

https://dspace.org/

The effect of a two-week sensory diet on infants with Regulatory Sensory Processing Disorder

Jorge, Jacqueline

2013-03-19
http://hdl.handle.net/10539/12555

Downloaded from a DSpace repository. https://dspace.org/

UNIVERSITY OF THE WITWATERSRAND

The effect of a two-week sensory diet on infants with Regulatory Sensory Processing Disorder

Jacqueline Jorge

A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, in fulfilment of the requirements for the degree of Master of Science in Occupational Therapy.

Ethical Clearance: M090339

Johannesburg, October 2012.

Declaration

I, Jacqueline Jorge, declare that this research report is my own work. It is being submitted for the degree of Master of Science in Occupational Therapy in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.



..... (Signature of Candidate)

22 day of Oct 2012

Acknowledgements:

I would like to acknowledge the assistance of the following people:

Department of Occupational Therapy at WITS.

My research report supervisor: Professor Patricia de Witt.

Denise Franzsen, for her feedback and assistance with statistics relating to the research study.

Paula Barnard-Ashton on her insights into research and the sensory integrative subject matter.

The postgraduate team at WITSï for feedback on protocol and assisting in preparing for initial submissions.

The postgraduate research support group

Occupational therapists specializing in infants, Kate Bailey and Francoise Harrison, who formed part of the expert panel who validated the questionnaire used during the parent interview.

Clinic sisters, Sr Megan, Sr Brenda and Sr Elize, who identified and referred fussy infants for the study.

Lastly to my family for supporting me through this process, and allowing me the time and space to complete my studies.

Abstract

This research aimed to determine the effect of educating parents on Regulatory Sensory Processing Disorder (RSPD) and implementing an Ayers-SI sensory diet over a two-week period. Twelve infants who met the criteria for RSPD were subdivided into two groups: 7-12 and 13-24 months. The data was obtained from a telephonic interview and completion of the Infant Toddler Symptom Checklist (ITSC). Following the two-week intervention, the ITSC was completed again and results were compared using the Wilcoxin Signed Rank Test. Although the research sample was small, findings indicate that the Ayers-SI sensory diet was effective in reducing signs of fussiness. The research group showed a significant change ($p=0.0024$) over the two-week period, with a greater change evident in the 7-12 month group. Self-regulation and attachment showed the most significant change. Difficulties with sensory processing for example, tactile, vestibular and auditory sensitivities appeared to persist, indicating a possible need for direct sensory integrative therapy to address them. In addition, the findings indicate that there is a lack of referral for Ayers-SI occupational therapy. This research adds value to the body of research which indicates the need for early intervention for possible prevention of later developmental difficulties.

Table of Contents

Declaration ii

Acknowledgements: iii

Abstract iv

Table of Contents v

List of figures x

List of tables xi

Definition of terms xii

Abbreviations xiv

CHAPTER 1 INTRODUCTION TO STUDY 1

1.1 Introduction 1

1.2 Problem statement 4

1.3 Purpose of the study 5

1.4 Aim of the study 5

1.5 Study objectives 6

1.6 Null-hypothesis 6

1.7 Justification for the study 6

CHAPTER 2 LITERATURE REVIEW 8

2.1 Introduction 8

2.2 Normal development of self-regulation and sensory modulation in infants 9

2.3 Regulatory Sensory Processing Disorder 10

2.3.1 History of the nomenclature of Regulatory Sensory Processing Disorder 10

2.3.2 Regulatory Sensory Processing Disorder defined 11

2.3.3 Aetiology of Regulatory Sensory Processing Disorder 11

2.4 Identification of Regulatory Sensory Processing Disorder through assessment 13
2.4.1 Assessments which evaluate Regulatory Sensory Processing Disorder..... 13
2.4.2 The Infant Toddler Symptom Checklist..... 15
2.5 Intervention: focus on Sensory Integration and its role and contribution to Regulatory Sensory Processing Disorder..... 17
2.5.1 Introduction to the intervention: focus on a family-centred and integrated approach..... 17
2.5.2 Ayers: Sensory Integration 18
2.6 Need for early intervention and prevention..... 23
2.7 Conclusion..... 24
CHAPTER 3 RESEARCH METHODOLOGY 26
3.1 Introduction..... 26
3.2 Research design..... 28
3.3 Selection of participants..... 29
3.3.1 Sample population..... 29
3.3.2 Sampling procedure..... 29
3.3.3 Sample Size 30
3.4 Data Collection tools..... 30
3.4.1 Data Collection Tools..... 30
3.4.2 Interview questionnaire development 31
3.4.3 Infant Toddler Symptom Checklist details..... 35
3.5 Research procedure 36
3.5.1 Recruitment of referral agencies..... 36
3.5.2 Recruitment and selection of infant participants 37
3.5.3 Data collection: pre-intervention 37
3.5.4 Intervention..... 39

3.5.5 Data collection: post-intervention 40
3.6 Data analysis 41
3.6.1 Data capturing and preparation for data analysis 41
3.6.2 Descriptive statistics 42
3.6.3 Quantitative analysis 42
3.7 Ethical considerations 43
3.8 Conclusion 44
CHAPTER 4 RESULTS 45
4.1 Introduction 45
4.2 Demographics of the sample 45
4.3 Birth and medical history 46
4.3.1 Birth history 46
4.3.2 Medical history 47
4.3.3 History of colic 47
4.3.4 Experience of specific symptoms of Regulatory Sensory Processing Disorder from inclusion criteria 47
4.4 Parent perceptions of Regulatory Sensory Processing Disorder 49
4.4.1 Onset of Regulatory Sensory Processing Disorder 49
4.4.2 Parentsôfour greatest concerns relating to infant participantsôRegulatory Sensory Processing Disorder based on the domain headings assessed in the Infant Toddler Symptom Checklist 49
4.4.3 Assistance sought in dealing with Regulatory Sensory Processing Disorder 51
4.4.4 Knowledge of Regulatory Sensory Processing Disorder and Ayers-Sensory Integration 53
4.5 Results of the Infant Toddler Symptom Checklist 54
4.5.1 Results of the Infant Toddler Symptom Checklist pre- and post-intervention 54

4.5.2 Change in Infant Toddler Symptom Checklist domains (pre and post-intervention) 56
4.5.3 Infant Toddler Symptom Checklist pre and post-test scores for the 7-12 month old age group 57
4.5.4 Infant Toddler Symptom Checklist pre and post-test scores for the 13-24 month old age group 59
4.6 Conclusion 62
CHAPTER 5 DISCUSSION 64
5.1 Introduction 64
5.2 Sample demographics 64
5.2.1 Division of infant participants into two age groups 65
5.2.2 Gender 67
5.2.3 Birth and medical history 67
5.3. Identification of Regulation Disorder for inclusion of infant participants in the study 69
5.4 Parent perceptions of the Regulation Disorder 71
5.5 Intervention using an Ayers-SI sensory diet 74
5.5.1 Discussion of results of the Infant Toddler Symptom Checklist: pre and post-intervention 74
5.5.2 Discussion of sensory strategies included in the sensory diet 77
5.6 Implications for occupational therapy: guidelines for intervention 78
CHAPTER 6 CONCLUSION 80
6.1 Introduction 80
6.2 Main findings 80
6.3 Suggestions for further study 81
APPENDICES 83
Appendix A.1 Interview questionnaire: first draft and validation comments 83
Appendix A.2 Final-interview questionnaire 90

Appendix B.1 Infant Toddler Symptom Checklist for each age group 97
Appendix B.2: Protocol sheet for Infant Toddler Symptom Checklist 105
Appendix B.3: Raw data: Infant Toddler Symptom Checklist 106
Appendix C.1: Information sheet for referral agencies 107
Appendix C.2: Information sheet and consent form 110
Appendix D: Research flyer with inclusion criteria 114
Appendix E.1 Explanation slides used as part of parent education 115
Appendix E.2: Sensory diet recommendations 116
Appendix F: Ethical clearance certificate 119
LIST OF REFERENCES 120

List of figures

Figure 3.1 Flow diagram indicating research procedure..... 27
Figure 4.1 Percentage of infant participants presenting with specific symptoms of Regulatory Sensory Processing Disorder (n=12) 48
Figure 4.2 Parents greatest concerns relating to infant participantsôRegulatory Sensory Processing Disorder based on the domain headings assessed in the Infant Toddler Symptom Checklist 50
Figure 4.3 Sources of advice used by parents to deal with infant participantsô problems 52
Figure 4.4 Value of advice obtained from clinic sisters and paediatricians as perceived by parents..... 52
Figure 4.5 Change in domain scores on the Infant Toddler Symptom Checklist for the total sample (n=12) 56
Figure 4.6 Change in domain scores on the Infant Toddler Symptom Checklist for 7-12 month old participants (n=6)..... 58
Figure 4.7 Change in domain scores on the Infant Toddler Symptom Checklist for 13-24 month old participants (n=6)..... 60
Figure 4.8 Pre and post-intervention scores compared to cut off scores for the participants 7-9 months (n= 4) and 10-12 months (n=2) of age 62
Figure 4.9 Pre and post-intervention scores compared to cut off scores for the participants 13-18 months (n= 1) and 19-24 months (n=5) of age 62

List of tables

Table 2.1 Explanation of the domains in the Infant Toddler Symptom Checklist..... 15
Table 4.1 Demographics of infant participants (n=12)..... 46
Table 4.2 Percentage of infant participants who presented with symptoms of Regulatory Sensory Processing Disorder in the two age groups..... 48
Table 4.3 Onset of Regulatory Sensory Processing Disorder 49
Table 4.4 Pre-intervention and post-intervention scores for total sample (n=12) 54
Table 4.5 Comparison of each infant participantôs total Infant Toddler Symptom Checklist score, pre and post-intervention, to the cut-off score for that age group... 55
Table 4.6 Effect size for each domain for the total sample (n=12) 57
Table 4.7 Pre-intervention and post-intervention scores for 7-12 month old participants (n=6) 57
Table 4.8 Effect size for each domain for 7-12 month old participants (n=6)..... 59
Table 4.9 Pre-intervention and post-intervention scores for 13-24 month old participants (n=6) 59
Table 4.10 Effect size for each domain for 13-24 month old participants (n=6)..... 61

Definition of terms

Self-Regulation: Self-regulation is the interaction between physiological maturation; the parentôs sensitivity to the infantôs needs and their ability to respond to his/her needs; and the infantôs adaptation to the environmentôs demands which results in the ability to participate in and perform various functions (1).

Regulatory Sensory Processing Disorder (RSPD): A child with RSPD is said to have a set pattern of responses and behaviours, observable over time and across settings that interferes with normal growth and development. Difficulties in sensory, motor and behavioural responses are required for a definitive diagnosis. Physiological difficulties involving sleep, eating and elimination, as well as difficulties in language or expression and cognitive functions may also be present (2).

Sensory Modulation Dysfunction: A pattern of dysfunction of Sensory Integration affecting registration, orientation or arousal difficulties. It may result in three main categories of behavioural responses/ thresholds: sensory seeking/craving, sensory over-responsivity (defensiveness) or sensory under-responsivity where a person under or over-responds to sensory input from the body or environment. These responses may be observed in the various sensory modalities e.g. vestibular, tactile and auditory systems (3,4).

Sensory Modulation: The ability to regulate and organise reactions to sensory input in a graded and adaptive manner (behaviour). The balancing of excitatory and inhibitory inputs and adapting to environmental changes (neuro-physiological) (3).

Sensory Integration: The neurological process that organizes sensation from oneôs own body and from the environment and makes it possible to use the body effectively within the environment; the entire sequence of central nervous system events from reception to the display of an adaptive environmental interaction (3).

Sensory diet: A planned and scheduled activity programme designed to meet a child's specific sensory needs (5).

Pervasive Developmental Disorder: A broad class of conditions that reflects a range of deficits, of which autism is the most well-documented condition (6).

Vestibular: Sensation derived from stimulation to the vestibular mechanism in the inner ear that occurs through movement and position of the head. It contributes to posture and the maintenance of a stable visual field (3).

Proprioception: Sensations derived from movement and joint position. It is derived from stimulation to muscle and to a lesser extent joint receptors, especially from resistance to movement (3).

Hypersensitivities (sensory defensiveness): A fight, fright/freeze or flight reaction to sensation/stress that most others would consider non-noxious (3).

The Developmental, Individual Difference, Relationship-based Model or Floortime: This is a model which provides a framework to understand the functional emotional development and unique profile of every child and a guide to create emotionally meaningful learning interactions that promote critical functional emotional developmental capacities. Floortime forms a part of the DIR Model and is a specific technique to follow the childôs natural emotional interests (lead) and at the same time help the child move towards greater mastery of their social, emotional and intellectual capacities (7).

Adaptive Response: This occurs when the infant/child is an active participant and performs a purposeful goal-directed activity that provides feedback (4).

Abbreviations

Ayers-SI:	Sensory Integration based Occupational Therapy, developed by Dr. J. Ayers
DC: 0-3R:	Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood
DIR:	Developmental, Individual Difference, Relationship-based Model
DSM IV ï TR:	Diagnostic and Statistical Manual - Text Revised
FEAS:	Functional Emotional Assessment Scale
ICD-10:	International Classification of Diseases and Related Health Problems, 10th Revision
ICDL	Interdisciplinary Council on Developmental and Learning Disorders
ICDL-DCIM	Interdisciplinary Council on Developmental and Learning Disorders ï Diagnostic Manual for Infancy and Early Childhood
ITSC:	Infant Toddler Symptom Checklist
ITSP:	Infant Toddler Sensory Profile
RSPD:	Regulation Disorder of Sensory Processing
SA:	South Africa
SMD:	Sensory Modulation Dysfunction
USA:	United States of America
WITS:	University of the Witwatersrand

CHAPTER 1
INTRODUCTION TO STUDY

1.1 Introduction

During normal development, self-regulation is developed when infants learn to take an interest in their surroundings while regulating their level of arousal, making it possible to respond to sensory input (8). This self-regulation is an interaction between physiological maturation; the parentôs sensitivity to the infantsôneeds and the ability to respond to his/her needs; and the infantôs adaptation to environmental demands. This process develops over the first two years of life, becoming more complex over time. It progresses from the regulation of homeostatic functions, to the regulation and formation of relationships and attachment, communication, sensory modulation, understanding causal relationships, and finally the development of self-initiated organised behaviours (1).

For some infants this natural process of self regulation does not occur typically and Regulatory Sensory Processing Disorder (RSPD) may be result.

The researcherôs interest in this topic originated from her clinical observations that many preschool children referred to occupational therapy for sensory modulation difficulties were reported to have experienced fussiness during infancy. This fussiness, described by parents, has been explained in the literature as Sensory Modulation Dysfunction (SMD) or regulation disorders (9,10). Until 2005, these conditions were seen as separate entities; with SMD being identified and treated by Sensory Integration trained occupational therapists and RSPD being identified by psychologists and treated by a multidisciplinary team, including Sensory Integration trained occupational therapists (9). These two conditions have been brought together

into a single diagnostic group, RSPD, which is documented in the Interdisciplinary Council on Developmental and Learning Disorders ï Diagnostic Manual for Infancy and Early Childhood (ICDL-DCIM) (11). According to this classification, RSPD is the umbrella term with SMD categorised as Type I RSPD. Two more types of RSPD have also been described (11). Regulatory Sensory Processing Disorder includes symptoms such as excessive crying; colic throughout infancy; need to control every aspect of the day such as when and how to play or interact; difficulties with feeding and sleeping; and a need for the parent to use excessive methods to calm the infant (2). Many of the children seen in the researcherôs practice also experienced tactile, vestibular and/or auditory sensitivities in addition to the fussiness.

Sensory processing difficulties are predominantly treated by Sensory Integration based Occupational Therapy, developed by Dr. J. Ayers (Ayers-SI), which is based on the work of Dr. Jean Ayers (3). In the United States of America (USA), infants with RSPD are identified within mental health clinics and treated using Ayers-SI by a mental health multidisciplinary team which includes psychiatrists, psychologists, counsellors and family support specialists (2). Thus, due to the strong sensory processing basis of RSPD, occupational therapists trained in Sensory Integration are well-equipped to treat this condition.

Regulatory Sensory Processing Disorders are evident early in life (9). This was demonstrated in a small study of 8-11 month old infants (24 typical and 11 with RSDP) who showed clear sensory regulation differences and higher baseline cardiac vagal tone (that is a physiological index of stress) (12) which affected sleep, eating, temper tantrums and other symptoms (13). Regulatory Sensory Processing Disorder can be identified in infants older than 6 months who appear to be fussy, irritable and who present with poor self-calming, intolerance of change, and a hyper-alert state of arousal (1,2). This set of behaviours affects daily adaptation, interactions and relationships (2).

DeGangi and Greenspan (14) created objective inclusion criteria in order to diagnose RSDP in infants more effectively. These criteria were used as inclusion criteria for this study and have also been used by DeGangi, Breinbauer, Roosevelt, Porges and

Greenspan (15), DeGangi, Porges, Sickel and Greenspan (16) as well as DeGangi, Sickel, Wiener and Kaplan (17).

According to the criteria, the infant should experience at least two of the following:

- Sleep disturbance: the infant takes more than 20 minutes to fall asleep and wakes more than twice in the night.
- Difficulties in self-consoling: as a result, the caregiver spends between two to four hours a day attempting to calm his/her infant.
- Feeding disorders: feeding difficulties not related to allergies or intolerance including refusal to eat, regurgitation and difficulties establishing a regular feeding routine.
- Hyper-arousal: the infant appears overwhelmed by sensory input and may avert gaze to avoid eye contact. The infant may also appear intense, wide eyed or hyper-active (14,15,16).

Three to four year longitudinal studies found that infants identified with RSPD experienced developmental and learning delays more frequently than infants who did not meet the inclusion criteria described above (15). This supports the researcherôs clinical observation that older children referred for occupational therapy that were fussy infants, may have actually presented with signs of RSDP at this young age.

The classification of RSDP is relatively new and was first described in 2006. It is therefore not well recognised in SA and is seldom used to diagnose infants or children with these symptoms. In addition, the disorder has not been classified in either the International Classification of Diseases and Related Health Problems, 10th Revision (ICD-10) (18) or the Diagnostic and Statistical Manual - Text Revised (DSM IV ï TR) (19). This may explain why it is not currently used by health practitioners in this country.

Interviews held with clinic sisters and paediatricians approached for the purpose of this study appeared to have a poor understanding of how to assist fussy infants and how to advise parents to cope with this difficulty. While both clinic sisters and paediatricians suggested that there has been a perceived increase in incidence of

fussy babies over the years. However, these conclusions are anecdotal and there are no precise figures or research to confirm this.

In South Africa (SA), parents currently only have books on sensory strategies to assist in the management of fussy infant behaviour and only those identified with severe sensory modulation difficulties are being treated. Identifying RSPD and offering Ayers-SI as early intervention, in the form of education and the provision of a sensory diet, may shorten the duration of therapy or reduce the severity of the symptoms.

1.2 Problem statement

In SA the need for early intervention and prevention is documented in the *Guideline for early childhood development services* by the Department of Social Development (20). This guideline recognises that when infants and young children with developmental difficulties are recognised early and managed appropriately, later difficulties are avoided. However for many fussy infants and children, such services are unavailable.

It has been documented that the early identification and intervention of RSPD is important, as it may lead to later difficulties if left untreated. This has been supported by two USA studies. The first, by DeGangi et al. (16), reported that 89% of infants with untreated RSPD experienced regulatory, developmental and sensory-motor deficits at a four year follow-up (n=22). The second by DeGangi et al. (15), indicated that 60% of infants with mild regulatory disorders (n=10) did not experience difficulties at 36 months, while 95% of infants with moderate regulatory disorders (n=22) had either motor language, cognitive development delays or parent-child relational problems when compared to typically developing infants (n=38). At the time of these studies, the negative long-term implications of RSPD were unknown (and were discovered through these longitudinal studies) and thus intervention was not offered to these infants.

In the USA, a framework for Early Identification and Preventative Intervention has been created by the Centre for Disease Control and Prevention and the

Interdisciplinary Council on Developmental and Learning Disorders (ICDL) (21). According to this framework, it is predicted that 17% of children in the USA will have a developmental challenge during their schooling, but that less than 50% of these difficulties are identified before starting school. The framework recognises that children with delays are identified once they are in formal schooling instead of during infancy and preschool years. This framework, like the SA *Guideline for early childhood development services* (20), has a strong focus on healthy functioning. Such a framework provides an opportunity to offer intervention to children with deviations from the healthy typically functioning norm. It also highlights the importance of understanding what constitutes healthy and normal development so that atypical functioning can be easily recognised.

A review of the literature showed that there have been no studies on RSPD in SA. Although clinic sisters and paediatricians interviewed perceived an increase in fussy behaviour in infants, they reported not diagnosing them with anything other than colic and/or reflux. This was true even when symptoms presented after the age of six months, although it is recognised that colic typically resolves by six months of age through natural maturation (16). They therefore correctly identify a deviation from normal development, but may not have appropriately labeled these symptoms, thus limiting referral for appropriate early intervention which would assist in preventing later learning difficulties.

1.3 Purpose of the study

In light of the need for early intervention and prevention, the overall purpose of this study is to explore whether infants with RSPD can be identified at an early age and if education of parents and a two-week intervention using an Ayers-SI sensory diet will affect the severity of the symptoms of RSDP experienced by infants as reported by their parents.

1.4 Aim of the study

The aim of the study is to determine the effect of parent education and an individualised two-week Ayers-SI sensory diet and whether they are beneficial in reducing the symptoms of infants who meet the criteria for RSPD.

1.5 Study objectives

To meet the above aim, two objectives were formulated:

- To establish what the parents of infants with RSPD knew about the condition and what they had done to deal with the problems through advice from medical professionals or their own investigations.
- To design and implement a two-week Ayers-SI sensory diet for infants with RSPD and evaluate its effectiveness.

1.6 Null-hypothesis

There was no change in regulatory behaviour in infants, between the ages of 7 and 24 months, with RSPD after a two-week Ayers-SI sensory diet programme and parent education.

1.7 Justification for the study

As an occupational therapist in private practice, the researcher found that very little was known about RSDP among other professionals and parents of infants with this condition. It was the researcherôs clinical experience that older children referred for occupational therapy with SMD (Type I RSPD) had benefited from the Ayers-SI approach and all had a history of fussiness as infants.

In clinical practice, these infants are not usually referred for occupational therapy. Of interest to the researcher was the possibility that early intervention for infants with RSPD, consisting of short-term indirect intervention through the provision of an Ayers-SI sensory diet and parent education, would be sufficient in reducing the severity of the symptoms in this cohort of patients.

Research by DeGangi, Breinbauer, Roosevelt, Porgess and Greenspan (15) found that 95% of infants diagnosed with moderate or severe regulation disorders presented with delays in development or interpersonal difficulties at age 3. These studies noted the benefits of early intervention (17). A study assessing the prevalence of parental perceptions of sensory processing disorders among kindergarten children found that 96 of 1795 (5.3%) children were perceived by their

parents as experiencing difficulties (22). This finding is consistent with estimates made in the literature that between 5 and 10% of children without disabilities experience sensory processing disorders (23). The long-term implications for development highlight the need for intervention during infancy.

Thus, early identification and treatment of RSPD may prevent later developmental and interpersonal difficulties. This will positively affect the family unit as parents and siblings of infants with RSPD may better understand the condition and be provided with specific tools through the provision of the Ayers-SI sensory diet to manage these symptoms. This may result in happier infants who are able to form secure attachments with their parents. The secure attachment would provide opportunities to develop self-regulation abilities and thus achieve the most complex level of self-regulation, that is, to be able to initiate organised behaviours which are observed in the childôs occupational performance in activities of daily living.

Improved regulation abilities could also result in cost savings for parents in terms of medical and therapy bills, as the infants are likely to experience fewer developmental and emotional difficulties later in life, as described by the literature.

The findings of this study can assist Ayers-SI therapists in providing evidence for the effectiveness of Ayers-SI in infants experiencing RSPD.

CHAPTER 2
LITERATURE REVIEW

2.1 Introduction

The literature review was conducted to support the purposes of the study. It explores the context of early intervention and the need for preventative approaches. It aims to determine current RSPD knowledge and related concepts in order to design and evaluate the use of the Ayers-SI sensory diet as an intervention strategy.

In performing the literature review, local and international searches were performed. The Ebsco Host database was used to find academic journal articles using the following search terms: ôregulation disorders in infantsô, ôregulatory-sensory processing disorderô, ôself-regulationô, ôsleep difficulties in infantsô, ôsensory processingô, ôsensory dietô and ôearly interventionô Prominent RSPD researchers were also searched, including ôDeGangi, Gô and ôGreenspan, Sô

Google was also used as a search engine using the same key words described above. This provided links to the ICDL, Zero to Three and Sensory Processing Disorder Foundation, all prominent USA organisations with access to research and current information on RSPD.

Journals found in the University of the Witwatersrand (WITS) library were also accessed as part of the literature review.

This literature review outlines the typical development of self-regulation and sensory modulation in infants as well as investigations into RSPD. The assessment tools which are available to diagnose the condition and various treatment interventions were explored, with a focus on Ayers-SI. The support for early intervention and prevention approaches was determined. The potential for the use of indirect therapy

through the use of Ayers-SI sensory diets was investigated as a means of influencing the symptoms of RSPD to prevent later learning difficulties and developmental delays.

2.2 Normal development of self-regulation and sensory modulation in infants

Self-regulation is a concept which begins to develop in infancy and refers to the ability to interact with the environment while regulating responses to sensory inputs and arousal. It includes the interaction between physiological homeostasis and maturation, the parentôs ability to be sensitive to the infantôs needs, and the infantôs ability to adapt to the environment through his/her behaviour (1).

The process of self-regulation at each stage of development is described by Lester, Freier and LaGasse (24) as the infantôs ability to perceive and modulate sensory information according to the ófour Aôsô (described below), effectively linking self-regulation to the process of Sensory Integration. According to the authors, the process of self-regulation is dependent on the infantôs ability to maintain an appropriate level of **arousal** and transition smoothly between states of sleep and wake. This can be seen as the process of sensory modulation. If the infant is able to modulate by maintaining appropriate arousal, then the infant is able to **attend** selectively to a task, add an emotional or **affect** response to the behaviour and finally produce an **action**. Thus, sensory modulation is at the core of self-regulation. The ófour Aôsôprocess is Sensory Integration, the sequence of events which begins with receiving an input and ends with a response to this input through an action (3).

The process of self-regulation described above is basic during the early months of infancy and refers to the infantôs ability to use the ófour Aôsôto regulate tasks such as feeding and sleeping, while relying heavily on the parent to assist in this process. However, as the infant develops towards toddlerhood this becomes more complex and begins to involve the ability to self-calm (independent of the parent), master sensory functions and later regulate attention and arousal to novel events (1,15).

The ability to regulate attention and arousal to novel events is important for later learning (1) and interaction and links the importance of self-regulation to development in later years.

2.3 Regulatory Sensory Processing Disorder

Clinical experience by Ayers and Ermer and Dunn in the RSPD ICDL-DMIC (9) found that prevalence estimates for Sensory Integration difficulties were between 5 and 10%. This indicates that there is a population of infants and children who experience difficulties with self-regulation, which is identified as RSPD in infants (9).

The difference between sensory processing disorder and RSPD was described by Dr. Shelly Lane (25). She confirmed that RSPD is identified only in infancy. Thus infants with RSPD would possibly present later with sensory processing disorder if difficulties persist. Also, a diagnosis of RSPD is made due to regulatory behaviour difficulties such as sleep and feeding; however, investigations into the causes of these difficulties are sensory in nature, thus involving sensory processing, of which sensory modulation is a primary part of the process.

RSPD is a relatively new disorder as is not described in either ICD-10 (18) or the DSM IV ï TR (19). However, studies into signs and expressions of disorders of self-regulation have been conducted since the 1970s (9,10). Occupational therapists, under the direction of Ayers, were defining and treating SMD (23), while regulation disorders were being documented and studied by psychologists under the direction of Greenspan (10). DeGangi, an occupational therapist and a clinical psychologist, has been instrumental in bringing these two parallel disorders towards a single expression of RSPD through her research, together with a multidisciplinary team consisting of many occupational therapists (9).

2.3.1 History of the nomenclature of Regulatory Sensory Processing Disorder

The classification of Regulation Disorder was first found in the Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early

Childhood (DC: 0-3R), which is a manual produced by the Zero to Three organisation. The disorder was first recognised in 1994 as Regulation Disorder (15). The manual was revised in 2005 and the disorder was named Regulation Disorders of Sensory Processing to incorporate and recognise the impact of sensory processing (a Sensory Integration concept) on regulation. The ICDL-DCIM was formulated in 2006, renaming the condition RSPD (11). For the purpose of this study, the disorder will be referred to as RSPD as this is the most recent classification provided (2).

2.3.2 Regulatory Sensory Processing Disorder defined

The ICDL-DMIC is a new manual and diagnostic tool which is being developed by a workgroup. This and the DC: 0-3R are the only two sources which recognise RSPD as a disorder. These manuals are not used in SA. Paediatricians and medical specialists in SA make use of the ICD-10 or the DSM IV-TR (2), and since RSPD is not mentioned in these texts, the diagnosis is infrequently made in SA. In doing research for the study it was found that paediatricians avoided diagnosis of behavioural or emotional problems experienced by the fussy infants, and rather diagnosed it as reflux, colic or ójust a sensitive / difficult babyô

A diagnosis of RSPD is typically made during infancy when sensory and motor difficulties are severe and disrupt daily routines and activities such as sleep, feeding, and play, and also result in emotional or behaviour challenges such as frequent emotional outbursts and poor adaptability to change (9). RSPD is defined according to three types: Type I–RSPD with Sensory Modulation Challenges; Type II–RSPD with Sensory Discrimination Challenges; Type III–RSDP with Sensory-based Motor Challenges. These are all diagnostic classifications of Sensory Integration Dysfunction or Disorders of Sensory Processing (9,3), and thus indicate a strong link to Ayers-SI.

2.3.3 Aetiology of Regulatory Sensory Processing Disorder

The aetiology of RSPD is unclear and not well documented. However, causes of RSPD have been postulated based on deficits in areas of self-regulation. The

development of self-regulation has been described as the development of the interaction between physiological maturation, caregiver response and the infantôs adaptation to environmental demands (1).

A largely supported theory for the aetiology of RSPD is explained by the neurobiological model of early brainstem functioning. Brainstem function and maturation is important for early self-regulation through the modulation of homeostatic or regulatory functions of cardiac vagal tone (26,27,12); circadian regulation of arousal (28); and modulation of internal states, for example, hunger and sensory inputs (29). These low-level functions interact with the development of emotion and attention regulation through higher neural structures of the hypothalamus, thalamus, limbic system and prefrontal cortex. This neurobiological model thus proposes that even transient dysfunctions of the brainstem would interrupt the maturation of the whole system that supports behaviour and emotion regulation (26).

Parent response and the environment or context has also been suggested as causes of RSPD (26,30). Geva and Feldman (26) proposed that the neurobiological cause cannot be seen in isolation and that the effect of brainstem dysfunction, together with the interaction between the child and his/her environment, is important to consider. According to this theory, early maturation of self-regulation is greatly dependant on the stimulation and social interactions from the infantôs primary caregiver. Becker, Holtmann, Laucht and Schmidt (31) found that RSPD is associated with poor mother and infant interactions. However another study investigating whether social interactions affected RSPD found that the quality of infant-parent relationships did not significantly predict the presence of RSPD, but that it increased the complexity and severity of the disorder (30). Both studies stated that parent indications of stress and response to their infant (30) as well as family adversity, for example, single parents, poor coping skills and young parents (31), were more prominent in the aetiology of the disorder (30).

Although parents may express concern regarding a genetic link to the disorder, no research supporting or refuting this was found (2).

Research within the psychological field has determined temperament-based links to the aetiology of RSPD (32). However, temperament in infancy is measured through expression of regulatory behaviours, for example, irregular routines, slow to adjust, poor reaction to novel experiences and ability to soothe. The study found that 54 month old children experiencing behavioural problemsð for example, aggression, anxiety and depressionð were temperamentally difficult at 9 months. These infants were classified as having RSPD and had cardiac vagal difficulties.

Thus the aetiology of RSPD appears to be based on the interaction between neurobiological, psychopathological and social contextual factors which are interdependent and affect each another.

2.4 Identification of Regulatory Sensory Processing Disorder through assessment

The assessments investigated in the literature were limited to those used by occupational therapists in identifying infants with RSPD. These are used together with clinical observations to obtain a clinical profile of infant sensory processing through regulatory behaviours. Four predominant assessment tools were identified in the literature to assess infants who fit into the age range for the study. Two of these are self-reported questionnaires and are dependent on the parental perception, the Infant Toddler Sensory Profile (ITSP) and the Infant Toddler Symptom checklist (ITSC). The other two assessments are carried out by a trained therapist, the Functional Emotional Assessment Scale (FEAS) and the Test of Sensory Functions in Infants (TSFI).

2.4.1 Assessments which evaluate Regulatory Sensory Processing Disorder

Certain standardised assessment tools have been identified as being important in aiding the diagnosis of RSPD (2) and could be used in this study for infants aged 7-24 months.

The FEAS was first developed by Greenspan, DeGangi and Wieder in 1992 (33). This is a criterion-referenced test for children aged between 7 months and 4 years. The test was developed to assess emotional function in infants and children with developmental and maturation based problems such as RSPD. The test is unique as it assesses infant and parent individual emotional capacities as well as their interaction. The test was validated on four samples of children 7 to 48 months (n=468 with 190 of these being infants with RSPD). Construct validity studies were adequate. Concurrent validity studies indicated the FEAS to be unique in the constructs it assessed. Inter-rater reliability studies were performed and these were adequate, however, it was suggested that the FEAS be video-recorded and scored by a multi-disciplinary group of professionals (33). This test was not used in the current study as it did not assess any specific regulatory behaviours and its focus on the emotional aspect was not the focus of this study.

The Test for Sensory Functions in Infants is often used when assessing infants aged 4-18 months and specifically assesses reactivity and adaptive responses to tactile, vestibular, visual and ocular inputs (14). It was designed by Greenspan and DeGangi in 1989. This test is considered the gold standard of assessment for infants. However, this test was also not included because the focus of this study is parental perceptions of fussiness and the effect of providing an Ayers-SI sensory diet on their perceptions. In addition, the test could not be used on the entire sample as it can only be used on infants aged 4-18 months.

The ITSP was developed by Dunn and Daniels in 2002. This is a self-reported test and items deal with sensory processing in children under 36 months (2,10). It is specifically divided into birth to 6 months and 7 to 36 months. The test was standardised in 2000 and 2001 on over 1000 infants with and without difficulties between birth and 36 months. Internal consistency (wide range) and test-retest reliability testing were performed and the results were good. Convergent and discriminate validity studies were performed with high correlations between the ITSP and ITSC (34). The ITSP was not used in this study because its information was strongly correlated with the ITSC. In addition, it focused more on sensory modulation and did not provide specific information relating to age ranges or cut-offs

to determine RSPD. It investigated the components observed in RSPD, but not the functional regulatory behaviours observed in the disorder (35).

The ITSC was developed by DeGangi and colleagues. This checklist considers self-regulation, attention, movement, listening, language and sound, looking and sight, and attachment (36,2). It is a valuable tool as it focuses on occupational behaviours, which is at the core of occupational therapy, and allows parents to more easily identify times of fussiness in relation to behaviour. The checklist is described in detail in the following section.

2.4.2 The Infant Toddler Symptom Checklist

2.4.2.1 Development of the Infant Toddler Symptom Checklist

The test was initially developed in 1987 by DeGangi, Poisson, Sickel and Wiener (36) with 57 items organised into nine domains (see Table 2.1). The test was developed in the USA using a sample of predominantly middle-class Caucasians. The first version was piloted on 30 typical infants and 15 infants with RSPD. After revision of items, data collection was conducted over 3 years. The test was then validated on two samples of infants between 7 and 30 months, 154 typical and 67 regulatory disordered infants. The inclusion criteria used to determine if infants had RSPD were the same as those used in this research (36). The ITSC can be found in Appendix B.1.

Table 2.1 Explanation of the domains in the Infant Toddler Symptom Checklist

Domain specifications for the ITSC	
Domain	Description of Domain
Self-regulation	Fussy-difficult behaviours including crying and tantrums, poor self-calming, inability to delay gratification, difficulties with transitions between activities, and need for other regulation (e.g. constant adult supervision).
Attention	Distractibility, difficulty initiating and shifting attention.
Sleep	Difficulty staying and falling asleep.
Eating or feeding	Gagging or vomiting which may be related to reflux or other oral motor problems, food preferences, and behaviour

	problems during feeding.
Dressing, bathing and touch	Tactile hypersensitivities related to dressing and bathing, aversion to exploring through the sense of touch, and intolerance of being confined (e.g. car seat).
Movement	High activity-level and craving movement, motor planning and balance problems and insecurity in movement in space.
Listening and language	Hypersensitivities to sound, auditory distractibility, auditory processing problems, and expressive and receptive language problems.
Looking and sight	Sensitivities to light and visual distractibility.
Attachment or emotional functioning	Gaze aversion, mood deregulation, flat affect, immaturity in play and interactions, separation problems, difficulty accepting limits and other behaviour problems.

2.4.2.2 Description of the Infant Toddler Symptom Checklist

The ITSC was developed in six variations. Five are specific to age groups: 7-9 months, 10-12 months, 13-18 months, 19-24 months and 25-30 months. The sixth variation is a general screening form.

2.4.2.3 Psychometric properties

Construct validity was obtained from an analysis of item discrimination indexes. Items with medium to large discrimination indexes were included. The false-delayed error rate ranged from 3–13% and the false-normal error rate ranged from 0ï 14%. It is thus accurate in differentiating normal from regulatory disordered infants. It was found that the checklist was least accurate for infants in the 25–30 month age range and was therefore not used in this study.

Concurrent validity tests found that the ITSC assessed uniquely different behaviours than those measured by other tests, as it was designed to assess constructs which had previously been overlooked (36).

Psychometric evidence on the quality of the ITSC suggests that the scores may be validly used to screen for RSPD. When coupled with other assessments, such as clinical observations, it was found to be a valid diagnostic tool.

In this checklist, infants scoring at or above the cut-off score are considered at risk for RSPD and were referred for intervention (36).

2.4.2.4 Uses of the Infant Toddler Symptom Checklist

Various authors have listed the ITSC as one of the primary assessment tools for the identification of RSPD (1,2).

Recommendations on the assessment of infants with regulation disorders suggest a combination of standardised assessments, at least three observations of occupational function, and information from parents and caregivers through checklists and interviews (1,2).

For the purpose of this study, the ITSC was the best assessment available for the nature of the information required in order to design and implement a specific and individualised sensory diet, as well as to compare the effect of this to cut-offs for RSPD pre and post-intervention.

2.5 Intervention: focus on Sensory Integration and its role and contribution to Regulatory Sensory Processing Disorder

2.5.1 Introduction to the intervention: focus on a family-centred and integrated approach

The use of the above assessments are important in creating a clinical picture of an infant in order to provide the most comprehensive and effective intervention. According to Dr. Lane (25), Sensory Integration based occupational therapy is the primary treatment modality for RSPD. Developmental, Individual Difference, Relationship-based Model (DIR)/Floortime trained specialists (37) are also well-

equipped to treat infants as they are trained to have a sensitivity for the nature of underlying sensory processing difficulties.

The literature on intervention for infants with RSPD was limited. One study reported on infants receiving a 12-week intervention, but the sample size was small and the treatment methodology was not reported in detail (17). This study also used Sensory Integration and DIR/Floortime as the two treatment modalities, confirming the opinion of Dr. Lane.

Gomez, Baird and Jung (38) and a chapter in the ICDL clinical practice guidelines by DeGangi (37) provide intervention-planning recommendations for the treatment of RSPD. Both sources advocate an integrated, family-centred treatment model. Gomez et al. suggest that intervention should include management of regulatory behaviours, for example, sleep, feeding and behaviour; providing parents with an understanding of how to interact with their infant; modifying the environment; and promoting appropriate infant responses to sensory experiences (38). DeGangi agrees with this, but suggests three formal therapeutic approaches to reach these goals: parent guidance, which focuses on specific regulatory difficulties such as sleep, feeding and other observed behaviours in the home environment; child-centered interactions, that is, DIR/Floortime, which encourages healthy parent-child interactions through the context of play; and Sensory Integration therapy which promotes organised attention, adaptive behaviour and focuses on normalising responses to sensory experiences (37).

2.5.2 Ayers: Sensory Integration

Ayers defines Sensory Integration as ñthe neurological process that organises sensation from oneôs own body and from the environment and makes it possible to use the body effectively within the environmentòpg 11 (39).

Sensory Integration trained occupational therapists recognise the importance of an appropriate state of arousal (regulation) in relation to the environment in order to express an adaptive response during various occupational activities such as sleeping, feeding and playing. They are trained to treat sensory-based difficulties

which restrict infants from responding to their environment with an appropriate adaptive response.

Ayers-SI therapists are thus valuable in guiding parents, and providing the Sensory Integration based occupational therapy suggested by DeGangi (37). Ayers-SI therapists who are trained in DIR or Floortime could also offer this service. The Ayers-SI treatment approach is therefore used in three ways in the treatment of infants (37,8). The first is parental education of sensory contributions to the infantôs behaviour. This assists in developing a successful relationship. Ayers-SI is also used in order to modify the environment to fit the infantôs needs. This is achieved through management strategies as well as the provision of a sensory diet (38,40). Lastly, Ayers-SI is used to provide individualised direct intervention in order to remediate sensory based problems. For the purpose of this study, the first two aspects were implemented. The literature on these two aspects will be discussed in detail.

Although literature on the efficacy of Ayers-SI on infants was not found, there are studies determining the efficacy of Ayers-SI on older children with sensory processing difficulties. Although more research is needed in this area, reviews of research indicate that the efficacy of Ayers-SI has not been established due to poor research methodology used in the studies (41). There is currently a strong drive towards using fidelity measures to determine the effectiveness of Ayers-SI (42).

Two studies including children who experience SMD, have reported improvements to parent perceptions of their childrenôs competence, self-regulation, and social abilities. Parents were also better able to support their children by using sensory strategies (sensory diets) and support themselves (43,44).

2.5.1.1 Parent Education

Parent guidance or education has been listed by both Gomez et al. and DeGangi as the first aspect of intervention for RSPD (37,38). In both parent perception studies, parent education was highly rated as a benefit of Ayers-SI from a parental perspective (44,43). This education included two aspects: an understanding of their childôs behaviour and techniques and strategies to use at home (provision of a

sensory diet). Both studies were, however, small qualitative studies on five families and may not be generalisable to the entire population. No studies were found that explained exactly what knowledge was provided and how this knowledge was specifically imparted to the parents.

Self-help books were highlighted by DeGangi as a way of supporting parent education in managing specific behaviours, for example, sleep or dietary problems (37). Importantly the self help books and access to internet were highlighted as a means to **support** the parent education, and do not replace the need for individualised parent education or therapy. In SA, the Baby Sense brand is well known and has had the most far-reaching impact in terms of educating parents on the importance of sensory input and the infantôs sensory world. Through the Baby Sense range of books and its website, many parents are able to obtain generalised sensory diet activity ideas (45,46,47).

DeGangi found that parental inexperience and mismanagement of behaviours in infants with RSPD made symptoms worse and thus highlighted the importance of helping parents understand their infants and how to respond to specific behaviours (37). This emphasises the importance of identifying RSPD at an early stage, as education would help parents to manage difficulties sooner (38).

2.5.1.2 Ayers-Sensory Integration strategy: sensory diet

In the literature review of intervention strategies available for treating RSPD, sensory diets were not specifically mentioned, although Sensory Integration therapy was. A sensory diet refers to a planned and scheduled activity programme which is designed by an Ayers SI occupational therapist to meet a child's specific and unique sensory needs (5). However, some information on the use and importance of sensory diets in managing sensory processing difficulties was found (5,3). A case study on using sensory strategies was also found (40). Research on sensory diets in infants was not found. This lack of research was confirmed by Dr. Lane. Principles guiding the design of sensory diets were taken from sensory integrative theory (3).

Sensory integration theory provides guidelines for treating SMD (48). Particularly relevant to this research is the hypothesis that if a childôs sensory diet is modified, then appropriate sensory modulation is more likely to occur, and therefore, an adaptive response is more likely to occur. Thus one could say that appropriate modulation supports appropriate functional responses. This supports using sensory diets for the indirect treatment of sensory modulation and regulation.

Sensory integration therapy in infants occurs in the context of everyday activities and routines, for example, when an infant is touched, dressed, fed or bathed (1). Thus, by modifying daily routines, changing the environment and using individualised sensory inputs, specific sensory responses are normalised (37) by using a sensory diet.

Research by DeGangi et al. (17) found that Ayers-SI was beneficial to infants with RSPD and that treated infants coped better than untreated infants, but still showed delays after treatment in comparison to typical infants (17).

In deciding which strategies would form part of the Ayers-SI sensory diet, the sensory integrative framework was consulted. The framework views various visual, auditory, vestibular, tactile, oral and proprioceptive inputs as alerting or organising in nature (8). Williamson and Anzalone (8) specified alerting or calming inputs for infants and toddlers. Inputs which are calming were chosen in this study. Vestibular and proprioceptive inputs have been identified as being of particular importance in treating SMD (49) and are valuable as part of an Ayers-SI sensory diet. Examples of vestibular activities included were rhythmic motor activities, such as rocking and swaying and proprioceptive activities included resistive activities as well as joint compressions. Other calming sensory inputs included tactile input through deep, firm touch, such as holding firmly for a hug or rhythmic patting; oral inputs, for example, sucking a pacifier; and auditory inputs using music with a steady, slow rhythm (8).

Advice regarding feeding difficulties was based on the baby-led weaning approach, developed by Rapley and Murkett (50). The book was based on an unpublished MSc study by Rapley. This process involves introducing solid foods, from about 6 months

of age, in their natural form without the need to spoon feed or puree foods. This gives the infant the control and ability to explore, making meal times enjoyable and allowing infants to move at their own pace. Research supporting this approach was recently published by Townsend and Pitchford (51). In their study, infants using baby-led weaning were compared to those fed using spoon-feeding methods. According to their results, infants using baby-led weaning ate healthier foods and were better able to regulate food intake and quantity. There was, however, no significant difference in terms of picky eating or fussy feeders.

In addition to the baby-led weaning approach, the following sensory aspects were deemed valuable with regards to feeding difficulties: scheduling feeding at a relaxing time, predictable routine or sequence of events and introducing changes in food texture slowly (52).

Advice regarding sleep was based on studies of normal sleep patterns in infants and sleep difficulty causes. Spruyt, Aitken, Charlton, Adamson and Horne (53) found that increased nocturnal sleep was correlated with improved approachability and adaptability during the day for infants i.e. improved regulatory behaviours, while decreased day sleep was linked to emotional regulation. The study concluded that sleep difficulties related to regulation should be evaluated and dealt with when evaluating an infantôs daytime behaviour (53). Intervention advice regarding night time sleep patterns and the ability to self-soothe was detailed by Burnham, Goodlin-Jones, Gaylor and Anders (54) in a study of 80 infants. According to the study a sleep association toy did not affect sleep. The two main predictors of improved self-soothing abilities at 12 months were: infants who spent most of their sleep time in their own cots and parents who waited before responding to infant awakenings. In addition to this, specific sensory modulation difficulties due to auditory, tactile or vestibular processing could influence an infantôs abilities to fall and stay asleep.

For the purposes of the study, the interventions selected were a consultation with parents to implement an Ayers-SI sensory diet and parental education to assist them in changing their responses to their childrenôs behaviour. This approach has been

endorsed by Reebye and Stalker (55), DeGangi (37) and Gomez et al. (38) and found to be a valuable intervention strategy.

2.6 Need for early intervention and prevention

The literature review shows that RSPD can be identified in infancy and may lead to later difficulties.

In the USA, it was identified that 17% of children have developmental challenges, but less than 50% of these challenges were identified before starting school (21). In SA no such data was found, however, the *Guideline for early childhood development services* (20) focuses on healthy functioning and recognises that by caring for infants and young children correctly, later difficulties can be avoided. This supports using early intervention to address difficulties which deviate from healthy functioning.

Research has shown that the identification and intervention of RSPD is important as it may lead to later difficulties if untreated. DeGangi et al. (16) indicated that 89% of untreated regulation disorders lead to later regulatory, developmental and sensory-motor deficits at a four year follow-up (n=22). The study was conducted on a small sample of infants and the results may therefore not be generalisable. It is possible that these difficulties could have been avoided or reduced if RSPD had been identified and treated during infancy. However, research has not yet been done to determine if long-term developmental, learning, sensory integrative, behavioural and emotional difficulties can be prevented by providing intervention in infancy (17).

DeGangi et al. (17) studied three groups of children between 7-30 months and then again at 36 months (n=50). The study compared a treated regulation disordered group (n=26), an untreated regulation disordered group (n=13) and a typical group (n=11). The study found that both treated and untreated groups continued to present with emotional and sensory integrative difficulties when compared to their typically developing counterparts. However, the treated group, which received 12 weeks of DIR or Floortime and Ayers-SI, showed half the emotional difficulties that the untreated group presented with (7% versus 15%). Infants who formed part of the treatment sample were not randomly selected, but were included based on the

parentôs interest and thus parentôs who struggled more with their infants opted to undergo treatment. This may have affected the results of the study as it may not reflect the population and thus results may not be generalisable. It also highlights the importance on parents as part of the team as active participation by the parents appears to have lead to adherence and improvements. Signs of tactile defensiveness, sensory integrative deficits, attention difficulties and self-regulation difficulties of sleep and feeding continued to present equally in these groups. Thus, the treated group experienced more severe difficulties than the untreated group at the start of the study. The study concluded that sensory processing difficultiesð for example, vestibular, auditory and tactile processing difficultiesð tended to persist while emotional responses (interactional problems through the parent-child relationship) which were not yet consolidated improved (17).

Untreated signs of RSPD in infancy may present in several ways throughout developmental stages over time (1). During the toddler stages the infant displays fight or flight responses indicating poor sensory modulation and regulation and thus struggles to develop autonomy and independence. They often also present with mood regulation difficulties. They also continue to struggle to self-calm, need predictability and present with separation anxiety from the parent who usually provides co-regulation. The preschool years may be marked by delays which become evident in fine and gross motor skills as well as distractibility, sensitivities to tactile and vestibular input, and language difficulties (1).

Prevention is important in avoiding these difficulties.

2.7 Conclusion

This literature review investigates the concepts of self-regulation and RSPD. Sensory Integration therapy is a recognised treatment modality for this disorder. Parent education and the provision of sensory diets are recognised Ayers-SI treatment approaches. Individualised direct Ayers-SI therapy is also a treatment method, but it was not used in this study due to time restrictions. Some studies allude to the importance of potential prevention of later difficulties by addressing RSPD in infancy with one indicating some positive effects of early intervention.

However, recommendations suggest that more studies should be done to determine appropriate duration and frequency of Ayers-SI intervention to determine how much input is required to effect long-term change. The use of a two-week Ayers-SI sensory diet contributes to the need for further research. The research methodology of this study addresses the need to quantify and measure change and effects over time.

The literature review was conducted to support the purpose for the study. It thus explored the context of early intervention and the need for preventative approaches. It aimed at determining the current knowledge of RSPD and related concepts in order to have designed, and evaluated the use of the Ayers-SI sensory diet as an intervention strategy.

CHAPTER 3
RESEARCH METHODOLOGY

3.1 Introduction

The research methodology and process had to be adapted from the initial protocol submission and ethical clearance approval. Initially the study was to be conducted by introducing therapeutic listening to 7 month old infants with RSPD over a six week period. However recruiting of possible participants rendered only one possibly infant participant over a four month period. Through discussions with parents as to their caution of partaking in the study it was found that most felt they could not commit to a program for 6 weeks due to time constraints. It was therefore decided to change the research intervention to make it more realistic for parents to apply and commit to. Thus the research period was shortened to two weeks and a sensory diet was introduced instead of a specific auditory intervention. In addition, the age range was widened in order to improve the sample size.

This current study used a quantitative and descriptive methodology to determine the effect of parent education and the provision of an individualised Ayers-SI sensory diet over a two-week period. This methodology was also used to determine whether the intervention was beneficial in reducing the symptoms of infants meeting the criteria for RSPD and to meet the objectives of the study as described in Chapter 1. The study was carried out in seven steps which are outlined in Figure 3.1.

This chapter describes each step taken in the study to clearly describe the research process and the decisions taken to ensure rigor.

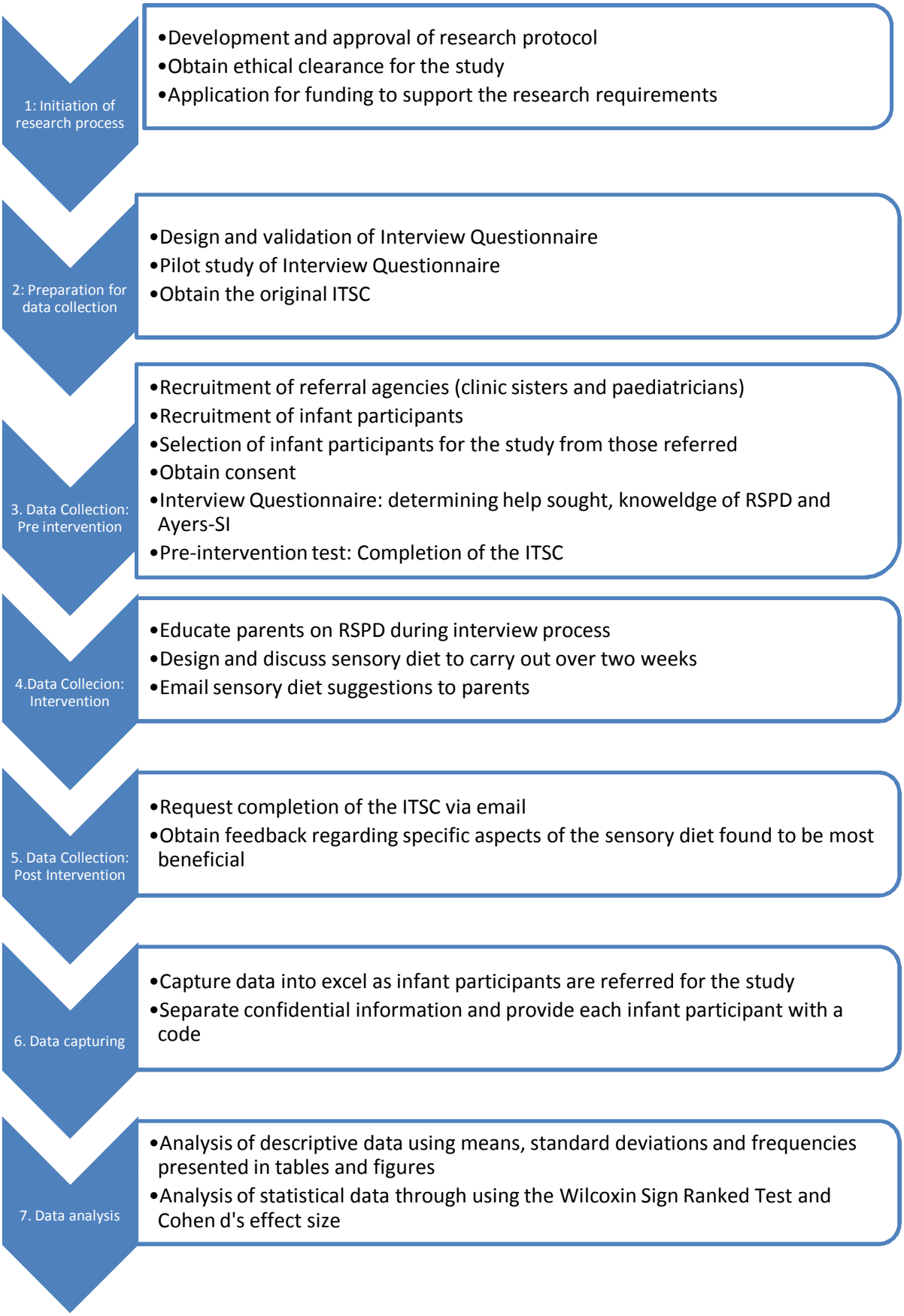


Figure 3.1 Flow diagram indicating research procedure

3.2 Research design

A descriptive, experimental pre- and post-intervention, quasi-experimental, quantitative study design was chosen.

Descriptive research was an appropriate methodology for this study since no such research had been conducted in SA and it explored parentsô knowledge of RSPD and Ayers-SI and advice that they had sought. This study adhered to the three aspects of a descriptive research design as it allowed the researcher: to explore the condition of RSPD in infant participants leading to greater understanding of the parental perceptions before and after an Ayers-SI intervention; it described information relating to infant participants which informed and guided the use of Ayers-SI on infant participants; and it characterised infants with RSPD by obtaining demographic data and birth history and analysing this information to support and make sense of the quantitative data obtained in the ITSC (56).

The design was quasi-experimental and not a true experimental design as a convenience sample was drawn from referrals. This allowed analysis of infant participantsô fussy behaviour in their home environments and during everyday activities of sleeping, bathing, feeding, playing and social interaction (56).

A pre-test post-test design was used to measure the effect of parent education and Ayers-SI sensory diet using the ITSC. The ITSC was used to record parentsô experience of RSPD in their infantsô before the intervention and then to measure the effect of the intervention by repeating the ITSC. This design was appropriate as it allowed for statistical data to be obtained and analysed to determine whether a sensory diet is effective in reducing RSPD symptoms (56).

The study is quantitative as the data collected through the ITSC was converted to a nominal measurement scale so that statistical information could be calculated (56). Question 4 on the interview questionnaire provided ordinal data as the parent was requested to rate their concerns in order of importance (56).

3.3 Selection of participants

3.3.1 Sample population

The population was limited to all fussy infants between 7 and 24 months with the same symptoms of RSPD as described by DeGangi and Greenspan (1). These symptoms formed part of the inclusion criteria for the study.

Infants aged 6 months or younger were not included in the study due to the high incidence of colic and reflux in this age group, as well as research which indicated that signs of colic usually resolved by 6 months of age (16). Toddlers from 24-36 months were also excluded as this age group has been reported to have a higher degree of fussiness, which was considered developmentally appropriate (36). In addition results of normative studies for this age group for the ITSC were least accurate for this age group (36). For convenience, the population was limited to infants within the Ekurhuleni metropolitan area at private clinics in Edenvale, Benoni, Boksburg and Kempton Park.

3.3.2 Sampling procedure

A non-probability sampling method was used for the research as infant participants were included in the study as they were referred. There was no control group and thus infant participants could not be randomly assigned to various groups (56). A convenience purposive sampling procedure was used by selecting a sample from the population which met the inclusion criteria (56). For this study, due to the limited number of fussy infants referred, all infants from the population met the inclusion criteria and were thus all included in the study. This method was necessary in order to collect a sample within the time constraints to complete the research report, over an 8 month period.

3.3.2.1 Inclusion criteria

- Infants aged between 7 and 24 months,
- Neuro-typical infants,
- Males and females,

- The infant participant had to meet at least two of the following criteria as described by the parent during the telephonic discussion with the researcher:
    - Sleep disturbanceð the infant takes more than 20 minutes to fall asleep or wakes more than twice a night.
    - Difficulties in self-consolingð the parent spends two to four hours a day attempting to calm the infant.
    - Feeding disordersð feeding difficulties not related to allergies or intolerance including refusal to eat, regurgitation and difficulties establishing a regular feeding routine.
    - Hyper-arousalð infant appears overwhelmed by sensory input and may avert gaze to avoid contact. They may appear intense, wide-eyed or hyper-active.

3.3.2.2 Exclusion criteria

Infants who were medically unhealthy or had a medical condition explaining excessive fussy behaviour were excluded from the study, for example, soft cleft palate affecting feeding.

3.3.3 Sample Size

A sample size of 15 was calculated to show significant difference at the 0.05 level using a power of 80% if a 5 point difference was detected after intervention (56).

3.4 Data Collection tools

3.4.1 Data Collection Tools

An interview questionnaire was used as part of the pre-test interview with the parent. The ITSC was also used at this pre-test stage and was provided after the interview. Following the intervention, the ITSC was again provided as part of the post-test.

3.4.2 Interview questionnaire development

In designing the interview questionnaire (Appendix A), the study objectives were referred to, to ensure that the ITSC and interview questionnaire elicited data which could be used to reach these objectives.

The interview questionnaire layout was determined to ensure that the interview followed a logical process. The first items dealt with demographics and birth history which the parent completed as part of a self report form (Appendix A.2 page 91 and page 92). Details on current difficulties experienced in each domain of the ITSC followed (page 93). The questionnaire ended with questions regarding where the parent had sought assistance and whether this had helped (page 94 and 95).

A cover page (Appendix A.2, page 90) was included which explained the purpose of the interview questionnaire. The second page requested infant and parent personal details, which was filed separately from the rest of the data. Questions regarding demographics and birth history were included to collect information about the infant participants to analyze the nominal data obtained and to ensure that the infant participant met the inclusion criteria. Questions 2 to 4 were included based on the domains assessed by the ITSC (36) namely self-regulation, attention, sleep, feeding, dressing, bathing and touch, movement, listening and language, looking and sight, and attachment or emotional functioning. Questions 5 to 9 and 13 to 20 were included to explore aspects in order to achieve the first objective of the study. Questions 10 to 12 were excluded during data analysis because they were deemed unnecessary.

The questionnaire consisted of two sections:

a) Demographic and birth history of the infant participant
b) Information about the infant participantôs symptoms of fussiness, parentôs knowledge of RSPD and help sought.

Section 1: Demographics and birth history

Demographic information included date of birth, gender and sibling order within the family.

The questions regarding birth history were taken from the ITSC cover page provided in the manual (36). To these were added some additional detail e.g. Caesarian section was made more specific by indicating whether it was emergency or elective and medical problems during birth was added to the Medical problems section. The birth history section consisted of 4 questions about the infant participantôs background, 4 questions about the pregnancy and birth, 2 about medical information and 2 about the parentôs background.

Section 2: Symptoms and parental knowledge

This section collected specific information pertaining to the infant participant, the parentôs understanding of the condition and the help that they had sought. The questions were related to the objectives of the study.

The first objective was *to establish what the parents of infants with RSPD knew about the condition and what they had done to deal with the problems through advice from medical professionals or their own investigations.* There were 8 questions that dealt with this. The specific questions were informed by interviews with clinic sisters and paediatricians as well as literature on the condition detailing the experiences of parents of infants with RSPD (2).

The second objective was *to design, implement and evaluate the effectiveness of a two-week Ayers-SI sensory diet in infants with RSPD* and was also supported by the interview questionnaire. The information relating to this objective was obtained through 5 questions on the interview questionnaire. These questions were important in order to ensure that the Ayers-SI sensory diet was specific to each infant participantôs individual profile.

3.4.2.1 Validity and reliability of the interview questionnaire

Once the first draft (see Appendix A.1) of the interview questionnaire was completed the validity and reliability had to be established before it could be used to collect data (56).

Reliability

Although split-half reliability is frequently used to test the reliability of questionnaires (56) it did not suit this particular interview questionnaire, as much of the data could not be converted to nominal data due to the open-ended nature of the questions. Inter-rater reliability was not conducted on the interview questionnaire as the researcher performed all the interviews. Instead, a pilot study was conducted to test the interview questionnaireôs reliability in obtaining the same information from each parent. In addition the researcher ensured that the questions were completed in the same order and asked in the same manner.

Reliability of information of the ITSC was supported by using the same checklist for both pre and post-test procedures. This ensured that each infant participant was tested on their own performance using the same tool in order to reliably compare the data.

Validity

The interview questionnaire was checked for face and content validity. The interview questionnaire contained face validity as the questions were made up of questions which achieved the two objectives (56). This was confirmed by a panel of experts who examined the questions in the interview questionnaire addressed the study objectives. The content validity was measured by consulting a panel of experts, the process followed and findings of which are detailed below (56).

In the Gauteng area, only three occupational therapists trained in Sensory Integration were known for their expertise in treating infants at the time of the study. Two agreed to participate in the process of establishing the content validity of the interview questionnaire. The two experts were contacted telephonically to explain the research, the process of content validity and to request their participation. After obtaining consent, each expert was emailed the interview questionnaire. The experts were asked to examine the interview questionnaire for comprehensiveness on the topic, whether the questions would produce the information to answer the two objectives, whether the language was clear, unambiguous and whether the flow of questions was logical.

Each expert was requested to make notes of their comments. During the consultation, each question was examined and discussed. Recommendations were incorporated into the final interview questionnaire which was used for the study. Below are details regarding these recommendations (Refer to Appendix A.1 to view these comments and suggestions for change).

- Both experts thought that the questionnaire was to be completed by the parent independently and thus queried the layout and lack of explanation of some items. That is, Question 2 did not specify enquiry into past behaviours while Question 3 did not specify the focus on current behaviours. Question 4 did not provide sufficient detail on how to rank items. However, once it was explained that it would be completed in an interview format, the experts were satisfied.
- In the section on demographic data on the first page it was recommended that the present age of the infant participant be included and that sibling information be included. It was also suggested that the caesarean section be split into elective, emergency and breech to provide more specific information. The questions on this page were not numbered, but this refers to the second, fourth and sixth items.
- It was suggested that a new item on medical problems during the birth process also be included to determine pre, peri and post-natal difficulties (Item 8).
- It was suggested that examples such as ear infections and epilepsy be added to clarify the item on medical history (Item 10).
- Question 20 regarding parentsû knowledge of whether regulation difficulties could lead to later problems was reworded to make it less negative for parents (Item 11).
- Making more space available to document sensory strategies and the follow-up of these strategies was suggested.

Changes were made as per these recommendations and the final interview questionnaire included 20 items. It was checked by a research supervisor to ensure confidentiality and that the questions in the questionnaire followed a logical

sequence (Appendix A.2). From this feedback, parent and infant participant personal details were separated onto different forms and each questionnaire provided a space for a patient code.

3.4.2.2 Piloting the interview questionnaire

Field pre-testing was used to pilot the interview questionnaire (56). Three parents of fussy infants from the Edenvale area participated in the pilot. Due to the small sample required for the study, only three participants were included in the pilot process. The pilot study infant participants that were recruited fell into the 7-12 month and 13-18 month age groups.

On completion of the interview the parents were asked whether they felt the questions were clear, whether they had any questions or felt that any relevant information regarding their infantôs history had been omitted from the interview questionnaire during a debriefing process.

The parents reported that the interview questionnaire was adequate, no changes were made to the questionnaire and thus the data from the pilot was included in the study.

3.4.3 Infant Toddler Symptom Checklist details

The ITSC was developed by DeGangi et al. (36). The ITSC was used to obtain data to achieve the second objective of the study and was selected as it had previously been used in research on infants with RSPD (15,36). The checklist was found to have adequate construct validity and reliability studies. Concurrent validity checks found that it was the only checklist designed to assess RSPD accurately. This checklist conducted in conjunction with other observations and standardised tests such as the Test of Sensory Functions of Infants (14) were found to be adequate in diagnosing RSPD. Other tests were not used in this current study as the focus was on parent perceptions of RSPD symptoms in their infants, pre and post-intervention.

The cover sheet (Appendix A.2, page 90), accompanying the ITSC and self report portion of the interview questionnaire, described the purpose of the checklist and how to rate infant behaviours. The parent was requested to tick ñnever or sometimesò, ñmost timesò, or ñpastò for each item. It was administered in one sitting and took about 10 minutes to complete. It was completed independently by the parent (36).

The cover sheet was followed by a two-page checklist specific to various age groups: 7-9 months, 10-12 months, 13-18 months and 19-24 months (See Appendix B.1). The age groups differed slightly in the number of items for each domain. The 13-18 and 19-24 month old groups included a concentration domain which was not included in the first two age groups. The checklist identified difficulties with self-regulation, sensory processing, emotional regulation and attention (36). These domains are detailed in Table 2.1 in the literature review. Chapter 4 discusses sensory processing or functions and includes the following ITSC items: dressing, bathing and touch; movement; listening and language; looking and sight.
The test was scored by the researcher on a protocol sheet, which was provided by the ITSC authors (36) where never or sometimes = 0, most times = 2 and past = 1. One item regarding time spent calming the child was scored differently, where 15-30 min = 0, 1-2 hours/day = 1 and 3 hours per/day = 2. The total test score was obtained by adding these scores and was then compared to a cut-off score for each age group. This was used to determine whether the infant participant was at risk for RSPD. A sample of a completed protocol sheet can be found in Appendix B.2.

3.5 Research procedure

3.5.1 Recruitment of referral agencies

Appointments were made with clinic sisters at private baby clinics within Ekurhuleni over a four month period. During this appointment, the research study was explained using the information sheet for the professional (Appendix C.1). The researcher explained the reason for the study, the inclusion criteria, research procedures, benefits, risks and costs involved and the objectives of the study. The clinic sisters who were interested in participating were provided with research flyers and inclusion

criteria checklist forms (Appendix D). They were requested to identify infants who met the inclusion criteria of the study and give the caregivers of these children the researcherôs contact details. This allowed for voluntary participation in the study as parents could then decide whether to contact the researcher. This approach could also have led to the small sample size in the study.

3.5.2 Recruitment and selection of infant participants

As the first contact the researcher had with the parent was telephonic, the researcher carried out a telephonic screening interview to ensure that infants met the inclusion criteria and were eligible to participate in the study. This discussion followed the information found on the research flyer, Appendix D. If the child met the inclusion criteria, the parent was invited to participate in the study after the research was explained. Appointments were made at the convenience of the parent at their home, work or the researcherôs practice to carry out the pre-test and plan intervention.

3.5.3 Data collection: pre-intervention

Data was collected over an eight month period. As there was a lack of referrals from paediatricians and clinic sisters during the early part of the data collection period, clinic sisters from other areas within Ekurhuleni were approached. In addition, a snowballing procedure was also used; during the interview the parents were requested to identify other parents with infants with similar difficulties to their own and encourage them to participate in the study.

The data collection process took approximately an hour. The parent was given the option of participating alone or with their spouse. The infant participant was not present during the interview to eliminate disruptions to the interview process.

3.5.3.1 Obtaining consent

At the appointment the parent was first provided with the information sheet which detailed the reason for the study, inclusion and exclusion criteria, research procedure, voluntary participation, risks, benefits and costs involved and how anonymity would be ensured. They were also provided with a consent form after

having been given time to read the information sheet and ask any questions (see Appendix C.2) which they were then required to sign. This was done for ethical considerations.

3.5.3.2 Pre-intervention assessment

Two data collection tools were used to collect the data at the pre-intervention interview.

Self-reported portion

The cover page, infant and parent detail page and the first page of the interview questionnaire were provided to the parent for completion (see Appendix A.2 P90-92). Infant and parent personal details were filed separately to ensure confidentiality.

Interview questionnaire (Appendix A.2 P93-P96)

The interview strictly followed the questions as set out in the interview questionnaire. All interviews were carried out by the researcher. This was to ensure that all interviews were conducted in the same manner and to collect the data in the most unbiased way.

During the interview, the researcher clarified terms as they arose e.g. self regulation was discussed as part of question 2 and RSPD was explained with question 19. The researcher wrote the responses to each question on the interview questionnaire which were entered into an excel document immediately following the appointment with the parent.

Infant Toddler Symptom Checklist (Appendix B.1)

The ITSC is a self-reported check list. The parent was asked to complete this after the interview, but before the provision of the Ayers-SI sensory diet and parent education. The parent was asked to read the first page of the ITSC which described how to complete the checklist (Appendix A.2, Pg90). The researcher remained in the vicinity in order to answer any queries that the parent may have had. Once this was complete, the researcher scored and reviewed these forms and then designed the Ayers-SI sensory diet for the infant to be used by the parent at home. During this

time the parent was waiting in the waiting room. The parent was then invited to join the researcher for the parent education and provision of the sensory diet.

3.5.4 Intervention

The intervention consisted of two parts: imparting knowledge through parent education and the design and provision of an Ayers-SI sensory diet.

3.5.4.1 Education of the parent on RSPD

Regulatory Sensory Processing Disorder was verbally explained to the parent, using supporting diagrams. The explanation included a description of sensory modulation and its impact on daily activities such as sleep, feeding and attachment (items on the ITSC). The link to later challenges as well as the need for early intervention was also explained. The slides of this explanation can be found in Appendix E.1.

The decision to explain sensory modulation was based on the observation that each infant participant in the study presented with Type I RSPD (sensory modulation challenges). Typical and atypical thresholds for sensory inputs were explained. This provided the parent with an understanding of the reason for their infantôs behaviour as well as the rationale for implementing the Ayers-SI sensory diet.

3.5.4.2 Design and provision of a sensory diet

The two-week Ayers-SI sensory diet was then outlined and detailed to the parent. The Ayers-SI sensory diet suggestions depended on each infant participantôs profile and on information obtained from the interview questionnaire (specifically Question 3 of the interview questionnaire). The indirect treatment provided through the Ayers-SI sensory diet was designed to target specific behaviours within the occupational performance areas, as described by the parent during the interview.

The Ayers-SI sensory diet provided specific handling techniques and activities to be used throughout the day, including how to create a sensory calm environment, the importance of movement and deep pressure to calm the infant, as well as specific information regarding sleep, feeding and play or attachment depending on the infant

participantôs profile. These principles were not accompanied by recommendations on frequency or specific times during which certain activities had to be carried out. It instead provided the parent with an understanding of the impact of sensory inputs on obtaining an optimal state of arousal (and signs of over arousal) and therefore assisting with modulation and decreasing fussy behaviour associated with RSPD. The researcher explained that deep pressure and proprioceptive input to the body through heavy work and resisted effort assists in obtaining an appropriate state of arousal; firm touch assists children with tactile sensitivities in being better able to tolerate unexpected touch; and that slow, rhythmic movement such as swinging, rocking and swaying, and the parent jumping on a trampoline while holding their infant, help to regulate arousal.

The specific information regarding sleep included the need for a predictable sequence of events, an appropriate sleep environment and the need to allow the infant an opportunity to self-soothe.

These handling techniques and activities were researched and taken from *Baby Sense, Your Sensory Baby and Sleep Sense* (46,47,45) as well as *Pediatric Disorders of Regulation in Affect and Behaviour: a therapists guide to assessment and treatment* (1); *Sensory Integration and Self-Regulation in Infants and Toddlers* (8); discussions with the expert panel of occupational therapists (during the validation of the interview questionnaire); and from clinical experience. These sources all provided specific Sensory Integration based intervention strategies. The advice provided as part of the sensory diet is detailed in Appendix E.2.

While the sensory diet was being communicated to the parent, the researcher made notes, and a copy of the programme was emailed to the parent after the interview. The parent was invited to contact the researcher with any queries pertaining to the sensory diet.

3.5.5 Data collection: post-intervention

Two weeks after the initial interview, the parent was contacted via email to request the completion of the second ITSC as well as to provide feedback on the

implemented Ayers-SI sensory diet electronically. They were asked for their perceptions on the aspects of the Ayers-SI programme that had been helpful or beneficial as well as the aspects that were not. The feedback from the Ayers-SI programme is not included in this research report, but was of interest to the researcher.

Following the scoring of the ITSC on the protocol sheet and the parentõs progress report, if the infant did not show any or adequate improvements in the two-week period, a more detailed Ayers-SI assessment was recommended and a list of occupational therapists trained in Sensory Integration was provided. In such cases multiple factors could be investigated for minimal progress such as parents adherence and consistency during the two week period, severity of infantõs symptoms of RSPD or possible undetected medical conditions during the two week period e.g. development of an ear infection or cold.

3.6 Data analysis

3.6.1 Data capturing and preparation for data analysis

The information from the interview questionnaire was organised into clusters and saved on separate sheets in an excel document. The page with infant and parent details was separated from the rest of the questionnaire and stored in a separate file. The first page (self-report) detailing birth history and current health was saved on a sheet in the excel document based on the code assigned to each infant.

Questions 2 and 3 pertained to clarification of the ITSC and were saved together in another sheet. In Question 4, the top three concerns of the parent were weighted to determine the main concerns identified by the parents. This weighting process was achieved by counting the frequency of which domains were highlighted as the top three concerns by the parents and then multiplying these to obtain a weighting. The frequency of one, two or three for each domain and then multiplying these by three, two or one. From this calculation, the top concerns of the research sample were obtained. Questions 5 to 9, investigated colic experienced, help sought and whether

this had been beneficial. Questions 13 to 20 were clustered together and they dealt with knowledge of Ayers-SI and RSPD.

Lastly, sensory strategies suggested as part of the sensory diet and parent responses on which were beneficial were collated in a table.

3.6.2 Descriptive statistics

Descriptive statistics were used to analyse demographic data and information obtained in the interview questionnaire. Frequencies and percentages were obtained from the raw data on demographics, where parents had sought help for their infant, whether this help had been beneficial, and their knowledge of Ayers-SI and RSPD.

Data collected from Question 3 was used only to design the Ayers-SI sensory diet for the intervention period and was not analysed in detail. Information regarding the strategies and follow-up were collated and documented but were also not analysed because they were unnecessary for achieving the study objectives.

Descriptive statistics were also used to analyse test items obtained in the ITSC. The data collected through the ITSC was analysed by obtaining means and standard deviations from the total scores and domains, and comparing these pre and post-intervention. This was performed for both age groups (7-12 and 13-24 months). The pre and post-intervention total ITSC scores were compared to the RSPD cut-off scores (36) to determine whether the result at the end of the intervention was within the normal range or still considered problematic.

3.6.3 Quantitative analysis

Quantitative statistics were used to analyse the effectiveness of the intervention programme by comparing the pre and post-intervention ITSC results. Raw ITSC scores can be found in Appendix B.3.

Non-parametric statistics were employed due to the small sample size. The Wilcoxin Signed Rank Test was used as it is especially useful when a small sample is not normally distributed. It is generally used to identify the magnitude of difference and the direction of change for correlated samples (56). It was thus sufficient for data

analysis in this study because the test was used to compare the overall difference in total ITSC score, pre and post-intervention. Results were considered significant if $p<0.01$ (57).

Cohenôs d effect size analysis was used to determine the size of difference between the total score means, pre and post-intervention, expressed as standard deviation units (56). An effect size of more than 1 SD was considered significant for this study while an effect size of 0.5 SD was seen as a moderate change.

Infant participants were grouped together to form a 7-12 month group (combining the 7-9 and 10-12 month groups) and a 13-24 month group (combining the 13-18 and 19-24 month groups). This was done to increase the number of infant participants in each category to perform statistical tests due to the small sample size. Effect size *d* was also calculated for each of the domains on the ITSC for the 7-12 and 13-24 months age groups in order to determine any significant post-intervention changes within groups and significant differences between groups.

3.7 Ethical considerations

The study was approved by the University of the Witwatersrand Human Research Ethics Committee. Ethical clearance was applied for and granted. The ethical clearance number is M090339 (see Appendix F).

Parents were provided with an information sheet which outlined the research purpose and method. It detailed the expected participation from participants including time expectations. Furthermore, the information sheet highlighted that participation was voluntary, participants could withdraw from the study at any time and that there was no charge for participation in the study. The information sheet also stated that if the infant still presented with RSPD after the intervention period, a list of Ayers-SI therapists in their area would be supplied. After parents read this information sheet, they signed a consent form (See Appendix C.2).

Anonymity of the data collected was ensured by providing each infant participant with a code from 1-12. Each sheet was labelled with this code to ensure that infant

participant information could be stored together. Contact details, which were essential for the follow-up aspect of the study, were kept separately from the rest of the data. Only the researcher had access to this information in order to contact the parent via email for communication following the intervention program and during the follow-up period.

Ethical considerations had to be made when developing and educating the parent on the sensory diet. That is, the information had to be provided in sufficient detail to ensure a good understanding of the underlying principles, so that the parent could carry it out at home as a therapeutic agent to ensure beneficence.

During the eight-month data collection period, as parents were entered into the study, appointments were set up immediately, and the research procedures described above were followed immediately. This was of ethical importance so that the parents could receive the intervention (which included parent education and the Ayers-SI sensory diet) as soon as their needs were made known to the researcher.

3.8 Conclusion

In conclusion, the research was planned using sound methodology and has been described in sufficient detail so that it may be replicated in another study.

The descriptive research enabled the researcher to establish what parents knew about RSPD and what procedures had been followed as part of managing the symptoms of fussiness in their infants. The quantitative research supported the aim of the study (to determine the effect of the Ayers-SI sensory diet on RSPD in infants) as statistical analysis could be performed to determine significant change by using a quasi-experimental pre-test post-test design on a sample of infants that met the study inclusion criteria.

CHAPTER 4

RESULTS

4.1 Introduction

The results of the study reflect the methodology described in Chapter 3. The data collected was analysed using both descriptive and non-parametric statistics in order to report the results of the study and support the study aim, objectives and null hypothesis.

The required sample size identified for the study was 15 infant participants. However in the eight-month data collection period, only 13 infant participants were referred despite many attempts made to gain additional referrals. One of the infant participants was excluded from the analysis of the results as the parent did not comply with the suggestions made and did not carry out the intervention programme within the two-week period between the pre and post-intervention assessments. Thus, the sample of 12 was small, which may have resulted in a Type II error (56). Therefore, the results may not be generalisable to the population.

4.2 Demographics of the sample

For the purpose of analysis, the infant participants were divided into two age groups: 7-12 months and 13-24 months. Table 4.1 shows that, seven of the 12 participants (58.3%) were male and five (41.66%) were female. Six participants were aged between 7 and 12 months and six were between 13 and 24 months.

Table 4.1 Demographics of infant participants (n=12)

Age	**7-12 months** (n=6)		**13-24 months** (n=6)	
	50%		50%	
Gender	**Male**	**Female**	**Male**	**Female**
	n=4 (66%)	n=2 (33%)	n=3 (50%)	n=3 (50%)

Nine of the infant participants were the first children born in the family which resulted in the parents feeling unsure about whether their child was being fussy or whether their behaviour was normal. The parents of the other three infant participants, who were not the first born, knew that the fussy behaviour was different to their other childrenôs behaviour.

4.3 Birth and medical history

4.3.1 Birth history

Five infant participants were delivered naturally, one via elective caesarean, five were emergency caesareans and one was a breech baby. Most of the infant participants (nine) were carried to full term and three were born before 38 weeks gestation, but were reported by the parents to have been medically stable at birth.

Of the sample, 33.33% (n=4) of mothers experienced difficulties during pregnancy. Two mothers experienced pre-term labour at 34 weeks which was medically stopped, one had pre-eclampsia and another had hypothyroidism (which was controlled with medication). Twenty five percent (n=3) experienced some difficulties during birth. One infant participant had the cord around their neck, one was breech and one experienced distress during premature labour.

After birth, 25% of the infant participants (n=3) experienced some difficulty: one struggled to latch sufficiently for successful breast feeding; the breech babyôs large head circumference was of concern and was monitored; and one infant participant, whose mother had hypothyroidism, was also found to have hypothyroidism and had

to be placed on medication. None of these medical conditions were considered severe and the infant participants were not hospitalised for prolonged periods as a result of these concerns.

4.3.2 Medical history

In total, 58.3% (n=7) of the infant participants did not have any health problems. The other five participants were reported to have had minor medical conditions: one experienced bronchitis and rotavirus (contracted while in hospital), two had allergic rhinitis and allergy concerns, two had ear infections, and one had an underactive thyroid (described previously). The infant participant with the underactive thyroid was expected to be more lethargic, but her condition was well monitored and controlled with medication.

4.3.3 History of colic

Eight infant participants (66%) were reported to have experienced colic. Six of the infant participantsôcolic was reported to have resolved: five participantsôsymptoms resolved at around 6 months of age and one resolved at 10 months. However, the signs of RSPD had continued to present in all six. In the remaining two infant participants, the colic symptoms did not resolve. Of these eight infant participants, five were prescribed medication but their parents were not given advice regarding management of the colic, for example, inclined sleeping position to reduce reflux. Three infant participants had used chiropractic services and one had had reflexology. Overall, three (25%) parents found the advice or medication to be helpful, while five (41.66%) found that it did not assist.

4.3.4 Experience of specific symptoms of Regulatory Sensory Processing Disorder from inclusion criteria

The parents of the 12 infant participants identified their infants as having at least two of the four behaviours related to fussiness listed as inclusion criteria for RSPD.

Figure 4.1 shows that all the infant participants experienced difficulties with sleep, seven experienced difficulties with self-consoling, five with feeding and five with hyper-arousal.

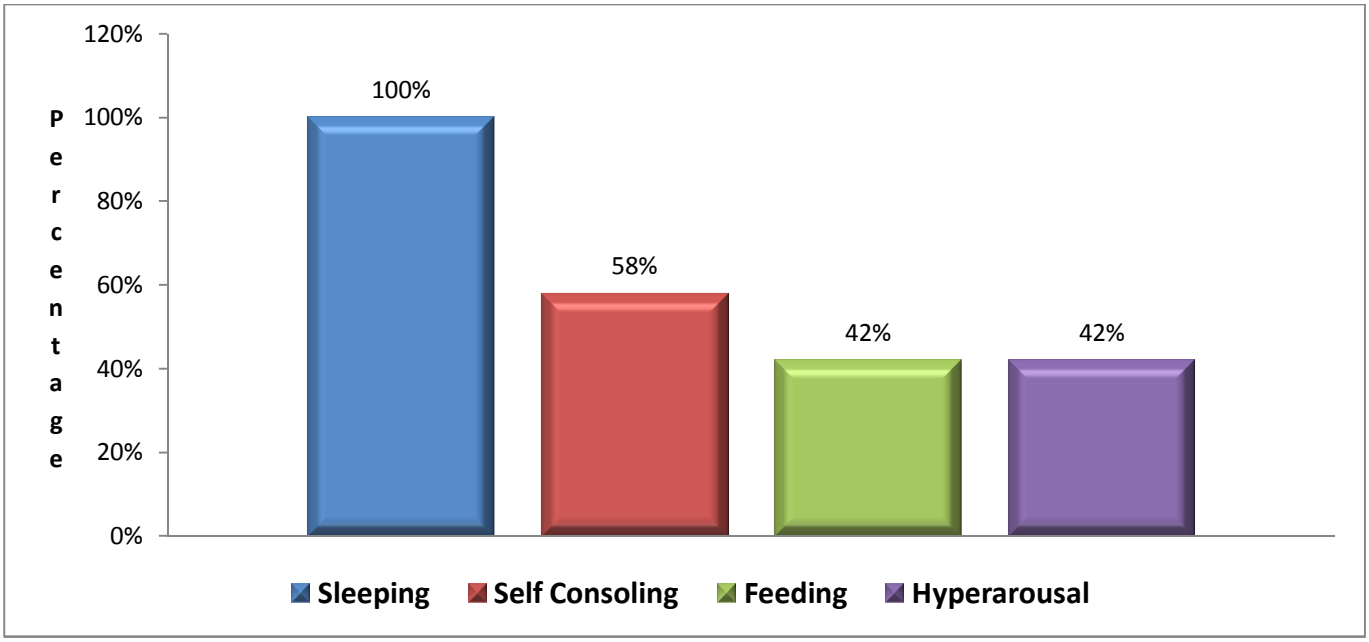


Figure 4.1 Percentage of infant participants presenting with specific symptoms of Regulatory Sensory Processing Disorder (n=12)

When comparing these symptoms between age groups, six infants in the 7-12 month age group experienced difficulties with sleep, four experienced self-consoling and feeding difficulties and two hyper-arousal. In the 13-24 month age group, six experienced difficulties with sleep, three experienced difficulties with consoling, one with feeding and three with hyper-arousal. This is shown in Table 4.2.

Table 4.2 Percentage of infant participants who presented with symptoms of Regulatory Sensory Processing Disorder in the two age groups.

	Sleeping	**Self-Consoling**	**Feeding Difficulties**	**Hyper-arousal**
7-12 month group (n=6)	100% (6)	66.66% (4)	66.66% (4)	33.33% (2)
13-24 month group (n=6)	100% (6)	50% (3)	16.66% (1)	50% (3)

4.4 Parent perceptions of Regulatory Sensory Processing Disorder

4.4.1 Onset of Regulatory Sensory Processing Disorder

Parents were asked to identify when signs of RSPD were first noted in their infant.

Table 4.3 Onset of Regulatory Sensory Processing Disorder

	Birth	6 weeks	4-6 months	7 months
Onset of regulation disorder	50%	25%	16.66%	8.33%

Six reported that their infant was fussy from birth and three from 6 weeks old. Another two reported the fussiness starting between 4 and 6 months and one parent stated that the fussiness was only noted from seven months.

4.4.2 Parents' four greatest concerns relating to infant participants' Regulatory Sensory Processing Disorder based on the domain headings assessed in the Infant Toddler Symptom Checklist

Parents were asked to rate which of the ITSC domains were of most concern to them. The top four concerns are highlighted in Figure 4.2. Sleep was the parentsô most predominant concern. Self-regulation and eating difficulties were viewed as equally concerning, followed by attachment.

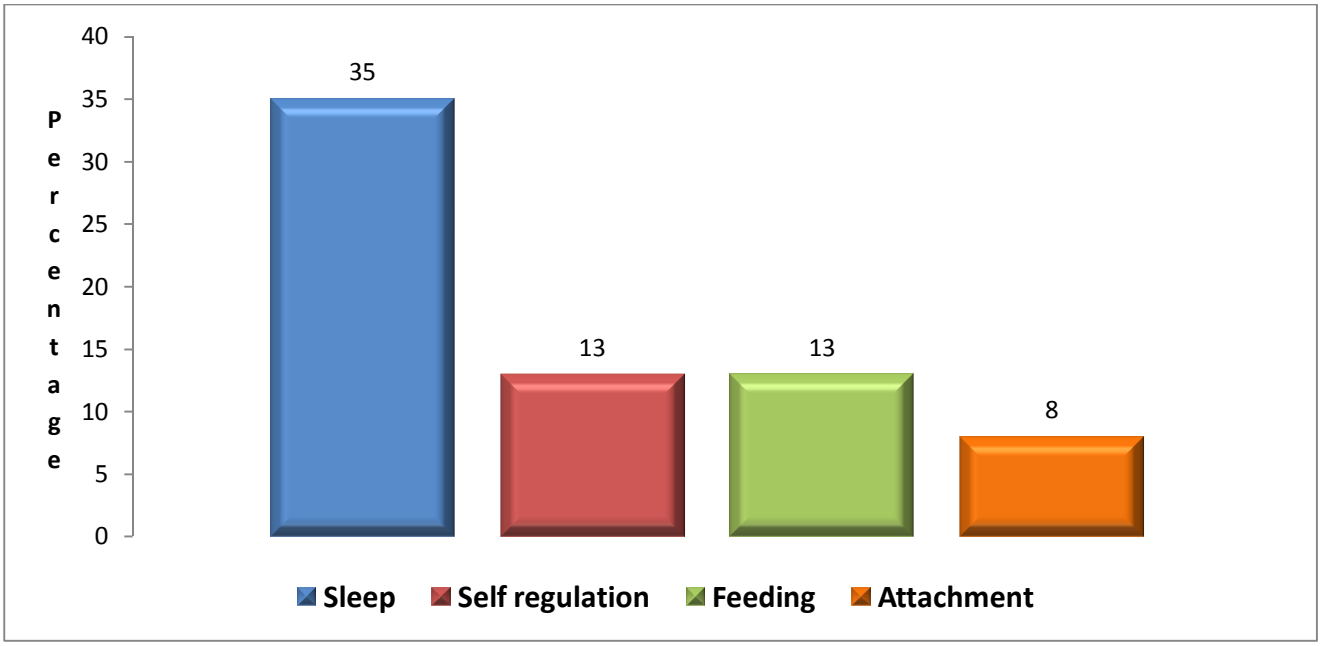


Figure 4.2 Parents greatest concerns relating to infant participantsôRegulatory Sensory Processing Disorder based on the domain headings assessed in the Infant Toddler Symptom Checklist

The following information provides more detail as to the reasons for the parentsô concern in each domain.

Sleep: Seven of the infant participants did not present with age appropriate sleep patterns during the day as they struggled to initiate day time sleep and only slept once exhausted. For night time sleep, all 12 infant participants experienced difficulties. Nine participants experienced difficulties with initiation of sleep and took longer than 30 minutes to fall asleep instead of the normal 10-20 minutes. Five infant participants woke between 3 and 5 times a night and four between 8 and 20 times a night, experiencing difficulties with maintaining sleep. Seven were co-sleeping: either in their parentsô bed or in their own bed with a parent and 11 required bottle or breast feeds which were developmentally unnecessary in order to fall asleep (45).

Self-regulation: Eight of the infant participants refused dummies and parents perceived this to be the basis for many of the sleep and self-soothing difficulties as they did not know how else to encourage self-regulation. This resulted in many of the infant participants relying on milk feeds (both breast and bottle feeds) to settle when upset or to facilitate sleeping. Five of the infant participants relied on their parent for

self-soothing in all situations while four of the infant participants were easily overwhelmed and two often threw tantrums.

Feeding: Difficulties around feeding were more prevalent in the 7-9 month group. Six infant participants experienced some form of difficulty around feeding: three parents indicated gagging and vomiting, two reported their infant having a limited food range and one infant participant experienced a poor appetite in the morning.

Attachment or emotional responses: Nine infant participants experienced difficulties with attachment and emotional responses. This included separation anxiety from the mother as well as difficulty forming a relationship with the father or other caregivers. The fathers or caregivers reported not knowing how to interact and maintain a pleasant interaction with the infant participant.

Although sensory processing was not raised as a parent concern, it is interesting to note that they did identify specific sensory-based difficulties which were affecting these behaviours of sleep, self-regulation, feeding and attachment. Six infant participants presented with tactile sensitivities regarding their face and dressing or bathing activities. Four experienced vestibular sensitivities, especially regarding gravitational insecurity. Five had auditory sensitivities and either screamed when surprised by unexpected noise or startled easily by noise within the environment and thus struggled to fall and stay asleep. Two infant participants had visual sensitivities and were distracted by visual inputs in their environment.

4.4.3 Assistance sought in dealing with Regulatory Sensory Processing Disorder

Figure 4.3 indicates that parents sought advice from multiple sources. All parents had sought advice from their paediatricians and clinic sisters.

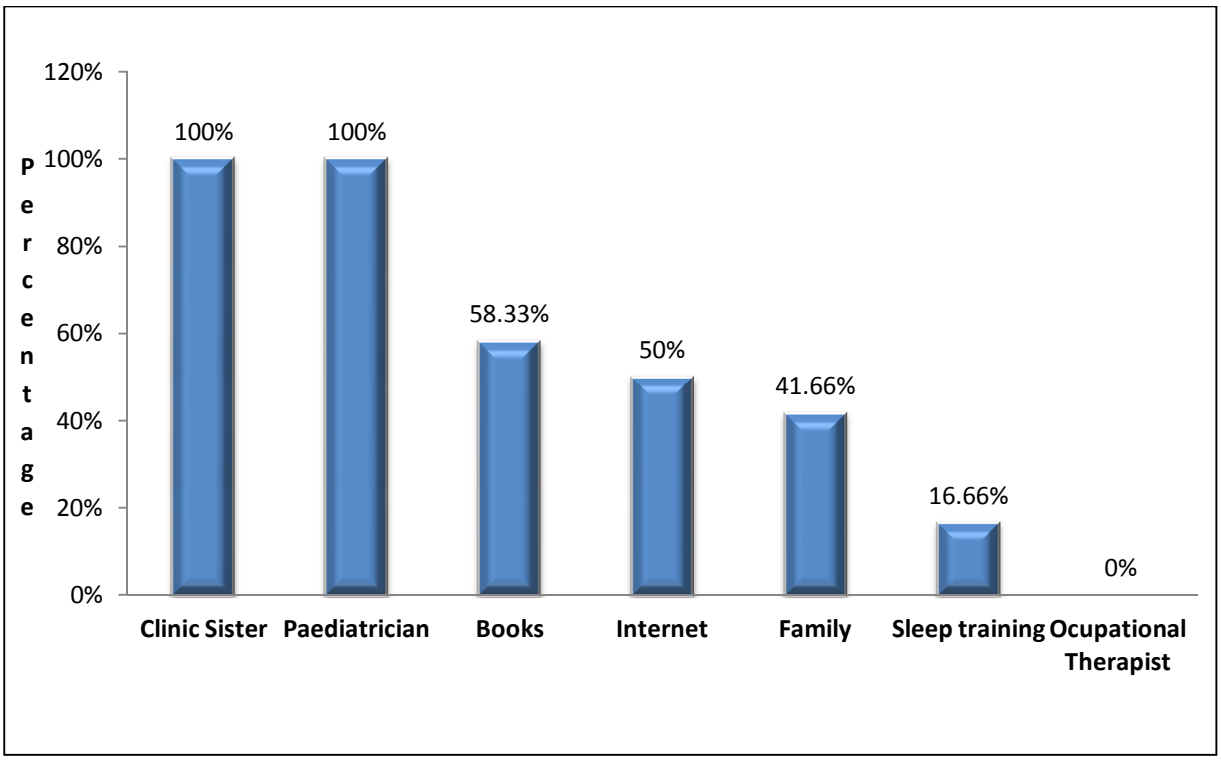


Figure 4.3 Sources of advice used by parents to deal with infant participantsô problems

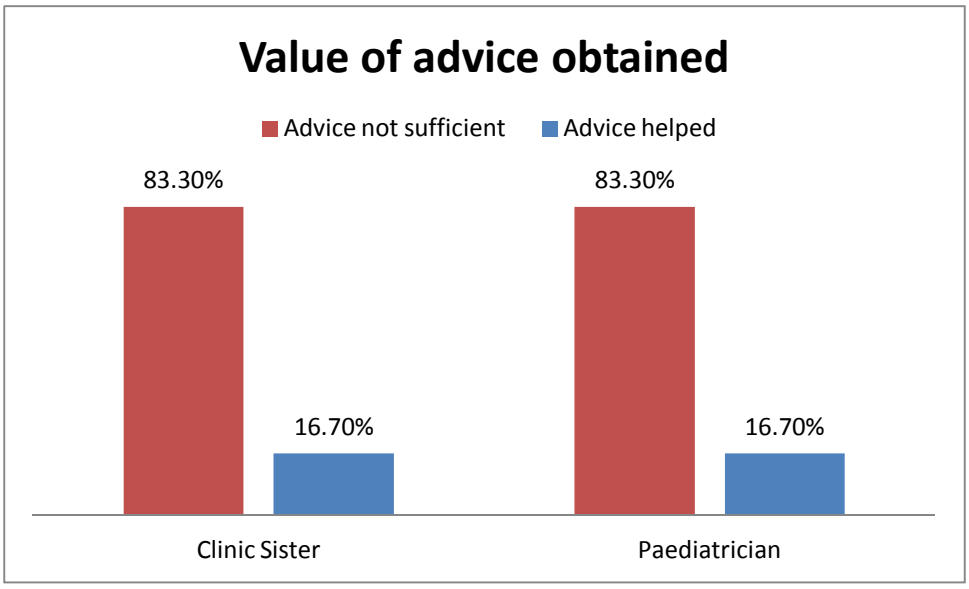


Figure 4.4 Value of advice obtained from clinic sisters and paediatricians as perceived by parents

Figure 4.4 demonstrates that although all parent participants consulted both their paediatricians and clinic sisters, 10 indicated that the advice or referrals made by the clinic sisters and paediatricians did not help sufficiently, although some of the advice

may have alleviated difficulties for a period of time. Only two of the parent participants found that the advice was helpful.

Seven parents accessed books for advice including: *Baby Sense*, *Sleep Sense*, *Toddler Sense* and *Baby Wise*. Varying levels of success were reported in relation to the information obtained from these books. Most parents reported that although the books provided insightful information, the implementation of the information was not always successful as each infant participant was different. Seven parents reported using sensory strategies described in *Baby Sense* to assist their children, but most felt that these attempts were unsuccessful.

A similar response was obtained from the six parents who used the internet and sought the advice of family and friends. Two parents attended sleep training, but reported that this did not make a difference.

4.4.4 Knowledge of Regulatory Sensory Processing Disorder and Ayers-Sensory Integration

Only one parent reported that they knew of RSPD. Nine parents felt they would have responded positively to their infant participant having such a diagnosis and would have felt relieved to know what was wrong, and that there was a way of obtaining help. Three parents felt that they preferred their infant participant not having a diagnosis, as this would label their infant. They were also afraid of the implications of such a diagnosis. None of the parents were aware that untreated difficulties associated with fussiness could lead to later areas of difficulty.

None of the infant participants in the study had been referred for occupational therapy, even those whose parents knew about Ayers-SI. Three parents had heard of Ayers-SI from colleagues or experienced it with older siblings, but did not seek the advice of such a therapist for their child. For all the parents, their first encounter with an occupational therapist for help with their infant was with the researcher.

4.5 Results of the Infant Toddler Symptom Checklist

4.5.1 Results of the Infant Toddler Symptom Checklist pre- and post-intervention

Table 4.4 shows that the mean total ITSC scores for the infant participantôs pre and post-intervention showed a significant change at the end of the two-week intervention period.

Table 4.4 Pre-intervention and post-intervention scores for total sample **(n=12)**

	Pre-intervention score	**Post-Intervention score**	**Effect size d**	**p -value**
Mean (SD)	18.92 (5.14)	11.33 (5.07)	1.47	0.0024

However, there was great variance in the amount of change for each infant participant, with individual improvements ranging between 2 and 16 points.

Table 4.5 provides information on each infant participantôs total pre and post-intervention score in relation to the cut-off score for that age group. Seven of the infant participants who were initially described as being fussy, were assessed as no longer at risk for RSPD according to the ITSC. Of the five infant participants who remained within the at-risk range for RSPD, four presented with a 6 or more point decrease after the two-week intervention. This suggests a reduction in the severity of RSPD symptoms and that they would possibly benefit from further intervention. One infant participant only improved by 2 points over the two-week period, although the parentôs subjective feedback indicated a good positive change in behaviour.

Table 4.5 Comparison of each infant participantôs total Infant Toddler Symptom Checklist score, pre and post-intervention, to the cut-off score for that age group.

	7 - 9 months		10 - 12 months		13 - 18 months		19 - 24 months	
	Pre test	**Post test**	**Pre test**	**Post test**	**Pre test**	**Post test**	**Pre test**	**Post test**
Cut-off	10		12		19		11	
Infant								
1			12	10				
2	19	5						
3	17	15						
4					22	18		
5	24	15						
6	19	6						
7			23	14				
8							26	20
9							12	7
10							11	6
11							24	8
12							18	12

Key:

At or above the cutoff mark

ñNormal / Average ñrange

The effect size of the change according to Cohenôs d indicates that there was a decrease in the scores after the intervention that is equivalent to 1.47 between the two means. This indicates a 73.1% improvement within the group after the intervention and places the improvement at the 93.3 percentile. As the improvement was greater than 1, it is accepted as a large effect size.

4.5.2 Change in Infant Toddler Symptom Checklist domains (pre and post-intervention)

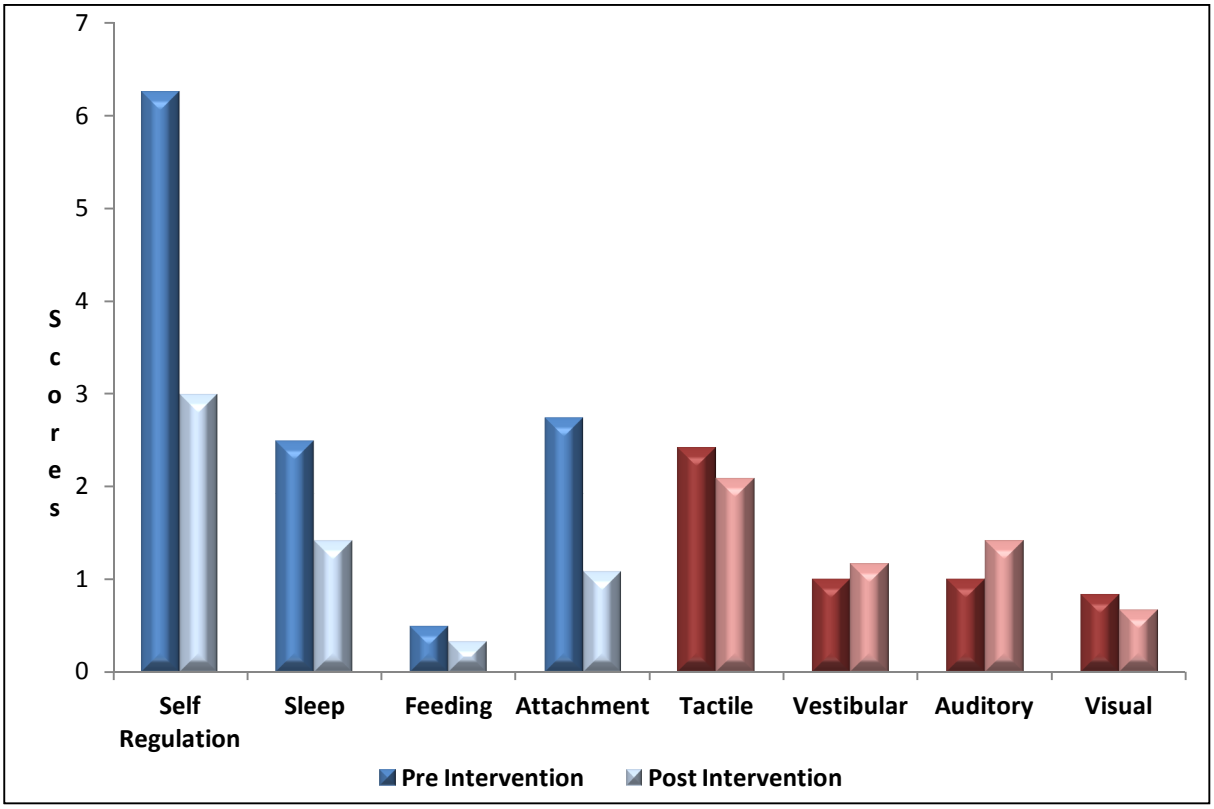


Figure 4.5 Change in domain scores on the Infant Toddler Symptom Checklist for the total sample (n=12)

Figure 4.5 shows that all domains improved except the vestibular and auditory domains. There was significant change in self-regulation (pÒ 0.01) and attachment (pÒ0.005). Although sleep changed, this was not statistically significant.

Table 4.6 records the effect size for each domain, but only self-regulation and attachment show a high effect size greater than 1. This indicates that the effect size for self-regulation after the intervention was at the 94th percentile and therefore considered to be large. Table 4.6 shows that all the domains, except the vestibular and auditory domains, improved after the intervention. The vestibular and auditory

domains indicated increased scores which indicate a slight regression during this period.

Table 4.6 Effect size for each domain for the total sample (n=12)

Domain	Effect Size d
Self-regulation	1.59
Sleep	0.80
Eating	0.13
Tactile	0.21
Vestibular	-0.12
Auditory	-0.26
Visual	0.16
Attachment	1.08

4.5.3 Infant Toddler Symptom Checklist pre and post-test scores for the 7-12 month old age group

4.5.3.1 7-12 months age group

The total ITSC scores were compared pre and post-intervention for the infant participants in the 7-12 month old age group. Table 4.7 shows that there was a significant change in the total mean scores after the two-week intervention period, with an effect size of 2.5 and a p-value of 0.025.

Table 4.7 Pre-intervention and post-intervention scores for 7-12 month old participants (n=6)

	Pre-Intervention score	Post-Intervention score	Effect size d	p-value
Mean (SD)	19 (5.95)	10.5 (3.92)	2.15	0.025

The effect size of 2.15 after the intervention period is greater in this group than that of the total group (d=1.47).

4.5.3.2 Infant Toddler Symptom Checklist domains

When the various domains of the ITSC were analysed for infant participants between 7 and 12 months, the self-regulation (p Ò 0.05) domain showed significant change (Figure 4.6). The changes were slightly different to those experienced by the whole group. This was interesting, but not significant. The tactile and auditory domains scores increased slightly indicating a decline in these domains, while the feeding domain remained the same and all other domains improved.

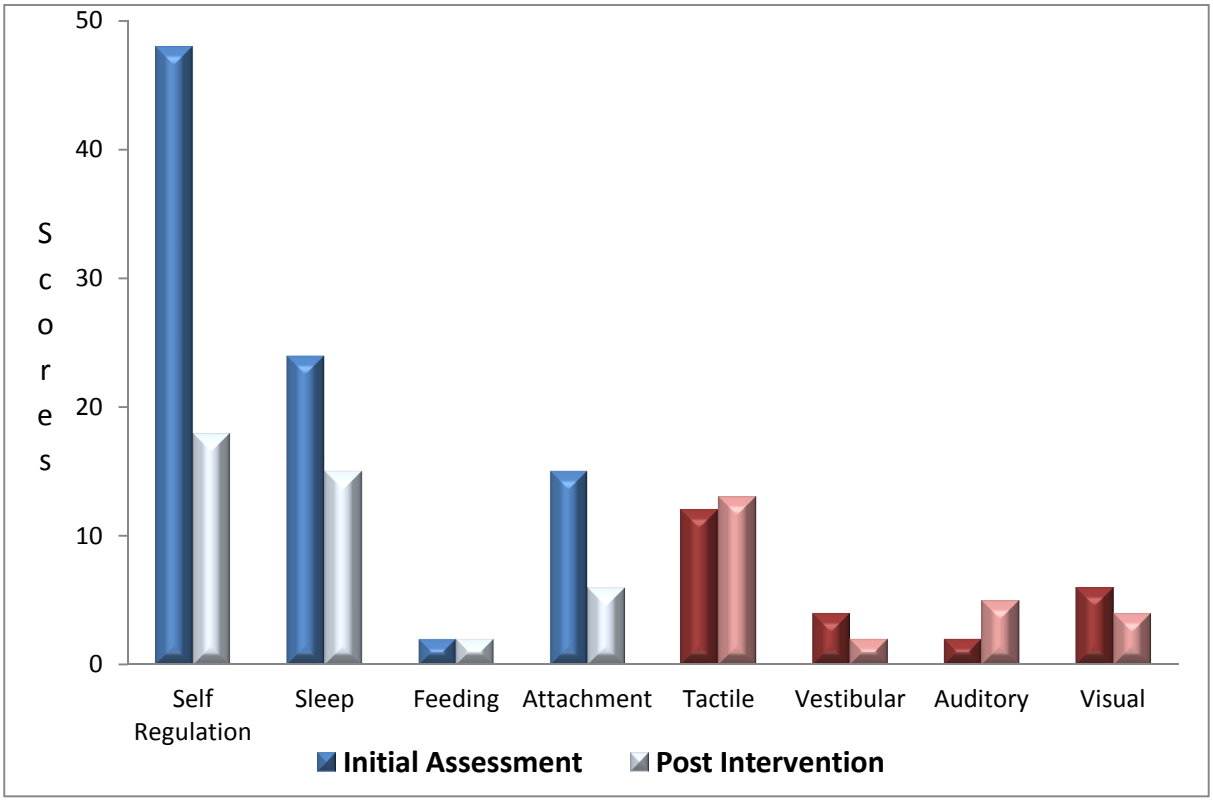


Figure 4.6 Change in domain scores on the Infant Toddler Symptom Checklist for 7-12 month old participants (n=6)

The effect size for each domain showed improvements except in the tactile and auditory domains. Only self-regulation and attachment improved after the intervention. The effect sizes of these two variables after intervention were 0.56 and

0.54, respectively, with the former at the 69th percentile (a 33% improvement) and the latter at the 62nd percentile (a 21.3% improvement). Both are considered medium effect sizes.

Table 4.8 Effect size for each domain for 7-12 month old participants (n=6)

Domain	Effect Size d
Self-Regulation	0.56
Sleep	0.34
Eating	0
Tactile	-0.07
Vestibular	0.29
Auditory	-1.46
Visual	0.27
Attachment	0.54

4.5.4 Infant Toddler Symptom Checklist pre and post-test scores for the 13-24 month old age group

4.5.4.1 13-24 month old age group

The total mean scores for the ITSC were compared pre and post-intervention for infant participants between 13 and 24 months. There was also a significant change in their post-intervention results after the two-week intervention period.

Table 4.9 Pre-intervention and post-intervention scores for 13-24 month old participants (n=6)

	Pre-Intervention score	Post-Intervention score	Effect size d	p-value
Mean (SD)	18.83 (6.27)	11.83 (5.95)	1.11	0.05

The effect size of the change according to Cohen's d indicates that there was a decrease in the scores after the intervention of 1.11 between the two means. This indicates a 58.9% improvement within the group after the intervention and places the

improvement at the 86th percentile. As the improvement was greater than 1, it is accepted as a large effect size.

4.5.4.2 Infant Toddler Symptom Checklist domains

When the various domains of the ITSC were analysed for the 13-24 month old participants none of the domains showed significant change (Figure 4.8).

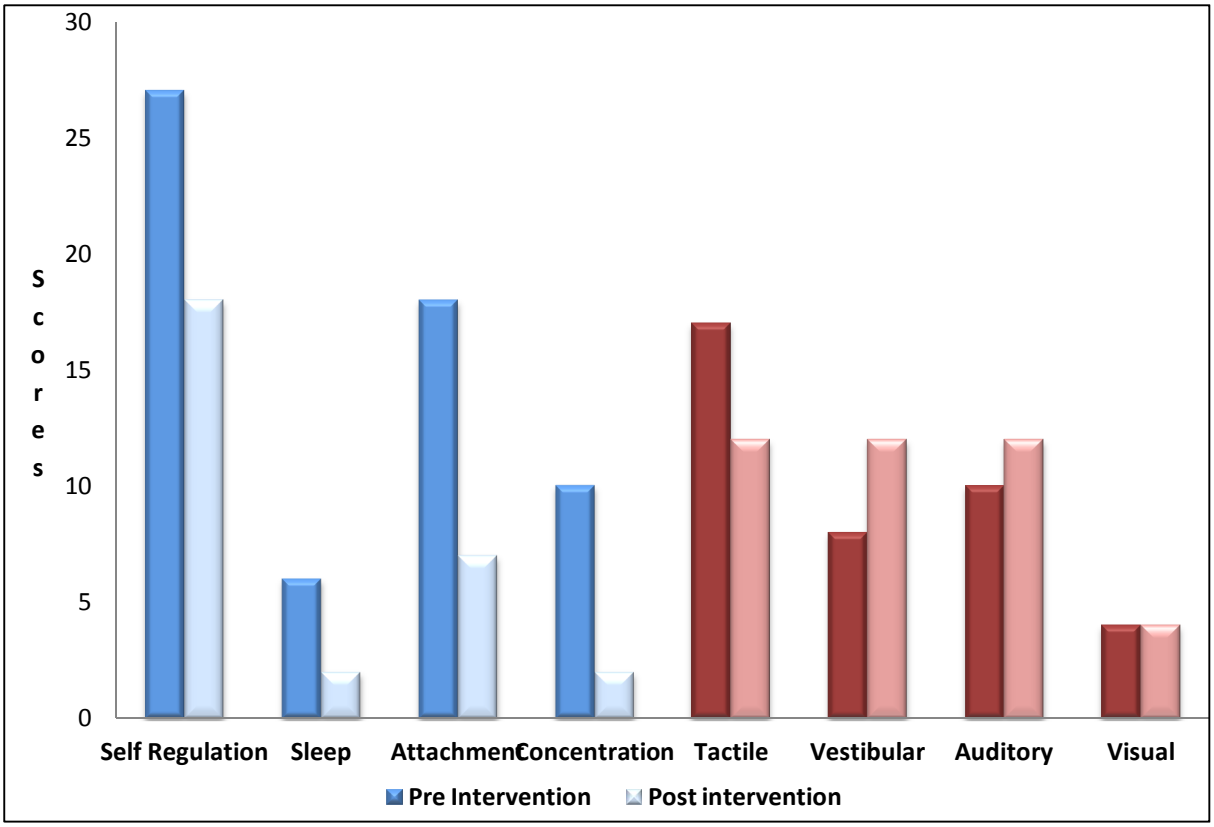


Figure 4.7 Change in domain scores on the Infant Toddler Symptom Checklist for 13-24 month old participants (n=6)

Four domains demonstrated improvements. The vestibular and auditory domains, deteriorated. This is explained in Chapter 5. The visual domain did not change.

Only a small effect size for each domain was found for the 18-24 month infant participants and none of the domains achieved a change greater than or equal to 1. Table 4.10 shows that attachment showed the greatest effect size of 0.87. Self-regulation and concentration were higher than in the previous age group (0.64 and 0.68, respectively). The deterioration of -0.17 in the auditory and -0.65 in the vestibular domains are small.

Table 4.10 Effect size for each domain for 13-24 month old participants (n=6)

Domains	Effect size d
Self-Regulation	0.64
Sleep	0.40
Eating	0.20
Tactile	0.45
Vestibular	-0.65
Auditory	-0.17
Visual	0.00
Attachment	0.87
Concentration	0.68

4.5.4.3 Cut off scores according to specific age groups

Figures 4.8 and 4.9 indicate that when the infant participants were divided into the correct ITSC age groups (7-9 months, 10-12 months, 13-18 months and 19-24 months) post-intervention, their scores were at the level of the cut-off scores used to indicate the presence of RSPD.

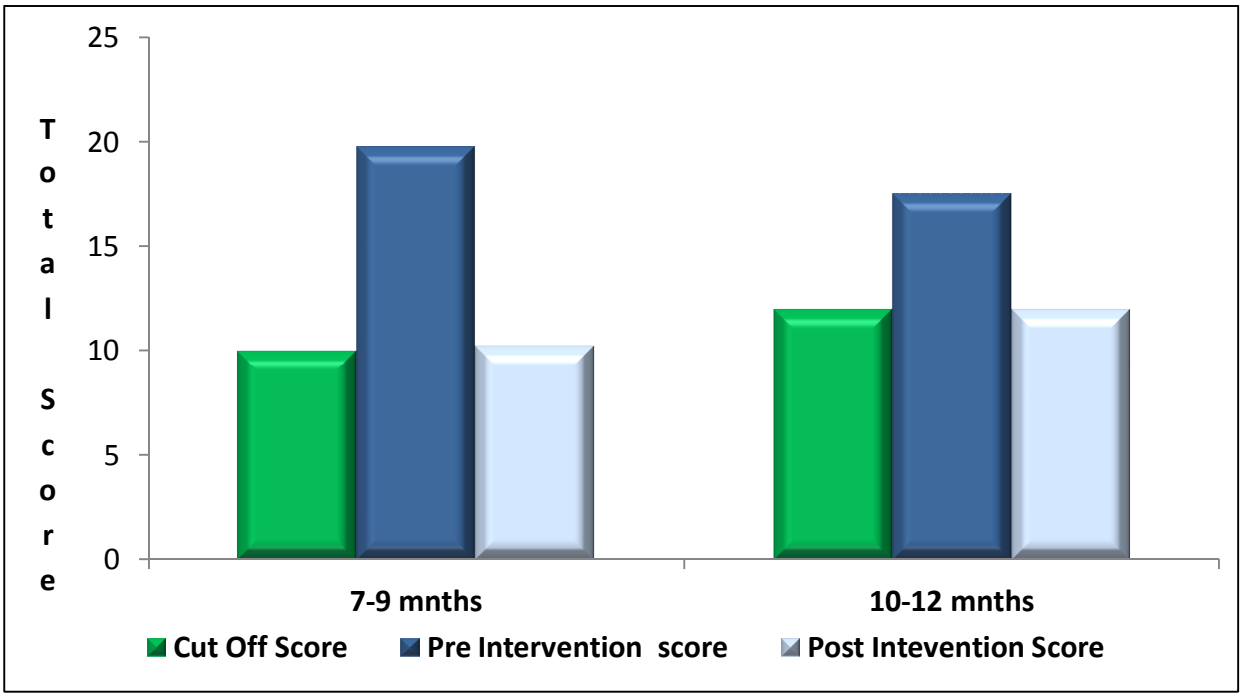


Figure 4.8 Pre and post-intervention scores compared to cut off scores for the participants 7-9 months (n= 4) and 10-12 months (n=2) of age

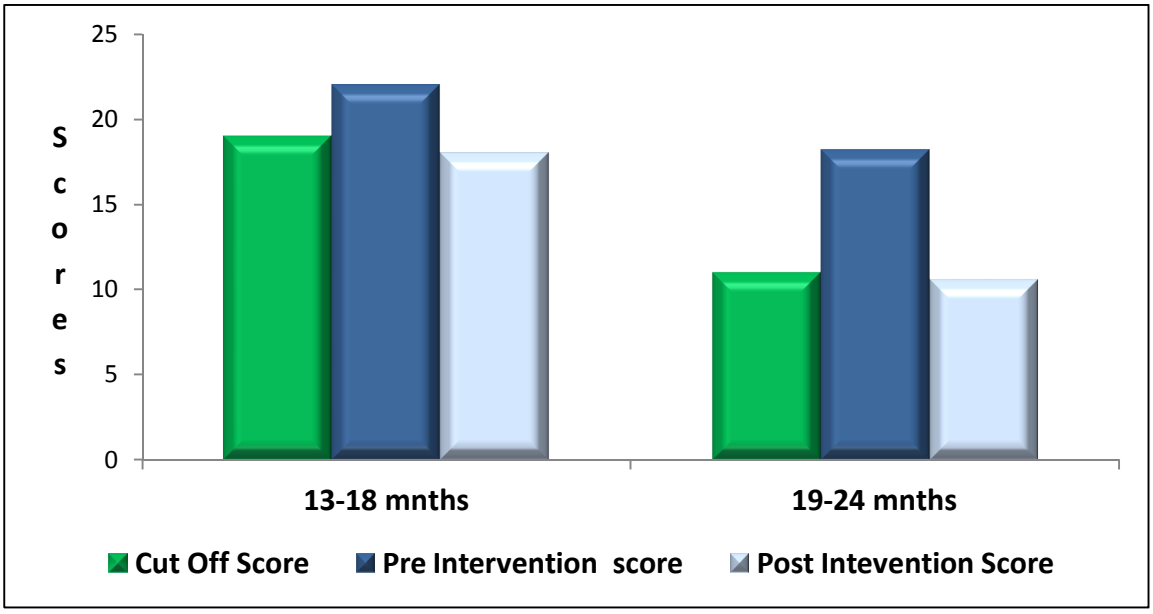


Figure 4.9 Pre and post-intervention scores compared to cut off scores for the participants 13-18 months (n= 1) and 19-24 months (n=5) of age

4.6 Conclusion

This section summarises the results of the qualitative and quantitative analysis according to the objectives of the study.

Objective 1:

Establish what the parents of infants with RSPD knew about the condition and what they had done to deal with the problems through advice from medical professionals or their own investigations.

None of the parents knew about RSPD or the long-term effects of the disorder, but nine parents felt that they would respond positively to having a diagnosis as it would provide them with a reason for their infantôs behaviour. Three of the parents felt that a diagnosis would label their infant and lead to negative implications. All the parents had sought help from their clinic sisters and paediatricians, but 10 found that the advice was not sufficient. Parents had also sought help by referring to books, the internet and family members. None had been referred for Ayers-SI occupational therapy.

Objective 2:

Design, implement and evaluate the effectiveness of a two-week Ayers-SI sensory diet for infants with RSPD.

The effect change in mean total ITSC scores indicates a significant change over the two-week period with p=0.0024 and an effect size of 1.47.

The total group demonstrated improvements in most ITSC domains, with self-regulation and attachment showing significant improvements and other domains showing marginal to moderate improvements. For the whole group, vestibular and auditory domains worsened over the two-week period.

The 7-12 month age group showed a higher level of improvement with an effect size of 2.15. The 13-24 month age group improved with an effect size of 1.11.

When arranged according to ITSC age groups and compared to cut-off scores, all age groups indicated scores at or below the RSPD cut-off range, post-intervention.

The null hypothesis is therefore rejected because a significant change in RSPD occurred after two-weeks of the Ayers-SI sensory diet intervention.

CHAPTER 5
DISCUSSION

5.1 Introduction

The purpose of this study was to determine the effect of parent education and an individual, indirect two-week Ayres SI sensory diet on reducing RSPD symptoms in infant participants. This chapter discusses the results reported in Chapter 4 in relation to the current literature and the implications of the results for occupational therapy practice. The discussion will be presented by critically reviewing the results in relation to the study sample demographics, how infant participants were indentified as meeting the inclusion criteria of RSPD, parental perception of RSPD pre- and post intervention results, and finally the implications of the results for occupational therapy practice.

5.2 Sample demographics

Although the study aimed to have a sample size of 15, it was only possible to recruit 13 infant participants over the eight-month data collection period. The results of one infant participant had to be excluded from the analysis, resulting in a sample size of only 12. The small sample size may have resulted in a Type II error (56) and therefore the results may not be generalised to the entire population.

Of the 12 infant participants, one infant participantôs scores presented with outlying results regarding vestibular processing. However, due to the already small sample size, it was decided that these results would be included in the study and the reasons for the results explained in this chapter.

The infant participant whose vestibular processing appeared to worsen during the two-week period with a four-point increase may have been due to a change in perception by the parents after the education session. With a better understanding of the underlying aspects affecting certain observed behaviours, the vestibular system

was then possibly correctly identified as problematic. It is thus hypothesised that had the parents received the education before completing the initial ITSC, the scores would not have changed to this degree for this particular infant participant. It is also possible that underlying vestibular difficulties became more noticeable once behavioural difficulties associated with sleeping, feeding and bathing had improved. This does not indicate that vestibular difficulties became worse, but that they were highlighted as other difficulties became less significant.

Although paediatricians and clinic sisters all confirmed an increase in infants with signs of fussiness, it remained challenging to obtain a larger research sample. It is possible that parents with infants with RSPD may have been too overwhelmed to participate in the study or that due to their busy life-styles it was too difficult to contact the researcher and participate in the study. In addition, clinic sisters and paediatricians were not requested to contact the parents of previously treated infants to tell them about the study. It is possible that parents did not return to these clinic sisters or paediatricians for further advice, as the initial advice provided by these professionals had not been beneficial. In such cases it is possible that parents would have seen no value in returning to their paediatrician or clinic sister for further advice. Furthermore, the fact that the researcher did not contact the parents, but instead requested that parents contact the researcher may have resulted in the small sample. In spite of this, the results are of clinical importance and have implications for Ayers-SI programmes that may be offered to infants who meet the RSPD criteria in the future, as no previous research on this specific aspect has been carried out to date.

5.2.1 Division of infant participants into two age groups

The specific age range of infant participants examined in this study was 7-24 months. The 12 infant participants were divided equally into two age groups within this defined age range: 7-12 months and 13-24 months. This division was decided upon due to the specific differences in milestone development between the two age groups. Between 7 and 12 months, infants are more dependent on their parents for mobility and sleep. Infants with feeding difficulties may also be identified at this stage as they are encouraged to start eating finger foods and may refuse or gag on foods

based on their differences in texture, taste and temperature of the food. By 13-24 months, infants are more independent and are walking, feeding more independently with finger or spoon-feeding, and are communicating and interacting more purposefully. Infants are now actively exploring the environment and want to share experiences through shared attention by pointing out new experiences, looking to their parents to get their attention and share the experience. This forms the basis for the development of communication and formation of relationships (33). This developmental clustering according to age made it easier to make sense of the results of the ITSC.

A study by Tirosh, Bendrian, Golan, Tamir and Dar (58) that investigated the epidemiology of RSPD among Israeli infants also separated infant participants into two groups. These researchers, however, divided infant participants into wider age ranges, namely 6-17 months and 18-36 months. Other researchers like DeGangi et al. (16,15) investigating RSPD did not divide infant participants into groups and used infant participants from a wider age range of 6-36 months, with a large variance in developmental milestones. This present study limited participants to an age range of 7-24 months because the ITSC was used as a data collection tool and normative studies have found the checklist to be least reliable in the 24-36 month age range (36). This finding was supported by the authors of another sensory based checklist: the Sensory Processing Measure (59). These findings are clinically supported by general opinions that 2-year-old toddlers are more challenging and fussy and at this age these behaviours are seen as typical. It would thus have been difficult to differentiate signs of RSPD from typical development and behaviour.

The variation in age range in various studies made the comparison of results between studies difficult. However, the developmental differentiation within the two age groups in this study was a useful scientific decision that provided valuable insights for clinical practice. Although the sample size was small, a trend seemed to emerge, with the younger age group presenting with generally higher levels of fussiness, but also showing improvements with a larger effect size. This and other clinically important differences between groups will be discussed in Section 5.5.1, indicating the value of the group delineation.

Therefore, although dividing infant participants into the two age groups chosen was unique to this study, it provided scientific and clinically valuable data.

5.2.2 Gender

The infant participants included in this study were predominantly male (58.3%). This finding was similar to studies by DeGangi et al. (15,16) and Reebye and Stalker (2), where males were also more prevalent than females, with percentages ranging from 55% to 82% of males in each sample. However, no literature was found to support or explain this phenomenon among infants that met the criteria for RSPD. A study by Weinberg et al. on typical 6-month-old infants (n=81) found that males tended to struggle more than their female counterparts to maintain self-regulation (60). Thus, the increase in males with fussy behaviour may be linked to this developmental occurrence rather than RSPD.

5.2.3 Birth and medical history

Information regarding infant participant birth and medical histories was included in the data collection in order to provide evidence that the exclusion criteria for the study were well enforced. This was ensured at various times: during the pre-test interview as well as during completion of the background information form which was part of the interview questionnaire.

Of interest in these findings was the high percentage of infant participants who were the first born (75%). No other studies have provided detail on this. It is possible that the high rate of first born infants experiencing signs of fussiness may be due to the inexperience of first-time parents who attempted to find help sooner, through discussions with clinic sisters and paediatricians, than other families whose infants were second or third born and who possibly first tried strategies that had assisted previous children or implemented advice obtained from an established support system. This information does not necessarily suggest that first born infants are at greater risk for RSPD, but may highlight the greater need for education and support for first-time parents.

All infant participants included in the study were reported to be medically healthy. This inclusion criterion was used to ensure that the outcome of the study would not be limited by a variable such as ill health. The same procedure of including only medically healthy infants was followed in other studies with infants experiencing RSPD (15,16,17).

The fact that RSPD occurred in infant participants who were considered medically healthy highlights the clinical importance of multi-disciplinary referral and assessment of children who present with fussiness. Paediatricians, who are trained in the medical model, should exclude a medical problem, but other professionals, such as occupational therapists, who base their assessment upon behaviours observed within occupational performance areas, should also be recognised as being necessary in the assessment and treatment of RSPD. This is supported by the experience of parents in this study, as shown in Figure 4.4, who all consulted their paediatricians for assistance but did not seem to have received helpful advice. These parents however felt as though they had been helped during the two-week period following parental education and Ayers-SI sensory diet as infant participants showed a decrease in fussy behaviours.

Although the infant participants were considered medically healthy, colic during their first six months was highly prevalent. Parents of infant participants reported observing signs of fussiness much earlier than six months of age; 50% reported fussiness from birth and 25% from six weeks. This suggests that the symptoms of RSPD may have been present and contributing to signs of colic from a much younger age. One could therefore hypothesize that introducing a sensory diet at an earlier stage may have been beneficial in reducing signs of RSPD sooner. These findings are also supported by the theory of sensory integration: that the sensory systems are developed in utero (with tactile and vestibular being most developed at birth) (8,3). Thus, difficulties in regulation (which were shown to be closely linked to sensory processing in Chapter 2) may be evident from birth and can therefore be treated.

Although most studies similar to this one only included infant participants from 7 months in order to exclude the interference of colic, a study by Lundqvist-Persson

supported the parentsôsubjective finding that this problem could be identified earlier. Lundqvist-Persson concluded that infant participants identified with self-regulation difficulties when they were three days old were at risk for later social development difficulties and RSPD at two years of age (61). This also indicates that providing an education program for parents and an Ayers-SI sensory diet to much younger infant participants identified with colic or signs of fussiness may be of clinical value. However, scientific investigation through further research is needed to confirm this.

5.3. Identification of Regulation Disorder for inclusion of infant participants in the study

All infant participants in the study who met the inclusion criteria were also identified as experiencing RSPD by using the ITSC. Although the sample size was small, this finding is of clinical significance as it indicates that the inclusion criteria may be a good quick-screening method to allow clinic sisters and paediatricians to identify infants who may potentially benefit from further assessments by an Ayers-SI therapist for RSPD. Studies by DeGangi et al. used the same inclusion criteria and also confirmed that they were sufficient in correctly screening infants for RSPD, as confirmed by the formal assessments (15,16,17).

The prevalence of each of the RSPD inclusion criteria for the infant participant sample was calculated for the whole group as well as for the 7-12 and 13-24 month age groups. This had not been done by other studies and was unique to this study.

Of interest was the difference in the type of symptoms experienced by the 7-12 month group versus the 13-24 month group. The researcher expected sleep, feeding and hyper-arousal differences. Sleeping difficulties were a problem for all infant participants. This finding was supported by research on sleep by Burnham et al. (54) and Thiedke (62). On analysis of these findings, the nature and reason for the sleep difficulties appeared to follow different trends for the two age groups. In the 7-12 month group, the sleeping difficulties appeared to be related to frequent night waking for bottle or breast feeds which were developmentally unnecessary. It is likely that as infant participants started to be introduced to solids, parents were unsure whether infants were sufficiently nourished and thus allowed more regular bottle or breast

feeds when they cried, assuming that this was the cause of the frequent waking. Many of the infant participants also reportedly refused dummies and parents therefore used the breast or bottle as a pacifier to self-soothe and return to sleep.

However, in the 13-24 month age group, much of the sleep difficulties centered around attachment and separation; with infants needing a parent to be present until they fell asleep as well as restlessness and poor day sleeps. Burnham et al. (54) confirmed separation anxiety sleep difficulties in this age group. They also found that older infant participants experienced sleep difficulties for longer, thus forming bad habits around sleep. This may explain why the older infants in this study took longer to respond to sensory strategies and why the parents of the older infants were more wary of leaving their infants to cry (as part of a specific sleep strategy), preferring instead to try other methods first. This view was also supported by Thiedke (62).

In the 7-12 month group, following sleep difficulties, 66% experienced self-consoling and feeding difficulties. Infant participants between 7 and 12 months were being introduced to solids and as a result more feeding difficulties were identified at this stage. These infants were also at the stage of development where they started to learn how to be more independent through mobility. Therefore, they needed to start learning how to self-console more independently, relying less on their parents. In the 13-24 month group, sleep difficulties was followed by 50% presenting with self-consoling and hyper-arousal difficulties and only 16% with feeding difficulties. In this group, hyper-arousal seemed to be more common which may be linked to increased mobility and independence, and so hyper-arousal may have been more noticeable and difficult to manage at this stage. Thus the differences in the type of symptoms experienced appear to be related to typical development, but were more prominent in infants with RSPD than in their typically developing peers.

When analyzing the initial total scores for the ITSC against cutoff scores for each age group, the severity of atypical function was notable. The 7-9 month age group scored between 7 and 14 points above the cutoff. This indicated a high level of RSPD and implied that RSPD was most pronounced in younger infants. This has implications for the need for early identification and intervention. The high scores in this age group may have been influenced by a few significant developmental

occurrences which were pronounced or more severe in infant participants with RSPD such as beginning solids, the experience of separation anxiety (a normal developmental experience at this time) and the knowledge that colic should no longer be a problem. No research was found to confirm this, although the developmental occurrences during these months are documented. In the 19-24 month group three of the five infant participants also presented with initial scores between 7 and 15 points above the cutoff. This may be linked to increased signs of fussiness as infants near the 24 month mark and the beginning of the 'terrible twos', as well as increased frustration as infants know what they want, but do not yet have the verbal capacity to communicate their needs to parents. It is important to note that these developmental phases are experienced by all infants in the same age group, but for infants with RSPD, these developmental phases pose additional challenges. Other studies did not delineate these age groups and thus support for this trend was not found in the literature and is the hypothesis of the researcher. The 10-12 and 13-18 month age groups scored close to the cutoff ranges (still experiencing RSPD but not as high). It is possible that during these age groups signs of fussiness are not as evident because infants may present with some relief of symptoms with the achievement of walking and mobility. Although no literature was found to support this, in clinical practice many mothers have reported that once their infant can get around independently, they seem happier.

With all the above observations, it would have been beneficial to have a larger sample size to determine whether these findings were indicative of possible trends between age groups or if they were individual differences among infant participants. The small sample size was the largest limitation of the study. Although the information obtained was valuable, it was difficult to generalise and formulate clinical suggestions based on the research. However, it provides a foundation for other research with larger sample sizes.

5.4 Parent perceptions of the Regulation Disorder

This study relied strongly on parental perceptions during pre and post-testing. This method was chosen as the researcher felt that this would give a valuable indicator of the reduction in signs of RSPD from a parent's perspective. That is, it investigated if,

with a proper understanding of the condition and the appropriate tools (through the sensory diet) to assist with the behaviours, parents perceived improvements in RSPD. The results show that this hypothesis was true in the context of this study.

However, it is important to critically evaluate the use of the ITSC and the items which appeared on it because the results of this study are based on those items. Parents have been identified as an important part of the treatment team (22,37) and thus, this form of testing is clinically valuable. It highlights the importance of parent education and coaching parents as indirect therapeutic agents. By addressing everyday behaviours through the regular use of sensory techniques from the sensory diet, improvements were noted over the two-week period. This supports the value of sensory diets.

However, the ITSC does have some limitations. The largest being the number of questions asked in each domain. Clinically, all parents in the study highlighted that sleep difficulties were the largest concern; however, the ITSC only has two questions regarding sleep. Therefore, it was not sufficiently sensitive to possible changes in sleep during the two-week intervention. This explains why the data did not reflect significant improvements in sleep, even though parents reported large improvements in infant sleep, with infants being able to link sleep cycles and fall asleep faster.

Furthermore, the results in the 13-24 month group showed increased fussy behaviour regarding vestibular input. However, many parents expressed that the questions in the movement and vestibular domain were developmentally appropriate for their child and they did not view them as negative behaviours. This was true for two infant participants, 4 and 12, who reported that their infants craved swinging. It is felt that this item was only identified after the two-week period as the sensory diet highlighted the importance of vestibular input and during this time it may have become clear to parents that their infants really enjoyed this movement.

Both groups reported auditory processing worsening during the two-week period. In analyzing the results, it was evident that for Participant 2, one of the auditory items was scored as being a problem in the past. In the ITSC this scored 1 point and

therefore skewed the result as it was not actually a problem after the two-week period (it had only been a problem in the past, but contributed to the total score). For Participant 5, only one item worsened as the infant participant was felt to be more distracted by environmental sounds than before. In the older age group, one participantôs auditory score worsened as the parents found that their infant was repeating phrases that had been heard. However, in an infant between 19 and 24 months one could interpret this item as a normal phase in the acquisition of language.

These critiques of the ITSC help to explain the worsening of some of the scores on the test. However, it should also be noted that although the test may not have been sensitive enough, it has been shown to have good validity and reliability (36).

The literature on RSPD has identified the need for comprehensive multi-disciplinary assessment of a child in order to make a diagnosis of RSPD (1,2,8). Although the ITSC is described as a valuable screening and diagnosis tool, its value has been found to be best extracted when used as part of a battery of other tests and observations. For the purpose of this study, the researcher was only interested in parentsô perceptions of RSPD and the post-intervention effects. However, the diagnosis of RSPD would have been better defined by the addition of the Test of Sensory Functions in Infants. This would be a recommendation for further research in this area. As a result, due to reliance on parental perception of infant participants, scores may have been influenced by a change in parental perception and not necessarily an objective report of changes in infant participantsôsymptoms.

In addition to the ITSC, which relies on parental perceptions, parents were also asked to rate which of the ITSC domains were of greatest concern. According to this rating, parents were most concerned about sleep (35%), self-regulation and feeding (13% each), followed by attachment (8%).

Due to parentsôconcerns with these areas of difficulty and general fussiness, all of them approached clinic sisters, paediatricians and other sources for advice, as indicated in Figure 4.3. It appears that, although parents actively sought advice,

either the advice was insufficient and not individual enough to assist with their infantôs specific set of difficulties or parents were unable to successfully implement the suggestions from these sources. Two studies which investigated parentôs perceptions of the sensory integrative approach found that parent education which was individual and specific to their infant (through the provision of a sensory diet) was most beneficial. Although the parents in these studies accessed books and the internet, these did not adequately equip parents with knowledge of exactly what would work best for their infants (44,43).

The lack of referral to Ayers-SI therapists indicates that occupational therapists are not identified as professionals who can assist and treat infants with RSPD. The links drawn in the literature review between RSPD, SMD and the Ayers-SI therapistôs role and expertise in assessing and treating these disorders using an individualistic, client-centered approach, supports the need for more referrals to Ayers-SI therapists in SA. This requires more team work between disciplines and RSPD education for other professionals. In the USA, occupational therapists trained in sensory integration are recognised as vital role players in the assessment and treatment of RSPD as part of a mental health team (2,8,1).

5.5 Intervention using an Ayers-SI sensory diet

5.5.1 Discussion of results of the Infant Toddler Symptom Checklist: pre and post-intervention

The provision of a sensory diet as a form of intervention over a two-week period was advantageous as it empowered parents with strategies which they could incorporate into everyday tasks. Most parents lead busy lives, meaning that their time is limited. Thus, this form of indirect therapeutic intervention was the most appropriate for parents to implement and commit to. The initial intention of assessing therapeutic listening over a six-week period and requesting parents to do this for 30 minutes twice a day was unrealistic and thus parents were unwilling to participate in this type of study.

The results of this study indicate that the sensory diet was of benefit to the families, because a significant decrease in the mean total score was found. This shows that

over the two-week intervention period all infant participants displayed a reduction in signs of RSPD. Seven infant participants fell within the normal range after the intervention and no longer presented as being at risk for RSPD. Although five of the participants remained at risk for RSPD, four of the five showed a six or more point decrease. The effect change for the total sample pre and post-test was 1.47, indicating a significant change. No similar literature was found to support or refute this finding. It would be beneficial to reassess the infant participants again at 36 months to determine the long-term effects of such intervention. This would also allow comparison with other studies (15,16).

In analysing the specific changes in the domains of the ITSC for the whole group, self-regulation and attachment showed significant changes. These two constructs of the ITSC deal more with infant interaction with others, such as being able to self-soothe independently or requiring adult assistance, the amount of sensory input tolerated before becoming overwhelmed, the need to ótun the showô and control each aspect, time spent calming the infant and separation anxiety.

Sleep also showed a decrease, but this was not significant. However, follow up from parents indicated good improvements in the area of sleep. It is felt that this was not highlighted by the ITSC as questions were limited and not specific to the difficulties experienced. For example, the 19-24 month questionnaire only contained one item about sleep: that the infant wakes more than three times a night and struggles to fall back to sleep. However, sleep difficulties for this age group tended to be that the infant had an inconsistent sleep routine and took a long time to fall asleep, but once asleep, either slept through or woke once a night. Thus the questions were not always sensitive to subtle improvements after the two-week period.

Of interest, are the areas measured in the ITSC that presented with the greatest changes pertaining to the two age groups. The 7-12 month group showed the largest significant change, with a large effect size of 2.15 between pre and post-testing on total ITSC scores. In this group, there was a significant decrease in self-regulation difficulties, decreases in sleep and attachment difficulties, and slight increases in tactile and auditory difficulties. This may indicate that sensory integrative based

difficulties require individualised direct Ayers-SI, but that a sensory diet was sufficient for the behavioural and emotional components.

The 13-24 month group also showed a large effect size of 1.11, but this is much smaller. In addition, vestibular and auditory difficulties increased slightly instead of decreasing.

The difference in effect size may indicate that younger infant participants responded more quickly to the sensory diet than the older group. This is likely because there has been less habit-formation around these behaviours and thus, two weeks was enough time to obtain a change in the younger group. However, the younger group also presented with higher total ITSC scores and thus had a large rate of change. It was generally found when discussing the sensory diet that, for example with regards to sleep, parents of older infants were less willing to allow their infants to cry to learn to self-soothe and opted to try other methods to stop frequent night waking.

Although the sample size was small, and thus slight individual differences made a large impact on the results, research by DeGangi et al. reported similar findings. Behaviour and emotion regulation showed improvements at 36 months after 12 weeks of intervention during infancy, while other difficulties, such as vestibular and tactile sensitivities, persisted (17). These findings were expected by the researcher. That is, by implementing the principles of the sensory diet by using vestibular, proprioceptive and deep pressure, behaviour in occupational performance areas such as dressing, bathing, feeding and sleeping improved. However, sensory processing and underlying modulation difficulties experienced in sensory systems were not treated by either the parent education or the sensory diet and require instead individualised direct Ayers-SI therapy. This information informs clinical practice and highlights the need for Ayers-SI therapists to ensure that underlying sensory processing is treated through individualised therapy while providing parents with a sensory diet and education.

5.5.2 Discussion of sensory strategies included in the sensory diet

The sensory diet formed a large portion of the intervention over the two-week period. Although research supports the use of sensory diets (44,37,40,2), what to include in the sensory diet was not formalised or stipulated. In all sources, tables listing which inputs in each sensory system were either alerting or calming were found. These were identified by the researcher and adapted to the individual needs of infant participants. The various sensory based suggestions used in the study can be found in Appendix E.2.

The sensory diet was not prescribed to be used for a specific duration or frequency, but rather strategies were to be used during the day and during infant daily tasks. These aspects of the sensory diet would make it difficult to replicate the study with precision and made it difficult to critically evaluate the use of the sensory diet. Thus, the effect of the sensory diets relied on post-assessment and parental perceptions. In a more rigorous study the use of the sensory diet could have been better monitored through parent diaries in which the strategies used and frequency of used would have to be stipulated. In addition more formal handouts regarding what behaviours to be observed following the introduction of the sensory diet could have been provided. The introduction of a control group would then also assist in ensuring that change of the two week period was due to the use of the sensory diet and not just maturation over that short period. Having said this, since the research was conducted over such a short period of time, the effect of maturation was limited.

The strategies which parents reported to be most beneficial in the sensory diet were proprioceptive and vestibular-based suggestions that affected self-regulation. This is supported by the sensory integration literature which highlights the importance of these inputs for calming and organising infants (8,3,48).

The sleep auditory input which reduced background noise and provided a rhythmic beat to lull infants to sleep was found to be beneficial with the introduction of a consistent sequence of events before bedtime, allowing infants to sleep in their own beds and reducing night feeds. These findings are consistent with recommendations by Williamson and Anzalone specifically for infants (8).

Reducing milk feeds at night appeared to have a positive effect on increasing infant appetites during the day. This, together with baby-led weaning, resulted in parents perceiving feeding as improved, although this was not significant on the ITSC.

The use of DIR or Floortime and a predictable routine were most important in assisting with issues of attachment and separation anxiety. In the intervention study by DeGangi et al., sensory integration therapy and DIR or Floortime was used during a 12-week intervention period. These approaches were found to be beneficial in teaching parents how to interact with infants, leading to improvements in attachment and self-regulation (17). The effect of DIR or Floortime was expected by the researcher, as the first stage of emotional development that this model addresses is co-regulation. The aim of which is to coach parents in how to assist infants to self-regulate and maintain an appropriate level of regulation and how to facilitate this when infants are unable to do this independently by using their own verbal and non-verbal cues.

5.6 Implications for occupational therapy: guidelines for intervention

As highlighted in the introduction to this chapter, the small sample for the study does not make it possible to generalise results to other infants with similar problems. However, the information presented provides interesting indicators of possible trends for occupational therapists trained in sensory integration for clinical practice and further research. These are discussed below.

It appears that infant participants who presented with RSPD with specific and marked sensory based modulation difficulties (e.g. vestibular, tactile or auditory sensitivities) showed some improvements with education and a sensory diet, but results suggest that they may still require direct individual Ayers-SI therapy.

Infant participants who presented with high scores in the self-regulation and attachment domains appear to have improved significantly with the sensory diet. It would have been of value to the parents, and from a scientific research perspective,

to follow-up with these participants to ensure that the sensory diet remained appropriate for infant developmental level and needs. This could have been done by the researcher via email at the same time as providing parents with feedback on the results of the study. Replies from parents could be filed together with the research data.

The sensory diet consisted primarily of vestibular and proprioceptive-based activities with a focus on providing calming and organising input. However, specific strategies relating to behaviours of concern were also largely beneficial (regarding sleeping, feeding and bathing). This is consistent with the literature on using sensory strategies to manage behaviour (1,8).

It is the opinion of the researcher that there was much value in educating the parents on RSPD and its impact on behaviour and that this insight provided an opportunity for parents to interact with their infants in different ways. The importance of parent education is supported by two studies and a document which specifically assessed the parentsô perspectives on the benefits of education as part of the therapeutic process (43,44,37). This may suggest that, for some infant participants, signs of RSPD may not truly have been reduced, but that improved understanding of the reasons for fussy behaviour, led to a reduction in the perception of certain behaviors as being a problem.For occupational therapists treating infants with RSPD, an understanding of the overlap between RSPD and SMD is important to recognize. Thus the approach to these infants would be similar to those with SMD.

In conclusion, Ayers-SI therapy appears to be a suitable intervention approach for RSPD. As described by DeGangi (37), intervention should follow a family-centered approach and this should include parent education, sensory diets and, if necessary, child-centered interactions (including Ayers-SI and approaches, such as DIR). This study highlights that infant participants presenting with milder forms of RSPD with more behavioural signs and fewer underlying sensory processing difficulties may have been sufficiently assisted by parent education and sensory diets. This supports the guidelines proposed by DeGangi and is thus valuable in providing guidelines for Ayers-SI therapists.

CHAPTER 6
CONCLUSION

6.1 Introduction

Following the results and discussion of the study, the main findings of the study and suggestions for further study are discussed in this chapter. Limitations of the study were discussed throughout Chapter 5 in order to link these to appropriate points in the study and are thus not discussed in this concluding chapter.

Although this study was conducted on a small sample, it demonstrates a significant change over the two-week intervention period. It also provides valuable information for current practice in SA regarding the identification of RSPD and parentsô knowledge of sensory integration based occupational therapy as a therapeutic medium to assist in managing and treating this condition.

6.2 Main findings

This study obtained valuable information pertaining to RSPD in infant participants, regardless of the small sample size. The study showed that parents recognised children as being unusually fussy within a very short period after birth (75% before 6 weeks), but they did not recognise it as a medical condition which may require intervention. This may be because these infants were confirmed by paediatricians as being medically healthy. Paediatricians and clinic sisters also did not easily recognise this unusual fussiness as RSPD and therefore did not know how to advise parents and did not refer them to an occupational therapist. This is affected by the diagnostic manuals used in SA for diagnosing conditions.

The research suggests that a program consisting of parent education and an Ayers sensory diet with sensory strategies tailored to the specific needs of the infants may reduce RSPD.

The results of this study provide more specific guidelines to Ayers-SI therapists regarding the possible type of intervention required for infants presenting with RSPD in clinical practice. The study suggests that infants presenting with high levels of attachment and poor self-regulation scores may benefit from only education and a sensory diet to manage RSPD. Those presenting with specific and severe sensory-based processing difficulties (e.g. tactile, auditory or vestibular difficulties) may require individualised direct Ayers-SI in addition to the parental education and sensory diet.

In this context, a sensory diet refers to a process where parents would consult with an Ayers-SI occupational therapist, who would train parents as therapeutic agents to implement an individualised program at home. Individualised direct Ayers-SI incorporates a sensory diet, but also includes the infant receiving regular therapy sessions with an Ayer-SI therapist who would use a sensory integration frame of reference to specifically treat underlying sensory processing difficulties. Only an occupational therapist trained in sensory integration is recommended to conduct sensory integration-based individualised therapy, because the foundational difficulties underlying RSPD have are of a sensory processing nature. The duration of therapy would depend on the severity of RSPD and how quickly the infant responded to therapy, judged by observations of improved sensory processing and performance in everyday activities. Costs would depend on the time and the frequency of the sessions required.

6.3 Suggestions for further study

Further study in the field of RSPD would be beneficial to Ayers-SI therapists as well as to the infants and parents struggling with this disorder.

A study similar to this one, but with a larger sample of infants from other socio-economic backgrounds, would be valuable to allow the results to be generalisable to the SA population. This would provide more information regarding the effectiveness of the Ayers-SI sensory diet with respect to gender, socio-economic group and cultural orientation regarding child-rearing practices. This would especially be of value in SA with our many different cultures, beliefs and practices.

Obtaining this information would provide Ayers-SI therapists with a protocol or guidelines for interventions for infants with RSPD and would thus have significant clinical value.

If it were possible for Ayers-SI therapists to collect their data to contribute to long-term intervention studies, this would be paramount in determining the nature of the Ayers-SI intervention (sensory diet and education vs. individualised therapy) relative to the severity of RSPD, as well as the dosage required for long-term change. This information would be useful in obtaining payment for preventative strategies and early intervention therapies from medical aids / National Health Insurance and provide paediatricians and clinic sisters with evidence that Ayers-SI is a recognised and proven intervention for the treatment of RSPD.

Having obtained this proof, similar studies of infants younger than 6 months could be conducted to determine whether colic is diminished through parent education and a sensory diet, that is, whether colic is a medical condition or is caused by undiagnosed RSPD. Information regarding this would provide occupational therapists, medical professionals and parents with a non-medicinal approach for managing colic.

All these suggestions for further study indicate the importance for Ayers-SI occupational therapists to participate in evidence-based practice and the importance of keeping good records through sound assessment and intervention procedures. Research such as this would benefit the profession and help it gain recognition among other medical professions as an important part of the multi-disciplinary team in treating and managing RSPD.

APPENDICES

Appendix A.1 Interview questionnaire: first draft and validation comments

Please note: Comments by Expert 1 are highlighted in yellow and comments by Expert 2 are highlighted in green

Thank you for taking the time to see whether the questionnaire I have prepared for my MScOT research report is valid. Attached please see the objectives of my study. With each question you will be requested to determine whether:

a) The question asked will contribute towards reaching study objectives – if not then it would not be considered valid,
b) If questions are structured and worded correctly.

Please also feel free to add suggestions to any other questions which you feel would assist in reaching the study objectives.

STUDY OBJECTIVES:

- Identify 'fussy' infants that met the criteria for RSPD.
- Establish what the parents of these infants knew about RSPD and what they had done to deal with the problems.
- Implement and establish the effectiveness of a 2 week Ayers-SI sensory diet with infants with RSPD.
- Create a guideline for clinical practice regarding the need for therapy versus parent consultations and home programme according to the severity of RSPD profile. *This would be clinically valuable, as well as possibly developing a pamphlet for education purposes to clinic and paediatricians*.

.....

Dear Parent,

The symptoms or presenting problems in the Infant Toddler Symptom Checklist are common complaints presented by parents when they seek help for their children. In order to help me understand your child's development and functioning from birth, I would appreciate your reading this list carefully and responding to each item.

Below is a parent questionnaire that provides information on your child's birth, early development and questions pertaining to your journey with your child thus far, in your search for help.

Your time in completing this form and then answering the questions in the interview is much appreciated.

Look at the language used above and make it more user friendly

Code: _____ Sex: _____ M _____ F

Date of birth: _____/_____/_____ Birth order _____

Include space for current age

Possibly include siblings name and age

Today's date: _____/_____/_____

Contact number: _____ (c) _____ (w) _____ (h)

Delivery: _____Natural _____Caesarean Full term: _____ Y _____N

Week's gestation _____

Separate delivery methods in more detail: include whether the birth was a breech

Separate caesarean into elective and emergency

Include birth weight

Medical Problems:

During pregnancy: _____ y _____N

Include the option for 'during birth process _____Y _____N

After birth: _____Y _____N

Perhaps investigate other possible correlations to fussiness such as whether pregnancy was planned or not; early trauma and separation, experience of post natal depression (more related to attachment issues)... this might be covered by the medical problems questions above.

If yes, please explain:

_____

_____

_____

Please list any current medical history e.g. allergies, hospitalisations, chronic medication:

Include other specific options such as epilepsy, ear infections....be more specific.

_____

_____

_____

Baby is currently: ____ bottle-fed _____breastfed

Perhaps ask for parent's occupation? This will give you an idea of functional level.

Highest grade or degree completed by mother :_____

Highest grade or degree completed by father: _____

1. When did you first notice that your child was being fussy / difficult? (age)

_____

Include a row for the table. So that question 2 is headed 'PAST' and 3 is headed 'PRESENT'

Will the parents complete this verbally in interview or just answer questions? It is a bit vague if parents are left to complete this questionnaire independently.

	2. When you first noticed your baby's fussiness, what behaviours did you observe with regards to...?	3. What behaviours do you currently observe that are of concern?
Self-Regulation / arousal		
Attention		
Sleep		
Eating		
Dressing/ bathing/touch		
Movement		
Auditory Input		
Visual Input		
Attachment / emotion		
Other		

4. Please rate your present concerns in order of importance: (1 is most important, 9 least)

Self-regulation	
Attention	Auditory
Sleep	Visual
Eating	Attachment / emotion
Dressing / bathing / touch	Other?
Movement	

5. Was your child described as *(remove these words)* a colicky infant? _____

   By whom?

   a. If yes: what age was this first ascribed to your baby? _____

   b. What medication was prescribed?

      _____

      _____

   c. When did these symptoms resolve?

      _____

   d. What other advice was given?

      _____

      _____

   e. Did any of the above help?

      _____

      _____

      _____

6. Where have you searched for help with your child's fussiness?

   _____

   _____

   _____

7. What has your paediatrician advised about your concerns? (medication, referrals, advice)

   _____

   _____

   _____

   a. Has this helped? _____

8. What has your clinic nurse advised about your concerns? (medication, referrals, advice)

_____

_____

_____

_____

   a. Has this helped? _____

9. Who else has given you advice regarding your difficulties and what was this advice? *Check spelling and add the word 'ADVICE' to the end of the sentence.*

_____

_____

   a. Has this helped? _____

10. Are you a stay-at-home mom Yes ☐ No ☐

    working? Yes ☐ No ☐

11. If working, who cares for your child during the day? (please circle)

    Crèche day mother at home other

12. Would you have the time to attend weekly therapy to assist your child? *Rather reword this to say 'how much time do you have available to attend therapy if needed' or possibly remove question.*

_____

13. With your current routine, would you be able to perform a daily home program e.g. sensory diet? *Rather say 'when in your day would you be able to perform a daily program?'*

_____

14. Have you heard of Ayers: SI?

_____

15. If so, where from?

_____

16. Have you tried to use any sensory based strategies to assist you *(Spelling)* child? If so, what?

_____

_____

_____

_____

_____

17. Do you feel that your child is developing age appropriately?

_____

_____

18. Has your clinic sister / paediatrician mentioned any concern about developmental milestones at checkups?

_____

_____

19. Are you aware that there is such a condition as regulation disorder in infants?

_____

20. How would you feel if you baby matched the diagnostic criteria for this?

_____

_____

21. Are you aware of any possible long term effects of infant fussiness / regulation disorder?
Perhaps ask this question in a different manner : are you aware that prolonged fussiness which is unresolved may lead to later emotional and developmental difficulties?

_____

_____

Is Regulation Disorder classified in the DSM IV-TR?

STRATEGIES SUGGESTED TO PARENTS:

_____

_____

_____

_____

_____

_____

FOLLOW UP: effect of strategies, what worked and what didn't / has baby's interaction and behaviour changed?

_____

_____

_____

_____

_____

_____

_____

Thank you for taking the time to complete the parent questionnaire, your participation in this research study is greatly appreciated.

Appendix A.2 Final-interview questionnaire

Dear Parent Today's date: _____/_____/_____

The symptoms or presenting problems in the Infant Toddler Symptom Checklist are common complaints presented by parents when they seek help for their children. In order to help me understand your child's development and functioning from birth, I would appreciate your reading this list carefully and responding to each item.

Respond with

- *Never or sometimes*, if your child has *never* had this difficulty, or has it infrequently/some of the time
- *Most times* if this is a difficulty your child experiences frequently of most of the time at present
- *Past,* if this was a problem in the past, but is no longer a problem

Following that is a parent questionnaire that provides information on your child's birth, early development and questions pertaining to your journey with your child thus far, in your search for help.

Your time in completing this form is much appreciated.

Contact Details (to be kept separate)

Baby's full name: _____ Sex: _____ M _____ F

Date of birth: _____/_____/_____

Parent's name: _____

Contact number: _____ (c) _____ (w) _____ (h)

Questionnaire

Code

_____

Baby

Sex: _____ M _____ F

Present Age: _____ Birth order _____

Siblings: (age/s) _____

_____

Was pregnancy _____ planned _____unplanned

Delivery: _____Natural Full term: _____ Y _____N Weeks gestation _____

_____ Elective C-section _____Emergency C-section ____ Breech

Birth Weight: _____

Baby is currently: ____ bottle-fed _____breastfed

Medical Problems:

- During pregnancy: _____ y _____N
- During birth: _____Y _____N
- After birth: _____Y _____N

If yes, please explain:

_____

_____

Please list any current medical history e.g. allergies, hospitalisations, medication, ear infections:

_____

_____

Highest grade or degree completed & occupation of mother :_____

Highest grade or degree completed & occupation of father: _____

1. When did you first notice that your child was being fussy / difficult? (age)

_____

	2. When you first noticed fussiness, what behaviours did you observe with regards to the below domains? (PAST)	3. What behaviours do you currently observe that are of concern? (PRESENT)
Self-Regulation / arousal		
Attention		
Sleep	Day Night	Day Night
Eating		
Dressing/bathing/ touch		
Movement		
Auditory Input		
Visual Input		
Attachment / emotion		
Other		

4. Please rate your present concerns in order of importance: (1 is most important, 9 least)

Self-regulation	Movement
Attention	Auditory
Sleep	Visual
Eating	Attachment / emotion
Dressing / bathing / touch	Other ?

5. Was your child a colicky infant? _____
    a. If yes: what age was this first ascribed to your baby? _____
    b. What medication was prescribed?

        _____

        _____

    c. When did these symptoms resolve?

        _____

    d. What other advice was given?

        _____

        _____

    e. Did any of the above help?

        _____

        _____

---

6. Where have you sought help with your child's fussiness?

    _____

    _____

    _____

7. What has your paediatrician advised about your concerns (medication, referrals, advice)?

    _____

    _____

    _____

    a. Has this helped? _____
8. What has your clinic nurse advised about your concerns (medication, referrals, advice)?

    _____

    _____

    _____

    _____

    a. Has this helped? _____
9. Who else has given you advice regarding your difficulties and what was this advice?

    _____

    _____

    a. Has this helped? _____

10. Are you a stay-at-home mom Yes ☐ No ☐

    working? Yes ☐ No ☐

11. If working, who cares for your child during the day? (please circle)

    Crèche day mother at home other

12. With your current routine, how much time would you have available for carrying out home programs e.g. sensory diet?

    _____

13. Have you heard of sensory integration based occupational therapy?

    _____

14. If so, where from?

    _____

15. Have you tried to use any sensory based strategies to assist your child? If so, what?

    _____

    _____

    _____

    _____

    _____

16. Do you feel that your child is developing age appropriately?

    _____

    _____

17. Has your clinic sister / paediatrician mentioned any concern about developmental milestones at checkups?

    _____

    _____

18. Are you aware that there is such a condition as Regulatory Sensory Processing Disorder in infants?

    _____

19. How would you feel if you baby matched the diagnostic criteria for this?

    _____

    _____

20. Are you aware that issues related to fussiness can be improved upon and that prolonged fussiness which is unresolved may lead to later emotional and learning difficulties?

_____

_____

STRATEGIES SUGGESTED TO PARENTS:

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

FOLLOW UP: effect of strategies, what worked, what didn't / has baby's interaction and behaviour changed?

_____

_____

_____

_____

_____

_____

_____

_____

_____

Appendix B.1 Infant Toddler Symptom Checklist for each age group

Infant/Toddler Symptom Checklist:
7 to 9 Months

Code: _____ Date_____

	Never or Sometimes	Most Times	Past
1. Self-Regulation			
A. Is frequently irritable, fussy			
B. Goes easily from whimper to intense cry			
C. Can't calm self effectively by sucking on pacifier, looking at toys, or listening to caregiver			
D. Is unable to wait for food or toy without crying or whining			
E. Must be prepared for change well in advance of event			
F. Demands adult company constantly			
G. Has temper tantrums (severe and frequent)			
H. Amount of time spent calming child during day (circle one): 15-30 minutes 1-2 hours 3 hours +			
2. Sleep			
A. Wakes 3 or more times in the night and is unable to fall back to sleep			
B. Requires extensive help to fall asleep; *specify:* rocking, long walks, stroking hair, car ride, other_____			
3. Eating or Feeding			
Gags or vomits			
4. Dressing, Bathing, Touch			
A. Is distressed by having face or hair washed			
B. Resists being placed in certain positions; for example, stomach or back			
5. Movement			
A. Is in constant movement—rocking, running about, unable to sit still for an activity			
B. Craves swinging and moving upside-down			
6. Listening, Language and Sound			
Is distracted by sounds not normally noticed by average person			
7. Looking and Sight			
A. Is sensitive to bright lights—cries or closes eyes			
B. Becomes excited in crowded, bustling settings such as supermarkets, restaurants			

continued

© 1995 by Therapy Skill Builders, a division of The Psychological Corporation / 1-800-866-4446
All rights reserved. / Catalog No. 4355

076-1643753-1

Infant/Toddler Symptom Checklist: **7 to 9 Months (continued)**	Never or Sometimes	Most Times	Past
8. Attachment/Emotional Functioning			
A. Has difficulty separating from parents, school, or babysitter			
B. Does not respond at all to limits, discipline			
C. Appears anxious or fearful of new people, situations			
D. Needs total control of the environment—"runs the show"			

How concerned are you about the symptoms you have checked above? (Circle one.)

Not concerned Slightly concerned Moderately concerned Very concerned

Comments:

© 1995 by Therapy Skill Builders, a division of The Psychological Corporation / 1-800-866-4446
All rights reserved. / Catalog No. 4355

Infant/Toddler Symptom Checklist: 10 to 12 Months

Code: _____ Date_____

	Never or Sometimes	Most Times	Past
1. Self-Regulation			
A. Is frequently irritable, fussy			
B. Goes easily from whimper to intense cry			
C. Is unable to wait for food or toy without crying or whining			
D. Demands adult company constantly			
E. Amount of time spent calming child during day (circle one): 15-30 minutes 1-2 hours 3 hours +			
2. Sleep			
A. Wakes 3 or more times in the night and is unable to fall back to sleep			
B. Requires extensive help to fall asleep; *specify:* rocking, long walks, stroking hair, car ride, other_____			
3. Eating or Feeding			
A. Gags or vomits			
4. Dressing, Bathing, Touch			
A. Resists cuddling, pulls away or arches			
B. Resists being placed in certain positions; for example, stomach or back			
C. Is distressed when clothes are removed			
5. Movement			
Is clumsy—falls, shows poor balance, bumps into things			
6. Listening, Language and Sound			
Is distracted by sounds not normally noticed by average person			
7. Looking and Sight			
Becomes excited in crowded, bustling settings such as supermarkets, restaurants			
8. Attachment/Emotional Functioning			
A. Avoids eye contact, turns away from the human face, prefers objects and toys			
B. Has difficulty separating from parents, school, or babysitter			
C. Appears anxious or fearful of new people, situations			
D. Needs total control of the environment—"runs the show"			

continued

© 1995 by Therapy Skill Builders, a division of The Psychological Corporation / 1-800-866-4446
All rights reserved. / Catalog No. 4355

076-1643753-2

Infant/Toddler Symptom Checklist:
10 to 12 Months (continued)

How concerned are you about the symptoms you have checked above? (Circle one.)

Not concerned Slightly concerned Moderately concerned Very concerned

Comments:

© 1995 by Therapy Skill Builders, a division of The Psychological Corporation / 1-800-866-4446
All rights reserved. / Catalog No. 4355

Infant/Toddler Symptom Checklist: 13 to 18 Months

Code: _____ Date_____

	Never or Sometimes	Most Times	Past
1. Self-Regulation			
A. Is frequently irritable, fussy			
B. Goes easily from whimper to intense cry			
C. Can't calm self effectively by sucking on pacifier, looking at toys, or listening to caregiver			
D. Is unable to wait for food or toy without falling apart			
E. Can't change from one activity to another without distress			
F. Demands adult company constantly			
G. Amount of time spent calming child during day (circle one): 15-30 minutes 1-2 hours 3 hours +			
2. Attention			
A. Is easily distractible, shows fleeting attention			
B. Has difficulty paying attention, is difficult to reengage			
C. Is unable to shift focus easily from one object or activity to another			
3. Sleep			
A. Wakes 3 or more times in the night and is unable to fall back to sleep			
B. Requires extensive help to fall asleep; *specify:* rocking, long walks, stroking hair, car ride, other_____			
4. Dressing, Bathing, Touch			
A. Doesn't want to wear clothing			
B. Prefers certain clothing, complains that certain garments are too tight or scratchy			
C. Is distressed by having face or hair washed			
D. Resists cuddling, pulls away or arches			
E. Hates sitting in car seat			
F. Resists being placed in certain positions, such as stomach or back			
G. Is distressed when clothes removed			
5. Movement			
Craves swinging and moving upside-down			

continued

© 1995 by Therapy Skill Builders, a division of The Psychological Corporation / 1-800-866-4446
All rights reserved. / Catalog No. 4355

076-1643753-3

Infant/Toddler Symptom Checklist: 13 to18 Months (continued)

	Never or Sometimes	Most Times	Past
6. Listening, Language and Sound			
Startles or is distressed by loud sounds such as vacuum, doorbell, or barking dog			
7. Looking and Sight			
Becomes excited in crowded, bustling settings such as supermarkets, restaurants			
8. Attachment/Emotional Functioning			
A. Avoids eye contact, turns away from the human face, prefers objects and toys			
B. Does not appear happy			
C. Does not initiate interaction with caregiver: Parent needs to woo infant/child constantly			
D. Does not interact reciprocally (back-and-forth exchanges with caregiver)			
E. Has difficulty separating from parents, school, or babysitter			
F. Does not respond at all to limit setting, discipline			
G. Appears anxious or fearful of new people, situations			
H. Needs total control of the environment—"runs the show"			
I. Everyone has difficulty understanding the child's cues or emotions			

How concerned are you about the symptoms checked above? (Circle one.)

Not concerned Slightly concerned Moderately concerned Very concerned

Comments:

© 1995 by Therapy Skill Builders, a division of The Psychological Corporation / 1-800-866-4446
All rights reserved. / Catalog No. 4355

Infant/Toddler Symptom Checklist: 19 to 24 Months

Code: _____ Date_____

	Never or Sometimes	Most Times	Past
1. Self-Regulation			
A. Goes easily from whimper to intense cry			
B. Can't calm self effectively by sucking on pacifier, looking at toys, or listening to caregiver			
C. Is unable to wait for food or toy without falling apart			
D. Must be prepared several times in advance before change is introduced			
E. Demands adult company constantly			
2. Attention			
A. Is easily distractible, shows fleeting attention			
B. Has difficulty paying attention, is difficult to reengage			
3. Sleep			
Wakes 3 or more times in the night and is unable to fall back to sleep			
4. Eating or Feeding			
A. Craves certain foods or drinks			
B. Is too distracted to stay seated for meals			
5. Dressing, Bathing, Touch			
A. Resists cuddling, pulls away or arches			
B. Hates sitting in car seat			
C. Resists being placed in certain positions, such as stomach or back			
6. Movement			
A. Is in constant movement—rocking, running about, unable to sit still for an activity			
B. Craves swinging and moving upside-down			
C. Is clumsy—falls, has poor balance, bumps into things			
7. Listening, Language and Sound			
A. Is distracted by sounds the average person doesn't notice			
B. Doesn't respond to verbal cues (hearing not a problem)			
C. Repeats or echoes previously heard words, phrases, or sentences			

continued

© 1995 by Therapy Skill Builders, a division of The Psychological Corporation / 1-800-866-4446
All rights reserved. / Catalog No. 4355

076-1643753-4

Infant/Toddler Symptom Checklist: 19 to 24 Months (continued)	Never or Sometimes	Most Times	Past
8. Looking and Sight			
Becomes excited in crowded, bustling settings such as supermarkets, restaurants			
9. Attachment/Emotional Functioning			
A. Does not play with other children—withdraws or is aggressive			
B. Does not respond at all to limits, discipline			
C. Needs total control of the environment—"runs the show"			

How concerned are you about the symptoms checked above? (Circle one.)

Not concerned Slightly concerned Moderately concerned Very concerned

Comments:

© 1995 by Therapy Skill Builders, a division of The Psychological Corporation / 1-800-866-4446
All rights reserved. / Catalog No. 4355

Appendix B.2: Protocol sheet for Infant Toddler Symptom Checklist

Infant/Toddler Symptom Checklist:
Protocol Sheet

CODE ___ 1 Date 5 August

Clinician Name_____

Scoring

- **Never or sometimes:** 0 points
- **Most times:** 2 points
- **Past:** 1 point

The item on self-calming ("Amount of time spent calming child during day") is scored as follows:

- **15-30 minutes:** 0 points
- **1-2 hours:** 1 point
- **3 or more hours:** 2 points

Points assigned: 0

Number of check marks in the **most times** column: 6
Multiply by 2: x 2
Points for **most times:** 12

Number of check marks in the **past** column: 0

Checklist total:
Add points for **self-calming** item: 0
most times: 12
past: 0
Total: 12

Interpretation

Age (in mos.)	Checklist total	Normal score	Deficient range
7–9		0–9	10+
(10–12)		0–11	(12+)
13–18		0–18	19+
19–24		0–8	9+
25–30		0–5	6+
General Screening form (all ages)		0–5	6+

© 1995 by Therapy Skill Builders, a division of The Psychological Corporation / 1-800-866-4446
This page may be reproduced for administrative use. / Catalog No. 4355

Appendix B.3: Raw data: Infant Toddler Symptom Checklist

Infant Toddler Symptom Checklist Data Collection : Initial Assessment											
Infant	Age band	Self Regulation	Sleep	Eating/ Feeding	Dressing/ Bathing/ Touch	Vestibular	Auditory	Visual	Attachment/ Emotion	Concentration	TOTAL
1	2	4	4	0	0	0	2	0	2		12
2	1	9	4	0	0	4	0	0	2		19
3	1	6	4	0	3	0	0	2	2		17
4	3	6	4	0	6	0	0	2	0	4	22
5	1	12	4	2	2	0	0	2	2		24
6	1	9	4	0	2	0	0	0	4		19
7	2	8	4	0	6	0	0	2	3		23
8	4	6	2	0	2	2	4	2	4	4	26
9	4	3	1	0	2	2	2	0	2	0	12
10	4	6	0	0	1	2	0	0	2	0	11
11	4	6	2	4	4	2	0	0	6	0	24
12	4	6	0	0	2	0	4	0	4	2	18
										Mean _Total	19

Infant Toddler Symptom Checklist Data Collection : Post Intervention										
Infant	Self Regulation	Sleep	Eating/ Feeding	Dressing/ Bathing/ Touch	Vestibular	Auditory	Visual	Attachment/ Emotion	Concentration	TOTAL
1	2	4	0	0	0	2	0	2		10
2	0	0	2	0	2	1	0	0		5
3	8	4	0	1	0	0	2	0		15
4	6	0	0	8	2	0	2	0		18
5	5	4	0	4	0	2	0	0		15
6	2	0	0	2	0	0	0	2		6
7	1	3	0	6	0	0	2	2		14
8	2	2	2	0	2	4	2	4	2	20
9	2	0	0	1	0	4	0	0	0	7
10	2	0	0	1	2	0	0	1	0	6
11	1	0	0	2	2	2	0	0	0	8
12	4	0	0	0	4	2	0	2	0	12
									Mean_Total	11

Appendix C.1: Information sheet for referral agencies

Dear Colleague

I am Jacqui Jorge, an Occupational Therapist in private practice in Edenvale. As part of my postgraduate studies at WITS, I am investigating the effect of a sensory diet over a two week period on fussy babies who experience Regulatory Sensory Processing Disorder (RSPD). I would be grateful if you would refer appropriate children to participate in this study.

Why am I doing this?

As an Occupational Therapist working in Private Practice I see babies and older children who are described by their parents as being ófussyô This has negative impacts on development as well as on attachment to the primary caregiver and thus emotional development. There are many babies who experience this; however these babies are seldom referred for therapy.

What is a Regulatory Sensory Processing Disorder?

Infants frequently display sleep disturbances and/or colic that resolves spontaneously by 6 months of age. If these early signs of irritability do not resolve by 6 months, this fussiness persists and is coupled with other symptoms such as poor self-calming, intolerance for change and a hyperalert state of arousal (1). Typically difficulties arise in sleep, self-consoling, feeding, attention and arousal, mood regulation or transitions. These infants are also often hyper or hypo responsive to sensory stimuli e.g. tactile, auditory, visual and vestibular information.

The infant should meet at least two of the following criteria for a diagnosis of Regulatory Sensory Processing Disorder to be made:

1. Sleep disturbance: the infant takes more than 20 minutes to fall asleep and wakes more than twice in the night.
2. Difficulties in self-consoling: the caregiver spends two to four hours a day attempting to calm her infant.

3. Feeding disorders: feeding difficulties not related to allergies or intolerance and include refusal to eat, regurgitation and difficulties establishing a regular feeding routine.
4. Hyperarousal: infant appears overwhelmed by sensory input and may avert gaze to avoid contact. They may appear intense, wide-eyed or ñhyperò

What is the process of the research and what is expected of the participants in the study?

Infants who meet the above mentioned criteria and who are between the ages of 7 and 24 months may be referred to participate in the research.
Birth history: full term birth and premature infants are included. Infants with diagnosed neurological impairments are excluded for the purposes of the study.

Once referred, the parent will contact the researcher and an appointment setup. The parent is requested to contact the researcher for ethical reasons, to ensure voluntary participation. At this appointment the parent will be asked to sign a consent form and participate in an interview lasting about one hour. In addition they will be requested to complete the Infant Toddler Symptom Checklist. Specific sensory integrative strategies will then be suggested and communicated to the parent to follow in a two week period through the use of a sensory diet. After this time they will be asked to once again complete the checklist.

Are there benefits to the babies?

The study is being done to determine the effect of the two week sensory diet program on the fussiness of the infants and thus the benefits will only be determined once the study is complete.

Are there risks to the babies?

Since the strategies provided are based on sensory integration theory, which is sound, there are no risks involved.

Are there any costs involved?

For the duration of the research period, the assessment and intervention will not be charged for. Should the parents wish to continue with occupational therapy the usual therapy fees may apply. However the parents will also be given a list of other occupational therapists trained in sensory integration in their area, should further intervention be necessary.

Dealing with confidentiality

Confidentiality will be ensured by the use of codes on data sheets and the names of the participants will be kept in a separate file available to the researcher only.

If you have any queries or would like more information, please contact me on 0723917781 or email me at jacquijorge@iafrica.com.

I hope that you will be able to refer suitable infants for this research.

Thank you

Jacqui Jorge

Appendix C.2: Information sheet and consent form

Information Sheet

Dear Parent,

I am Jacqui Jorge, an Occupational Therapist in private practice in Edenvale. As part of my postgraduate studies at WITS, I am determining the profile of infants with regulation difficulties. I would be grateful if you and your child could participate in this study.

Why am I doing this?

As an Occupational Therapist working in Private Practice I see babies and older children who are described by their parents as being fussy. This has negative impacts on development as well as on attachment to the primary caregiver and thus emotional development. These babies are seldom referred for therapy. I would like to investigate reasons for this fussiness in more detail as well as offer a few sensory strategies to assist at home.

What is Regulatory Sensory Processing Disorder?

Infants frequently display sleep disturbances and/or colic that resolves spontaneously by 6 months of age. If these early signs of irritability do not resolve by 6 months, this fussiness persists and is coupled with other symptoms such as poor self-calming, intolerance for change and a hyperalert state of arousal (1). Typically difficulties arise in sleep, self-consoling, feeding, attention and arousal, mood regulation or transitions. These infants are also often hyper or hypo responsive to sensory stimuli e.g. tactile, auditory, visual and vestibular information.

For the purpose of this research study, the infant should meet at least two of the following criteria for Regulatory Sensory Processing Disorder to be considered:

1. Sleep disturbance: infant takes > 20 minutes to fall asleep & wakes more than twice in the night.
2. Difficulties in self-consoling: the caregiver spends 2-4 hours a day attempting to calm her infant.
3. Feeding disorders: feeding difficulties not related to allergies or intolerance and include refusal to eat, regurgitation and difficulties establishing a regular feeding routine.
4. Hyperarousal: infant appears overwhelmed by sensory input and may avert gaze to avoid contact. They may appear intense, wide-eyed or ñhyperò.

What is the process of the research and what is expected of the participants in the study?

Infants who meet the above mentioned criteria and who are between the ages of 7 and 24 months may be included in the research.

Full term birth and premature infants are included. Infants with diagnosed neurological impairments are excluded for the purposes of the study.

Once this consent form has been signed and if your infant fits the above criteria, the researcher will meet with you. The interview questionnaire will be completed which investigates what strategies you have tried, as well as other questions around your infant. In addition you will be provided with the Infant Toddler Symptom Checklist. This takes 5-10minutes to complete and will determine your childôs specific profile.

At this meeting, sensory strategies as part of a sensory diet, specific to the needs of your child will be communicated to you to carry out at home. Another follow up after 2 weeks will be done electronically to determine whether these strategies were helpful through again completing the Infant Toddler Symptom Checklist. Should your infant still present with signs of Regulatory Sensory Processing Disorder after this, you may referred for sensory integration based occupational therapy. A list of sensory integration trained occupational therapists in your area will be supplied.

Are there benefits to the babies?

The sensory strategies recommended will be specific to your infants profile and thus may benefit your baby as it may assist with fussiness.

Are there risks to the babies?

There are no risks involved in the sensory strategies recommended, or through completion of the questionnaires and checklists.

May I withdraw my baby from the study?

You may withdraw from the study at any time without having to give a reason. The study is completely voluntary and not taking part in it, or withdrawing from it, carries no penalty of any sort.

Are there any costs involved?

There are no costs involved for the checklist completion, meeting with therapist, questionnaire, sensory strategies advice or follow up. Should you need to continue with occupational therapy after this time, the usual therapy fees would apply and a list of sensory integration trained occupational therapists in your area will be provided to you.

Dealing with confidentiality

Confidentiality will be ensured by the use of codes on data sheets and the names of the participants will be kept in a separate file available to the researcher only.

If you have any queries or would like more information, please contact me on 0723917781 or email me at jacquijorge@iafrica.com.

If you are happy to participate with your baby in the study, please read and sign the attached consent form.

Thank you

Consent Form

I agree to allow my baby to participate in the study outlined in the information sheet.

Parent:

Name & Surname: _____

Signature: _____

Infants name & Surname: _____

Date: _____

Appendix D: Research flyer with inclusion criteria

HAS YOUR BABY BEEN TERMED 'FUSSY' ?

IS YOUR BABY BETWEEN 7 & 24 MONTHS OLD AND MEETS ANY TWO OF THE FOLLOWING:

(tick the applicable boxes)

		YES	NO
Sleep disturbance	he/she takes more than 20 minutes to sleep & wakes more than twice at night.		
Difficulties in self-consoling	you spend two to four hours a day attempting to calm your baby.		
Feeding disorders	feeding difficulties not related to allergies or intolerance: including refusal to eat, regurgitation and difficulties establishing a regular feeding routine.		
Hyperarousal	your baby appears overwhelmed by sensory input and may avert gaze to avoid contact. He/she may appear intense, wide-eyed or "hyper".		

If Yes... I would appreciate it if you would consider joining my research study – (its free)

THE EFFECT OF A TWO-WEEK SENSORY DIET ON INFANTS WITH REGULATORY SENSORY PROCESSING DISORDER.

Sign consent form.

Complete the Infant Toddler Symptom Checklist

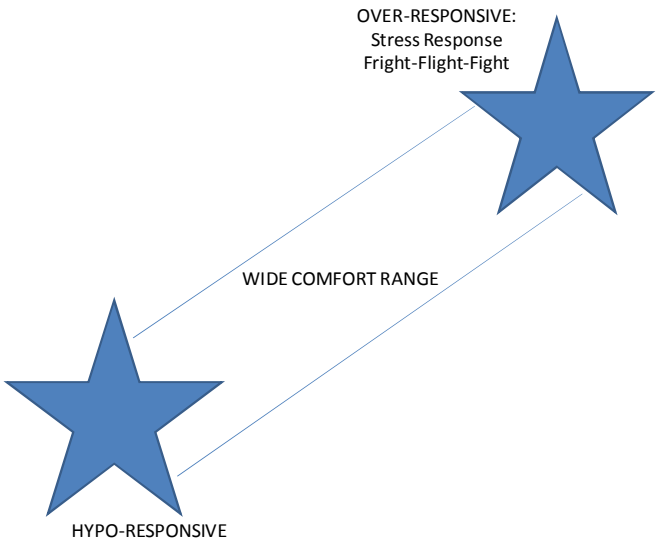
Complete questionnaire and interview (in a meeting)

Offer sensory strategies to try at home

After 2 weeks, researcher will contact you to follow up on sensory strategies.

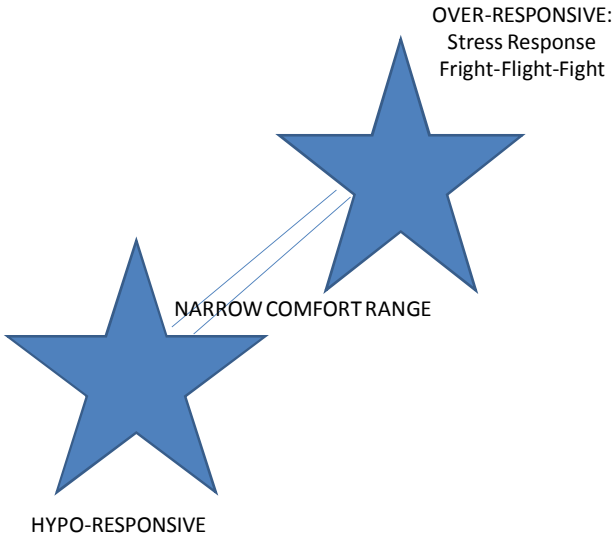
Thank you for your time. If you are interested in participating please ask your clinic for the consent form and checklist or contact Jacqui Jorge 0723917781 or jacquijorge@iafrica.com

Appendix E.1 Explanation slides used as part of parent education



(Taken from Kerry Wallace, 2010)

Typical threshold and sensory modulation: the infant has a wide comfort range and can tolerate multi-sensory input from the environment for an appropriate length of time before entering the over-responsive stress state.



Atypical threshold experienced in RSPD: the infant has a narrow comfort range and thus cannot tolerate much sensory input without becoming over-responsive in a stress state, resulting in fight, flight, fright responses.

Appendix E.2: Sensory diet recommendations

Self-Regulation	
Proprioception	Proprioceptive input : this included joint compressions through activities such as being held by the parent who is jumping on the trampoline, adding weight to push carts by placing a brick onto it, allowing mobile infants to carry rucksacks and pull heavy items around, as well as deep pressure hugs and joint compressions.
Vestibular	Vestibular input in late afternoon, including inversion, swinging, rocking: the importance of a steady, slow rhythm was communicated.
	Vestibular: support for insecurity: for during washing hair and nappy changes, but placing the parents arm around the baby's head and neck while moving back in space. Also the use of a wedge shaped cushion was suggested, to decrease the incline.
Auditory	Sacred drums: music on repeat throughout the night. This particular CD has a steady, grounded, earthy beat.
	Auditory: ensure eye contact when giving instructions to the infant.
Tactile	Tactile input: vibration / hold firmly. The importance of firm touch was explained. For those struggling with dressing the parent was shown to hold the infant's body firmly and to quickly and firmly dress him/her.
	Sleep association toy: of the family's choice. For younger infants a taglet (which is a square piece of cloth with clothes labels sewed onto the edges, sold by the Baby Sense Brand) was suggested while for older infants a soft cuddly toy of their choice was suggested.
Visual	Brushing protocol, this was suggested only to infants who presented with severe signs of tactile sensitivities to clothing, dressing, bathing, bed sheets .
Sleep : night	Sequence of events for bedtime routine: this included starting with a calming routine earlier in the evening – from about 6pm. It also included changing the order of events e.g. for infants who hated dressing, bathing and dressing was recommended before dinner time to allow the infant time to recover from the experience. The general sequence was dinner, bath, quiet play time, say good-night, into room, read book, lights off and sleep.
	Sleep in own bed and stay in own room during the night independently: this

	advice included infants staying in their own beds, parents returning to parents bed as well as older infants moving out of the cot and into a bigger bed.
	Reduce bottle/breast feeds at night: both breast and bottle. For breast: infants were either offered a dummy or left to moan and learn to self-soothe. For bottle fed infants : milk volume was decreased, or water introduced instead of milk.
	Environment temperature and humidifier (winter).
	Dummy clip : for infants who could self-soothe with dummy but lost it during the night.
	Allow to cry to learn to self-sooth: this was suggested as most parents intervened as soon as the infant started to moan. The cry was limited to about 20 minutes. Parents were not encouraged to go into the room after 5 or 10 minutes as this only taught the infant that the parent would eventually come, and led to prolonged periods of crying.
	Shush-pat sleep training: this option was mentioned to all parents but not encouraged as it still created dependency and resulted in prolonged difficulties. It was however an option for infants who experienced severe anxiety and was the preferred method of parents of older infants.
	Lights off.
Sleep : day	Encourage later morning nap.
	Limit afternoon nap slightly : this was to ensure that infants were ready for sleep at bed time to reduce the amount of time it took to fall asleep.
Eating	Baby led weaning: this approach utilises finger feeding or a variety of foods and gives the infant more control.
	Oral preparation: this refers to the provision of deep tactile input around the mouth, to the cheeks and gums before introducing a meal, especially for infants with oral tactile sensitivities.
Attachment	Allow child to be settled by someone else with you in the same environment: this allows the infant to experience that someone else besides mom can help to soothe and calm the infant.
	Individual play time with mom / floortime: concepts such as co-regulation and shared attention were explained to the parents. The watch, wait and wonder approach was often explained whereby the parent is encouraged to spend some time each day just watching their infant play thereby encouraging independence and reducing anxiety.

	Peek a boo games.
	Predictability and routine : reducing anxiety and creating structure.
	Say good bye to child: many parents 'escaped' from the house instead of teaching their infant that they were going to leave and would come back. Thus any time the parent left the room the infant started to scream and become anxious, unsure if the parent would return.

Appendix F: Ethical clearance certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Mrs Jacqui Jorge

CLEARANCE CERTIFICATE	M090339
PROJECT	The Effect of Therapeutic Listening on Infants
INVESTIGATORS	Mrs Jacqui Jorge.
DEPARTMENT	Occupational Therapy Department
DATE CONSIDERED	09.03.27
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 09.04.29 CHAIRPERSON .....
(Professor P E Cleaton Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Mrs P De Witt

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

LIST OF REFERENCES

1. DeGangi G. Pediatric Disorders of Regulation in Affect and Behaviour: a Therapist's guide to assessment and treatment USA: Elsevier Science; 2000.

2. Reebye P, Stalker A. Understanding regulation disorders of sensory processing in children: managements strategies for parents and professionals UK: Jessica Kingsley Publishers; 2007.

3. Bundy A, Lane S, Murray E. SI: Theory and Practice. 2nd ed. Philadelphia: FA Davis Company; 2002.

4. Murray-Slutsky C, Paris B. Exploring the Specturm of Autism and Pervasive Developmental Disorders Tucson: Therapy Skill Builders; 2000.

5. Biel L. Sensory Smart. [Online]. [cited 2012 March 07. Available from: www.sensorysmarts.com.

6. Case-Smith J. Occupational Therapy for Children. 5th ed. Missouri: Evolve; 2005.

7. ICDL. [Online]. [cited 2011 12 12. Available from: www.icdl.com.

8. Williamson G, Anzalone M. Sensory Integratio and Self-Regulation in Infants and Toddlers USA: Zero to Three; 2001.

9. Miller L, Anzalone M, Cermack SLS, Osten B, Wieder S, Greenspan S. SPD Foundation. [Online].; 2006 [cited 2012 March 15. Available from: www.spdfoundation.net.

10. Miller L, Robinson J, Moulton D. Sensory modulation dysfunction: idenfitifcation in early childrood. In Disorders with an onset in infancy or toddlerhood. USA p. 247-268.

11. Greenspan S, Wiener S. ICDL. [Online].; 2006 [cited 2012 March 15. Available from: www.icdl.com.

12. Porges S. Cardiac Vagal tone, A physiological index of stress. Neuroscience Biobhevaioural Review. 1995; 19(2).

13. DeGangi G, DiPietro J, Greenspan S, Porges S. Psychophysiological Characteristics of the Regulatory Disordered Infant. Infant Behaviour and Development. 1991; 14.

14. DeGangi G, Greenspan S. Test of Sensory Functions in Infants (TSFI) Manual USA: Western Psychological Services; 1989.

15. DeGangi G, Breinbauer C, Roosevelt J, Porgess S, Greenspan S. Prediction of childhood problems at three years in children experiencing disorders of regulation during infancy. Infant Mental Health Journal. 2000; 21(3): p. 156-175.

16. DeGangi G, Porgess S, Sickel R, Greenspan S. Four year follow up of a sample of regulatory disordered infants. Infant Mental Health Journal. 1993 Winter; 14(4): p. 330 - 343.

17. DeGangi G, Sickel R, Wiener A, Kaplan E. Fussy babies: to treat or not to treat? British Journal of Occupational Therapy. 1996 October; 59(10): p. 457-464.

18. WHO. World Health Organisation. [Online].; 2012 [cited 2012 Month 15. Available from: www.who.int.

19. Association AP. Diagnostical and Statistical Manual of Mental Disorders: DSM-IV-TR: 4th Edition Text Revision. 4th ed. Washington DC: American Psychiatric Association; 2000.

20. Development DoS. South Africa Government Online. [Online].; 2011 [cited 2012 March 15. Available from: www.info.gove.za.

21. Cordero J, Greenspan S, Bauman M, Brazelton T, Dawson G, Dunbar B, et al. Interdisciplinary Council on Developmental and Learning Disoders. [Online].; 2006 [cited 2012 March 15. Available from: www.icdl.com.

22. Ahn R, Miller L, Milberger S, McIntosh D. Prevalence of Parents' Perceptions of Sensory Processing Disorders Among Kindergarten Children. The American Journal of Occupational Therapy. 2004 May/June; 58(3).

23. Ayres A. Sensory Integration and Praxis Tests Los Angeles: Western Psychological Services; 1989.

24. Lester B, Freier K, LaGasse L. Prenatal cocaine exposure and child outcome: what do we really know. In Williamson G, Anzalone M. Sensory integration and self regulatoin in infants and toddlers: helping very young children interact with their environment. Washington DC: Zero to Three; 2001. p. 18-21.

25. Lane S. Interview with Dr Shelly Lane. 2012. Held with the research in South Africa.

26. Geva R, Feldman R. A neurobiological model for the effects of early brainstem functioning on the development of behaviour and emotion regulation in infants: implications for prenatal and perinatal risk. Journal of Child Psychology and Psychiatry. 2008; 49(10).

27. Porges S, Doussard-Roosevelt J, Portales A, Greenspan S. Infant regulation of the vagal 'brake' predicts child behaviour problems: a psychobiological model of social behaviour. Developmental Pyschobiology. 1996; 29(8).

28. Batterham R, Ffytche D, Rosenthal J, Zelaya F, Barker G, Wither D, et al. PYY moduilation of cortical and hypothalamic brain areas predicts feeding behaviour in humans. Nature. 2007; 450.

29. Karlsson K, Gall A, Mohns E, Seelke A, Blumberg M. The neural substrates of infant sleep in rats. PloS Biology. 2005; 3.

30. Postert C, Averbaeck-Holocher M, Achtergarde S, Muller J, Furniss T. Regulatory disroders in early childhood: correlates in child behaviour, parent-child relationship, and parental mental health. Infant Mental Health Journal. 2012; 33(2).

31. Becker K, Holtmann M, Laucht M, Schmidt M. Are regulatory problems in infancy precursors of later hyperkinetic symptoms? Acta Paediatrica. 2004; 93.

32. Dale L, O'Hara E, Schein R, Inserra L, Keen J, Flores M. Measures of infant behavioural and phyiological state regulation predict 54 month behaviour problems. Infant Mental Health Journal. 2011; 32(4).

33. Greenspan S, DeGangi G, Wieder S. The functional emotional assessment scale (FEAS) for infancy & early childhood USA: ICDL; 2001.

34. Education P. Pearson Assessments. [Online].; 2008 [cited 2012 March 22. Available from: http://www.pearsonassessments.com/.

35. Gouze K, Hopkins J, LeBailly S, Lavigne J. Re-examining the Epidemiology of Sensory REgulation Dysfcuntiona nd Comorbid Psychopathology. Journal of Abnormal Child Psychology. 2009; 37.

36. DeGangi G, Poisson S, Sickel R, Wiener A. Infant/Toddler Symptom Checklist Texas: Therapy Skill Builders; 1995.

37. DeGangi G. An Integrated intervention approach to treating infants and young chidlren with regulatory, sensory processing, and interactional problems. In ICDL. ICDL Clinical practice guidelines.: ICDL p. 15-.

38. Gomex C, Baird S, Jung L. Regulatory Disorder Indentification, Diagnosis, and Intervention Planning. Infants and Young Children. 2004 October-December; 17(4).

39. Ayres J. Sensory Integration and the Child Los Angeles: Western Psychological Services; 1979.

40. Dunstan E, Griffiths S. Sensory Strategies: Practical support to empower families. New Zealand Journal of Occupational Therapy. 2008; 55(1).

41. Leong H, Carter M. Research on the efficacy of sensory integration therapy: past, present and future. Australasian Journal of Special Education. 2008 April; 32(1).

42. Parham L, Smith-Roley S, May-Benson T, Koomar J, Brett-Green B, Burke J, et al. Development of a fidelity measure for research on the effectiveness of the Ayres Sensory Intergration Intervention. The American Journal of Occupational Therapy. 2011 March/April; 65(2).

43. Cohn E, Miller L, Tickle-Degnen L. Parental hopes for therapy outcomes: children with sensory modulation disorders. The American Journal of Occupational Therapy. 2000 January/February; 54(1).

44. Cohn E. Parent perspectives of occupational therapy using a sensory integration approach. The American Journal of Occupational Therapy. 2001 May/June; 55(3).

45. Faure M, Richardson A. Sleep sense Welgemoed: Metz Press; 2007.

46. Faure M, Richarson A. Baby Sense Welgemoed: Metz Press; 2000.

47. Faure M. Your sensory baby: gentle routines for happy days and peaceful nights Great Britain: Dorling Kindersley Limited; 2011.

48. Kramer P, Hinojosa J. Frames of Reference for Pediatric Occupational Therapy. 2nd ed. Philadelphia: Liipincott Williams & Wilkins; 1999.

49. Case-Smith J. An efficacy study of Occupational Therapy with high-risk neonates. The American Journal of Occupational Therapy. 1988;: p. 499-505.

50. Rapley G, Murkett T. Baby -led weaning: Helping your baby to love good food Great Britain: Vermilion; 2008.

51. Townsend E, Pitchford N. Baby knows best? The impact of weaning style on food preferences and body mass index in early childhood in a case-controlled sample. British Medical Journal Open. 2012 February; 2(1).

52. Chatoor I. Sensory food aversions in infants and toddlers. Zero to Three. 2009 Janurary: p. 44-49.

53. Sprut K, Aitken R, So K, Charlton M, Adamson T, Horne R. Relationship hbetween sleep/wake patterns, temperament and overall development in term infants over the first year of life. Early Human Development. 2008; 84.

54. Burnham M, Goodlin-Jones B, Gaylor E, Anders T. Nightime sleep-wake patterns and self soothing from birth to one year of age: a longitudinal interventions study. Journal of child psychology and psychiatry. 2002; 43(6): p. 713-725.

55. Reebye P, Stalker A. Regulation disorders of sensory processing in infants and young children. BCMJ. 2007 May; 49(4).

56. Kielhofner G. Research in Occupational Therapy: methods of Inquiry for Enahancing Practice Philadelphia: FA Davis Company; 2006.

57. Inc S. Statsoft Electronic Statistics Textbook. [Online].; 2011 [cited 2012 03 20. Available from: http://www.statsoft.com/textbook/.

58. Tirosh E, Bendrian S, Golan G, Tamir A, Dar M. Regulation disorders in Israeli infants:epidemiologic perspectives. Journal of child neurology. 2003; 18(11).

59. Henry D, McClary M. The Sensory Processing Measure-Preschool (SPM-P)-Part Two: Test-Retest and Collective Collaborative Empowerment, Including a Father's Perspective. Journal of

Occupational Therapy, Schools & Early Intervention. 2011; 4(1).

60. Weinberg M, Tronick E, Cohn J, Olson K. Gender differences in emotional expressivity and self-regulation during early infancy. Developmental Psychology. 1999 January; 35(1).

61. Lundqvist-Persson C. Correlation betwen level of self-regulation in the newborn infant and developmental status at two years of age. ACta Paediatrica. 2001; 90.

62. Thiedke C. Sleep disorders and sleep problems in childhood. Americal Family Physician. 2001 Januarg; 63(2).