smell fresh flowers when I see them.					

Comments

Item		B. Movement Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
	9	I'm afraid of heights.					
	10	I enjoy how it feels to move about (for example, dancing, running).					
	11	I avoid elevators and/or escalators because I dislike the movement.					
	12	I trip or bump into things.					
	13	I dislike the movement of riding in a car.					
	14	I choose to engage in physical activities.					
	15	I am unsure of footing when walking on stairs (for example, I trip, lose balance, and/or need to hold the rail).					
	16	I become dizzy easily (for example, after bending over, getting up too fast).					

Comments

Item		C. Visual Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
	17	I like to go to places that have bright lights and that are colorful.					
	18	I keep the shades down during the day when I am at home.					
	19	I like to wear colorful clothing.					
	20	I become frustrated when trying to find something in a crowded drawer or messy room.					
	21	I miss the street, building, or room signs when trying to go somewhere new.					
	22	I am bothered by unsteady or fast moving visual images in movies or TV.					
	23	I don't notice when people come into the room.					
	24	I choose to shop in smaller stores because I'm overwhelmed in large stores.					
	25	I become bothered when I see lots of movement around me (for example, at a busy mall, parade, carnival).					
	26	I limit distractions when I am working (for example, I close the door, or turn off the TV).					

Comments

Item		D. Touch Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
	27	I dislike having my back rubbed.					
	28	I like how it feels to get my hair cut.					
	29	I avoid or wear gloves during activities that will make my hands messy.					
	30	I touch others when I'm talking (for example, I put my hand on their shoulder or shake their hands).					
	31	I am bothered by the feeling in my mouth when I wake up in the morning.					
	32	I like to go barefoot.					
	33	I'm uncomfortable wearing certain fabrics (for example, wool, silk, corduroy, tags in clothing).					
	34	I don't like particular food textures (for example, peaches with skin, applesauce, cottage cheese, chunky peanut butter).					
	35	I move away when others get too close to me.					
	36	I don't seem to notice when my face or hands are dirty.					
	37	I get scrapes or bruises but don't remember how I got them.					
	38	I avoid standing in lines or standing close to other people because I don't like to get too close to others.					
	39	I don't seem to notice when someone touches my arm or back.					

Comments

Item		E. Activity Level	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
	40	I work on two or more tasks at the same time.					
	41	It takes me more time than other people to wake up in the morning.					
	42	I do things on the spur of the moment (in other words, I do things without making a plan ahead of time).					
	43	I find time to get away from my busy life and spend time by myself.					
	44	I seem slower than others when trying to follow an activity or task.					
	45	I don't get jokes as quickly as others.					
	46	I stay away from crowds.					
	47	I find activities to perform in front of others (for example, music, sports, acting, public speaking, and answering questions in class).					
	48	I find it hard to concentrate for the whole time when sitting in a long class or a meeting.					
	49	I avoid situations where unexpected things might happen (for example, going to unfamiliar places or being around people I don't know).					

Comments

Item		F. Auditory Processing	ALMOST NEVER	SELDOM	OCCASIONALLY	FREQUENTLY	ALMOST ALWAYS
	50	I hum, whistle, sing, or make other noises.					
	51	I startle easily at unexpected or loud noises (for example, vacuum cleaner, dog barking, telephone ringing).					
	52	I have trouble following what people are saying when they talk fast or about unfamiliar topics.					
	53	I leave the room when others are watching TV, or I ask them to turn it down.					
	54	I am distracted if there is a lot of noise around.					
	55	I don't notice when my name is called.					
	56	I use strategies to drown out sound (for example, close the door, cover my ears, wear ear plugs).					
	57	I stay away from noisy settings.					
	58	I like to attend events with a lot of music.					
	59	I have to ask people to repeat things.					
	60	I find it difficult to work with background noise (for example, fan, radio).					

Comments

APPENDIX D

PSI Short Form

Instructions

This questionnaire contains 36 statements. Read each statement carefully. For each statement, please focus on the child you are most concerned about, and circle the response that best represents your opinion.

Circle the SA if you strongly agree with the statement.

Circle the A if you agree with the statement.

Circle the NS if you are not sure.

Circle the D if you disagree with the statement.

Circle the SD if you strongly disagree with the statement.

For example, if you sometimes enjoy going to the movies, you would circle A in response to the following statement:

I enjoy going to the movies. SA (A) NS D SD

While you may not find a response that exactly states your feelings, please circle the response that comes closest to describing how you feel. YOUR FIRST REACTION TO EACH QUESTION SHOULD BE YOUR ANSWER.

Circle only one response for each statement, and respond to all statements. **DO NOT ERASE!** If you need to change an answer, make an "X" through the incorrect answer and circle the correct response. For example:

I enjoy going to the movies. SA A NS (X) (SD)

Before responding to the statements, write your name, gender, date of birth, ethnic group, marital status, child's name, child's gender, child's date of birth, and today's date in the spaces at the top of the questionnaire.

Name_____ Gender ____ Date of birth _____ Ethnic group _____ Marital status_____

Child's name_____ Child's gender_____ Child's date of birth _____ Today's date_____

SA = Strongly Agree A = Agree NS = Not Sure D = Disagree SD = Strongly Disagree

1.	I often have the feeling that I cannot handle things very well.	SA	A	NS	D	SD
2.	I find myself giving up more of my life to meet my children's needs than I ever expected.	SA	A	NS	D	SD
3.	I feel trapped by my responsibilities as a parent.	SA	A	NS	D	SD
4.	Since having this child, I have been unable to do new and different things.	SA	A	NS	D	SD
5.	Since having a child, I feel that I am almost never able to do things that I like to do.	SA	A	NS	D	SD
6.	I am unhappy with the last purchase of clothing I made for myself.	SA	A	NS	D	SD
7.	There are quite a few things that bother me about my life.	SA	A	NS	D	SD
8.	Having a child has caused more problems than I expected in my relationship with my spouse (or male/female friend).	SA	A	NS	D	SD
9.	I feel alone and without friends.	SA	A	NS	D	SD
10.	When I go to a party, I usually expect not to enjoy myself.	SA	A	NS	D	SD
11.	I am not as interested in people as I used to be.	SA	A	NS	D	SD
12.	I don't enjoy things as I used to.	SA	A	NS	D	SD
13.	My child rarely does things for me that make me feel good.	SA	A	NS	D	SD
14.	Sometimes I feel my child doesn't like me and doesn't want to be close to me.	SA	A	NS	D	SD
15.	My child smiles at me much less than I expected.	SA	A	NS	D	SD
16.	When I do things for my child, I get the feeling that my efforts are not appreciated very much.	SA	A	NS	D	SD
17.	When playing, my child doesn't often giggle or laugh.	SA	A	NS	D	SD
18.	My child doesn't seem to learn as quickly as most children.	SA	A	NS	D	SD
19.	My child doesn't seem to smile as much as most children.	SA	A	NS	D	SD
20.	My child is not able to do as much as I expected.	SA	A	NS	D	SD
21.	It takes a long time and it is very hard for my child to get used to new things.	SA	A	NS	D	SD

For the next statement, choose your response from the choices "1" to "5" below.

22.	I feel that I am: 1. not very good at being a parent 2. a person who has some trouble being a parent 3. an average parent 4. a better than average parent 5. a very good parent	1	2	3	4	5
23.	I expected to have closer and warmer feelings for my child than I do and this bothers me.	SA	A	NS	D	SD
24.	Sometimes my child does things that bother me just to be mean.	SA	A	NS	D	SD
25.	My child seems to cry or fuss more often than most children.	SA	A	NS	D	SD
26.	My child generally wakes up in a bad mood.	SA	A	NS	D	SD
27.	I feel that my child is very moody and easily upset.	SA	A	NS	D	SD
28.	My child does a few things which bother me a great deal.	SA	A	NS	D	SD
29.	My child reacts very strongly when something happens that my child doesn't like.	SA	A	NS	D	SD
30.	My child gets upset easily over the smallest thing.	SA	A	NS	D	SD
31.	My child's sleeping or eating schedule was much harder to establish than I expected.	SA	A	NS	D	SD

For the next statement, choose your response from the choices "1" to "5" below.

32.	I have found that getting my child to do something or stop doing something is: 1. much harder than I expected 2. somewhat harder than I expected 3. about as hard as I expected 4. somewhat easier than I expected 5. much easier than I expected	1	2	3	4	5

For the next statement, choose your response from the choices "10+" to "1-3."

33.	Think carefully and count the number of things which your child does that bother you.	10+	8-9	6-7	4-5	1-3

30. My child gets upset easily over the smallest thing.					
31. My child's sleeping or eating schedule was much harder to establish than I expected.	SA	A	NS	D	SD
For the next statement, choose your response from the choices "1" to "5" below.					
32. I have found that getting my child to do something or stop doing something is: 1. much harder than I expected 2. somewhat harder than I expected 3. about as hard as I expected 4. somewhat easier than I expected 5. much easier than I expected	1	2	3	4	5
For the next statement, choose your response from the choices "10+" to "1-3."					
33. Think carefully and count the number of things which your child does that bother you. For example: dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc.	10+	8-9	6-7	4-5	1-3
34. There are some things my child does that really bother me a lot.	SA	A	NS	D	SD
35. My child turned out to be more of a problem than I had expected.	SA	A	NS	D	SD
36. My child makes more demands on me than most children.	SA	A	NS	D	SD

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APPENDIX E

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Sensory Self-regulatory Questionnaire (Pre-Test)

Self-regulation contributes towards one's quality of life and plays an important role in stress management.Self-regulation is the ability to adjust or regulate the level of alertness depending on the time of the day and the stimuli presented. For example, adjusting your sleep-state in the morning to becoming more alert and engaging at work, or calming your body down after dropping your kids off at school, or adapting to your work environment to meet various work demands, then returning home at the end of the day and preparing your body to sleep at night. Optimal self-regulation plays an important component in helping us function optimally throughout our day. We all have different strategies that we use to self-regulate or self-calm. Such activities could include the following: physical exercise, meditation, quiet time, listening to music, taking a bath, having a massage or being in nature.

Understanding how you as an adult self-regulate, will help you gain greater understanding of your child's self-regulatory strategies and how to support your child's sensory needs for self-regulation. This survey is to find out more about your sensory self-regulatory strategies.

Please complete the survey below.

Thank you!

Participants Code: _____

Date _____

INSTRUCTIONS

Please check the box that best describes your opinion to each statement. Your first reaction to each statement should be your answer.

		Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
1	I know what to do to calm myself down	○	○	○	○	○
2	I know what activities make me feel more alert	○	○	○	○	○
3	I feel like the activities that I perform in my day sufficiently keep me in a calm or regulated state	○	○	○	○	○
4	I tend to perform regulatory or self-calming activities in reaction to feeling overwhelmed, stressed or anxious	○	○	○	○	○
5	I tend to perform regulatory or self-calming activities to prevent feelings of overwhelm, stress or enxiety	○	○	○	○	○
6						

	I rely on others to plan and encourage me to perform various regulatory or self-calming activities in the day	○	○	○	○	○
7	I plan and actively perform regulatory or self-calming activities in the day	○	○	○	○	○
8	I become irritable and agitated if I don't have time in my day to perform a regulatory or self-calming activity	○	○	○	○	○
9	I have a quiet space in my home, garden or neighborhood that I am able to use to self-calm	○	○	○	○	○
10	I make use of this quiet space when I find that I really need to calm down	○	○	○	○	○

Should you feel that you need to elaborate on any of the above-mentioned statements, please make your necessary comments here: _____

11 Which statements are most relevant to you that prevent you from participating in calming activities in your week:

- ☐ I feel too stressed and overwhelmed
- ☐ I feel like I don't have enough time for myself
- ☐ I feel like I have minimal access to resources
- ☐ I feel like I don't know what activities to do

12a List three (3) top activities that you find calm you down the most:
Activity 1: _____

12b Activity 2: _____

12c Activity 3: _____

With each of your listed activities above select the relevant frequency:

	Daily	2-6 times per week	Once a week	Twice a month	Once a month	Less than once a month
Activity Choice 1	○	○	○	○	○	○
Activity Choice 2	○	○	○	○	○	○
Activity Choice 3	○	○	○	○	○	○

13 Do you have any particular habits that you perform regularly or when stressed?
Such as nail biting, grinding your teeth...

- ○ Yes
- ○ No

If so, what?

_____

14 When feeling anxious or overwhelmed, what seems to help?

- ☐ I need to distract myself and keep myself busy
- ☐ I need to participate in a relaxing activity
- ☐ I need to particiate in a grounding activity, such as physical exercise.
- ☐ I just need time alone

What type of activities do you find seem to help when you are feeling anxious or overwhelmed?

_____

15 Do you smoke?

- ○ Yes
- ○ No

How many cigarettes do you smoke per day?

_____

16 How often do you consume alcohol?

- ○ 4-7 days a week
- ○ 1-3 days a week
- ○ Never

17 Do you tend to overeat during times of stress?

- ○ Yes
- ○ No
- ○ Unsure

18 What type of foods do you tend to or enjoy eating?

- ☐ Sweet foods
- ☐ Salty foods
- ☐ Spicy foods
- ☐ Sour foods
- ☐ Crunchy foods

19 What forms of caffeine do you consume?

- ☐ Tea
- ☐ Coffee
- ☐ None/Decaf

How many times per day do you typically consume caffeine?

- ○ 1-2 times a day
- ○ 3-4 times a day
- ○ 5 or more times a day

20 How do you respond to caffeine?

- ○ It calms me down
- ○ It alerts me enough to get me going
- ○ It's too alerting and makes me feel jittery

21 When feeling stressed and overwhelmed, do you feel numb, separate or disconnected from your body?

- ○ Yes
- ○ No
- ○ Unsure

22 When feeling stressed and overwhelmed, do you feel separate or disconnected from others?

- ○ Yes
- ○ No
- ○ Unsure

23 Currently, how connected do you feel to your body? Rate this by selecting the number that best describes how you are feeling now.

Totally separate | In-between | Fully aware

(Place a mark on the scale above)

24 How would you rate your self-calming strategies as a whole? In other words, how effective do you find your self-calming mechanisms?

Very poor | Average | Very good

(Place a mark on the scale above)

25 Do you feel the need to gain a better understanding of your own regulatory and self-calming abilities and needs?

- ○ Yes
- ○ No
- ○ Unsure

26 How open are you to learn different strategies to support you to be more regulated?

Not at all | Somewhat motivated | Very motivated

(Place a mark on the scale above)

27 Do you think that when you do not practice regulating or calming activities, this might have a negative impact on your own sense of well-being?

- ○ Yes
- ○ No
- ○ Unsure

28 Do you think that when you do not practice regulating or calming activities, this might have a negative impact on those around you?

- ○ Yes
- ○ No
- ○ Unsure

APPENDIX F

The initial version of the sensory self-regulatory questionnaire, the details of the changes and scoring relating to the content of the questionnaire.

INITIAL QUESTIONS	RELEVANCE	CLARITY	SIMPLICITY	AMBIGUITY	TOTAL SCORE (PERCENTAGE)	QUESTION OR ITEM CHANGED	FINALISED QUESTIONS
I know what activities calm me down	12	10	11	10	90%	√	I know what to do to calm myself down
						√	I know what activities make me feel more alert
I feel like the activities that I perform in my day sufficiently calm me down	10	9	8	9	75%	√	I feel like the activities that I perform in my day sufficiently keep me in a calm or regulated state
I feel like I don't perform enough regulatory or self-calming activities in my day	9	10	10	10	81%	√	Removed - Too similar to previous question
I tend to perform regulatory or self-calming activities in reaction to how I am feeling, rather than in a preventative manner	11	10	10	10	85%	√	I tend to perform regulatory or self-calming activities to prevent feelings of overwhelm, stress or anxiety.
I rely on others to plan and encourage me to perform various regulatory or self-calming activities in the day	12	11	12	12	98%		I rely on others to plan and encourage me to perform various regulatory or self-calming activities in the day
I like to plan and actively perform regulatory or self-calming activities in the day	10	8	11	10	81%	√	I plan and actively perform regulatory or self-calming activities in the day
I become irritable and agitated if I don't have time in my day to perform a regulatory or self-calming activity	12	11	11	11	94%		I become irritable and agitated if I don't have time in my day to perform a regulatory or self-calming activity
I have a quiet space in my home that I am able to use to self-calm	11	11	11	11	92%	√	I have a quiet space in my home, garden or neighborhood that I am able to use to self-calm

INITIAL QUESTIONS	RELEVANCE	CLARITY	SIMPLICITY	AMBIGUITY	TOTAL SCORE (PERCENTAGE)	QUESTION OR ITEM CHANGED	FINALISED QUESTIONS
I try make use of this quiet space when I find that I really need to calm down	12	11	11	11	94%	√	I make use of this quiet space when I find that I really need to calm down
Which factors influence your participation in performing calming activities in your day or week 1. *I feel too stress and* 2. *Not enough time* 3. *Minimal access to resources* 4. *Don't have time for myself* 5. *I don't know what activities to do*	11	10	10	10	85%	√	Which statements are most relevant to you that prevent you from participating in calming activities in your week. 1. *I feel too stress and overwhelmed* *I feel like I don't have enough time for myself* 3. *I feel like I have minimal access to resources* 4. *I feel like I don't know what activities to do*
List three (3) top activities that you find calm you down the most. With each of these listed activities *Frequency: Never, Daily, Once a week, 2-6 times a week, twice a month, once a month.*	12	12	12	12	100%	√	List three (3) top activities that you find calm you down the most. With each of these listed activities above, select the relevant frequency: *Frequency: Daily, 2-6 times a week, once a week, twice a month, once a month, less than once a month*
Do you have any particular habits that you perform on a daily basis or when stressed? Such as nail biting, grinding your teeth *Yes; No;* *If so, what?*	12	10	9	9	83%	√	Do you have any particular habits that you perform regularly or when stressed? Such as nail biting, grinding teeth... *Yes; No;* *If so, what?*

INITIAL QUESTIONS	RELEVANCE	CLARITY	SIMPLICITY	AMBIGUITY	TOTAL SCORE (PERCENTAGE)	QUESTION OR ITEM CHANGED	FINALISED QUESTIONS
When feeling anxious or overwhelmed, what seems to help? *I need to distract myself and keep myself busy ; I need to soothe or ground myself by_____ ; I just need time alone*	11	10	10	10	85%	√	When feeling anxious or overwhelmed, what seems to help? *I need to distract myself and keep myself busy ; I need to participate in a relaxing activity, I need to participate in a gorudning activity (such as physical exercise); I just need time alone* *What type of activites do you find seem to help when you are feeling anxious or overwhelmed?*
Do you smoke? *Yes/No*	12	12	12	12	100%		Do you smoke? *Yes/No*
If you do smoke, how many cigarettes do you smoke per day?	12	12	12	12	100%		If you do smoke, how many cigarettes do you smoke per day?
How often do you consume alcohol? *4-7 days a week ; 1-3 days a week ; never*	12	12	12	12	100%		How often do you consume alcohol? *4-7 days a week ; 1-3 days a week ; never*
How many alcoholic drinks do you consume in one sitting?	9	12	12	12	94%	√	Removed - Not relevent
Do you tend to overeat during times of stress? *Yes; No; Unsure*	12	12	12	12	100%		Do you tend to overeat during times of stress? *Yes; No; Unsure*

INITIAL QUESTIONS	RELEVANCE	CLARITY	SIMPLICITY	AMBIGUITY	TOTAL SCORE (PERCENTAGE)	QUESTION OR ITEM CHANGED	FINALISED QUESTIONS
When overeating, what foods do you tend to eat? *Sweet foods ; salty foods ; spicy foods ; sour foods ; crunchy foods*	12	12	12	12	100%	√	What type of foods do you tend to enjoy eating? *Sweet foods ; salty foods ; spicy foods ; sour foods ; crunchy foods*
What form of caffeine do you consume? *Tea ; coffee ; None/decaf*	12	12	12	12	100%		What form of caffeine do you consume? *Tea ; coffee ; None/decaf*
How many times per day do you typically consume caffeine? *None ; 1-2 times ; 3-4 times ; 5 or more times*	12	12	12	12	100%		How many times per day do you typically consume caffeine? *None ; 1-2 times ; 3-4 times ; 5 or more times*
How do you respond to caffeine? *It calms me down ; it alerts me enough to get me going ; It's too alerting and makes me feel jittery*	11	11	12	12	96%		How do you respond to caffeine? *It calms me down ; it alerts me enough to get me going ; It's too alerting and makes me feel jittery*
Do you feel separate or disconnected from your body? *Yes, No, Unsure*	11	10	10	10	85%	√	When feeling stressed and overwhelmed, do you feel numb, separate or disconnected from your body? *Yes, No, Unsure*
						√	When feeling stressed and overwhelmed, do you feel numb, separate or disconnected from others? *Yes, No, Unsure*

INITIAL QUESTIONS	RELEVANCE	CLARITY	SIMPLICITY	AMBIGUITY	TOTAL SCORE (PERCENTAGE)	QUESTION OR ITEM CHANGED	FINALISED QUESTIONS
Rate your mind-body connectedness by selecting the number that best described how you feeling now *Rating scale from 1-10* *1 Totally separate → 10 Fully present*	11	10	10	10	85%	√	Currently, how connected do you feel to your body? Rate this by selecting the number that best describes how you are feeling now. *Rating scale from 1-10* *1 Totally separate → 10 Fully present*
How would you rate your self-calming mechanisms? *Rating scale from 1-10* *1 Very poor → 10 Very good*	12	8	8	8	75%	√	How would you rate your self-calming strategies as a whole? In other words, how effective do you find your self-calming mechanisms? *Rating scale from 1-10* *1 Very poor → 10 Very good*
Do you feel like you need some more insight or help with your self-regulation or self-calming? *Yes; No; Unsure*	12	11	11	11	94%	√	Do you feel the need to gain a better understanding of your own regulatory and self-calming abilities and needs? *Yes; No; Unsure*
How motivated do you feel to learn different strategies to help you be more regulated? *Rating scale from 1-10* *1 Not at all → 10 Very motivated*	12	11	11	11	94%	√	How open are you to learn different strategies to support you to be more regulated? *Rating scale from 1-10* *1 Not at all → 10 Very motivated*
							Do you think that when you do not practice regulating or calming activities, this might have a negative impact on your own sense of well-being? *Yes; No; Unsure*
							Do you think that when you do not practice regulating or calming activities, this might have a negative impact on those around you? *Yes; No; Unsure*

APPENDIX G

R14/49 Ms Carryn Martin

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M150852

NAME: (Principal Investigator)	Ms Carryn Martin
DEPARTMENT:	Occupational Therapy Wilgeheuwel Hospital Private Practice,Lonehill
PROJECT TITLE:	A Stress Management Programme for Mothers of Children with Sensory Modulation Disorder: A Sensory Modulation-Based Approach
DATE CONSIDERED:	28/08/2015
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Denise Franzsen

APPROVED BY: Professor P Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 14/10/2015

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

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 10004, 10th floor, Senate House/2nd Floor, Phillip Tobias Building, Parktown, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.**

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX H

Information Sheet and Informed Consent

Resize font:

Good Day,

My name is Carryn Martin and I am currently completing my research to obtain my Master's degree in occupational therapy at the University of Witwatersrand. My research is looking at the effectiveness of a stress management programme for mothers who have children with sensory modulation difficulties and who have sensory over-responsiveness themselves. It would be greatly appreciated if you could consider participating in my research.

Why am I inviting you to take part in my research?

Research has found that mothers of children with varying developmental difficulties had significantly poorer health and higher parenting stress than their partners. Higher levels of stress were also found in parents who have children with sensory modulation difficulties. The challenges of having a child with sensory modulation difficulties may be compounded by the mothers own sensory sensitivities (due to the genetic predisposition) and their limited coping mechanisms. This can further contribute to their stress levels. Research has found that in order to significantly reduce the parents stress levels, specific focus needs to be made on the parents (specifically mothers) well-being and stress management. This has led to my research, which is what I am inviting you to take part in.

What are you required to do to be a part of my research?

You will be required to take part in a 12 week stress management programme, which will be conducted by myself. This will include the following:

- 5 individual sessions and 1 group session at a practice in Lonehill.
- Various activities will need to be done at home that will help reduce your stress levels.
- On initiation and at the end of the programme, you will be required to complete questionnaires. This will used for my research analysis and to help individualise the stress management programme so that it caters for your needs.
- Some stress management resources will be provided to you free of charge. Any additional resources that you wish to purchase will be at your own cost.

What are the benefits for you?

- The programme is designed to help you benefit from the programme as much as possible and there are no risks involved when taking part of my research.
- This is a unique stress management programme that will help create a different perspective on your stress levels and how to manage them. During our time together, I will help you understand why you respond to sensory input the way you do and the effects of your coping mechanisms on your stress levels. My aim is to empower you, create spaces for self-healing and provide you with various skills so that you are able to cope and manage your current and future stress levels. Counselling will be made available on request and if deemed necessary.

How do you qualify to participate in the research?

Once I have received your consent and willingness to take part in the research, you will firstly be required to complete a sensory questionnaire. This questionnaire will help me establish your sensory profile, as well as assess as to whether you meet the inclusion criteria for the research. You will need to display sensory over-responsiveness in one of your sensory systems, as well as display a "sensory sensitive" or "sensory avoiding" sensory profile, in order to be accepted to participate in this research.

In addition to this, you also need to meet the following criteria in order to patriciate in the research.

- You need to agree to attend the full Stress Management programme, as well as agree to comply with the various activities recommended during the programme.
- You have not been formally diagnosed as having post-traumatic stress disorder or have recently been involved in a traumatic event (within the last year).
- You are not participating in another psychological or stress-based programme.

Should you feel that you do not meet the inclusion criteria, you are more than welcome to decline my invitation without providing a reason.

Should you meet the inclusion criteria and agree to participate in the research, I will arrange our first consultation date with you, so that we can start the process.

Is there any other important information that you need to know that protects you as an individual?

Yes.

1. Although confidentiality cannot be ensured due to the nature of the group work programme, the information shared to me throughout the research or programme will be kept strictly confidential. The use of codes will be made to ensure that confidentiality is maintained. I will not use any names on the various forms or questionnaires used. The list of codes and names will be used to link the mothers names to the questionnaires used, which will be locked in an office.
2. The programme is completely voluntary and you reserve the right to withdraw from the programme at any time, without giving any reason.
3. The results of the research will be made available to you once the research has been finalised.

If you have any queries or require more information, please do not hesitate to contact me on 072 858 8083. If you would like to take part in the research, please read and sign the attached consent form.

If you have any ethical concerns please contact the chairperson of the Wits Human Research Ethics Committee, Prof P Cleaton-Jones on 011 7171234 or at zanele.ndlovu@wits.ac.za

Thank you,

Kind regards,

Carryn Martin

INFORMED CONSENT

By signing this informed consent, you will be agreeing to take part in the research study and have read and agreed with all information outlined below and in the letter of invitation.

The following elements are important to consider when agreeing to participate in the research:

1. The aim of the research is to evaluate the effectiveness of a 12 week stress management programme for mothers with sensory over-responsiveness, as well as to investigate the relationship of the mothers perceived stress levels, their sensory profiles and how they self-regulate.
2. The stress management programme is designed to help you benefit from the programme as much as possible, which is aimed to empower you and create spaces for self-healing. There are no risks involved when partaking in the programme.
3. Your personal information will be kept strictly confidential.
4. The programme is voluntary and you have the right to withdraw from the programme at any time, without giving any reasons.

By signing this form, you confirm that you understand the information provided and you agree to the conditions in it.

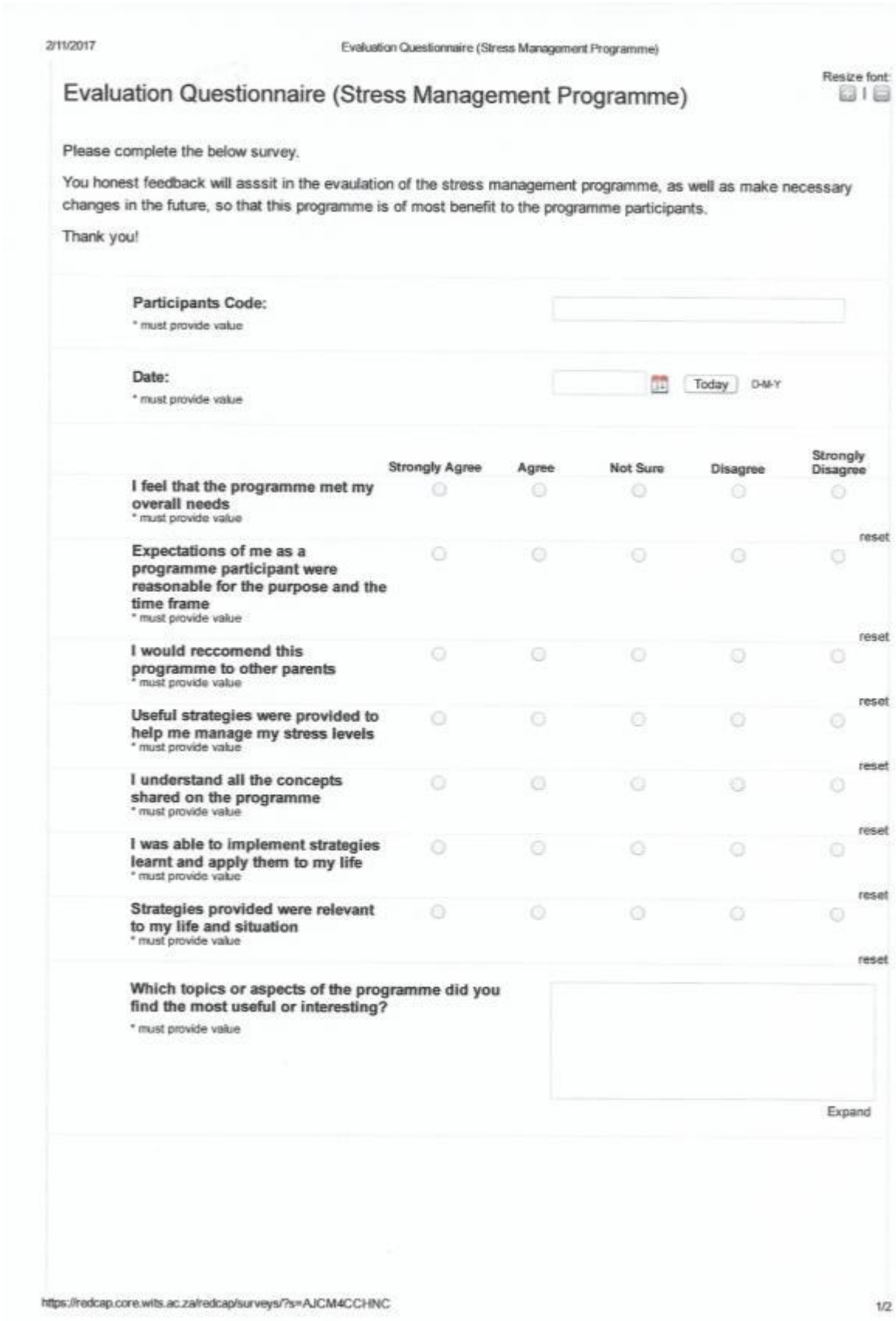
Participants Name:
* must provide value

Date:
* must provide value
Today D-M-Y

Signature:
* must provide value
Add signature

Submit

APPENDIX I



2/11/2017 Evaluation Questionnaire (Stress Management Programme)

Resize font:

Evaluation Questionnaire (Stress Management Programme)

Please complete the below survey.

You honest feedback will asssit in the evaulation of the stress management programme, as well as make necessary changes in the future, so that this programme is of most benefit to the programme participants.

Thank you!

Participants Code:
* must provide value

Date:
* must provide value
Today D-M-Y

	Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree	
I feel that the programme met my overall needs * must provide value	○	○	○	○	○	reset
Expectations of me as a programme participant were reasonable for the purpose and the time frame * must provide value	○	○	○	○	○	reset
I would reccomend this programme to other parents * must provide value	○	○	○	○	○	reset
Useful strategies were provided to help me manage my stress levels * must provide value	○	○	○	○	○	reset
I understand all the concepts shared on the programme * must provide value	○	○	○	○	○	reset
I was able to implement strategies learnt and apply them to my life * must provide value	○	○	○	○	○	reset
Strategies provided were relevant to my life and situation * must provide value	○	○	○	○	○	reset

Which topics or aspects of the programme did you find the most useful or interesting?
* must provide value

Expand

https://redcap.core.wits.ac.za/redcap/surveys/?s=AJCM4CCHNC 1/2

I feel that this programme help me:

* must provide value

- ☐ Gain greater insight into my stress levels
- ☐ Gain greater insight into the effect of the stress levels on my well-being and life in general
- ☐ Gain greater insight into my body's sensory needs
- ☐ Gain a different perspective on life
- ☐ Manage my child's sensory needs better
- ☐ Manage my child's challenging behaviour better
- ☐ Cope with everyday stress better
- ☐ Recover from a stressful situation quicker or better
- ☐ Manage my overall daily stress
- ☐ None of the above
- ☐ Other

What changes, if any, would you recommend for this programme?

Expand

Any additional comments?

Expand

Submit

APPENDIX J

DEMOGRAPHIC QUESTIONNAIRE
TO BE KEPT SEPARATE

PERSONAL INFORMATION

Participant Code: _____

Age: _____

Contact number: _____

Email Address: _____

Residential suburb: _____

First language: _____

DEMOGRAPHIC QUESTIONNAIRE

Marital status:

- ☐ Married
- ☐ Separated
- ☐ Divorced
- ☐ Single
- ☐ Widowed

MEDICAL BACKGROUND

Do you suffer from any allergies?

- ☐ Yes
- ☐ No
- ☐ If yes, what

  _____

Have you or do you suffer from any of the following conditions:

- ☐ Hypotension
- ☐ Hypertension
- ☐ Epilepsy / seizures
- ☐ Cholesterol
- ☐ Asthma
- ☐ Diabetes
- ☐ Irritable bowel syndrome
- ☐ Chronic pain
- ☐ Bipolar
- ☐ Schizophrenia
- ☐ Depression
- ☐ Anxiety disorders
- ☐ Alcohol or drug abuse
- ☐ Other:

  _____

  _____

Do you frequently suffer from colds or flu?

- ☐ Yes
- ☐ No

Are you currently taking any medication?

- ☐ No
- ☐ Yes
  Name and reason: _____
  _____

Have you had any major life events that has happened in the last year (for example, a divorce, death of relative, accident etc.)?

_____
_____
_____

Do you have any sleeping difficulties?

- ☐ No
- ☐ Yes
  Reason: _____
  _____

Are you a restless sleeper?

- ☐ Yes
- ☐ No

How many hours do you sleep per night on average?

- ☐ 2-5 hours
- ☐ 6-8 hours
- ☐ 9-10 hours
- ☐ 11-12 hours

Which statements apply to you?

- ☐ You wake up three or more times a night and are unable to fall back to sleep
- ☐ It takes you over 30 minutes to fall asleep at night
- ☐ You have nightmares or sleep terrors
- ☐ You do not feel well rested when you wake up in the morning
- ☐ You always feel tired
- ☐ You can't sleep without white noise (such as an oscillating fan or A/C)

CHILDREN

	Age of child/ children:	Schools that your child/ children attend:	Child/ children in therapy:	Date that your child/ children started therapy
1				
2				
3				
4				
5				

EDUCATION/EMPLOYMENT

What is your highest level of education?

- ☐ High school
- ☐ Technical College
- ☐ University degree
- ☐ Postgraduate degree
- ☐ Other: _____

Employment:

- ☐ Full-time
- ☐ Part-time
- ☐ Unemployed
- ☐ Housewife

What are your working hours?

- ☐ Less than 10 hours per week
- ☐ Between 10-20 hours per week
- ☐ Between 21-30 hours per week
- ☐ Between 31-40 hours per week
- ☐ Greater than 40 hours per week